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Repetition, regulation and reappraisal: information behaviour in persistent coping with chronic illness in families

Lindsay K. Brown & Tiffany C.E. Veinot

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Abstract

Introduction. Little is known about how specific information behaviours and coping strategies intersect within family groups over time, thus we report on a longitudinal investigation of the information and coping behaviours of families managing chronic illness.

Method. Longitudinal, mixed methods study with family group interviews, individual interviews, and surveys of HIV/AIDS or Type 2 diabetes patients and their family members (n=38 families and 97 individuals).

Analysis. Descriptive and correlational quantitative analyses of survey data. Multicycle coding of interview data.

Results. Families primarily used incidental information behaviours as they coped with chronic illness in the long-term, reflecting a *persistent coping* process. Persistent coping encompassed ongoing cognitive appraisal/reappraisal through daily monitoring and routinised, repetitive information behaviour. Seeking spiritual support, the most common coping strategy, and coping-related information behaviours, such as seeking, using or avoiding information to maintain hope or to provide cognitive reassurance, helped with emotional regulation in response to the stress of illness.

Conclusion. Information behaviour and coping in families managing chronic illness was routinised and focused on monitoring for changes as families continuously appraised whether their current coping strategies were sufficient. Information use was primarily focused on regulation of emotional responses to the illness-related stressor.

Introduction

Chronic illnesses are lifelong, incurable health conditions. More than 76% of US adults have at least one chronic illness (Watson, Wiltz, Nhim, Kaufmann, Thomas, & Greenlund, 2025). Chronic illnesses require long-term lifestyle and medical management. Therefore, their management becomes embedded in patients' lives, relationships, and homes (e.g., Mirzaei et al., 2013). Chronic illness diagnoses are often sources of stress for both patients (Livneh, 2022) and their families (Schott & Badura, 2024; Damen et al., 2022). This stress, a feeling that environmental stimuli are taxing an individual's available resources or endangering their well-being (Lazarus & Folkman, 1984), can have harmful impacts on the health of both patients and their family members (Schott & Badura, 2024; Stein & Rotheram-Borus, 2004). Hence, families must effectively cope with chronic illness to manage stress and benefit members' long-term health (Livneh, 2022).

Coping strategies, 'thoughts and behaviours used to manage the internal and external demands of a stressful situation' (Stephenson & DeLongis, 2020, p. 55), are psychosocial responses to stress. Individual coping may make illness-related stress feel manageable (Felton & Tracey, 1985) for individuals, particularly when strategies are rooted in self-compassion (Ewert et al., 2021). Coping may also occur at the family level (Årestedt et al., 2014). Family members help patients cope with their illnesses (Cole & Reiss, 2013), while also coping for themselves. Furthermore, dealing with chronic illness as a family necessitates ongoing efforts to 'create new patterns for family functioning' (Årestedt et al., 2014, p. 31).

Information plays a role in coping among both patients and their family members (e.g., Mason et al., 2022). Various information behaviours—defined here as the ways in which people interact with information, including information seeking, sharing, and use (Bates, 2010)—may occur within different types of coping actions. For instance, seeking new information, either together or individually, and being attentive to threatening information (*monitoring*) are often identified within health psychology as active coping behaviours (Ben-Zur, 2002). Similarly, avoiding information (*blunting*) (Ben-Zur, 2002) can help people with chronic illness by minimising anxiety or perceived threat (Ben-Zur, 2002). Information use, the *application* of information to a given situation (Kari, 2010), can also play a role in coping as information helps patients form cognitive representations for their illness (Chen, 2015). These representations help patients to make sense of their illness (Chen, 2015; Hagger & Orbell, 2022), particularly understanding symptoms, lifestyle needs, and treatment options (e.g. Clarke et al., 2016; Livneh & Martz, 2014). Information may also be sought and/or used for the purposes of *emotional regulation*, a process of controlling which, when, and how emotions are experienced as well as how they are expressed (Gross, 2014; Trudel-Fitzgerald et al., 2024).

Despite recognition of the relationship between information behaviours and coping, little is known about how family groups use information behaviours in their coping processes through time. Limited work has hinted at complexity as people balance their own and others family members' preferences for illness-related uncertainty (Brashers et al., 2002). Additionally, although scholars have highlighted the fact that illness-related information behaviour varies in intensity over time (Chen, 2016), there is limited understanding of the roles that information may play in *long-term* coping processes. That is, after the confusion and uncertainty of the pre- and initial-diagnosis period (e.g.; Chen, 2015; Benham-Hutchins et al., 2017) has passed, what information behaviour emerges, and how does it relate to coping? Accordingly, we ask the following research questions:

RQ1: *What information behaviours do families perform in the process of coping with chronic illness?*

RQ2: *What role, if any, do these information behaviours play in family-based coping?*

RQ3: *How do the dynamics of information behaviour and family-based coping change over time, if at all?*

Literature review

The process of coping with chronic illness

Coping has been studied within health psychology for over 40 years, and it is conceptualised as a process involving responses to a stressor—an environmental stimulus which may trigger distress in an individual—ideally leading to *psychological adjustment* to that stressor over time (Milky & Nayak, 2023). Coping responses include ongoing and changing *cognitive* and *behavioural efforts* to manage the psychological demands of the stressor (Lazarus & Folkman, 1985). Coping strategies have been classified as having a focus on solving problems or managing emotions, and as passive or active (Biggs et al., 2017). Furthermore, psychological research acknowledges that coping can occur at an individual (e.g.; Ewert et al., 2021) and at a family level (e.g.; Falconier & Kuhn, 2019).

Extant psychology literature establishes that information acquisition plays a part in both the cognitive and emotional aspects of coping (Stanisławski, 2019). Cognitively, a key intersection of information behaviour and coping is at the management of *uncertainty*, or the anticipation of a poorly defined threat (Monat et al., 1972). Uncertainty is important for chronic illness, which represents a source of significant ‘biographical disruption’ requiring individuals to reconceptualise their lived realities with a new understanding of their bodies with chronic illness (Williams, 2000). Relatedly, key issues such as prognosis and optimal therapy are often unknown at diagnosis (Clarke et al., 2016; Chen, 2015). Such uncertainty can elicit negative emotional responses, such as fear, due to feeling cognitively unprepared (Peterson & Moon, 1999). Although uncertainty is not always a negative experience (e.g., Wilson et al., 2005), it can heighten responses to adverse events and dampen responses to positive events (Gu et al., 2020). Indeed, fear of the unknown, a ‘perceived absence of information at any level of consciousness or point of processing’, has been proposed as a fundamental fear, and a key cognitive element of anxiety (Carleton, 2016, p. 5). Critically, information acquisition and avoidance have been posited to both increase and decrease uncertainty. Nevertheless, this work has typically maintained a rather uncomplicated view of information behaviour, often reducing it to survey measures of whether information seeking occurred (or not) (e.g., Dekker & de Groot, 2018; Moos & Holahan, 2007; Stanton et al., 2007).

Coping research studies *cognitive appraisal*, wherein individuals evaluate aspects of their environment to determine appropriate coping responses depending upon whether they see them as stressors (Biggs et al., 2017). Individuals also appraise the efficacy of their coping responses, and may reappraise them over time (Biggs et al., 2017). Much psychology research has explored cognitive appraisal when coping with illness-related stress (e.g., Sun et al., 2024), but it has had limited focus upon the role of information behaviour in cognitive appraisal.

Information behaviour in chronic illness

Information science research has established that chronic illness diagnosis often prompts a variety of information needs for patients (Clarke et al., 2016; Ayers & Kronenfeld, 2007). Information needs also emerge for patients’ family members (Veinot, 2009a; Veinot, Kim, et al., 2011). However, patients and family members may have conflicting assessments of the need for information in specific situations (Brown & Veinot, 2021; Veinot, Kim, et al., 2011).

Despite family members’ potentially distinct information needs, their needs are often poorly met by healthcare institutions (e.g. Yuen et al., 2018). Relatedly, patients and family members often use different information sources. Patients usually have direct access to their health care providers as information sources (e.g., Lamore et al., 2017), while family members rely more upon the patient in their lives for information (Barbarin et al., 2016).

Information acquisition has been established as a means of monitoring individuals’ non-work worlds—everyday life information seeking (Savolainen, 2023)—and can help meet the chronic illness-related information needs which become embedded in the day-to-day lives of patients and

their family members. Some information acquisition within families can be intentional and collaborative, such as *joint information seeking* in which individuals seek to meet a shared information need together in the same time and space, or *tag-team information seeking* where individuals break off to seek information about a shared need and then report back to each other (Veinot, 2009b). Information acquisition within families can also be incidental (Williamson, 1998; Erdelez & Makri, 2020), with patients and/or their family members being exposed to information about chronic illness from their networks or environments, without seeking information intentionally (Veinot, 2009b). This may be particularly salient in the information acquisition of those dealing with chronic illness as individuals may have unrecognised information needs and therefore not seek information actively as often as needed (St. Jean, 2017). Additionally, family members may intentionally serve as proxy informants for others (Reifegerste et al., 2020; Jones, Wright, et al., 2018), potentially prompting awareness of needed information.

To date, information use in relation to chronic illness has received less attention than information acquisition. However, some research has shown that information use can help patients make sense of their experiences by developing illness representations (Chen, 2015, 2016). Health information can be used to assist patients in achieving self-determination, a core psychological concept related to well-being, including forming identity, and asserting autonomy (Lee et al., 2021; Wolf & Veinot, 2015; Zhang, 2016). Individuals can also use information to support their own illness-related decisions and behaviours (e.g., Greyson & Johnson, 2016; Threats & Bond, 2021; Veinot, Meadowbrooke, et al., 2013). They may also use information to influence the health behaviours of family members with chronic illness (Veinot, Kim, et al., 2011; Brown & Veinot, 2021). Nevertheless, we know little about how information is used within family coping, particularly if the information is first acquired collaboratively.

Finally, it is known that chronic illness and associated information needs fluctuate over time. Yet there is limited longitudinal research regarding health information behaviours. Those who used longitudinal methods have primarily focused on individual information behaviours (St. Jean, 2012; St. Jean et al., 2018; Chen, 2012, 2017). Little work has investigated longitudinal information behaviour within family groups, and even less has charted its relationship to illness-related coping.

Methods

Study data were collected with families managing one of two chronic illnesses: HIV/AIDS or type 2 diabetes in a state in the US Midwest. HIV/AIDS and diabetes were selected to provide variety in treatment and lifestyle requirements. Families participated in the study for two years on average, including up to five contacts. In this paper, we use the symbols 'T1', 'T2', 'T3', 'T4', and 'T5' to designate which of the five contacts were the source of reported data. This study was approved by the university's Health Sciences and Behavioral Sciences Institutional Review Board.

Recruitment

Patients were recruited via flyers through illness-specific nonprofits; via in-person recruitment in waiting rooms at a large veterans health affairs centre; or a university's online participant-recruitment service. Recruitment used quota-sampling to ensure roughly equal family numbers from each illness group. Patients recruited their family members into the study using snowball sampling. The definition of *family member* was left to patients' discretion to allow for close people outside of biological and legal family. Participants were provided with a \$20 incentive payment after each interview. Thirty-eight family groups were ultimately recruited, including a total of 97 individual patients and family members.

Data collection

Data collection methods included individual and family group interviews and individual surveys (figure 1). Semi-structured individual interviews (Johnson, 2002) followed the ‘family case method’ (Handel, 2014) whereby individual perspectives were sought about the family (Åstedt-Kurki et al., 2001). Additionally, family group interviews were conducted as modified focus groups (Eggenberger & Nelms, 2007). Interviews were conducted at participants’ chosen locations, lasted 90-120 minutes, were audio-recorded, transcribed verbatim, verified, and de-identified.

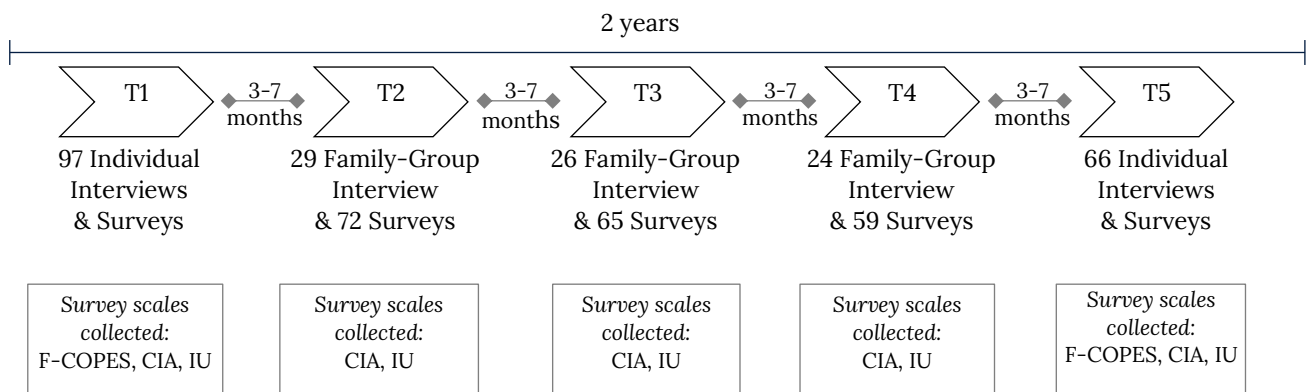


Figure 1. Data collection timeline.

F-COPES = Family crisis-oriented personal evaluation scales;
CIA = Collaborative information acquisition, IU = Information use.

Measures

Surveys, completed individually by both patients and family members, included demographic questions and, for patients, health-related questions (self-rated health, current therapy, current laboratory measures). Surveys for both included scale indices of collaborative information acquisition, information use of collaboratively acquired information (Jones, Piscotty, et al., 2023; Veinot, Meadowbrooke, et al., 2013; Veinot, 2009b), and family coping styles (McCubbin et al., 1981). Subscales for all three topic scales evaluated specific coping strategies used, form of collaboration in information acquisition, and application domain of information use and are listed and described in Table 1.

Measure name		Description	Sample question
Overall coping (F-COPES) (28 questions) (McCubbin, et al., 1981)			Response prompt: When we face health-related problems or difficulties in our family, we respond by... Response scale: 1) Strongly disagree, 2) Disagree, 3) Neutral, 4) Agree, 5) Strongly agree
Acquiring social support (9 questions)	Families' ability to gain support from personal social contacts ¹	-	Sharing our difficulties with relatives.
Mobilising family to acquire and accept help (3 questions)	Families' ability to access community resources and other help ¹	-	Seeking assistance from community agencies or programs designed to help families in our situation.
Passive appraisal (4 questions)	Families' ability to accept problematic issues and minimise reactivity ¹	-	Accepting stressful events as a fact of life.
Reframing (8 questions)	Families' ability to redefine stressful events to feel more manageable ¹	-	Defining the family health problem in a more positive way so that we do not become too discouraged.
Seeking spiritual support (4 questions)	Families' ability to obtain spiritual or religious support ¹	-	Attending religious services.
Overall collaborative information acquisition (CIA) (13 questions) (Veinot, 2009b; Jones, Piscotty, et al., 2023; Veinot, Meadowbrooke, et al., 2013)			Response prompt: In the past 4 months, I got diabetes (or HIV/AIDS) information when... Response scale: 0) Never, 1) Rarely, 2) Occasionally, 3) A moderate amount, 4) A great deal
Joint information acquisition (6 questions)	Multiple individuals seeking health information synchronously to meet an acknowledged, shared information need ²	-	With a family member, I contacted people or organisations that might help me.
Mediated information acquisition (7 questions)	Individuals are exposed to health information through social interactions that may not be intended to be health-related interactions ²	-	On his or her own, a family member contacted people or organisations that might help me.
Overall information use (IU) (16 questions) (Jones, Piscotty, et al., 2023; Veinot, et al., 2013)			Response prompt: In the past 4 months, I used diabetes (or HIV/AIDS) information that my family helped me get in order to... Response scale: 0) Never, 1) Rarely, 2) Occasionally, 3) A moderate amount, 4) A great deal
Emotional (4 questions)	Information used to meet psychological or emotional needs	-	Help me feel hopeful about my diabetes (or HIV/AIDS).
Decision-making and health behaviour (3 questions)	Information used to make decisions or to change/validate health behaviours	-	Make diabetes- (or HIV/AIDS-) related treatment or self-care decisions.
Health/social care interactions (4 questions)	Information used in conversations with medical providers or community organisations	-	Double-check my health care provider's recommendations for managing diabetes (or HIV/AIDS).
Family interactions (5 questions)	Information used for family interaction	-	Educate a member of my family about diabetes (or HIV/AIDS).

Table 1. Survey scale measures.

Data analysis

Qualitative data analysis

Interviews were analysed using a multistage approach with NVivo software (QSR International Pty Ltd, 2020). This started with provisional and structural coding (Saldaña, 2009) using a preliminary codebook based on collaborative information behaviour (Veinot, 2009b; Veinot, Kim, et al., 2011) and family coping (McCubbin et al., 1981) research.

Second-cycle inductive coding (Saldaña, 2009) then focused on study research questions. This included pattern and process coding (Saldaña, 2009) to develop an understanding of how coping processes unfolded in study families.

Quantitative data analysis.

Scale values were calculated by combining each participant's responses to survey questions for the given scale/subscale at each contact and then dividing this by its number of questions. This resulted in final values that ranged according to the original survey response scale. These were either 0-4 (never to often) for both information behaviour scales or 1-5 (strongly disagree to strongly agree) for the coping scale. These scale values were summarised descriptively and compared within families by subtracting the highest individual scale value from the lowest within each family at each time.

Results

Demographics

In total, 97 individuals and 38 family groups participated. Of these, 23 families and 66 individuals remained enrolled until the last contact (T5) (*table 2*). Participants were majority White/Caucasian (63%) or Black/African American (30%). The sample included more women than men.

	Time 1 (T1)	Time 2 (T2)	Time 3 (T3)	Time 4* (T4)	Time 5 (T5)
<i>Family groups by disease type</i>					
Diabetes	20	15	13	13	13
HIV/AIDS	18	14	13	11	10
Total family groups (retention rate)	38	29 (76%)	26 (68%)	24 (63%)	23 (61%)
<i>Individuals – race/ethnicity</i>					
White	61 (63%)	48 (67%)	41 (63%)	38 (64%)	41 (62%)
Black/African American	29 (30%)	19 (26%)	21 (32%)	17 (29%)	21 (32%)
Hispanic/Latino	4 (4%)	4 (6%)	2 (3%)	2 (3%)	2 (3%)
Asian/Pacific Islander or Native American	3 (3%)	1 (1%)	1 (2%)	2 (4%)	2 (3%)
Total Individuals (Retention Rate)	97	72 (74%)	65 (67%)	59 (61%)	66 (68%)
<i>Individuals – gender</i>					
Women	54	39	36	35	39
Men	43	33	29	24	26
<i>Patient health status</i>					
Months since diagnosis at study start. (median [IQR])	132 [72-412]	--	--	--	--
Self-reported health** (median [IQR])	3 [3-4]	3 [3-4]	3 [3-4]	3 [3-4]	3 [3-4]
CD4 count (HIV) [†] (median [IQR])	562 [333.25- 880.50]	568 [503- 887.50]	550 [407.50- 837.50]	675 [507.25- 870]	700 [446-779]
Viral load (HIV) [‡] (median [IQR])	0 [0-75]	49 [36-65.25]	58 [48-32500]	62 [45- 10056.25]	36 [18-48.5]
HbA1c (diabetes)* (median [IQR])	7 [6.75-8.35]	7 [6.43-8.63]	7 [6.83-8]	7 [6.45-7.45]	7 [6.25-7.65]
*Includes opt-in home tour, resulting in exclusion of some at Time 4 only. ** Self-reported health ranges from 1 = poor to 5 = excellent [†] CD4 measures immune cells in blood, higher values indicate better HIV control. Tested regularly for monitoring of HIV status in treatment (Hayden, et al., 2017) [‡] Viral load measures the amount of HIV cells in blood, higher values indicate more active/less controlled HIV, sometimes tested to monitor for possible treatment failure (Hayden, et al., 2017) * HbA1c measures 3-month average blood sugar percentage in blood, 7 or lower generally indicates better diabetes control (Eyth, et al., 2025)					

Table 2. Participant demographics.

Family illness context

Most patients and their family members had been dealing with HIV or diabetes for multiple years (median 132 months; Table 2). Patients, on average, reported their health as being fair to good throughout the study (Table 2). Relatedly, median disease-related count values (CD4 counts and viral loads for HIV patients and HbA1c for diabetic patients) were also largely consistent throughout the study and indicative of good disease control. As such, family members and patients described the illness as a background stressor in their day-to-day lives, rather than as an acute current stressor. As one family member described:

...once you find out this is your lifestyle - this is how you need to eat and this is how you need to take care of yourself - that's just how you live...he's had [diabetes] so long...it's just his lifestyle. [DF-F2-00-01-01, family member, T1]

RQ1: What information behaviours do families perform in the process of coping with chronic illness?

Most participants had reported performing family coping (F-COPES) behaviour infrequently during the study (Table 3, measured at first and last contacts). Coping scores were low across all five coping categories, with median values below neutral (3) for overall coping as well as 3 of the 5 coping subscales (Table 3). *Seeking spiritual support* and *acquiring social support* had slightly higher median values, but they were still below agreement. Coping subscales showed little difference between family members.

Mean (SD)	Time 1 (T1) n = 97	Time 2 (T2) n = 72	Time 3 (T3) n = 65	Time 4 (T4) n = 59	Time 5 (T5) n = 66
<i>Agreement with use of coping strategies*</i>					
Mobilising family to acquire and accept help	2.35 (0.639)	--	--	--	2.18 (0.552)
Passive appraisal	2.59 (0.672)	--	--	--	2.58 (0.488)
Reframing	2.47 (0.369)	--	--	--	2.29 (0.340)
Acquiring social support	3.53 (1.07)	--	--	--	3.13 (0.689)
Seeking spiritual support	3.29 (0.790)	--	--	--	3.27 (1.09)
Overall coping	2.91 (0.416)	--	--	--	2.73 (0.403)
<i>Frequency of information use behaviours**</i>					
Information used for health behaviour and decision-making	2.01 (1.15)	1.66 (1.16)	1.32 (1.34)	1.02 (1.25)	1.07 (1.30)
Information used for psychological or emotional purposes	1.51 (1.14)	1.33 (1.12)	1.12 (1.08)	0.690 (0.979)	0.790 (1.04)
Information used for interacting with health and social care	1.36 (1.17)	1.11 (1.09)	0.873 (1.14)	0.487 (0.924)	0.544 (0.951)
Information used for family interaction	1.34 (1.11)	0.959 (0.943)	0.764 (1.01)	0.396 (0.759)	0.495 (0.785)
Overall information use	1.51 (1.01)	1.18 (0.983)	0.981 (1.01)	0.547 (0.828)	0.667 (0.883)
<i>Frequency of collaborative information acquisition**</i>					
Mediated information acquisition	0.760 (0.688)	0.701 (0.744)	0.612 (0.745)	0.371 (0.509)	0.472 (0.628)
Joint information acquisition	0.715 (0.739)	0.787 (0.861)	0.558 (0.816)	0.342 (0.628)	0.344 (0.518)
Overall collaborative information acquisition	0.830 (0.763)	0.755 (0.771)	0.631 (0.789)	0.370 (0.555)	0.415 (0.546)
* scales range from 1 (strongly disagree) to 5 (strongly agree)					
** scales range from 0 (never) to 4 (often)					

Table 3. Self-reported coping strategies and information behavior over time.

Information Acquisition

The reported frequency of collaborative information acquisition was similarly low. For collaborative information acquisition, overall collaborative information acquisition and the joint and mediated acquisition subscales had median values between 0 (never) and 1 (rarely) for all time points.

Despite the overall low survey scale values, qualitative data revealed that coping and information behaviours were built into routines for managing the illness. Specifically, healthcare-recommended routines such as quarterly laboratory testing, daily blood sugar tracking, medication taking and follow-up healthcare provider visits were anticipated, regular information sources. One patient explained, '*...I'm always gonna keep up with it because I have doctor's appointments on a regular basis, take meds on a regular basis, get bloodwork and we'd see...if they're not working in the right direction*' [HP-M1-00-24-00, patient, T3]. When things were going well, and with the confidence that they could detect a negative change (*reframing*), many participants chose not to actively dwell upon the illness.

Observation of the patient was also an important and ongoing source of information, both for patients and family members. This could also be assessed through daily routines, like tracking adherence by watching a patient take medication at a shared meal, or it could be discovered through regular conversation. A family member explained, '*I'm...always checking on [patient], I'll call him on my breaks or my lunch, and then I call him on my way home*' [HF-F2-00-17-02, T3]. These monitoring behaviours produced an awareness of the status of illness management which, when it met requirements, also permitted low ongoing coping effort through cognitive reframing of the illness-related stress. One family member explained, '*...in dealing with him, because he's not sickly or anything like that, it's not a big deal*' [HF-F1-00-12-01, family member, T5].

Both patients and family members also acquired information about their illness incidentally through monitoring their environments. Specifically, other people with the illness whom they knew personally were monitored, allowing them to appraise their own illness management by comparison. A participant explained, '*My neighbour of long time, his health was failing because of diabetes. I hear it everyday...*' [DF-M1-00-10-01, family member (also diabetic), T5]. As this quote shows, such information was obtained in regular conversations. Information could also be obtained through ongoing media consumption. For instance, a patient with HIV discussed a news story about a person having the HIV virus eradicated from their body. He said:

I was at work when I first heard [radio story] about it, it was exciting. That's major...Gives renewed hope to a lot of people. But, yeah, it's not really so much for myself but it makes...finding a cure a little bit more realistic...it's refreshing to hear it's not been forgotten. [HP-M2-00-14-00, patient, T5]

Information acquisition focused on monitoring the situation sometimes gave way to more active information seeking. This typically occurred either because of a change in patient's health status or therapy, or due to emerging scientific discoveries like the one above. Some patients engaged in active information seeking to improve their current therapy after incidental information acquisition, again often obtained via routines like watching television or listening to the radio. For instance, an insulin pen advertisement on television prompted a diabetes patient and her family members to seek information on it as they knew she was struggling to maintain adherence to her insulin. The family discussed it at the T3 family group interview:

DP-F2-00-05-00 (patient): There's a lot of advertising lately about a pen...so that you don't have to do the vial and the needle and all that.

DF-F2-00-05-01 (wife): It doesn't have to be refrigerated like the other things.

DF-F2-00-05-02 (*mother*): It'll come to you right in the mail, you just have it sent to your house.

...

DP-F2-00-05-00 (*patient*): But when I asked [doctor] about it, I was told I can't get it...[health system] will not provide it to me

When the patient was unsuccessful, another family member continued to independently seek information without being directly asked to do so, to find an alternative means of access with a goal of sharing it with her stepdaughter.

...it's something that DP-F2-00-05-00 wanted to be on. I think DP-F2-00-05-00's issue was more a financial ...And my sister is usually very good at knowing places that would...help her financially, or programs that are out there ..."

[DF-F2-00-05-03, *family member*, T5]

Information Avoidance

Many participants wished to avoid information about potential negative health consequences of their condition. Rather, they wanted to deal with it only if or when complications arose, focusing instead on maintaining healthy behaviour in the present. However, avoidance of information about potential negative consequences was not universal, even within families. A family member speaking about the risk of diabetes-related complications, said: *'I'm scared to death. I don't want my legs to be amputated or my toes or my feet, it's scary ... and it seems to me that my sister and my mom were in denial and it's like...I'm too smart...to be in denial'* [41-DF-F2-00-41-04, T5].

Information Use

Use of information acquired collaboratively was infrequent. Median values were between 0 (never) and 1 (rarely) for all time points except T1 when the median value was 1.47 (between rarely and occasionally) and T2 when the value was 1 (rarely). Most subtypes of information use followed this pattern but with even lower median values, except for information use for decision making, which had a median value of 2 (occasionally) at T1 and 1.66 (between rarely and occasionally) at T2, and 1 (rarely) at T3. Information used for emotional purposes was the next most frequently reported behaviour, with median values of at least 1 (rarely) for T1-T3.

Notably, there was frequent quantitative disagreement in the reports of the frequency of these behaviours across different people in the same family unit (Table 4). The most pronounced differences were seen for information use: all subscales had a median within family difference above 1 for the first 3 contacts.

Median (IQR)	Time 1 (T1) n = 97	Time 2 (T2) n = 72	Time 3 (T3) n = 65	Time 4 (T4) n = 59	Time 5 (T5) n = 66
<i>Coping strategies*</i>					
Mobilising family to acquire and accept help	0.66 (0.33-1.00)	---	---	---	0.67 (0.33-0.83)
Passive appraisal	0.75 (0.50-1.13)	---	---	---	0.50 (0.25-0.75)
Reframing	0.38 (0.13-0.50)	---	---	---	0.25 (0.13-0.63)
Acquiring social support	0.78 (0.44-1.11)	---	---	---	0.56 (0.39-0.78)
Seeking spiritual support	0.75 (0.50-1.19)	---	---	---	0.75 (0.13-1.00)
Overall coping	0.26 (0.10-0.48)	---	---	---	0.32 (0.11-0.46)
<i>Information use behaviours**</i>					
Information used for health behaviour and decision-making	1.33 (0.67-2.33)	1.33 (0.67-1.67)	1.00 (0.33-2.00)	0.83 (0.00-2.17)	0.67 (0.00-2.17)
Information used for psychological or emotional purposes	1.50 (1.00-2.06)	1.38 (0.25-1.56)	0.75 (0.50-1.50)	0.75 (0.00-2.25)	0.50 (0.00-1.50)
Information used for interacting with health and social care	1.50 (0.75-2.25)	1.29 (0.75-1.75)	0.63 (0.00-1.50)	0.25 (0.00-0.88)	0.25 (0.00-1.38)
Information used for family interaction	1.20 (0.80-1.80)	0.90 (0.45-1.20)	0.80 (0.10-1.60)	0.00 (0.00-1.00)	0.20 (0.00-0.60)
Overall information use	1.19 (0.84-1.78)	1.06 (0.50-1.56)	0.66 (0.27-1.31)	0.31 (0.00-0.95)	0.31 (0.19-0.88)
<i>Collaborative information acquisition**</i>					
Mediated information acquisition	0.79 (0.43-1.11)	0.43 (0.14-0.82)	0.57 (0.11-1.18)	0.36 (0.14-0.57)	0.43 (0.14-0.89)
Joint information acquisition	0.67 (0.33-1.17)	0.67 (0.17-1.00)	0.42 (0.17-0.67)	0.17 (0.00-0.58)	0.33 (0.00-0.67)
Overall collaborative information acquisition	0.81 (0.46-1.00)	0.46 (0.15-0.85)	0.46 (0.15-0.88)	0.19 (0.06-0.67)	0.23 (0.08-0.85)
Note: Lower values indicates greater agreement; higher values indicate greater disagreement in reported behaviours. * scales range from 1 (strongly disagree) to 5 (strongly agree) ** scales range from 0 (never) to 4 (often)					

Table 4. Median within-family agreement for information behaviour and coping subscales.

Qualitatively, one of the primary uses of information obtained collaboratively was *appraisal* of the status of the illness and of ongoing coping strategies and health behaviour. This typically involved comparisons between what was currently happening and information about optimal disease management, allowing participants to determine if their current coping activities and resources were sufficient, providing cognitive reassurance if this appraisal was positive or prompting adjustments to either coping or resources if not. For example, a diabetes patient said that she was ‘...eating a little better...doing a little bit more of what I am supposed to and not the stuff I’m not supposed to’ [DP-F1-00-10-00, T2]. Alternatively, participants compared their own or family member’s health status to other patients. For instance, after discussing his neighbour’s failing health, DF-M1-00-10-01 said at T5, ‘I thank God that nothing has occurred to me’.

RQ2: What role, if any, do these information behaviours play in family-based coping?

Overall, the greatest frequency of, and largest correlations between information behaviours and coping, were for seeking spiritual support and acquiring social support. Therefore, we focus on these coping types here. For seeking spiritual support, Table 3 shows that this strategy was the most commonly used approach. Although information behaviours may play some role in seeking spiritual support, quantitative analyses indicated that this was limited (Table 5). There was a weak, but significant, correlation between seeking spiritual support and collaborative information acquisition (r^2 : 0.194). This focused primarily on mediated information acquisition (r^2 : 0.182). Correlations with information use were slightly stronger, but still weak (ranging from r^2 of 0.207 for information use for healthcare interactions to 0.285 for information use for decision making).

R2 (p-value)	Acquiring social support	Mobilizing family to acquire and accept help	Passive appraisal	Reframing	Seeking spiritual support	Overall coping
<i>Information use behaviours</i>						
Information used for health behaviour and decision-making	0.38***	0.24***	-0.15	0.19**	0.28***	0.38***
Information used for psychological or emotional purposes	0.42***	0.34***	-0.17**	0.14	0.27***	0.37***
Information used for interacting with health and social care	0.31***	0.24***	-0.11	0.17**	0.21**	0.31***
Information used for family interaction	0.37***	0.30***	-0.04	0.27***	0.23***	0.38***
Overall information use	0.39***	0.31***	-0.14	0.22***	0.27***	0.38***
<i>Collaborative information acquisition</i>						
Mediated information acquisition	0.40***	0.28***	-0.01	0.20**	0.18**	0.41***
Joint information acquisition	0.25***	0.19**	-0.09	0.22***	0.10	0.24***
Overall collaborative information acquisition	0.36***	0.27***	-0.03	0.22***	0.19**	0.37***
*** - $p < 0.01$, ** - $p < 0.05$						

Table 4. Self-reported coping strategies and information behavior over time.

Qualitatively, many participants made references to using faith and spiritual information to respond to or motivate coping with current realities or to appraise resources or regulate emotional responses to future potentialities (Table 6). Information shared about relevant bible passages was used to help participants figure out next steps and spiritual reflection was sometimes associated with other practical tasks, as this HIV positive patient described: 'I pray every morning...I do my exercises...and then I take my medication, read the Bible' [HF-M1-00-44-01, T1]. Faith and belief could also be used to reinforce information from medical providers (Table 6).

Related information types and behaviours	Description	Sample Quotes
Responding to current illness realities	Thanking God for current health	'And, I've never had that problem [severe blood sugar crashing], thank God'. [DF-M1-00-10-01, family member (also diabetic), T1] 'By the grace of God, I'm still here'. [HP-F1-00-47-00, patient, T5]
Finding motivation to cope with current illness realities	Engaging with spiritual text/activities (Bible reading, praying, attending church services)	'I read my Bible...different verses that people suggest to me...[it] really puts me into the mindset of motivation and of doing positive things especially when I'm down...I turn to...meditation, reading the Bible or something, just so I can get that positive vibe back'. [DP-F1-00-10-00, patient T3] '...when I get frustrated, I just turn around and say a little prayer in my head, "God take this away from me", and He does'. [HP-M2-00-21-00, patient, T5]
	Trusting in medicine through faith in God	'I was taking the medicine, because...I have sense enough to know that God can work through doctors and work through the medication...God is getting through [the doctors] to help me'. [HP-F1-00-44-00, patient, T1]
Appraising resources for future potentialities	Making prayer requests	'...[my close friend from church] listens, prayerful, she would pray with me, she would help me to come to a solution'. [HF-F1-00-26-01, family member, T1]
	Believing that God will help when issues arise	'... the last time I've been tested [for HIV], I hadn't got it yet but you know, I believe so much in God that it's not bothering me. I'm not scared of it, that's the difference'. [HF-M1-00-44-01, family member, T1] 'We're both...believers in "Whatever is gonna happen is going to happen". I mean you have God and the doctors. The doctors have control over a lot of things, but God has control over a lot more, so...' [HF-M2-00-02-01, family member, T5]
Regulating emotional response to future potentialities	Future or current complications are part of God's plan and nothing to be afraid of	'He was like, "Honey, you've got too much on your plate again. Didn't God slow you down?"...Cause God did your knee because you were always constantly going". [DF-F2-00-11-02, family member, T5] 'I'm not scared of HIV because I believe in God and...if you really believe in God and you know where you're going, which is heaven, I'm not worried about it because you're not going to die until He wants you to come home anyway no matter what you have'. [HF-M1-00-44-01, family member, T1]

Table 6. Seeking spiritual support sample quotes and related information types.

Acquiring social support was positively correlated with all information use and acquisition subscales. The strongest correlations were between acquiring social support and mediated information acquisition and information use for emotional purposes (both had r^2 values above 0.40).

Qualitatively, acquiring social support could be seen with participants reaching out to others for help. One family member reached out to family friends to share about current realities of patient health and process related emotions; ‘They just listened to me vent. They are my ventees. They received my venting’ [DF-F2-00-05-01, family member, T5]. Sometimes acquiring social support also gave people access to mediated information about the illness from others. This could also lead into reappraisal of one’s experiences in a way that made them less fear-inducing. For instance, this diabetic patient received reassurance from a close friend during a hospitalisation:

... [close friend] called and asked how I was doing... I was telling him how upset I was about them...giving me insulin right away, and he said, ‘Well, that’s just because they can control it better’...While you’re hospitalised. [DP-M2-00-08-00, patient, T1]

RQ3: How do the dynamics of information behaviour and family-based coping change over time, if at all?

Although quantitative scores for both types of information behaviour and family-based coping remained relatively low throughout the study, some participants did demonstrate fluctuations (Figures 2-3). Changes were primarily among those who started the study reporting higher levels for these behaviours, with decreasing information and coping behaviours by study completion (families 3, 10, or 11 in Figures 2-3). Most participants who started the study reporting lower values maintained low values throughout. This was also evident in participant accounts, like this family member: ‘I guess when I cross that path, you have to take the bad with the good. Or the good with the bad, however you wanna say it. I just have to wait’ [DF-M1-00-10-01, family member, T5].

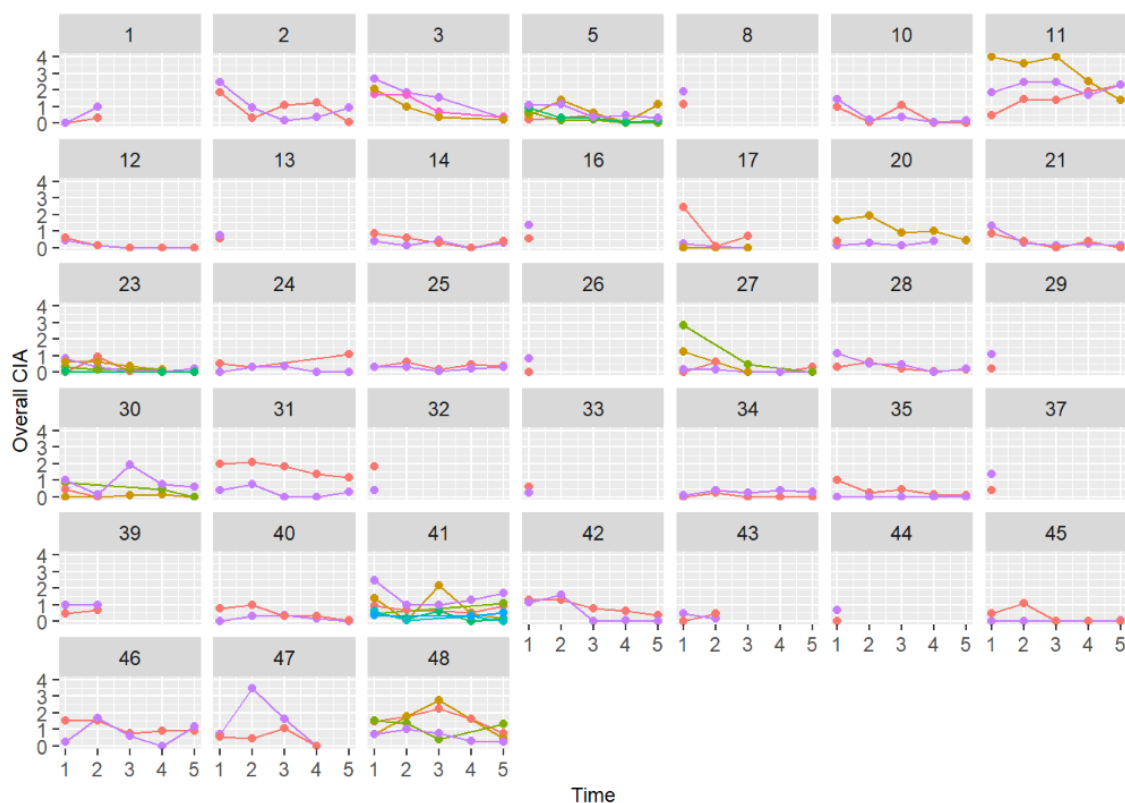


Figure 2. Overall collaborative information acquisition (CIA) over time. Each color represents a unique participant; each sub-graph represents a unique family group. Response scales range from 0, never, to 4, often.

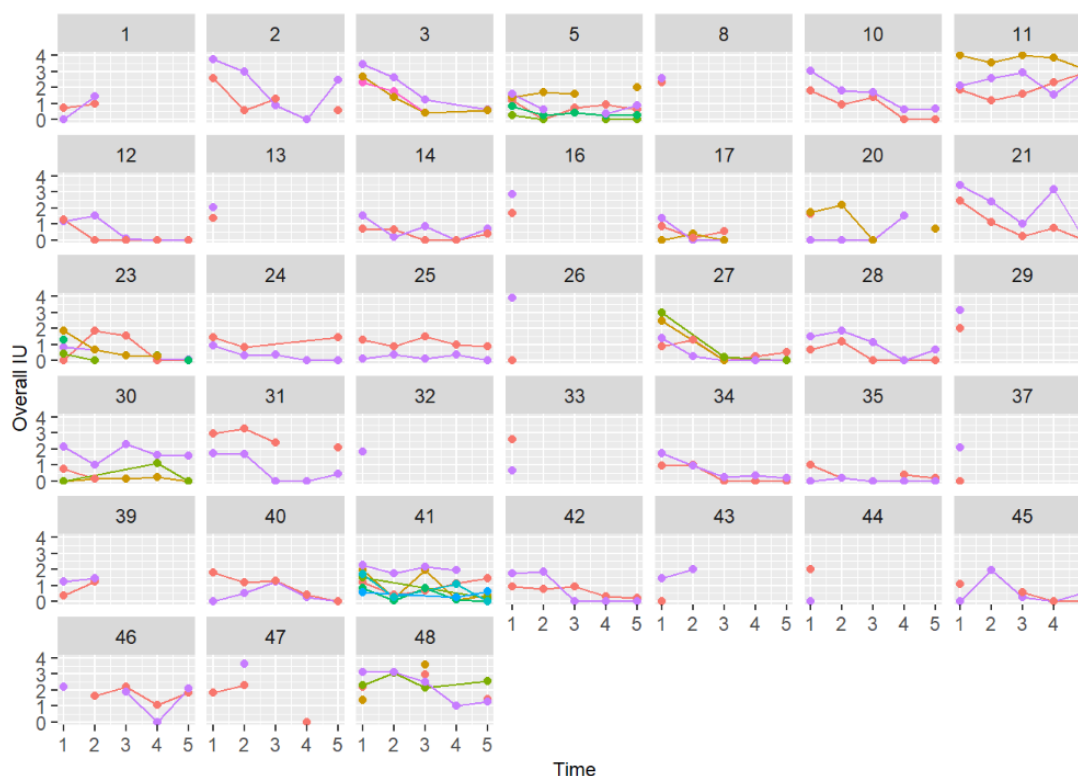


Figure 3. Overall information use (IU) over time.

Each color represents a unique participant; each sub-graph represents a unique family group. Response scales range from 0, never, to 4, often.

When information behaviour frequency did increase, it was typically transient. Qualitatively, some participants experienced illness-related changes, which necessitated greater information acquisition to maintain coping. This family provides an example at T4:

DF-F2-00-25-01 (*wife*): I look up his medications...to find out...side effects and...he had a bad cough...and the side effect from one of those pills was coughing...

Interviewer: ... so you were able to figure that out by looking online....

DP-M2-00-25-00 (*patient*): ...I told...Dr. [name] about it and she switched me over to something else.

This approach to dealing with transient changes as needed is also evident in this family member's description:

...we just deal with things as they come up...she's...at a level where it doesn't bother her until she gets sick...It's like being on a level plane and then all of the sudden she gets sick... things get her a little out of whack and then things come back into whack. [HF-M2-00-02-01, T5]

There were also some cases in which participants responded that they were performing less information behaviour in the survey, even as they described an increase in routinised forms of this behaviour in interviews. For instance, family 11 did not exhibit an upward trend in information acquisition or use but the patient described his development of new information behaviour routines at T3 after attending a diabetes education seminar earlier:

I walked into the grocery store... and right away I am picking up boxes and looking at carbohydrates, sugar, how much salt is in it...and then it hit me I never used to do this...
[DP-M2-00-11-00]

Discussion

Most participants had reached a state in which they utilised a persistent form of coping to manage illness on a day-to-day, routine basis. Overall, patients and family members reported low levels of family-based coping and collaborative information behaviours throughout the study which generally continued to trend down as the study progressed. Even so, participants still engaged in some information acquisition and use, primarily geared towards monitoring the status of the illness and appraising their current approach to managing it. Primarily, related information was acquired incidentally through health management routines and ongoing observation of the patient and the environment. Information gained at various times was also used when forming new health management routines, such as checking food labels at the grocery store. These behaviours helped participants to determine if there was a need for more information, or for any shifts in their coping approaches. The reliance upon routine information acquisition and monitoring, as well as ongoing appraisal, fell under what we call *persistent coping*. We posit that this occurs when there is a chronic, low-level stressor for which current coping processes are sufficient. Though reported values of coping and information behaviour were generally low, weak but significant correlations were observed between support-seeking coping strategies (spiritual or social) and each of: mediated information acquisition and information use for emotional purposes, healthcare or family interactions, and decision-making.

Information behaviour in persistent coping aligns with Savolainen's (2023) model of 'everyday life information seeking'. This model holds that individuals monitor their non-work worlds on an ongoing basis to make sense of them. Everyday life information seeking centres around mastery of life, which provides a sense of control and management regarding how well the 'order of things' in life has been maintained (Savolainen, 1995). However, study findings expand upon prior everyday life information seeking work by providing a detailed account of mastery of life in an illness context and expand on findings in other contextual domains about the impact of gained confidence on information behaviours over time (Greyson, 2016). This is also seen in the downward trajectory of observed information behaviour frequency, as greater confidence may have led to decreased perceived information need. Furthermore, the present research shows how appraisal happens on a repeated basis, and how deviations from the expected can result in increased stress and temporary information seeking until an acceptable stress level is again reached.

Psychology research asserts that coping is a process with multiple stages aimed at reacting to a stressor with eventual psychological adjustment (Milky & Nayak, 2023). Coping begins at cognitive appraisal, with reappraisal of coping strategies happening as coping achieves psychological adjustment (Biggs et al., 2017). We enrich this portrait of appraisal and re-appraisal by characterising the ongoing information behaviours that support them. We contend that the information behaviours and ongoing reappraisal revealed in study findings may be a previously unidentified, information-focused coping strategy.

This study also follows prior work (Brown & Veinot, 2021; Veinot, Kim, et al., 2011) in complicating the idea of collaboration in information behaviours. Study participants shared a stressor with their family members but did not necessarily engage in the same coping and information behaviours. This was evident, for example, in how much participants wanted to know about what could happen in the future. Similarly, prior research has established that people have different tolerance for uncertainty (e.g. Brashers et al., 2002; Guan et al., 2021; Massazza et al., 2023). Practitioners should consider different roles and preferences in families managing chronic illness when designing information products and services. For instance, information products could provide introductions

to everyone, alongside more in-depth information that users could choose to view or not through 'expand' options or links.

Study findings reinforce the idea that information has important affective dimensions (e.g., Liu et al., 2025; Savolainen, 2014; Nahl, 2007). A common use of information in family-based coping was for emotional regulation, such as for maintaining hope. Relatedly, information avoidance was also present in these data and this behaviour has long been understood as an effort at emotional regulation through the avoidance of fear (Heinström et al., 2022; Cheng, Zhang, et al., 2024). Continuing to delve into these affective dynamics of information behaviour in chronic illness may assist with supporting the mental well-being of chronically ill individuals and their family members.

This study also demonstrated that a key means of coping with the stress of chronic illness is spiritual. Indeed, many participants turned to their faith for motivation and emotional regulation. Some also treated spiritual texts as information sources to manage uncertainty, similar to previous health research (Cadge & Bergey, 2013). These findings provide additional empirical evidence indicating the importance of everyday lived religious practices, such as bible reading or prayer, as important information activities for meaning making about higher things in life, like chronic illness (Caidi et al., 2025) indicating that facilitation of spiritual information seeking (Nangia & Ruthven, 2023) may be an important place of intervention for health information providers. However, more research is needed to better understand if this spiritual link is relevant to persistent coping in general, or specifically persistent coping with chronic illness as health issues have long been understood to prompt increased religiosity (e.g. Roger & Hatala, 2018).

Most study families engaged in incidental, routinised behaviour rooted in observation rather than active information seeking behaviour throughout the study. This affirms prior work indicating that chronic illness patients transition to monitoring after developing acceptance and management strategies (Chen, 2016). This paper extends that insight by showing why people may subsequently transition out of this monitoring phase to more active seeking, such as health status changes and scientific advancements. Future work should consider how such transitions might be leveraged in health information practice to encourage more timely satisfaction of previously unrecognised information needs (St. Jean, 2017).

Limitations

Participants came from one midwestern US state, making geographical generalisability uncertain, particularly concerning spirituality-related findings. Such findings may be more common in the US than in other national contexts due to the greater religiosity of the US population as compared to other more secular nations (Fahmy, 2018). Relatedly, the high representation of middle-aged and older adults, as well as African American adults (Cox, 2025), may have increased the resonance of spiritual coping and other demographic groupings may demonstrate different patterns of coping. Quantitative results are reported descriptively only due to limited statistical power. Results could also differ for other chronic illnesses with different trajectories of symptoms and complications, or treatment effectiveness. Indeed, most participants having stable health may partly explain the finding of persistent coping.

Conclusion

This study investigated the relationship between family-based coping and information acquisition and use over time in chronic illness. Findings revealed that information acquisition and use observed were embedded into routine as a part of day-to-day monitoring of the chronic illness being managed. This took place until changes triggered movement out of this monitoring phase. Findings also identified a persistent form of coping involving sustained information use for cognitive reappraisal. This information behaviour also aided families in maintaining a sense of control and regulating negative emotions, allowing participants to feel hope for the future.

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About the authors

Dr. Lindsay Brown received her PhD in information from the University of Michigan's School of Information. Her research interests are health disparities and inequities, health informatics, and the role of information and information technology in health for marginalised groups. She can be contacted at likathry@umich.edu <mailto:likathry@umich.edu>

Dr. Tiffany Veinot is the Joan C Durrance Collegiate Professor of Information, a professor of Learning Health Science, and a professor of Health Behaviour and Health Equity at the University of Michigan's School of Information, Medical School, and School of Public Health respectively. She received her PhD from the University of Western Ontario and her research interests include community health informatics and using health technology to reduce health disparities and improve the health of marginalised groups. She can be contacted at tveinot@umich.edu <mailto:tveinot@umich.edu>

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