Decisions to Seek and Share: A Mixed Methods Approach to Understanding Caregivers Surrogate Information Acquisition Behaviors

DISSERTATION

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Abstract

Introduction: Surrogate information seeking (SIA), or the act of seeking information on behalf of another, is a common health behavior. However, the phenomena remains under studied. The first study tests key propositions of the Lay Information Mediary Behavior (LIMB) model in order to understand surrogates' motivations for SIA, engagement in active and passive SIA behaviors, and willingness to share information with care recipients. The second study tests an extended Cognitive Mediation Model (CMM) to further understand the cognitive mechanisms linking surrogates' seeking and sharing behaviors. **Study 1:** Semi-structured interviews were conducted with caregivers of breast, endometrial, and ovarian cancer patients (*n* = 19). Thematic analysis of these interviews suggested that caregivers engaged in active and passive SIA for intrinsic and extrinsic reasons. Caregivers predominantly sought information to close their own knowledge gaps, but they still shared new or novel information with their care recipient. **Study 2**: A cross-sectional survey was administered to the caregivers of breast cancer patients diagnosed within the last two years (*n* = 130). Partial support was found for the proposed model. Distal variables including surveillance gratifications, information requests, and caregivers' perception of patient information gathering capacity were associated with active and passive SIA behaviors. SIA behaviors, in turn, were associated with attention and elaboration. Perceived knowledge and elaboration were associated with sharing information with care recipients, but cognitive processing did not play a role in caregivers' perceptions of knowledge. **Conclusion:** Taken together, the studies in this dissertation suggest that while information surrogates are occasionally extrinsically motivated, most SIA is intrinsically-motivated. Caregivers engage in active and passive SIA, and share with their care recipients. Additional motivations, such as surveillance gratifications and perceived patient information gathering capacity, were associated with SIA behaviors, which were in turn associated with deeper elaborative processing. However, deeper elaborative processing was not associated with greater perceived knowledge. The inability of the CMM to predict how surrogates learn information, and the infrequency of extrinsically motivated searches suggest that future research should focus on identifying additional mechanisms connecting seeking to processing, including traditional theories of information seeking. Interventions should focus on making caregiver education accessible and identifying patient and caregiver information needs.

Dedication

This dissertation is dedicated to my mother MJ and sister Rachel who have supported me through this journey from the very beginning, and never stopped believing in me, as well as my other family members including my father Steve, stepmother Lori, stepfather Jerry, and stepsister Kristen.

It is dedicated to my friends, Bridget, Simon, Kara, Kate, Nathan, George, Kelly, and Tiffany, who have become family and taught me that I am worthy of love as I am.

It is dedicated to the members of Nyanmode, Sarah, Ben, Maddie, Courtney, and Emma, whose love and encouragement is always felt, even if from afar.

It is dedicated to the memory of my hero Ronald E. McNair, Ph.D., whose story and legacy inspired me to pursue graduate studies.

It is dedicated to all of the first generation students who will make this journey in the future.

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Fields of Study

Major Field: Communication

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Chapter 1: Introduction

Currently, 1 in 5 adults act as caregivers to friends or family members who face difficulty completing the activities of daily living (National Alliance for Caregiving, 2015). With an aging population, more spouses, adult children, and other family members than ever before will become caregivers to family members within the coming years (Centers for Disease Control and Prevention, 2018). Understanding the needs of caregivers, or the informal or unpaid persons providing emotional support or assistance with activities of daily living (Hunt, 2003), is an area of public health concern, particularly since caregivers face many unmet psychological (e.g. burden and burnout), physiological (e.g. many caregivers have chronic health issues themselves), and informational needs (Wang, Molassiotis, Man Chung & Tan, 2018).

The goal of this dissertation is to understand more about the process of surrogate information acquisition (SIA), or the act of seeking health information on behalf of another person (Abrahamson, Fisher, Turner, Durrance, & Turner, 2008; Sadasivam et al., 2013). Research on caregivers has predominantley focused on the informational needs of the caregivers of palliative care patients, or dementia and stroke patients (see Washington, et al., 2011 for systematic review). Informational needs broadly describe caregivers’ knowledge insufficiencies on specific topics (e.g. wound dressing) and preferences for information delivery (e.g. percentages versus words; Savolainen, 2016;

2012; Washington, et al., 2011). Informational needs are considered met when caregivers feel satisfied when they have an adequate amount of information presented in a format that they prefer (Savolainen, 2016; Washington, et al., 2011).

Understanding the informational needs of caregivers is important component of alleviating caregiver burden. However, research has not adequately examined caregivers' unique informational needs across specific cancer sites (e.g. breast versus lung; Wang, et al., 2018; Washington, et al, 2011) or how these needs are met through SIA. The present studies focus on caregivers in the context of breast, endometrial, and ovarian cancer. Breast cancer is the most common cancer in women (National Cancer Institute, 2020). Ovarian and endometrial cancers, while less prevalent (National Cancer Institute, 2020), are still among the top ten most common cancer sites for women (World Cancer Research Fund, 2019). Despite evidence suggesting that informational interventions reduce caregiver burden (Applebaum & Breitbart, 2013; Northouse, Katapodi, Song, Zhang & Mood, 2010 for reviews), informational and educational interventions for caregivers remain few and far between (particularly as compared to stress and coping interventions).

Although SIA is common in the general population, as well as among caregivers (Cutrona, et al., 2015) as a form of support to their patients (Bevan & Pecchioni, 2008), the behavior is not well understood within the larger literature on health information acquisition. This study uses mixed methods to focus broadly on information acquisition, including surrogate information seeking, scanning, and monitoring, drawing on the Lay Information Acquisition Model (LIMB model; Abrahamson, 2007) and the Cognitive Mediation Model (CMM; Eveland, 2001). Past studies of SIA are mostly descriptive in nature, focusing on the characteristics of seekers (Cutrona et al., 2015; Oh, 2015; Reifegerste, Bachl, & Baumann, 2017; Sadasivam et al., 2013) and the patients for whom they seek information (Massey, 2016; Ramirez, Leyva, Graff, Nelson, & Huerta, 2015; Reifegerste et al., 2019), leaving core assumptions of surrogate behavior unobserved and untested, including mechanisms linking SIA motivations to caregiver and patient outcomes.

Understanding Surrogate Information Acquisition

Information acquisition behaviors include information seeking (i.e. actively or purposefully seeking information on a health topic; Niederdeppe et al., 2007), scanning (i.e. passively acquiring health information unintentionally through media use or interpersonal discussions; Hornik & Niederdeppe, 2008), and monitoring (i.e. passively acquiring health information to confront a threatening situation; Rees & Bath, 2001). Most of what is known about SIA relates to information seeking, although scanning is a more common health information acquisition behavior than seeking (Niederdeppe et al., 2007). Both active and passive information behaviors are shown to influence medical decision making (Niederdeppe et al., 2007) and to mediate the relationships between individual differences, cognitions, and health behaviors (Bigsby & Hovick, 2018). Thus, conceptualizing information acquisition broadly is not only warranted, but necessary, to clarify the extent to which surrogates engage in each type of behavior and the impact of those behaviors more broadly.

SIA is often pursued and delivered as a form of informational support (Cutrona et al., 2015; Fennell, Heckel, Wilson, Byrnes, & Livingston, 2016; Heckel, Fennell, Mohebbi, Byrnes, & Livingston, 2017; Rutten, Squiers, & Treiman, 2006). Surrogate searches are frequently performed alongside other caregiving tasks such as communicating with healthcare providers (Cutrona, et al., 2015), and information surrogates may play an important role as potential gatekeepers and translators of information to patients (Ramirez et al., 2015). Although information surrogates report healthcare professionals as their preferred source of health information (Abrahamson et al., 2008; James et al., 2007), many turn to the internet first (Cutrona et al., 2015; Jacobs, Amuta, & Jeon, 2017), searching predominantly for disease and treatment specific information (Cutrona, et al., 2015; Lee, et al., 2015). Taken together, these findings suggest that surrogates may seek information to decrease perceived knowledge insufficiencies in addition to seeking to provide informational support. However, little is known about decisions to seek and share information, or how surrogates process and utilize the information once they have sought it.

Characteristics of Surrogates and Care Recipients

Information surrogates are more likely to be married, middle-aged (Cutrona et al., 2015), female (Oh, 2015), parents (Oh, 2015), and in good health (Sadasivam et al., 2013). Additionally, information surrogates typically have strong social ties with the person or people they seek information for, as surrogates often act as primary caregivers for their spouses and parents (Bangerter, Griffin, Harden, & Rutten, 2019; Feng & Xie, 2015; Reifegerste et al., 2017; Sadasivam et al., 2013). Minorities may be less likely to conduct surrogate information searches (Bangerter et al., 2019; Sadasivam et al., 2013), although this finding is not consistent across studies (Cutrona, et al., 2015). Furthermore, SIA is positively associated with information surrogates' education level in most (Abrahamson et al., 2008; Reifegerste et al., 2017; Rutten et al., 2006), but not all (Cutrona et al., 2015; Oh, 2015; Sadasivam et al., 2013) studies, and surrogates from lower SES households report less confidence in their ability to seek health information (Bangerter et al., 2019).

Care recipients that surrogates acquire information on behalf of are more likely to be male, older than the surrogate, and have less education (Abrhamson, et al., 2008). These care recipients are more likely to have a chronic disease (Reifegerste et al., 2019) and less access to health information (Massey, 2015; Ramirez, et al., 2015). Illness stage (e.g. diagnosis, treatment, survivorship) may also change the informational needs of both patients and surrogates (Cameron, Naglie, Silver, & Gignac, 2013; Echlin & Rees, 2002; Rutten, Arora, Bakos, Aziz, & Rowland, 2005; Washington et al., 2011). For example, family caregivers were shown to conduct fewer information searches during the disease diagnosis phase than during treatment, in order to provide care and make medical decisions (Andreassen, Randers, Näslund, Stockeld, & Mattiasson, 2005; Given, Given, & Kozachik, 2001; Iconomou, Vagenakis, & Kalofonos, 2001; Lord, Livingston, & Cooper, 2015; Rolland, Emanuel, & Torke, 2017; Washington et al., 2011). Still, the extent to which SIA is requested by patients (versus unprompted seeking and scanning on behalf of the patient) is less understood (Abrahamson, et al., 2008), as well as the circumstances under which information surrogates share or withhold information.

Study 1 uses qualitative methods (interviews) to describe the SIA process (beyond the identification of demographic characteristics of information surrogates) and the people they seek on behalf of and assess the largely untested propositions of the Lay Information Mediary Behavior (LIMB) model. Building on this work, Study 2 quantitatively tests a model of surrogate information acquisition and sharing based on the Cognitive Mediation Model. Together, this work provides new insights on the process of and communication outcomes associated with SIA. Furthermore, this work may aid in the development of interventions to help fulfill the informational needs of patients and caregivers.

Chapter 2: Theoretical Perspectives on SIA

Overview

Surrogate information acquisition (SIA) studies have predominantly utilized the Lay Information Mediary Behavior (LIMB) model (Abrahamson & Fisher, 2007) and Comprehensive Model of Information Seeking (CMIS; Johnson & Meischke, 1993) as guiding theoretical frameworks. In this chapter, a review of the literature discusses key predictions of the LIMB model and CMIS models and their application to SIA. Gaps in literature, including the need for empirically-grounded descriptions of the SIA process, limitations of current information seeking theories in predicting SIA, and SIA-related outcomes are also identified.

General Model of Lay Information Mediary Behavior. To date, the LIMB model is the only framework focused specifically on SIA. The model describes and defines information surrogacy, individual and societal level factors motivating SIA, and outcomes resulting from SIA (Abrahamson & Fisher, 2007). In the LIMB model, information surrogates (i.e., lay mediaries) are conceptualized as individuals who perceive another person as having an informational need and engage in seeking or acquiring information on behalf of that other person.

The LIMB model proposes that SIA is both *intrinsically* and *extrinsically* motivated. That is, information surrogates may identify an information need either unprompted (intrinsic motivation) or as an explicit request for help from another person (extrinsic motivation). Information surrogates are also assumed to be in good health, and to possess adequate health literacy to navigate information systems and synthesize information for patients (Abrahamson & Fisher, 2007). Patient factors may influence SIA behavior. Negative affect, such as anxiety, fear, or frustration may prompt patients to request help from an information surrogate to navigate information systems. A patient's physical condition, as well as their level of health literacy and language fluency, may also prevent them from conducting successful information searches; thus, an information surrogate may be solicited for help. Potential caregiver and care recipient outcomes of SIA, as outlined in the LIMB model, may be both positive (i.e., increased social capital and satisfaction of providing informational support) and negative (i.e., information overload, or being unable to meet the patient's informational needs; Abrahamson & Fisher, 2007).

Critique of LIMB model. Overall, the LIMB model (Abrahamson & Fisher, 2007) is valuable because of its explication of surrogate information seeking behavior used in SIA research (Buchanan, Jardine, & Ruthven, 2019; Cutrona et al., 2016; Cutrona et al., 2015); however, application of the LIMB model in empirical research is rare (Abrahamson, et al., 2008). Limited use of the LIMB model may stem from two conceptual issues with the theory. In some ways, the theory is quite limited; infrequent use of the theory may be because the theory makes few, if any, testable hypotheses and focuses predominantly on information seeking (ignoring other valuable SIA behaviors such as information monitoring and scanning). Additionally, the theory does not discuss the intrinsic and extrinsic seeking motivations of patients and information surrogates in equal detail. For example, the LIMB model discusses care recipients' negative emotion (e.g. worry or fear Abrahamson & Fisher, 2007), but the model does not explicitly address the role of information surrogates' emotion (e.g. worry or fear) in motivating SIA, even though information surrogates' emotional state may be an important intrinsic motivator. Similarly, the LIMB model does not address how caregiver motivations impact decisions to share information with patients, while proposing that surrogates may share or withhold information at their discretion (Abrahamson & Fisher, 2007).

In other ways, the LIMB theory lacks parsimony, a necessary component for a theory with strong predictive power (Chaffee & Berger, 1987). The LIMB model describes the psychological processes of information surrogate and recipient, as well as their physical and social (e.g. network integration) characteristics. The theory also includes the dyadic interaction of surrogate and recipient, as well as interactions between surrogate and information systems in the information seeking process. Because the LIMB model describes individual behaviors as well as social structures within the same model, it is difficult to falsify, and therefore difficult to make predictions based upon the theory.

Comprehensive Model of Information Seeking (CMIS). As an alternative to the LIMB model, some health communication scholars have applied the Comprehensive Model of Information Seeking (CMIS) to SIA (Johnson & Meischke, 1995). The CMIS is grounded in the Health Belief Model (Rosenstock, 1960, 1974) and Uses and Gratifications theory (UG; Katz, Blumler, & Gurevitch, 1973). Within the CMIS, distal, individual characteristics (i.e. seeker demographic characteristics, direct experience with a health condition, salience of risk, and efficacy beliefs associated with prevention and treatment) indirectly predict information seeking behavior via information carrier factors, including carrier characteristics (i.e., the tone of information presented, presentation of information, and seeker trust in source) and information utility (i.e., the relevance and importance of the information available, Johnson et al., 1995).

The CMIS has been applied broadly across various health contexts (DeLorme, Huh, & Reid, 2011; Paek, Choi, & Hove, 2017), including SIA. Previous studies have shown main effects of individual characteristics (i.e., risk salience, efficacy beliefs) on information seeking (Hartoonian, Ormseth, Hanson, Bantum, & Owen, 2014; Johnson, Donohue, Atkin, & Johnson, 1994; Rains, 2007), while mediated effects of individual characteristics on information seeking via carrier characteristics (Paek et al., 2017; Van Stee & Yang, 2018) and informational utility (DeLorme et al., 2011; Van Stee & Yang, 2018) were shown in other studies, as predicted by the CMIS. Although not a complete test of the model, Oh (2015) showed that individual characteristics, distal variables in CMIS, such as demographic (e.g. gender, marital status), direct experience (e.g. self-rated health), and beliefs (e.g. self-efficacy) significantly predicted surrogate information acquisition. However, carrier factors (trust in the internet) were not significantly associated with surrogate seeking (Oh, 2015). In an experimental test, salience, an individual characteristic variable in CMIS, was manipulated such that participants' intentions to engage in SIA were higher when the target's illness was more salient. Salience was in turn directly associated with behavior. In the same study, beliefs, another individual characteristic variable in CMIS, were not manipulated but were indirectly associated via utility (Reifegerste, Blech & Dechant, 2020).

Critique of the CMIS model. Although Oh and Reifegerste's work demonstrated the CMIS's utility in predicting SIA (2015; 2020), use of the CMIS model is limited in its ability to predict and describe information seeking behaviors, including SIA. Broadly, information seeking scholars have called into question the temporal order of the relationships hypothesized in CMIS. For example, the perceived utility of information is hypothesized to predict information seeking behavior, but in many cases the relevance of information cannot be assessed until after it has been sought (Robson & Robinson, 2013). Additionally, the theory doesn't account for individual knowledge, whether it is their knowledge insufficiency (discrepancy between how much they know and how much they *want* to know) or their existing knowledge level. However, other theories of information seeking (Planned Risk Information Seeking Model, extensions of Risk Information Seeking and Processing model) demonstrate that knowledge is closely associated with information seeking (Kahlor, 2010; Kahlor & Rosenthal, 2009).

Pertaining to SIA specifically, the CMIS accounts only for intrinsic motivators, or motivations to obtain internal satisfaction or reward, of surrogate information acquisition (e.g. the surrogate's perceived risk salience). Although these factors may influence surrogate information acquisition, they do not address the role of extrinsic motivations such as care recipient requests for information. Exploring the extrinsic motivations of SIA is important for several reasons. First, care recipient information requests may result in more purposeful seeking and monitoring behaviors by caregivers (as opposed to scanning), as well as sharing of information, because they are expected to report back to their care recipients. Understanding the prevalence of information requests may help us to understand more about the way informational needs and support contribute to caregiver burden.

Second, the CMIS does not address what people do with information once they acquire it. Understanding outcomes beyond the act of information acquisition is critical in understanding phenomenon like SIA, as past research has demonstrated that seeking health information may impact health outcomes (Bigsby & Hovick, 2018). Although extended CMIS models have demonstrated a link between information seeking and health outcomes (Lee & Kim, 2015), and CMIS research in the SIA context suggests that surrogate behaviors may impact emotional support (Reifegerste, et al., 2020), these models are ill-suited for the SIA context. SIA is often conducted with the intention of providing informational support to care recipients (Abrahamson, et al., 2008; Cutrona et al., 2015; Fennell et al., 2016; Heckel et al., 2017; Rutten et al., 2006), which implies the sharing of information. The CMIS model does not account for processing and encoding of information, an important component of information sharing (Craik & Turving, 1975). Although carrier factors and utility (mechanisms in CMIS) may be associated with the depth of information processing (e.g. heuristic or systematic), these mechanisms do not account for the actual processing of information. Additionally, the model fails to suggest theoretical mechanisms which may link information seeking to information sharing. Thus, in order to predict information sharing as an outcome, additional theoretical models are needed to fully capture and predict the phenomenon of SIA.

The Cognitive Mediation Model

This dissertation draws on the Cognitive Mediation Model (CMM). In general, the theory predicts that surveillance gratifications, or the use of media to obtain information on certain topics (as opposed to entertainment; Perse, 1990; Schneider & Shiffrin, 1977), will be associated with greater political knowledge via cognitive mediators attention and elaboration. Although the CMM was designed to look at political news media exposure and knowledge specifically, Eveland (2001) theorized that the model likely applied to non-political knowledge acquisition as well. Past research has demonstrated that the theory applies to health contexts (Jensen, 2011), and extensions of the theory suggest that the CMM may predict interpersonal communication (Eveland, 2004), such as information sharing. Because the theory (and its extensions) accounts for media use (one potential form of information acquisition), proposes interpersonal communication is a likely outcome of learning, and identifies cognitive mechanisms linking information acquisition behavior to interpersonal discussion, the CMM is an ideal theory for examining surrogates' decisions to seek and share information.

CMM Overview. The CMM's core predictions are rooted in the theoretical domains of information processing (the internal process of making sense of external stimuli Moskowitz, 1999), and media selection (cognitive differences associated with media use). The CMM's predictions about information processing are based upon on the Elaboration Likelihood Model (ELM; Petty & Cacioppo, 1986). The ELM proposes that those who are motivated and able to process information will do so more deeply by paying attention to information and linking it to existing knowledge structures (Petty &

Cacioppo, 1986). Deeper processing is believed to result in more lasting beliefs, attitude change, and ultimately health behavior change (Petty & Cacioppo, 1986). Thus, the CMM proposes that those who pay attention to media and elaborate upon the content will have greater knowledge of the topics discussed in news content.

The CMM's predictions about media use and selection are rooted in Uses and Gratifications (UG) theory (Katz, Blumler, & Gurevitch, 1973), which posits that specific media use gratifications are associated with different types of processing. For example, surveillance gratifications (i.e., viewing media for informational purposes) are associated with central processing whereas entertainment gratifications (viewing media to fill time) are more likely associated with peripheral processing (Perse, 1990; Schneider & Shiffrin, 1977). Thus, the CMM predicts that stronger surveillance gratifications are associated with deeper information processing (Eveland, 2001). The CMM is also grounded in Media System Dependency Theory (MSDT; Ball-Rokeach & DeFleur, 1976), which posits that the more individuals depend on media for acquiring knowledge the more likely they are to learn from it.

Six hypotheses encompass the original CMM (Figure 1). First, surveillance gratifications, a person's use of media to obtain information on specific topics, are directly and positively associated with greater knowledge. Surveillance gratifications, in turn, are positively and directly associated with deeper attention paid to media content and elaboration on this content, which are associated with greater content knowledge. Thus, the relationship between surveillance gratifications and knowledge is mediated by attention to and elaboration of media content.

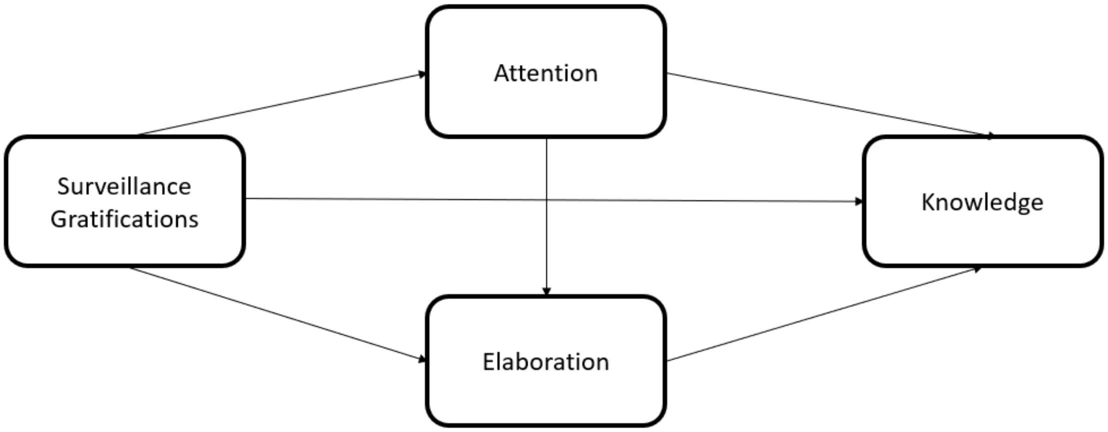

Figure 1. The original Cognitive Mediation Model (Eveland, 2001). All hypothesized relationships are positive.

Studies have consistently supported the core hypotheses in the CMM linking surveillance gratifications to political knowledge via attention and elaboration (Eveland & Dunwoody, 2002; Eveland Jr, 2001, 2002; Eveland Jr, Marton, & Seo, 2004; Eveland Jr, Shah, & Kwak, 2003; Wei & Lo, 2008). Additionally, surveillance gratifications were indirectly associated with science knowledge (Ho, Yang, Thanwarani, & Chan, 2017), flu prevention knowledge (Ho, Peh, & Soh, 2013), and cancer knowledge (Jensen, 2011;

King, Jensen, Carcioppolo, Krakow, & Sun, 2015; Lee, Ho, Chow, Wu, & Yang, 2013) via CMM mediators attention and elaboration.

Support for surveillance gratifications for information surrogates seems to exist as well. Information surrogates turned to mediated information seeking in order to overcome barriers to patient information (Bevan & Pecchioni, 2008; Peterson, Hahn, Lee, Madison, & Atri, 2016) and clarify information previously given by healthcare providers (Garrett & Cowdell, 2005). Therefore, it is proposed that a caregiver's acquisition of information for specific purposes (surveillance gratifications) will be positively associated with the information surrogate's engagement in information acquisition (seeking, scanning, and monitoring, H1a-c).

Application to SIA. The CMM may be particularly useful in the context of SIA for several reasons. First, unlike the LIMB model, which is descriptive in nature, the CMM sets forth testable hypotheses relating to specific, individual level, cognitions. Second in order to effectively learn something from the material sought and share it with care recipients, surrogates must process acquired information (Craik & Turving, 1975). Unlike CMIS, the CMM accounts for information processing. Some theories of information acquisition such as the Risk Information Seeking and Processing model (RISP; Griffin, Dunwoody, & Neuwirth, 1999) and the Structural Influence Model (SIM; Viswanath, 2008) have examined the associations between information seeking motivations, information processing, information seeking behaviors, (Griffin, Neuwirth, Giese, & Dunwoody, 2002; Kahlor, Dunwoody, Griffin, & Neuwirth, 2006; Kahlor, Dunwoody, Griffin, Neuwirth, & Giese, 2003) and knowledge (Hovick, Liang, & Kahlor, 2014; Kahlor & Rosenthal, 2009) through theoretical extensions and follow up studies. However, these theories do not consistently account for information processing and knowledge, unlike the CMM which predicts a relationship between information processing and knowledge within its core hypotheses.

Very little work has been done in the domain of SIA to understand how information processing and knowledge may impact the well-being of surrogates and their care recipients. However, surrogate information seeking was associated with attention to health information (Cutrona, et al., 2015; Oh, 2015) and information processing may benefit caregivers by increasing knowledge (Stajduhar, Funk, & Outcalt, 2013). Processing may also help caregivers cope with uncertainty or the negative emotions associated with caregiving (Kim, Kashy, Spillers, & Evans, 2010; Magsamen-Conrad, Dillon, Verhoff, & Faulkner, 2018; Rees & Bath, 2001) and is associated health threat coping (Gleicher & Petty, 1992; Millar & Millar, 1998).

However, the original CMM only examines one gratification and one outcome, knowledge. In order to better capture the phenomena of SIA, an extended CMM is tested in the present study. Past use of models rooted in CMM, but extending the theory's predictions, resulted in insights about the role of gratifications beyond surveillance in information processing (Beaudoin & Thorson, 2004; Eveland, 2004) and outcomes beyond knowledge (Ho, Peh, & So, 2013). Thus, models are rooted in CMM, but extend its predictions to additional distal variables and outcomes, may be particularly useful in examining SIA as a process involving motivations to both acquire and share information. Existing theories of information seeking (CMIS, RISP PRISM; Griffin, et al., 1999;

Johnson & Meischke, 1995; Kahlor, 2009) are less useful in the SIA context because they focus almost exclusively on intrinsic factors and perceptions associated with personal information seeking (e.g. the information surrogate's perception of care recipient risk). Although the LIMB model does account for extrinsic motivations for SIA, specifically in the form of care recipient's information requests, ultimately the model falls short in explaining how extrinsic seeking motivation may lead to information sharing. The extensions of the CMM proposed in the present study may account for additional motivations that are known to be associated with SIA such as medical decision making (Cutrona, et al., 2015), and information sharing (Abrahamson, et al., 2008), while extending what is known about SIA and processing. Discussions of such extensions, as well as underlying support, are discussed below.

An Extended CMM.

The proposed study will test a new, extended CMM (Figure 2), which includes the addition of two media use gratifications from previous literature (Beaudoin & Thorson, 2004): guidance gratifications (consuming media for the purpose of decision making; Gantz, 1978), and social utility gratifications (consuming media to fuel future discussions; Gantz, 1978). Three additional information seeking motivations are also added to the model, caregivers' perception of care recipient risk (i.e., extent to which caregivers believe their care recipient's cancer is severe and they are vulnerable to adverse outcomes (Lee, et al., 2013), caregivers' perception of care recipient information gathering capacity (i.e., surrogate perceptions of their care recipient's ability to seek health information (Johnson, 2005) and the frequency of SIA requests (Abrahamson &

Fisher, 2007). Finally, the extended model tested here also builds off prior CMM work (Wei & Lo, 2008) that adds media exposure to the model. In the present study, information acquisition behavior (i.e., surrogate information seeking, scanning, and monitoring) acts similarly to media exposure, and acts as a mediator of media gratifications and motivations on attention and elaboration. The model is also extended to link perceived knowledge to information sharing. Each component of the proposed model (Figure 2) is elaborated on below, with theoretical justifications and specific contributions to the surrogate information seeking literature explained.

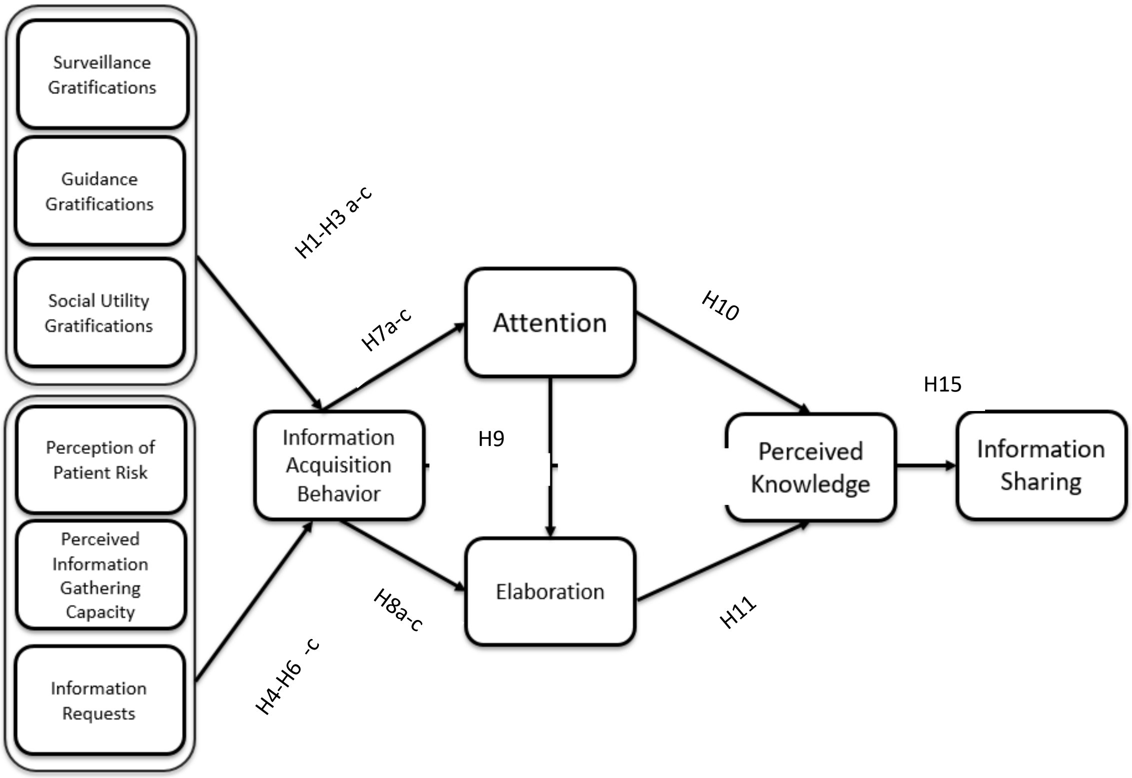

Figure 2: The extended cognitive mediation model adapted for surrogate information acquisition and outcomes. Note that H12-14, while not listed in this model, describe the indirect effects of gratifications (surveillance, guidance, and social utility) on perceived knowledge via SIA, attention, and elaboration.

Gratifications. The proposed model will test the addition of guidance and social utility gratifications to the CMM, which has been done in prior CMM studies (Beaudoin & Thorson, 2004). These additions are theoretically supported because Uses and

Gratifications theory predicts that a multitude of gratifications, not just surveillance, are associated with learning (Gantz, 1978). Gratifications associated with the desire to learn or acquire more information (e.g. surveillance, guidance) are associated with greater retained information (Gantz, 1978). People who use media for entertainment or to pass the time also retain information, but may retain less information than those with media gratifications associated with purposeful learning (Gantz, 1978).

Guidance gratifications. Media may be used to help someone decide how they feel about an issue (i.e., affective guidance gratifications) or how to act (i.e., behavioral guidance gratifications Gantz, 1978; Palmgreen, Wenner, & Rayburn, 1980). The present study accounts for both types of guidance gratifications. As suggested by Uses and Gratifications Theory (Gantz, 1978; Rubin & Perse, 1987), if someone uses media to make a decision about how to feel or act, their level of processing of the media likely will be deeper, as will their knowledge (Lometti, Reeves, & Bybee, 1977). Guidance gratifications are generally supported in prior tests of models that extend core CMM hypotheses extended, predicting political and health knowledge (Beaudoin & Thorson, 2004; Ho, et al., 2013) via attention and elaboration.

Guidance gratifications may influence surrogate information acquisition in two important ways. First, information surrogates may collect information for care recipients' use in medical decision making (Feltwell & Rees, 2004). Second, information surrogates may also act as medical surrogates (Torke, Petronio, Sachs, Helft, & Purnell, 2012), making decisions on behalf of their care recipient. In this case, SIA may be used by caregivers to make informed decisions regarding their care recipient's medical care

(Washington et al., 2011). Thus, it is hypothesized that caregivers use information for the purpose of decision making (guidance gratifications) will be positively associated with information surrogate's engagement in information acquisition (seeking, scanning, and monitoring H2a-c).

Social utility gratifications. Social utility gratifications, or the consumption of media in anticipation of future conversation (Katz et al., 1973), are also included in past CMM extensions (Beaudon & Thorson, 2004). Anticipation of a future conversation may result in greater knowledge gains because individuals are more thoroughly motivated to process that information in order to understand it, learn about it, and discuss it (Eveland, 2004). Gantz's (1978) framework applies to social utility as well, as individuals may acquire information in order to discuss it later, and process it more deeply as a result. Additional theoretical justification for social utility gratifications as a motivator of media use can be found in models of cognitive tuning, which predict that anticipation of a conversation activates the type and number of cognitive structures, influencing information processing (Zajonc, 1960). Indeed, social utility gratifications have predicted political (Beaudoin & Thorson, 2004; Eveland, 2004), science (Ho, et al., 2017), and health (Ho, et al., 2013) knowledge via attention and elaboration.

Social utility is particularly relevant in SIA because surrogates may have the intention of passing this information onto patients (Abrahamson, et al., 2008). Indeed, caregiver information gathering is typically performed with the intention of making patients aware of various health services and alleviate stress (Arrington, 2005), as well as for synthesizing and gatekeeping information so that patients get only high quality information (Ramirez, et al., 2015). Additionally, a great deal of caregiving duties are shared among friends and family members (National Institute on Aging, 2018), and caregivers want health information relevant to the patient's condition (Petronio, Sargent, Andea, Reganis, & Cichocki, 2004). Thus, surrogate information seeking may also serve a social utility in order to better inform friends and family members about the patient's condition (Feltwell & Rees, 2004). It is hypothesized that caregivers' perception of information's social utility will be positively associated with surrogate information acquisition (seeking, scanning, and monitoring H3a-c).

Information seeking motivations. Although the CMM is primarily concerned with the role of media gratifications in knowledge acquisition, additional antecedents, stemming from theories of information seeking, may also inform SIA. Two variables adopted from the information seeking literature are integrated within the proposed model tested here (Figure 2): caregivers' perceptions of their care recipient's risk and information gathering capacity. Finally, care recipients' information requests are also included as an antecedent variable, as proposed by the LIMB (Abrahamson & Fisher, 2007).

Surrogate perception of care recipient risk. According to the Health Belief Model (Rosenstock, 1974), risk perceptions comprise individuals' perceived severity and susceptibility to a hazard. Severity describes the extent of the harm that would be caused by the threat if no action were taken, while susceptibility describes the individual's perceived vulnerability to a hazard (Rosenstock, 1974). Justification for the addition of surrogate perception of care recipient risk comes from Eveland's (2001) conceptualization of the CMM, which suggests that factors other than media gratifications may influence learning from media use. Additionally, theories of information seeking (e.g., PRISM) and information seeking and processing (e.g., RISP) propose that when a threat is perceived as personally relevant (susceptible) and dangerous (severity), individuals are more likely to intend to seek (Kahlor, 2010) and more likely to systematically process (Griffin, et al., 1999) the information. However, the present study will be among the first studies to assess surrogates' perceptions of care recipient risk (as opposed to patients' perception of risk) on information-related outcomes.

Perceived risk is a consistent and indirect predictor of information seeking (Hovick et al., 2014; Kahlor, 2010) as well as knowledge (Hovick et al., 2014). Additionally, one CMM study showed that risk perception indirectly predicted cancer knowledge via attention and elaboration (Lee et al., 2016). Patient risk perception is positively associated with surrogate information acquisition (McQueen, Vernon, Meissner, & Rakowski, 2008) and there may be reason to believe that surrogates' own perception of risk motivates SIA. Indeed, information surrogates may use information acquisition as a way to regulate their own affective responses to their care recipients' diagnosis and treatment (Abrahamson et al., 2008; Feltwell & Rees, 2004; Kernisan, Sudore, & Knight, 2010; Stajduhar et al., 2013; Magsamen-Conrad, Dillon, Billotte Verhoff, & Faulkner, 2018). As in past studies examining patient risk, it is hypothesized that caregiver perception of care recipient risk is positively associated with information acquisition (H4a-c).

Perceived care recipient information gathering capacity. Information gathering capacity encapsulates one's ability to gather information given their individual characteristics and environment (Griffin, et al., 1999), and the concept closely resembles the concept of self-efficacy, or perceived behavioral control from the Theory of Planned Behavior (Ajzen, 1991). Although previously untested in the context of the CMM, the variable is a good fit for the proposed model because information gathering capacity is also associated with information processing in both the RISP (Griffin, et al., 1999) and Cognitive Processing of Risk Information (Johnson, 2005) models. These models suggest that when self-perceived information gathering capacity is high, information seeking and deeper processing is more likely to occur (Griffin, et al., 1999; Johnson, 2005). In tests of RISP, information gathering capacity is positively associated with information seeking and systematic processing (Clarke & McComas, 2012; Yang & Kahlor, 2013) and inversely associated with heuristic processing (Yang, Rickard, Harrison, & Seo, 2014).

As the proposed study is set in the context of SIA, it is hypothesized that an information surrogate's perception of care recipient's information gathering capacity will be inversely associated with information acquisition (seeking, scanning, and monitoring) (H5a-c). Indeed, caregivers may be motivated to engage in SIA when they perceive a care recipient's capacity to seek information, as low as surrogates tend to act on behalf of older, less educated, and chronically ill patients (Abrhamson, et al., 2008; Reifegerste et al., 2019). Caregivers may be more likely to engage in SIA when their care recipient is less able or likely to seek information themselves, as in situations where patient access to health information is limited by technology (Massey, 2015) or health literacy (Ramirez et al., 2015).

Information requests. A final motivator of SIA, inspired by the LIMB model, is care recipient information requests (Abrahamson & Fisher, 2007). Information requests are made in instances where care recipients have insufficient knowledge, are unable or unwilling to perform their own information searches, and ask another person to act as an information surrogate and seek on their behalf (Abrahamson & Fisher, 2007). The LIMB model does not make any specific predictions as to whether or not an information requests will increase sharing behaviors, but others have theorized that care recipients may delegate their information acquisition, and desire family members to step in and seek (Krieger, 2014). Actual evidence of information requests by patients to caregivers is limited. Past research suggests that care recipients may request that care givers make medical decisions on their behalf because they feel overwhelmed (Speice, et al., 2001). However, only one study to date has determined that information requests are made by care recipients to information surrogates, which are associated with surrogate searches (Abrahamson & Fisher, 2008). Thus, further work is crucial in understanding how information requests motivate SIA. It is hypothesized that care recipient's requests for information will be positively associated with surrogate information acquisition (seeking, scanning and monitoring H6a-c).

Information acquisition behavior. The proposed model retains the original cognitive processing variables outlined in the CMM, attention and elaboration, but adds in an additional prediction that information acquisition behaviors (i.e., seeking, scanning and monitoring) mediate the effects of distal variables on elaboration and attention. Past extensions of the CMM have included media exposure as a variable linking gratifications to attention and elaboration (Wei & Lo, 2008), accounting for the lack of consideration for media exposure in the original CMM (Eveland, 2001). Information acquisition is hypothesized to behave similarly in this study to the media exposure variable in Wei and Lo's study (2008); however, the present study considers information acquired cumulatively from both media and interpersonal channels via active and passive methods of acquisition. This approach is similar to CMIS studies (grounded in UG theory), which account for information acquisition through mediated and interpersonal channels (DeLorne, et al., 2011; Hartoonian, et al., 2014).

Further justification for the addition of SIA to the model comes from core predictions in Uses and Gratifications theory, which suggest that gratifications sought (e.g. initial motivations for consuming media: surveillance, guidance, and social utility gratifications) are connected to gratifications obtained (i.e. media outcomes) through media exposure, (Katz et al., 1973) and learning (Gantz, 1978). Additionally, gratifications are associated with information acquisition behavior (Yoo & Robbins, 2008), and media exposure are associated with learning through attention and elaboration (Jensen, 2011; Wei & Lo, 2008).

Finally, building on the Risk Information Seeking and Processing Model (RISP, Griffin, et al., 1999) and the Structural Influence Model (SIM, Viswanath, et al., 2008) the link between information acquisition (seeking, monitoring and scanning) and information processing (attention and elaboration) is examined. Dual processing theories suggest that those who are willing and able to process messages are more likely to do so systematically (Petty & Cacioppo, 1986), suggesting that those who engage in purposeful information seeking are more likely to process that information. Indeed, information seeking is associated with deeper cognitive elaboration (Zhao & Cai, 2008). While information scanning and monitoring are less purposeful forms of information seeking (Niederdeppe, et al., 2007), there is still reason to believe that they will be associated with cognitive processing (in the case of the present study, attention and elaboration). Attention is believed to play a critical role in passive forms of information acquisition such as scanning and monitoring (Hornik, et al., 2010), as attention to information separates passive SIA from mere exposure. If information catches a surrogates' attention, deeper elaboration is possible, because elaboration is indirectly associated with knowledge via attention in the CMM (Eveland, 2001). Thus, information acquisition behaviors (seeking, scanning, and monitoring) will be positively associated with attention (H7a-c) and elaboration (H8a-c). As predicted in the CMM (Eveland, 2001) attention will also be positively associated with elaboration (H9).

Outcomes associated with SIA. Although the CMM was conceptualized with a focus on knowledge as the dependent variable of interest (Eveland, 2001), previous extensions of the CMM have linked knowledge to behaviors and intentions (Ho et al., 2013; Lee et al., 2013). Psychological models of self-regulation predicted (and found support for) the mediating role of knowledge in the relationship between processing and behavior (Nenkov et al., 2007), such that those who attend to and elaborate on media may learn more about potential health outcomes and regulate their behavior as a result. The present study focuses on perceived caregiver knowledge as an immediate result of surrogates' information processing, which will be associated with information sharing.

Caregivers' perceived knowledge. Although many tests of the CMM are concerned with recall of factual knowledge (Eveland, 2001) and knowledge structure density (Eveland & Dunwoody, 2002), the proposed model is interested in the caregivers' perception of cancer knowledge. There are ample reasons to examine perceived knowledge. First caregivers of patients at varying stages of diagnosis, treatment, and survivorship will be surveyed, thus a factual knowledge test would be difficult to administer. Second, perceived knowledge (instead of factual knowledge) was used in other tests of the CMM. Perceived knowledge mediated the relationship between news attention and policy support (Ho, Looi, Leong, & Leung, 2019). Perceived knowledge was also positively and significantly associated with attention to news items (Ho et al., 2019), as well as elaboration of information (Smith, Fabrigar, Macdougall, & Wiesenthal, 2008). Finally, perceived knowledge was indirectly and positively associated with information sharing (Crook et al., 2016). Although subjective and objective knowledge are not interchangeable constructs (Klerck & Sweeney, 2007), this body of past work justifies the use of percieved knowledge within the present extension of the CMM. Thus, it is hypothesized that attention and elaboration will be positively associated with perceptions of care recipient knowledge (H10 & H11). Additionally, based on the predictions of the CMM, which link gratifications to knowledge (Eveland, 2001; Eveland, 2004; Beaudoin & Thorson, 2004) as well as perceptions of knowledge (Ho, et al., 2019) it is hypothesized that gratifications (survelience, guidance, and social utility) will have an indirect effect on perceptions of knowledge via information acquisition (seeking, scanning, and monitoring), attention, and elaboration (H12a-c, H13a-c, H14a-c).

Information sharing. In this dissertation, health information sharing describes the process of information surrogates relaying (or withholding) information sought to patients or other third parties, such as family members. A previous theoretical extension of the CMM predicted that messages will be processed more deeply, and factual knowledge of political news would be greater, when a person anticipates a future discussion of that content (Eveland, 2004). These hypotheses are rooted in the Uses and Gratifications literature on social utility gratifications (Katz et al., 1973), which suggests that anticipation of a future conversation is a key motivator for media use and further elaboration (Rubin & Pearse, 1978). Further linking perceptions of knowledge to information sharing, Diffusion of Innovation theory suggests that in order for information sharing to occur, an individual must learn about an innovation (e.g. health behavior, new technology, etc.) and perceive the innovation to be useful before promoting it to others (Rogers, 2002). In the context of SIA, caregivers may act as diffusors of innovation when they learn about new treatment options or preventative behaviors. Empirical evidence linked perceptions of individual knowledge to sharing health information with friends, coworkers, and family members (Crook et al., 2016). Of SIA specifically, there is evidence suggesting that sharing occurs between surrogates and patients. Caregivers are likely to pass information onto patients when their information needs are met (Bevan & Pecchioni, 2008). Meanwhile patients may rely on friends and family members as a source of information (Pecchioni & Sparks, 2007), or receive web-based information through interpersonal sources, such as family caregivers (James, Daniels, Rahman, McConkey & Young, 2007; Massey, 2015). Therefore, it is predicted that perceived knowledge will be positively associated with information sharing (H15).

Dissertation Overview

In order to extend what is known about surrogate information acquisition a two-part, mixed methods study was conducted. An overview of each study and specific study research questions and hypotheses is provided.

Study 1. Informed by LIMB model, Study 1 attempts to understand the informational needs and preferences of breast, endometrial, and ovarian cancer caregivers by focusing specifically on the topic of SIA, whereas studies often assess it as part of a larger investigation on caregiving (e.g. Washington, et al., 2011). The LIMB model specifically proposes that information surrogates will seek based on care recipients' requests for information (i.e., extrinsic motivations) and caregivers' perceptions of care recipient informational need (i.e., intrinsic motivations; Abrahamson & Fisher, 2008). The LIMB model also suggests that information acquisition can be acquired from many channels, resulting in outcomes such as information sharing or withholding (Abrahamson & Fisher, 2008). However, little is known about the extent to which the propositions of the LIMB model actually describe the SIA process. Thus, the qualitative component of this dissertation will assess LIMB model propositions and act as formative research for the new, extended CMM model tested here.

Study 1 is guided by six main research questions that map onto LIMB model propositions. First, what are the preferred information sources and channels used by information surrogates (RQ1)? And, to what extent is SIA extrinsically (RQ2) or intrinsically (RQ3) motivated? Second, to what extent do surrogates engage in active or passive information acquisition (RQ4)? Next, what motivates surrogate decisions to share or withhold information, and what other outcomes are associated with SIA (RQ5)? Finally, the study seeks to understand how the informational needs of caregivers, and SIA behavior overall, change over time (RQ6).

Study 2. This study quantitatively tests a new extended CMM, grounded in prior CMM expansions (Beaudoin & Thorson, 2004; Eveland, 2004), to better understand how individual cognitions influence the processing of information sought by information surrogates, and how that processing informs caregivers' perceptions of knowledge, caregiver burden, and sharing of information. It is predicted that gratifications (surveillance H1a-c, guidance H2a-c, social utility H3a-c), perceived care recipient risk (H4a-c), and information requests (H6a-c) will be positively associated with SIA behaviors (seeking, scanning, and monitoring). Perceived information gathering capacity will be negatively associated with SIA (H5a-c). SIA (seeking, scanning and monitoring), in turn, will be positively associated with attention (H7a-c) and elaboration (H8a-c), while attention will be positively associated with elaboration (H9). Attention and elaboration, in turn, will be positively associated with greater knowledge (H10 & H11). Thus, the effect of gratifications (surveillance (H12a-c), guidance (H13a-c), and social utility (H14a-c) on perceived knowledge will be indirect via information acquisition behavior, attention, and elaboration. Finally, it is hypothesized that perceived knowledge will be positively associated with information sharing (H15).

Chapter 3: Study 1 Methods

Qualitative Study Procedures

Caregiver qualitative interviews (*N*=19) began in September 2019 and continued until thematic saturation occurred in December 2019. Participants were initially eligible for the study if they were currently caring for a family member who had been (a), diagnosed as having breast, endometrial, or ovarian cancer (b) within the past six months (c), and lived within fifty miles of their care recipient (d). Volunteers were also informed that caregiving behaviors and activities included anything involving coordinating doctors' visits, helping with housework, or providing emotional support, among other duties. However, these initial inclusion criteria proved to be too restrictive, and an insufficient number of participants were recruited. Thus, in October of 2019, the inclusion criteria were widened such that participants were eligible if they were currently caring *or had recently provided care* for a family member (a), diagnosed as having breast, endometrial, or ovarian cancer (b), within the past five years (c). In addition to allowing for past caregiving, the distance restriction (i.e., living within fifty miles of the care recipient) was removed from the study. The expansion of the inclusion criteria allowed past caregivers in the study, although it did mean that generalizations about the SIA process would be harder to make. However, by doing so, additional insights on SIA could be gained by exploring the informational needs of current versus former caregivers.

Past research suggests that the informational needs of these two groups are different, but this has not been explored in the context of breast or gynecological cancers (Andreassen, et al., 2005; Iconomou, et al., 2001).

Participant recruitment. Interview participants were recruited through two methods. First, participants were recruited through Research Match, an NIH sponsored national registry of over 140,000 volunteers that is funded and maintained through the Clinical and Translational Science Awards Consortium at Vanderbilt University and made available through a partnership with Ohio State University. The opt-in nature of the tool allows pre-registered individuals to participate in research studies that they are interested in. Participants were also recruited using Study Search, an online list of Ohio State University studies seeking volunteers. If a visitor to the Study Search page was interested in the study, they were able to contact the researcher directly via email or phone based on information given on the webpage.

Research Match volunteers were contacted by the researcher through the Research Match system (*n* = 56,158) and given basic information about the study. Interested volunteers (*n* = 157) were emailed additional information as well as an intake survey where participants were asked provide basic information about themselves and their care recipient (e.g. age, sex, education, income, race/ethnicity, relation to care recipient, time since diagnosis, caregiving duties performed, time spent caregiving, distance between caregiver and care recipient, and type/stage of cancer) and indicate their availability for a phone interview (*n* = 43). After completing the intake survey, participants were sent a confirmation email by the researcher including the scheduled date and time of their phone interview. A reminder email with the same information was also sent at least 24 hours before the interview was scheduled to occur. Of the interviews that were conducted *(n* = 21), two were not included in the analysis because they did not meet study inclusion criteria. Specifically, these participants (*n* = 2) indicated on the intake survey that they met study inclusion criteria, the interviewer learned at some point during the interview that they were in fact not a caregiver of a current or former breast, endometrial, or ovarian cancer patients. Interviews that met the study inclusion criteria (*n* = 19) were transcribed for data analysis.

Interview guide. Interviews (for an interview guide, see Appendix A) began with participants broadly discussing their care recipient, and the caregiving tasks that they routinely performed (e.g. “have you ever done any of your own research surrounding your family member’s cancer”). Then, participants were asked several open ended questions to assess their information acquisition behaviors (e.g. prevalence of seeking, scanning and monitoring, “do you ever notice information about breast cancer even when you aren’t looking for it specifically?”). Participants were then asked to expand upon the motivations they had for seeking information (e.g. information requests, “does your care recipient ever ask you to look up information.”), as well as motivations for sharing or withholding information that was obtained from their care recipient (e.g. “Do you tell your care recipient what you find after seeking information?”). The researcher assessed participants’ preferences for information sources (e.g. “So, you would say your primary source of information comes from the internet?”). The researcher asked participants if their informational needs changed over time, (e.g. “you mentioned your mother is in remission now has the way you searched for information changed since you found that out?"). Finally, the researcher asked caregivers if there was anything they didn't know about their care recipient's cancer that they wanted to know (e.g. "what would you still like to know about your care recipient's cancer?").

All interviews were semi-structured – they largely followed the interview guide, but included unprompted questions to clarify a response. The interviews typically lasted 30-60 minutes. All participants were given $20 USD electronic gift card as an incentive for participation. A debriefing email was sent to participants within 24 hours of the interview.

Data Analysis

A goal of 20 interviews with family caregivers was set a priori. Although only 19 interviews are included in analysis, the study reached the point of thematic saturation, with no new themes emerging. Given the goal of this study, which was to gather evidence to support key assumptions of the LIMB model, and use the results to inform Study 2, analysis consisted of a qualitative description approach (Sandelowski, 2000; 2010) as well as thematic analysis (Braun & Clarke, 2006) to identify key themes and responses that aligned with the study research questions. The aim of qualitative description is to describe an event as it occurs (Sandowlski, 2000), which is useful for phenomena such as SIA that are not well understood. Using this approach allows for the interpretation of data in a way that stays close to the original meaning as articulated by the participant, while answering key research questions (Sandowlski, 2010).

The second methodological approach used was thematic analysis. The aim of thematic analysis is to rigorously and systematically identify patterns in participants' responses and highlight the most important themes within data to make sense of a specific phenomenon (Vaismoradi & Turunen, 2013). Thematic analysis is a particularly useful and relevant method of analysis for this study, which is grounded in the LIMB model, because it can be used to answer predefined theoretical questions, (Braun & Clarke, 2006). Using thematic analysis, major themes are identified through the coding of data and refinement of codes (Aronson, 1995).

An initial codebook was developed by the researcher largely based upon the interview guide, informed by LIMB model (Abrahamson & Fisher, 2007), as well as observations from study interviews. The codebook (Appendix B) included the following broader codes with subcodes: surrogate information acquisition (e.g. seeking, scanning, monitoring, or avoiding information), reasons to seek or share (e.g. uncertainty management, medical decision making, support), outcomes of surrogate information acquisition (e.g. share, withhold, or gatekeep), caregiving activity (e.g. communicate with healthcare provider, housework, transportation), information source (e.g. doctor or healthcare provider, internet (general), support group), information source preference (e.g. fulfils/does not fulfil need). Additional broader codes were also included such as risk perception, change in information needs over time, and caregiver burden.

Using the initial codebook, the researcher and undergraduate research assistant each coded 3 initial transcripts. Then, the coders met to discuss and assess intercoder agreement across transcripts, and make adjustments to the codebook as needed. After these adjustments to the codebook, this process was repeated until the coders identified no new codes. After finalization of the codebook, each transcript was coded independently by each coder using the web-based, qualitative analysis application Dedoose, which allows for blind coding of qualitative data. Each transcript was coded line by line, and coders assigned codes and subcodes where applicable. After a transcript was coded, the independent coders met to discuss and resolve any discrepancies in coding on the transcript to achieve 100% intercoder reliability. In most cases, discrepancies were minor due to different levels of specificity in applying the codes. To obtain agreement, each coder presented their interpretation of a passage, and justified their use of codes. After this discussion, a consensus was reached on the appropriate code, with some passages needing more in depth-discussions due to the complexity of the data.

Upon completion of coding, the frequencies and co-occurrences of codes were examined to gain a broad understanding of the major and minor findings and themes. The study team met several times to meet and discuss themes. Queries were also run to assess differences in coding based on participant demographics.

Chapter 4: Study 1 Results

Caregiver participants in this study were predominantly female (*n* = 18), and predominantly the daughters and daughters in law of their care recipients (*n* = 10); however, mothers (*n* =3), granddaughters (*n* = 2), sisters (*n* =1), cousins (*n* = 1), nieces (*n* = 1), and husbands (*n* = 1) also participated, who cared for women with breast (*n* = 15), endometrial (*n* = 2), or ovarian (*n* = 2) cancer. Our sample was well-educated, with most participants having at least four years of college education (*n* = 15) and about a third having careers in the areas of healthcare or biomedical sciences (*n* = 6). Care recipients also were predominantly female (*n* = 18) and over half (*n = 11)* had at least some college. Most care recipients (*n* = 17) were still living, and most lived less than fifty miles from their caregiver (*n* = 16). Care recipients' cancer stage was varied across the sample: I (*n* = 6), II (*n* = 4), IIIb (*n* = 2), IV (*n* = 5). No data on stage was available for a few participants (*n* = 2).

Caregivers reported engaging in a variety of caregiving tasks, including communicating with healthcare professionals (*n* = 16), arranging outside services (such as visiting nurses *n* = 6), emotional support (*n* = 11), housework (*n* = 10), medical and nursing tasks (*n* = 8), and providing transportation (*n* = 9). Caregivers had provided care for an average of 15.7 months (range 3-48), for an average of 20.23 hours a week (range

1-60). Most participants reported they had help with these tasks from either another family member or professional caregiver (*n = 13).*

Caregivers' Information Acquisition Behaviors

Although nearly half of the caregivers interviewed cared for patients who sought information themselves about their own condition, all caregivers engaged in some form of SIA. Furthermore, our findings suggest that nearly all caregivers engaged in what could be considered active information acquisition *(n*=18). Active information acquisition involved caregivers' desire to have specific information and purposeful seeking of information, either prompted or unprompted by their care recipients. As one participant (P2, age 56) who provided care for her mother said, "I hop on the Internet, and, like, the verb Google it, and see what comes up, you know?"

Most caregivers also described engagement in more passive forms of information acquisition *(n*=15). Passive information acquisition included instances of caregivers encountering information about cancer without having specifically sought it out (such as encountering an article about breast cancer while scrolling through their social media feed), as well as instances where caregivers, while not actively seeking, were on alert for additional information relevant to their care recipient's condition in order to alleviate their anxiety about their care recipient's cancer and regain a sense of control over the situation. As one participant (P2, age 56), who provided care for her blind mother with breast cancer said, "I'm always on the lookout for something that might help her." Passive information acquisition also occurred for some, but not all caregivers, during care recipients' visits with their healthcare professionals. In these instances, caregivers would passively obtain information their care recipient's cancer by sitting in on visits with healthcare professionals. Caregivers would not ask questions or seek additional information from healthcare professionals out of respect for their care recipient's privacy and autonomy, even if they wanted to.

Multiple surrogates. Regardless of whether or not caregivers' SIA was active or passive, about a fourth of interviewed caregivers (*n*=5) reported that they were not the only family members engaged in SIA. Others within the family also acted as information surrogates, seeking information about the care recipient's condition to share with the care recipient and family members (including other information surrogates). For example, one caregiver (P9, age 40) noted that sharing SIA duties with her sisters meant that if one person found information particularly confusing, another could take over. "I think I remember going back and forth with some of my sisters, and it would be like, "Oh, looking this up. I don't understand. Can you check it out?" Sharing information between surrogates was common when both children and spouses of care recipient shared in caregiving *and* information surrogate duties. Interestingly, having multiple surrogates within a family seemed to alleviate the burden of SIA because one surrogate could act as a gatekeeper for other caregivers, filtering out distressful information and reducing knowledge insufficiencies. For example, one caregiver (P5, age 26) reported that her father acted as a gatekeeper when her mother was first diagnosed with breast cancer. "My dad really, really played that role and went to talk to, like, 1,000 oncologists, and surgeons, and healthcare providers, and everyone. I think a lot of it was that my parents were really concerned about burdening us with it."

Information Acquisition Over Time

About half of the caregivers sampled within this study reported changes in their own cancer information needs as well as their own information acquisition behaviors during their care recipient's transition from cancer patient to cancer survivor. Some caregivers noticed a change in the quantity of information they needed to perform caregiving functions, as well as the breadth of topics for which they sought information. For example, some caregivers described seeking information more frequently during the time of their care recipients diagnosis and treatment, as the caregivers scrambled to educate themselves about cancer and aid their care recipient in medical decision making. As one participant, (P19, age unknown) who didn't know a lot about the specifics of cancer said, "At first, it was like anything I could find." For some caregivers, this transition marked the reduction of active information seeking as passive information behaviors became more common. For other caregivers, active searches remained common, but became more targeted in their focus. Fear of recurrent cancer, and a second cancer diagnosis, spurned additional SIA for some caregivers. As a care recipient (P17, age 57), caring for her step daughter with recurrent breast cancer said, "What happens when you go in remission is you relax. You don't focus on cancer. When you find out there's been a reoccurrence…your alarms start goin' off again, and you're back in research mode, I think."

Motivations for SIA

Whether they used active or passive forms of information acquisition, caregivers reported that they were both *extrinsically* **(**e.g. information requests**),** as well as *intrinsically* (e.g., unprompted) motivated to engage in SIA.

Extrinsic motivation. A little more than one-third (*n* =7) of all caregivers were extrinsically motivated to seek information through cancer information requests from their care recipient, and all of these requests motivated active information seeking by caregivers. Caregivers tended to receive requests for information if their care recipient was physically unable to seek information themselves (e.g. blind), or lacked the efficacy to do so themselves (e.g. did not feel comfortable using the internet to conduct a search). Of all information topics associated with SIA (e.g. general cancer knowledge, medical decision making, and future patient outcomes), care recipients' requests for information were most often associated with information about medical decision making, suggesting that patients needed support in understanding risks and benefits of treatments and managing healthcare systems.

Intrinsic motivation. All participants engaged in some kind of intrinsic (unprompted) SIA (*n* =19), and did so more frequently than extrinsically motivated SIA (*n* = 7). However, two distinctive kinds of intrinsically-motivated SIA emerged. First, there was support for the kind of intrinsic SIA defined by Abrahamson & Fisher (2007), whereby caregivers identified the unmet informational needs of care recipients (e.g. general knowledge about cancer, medical decision making, and future patient outcomes), and caregivers subsequently engaged in SIA for the purpose of providing care and support to recipients. In the second kind of intrinsic SIA, caregivers were motivated to seek information to reduce their own knowledge gaps in topic areas (e.g. general knowledge about cancer, medical decision making, and future patient outcomes) for the purpose of providing better care and support. This form of SIA was independent of their care recipient's informational needs or knowledge levels.

Intrinsic SIA to meet care recipients' informational needs. Some caregivers thought that their care recipient needed more information on a certain topic, and conducted a search without a request from their caregiver. For example, one caregiver (P8, age 58) looked into the risks and benefits associated with the treatment options available to her mother, so that her mother could make an informed decision her treatment. She said, "when we were trying to decide whether radiation post-mastectomy was an option for her…I recall we looked at a couple of different studies about, you know, the incidence of recurrence, um, in the elderly? She was open to, you know, talking about it."

Intrinsic SIA to meet caregiver information needs. As previously stated, only a portion of caregivers were asked by their care recipients to acquire more information. Beyond requests for information, few caregivers were intrinsically-motivated to seek information with the explicit purpose of sharing it with their care recipients later on (*n* =5). This finding suggests that caregivers were intrinsically-motivated to acquire information based on their *own* informational needs.

Although caregivers predominantly acquired information to meet their own informational needs, this form of intrinsic information acquisition still fell under the blanket of SIA because the information acquired could benefit care recipients if it led caregivers to provide better emotional support to care recipients or engage in patient advocacy in healthcare settings. Some caregivers engaged in both types of intrinsically-motivated SIA (for care recipient and caregiver). As P8 continued to discuss, “Before an appointment, we’d discuss it at home and make a list to make sure all of her concerns, and any of mine, were addressed. I’d be the note taker, the “reminderer”, um, to make sure questions are being answered…write down notes about any changes or any after-care. Then also, doing, you know, on my own… reading and online research about her specific diagnosis.” In situations where caregivers sought to increase their own knowledge levels about cancer, caregivers often perceived their care recipients as being quite knowledgeable about cancer, and some caregivers felt that no matter how much they researched, they would never know *as much* about cancer as their care recipient. Despite this, caregivers were-intrinsically motivated to be knowledgeable about cancer in order to manage their own uncertainty about their care recipient’s future, alleviate their anxiety about their care recipient’s risk, and provide support to their care recipient. One caregiver, (P11, age unknown) provided care for her self-seeking sister self-seeker talked about using information to support her sister.

> “All my information was like a shield to me. If I was getting anxiety and I was fearing things…The fact that I had all this information helped me be more solidly there for my sister in terms of information because I had answers…Nothing that she threw at me was something that I hadn’t heard before.”

However, in some cases, caregivers actively sought information as a way to avoid burdening their care recipient with questions they may have had about cancer. Some caregivers thought that it was not appropriate to ask about their care recipient's diagnosis and prognosis. Other caregivers thought that asking a recipient directly would be burdensome or distressful for the care recipient. One participant who provided a great deal of emotional support for her cousin (P1, age 32) said, "Well, I wanted to know the prognosis, you know…I didn't want to ask her, "Are you gonna live or die? What are the chances of you living?" That's something I tried to look up on my own."

Caregivers had several additional motivations for engaging in SIA, which are further detailed below. These motivations were predominantly *intrinsic.* However, there were occasions when caregivers were requested to seek information in these areas. Thus, motivations that accompanied extrinsic searches may also be discussed here briefly. It should also be noted that motivations for SIA held a great deal of overlap with motivations to *share* information with care recipients. Although this section focuses on motivations predominantly affecting *SIA,* these motivations are also important to consider when discussing caregivers' motivations to share information with care recipients.

Social Support. Caregivers acquired and shared information about cancer as a way to support their care recipients in several different ways. First, caregivers sought information as a way to provide emotional support. Caregivers felt that they could use information to provide more relevant, and genuine emotional support for their care recipients. One caregiver wondered (P9, age 40) about what to do for her mother after treatment ended. She commented, "I went back…and I started reading that stuff, just to remind myself, okay remember there will always be these gaps in terms of what was communicated, what was actually done. What I've tried to do more so than anything, is just literally ask my mom what she needs." Caregivers also acquired and selectively shared information as a form of informational support, using information to reduce care recipient's information insufficiencies and synthesizing complex information. Finally, caregivers sought information in order to better provide instrumental support. One (P15, age 34) caregiver was asked by her mother to seek information about vitamin E oil to treat radiation burns, and then purchase the oil for her. In recounting the exchange she recalled that her mother asked her, "You can be my human Google. I'm just gonna give this task to you…You go ahead and do this." For the most part, caregivers intrinsically acquired information to provide support, except in situations where instrumental support was requested by care recipients.

Information insufficiency. Caregivers were both intrinsically and extrinsically motivated to acquire information in order to decrease their own and their care recipients' information insufficiencies in at least one of three informational areas: general disease related knowledge (e.g. cancer terminology and basic epidemiology), medical decision making (e.g. recurrence risk in different treatment options, which surgeon to see), and what to expect in the future (e.g. survivorship care).

General disease knowledge insufficiency. For most caregivers, information was obtained in order to fill in gaps in their own general knowledge of cancer. Some caregivers had minimal knowledge of cancer, and they sought to understand terminology and basic epidemiology. As one participant (P9, age 40) caring for her mother said, “Starting off I just needed to understand the basics of what cancer—what this meant and why using them effectively—when you have Stage 2 cancer. Why don’t you get radiation?” Other caregivers, especially those who had higher levels of education, or were current or former healthcare professionals, desired more detailed and complex information to satisfy their knowledge insufficiencies. As one current graduate student caregiver (P15, age 34) said, “I got a lot of satisfaction and a lot of peace from, like, being able to research into, like, the scientific nook and cranny of something.” Caregivers did engage in selective sharing to reduce their care recipient’s knowledge insufficiencies. However, for many caregivers general disease information acquisition was intrinsically-motivated, and done so for the sake of closing their own knowledge gaps, not for the sake of educating their care recipients.

Medical decision making. Most caregivers actively sought information in order to contribute to care recipients’ health-care decision-making, acquiring information to inform caregivers about which healthcare providers to use, which hospitals and treatment centers to go to, and what treatments to receive. As one cancer survivor and current caregiver (P15, age 34) said, “I did a lot of spadework to help find a surgeon for her…I just wanted to make sure she had someone who was an expert in the field…and had experience working with women of color and could have empathy.” Passive information acquisition was also common in this domain, as caregivers were on the lookout for clinical trials, and tended to notice information about natural or alternative treatments even if they weren’t actively seeking it. Caregivers’ perception of patient risk influenced these searches, as caregivers were concerned with selecting treatment options that might do more harm than good for their care recipient.

Understanding future patient outcomes. Most caregivers engaged in some kind of information acquisition (active or passive) to understand what was normal through the course of their care recipient's diagnosis, treatment, and survivorship, and to contextualize their patient's risk. Indeed, caregivers acquired information in attempt to regain a sense of normalcy throughout the chaotic process of diagnosis and treatment. As one participant (P15, age 34) said, "The greatest benefit I get out of that (seeking information) is knowing that other people dealt with a similar diagnosis." Indeed, for some caregivers, information acquisition was a way to manage their anxiety concerning their care recipient's health and well-being. Other caregivers acquired information in this domain in order to develop a better understanding survivorship care, as well as understanding and preventing recurrence as their patient's treatments drew to a close. For those providing care for patients at advanced stages of cancer, caregivers sought to understand how long their care recipients could manage the disease with continuing treatment. One caregiver (P18, age 29) who provided care for her mother with advanced stage ovarian cancer, "It's kind of looking to the future too. Once her treatment stops working, what would become the other treatments that might be worth asking about?"

Topic avoidance. No caregiver completely avoided information about their care recipient's cancer. However, a small number of caregivers avoided certain topics of information because they felt such information amplify their current level of anxiety, or that they would dwell on negative information if they uncovered it. For these caregivers, having a basic level of knowledge about their care recipient's cancer (e.g. simply knowing the diagnosis and available treatments) was adequate, so they did not seek additional information on topics that they considered upsetting, such as survival rates, or other information pertaining to future patient outcomes. One participant (P5, age 26) providing long distance care for her mother with breast cancer said, "At first I definitely didn't (seek)… I didn't want (to) see how many women per year die of breast cancer, all those kinds of statistics. I just didn't wanna chance upon any of that." Other caregivers avoided additional information regarding medical decision making after their care recipient made a treatment decision in order to avoid second guessing those decisions. Finally, a small portion of caregivers reported they said that they did not seek information on a certain topic because they already knew a great deal about cancer and caregiving due to their personal experiences in the healthcare field, or through their personal experiences with cancer.

Information Channels and Preferences

Caregivers acquired information through a number of channels and from varied sources. For caregivers, interpersonal communication was the most frequently used channel for information acquisition, followed by the internet. Healthcare professionals were overwhelmingly the most accessed source of information from interpersonal channels; however, some caregivers reported seeking information from family and friends. The internet was a frequently accessed channel for information, and caregivers tended to access information from multiple sources (e.g. official websites such as Mayo Clinic, online social support groups, peer reviewed articles). Other media channels, such as television or books were less frequently used channels, and caregivers who typically had at least four years of college education or more tended to use more sources and channels.

Caregivers' perceptions of the usefulness of different sources and channels varied as well. Almost half of participants said that healthcare providers met their informational needs, providing adequate information in an understandable format. However, only a few participants relied *only* on their healthcare professional as a source of information, and other caregivers explicitly said that healthcare providers did not provide adequate information, prompting additional information searches. For example, one caregiver (P7, age 50) consulted multiple interpersonal sources including doctors, friends, and other family members, and used these conversations to reduce her knowledge gaps.

> "I don't feel like that information was ever offered down here. It wasn't until talking to other people I was like, "Oh, I didn't know that I should be looking at that." That's when we started looking for other doctors and a second opinion…"

Caregivers' use of multiple channels suggests that healthcare providers may meet caregivers' informational needs in one domain, but not another, and this typically prompted searches from another source or channel, specifically the internet. Some caregivers thought that the internet provided access to quality sources with adequate information about cancer and caregivers. Conversely, others thought that the internet, while a potentially useful tool, was an easy channel through which misinformation or distressful information could be easily found.

Caregivers tended to use multiple channels and sources because one was not enough to eliminate their knowledge insufficiencies, fill in memory gaps (e.g. recall the specific detail discussed at an appointment), or answer new questions that arose after receiving new information. Corroborating information across channels and sources was a motivating factor in caregivers' SIA as they hoped to vet information from various sources, and clarify previous discussions they'd had with their care recipient and healthcare providers. For some of the caregivers, their own training and experiences in healthcare, their past experiences as a caregiver, or their own past experiences with cancer contributed to higher levels of knowledge about cancer and cancer treatment. As a nurse practitioner (P13, age 67), who provided care for her daughter said, "As a healthcare provider I have lots of perspectives. As a woman's health nurse practitioner and as a midwife, I have a lot of experience with giving initial screening of women, and so I've done thousands of breast exams." These participants used these experiences and knowledge to provide care by acting as advocates for their care recipients in healthcare settings, communicating with healthcare professionals, and distilling complex medical information to their care recipients.

Most caregivers appeared to have criteria for judging the utility of a source or channel. Many caregivers were aware of, or encountered bad encountered bad information in the past, and this could have contributed to caregivers' reliance on multiple channels and sources. Regardless of the channel or source that caregivers used, participants found that sources that they deemed credible (i.e. coming from trusted health authorities such as the CDC, provided information that was grounded in scientific evidence), and accessible (i.e. they could find and understand the information provided) were the most useful in meeting their information needs. As one participant (P14, age 48), who preferred to use the internet said, "I do go for reliable sources for sure... Like, I go to the Mayo Clinic and to the American Cancer Society." Similarly, caregivers were wary of sources that they deemed inaccessible (i.e. they could not understand the information, or it contained too much medical jargon), or contained misinformation (i.e. suggested treatments that were harmful or not supported by evidence). Additionally, caregivers were split on whether or not they wanted information that was didactic (e.g. statistical information, survival rates), or experiential (e.g. hearing about someone else's experience with a particular drug or experiences with a specific doctor). For example one caregiver (P16, age 33) who preferred personal accounts said, "People that really like who they doctored with are happier…That's exactly what I wanted when Mom got her diagnosis. I want to be one of those happy people." Another participant, (P9, age 40) who preferred scientific information said, "I wasn't even really interested in personal narrative. My searching is really solely concentrated in the area of just like, "What does the science say? What do doctors or what does medicine say about this?" I didn't really want to spend any time immersed in the actual individual stories of cancer patients."

Caregivers' Selective Sharing of Information with Care Recipients

Although some caregivers expressed a desire to be completely transparent with their care recipient in telling them everything they'd learned about cancer, the majority of care recipients reported that they instead *selectively shared* information with their care recipient as a result of SIA. Selective sharing involved passing on some, but not all of the information that they acquired about cancer to their care recipients. Selective sharing often meant omitting repeated information or distressful information when sharing information with their recipient. However, no care recipient reported purposefully withholding *all* of the information they acquired because they believed their care recipient would find it to be too upsetting or complex.

Selective sharing was done for several reasons. First, caregivers said they synthesized and distilled information in a way that was easy for their care recipients to understand. As one participant (P15, age 34) said, “They want that summarized, accessible version of results…It, sort of like, falls upon us to do interpreting on, like, many different levels.” In other instances, selective sharing served a gatekeeping function whereby caregivers would withhold information from care recipients in order to protect them from they believed could be misinformation (e.g. treatments or cures that were not grounded in scientific evidence) or shield care recipients them from information that they would find distressful (e.g. survival or reoccurrence rates), while supplying them with information that caregivers deemed useful. For example, one caregiver (P14, age 67) found, and debated on whether or not to share an article she thought was particularly relevant to her daughter’s cancer, especially since the surgeon said that her lymph nodes were the same color as the ink in her tattoos.

> “The most important article that I read, I spent maybe five days deciding whether or not to share with her. There’s not sufficient information about it. Tattooing, as a cause… I asked her if she wanted to know about an article that she might find a little bit scary…I didn’t give her all the article.”

For caregivers, information related to medical decision making was selectively shared with care recipients more so than any other information topic area. Caregivers typically expressed their preferences and wishes for care recipients' medical decision making, but ultimately left the final decision to their care recipient. Other caregivers had strong opinions about what kind of treatment their care recipient should get, what doctors to see, and where to receive care. In these instances, caregivers influenced medical decision making through selective sharing.

Overall, information surrogates' motivations to share information with care recipients overlapped a great deal of overlap with their motivations to seek information (e.g. information requests and gaps in care recipient knowledge were associated with seeking *and* sharing), and the characteristics of information (e.g. information from quality sources was more likely to be shared) further influenced motivations to share. However, several distinctive motivations to share emerged from interviews, and a more detailed account of these features are detailed below.

Novel information and repeated information. Caregivers were likely to share information acquired if they believed that their care recipient had not heard the information before, and the information would could reduce the care recipient's knowledge insufficiencies in the topic areas outlined above. As one participant (P2, age 56) noted, "if it's something new or innovative, or they just discovered something that it just happens to pop up in my feed or something…I'll read it to her." However, if the caregiver believed that their care recipient had heard the information already, care recipients would not repeat the information. As P2 went on to explain, "If it's just something that I'm just looking up on my own and, you know, maybe we've already talked about it but I'm just kind of lookin' up some more stuff I don't even mention it."

Quality of life. Overall, caregivers were motivated to share information that would improve their care recipient's treatment outcomes, reduce risk of recurrence, and improve or maintain their mental health. As one participant, (P4, age 28) who cared for her aunt said, "I bring some of it up to see if she thinks it would help, or if it's a good idea, or if it's something she's even willing try." Similarly, caregivers in our study elected not to share information that they thought was likely to cause physical harm or psychological distress with the care recipient. In regards to physical harm, one participant (P1, age 32) who spent a lot of time researching alternative treatments said, "I personally think that cannabis is probably good for cancer…But I've never told her, "hey, I think you should try this." I would feel totally terrible if I recommended something and it didn't work and she got worse." And in regard to psychological harm, another participant (P16, age 33) who did not want to worry her mother said, "it depends on the subject, how important that subject is…I can tell what she really wants to hear and what she doesn't really want to hear. And I sugar coat it."

Summary

The findings presented here provide needed evidence for key propositions of the LIMB model. Specifically, information surrogates engage in active as well as passive forms of information seeking. Surrogates also appear to be intrinsically and extrinsically motivated to acquire information, but these motivations are complex. Caregivers seek based on care recipient information requests, as well as their own informational needs and their perception of their care recipients’ informational needs.

Chapter 5: Study 2 Methods

Procedures

In Study 2, the researcher utilized a cross-sectional (non-experimental) survey to assess study hypotheses. Inclusion criteria were similar to that of Study 1. Specifically, participants were eligible for the study if they were over the age of eighteen, fluent in English, and were providing or had provided care (coordinating doctors' visits, helping with housework, or providing emotional support, among other duties) to a family member with breast cancer diagnosed within the past two years. As in Study 1, Study 2 recruitment occurred via Research Match and Study Search (*n* = 141,338 contacted, *n* = 527 interested, *n* = 299 consented). Surveys were administered from January, 2020 to April 2020. Due to the researcher's inability to recruit an adequate number of participants to attain statistical power using Research Match alone, particularly given that recruitment occurred during the onset of the COVID-19 pandemic, recruitment also occurred via other methods such as research mailing lists and research registries such as the Communication Research and Theory Network (CRTNET, *n* = 48 clicked link, *n* = 8 consented), National Caregiving Alliance research registry (*n* = 15 consented), Facebook advertisements (*n* = 1 consented), and snowball sampling via Facebook (*n* = 4 consented), for a total of *n* = 327. Additional cases were removed from the dataset if the participant failed to meet study inclusion criteria. Consented volunteers were automatically sent to the end of the survey if they that they had not cared for a family member with breast cancer within the past two years (*n* = 186). Cases were also removed if a participant acted as a caregiver for a non-family member with breast cancer (*n* = 4). Cases were also dropped if participants failed two or more of the study attention check items (*n* = 5), completed the study in less than five minutes (*n* = 1) or indicated they had not sought information on behalf of their care recipient (*n* = 1). Thus, the effective sample size was *N*=130.

A power analysis was conducted a priori in G*power (Faul, Erdfelder, Buchner, & Lang, 2009). Assuming a maximum of 10 predictor variables (6 distal variables predicting SIA behaviors and 4 control variables) in a multiple regression model for each outcome variable (with an alpha of .05), to achieve acceptable power > .80 (Cohen, 1988) and a medium effect size (f^2=.15), a final *N* = 118 was needed. Thus, the study was appropriately powered for the proposed analysis.

Upon clicking the survey link, participants were given one final message reminding them of study inclusion criteria and incentive. Then participants indicated consent and started the survey (Appendix C). Upon completion of the survey, participants saw a debriefing message. As an incentive to participate in the study, ten electronic gift cards valued at $20 were randomly awarded to study participants recruited across all platforms. To minimize identifying information of participants, email addresses for study incentive were collected separately from main survey responses. Participants were given the option to leave the study at any time via a link at the bottom of the page that allowed them to exit the survey and proceed to the study debrief and incentive page.

Measurement and Instrumentation

Participants were asked to indicate if they were a current or former caregiver, and based on their response, viewed the survey in either the present tense (e.g. "when I seek information") to account for current caregiving or past tense (e.g. "when I sought information"). Additionally, to ensure consistency between current and past caregivers, all participants were asked to think information seeking following their care recipient's initial diagnosis and start of treatment. Furthermore, to account for the wide variety of caregiving relationships (e.g. spousal, parental, etc.), participants were asked an open-ended question, "the person that you provide/provided care for is your…" with a space to specify the person for whom they provided care (e.g. mother, wife, etc.). Their response to this question was piped into items through the course of the survey (e.g., if a participant indicated they provided care for their mother, items would read, "I look for information about my mother's breast cancer by paying attention to what is going on around me."). Unless otherwise noted, items on the survey were measured on a scale of 1 (strongly disagree) to 7 (strongly agree).

Confirmatory Factor Analysis

Although previously validated scales were predominantly used, a confirmatory factor analysis (CFA) was conducted to ensure that all of the study variables, none of which are theorized to be latent constructs, did not load onto multiple factors. This was particularly important because many of these scales have not been used in the context of SIA.

A measurement model was tested in MPLUS, comprised of 7 factors and 35 indicators. The model included all main study scales with more than two items. Although it is common perception that models with acceptable fit have an root mean square error of approximation (RSMEA) value of < .08, a comparative fit index (CFI value of > .90), Tucker-Lewis Index (TLI) value of > .95, χ 2 p > .05, and standardized root mean square residual (SRMR) < .08 (Kline, 2005; Hooper, 2008), there is some work suggesting that model fit may be impacted by sample size (Sivo, Fan, Witta & Wilse, 2006). Given the current study's sample size, an SRMR < .12 may be acceptable (Sivo, et al., 2006). Thus, the model met two of these criteria (RMSEA= .072, 90% CI [.06, .08], $p < .05$, SRMR = .97*)*, while other indices of fit did not reach cutoffs for acceptability (CFI = .84, TLI = .82, χ 2 = 2804.31 (595), p < .05). Several items loaded poorly (factor loadings < .5) and were removed from the model (as described below for each measure). After dropping these items the measurement model was retested. This model, while exhibiting less than exceptional fit, still met criteria for two of the tested fit indices (RMSEA est .078, 90% CI [.070, .086], p < .05, SRMR = .12); although the other fit indices did not meet the minimum criteria for acceptability (CFI =.82, TLI = .80, χ 2 = 2774.51 (561), p < .05). After removal of items, all factors loaded on a range of .52 to .91.

Demographic variables

Caregiver Demographic Questions. Most demographic questions were based off of those included in the Health Information National Trends Survey (HINTS; National Cancer Institute, 2018). These include sex, ethnicity (Hispanic/non-Hispanic), race, self-reported health, and education.

Caregiving information. Participants were asked a set of caregiving questions previously used in the HINTS 5, Cycle 2 dataset (National Cancer Institute, 2018). Caregivers provided basic demographic information about their care recipient (e.g. cancer stage, care recipient education, ethnicity, race, and relationship). Additional caregiving questions included items such as, "Thinking about the individual for whom you are currently providing the most care. About how many hours per week do you spend in an average week providing care?" Caregivers were also given a list of common caregiving tasks and asked to check off all tasks that they typically performed and response options such as, "Managing finances such as paying bills or filling out insurance claims," and "housework."

Main Model Variables

Surveillance gratifications. Surveillance gratifications were measured with four items adapted from previous CMM tests (Beaudoin & Thorson, 2004 & Ho, et al., 2013) as well as Eveland (2001). Example questions include, "I want to know what's going on with my care recipient's health," and "I want to know if there are any new treatment options available." The final measurement model showed all four items loaded on a single factor (values in the range of .62-.78). Reliability for these items were acceptable (α = .81) and the mean of these items was used in analyses.

Guidance gratifications. Guidance gratifications were measured with three items adapted from previous CMM questionnaires (Beaudoin & Thorson, 2004 & Ho, et al., 2013). Questions focused on the role of information in decision making. Example items include, "the information helps me decide if I should do something to help manage my care recipient's symptoms," and "the information helps me decide what to do to help manage my care recipient's symptoms." The final measurement model showed all three items loaded on a single factor (values in the range of .52-.91). Reliability for these items were acceptable (α = .77) and the mean of these items was used in analyses.

Social utility gratifications. Social utility measures included four items adapted from previously utilized questionnaires (Beaudoin & Thorson, 2004; Eveland, 2004; Ho, et al., 2013). Example items for this variable include, "I want to be able to advise my care recipient about their healthcare decisions," and "I want to be able to inform my care recipient about their healthcare options." The final measurement model showed all four items loaded on a single factor (values in the range of (.54-.95). Reliability for these items was good (α = .84) and the mean if these items was used in analyses.

Perceived care recipient risk. Perceived care recipient risk was measured with five items from the Child Vulnerability Scale (Forsyth, Horwitz, Leventhal, Bruger, & Leaf, 1996), adapted to reflect caregivers perceptions' of care recipient health. This scale was chosen because it encapsulates a caregiver's perception of care recipient vulnerability (susceptibility). Sample items include, "my care recipient seems much sicker than others diagnosed as having breast cancer." Additional items assessing severity were added from past risk perception research (Hovick, Kahlor & Liang, 2014) and adapted to fit the context. Example items include, "my care recipient's breast cancer was severe." One item ("I often think about calling the doctor for my care recipient.") was removed due to low factor loading (.40). The final measurement model showed all four items loaded on a single factor (values in the range of .54-.95). Reliability for the final four items was good (α = .87) and the mean of these items was used in analyses.

Perceived care recipient information gathering capacity. Perceived care recipient information gathering capacity was measured with six previously validated items from Johnson (2005). Items were modified to refer to the caregiver's perception of the care recipient's capacity to capture the inverse relationship between perceived care recipient information gathering capacity and SIA. Sample items include, "my care recipient would know where to go to get more information," and "my care recipient would know how to separate facts from fiction. The final measurement model showed all six items loaded on a single factor (values in the range of .54-.90). Reliability for these items was good (α = .89) and the mean of these items was used in analyses.

Information Requests. Information requests were measured with five items based upon those in Abrahamson and coauthors' questionnaire items (2008). These included questions pertaining to past information requests, e.g. "has your care recipient ever asked you to actively seek information about their breast cancer diagnosis from any source," as well as questions pertaining to perceptions of intrinsic and extrinsic motivation, e.g. "when I conduct searches regarding my care recipient's breast cancer it is because they want me to." One reverse coded item was removed due to low factor loading at .24 ("when I conduct searches regarding my care recipient's breast cancer it is because I want to."). The final measurement model showed all four items loaded on a single factor (values in the range of .72-.90). Reliability for the final four items was good (α = .87) and the mean of these items was used in analyses.

Information acquisition behavior. Information acquisition behavior included items assessing purposeful information seeking, as well as less purposeful acquisition behaviors such as scanning and monitoring. Information seeking variables were adapted from previously validated items the HINTS survey, as well as Johnson, 2005; Kelly et al., 2010, and Lewis, Martinez & Caramel, 2017. Seeking items include "I have actively sought information about my care recipient's breast cancer" while scanning items ask about less purposeful information acquisition "I have encountered or heard information about my care recipient's breast cancer diagnosis even when I was not actively looking for it," and monitoring items ask about keeping up with information such as, "I purposefully monitor or pay attention to information about my care recipient's breast cancer." Two items were included for seeking (r =.85), scanning (r = .27), and monitoring (r = .48). Each behavior was examined separately with the mean of each behavior was used in analyses.

Attention. Attention was measured using items adapted from previous CMM studies (Eveland, 2001; Jensen, 2011). In previous studies, participants were asked how much attention they paid to political stories in newspapers, television, etc. Modified items reflected the sources that individual participants used for information about breast cancer. Participants were asked to report the channels of information from which they obtained information about breast cancer (e.g. newspaper, television programs, magazines, internet sources). Participants were then asked "in general when you encounter information relevant to your care recipient's condition in (selected channels of information, e.g. newspaper, television programs, magazines, internet sources) do you tend to pay…" with response options ranging from no attention to a lot of attention. Attention was calculated by taking the sum participants' attention scores, and dividing it by the number of channels they used. Thus, the mean of each individual's score was calculated and used in analyses.

Elaboration. Elaborative processing was adapted from five items previously validated by Eveland (2001) to reflect the processing of health information. Due to low factor loading, one reverse coded item was removed, "I rarely spend much time thinking about the information I read or hear about my care recipient's health." Sample items include, "information often comes to have a broader meaning relevant to my care recipient's health after I've had a chance to think about it." Due to low factor loading (.24), one reverse coded item was removed, "I rarely spend much time thinking about the information I read or hear about my care recipient's health." The final measurement model showed all four items loaded on a single factor (values in the range of .56-.85). Reliability for these final four items were acceptable (α = .78) and the mean of these items was used in analyses.

Outcome Variables

Perceived knowledge. Perceived caregiver knowledge was measured using a single item adapted from existing measures (Griffin, Neuwirth, Dunwoody, & Giese, 2004; Ho et al., 2019). "Considering everything that there may be to know about your care recipient's diagnosis where 1 means "nothing" and 7 means "almost everything, how much do you think you currently know about your care recipient's diagnosis?" This single item score was used in analyses.

Information sharing. Information sharing was measured using measure based off of those used by Crooks and coauthors (2016). Specifically, two items asked participants about their past sharing of information with their care recipient. Sample items include, "after seeking information relevant to your care recipient's health, to what extent have you shared this health information with the patient?" and "after encountering information relevant to your care recipient's health, to what extent have you shared this information with the patient?" Both pertaining to sharing with the care recipient were retained (r = .75) and the mean of the items was used in analyses.

Data Analysis

All data analyses concerning main hypotheses testing were conducted using the statistical analysis package SPSS version 24. Descriptive analyses (including means and standard deviations) and correlations between model variables were run to examine the data. Spearman correlations were used to assess correlations between model variables due to slight non-normality exhibited by some model variables (Table 1). After the final N = 130 were retained for the final sample, a missing value analysis was conducted in SPSS. As a result of this analysis it was determined that no study variable in the final data set had more than 2.3% of cases missing. Thus, listwise deletion was appropriate for dealing with missing data (Pigott, 2001). The direct and indirect relationships between model variables were then assessed via multiple linear regression. Mediation analyses were conducted using the SPSS macro PROCESS (Hayes, 2017) specifically model numbers 4 & 6 to assess mediation and serial mediation. The PROCESS macro uses a bootstrapping technique to generate a 95% confidence interval in order to assess the indirect effects of mediation (Hayes, 2017) in addition to testing the direct effects using the procedures outlined by Baron & Kenny (1986) to assess direct effects of mediation (Preacher & Hayes, 2004).

Table 1

Spearman Correlations for Main Study Variables

	1.	2.	3.	4.	5.	6.	7.	8.
1. CG Age								
2. # of Tasks	.15							
3. CG Education	.01	-.22*						
4. Surveillance Grats	-.01	.21*	-.03					
5. Guidance Grats	-.01	.25**	-.12	.41**				
6. Utility Grats	-.15	.35**	-.21*	.52**	.59**			
7. Info Requests	>-.01	.30**	-.20*	.23**	.21*	.37*		
8. CG Perc Patient Risk	-.21*	.14	-.15	.35**	.05	.20	.11	
9. CG Perc Patient Info Capacity	.23**	-.34**	.42**	-.50**	-.60**	-.25**	-.13	-.26**
10. Seeking	.13	.28**	.03	.46**	.16	.28**	.33**	.14
11. Scanning	-.32**	.04	-.12	.14	.24**	.23**	.25**	>.01
12. Monitoring	.08	.22*	-.03	.40**	.31**	.39**	.24**	.03
13. Attention	.09	.12	-.12	.50**	.32**	.26**	.15	.12
14. Elaboration	.07	.23**	-.15	.36**	.47**	.45**	.22*	.06
15. CG Perc knowledge	.29**	.32**	-.10	.12	.27**	.27**	.40**	-.14
16. Sharing	.15	.37**	-.16	.22*	.37**	.47**	.54**	.03

Note: CG = caregiver, # of Tasks = number of caregiving tasks participants regularly performed, Grats = gratifications, Perc = perceived

		9.	10.	11.	12.	13.	14.	15.	*M*	*SD*
1.	CG Age								45.40	16.67
2.	# of Tasks								3.88	1.54
3.	CG Education								7.45	1.50
4.	Surveillance Grats								6.45	.82
5.	Guidance Grats								5.77	1.11
6.	Utility Grats								6.04	1.15
7.	Info Requests								3.76	1.76
8.	CG Perc Patient Risk								3.70	1.57
9.	CG Perc Patient Info Capacity								4.71	1.50
10.	Seeking	.07							6.10	1.11
11.	Scanning	-.06	.13						4.37	1.48
12.	Monitoring	.15	.64**	.30**					5.94	1.04
13.	Attention	.07	.28**	.22**	.40**				6.02	.88
14.	Elaboration	.01	.38**	.30**	.45**	.31**			5.45	.98
15.	CG Perc knowledge	.03	.26**	.08	.28**	.22**	.26**		5.51	1.17
16.	Sharing	.02	.27**	.18*	28**	.18*	.40**	.62**	5.19	1.39

To assess the homogeneity of the sample, and identify individual difference variables to control for, t-tests and simple linear regressions were run to assess individual difference variables on study outcomes (perceived knowledge and sharing). Looking first at caregiver demographics, caregiver age (perceived knowledge: F (1, 126) = 11.20, B = 4.53, SE = .31, sharing: F (1,125) = 1.33, B = .01, SE = .01)) and caregiver education (perceived knowledge: F (1,127) = 13.25, B = -.24, SE = .07, $p < .05$, sharing: F (1, 126) = 13.93, B = -.29, SE = .09)) were significantly associated with study outcomes ($p < .05$) and retained for analysis in the main study. Looking next at care recipient characteristics, stage of cancer did not significantly impact ($p > .05$) caregivers' perceived knowledge or information sharing (F (1, 112) = 2.65, B = -.15, SE = .09)) and sharing (F (1,111) = .03, B - .02, SE = .11)) and was not included in further analysis.

Looking next at caregiving characteristics, no significant differences ($p > .05$) were found for perceived knowledge or information sharing based on current versus past caregiving status (knowledge: t (127)= .82, sharing: t (126) = 1.52)), whether the care recipient was living or deceased (knowledge: t (126) = -1.88, sharing: t (125) = 1.17)), or whether or not the caregiver had help with caregiving tasks (knowledge: t (127) = .65, sharing: t (126) = 1.19)). Thus, these variables were not controlled for in the final analysis. However, number of caregiving tasks (perceived knowledge: F (1,127) = 12.55, B = 4.62, SE = .06)), sharing: F(1, 126) = 20.48, B = 3.93, SE = .30)) was significantly ($p < .05$) associated with study outcomes; thus, it was the only care recipient characteristic variable retained for further analysis. The final variables retained as controls for tests of the main study hypotheses were caregiver age, education, and number of caregiving tasks.

Chapter 6: Study 2 Results

Caregiver and Care Recipient Characteristics

As shown in Table 2, caregivers were predominantly female (*n* = 96, 73.86%), white (*n* = 101, 77.69%), had some form of college degree (associates, bachelor, or post grad, *n* = 96, 77.86%) and reported being in excellent or very good health (*n* = 68, 52.30%). Most of the caregivers surveyed were former caregivers, providing care within the past two years (*n* = 77, 59.23%) to family members living less than fifty miles away (*n* = 109, 83.85%). Participants provided care for their mothers (*n* = 63, 48.46%), spouses (*n* = 23, 17.69%), siblings (*n* =19, 14.61%), and other family members. Care recipients were likely to still be living (*n* = 117, 90.0%), and most care recipients did not have advance stage breast cancer (Stages 0-II *n* = 79, 60.77%). For a full presentation of care recipient demographics, see Table 3.

Main Model Tests

Direct predictors of surrogate information acquisition. To test the proposed study model (Figure 2), the direct effects of study variables were first assessed (Table 4), beginning with the association between of distal variables (surveillance gratifications, guidance gratifications, utility gratifications, information requests, caregivers' perception of care recipient risk, and caregiver's perception of care recipient information gathering capacity) and SIA behaviors (seeking, scanning, and monitoring). Surveillance gratifications were positively ($p < .05$) associated with surrogate information seeking and monitoring (H1a & H1c supported) but were not associated with scanning ($p > .05$, H1b not supported). However, neither guidance gratifications nor social utility gratifications were associated with surrogate information seeking, scanning, or monitoring ($p > .05$, H2a-c & H3a-c not supported).

As shown in Table 4, caregiver perceptions of care recipient risk were not associated with surrogate information seeking, scanning, or monitoring ($p > .05$; H4a-c not supported). Caregivers' perceived care recipient information gathering capacity also were unassociated with surrogate scanning (H5b not supported). Caregivers' perception of care recipient information gathering capacity was associated with surrogate seeking and monitoring, but not in the expected direction (H5a & H5b partially supported); specifically, those who perceived their care recipient as being more capable of gathering information engaged in more surrogate seeking and monitoring. Finally, care recipient information requests were significantly and positively associated with information seeking and scanning ($p < .05$, H6a & b supported), but not monitoring (H6c not supported, $p > .05$).

Table 2

Caregiver Demographic Characteristics (N=130)

Characteristic		% (Frequency)
Sex		
	Female	73.10 (95
	Male	26.20 (34)
	Not Indicated	0.80 (1)
Age		
	20-29	15.26 (20)
	30-39	22.90 (30)
	40-49	24.43 (32)
	50-59	17.55 (22)
	60-69	12.21 (16)
	70-79	3.10 (4)
	80-89	3.10 (4)
	Not Indicated	1.50 (2)
Race		
	White	77.10 (101)
	Black/African American	7.60 (3)
	Asian	5.30 (7)
	American Indian or Alaska Native	3.10 (4)
	Some other group	5.30 (7)
Education		
	High School	8.5 (11)
	Post High School Training	1.5 (2)
	Some College	16.2 (21)
	Associates Degree	12.3 (16)
	Bachelors Degree	33.8 (44)
	Post Graduate Degree	27.5 (36)
Health Status		
	Excellent	16.2 (21)
	Very Good	36.2 (47)
	Good	33.1 (43)
	Fair	10.8 (14)
	Poor	3.1 (4)
	No Response	0.8 (1)
Caregiver Status		
	Current	40.8 (53)
	Former (within past 2 years)	59.2 (77)
Long Distance		
	Less than 50 miles	83.8 (109)
	More than 50 miles	13.8 (18)
	No response	2.3 (3)
Help With Caregiving		
	Has help	77.7 (101)
	Does not have help	22.3 (29)

Table 3

Care Recipient Characteristics (N=130)

Characteristic		% (Frequency)
Sex		
	Female	97.77 (127)
	Male	2.23 (3)
Relationship to Caregiver		
	Caregiver's Spouse	17.70 (23)
	Caregiver's Parent	48.5 (63)
	Caregiver's Grandparent	4.60 (6)
	Caregiver's Sibling	14.60 (19)
	Caregiver's Aunt or Uncle	3.80 (5)
	Caregiver's Cousin	2.30 (3)
	Caregiver's Child	5.4 (7)
	Not Indicated	3.01 (4)
Hours Cared For		
	0-5	19.2 (25)
	6-10	19.2 (25)
	10-15	11.5 (15)
	16-20	13.8 (18)
	21-25	4.6 (6)
	26-30	7.7 (10)
	31-35	4.6 (6)
	36-40	6.9 (9)
	41+	8.5 (11)
	Not Indicated	3.8 (5)
Stage of Cancer		
	0	3.80 (5)
	I	24.6 (32)
	II	32.3 (42)
	III	16.2 (21)
	IV	10.8 (14)
	Not indicated	12.3 (16)
Deceased		
	Living	90.00 (117)
	Deceased	9.2 (12)
	Not Indicated	0.8 (1)

Direct predictors of attention, elaboration, and knowledge. The direct effects of SIA behaviors (seeking, monitoring, and scanning) on attention and elaboration were next assessed. A separate linear regression model was run for each SIA behavior (e.g. one model examining the effect of seeking on attention and elaboration, a second examining the effect of scanning on attention and elaboration, and a third examining the effect of monitoring on attention and elaboration). Three separate models were tested to mirror the indirect effect analyses shown below. Furthermore, examining all three SIA behaviors in a single model could mask the effects of a single behavior on attention and elaboration. The active and goal-driven nature of information seeking may lend itself to more naturally to elaboration, while attention may be more important in scanning and monitoring; attention has been described as a factor distinguishing passive forms of information acquisition such as scanning and monitoring from mere exposure (Hornik, et al., 2013). As shown in Table 5, across models, information seeking, monitoring and scanning were all significantly and positively associated with attention (H7a-c supported). Additionally, models showed information seeking, monitoring, and scanning were all significantly and positively associated with elaboration (H8a-c supported**).** Attention was significantly and positively associated with elaboration in the information seeking and scanning models (*p* < .05), but not the information monitoring model **(***p* > .05 H9 partially supported). Attention and elaboration (Table 7) were not associated with knowledge (*p* > .05 H10 & 11 not supported).

Tests of Indirect Effects. Per the CMM, indirect relationships were proposed between gratifications (surveillance, guidance, and social utility) and perceived knowledge via SIA (seeking, scanning, and monitoring), attention and elaboration. However, as shown in Table 6, no indirect effects were detected (H12a-c, H13a-c & H14a-c not supported).

Direct predictors of information sharing. Finally, the relationship between perceived knowledge and information sharing was assessed. A positive relationship was detected between perceived knowledge and information sharing ($p < .05$) H15 supported). Crook's (2016) model of information sharing suggests that perceived knowledge is associated with information sharing, similar to what was proposed here. The CMM suggests that knowledge is influenced by the degree to which information is paid attention to and elaborated upon (Eveland, 2001). Although no formal study hypotheses addressed the relationship between cognitive processing variables (attention and elaboration) and sharing, the proposed study model (Figure 2) suggests such a relationship. Thus, the effects of attention and elaboration on sharing were assessed post-hoc in order to further understand the role of information processing on information sharing. Post-hoc analyses (Table 7) show a significant and positive relationship between elaboration and information sharing, but not with attention.

Table 4

Multiple Regression Analyses to Test Direct Relationships between SIA Predictors and SIA Behaviors

	Seeking (N=123)		Scanning (*N* = 123)		Monitoring (*N* = 122)	
	B	SE	B	SE	B	SE
Caregiver Age	<-.01	.01	-.03	.01*	<-.01	.01
Caregiver education	.02	.06	-.27	.09*	-.07	.06
Number of caregiving tasks	.13	.07	-.01	.09	.09	.06
Surveillance gratifications	.60	.15**	.10	.20	.47	.14*
Guidance gratifications	-.12	.10	.22	.14	.01	.10
Social utility gratifications	-.06	.12	-.08	.16	.12	.11
Information Requests	.16	.06*	.17	.08*	.05	.05
Perceived care recipient risk	-.01	.06	-.10	.09	-.04	.06
Info gathering capacity	.15	.07*	.03	.09	.16	.06*
F	5.35 (9, 114)		4.38 (9, 114)		5.52 (9,113)	
R^2	.30		.26		.31	

Note: * $p \leq .05$ ** $p \leq .001$

Table 5

Multiple Linear Regressions to Test Direct Relationships Between SIA Behaviors and CMM Mediators

	Model 1 Seeking				Model 2 Scanning				Model 3 Monitoring			
	Attention *N* =127		Elaboration *N* = 126		Attention *N* = 127		Elaboration *N* = 126		Attention *N* = 126		Elaboration *N* = 125	
	B	SE	B	SE	B	SE	B	SE	B	SE	B	SE
CG Age	.01	.01	<.-.01	.01	.01	$.01^{*}$	<.01	.01	.01	<.01	<-.01	.01
CG Education	-.17	$.05^{*}$	-.09	.06	-.14	$.05^{*}$	-.04	.06	-.14	$.05^{*}$	-.07	.06
#of CG Tasks	-.01	.05	.09	.05	.02	.05	.12	$.05^{*}$	-.02	.05	.09	.05
SIA	.17	$.07^{*}$	.21	$.08^{*}$	.12	$.05^{*}$	.16	$.06^{*}$	.32	$.07^{**}$	.32	$.08^{**}$
Attention			.26	$.10^{*}$			.27	$.10^{*}$			.17	.10
F	5.68 (4, 123)		7.41 (5, 121)		5.22 (4, 123)		7.24 (5, 121)		9.98 (4, 122)		9.09 (5, 120)	
R^2	.16		.23		.15		.23		.25		.28	
$R^2\Delta$			.04				.05				.02	

Note: $^{*}\ p \leq .05$ $^{**}\ p \leq .001$, SIA = the information acquisition behavior listed in each model header, CG = caregiver

Table 6

Indirect Effects of Distal Variables on Perceived Knowledge

Distal Variable	SIA	Model 1 Attention			Model 2 Elaboration			Model 3 Attention and Elaboration		
		Bootstrap Est.	Bootstrap SE	95% CI	Bootstrap Est.	Bootstrap SE	95% CI	Bootstrap Est.	Bootstrap SE	95% CI
Surveillance Grats	Seeking	<.01	.01	-.01, .01	.01	.01	-.01, .05	<.01	<.01	<-.01, <.01
	Scanning	<.01	<.01	-.01, .01	.01	.01	-.01, .02	<.01	<.01	<-.01, <.01
	Monitoring	<.01	.01	-.02, .03	.02	.02	-.01, .03	<.01	<.01	<-.01, .01
Guidance Grats	Seeking	<.01	<.01	<-.01, .01	<.01	<.01	<-.01, .01	<.01	<.01	<-.01, <.01
	Scanning	<.01	<.01	-.01, .01	<.01	.01	<-.01, .01	<.01	<.01	<-.01, <.01
	Monitoring	<.01	<.01	<-.01, <.01	<.01	.01	-.01, .02	<.01	<.01	<-.01, <.01
Social Utility Grats	Seeking	<-.01	<.01	<-.01, .02	<.01	<.01	-.01, .01	<.01	<.01	<-.01, <.01
	Scanning	<.01	<.01	-.01, .01	<.01	<.01	<-.01, .01	<.01	<.01	<-.01, <.01
	Monitoring	<-.01	.01	-.03, .02	<.01	.01	-.02, .03	<.01	<.01	<-.01, <.01

Note: No models were statistically significant, Grats = Gratifications

Table 7

Multiple Linear Regressions to Test Direct Relationships Between CMM Mediators and Outcomes

	Perceived Knowledge[a] (*N* =126)		Sharing[b] (*N* = 126)		Sharing[c] (*N* = 125)	
	B	SE	B	SE	B	SE
Caregiver Age	.02	.01*	-.01	.01	-.01	.01
Caregiver Education	-.16	.07*	-.06	.07	-.04	.07
Number of Tasks	.14	.06*	.17	.06*	.13	.06*
Attention	.07	.12			-.01	.11
Elaboration	.15	.11			.29	.10*
Perceived Knowledge			.63	.09**	.61	.09**
F	8.30 (5, 121)		22.29 (4, 122)		17.68 (6, 119)	
R^2	.24		.42		.47	

Note: $^{*}\ p \leq .05$ $^{**}\ p \leq .001$
[a] H10&11, [b] H15, [c] posthoc analysis

Chapter 7: Discussion

This dissertation expands upon a body of work on SIA that has predominantly highlighted the characteristics of information surrogates and their care recipients (Bangerter, et al., 2019; Cutrona, et al., 2015; Sadasivam, et al., 2013; Ramirez, et al., 2015) and primarily focused on information seeking (e.g., Abrahamson et al., 2008; Cutrona, et al., 2015; Oh, 2015). The main aims of this dissertation were to assess the actual SIA process (Study 1) and shed light on the cognitive processes motivating SIA and sharing (Study 2). The theoretical and conceptual implications of both studies will be discussed, followed by a brief discussion of the larger implications for health communication practice.

Study 1

Study 1 utilized qualitative methods to understand caregiver motivations for SIA and sharing. While care recipients occasionally made information requests to caregivers, Study 1 results show that intrinsically-motivated (i.e., unprompted by care recipients) SIA was more common that extrinsically motivated (i.e., prompted by care recipients) searches. When acquiring information, caregivers used active (e.g., seeking) and passive (e.g., monitoring and scanning) strategies, and selectively shared information they found with their care recipients, even if their initial seeking motivations were intrinsic. Although more research is needed, the prevalence of intrinsic motivations for information acquisition found in Study 1 suggests unmet informational needs may be common among cancer caregivers, and caregiver interventions that focus on providing quality information that meets caregivers' specific informational needs are crucial for reducing caregiver burden.

Active and passive SIA. All of the interviewed caregivers engaged in some kind of active or passive SIA, demonstrating how common SIA is (Abrahamson & Fisher, 2007; Cutrona, et al., 2015). These findings regarding passive forms of SIA are important because most SIA studies have focused on seeking (Cutrona, et al., 2015; Oh, 2015, Ramirez, et al., 2015; Reifegerste, et al., 2017; Sadasivam, et al., 2013), even though most information acquisition is passive (Niederdeppe, et al., 2007). Passive forms of information seeking may positively impact health outcomes via beliefs and behaviors (Bigsby & Hovick, 2017; Waters, Wheeler & Hamilton, 2016), so future research should strive to further our understanding of passive forms of SIA and the outcomes associated with it.

Additionally, it should be noted that although caregivers described differences in active versus passive information acquisition, the distinction between these behaviors was occasionally unclear. For example, caregivers described instances where they came across information without intentionally looking for it (e.g. scanning), which would trigger more active informational searches. One possible explanation for passive information acquisition triggering active seeking is that exposure to information via passive acquisition may make certain topics more cognitively accessible (i.e. easily recalled in memory), and information about more accessible topics may be more likely to be actively sought (Nabi, 2003). Indeed, in areas where specific health issues are widely-known (e.g. opioid overdose), and therefore more accessible in memory due to things like local news coverage or personal experiences, online information seeking on that topic is likely to be high (Ardent, 2020). Thus, more work should be done to understand active and passive information seeking behaviors, especially when specific topics are especially salient to seekers. Caregiver interventions and practitioners should look to specifically harness the potential power of passive information acquisition by disseminating relevant, targeted information through channels that are accessible without active information seeking, such as mailing lists and social media feed posts.

Extrinsic and intrinsic motivations for SIA. The LIMB model (Abrahamson & Fisher, 2007) proposes SIA is both *intrinsically* and *extrinsically* motivated; Study 1 provides further support for these propositions. Caregivers engaged in SIA due to explicit requests from care recipients (less common) or via unprompted searches (most common) in order to meet the informational needs of themselves and their care recipients. Additionally, study results provide new information into how intrinsic and extrinsic motivations could impact information acquisition. In this study, caregivers reported care recipients made information requests to caregivers, predominantly in situations where care recipients were physically (e.g. blind) unable to search for information themselves or did not feel comfortable in doing so (e.g. did not feel they could use the internet effectively). Several potential explanations for this may exist. In Study, 1 it seemed that most care recipients were willing and able to seek information if they wanted it. However, in other caregiving contexts, this may not be the case. Aging adults often feel frustrated at relinquishing power and the changing parent-child dynamics in the caregiving process (Pyke, 1999). Care recipients, especially aging parents cared for by their children, may feel hesitant to request information in order to maintain power in their current parent-child dynamic.

In terms of intrinsic (unprompted) motivations, Study 1 findings call into questions the basic conceptual definitions of surrogate information seeking that are derived from the LIMB model (Abrahamson & Fisher, 2007). Abrahamson and coauthors perceive lay information mediaries (i.e., information surrogates) as individuals who perceive another as has having an unmet informational need and seek on their behalf (2007). However, caregivers in this study more often engaged in SIA to reduce their *own* information insufficiencies than to reduce their care recipient insufficiencies; thus, instead of thinking of SIA as a behavior performed on *behalf of* another person, a broader conceptualization and measurement of SIA that considers information sought *about* another person's health for the sake of the care recipient *or* the surrogate is needed.

Further conceptualization of intrinsic and extrinsic motivations of SIA may benefit from looking at Self Determination Theory (SDT), which is concerned with predicting how intrinsic and extrinsic motivations drive behaviors (Deci & Ryan, 1980). Specifically, SDT perspectives define intrinsic motivations as motivations that are driven by internal reward (Deci & Ryan, 2000), including the need to satisfy one's own curiosity (Deci & Ryan, 1980), as may be the case in SIA. Extrinsic motivations are motivated by external factors, such as praise or compensation. In the case of SIA, this may be praise or appreciation from the care recipient or recognition from other family members. SDT conceptualizations of intrinsic and extrinsic motivations map onto the findings of Study 1 better than Abrahamson & Fisher's conceptual definitions (2007), which suggest that caregivers sought to educate themselves most often to satisfy their own information needs and curiosity (intrinsic), while occasionally seeking to educate their care recipient (extrinsic). Re-conceptualizing intrinsic and extrinsic SIA motivations in this way would be useful in connecting the SIA literature to a larger body of literature linking SDT to health outcomes (see Ng, et al., 2012 for meta-analysis). An SDT perspective may also be critical in understanding the role of SIA in caregiver burden, as some work has indicated that extrinsic motivations can undermine intrinsic motivations (Desi, Koestner & Ryan, 1999). Specifically, pressure to seek extrinsically could reduce intrinsic searches by caregivers, resulting in greater information insufficiencies.

For cancer caregivers, cancer information is the most prominent unmet need (Wang, et al., 2018; Washington, et al., 2012). Indeed, caregivers in study 1 acquired information to reduce information insufficiencies in three areas: (1) general cancer information, (2) information pertaining to medical decision making for their care recipient, and (3) future care recipient health outcomes. Particularly because others have shown caregivers most urgently need information pertaining to illness and treatment and care (Wang, et al., 2018), and want disease and treatment specific information (Cutrona, et al., 2015; Lee, et al., 2015), caregiver education interventions are critical in these topic areas.

Prior research shows information surrogates are more likely to be family members with strong ties to their care recipient (Feng & Xie, 2015). Study 1 further demonstrates that family dynamics may influence SIA, and they suggest that communication between family caregivers is integral to the process of SIA. When multiple family members acquired information and selectively shared that information with other caregivers, some family members could avoid directly encountering information that was distressful while others could find, synthesize, and disseminate that information to other caregivers and the care recipient. Study 1 therefore extends the idea of information surrogates as gatekeepers (Ramirez, et al., 2015), not just to their care recipients, but also to other family caregivers. Multiple, coordinated caregivers may be able to simultaneously reap the benefits of health information seeking (Bigsby & Hovick, 2017; Jiang & Street, 2016; Waters, et al, 2016), while minimizing the adverse consequences of information overload and avoidance (Chae, 2015; Ramirez & Carmona, 2018).

Future research should examine how information flows through family information networks, with a specific focus on theories of family communication. Family communication patterns (FCP, Koerner & Fitzpatrick, 2002) can impact intentions to discuss certain topics among family members (Hovick, Thomas, Watts & Tan, 2019; Rauscher, Hesse, Miller, Ford & Youngs, 2015). Closeness and relational connectedness may also be an important factor. Although it wasn’t explicitly asked on the interview guide, caregivers interviewed seemed to feel very close to their care recipient and other family members with which they may have shared caregiving duties. Focusing on the bonds between family members and the perceived closeness that caregivers and care recipients feel towards one another may be critical for not only understanding caregiver and care recipient health (Haslam, Cruwys, Haslam & Jetten, 2015), but may also be particularly useful in future research for understanding the role of SIA in caregiving.

Other SIA motivations. Abrahamson & Fisher (2005) conceptualize SIA as something surrogates do in response to their perception of another's informational needs, and describe support as an outcome of SIA (2007); other literature also has focused on SIA as a form of informational support (Cutrona et al., 2015; Fennell, et al., 2016; Heckel, et al., 2017; Rutten, et al., 2006). Study 1 showed that information surrogates acquired information to fulfill different supportive functions, which mirrored existing social support typologies in the literature (e.g., House, 1981; Cutrona & Russel, 1990) including to porivde informational support (e.g. providing information to care recipients about local oncologists), as well as emotional support (e.g. providing comfort) and instrumental support (e.g. buying supplements or paying for a housekeeper).

Caregivers in Study 1 felt that if their own informational needs were met, they could better understand what support type their care recipients needed the most (e.g. informational, emotional, instrumental) and then provide that kind of support. This method of identifying care recipients' support needs reflects the Optimal Matching Model of Social Support model (Cuterona & Russel, 1990), which suggests that helpers want to provide the most effective and appropriate kind of support in a given situation.

Similarly, Burleson's (1982) Hierarchy of Supportive Communication (1982) suggests that the most effective support messages are those that acknowledge the feelings of the support recipient, and try to help the recipient gain perspective. In this study, caregivers sought information in order to understand their care recipients' diagnosis and prognosis and engage in perspective taking. In doing so, caregivers felt they could provide emotional support to that was relevant, and not dismissive of the severity of their care recipients' cancer. However, in this context specifically, there were times when it was difficult to fully understand if caregivers shared information to provide emotional or informational support. Thus, it may be better to look at relational connectedness, or global conceptualizations of social support.

The findings of Study 1 regarding caregivers' enacted support may also be explained, at least in part, by the study inclusion criteria. The present study examines the interpersonal relationships between (predominantly) female family members. Most (*n* = 18) caregivers interviewed were female, and all patients were female. It should be noted that the gender dynamics of the caregiver and care recipient dyad might be particularly influential in understanding the prevalence of seeking and sharing behaviors in Study 1. Women are more likely than men to seek emotional support, and are typically better at producing supportive message (MacGeorge, Feng & Burleson, 2011). Thus, it is imperative to conduct further research with mixed gender dyads, as well as dyads where both the care giver and care recipient are male.

Finally, it is worth exploring the extent to which caregivers engage in SIA as a form of support seeking to alleviate their own psychological burden. Several interviewed participants discussed using forums or support groups as a source of information. Support for caregivers is critical in preventing caregiver burden (Ong, et al., 2018) and may be particularly important in understanding SIA behaviors because interviewed caregivers tended to seek health information, as well as social support from their family members.

This, taken with the finding that surrogates seek information to provide better emotional support, calls into question the distinction between informational and emotional forms of social support in this context. Study 1 results suggest that, for many caregivers, information could provide emotional support or comfort, and further theorization in this area is needed given current typologies of social support.

It is typical for breast cancer patients to perform a great deal of *emotion work,* or management and/or maintenance of others' affect while disclosing their own cancer diagnosis (Yoo, Aviv, Levine, Ewing & Au, 2010). As a result, cancer patients may end up providing a great deal of comfort or support to the people to whom they disclose, instead of soliciting and receiving support as they may intend (Yoo, et al., 2010). Interviewed participants seemed to be aware of this problem, and wanted to avoid situations where their care recipient would have to educate or provide comfort to them as caregivers. Furthermore, demonstrating that caregivers engaged in SIA for the purpose of avoiding certain topics of conversation with the care recipient is a distinctly new finding in the SIA literature. Caregivers avoided information regarding cancer prognosis and survival rates, and future research should further explore how caregivers and care recipients negotiate conversations about these topics.

Information sharing. Study 1 is among the first to document the practice of information sharing (albeit selectively) between caregivers and care recipients as a result of SIA. The findings of Study 1 build on evidence showing information surrogates as synthesizers and gatekeepers of information (Ramirez, et al., 2015), as well as providers of informational support to their care recipient (Cutrona, et al., 2015; Fennel, et al., 2016;

Heckel, et al., 2017; Rutten, et al., 2006). Caregivers were motivated to share information with their care recipient if they believed that that the information was new (i.e., information care recipients hadn't heard before) and would improve their quality of life.

These findings have several implications. First, caregivers' preference for sharing new information with a care recipient may suggests caregivers act as diffusers of health information to their care recipients. Evidence of diffusion is already seen in the SIA literature, as people who do not have access to the internet still learn about health content through surrogate searches (Massey, 2016). Second, caregivers interviewed were predominately female (n = 18), and this may have influenced willingness to share information. Indeed, the genetic risk communication literature suggests that women tend to take on responsibility for disseminating information about cancer risk within the family (Agincourt-Canning, 2001). Finally, because caregivers only wanted to report information that they thought their care recipient hadn't heard before, caregivers made assumptions about care recipients' existing knowledge levels and shared information they sought based on those assumptions. Although the LIMB frames SIA as a means for reducing care recipient knowledge gaps (Abrahamson & Fisher, 2007), caregivers could conversely deepen knowledge gaps by misjudging care recipient knowledge and withholding information. Future informational interventions should focus on ensuring that both caregivers and care recipients receive up-to-date, high quality information from a trusted source in order to help alleviate caregivers' perceived responsibility to seek and share relevant information with their care recipients.

Study 2

Study 2 tested a newly proposed, extended CMM model that accounted for active and passive SIA behavior *and* information sharing, building on existing SIA research examining individual differences (Cutrona, et al., 2015; Oh, 2015) and limited cognitive (Reifegerste, et al., 2020) predictors of SIA. The proposed model was only partially supported, as none of the indirect relationships and half of the hypothesized direct effects were significant. However, the data provide useful insights into the cognitive processes associated with SIA and new directions for SIA research. In particular, surveillance gratifications, information requests, and caregivers' perception of care recipient information gathering capacity were associated with one or more SIA behaviors, and all forms of information acquisition were associated with attention and elaboration. Perceptions of knowledge were associated with sharing, but attention and elaboration were not significantly associated with perceptions of knowledge (see Table 8 and Figure 3 for a summary of study findings). The subsequent sections will describe the main takeaways of Study 2, and the implications for theories of information seeking and the CMM.

Predictors of SIA. Of the six proposed distal predictors, only surveillance gratifications, information requests, and perceived care recipient information gathering capacity were significantly associated with any type of SIA. Guidance gratifications, social utility gratifications, and perceptions of care recipient risk were unassociated with SIA. The following sections will discuss significant predictors in greater detail, emphasizing their role in the hypothesized model predicting both active (i.e. seeking) and passive (i.e. scanning and monitoring) forms of SIA.

Surrogate seeking and monitoring. Surrogate seeking was significantly and positively associated with the greatest number of hypothesized distal predictors (surveillance gratifications, information requests, and perceived care recipient information gathering capacity). These findings are not surprising, given that information seeking is active and goal-oriented (Niederdeppe, et al., 2007) and, thus, more likely to be motivated by media gratifications or cognitive factors (Yoo & Robbins, 2008). Monitoring also was significantly and positively associated with surveillance gratifications and perceived information gathering capacity. Although monitoring is a more passive form of information acquisition than seeking, it is arguably a motivated behavior brought about by the need to cope with a stressful situation (Rees & Bath, 2002). Much like in Study 1, these findings call into question the role of passive information behaviors in prompting purposeful information searches.

Indeed, surveillance gratifications are theorized to result in more guided, informational media use (Gantz, 1978), and this is supported in the positive and significant association between surveillance gratifications and information seeking and monitoring in Study 2. The positive relationship between surveillance gratifications and information seeking and monitoring is in alignment with prior theorization (Gantz, 1978), which suggests that when surveillance gratifications motivate media use (as opposed to other gratifications such as entertainment), media use is more guided or purposeful. Thus, it might be worthwhile for practitioners to find ways to reach caregivers who tend to not use media for informational purposes through health narratives or entertainment education messages.

Caregivers' perception of care recipient information gathering capacity also was significantly associated with surrogate seeking and monitoring, but not in the hypothesized direction. In this study, the more a caregiver thought their care recipient was capable of seeking their own information, the more information they acquired. One explanation for this finding could come from theories of information seeking behavior, including the Risk Information Seeking and Processing Model (RISP) and Planned Risk Information Seeking Model (PRISM; Griffin, et al., 1999; Kahlor, 2010), which posit that subjective norms directly and positively impact information seeking behavior. Indeed, studies have shown subjective information seeking norms are one of the strongest and consistent predictors of information seeking behavior (meta-analysis: Yang, et al., 2014). In the case of Study 2, which was focused on family caregivers, it could be that health information acquisition was highly normative in the families of surveyed participants. This seemed to be the case in Study 1; thus, care recipients were able to acquire their own health information

Table 8

Overview of Study Predictions and Outcomes

Variable	Related hypotheses	Results
Surrogate Seeking	Positively associated with surveillance gratifications (H1a)	Supported
	Positively associated with guidance gratifications (H2a)	Not supported
	Positively associated with social utility gratifications (H3a)	Not supported
	Positively associated with perceptions of care recipient risk (H4a)	Not supported
	Negatively associated with perceptions of care recipient info gathering capacity (H5a)	Partially supported
	Positively associated with information requests (H6a)	Supported
Surrogate Scanning	Positively associated with surveillance gratifications (H1b)	Not supported
	Positively associated with guidance gratifications (H2b)	Not supported
	Positively associated with social utility gratifications (H3b)	Not supported
	Positively associated with perceptions of care recipient risk (H4b)	Not supported
	Negatively associated with perceptions of care recipient info gathering capacity (H5b)	Not supported
	Positively associated with information requests (H6b)	Supported

Surrogate Monitoring	Positively associated with surveillance gratifications (H1c)	Supported
	Positively associated with guidance gratifications (H2c)	Not supported
	Positively associated with social utility gratifications (H3c)	Not supported
	Positively associated with perceptions of care recipient risk (H4c)	Not supported
	Negatively associated with perceptions of care recipient info gathering capacity (H5c)	Partially supported
	Positively associated with information requests (H6c)	Not supported
Attention	Positively associated with surrogate seeking (H7a)	Supported
	Positively associated with surrogate scanning (H7b)	Supported
	Positively associated with surrogate monitoring (H7c)	Supported
Elaboration	Positively associated with surrogate seeking (H8a)	Supported
	Positively associated with surrogate scanning (H8b)	Supported
	Positively associated with surrogate monitoring (H8c)	Supported
	Positively associated with attention (H9)	Partially supported
Knowledge	Positively associated with attention (H10)	Not supported
	Positively associated with elaboration (H11)	Not supported
	Positively and indirectly associated with surveillance gratifications (H12a-c)	Not supported
	Positively and indirectly associated with guidance gratifications (H13a-c)	Not supported
	Positively and indirectly associated with social utility gratifications (H14a-c)	Not supported
Sharing	Positively associated with attention (post-hoc)	Not supported
	Positively associated with elaboration (post hoc)	Supported
	Positively associated with knowledge (H15)	Supported

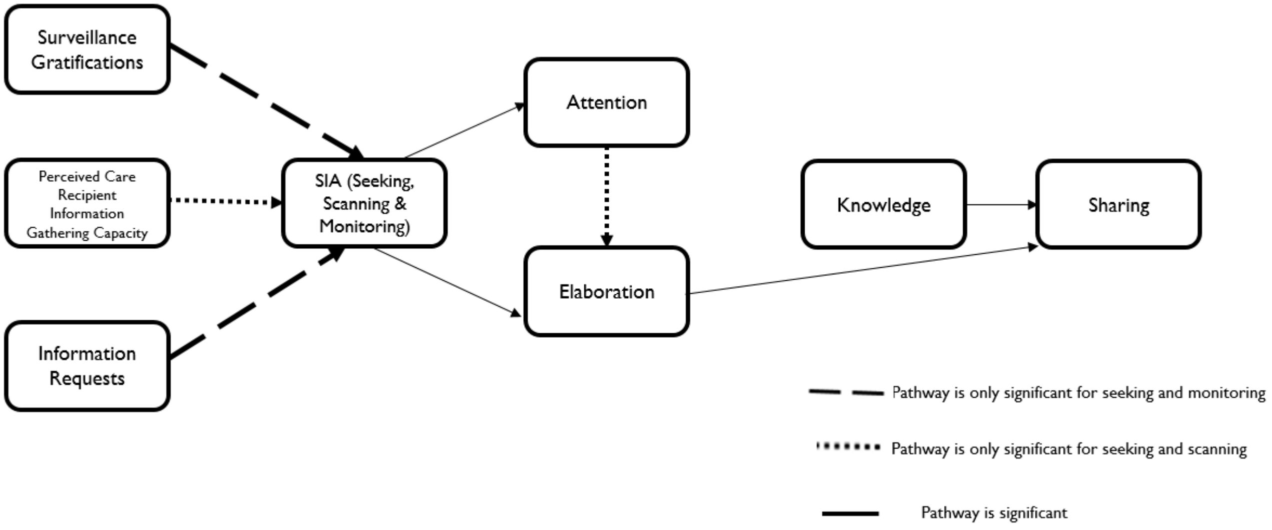

Figure 3: The extended CMM, with significant relationships highlighted

Finally, care recipients' information requests were also associated with surrogate information seeking, which is in in alignment with the LIMB model (Abrahamson & Fisher, 2007; Abrahamson, et al., 2008). This finding in Study 2 provides further support for the relationship between information requests and SIA, as described in Study 1. It appears then that if care recipients make a request for information, caregivers are likely to seek on their behalf, so promoting clear communication of care recipients' information needs to caregivers may be one way to reduce care recipients' information insufficiencies.

Surrogate scanning. Scanning was associated with one hypothesized distal variable, information requests. This is not surprising, given that surrogate scanning is a passive, unguided form of information acquisition (Niederdeppe, et al., 2007) and the distal variables within the tested model are typically associated with active information seeking or media use (Eveland, 2001; Griffin, et al., 1999; Kahlor, 2010; Rubin & Pearse, 1987). However, according to LIMB model propositions, information surrogates may acquire information passively, (Abrahamson & Fisher, 2007). Although the present studies established surrogates' use of passive forms of SIA such as scanning, future research must begin understand additional individual differences that may contribute to a caregivers' surrogate scanning and seeking behaviors as well as the effects of passive SIA on caregiver beliefs and purposeful SIA behaviors.

Unsupported distal variables. Guidance gratifications, social utility gratifications, and caregiver perception of care recipient risk were not significantly associated with any form of SIA. This was surprising, given prior support for both gratifications (Beaudoin &

Thorson, 2004; Eveland, 2004; Ho, et al., 2014; Ho, et al., 2017), and for risk perception in the CMM (Lee et al., 2016). The results of Study 1 could explain the lack of associations between these gratifications and SIA in Study 2. Caregivers in Study 1 were not likely to acquire information for the purpose of talking about it later (social utility gratifications), did not typically make medical decisions on behalf of their care recipients (guidance gratifications as operationalized in Study 2), and did not seem motivated by their care recipients' risk. Another possible explanation lies in the CMM (Eveland, 2001), which hypothesizes a direct relationship from gratifications to attention and elaboration. It may be that the distal variables in the model have a stronger direct relationship with attention and elaboration than the hypothesized relationship with SIA behaviors. This is important to consider, as the present study is interested specifically in information acquisition behaviors, while most tests of the CMM are more concerned with motivations for media use than actual method or amount of media exposure (Wei & Lo, 2008).

A final explanation for the lack of significant findings for surveillance and guidance gratifications lies in the theoretical framework tested in Study 2. The CMM is a theory of media use (Eveland, 2001), and is rooted in theories of media selection and processing (e.g. Uses and Gratifications, Katz, et al., 1973). Although information acquisition through mediated sources is arguably an important part of SIA, SIA, situated in this study with a focus on sharing information, is largely an interpersonal phenomenon. Thus, a framework focused on interpersonal communication motivations and goals, such as Rubin and Rubin's theory of interpersonal motives, grounded in Uses and Gratifications theory, may be better suited for the present context (1992). Indeed, Study 1 suggested that caregivers were motivated to share information, and did so with the intent to achieve specific goals (e.g. inform the care recipient of something new). Some of Rubin & Rubin's (1992) interpersonal antecedents (e.g. health, internal control) and motives (e.g. control, affection) may map onto some of the motivations for seeking and sharing information found in Study 1, and in turn result in deeper cognitive processing and knowledge.

SIA and cognitive processing. Seeking, scanning, and monitoring were all directly and positively associated with attention to and elaboration on breast cancer information. Theories of information seeking and processing such as RISP (Griffin, et al., 1999) and SIM (Viswanath, 2008) suggest that information seeking may result in deeper elaborative processing (as opposed to mere exposure to a message) resulting in changes in attitudes, beliefs, and health behavior (Griffin, Dunwoody & Yang, 2013; Kontos, Bennet & Viswanath, 2007). Study 2 supports a link between information acquisition and deeper elaborative processing, and this is important because despite the potential implications of the theorized link between information seeking and processing on health interventions and health behaviors, such relationships are rarely tested (Waters, et al., 2016; Zhao & Cai, 2008). Study 2 provides much needed support for these claims. However, additional research must be done to determine to what extent information surrogates' processing of information may actually result in attitude and health behavior change. This is an important first step in improving caregiver quality of life and reducing caregiver burden.

Study 2 findings also suggest that less purposeful forms of information acquisition, such as scanning and monitoring can also increase the likelihood elaborative processing. Even if information scanning and monitoring are more common than information seeking (Niederdeppe, et al., 2007), scanners and monitors of information may still be able to reap the benefits of deeper message elaboration, such as health behavior change (Lee, et al., 2013), through passive forms of information acquisition (Waters, et al., 2016). Thus, future research should further explore the extent to which SIA may actually result in attitude, belief, and health behavior change and the impact this may have on caregivers and care recipients.

Perceived knowledge and sharing. Study 2 results showed knowledge was associated with sharing (along with elaboration), but not attention and elaboration. This finding is similar to that of Crook and coauthors (2016) who found that perceived knowledge was positively and indirectly associated with information sharing. Thus, it appears that when people feel knowledgeable about a topic they are more likely to share it with a care recipient. However, future work should continue to identify and test other mechanisms that may link perceived knowledge to information sharing, especially given their importance in Crook's model of health information sharing. However, with the findings of study 2 in mind, practitioners should ensure that they provide caregivers with quality information that is easy to understand in order to promote sharing relevant information with care recipients.

The lack of significant findings between perceived knowledge, attention, and elaboration, was surprising, given support for direct relationships between SIA behaviors, attention, and elaboration. One explanation is that in many tests of the CMM, attention and elaboration are associated with objective tests of knowledge (Beaudoin & Thorson, 2004; Eveland, 2001; Eveland & Dunwoody, 2002). Partial tests of the CMM have found that attention was associated with perceptions of knowledge, (Ho, et al., 2019) and that perceived and objective knowledge are distinct, but highly correlated constructs (Klerck & Sweeny, 2007). Although perceived and objective knowledge are often highly correlated, they may not be the case in the context of breast cancer knowledge. In this case, caregivers could have been exposed to a great deal of information, and processed it, without having specific informational needs met. This concept is similar to information insufficiency in information seeking theories such as RISP (Griffin, et al., 1999). This explanation is bolstered by Study 1, where caregivers described having fewer unmet informational needs, but needing (and failing to find) highly specified information relevant to their care recipients' cancer. Thus, factors other than elaborative processing (e.g., information overload, Ramirez & Carmona, 2018) may better predict perceived knowledge, especially in the domain of breast cancer where information is widely available. From a practical standpoint, this suggests that the success of caregiver education interventions hinges on identifying caregivers' specific informational needs and providing them with that information.

As a result of the null findings surrounding attention, elaboration, and knowledge, a post-hoc analysis was conducted in order to determine whether attention and elaboration played a role in surrogates' decisions to share information. Indeed, elaboration was significantly and positively associated with information sharing alongside knowledge, suggesting that caregivers who are willing and able to process information are more likely to share it. Thus, it is critical that practitioners disseminate information that is interesting and accessible in order to promote information processing, especially among a group of people that may already be under a high cognitive load, and less able to process health messages.

Future directions for research. The CMM was used Study 2 because of hypotheses that predict that media gratifications might result in deeper processing in hopes of a future conversation (Eveland, 2004). The findings of Study 2 suggested that the CMM, at least in the context of breast cancer, may not be the best theoretical explanation for SIA behaviors and outcomes. One major criticism against use of existing information seeking theory (i.e., RISP, PRISM, Griffin, et al., 1999; Kahlor, 2010) is that these theories do not account for information requests or sharing. However, both dissertation studies suggest that although information requests do motivate information seeking, intrinsic motivations may be a stronger driver of SIA behavior. Given that intrinsic motivations seem to be the main driver of SIA, reexamining surrogate information behaviors through the lens of these theories may be particularly useful given the lack of support for the CMM here.

Information seeking predictors such as information requests and perceptions of care recipient information gathering capacity did influence SIA, but not perceived risk. Shifts in information seeking theorization, brought about by recent meta-analysis (Yang, et al., 2016), suggest that perceived risk may be a weaker predictor of information seeking in traditional information seeking models such as RISP and PRISM (Griffin, et al., 1999; Kahlor, 2010) than existing knowledge and information seeking norms. However, this does not mean that other theorized predictors of information seeking should be excluded from SIA models. In Study 1 some participants did describe negative affect, such as fear and anxiety for their care recipient's life and health, as an important motivating factor in SIA, especially when their care recipient was first diagnosed as having cancer; thus, negative affect may be a more influential predictor than perceived risk. Negative affect is a direct predictor of information seeking and intentions across theoretical models of information seeking (Kahlor, 2010; RISP, Griffin et al., 1999; Risk Perception Attitudes (RPA), Rimal & Real 2003). Future work should establish the potential influence of affect, subjective norms and other predictors of information seeking from other major information seeking theories (e.g., Griffin, et al., 1999; Kahlor, 2010) in the SIA context." Future work should establish the role of negative affect, as well as other known predictors of information seeking such as subjective norms (e.g., Griffin, et al., 1999; Kahlor, 2010) in the SIA context.

Implications for Intervention

Taken together, both studies highlight the need for additional education interventions for caregivers and care recipients. Study 1 highlighted the unmet informational needs of caregivers, which is concerning because caregivers unmet informational needs are associated with caregiver burden and reduced quality of life (Lambert, et al., 2012). Effective caregiver education interventions may reduce other unmet caregiver needs, further reducing caregiver burden. For example, an education intervention could inform caregivers of respite care services available, decreasing their fatigue and burden. Informational interventions for caregivers are effective (Applebaum & Breitbart, 2013; Northouse, et al., 2010); thus, the widespread implementation of caregiver interventions are critical for caregiver and care recipient health.

In Study 1, caregivers sought information in order to understand future patient outcomes. Caregiver information needs and acquisition behaviors changed over time and thus, across the survivorship care continuum. Cancer survivorship is under researched in comparison to cancer prevention and treatment and survivorship care plans remain underutilized (Baker, 2020). This lack of comprehensive survivorship care may contribute to the caregivers of survivors' unmet informational needs and negatively impact survivor health outcomes. Thus, further understanding the informational needs of caregivers over time from transition from cancer patient to cancer survivor is essential.

In both studies, care recipients made information requests to their care recipients. While it is not certain, this finding could suggest that care recipients' information needs may be unmet by their healthcare providers, or that they face barriers accessing the information they need. Family members are often placed in the role as translators and advocates in the healthcare system, especially if their care recipient is a non-English speaker (Cohen, Moran-Ellis & Smaje, 1999). Information surrogacy may be one other role placed upon caregivers in this position. Thus, it is important that in addition to providing up to date, accessible, and personalized information to care recipients, healthcare providers and health systems should make a concerted effort to included family caregivers in the process of patient education. Family based breast cancer information and education interventions have been successfully implemented for late stage and recurrent breast cancer patients and their caregivers (Northouse, Kershaw, Mood & Schafenacker, 2005; Northouse, et al., 2013), and the success of these programs may translate to similar interventions for earlier stage breast cancer patients and their families.

Limitations

Both dissertation studies have limitations to note. Qualitative research cannot be generalized to the larger population (Carminati, 2018); thus, the SIA behaviors and outcomes described in Study 1 may not accurately describe SIA behaviors and outcomes for patients with cancers at different sites (e.g. lung cancer) or other types of diseases (e.g. dementia). Future research examining the SIA behaviors that are associated with caregivers of other diseases is needed especially because of the prevalence of breast cancer in the United States. Breast cancer survival rates are relatively high (American Society of Clinical Oncology, 2019), which may suggest that most care recipients, beyond their cancer diagnosis, were in relatively good health, and were able to seek their own information if needed. In both studies participants were highly educated. This may have resulted in a biasing of results, as education is linked to SIA behaviors (Abrahamson et al., 2008; Reifegerste et al., 2017; Rutten et al., 2006). More work should be done to understand caregivers who identify as non-seekers, or caregivers who rely *only* on passive forms of information acquisition, as isolating this segment of the caregiver population may be intergal for identifying caregiver needs and reducing burden.

Study 2 was also limited in scope and generalizability. Although the study was adequately powered, a larger sample size is desired in future studies in order to examine more nuanced differences between participants, especially given the fact that study demographics of Study 2 mirror those in Study 1, participants were predominantely female, and there is a concern that gender plays a critical, understudied role in SIA. Study 2 is also cross-sectional survey, so causal claims cannot be made about any of the significant associations presented here. However, the primary goal of this study was to test a model linking SIA to information sharing, a theorized, but untested outcome of SIA (Abrahamson & Fisher, 2007). The study adapted items from prior CMM research (Eveland, 2001; Eveland, 2004; Ho, et al., 2016), which focused on media use. Many of the survey items adapted from the CMM asked about interpersonally motivated media use. Thus, the items could have been double barreld. It should also be noted that data were collected during the onset of the COVID-19 pandemic. It is unknown the extent to which this event may have led to sampling bias or study attrition, but likely to have had some impact on the data presented here. A final limitation of the study is that the means for the scales for the variables used in the main model were all above the scales' midpoint, with some means being as high as 6.10 on a 7 point scale.

Conclusion

Despite the growing number of studies focused on SIA, few have focused on understanding the cognitive processes and outcomes associated with SIA. Taken together, the results of both studies highlight the caregivers' engagement in passive forms of SIA (such as seeking and monitoring), surrogate seeking as a result of information requests, and informationsharing information with care recipients. Additionally, in testing a new, extended CMM, Study 2 presents several potential boundary conditions of the theory (i.e., most gratifications did not predict SIA, and attention and elaboration were unassociated with percieved knowledge), and presents additional questions for future research and theorizing on the topic of SIA.

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Appendix A: Study Interview Guide

Eligibility Information

1. What is your age in years?
2. Are you currently providing assistance to a family member with breast, ovarian or endometrial cancer? This may include providing emotional support, communicating with health care professionals, or performing medical/nursing tasks
    a. Yes
    b. No
3. How far away would you say (in miles) that you live from your care recipient?
    a. Continuous, fill in the blank

4. How long ago was your care recipient diagnosed with cancer?

    a. Continous (0-11 months and 1-4 years)More than 5 years

5. Have you ever sought informaiton about your care recipient's condition? (e.g. breast, endometrial, or ovarian cancer). This can be from any source such as online, from friends, or informaitonal pamphlets.

Interview Information

6. An important component of this study is participation in an interview, anticipated to take between 60 and 90 minutes. Are you willing to participate in such an interview?
    a. Yes/No
7. What is your name? (text entry box)
8. What is your email address? (text entry box)
9. For future correspondence interview confirmation and reminder, what method of contact would you prefer? Our research team will contact you within 24 hours to confirm the interview timeslot, and once 24 hours before the interview as ar reminder.
    a. Phone
    b. Email
    c. Both

10. For the interview portion of the study what method of contact would you prefer?
    a. Phone
    b. Skype

11. Please supply your phone number/Skype ID#. (Text entry box)

12. Please select a timeslot for your interview. Interviews are anticipated to take approximately 60 to 90 minutes.
    a. A list of available dates and times will be included from a drop down menu.

Demographic information

13. What is your sex?
    a. Male
    b. Female
    c. Prefer not to answer
14. What is your ethnicity?
    a. Not of Hispanic origin
    b. Hispanic origin
15. Would you identify your race as: (select all that apply)
    a. White
    b. Black or African American
    c. American Indian or Alaska native
    d. Asian
    e. Not listed
16. Please select your highest level of education
    a. Never attended school or only attended kindergarten
    b. Grades 1-8 (elementary)
    c. Grades 9-11 (some high school)
    d. Grade 12 or GED (Highs school graduate)
    e. College 1-3 years (some college or technical school)
    f. College 4 years (college graduate)
    g. College 4+ years (Masters, professional, or doctoral degree)
    h. Prefer not to answer
17. Is your annual income from all sources:
    a. Less than $10,000
    b. $10,000 to less than $25,000
    c. $25,000 to less than $35,000
    d. $35,000 to less than $50,000
    e. $50,000 to less than $75,000
    f. $75,000 to less than $100,000
    g. $100,000 to less than $200,000
    h. More than $200,000

Caregiving Information (QUALTRICS)

18. What is your care recipients' sex?
    a. Male
    b. Female
    c. Prefer not to answer
19. What is your care recipient's ethnicity?
    a. Not of Hispanic origin
    b. Hispanic origin
20. Would you identify your care recipient's race as: (select all that apply)
    a. White
    b. Black or African American
    c. American Indian or Alaskan native
    d. Asian
    e. Not listed
21. Do you mind telling me how you are related to the person for whom you provide care?
    a. Blank response box
22. Please select your care recipient's highest level of education:
    a. Never attended school or only attended kindergarten
    b. Grades 1-8 (elementary)
    c. Grades 9-11 (some high school)
    d. Grade 12 or GED (Highs school graduate)
    e. College 1-3 years (some college or technical school)
    f. College 4 years (college graduate)
    g. College 4+ years (Masters, professional, or doctoral degree)
    h. Prefer not to answer
23. What stage of cancer was your care recipient diagnosed with?
    a. 0
    b. I
    c. II
    d. IIIa
    e. IIIb
    f. IIIc
    g. IV
24. Thinking about the individual for whom you are currently providing the most care. About how many hours per week do you spend in an average week providing care?
25. Think about the individual for whom you are currently providing the most care. About how long have you been providing care for this person? Your best estimate is fine.

26. Think about the individual for whom you are currently providing the most care. Do you help your care recipient with any of the following activities:
    a. Performing medical/nursing tasks (for example, giving medicine, changing bandages, managing side effects or symptoms)
    b. Communicating with health care professionals like doctors, nurses, or social workers about his/her care. This includes attending doctors' appointments and treatment appointments.
    c. Arranging for outside services such as nurses, home care aides, Meals on Wheels, or other community services
    d. Spending time with him/her and providing companionship or emotional support
    e. Managing finances such as paying bills or filling out insurance claims
    f. Housework
27. Think about the activities you do for your care recipient. Does anyone else help you with these activities?
    a. Yes/No
28. Next steps: you will receive a message within 24 hours confirming your interview timeslot and preferred method of contact. Thank you for your participation.

Draft Interview Guide (INTERVIEW)

Introduction Questions

1. I'd like to start out by asking you to tell me a little bit about your experiences as a caregiver.
    a. Probe: who do you care for, and what kinds of things do you do?
    b. Probe: Who do you provide care for, and for how long have you provided care?
    c. Probe: Can you tell me a little bit about how your family handled your care recipient's diagnosis?
    d. Probe: are there any conflicts or tensions related to caregiving in your family?
    e. Probe: Can you tell me a bit more about your relationship with the person for whom you care?

2. One of the components of caregiving that we are interested in is health information seeking. What comes to mind for you when I mention the term information seeking?
    a. Probes: experiences with different types of media, or interpersonal sources (family members, doctor)

3. Do you tend to seek information about your own health? If so, why?

4. Do you tend to seek information about your care recipient's health? If so, why?

5. When you seek health information, what sources do you prefer to utilize?
    a. Probe: do the sources you use for yourself versus your care recipient differ?
    b. Probe: what about talking to your care recipient or other caregivers/family members to stay updated?

I want to focus specifically on your experiences seeking information about your care recipient's condition now. Please keep your experiences seeking information about (CANCER TYPE) in mind for these questions.

6. How would you say that you apply the information you encounter after an information search?
    a. Probe: Would you say that seeking information is beneficial or harmful?

7. Has your care recipient ever specifically asked you to conduct an information search on their behalf? If so, how did they ask you?
    a. Probe: What did they ask you to search for?

8. Do you tend to share information with your care recipient after you seek it? Or, is it something that you tend to keep private? Why?
    a. Probe: does it make a difference if they asked for information, versus if you sought it yourself?
    b. Probe: How do you decide what information to share?
    c. Probe: What, if anything, happened after you shared?
    d. Probe: How do you decide what information to withhold?
    e. Probe: What, if anything, happened after you withheld?

9. Would you say that you seek information on your care recipient's condition for yourself, or for your care recipient?

10. Since your care recipient's diagnosis, have your information searches changed? This could be changes in sources preferred, changes in information needed, changes in frequency of information searches, or anything else that comes to mind.

11. Can you tell me about any times where you've encountered information about (recipient's condition) without purposefully looking for it?
    a. Probe: what about receiving advice from others?

    b. Probe: What about seeing an article on social media or in the news?
    c. Probe: would you say that you’re more likely to notice this kind of information, even if you’re not looking for it?

12. Is there any area you’d say you’re lacking knowledge in?

13. Is there anything else you’d like to tell me about your experiences?

Appendix B: Codebook

Notes

1. You should almost always tag a child code (blue) with a parent code (green)
    a. Example: Reason (green parent code) + novel info (blue child code)

2. If multiple parent codes are present in the same passage (e.g. a participant talks about reasons to seek and to share within the same passage) you should (typically) split these into two passages, even if the text is identical. The exception is for outcome / SIA codes and Reason codes.
3. Make sure you highlight *all* relevant text into the same passage instead of splitting into multiple passages.

Glossary

1. Caregiving activity: things that people do while looking after their care recipient. This info is listed in the top from the intake survey, but I'm thinking of just coding what they list in the interview also.

2. Change in information needs: For example, "I don't look up things anymore now that she's in remission." That implies that they looked up information before she was in remission, but do not do so now.

3. Information sources used: places caregivers come across information. I have internet as a general source, but other participants may specify (e.g. looking up peer reviewed articles or official websites). These should be relatively straight forward.

4. Outcomes: what happens as a result of information seeking. Some, but not all of these
    a. Share: participants tell new information, or presumably new information to their care recipients
    b. Discussion: the difference between this and sharing is that patients and caregivers either receive this information at the same time (e.g. from HCP), or

they've both encountered this information and talk about it. None or little of the information is new. Most likely done to corroborate or clarify info. This is used for situations where sharing doesn't quite describe what is going on.

    c. Gate keep: participants talk about selectively withholding and sharing information, possibly based on a reason
    d. Information overload: feeling as if they've been exposed to too much information and cannot synthesize
    e. Make own risk salient: some participants were worried about hereditary breast or ovarian cancer based upon their caregiving experience
    f. Share: sharing information meant that the caregiver told something to the care recipient that they presumed the care recipient did not know
    g. Withhold information: Did not tell a care recipient something they saw/searched for , due to some reason

5. Reason: broadly reasons can describe reasons information was required, or reasons why outcomes occurred. An outcome is usually, but not always present (e.g. because scanning is passive, they may not have reported a reason why they were doing it). Some reasons are exclusive to seeking or outcomes, but there is some overlap.
    a. Corroborate: make sure that information they've heard is repeated elsewhere
    b. New information: new information
    c. Information already known by care recipient: information care recipient already had
    d. Information request: caregiver is asked to seek by care recipient
    e. Social utility: they want to talk about something specific later on (e.g. treatment)
    f. Medical decision making: seeking information about deciding which doctor to visit, treatment to receive, care to provide in the home. We might break this out into other categories later?
    g. Manage uncertainty: doing something to reduce the insecurity in their own state of knowledge
    h. Alleviate anxiety: specifically use information to change mood/perspective
    i. Avoid harm: this is typically used for withholding information. Caregivers did not seek or share information sought because they didn't want to harm their care recipient. Either through physical or emotional distress
    j. Open communication/honesty: caregiver would report information because they felt a responsibility to be honest
    k. Improve quality of life: seeking or sharing so something can be done to improve care recipient's comfort/ day to day life
    l. Respect privacy: instances where caregivers were curious about their care recipient's condition. The care recipient had this information, but the care giver did not want to ask because they felt that asking was a burden.

        - i. Example: “I wanted to know what her chances of living were, but I didn’t want to ask.”
    - m. Support: 1. care giver wanted to support care recipient by doing the work of seeking info 2. Caregiver wanted to provide better, more effective emotional support and sought information to do so.
    - n. Don’t want to dwell on information: Again I don’t know how much we will use this. I am thinking it will or would crop up in situations where
        - i. Avoided seeking because they didn’t want to excessively think about/ruminate on info
        - ii. Avoided telling so their care recipient didn’t excessively think about or ruminate on info (which could be subsumed into the reason -> avoid harm category, which is why I am unsure)

6. Risk Perception: Do we need to code these?
    - a. I would say if you see something about “the diagnosis isn’t that bad” or “this was an aggressive kind of cancer” or something that refers to risk, just code it with the “risk perception” parent code (green). We can go back to his later.

7. SIA: caregiver acquiring information in some way.
    - a. Self seeking: caregiver reports seeking info about their own health, or health (non caregiver related) in general.
    - b. Does not seek information (this could be topic specific) and almost everyone identified as an info seeker in the sample.
    - c. Multiple surrogates: multiple caregivers/people are surrogate seeking
    - d. SIA unclear: info acquisition is happening, but it’s not 100% clear in transcript if it’s purposeful or passive (inferred).
    - e. Surrogate avoiding: avoiding info
    - f. Surrogate monitoring: Keeping up with new information, keeping tabs on an area of interest, returning to a field of information for new updates
        - i. This should be used less frequently than other forms. We discussed last meeting coding this as scanning/seeking (depending on context). If you see an instance where it’s *clearly* happening, code it this way too. No pressure if you miss something here the first couple of passes.
    - g. Surrogate scanning: passively coming across health information in the environment (e.g. seeing an article in Facebook feed.
        - i. I am **pretty sure** we will code doctor visits and info from doctors in this way.
    - h. Surrogate seeking: purposeful seeking/info acquisition behavior.

8. Source preference: these are pretty straight forward. They should be tagged alongside an info source parent and child tag. Like and dislike are basic descriptors, and can accompany other source preference tags if needed (source preference -> like & credible)

a. Does fulfill need: basically they find what they want (e.g. the internet sources I used told me everything I need to know)
b. Does not fulfill need: they still have questions/confusion after using a source (e.g. I was really confused by what the doctor told me)

Appendix C: Study 2 Questionnaire

Instructions: This first set of questions concerns basic, demographic information about yourself. Please answer these questions to the best of your ability.

Screener questions

1. What is your age in years?

2. Which of the following best describes your caregiver status? Caregiving includes providing emotional support, communicating with health care professionals, or performing medical/nursing tasks.
    a. I am currently providing care for a family member who has been diagnosed with breast cancer
    b. My family member is currently cancer free, but I still provide care for them due to other health issues
    c. I am not providing care currently, but I did provide care for a family member with breast cancer within the past two years
    d. I have never provided care for a family member with breast cancer
    e. I provided care for a family member with breast cancer more than two years ago

Demographic Questions (HINTS, 2019 unless otherwise noted)

1. I am:
    a. Male
    b. Female
    c. Nonbinary
    d. prefer not to respond

2. What is the highest grade or level of schooling you completed?
    a. Kindergarten or never attended school
    b. Elementary school only (grades 1-8)
    c. 9-11 years (some high school)
    d. 12 years or completed high school or GED
    e. Post high school training other than college
    f. Some college, no degree
    g. Associates degree
    h. College graduate (4 year degree)
    i. Post graduate (masters, doctoral, or professional degree)
    j. Prefer not to respond

3. What is your ethnicity?
    a. Not of Hispanic origin
    b. Hispanic origin
    c. Prefer not to respond

4. Would you identify your race as:
    a. White
    b. Black or African American
    c. American Indian or Alaska Native
    d. Asian
    e. Native Hawaiian or Pacific Islander
    f. Biracial or multiracial
    g. Not listed Prefer not to respond

5. In general, would you say your health is:
    a. Excellent

   b. Very good
   c. Good
   d. Fair
   e. Poor
   f. Prefer not to respond

Care Recipient Demographics (Adapted from HINTS, 2019 unless otherwise noted)

1. The person that you provide or provided care for is your....(e.g. mother, sister, step-mothe) **(Responses to this question are piped into subsequent questions)**

2. The following questions will ask you to provide a little bit more information about your (**Care Recipient)** and their cancer diagnosis. Please answer these questions to the best of your ability.

3. In what year was your **(Care Recipient)** diagnosed as having breast cancer?

4. Is your **(Care Recipient)** deceased?
   a. Yes
   b. No
   c. Prefer not to respond
5. What is your **(Care Recipient**'s) ethnicity?
   a. Not of Hispanic origin
   b. Hispanic origin
   c. Prefer not to answer
6. Would you identify your **Care Recipient's** race as:
   a. White

   b. Black or African American
   c. American Indian or Alaska Native
   d. Asian
   e. Native Hawaiian or Pacific Islander
   f. Biracial or Multiracial
   g. Not listed
   h. Prefer not to respond

7. What is the highest grade or level of schooling your ${Q17/ChoiceTextEntryValue} completed?
   a. Kindergarten or never attended school
   b. Elementary school only (grades 1-8)
   c. 9-11 years (some high school)
   d. 12 years or completed high school or GED
   e. Post high school training other than college
   f. Some college, no degree
   g. Associate's Degree
   h. College graduate (4 year degree)
   i. Post graduate (masters, doctoral, or professional degree)
   j. Prefer not to answer

8. What stage of cancer was your **(Care Recipient)** diagnosed with?
    a. 0
    b. I
    c. II
    d. III
    e. IV
    f. Don't know
    g. Prefer not to respond

9. If I were to describe my **(Care Recipient)**'s breast cancer, I would describe it as:
    a. Caught at an early stage, having no evidence of cancer cells or non-cancerous abnormal cells breaking out of the part of the breast in which they started, or getting through to or invading neighboring normal tissue
    b. Caught at an early stage, having spread to the lymph nodes but not to other parts of the body
    c. The cancer is or was invasive, having spread to other parts of the body, grown, or both
    d. The cancer has or had not spread to bones or organs, but it’s considered advanced, and it’s harder to fight.
    e. Breast cancer cells have or had spread far away from the breast and lymph nodes right around it to areas such as the bones, lungs, liver, and brain.
    f. Don't know
    g. Prefer not to respond

Caregiving Tasks (HINTS, 2019 unless noted)

1. About how many hours per week do you spend in an average week providing care for your **(Care Recipient).** Your best estimate is fine.

2. About how many hours per week did you spend in an average week providing care for your **(Care Recipient).** Your best estimate is fine.

3. About how long have you provided care for your **(Care Recipient)**? Your best estimate is fine.

4. Do you help your **(Care Recipient)** with any of the following activities: (Please select all that apply).
   a. Performing medical/nursing tasks (for example, giving medicine, changing bandages, managing side effects or symptoms
   b. Communicating with health care professionals like doctors, nurses, or social workers about his/her care. This includes attending doctors' appointments and treatment appointments
   c. Arranging for outside services such as nurses, home care aides, Meals on Wheels, or other community services
   d. Spending time with him/her and providing companionship or emotional support
   e. Managing finances such as paying bills or filling out insurance claims
   f. Housework
   g. Other tasks/not listed
   h. Prefer not to respond

5. Did you help your **(Care Recipient)** any of the following activities: (Please select all that apply).
   a. Performing medical/nursing tasks (for example, giving medicine, changing bandages, managing side effects or symptoms
   b. Communicating with health care professionals like doctors, nurses, or social workers about his/her care. This includes attending doctors' appointments and treatment appointments.
   c. Arranging for outside services such as nurses, home care aides, Meals on Wheels, or other community services
   d. Spending time with him/her and providing companionship or emotional support

   - e. Managing finances such as paying bills or filling out insurance claims
   - f. Housework
   - g. Other tasks/not listed
   - h. Prefer not to respond

6. Think about the activities you do for your **(Care Recipient)**. Does anyone else help you with these activities? (Please select all that apply).
   - a. Paid health aide
   - b. Another family member
   - c. Friend
   - d. Your partner or spouse
   - e. **(Care Recipient's)** partner or spouse
   - f. Other
   - g. Prefer not to respond

Comorbidity control question (Original Item)

7. Does your **(Care Recipient)** have other conditions, illnesses, or chronic diseases which require your care?
   - a. Yes
   - b. No
   - c. Prefer not to respond

Long distance caregiver control question (Original Item)

8. Approximately how far away in miles does your **(Care Recipient)** live from you?

Information Seeking Questions (HINTS, 2019)

Instructions: The following questions will ask you about your experiences and preferences with information about breast cancer. Please think about your **(Care Recipient's)** breast cancer diagnosis and treatment when answering these questions.

1. Do you ever look for information about your **(Care Recipient's)** breast cancer from any source?
2. When finding out information about your **(Care Recipient's)** breast cancer diagnosis, treatment, or recovery, what sources do you tend to go to? Please mark all that apply.

3. When finding out information about **(Care Recipient's)** breast cancer diagnosis, treatment, or recovery, what source do you ***prefer most***? Please select only one.

(Responses for question 2 and 3 are the same and repeated in survey)

a. Books
b. Brochures, pamphlets, etc
c. Cancer organization
d. Family
e. Friend/Co-Worker
f. Doctor or health care provider
g. Internet
h. Library
i. Magazines
j. Newspapers
k. Complimentary, alternative, or unconventional practitioner
l. My ${Q17/ChoiceTextEntryValue}
m. Other/Not listed

Main Study Questionaire: All items assessed on a strongly disagree (1) to strongly agree (7) scale unless otherwise noted.

Information Seeking (Kahlor, 2010)

1. I actively seek information about my **(Care Recipient's)** breast cancer.

2. I purposefully look for information about my **(Care Recipient's)** breast cancer.

(Scanning, Kelly et al., 2010)

1. I encounter or hear information about my ${Q17/ChoiceTextEntryValue}'s breast cancer, even when I am not actively looking for it.

2. When it comes to my ${Q17/ChoiceTextEntryValue}'s health, I'm content to let information come to me in the course of my daily life.

Monitoring (Lewis, Martinez & Caramel, 2017)

1. I purposefully monitor or pay attention to information about my ${Q17/ChoiceTextEntryValue}'s breast cancer.

2. I look for information about my ${Q17/ChoiceTextEntryValue}'s breast cancer by paying attention to what's going on around me.

Information Requests (Abrahamson, et al., 2008 & Original items)

Original items indicated with *

Instructions: The following questions will ask you a little bit more about your experiences and preferences with information about breast cancer. Please think about your **(Care Recipient's)** breast cancer diagnosis and treatment when answering these questions.

1. Has your **(Care Recipient)** ever asked you to actively seek information about their breast cancer diagnosis, treatment, or recovery from any source?

2. My **(Care Recipient's) has not** asked me to seek information about their breast cancer. (Reverse coded)

3. If I conduct an information search regarding my **(Care Recipient's)**'s breast cancer, it is because my **(Care Recipient)** asks me to. *

4. When I conduct information searches regarding my **(Care Recipient's)** breast cancer, it is because **I** want to.*

5. When I conduct information searches regarding my **(Care Recipient's)** breast cancer, it is because my **(Care Recipient's)**wants me to.*

Surveilence Gratifications (Adapted from Eveland, 2001 & Jensen, 2011)

Instructions: The following questions will ask you a little bit more about your experiences and preferences with information about breast cancer. Please think about your **(Care Recipient's)** breast cancer diagnosis and treatment when answering these questions.

1. I want to know if there are any new treatment options available for my **(Care Recipient's)**.
2. I want to understand what's going on with my **(Care Recipient's)** health.
3. I want facts to back up my opinions about my **(Care Recipient's)** health.
4. I want information that makes me think critically about my **(Care Recipient's)** health.

Instructions: The following questions will ask you a little bit more about your experiences and preferences with information about breast cancer. Please think about your **(Care Recipient's)** breast cancer diagnosis and treatment when answering these questions.

Guidance Gratifications (Beaudoin, 2004)

1. The information helps me decide if I should be worried about my **(Care Recipient's)** health.

2. The information helps me decide if I should do something to help my **(Care Recipient's)** manage their treatment side effects.

3. The information helps me make up my mind on how to help manage my **(Care Recipient's)** symptoms.

Instructions: The following questions will ask you a little bit more about your experiences and preferences with information about breast cancer. Please think about your **(Care Recipient's)** breast cancer diagnosis and treatment when answering these questions.

Social Utility Gratifications (Beaudoin & Thorson, 2004; Ho, et al., 2016)

1. I want to be able to advise my **(Care Recipient's)** about their healthcare decisions.

2. I want to be able to inform my **(Care Recipient's)** about their healthcare options.

3. I want better inform my **(Care Recipient's)** so they know what to expect in a situation that is going to happen in the future.

Instructions: The following questions will ask you a little bit more about your experiences and preferences with information about breast cancer. Please think about your **(Care Recipient's)** breast cancer diagnosis and treatment when answering these questions.

Perception of Patient Risk (Forsyth, Horwitz, Leventhal, Bruger, & Leaf, 1996; Hovick, Kahlor & Liang, 2014)

1. I would describe my **(Care Recipient's)** breast cancer as: (not severe (1)-severe(7).

2. I often think about calling the doctor for my **(Care Recipient)** .

3. My **(Care Recipient)** is frequently ill.

4. I am often concerned that my **(Care Recipient)** doesn't look as healthy as they should.

5. My **(Care Recipient's)** seems sicker than other people diagnosed with breast cancer.

Instructions: The following questions will ask you a little bit more about your experiences and preferences with information about breast cancer. Please think about your **(Care Recipient's)** breast cancer diagnosis and treatment when answering these questions.

Perceived Patient Information Gathering Capacity

1. My **(Care Recipient)** knows what questions to ask healthcare professionals.

2. My **(Care Recipient)** does **not** know what questions to ask healthcare professionals.

3. My **(Care Recipient)** knows where to go for more information.

4. My **(Care Recipient)** can readily take the time to gather any additional information they might need.

5. I think that much of the information would be too technical for my **(Care Recipient)** to understand.

6. I think that my **(Care Recipient)** would know how to separate fact from fiction.

7. I think my **(Care Recipient)** could understand information on this topic if they make the effort.

Instructions: The following questions will ask you a little bit more about your experiences with encountering information about breast cancer. Please think about your **(Care Recipient's)** breast cancer diagnosis and treatment when answering these questions.

Attention (Eveland, 2001)

1. In general, when you seek or encounter information relevant to your **(Care Recipient's)** breast cancer in **(SELECTED INFORMATION SOURCE)** do you tend to pay... (very little (1)-a lot (7) of attention). (This question repeated for each information source selected)

Instructions: The following questions will ask you a little bit more about your experiences with encountering information about breast cancer. Please think about your **(Care Recipient's)** breast cancer diagnosis and treatment when answering these questions.

Elaboration (Eveland, 2001)

1. Information often comes to have a broader meaning relevant to my **(Care Recipient's)** health after I have a chance to think about it.

2. Often when I think about something I've learned in regards to my **(Care Recipient's)** health I recall it later and think about it.

3. I often interpret new information about my **(Care Recipient's)** health in a way that helps me make sense of it.

I rarely spend much time thinking about the information I read or hear about my **(Care Recipient's)** health. (Reverse coded)

4. When I come across health information, I find myself tying the information to ideas I had about my **(Care Recipient's)** health before.

Knowledge (Griffin, Neuwirth, Dunwoody, & Giese, 2004; Ho et al., 2019)

1. Considering everything that there may be to know about your care recipient's condition where 1 means "nothing," and 7 means "almost everything" how much do you think you currently know about your **(Care Recipient's)** health condition?

Instructions: The following questions will ask you a little bit more about your experiences with encountering information about breast cancer. Please think about your **(Care Recipient's)** breast cancer diagnosis and treatment when answering these questions.

Information Sharing (Crooks, et al., 2016)

1. After seeking or encountering information relevant to my **(Care Recipient's)**breast cancer, I tend to share this information with them.

2. After encountering information relevant to my **(Care Recipient's)** breast cancer, this information tends to come up in conversation with them later on.

After encountering information relevant to my **(Care Recipient's)** breast cancer, I tend to talk about this information with other family members.

3. After encountering information relevant to my **(Care Recipient's)** breast cancer, I tend to talk about this information with healthcare providers.