

CALIFORNIA STATE UNIVERSITY, NORTHRIDGE

Exploring Perceptions of Patient-Informal Caregiver Dyads on Communication and
Collaboration Around Chronic Illness Management

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Dedication

This study is dedicated to chronic illness researchers Dr. Ranak Trivedi, Rashmi Risbud, and Dr. Judith DeBonis, who have made invaluable contributions to chronic illness and healthcare research. Dr. Lauren Willner is acknowledged for advising this research. Honored in this paper are researcher Alessandra Rizzotti's parents, Jeffery Rizzotti, who died of Parkinson's and Cancer, and her mother, who is living with arthritis and other illnesses. Researcher Lisa Yount would like to dedicate this study to her grandparents, who are both simultaneously at the end of life with Alzheimer's disease. Finally, this is dedicated to all patients and caregivers who are experiencing chronic illness, waiting for cures. This project and research was funded by California State University, Northridge and the Clinton Global Initiative University in 2017.

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Abstract

Exploring Perceptions of Patient-Informal Caregiver Dyads on Communication and Collaboration Around Chronic Illness Management

By

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Master of Social Work

This qualitative study explores chronic illness management among patient-informal caregiver dyads. Expanding on studies characterized by chronic heart failure (Trivedi, 2017) and depression (Risbud et al., 2017), the research question asked: How do individuals in patient-informal caregiver dyad relationships characterized by varying chronic illnesses communicate and collaborate around management? Seven patient-informal caregiver dyads who were in partnerships or marriages participated in open-ended, semi-structured interviews. Grounded theory analytic techniques such as open and focused coding were used to ensure rigor in data analysis. Findings were that communication and collaboration were key to illness management, including expressions of love and humor, as well as teamwork in decision-making and treatment planning. Unexpected emerging themes included coping through art and making meaning of illness. Future research would benefit from diversity in dyad sampling regarding race, ethnicity, age, sexuality, and types of illnesses studied. More focus is needed on expressions of love and creativity in managing chronic illness.

Keywords: [chronic illness, informal caregivers, couples, management, communication, collaboration, making meaning]

Introduction

One hundred fifty-five million Americans suffer from chronic illnesses, while 68 percent have two or more (American Group Psychotherapy Session, 2013; Trivedi, 2017). Chronic illness is often described as an unpredictable symptom recurrence in which the person is rarely cured and the disease has to be managed over an indeterminable amount of time (Årestedt, Benzein, Persson, & Rämgård, 2016; Holman, & Lorig, 2004; Kotronoulas, Wengstrom, & Kearney, 2013). This has become a national epidemic that not only affects the people with the chronic illnesses, but also an additional 39.8 million informal caregivers for chronically ill adults (Coughlin, 2010). Informal caregivers are unpaid family and friends who care for those who have an illness that requires regular management and assistance (Family Caregiver Alliance, 2017). Experiencing a chronic illness involves a patient regularly working with doctors and oftentimes, caregivers, to manage the illness. Chronic illness has also been described as a shared experience between a caregiver and the person with the illness (Holman, & Lorig, 2004; Kotronoulas et al., 2013; Wagner et al., 2001). This patient-informal caregiver relationship is particularly relevant to healthcare, as any change in functioning of one individual in the relationship changes the functioning of the other, as well as their interactions with the medical care system (Årestedt et al., 2016; Holman, & Lorig, 2004; Kotronoulas et al., 2013; Trivedi, 2017; Wagner et al., 2001).

The most common types of chronic illnesses, as specified through The Centers for Disease Control (CDC) (2017), include heart disease, stroke, cancer, type 2 diabetes, obesity, and rheumatoid arthritis, which are all costly to manage. There are many other types of illnesses that affect Americans, but the costs associated with chronic illness seem

to focus on these common illnesses. Managing chronic illnesses account for 75 percent of America's healthcare costs (Trivedi, 2017); thirty percent of people with chronic illness use a mix of both paid and unpaid care (U.S. Department of Health & Human Services, 2015) and almost two-thirds of people ages 65 and older rely exclusively on informal care for their needs (Family Caregiver Alliance, 2017). People with chronic illnesses and informal caregivers experience many burdens related to care that may result in lower quality of life, fatigue, social isolation, depression, increased mortality and risk for disease, increased comorbidity, sickness, lack of affordable housing, decreased self-care, as well as increasing individual healthcare needs (Aoun et al., 2012; Choi, 2010; McCabe, Firth, & O'Connor, 2009; McMillan et al., 2005; Sansom-Daly, Peate, Wakefield, Bryant, & Cohn, R. 2012; Washington, & Rakes, 2015).

Managing a chronic illness involves reducing negative social, psychosocial, and physical consequences for patients, for which the patient-informal caregiver relationship is often responsible on a regular basis. Managing an illness includes encouraging and teaching patients how to medically, behaviorally, and emotionally regulate their health using their own resources, including setting goals, monitoring the illness, decision-making, taking action, and gaining information to cope with the difficulties of being affected by the illness (McQuaid, Tien, & Apter, 2008; Holman, & Lorig, 2004). Chronic illness management is difficult for people in patient-informal caregiver relationships; to date, most research has focused on patient barriers, including knowledge of disease, communication, socioeconomic factors, as well as relationships with providers and family, and a lack of social and professional support (Trivedi, 2017).

Few studies simultaneously explore the perceptions of barriers to illness management for both people in the patient-informal caregiver relationship (Trivedi, 2017). Trivedi (2017) has specifically explored patient-informal caregiver relationships characterized by the experience of the congestive heart failure diagnosis while researcher Risbud and associates (2017) has explored managing depression in patient-informal caregiver relationships. This specific study will expand on Trivedi (2017) and Risbud's (2017) research studies to explore perceptions of patient-informal caregiver dyads on the barriers and influencers of chronic illness management through the question: How do individuals in patient-informal caregiver relationships characterized by varying chronic illnesses communicate and collaborate around managing chronic illnesses?

Literature review.

Background.

Informal caregiver roles are often underestimated in illness management. Caregiver involvement can result in better adherence to medications and lifestyle recommendations, increased monitoring of patients through co-habitation, shared enrichment activities such as preparing and eating meals together, better care coordination with teams, better outcomes upon discharge from hospital stays, and better well-being through emotional support (Trivedi, 2017). However, chronic illness management is difficult for both people in patient-informal caregiver relationships and most research is focused on patient barriers such as knowledge, communication, socioeconomic factors, relationships with providers and family, barriers experienced by family caregivers, role strain, and lack of social and professional support (Trivedi, 2017). Few studies have focused on patient-informal caregiver perceptions of barriers to chronic

illness management, such as lack of knowledge and education, lack of communication, and negative bonds (Trivedi, 2017).

Illness management approaches.

Chronic illness management often involves a patient initiating regular check-ins with the self, caregivers, and medical providers about behavior, medical health, and mental health; these regular check-ins are necessary for maintaining the well-being of the patient (Ory et al., 2013). Rather than focusing on relationships with informal caregivers, most studies focus on individualistic interventions for patients.

Management tools used for individuals have included evidence-based practices (EBPs), technological tools, and communication clinics. EBPs such as Cognitive Behavioral Therapy (CBT), Acceptance and Commitment Therapy (ACT), and Motivational Interviewing (MI) have been tested with individuals with chronic illness (Bennett, Shafran, Coughtrey, Walker, & Heyman, 2015; Ehde, Dillworth, & Turner, 2014; Koenig, Pearce, Nelson, & Daher, 2015; Thirsk, & Clark, 2014; Losada et al., 2015; Okai et al., 2013). It can be assumed that individual improvements would benefit patient-informal caregiver's perceptions of chronic illness management, but there is limited understanding of how these EBPs affect patient-informal caregiver relationships, as they are only delivered to individuals rather than both people in the patient-informal caregiver relationship (Bennett et al., 2015; Ehde et al., 2014; Koenig et al., 2015; Losada et al., 2015; Okai et al., 2013).

Illness management techniques focus on increasing the individual's knowledge, awareness, or consciousness of their chronic illness, which include technological tools (Trivedi, 2017) such as email, phone reminders, online applications, social media support

groups, or websites that involve web chats, discussion boards, and educational videos. These tools have the potential to improve communication between people with chronic illnesses and informal caregivers. However, there are limited studies on technological tools designed for patient-informal caregiver communication (Atherton, Sawmynaden, Sheikh, Majeed, & Car, 2012; Blom, Zarit, Zwaafink, Cuijpers, & Pot, 2015; Gallagher-Thompson et al., 2010; Kingod, Cleal, Wahlberg, & Husted, 2017; Perron, 2002).

Lewis, Malik, Adams & Patel (2016) examined communication clinics in hospitals established to improve the communication between caregivers and ill individuals who also had interdisciplinary teams aiding in managing their illnesses. The researchers studied ten patient-informal caregiver relationships, and the communication clinic consisted of a clinician, case manager, ward staff, the caregiver, and the patient. The study showed improvement in not only patient and clinician morale, but also showed less anxiety among the caregivers, more empowerment in the decision-making process, positive feedback, and greater satisfaction from the caregiver and the patient (Lewis et al., 2016). This study demonstrated how interdisciplinary communication about the diagnosis is crucial for chronic illness management, yet more studies need to be done among patient-informal caregiver dyads. A limitation to this study is that the focus was on older adults with dementia, but not other less debilitating chronic illnesses. In addition, not enough people of varying demographics were studied. It would be beneficial to gain larger samples of varying demographics to understand how interdisciplinary communication in hospital settings affects patient-informal caregiver perceptions of chronic illness management.

Current research on patient-informal caregiver perceptions of management.

Within a study of 17 patient-informal caregiver relationships characterized by the experience of congestive heart failure, Trivedi (2017) demonstrates that quality of patient-informal caregiver relationships can improve perceptions of chronic illness management; yet more research needs to document the perceptions of management among patient-informal caregiver relationships characterized by varying chronic illnesses. In a qualitative study of 18 patients with depression and seven in-home caregivers, Risbud et al. (2017) demonstrates that patient-informal caregiver relationship closeness, understanding, and explicit role-making in the patient-informal caregiver relationship improved perceptions of management, yet more needs to be studied with samples of people characterized by other chronic illnesses.

Daily enrichment activities between informal caregivers and chronically ill patients have the potential to improve management in both parties (Li, & Loke, 2013), yet a systematic review of 35 articles (Li, & Loke, 2013) focused more on caregiver perceptions and not on patient perceptions within the relationship. Emotional and peer-support through group therapy and mentoring are proven to relieve the stress of caregivers and people with chronic illnesses as separate groups, but there are minimal studies on support groups for both people in patient-informal caregiver relationships (Lauritzen, Pedersen, Sorensen, & Bjerrum, 2015; Maslow et al., 2013).

The illness management techniques available for stress alleviation between chronically ill patients and their caregivers have mostly been tested among adults ages 65 and older as well as caregivers of more terminal illnesses. In addition, chronic illness management studies are often more attuned to the needs of the person-in-care versus the

caregiver, which leads to disconnection in the support available for maintaining the health of both people in the patient-informal caregiver relationship (Barrera-Ortiz, Carrillo-González, Chaparro-Díaz, Afanador, & Sánchez-Herrera, 2011). Because age and disease groups as well as types of management techniques, scales for measuring quality of life with chronic illnesses, and caregiver management outcomes varied in all of these research articles, meta-analysis was not possible. Although management techniques for illnesses such as diabetes and asthma have been studied in multiple articles (Bennett et al., 2015; Dean, Walters, & Hall, 2010; Maslow et al., 2013; Reynolds, Mrug, & Guion, 2013; Sansom-Daly et al., 2012), more consistency in interventions as well as the types of samples of adults are needed in studies to make more definitive conclusions about adult patient-informal caregiver perceptions on chronic illness management.

Diversity of samples was also lacking across all research, particularly among chronically ill groups of color, such as African Americans or Latinos facing poverty, which present high chronic illness rates and need for informal caregivers due to past trauma experiences, lack of access to healthy food, and lack of healthcare (Anzaldúa, 2014). In addition, caregiver studies involved a majority of female and Caucasian caregivers, demonstrating a need to study more informal caregivers of color and various genders (Aoun et al., 2012; Chentsova-Dutton et al., 2002; Choi, 2010; Wittenberg-Lyles et al., 2012). Some of the research on caregivers reported having small sample sizes and most of the studies focused on terminal illness, such as Aoun et al. (2012), Chentsova-Dutton et al. (2002), and Choi (2010), with little exploration about patient-informal caregiver perceptions of chronic illness management. Thus, it would be beneficial to

have more understanding of people of color and younger populations amongst patient-informal caregiver dyads.

Although this study aimed to address all gaps in literature mentioned above, it was not completely feasible due to limitations in time available and sampling techniques. The following research aimed to explore the ways in which patients and informal caregivers affected by varying chronic illnesses navigate illness management. Through the literature review, it was determined that more needs to be studied about barriers in illness management, the use of illness management techniques such as EBPs, technological tools, and communication clinics for patient-informal caregiver dyads. In addition, more could be studied about patient-informal caregiver roles, closeness, understanding, daily enrichment, as well as emotional support among patient-informal caregiver dyads. The aim of this study was to explore barriers in illness management, communication tools used, as well as what makes communication and collaboration more feasible among patient-informal caregiver dyads. The objective of this study was to understand the various types of communication and collaboration that are both beneficial and challenging amongst patient-informal caregiver dyads.

Methods

Both deductive and inductive approaches were used to code data in this qualitative study. Using deductive or a priori coding derived from Trivedi (2017) and Risbud's (2017) interview guides and research questions, pre-codes were established, such as collaboration, communication, management, technology, and support (Saldaña, 2016). Open codes were used to analyze all interviews after transcription. Not originally intended for research, new emerging themes were discovered through an inductive coding approach that involved identifying frequent sub-themes that became focused codes.

Participants.

Seven patient-informal caregiver dyads were recruited for this study, totaling 14 individual participants. Illnesses presented were: ulcerative colitis, Crohn's disease, multiple sclerosis, cystic fibrosis, brain and nerve damage, T-cell lymphoma, and Hashimoto's thyroiditis. Four couples included caregivers with chronic illnesses that caregivers considered less severe and thus did not rely on the patients for illness management. Caregiver illnesses included asthma, rheumatoid arthritis, fibroids, and chronic back pain. Participants lived in a metropolitan area of the western United States. All but one group of participants identified as being Caucasian and heterosexual, with one dyad identifying as both multiethnic and queer. The average age range of participants was late 20's to mid 40's. All of the participants were either married or in a committed relationship with their informal caregiver. See Appendix D for a breakdown on patient-informal caregiver demographics.

Data collection.

The California State University Standing Advisory Committee for the Protection of Human Subjects approved this study through an IRB application process. Participants were recruited using email and social media (see Appendix B) with a survey form (see Appendix C) to pre-screen participants and determine eligibility in the month of December 2017. Snowball sampling was used among online and offline chronic illness and informal caregiver support groups as a way to encourage participants to reach out to other potential subjects (Babbie, 2008).

A pre-survey was conducted to determine the eligibility of potential participants, which required that they were over age 18 and managing a chronic illness with an informal caregiver who they were willing to be audio recorded with in an interview (see Appendix C for the pre-survey). Once participants were determined eligible, a qualitative interview of the patient-informal caregiver dyads was created and implemented (see Appendix A).

One researcher met with the participants in the months of January and February of 2018. Each interview was conducted at the participants' homes. The participants were audio recorded, and those interviews were transcribed electronically by a professional service for the sole purpose of data analysis. Each interview was an hour and a half to over two hours and there was one interview for each dyad. Field notes and memos allowed researchers to keep track of biases that arose throughout the research process, as well as reflect on the research process itself.

Data analysis.

Grounded theory analytic techniques were used for data analysis, which involved multiple cycles of coding, including a first and second cycle of coding that started with open coding, in which over five themes from the interview guides were used (Saldaña, 2016). Themes such as illness management techniques, communication, collaboration, support systems, and interventions used aided the researchers in discovering patterns among the data that pointed to how the patient-informal caregiver dyads understood management of chronic illness (Rubin, & Babbie, 2014). In the second cycle of coding, focused coding was used to identify 20 themes and subthemes in relation to the research question (Saldaña, 2016), which included making meaning of the illness and art as a coping tool. Coding was conducted by-hand on the transcriptions and electronically by each researcher individually, then was later sub-coded through co-coding as a team into general themes pertaining to the research question in order to ensure rigor and accuracy.

Statement of reflexivity.

Researcher Alessandra Rizzotti has an insider perspective from both patient and caregiver perspectives. As someone with a chronic illness who helped her father through the management of Parkinson's and who later served as a mental health clinician intern to chronically ill individuals, she understands patient-informal caregiver illness management issues. However, Rizzotti does not have a caregiver living with her, which is why she was interested in how people with chronic illness manage their illness with their partners or loved ones. Rizzotti's access to health management resources gives her privilege that influenced her lens on how she sees self-management. Thus, it was important that the research explored the perspective of what self-management looked like

for those of varying demographics so that it was understood where gaps were and how this population could be better served.

Researcher Lisa Yount was a social work intern in hospice with people who had terminal illnesses at a nonprofit organization. In the past, she worked with individuals with serious mental illnesses, and saw how they struggled and remained resilient with outside support. As she saw her grandparents living with Alzheimer's go through the end of life process, she simultaneously witnessed how her patients with illness and their caregivers coped through the end of life process. Her goal is to offer support for families as they manage their health towards the end of life. Lisa sees how relationships between caregivers and ill patients are often compromised due to the complexities of managing the illness together. However, her perspective comes from an end of life process, rather than the process of managing chronic illness. Researchers offered both insider and outsider perspectives that shaped how data was analyzed and discussed.

Results

Communicating around illness management.

Both the patients and informal caregivers communicated with themselves about illness management as well as communicating with each other by acknowledging their personal needs, fighting with the illness, or trying to fix the illness. Expressing gratitude, love, care, and humor with one another made it easier to manage illness. Face-to-face verbal communication, as well as texting, were preferred means of communication about illness management.

Communication with the self.

Patients often had to communicate with themselves in order to manage their illness. This included meditating, thinking about their symptoms, checking in on their feelings, knowing what time to take medications, what to eat, and telling themselves to rest. All of the patients had to remember to take medications and schedule their own doctors' appointments. Patients often juggled between acknowledging their illness completely and minimizing it so that they could participate in pleasurable activities, even if they knew the activities would exacerbate their symptoms. For example, one patient with Crohn's disease would do regular "gut checks" with herself each morning and night to assess her ability to engage in activities with her informal caregiver. Some patients wanted to fight against the illnesses in order to not only have a sense of control about something that they knew they could not control, but also because they did not want to feel a sense of loss about activities they used to do. A patient with the inflammatory bowel disease ulcerative colitis described what it was like to have a "flare-up," which is what occurs when someone has an exacerbation of chronic illness symptoms; this made it

hard for her to be fully present in conversations with her partner or other relationships. She demonstrated her own denial and minimization of her illness through breaking her diet or engaging in addiction, which negatively affected her illness management as well as her relationship with her informal caregiver. Patients internally communicated anxiety, self-awareness, denial, a fight, a need to adjust to new identities, and navigating when and where to express themselves. Ultimately, fighting the illness internally would strain the relationship with the informal caregiver, but if a level of acceptance about the illness was achieved on both ends, there was more ease in management.

Each informal caregiver participant appeared to want to “fix” the patient’s illness and would grapple with that desire internally on a regular basis. Some caregivers constantly communicated their anxiety about fixing the illness, despite knowing that the illnesses the patients had were incurable and would therefore not change regardless of them trying to fix anything. Some of the caregivers interviewed had high expectations of their roles and grew frustrated about not meeting their own expectations. The caregiver of the patient with multiple sclerosis noticed how trying to fix things did not help the patient in managing her illness: “What gets in the way of helping, if I look at all the things, it is a mindset that there is a fix at this given moment. I need to get that out of my head.” Some caregivers struggled with trying to fix the illness more than others. If the caregivers had accepted the state of the illness, they were less likely to struggle with it. It was observed that the informal caregiver would often omit their own illnesses or issues that they would struggle with in order to focus on the patients. Overall, most caregivers experienced feeling alone in their own struggles at times.

Communication together.

The patient-informal caregiver dyads in this study communicated about the illness through metaphors, symptoms, and expressing needs. For example, chronic illness was often described in metaphors as an unwanted presence, or a “third person” that caused a type of disruption in day-to-day living for both patients and caregivers. Instead of defining their illnesses using concrete medical definitions, chronically ill patients and their caregivers described how patients’ bodies were affected through symptoms. Chronic pain, migraines, inflammation, fatigue, infections, and anxiety were the most common symptoms tied to the experience of living with chronic illness. In most interviews, both patients and caregivers had related to each other by speaking about other illnesses shared in their families. Patients communicated about how their illnesses evolved by recounting familial stories that tied their autoimmune issues to genetics. Caregivers would relate to these familial stories by sharing their own familial stories about chronic illness, and this common bond created ease in the patient-informal caregiver relationships.

Direct communication of needs and feelings between the patient and informal caregiver was crucial; the needs of each party had to be considered in order to maintain wellness on both sides of the dyad so that the illness was more manageable. The pairs discussed that expression of love and affection played large roles in their well-being, which was demonstrated through touch and expressing gratitude and admiration for one another. Empathizing, listening, attuning to nonverbal cues, having a sense of humor, verbalizing face-to-face, and texting were the most effective approaches to communicating together. What helped all patient-informal caregiver dyads in managing illness was having positive routines around physical touch. For example, a patient with

brain and nerve damage would play “tickle games” and go in the hot tub with his informal caregiver; the patient with cystic fibrosis would give foot rubs to his informal caregiver and she would buy him massages, and the patient with T-cell lymphoma would have regular “heart hugs” with her informal caregiver in which they embraced and kept their chests together for a long period of time. All couples held hands, rubbed each other’s backs, and looked into each other’s eyes throughout the interviews, except one couple.

How patients and informal caregivers were feeling in the relationship would often change how the illness was managed through communication and collaboration. There was a common experience shared in which the patient did not want their romantic partner to fully become a caregiver, and yet the severity of the illness dictated how much of a caregiver the romantic partner became. Many couples reported having to regularly do check-ins with each other about their physical needs. The caregiver of the patient with Crohn’s disease stated:

It became really a one-way street and then it was like caretaker instead of husband, which that's not a great way to live as a married couple. To me, that took longer to sort of hash out on both our ends. I feel like we're in a pretty good place now where we respect each other's individual needs.

Expressing admiration and gratitude for one another reminded many patient-informal caregiver dyads what kept them in the relationship, even when there were challenges. Nearly all interviewees expressed love, affection, admiration, and gratitude of one other, which allowed them to relate to each other in more positive ways so that illness management was more effective.

More than half of the participants utilized humor throughout the interview process and found that humor was a part of their relationship prior to the presence of the illness. Humor appeared to be an important aspect of illness management, as it allowed them to maintain distance from feelings of negativity around the illness. Some used dark humor to exaggerate their symptoms and caregiving needs; patient-informal caregiver dyads even went as far as to discuss mortality and who was going to die sooner in the relationship. A patient-informal caregiver dyad managing cystic fibrosis stated that humor was the way they got through everything. On the first date, they had both revealed health issues:

Caregiver: Well, I immediately started planning our like double deaths. Like I just immediately coped through the negative, and he copes through the positive, and I'm like, 'No, we'll just like, just do like a double suicide and it'll be fine...I'll help you die. You don't need to live with this disease, nobody needs to live with that. Just kill yourself, it's so much easier.'

An unexpected finding was that patient-informal caregiver dyads studied used minimal online communication within their relationships regarding the illness. The patient-informal caregiver dyad of T-cell lymphoma had been connected to an online cancer community that did a camping trip together and expressed that it was beneficial for the patient-informal caregiver relationship once the online group met in person; they expressed a desire to continue communication in-person with the group, but had not yet pursued it. They demonstrated that making an online to in-person connection was key to expressing vulnerability and being able to open up about their feelings. Though, overall, it appeared as though many patient-informal caregiver dyads preferred face-to-face verbal

communication for social support, versus online communication. If patient-informal caregiver dyads had an ability to communicate with themselves and each other, they were more likely to be able to collaborate more effectively in managing chronic illness.

Collaborating around illness management.

As couples in marriages or partnerships, these patient-informal caregiver dyads were frequently negotiating their roles as partners around the chronic illness, which changed how they collaborated around managing the illness. Through either receiving regular medical care or making lifestyle changes, patients tried to mostly manage their illnesses on their own, only occasionally communicating a desire for their informal caregivers to take part in doctor visits or behavioral self-care. However, collaboration with caregivers would often mostly involve support around daily emotional and physical needs. Whether collaboration was with the self or conducted within the patient-informal caregiver dyad, it was necessary to collaborate with the illness regularly, which involved teamwork, decision-making, and treatment planning. These collaborations would often influence one another.

Many of the dyads discussed having a sense of pride in the way they worked as a team, referencing that they lived their life to the fullest despite the illness and that they had a natural ease with the workflow involved in illness management. Caregivers would demonstrate serving as motivating factors for the patients. Overall, teamwork was instrumental in managing illness. One couple managing Crohn's disease described a common role reversal that most patient-informal caregiver dyads shared during collaborative teamwork, which emotionally affected the whole family:

Patient: It completely changed my relationships (with my daughters) because one was tucking me into bed instead of me tucking her into bed...Our daughters will make me a cup of tea, get my favorite blanket, make sure that their homework isn't laid out on the couch so that I can sit down and get the rest that I need...I was on all these crazy medications and maybe I was on painkillers and couldn't really read to her. There have been times when we have reversed that, where I'm like, 'Oh, you read to me,' because it's like maybe I can't. I don't feel well. It's like I don't want to rely on her. I don't want her to feel like she has to do those things, so that's been a bit of a challenge is the heartbreak of that and balancing that and letting her know because she has a lot of questions about it...

Caregiver: It's interesting because you talk to me like as a caregiver. I think really the whole family is involved in that.

Ultimately, within teamwork, most patients and caregivers emphasized that allowing the patients to maintain a sense of autonomy was key for illness management, individual well-being, as well as the relationships' well-being. Giving the patient space and independence proved to have better relationship outcomes between the patient and the caregiver when managing and collaborating around chronic illness management. A caregiver of a patient with multiple sclerosis described:

I'm never going to put two hands on her shoulders and say, "We're doing X."

That's not how she's wired and it's not how I'm wired candidly. There are times I feel like that's like, 'Do we need to do that now? No, she'll get there.' It's a balance of, in some case, I think, her being very determined, very stubborn, and having a very specific view of how things are, and in fairness, no one knows what

she's going through more than she does...She needs to get there on her own terms... it's self-determination that I cannot take from her.

Decision-making.

Many of the patient-informal caregiver dyads discussed the challenges of making decisions due to chronic illness changes. The first decision many had made together was deciding whether they wanted to commit to each other in a romantic relationship or not. Many caregivers expressed hesitancy if the patient had already been diagnosed upon meeting them because they were “natural caregivers” and feared being caregivers rather than partners. If the caregivers were already committed to their partners upon diagnosis, they said “love” and “children” outweighed their decision to stay committed. A caregiver managing T-cell lymphoma eventually realized, as most caregivers did, that being there for a human being they loved was an important part of their value system and they had the willingness and ability to do so:

Being a person who provides care was a thing that I naturally do anyways and I was scared of being that... Now that I look back on it, I'm like what? It's like being there for a human being...But we had just started, and so I was really scared of what that meant and having to negotiate my time and hers...

Patient-informal caregiver dyads would often do a lot of lifestyle planning, including diet, exercise, travel, and making art around the illness, which was the next stage of their decision-making. Diet management included discussing illness in relation to nutrition, decision-making about what to cook, where to eat out and when, and relaying diet restrictions to restaurants, family members, and friends. Some caregivers would express frustration about having to change or monitor the patient's diets. However,

the Hashimoto's thyroiditis patient's caregiver willingly participated in changing his diet along with hers to mostly plant-based, raw, or paleo detoxes. Giving up dairy, doing candida cleanses, not eating sugar, and trying fasting were common patient diet trends in which the caregivers did not always participate but aided in supporting the patient.

Exercising was often done as a patient-informal caregiver dyad through yoga, hiking, swimming, and walking, but also alone if patients felt as though they were able-bodied enough to do so. For example, one caregiver of a patient with brain and nerve damage stated: "When the pool was warmer I would make him tread water and we would exercise in the pool...just kind of move around a little more." She would also do yoga with him every morning to get him motivated and to help him ease his chronic pain. This also benefited her rheumatoid arthritis. Traveling involved patient-informal caregiver dyads considering all the medical equipment, food, and needs they had. For example, the cystic fibrosis patient-informal caregiver dyad opted to drive instead of fly because of medical equipment they had to travel with, while other couples avoided traveling long distances for fear of flare-ups. What would seem to be regular lifestyle decisions around diet, exercise, and travel would often be more laborious to patient-informal caregiver dyads.

To maintain mental health and wellness, the third stage of decision-making involved patient-informal caregiver dyads making decisions to do self-care that involved attending therapy both individually and together, as well as support groups, though most caregivers and patients were not engaging in support groups as much as they wanted to. A patient with Crohn's disease stated a common thought about therapy that most patients experienced:

Patient: With chronic illness, it does kind of become part of your identity, so it's like you have to contend with the emotional side... it's why I went into therapy because I wasn't dealing with the illness.

Caregiver: I would say in a very real way for anyone going through something like this, get therapy... You got to take care of the, what do you want to call it, the brain as well as the body or the spirit or whatever you want to say. Treat yourself mentally, as well.

Patient: Right, because so much of it is your brain. Whether it's like you have a neurological or an autoimmune disorder, a lot of it is triggered by the brain, so you do have to find what works for you...

Patient-informal caregiver dyads also coped through making art and had to make decisions about whether to create together or not. For example, the patient with cystic fibrosis made all his personal art about managing his illness, such as paintings of his lungs and medical supplies, as well as a balloon installation that related to his lung failure; however, he made art with his caregiver that was about "lighter topics," such as illustrating a children's book together. They had made that decision because she wanted to make something that was not too personal but would serve as a creative outlet for both of them. On the contrary, the patient with T-cell lymphoma had made video art about illness management with her caregiver. In the video, large puppet fingers are pushing acupuncture herbal medications out of a tin can, causing it to topple over:

It's a pretty accurate representation of what it feels like to have to do teamwork on something that's really, really frustrating. I was feeling really frustrated about how tedious it was just taking care of my body so we made it together to process...

Oftentimes, caregivers decided to be witnesses and sources of support to the patient's creative pursuits related to illness, but also had creative outlets for themselves unrelated to illness. For example, the caregiver of the man with brain damage drove him to most of his standup performances because his illness did not allow him to drive. However, her creative outlets involved creating art for children. The patient with Hashimoto's thyroiditis had made a one-woman show about her body image and educational graphic pamphlets about her illness, which her caregiver helped promote. However, he made short films as his creative outlet. The patients and caregivers managing multiple sclerosis and ulcerative colitis made music, took photos, crafted, or acted as creative outlets, but did not make these activities tied to illnesses, though those activities were beneficial to their mental health and thus, overall well-being. Decision-making constantly occurred among the caregivers and patients around lifestyle choices, such as deciding to commit to one another, diet, travel, therapy, and coping through creative outlets.

Treatment-planning.

To manage illnesses together, patients had researched multiple treatments and symptoms, which they would often discuss with their informal caregivers from emotional and physical perspectives. Caregivers would participate in regular procedures for illnesses, such as attending magnetic resonance imaging procedures (MRIs), surgeries, or in-hospital non-invasive procedures. Most of the time, if the procedures or doctor's visits were not considered potentially life-threatening situations for the patient, the caregiver would not attend them. For example, the caregiver of the patient with cystic fibrosis often struggled with feeling as though she wanted to be present at every lung clearance

procedure in case they did not go well because of past issues with doctors, but knew she had to work in order to maintain financial well-being in the relationship. In one emergency lung surgery in which doctors had to give the patient a medically induced coma to manage his carbon levels, she described that she had been instrumental in attuning to the patient's nonverbal cues, which had led her to collaborate with the doctors on adjusting treatment so that they did not have to give the patient a permanent tracheotomy.

All the participants discussed how treatment was ongoing and would be a regular part of their day-to-day for the rest of their lives. Patients and informal caregivers adjusted treatment plans based on the energy and pain levels of the patient. Taking medication, such as an immunosuppressant, opioids, steroids, or marijuana, would often influence patients' abilities to be productive or present for activities that they wanted to do with their caregivers. Sometimes patients opted out of taking medication, or would take too much just to be able to function. Caregivers mostly supported them in their treatment plans, but for patients with addictions to opioids or substances other than marijuana, the caregivers seemed wary of patient's treatment choices. Many patient-informal caregiver dyads discussed how treatment was difficult to obtain, as the illnesses were constantly changing. A patient with Hashimoto's thyroiditis described trying over ten treatments and still not having answers about how to better manage her illnesses. Her caregiver even mentioned treatments that she left out throughout the interview, demonstrating how invested he was in her treatment planning.

Patient: Okay let me try to get it all. Hypnosis. Ineffective for me for the most part. Like I felt some stuff, but it wasn't ultimately that effective. Chelation orally

and chelation IV-wise, that's been a huge part of my treatments. Herbal antifungals and antibiotics. Regular antibiotics and antifungals. God, then there's just management stuff. Heavy doses of Advil and Tylenol before I got migraine meds, and now I'm on a migraine med called Zolmitriptan. Hot yoga has been a huge part of my recovery...Heavy supplementation, heavy micronutrient supplementation. I've done liver detox protocols. I've eaten raw, I've eaten autoimmune paleo. I've done colonics, those weren't very effective for me. Oh, I'm on thyroid replacement. I need thyroid replacement probably permanently, so hormone replacement I've done. That might be it.

Caregiver: “Progesterone...Saunas and UV treatments for Lyme...”

Some caregivers expressed their frustration with treatments being unclear at times. One caregiver of a patient with multiple sclerosis discussed how treatments need improvement:

...in this modern world where we have real time data...we can measure glucose and blood pressure, your pulse...yet for her disease, we're looking at a sketch, super sketchy digital photo (MRI). I don't mean to belittle the technology, it's amazing, but we're looking at this almost like the way one might imagine someone was dealing with cancer in the forties or fifties. In theory, there's something in there, I'm not quite sure how bad it is...it feels like reading tealeaves.

Treatment planning was necessary in order to manage chronic illness; it also played a role in influencing the quality of life of the patients and caregivers within the relationship. Overall, having support from the informal caregiver made it easier for the

patient to engage in treatment planning, unless barriers such as addiction were present. In a relationship in which constant collaboration and communication are necessary for illness management, the patient-informal caregiver dyads were interdependent on each other, as they took part in managing the illness and relationship together. Overall, collaboration through teamwork, decision-making, and treatment planning are key to effective illness management.

Through both communication and collaboration, patient-informal caregiver dyads made meaning of the illness. Patients and informal caregivers often came up with metaphors and stories about the illnesses together, which helped them relay information to doctors as well as to themselves when tracking symptoms. Making meaning of the course of the symptoms as well as how the illness affected their lives allowed them to be able to manage the illness. Some couples found solace in making illness a part of their life narratives by creating art around it, such as the patient with brain damage who wrote a book and standup about his illness and involved his caregiver in his standup, the patient with T-cell lymphoma who made acupuncture her new career so that she could support patients like herself and created art with her caregiver about illness management, or the patient with Hashimoto's thyroiditis who hosted nutrition talks in her and her caregiver's home on how to better manage diet for chronic illness. Overall, illness became a focus of many of the patient-caregiver dyads' lives, which changed the course of how they saw their own life narratives.

Discussion

The purpose of this study was to discover how seven patient-informal caregiver dyads engage in illness management through communication and collaboration by expanding on existing research from Trivedi (2017) and Risbud et al. (2017). Although the literature review demonstrated how EBPs, communication clinics, and technological tools have been used in chronic illness management, this was not reflected in this study. Barriers of communication, quality of patient-informal caregiver relationships, role-making, and enrichment activities were proven to positively influence illness management in this study, as indicated in the literature review. Overall, this study expanded research in the literature review by including younger couples with varying chronic illnesses, as opposed to those age 65 and older facing terminal illness. This study indicated that communication and collaboration are key to chronic illness management.

Among patient-informal caregiver dyads studied, communicating and collaborating were often done with love, care, and affection. Each participant expressed their admiration and gratitude for one another, which helped them build a sense of mutual support for one another that made it easier for them to face adversities around illness management or caregiving. Weingarten (2013) describes that self-loss for chronically ill patients can be an excruciating experience in which the patient and informal caregiver become diminished and there either is love or terrible strain in the relationship, but this study demonstrated more love than strain in patient-informal caregiver relationships. It was clear in one dyad studied that there was strain present in the relationship because the caregiver and patient did not communicate with as much love, empathy, and affection, but rather anger and frustration. It can be assumed that the better quality of the

relationship, the more successful that patient and informal caregivers are at tackling their roles around chronic illness management. Most patients in the study acknowledged that they probably would not be successful in the management of their illness if they did not have their informal caregiver to listen to them with a sense of care and love throughout their process. However, more studies are needed on how expressions of love and care influence chronic illness management, as Weingarten (2013) also demonstrates.

Constant communication with the self as well as together affected management of the illness, as well as the relationship itself. Whether the communication was verbal, face-to-face, or through text messaging, there appeared to be constant communication within the patient-informal caregiver relationship, whether it was about the illness or not. Online communication was a form of communication that some research studies in the literature review discussed as an effective tool for patients and caregivers (Hamm et al., 2013), yet this was not used as much as verbal and text communication in this study. Most of the interviewees demonstrated that they did not talk about the illness often if flare-ups or the illness were dormant at that time. However, if there was a medical appointment, medication needing to be administered, flare-ups, or pain, then the patient was more likely to reach out to the caregiver. Furthermore, if the caregiver noticed that the patient was flaring up, they were more likely to communicate to the patient and ask for their needs, all through text or face-to-face communication. It would be beneficial to further study the modes of communication with which patient-informal caregiver dyads manage illness and when they are used.

No technology tools such as applications or communication clinics with hospitals were used with these dyads, which are tools that other research in the literature review

proved to be helpful (Atherton et al., 2012; Blom et al., 2015; Gallagher-Thompson et al., 2010; Kingod et al., 2017; Perron, 2002). Without consistent communication between the patient and the caregiver, however, interviewees expected the illness to be more difficult to manage. According to Weingarten (2013), caregivers tend to inhibit themselves or even keep secrets of their feelings with the thought they may be protecting the person with the illness, when research shows that sharing feelings among patients and caregivers is actually better for the relationship itself. When the patient-informal caregiver dyads in this study shared their internal vulnerabilities with one another, there was more ease in illness management. It is thus suggested that more studies are done on how caregivers express vulnerability and practice direct communication within the patient-informal caregiver dynamic and how it affects illness management.

The use of teamwork and ‘dyadic coping’ associated with illness management in this study demonstrate that couples’ interventions on collaboration may be more impactful than individual interventions in illness management (Berry, Davies, & Dempster, 2017; Weingarten, 2013). Both patients and caregivers in this study had to use some tool of dyadic coping in order to handle the illness more pragmatically, such as treatment planning, decision-making, working as a team, and utilizing universal coping tools that are apparent in most research, including talk therapy, seeking outside support systems, yoga, exercise, and communicating vulnerabilities with one other, yet none mentioned EBPs as forms of therapy that other research in the literature review pointed to being helpful (Bennett et al., 2015; Losada et al., 2015; Okai et al., 2013). For one couple in the study, attunement and teamwork was not as present, which caused the patient to rely on addictions as other forms of coping. It is thus recommended that more studies be

done on the specific types of therapy and teamwork approaches used amongst patient-informal caregiver dyads, and how addictions affect collaboration.

Autonomy was a common sub-theme in the patient-informal caregiver theme of collaboration. Autonomy can be defined as the individual taking control over their own decision-making, as well as other activities that signify freedom, self-determination, and independence (Hedman et al., 2015). Many of the patients studied had autonomy that was encouraged by the caregiver within the collaborative relationship, which was necessary for the wellness of the patient-informal caregiver relationship, though more needs to be studied on autonomy amongst patient-informal caregiver dyads.

Coping through art making was a common sub-theme and was one of the most important tools patient-informal caregiver dyads used for illness management. This was a new phenomenon that was not addressed in the initial set of qualitative questioning and would need further study to understand the relationship between creating art as a form of communication and coping around managing chronic illness. Although most dyads engaged in art individually and had only occasionally collaborated with their caregivers, art has been proven to help those facing chronic illness, as demonstrated by Malchiodi's *Art Therapy and Health Care* (2012) and the UnLonely Project, which focuses on creative expression to decrease chronic loneliness symptoms through social engagement art projects (Latson, 2018). Thus, creating an intervention involving patient-informal caregiver dyads and art-making may further understanding of the relationship between patient-informal caregiver dyads and art. The next goal of researcher Alessandra Rizzotti would be to create a support group for patients and informal caregivers to process chronic illness narratives through art making.

Making meaning of the illness between the patient and the informal caregiver was an unexpected theme throughout the study. According to research by Weingarten (2013), there is a lack of research on how patient-informal caregiver dyads make meaning of illness together due to how they relate to the illness differently. However, sudden changes in symptoms that disrupt the past, present, and future of a person with illness are used as meaning markers for chronic illness (Charmaz, 2006), which is what this study confirmed about how patient-informal caregiver dyads made meaning of illness. Dyads not only made meaning of the illness itself by discussing symptoms and creating metaphors for illness, but also by trying to transform how they related to the illness in the narratives of their lives. In this study, if patients and caregivers were struggling with addiction or if illness disrupted their adult development, they often let the chronic illness become the main topic of conversation, or their narrative. For those who were trying to create new relationships to the illness by growing from the illness, it was transformed into a positive narrative, through creating art around their illness or finding work in health-related fields, such as acupuncture or nutrition coaching. More studies would need to be done on what causes patient-informal caregiver dyads to make meaning of illness and what causes chronic illness narrative dominance in patient-informal caregiver dyads.

The themes of communication, collaboration, and making meaning of the illness were key to chronic illness management. Making meaning, expressing love, care, and affection, as well as coping through art would need further exploration as influencing factors in managing chronic illness. This study offers a new perspective in chronic illness research by expanding on research available on younger couples living with chronic illnesses.

Implications

Chronically ill patients and their informal caregivers are often served by social workers in community mental health and medical settings, especially after the Affordable Care Act made healthcare more widely available to underserved populations in poverty (U.S. Department of Health and Human Services, 2015). It is thus critical to understand the effects of chronic illness on the biopsychosocial and spiritual wellness of the patient as well as the caregiver. This study demonstrated that patient-informal caregiver dyads would benefit from additional support and more research would shed light on their experiences.

By knowing the complex relationship that chronic illness has to mental health as well as the environment, social workers can be instrumental in changing how medical professionals and outside supports provide proper illness management for patient-informal caregiver dyads to avoid unnecessary flare-ups and hospital visits whenever possible. Based off of the literature review in this research, it appears as though chronic illness will continue to rise, so more social workers would benefit medical and mental health settings in assisting and giving support to patient-informal caregiver dyads.

Limitations

Although this study provided the results that the researchers were intending, the most significant limitation included the lack of diversity that the study encased. All the participants were married or in a relationship with each other, deeming the partner as the informal caregiver, which did not allow for exploration of friends or other family members as informal caregivers. Other limitations included most of the patient-informal caregiver dyads identifying as white and heterosexual, with all but one couple identifying as queer and multiethnic, and only one couple having children. Researching perspectives of those who are queer, multiethnic, have children, and are living with chronic illness, would be beneficial. In addition, many of the participants were in committed relationships already having been diagnosed. Only two participants were diagnosed while in the relationship. Conducting a comparison study of couples diagnosed before and after being in a relationship could expand upon research.

Although the sample included varying chronic illnesses, it posed limitations by being too small of a sample size to make significant contributions. The most common chronic illnesses as noted by the CDC, such as asthma, rheumatoid arthritis, and diabetes (2017) or the illnesses studied by Trivedi (2017) and Risbud et al. (2017), such as chronic heart failure and depression, could have been a part of this study, but snowball sampling did not allow for this and the caregivers who had asthma and rheumatoid arthritis minimized their experiences when asked about them. Further research is needed on patient-informal caregiver couples' illness management across all the illnesses studied, especially Hashimoto's thyroiditis, Crohn's disease, brain damage, and ulcerative colitis, though there have been some studies on patient-informal caregiver dyads managing

cystic fibrosis, multiple sclerosis, and T-cell lymphoma. In addition, further research is needed on caregivers that manage their own chronic illnesses.

Researchers' biases were considered a limitation in this study. One researcher offered an insider perspective due to having experience as a patient and caregiver, while the other offered an outsider perspective as someone who only had relatives living with chronic illnesses, which sometimes led to barriers in communication and collaboration within the project during coding and analysis. Furthermore, some of the interviews could have potentially lacked rich data due to length, with participants going off-topic or on tangents and failing to make room for more questions, or relevant data.

Conclusion

This study produced positive and intended results, though some results differed from the original research of the initial literature review. The participants were able to provide rich information with answers regarding pre-determined themes around managing illness, communicating, and collaborating, while making meaning of the illness, as well as coping through art were sub-themes that arose from research.

Due to the small sampling in the research of Trivedi (2017) and Risbud et al. (2017) as well as the small sampling in this study, it is recommended that more studies are conducted on patient-informal caregiver dyad communication and collaboration around illness management within younger populations managing illnesses such as depression, chronic heart failure, multiple sclerosis, Hashimoto's thyroiditis, Crohn's disease, ulcerative colitis, cystic fibrosis, brain damage, and T-cell lymphoma. Future studies on how love, care, affection, and making meaning about illness influence patient-informal caregiver communication and collaboration around illness management would expand upon chronic illness research that is currently available. This study emphasized the use of art in coping around chronic illness, which could warrant further research. Future studies could focus on less common chronic illnesses, as well as illnesses in various stages of management, particularly the beginning stages of management, which is what many of the couples in this study studied were facing. More research could be done on how social work can play a role in not only the physical and behavioral wellness of patient-informal caregiver dyads, but also emotional and mental wellness.

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Appendix A: Patient-Informal Caregiver Interview Guide for This Study, Based off Trivedi (2017) and Risbud's (2017) Interview Guides

Date:

Time:

Hello [interview participant name], My name is [interviewer name]. Thank you for taking the time to talk with us today.

We are talking with you because we want to understand how patients with chronic illness and their informal caregivers (ie friends and family members) work together to manage health care. Over the next little while, I'll be asking you several questions. There are no wrong answers. People have different experiences and points of view, and we want to hear them all. Your comments will be kept confidential. Your participation is voluntary and you can ask to skip a question or to stop the interview at any time.

We will give you a gift card of \$20 after the interview and surveys are complete as a thank you for your participation. Do you have any questions?

In order to make sure we capture all of the information you give us, we would like to record this call. Okay, to confirm, I'm starting the recording. **[Hit record button.]**

MANAGEMENT

1. First we would like to talk with you about the chronic illness. Chronic illness in our study means a disease that is usually incurable and requires regular management in which patients are informed and actively participating with providers and caregivers in maintaining their health. What does chronic illness mean to you?
2. What illness do you have specifically? What is it and what are the symptoms?
3. When was the diagnosis?
4. Caregivers in our study are unpaid family members and friends who are not medically trained but are proactive in assisting the patient with management. What is the role of the caregiver in your relationship? What does caregiving mean to you?
5. When did you start managing the illness together?
6. What stage is the illness at and how has it affected your day-to-day?
7. Next, we'd like to hear more about what it takes to manage the condition. Chronic illness management according to our study involves regular day-to-day maintenance of your health including coping, social support, diet planning, and action plans. What are things that support you in regular management?

COMMUNICATION

1. Communication in chronic illness management involves exchanging information or meaningful connection between people. Can you give an example of how you communicate that is helpful?

2. Can you give an example of communication that is not helpful?

COLLABORATION (WORKING TOGETHER)

1. Collaboration in chronic illness management involves coming up with strategies together to better maintain the health of the patient, such as keeping track of medication and symptoms and talking with doctors. Can you give an example of how you collaborate in a way that is helpful?
2. Can you give an example of collaboration that is not helpful?

SUPPORT

1. Support in chronic illness management can involve helpful communication and collaboration in the patient-informal caregiver pair or it can involve receiving help from outside sources. How have you found support in your relationship?
2. How have you found support outside your relationship?
3. What support do you think you need to manage this chronic illness?

Appendix B: Social Media Advertisement Outreach for Snowball Sampling

CHRONIC SUPPORT



Managing a chronic illness takes a lot of commitment on the part of patients, doctors, and their caregivers. Are you someone with a chronic illness or are you an informal caregiver (family or friend) of someone who is chronically ill? If so, then please consider sharing your experiences as a research participant in a study examining how patients and caregivers communicate and work together around managing the illness. Please click the link for a pre-screening to determine if you are eligible. Participants will receive a \$25 gift card. Participants will remain anonymous. Email chroniccapstone@gmail.com or sign up here: [http://bit.ly/2yCoLoB\(Appendix BOffice1\)](http://bit.ly/2yCoLoB(Appendix BOffice1))).

Appendix C: Pre-Screening Survey for Study Eligibility

Information provided on this form will be used for determining your eligibility for our final student thesis project about patient-informal caregiver communication and collaboration around managing the illness that is present. Any information that identifies you will not be used, such as name, phone number, email, etc.

- Name
- Are you over age 18? (Yes/No)
- Email
- Phone Number (Optional)
- Are you a person with a chronic illness or informal caregiver?
- If answered as a person with a chronic illness, what is your chronic illness diagnosis?
- Are you willing to be interviewed together with your informal caregiver or patient present with you?
- Would you be willing to be interviewed over the phone if not available in person?

Appendix D: Demographics of Participants

Illness	Years Living With Illness	Caregiver Relationship	Years of Relationship	Years Caring for Illness	Patient Age	Caregiver Age	Patient Gender	Caregiver Gender	Patient Race	Caregiver Race
Multiple Sclerosis	3	Married	4	3	36	42	Female	Male	White	White
Crohn's Disease	4	Married	20	4	36	36	Female	Male	White	White
Cystic Fibrosis	35	Married	15	15	35	35	Male	Female	White	White
Hashimoto's	22	Partner	2	2	32	34	Female	Male	White	White
Colitis	11	Partner	2	2	25	28	Female	Male	White	White
Brain Tumor	20	Partner	2	2	42	26	Male	Female	White	White
T-Cell Lymphoma	7	Partner	5	5	29	27	Female	Female	Asian	Hispanic

Appendix E: Participant Information Form

California State University, Northridge CONSENT TO ACT AS A HUMAN RESEARCH PARTICIPANT

Exploring Perceptions of Patient-Informal Caregiver Dyads on Communication and Collaboration Around Chronic Illness Management

You are being asked to participate in a research study conducted by students Alessandra J. Rizzotti and Lisa R. Yount, MSW Candidates, as part of the requirements for the MSW degree in California State University Northridge's Social Work Department. Participation in this study is completely voluntary. Please read the information below and ask questions about anything that you do not understand before deciding if you want to participate. A researcher listed below will be available to answer your questions.

RESEARCH TEAM

Researchers:

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Faculty Advisor:

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PURPOSE OF STUDY

The purpose of this research study is to explore how chronically ill patients and their informal caregivers communicate and work together around managing illness.

PARTICIPANTS

Inclusion Requirements

You are eligible to participate in this study if you are:

- At least age 18 and older.
- Are a patient with a chronic illness that is not considered terminal
- OR an unpaid informal caregiver (family or friend) of a person with a chronic illness that is not considered terminal

Time Commitment

This study will involve approximately 1 hour of your time on a weekend which will be set up at a time that is convenient for you.

PROCEDURES

The following procedures will occur: A pre-screening questionnaire will be sent out to pre-screen participants and determine eligibility (participants must either have chronic illnesses or be informal caregivers and they must be willing to be interviewed together as a pair). In the interview, participants will be interviewed about how they communicate and collaborate around self-management in the patient-informal caregiver relationship.

RISKS AND DISCOMFORTS

The possible minimal risks and/or discomforts associated with the procedures described in this study include: mild emotional discomfort and embarrassment. There are no known harms or discomforts associated with this study beyond those encountered in normal daily life. You can opt out of the study at any time and identifying factors will not be published.

BENEFITS

Subject Benefits

There is no direct benefit to participants. However, your participation will inform benefits to others.

Benefits to Others or Society

Society will benefit from this study by seeing what types of communication and collaboration help foster self-management among patient-informal caregiver relationships.

ALTERNATIVES TO PARTICIPATION

The only alternative to participation in this study is not to participate.

COMPENSATION, COSTS AND REIMBURSEMENT

Compensation for Participation

You will receive one \$25 gift card for participating in one hour interview. If you decide to withdraw from the study or are withdrawn by the research team, you will receive compensation.

Costs

There is no cost to you to participate in this study.

Reimbursement

You will be refunded for the following expenses that you may incur, including parking fees and transportation fees. However, researchers will travel to you to avoid such costs.

WITHDRAWAL OR TERMINATION FROM THE STUDY AND CONSEQUENCES

You are free to withdraw from this study at any time. **If you decide to withdraw from this study, you should notify the research team immediately.** The research team may also end your participation in this study if you do not follow instructions, miss scheduled visits, or if your safety and welfare are at risk.

CONFIDENTIALITY

Subject Identifiable Data

All identifiable information that will be collected about you will be removed at the end of data collection. No names will be used in the reporting of this study.

Data Storage

All research data will be stored on a laptop computer that is password protected. The audio recordings will also be stored in a secured hard drive that will be password protected then transcribed and erased as soon as possible.

Data Access

The researchers and faculty advisor named on the first page of this form will have access to your study records. Any information derived from this research project that personally identifies you will not be voluntarily released or disclosed without your separate consent, except as specifically required by law. Publications and/or presentations that result from this study will not include identifiable information about you.

Data Retention

The researchers intend to keep the research data until analysis of the information is completed and then it will be destroyed.

Mandated Reporting

Under California law, the researchers are required to report known or reasonably suspected incidents of abuse or neglect of a child, dependent adult or elder, including, but not limited to, physical, sexual, emotional, and financial abuse or neglect. If any researcher has or is given such information, she may be required to report it to the authorities.

IF YOU HAVE QUESTIONS

If you have any comments, concerns, or questions regarding the conduct of this research please contact the research team listed on the first page of this form.

If you have concerns or complaints about the research study, research team, or questions about your rights as a research participant, please contact Research and Sponsored Projects, 18111 Nordhoff Street, California State University, Northridge, Northridge, CA 91330-8232, or phone 818-677-2901. If you need self-management support around your chronic illness, please contact a physician or local specialist about your illness.

VOLUNTARY PARTICIPATION STATEMENT

You should not sign this form unless you have read it and been given a copy of it to keep. **Participation in this study is voluntary.** You may refuse to answer any question or discontinue your involvement at any time without penalty or loss of benefits to which you might otherwise be entitled. Your decision will not affect your relationship with California State University, Northridge. Your checks below indicate that you have read the information in this consent form and have had a chance to ask any questions that you have about the study.

I agree to participate in the study.

I agree to be audio recorded

I do not wish to be audio recorded

Appendix F: Addendum

ADDENDUM – Exploring Perceptions of Patient-Informal Caregiver Dyads on Communication and Collaboration Around Chronic Illness Management

Exploring Perceptions of Patient-Informal Caregiver Dyads on Communication and Collaboration Around Chronic Illness Management is a joint graduate project between **Alessandra J. Rizzotti** and **Lisa R. Yount**. This document will explain the division of responsibilities between the two parties. Any additional information can be included in a separate document attached to this Addendum page.

Alessandra J. Rizzotti is responsible for all the following tasks/document sections:

- Conducting all seven qualitative interviews
- Pre-coding all seven qualitative interviews
- Co-writing and research for literature review
- Writing introduction and problem statement

Lisa R. Yount is responsible for all the following tasks/document sections:

- Line by line coding all seven qualitative interviews by hand and electronically
- Focus coding all seven qualitative interviews
- Co-writing and research for literature review
- Writing study limitations and conclusion

Both parties shared responsibilities for the following tasks/document sections:

- Contacting participants
- Research for literature review, methods and problem statement
- Co-writing analysis, results and literature review
- Receiving funding for Capstone Project
- Editing final paper

Alessandra J. Rizzotti

Date

Student ID

Lisa R. Yount

Date

Student ID

**Committee Chair
Dr. Lauren Willner**

Date

**Committee Chair
Dr. Wendy Ashley**

Date

**Committee Chair
Dr. Jodi Brown**

Date

**Graduate Coordinator
Dr. Eli Bartle**

Date

**Department Chair
Dr. Eli Bartle**

Date