Information behavior and social control: Towards an understanding of conflictual information behavior in families managing chronic illness

Lindsay K. Brown, MHI; Tiffany C. Veinot, MLS, PhD

Lindsay Kathryn Brown, MHI University of Michigan, School of Information 3432 North Quad, 105 S. State St., Ann Arbor, MI 48109 Email: likathry@umich.edu, Phone: (248) 924-4126

Tiffany Christine Veinot, MLS, PhD (Corresponding Author) University of Michigan, Schools of Information and Public Health 3443 North Quad, 105 S. State St., Ann Arbor, MI 48109 Email: tveinot@umich.edu, Phone: (734) 615-8281

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Abstract

The relationship between information and control interests social scientists; however, much prior work has focused upon organizations rather than families. Work on interactive information behaviors has also focused on organizations, and on collaboration rather than conflict. Therefore, in families managing chronic illness, we investigated information behaviors in the context of health-related social control, and the impact of control on patient health behavior. We conducted a qualitative analysis of interviews with 38 family groups and 97 individuals over two years. Findings revealed conflictual information behavior, which enacted competitions for control and influence between family members and patients. In response to perceived patient health behavior-related problems, family members sought, shared and used information for social control of patients by enforcing norms, leveraging expertise, performing surveillance, and structuring the environment. These behaviors clashed with patients' interests and perspectives drawn from their own information acquisition. Patients responded by assessing family-presented information, and using information to resist or appease norm enforcement, refute or agree with expertise, and permit or block surveillance. Over time, some patient behaviors changed; alternatively, patients blocked family access to information about themselves, or family members retreated. Results challenge presumptions of benefit and harmony that have characterized much prior information behavior research.

Keywords: information use, conflict, qualitative research, information seeking

Word count: 9,482

Introduction

Chronic illnesses are incurable conditions requiring long-term management through medical treatments and/or lifestyle changes (Buttorff et al., 2017). Approximately 60% of US adults have at least one and approximately 40% have two or more (National Center for Chronic Disease Prevention and Health Promotion, 2019). Chronic illness management frequently requires changing everyday behaviors; most illness management happens at home and is often embedded in patients' family relationships.

Family members play critical roles in managing chronic illnesses. One in five US adults is an informal caregiver assisting an ill friend or family member (Division of Population Health, 2018). People with chronic illnesses in committed relationships tend to live longer than their unattached counterparts (Lipowicz, 2014). Alongside this benefit, research increasingly examines health-related social control, or social pressure to change behavior, as a partial explanation (Helgeson et al., 2016). Research on health-related social control focuses on others' efforts to improve patient health behaviors (e.g., diet) and outcomes (e.g., blood glucose).

Self-care and informal caregiving involve significant information work, including seeking, managing, and using health information (Costello, 2016). Although those with chronic illness can perform information work independently, family members may assist (Fox & Duggan, 2013). However, the extent of information behavior's role in health-related social control has not been considered. Previous policy-oriented information science research has stressed information's potential use to exert control over others (Beniger, 1986; Mechanic, 1962), suggesting its potential role in health-related social control. If information behavior is used to exert control in relationships, patients may not always react positively to informal caregivers' information seeking, sharing, and use; our pilot work in this area pointed to this possibility (Veinot et al., 2011). Thus, we ask:

RQ1: What role, if any, does information behavior (individual and interactive) play in health-related social control in families dealing with chronic illness?

RQ2: How do patients react to perceived health-related social control involving information behavior?

Information science is increasingly charting relationships between information behavior and health behavior (e.g. Pluye et al., 2019); we define health behavior as choices and actions which may impact health outcomes. Studies have demonstrated associations between information behavior and health-related motivations, behaviors, and clinical outcomes (Meadowbrooke et al., 2014; Veinot et al., 2016). However, the potential impact of *other people's* information behavior on patients' health behavior has received little attention. Therefore, we ask:

RQ3: How do family members' attempts to use information to control patient health behaviors influence those behaviors, if at all?

The long-term nature of illness means that information behaviors may change over time, particularly as diseases progress or move between acute phases and remission. Furthermore, caregiving roles and information needs may evolve. Therefore, time may be a critical aspect of the relationship between health-related social control and information and health behaviors. However, most research that considers time has relied on cross-sectional approaches (e.g., Samerski, 2018) and retrospective reports (e.g., Eschler, 2017). Therefore, we investigate the following question prospectively:

RQ4: How does the relationship between social control and information behavior change over time?

Literature Review

Health Information Behavior

Individual information behavior.

Information behavior is the "totality of human behavior in relation to sources and channels of information acquisition" (Wilson, 2000, p. 49). Much work on information behavior, including health-related research, analyzes it as an individual phenomenon (Ellis & Haugan, 1997); that is, performed by individuals in order to satisfy individual needs, gaps in understanding, or goals (Savolainen, 2006).

Individual information behavior includes *information acquisition*, or obtaining new information through active and passive seeking (Wilson, 2000), and incidental unintended information acquisition (Williamson, 1998). *Information avoidance*, "any behavior designed to prevent or delay the acquisition of available but potentially unwanted information" (Sweeny et. al, 2010, p. 340), can also be an individual information behavior. *Information assessment*, another individual information behavior, is an "iterative process" involving "one or more judgements" about information sources (Hilligoss & Rieh, 2008). Such judgements include *credibility*, believability of an information source (Hilligoss & Rieh, 2008); *accuracy*, the correctness or precision of the information; and *situational relevance*, the extent to which information bears upon the "situation, task or problem at hand" (Saracevic, 2007). *Information use* as an individual information behavior (Wilson, 2000) is defined here as applying a tool or resource to a given process (Kari, 2010).

Despite their importance to chronically ill people, formal healthcare typically meets information needs of individual family caregivers poorly (e.g. Mason, 2008). Thus, caregivers often seek information independently (Barrett, 2004). Yet most research has examined the behaviors of individual *patients* (Abrahamson et al., 2008), while relatively little has considered

caregivers (see Kazmer et al., 2013 and Veinot, 2009b for exceptions). Caregivers typically experience illness through another's body and lack access to patients' information sources, such as healthcare providers. This suggests a need to understand their specific individual information behaviors.

Research has shown that individual information behavior may shift in the context of health, as people adjust to illnesses or move from acute to chronic stages. Such work typically gathers retrospective accounts through cross-sectional designs (e.g. Eschler, 2017). However, due to potential recall bias, prospective longitudinal work examining the evolution of behaviors in real time is needed. The present study, with multiple data collection contacts over a two-year period, begins to address this gap.

Interactive information behavior.

A growing body of literature explores information behavior involving *interaction* in which two or more people communicate with, or react to, one another (Interaction, n.d.). Some previously described information behaviors are inherently interactive; for instance, *information sharing* has been defined as communicating information that has already been acquired (Talja & Hansen, 2006, p. 114). Notably, information sharing may be common among family caregivers since half of all health-related Internet searches are conducted on behalf of others (Sadasivam et al., 2013). Moreover, family caregivers may share obtained information, thus helping others overcome barriers to information seeking (Abrahamson et. al, 2008).

Furthermore, Goffman (1963) introduced the concept of *information control* to describe the management of information about the self in the context of stigmatized identities. The concept explains ongoing decisions stigmatized people make about what to reveal about their stigmatized characteristic, and to whom.

Other research has focused on demonstrating that aforementioned individual information behaviors, such as acquisition, assessment, and use, can also be interactive (e.g., Brashers et al., 2002; Shah, 2014; Veinot, 2009b, Wolf & Veinot, 2015). Particular attention has been accorded to situations of collaboration (e.g. Wu et al., 2018), or "working together synergistically to achieve a common goal" (Shah, 2014, p. 218). Collaborative information behaviors involve seeking, sharing, and use to resolve shared information needs (Poltrock et al., 2003). This process includes (1) collaboration and (2) resolving an information need together by seeking, retrieving, and using information to solve a problem (Reddy & Jansen, 2008). Collaborative information acquisition can include both behaviors performed together, and coordinated behaviors performed separately but synergistically (Shah, 2014).

Collaborative information behavior has primarily been studied in organizations and education. Perhaps making collaboration more likely, organizational settings have clearly defined roles, hierarchies, task foci, and task segmentations (Elbeshausen et al., 2015). Educational settings also have clear and segmented tasks, although not clearly defined hierarchies (Hyldegård, 2009). Workplaces and schools *require* that tasks be completed for pay or grades, creating incentives to collaborate.

This differs from informal settings such as families. Families may have less clearly defined roles, responsibilities and tasks, and deeper emotional connection to information needs (Veinot, 2009b). Therefore, although families dealing with illness may be motivated by complex information needs (Reddy & Jansen, 2008), they are also likely motivated by other factors, including caring (Rosland et al., 2013) and stress management.

Less well-recognized is the fact that family members' information behaviors may conflict with one another, such as when one spouse acquires information about an illness, while the other avoids it (Brashers et al., 2002). Illness-related stress and caregiving can also be general sources of conflict in families (Checkovich & Stern, 2002), and illness-related information behavior may be contextualized by broader family conflict, or active opposition between family members (Marta & Alfieri, 2014). To more fully characterize interactive information behavior, it is important to examine family information behaviors in the context of potential conflicts, as when health-related social control occurs.

Information and Behavior Change

For many chronic conditions, health outcomes are associated with health behaviors; thus, encouraging positive behavior change is important. Information behaviors have been connected with various models of health behavior change (Greyson & Johnson, 2016). However, scant attention has been paid to interactive information behaviors. This gap is critical given the impact of social influence through persuasion, modeling, and normative influence (Godin & Kok, 1996; Latkin & Knowlton, 2015; Robinson et al., 2014) as well as other contributions of social connections, such as health-related information provided via social networks, which has been identified as a resource provided via social capital (Pettigrew, 2000; Veinot, 2010). Social capital has been positively associated with self-rated health (Kawachi & Berkman, 2000). Nevertheless, little is known about the potential influence of interactive information behavior on individual health behaviors. This paper addresses this gap by considering the role of family information behavior in patient health behavior.

Health information is not always associated with positive outcomes. There is a risk of finding misinformation (Morahan-Martin & Anderson, 2000). Some deliberately avoid stressful information (e.g. Rubenstein, 2009). In early work, we found that family information sharing could cause interpersonal tension (Veinot et al., 2011). Thus, understanding potential negative impacts of health information behavior within families is important.

Information, Power, and Control

The relationship between information, power, and control has been a focus of social science and organizational theory. Power is defined as a productive relation present at all levels of social life (Foucault, 1977). Control is tied to one form, discipline, which regulates behavior by organizing space, time, and behavior (Foucault, 1977). Discipline is exercised at the level of institutions (hospitals, schools, etc.) and of interpersonal connections (i.e. families) (Foucault,

1977). Information has been related to power and control through a) expertise, b) norm enforcement, c) surveillance, and d) access to information.

Information begets power through *norms* that direct socially acceptable behavior (Bicchieri, 2005). "Social control" has been linked to social norms, diminishing the need for coercion (Meier, 1982). Norms, internalized as perceptions, beliefs, and motivations (Godin & Kok, 1996), lead individuals to act in accordance with behavioral ideals (Cialdini et al., 2006). Perceived norms derive from information about others' behavior ("descriptive norms") (Rivis & Sheeran, 2003), and what others want us to do ("injunctive norms") (Montano & Kasprzyk, 2015).

Growing attention is given to expression of power through *expertise*, which can be expressed through discipline that regulates behavior (Foucault, 1977). Expertise, or expert knowledge, legitimizes control over others through *authority*, a power to perform action accepted by others (Klauser, 2017). Expertise-related authority plays out in role-based interactions (e.g. doctor to patient) and institutional behavior. Patients may attempt to appropriate medical authority by presenting themselves as knowledgeable about health (Wolf & Veinot, 2015). Expertise and authority allow individuals to exert control within organizations (Gray & Silbey, 2014), institutions (Jones & Moore, 1993), systems (Klauser, 2009), and over other individuals (Beniger, 1986).

Surveillance studies, which owes a conceptual debt to Foucault (1977), argues that surveillance technologies are omnipresent and ever-expanding. Under perpetual surveillance, behavior is controlled even without direct observation (Green, 1999). For example, surveillance cameras, in theory deployed to protect and secure, can provide information to police and governments to discipline citizens for "unacceptable" behaviors (Klauser, 2009, 2017). In the health context, 20th century medicine shifted from treating the ill to surveilling the healthy and attempting to control health at the population level (Armstrong, 1995). Surveillance medicine includes tools such as remote patient monitoring or mobile health applications designed to prompt behavioral changes (Lupton, 2012).

Information can be a source of power (Mechanic, 1962). Organizational studies research has explored efforts to control "who knows what" at work. Those whose training provides access to information are "skilled," with accompanying power and prestige (Jackson, 1991). Inequitable information access reinforces disparities in social privilege (Lievrouw, & Farb, 2003). Yet, people with less power may leverage information to enhance or preserve their positions. In workplaces, lower-status workers access power by controlling information about organizational procedures, policies, and norms (Mechanic, 1962).

Information, power, and social control are linked; yet, no comprehensive exploration of their exertion in interpersonal contexts exists. Consequently, this paper analyzes relationships between information behaviors and health-related social control.

Health-Related Social Control

Social control, or attempting to influence and regulate others' behaviors, is common in social relationships (Lewis & Rook, 1999). *Health-related* social control prompts behaviors linked to positive health outcomes (Umberson, 1992). Health-related social control may be coercive (i.e. nagging and guilt) or persuasive (i.e. discussion) (Lewis et al., 2016) and occurs across many types of relationships, including partnerships (e.g. Cornelius et al., 2018). Partners in committed relationships both initiate and receive health-promotion-oriented exchanges, including social control (Franks et al., 2016). Patients with dense family networks are also likely to experience social control alongside emotional support and practical aid (Widmer et al., 2018). Health-related social control has been correlated with patient behavior change and improved health outcomes (e.g. Tucker & Mueller, 2016) but may also have unintended negative emotional impacts (Fekete et al., 2009) or prompt resistance that reinforces negative behaviors (Brunson et al., 2014).

Thus far, health-related social control research has focused on documenting tactics and effects of social control; little attention has been paid to the role of information behavior.

Methods

Overview

This two-year longitudinal study included families managing diabetes or HIV/AIDS, conditions selected to represent variation in chronic disease experiences (e.g., communicability; treatment types; stigmatization levels). Data collection occurred between winter 2010 and winter 2013. The University of Michigan's Institutional Review Board approved the study.

Recruitment

Eligible patients were diagnosed with either Type 2 diabetes or HIV/AIDS and were willing to recruit family members involved in their care, resulting in recruitment of family clusters. Patients were recruited in person while exiting appointments at a Veterans Affairs Medical Center; via three disease-specific non-governmental organizations through flyers and/or newsletters; and through postings on a university-based research recruitment website. Participants defined families however they wished, including partners, parents, adult children, siblings, aunts, uncles, cousins, and close friends. Participants received a \$20 gift card at each interview.

Data Collection

There were five interview contacts in total with individual interviews occurring at Times 1 and 5, group interviews occurring at Times 2, 3 and 4, and optional home tours also occurring at Time 4 (Figure 1). Individual in-depth, semi-structured interviews (Johnson, 2002) were conducted with each family member in accordance with the "family case method" (Handel, 1997); this permitted discussions participants may not have been willing to have in a family setting (Åstedt-Kurki et al., 2001). Family group interviews represented a modified focus group involving only people who knew one another (Eggenberger & Nelms, 2007). Interviews centered on day-to-day disease management, information behaviors, family relationships, and interactions, were conducted in participant-selected locations, lasted between 90 minutes and two hours, and were audio-recorded and transcribed verbatim. Interviewees completed demographic surveys at each contact.

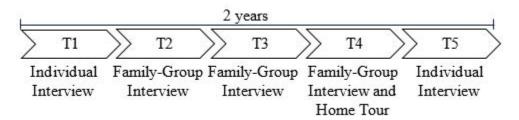


Figure 1. Data Collection Timeline

Data Analysis

Multi-stage analysis of interview transcripts was conducted using NVivo software. An initial coding cycle included provisional and structural coding (Saldaña, 2009) and a preliminary codebook, with codes and definitions determined by existing literature on information and control (see above), health information behavior (Veinot, 2009b; Veinot et al., 2011), social support (House, 1981), and health-related social control (Fekete et al., 2006).

Second-cycle coding focused on information behavior and social control; it involved pattern and process coding (Saldaña, 2009). A third cycle of selective coding (Corbin & Strauss, 2008) synthesized overall themes. These cycles were supported by qualitative memoing (Corbin & Strauss, 2008) and exploratory data displays (Miles & Huberman, 1994) to elaborate on identified patterns. We focus here on coercive and persuasive control strategies rather than supportive behaviors since they were prevalent in the findings; additionally, supportive information behaviors such as reminding and encouragement were discussed elsewhere (Barbarin et al., 2015).

Results

Characteristics of Participants

As Table 1 shows, 38 families with a total of 97 individuals were recruited at time 1. By time 5, 61% of families (n=23) remained, accounting for 68% of the individuals recruited (n=66). Approximately 60% of participants where white and 30% African American. Gender was roughly balanced.

Table 1.					
Participant demographic	S.				
	Time 1	Time 2	Time 3	Time 4*	Time 5
Family Groups by Disea	se Type				
Diabetes	20	15	13	13	13
HIV/AIDS	18	14	13	11	10
Total Family Groups	38	29	26	24	23
(Retention Rate)		(76%)	(68%)	(63%)	(61%)
Individuals – Race/Ethr	nicity				
White	61	48	41	38	41
	(63%)	(67%)	(63%)	(64%)	(62%)
Black/African-	29	19	21	17	21
American	(30%)	(26%)	(32%)	(29%)	(32%)
Hispanic/Latino	4	4	2	2	2
	(4%)	(6%)	(3%)	(3%)	(3%)
Asian/Pacific Islander	3	1	1	2	2
or Native American	(3%)	(1%)	(2%)	(4%)	(3%)
Total Individuals	97	72	65	59	66
(Retention Rate)		(74%)	(67%)	(61%)	(68%)
Individuals – Gender					
Women	54	39	36	35	39
Men	43	33	29	24	26
*Includes opt-in home to	ur, resulting i	n exclusion of	some at Time	4 only.	

All families mentioned health-related social control-related behaviors in at least one interview contact. Among those interviewed multiple times (n=29), 86% of families (n=25) mentioned social control at two or more interviews. The most common form was *pushing* (telling patients what to do; see Table 2), mentioned by 64%. Other common behaviors included *questioning patient behavior, structuring the environment*, and *raising concerns. Guilting* and *repeating to reinforce points* were the least commonly discussed. Table 2 maps each behavior onto information and control approaches. These and other strategies and approaches are explored in the following sections in the context of information behavior and are synthesized in a preliminary model in Figure 2.

Because these behaviors reflected opposition between family members, we collectively label them "conflictual information behavior," defined here as human behavior in relation to sources and channels of information that is characterized by, or expresses, a clash of opposing

perspectives or interests between two or more people or groups. Accordingly, conflictual information behavior (e.g., acquisition, sharing, control, assessment, use) enacts—and its meaning emerges from—competition for control and influence between two or more people or groups. Conflictual information behavior thus reflects efforts to enact social control and influence, and attempts to accommodate or resist these efforts.

Table 2.		1 1.	1 1 . 1 .	1 , 1			
Family membe	Number of family groups that describe this strategy						
Information -Related Form of Social Control	Type of Information Behavior	Social Control Strategy	Type of Social Control Strategy	Definition	Representative Quotes	Families in at least one interview	Families in at least two interviews
Enforcing Norms	Information Sharing	Pushing	Coercive	Telling patients what to do, demanding changes to meet behavioral standards.	" you ain't supposed to be eating thisyou've got to keep your sugar in control."	25 (66%)	17 (65%)
Enforcing Norms	Information Sharing	Raising Concerns	Persuasive	Expressing concern to prompt conforming to a behavioral standard. Discussing potential consequences of behavior.	"I tell herI feel better without [taking diabetes medication] [she says] 'I want you to be around a long time.'"	20 (53%)	13 (45%)
Enforcing Norms	Information Sharing	Repeating to Reinforce Points	Persuasive	Repeating a message hoping it will be effective over time.	"all the complaininghas finally sunk inhe realizes he's got to change his eating habits."	6 (16%)	0

Enforcing Norms	Information Sharing	Guilting	Coercive	Blaming patients' health behaviors for family issues and/or leveraging family relationships to establish good behaviors as obligations to family.	"Itell her 'You act like you don't care anymore whether you live or die you don't care for me, if you want to leave me like that'"	5 (13%)	0
Leveraging Expertise	Information Sharing	Proxy Informing	Persuasive	Finding information on patients' behalf; encouraging patients to absorb it.	"I don't say I looked up stuff on the internet today and blah-blahblah-blahblah-blahblah looportune moment to give her that information"	14 (37%)	4 (14%)
Leveraging Expertise	Information Sharing	Teaming Up	Persuasive	Recruiting others to influence behavior; may involve sharing health information with others.	"[Sister] is the dialysis [nurse] If I have trouble, I says, "I guess I'm going to have to text or call [brother-in-law] and [sister], let them know"	9 (24%)	1 (3%)
Performing Surveillance	Information Use	Questioning Patient Behavior	Persuasive	Asking patients if they're allowed to do something; veiled criticism.	" she'll say 'You've had too many of those?' If I'm eating something I shouldn't"	18 (47%)	10 (34%)
Structuring the Environment	Information Use	Controlling objects or spaces	Coercive	Manipulating patients' environment to prompt changes.	Secretly replacing sour cream with Greek yogurt.	18 (47%)	8 (28%)

RQ1: What role, if any, do information behaviors (individual and interactive) play in health-related social control in families dealing with chronic illness?

Acquiring Information and Defining Problems.

Family Members. As Figure 2 shows, family members acquired information to define problems and facilitate other information behavior that enacted social control (see Table 2). This included information about health standards and preferred health behaviors (standards); the reality of patients' current health status and behaviors (realities); and potential consequences of misalignment (potentialities) (Figure 2). Family gathered information individually or interactively, using methods including searching online, attending patients' healthcare appointments, and observing patients. Information acquired through prior or personal experience was used to form longer-standing health-related beliefs that were also used to define problems. Such information acquisition and related perspectives and interests were inputs into information behavior to enact health-related social control (Figure 2).

Patients. Family and patients often had different information sources concerning standards, realities, and potentialities. Patients more often relied upon healthcare providers, laboratory tests, and bodily experiences. Family access to this information primarily depended on patient willingness. Additionally, patients obtained information that family shared as part of family social control efforts. Often, family shared information reflecting their own definitions of problems, with which patients did not necessarily agree.

Information Sharing to Enact Health-Related Social Control.

Family members. Family members most commonly attempted to exert control by enforcing norms (Table 2) through *information sharing*. Primarily, this involved expressing what they wanted patients to do, or injunctive norms, alongside sharing information about *standards* and *potentialities*. Information sharing took the form of persuasive social control strategies such as *raising concerns* and *repeating* points. Coercive forms of information sharing that exerted control included *pushing* and *guilting*, which involved telling patients what to do or making them feel guilty (Table 2).

When *leveraging expertise*, participants *shared information* from sources they deemed credible, including doctors, nurses, internet sites, pamphlets/brochures, workshops/classes, books, and television hosts such as Dr. Oz. Family often sought information individually when patients were first diagnosed "to set [their] mind[s] at ease...." Such information, and that acquired at other times, was shared through two persuasive strategies, proxy informing and teaming up. In proxy informing, family shared information such as news articles to prompt change. Proxy informing also involved attempts to make change more actionable (i.e. sharing exercise videos), choosing opportune information sharing moments, and convincing patients to pay attention to information. Family also referenced information sources to bolster their credibility. *Teaming up*, utilized expertise through bringing in more authoritative others, such as medically trained family or friends, to share information with patients.

Information Use to Enact Health-Related Social Control.

Family members. As mentioned, information use refers to applying information as a resource in some process. Information use was most aligned with the social control process of performing surveillance. One surveillance-motivated use was questioning patient behavior (Table 2), which occurred when family observed and commented, like asking diabetic patients if they were allowed to have so much sugar, intending to prompt reconsideration.

Surveillance-based information was facilitated partly by *structuring the environment*, primarily by organizing kitchens, and the placement of medications and medical devices. Some family controlled foods entering the home to ensure that patients followed a healthy diet. Some did this with the patient's knowledge, constructing healthy lunches. Others were clandestine: one wife of a diabetic patient replaced sour cream with Greek yogurt based on information acquired from a publication of the celebrity chef, Emeril Lagasse. Another hid potato chips where her husband would not find them after she acquired information about their impact on blood glucose.

Figure 2 – Preliminary Model of Conflictual Information Behavior

Competition for Control and Influence

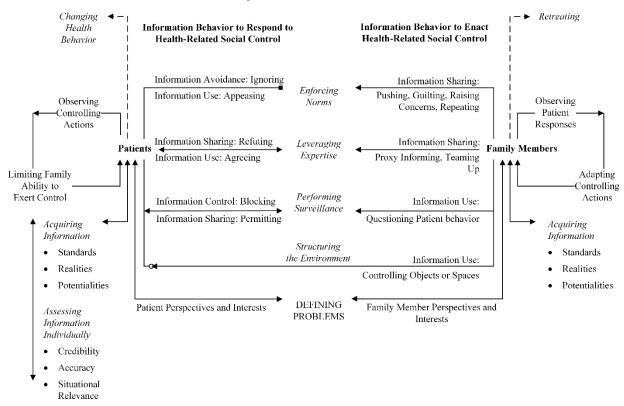


Figure 2. Preliminary Model of Conflictual Information Behavior

RQ2: How do patients react to perceived health-related social control involving information behavior?

Table 3. Patient inform	nation use to re	espond to heali	th-related social	control.	ı	
					Number of family groups describing this response	
Patient Informatio n Use in Reacting to Social Control	Type of Informatio n Behavior	In Response to What Social Control Strategy	Definition	Representative Quotes	In at least one intervie w	In at least two interview s
Ignoring	Information Avoidance	Enforcing Norms	Patients refused to comply with family, generally ignoring them.	"[I] let it fly over [my] head."	11 (29%)	2 (7%)
Appeasing	Information Use	Enforcing Norms	Patients complied even if they didn't agree or want to change.	"I thought, 'maybe I should cut back'just to satisfy [family member]."	7 (18%)	1 (3%)
Refuting	Information Sharing	Leveraging Expertise	Patients used their own information sources to refute suggestions.	"[they] make comments likeyou shouldn't be eating that,'that's when they getschooled"	14 (37%)	6 (20%)
Agreeing	Information Use	Leveraging Expertise	Patients accepted that recommende d changes were necessary.	"I'mthickheade dand I don't want to goto the doctor, but I have to."	6 (16%)	1 (3%)
Blocking	Information Control	Surveillanc e	Patients prevented	"Sometimes they sayI'm going to	19 (50%)	5 (17%)

			family	ask		
			control by	[Doctor]and I		
			limiting the	don't feel		
			information	comfortable with		
			family	that, so 'I don't		
			received.	need you in		
				there.'"		
Permitting	Information	Surveillanc	Patients	"I live under his	10	5
	Sharing	e	allowed	roof I either	(26%)	(17%)
			family	conformor		
			surveillance	move on."		
			because they			
			recognized			
			its value or			
			felt unable to			
			stop it.			

Patients' reactions to information behaviors that enacted health-related social control often reflected a desire to maintain control over themselves and to influence family members in return. The result was information behavior that enacted or expressed competition for control and influence between patients and family members. This could involve repeated interpersonal tension or argumentation. As one patient said, "...if you push at me...I push back." Many patients based their responses to control on affective reactions (anger, apathy, or reassurance) rather than information content, especially when angered. However, in some cases, patients did actively assess information their family members shared.

Information Assessment to Respond to Health-Related Social Control.

When family shared information in attempts to enforce norms or leverage expertise, patients assessed it using three main criteria: *credibility, accuracy,* and *situational relevance* (Figure 2). These evaluations often caused rejection of the information, which became a form of resistance to control.

Evaluations of information givers' credentials and behavior were used with or instead of assessments of the credibility of the information they shared. Family members' professional and educational credentials and personal credibility sometimes worked against them; those with medical training could be criticized for being overly pushy. One patient sardonically asked, "Have you ever lived with someone studying to be a nurse?" Some credibility evaluations focused on tendencies towards embellishment: "...he thinks I overreact on almost everything anyway...." Personal credibility also related to family members' own behaviors, sometimes seen as hypocritical: "She doesn't like... us...snacking...she's just diving...in...like the rest of us."

When evaluating *accuracy*, patients decided whether they believed information and related problem definitions. Often, this involved checking information against existing knowledge, as

when this patient's former partner told her she was eating too much: "No...I'm snacking because I'm taking care of diabetes." However, patients occasionally sought additional information to evaluate family's information, revealing a problem not yet considered.

When patients felt their family's information was accurate, some evaluated whether or not it *was situationally relevant*. They assessed situational against risks and benefits and/or sacrifices and rewards. Patients determined whether the risk of not changing their behaviors outweighed the benefit of not changing. A few who had behaved a certain way for a long time and experienced no ill-effects saw the risk as minimal: "I've been doing this for 20 years....it must work enough because my sugar is under control...."

Another facet of situational relevance assessment involved patients evaluating family information by comparing the sacrifice of changing to the potential rewards. Such considerations were most important to older patients who felt living longer would not compensate for losing things they loved. A diabetic patient rejected his children's contention that he should stop eating hot dogs: "...76 years doing what I've been doing...what am I going to do? Knock a couple of years off my life?" Such assessments could then be inputs into other behaviors that responded to health-related social control from family, such as information avoidance (see Table 3).

Information Avoidance to Respond to Health-Related Social Control.

Ignoring was one response to norm enforcement; this involved simply refusing to listen to family directives, or to take them into account, a form of passive resistance to control.

Information Sharing to Respond to Health-Related Social Control.

When family leveraged expertise, some patients leveraged expertise by *sharing information* in return as a method of resisting control, *refuting* claims with their doctor's advice, laboratory tests, or other authoritative sources (Table 3).

Responses to surveillance that were more accommodating towards control included *permitting*, a form of passive *information sharing* about the self. Permitting occurred either because someone deferred to another's authority, or because patients appreciated some behaviors, such as ensuring follow-up of health issues during doctor's visits even if it could be frustrating. As this patient said,

"She'll...make suggestions, like, 'He needs to be tested for sleep apnea.'

I: Does that feel helpful...?

P: ...at times. At times it feels interfering."

Some patients also followed routines set by family members to ensure that they were "behaving" (Table 3). For instance, one participated when a family member placed a blood glucose monitor on the dinner table so the patient could be observed testing. Another took his pills at the same time and place every day, observed by a family member to ensure adherence.

Information Control to Respond to Health-Related Social Control.

The main form of information control about the self was *blocking*, a form of resistance towards control. This primarily involved barring family from appointments but could extend to avoiding those attempting to surveil them (Table 3).

Information Use to Respond to Health-Related Social Control.

Information use in response to family control included two accommodating responses. A few described *appeasing* family by changing health behavior, as one diabetic patient did regarding energy drinks (Table 3). However, patients could also be persuaded, ultimately *agreeing*, such as in accepting the need to go to the doctor and then doing so.

RQ3: How do family members' attempts to use information to control patient health behaviors influence those behaviors, if at all?

As outlined, several patients changed behavior in response to controlling actions, occasionally due to information content when they began *agreeing* with the leveraging of expertise. However, changes were often motivated by emotional and social dynamics. For example, in *appeasing*, several patients made changes they felt were unnecessary simply to alleviate family stress.

While patients assessed family-provided information when making decisions, information content was less impactful than what can be termed "psychosocial information" about family feelings, motivations, and personalities. If patients believed family members were bossy, they were less likely to consider changes regardless of the perceived accuracy of recommendations. Generally, persuasive behaviors (e.g., proxy informing, raising concerns) were more effective than coercive behaviors in stimulating behavior change.

Efforts at *structuring the environment* were most consistently effective because patients tended to be either unaware of or unwilling to take over the responsibilities involved (e.g., cooking). However, this strategy was limited to family with substantial influence over patients' routines and living spaces.

RQ4: How does the relationship between social control and information behavior change over time?

Patients and family began to acquire information not just about standards, realities and potentialities, but also the effectiveness of their own actions. Family observed patient responses to controlling behaviors, and patients observed the behaviors their family used to enact control. Some patients and family then made changes to limit or change controlling behaviors (Figure 2).

Family members. Family observations of responses to controlling behavior prompted adaptations. In some cases, adapting involved *continuing* behaviors perceived as effective. If a

patient measured blood glucose only when family structured the environment to facilitate it, family would continue doing so.

Strategies also *changed*, often from coercive to persuasive, or other approaches altogether. One family member, rather than pushing, began persuading her husband by soliciting his opinions (*i.e.*, *don't you think it's a good idea?*). Finally, family reported *retreating* after negative responses; some came to believe control was counterproductive. More often, family retreated out of perceived self-preservation; they felt burdened by trying (and failing) to influence patients' behaviors: "*I... have taken a step back for my own sanity....if she's not gonna care, then I can't do anything...."*

Patients. For patients who did not appease, agree or permit, change primarily involved limiting family's ability to exert control, frequently by blocking information access or by avoidance. They could avoid all interactions and dissolve relationships; an HIV-positive patient moved to get away from his controlling sister. More often, patients avoided health-related interactions and focused on other topics with controlling individuals. One described ignoring his mother's requests to check his blood sugar: "....I don't want to hear anymore. I feel fine, trust me."

Discussion

Patients and family members engaged in conflictual information behavior in competition for control and influence. Information behaviors enacted, or responded to, health-related social control. Family and patients often had different information sources and defined health problems differently; this reflected differing perspectives and interests. Family shared information to enforce norms and leverage expertise, thereby exerting control over patients' health behavior. Family used information to question patient behavior as part of performing surveillance and to take actions that structured the environment. Patients either resisted these attempts by avoiding information (ignoring), sharing information themselves (refuting), or blocking family access to information about themselves (information control). Alternatively, they accommodated family control by passively sharing information about themselves (permitting surveillance) or using information and changing behavior as family members desired (appeasing, agreeing). Relationships changed over time, with family adapting or retreating, and patients primarily blocking unwanted efforts. In some families, patients changed their behaviors, more often in response to persuasive behaviors or those that structured the environment, of which patients were often unaware.

Information behaviors between patients and family frequently expressed opposing perspectives and interests—leading us to coin the term "conflictual information behavior." This concept is a counterpoint to research viewing information as inherently helpful (Savolainen, 2006), and joins scholarship on misinformation (Morahan-Martin, & Anderson, 2000), using information to resist clinician directives (Wolf & Veinot, 2015), and information overload and

anxiety (Bawden & Robinson, 2009) in acknowledging the potential for negative outcomes. However, our study uniquely locates this in the context of interpersonal interactions, presenting interpersonal friction as a potential negative outcome. We contrast the concept of conflictual information behavior with collaborative information behavior and locate both under the umbrella of "interactive information behavior." Unlike conflictual information behavior, collaborative information behavior research emphasizes consensus through common ground and shared goals (e.g., Poltrock et al., 2003; Hertzum, 2008). In contrast, study participants often disagreed about problem definitions, or whether problems even existed; in part, this could be linked to different information sources, with much family information access being once-removed and determined by patients. This aligns with prior work showing that families' information needs are often poorly met within health care (Mason, 2008; Rees & Bath, 2000). Accordingly, the model presented here contrasts with those focused on collaborative information behavior in that it does not highlight a shared information need (e.g., Karunakaran et al., 2013; Veinot, 2009b), but rather differing perspectives and interests that enter into defining problems (Figure 2).

Conflictual information behavior encompasses some behaviors that other researchers have described, as outlined in the introduction, such as information acquisition, assessment, sharing, control, and use. However, the concept of conflictual information behavior situates these behaviors in a clash of opposing perspectives or interests between people; in the present study, such previously described behaviors **were given meaning** by this interpersonal clash. Moreover, this context shaped how these behaviors unfolded, leading to different dynamics than previously observed, even in the context of similar behaviors. For example, similar to prior work, patients in this study used known criteria to assess information family members provided, such as credibility. Yet, they also evaluated them in the context of family intent and conflictual relationship dynamics. The result was that use of these criteria took an unexpected form: some patients used information givers' credentials (i.e. having a medical background) *against* their credibility because they felt those individuals were professionally predisposed to be controlling. Accordingly, the concept of conflictual information behavior illuminates varied meanings of similar behaviors, and potentially counterintuitive behaviors and their outcomes.

Empirically, the concept of conflictual information behavior also casts analytical attention upon novel forms of information sharing, avoidance, control, and use. Findings highlight the persuasive character of information sharing in the context of opposing perspectives and interests. Claims of authority to persuade have been identified in discursive information behavior research (e.g., McKenzie, 2004; Tuominen & Savolainen, 1997). However, this study also revealed persuasive information behaviors not previously documented, such as raising concerns and repetition in relation to enforcing norms, and leveraging expertise through teaming up. Furthermore, although proxy informing-like behavior was identified in Abrahamson et al.'s (2007, 2008) lay information mediary study and related model, that research did not consider the possibility that information sharing may be unwanted or benefit givers more than receivers—or that it would be accompanied by efforts to persuade patients to accept that information.

Additionally, coercive information sharing behaviors such as pushing and guilting were not previously documented.

A further novel aspect of the concept of conflictual information behavior is its emphasis on information use that reflects resistance and accommodation to others' behaviors. As Figure 2 shows, patients accommodated family members by appeasing them, agreeing with them, or permitting their surveillance, typically defusing or suppressing conflict. In approaches that perpetuated conflict, patients thwarted family members' attempts to control them by ignoring them or refuting their claims. Similar to Goffman's (1963) theory of information control, patients also blocked others' access to information about the self. Prior work highlights selective approaches to self-revelation, with family members often being those to whom people with stigmatized health conditions disclose their experiences (Veinot, 2009a). In contrast, patient participants engaged in blocking behaviors, such as excluding family members from healthcare appointments, to limit perceived intrusion.

Another unique component of the study and related model is the inclusion of empirical findings derived from longitudinal research. Findings showed that participants' information behaviors fluctuated due to observing others' reactions. Occasionally, this was due to successful behavior change or successful efforts to limit control. However, when information behavior to enact social control proved ineffective, some family members changed tactics or curbed their efforts to preserve their "sanity." While previous research has shown that patients' information acquisition efforts may change over time, this is the first study we know of showing similar reductions in family effort. Unlike in prior research with patients (Chen, 2016), family reduced their acquisition and use due to lack of success or limitations patients instituted, rather than resolution of a need. There is need for further longitudinal research on information behavior over time, and this study suggests the value of considering this from an interactive perspective.

Findings show that research on the information behavior-health behavior link would be enriched by further exploring the role of family in generating change. In some cases, participants' behavior improved due to being persuaded, "giving in," or family's environmental structuring. In contrast, previous research has focused on individual information acquisition and use. For example, acquisition and use have been associated with intentions to receive an HIV test (Meadowbrooke et al., 2014), and self-reported testing behavior (Veinot et al., 2016). This suggests that attention to family relationships could illuminate the information behavior-health behavior link. Furthermore, results suggest that informational interventions may be more effective if they assist family members in managing their own distress and not engendering resistance among patients.

Classic control mechanisms, such as surveillance, function via organizing space and time (Foucault, 1977). Although these concepts were primarily developed in relation to institutional power, especially surrounding prison design (Foucault, 1977), we have shown that these tactics are also utilized in informal, interpersonal interactions, though likely with different motivations. More research into how surveillance functions at an interpersonal level could further reveal how individuals respond to surveillance by those with whom they have personal relationships.

This study has limitations. Participants were from a single US Midwestern state; research in other areas is needed. Additionally, the results are contextualized by family illness management; more analysis is needed to determine if similar patterns exist in other family-based information behaviors.

Nonetheless, this study has critical implications for understanding interactive information behaviors in high-stress interpersonal contexts over time. To further develop the concept of conflictual information behavior and the model presented here, we recommend further study of information behavior in situations of conflict. Like sociologists before us (Veinot & Williams, 2012), we thus contend that it is important to challenge assumptions of benefit and consensus. We also suggest that conflict and competition for control and influence may be more important drivers of information behavior than has been previously recognized.

Conclusion

We explored how information behaviors related to health-related control function in families managing chronic illness. We found that patients and family engage in information behaviors as they vie for control and influence in managing chronic illness. These findings complicate existing understandings of interactive information behaviors; in this interpersonal context, differences in perspectives and problem definitions, controlling actions, and reactions were characterized by conflict. Therefore, we introduce the concept of *conflictual information behaviors*, and a preliminary Model of Conflictual Information Behavior; these contributions challenge us to reconsider presumptions of benefit and harmony in information behavior.

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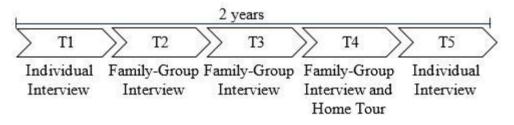
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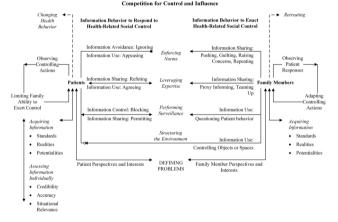
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Figure 2 – Preliminary Model of Conflictual Information Behavior



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