

Exploring Communal Coping: Witnessing the Process of Empowerment Unfold
During Shared Medical Appointments

by

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ABSTRACT

Chronic illness can be a stressful experience that requires coping and support. In the last twenty years, Shared Medical Appointments (SMAs) were developed in U.S. healthcare as a response to the rising rates and challenges of chronic disease management. Due to the infancy of the SMA model, however, little is known or understood about the benefits of group medical care for patients. To date, scholars have not explored or systematically observed the communicative aspects of the SMA model. Communal coping, a theoretical framework that foregrounds group interaction and communication, offers a pragmatic lens for exploring how patients collectively cope with the stressors of chronic illness in the context of SMAs. Using qualitative methods, I conducted participant observation of SMAs at a Veterans Affairs hospital to analyze the communicative, transactional nature of communal coping as it unfolded among heart failure patients, family members, and providers in context. I also conducted interviews with SMA attendees. Analysis is based on 56 hours of fieldwork and 14 hours of interviews. Findings of this dissertation revealed group members who attended heart failure SMAs engaged in communal coping to manage the stressors of chronic illness. Group members moved through four primary phases of the communal coping process: (1) establish a communal coping orientation; (2) discuss shared stressors; (3) engage in cooperative action; and (4) practice communal reflexivity. Findings suggest patients become empowered by group interaction during SMAs as they move through each phase of the communal coping process. This dissertation also highlights various communicative strategies providers' use during SMAs to facilitate communal coping and group interaction. Theoretically, this dissertation expands upon existing knowledge of

communal coping by exploring how individuals embody and socially construct the communal coping process. Specifically, this dissertation extends past models of communal coping with the addition of the communal reflexivity phase and through conceptualizing communal coping as a facilitated process of empowerment. Pragmatically, this research also offers insight to the benefits patients derive from attending SMAs, such as reduced feelings of stigma and isolation and improved motivation.

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CHAPTER 1

INTRODUCTION

Because, when you have problems with this [points to chest], it's really personal, because it's your heart that's beating, you know? When it doesn't beat right, it scares the hell out of you. When you go into the hospital, and they have the stuff connected to you, it's scary. And to know that every guy you're with has either gone through that or has similar, you know, experiences and it's, it's, it's better. It makes you feel better.

Elvis, HF patient, Interview (8-14-14)

You know sharing the experience that, you know, other people are going through the same thing and that you're not alone and because sometimes you feel like, you know, no matter how hard you try, you're just pedaling backwards, but now we feel like we're going forward from, just, you know other people talking about the changes in their life and it's a reality check. You know, you really do need to make changes to make the difference. If you're not willing to make changes, your health isn't going to get any better.

Elvira, Family Member, Interview, (8-14-14)

Health communication scholars have extensively explored the experience of living with chronic illness (Kim, Park, Yoo, & Shen, 2010; Kreps, 2012). This body of research has revealed the myriad challenges associated with shifting identities (Sharf & Vanderford, 2003), patient-provider communication (Duggan & Thompson, 2011; Street, 2009), decision-making (Politi & Street, 2011), and the burdens of caregiving (Miller, Shoemaker, Willyard, & Addison, 2008). Indeed, chronically ill individuals and their

families must manage many stressors when confronted with the diagnosis of a serious disease. But how do the chronically ill cope with this stress? As an area of research, stress and coping have traditionally been studied within the field of psychology. In the past, coping has largely been conceptualized as an individual process with much of the research emphasizing personal coping mechanisms that occur in isolation (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984). In the last 10 years, however, communication scholars have begun to explore the social and communicative nature of coping (Afifi, Hutchinson, & Krouse, 2006).

One particular approach that emphasizes the inherently social and communicative process of dealing with stress is communal coping. Communal coping is a relatively new theoretical framework that is often compared to dimensions of social support (Afifi et al., 2006; Lyons, Mickelson, Sullivan, & Coyne, 1998). These two concepts should not be conflated, however. Social support is characterized as efforts to support an individual in need, but communal coping assumes that stressors shared by a group of people are managed together (Afifi et al., 2006; Lyons et al., 1998). Thus, people collaboratively cope and identify solutions to challenges when they perceive of a stressor as a shared experience, rather than managing stress in isolation.

Communal coping has served as a framework for studying a variety of life stressors in different contexts and relationships. Previous research has explored age-related stressors in assisted living (Lawrence & Schiller Schigelone, 2002), community evacuation following wildfires (Afifi, Felix, & Afifi, 2012), smoking cessation in couples (Rohrbaugh, Shoham, Skoyen, Jensen, & Mehl, 2012), and negotiating new roles in post-divorce families (Afifi et al., 2006). Studies have also shown that coping with others can

help alleviate stress and promote positive health and relational benefits (Bodenman, 2005; Lewis et al., 2006). This breadth of research illuminates the appropriateness of a communal coping framework in various contexts, while also pointing to specific outcomes of the communal coping experience. Despite the stressful nature of chronic illness, however, communal coping in response to a serious chronic health condition has gone understudied. This oversight is likely due to the relative infancy of communal coping research.

The original model of communal coping focused mainly on distinguishing social coping from individual coping and sought to highlight these differences (Lyons et al., 1998). Developments in communal coping research, particularly within the communication discipline, emphasize the social and transactional nature of the coping process, highlighting specific communicative strategies and features that people use to cope collectively (Afifi et al, 2006). Even with this movement to conceptualize communal coping as an interpersonal process, however, researchers have underutilized methods that capture this communicative interplay. Namely, surveys are commonly used as a method to assess the degree of communal coping and/or its effects (Afifi et al., 2012; Koehly et al., 2008). These methods have helped scholars arrive at potential outcomes and typologies of communal coping behaviors but fail to capture the dynamic, relational, and communicative features of communal coping. The few studies that do use qualitative measures mostly rely on interview and focus group techniques in which participants are asked to retrospectively describe communal coping behaviors and actions (Afifi et al., 2006; Lawrence & Schiller Schigelone, 2002). What remains missing from the research, then, is an in-depth understanding of the transactional nature of the communal coping

process as it unfolds through communication and social interaction. Communication scholars who use ethnographic, situated methods of study are uniquely positioned to offer such insight to our understanding of the experience of communal coping. Therefore, the primary purpose of this dissertation is to explore the social and relational dynamics of the communal coping process in context. An understanding of this process might help shed light on features and factors that enable groups to work collectively to manage stressful life circumstances.

One context that is ripe for the study of communal coping as it relates to chronic illness is the Shared Medical Appointment (SMA). The Shared Medical Appointment is a relatively new model of healthcare that involves grouping patients with similar health issues together for the purposes of conducting health screenings, providing health education, and encouraging peer support (Noffsinger, Sawyer, & Scott, 2003). I argue that SMAs serve as ideal sites to study the communal coping process as it pertains to chronic illness for a variety of reasons. First, patients often share a complex health issue that can induce lifestyle changes and potentially cause a great deal of stress (Bartley & Haney, 2010; Berger-Fiffy, 2012). Therefore, discussing health-related stressors is a predominant goal of SMA interaction and a central feature of the communal coping process (Noffsinger et al., 2003). Furthermore, group interaction and learning how to successfully cope with chronic illness are intended outcomes of participating in SMA sessions (Kirsch et al., 2008).

Much like communal coping, however, SMA research is relatively limited in scope and often focuses on the health outcomes associated with attending SMAs rather than the processes of group communication. Many SMA scholars have noted the

potential value of peer interaction for managing chronic illness (Cohen, Hartley, Mavi, Vest, & Wilson, 2012; Dickman, Pintz, Gold, & Kivlahan, 2012), but none have actually observed and systematically studied the process or features of group communication during SMA sessions. Both clinicians and patients could benefit from a greater understanding of how group interaction might enable patients to successfully cope with chronic illness. Additionally, understanding how patients interact in a group healthcare setting could add to what we know about the potential benefits of SMAs. As such, a communal coping approach to the study of SMAs could illuminate how group communication functions in and through SMAs. In this dissertation, I seek to bridge the context of SMAs with the concept of communal coping to understand how patients cope with chronic illness collectively.

Preview of the Dissertation

This first chapter was designed to orient you to the primary foci of this dissertation. Specifically, the goals of my research are to simultaneously gain an understanding of the process of communal coping and the communicative features of group interaction within the context of SMAs. In Chapter Two, I describe the purpose of, design, and past research on Shared Medical Appointments (SMAs). In reviewing this literature, I point to the opportunities that both a qualitative and communicative lens can offer to our understanding of the SMA experience. In Chapter Three, I distinguish communal coping from traditional conceptualizations of coping, describe the foundational model of communal coping, and highlight predominant contexts and methodological approaches to the study of communal coping. In this chapter, I also identify spaces where additional communication research might usefully illuminate the

communal coping process as well as specifically pinpoint SMAs as a site of study.

Chapter Three concludes with the specific research questions that guide the research.

In Chapter Four, I describe the research methods I use to answer my proposed research questions, including an explanation of the specific site, observational and interview procedures, participants, and data analysis processes. In Chapter Five, I explore findings on the communal coping process as it unfolds in the context of heart failure SMAs. In this findings chapter, I also highlight key communicative strategies employed by healthcare providers as they facilitate interaction during SMAs as well as patients' and family members' retrospective sensemaking of their participation in communal coping and group healthcare. Finally, in Chapter Six, I discuss the potential theoretical and practical implications that accompany my findings as well as propose areas for future research for both the study of communal coping and SMAs.

CHAPTER 2

U.S. HEALTHCARE AND SHARED MEDICAL APPOINTMENTS

We need those kinds of transformations in healthcare right now, because we're being told that there's more and more patients who need to be cared for.

Population is aging. Costs are going up, and we really need to be experimenting with these types [SMAs] of forms of care.

(Sandesh, Cardiologist, Interview 11-6-14)

In 2012, the Centers for Disease Control (CDC) estimated that half of all U.S. adults, nearly 117 million people, have at least one chronic disease. Medical experts fear the number of people living with chronic illness could rise to as many as 157 million by 2020 (Bodenheimer, Chen, Bennett, 2009). There is also growing concern that our current medical system is incapable of sustaining the future healthcare demands of chronically ill patients. Experts anticipate a shortage of over 90,000 physicians by 2020 (AAMC, 2014) and the likely shortage of primary care physicians is particularly pronounced. These statistics represent two major trends the U.S. healthcare system is currently facing – increased chronic illness and rising healthcare needs.

Evidence suggests we might already be confronting the burdens of these pressing issues. A recent survey of physician wait times revealed patients in the private sector can wait up to 66 days to see a primary care physician (Merritt Hawkins, 2014). These challenges become further exacerbated due to the predominant design of healthcare delivery. In the U.S., healthcare has traditionally been administered from an acute care mindset. In this design, patients with short-term ailments can be treated quickly and generally require little follow-up, health education, or self-care training (Bronson &

Maxwell, 2012). The acute care model, however, is ill-equipped to treat the needs of chronically ill patients who require more information, training, and support to address the demands of their complex health conditions (Benjamin, 2010; Noffsinger, Sawyer, & Scott, 2003). Patients with chronic health issues also need ongoing care that often requires more frequent clinical appointments and interactions with various types of health professionals and specialists. One study revealed that patients with five or more chronic conditions attended an average of 37 office visits per year, received medical care from 14 different physicians, and were prescribed upwards of 50 different medications (Warshaw, 2006). It is estimated that one in four Americans manage multiple chronic conditions (MCCs), and as many as 75 percent of people over the age of 65 have MCCs (Anderson, 2010). People experiencing MCCs face lower quality of life, a higher risk of mortality, and are more likely to receive “suboptimal care” (Benjamin, 2010, p. 626).

Aside from physical and medical challenges, the chronically ill also face emotional and relational challenges that accompany the diagnosis and management of a chronic health condition (Lyons, Sullivan, Ritvo, & Coyne, 1995). Chronic health issues have been cited as a top source of stress for some Americans. In the spring of 2014, NPR, the Robert Wood Johnson Foundation, and the Harvard School of Public Health conducted the comprehensive study on the “Burden of Stress in America.” Of a sample of 2,505 respondents, 43% reported a health-related event (i.e. illness/disease, death of a loved one) as their top source of stress. The study also revealed individuals with poor health (60%) or those who had a chronic illness (36%) were more likely than the general public to report they had experienced “a great deal of stress” in the last year.

Given the rising trends of chronic illness and greater demands for patient access to care, it is not surprising that healthcare providers have begun to seek updated models of healthcare delivery to address chronic health issues. Shared Medical Appointments have emerged as a model of care designed primarily to meet to the needs of patients with chronic conditions. This model of care introduces a team-based approach typically not found in traditional methods of healthcare delivery. “Evidence strongly suggests that multidisciplinary teams in primary care and public health—rather than care provided principally by primary care clinicians or specialists alone—are best suited to deliver higher-quality and lower-cost chronic care and prevention” (Bodenheimer et al., 2009, p. 72). Despite this evidence, however, SMAs remain a relatively underutilized and understudied model of care within the U.S. (Berger-Fiffy, 2012). In the following sections, I explain the design and focus of Shared Medical Appointments (SMAs). I also describe the current state of SMA research as well as important aspects of the SMA model that could benefit from additional study.

Understanding SMAs: Key Features and Existing Research

Clinical psychologist Edward Noffsinger, dubbed the “father of SMAs,” developed the Shared Medical Appointment format for clinical care in 1996 after he experienced his own chronic health issues that required increased medical care (Bartley & Haney, 2010; Berger-Fiffy, 2012). Noffsinger was frustrated by the lack of access to his doctor, the short time frames for office visits, and a lack of quality, patient-centered care. He believed there was a better way to provide greater patient access to quality healthcare, while also reducing the burdens of cost and time on providers. Essentially, “SMAs use multidisciplinary patient-centric methods which are effective in improving

outcomes associated with chronic disease” (Cohen, Hartley, Mavi, Vest, & Wilson, 2012, p. 1288). SMAs have several unique features that are believed to improve patient care and satisfaction, including the amount of time patients receive for care, the group support format, the inclusion of health education, and a health-care team approach (Cohen et al., 2012; Dickman, Pintz, Gold, & Kivlahan, 2012; Edelman et al., 2012; Jaber et al., 2006).

At its core, an SMA session is conducted by a team of health professionals and combines features of a traditional medical appointment with health education and group support (Sikon & Bronson, 2010). With this combination, SMAs typically last between 60 minutes and 2 hours, with four to ten patients in attendance (Dickman et al., 2013). Patients are often encouraged to invite family members and/or close others to also attend sessions. Therefore, SMAs could have ten to twenty individuals present in a single session.

Given this structure, it is clear that the SMA model has the potential to deal with some of the critical cost and access crises facing today’s health care system. However, many proponents of SMAs also believe the group structure offers greater benefits and added value for both patients and providers (Berger-Fiffy, 2012; Bronson & Maxwell, 2012; Kirsch et al., 2007). A full-scale SMA generally begins with a private health screening followed by an interactive group education session that focuses on self-care behaviors and various health topics such “medical and pharmaceutical management, nutrition, exercise, and psychosocial contributors to health and illness” (Jaber et al, 2006, p. 276). The longer timeframe could also allow patients to have more contact with providers, more time to ask questions, and more time for providers to explain disease-related information and address patient concerns (Noffsinger et al., 2003). Thus, SMA

patients not only receive important routine medical checkups, but also receive valuable health education and learn skills for successfully managing their health condition (Bronson & Maxwell, 2012).

The inclusion of multiple patients in one session certainly differentiates this model from a traditional individual appointment. The group format is believed to serve many functions, including reduced provider caseloads, enhanced social learning and support among patients, and increased patient involvement in the health care process (Jaber et al., 2006). Another important feature of the SMA format is a medical team approach. An SMA team consists of a group of providers who specialize in various areas of medicine and care (Noffsinger et al., 2003). This team may include pharmacists, dietitians, nurse practitioners, and physical or occupational therapists, depending on the particular health condition being addressed in a session (Bronson & Maxwell, 2012). While healthcare teams have become more common in recent years due to the needs of chronically ill patients, traditionally teams have met without the patient to assess needs and develop treatment plans (Real & Poole, 2011). The SMA structure, however, necessitates a team-based approach to provide adequate health education for patients managing complicated conditions. Given the complex nature of most chronic diseases, coordination of care is essential to a patient's quality of life and to successfully facilitate self-care management (Benjamin, 2010).

In a team approach, providers can create individualized care plans that complement various areas of treatment (Noffsinger et al, 2003; Real & Poole, 2011). For instance, a dietician is often present in SMA sessions specializing in heart failure because a low-sodium diet is vital to successful disease management. The dietician might offer

tips for grocery shopping or eating out while on a low-sodium diet in addition to educating patients about hidden sources of sodium. Similarly, the pharmacist might explain how diuretics help remove excess fluid from the body when the patient eats too much sodium. In this way, each provider educates patients based on his or her area of expertise while also complementing the information other providers share in the session. Coordination of care, then, can occur alongside the patient during SMAs, rather than behind closed doors.

Overall, the SMA format bears little resemblance to the typical 15-minute individual appointment in which providers often have little to no time to offer educational information and patients have little time to ask questions. Additionally, the peer-to-peer interaction is a feature that patients would typically have to seek out on their own outside of the clinical context in the form of online or face-to-face support groups. It is this combination of SMA features that are thought to contribute to quality care and potentially alleviate the challenges associated with rising rates of chronic illness and issues of patient access (Bronson & Maxwell, 2012). Despite their potential value, however, SMA research and implementation is still relatively limited. In the next sections, I will highlight my discovery of the SMA model as well as the current scope of SMA research.

Discovering Shared Medical Appointments

In December 2013, I was approached by a colleague at the Veterans Affairs Hospital to study SMAs. At the time, I had been working with physicians and researchers at the VA for almost two years to understand potential barriers physicians faced in prescribing a particular type heart medication. Similar to the issues of access mentioned earlier, providers described struggles to properly monitor and treat patients on this

medication due to, among other problems, an overburdened healthcare system. My colleague and I had just completed data collection on this study and were discussing the challenges of patient access when he began telling me about the SMA program he had started in his department.

I can recall politely asking him to tell me what “SMA” stood for because I had never even heard of the acronym, much less had a working knowledge of this care model. He proceeded to tell me that he had helped establish an SMA program in the heart failure clinic to assist patients who had recently been diagnosed with heart failure or experienced a recent hospitalization due to this chronic and complex health condition. The primary goal of the SMA, he told me, was to give people the tools they needed to practice better self-care and keep them out of the hospital. As part of their model, patients attended four bi-weekly sessions during which they covered everything from nutrition to stress management. “Why don’t you just come see a session to get a sense of how they work. We meet every Thursday morning from 9:30 to 11:00,” he offered.

I gladly accepted his invitation and, curious to understand how SMAs worked, I attended my first heart failure SMA on January 9, 2014. What I witnessed in that hour and half would change the way I thought about medical appointments. I watched complete strangers talk openly about their lives, their struggles, and their triumphs. I saw a team of health care professionals listen attentively and offer advice on everything from medications to managing the anxiety of chronic illness. And I witnessed peers offering advice to peers and telling stories about the strategies that have worked for them in managing their illness.

I was amazed by the open format for discussion, so unlike a typical individual appointment. I vividly remember leaving that first session energized by the experience, so much so that I barely made it to my car before I called my good friend and colleague, Tara, to tell her what I had just seen. “It was amazing!” I told her. “People were really engaged and talking, and the doctor’s were so involved with the patients. This wasn’t at all what I was expecting. SMAs are the coolest things I have ever seen!”

It really didn’t take much convincing past that initial visit for me to get on board with studying SMAs. My first order of business, however, was to find out as much as I could about this model. At first, I thought perhaps I had never heard of SMAs simply because I had no medical expertise or experience with chronic health issues. Out of curiosity, I asked friends, family members, and colleagues who had medical backgrounds if they had ever heard of “SMAs.” I talked to my sister-in-law who is a surgical technician, a family friend who is an OB/GYN nurse, an acquaintance who is in medical school, various health communication scholars who study clinical communication, and friends and family who have chronic health issues. To my surprise, most said the same thing – “I’ve never heard of a shared medical appointment before. What is it?”

It seems, then, that the lack of knowledge about SMAs extends into the medical world as well. It is not surprising, that when my colleague at the VA pitched me the idea of studying SMAs for my dissertation, he did so with the explanation that there is relatively little existing research on SMAs overall. What I found in my early review of the SMA literature is that the lack of research on this model might be attributed to a number of things, including lack of administrative support, inconsistent research findings,

and an evidence-based health outcomes approach to medical research. In the next section, I highlight what we know from the current body of SMA research.

The Current Scope of SMA Research

Over the last two decades, the popularity and implementation of SMAs has increased in large-scale hospital systems such as Harvard Vanguard, the Veteran's Affairs Healthcare System, and Stanford University Medical Center (Berger-Fiffy, 2012; Edelman et al., 2012). However, SMAs have been slow to take hold in other hospitals because of the perceived risk of implementation. SMAs are resource-heavy installments that require large-scale staffing and additional time and space – precious resources in an overburdened system (Sikon & Bronson, 2010). Despite potential benefits of SMAs to address major health care issues such as patient access, hospital administrators question the payoff. Given the increased push for evidence-based medical research over the past decade (Zimmerman, 2013), there is an emerging body of literature focused on the outcomes of SMAs to assess the value of this model of care. However, scholars recognize the relative “infancy of this patient care approach” (Berger-Fiffy, 2012, p. 255). Two areas that have received some attention from researchers, health outcomes and attitudinal outcomes, will be considered in the following sections.

Health outcomes. Previous SMA research has focused largely on measuring the health outcomes following SMA attendance, and much of the SMA literature relies on quantitative, self-report data. Two systematic reviews explore patient health outcomes associated with participation in SMAs (Edelman et al., 2012; Jaber et al., 2006). Some research has demonstrated improved healthy eating behaviors (i.e. increased fruit and vegetable intake), decreased ER admissions, and increased health information sharing

following SMA intervention (Edelman et al., 2012; Jaber et al., 2006). Patients also reported an increase in disease-related knowledge following participation in SMAs as compared to a traditional individual appointment (Clancy et al, 2007). Research has also suggested the long-term success of SMA interventions. A five-year follow-up study on Type II diabetics revealed increased problem-solving skills in patients who had attended SMAs (Trento et al, 2004).

Despite these positive findings, scholars have also noted inconsistent results across SMA studies regarding patient self-efficacy and healthy eating behaviors (Jaber et al., 2006). One study found that patients who participated in SMAs experienced higher levels of self-efficacy in communicating with their physicians, but no change in their ability to administer self-care (Scott, Connor et al., 2004). Similarly, in their comparison of heart disease patients in SMAs to patients in individual appointments, researchers found SMA patients improved their fruit and vegetable intake, but showed no difference in their saturated fat intake (Masley, Phillips, & Copeland, 2001). Jaber et al (2006) speculated about these inconsistencies and argued that “healthy behavior and self-efficacy improvement is much more complex and linked to the facilitator’s skills in motivational interviewing, presence of behavior-specific objectives, and patients confidence level” (p. 287). These mixed results call for further research on the interactions that occur among SMA participants and the structuring and context of communication within SMA sessions.

Attitudinal outcomes. Perhaps the most consistent results in SMA research are found in patient reports of increased satisfaction as a result of attending SMAs (Edelman et al., 2012; Jaber et al, 2006). Research has indicated that patient satisfaction stems from

increased time with providers, improved self-care education and coordination of care (Dickman et al., 2012). Patients also frequently cite peer support as an additional source of satisfaction. Indeed, scholars frequently speculate that the interaction among peers during SMAs promotes social support (Cohen et al, 2012; Jaber et al, 2006) and social learning (Berger-Fiffy, 2012, Dickman et al, 2012). They also assume peer-to-peer interaction facilitates improved self-efficacy and disease-specific knowledge in patients (Jaber et al., 2006). As Bronson and Maxwell (2012) noted:

If a patient forgets to ask about a specific concern, chances are someone else will bring it up. Patients frequently support and advise one another based on personal experience. It is very powerful to be held accountable by a peer group for efforts to improve lifestyle and adherence to recommended treatment programs” (p. 375).

Unfortunately, the current SMA data does not specifically study, explore, or even measure group interaction. Although patients commonly report improved clinical satisfaction, their individual perspectives on SMAs, and the group format, are underrepresented in existing research. SMA patients are often asked to complete satisfaction surveys which offer little space to provide detailed and contextual insight about patient experiences in such a context. As Edelman and colleagues (2012) noted, “effects on patient and staff experience remain largely unknown” (p. 32).

To my knowledge, only one study has been conducted to date that directly asks patients to elaborate on the features of SMAs that contribute to satisfaction and their perceptions of the value of attending SMAs. Cohen and colleagues (2012) conducted a series of five focus groups with Veterans who attended SMAs on smoking cessation and weight management. During focus groups, patients described valuing the group support

they received from other patients, feeling satisfied with the level of involvement and interaction they had with the health care team in making decisions, and being empowered to practice self-care. As Cohen et al. (2012) summarized,

patients reported feeling validated and supported and realized that they were not alone in their concerns. They enjoyed sharing their strategies on coping with a chronic illness and felt they were a part of the care giving process. (p. 1288)

These findings, although sparse, highlight the value that patients place on the group experience of attending SMAs. What remains missing from current SMA research, then, is an understanding of the communicative features and nuances of peer interaction. Past research in other contexts has demonstrated that peer-to-peer support can be an important moderator of positive health outcomes (Mullen, 2010). For example, studies have shown people experience improved mental and physical health after attending face-to-face support groups (Hogan, Linden, & Najarian, 2002), as well as greater levels of information and understanding about their illness (Beck & Keyton, 2014). People who participate in support groups report feeling they are not alone in their experience (Beck & Keyton, 2014; Cozaru, Papari, & Sandu, 2014; Goldsmith & Albrect, 2011; Lederman & Menegatos, 2011). In this way, support groups can offer positive encouragement, catharsis, and even an expanded social network (Cozaru, 2014). Thus, understanding how patients interact with one another in the context of SMAs, and how providers facilitate peer-to-peer interaction, could illuminate the potential successes and failures of SMA involvement on health outcomes and patient satisfaction. Furthermore, insight to patients' lived experiences and an in-depth understanding of SMA interactions might act as a

persuasive form of much-needed “evidence” that administrators need to encourage a more widespread adoption of SMAs.

Lenses for Understanding Group Interaction

There are a number of lenses through which we could explore the SMA experience to understand how patients and providers interact in such a space and, more specifically, how patients interact with one another. In the past, health communication scholars have adopted a patient-centered approach to study the clinical experience. Patient-centered health communication research explores the socially constructed nature of the patient-provider interaction, highlighting how meanings regarding health and illness unfold through communication and interaction (Lambert et al., 1997; Sharf & Vanderford, 2003; Street, 2003). This perspective emphasizes the psychosocial aspects of illness and the experience of the patient managing disease. Indeed, the rich body of patient-centered care and communication research places an emphasis on understanding the role communication from both patients and providers plays in facilitating a positive clinical experience (Epstein & Street, 2005). However, patient-centered communication research has extensively studied the classical dyadic conceptualization of the clinical relationship – patient and provider (see Michie, Miles, & Weinman, 2003 for a review). This perspective does not account for the process of peer-to-peer interaction in a group clinical setting.

Another potential lens that more clearly situates group communication in the foreground of study is the support group literature. Research has demonstrated the capacity for peer-to-peer communication to encourage positive outcomes for chronically ill individuals (Mullen, 2010). Support groups have historically existed outside of the

clinical context, however, and are often led by peers rather than medical professionals (Goldsmith & Albrecht, 2011). Thus, support group research often does not account for the inclusion of clinical information sharing that is a central feature of the SMA model. Furthermore, support groups often serve as a context for studying social support. Although social support is a valuable lens for understanding how individuals receive and give support to others, this framework does not consider the dynamic and social process of shared coping that occurs through mutual support exchange and collective problem-solving (Afifi et al., 2006; Lyons et al., 1998).

Thus, though these two popular ways of studying communication and health outcomes hold some potential for illuminating communicative processes within SMAs, they both fall short in critical areas. The patient-centered communication approach does not consider the context of group interaction and the role of peer-to-peer communication, and the social support perspective does not consider the shared process of mutual support. However, one conceptual lens for understanding group interaction and mutual peer support that has recently gained currency in the communication discipline has the potential to overcome these challenges. This is the model of communal coping proposed by Lyons and colleagues (1998) and developed in the communication discipline by Afifi, et al. (2006).

Typically situated within the field of psychology, a communal coping framework explores how individuals who share similar life stressors band together to cope and develop strategies for managing challenges. From this perspective, an issue is perceived of as a group problem that can be addressed through collective problem-solving and shared coping. Additionally, communication is situated as a central feature of the

communal coping model, which describes coping as a social, communicative process. Although this framework has not previously been used in a clinical context, communal coping is a broad concept that has been successfully applied to dyadic relationships, families, and communities. Because patients must cope with the stressors of chronic illness, and SMAs are intended, at least in part, to encourage group interaction and support for the sake of managing chronic illness, a communal coping framework could shed light on how patients cope with illness together and how the coping process is facilitated through communication during SMAs. In the next chapter, I provide more in-depth background on coping research as well as explain the communal coping model and the existing research on this subject.

CHAPTER 3

A COMMUNAL COPING FRAMEWORK

Seeing that once they bring it up, discussions take place and they, too, I could see them learning and I could see them feeling better. Some people came there with a lack of knowledge of some things and left from the class knowing a lot more than they did when they first came in. And by them opening up like that was kind of, enlightened me and I didn't feel as, I felt if I shared my feelings, I guess, of things that bothered me, I could get help from the group, by listening to what they had to say and today maybe try those suggestions.

(Charlie, SMA Patient, Interview, 10-16-14)

Stress and methods of coping have occupied a long tradition of study within the field of psychology. In recent years, however, communication scholars have begun to explore how individuals cope socially and communicatively with one another. Many have argued that coping is a social process, thus introducing the concept of communal coping. In the following sections I highlight the foundational aspects of communal coping and discuss some key findings from communal coping research to shed light on the areas where communication scholars might contribute to this emerging body of work. I then argue that the communal coping model is an appropriate lens for understanding how shared medical appointments help patients manage the challenges of chronic health conditions and propose specific research questions.

Foundations of Communal Coping

Diagnosis of a chronic illness is one of many life situations that can drastically affect a person's sense of well-being and induce a stress response. According to Cohen and Wills (1985), "stress arises when one appraises a situation as threatening or otherwise demanding and does not have an appropriate coping response" (p. 312). When confronted with stressful life experiences, like a serious medical diagnosis, individuals go through a series of appraisals to assess two important issues: (1) the level of threat a stressor poses to their overall well-being (primary appraisal), and (2) the amount of resources and abilities they possess to combat the stressor (secondary appraisal) (Lazarus & Folkman, 1984). The coping process, then, follows the perception that a stressor poses a serious threat that requires action (Folkman & Mozcowitz, 2004). Coping is defined as an individual's "thoughts and behaviors used to manage the internal and external demands of situations that are appraised as stressful" (Folkman & Mozcowitz, 2004, p. 745). In other words, coping involves relying on any means available, both cognitive and behavioral, to reduce the experience of stress.

Traditionally, coping processes have been divided into two categories – problem-focused coping and emotion-focused coping (Lazarus & Folkman, 1984). In problem-focused coping, individuals work toward changing their current situation or actively managing the problem itself. These problem-focused "efforts are often directed at defining the problem, generating alternative solutions, weighting the alternatives in terms of their costs and benefits, choosing among them, and acting" (Lazarus & Folkman, 1984, p. 152). For instance, if a patient is unhappy with her provider's level of interaction and communication, she might first identify why the provider's behavior is problematic

for her, seek out alternative providers, and then select the best option based on her needs and circumstances. In contrast, emotion-focused coping involves the use of cognitive and behavioral strategies to manage and reduce the emotional response to a stressor.

Emotion-focused coping strategies could include distancing, avoiding, distracting, and/or using selective attention. As an example, a newly diagnosed cancer patient might chose to avoid talking about her diagnosis or reading about her particular cancer on WebMD to reduce feelings of fear and anxiety.

Although individuals who employ these methods of coping might seek out the support of others, coping has traditionally been conceptualized and studied as an individual process conducted in isolation (Berg, Meegan, & Deviney 1998; Lazarus, 1966; Lazarus & Folkman, 1984; Lyons et al., 1998), which did not account for the ways in which groups and social units collectively managed stress. Thus, early work on social coping processes sought to bridge this gap by exploring contexts in which coping was a dyadic or group endeavor (Berg et al, 1998; Lyons et al., 1998). For instance, Berg et al. (1998) developed the social-contextual model of coping to account for joint problem-solving processes that occur in dyadic relationships, especially in close interpersonal relationships. The researchers explained that their previous coping research, which emphasized individual coping across the lifespan, revealed that involvement in interpersonal relationships was a key part of the coping process. Specifically, “the interpersonal nature of individuals’ appraisals predicted at a broad level the social nature of individuals’ strategies for dealing with everyday life stressors” (p. 243). In other words, the more a person perceived a stressor to be shared with a close relational partner, the more likely that individual was to engage in joint problem solving with that partner.

Simultaneously, Lyons and colleagues (1998) developed an initial model of communal coping to describe the collaborative nature of coping among members of a social unit who face a shared stressor. This model serves as the foundation for communal coping research and will provide the theoretical focus of this dissertation. In the next section, I lay out the various components and features of Lyons et al.'s (1998) model.

A Model of Communal Coping

Early scholars of social coping sought to differentiate individual coping from social coping processes. Thus, Lyons and colleagues (1998) provide a visual model to distinguish among the varying conceptualizations of coping. In this model (Figure 1), coping processes are separated into four quadrants along the dimensions of appraisal (individual problem vs. communal problem) and action (individual responsibility vs. group responsibility) to differentiate between individual and social coping methods. We can view each quadrant as a combination of these two dimensions: my problem-my responsibility, our problem-my responsibility, my problem-our responsibility, and our problem-our responsibility.

Quadrant 1 represents an individual who views a situation as “my problem-my responsibility.” In this orientation, the person is likely to manage the stressor alone. This falls in line with traditional individualistic conceptions of coping where individuals assume sole responsibility for managing a stressor. Social forms of coping are more evident in quadrants 3 and 4 of the grid. In an “our problem-my responsibility” orientation, at least two individuals view the stressor as a shared experience, but the responsibility to act falls to one person in the social unit or dyad. Lyons et al. (1998) offer an example of a married couple where one spouse is suffering from Alzheimer’s disease.

In this case, both members see the disease as a shared stressor, but the healthy spouse might determine that it is his/her responsibility to offer social support and act as the sole caregiver. Conversely, a person who holds a “my problem-our responsibility” orientation

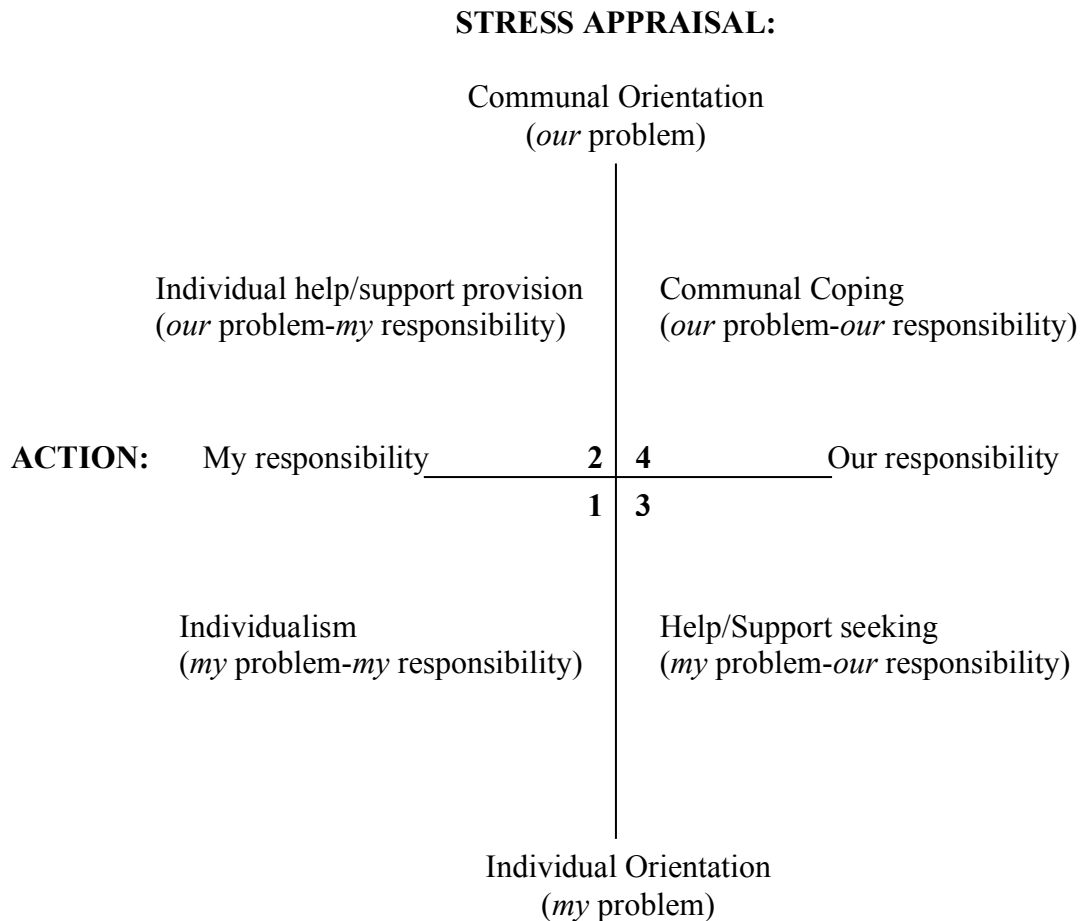


Figure 1. Individual and social coping processes.

Note: Adapted from “Coping as a Communal Process.” by R. F. Lyons, K. D. Mickelson, M. J. L. Sullivan, and J. C. Coyne, 1998, *Journal of Social and Personal Relationships*, 15, p. 586.

might see his/her Alzheimer's diagnosis as an individual problem, but reaches out to the spouse for additional resources and support. These two types of social coping (our-problem-my responsibility, my problem-our responsibility) most closely align with the conceptualizations of social support.

Social support frameworks (represented by quadrants 2 and 3) have commonly been used to understand coping processes that occur within a social network as well as within health-related support groups (Goldsmith & Albrecht, 2011). Lazarus and Folkman (1984) acknowledged social support as an important "resource" that individuals can draw upon to "buffer" against the affects of stress (p. 158). However, a social support perspective still assumes that the person offering support appraises the stressor as the other person's struggle or responsibility, rather than as a shared stressor that can and should be managed collaboratively. Social support is conceptualized as the actions that people enact to help social network members or relational partners who are in need of assistance (Goldsmith & Albrecht, 2011) typically through offering informational, emotional, and/or tangible support (Lazarus & Folkman, 1984). In this regard, social support involves allocating resources to another person in need, or accepting resources from others.

In contrast, communal coping, which is represented in quadrant 4 of Lyons et al.'s (1998) model, involves appraising a stressor as "our problem (a social appraisal) vs. 'my' or 'your' problem (an individualist appraisal)" (p. 583). It is this social appraisal and sense of shared responsibility for action that distinguishes communal coping from the provision or receipt of social support. "Regardless of whether the stressor produces similar consequences for all, communal coping involves thinking and acting as if a

stressor is shared” (Lyons et al., 1998, p. 583). Rather than offering aid in some way to help a person cope with an individual stressor, as is often the case with social support, “communal coping requires that the members of a group assume mutual responsibility for a stressor and act on it together in a proactive manner” (Afifi et al., 2006, p. 381). As Lyons et al. (1998) explained, “communal coping elicits coordinated actions for mutual benefit: social support is a process that does not require coordination among providers or mutual benefit” (p. 587). In a communal coping orientation, a stressor is appraised as shared by members of the social unit who then actively work together to engage in problem-solving and collective action. Stressors that occur within a collaborative, social context are best described as “the property of a social unit rather than of an individual” (Berg et al., 1998, p. 241). Following from this basic distinction regarding the social appraisal of stress, Lyons and colleagues (1998) noted several key factors that are present in communal coping situations.

Features and purposes of communal coping. In the original model of communal coping, Lyons et al. (1998) described three important components of communal coping. First, at least one member of the group must possess a communal coping orientation. A communal coping orientation is determined by “a belief that joining together to deal with a particular problem is beneficial, necessary, and/or expected” (p. 584). Second, group members communicate about the shared stressor through discussing the details and meanings of the stressor. Finally, communal coping involves cooperative action in which group members collectively develop strategies that will help them address and overcome the challenges of their shared stressor. These components further

illustrate how communal coping differs from social support by emphasizing the interrelated nature of shared responsibility and action.

Lyons and colleagues (1998) explained that group characteristics and styles of communal coping could vary depending on the needs and preferences of group members. Some groups might have a designated leader or engage in a democratic approach in which all members contribute to the coping process. In other instances, group members might have varying levels of experience and expertise regarding the specific stressor and would contribute more or less to the coping process. Lyons and colleagues (1998) noted that not all group members must equally participate in order for communal coping to occur. In fact, communal coping might not always occur by choice. Rather, there are instances in which a circumstance or social structure necessitates a communal response. For instance, community members affected by wildfires must work together to quickly and efficiently orchestrate evacuations for the safety of the whole community (Afifi, Felix, & Afifi, 2012). Beyond instances like natural disasters, Lyons et al. (1998) mentioned three motivations for people to adopt a communal orientation to coping: (1) for stress management; (2) for relational maintenance; and, (3) for the self. All three of these motivations can be illustrated through the case of chronic illness.

Chronic health conditions act as serious life stressors and can profoundly affect overall daily functioning, abilities, resources, and identities. The stress associated with illness can be too great to manage alone, thus motivating people to cope in a collective context (Lyons et al, 1998). One benefit of communal coping could be the opportunity to gather additional resources and strategies, which would aid in stress reduction and

management. In this way, the “perceived enormity of a challenge or stressor may be reduced” (Lyons et al, 1998, p. 588).

Chronic illness can also drastically affect the health of relationships. Thus, Lyons and colleagues (1998) argue the act of sharing resources and engaging in cooperative problem-solving, especially in close relationships, could help relational partners successfully maintain their relationships (Lyons et al., 1998). Relational motivations for engaging in communal coping might extend from an empathy-driven or responsibility-driven mindset. Empathy-driven coping generally occurs from altruistic motivations to protect close relational partners “where affectionate bonds are strong” and maximize their well-being, sometimes at personal expense (p. 590). Responsibility-driven coping, on the other hand, is more commonly present in relationships with weaker ties and stems from perceived roles and associated responsibilities. Communal coping does not always occur from an altruistic intent, however. As Lyons et al., (1998) noted, “individuals can engage the collective resources of group problem-solving solely for their personal well-being” (p. 591).

Aside from stress management and relational development and maintenance, communal coping has the potential added benefit of personal validation and social integration. With chronic health issues, individuals often experience a decreased social network and sense of control over their lives (Wright, Johnson, Bernard, & Averbek, 2011). For some, “being sought out to help address a problem or stressful circumstance may be considered a form of social validation that one is competent, valued, loved and possesses solid membership in the group” (Lyons et al., 1998). Indeed, engaging in collective problem-solving could further reify social roles as well as verify a sense of

interdependence and attachment to others. “The motive for communal coping, then, may lie not only in the outcome of the effort, but in the process, e.g. arousal, diversion from the ordinary, and pleasure that comes from meeting a challenge” (Lyons et al., 1998, p. 592).

Together, these features and motivations demonstrate the capacity of communal coping to offer a variety of benefits to both individuals and groups who experience chronic illness. Despite the ease of which motivations for communal coping apply to the chronically ill, however, little research has actually studied this phenomenon. In the next section, I review the existing research on communal coping and point to areas where health communication scholars might attend to this important area of study.

Reviewing Communal Coping Research

Lyons et al.’s (1998) model has provided a strong foundation for the existing communal coping research. Recently, Afifi and colleagues (2006) have expanded upon Lyons et al.’s (1998) model through examining communal coping as it occurs in post-divorce families. The researchers argue that previous models of communal or relational coping (i.e. Berg et al., 1998; Lyons et al., 1998) fail to consider how group communication, varying coping methods, and certain group characteristics, such as group norms and power, influence the coping process. To move beyond this weakness, Afifi et al. (2006) develop a model that highlights the “transactional and fluid nature of the coping process that characterizes many naturally formed social groups” (Afifi et al., 2006, p. 385). Much like Lyons et al.’s (1998) original model of communal coping, Afifi et al. (2006) distinguish individual from social forms of coping, but with the distinction that individual forms of coping still occur within a social context. For instance, they offer

the example of a post-divorce mother facing financial struggles. Within the family unit, financial issues can affect all members of the family. However, the mother might choose to see the stressor as something she needs to take responsibility for and subsequently conceal the stressor from her children or manage the budget on her own.

In this way, Afifi et al.'s (2006) model accounts for family members holding varying levels of responsibility at different times in the coping process depending on the nature of the stressor. Additionally, the researchers found that coping is an interdependent process when it occurs within a social context or unit. In other words, the coping practices of one group member can affect how other group members cope, demonstrating the "fluid and dynamic nature of the coping process" (Afifi et al., 2006, p. 403). For example, if one family member perceives of the stressor as a joint responsibility, this could encourage other members to appraise of the situation as a shared endeavor and encourage communal coping to occur. Afifi et al. (2006) maintained that coping strategies are often negotiated as group members interact with one another, highlighting the communicative, social, and active nature of the coping process. What remains consistent from Lyons et al.'s (2006) model, however, is the conceptualization of communal coping as shared appraisal and action among all members within the social group. The researchers explained that communal coping within naturally formed groups involves members perceiving they are "one unit working together, rather than as separate individuals working in isolation" (Afifi et al., 2006, p. 395). Afifi et al.'s (2006) work provides a push to expand our understanding of communal coping, but empirical research on communal coping remains relatively sparse. The following sections point to what we

currently know about communal coping from the existing research and, given this research, highlights the potential contributions and focus of this dissertation.

Contexts and strategies of communal coping. In the past, communal coping research has been conducted in two primary contexts – specific communities and close relationships (i.e. spouses, families). Community-oriented research has explored how residents of an assisted living facility cope with the stressors of advanced age (Lawrence & Schiller Schigelone, 2002), how community members manage the uncertainty of natural disasters and work together during and after the spread of multiple wildfires (Afifi et al., 2012), and how refugees band together to navigate the challenges of entering a new cultural context (Guribye, Sandal, & Oppedal, 2011). Relationally-oriented or dyadic communal coping research has often focused on health-related stressors and how spouses and families cope when the health of one or more members is compromised. This research has explored how married couples pool resources to promote positive health-behavior change (Lewis, McBride, Pollak, Puleo, Butterfield, & Emmons, 2006), encourage one another to stop smoking (Rohrbaugh, Shoham, Skoyen, Jensen, & Mehl, 2012), and manage chronic illness (Kowal, Johnson, & Lee, 2003). Communal coping has also been examined in families facing divorce (Afifi et al., 2006), pregnancy (Afifi et al., 2006) and among sisters who have the potential to develop hereditary breast and ovarian cancers (Koehly et al., 2008).

Within these contexts, previous studies have identified various means of engaging in communal coping. Afifi and colleagues' (2006) research on post-divorces families revealed members held family meetings and negotiated privacy boundaries as predominant methods of communal coping. In their study of age-related communal

coping, Lawrence and Schiller Schigelone (2002) identified types of “communal assistance” that residents reciprocally enacted within their community. These types included compensatory assistance, in which group members drew on their collective strengths to supplement the weaknesses or needs of one another, and group-oriented assistance, such as using the buddy system, to regularly and systematically looking out for the safety and well-being of other community members. Finding common ground with group members (Lawrence & Schiller Schigelone, 2002) and communicating shared goals (Guribye et al., 2012) have also been noted as important strategies for arriving at a shared appraisal and communal orientation.

Benefits and consequences of communal coping. Beyond methods of enacting communal coping, research has looked to the potential health and relational benefits of communal coping. For example, communal coping has demonstrated the capacity to buffer against the negative health effects associated with uncertainty and stress (Afifi et al., 2012; Afifi et al., 2006). Additionally, couples who perceived a health stressor or health risk as shared were more motivated to enact positive health behavior change (Lewis et al., 2006) such as safe-sex practices for individuals with HIV (Montgomery, Watts, & Pool, 2012) and smoking cessation in romantic couples (Rohrbaugh, 2012). Communal coping can also strengthen relationships and bonds. Research on spousal communication and coping suggests that actively confronting stressors and communicating about feelings together results in greater relationship satisfaction than if individuals deal with the stressor alone (Acitelli & Badr, 2005). “The better that partners *together* are able to cope with stress, the higher their chance for optimal marital satisfaction and stability” (Bodenmann, 2005, p. 46). Engaging in communal coping can

also lead group members to develop long-term resources for future stressors. A study of Norwegian Tamil refugees found that communal coping encouraged community members to consider potential future stressors and develop strategies that could prevent these issues from arising; the researchers referred to this practice as “communal proactive coping” (Guribye et al, 2012).

However, communal coping can also have negative health consequences for group members, namely the potential for maladaptive coping methods to “spill over” into other group members (Lewis et al., 2006). In a study of sisters with a shared hereditary cancer gene, communal coping and anxiety were linked, suggesting that the stress levels of one sister had the capacity to influence the stress of the other sister. The researchers explained that this might be due to the increased nature of communication about the anxiety of anticipating a future cancer diagnosis (Koehly et al., 2008). Afifi et al., (2006) found similar spillover effects in post-divorce families. In some instances, parents shared too much information with their children and placed too much shared responsibility on the family unit.

Similarly, communication scholars have explored the negative consequences of co-rumination (Afifi T., Afifi W., Merrill, Denes, & Davis, 2013; Boren, 2013/2014). Although not specifically linked to communal coping, co-rumination has been studied as a potentially harmful bi-product of social support when individuals “engage in negative and excessive amounts of discussion about their problems” (Boren, 2013, p. 254). Research has suggested co-rumination can negate the positive psychological benefits of social support and even lead to emotional exhaustion (Afifi et al., 2013; Boren,

2013/2014). Thus, communal coping, in some instances, could create additional distress, rather acting as a positive coping mechanism for the collective.

Communal coping as communicative. The social nature of the communal coping process lends itself to the study of how group members communicatively navigate collaborative problem solving and resource sharing. As Afifi et al. (2006) noted, “the way that people experience and manage stress often reveals itself through communication. Coping occurs through interaction with others and often is a collaborative meaning-making process with friends and family members or others who are experiencing similar stressors” (Afifi et al., 2006, p. 382).

Previous research has explored the use of “we” language as an explicit marker of a communal coping orientation. “We-talk” has been explored in studies of post-divorce families (Afifi et al., 2006), members of an elderly assisted living community (Lawrence & Schiller Schigelone, 2002), and couples enrolled in a smoking cessation program (Rohrbaugh et al., 2012). Families often used “we-talk” to describe how they worked together to solve problems and remain resilient during challenging times. They also utilized “we” language to convey shared responsibility (e.g., “we make decisions together”) and collectively brainstormed for possible solutions to challenges. Elderly individuals expressed “we-talk” when describing the experience of managing the stressors of old age even when they were individually interviewed (Lawrence & Schiller Schigelone, 2002). One participant explained, “when you say ‘an older person,’ we’re all pretty much in the same category here.” The researchers described statements like this as an expression of “solidarity” among community members due to their shared advanced age. Similarly, the use of “we-talk” was prevalent among couples where both partners

smoked, demonstrating a shared appraisal of the stressor (Rohrbaugh et al., 2012). Beyond “we-talk,” communal coping can be expressed through discussing shared stressors and identifying strategies and solutions (Afifi et al., 2006; Guribye et al., 2012). For instance, families frequently held family meetings in which group members directly discussed their joint stressors (Afifi et al., (2006).

Although “we-talk” can signify a communal coping orientation and a shared appraisal of a stressor, the measurement and analysis of a single linguistic unit fails to shed light on the complexity of the coping process as it unfolds through communication and interaction. “Mapping individual dispositions or statements about coping competencies does not provide insight into the complex interplay between people’s coping strategies and the influence of social events on these strategies” (Guribye et al, 2011, p. 10). As described earlier, Lyons et al.’s (1998) model clearly emphasizes talk as a central function of the communal coping process as group members discuss shared stressors together and work toward identifying solutions and strategies. Thus, communal coping literature could benefit from a clear understanding of what communal coping looks like in action through communication. In the next section, then, I point to the communicative and process-oriented focus of this dissertation.

The Current Study: Understanding the Process of Communal Coping

In reviewing the literature, we can see that the existing body of communal coping research largely emphasizes outcomes or typologies. Methodologically, past research has prioritized retrospective, self-report, and interview measures for studying the outcomes of communal coping, rather than observing the interactive features and processes of communal coping (Afifi et al, 2006; Afifi et al., 2012; Koehly et al, 2008; Lawrence &

Schiller Schigelone, 2002). For instance, Afifi et al. (2006) explored communal coping in post-divorce families through conducting structured interviews and focus groups with children, parents, and parents' new spouses or dating partners. During individual interviews, the researchers asked participants to "first create an exhaustive list of all the stressors they experienced related to the divorce process, how they coped (effectively or ineffectively) with each of them, and the strengths of their family on a sheet of paper" (Afifi et al., 2006, p. 386). During focus groups, individual family members were asked to identify two stressors that were shared by all group members and discuss how they coped with these stressors. Similarly, Lawrence and Schiller Schigelone (2002) stated that the purpose of their study was to explore "the ways in which older adults address the stressors of aging as a community rather than as individuals" (p. 690). To address this goal, they held individual interviews with residents of an assisted living facility, facilitated a single focus group with five community members, and engaged in approximately six hours of field observation during residents' lunch time, although they noted that observational data was not a primary data point for their study.

The findings from each of these studies have contributed to our understanding of life stressors and potential communal responses to those stressors. But what the research fails to address and explore is the real-time unfolding and exchange of the communal coping process. As Afifi et al. (2006) acknowledged in their essay, "the very definition of communal coping implies that coping is an ongoing and fluid exchange of ideas and negotiations among people. In this sense, coping is a free-flowing process of meaning generation among individuals and not merely a static beginning or end state" (Afifi et al., 2006, p. 383). Process-focused research places value on the interactions that take place

between members, rather than the impact of such interactions (i.e. outcome-focused research) (Pistrang & Barker, 2005). Thus, ethnographic and situated approaches to the study of communal coping could help us understand how coping occurs among group members through communication.

One possible site where we could observe the communal coping process is during SMAs. As discussed in Chapter Two, group communication is a central feature of the SMA context (Berger-Fiffy, 2012). Further, patients who are diagnosed with the same chronic health condition meet to discuss their shared disease (i.e. shared stressor) during sessions, which suggests that patients discuss the stressors of their illness. Finally, the sessions are conducted by a health professional whose role is to encourage group interaction and communication. This is similar to Lyons et al.'s (1998) framing of a communal orientation – the belief that gathering together to address a shared stressor is a positive and beneficial experience. Given these features, and the areas of both SMA and communal coping research that need to be explored, I propose the following research question:

RQ1: How does the process of communal coping unfold among group members during shared medical appointments?

Aside from exploring the process of communal coping among peers, the following study also has the potential to provide insight to how the communal coping process might be facilitated by clinical professionals. As I described earlier, the majority of past research has looked at communal coping within the context of close personal relationships, such as families and marriages. Indeed, Lyons et al., (1998) suggested that communal coping is more likely to occur in ongoing, established groups (i.e. families)

given the social expectations and obligations that accompany close relationships. However, these scholars also argue that a communal orientation to coping can still occur in newly formed groups among individuals who lack a shared history, but who still identify as having a shared stressor with others (Lyons et al., 1998, p. 585). Furthermore, communal coping has never been explored within a clinical context in which a skilled medical practitioner is responsible for facilitating group interaction. Thus, the following study also seeks to understand how a medical professional facilitates communal coping in the clinical context. The following research question highlights this secondary focus:

RQ2: How do medical professionals facilitate the communal coping process during shared medical appointments?

In summary, the unique structure and purpose of the SMA model and the group focus of a communal coping framework compliment one another. A communal coping framework might shed light on the value of group interaction in facilitating a positive patient experience in the context of SMAs; the SMA context might usefully inform the process of communal coping as it unfolds among SMA members. Thus, a primary goal of this dissertation is to marry the context of SMAs with the concept of communal coping so that these two bodies of literature might usefully inform one another. In the next chapter, I will review the methods used to address the proposed research questions. I will also describe the particular SMA context that served as the site of this study, the methods of data collection, and the characteristics of participants.

CHAPTER 4

METHODS AND CONTEXT

To explore the research questions outlined above, I used qualitative methodologies to access “the meanings people place on the events, processes, and structures of their lives” (Miles & Huberman, 1994, p. 10). I also employed an iterative approach, shifting back and forth between “existing theories and research interests on the one hand, and emergent qualitative data on the other” (Tracy, 2013, p. 8). I gathered data with two qualitative methodological tools: field observations and interviews. The following sections describe the site of study, participants, and my role as a researcher. I also describe the data collection procedures for participant observations and interviews. Lastly, I provide a chronological account of the data analysis procedures I conducted in order to answer my research questions.

Study Site: SMAs at the Phoenix Veteran’s Administration Hospital

In June 2014, I began attending shared medical appointments (SMAs) in the cardiology division of the Phoenix VA. These SMAs were tailored specifically to the needs of heart failure patients focusing on health education, self-care, and social support practices pertinent to the experience and management of advanced heart failure. Newly enrolled patients attended a series of four bi-weekly sessions that lasted approximately 90 minutes to two hours. Sessions always occurred on Thursday mornings from 9:30-11:00 am in the Phoenix VA cardiology division. Patients, and any family members they chose to bring with them, sat around a conference table with their first names written on table tents in front of them. The scene often resembled a focus group session except for the nurse practitioners sitting in the corner on computers typing up care plans and notes.

Providers, often wearing plain clothes, sat at the table with patients and family members. Sessions were generally led by the clinical psychologist on staff, but team members often took on different leadership roles depending on what topic was being discussed.

In talking with the SMA health care team, I came to learn they had been conducting heart failure SMAs for over a year when I entered the scene. While some SMAs are designed to follow a specific format for each session, this team conducted open-ended SMA sessions by asking patients to offer up suggestions for discussion. The focus of each session, then, was driven by the particular needs and preferences of the patients and family members.

My entrance to this site was the result of a previously established professional relationship with the Phoenix VA. Therefore, the sampling of this site was “opportunistic” (Miles & Huberman, 1994, p. 28) because my access came as an unexpected invitation to conduct research on SMAs because of my qualitative research expertise and knowledge of health communication theories and concepts. Given the challenge of gaining access to the clinical context as an outside researcher, and the relative infancy of SMA programs and our understanding of this care format, I saw value in “taking advantage of the unexpected” to help further our knowledge of health communication in the SMA context (Miles & Huberman, 1994, p. 28). Additionally, my review of the SMA literature revealed no observational research had been conducted before.

To develop an introductory understanding of the purpose and function of SMAs, I was invited to view a few SMA sessions prior to starting my research. I was introduced to the health care team who was responsible for not only implementing the SMA program in

the cardiology division, but who also planned and facilitated the sessions each week. I attended three consecutive sessions, totaling six hours in the field, observing the format of the SMAs, taking raw notes (Tracy, 2013), and conducting informal “briefing interviews” with members of the SMA healthcare team to understand the group’s goals and focus (Lindloff & Taylor, 2011, p. 109). This allowed me to determine bodies of literature in health communication that could act as guiding frameworks and sensitizing concepts for the proposed study (Glaser & Strauss, 1967), as well as establish rapport with the healthcare team and address any of their concerns regarding the design and focus of the study. Following a brief meeting during which I explained the general purpose and focus of my proposed dissertation, the team granted me access to observe SMAs and also provided helpful suggestions on methods for recruiting participants. One of the nurses recommended that I come to the end of an SMA session to administer informed consent to those patients so that if anyone objected to being part of the study, they would be able to place that patient in another group that would not be observed. This would allow me to still observe the other patients who were comfortable participating in the study.

Provider roles. The SMA healthcare team consisted of six providers with different specialties and roles. In order to provide clarity and understanding of the findings of this study, I provide here a brief description of each of their designated roles in conducting SMAs. I use the pseudonyms providers chose along with their professional titles.

Nurse Sunshine, the cardiology nurse, was in charge of recruiting and scheduling patients for SMAs. She contacted patients via phone and or one-on-one appointment following a recent heart failure hospitalization to encourage them to attend SMAs. On the

day of SMAs, her primary role was to be a documenter. In this role, she helped record clinical notes for each patient at the session as well as any health referrals other members of the healthcare team recommend a patient complete. For instance, if the pharmacist recommended a patient should use a pillbox to better manage medications, Nurse Sunshine would record this request in the patient's clinical records. Given her role as a documenter, Nurse Sunshine had little interaction with patients during SMA sessions. Similarly, Dietician Lynn acted as the other documenter and often had little interaction with patients during sessions unless called upon to do a specialized discussion on diet-specific issues. During one of the sessions, she conducted training on reading labels, but this was a fairly infrequent occurrence. She and Nurse Sunshine split the duties of recording the details of health referrals and consultations that occurred during SMAs given the high volume of patients who attended the sessions.

Nurse Practitioner Annie described her role as the "medical provider" on staff. She was responsible for checking patients' vitals and labs before they began SMAs such as blood pressure and weight. Based on her medical exam, she made recommendations to the patient and/or the SMA healthcare staff about the kinds of medical changes that were needed (e.g., changing the dose of drug). Like Nurse Sunshine and Dietician Lynn, Nurse Practitioner Annie had little interaction with patients during SMAs. In her role, she observed the sessions and offered more in-depth information on cardiology and/or interpreted medical information for patients as needed.

Dr. Jerome and Dr. Susie functioned as the SMA moderators. Dr. Jerome, a clinical psychologist, shared with me that he had no specialized knowledge of heart failure before he became involved with SMAs in the heart failure clinic. This is partly

why it was essential to have a specialized medical provider on staff, such as Nurse Practitioner Annie, to answer any technical questions about the disease. Dr. Jerome was the primary moderator of the group and was most frequently in charge of leading the daily discussion. Dr. Susie, the clinical pharmacist, would often co-moderate with Dr. Jerome, but tended to focus her discussions on medication management. Together, they took input from all team members to determine the best focus of discussion for each SMA session. The team members generally talked for about ten minutes before a session began to highlight any issues that might need to be addressed. For instance, before one SMA session, I observed the team collectively determine it was too soon to talk about end-of-life care because there were members in the group who were attending their first session the team felt the topic would be too sensitive to address. Thus, although Dr. Jerome and Dr. Susie were generally in charge of facilitating discussion, they also frequently tailored the focus based on team members' recommendations as well as patient needs.

Finally, Dr. Dev, the cardiologist, was responsible for implementing the SMA program in the heart failure clinic at the Phoenix VA. Because Nurse Practitioner Annie acted as the resident "medical provider" during SMAs, Dr. Dev did not generally attend SMA sessions. Instead, he maintained a supervisory role for the healthcare team and the SMA structure, and held regular meetings with the team to check on progress. He also maintained individual appointments with many of the patients who attended SMAs and was sometimes responsible for referring patients to the program. In the next section, I describe the breadth of Dr. Dev's roles in this study in more detail.

Researcher roles and ethical considerations. My access to this generally private medical space came from a position of privilege. I was granted access to the VA because of previous research I had conducted with my colleague, Dr. Sandesh Dev. I should be clear in acknowledging that Dr. Dev held multiple roles during the course of this project. First, Dr. Dev is the creator of the heart failure SMA program at the Phoenix VA. Second, Dr. Dev and I have worked together on multiple research projects before and during my time conducting the current project. Third, Dr. Dev, in minimal capacity, was a research participant in this study. I conducted a formal interview with him near the end of my fieldwork to gather contextual data about the design and purpose of heart failure SMAs. And finally, Dr. Dev is also a member of my dissertation committee. Collectively, the breadth of Dr. Dev's participation in this project offered certain strengths and issues of concern with regard to my role as a researcher.

A primary strength of my researcher role was the opportunity to access a highly restricted site and a highly understudied population. Dr. Dev played an integral role in granting me access to attend SMAs, but also helped me to navigate the complex VA system and rigorous procedures necessary for conducting research in this space. Without his cultural knowledge of the VA system, and access to the relationships he had already forged through his employment at the Phoenix VA, I would not have been able to conduct this research. In this setting, an invitation to conduct research was a necessity.

Additionally, because Dr. Dev implemented the SMA program in the cardiology division at the Phoenix VA, he could provide valuable background knowledge about the goals of the SMA program, explain the roles of the healthcare team, and synthesize SMA scholarship. This information was vital in determining how to focus my observations to

enhance the current SMA literature as well as make sense of the inner workings of the SMA structure, personnel, and patient needs. For instance, during initial discussions with Dr. Dev about SMAs, he told me the goal of their SMAs was to enhance self-care knowledge, especially for those patients who have been recently diagnosed with heart failure or have demonstrated several relapses and could use additional health counseling. This information provided insight into how the healthcare team identified potential SMA participants as well as the intended goals and foci of SMAs. Aside from granting me access to the site, however, Dr. Dev also vouched for my credibility with the SMA healthcare team. Prior to beginning fieldwork, Dr. Dev invited me to attend a meeting with the SMA team to brief them on the goals of my research project as well as my credentials. This was an important step in developing trust with the team I would work so closely with for the next seven months.

In conjunction with these privileges, my researcher role also held a few concerns. First, the healthcare team might have felt obligated to allow me to observe SMAs because Dr. Dev is their supervisor. I did not, however, sense concern about my involvement in SMAs as members of the healthcare team often referred to me as “one of the family” or “part of the team.” I understand, however, that these types of comments may only reflect my ability to adapt to the culture of their team. Furthermore, Dr. Dev is a proponent of SMAs and has vested interest in promoting the success of the program and expanding knowledge of SMAs for the medical field. Thus, I had to remain cognizant that my observations and interviews were conducted not for the purpose of supporting the cause of SMA implementation, but for the sake of understanding the experience of SMAs. As such, I invited participants to speak to both the strengths and weaknesses of their

experience of SMAs to provide a rounded perspective of the process. Dr. Dev was supportive of a critical examination of potential SMA issues in the hopes that this information could help further strengthen future SMAs. Frequently, he invited me attend their team meetings to speak to the group about general findings from my observations and patient interviews to discuss potential improvements. Members of the healthcare team also frequently invited my feedback during the course of my fieldwork.

Additionally, as a non-medical expert entering the clinical world, and also a non-patient, I maintained awareness of my role as an “outsider,” a “civilian.” I entered SMAs not as an expert regarding disease or illness, but as an expert regarding relationships, interaction, and qualitative research. I was, for all intents and purposes, a curious observer, seeking to learn from all those who gathered in this context. I recognized the limits my outsider role posed to my understanding of the SMA process and the unique health-related and personal struggles of Veterans. I was also keenly aware of my ethical responsibilities to protect and preserve the delicate, and sometimes painful, process of healthcare delivery. At the time of completing a detailed and lengthy (nearly three months) IRB process, as well as the previous months of credentialing I went through to become a VA “employee,” I balked at the hoops and barriers this organization placed in my path. Having now completed this research project, and interacted with Veterans and their families, I have a newfound respect for the lengths the VA will go through to protect their patients.

Death may be a reality for many members of this unique cultural group and I aimed to respect the seriousness of their reasons for gathering in this space. As I walked down the crowded hallways of the Phoenix VA and I met eyes with hundreds of service

men and women along the way, I felt honored to be among them. I do not take lightly the opportunity I have been afforded to observe SMA sessions, and I remain grateful to all those who so willingly invited me in to witness the unfolding of their professional and personal lives. I took the weight of this responsibility with me into the field, always remaining aware that I could arrive at only a partial understanding of their worlds. As such, the purpose of my research was as much in service to the VA hospital system, and all those who administer care, as it was to the Veterans.

Aside from remaining aware of my role and Dr. Dev's role in this study, I addressed ethical considerations and issues of concern with a variety of strategies. First, I rigorously practiced the required consent and documentation procedures for conducting research at the VA. I attended a one-on-one training session with the senior clinical research coordinator at the Phoenix VA to ensure I followed proper protocol. Following each SMA session, I documented patients' participation in the clinical records system per VA requirements. Additionally, I used pseudonyms for all participants, and stored all audio files, transcripts, and paperwork in secured locations at the VA. All transcripts were stripped of personally identifiable information before I outsourced them to my personal computer to protect participant confidentiality. Additionally, I conducted all interviews in a private setting to ensure both patients and providers could speak openly and honestly about their experiences without fear of retaliation. I also regularly checked in with the healthcare team to ensure I was following proper procedures and not interfering with the clinical process, their roles, or the patients' needs. Collectively, I carefully considered my role and privilege as a researcher throughout the process of research design, data collection, and analysis. I attempted to remain respectful of the

cultural practices of the VA system and to prioritize patients' voices and experiences in this study.

Participants, Recruitment, and Consent Procedures

Prior to any recruitment and consent procedures, this study received IRB approval from ASU and the Phoenix VA hospital (see Appendix A for a copy of both approval letters). Participants in this study included patients (Veterans), family members, and healthcare providers who attended and facilitated SMA sessions (see Table 1 for a summary of participant demographics). Patients, once enrolled in SMA interventions, generally attended bi-weekly 2-hour group sessions for a total of four sessions. I recruited participants during the entirety of my time in the field as new patients entered the sessions. Because patients were enrolled in an ongoing basis, and cohorts of first-time SMA attendees were relatively rare, most SMA sessions included a mix of patients at varying stages of the SMA process. In other words, a single SMA session might include patients attending their first sessions alongside patients attending their final session. This created a mix of perspectives, experiences, and levels of health knowledge that determined the direction of discussion for any given session.

Participants were recruited to be part of the study either prior to attending their first SMA session or the morning of their first session. This often occurred an hour before the SMA session began while patients and family members were completing labs and paperwork. The cardiology nurse, Nurse Sunshine, also told patients over the phone during SMA scheduling that I was conducting a study and would be asking them about their interest in being a research participant. During consent procedures, I explained the general purpose and focus of the study, and collected signed informed consent, HIPPA,

and voice consent forms. Participants were given extra time to ask questions about the study and to make an informed decision about their willingness to take part in the research, and no one declined to participate. Interviewees were later recruited from those patients, family members, and healthcare providers who attended and consented to be observed in SMA sessions.

Table 1

Summary of Participant Demographics

Participant Information	Number of Participants
Total Participants in Study	53
Participant Type/Role	
Patients	32
Family Members	15
SMA Providers	6
Participant Sex	
Males	34
Females	19

Data Collection Procedures

To understand how the communal coping process unfolded in context and how providers facilitated this experience, I drew on two primary forms of data collection – field observations and interviews. These methods of data collection were carried out at the Phoenix VA Hospital in the cardiology division from June 2014 to December 2014 for a total of seven months in the field. Combined, I conducted 70 total research hours that resulted in 551 pages of single-spaced data (see Table 2 for a summary of collected

data). In the following sections, I describe the procedures for enacting observations and interviews.

Field observations. I engaged in observational fieldwork to develop an in-depth understanding of the communicative features of SMAs as well as the process of communal coping as it unfolds in context. During observations I acted in the role of “unobtrusive (nonreactive) observer” (Angrosino, 2005, p. 732) because I did not actively take part in the SMA session. My role was to watch, listen, and take notes on the communicative processes that occurred in context among social actors. In this role, I attempted to avoid disrupting the natural flow of communication that generally occurred among participants.

In total, I attended 20 SMA sessions totaling approximately 56 hours of observational fieldwork. SMA sessions generally lasted 90 minutes to 2 hours, but providers often stayed with patients after the session ended to speak with them one-on-one. There was also 30-minute set-up and debrief period before and after each SMA session. I took notes throughout all of these experiences. My sampling strategy for SMA sessions was based on convenience and availability (Tracy, 2013). Because SMA sessions are only conducted on Thursdays at a specified time, I attended all SMA sessions that patients granted me permission to attend and until I reach theoretical saturation in my observations (Glaser & Strauss, 1967).

During observations, I wrote raw records (Emerson, Fretz, & Shaw, 1995; Tracy, 2013) noting both verbal and nonverbal behaviors making sure to elaborate on potential underlying assumptions, or “tacit knowledge” (Tracy, 2013, p. 119). During the first half of my fieldwork, I focused my observations on understanding the flow of communication

and the group dynamic because I was unfamiliar with this context. At this stage, my goal was simply to understand “what’s going on here?” During the second half of my observations, I engaged in theoretical construct sampling (Tracy, 2013) by focusing my energies on exploring patterns of communication among group members as well as the role of the facilitator in encouraging group communication and patient involvement. I also focused more closely on the process of communal coping while remaining mindful and aware of experiences that fall outside the communal coping framework to allow for emergent data. I transferred raw records into detailed, typed field notes utilizing “thick descriptions” (Geertz, 1973) to describe the scene within 48 hours of observation. Alongside observations, I also audio recorded SMA sessions. These audio recordings helped supplement and contextualize the data in my field notes and allowed me to capture, explore, and analyze verbatim exchanges among SMA members. In total, my observations yielded 160 pages of typed single-spaced fieldnotes.

Semi-structured interviews. In addition to observations, I also conducted formal respondent interviews (Tracy, 2013) with SMA participants to draw on patient, provider, and family member perceptions and experiences of SMAs. For interviews, I utilized a purposive sampling strategy (Lindlof & Taylor, 2011), approaching individuals for interviews based on their specific roles and involvement in heart failure SMAs at the Phoenix VA. This sampling strategy allowed me to meaningfully collect data “that fit the parameters of the project’s research questions, goals, and purposes” (Tracy, 2013, p. 134). My sampling strategy was purposive in selecting individuals who could provide a variety of perspectives, including both the patient and family member perspective of SMAs, as well as clearly articulate and draw on a variety of experiences from attending

multiple sessions. Patients and family members were selected for interviews based upon their attendance at a minimum of three SMA sessions. I also conducted respondent interviews with each member of the SMA heart failure team. The purpose of these interviews was to understand the providers' unique roles, expectations, and goals for patients and families who attended SMAs, and to understand the challenges of conducting and implementing the SMA model.

During interviews, I adopted a deliberate naïveté stance by “maintaining openness to new and unexpected findings (Tracy, 2013, p. 142), and withholding judgment. To conduct interviews I used a semi-structured interview guide that focused on eliciting patient, family member, and provider experiences and perceptions of the SMA format, communicative processes, and group dynamic (see Appendix B for patient interview guide and Appendix C for provider interview guides). During interviews, I maintained a *verstehen* approach by listening and understanding from an empathic stance (Miles & Huberman, 1994). Interviews lasted from 25 minutes to 75 minutes and were audio recorded with the consent of participants and later transcribed by a contracted VA transcriptionist. Recordings were transcribed verbatim from the original audio and checked for accuracy. In total, interviews comprised 14 hours of fieldwork and resulted in 400 pages of single-spaced data.

With a semi-structured guide, interviews allowed participants a space to tell stories, offer up their opinions, and describe their experiences in detail (Lindlof & Taylor, 2011). I conducted all interviews at the Phoenix VA hospital per request of the VA IRB. The specific location within the hospital changed with each interview due to space constraints, but all interviews were conducted in a private setting to ensure participant

confidentiality and privacy. Interviews with patients and family members occurred following their third or fourth SMA session allowing participants to readily draw on recent experiences. All patients and family members were approached to participate in interviews two weeks prior to scheduling the interview date in order to give them time to review their schedules and determine if they were willing and able to spend additional time at the VA hospital following their next SMA session. Provider interviews were based on their schedules.

Table 2

Summary of Collected Data

Type of Data	Amount of Data Collected
Total Research Hours	70 hours
Total Pages of Single-spaced Data	560 pages
Interviews	19 interviews (13 patients & family, 6 providers) 14 hours of audio data 400 pages of single-spaced transcripts
Participant Observation	20 SMA sessions attended 56 hours of fieldwork 160 pages of single-spaced fieldnotes

Data Analysis

Data was analyzed through an iterative process in which I moved back and forth among data collection, analysis, and consulting literature on communal coping to further develop coding schemes (Miles & Huberman, 1994). Coding and analysis occurred through a multi-step process. First, about halfway through my data collection, I began writing analytic memos (Charmaz, 2006) in my fieldnotes to document my thoughts

about emergent themes in my observations. The process of writing analytic memos encouraged me to reflect on the state of my data collection and to identify themes that were central to the lived experience of attending SMAs (Charmaz, 2006/2011). Through writing analytic memos, I recognized the centrality of communal coping as patients interacted with one another during sessions to collectively discuss ways of coping with heart failure. For instance, one of my early analytic memos described the process of being vulnerable with other group members through expressing emotions. I likened this observation to the experience of discussing stressors – a key component of the communal coping process.

Second, I engaged in data immersion after completing my fieldwork and interviews (Tracy, 2013). Through data immersion, I read and re-read all of my fieldnotes and interview transcripts asking myself “what’s happening here in regard to the communal coping process?” During the data immersion phase, I thought deeply about patterns that were emerging in the data and discussed these trends with colleagues to make sense of my initial analysis. I also continued to write analytic memos to document these thought processes and began refining my research questions to reflect my narrowed focus on communal coping processes and facilitator strategies. As Lindloff and Taylor noted, “the research literature can sensitize you to what could be important in the data” (2011, p. 247).

Third, I conducted verbal exchange analysis (Goodall, 2000; Saldana, 2009). Goodall (2000) described this type of analysis as, “a way of analyzing the meaning from an *outsider’s perspective*, from an *observer’s* critical vantage [emphasis in original]” (p. 106). This method of analysis is useful for “noticing and coding dimensions of talk”

(Lindlof & Taylor, 2011, p. 249). Verbal exchange analysis involves analyzing and interpreting verbatim transcripts to identify “types of conversation and personal meanings of key moments in the exchanges” (Saldana, 2009, p. 113) and develop a coding scheme. The first cycle of verbal exchange analysis involves coding for five types of verbal exchanges: phatic communication/ritual interaction, ordinary conversation, skilled conversation, personal narratives, and dialogue (Goodall, 2000). To do this, I uploaded all of my fieldnotes and interview transcripts into NVivo 10 qualitative data analysis software to help me organize and categorize my data into broad-bin nodes (Tracy, 2013) for each of the five types of verbal exchanges. During this phase, I began constructing a codebook of first-level codes (Tracy, 2013) that provided a brief definition and description of each of the five types of verbal exchanges. For instance, phatic communication was defined as an introductory form of communication that generally occurs at the start of a new relationship and functions to determine roles and rules among social actors (Goodall, 2000). Thus, I applied the category of “phatic communication” to any verbal exchanges that initiated relational development and established roles. I then further broke down the material in each of these categories into descriptive nodes that highlighted specific types of phatic communication. For instance, I used the in vivo code “experts” to describe instances where the SMA facilitator explicitly called patients “experts.”

Finally, I engaged in the second level of verbal exchanges analysis by asking the questions “what does it all add up to? What does it *mean*?” (Goodall, 2000, p. 107).

As Goodall (2000) described:

this second level is aimed at getting close to the *personal* meanings of exchanges, which is a formal way of suggesting that *you* are isolating key moments in the exchange and attributing special meaning to them...data that shape and inform an interpretation of a culture or subculture. (p. 108, emphasis in original)

As such, I conducted second-level coding (Tracy, 2013) by linking theoretical concepts to the existing coding scheme to reveal “the deeper meanings of the exchange” (Goodall, 2000, p. 105). For instance, I recognized that various methods of phatic communication aligned closely with the concept of a communal coping orientation as described in Lyons et al.’s (1998) research, but they also revealed the development of a shared identity. During second-cycle coding, I continued to log and define analytic codes in my codebook. Additionally, per Goodall’s (2000) method of verbal exchange analysis, I wrote extensive reflections about various verbal exchanges to understand the “unfolding story” that was emerging in the data and through communication.

Summary

Chapter Four provided a roadmap of the places, people, and methods that were involved in conducting the current study and analyzing the data. Participant observations and interviews were the primary sources of data, and verbal exchange analysis provided the foundation for developing codes and themes. In the next chapter, I will highlight the primary findings on communal coping that emerged from my time in the field. Chapter Five is organized into four primary sections that highlight and describe the various phases of the communal coping process.

CHAPTER 5

COMMUNICATIVE FEATURES OF THE COMMUNAL COPING PROCESS

Communal coping has been described as a transactional, social process (Afifi et al., 2006) that occurs among group members who share a similar life stressor (Lyons et al., 1998). Despite this definition, however, little research has explored the communicative features of communal coping and how this transactional process unfolds in context. Through my observations of heart failure SMAs, I recognized a series of four phases of communal coping that group members move through as they collectively discuss chronic illness: (1) establishing a communal coping orientation; (2) discussing shared stressors; (3) engaging in cooperative action; and (4) practicing communal reflexivity. Throughout this chapter, I describe the transactional communicative processes that occur in each of these communal coping phases by highlighting the type of verbal exchange that drives group communication in each of these phases (Goodall, 2000).

Phase One: Establishing a Communal Coping Orientation

In Goodall's (2000) description of different types of verbal exchanges, he identified phatic communication as a primary type of interaction that occurs in the initial stages of relational formation. Essentially, phatic communication functions to establish an introduction and highlight commonality among relational members. Phatic communication is often characterized by greetings, and turn-taking sequences in which questions are posed and answered in order to reveal status, roles, and/or common ground.

In this study, I describe phatic communication as the introductory form of communication through which a communal coping orientation is established in the context of SMAs.

In considering the key components of communal coping as described by Lyons et al. (1998), a communal coping orientation must be established by at least one person in the group who believes there is inherent value in coming together to solve a problem collectively. In the early stages of the communal coping process, members of the SMA healthcare team take on the responsibility of promoting and explaining the group process to potential patients. In essence, the SMA team works toward “selling” the concept of a communal coping orientation to SMA attendees. This promotion is carried out in a variety of ways including conversations before the first session even begins as well as introductory forms of communication that occur at the first meeting. The following sections describe various types of phatic communication, both verbal and nonverbal, that are facilitated by members of the healthcare team.

Pre-SMA Orientation: An Invitation from Nurse Sunshine

The work of establishing a communal coping orientation often begins at the moment patients are invited to be part of the heart failure SMA. Nurse Sunshine is generally responsible for identifying patients who are suitable for the program and inviting them to attend. The SMA is appropriate for all heart failure patients, but is primarily constructed and provided for individuals who have recently been discharged from the hospital and/or demonstrate a need for additional information and support. Ultimately, the goal is to help patients with advanced stages of heart failure feel confident and capable of engaging in successful self-care at home in order to avoid serious

complications, subsequent hospitalizations, and/or a premature death. During an interview with Nurse Sunshine, I asked her to explain the types of information she generally shared with patients about SMAs before they agree to attend:

I give them our list of topics and let them know that we'll cover all of those things, but if they have certain questions or certain topics that are of particular interest to them, to let us know. I always tell them that it's a group of them and a group of us. Cause I think they need to know that they're gonna be in a room with 15 plus people. And usually I tell them, a lot of people are on the fence; "I don't like groups," "I don't want to come for an hour and a half," "I don't want to be here four times." And I usually say, "just come once, and if you don't want to come after that, no one's gonna force you, but try us out once." And I don't like to tell them a lot because ... everybody's experience is different and like when there's only two or three patients, it's certainly different than when there's 6 plus whomever else and so I just let them know that whatever needs they have, we'll get them addressed and there's an expert for most, like if you have a medicine question, the pharmacist asks it, or answers it; and if you have a question about your diet, we'll get you with the dietician, so that they know.

In this way, Nurse Sunshine begins to encourage group-mindedness in patients before they ever enter the SMA context by explaining to them the general benefits of interacting in a group setting. She focuses primarily on the benefit of having access to multiple providers at once. This could be a strategy to differentiate SMAs from a "group therapy" format that many Veteran patients say they are hesitant to attend.

SMA Room Design: Communal Coping as Nonverbal

Beyond Nurse Sunshine's initial promotion of the group structure, and her attempts to describe the benefits of attending a group session for heart failure, the set-up of the SMA room also serves to nonverbally communicate a communal orientation. At the Phoenix VA, heart failure SMAs are held in a conference room in the cardiology department where patients, family members, and the SMA facilitators sit around an oblong conference table for their 90-minute session. Practitioners who facilitate SMAs are encouraged to situate all group members in a circle to promote group communication (Noffsinger et al., 2003).

Aside from this seating arrangement, the providers situate a name card with each patient and family member's first name in front of them on the table. Throughout the sessions, then, the healthcare providers are able to refer to the patients and family members by their first names, establishing a sense of familiarity and comfort. With this system, SMA attendees are also able to use one another's first names when speaking with each other. This allows for a connection to occur not just between patient and provider, but also among peers.

The First SMA: Explaining Roles and Finding Common Ground

During my observations, I noticed Dr. Jerome used a consistent series of communication tools to orient patients to the SMA context during their first session. These tools included situating the patient as "expert," inviting patients to share stories about their heart failure diagnosis and/or recent hospitalizations, and using a "four-lane highway" metaphor to discuss chronic illness. I describe each of these forms of communication in the following sections.

Situating patients as “experts.” At the beginning of patients’ first group appointment, Dr. Jerome acts as the primary facilitator of phatic communication by explaining the expectations and roles for everyone in the group and describing the purpose of SMAs. The following excerpt from my fieldnotes shows how Dr. Jerome described these roles to a group of new patients and family members:

“Welcome to the session everyone. My name is Dr. Jerome, and I’m a clinical psychologist. This is Dr. Susie our pharmacist and she and I are co-moderators of this session.”

Dr. Jerome goes on to explain a little bit to the group about what SMAs are and how they work.

“We want you to think of this like a medical appointment, but instead of meeting one-on-one with a physician you meet with a team. We have two teams in these sessions: a team of medical experts and a team of patients.” He goes on to tell the group that SMAs started several years ago and that, “what they’ve found is that Veterans learn a lot from each other and so you guys are kind of experts on your own health conditions....and there’s a lot evidence that shows attending a shared medical appointment actually extends people’s lives. So not only the length of their lives, but also the quality of their lives.”

Dr. Jerome frequently used a variation of this script for members who were attending their first SMA session. By labeling patients and family members as “experts” at the very start, Dr. Jerome invites patient participation by calling attention to the knowledge they can bring to the table. Situating the patient as “expert” is also important for differentiating SMAs from traditional one-on-one appointments in which patients

might be accustomed to their physicians dictating the conversation. Here, patients are explicitly recognized as holding an equally valuable amount of knowledge and experiences to contribute to the group. This serves to establish a communal expectation that each individual sitting around the table has something to contribute to the group and clearly identifies the specific roles they should take on during their time together. Establishing relational roles is a primary purpose of phatic communication (Goodall, 2000).

Further, Dr. Jerome's brief introduction functions to describe the unique structure of SMAs. Although Nurse Sunshine explained in our interview that she generally orients patients during her initial conversation with them about SMAs, patients and family members frequently shared during interviews that they knew very little or nothing at all about SMAs. When I asked Sue, JJ's wife what she knew about SMAs before starting their first session she told me, "we didn't know what to expect." Dorsey also shared he had no expectations before attending his first session.

Patients and family members also expressed their initial discomfort about attending what they perceived to be a "group therapy session." For instance, when I asked David what he knew about SMAs before he started attending the groups he shared, "Well, I knew it was a group therapy thing and that in itself, is sort of a turn off for me. I just don't care for it that much. What I have learned is this [SMAs] has been a very good thing and I've gotten a lot out of it." Angie echoed similar feelings saying, "Well, I didn't know anything about them... and I was pretty apprehensive. I'm not good with groups of people where I don't people... and I was not, at all sure that Al would be...I actually thought he would get through one and say, "I'm not going back to that." These comments

suggest phatic communication is necessary for describing roles as well as addressing any confusion or misconceptions about the SMA model to encourage group member involvement and reduce potential concerns about group interaction.

Sharing diagnosis stories. After describing the purpose and value of SMAs, Dr. Jerome would often invite patients attending their first session to share how they were diagnosed with heart failure. This question was posed in an open-ended way, allowing patients to determine the level of detail and information they were comfortable sharing with the group. Patients would frequently describe symptoms leading up to their diagnosis, which often resulted in some type of hospitalization and/or surgery. As patients described the details of their symptoms, such as the breathlessness, difficulty sleeping, and trouble doing physical activities, others patients and family members nodded their heads in agreement. The following example from my fieldnotes shows how this interaction unfolds:

Dr. Jerome turns to Robert, a newcomer to the group, and asks him to share his diagnosis story.

Robert describes himself as a “pretty healthy guy” who was “diagnosed a couple of years ago with a-fibrillation, no symptoms whatsoever, and so I just took that like a normal guy like ‘oh, nothing to worry about, right?’”

A collective “Mmmhmm” comes from the group of patients and family members. Robert says he kept going on like things were normal, working and “making his heart race” and then developing symptoms like shortness of breath. He started to notice that he also needed to sleep sitting up at night just in order to breathe. He knew this “wasn’t a good sign and went straight to the ER” where he

was told he had heart failure because his heart had been weakened from repeated arrhythmia.

“Do other people remember the first time they were hospitalized?” Dr. Jerome asks the group.

A resounding “Mmhmm” comes from the group as I see patients and family members nodding heads in unison.

Several of the patients then launch into telling their own backstories, echoing similar experiences of assuming they were healthy or fine when, in fact, they were having serious health issues.

Bill, who leans back in his chair with his arms crossed in front of his chest, says that he thought he had pneumonia caused by being out in the big dust storm that happened in Phoenix in 2011. He went to the doctor and was told two-thirds of his lungs were filled with fluid. He was hospitalized and had four stents put in.

“How did you feel after that?” Dr. Jerome asked Bill.

“I felt pretty bad, but two day after I had the stents put in nothing ever happened. I was swimming laps, playing basketball and that was 2 days afterwards, but that was 2010. My heart function back then was 50-55, which is normal, and my heart function now went down to 20-25....I’m just fatigued all the time.” Bill explains he recently started getting more easily fatigued and having difficulty breathing.

Howard then begins to tell the same story he told on his first session about his heart attack, needing to be taken to the closest hospital (that wasn’t a VA

facility) because there wasn't time, then being transferred to Tucson to have four valves replaced and a pacemaker put in.

"It took a long time and a lot of rehabilitation, but now I feel good."

Dr. Jerome shares that previous patients have talked about the fear and anxiety they have because of their health condition and hospitalization. "Can you relate to that at all or was it not a big deal?" He asks the group.

"I can relate," Bill says with his arms crossed as he leans back in his chair and looks at the floor.

"What about you, Larry?" Dr. Jerome asks.

"I didn't feel scared the first time, but I did the second time because I was almost twenty years older."

This extended excerpt illustrates the communal nature of story sharing. Personal narratives of diagnosis and hospitalization revealed the traumatic experience of illness as patients described the fear and confusion they felt in those moments of crisis. In the example above, we see Robert self-disclose about the confusion and shock he felt when he was diagnosed with heart failure because he thought he was "healthy." Goodall (2000) described personal narratives as a way to "situate, coordinate, detail, and explain or retell pivotal events in a personal or organizational life" (p. 104). In Robert's case, we see him provide a chronological account of not only the moment of diagnosis, but also the details of his life leading up to his diagnosis and how the experience unfolded. Patients' stories, then, provided a space for patients to re-construct the road to assuming their new identities as heart failure patients. As Sharf and Vandeford (2003) explained, storytelling can allow individuals to "make sense of unexpected, random events as they

construct accounts of what they experienced...to create some understandable pattern” (p. 17). For instance, we see Howard make sense of the pattern of his experience as he describes the chaotic process of being rushed to the hospital for his heart failure. Through sharing his story, he is able to understand how those events unfolded in sequence.

Aside from providing details of diagnosis, Goodall (2000) described personal narratives as a form of “mutual self-disclosure” (p. 104). As shown in the example, as Robert opened up about his experiences, Dr. Jerome used his story as an opportunity to encourage others to self-disclose their stories of diagnosis. As a result, Bill, Howard, and Larry all revealed similar experiences, perceptions, and symptoms regarding heart failure. Through this process, Dr. Jerome helped patients see common ground as they shared their diagnosis stories. In this way, one patient’s story acted as a trigger to identifying shared identity through discussing their shared condition. As Lyons et al. (1998) described, a key part of establishing a communal coping orientation is the recognition of a shared experience. Thus, story sharing at the start of SMAs might further concretize the value and necessity of working collectively to cope with illness in this context as patients begin to recognize the similarities in their stories. As Sharf and Vandeford (2003) noted, “the very voicing of an illness experience in story form is itself an act of healing and agency” (p. 17).

Describing the “four-lane highway” metaphor. As a follow-up to their diagnosis stories, which often highlighted the stressful nature of chronic illness, Jerome would shift their focus to what he referred to as the “four-lane highway” metaphor. Essentially, the four-lane highway metaphor served as a visual representation to illustrate where patients were in terms of their health and to further identify how attending SMAs

and being in a group structure could enhance their quality of life moving forward (see Figure 2 for a photograph of this drawing). My field note observations chronicle Jerome deploying this metaphor in an initial SMA session:

There's a small white board on the left side of the conference room next to the projector screen. Jerome walks to the board shortly after making introductions and welcoming everyone to the session. He grabs an orange marker and draws 5 parallel lines from top to bottom on the board. He labels the first four columns with number 4, 3, 2, 1. In the final column he makes two sets of horizontal hash marks which he calls "rumble strips," and on the other side writes "100 ft. cliff = death."

He tells the group they can look at life like a "four-lane highway" and when we're young we start in lane four where we have lots of room to navigate, but as we get older we have fewer and fewer lanes to use. The rumble strips, just like we would find on a highway, signify "danger."

He explains the first set of rumble stripes are the symptoms of heart failure like shortness of breath, and the second rumble strip is hospitalization. On the other side of that is a "50 foot cliff" and that's "lights out, the end game."

As Dr. Jerome walks the group this metaphor for life and illness, patients watch intently, nodding their heads, and murmuring "Mmhmm" under their breath.

"So when you're young, you can have a large pizza and a bucket of wings because you have more lanes than you do now? What do you think would happen if you ate a large pizza and a bucket wings now?"

David, one of the returning patients, laughs and says “you’d take on a lot of water.”

“You’re right, David! We would,” says Jerome. “So, what we want to do is to keep you off this rumble strip. But if you do hit this first rumble strip, we want you guys to be able to do what we call self-management skills. Which would mean like taking an extra water pill to try to get that fluid off, or thinking, ‘I better start to pay attention to my sodium now.’ The whole point of this shared medical appointment is we want to keep people out of the hospital.”

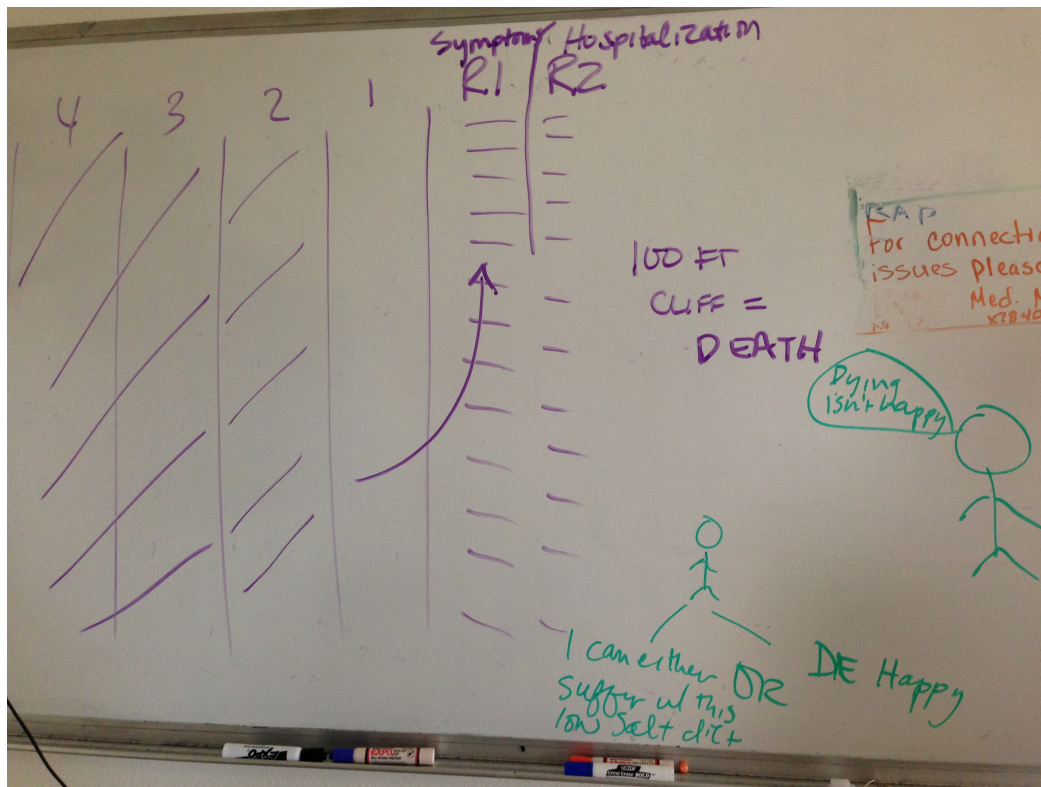


Figure 2. Photograph of the four-lane highway metaphor drawing during an SMA session on heart failure.

Through this metaphor, Dr. Jerome illustrates the realities of death associated with having heart failure by acknowledging the presence of the “100-foot cliff.” This metaphor, which the team adopted from a team at the Cleveland VA hospital, serves to orient patients to where they are in terms of their health. Dr. Jerome’s use of “we” language during his description of this metaphor further facilitates and reinforces a sense of shared identity by acknowledging that they all have reduced lanes as they age and need to think more carefully about their daily choices. In this way, Dr. Jerome also uses the metaphor to emphasize the control that patients have in managing their condition through making healthy choices. During my interview with Dr. Jerome, he explained that part of his goal in using the four-lane highway metaphor was to call attention to the choices patients make and how this affects their health:

So my big, broad thing that I’m gonna tell people, is we support you whatever choices you want to make, we support you, but this is your highway and you have control and so this is your news flash. You can stay off the rumble strips or not.

Thus, Dr. Jerome uses the metaphor as a type of scare tactic to motivate patients to take control of their health as well as re-emphasize patients’ roles as “experts” in managing heart failure. For patients, this metaphor holds weight long after their first session. In my later observations and interviews with patients, many of them would call upon this metaphor as a memorable moment for them in attending SMAs. For instance, Russell told me the metaphor helped him better understand his health circumstances. He noted, “that one example that he draws there on the board you know about the four lanes and the rumble strips, you know? I guess that did more for making me understand where I’m at.” Dorsey also highlighted the motivational power of this metaphor:

Dorsey: And the rumble strip thing that he did a couple classes ago, that's another one that I took away from, cause I go home and tell my girlfriend about that.

Trisha: What did you take, yeah, what did take from that four lane highway metaphor?

Dorsey: That I want to be as far to the left as possible 'cause going over to the right two or three lanes, I don't want, I ain't ready to go over that cliff.

Russell and Dorsey's comments suggest the four-lane highway metaphor acts as a useful tool for envisioning the severity of their health condition and the importance of maintaining a healthy lifestyle. Furthermore, their comments highlight the ability of this metaphor to help them understand the importance of change and orient them to their role in the process of successfully managing heart failure. Thus, the motivating nature of this metaphor might further encourage patients to take advantage of the group structure and view the group session as a space to develop strategies for staying out of the hospital and maintaining a healthier lifestyle.

In summary, a communal orientation is established through both verbal and nonverbal communication and functions to orient patients to the value of group interaction in managing heart failure as well as acknowledge their individual and collective roles in the process of attending SMAs. Nurse Sunshine and Dr. Jerome play important roles in promoting the group structure before and during the first SMA session. Through their use of various types of phatic communication, and inviting patients to share their personal narratives of heart failure diagnosis, they aid in the development of a communal orientation among group members before and during the first SMA session as

they explicitly highlight the value of group interaction for managing heart failure. In the next section, I describe the second phase of communal coping that emphasizes discussion the stressors of chronic illness.

Phase Two: Discussing Shared Stressors

Following the establishment of a communal coping orientation, conversation often shifted to a discussion about the stressors of chronic illness and the perceptions patients and family members had about their challenges with managing heart failure. This suggested that once SMA members had an understanding that they all shared a similar issue, as developed through phatic communication and sensemaking narratives, they could begin the work of acknowledging the issues of their illness that caused distress. This process of discussing shared stressors is a second foundational act of communal coping and includes sharing details about “how the situation currently affects the individuals and their relationships/social group, and the anticipated impact on them” (Lyons et al., 1998, p. 584). Though this process is often identified in the communal coping literature, the ways in which it unfolds in interaction are not described. I argue in this section that this aspect of communal coping occurs through ordinary conversation.

As a type of verbal exchange, Goodall (2000) defined ordinary conversation as “patterns of questions and responses that provide the interactants with data about personal, relational, and informational issues and concerns, as well as perform the routine ‘business’ of verbally acquiring, describing, analyzing, evaluating, and acting on information in everyday life” (p. 103). During heart failure SMAs, ordinary conversation revolved around a discussion of the illness itself and the myriad challenges and changes chronic illness posed for both patients and family members. In this section, I argue that

communicating about stressors occurs through emotional expression that triggers mutual self-disclosure, or chaining. I also provide evidence that discussing shared stressors provides an additional layer of connection as patients acknowledge a shared appraisal of their collective condition.

Providing Context: The Complexities of Heart Failure

As a health condition, heart failure requires a great deal of medical supervision, health knowledge, and personal self-care. In my fieldnotes, I frequently commented on the confusing and complicated nature of this condition and the lengthy list of medical terms, medications, and biological functions of heart failure. These notes reflect my own struggles to understand everything related to managing heart failure:

It requires a lot of concentration to understand this information and make sense of it all. It's very complicated material, and I feel lost a lot of the time when they [providers] begin to discuss medications, symptoms, and clinical tests/numbers. I often wonder how the patients keep track of it all.

This note came in response to watching the healthcare team describe the different tests, numbers, and acronyms associated with heart failure as they displayed patients' medical information on a PowerPoint slide. Part of the goal of SMAs is to get patients to a place where they feel more comfortable with this information and have a stronger understanding of their condition. To do this, though, requires unpacking the complexity of illness including both the biological and psychological components patients and family members experience.

In my interviews, members of the heart failure team shared that the average prognosis for a newly diagnosed heart failure patient is approximately five years to live.

For those with advanced stages of heart failure, this prognosis might be significantly less. There is no cure for heart failure; therefore, treatment focuses not on curative measures but on successful disease management.

As one patient put it, “managing heart failure is a 24/7 process.” Patients and family members must conduct day-to-day monitoring to keep the disease in check. In order to do this, providers encouraged heart failure patients to keep a daily food log to effectively track their sodium levels. They were also encouraged to weight themselves every morning to track their fluid retention and then take the necessary steps to reduce swelling. Furthermore, heart failure patients were often prescribed several medications that placed additional restrictions on their diet and their schedules. In order to be effective, many of their medications required multiple doses throughout the day taken at specific intervals. One of the most commonly prescribed medications for heart failure patients is Furosemide, which is a diuretic intended to remove additional fluid from the system and improve heart function. Patients frequently talked about their increased need to use the restroom and how this often made it difficult to go anywhere for an extended amount of time without having a bathroom nearby.

Thus, much of the discussion around stressors during SMAs revolved around acknowledging the challenges of lifestyle change. Aside from these daily stressors, patients often described feeling a loss of identity in their inability to do the things that they once did before their diagnosis. I provide this summary of heart failure to call attention to the multi-faceted nature of illness. When heart failure patients enter SMAs, they are often overwhelmed by their condition. In early SMA sessions, conversation often revolved around acknowledging and discussing these stressors. Thus, stress management

is a key part of the SMA curriculum. In the next sections, I highlight how patients discussed shared experiences.

Discussing Shared Experiences: A Chain Reaction

Chronic illness poses many life challenges that can induce feelings of stress. During SMAs, responses to stress were expressed as strong emotional reactions. As noted in Chapter Three, stress occurs when a person perceives of a situation as threatening and/or as something that exceeds their current capabilities or resources to cope (Folkman & Mozcowitz, 2004). During SMAs, patients attending their first or second sessions were often still reeling from a recent hospitalization, diagnosis, or setback related to heart failure.

As group members were invited by the SMA facilitators to talk about how they manage heart failure, patients voluntarily shared information about the stressors of living with their condition. Through my observations, I noticed this information sharing often resulted in a chain reaction of mutual self-disclosure. As one patient shared about a particularly difficult aspect they have experienced, other patients expressed similar thoughts and sentiments about the situation. This often occurred when patients discussed lifestyle changes related to dietary restrictions or taking medications. The following extended excerpt illustrates this chain reaction:

“Do you think people with heart failure think it’s not worth it to cut back on sodium because they think ‘it’s too late for me’?”Dr. Jerome asks.

Dennis and Randy both nod their heads.

“I’m 64 years old and I’m used to eating whatever I want! It’s very hard. No, I don’t think I can eat whatever I want just because of the meds, but it’s very hard,” Dennis shares.

Dr. Jerome responds by saying, “You want to make changes, but it’s difficult. Does anyone else feel the way Dennis does?”

Michael begins laughing and says, “You could have just spoken for me!”

“I think we’re all dealing with it.” Andrew says at the other end of the table. “For me, I love pasta and you can hardly find a low sodium pasta sauce unless you make it yourself. I don’t have time do that! We [he and his adult children] did find one that’s low sodium and it tastes like shit.”

Everyone in the group laughs.

Michael then begins pointing to all of the patients sitting around the table and numbering them off counting, “1, 2, 3, 4, 5. There are five of us here with heart failure. What I want to know is what would be different if there was a similar group of people with a similar age sitting around this table who didn’t have heart failure. Why didn’t they get heart failure? I want to be in the control group.”

Dr. Jerome tells him this is a great question and shares that behaviors across a lifetime act as a contributing factor, but that looking at the past doesn’t changes their circumstances.

Linda echoes similar sentiments sharing that she’s really frustrated with the dietary restrictions that they must maintain. “I was raised on a farm! We ate food. Real food. We didn’t eat bland things. You know, smoking is a habit, but

eating is something different. And the worst thing is checking the labels because then I realize I can't eat anything. I like the taste of salt and I just can't stand some of this bland food."

"Isn't that the point of food?!" Dennis says, his tone louder than before. To enjoy it?! Huh?!" He's making a waving gesture with his arms as he says each word.

"That's a belief about food, yes." Dr. Jerome says. "But the point of food is nourishment."

This excerpt reveals a number of functions taking place. First, patients are clearly identifying dietary restrictions as a common source of stress. Each member of the group comments on the frustrations of eating a lower-sodium diet. Beyond simply identifying a shared stressor, however, this chain reaction of responses also reveals a shared perception that dietary changes are difficult to achieve and maintain as each group member echoes similar feelings. This is what Lyons et al. (1998) referred to as social appraisal in which group members begin to classify a stressor as "our problem." As group members self-disclose about their emotions, others begin to engage in similar levels of self-disclosure and emotional expression.

A social appraisal is evident through the language that some group members use in responding to Dennis. Michael directly acknowledges this shared perception by expressing that Dennis's words accurately summed up his own thoughts. Andrew also acknowledges the similarity of their experiences through the use of "we language," a distinct signifier of a communal coping orientation (Rohrbaugh et al, 2012). Thus, in the context of SMAs, patients arrive at a social appraisal through this process of chaining and

mutual self-disclosure. As one member expresses experiences and emotions around a particular aspect of heart failure, others acknowledge and verbalize similar feelings and challenges.

It is also important to point out the potentially consequential nature of group venting and mourning, however. In the above example, Dennis's comments spark a chain reaction of emotional expression that could potentially border on co-rumination (Boren, 2013/2014), which involves an unhealthy focus on talking about negative experiences. As patients engage in venting and mourning, they might be inclined to dwell on aspects of their lives they have little control over, which could lead to heightened states of distress (Afifi et al., 2013). In the facilitated context of SMAs, however, Dr. Jerome often redirects or reframes the conversation when patients begin to focus too long on negative emotional states. For instance, in the above example, Dr. Jerome reminds the group that food is meant to nourish the body when they seem to become fixated on the enjoyment of food. Additionally, during my observations I noted Dr. Jerome would frequently respond to patients' venting and mourning by drawing on a metaphor or hypothetical story that emphasized personal control (see Phase Three section of this chapter for a more detailed description of Dr. Jerome's metaphors and hypothetical stories). As such, the facilitator not only plays an important role in generating discussion about stressors during the second phase of the communal coping process, but he is also helps prevent group dissent and unhealthy emotional fixations.

Connecting Through Shared Emotions

Through my observations, I noted that aside from creating a shared appraisal, discussing shared stressors also allow patients to express the strong emotional reactions

that can accompany living with a chronic illness. Expressing emotions was a communal event as patients opened up about their feelings and validated one another's emotional reactions. Emotional expression occurred in two primary ways: venting and mourning.

Venting often occurred when patients felt a sense of restriction or confusion due to their heart failure. For example, in one session, I chronicled an interaction in which one group member began venting about medications and confusion about his current health status:

TJ begins to express some frustration with his current level of health by telling the group that he's not seeing any improvements in his health and that no one is telling him he's improved at all in the last year and a half.

Just then, Elvira, Elvis's wife, leans her head into the center of the table so she can see TJ. She tells him that Elvis experienced the same situation a few years ago. She explained the doctors had struggled to find the right combination of medicines and the proper dosages, but that they eventually got there.

"It was an emotional roller coaster, but there is light at the end of the tunnel," Elvira says with a smile.

In this example, we see the communal nature of emotional expression occur as Elvira validates TJ's experiences through sharing that her husband once felt the same way too. Elvira also acts to normalize TJ's experiences through explicitly acknowledging that heightened emotions and feelings of frustration are a normal part of navigating chronic heart failure. Thus, discussing shared emotions is an additional way for group members to arrive at shared experiences and appraisals.

Similarly, in acknowledging their shared identity as patients of heart failure, group members also called attention to the loss of their previous identities as active, healthy individuals. In discussing their shared experiences with illness, they also connected over their loss of the past. In one example of mourning, Stephen and Elvis talk about the changes in their level of activity since being diagnosed with heart failure:

“How many problems do people have with stress? ‘Cause there are some days that it’s ok and some days that just really get to me,” Stephen asks as he sits at the head of the long conference table. His elbows rest on the table with his chin perched on top of his folded hands. The weight of his thick body leans forward as his blue, bloodshot eyes look to his peers at the table for answers.

“What does everyone think?” Dr. Jerome asks the group.

Elvis, who sits at the other end of the table next to his wife Elvira, responds by sharing about some of the challenges he’s dealing with regarding the things he can’t do anymore, like karate.

“I used to do more, and now I feel like I can’t do anything,” Elvis says quietly. “I’m taking three pages of medications [motions to a sheet of paper in front of him]. I took a picture of the pile [of pill bottles] one day.”

“A mountain of medications,” Al, a fellow patient, says with a light chuckle. The group laughs in response and they all nod their heads and look at Elvis. Some of them murmur things like “yes,” and “I know what you mean.”

“Yeah, I’m not able to do as much now either. I used to go hunting and fishing all the time with Stephen Jr.” Stephen motions to his adult son sitting next to him at the table. “But I just don’t feel like I have the energy anymore.

This excerpt again illustrates that emotional expression encourages the process of mutual self-disclosure and chaining. As Elvis freely shares about the changes in his life, Stephen feels comfortable to acknowledge that this is also a source of stress for him. Through their discussion, Elvis and Stephen arrive at the conclusion that heart failure inhibits their quality of life. In this way, patients not only connect through their shared experiences, but also through a shared emotional appraisal of those experiences.

Venting and mourning allow patients to connect at an emotional level, but these acts also reveal shared appraisals of common stressors. A sense of shared appraisal, or the perception that a stressor is shared, is a key feature that distinguishes communal coping from other forms of social support or individual coping (Lyons et al., 1998). As group members collectively vent and mourn, they acknowledge their shared appraisal of heart failure as a serious threat to their well-being and also acknowledge deficiencies in their abilities to cope with illness. Lazarus and Folkman (1984) described this as “primary appraisal,” as people assess the severity of their condition and the level of threat the stressor poses to quality of life. This signals the need for members to act on their collective challenges and engage in coping. The recognition of a threat motivates people to cope – to take action to manage their stress. Thus, identifying shared experiences and appraisals is an important act in shifting members into group problem-solving mode.

The communicative acts of venting and mourning are also important processes in helping patients arrive at the conclusion that they are “not alone” in their experiences. Indeed, this is a critical experience as patients adjust to their new identities as heart failure patients. During interviews, I asked patients to share memorable experiences from attending SMAs. Overwhelmingly, both patients and family members noted the value of

hearing about others' challenges in managing heart failure and the stressors of chronic illness. For instance, during our interview at the end of his fourth session, Bob said:

Bob: I think the longer you go and the more involved the more you get that you can talk, you can talk about things that you need to talk about. You can talk about things that need to be brought out, for your own good, if nothing else, and get some feedback. You're finding that a lot of people that went through the same things, you're not unusual.

Trisha: So, you're saying that it's good to hear that from the other patients.

Bob: Yes, exactly. We're not, we're not the only ones... One of the biggest things about the group that I like is, yeah, because you're not the only one doing this. You think you are. "Cause I'm the only one that's sacrificing." No you're not. It's not so abnormal as you think it is.

For Bob, hearing about others' experiences not only validated his own feelings and frustrations, but it also helped to normalize his condition and reduce a sense of isolation.

Dave, another patient, shared similar sentiments during an interview:

It's great because they're all...experiencing the same thing I'm experiencing, so that makes me feel better. Like Charlie was saying, "It's nice to know that there's people out there with your same disease." And I'm not an ignorant man, but I know, that other people have the exact the same thing I have, but you don't know that person. When you have somebody in that room with you, well, oh yeah, you know, that's exactly, yeah Dave, I feel the same thing. That's very reassuring that I'm sitting there talking with someone that's feeling like you're in it.

Notice how Dave highlights the value of “feeling” in this excerpt. He directly acknowledges the value of connecting with his peers through their shared emotional appraisals of their condition. Lyons et al., (1998) noted individuals can be motivated to engage in communal coping for the relational benefits associated with group interaction and the opportunity to become part of a community. The comments above suggest patients develop a sense of community as they discover they are not alone in their experiences.

Members of the healthcare team also highlighted the community-oriented nature of the SMA context as a primary benefit for patients. In my interviews, providers commented about seeing the comfort patients received from learning they are not alone. For instance, when I asked Dr. Susie what she thought were the most valuable aspects of SMAs for patients and family members, she responded by saying, “the patient support, but amongst the patients themselves. To know that they’re not alone, that they share the same experiences and that they need to engage themselves amongst their discussions on how they manage different aspects of heart failure.” Dr. Jerome elaborated on these same elements during our interview:

Dr. Jerome: ...I think that whole group dynamic where they’re ... supporting each other and they see that they’re not alone, is a huge, it’s a huge thing they get in groups. When you realize that you’re not the only one with this and you see other people trying hard ... it’s pretty powerful for them.

Trisha: Why do you think, why do you think that’s such a powerful experience for patients, if you had to speculate?

Dr. Jerome: I think like, inherently, people don't want to feel different, none of us want to feel different, and so, when we have an experience, any kind of experience, it's like if we were to call it "a negative experience" like an isolating experience. What makes us, I call it super glue, what bonds us with people is knowing that other people may have felt similar.

Overall, patients and family members emotionally connect with one another through communally venting and mourning. These acts of emotional expression allow individuals to verbally acknowledge key stressors associated with heart failure while simultaneously learning they are not alone in their experiences. This connection acts to reduce patients' feelings of isolation and normalize the challenges of managing heart failure.

Guiding Discussion of Shared Experiences: Facilitator Strategies

As a type of verbal exchange, ordinary conversation involves asking questions for the purpose of revealing personal information and concerns (Goodall, 2000). During SMAs, ordinary conversation serves three functions: to connect patients in their shared experiences, to reveal aspects of illness that are the most challenging for patients to manage, and to uncover potential deficiencies in patient knowledge or resources for coping. As shown in the previous exemplars, patients discussed dietary restrictions and managing their new identities as primary sources of stress. These discussions provided the healthcare team with important information on what strategies or resources patients might need to cope. But how do SMA facilitators encourage patients and family members to share about their experiences?

Throughout my observations, Dr. Jerome asked questions that would trigger patients and family members to discuss their emotions and experiences. In instances where an individual patient shared about an area of heart failure or personal experience they find distressing, Dr. Jerome generally responded by asking other group members if they have shared similar experiences. For instance, in the discussion with Dennis over dietary changes and restrictions, Dennis says, “I’m 64 years old and I’m used to eating whatever I want! It’s very hard. No, I don’t think I can eat whatever I want just because of the meds, but it’s very hard.” Dr. Jerome responds to Dennis’s comment by acknowledging his frustrations and then asking the group, “Does anyone else feel the way Dennis does?” This question then triggered Michael to say that he feels the same way, thus beginning the chaining of mutual self-disclosure. Dr. Jerome posed a similar question when Stephen asks how others manage their stress. He asks, “What does everyone think?”

In other instances, Dr. Jerome’s invitation to share came as a result of responses to individual group members’ nonverbal communication. In some sessions, especially when the topic of discussion was related to death and dying, patients and family members were less apt to immediately vocalize their feelings. One of the SMA topics of discussion was end of life planning in which the healthcare team talked about palliative care and advance directives. Understandably, this is a difficult subject to discuss for both the providers and the patients and families. During difficult discussions like these, Dr. Jerome closely watched nonverbal behaviors and asked patients to share their thoughts. For instance, in a discussion about advance directives, David, a generally vocal patient had been quiet most of the session. In my field notes, I wrote the following observation:

Dr. Jerome asks Al to share about his experience completing the advance directive. David and Alice sit across the table from Al and Angie. Typically a vocal person, David has been surprisingly quiet today. Dr. Jerome looks over at David who is looking down at the table.

“What are you thinking, David?” Dr. Jerome asks.

“I procrastinate on it because it’s the final step,” David admits. Alice nods her head, her eyes are downcast.

Dr. Jerome nods his head and says he understands, telling David and the group that this is a common feeling that other SMA members have about completing advance directives.

“There’s this feeling like if I fill this form out, I’m ready to die,” David admits.

Alice nods her head and so do other people around the table.

“What are you thinking Alice?” Dr. Jerome asks.

She says she’ll do whatever David wants when that time comes, but she just doesn’t want to think about it.

In this example, Dr. Jerome noticed the shift in David’s level of engagement and used an open-ended question to invite him to talk about his feelings regarding advance directives, and David shared in response. Thus, nonverbal communication, if noticed by the facilitator, can serve to trigger discussion about emotions. Responding to nonverbal communication is an important process to note because the expression of emotion involves a physiological component that is sometimes more present than the verbal act of expressing emotions (Planalp, 2001). This highlights the value of having a behavioral

psychologist facilitate SMA discussions because of the added knowledge of subtle emotional cues.

Although the questions posed by the facilitator might seem general, they serve an important function in directly inviting other group members to talk, share, or respond to patient comments and experiences. This question and answering format is in line with the function of ordinary conversation to engage in a question and answer format to reveal areas of concern (Goodall, 2000). Dr. Jerome's invitations gave group members permission to draw on their personal experiences and further solidify their role as "expert" in the context of SMAs. In interviews and at the end of SMA sessions, patients and family members often acknowledged Dr. Jerome's ability to get people involved and create an inclusive environment that made them feel comfortable sharing with others. For instance, during our interview, Al told me he felt "Dr. Jerome...has made it easy for people to participate...in some of the questions he poses." Similarly, when I asked Elvira what she and Elvis' experiences were like interacting with the healthcare team, she responded, "to me, they try to get everybody involved. And...everything that you say is, you know, really important, you know and they make you feel really good."

In summary, the second phase of communal coping involves patients discussing shared stressors associated with heart failure and expressing the emotional challenges of their shared condition. Through mutual self-disclosure, patients connect through their shared experiences and emotional appraisals of heart failure stressors and arrive at a social appraisal of those stressors. This is a significant finding because past research has indicated social appraisal is an essential component of communal coping (Afifi et al., 2006; Lyons et al., 1998), but has not explained how group members arrive at a social

appraisal. The findings in phase two demonstrate a social appraisal is reached through mutually sharing about personal hardship. During this phase, the facilitators use a question and answer format, or ordinary conversation, to encourage patients to discuss and reveal personal challenges and respond to one another's mutual issues. This helps patients arrive at the conclusion that they are "not alone" in their experiences. In the next section, I highlight the next phase of communal coping – discussing shared resources.

Phase Three: Engaging In Cooperative Action

Cooperative action, or collective problem solving, is the final stage of the communal coping process (Lyons et al., 1998). In this phase, individuals work together to pool resources and "construct strategies that are aimed at reducing the negative impact of the stressor and to address the adaptational demands of the circumstance" (p. 584).

Beyond this definition, however, there is little discussion in the past literature of how group members communally share and discuss resources and strategies in an effort to manage stress. I found, in the context of SMAs, group members communally construct resources through skilled conversation led by the group moderators and carried out by patients and family members. The findings suggest that this stage of the communal coping process serves an important function in helping group members cope through encouraging empowered thinking and being.

Goodall (2000) discussed skilled conversation as efforts to engage in conflict management, argumentation and/or debate, or negotiation. Skilled conversation is characterized by actions such as identifying priorities, decision-making, reaching an agreement, and/or creating a plan (Senge, Roberts, Ross, Smith, & Kleiner, 1994). Essentially, skilled conversation involves drawing on different perspectives to arrive at a

shared conclusion. In the context of SMAs, the goal for skilled conversation is to help group members arrive at the conclusion that they have skills to cope successfully with chronic illness and that they can learn from each other's experiences. Thus, the skilled conversation phase acts as the initial step of coping as group members actively discuss ways to manage the collective stressors associated with heart failure.

In the previous two phases of the communal coping process within the SMAs I observed, patients built a connection through their shared identities and experiences. This connection, and shared appraisal that heart failure negatively affects their quality of life, led group members to think and work collectively to identify, discuss, and practice potential strategies to reduce stress and daily struggles. Folkman and Mozcowitz (2004) defined coping as, "thoughts and behaviors used to manage the internal and external demands of situations that are appraised as stressful" (p. 745). In other words, coping involves using a variety of methods, both cognitive and behavioral, to reduce the experience of stress. In this section, I highlight how group facilitators encouraged group problem solving to determine ways of coping with the stressors of heart failure. I also describe how peers interacted with one another to share resources, plan for the future, and empower one another through shared expertise and re-appraisal.

Using Metaphors to Facilitate Patient Empowerment

As previously discussed, patients described a loss of identity and control over their daily lives due to perceived restrictions revealing a sense of disempowerment. In order to feel capable of coping with chronic illness, an important next step was to help group members acknowledge what is in their control and identify strategies they could enact to effectively manage their condition. Dr. Jerome used a number of metaphors

throughout SMA sessions, each centered on encouraging group members to conclude that they have control over some aspects of their illness and empowering patients to take responsibility for those choices.

One metaphor Dr. Jerome often used to encourage this mindset was a set of Russian nesting dolls (see Figure 3 for a photograph). He used these dolls to illustrate the different selves of an individual – a “feeling self” and a “wise self.” In this metaphor, he would explain to the group that the “feeling self” makes decisions based on desires and impulses, and that the “wise self” makes decisions based on logical, rational thoughts.



Figure 3. Photograph of the Russian Doll set Dr. Jerome used during SMA sessions to visually describe the Russian Doll metaphor.

Metaphors, like the Russian Doll example, were most commonly used as a He instructed patients, when faced with making choices about managing their health, to ask themselves which “self” is speaking and encouraged them to listen to their “wise self” in

order to make sound decisions that would promote health, rather than give in to impulsive behaviors, such as eating salty foods or choosing not to exercise. follow-up to venting or mourning, especially when patients were describing difficulties managing diet or exercise. As noted in Phase Two, patients could border on co-rumination by becoming fixated on discussing their negative experiences (Boren, 2013/2014). In response to their heightened emotional reactions often present during venting and mourning sessions, Dr. Jerome would often draw on metaphors or hypothetical stories to redirect patient focus and encourage them to consider behaviors and attitudes that are within their control. In the following example, we see Dr. Jerome respond to a discussion about the stressful nature of managing heart failure, especially dealing with end of life planning, by using a metaphor he called “chords of energy” I chronicled this discussion in my fieldnotes (see Figure 4 for a photograph of this metaphor):

Dr. Jerome shifts the focus of discussion from advance directives to managing stress. On the white board in the corner of the room, Dr. Jerome draws two clouds and a stick figure person below the clouds. The cloud on the left is labeled, “things that are 100% in my control,” and the cloud on the right reads, “things that are only partially or not at all in my control.”

“I want you to imagine we have two energy sources,” he tells the group. “Imagine you have 100 cords of energy coming out of your head and they plug into one of these two clouds. When we put our energy into things that can’t be controlled, we experience depression, anger, and anxiety,” Dr. Jerome says, as he draws lines to the cloud on the right side.

Dr. Jerome continues the metaphor and uses watching the news as an example of inducing stress and seeing a lot of things out of our control.

“Me being angry at home doesn’t change what happens in Congress. Let’s say you think we need better gun control laws. Maybe you’ve watched the news and you see another school shooting and you think, if everyone just had a gun they would have been able to stop them from doing that, or whatever you think.” He makes large gestures, using his hands to motion to the group, and back to the board, bouncing on his toes as he talks.

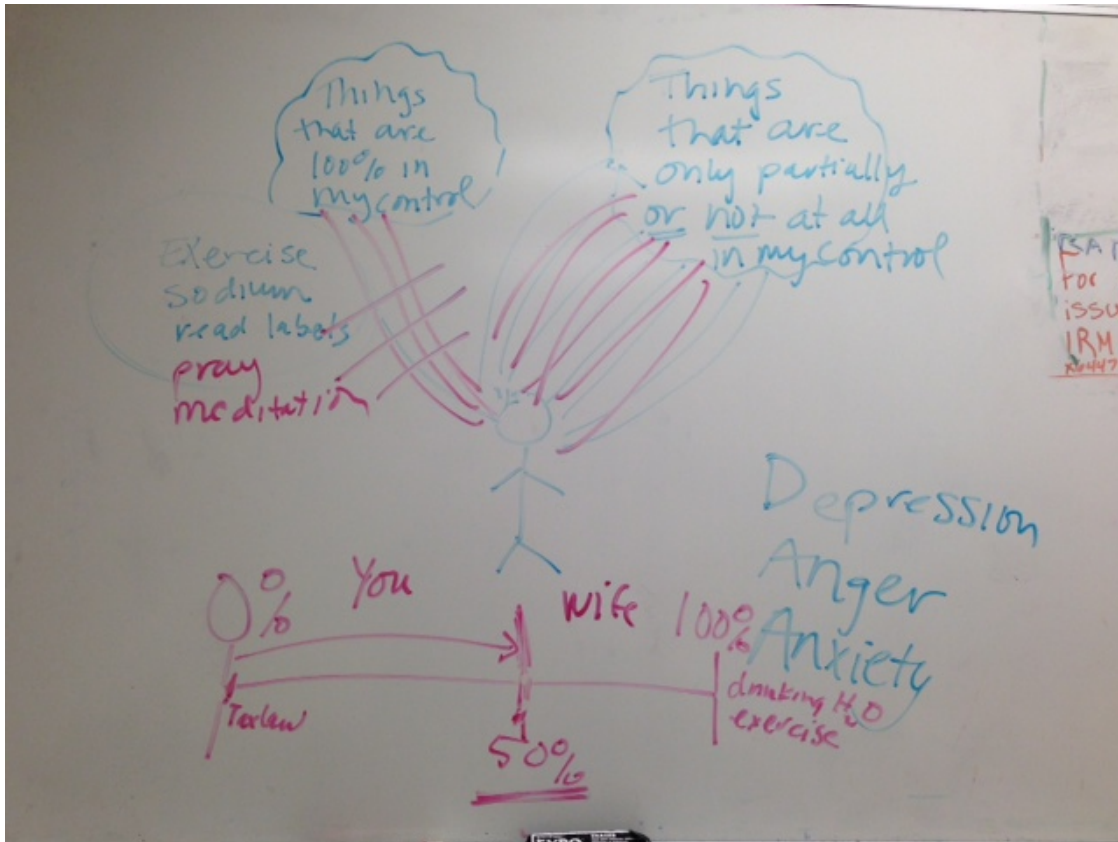


Figure 4. Photograph of Dr. Jerome’s drawing of the “chords of energy” metaphor during a heart failure SMA session.

His voice is loud, almost booming in this space, like a preacher standing at a pulpit giving a sermon. The patients and family members nod their head, almost in unison, listening intently, watching his gestures and looking at the board.

“What’s the point that I’m trying to make?” Dr. Jerome asks.

“Let it go! Move on!” yells Annie, the wife of a patient.

“That’s right, Ann! Let it go.”

Dr. Jerome then leads them into a discussion about the things that that they do have in their control and asks the group to generate a list. One patient says “exercise,” another patient says “take your medications,” and “read food labels.” As patients share these strategies, Dr. Jerome writes them on the board next to the stick figure and calls on patients as he goes down the list of things “100% in your control.”

“John? Is lifting some cans of soup at home for exercise in your control?”

Dr. Jerome asks, pointing to John at the table.

“Yes is it,” says John in response.

“What am I getting here?” He motions back to the board.

“That you got a choice!” John says enthusiastically.

“Yes! You have a choice,” Joseph, another patient, says in response.

During the SMAs I observed, metaphors, such as this example, acted as tools for helping group members collectively acknowledge a sense of control and establish a shared mindset of responsibility and action. This example illustrates the mental shift that occurs for patients as Dr. Jerome encouraged them to consider the skills and behaviors they have that provide the capacity to manage. Through this metaphor, Dr. Jerome

created shared understanding among the group members that collectively, and individually, they have a choice to manage their behaviors and promote health. This collective mindset occurred as different group members joined in the exercise of identifying behaviors in their control. Additionally, this level of group involvement encouraged the process of collective problem solving that characterizes communal coping. As group members attended to the metaphor, they worked together to generate ideas about the actions they can take to reduce stress and manage heart failure successfully thereby benefitting everyone in the group.

Some of the metaphors used by Dr. Jerome also served to help patients engage in a reappraisal of their shared stressors. One example from my observations that illustrates this process of re-appraisal is “the story of Janice and Brenda.” Dr. Jerome uses the Russian dolls as a visual tool to remind patients of their different selves. He sets up this hypothetical story by telling the group that Janice and Brenda are sisters who were married to two brothers named Tim and Tom:

“Don’t ask me how that happened,” Dr. Jerome jokes. “That’s just how it worked out.” The group laughs.

At this point, he has his Russian nesting doll set with the smaller doll tucked inside the larger one. He explains that when Janice was younger, she had a scary experience while flying and now she worries about air travel. It makes her nervous even though the logical part of her brain says that it’s safer than driving.

“Where does that worry part of Janice live?” Dr. Jerome asks the group. “Inside of Janice.” He pops open the Russian doll to reveal the smaller one.

He goes on to explain that Brenda didn't have a negative experience with flying, so she doesn't worry about air travel. When their husbands go on a business trip together and have to fly across the country, Brenda, knowing that Janice will probably be worrying about her husband, suggests they go to the park to distract her.

While Dr. Jerome is talking, the group is watching his every move. Alice, David's wife, is taking notes and nodding.

"So, who do you think is enjoying her time at the park?" Dr. Jerome asks.

"Brenda," the group responds in unison.

"And what do you think Janice is doing?"

"Worrying."

"Do you think Janice is enjoying the park and enjoying time with her sisters and her kids? Or is she thinking about the plane? Does Janice's worry create a protective bubble around this plane and keep it safe?"

"No!" says the group. Some of them smile and shake their heads.

Dr. Jerome goes on to talk about the "quirky things that we do when we're worried about something" and he links this back to things that are out of their control and the things that are in their control, reminding them that they can do things like eat well, check labels, reduce their sodium, and exercise.

"So what am I getting at Elvis?" He looks at Elvis and Elvira at the other end of the room.

"That there are things out there that we can't control," Elvis responds.

“Yeah. This Dr. Jerome [pointing to the smaller doll] likes to read the economic report before bed. I like to check and make sure everything is ok with my retirement and stocks and everything. Do you think that’s a good idea for me to be doing?”

Al makes a face with his mouth turned down and shakes his head.

Dr. Jerome then looks at Stephen, who is sitting close to his side, and asks him what he thinks about all this.

“There’s nothing you can do about it. You should handle things within reason and not blow them out of control,” Stephen replies. Earlier in the session, Stephen had shared that he was really worried about death and dying so much so that it kept him awake at night.

Dr. Jerome then begins to tell another hypothetical story about his “son” who tried out for the baseball team and didn’t make it. “So, what do I do? Do I go to my son’s room and sit with him and call attention to the fact that he didn’t make the team? No, I say, ‘I’m sorry this happened. But let’s do something else.’”

Dr. Jerome then links this to the experience of having heart failure and says to the group, “This is a bummer and I’m sorry it happened to you, but you don’t have to dwell on the negatives.”

“You don’t give up. You re-evaluate. You look at where you are today,” says David. “Live for today. Figure out how you can improve yourself so you can do more tomorrow.”

“A lot of things we could do in the past, we just do them differently now,” says Al. “We don’t have to give up the things we love. We just have to approach them differently. You don’t run, you walk.”

In this example, we see the nesting doll metaphor and related stories as tools to help group members reframe their experiences. As Dr. Jerome asked patients to respond, they shifted their perception from dwelling on the past to determining how to live a fulfilling life in the future. We see this as Stephen, Al, and David all language this shift in perception and summarize the moral of Dr. Jerome’s stories. Through metaphors, Dr. Jerome also facilitated a sense of empowerment by encouraging personal and group responsibility. Essentially, he shifted responsibility to the patients by encouraging group members to work together to devise a plan of action for engaging in better self-care and reframing their perceptions of illness.

During subsequent interviews, patients called upon the power of metaphors to help them shift their focus and understand their illness in a new light. When I interviewed Andrew about his experiences attending SMAs, he shared that one of the most helpful aspects of attending SMAs was learning about the “illusion of helplessness vs. the illusion of control” that Dr. Jerome had discussed that day:

Andrew: I don’t want to end back in here [the hospital] with, you know IVs hanging out of my arms again for a while. So, but that’s the most stressful, fear of being re-hospitalized.

Trisha: So. Do you, in what way if any do you think that fear is sort of addressed in these group appointments for you?

Andrew: Well, knowing what causes this specific episode...and things that I can control...which is what we discussed today. What can you control. And you really can only control certain things, so if you know what you can control, the better options you have to make the right decisions and not have those things happen.

Similarly, Elvira, Elvis's wife, echoed similar sentiments when I asked her how she felt about the group format. "And I think...the mediators or the instructors or whatever, you know they really leave it open to, you know, the veterans to share with each other, and then they usually come back with a comparative, a story and how to put it into a story form where it helps you better understand."

Collectively, metaphors serve as a form of skilled conversation used by the facilitator to encourage patient empowerment. As noted, skilled conversation can be a form of negotiation that encourages identification of priorities and/or decision-making (Senge, 2004). In his facilitation, Dr. Jerome highlighted the importance of prioritizing health, making sound decisions that positively contribute to successful self-care, and acknowledging the decisions that are within their control. Metaphors, then, act as a type of negotiation tactic facilitators can use to encourage patients to reframe their thoughts about chronic illness.

Peer Re-Appraisal and Shared Expertise

Aside from metaphors, which were generated by the facilitator, there were also spaces where patients offered up their own strategies and experiences to help encourage others to take action. In these instances, skilled conversation occurred as patients and family members were asked to share about their experiences engaging in certain behaviors related to managing heart failure. In some instances, like the following

example, patients shared their strategies in response to a fellow patient's frustrations:

"Cooking for just yourself is hard. You know?" Russell, one of the patients, says to the group. He shares that he is a single man and lives alone. "You get into the habit where you just throw something in the microwave. And keeping it within the 1500 [milligrams of sodium] is, yeah." He sits at the head of the table closest to the door. His little rust-colored dog, named Snook, sits silently underneath his chair. The group members nod their heads in response to this comment.

Howard raises his hand and tells the group he has a suggestion for how to get around this issue. He shares that he and his wife have found the crockpot to be really helpful in putting flavor into food without adding salt. "You wouldn't believe how much flavor it brings out. We found out it's a much healthier way to eat," he shares.

"That's great, Howard. What are some seasonings you can use besides salt to add flavoring?" Dr. Jerome asks the group.

"You could use no salt seasoning or pepper," Big Bill offers.

"Mrs. Dash," Robert says. This is his first SMA session.

"Tell us about that," says Dr. Jerome.

"Well, it's a no salt seasoning with a lot of different herbs and spices and it's sodium free. Lemon juice is another. Garlic. Onion. Lime. You gotta find other ways to make it taste good cause if you're used to eating salt..."

"It don't taste good!" Big Bill laughs, finishing Robert's sentence. Others in the group laugh too.

“You know I’ve only been low sodium for 2 weeks, but I’ve noticed now that if I eat something at the salt level I used to eat it tastes extra salty. So it doesn’t take long for your taste buds to adjust down,” Robert says. “Something like ranch dressing. You don’t realize how much salt is in ranch dressing. You know you’re dipping good vegetables into it, but it’s just loaded with salt!”

“How did you figure that out?” Dr. Jerome questions.

“Labels. Reading the labels,” Robert replies.

In this example, we see individual coping methods become communal strategies as patients share their personal tips and strategies with the group. In response to Russell’s concern about eating packaged foods, Howard offered up using the crockpot as a tool he and his wife have found especially helpful in maintaining a low-sodium diet. Similarly, Robert suggested Mrs. Dash is a good no-salt substitute for flavor. Indeed, these are two strategies other patients, such as Russell, could try out to ease the challenges of eating a low-sodium diet. More important, however, are Howard and Robert’s added assessments of the legitimacy of those alternatives. For instance, as Howard shared about using the crockpot, he explicitly called out the flavorful nature of the food, suggesting to others who might consider using this method that the crockpot helps maintain a low-sodium diet without a loss of enjoyment.

This example also demonstrates a re-appraisal of a perceived stressor. As discussed in the section on stressors, patients acknowledged restrictions and lifestyle changes as primary sources of stress. At this stage of the communal coping process, however, we see some patients reevaluate the severity of those experiences that were initially perceived as stressful until, through trial and error, they were able to successfully

adjust without completely cutting out the things that they once enjoyed before diagnosis.

In interviews, patients described others' reappraisals and positive changes as catalysts that motivated them to also make changes and try some of their peers' strategies. When I asked David during our interview to share about a memorable experience from attending SMAs, he discussed listening to one of the other patients in a previous session talk about the weight loss he had experienced from reducing his sodium and drinking more water:

You know, one gentleman there, at first when they were talking about his change in diet resulting in a dramatic weight change for him; he'd lost 12 pounds and I said, "I want to go sit next to him," and I listened to what he had to say about it and I learned a lot from him in that session as to what I needed to do when I went home; which was read those labels and look at things and make intelligent choices.

And David meant what he said. In the time between his second and third sessions, after hearing about his peer's changes, David lost 30 pounds of water weight as a result of changing his diet and taking his medications properly. By this stage, some patients began to make changes based on information received in earlier sessions. Essentially, they brought their experiences to the table and shared the outcomes of their changes, often telling tales of triumph as they noticed physical or cognitive changes. Witnessing these changes acted as a form of hope for others group members who saw that change and improvement were possible.

David's examples also highlight the trust patients place in the expertise of their peers. During our interview, Al described the lasting effects of peer advice due to the personal nature of the exchange:

Talking to these individuals in this small meeting, it stays with me. I might think about something that one of these people [patients] has said, three or four days later and go, Oh, yeah, that's what they meant by that. It's something I can actually use in my day-to-day life.

Al's comment came in response to my question about the differences he saw between traditional one-on-one medical appointments and the SMAs. Dorsey shared similar feelings when I asked him what he liked most about SMAs:

Especially like today when that the one guy's wife, she had all the little print outs of how much salt is in everything, that there. Cause I'm gonna go home today and have my girlfriend get on line and print those things out so I know exactly how much salt is in it... That way I can look at those, look at those flow charts and say okay, I can take, I can have this, and have this and it equal out to that much salt, so that's a good thing that I learned.

These comments suggest the information patients receive from their peers holds value and significance for them in managing their illness. Scholars in psychology would refer to this as social learning in which group members learn from the experiences of like others and begin to model similar behaviors (Bandura, 1977). Charlie's comment in our interview sums up how this process of social learning unfolds from a patient perspective:

I could see them [his peers] learning and I could see them feeling better. Some people came there with a lack of knowledge of some things and left from the class

knowing a lot more than they did when they first came in. And by them opening up like that ... enlightened me and I didn't feel as, I felt if I shared my feelings, I guess, of things that bothered me, I could get help from the group, by listening to what they had to say and today maybe try those suggestions.

Thus, patients felt empowered by witnessing their peers make successful changes. They came to a sense of hope that they, too, might be able to make changes to feel better.

Being on the sharing end of this experience also had an added benefit of empowerment. Patients began to see themselves as helpers rather than as victims of their illness – people with the capacity to encourage others to make positive changes. In SMAs, some patients viewed sharing their successes as a pro-social behavior that could benefit the collective. During our interview, JJ and his wife Sue explained the value of helping others:

Trisha: What about interacting with the other patients in the session; what do you think about that experience?

JJ: well it was all right, you know. If I can help somebody else, out of a jam, that's a cool thing. I don't mind that.

Trisha: Do you feel you've done that?

JJ: It's good to see, looks like he's [another patient] lost a little bit of weight since last time and he's cut down on the cigarettes and stuff like that, so that's a good thing. I help somebody get over a hump, that's fine. I like that.

Trisha: Yeah, how, how do you think you helped with that?

JJ: Just letting 'em know it wasn't all that hard to do. Just a matter of puttin' your mind to it and doin' it...just subtle hints, things that happened to me, you know.

Trisha: Okay, so you felt like you were able to help him?

JJ: Well, he did it himself, but you know, maybe I gave him an idea that it might actually work.

Trisha: Yeah. Okay. What does that do for you? To be able to kind of share your experiences or help somebody else?

JJ: Well, right away, if I help somebody else, I'm glad to do it. I said, if I didn't [help someone else] then, I wasted my time didn't I?

Trisha: Do you feel you wasted your time.

JJ: No. Not at all.

Sue: We're supposed to be our brother's keeper. If we can help get them through something a little easier than that's what we're supposed to be doing.

Here we see JJ and Sue assume the duty of helping others through difficult situations. JJ's comments suggest that, in witnessing someone change behavior because of his advice, he begins to feel better about his own circumstances, as though his past hardship was not in vain. Andrew shared similar sentiments during our interview after his final SMA session. One of his peers, Linda, the only female patient that attended SMAs during my observation, had directly asked for his advice about how to prioritize her heart failure over other health conditions. Andrew reflected on this experience when I asked him what he thought were the most valuable parts of attending SMAs:

Andrew: Well, I think that the, just the opportunity share and let people know what I've been through over the last four or five weeks. I'm sure that it helped one lady today in class, cause she said it helped, you know. So, if I can help someone else then it helps me, as well.

Trisha: That's a really great point. How, how does that help you, by helping her?

Andrew: Well, it gives me a sense of knowing that, you know, what I've been able to accomplish, maybe it will help her accomplish the same thing.

These examples highlight the idea that group discussion has the capacity to empower individuals through motivating others to make changes. The act of helping can allow patients to shift their identity to a position of authority rather than viewing themselves as a victim of their circumstances.

In summary, the collective action phase of the communal coping process in SMAs involves patients discussing methods of coping with heart failure. The facilitator plays an important role in initiating this discussion by using metaphors, a form of skilled conversation that encourages patients to shift away from discussing stressors and focus on collectively developing coping strategies and becoming empowered to manage their condition. Patients begin to take a more active role in this phase and assert more expertise than in previous phases of communal coping by sharing their own strategies with the group. Collective action, then, promotes coping through sharing strategies but also through empowering group members to reframe their experiences as they witness their peers succeed and improve their health. In the next section, I highlight a new phase of the communal coping process that extends Lyons and colleagues' (1998) previous work – communal reflexivity.

Phase Four: Practicing Communal Reflexivity

After engaging in the previous stages of the communal coping process (acknowledging shared identity, discussing shared experiences, and evaluating shared resources), patients and family members often discussed changes experienced as a result

of attending SMAs. This led to a final phase of communal coping that moves beyond the components described by Lyons and colleagues (1998). I refer to this phase as communal reflexivity, and it is characterized by reflexive dialogue as patients and family members talk about the changes they have noticed in their behaviors, health, and knowledge, and the affects of these changes.

Goodall (2000) described dialogue as a “rare” type of conversation that moves talk beyond “exchanges of information and the coordination of new understandings” to a higher level of understanding and insight among group members (p. 104). In action, dialogue has been described in the organizational communication literature as a reflexive practice that encourages individuals to reflect upon, question, and discuss their behaviors, attitudes, and/or assumptions (Barge, 2004; Cunliffe, 2002). As a communicative and relational process, reflexive dialogue invites individuals to critically make sense of their experiences and roles through verbalizing the relationship between their attitudes and their actions in a group context (Barge, 2004).

Through my observation, I found that reflexive dialogue stemmed from a process of invitational reflexivity. In his work on reflexivity as a managerial practice, Barge (2002) described invitational reflexivity as a moment when managers invite others into “conversations that appreciate and respect others’ moral logic” (p. 83). During SMAs, Dr. Jerome and Dr. Susie essentially invited patients to explore the “logic” they ascribed to their personal changes, improvements, and in some instances, past mistakes or misconceptions. In response, I found patients and family members reflected upon and critiqued changes in their physical health, levels of knowledge, and attitudes toward

illness. The following section illustrates the process of invitational reflexivity and reflexive dialogue in action.

Invitational Reflexivity and Reflexive Dialogue in Action

During their final SMA sessions, Dr. Jerome and/or Dr. Susie would invite patients and family members to reflect upon their experiences attending SMAs and to describe any changes they had made as a result of coming to the group meetings. Dr. Jerome and Dr. Susie would often do this by calling on a specific patient or family member. For instance, at the beginning of their final session, Dr. Jerome asked Dave and Pat, “what are you thinking about this being your last session?” In response, Dave reflected on how he used to feel very confused about his heart failure:

“It sucks!” Dave says in response to Dr. Jerome’s question.

“We still want to come!” Pat, Dave’s wife says. “Actually it’s kind of scary because we’ve been coming every two weeks and it kind of keeps you accountable. You know”?

Dr. Jerome asks Charlie if he has any thoughts.

“I kind of wish it would continue for a while too,” admits Charlie.

Dr. Jerome says it’s “pretty typical” for patients to feel sad when their sessions are over.

“Do you know why we feel that way?” Dave asks Dr. Jerome.

“No, please tell us,” Dr. Jerome responds.

“Cause for me this [heart failure] is all new. I never knew nothing about heart stuff, sodium levels, blah, blah, blah. But these classes have done some much for me. I mean educating me.”

Dr. Jerome asks John to summarize some of things he's taken away from these sessions in terms of taking care of his heart. John reiterates that he had not known the connection between fatigue and sodium consumption.

“And that's the scariest part. The unknown. And when you don't know nothing about this problem [heart failure], this helps so much,” John says, making a circular motion with his finger and pointing to the group.

Dr. Susie responds by asking, “And how empowered do you feel now in your fourth session? Do you feel more comfortable now than you did before?”

“Oh my god! Absolutely!” John interrupts. “I'm in control of my life. [laughing] We have control over my life,” he gestures to his wife Pat. “How much sodium is in that, John?” He says in a mocking voice as he look at Pat. She laughs and pokes him in the side with her finger.

“Now it's a way of life. Before I just took the pill and I didn't know why or how come, and I thought that would take care of everything. Learning all that that we know now I can carry out my life. I don't need another class here, but it's just helpful knowing that you can [attend another session]. It's like kicking the baby bird out of the nest. We can do good on our own. I know about sodium, I know about the excess weight, and the pills, and nutrition. Yeah, yeah, oh yeah! We're much more on top of things and I can control my life now.”

In this example, we see Dave, Pat, and Charlie call attention to the desire to keep attending the group sessions. For Pat, this desire stems from a concern of being less “accountable” in managing her husband's heart failure, suggesting the group members encourage them to actively conduct self-care. For Dave, the lack of knowledge about

managing heart failure is a scary prospect because he is “new” to the disease. Through invitational reflexivity, however, we see Dr. Jerome and Dr. Susie encourage Dave to explore how his levels of knowledge and ability to practice self-care have improved as they invite him to share about his experiences. As Dave reflects upon his previous deficiencies in knowledge, and calls attention to issues of sodium, nutrition, medication, and weight gain, he highlights his newfound understanding of the multifaceted nature of self-care and verbally acknowledges his own improvements. As Isaacs described (1999), dialogue helps individuals “reach new understanding and, in doing so, to form a totally new basis from which to think and act” (Isaacs, 1999, p. 19). For Dave, reflexive dialogue occurs as he verbally maps out the types of behaviors he needs to enact in the future to stay healthy. Reflexive dialogue, then, can allow patients to acknowledge new ways of thinking and acting (Barge, 2004; Cunliffe, 2002).

Furthermore, the facilitators’ specific questions encourage Dave to identify issues in his reasoning about the purpose of taking his medications. During my interview with Lynn, the dietician on the team who also functions as a documenter, she described Dr. Susie and Dr. Jerome as “guides” who help patients and family members better understand their condition. Through invitational reflexivity, then, patients are encouraged to express a heightened state of awareness. As Dr. Susie invited John to consider how SMAs had “empowered” him, John chose to highlight a new sense of control, suggesting a new insight to his role in managing his heart failure. John’s comments also point to an important shift in identity as he acknowledges that he and Pat can now leave “the nest” and draw on the resources they have obtained from the group setting.

In similar instances, invitational reflexivity led patients to recognize previous assumptions they had about their illness and acknowledge how those assumptions negatively affected their health and quality of life. At his final session, Dr. Jerome asked Howard to share with the group what he had learned while attending SMAs. Dr. Jerome's questions prompted Howard to describe the new insight he had about what led to his heart issues:

Dr. Jerome turns to Howard and asks him to share what he has learned.

“The one thing that I learned is, it wasn't the gigantic things that screwed me up. It was the tiny little insignificant things that didn't matter and I just kept stacking them up... It's not what you eat, it's not your attitude, the most important thing is to realize that everything that you do that's negative is what ...brought you into this hospital. That's what did it. Get off your butt and realize that what put you in this hospital... it's all those little tiny things.”

In this example, Howard acknowledges the role he played in his heart condition and critically reflects upon his responsibility for negative health outcomes. Similarly, Charlie described his own awareness of how his thoughts affect his actions:

“How has your fatigue improved, Charlie?” Dr. Susie asks him.

“I think it's improving. I just needed a little push. It's just that I'm letting, I'm guess I'm letting the spirit of the moment rule, instead of being like, 'alright Charlie, you don't need to set that snooze button again, just get your butt up.' If I do that I start feeling better.”

“Wow! Well it sounds like you've made improvements,” Dr. Susie replies.

“I don’t feel like I’m being limited by my heart problem. It’s more of a mental thing for me.” Charlie says.

Here, Charlie describes his awareness about the thought processes that make it hard for him to lead a more active life. In his previous SMAs, Charlie talked frequently about his constant state of depression and, at times, suicidal thoughts as a result of his condition and the death of his wife the previous year. In this moment of dialogue, however, Charlie acknowledges that he can change his way of thinking to encourage himself to get out of bed in the morning and overcome his fatigue. Further, his comments reflect his newfound belief that he can make a choice to change his attitudes and, subsequently, his behaviors. During my interview with Dr. Susie, I asked her to speak about the types of strategies she used to encourage patient “empowerment” during SMAs. She responded by saying:

By bringing it back to them and us not telling them [what to do], but them figuring it out on their own... you know like we had with Charlie... In the beginning he was very reluctant or not very engaged in the sessions and at this point, you know we’ve given him the tools and I guess comprehension of what he can do make himself feel better.

These examples illustrate how reflexive dialogue encourages patients to interpret, discuss and reflect upon the connections between their attitudes and behaviors.

Comments like the above examples suggest reflexive dialogue occurs as patients express self-awareness about the consequences of their cognitions and behaviors, but also acknowledge their own self-motivation and empowerment. In my interview with Nurse Sunshine, she labeled patients’ moments of increased self-awareness as their “aha moments.” Nurse Sunshine described, from her perspective, how this occurs:

They all have their “aha” moment. And everyone has it, like very vocally...all of a sudden you just like see it click for them... and then all of a sudden they’re big advocates for the class and everybody should do it and you get so much out of it and you should come and you’re gonna be fine. I don’t know anybody who really hasn’t had one. Like even the guy who only came to three sessions, and didn’t want to come at the end. He still had one [an aha moment], about his meds. And like why he had to weigh himself every day and take his meds.

For Nurse Sunshine, reflexivity occurs as individual patients begin to vocalize how their understanding of their illness has shifted. Her comments also highlight the individualized nature of invitational reflexivity and reflexive dialogue. I highlight these examples to demonstrate the individualized focus the facilitators are placing on patients through constructing these questions. This is significant because, in previous sessions, Dr. Jerome and Dr. Susie would often pose questions to the group or use metaphors and examples that applied to everyone. Near the end of SMAs, however, Dr. Jerome and Dr. Susie explicitly called attention to patients who were attending their final SMA sessions and directly asked them to share about their experiences. During our interview, Dr. Jerome described this as the “funnel technique” in which the conversation is started “far away from the person so that the spotlight isn’t on them” through using metaphors and inviting group conversation. Eventually, the “spotlight” gets pointed directly at individuals to invite to critique their own behaviors and develop their own conclusions. In speaking about the funnel technique, Dr. Jerome explained:

...that’s what then builds motivation and they’re more willing to buy in than me saying, ‘Come on Trisha, you can exercise!’... There’s been a lot of research that

when a person says the change, it's much more valuable than me saying it. For you to say why...I gotta watch my diet or I gotta watch my sodium. The chances of the change happening is way more effective.

From Dr. Jerome's perspective, then, reflexive dialogue encourages patients to acknowledge the importance of changes for themselves in order to be more motivated to continue practicing those behaviors. This is similar to the retrospective, social, and embodied process of sensemaking in which individuals communicatively piece together experiences to create a coherent whole (Weick 1995). As patients share their stories of change during their final SMA session, they make sense of the chaotic nature of illness as well as their own transformations in health. In their study of Alcoholics Anonymous attendees, Lederman and Menegatos (2011) found storytelling encouraged intrapersonal dialogue and self-awareness as individuals witnessed their own identity transformation through ordering their experience in story form (Lederman & Menegatos, 2011).

Aside from facilitating self-awareness and sensemaking, encouraging patients to engage in reflexive dialogue might also help them transition to managing stressors and engaging in problem solving on their own as they leave the group context. As Senge (1994) noted, "some of the most powerful contributions to a collective conversation can come from people who are learning to listen, not to the group, but to themselves" (Senge, 2004, p. 375). Thus, invitational reflexivity and reflexive dialogue during SMAs encourages critical self-awareness, personal empowerment, and motivation in patients.

In summary, communal reflexivity is a new phase of the communal coping process that I observed during SMAs. In this final phase, patients verbally express the improvements they have made in their health, behaviors, and attitudes, and they are able

to critically examine the positive and negative consequences of their choices. Facilitators use invitational reflexivity to explicitly encourage patients to acknowledge and verbalize personal change as a result of attending SMAs. Through reflexive dialogue, patients reveal a sense of personal motivation to practice self-care and improve their quality of life. I finish this chapter with a brief summary of the overall findings for this study.

Summary

In this chapter, I described the primary findings on the transactional nature of the communal coping process. I showed that communal coping for heart failure patients occurs in four distinct phases as they attend SMA sessions: communal coping orientation, discussing shared stressors, engaging in cooperative action, and practicing communal reflexivity. Collectively, these phases reveal the development of personal empowerment as patients work and communicate together to improve their health and quality of life. During each phase, providers use various forms of communication to facilitate group interaction, including situating the patient as expert, inviting patients to express their emotions, drawing on metaphors to encourage collective action, and inviting patients to practice self-reflexivity as they prepare to leave the SMA context. Overall, the findings show how patients and providers connect and communicate during each stage of the communal coping process. In Chapter Six, I discuss the significance of these findings for both the communal coping and SMA literatures. I also highlight and discuss potential future areas of study, limitations of the current research, and practice my own self-reflexivity by looking back at my fieldwork. To finish this dissertation, I provide practical suggestions for conducting applied government research in a health context.

CHAPTER 6

DISCUSSION AND CONCLUSIONS

Overall, the purpose of this study was to explore communal coping as it occurred in SMAs at the Phoenix VA hospital. In the first three chapters of this dissertation, I provided a review of the literature on SMAs and communal coping. This review revealed promising avenues for situated, observational study of both SMAs and communal coping to explore how the communicative and relational qualities of these experiences unfolded in interaction. In Chapter Four, I described the methods I employed to explore these avenues of study, and in Chapter Five I highlighted the predominant findings regarding the communal coping process as it occurred in SMAs. Thus, in Chapter Six I will reflect upon the significance of these findings and emphasize key contributions to the communal coping and SMA literatures. First, I provide a summary of the primary findings of this study and highlight how those findings attend to the research questions I proposed in Chapter Three. Second, I discuss how the findings of this study complicate and extend our knowledge of the communal coping process, and I provide a visual representation of the process model of communal coping. Third, I discuss how this study contributes to our understanding of the SMA experience. In both of these sections, I also consider opportunities for future research. Finally, I engage in self-reflexivity by highlighting the lessons I have learned through conducting applied health communication research.

Attending to the Research Questions

Given the paucity of research on both the communal coping process and the communicative features of patient-provider interaction during SMAs, I proposed broad research questions to enhance our understanding of these experiences. Through my

research on heart failure SMAs at the Phoenix VA hospital, I sought to answer two primary questions: How does the process of communal coping unfold among group members during shared medical appointments? And how do medical professionals facilitate the communal coping process during shared medical appointments? My analysis attempted to shed light on the various phases of the communal coping process and how this process unfolds communicatively among group members. Through observations, I found the communal coping process, in the context of heart failure SMAs, unfolded as a series of four distinct phases. Furthermore the communal coping process occurs through a variety of types of talk, ranging from phatic communication to dialogue. The providers who moderated SMAs also played an important role in facilitating the communal coping process among patients and family members. The sections below provide a summary of the findings and also highlight the answers to my research questions.

How the communal coping process unfolds. The first phase of the communal coping process involved establishing a communal coping orientation among SMA group members. Lyons et al. (1998) described a communal coping orientation as the belief, held by at least one group member, that coming together to cope with a shared stressor is beneficial. In phase one, providers took a central role in establishing a communal coping orientation by describing the benefits of SMAs before and during patients' first SMA session. Phase one also helped established a common shared identity because patients were invited to provide details about their stories of diagnosis. Diagnosis stories helped to centralize the experience of illness and encouraged patients to recognize their shared identity as patients of heart failure. Shared identity was also established through labeling both patients and providers as "experts." My findings suggest phatic communication,

which serves to establish relational rules and roles (Goodall, 2000), is a primary type of communication used to promote a communal coping orientation by helping group members establish common ground through their shared condition.

The second phase of the process involved discussing shared stressors. During this phase, patients often focused on discussing the difficulties of adapting to the lifestyle changes associated with chronic illness and expressing their emotional reactions to these changes. Patients primarily expressed their emotions through venting and mourning, which often triggered mutual self-disclosure, or chaining, in other patients. Through this process, patients began to acknowledge their shared experiences and perceptions of stressors. This process is known as a social appraisal where group members perceive of the stressor as “our” problem (Lyons et al., 1998). Through emotional expression and social appraisal, patients recognized they were “not alone” in their experiences. In my interviews, many patients highlighted the value of acknowledging shared appraisals of the stressors of heart failure. My findings also suggest this phase of the communal coping process is predominantly characterized by ordinary conversation, or “patterns of questions and responses” that provide group members with information about personal and collective concerns and allow them to analyze those concerns (Goodall, 2000, p. 103). Patients were able to acknowledge and analyze their primary concerns through sharing their emotions and discussing shared stressors.

The third phase of the process involved engaging in cooperative action to share resources. Cooperative action is described as the active part of the communal coping process in which group members collectively pool resources to manage stressful situations (Lyons et al., 1998). In this phase, patients discussed and shared personal

strategies they used to cope with heart failure. As they discussed these strategies, patients began to re-appraise the severity of their condition through sharing personal successes and identifying alternative ways of successfully living with, and managing, heart failure. Additionally, patients became empowered through the experience of problem-solving with their peers. In interviews, patients described the motivating power of learning from their peers' successes and they described feeling motivated and empowered to make their own changes. Similarly, patients who shared about their successes felt empowered by their ability to help their peers become healthier. The phase of cooperative action was characterized by skilled conversation as patients identified priorities for leading a healthier lifestyle and arriving at a shared conclusion that they have the abilities to successfully manage heart failure.

Finally, the fourth phase of the communal coping process involved engaging in communal reflexivity. During this phase, patients reflected upon their newfound abilities to cope with heart failure. Through reflexive dialogue (Barge, 2004; Cunliffe, 2002), patients were also encouraged to engage in self-critique as they considered the changes they had made to their health behaviors and knowledge as they attended SMAs. Facilitators invited this process of reflexivity as patients attended their final session. Through reflexive dialogue, patients were provided with a platform to make sense of the group experience and publicly acknowledge improvements to their own motivation and ability to successfully manage illness. Patients also expressed heightened personal awareness as they identified the links between their thoughts and actions as they worked toward becoming healthier individuals.

How providers facilitate communal coping. Through my observations, I noted the central role of providers in facilitating group interaction that constituted communal coping – something that has not been a focus of past communal coping research (Afifi et al., 2006; Lyons et al., 1998). In the context of heart failure SMAs, communal coping unfolded as a process that was regularly facilitated by the medical team. Through each phase, the SMA facilitators used various communicative strategies to encourage patient involvement and communal coping.

First, providers created a space that encouraged patient involvement by situating patients as “experts,” both in the labels they explicitly ascribed to patients and in the design of the seating arrangement (Noffsinger et al., 2003). Patients were also encouraged by providers to share and speak early on in their attendance at SMAs as they were invited to tell stories about their heart failure hospitalizations and diagnoses. This process of sharing encouraged group members to recognize their shared identity as well as establish and reinforce a communal coping orientation.

Second, providers encouraged patients to discuss the challenges of living with heart failure and to express their emotions surrounding those experiences. Providers encouraged this group discussion through an open-ended question and answer format (Goodall, 2000) that invited patients to respond to one another’s experiences. This process encouraged patients to acknowledge shared stressors as well as verbalize their shared appraisal of those stressors. Acknowledging shared experiences is a key part of the communal coping process (Lyons et al., 1998), and this case demonstrates the powerful role providers have in creating this acknowledgement. Providers also responded to

nonverbal behaviors that indicated personal distress by inviting patients to verbalize their emotions. This further encouraged group discussion of stressors.

Third, providers drew on metaphors and hypothetical stories that served as centralized experiences that all members of the group could understand and discuss. Through talking about these metaphors and hypothetical stories, and the characters embedded within them, patients identified their collective skills and knowledge to draw upon in coping with heart failure. Providers also encouraged patients to draw on their personal expertise to help the other members of the group. This promoted feelings of empowerment (Anderson & Funnell, 2010) and broadened patients' repertoire of coping skills.

Finally, providers invited group feedback and self-reflexivity near the end of the communal coping process. As patients prepared to leave the SMA context, providers created a space for patients to reflect upon and verbalize their changes and witness the transformation of their peers. Providers used invitational reflexivity to encourage patients to engage in sensemaking (Barge, 2004; Cunliffe, 2002) about their experiences attending SMAs and to acknowledge their newly formed skills for coping. This provided patients with the opportunity to verbally express a sense of empowerment and heightened self-awareness (Anderson & Funnell, 2010).

In sum, with regard to the research questions, the communal coping process unfolds as a series of four phases involving distinct interactive processes, and the SMA moderators play a central role in facilitating each phase of the communal coping process through specific communicative techniques. Aside from addressing the research questions, however, the findings of my study usefully extend our understanding of

communal coping and the experience of SMAs in a number of ways. In the next sections, I highlight the significance of the findings of this study as they relate to, extend, and complicate past research.

Communal Coping: Contributions and Implications

In Chapter Three, I summarized the current literature and previous conceptualizations and models of communal coping. This summary revealed the relative infancy of communal coping research, overall. Although past research has described communal coping as an interactive, transactional process (Afifi et al., 2006) that involves the pooling of resources among individuals who share a common stressor (Lyons et al., 1998), scholars have yet to observe how the communal coping process occurs in context. Instead, past scholarship has largely sought to distinguish communal coping from individual forms of coping and social support and has emphasized the general features of communal coping (Afifi et al., 2006; Berg et al., 1998; Lyons et al., 1998). The current study, however, extends our understanding of the communal coping process in a variety of ways.

First, this study shows how the communal coping process unfolds communicatively among group members in context. Previous research has provided little insight to the specific types of behaviors that socially construct the communal coping experience for group members (Afifi et al., 2012; Lyons et al., 1998; Rohrbaugh et al., 2012). The findings of this study add to the literature by providing a detailed account of the communicative features of communal coping at each phase of the process. My findings show the variety of types of talk, ranging from phatic communication to dialogue (Goodall, 2000), that constitute the process of communal coping. These findings

complicate past communicative conceptualizations of communal coping that have emphasized “we-talk” as a primary communicative indicator of communal coping (Afifi et al., 2006; Lawrence & Shiller Schigelone, 2002; Rohrbaugh et al., 2012). “We-talk” occurs when individuals use the word “we,” or “first-person plural pronouns... as an implicit marker of communal problem-resolving processes” (Rohrbaugh et al., 2012, p. 108). However, the current study shows group problem-solving processes are also marked by the use of shared metaphors and hypothetical stories. The use of “I-language” in the form of personal success stories also signified communal coping as individual group members sought to motivate and encourage their peers by sharing personal triumphs.

Furthermore, the results of this study describe specific acts of communication that occur among social actors during each phase of the process. For instance, a communal coping orientation in the context of SMAs is established through explaining the value of group interaction and clearly designating roles. Further, patients discuss stressors by expressing the emotional challenges of heart disease and engaging in mutual self-disclosure. These specific communicative features have not been described in previous communal coping research. Although Lyons et al. (1998) provided a list of the key components of the communal coping process (i.e. communal coping orientation, shared stressor, cooperative action), their original model did not provide clear explanations of how each of these components occurs in context.

Additionally, as I described in Chapter Three, research extending Lyons et al.’s (1998) work has largely used quantitative assessments to measure the outcomes of communal coping and/or used interview and focus group data to invite members to

describe how they have coped with close others (Afifi et al., 2006; Afifi et al., 2012; Koehly et al., 2008; Rohrbaugh et al., 2012). Participant observation in the current study, however, has helped illuminate the embodied process of communal coping. Specifically, this study has shown communal coping involves emotional expression that occurs as members collectively vent and mourn, and social appraisal, in which group members perceive of a stressor as shared (Lyons et al, 1998), is developed through the process of chaining as group members practice mutual self-disclosure. Additionally, participant observation in this study revealed cooperative action occurs through individual and collective storytelling as members attend to various metaphors and hypothetical stories. Thus, my findings further shed light on the transactional (Afifi et al., 2006), communicative features of the communal coping process.

Second, this study shows that communal coping can occur in groups outside of family or spousal relationships. In past research, scholars have predominantly conceptualized communal coping as an act that occurs in close personal relationships in which individuals share a history as well as relational obligations to help one another cope through challenging life circumstances (Afifi et al., 2006; Berg et al., 1998; Lyons et al., 1998). The findings of my study, however, show the capacity for individuals who lack a shared history to engage in communal coping. For instance, patients and family members attending SMAs explicitly noted their desire to share their experiences and circumstances for the purpose of helping the group. This finding is significant to the communal coping literature because it expands the types of contexts and relationships in which communal coping might be explored.

Additionally, the findings of this study show that communal coping can occur as a facilitated process. As demonstrated in Chapter Five, the facilitator was responsible for helping group members arrive at a social appraisal and cooperative action. These findings extend past communal coping research that has focused on communal coping as unfolding as an organic, emergent, and ongoing response to stressors among close relational partners (Afifi et al., 2006; Lyons et al., 1998). Specifically, it shows that communal coping also unfolds when a leader helps facilitate group interaction and the coping process. Furthermore, the findings suggest the facilitator can also help prevent the potentially negative consequences of communal coping and group interaction, such as co-rumination (Boren, 2013), by redirecting the conversation and motivating members to engage in cooperative action when they begin to dwell on personal hardships. As such, facilitators not only encourage communal coping to occur among those who lack a shared history, they can also help prevent group dissent and negative feedback loops that might inhibit the communal coping process.

Finally, the findings of this study show that the communal coping process also includes an additional element of sensemaking, which extends and complicates previous models of the communal coping process (Afifi et al., 2006; Berg et al., 1998; Lyons et al., 1998). Whereas past models have only emphasized three primary components of communal coping (e.g. communal coping orientation, discussing shared stressors, cooperative action) (Afifi et al., 2006; Lyons et al., 1998), the current study shows the presence of an additional fourth component that I label communal reflexivity.

During the final phase of the communal coping process in SMAs, patients practiced self-reflection and self-critique regarding their experiences attending group

sessions. Through reflexive dialogue (Barge, 2004; Cunliffe, 2002), patients critically examined the changes they had made in their health, behaviors, and attitudes. The significance of the communal reflexivity phase, then, is to provide an opportunity for group members to concretize and verbalize the value of the communal coping experience and acknowledge what they have learned as a result. In essence, patients can make sense of the coping process as they chronicle the changes they have been able to make since their first sessions. Sensemaking, in past research, has been described as an embodied, social, retrospective process that allows individuals to organize their experiences (Sharf & Vandeford, 2003; Weick, 1995; Weick, Sutcliffe, & Obstfeld, 2005). This sensemaking process reveals two important additions to the conceptualization of communal coping.

First, findings in the communal reflexivity phase suggest communal coping unfolds as a process of embodied learning. Past conceptualizations of communal coping, and coping in general, have not viewed the process of coping as a learning experience (Afifi et al., 2006; Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984; Lyons et al., 1998). In the current study, however, we see individuals learn not only about their illness, but also how their actions and attitudes affect their perceptions of illness. In her work on management training and reflexive dialogue, Cunliffe (2002) provided a detailed definition of the learning process:

Learning may therefore be reframed as an embodied (whole body), responsive understanding in which we are ‘struck’ and moved to change our ways of talking and acting: an embodied rather than purely cognitive understanding...being struck is an anticipation of unfolding understanding, of making new connections between tacit knowledge and explicit knowledge as we construct our sense of

situations in ways not visible to us previously... by exploring and articulating feelings and features from within the experience. In doing so, we may question and construct new possibilities, new ways of talking and acting. As such, 'being struck' offers an opportunity for learning, for making sense as we work through the experience. (p. 42)

In considering this definition in relation to communal coping, SMA patients come to understand their newfound abilities to cope with heart failure as they practice self-reflexivity in the group setting. They begin to question their assumptions by verbalizing the cognitive patterns they once had about their illness, and they acknowledge "new possibilities" as they describe the changes they have been able to make as a result of attending the group sessions. Thus, as patients engage in communal reflexivity, and are "struck" by the experience of communal coping, they produce new understanding about their illness and abilities to cope successfully in the future. For example, during communal reflexivity, patients would emphasize how the knowledge they obtained from the group allowed them to feel more capable of practicing self-care. These feelings of self-efficacy also point to the second element of the communal coping process – empowerment.

Aside from conceptualizing communal coping as a process of embodied learning, this study shows that communal coping unfolds as a process of empowerment (see Figure XX for a conceptual model). Through reflexive dialogue, patients revealed an increased sense of empowerment to effectively cope with heart failure. Patients described having a better understanding of their disease, and also shared that they felt more equipped to address the psychological and emotional challenges of having a terminal illness. The term

empowerment was first popularized by Paolo Freire to describe the value of education and group dialogue in helping individuals think critically about their worlds and take an active part in transforming their own realities (Freire, 1970). Since then, empowerment has been further defined in the psychology literature as a community process characterized by critical reflection and group interaction in which people gain greater control over their lives (Perkins & Zimmerman, 1995). As patients in the SMA community work through each phase of the communal coping process, they become empowered by the experience of learning from one another and about themselves.

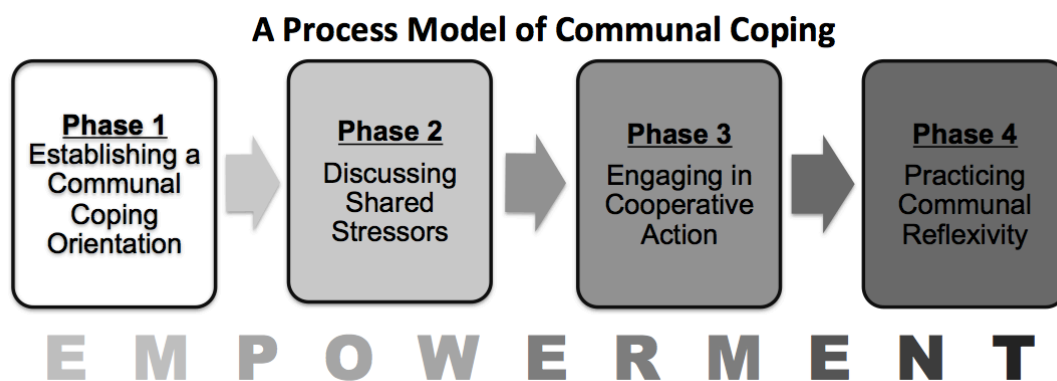


Figure 5. A visual process model of communal coping.

Collectively, framing communal coping as an embodied process of learning and empowerment complicates previous conceptualizations of communal coping. Past models have primarily described the various forms of coping to distinguish individual from social coping (Afifi et al., 2006; Berg et al., 1998; Lyons et al., 1998). The current study, however, highlights the process-oriented nature of communal coping by showing how communal coping unfolds over time among social actors (see Figure XX for the process model of communal coping). From the perspective of the current model, communal

coping involves more than the act of discussing stressors and engaging in collective problem solving as the original model emphasizes (Lyons et al., 1998). Rather, the current model suggests communal coping involves an ongoing process of learning that generates feelings of empowerment and, subsequently, motivation to actively cope with challenging issues as group members move through each phase of the process.

Collectively, these contributions point to potential areas of future research. Because of the applied nature of the current study, I employ “parameter-setting language” to highlight future research, further connect context with theory, and to identify the “usefulness of theory in describing, predicting, or explaining broadly conceived social phenomena *except when* or *especially when* [emphasis in original] the theory is applied to general context classifications” (Keyton, Bisel, & Ozley, 2009, p. 155). As such, I highlight three primary areas of future research that scholars might find fruitful.

First, the results of this study demonstrate a communal coping framework describes how individuals who lack a shared history engage in social coping practices, *especially when* a trained expert facilitates the coping process. As such, other facilitated contexts, such as health-related support groups, might also benefit from a communal coping framework because individuals who join a support group often lack a shared history, but share a common condition (Beck & Keyton, 2014). Although recent studies have sought to demonstrate the intersection between support groups and a communal coping framework (Cripe, 2010), unlike the current study, the majority of support group research has foregrounded a social support perspective (Goldsmith & Albrecht, 2011). A communal coping framework, however, might further complicate how group members in a support group setting work together to cope with collective issues. Specifically, a

communal coping lens might explain why some support groups are more successful at helping individuals manage difficult situations than others. Past social support literature has noted the inconsistencies in the achieved health benefits of support groups (Helgeson, Cohen, Schulz, & Yasko, 2000; Hogan, Linden, & Najarian, 2002; Wright et al., 2011). Additionally, scholars who study communal coping should continue to study how medical professionals, community leaders, and/or family members facilitate the communal coping process. An understanding of such a process could shed light on foundational strategies or practices that encourage successful communal coping in various contexts, especially within groups who lack a shared relational history. Because communal coping has been traditionally studied in the context of close personal relationships, future scholars should also seek to understand if communal coping is a facilitated process within families and spouses. How, if at all, does “facilitation” occur when all members of a group or dyad share a relational history? An understanding of the facilitated nature of communal coping can be achieved through continued observational study of group interaction in families, spouses, and non-naturally occurring groups.

Second, the results of this study show a communal coping framework helps describe the social experience of coping *except when* communal reflexivity or sensemaking occurs. As noted earlier in this chapter, the current study is the first to highlight the communal reflexivity phase and sensemaking experience of the communal coping process. Future scholars, then, should explore how, if at all, individuals engage in communal reflexivity and sensemaking as part of the communal coping process, and what value this phase of the process holds for group members in families and non-naturally occurring groups. This could be accomplished if researchers conducted

observations of families or support groups and they engaged on communal coping. Further research on the value of communal reflexivity could also be achieved through conducting follow-up interviews with family or group members who display this type of communication. Scholars might ask questions such as, “how would you describe your experience discussing the changes you have made while attending this group?” Or, “how does it feel to share with your family/group members the accomplishments you have made in managing the stress of your shared condition?” Answers to these questions could further expand upon the concept of self-reflexivity as it pertains to communal coping and explore if this is a practice that other types of groups engage in.

Finally, the results of the current study show a communal coping framework explains how individuals become empowered by the social experience of coping, *except when* they leave the group context. Regardless of whether individuals engage in communal coping with strangers, spouses, or family members, there might be times when they are forced to cope on their own. As such, future research should continue to explore how, if at all, various features of communal coping empower individuals to cope beyond the group context. The current study did not engage in follow-up interviews or observation to explore how individuals maintained feelings of empowerment once they left the group setting. Thus, future research could benefit from longitudinal work that tracks how, if at all, individuals continue to practice communal coping methods when they are coping in an isolated context or unable to practice communal coping due to distance, or loss of family or group attachment. An understanding of the long-term benefits of communal coping might provide further support for the value of group interaction around stressful life experiences.

Shared Medical Appointments: Contributions and Implications

In Chapter Two, I provided a review of the past research on shared medical appointments. This review revealed an absence of research on the communicative and interactional features of the SMA experience and demonstrated a clinical emphasis on measuring the biomedical outcomes of SMAs and quantifying the patient experience through satisfaction surveys (Dickman et al., 2012; Jaber et al., 2006). Although these findings have demonstrated the relative value of SMAs in improving patients health knowledge and medical satisfaction, scholars have pointed to the need to understand *how* and *why* patients experience positive outcomes (Bartley & Haney, 2010; Berger-Fiffy, 2012; Edelman et al., 2012). In this section, I highlight how the findings of this dissertation contribute to our understanding of shared medical appointments.

First, on a broad level, the findings from this study show how individuals (e.g., patients, family members, and providers) interact and communicate during SMAs. These descriptive findings add to the past SMA literature by highlighting the communicative features that construct SMA interaction, an area of study that past SMA scholarship has not explored (see Edelman et al., 2012 and Jaber et al., 2006 for a review of past SMA scholarship). More specifically, this study shows how providers facilitate group interaction during SMAs and encourage peer-to-peer support. For instance, the current study shows providers who facilitate SMAs draw on a range of communicative tools, including open-ended questioning, responding to nonverbal behaviors, using metaphors, and explaining the role of the patient, to promote patient involvement. Past health communication research has extensively explored patient-provider communication in traditional one-on-one appointments, but not in a group medical setting (see Duggan &

Thompson, 2011 for a review). This study suggests many of the patient-centered communication strategies, specifically discussing roles and responsibilities, responding to and validating emotions, inviting patient involvement, and sharing information, that have been used in a traditional medical appointment (Epstein & Street, 2005) can be successfully transferred to a group setting and used to encourage patient involvement in the medical encounter, promote group cohesion, and facilitate peer-to-peer interaction. Whereas past SMA research has emphasized the medical outcomes of SMA interaction (Edelman et al., 2012; Jaber et al., 2006; Scott et al., 2004; Masley et al., 2001), the findings of this study complicate past SMA research by showing how providers explain roles and responsibilities, draw on a question-and-answer format to encourage patient involvement, and share health information through metaphors and hypothetical stories to facilitate the SMA process from start to finish. The results also suggest the combination of these communicative strategies contribute to valued health and behavioral outcomes in patients.

Furthermore, the current study shows that patients provide peer-to-peer support by validating each other's emotional responses to, and lived experiences with, chronic illness and through engaging in mutual self-disclosure. Past SMA research has suggested peer-to-peer support is an important feature of SMAs that improves patient satisfaction (Berger-Fiffy, 2012; Bronson & Maxwell, 2012; Cohen et al., 2012). However, scholars have not conceptualized how peer support actually occurs during SMAs. Thus, the findings of the current study show how peer support occurs in action. Further, the results suggest peer support begins as a process that is encouraged and facilitated by SMA providers, but is carried out by patients as they openly share about their experiences.

Finally, the results of my study suggest that patients become empowered through recognizing shared hardship among peers, helping one another reframe the severity of illness by sharing success stories and strategies, and verbally acknowledging personal improvements as a result of group interaction. In other words, patient empowerment through SMAs comes from addressing the psychosocial challenges of chronic illness, rather than solely addressing the improvement of biomedical knowledge. This is important to note as past SMA research has predominately measured disease-specific knowledge as an indicator of the success of SMA intervention (Edelman et al., 2012; Jaber et al., 2006; Masley et al., 2001). The findings of my study show, however, that patients place more value on the opportunity to identify, discuss, and address the stressors and emotional hardships of chronic illness, and connect with individuals who share their same condition, rather than solely gain knowledge about their disease or spend more time with provider as past research has suggested (Berger-Fiffy, 2012; Dickman et al., 2012; Sikon & Bronson, 2010).

Collectively, the findings of the current study point to potential future areas of SMA research. First, this study shows the vastly rich and complex communicative landscape that socially constructs the SMA experience. As such, I implore health communication scholars to further explore how the group medical process is communicatively constructed and facilitated. Also, scholars should seek to understand the SMA experience from a variety of perspectives to highlight the various features of the group context that offer value to all constituents, including patients, providers, and family members. As previous scholars have acknowledged, little is known or understood about the experience of patients or providers in the SMA context (Edelman et al., 2012).

Findings in this area of research could help further refine the SMA model and enhance patient and provider satisfaction.

Second, given the importance of peer support and interaction during SMAs, as demonstrated by the current study and past research (Cohen et al., 2012), scholars should seek to understand the specific types of peer support that provide patients with the most benefit during SMAs. This study would suggest that emotional support is an important element of the SMA experience for heart failure patients. However, a study that looks at SMAs for less life-threatening or chronic health conditions, such as pregnancy, might suggest informational support is more valued. Understanding the differing roles of peer support could be achieved through continued observational research coupled with patient interviews and behavior-specific satisfaction surveys.

Understanding the types of peer support patients find most valuable could also shed light on the strategies providers should employ while facilitating SMAs. Additional research should explore provider characteristics that lead to successful SMA facilitation. This study suggests the ability to recognize and respond to emotional cues, encourage group interaction, and reframe stressful experiences lead to successful facilitation. Given the central role the medical provider plays in facilitating the SMA experience and encouraging group cohesion, understanding positive provider characteristics and skills could encourage the development of future SMA training. Aside from provider qualities and characteristics, however, future SMA research should seek to understand the long-term benefits of peer support and SMA intervention. Although I witnessed patients make positive changes throughout their four SMA sessions, future longitudinal work could help shed light on how, if at all, patients continue to successfully manage the stressors of

chronic illness after they leave the group context. In the next section, I reflect upon my time in the field and offer practice suggestions for future government and applied researchers.

Lessons Learned: Reflections on Applied Research

The black sign reads Building 21 in bold white letters. “I’m in the right place,” I think to myself. As I walk toward the non-descript white stucco building, I catch my reflection in one of the doors. The doors of the building are covered in a silvery reflective film, which I suppose is intended to block out the hot desert sun. Or could it serve a more serious purpose, like blocking radio signals? I may never know. I’m here to get my CPRS access codes. I walk through the doors, round the corner, and lightly tap on the first office door. As I wait for an answer, I scan the area around me. The hallways are bare white with harsh overhead fluorescent lighting. From where I stand, I can look down two short, identical corridors. All of the doors are closed and most likely locked. I’m here to meet Joe.

Suddenly, Joe swings open the door. The overhead lights glint off his bald head.

“Hey! We’re going over here,” he says in a clipped, gruff voice. He’s wearing a camouflage t-shirt and a yellow lanyard around his neck with his credentials attached at the end. His ID card swings from side to side like a pendulum as he walks quickly out of the office and makes a beeline for the adjacent door. Grabbing the ID at his chest, he holds the card to a white pad on the wall and a small light turns green. The door audibly clicks open and we walk down another bland hallway and stop at another nondescript door. Joe uses his key card again to open the door.

“I’ve got to get your codes. They’re locked up.” I start to follow him, but he barely opens the door wide enough for his thick body to slip through. I pick up on the hint – I’m not allowed in this room. As the door shuts behind him and locks, I catch just a glimpse of wall-to-ceiling gunmetal gray filing cabinets.

Joe abruptly opens the door after what seems like mere seconds holding a sheet of white paper in his hand. He makes a “follow me” motion with his hand and leads me down the hallway to a small room of workstations with computers.

“Ok, log in,” he says, and points to a computer in the corner of the dimly lit room.

I pull out my phone, which now holds a list of various codes and passwords I have been unable to keep track of in my head. I’m sure this could be considered a security hazard if my phone ever fell into the wrong hands, but I’m willing to take the risk to expedite a few processes.

Joe stands near the hallway entrance with a wide stance, his beefy arms folded across his chest – the ultimate power pose. He glances back and forth down the hallway and back to me as I wait for my credentials to be verified by the computer system. This is never a quick process.

I look at Joe from across the room. “How long will it take for me to show up in the system?” I ask.

“You should be up and going within minutes once you log in,” Joe says.

“Wow! I’m actually really surprised by that. It seems like everything else seems to take forever,” I admit.

He chuckles lightly, but it’s a laugh of exasperation. “That’s the VA way,” he says, as he rolls his eyes.

I smile. “You know, I keep waiting for you to tell me that you’ve actually been recruiting me for some secret government operative position and that the first part of the process is to test my resilience to see if I can cut it. I had no idea I’d have to go through this much work just to do my research.”

Joe shakes his head as he readjusts his power stance. “I know. Crazy, isn’t it?”

This dissertation, like most dissertations (I assume), was a labor of love. I fully expected to be challenged by the process from start to finish, and I was prepared to spend months of my life mulling over the details of my fieldwork, tirelessly producing draft upon draft, and agonizing over semantics. What I was not prepared for, however, were the rigors of government research. The story above came from my fieldnotes in which I chronicle the experience of getting my “access codes” to enter the clinical records system to record patients involved in the study. The story highlights the seemingly clandestine nature of operating within the VA system. Aside from chronicling my observations during SMAs, I recorded moments such as these to capture the experiences of conducting government research.

To be clear, though, this was not just any government research. This was government research during a time of crisis. On April 23, 2014, about one month after I received IRB approval for my study, the Phoenix VA hospital made headlines when CNN published an article claiming close to 40 veterans had died while waiting for medical care (Bronstein & Griffin, 2014). Dr. Sam Foote, a retired physician from the Phoenix VA, reported that the hospital administration had falsified patient wait time records and created a “secret waiting list” to hide the names of close to 1,600 Veterans awaiting care.

These allegations launched an investigation of the entire Veterans Affairs Health Care System and revealed a history of fraud. Indeed, I began my research at the VA system when it was the most vulnerable and under public and legal scrutiny. Aside from entering the scene at a time of crisis, however, was the added challenge of studying the privacy-laden culture of the medical world.

Many health communication scholars face challenges gaining access to the clinical context; there are strict laws and regulations in place that protect patient privacy and security. But gaining access to a federally funded, nationwide medical system proved to be a whole different battle – and I was not battle-ready. My academic training had not prepared me for the hours of privacy trainings, lengthy background checks, informed consent audits, and mountains of paperwork that I would need to complete during my time in the field. In this context, fieldwork often gave way to paperwork.

In truth, my academic identity and credentials afforded me no free passes and, in some cases, made the process more difficult. I was straddling the line between insider and outsider trying to learn two different languages for research design. When I decided to do my dissertation at the VA, I simply had no idea how many miles of red tape separated me from my research. And, so, in an attempt to make the most out of a challenging situation, I offer some insight and suggestions for current and future scholars who hope to develop successful research partnerships outside of the academy, especially in the realms of healthcare and government work.

Plan for Delays

Government work, in general, is not quick work. “Red tape” in the form of excessive bureaucracy is not a stereotype, but a reality. This means government research

is not a quick process either. There were several unexpected delays that came up in the process that had not been present in my previous experiences with research. First, gaining access involved getting permission from not only the resident gatekeeper, but also from the government. In order to access all of the necessary systems I would need to eventually conduct my research, I had to complete a background check and fingerprinting, and receive the appropriate credentials to become a “without compensation employee.” These credentials included ID badges, access codes, and passwords. I also had to complete multiple mandatory government and research-oriented online ethics training modules on a yearly basis.

Once I had completed necessary training and credentialing (a process that took more than a month), I was informed by my VA colleague that we needed to begin the IRB application as early as possible because it would take at least two months for approval. It actually took longer – three months from the time we started writing the application until the date we received official approval. This was because the VA IRB holds a monthly review process rather than the rolling review process that typifies the academic IRB system. Thus, every detail of the study (including consent forms and drafts of the interview protocol) needed to be written and submitted before the designated submission date. We would then need additional time to make revisions, if necessary, before resubmission for final review to receive approval.

My tip, then, is to extend the anticipated timeline for your study by a minimum of six months. This allows for the necessary front-end work of gaining access and becoming established in the system. These experiences also point to the importance of asking about training and access procedures before deciding to conduct research with an organization.

Gather as much information as you can from organizational insiders and gatekeepers before you plan to conduct your research in order to avoid further delays in the process.

Follow the Rules

Government research is heavily laden with legalese and strict expectations for “following proper procedure.” I was warned early on that making a mistake and failing to follow the rules could be punishable by law. I could also be at risk for being stripped of my research rights, denied access to my data, and if serious enough, prosecuted. These warnings were certainly enough to make me want to follow the rules. Unfortunately, as all researchers do at one point or another, I made a mistake.

During the first week of recruitment and consenting, I realized the consent form was invalid because a required approval date had not been included on the form. I spoke with my contact at the VA IBR office who thanked me for bringing the issue to her attention and within a couple of days sent me the correct copy. But what was I to do with the signed, incorrect forms? I didn't ask. I didn't think about it. Instead, I decided the best thing to do was to re-consent those patients who had signed the incorrect form, have them sign the new form, and then shred the old documents at the VA. I thought I was being careful and smart in doing this, rather than hold on to the invalid documents. I found out later, however, that this was considered a “serious violation” (as the head clinical researcher put it) because I had “destroyed government documents.”

Luckily, I did not receive any major penalties because this was a first offense and I was new to the process. But a report of this violation and destruction of records was filed for investigation and sent for review by the VA-wide research agency in Washington, D.C. One colleague referred to this branch as “the big bad wolves” of

research in the VA. In response, I had to answer several questions over the phone and write a lot of emails to explain, confirm, describe, and retrace my steps in making that decision before the issue was finally considered resolved.

In retrospect, my best course of action would have been to contact someone in the research office to ask advice on the proper procedures before doing anything with the invalid documents. This would have likely saved me, and others, a great deal of time, energy, and anxiety. My suggestion, then, is to contact your IRB representative to ask advice on proper procedures. Although asking the question might reveal a long, drawn-out procedure that you need to follow, it is certainly better to follow procedure than to go rogue and suffer the consequences. And, remember, time is different in the VA system (see Lesson One), so there may be delays before the situation is resolved. Act early, then, and notify the appropriate people of mistakes as soon as possible.

Be Flexible

Along with the time challenges of government research, I learned quickly that in order to conduct qualitative medical research I needed to be flexible and patient. The VA system, in general, is an overburdened medical system. This translated into constraints on resources, time, personnel, and space. As a researcher, I was affected by these constraints in terms of when and where I could conduct interviews, listen to audio data, read transcripts, or even sit down to record my fieldnotes. Additionally, once patients left the VA facility and were no longer attending the sessions I was observing, I could not be in contact with them. I also could not remove data from the facility, or meet with interviewees off campus.

This meant flexibility was a necessity to conduct my research. Thus, I remained flexible by taking office space wherever and whenever it was available. On many occasions, I sat at the desks of VA employees who were out of the office for the day. I also pleaded with colleagues to let me borrow their office chair or computer when it wasn't in use, even if it was only during their lunch break. I also condensed my interview guides to address only the most pertinent questions so that I could get patients in and out of an interview within a short amount of time, especially if they had other medical appointments they needed to attend. I also accepted that I simply could not collect all of the data that I might have wanted to, such as member reflections, or follow-up interviews. The contextual constraints simply did not allow me to enact these procedures that could have potentially strengthened my research. As such, I encourage researchers of all types, but especially those who conduct applied research in a highly constrained system, to remove ego from the equation in order to be flexible to the needs of your participants and the needs of the context.

Develop Relationships

Although the previous lessons are important for logistical and ethical purposes, perhaps the most memorable lesson I learned during my time at the VA was the importance of developing meaningful relationships with the people I encountered in the field. As I've described, my experience conducting research in the VA system was challenging on many levels and, at times, frustrating and exhausting. I was often confused by the procedures I needed to enact, worried about the things I was doing incorrectly, and even frustrated by the lack of parking spaces available at the hospital (which I quickly learned is a running joke at the Phoenix VA). But during each of these

challenges, someone was always willing to help me, and I found myself slowly getting to know the individuals I was working with on a personal level. For instance, over the course of several meetings with Joe on research-related protocol, I learned we both grew up in Central Illinois and had roots in farming. He shared with me his hopes of moving back to Illinois some day to spend more time with his dad, we talked about traveling abroad, and we joked about our abilities to spot Illinoisans from a mile away given their practical perspective on life.

At the time that these interactions unfolded, I saw these moments as opportunities to connect with the people who could help me successfully work within the organization. In retrospect, however, small conversations such as these helped sustain me through the moments when I wanted to give up. The relationships that I developed with the SMA healthcare team and the research staff helped to offset the challenges of the work, make me feel more connected to the organization, and boost my spirits when things seemed overwhelming. Aside from providing practical support, these colleagues helped me learn to laugh at mistakes and poke fun at the absurdities and, along the way, invited me into their personal and professional worlds. Ironically enough, I discovered as I was studying the process of communal coping in my research, I myself was practicing communal coping with my fellow VA colleagues.

It is important as researchers that we find ways to develop relationships with those who participate in our study, but it is equally as important to connect with those who help make the research process possible. I am eternally grateful for the relationships I have developed with my colleagues at the VA and I know I am a more compassionate researcher because of their willingness to be open, honest, and, at times, vulnerable. I

believe as researchers, we must be willing to be as vulnerable as those who invite us into their worlds. And so, I encourage applied scholars to take moments to set aside the goals of the research study, put down the pen and the recorder, and remove the critical lens to make those important connections and forge meaningful relationships in the field.

Conclusions

Overall, this dissertation added to our understanding of the communal coping process as it occurs within non-naturally occurring groups. Additionally, the findings of this study shed light on the complex relational and communicative features that socially construct the SMA experience for patients, family members, and providers. These findings collectively contribute to literature on communal coping and SMAs.

Furthermore, my reflections on government research in a healthcare setting point to pragmatic strategies for successfully conducting applied research. In the future, scholars should continue to emphasize the communicative experience of the communal coping process as well as seek to understand how the patient-provider relationship develop within a group medical context.

REFERENCES

- Acitelli, L. K., & Badr, H. J. (2005). My illness or our illness? Attending to the relationship when one partner is ill. In T. A. Revenson, K. Kayser, & G. Bodenmann (Eds.). *Couples Coping With Stress: Emerging Perspectives on Dyadic Coping* (pp. 121-136). Washington, D.C.: American Psychological Association.
- Afifi, T., Afifi, W., Merrill, A. F., Denes, A., & Davis, S. (2013). "You need to stop talking about this!": Verbal rumination and the costs of social support. *Human Communication Research, 39*, 395-421. Doi:10.1111/hcre.12012
- Afifi, T. D., Hutchinson, S., & Krouse, S. (2006). Toward a theoretical model of communal coping in postdivorce families and other naturally occurring groups. *Communication Theory, 16*, 378-409. doi: 10.1111/j.1468-2885.2006.00275.x
- Afifi, W. A., Felix, E. D., & Afifi, T. D. (2012). The impact of uncertainty and communal coping on mental health following natural disasters. *Anxiety, Stress, & Coping, 25*(3), 329-347.
- Angrosino, M. V. (2006). Recontextualizing observation: Ethnography, pedagogy, and the prospect for progressive political agenda. In N. K. Denzin and Y. S. Lincoln (eds.), *Handbook of qualitative research* (3rd ed., pp. 729-746). Thousand Oaks, CA: Sage.
- Bandura, A. (1977). *Social learning theory*. Englewood Cliffs, NJ: Prentice-Hall.
- Barge, J. K. (2004). Reflexivity and managerial practice. *Communication Monographs, 71*(1), 70-96. Doi: 10.1080/03634520410001691465
- Bartley, K. B., Haney, R. (2010). Shared medical appointments: Improving access, outcomes, and satisfactions in patients with chronic cardiac diseases. *Journal of Cardiovascular Nursing, 25*(1), 13-19.
- Beck, S. J., & Keyton, J. (2014). Facilitating social support: Member-leader communication in a breast cancer support group. *Cancer Nursing, 37*, 36-43. doi: 10.1097/NCC.0b013e3182813829
- Benjamin, R. M. (2010). Multiple chronic conditions: A public health challenge. *Public Health Reports, 125*, 626-627. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2924996/#B2>
- Berg, C. A., Meegan, S. P., Deviney, F. P. (1998). A social-contextual model of coping with everyday problems across the lifespan. *International Journal of Behavioral Development, 22*, 239-261.

- Berger-Fiffy, J. (2012). The “nuts and bolts” of implementing shared medical appointments: The Harvard Vanguard medical associated experience. *Journal of Ambulatory Care Management*, 35(3), 247-256. doi: 10.1097/JAC.0b013e3182582c0a
- Bodenheimer, T., Chen, E., & Bennet, H. D. (2009). Confronting the growing burden of chronic disease: Can the U.S. health care workforce do the job? *Health Affairs*, 28(1), 64-74.
- Bodenmann, G. (2005). Dyadic coping and its significance for marital functioning. In T. A. Revenson, K. Kayser, & G. Bodenmann (Eds.). *Couples Coping With Stress: Emerging Perspectives on Dyadic Coping* (pp. 33-49). Washington, D.C.: American Psychological Association.
- Bohm, D. (1996). *On dialogue*. New York, NY: Routledge.
- Boren, J. P (2013). Co-rumination partially mediates the relationship between social support and emotional exhaustion among graduate students. *Communication Quarterly*, 61(3), 253-267. Doi:10.1080/01463373.2012.751436
- Boren, J. P. (2014). The relationships between co-rumination, social support, stress, and burnout among working adults. *Management Communication Quarterly*, 28(1), 3-25. Doi:10.1177/0893318913509283
- Bronson, D., & Maxwell, R. (2012). Shared medical appointments: Increasing patient access without increasing physician hours. *Cleveland Clinical Journal of Medicine*, 71(5), 369-377.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.
- Charmaz, K. (2011). Grounded theory methods in social justice research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (4th ed., pp.359-380). Thousand Oaks, CA: Sage
- Clancy, D., Huang, P., Okonofua, E., Yeagear, D., Magruder, K., Simpson, K., . . . Bradford, D. (2007). Group visits: Promoting adherence to diabetes guidelines. *Journal of General Internal Medicine*, 22(5), 620–624.
- Cohen, S., Hartley, S., Mavi, J., Vest, B, & Wilson, M. (2012). Veteran experiences related to participation in shared medical appointments. *Military Medicine*, 117(11), 1287-1292.

- Cozaru, G. C., Papari, A. C., & Sandu, M. L. (2014). The effects of psycho-education and counselling for women suffering from breast cancer in support groups. *Procedia-Social and Behavioral Sciences*, 128, 10-15. doi:10.1016/j.sbspro.2014.03.110
- Cripe, E. T. (2010). *Breastfeeding support explored through mixed methods: How support groups can function as an effective health intervention* (doctoral dissertation). Retrieved from ProQuest (3425718).
- Cunliffe, A. L. (2002). Reflexive dialogical practice in management learning. *Management Learning*, 33(1), 35-61.
- Dickman, K., Pintz, C., Gold, K., Kivlahan, C. (2012). Behavior changes in patients with diabetes and hypertension after experiencing shared medical appointments. *Journal of the American Academy of Nurse Practitioners*, 24, 43-51.
- Duggan, A. P., & Thompson, T. L. (2011). Provider-patient interaction and related outcomes. In T. L. Thompson, R. Parrott, & J. F. Nussbaum (Eds.), *The Routledge Handbook of Health Communication* (2nd ed., pp. 414-427). New York, NY: Taylor & Francis.
- Edelman, D., McDuffie, J. R., Oddone, E., Gierisch, J. M., Nagi, A., & Williams, J. W. (August, 2012). Shared medical appointments for chronic medical conditions: A systematic review. *Washington DC: Department of Veterans Affairs*.
- Emerson, R. M.; Fretz, R. I. & Shaw, L. (1995). *Writing ethnographic fieldnotes*. Chicago: University of Chicago Press.
- Epstein, R. M., & Street, R. L. J. (2007). Patient-centered communication in cancer care: promoting healing and reducing suffering. NIH Publication No. 07-6225, Bethesda, MD.
- Freire, P. (1970). *Pedagogy of the oppressed*. New York, NY: Herder & Herder.
- Folkman, S., & Moskowitz, J. T. (2004). Coping: Pitfalls and promise. *Annual Review of Psychology*, 55, 745-774. doi: 10.1146/annurev.psych.55.090902.141456
- Geertz, C. (1973). *The interpretation of cultures*. New York: Basic Books.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.
- Goldsmith, D. J., & Albrecht, T. L. (2011). Social support, social networks, and health: A guiding framework. In T. L. Thompson, R. Parrott, & J. F. Nussbaum (Eds.), *Handbook of health communication* (pp. 335-348). Mahwah, NJ: Lawrence Erlbaum.

- Goodall, H. L., Jr. (2000). *Writing the new ethnography*. Lanham, MD: AltaMira Press/Rowman & Littlefield.
- Guribye, W., Sandal, G. M., & Oppedal, B. (2011). Communal proactive coping strategies among Tamil refugees in Norway: A case study in a naturalistic setting. *International Journal of Mental Health Systems*, 5(9), 1-13.
- Helgeson, V. S., Cohen, S., Schulz, R., & Yasko, J. (2000). Group support interventions for women with breast cancer: Who benefits from what? *Health Psychology*, 19(2), 107-114.
- Hogan, B. E., Linden, W., & Najarian, B. (2002). Social support interventions: Do they work? *Clinical Psychology Review*, 22, 381-440.
- Isaacs, W. (1999). *Dialogue and the art of thinking together: A pioneering approach to communicating in business and in life*. New York, NY: Doubleday.
- Jaber, R., Braksmajer, A., Trilling, J. S., (2006). Group visits: A qualitative review of current research. *JABFM*, 19(3), 276-290.
- Keyton, J., Bisel, R. S., & Ozley, R. (2009). Recasting the link between applied and theory research: Using applied findings to advance communication theory development. *Communication Theory*, 19(2), 146-160. Doi: 10.1111/j.1468-2885.2009.01339.x
- Kim, J., Park, S., Yoo, S. & Shen, H. (2010). Mapping health communication scholarship: Breadth, depth, and agenda of published research in *Health Communication*. *Health Communication*, 25, 487-503. doi: 10.1080/10410236.2010.507160
- Kirsh, S., Watts, S., Schaub, K., Strauss, G., O'Day, M. E., Ober, S., Taylor, G., Kern, E., Lawrence, R., & Aron, D. C. (December, 2008). VA shared medical appointments for patients with diabetes: Maximizing patient & provider expertise to strengthen care management. *Diabetes Mellitus QUERI, VA HSR&D*.
- Koehly, L. M., Peters, J. A., Kuhn, N., Hoskins, L., Letocha, A., Kenen, R., Loud, J., Greene, M. H. (2008). Sisters in hereditary breast and ovarian cancer families: Communal coping, social integration, and psychological well-being. *Psycho-Oncology*, 17, 812-821. doi: 10.1002/pon.1373
- Kowal, J., Johnson, S. M., & Lee, A. (2003). Chronic illness in couples: A case for emotionally focused therapy. *Journal of Marital and Family Therapy*, 29(3), 299-310.
- Kreps, G. L. (2012). The maturation of health communication inquiry: Directions for future developments and growth. *Journal of Health Communication*, 17, 495-497.

- Lambert, B. L., Street, R. L., Cegala, D. J., Smith, D. H., Kurtz, S., & Schofield, T. (1997). Provider-patient communication, patient-centered care, and the mangle of practice. *Health Communication, 9*, 27-43.
- Lawrence, A. R., & Schiller Schigelone, A. R. (2002). Reciprocity beyond dyadic relationships: Aging-related communal coping. *Research on Aging, 24*, 684-704. doi: 10.1177/016402702237187
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY: Springer Publishing Company.
- Lederman, L. C., & Menegatos, L. M. (2011). Sustainable recovery: The self-transformative power of storytelling in Alcoholics Anonymous. *Journal of Groups in Addiction & Recovery, 6*, 206-227. doi: 10.1080/1556035X.2011.597195
- Lewis, M. A., McBride, C. C., Pollak, K. I., Puleo, E., Butterfield, R. M., & Emmons, K. M. (2006). Understanding health behavior change among couples: An interdependence and communal coping approach. *Social Science & Medicine, 62*, 1369-1380. doi:10.1016/j.socscimed.2005.08.006
- Lindlof, T. R., & Taylor, B. C. (2011). *Qualitative Communication Research Methods, 3rd Edition*. Thousand Oaks, CA: Sage.
- Lyons, R. F., Mickelson, K. D., Sullivan, M. J. L, & Coyne, J. C. (1998). Coping as a communal process. *Journal of Social and Personal Relationships, 15*, 579-605. doi:10.1177/0265407598155001
- Lyons, R., Sullivan, M., Ritvo, P., & Coyne, J. (1995). *Relationships in chronic illness and disability*. Thousand Oaks, CA: Sage.
- Masley, S., Phillips, S., Copeland, J. R. (2001). Group office visits change dietary habits of patients with coronary artery disease. *Journal of Family Practice, 50*, 235-239.
- Merritt Hawkins (2014). *Physician appointment wait times and Medicaid and medicare acceptance rates*. Retrieved from <http://www.merrithawkins.com/uploadedFiles/MerrittHawkings/Surveys/mha2014waitsurvPDF.pdf>
- Michie, S., Miles, J., & Weinman, J. (2003). Patient-centeredness in chronic illness: What is it and does it matter? *Patient Education and Counseling, 51*, 197-206.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative Data Analysis*. Thousand Oaks, CA: Sage.

- Miller, K. I., Shoemaker, M. M., Willyard, J., & Addison, P. (2008). Providing care for elderly parents: A structural approach to family caregiver identity. *Journal of Family Communication, 8*, 19-43.
- Montgomery, C. M., Watts, C., & Pool, R. (2012). HIV and dyadic intervention: An interdependence and communal coping analysis. *PLoS ONE, 7*(7), 1-8. Doi: 10.1371/journal.pone.0040661
- Mullen, G. E. (2010). Patient education: The value of support groups. *Nutrition in Clinical Practice, 25*(5), 555-557.
- Noffsinger, E., Sawyer, D. R., & Scott, J. C. (2003). Group medical visits: A glimpse into the future? *Patient Care, 37*(3), 18. Retrieved Feb. 13, 2014 from <http://bi.galegroup.com.ezproxy1.lib.asu.edu/essentials/article/GALE%7CA99811961/2114c61319e390f1a477b8130cc65053?u=asuniv>
- NPR, Robert Wood Johnson Foundation, and Harvard School of Public Health. (2014). *The burden of stress in America*. Retrieved from http://www.rwjf.org/content/dam/farm/reports/surveys_and_polls/2014/rwjf414295
- Perkins, D. D., & Zimmerman, M. A. (1995). Empowerment theory, research, and application. *American Journal of Community Psychology, 23*(5), 569-579.
- Pistrang, N., & Barker, C. (2005). In T. A. Revenson, K. Kayser, & G. Bodenmann (Eds.), *Couples Coping With Stress: Emerging Perspectives on Dyadic Coping* (pp. 97-119). Washington, D.C.: American Psychological Association.
- Planalp, S. (2001). *Communicating emotion: Social, moral and cultural processes*. New York, NY: Cambridge University Press.
- Politi, M., & Street, R. L., Jr. (2011). Patient-centered communication during collaborative decision making. In T. L. Thompson, R. Parrott, & J. F. Nussbaum (Eds.), *The Routledge handbook of health communication* (2nd ed., pp. 399-413). New York, NY: Taylor & Francis.
- Rohrbaugh, M. J., Shoham, V., Skoyen, J. A., Jensen, M., & Mehl, M. R. (2012). We-talk, communal coping, and cessation success in a couple-focused intervention for health-compromised smokers. *Family Process, 51*(1), 107-121.
- Saldaña, J. (2009). *The coding manual for qualitative researchers*. Thousand Oaks, CA: Sage.
- Senge, P. M., Roberts, C., Ross, R. B., Smith, B. J., & Kleiner, A. (1994). *The fifth discipline fieldbook: Strategies and tools for building a learning organization*. New York, NY: Doubleday.

- Sharf, B. F. & Vanderford, M. L. (2003). Illness narratives and the social construction of health. *The Handbook of Health Communication*. In T. L. Thompson, A. M. Dorsey, K. I. Miller, & R. Parrott (Eds.), *Handbook of health communication* (pp. 9-34). Mahwah, NJ: Lawrence Erlbaum.
- Sikon, A., & Bronson, D. (2010). Shared medical appointments: Challenges and opportunities. *Annals of Internal Medicine*, 52(11): 745-746.
- Street, R. L., Jr. (2003). Communication in medical encounters: An ecological perspective. In T. L. Thompson, A. M. Dorsey, K. I. Miller, & R. Parrott (Eds.), *Handbook of health communication* (pp. 63-89). Mahwah, NJ: Lawrence Erlbaum.
- Street, R. L., Jr. (2009). How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Education and Counseling*, 74, 295-301. Doi: 10.1016/j.pec.2008.11.015
- Tracy, S. J. (2013). *Qualitative research methods: Collecting evidence, crafting analysis, communicating impact*. Malden, MA: Wiley-Blackwell.
- Trento, M., Passera, P., Borgo E, Tomalino, M., Bajardi, M., Cavallo, F., & Porta, M. (2004). A 5-year randomized controlled study of learning, problem solving ability, and quality of life modifications in people with type 2 diabetes managed by group care. *Diabetes Care*, 27, 670-675.
- Warshaw, G. (2006). Introduction: Advances and challenges in care of older people with chronic illness. *Generations*, 30, 5-10.
- Weick, K. E. (1995). *Sensemaking in organizations*. Thousand Oaks, CA: Sage Publications.
- Weick, K. E., Sutcliffe, K., & Obstfeld, D. (2005). Organizing and the process of sensemaking. *Organization Science*, 16(4), 409-421.
- Wright, K. B. Johnson, A. J., Bernard, D. R., & Averbek, J. (2011). Computer-mediated social support: Promises and pitfalls for individuals coping with health concerns. In T. L. Thompson, R. Parrott, & J. F. Nussbaum (Eds.), *Handbook of health communication* (pp. 349-362). Mahwah, NJ: Lawrence Erlbaum.
- Zimmerman, A. L. (2013). Evidence-based medicine: A short history of a modern medical movement. *American Medical Association Journal of Ethics*, 15(1), 71-76. Retrieved from <http://journalofethics.ama-assn.org/2013/01/pdf/mhst1-1301.pdf>

APPENDIX A

IRB APPROVAL LETTERS – PHOENIX VA AND ASU

REPORT OF SUBCOMMITTEE ON HUMAN STUDIES
(IRB Subcommittee approval form)

Department of Veterans Affairs

Project/Program Title: Exploratory study of communication and perceptions in HF shared medical appointments (eRD 1040)
Principal Investigator: Sandesh Dev, MD
VAMC: 644 – Phoenix VA Health Care System Institutional Review Board **Review Date:** April 9, 2014

COMMITTEE FINDINGS

1. The information given in the Informed Consent under the Description of Research by Investigator is complete, accurate, and understandable to a research subject or a surrogate who possesses standard reading and comprehension skills. YES
 NO
 N/A
- Reviewed** Consent Version Date: 140323 **Approved** Consent Version Date: 140323 YES
 NO
 N/A
2. The informed consent is obtained by the principal investigator or a trained and supervised designee under suitable circumstances. YES
 NO
 N/A
3. Every effort has been made to decrease risk to subject(s)? YES
 NO
 N/A
- Reviewed** Protocol Version Date/No. 140307
Approved Protocol Version Date/No. 140421
Approved Investigator's Brochure Dated: NA
Approved Risk/Benefit Ratio: Minimal
4. The potential research benefits justify the risk to subject(s)? YES
 NO
- Approved for number** of subjects to be consented: 200
AND / OR
Approved for number of records to be reviewed: NA
5. If subject is incompetent and surrogate consent is obtained, have all of the following conditions been met: (a) the research can't be done on competent subjects; (b) there is no risk to the subject, or if risk exists, the direct benefit to subject is substantially greater; (c) if an incompetent subject resists, he will not have to participate; (d) if there exists any question about the subject's competency, the basis for decision on competency has been fully described? YES
 NO
 N/A
6. If the subject is paid, is the payment reasonable and commensurate with the subject's contribution? YES
 NO
 N/A
7. Were the members of minority groups and women included in the study population whenever possible and scientifically desirable? YES
 NO
 N/A
8. Comments: Full Review *Expedited Review

* Please refer to the **attached document** explaining why this study was expedited.

Approved for (no. of months) 12 Expiration Date April 9, 2015

PVAHCS 1/9/14gm

RECOMMENDATIONS:

- APPROVED**
 - *APPROVAL-** pending minor changes
 - *TABLED**—major changes, requires full review
 - *DISAPPROVAL**—requires resubmission
- *MEMO attached
- Comments: Refer to memo dated 140411

4/21/2014

X Sherman M. Harman, MD

IRB Chair/Designee, IRB Subcommittee

Signed by: Harman, Sherman M.

PVAHCS 1/9/14gm



APPROVAL: EXPEDITED REVIEW

Sarah Tracy
 Human Communication, Hugh Downs School of
 480/965-7709
 Sarah.Tracy@asu.edu

Dear Sarah Tracy:

On 3/27/2014 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	Exploratory Study of Communication and Perceptions in Heart Failure Shared Medical Appointments
Investigator:	Sarah Tracy
IRB ID:	STUDY00000849
Category of review:	(7)(b) Social science methods, (5) Data, documents, records, or specimens
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none"> • VA required consent version, Category: Consent Form; • Hoffman ASU SMA Study IRB, Category: IRB Protocol; • VA Protocol 3-11-14, Category: Other (to reflect anything not captured above); • Data Use Agreement, VA & ALPHA Transcription , Category: Other (to reflect anything not captured above); • VA ASU Academic Affiliation Agreement Letter, Category: Other (to reflect anything not captured above); • Recruitment Script for Non-Veterans.pdf, Category: Recruitment Materials; • Hoffman Recruitment Script for Veterans.pdf,

	Category: Recruitment Materials;
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The IRB approved the protocol from 3/27/2014 to 3/25/2015 inclusive. Three weeks before 3/25/2015 you are to submit a completed "FORM: Continuing Review (HRP-212)" and required attachments to request continuing approval or closure.

If continuing review approval is not granted before the expiration date of 3/25/2015 approval of this protocol expires on that date. When consent is appropriate, you must use final, watermarked versions available under the "Documents" tab in ERA-IRB.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc: Trisha Hoffman
Trisha Hoffman

APPENDIX B

INTERVIEW GUIDE FOR PATIENTS AND FAMILY MEMBERS

SMA Patient/Family Member Interview Guide

Introduction: Thank you for agreeing to participate in this study. As you read in the consent form, I am interested in better understanding shared medical appointments, how they function, and individuals' perceptions about the effectiveness of this form of clinical care.

As a reminder, you previously signed a consent form and a voice consent form at the shared medical appointment session in order to participate in this study. With your permission, I would like to audio record you during our interview as well so that I can transcribe our discussion later. Remember, your participation is voluntary and you may discontinue your participation at any time. This interview will last approximately 45-60 minutes, but may take less time depending on how detailed your answers are. If I ask a question that makes you uncomfortable, you can skip over it. Do I have permission to audio record? Do you have any questions before we begin?

Interview Questions

***Ask questions to both patient and caregiver when they are both present.**

1. I'll be asking you to use a fake name during this interview in order to protect confidentiality. What fake name would you like to go by [patient & caregiver]?
2. [Warm-up] Tell me a little about yourself.
Possible Probes (if needed):
 - a. Where are you from?
 - b. What branch did you serve in?
 - c. Tell me about your family. [To caregiver] What role do you play in _____ life?
3. I'd like to start by asking you what brought you to attend SMAs.
 - a. How or why did you begin attending SMAs?
 - b. What health "event," if any, occurred for you before you started coming to SMAs?
 - c. How would you describe your health before starting the SMA sessions?
4. I'd like you to think back to before you started attending SMAs.
 - a. What, if anything, did you know about SMAs?
 - b. What were your expectations of SMAs before you began attending these sessions?
 - c. Did you have any concerns/issues?
5. [Grand tour] Tell me what it's like to be a patient [and a family member] in SMAs.
Possible Probes (if needed):
 - a. What are your thoughts about the format?

- b. The other patients involved?
 - c. The care team conducting the sessions?
6. Can you tell me about a memorable moment or experience you had from the SMA sessions you've attended? What stands out to you?
- a. Why was this experience or moment memorable?
7. What are your thoughts about the group format?
- Possible Probes:*
- a. What is it like to interact with fellow patients/Veterans/family members?
 - b. What has it been like sharing your experiences and health information with other patients?
 - i. What has been your level of comfort with sharing your information in the group setting?
 - ii. Has that level of comfort changed throughout attending sessions?
 - c. How, if at all, do you feel supported by your peers?
8. What are your experiences interacting with the healthcare team?
- a. How would you describe their relationship with you as a patient?
 - b. As a family member?
 - c. How, if at all, do you feel supported by the healthcare team?
 - d. Are there any strategies or information that the care team uses that you believe are helpful? If so, could you share a couple of examples?
9. How would you compare SMAs to a traditional one-on-one appointment?
- a. Do you have a preference for one format over the other? If so, please explain why.
10. What aspects of SMAs have been the most helpful for you as a patient? As a family member?
11. In the process of attending SMAs, have you (or your family) noticed any changes in your health or your self-care? If so, could you share a couple of examples?
12. In your opinion, what are the most helpful aspects of SMAs?
13. Do you have any suggestions for improvements that could make SMAs better for future patients (and family members)? If so, please explain.
14. If you had a friend or family member who was trying to decide if they should attend SMAs for a health condition, would you encourage them to do so? If yes, why? If no, why? Please explain your thoughts.
15. Is there anything else you would like to add that I have not covered?

16. I'd like to get just a few demographics from you:

- a. Are you married/partnered or single? [ask if spouse isn't present]
- b. What's your highest level of education?
- c. How would you describe your race/ethnicity?

17. Do you have any questions for me about the study before we leave here today?

APPENDIX C
INTERVIEW GUIDE FOR PROVIDERS

SMA Provider Interview Guide

Introduction: Thank you for agreeing to participate in this study. As you read in the consent form, I am interested in better understanding shared medical appointments, how they function, and individual's perceptions about the effectiveness of this form of clinical care.

As a reminder, you previously signed a consent form and a voice consent form at the shared medical appointment session in order to participate in this study. With your permission, I would like to audio record you during our interview as well so that I can transcribe our discussion later. Remember, your participation is voluntary and you may discontinue your participation at any time. This interview will last approximately 45-60 minutes, but may take less time depending on how detailed your answers are. If I ask a question that makes you uncomfortable, you can skip over it. Do I have permission to audio record? Do you have any questions before we begin?

Interview Questions

1. I'll be asking you to use a pseudonym during this interview in order to protect confidentiality. What name would you like to go by?
2. Can you tell me how you became involved with heart failure SMAs?
 - a. What did you know about SMAs before you started?
 - b. Why did you decide to work on this SMA team?
 - c. Did you receive any formal training before beginning work on SMAs?
3. How would you describe your role during SMA sessions?
 - a. Please tell me about an example that illustrates this role.
 - b. How, if at all, does working in a care team shape that role?
 - c. What are your goals as a provider in these sessions?
4. How do you feel about working in a team format?
 - a. How would you describe your experience working with this group?
 - b. What benefits, if any, have you experienced working in this format?
 - c. What challenges, if any, have you experienced working in this format?
5. Tell me about a memorable experience you've had from working in SMAs.
 - a. Why does this experience stand out to you?
6. What do you believe are the most valuable/beneficial aspects of SMAs?
 - a. For patients and family members?
 - b. What types of voluntary feedback, if any, have you received from patients?

and family members about SMAs?

7. What do you believe are the biggest challenges in conducting SMAs?
 - a. Specifically, how do you manage the group format?
 - b. Are there any risks for you as a provider in conducting SMAs?

8. I have noticed that the moderators use several different strategies to involve patients during SMAs. Which strategies do you believe are the most useful for encouraging patient participation and understanding during SMAs?
 - a. Could you provide me with an example?
 - b. How do you see these strategies affecting patients and family members?
 - c. Metaphors? Quizzing? Asking for patient feedback? Positioning the patient as expert? Silence?

9. I have noticed that patients and family members share a lot of personal information about their lives during the sessions. Why do you think this occurs?
 - a. What features of SMAs, if any, do you believe contribute to this open exchange of information?
 - b. Are there any particular strategies or topics you think encourage sharing or support among SMA members?

10. What types of changes have you seen in patients as they move through SMA sessions? Could you provide some examples or memorable stories from past experiences?

11. If you were to change anything about how the SMAs are conducted, what would that be, if anything, and why?

12. What advice could you offer to providers who are thinking about starting their own SMA program?
 - a. What are the most important things they should consider or incorporate to have a successful outcome?
 - b. What types of reactions/feedback, if any, do you get from providers/students who observe SMAs?

13. Is there anything else you would like to add that I have not covered?

14. Do you have any questions for me about the study before we leave here today?