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# A Patient Engaged: Examining the Benefits of Formal Patient Engagement

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A PATIENT ENGAGED: EXAMINING THE BENEFITS OF FORMAL PATIENT  
ENGAGEMENT

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A Thesis  
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the Graduate School of  
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In Partial Fulfillment  
of the Requirements for the Degree  
Master of Arts  
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by  
Jeanne Marie Petrizzo  
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Accepted by:  
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## ABSTRACT

Patient engagement studio models exist to create a platform for patients to offer input on research projects at health systems and academic health centers. While these models are gaining popularity, little research exists that captures the benefits for participants. In this ethnographic study, I examined the benefits of patient engagement for participants at a large Southeastern academic health center. Through individual interviews and field observation, I sought to understand the experiences of patients and what they gained, and how those benefits could be applied to other health care settings. Patients' responses in interviews and actions in each studio indicated that the following benefits exist: education, empathy, and empowerment. These benefits often worked in relation with each other, as well as offered additional insight on positive patient-physician communication models and effective communication channels in health care.

## DEDICATION

Without question, this study is dedicated to the pioneering patients who agreed to dip their toes into the water and then dive into the new concept of patient engagement. Thank you for letting me interview you, sit with you in each studio, and learn from you.

## ACKNOWLEDGMENTS

Dr. Kristen Okamoto, for all the practical guidance on this project, yes, but even more, the consistent, constant encouragement from the very beginning, even when this study was still in the incubator stage as a class paper. Thank you for the journal you gave me on the day of my proposal—I read the front quote a lot. Believe. Believe. Believe.

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## CHAPTER ONE

### INTRODUCTION

Beyond patient experience surveys or office visit questionnaires in the health care industry, a new form of patient feedback and engagement is emerging. In 2010 Congress authorized the formation of the Patient-Centered Outcomes Research Institute (PCORI) as a vehicle for practical research in a health care setting that sought to explore questions conventional health research could not answer (“Our Story,” 2017). Specializing in comparative clinical effectiveness research (CER), or research that is in the best interest of public health, PCORI has since become the largest public research funder of CER-related research (“Our Story,” 2017). From CER emerged patient and community engagement as a means of including health care stakeholders, such as patients, community partners, and caregivers, as part of the research process. This engagement format’s intention is to effectively ensure that the study at hand has stakeholders’ best interests in mind (“What We Mean,” 2015).

The patient engagement studio (PES) under investigation in this study was introduced in 2016 as a resource for researchers within its affiliate health system and with collaboration from its academic partners. The goal of this studio is to provide an avenue for patients to be recognized as formal members of a research team where they are given the opportunity to offer feedback on and critique proposed studies by researchers throughout the research process. Woolf, Zimmerman, Haley, and Krist (2016) stated that similar patient engagement models have influenced and are influencing the manner in which researchers approach their studies as they understand the power and impact that

patient feedback can bring to research. Formalized patient input has provided a voice to vulnerable populations, such as minorities, people with disabilities, and members of the LGBTQ community, thus aiding in establishing relevance and practical application, while also commanding respect as either a patient or a member of a vulnerable population (Woolf et al., 2016). A model like the one featured in this study employs the contributions of patients through common formats like focus groups, but the studio takes patient feedback a step further by encouraging a platform for actual input on the research study itself (Joosten et al., 2015). This feedback can include anything from comments on patients' emotional needs in the midst of an otherwise sterile medical research study to ideas on the best method to disseminate results beyond just a peer-reviewed journal.

A formal patient engagement framework is a conduit for the voices of patients to be heard and received as formal input, which holds the potential power to alter the course of a study and change its design, as researchers implement feedback accordingly. In turn, this elevation of voices has the potential to provide a springboard for equality, or a more horizontal understanding and working relationship between patients and researchers, and beyond that, health care providers in general. With the current volatility of the health care system, patient empowerment is more vital than ever.

As such, the purpose of this study was to explore if patients have experienced benefits both within a studio and outside this formal framework in other health care settings, and then identify what those are. Beyond exploring the medical care benefits of more informed, patient-centered research, this study sought to identify ways in which a patient's involvement in formal engagement reverberated outside of the engagement

framework. It is my hope that by identifying benefits for patients involved in the PES, organizers would be motivated to initiate the creation of studio, to increase infrastructure that allows them to invite additional patients, and to make a stronger case when applying for grant dollars. Also, because effective medicine is steeped in effective communication, I hope that health care providers in general may understand and apply appropriate communicative behaviors identified in this study that will enrich their patients' well-being. Based on my research, I maintain that a PES acts as the crosswalk at the intersection of knowledge and power, a place where patients find themselves constantly as it relates to their health.

The framework of a patient and/or community engagement studio can be replicated at other institutions, furthering these positive changes in both a patient's understanding of him- or herself. Beyond formal patient engagement, the results of this study could translate into enhancing the patient-physician relationship by increasing a patient's confidence as it pertains to medical knowledge and language and interactions in a health care setting. Additionally, basic dialogical-inspired techniques could be considered for implementation for any patient, whether or not they participate in an engagement studio. This could occur in the various contexts patients interface with a health care system, whether it be through health messaging collateral and office visits, or as caretakers of loved ones.

For the sake of this study, it is crucial to establish both the theoretical lens through which I view dialogue and its function, and also a specific definition of patient engagement pertinent to the discussion at hand. I turn to the expertise of sociologist and

dialogue expert Arthur Frank (2005), who draws extensively from the writings of Russian philosopher Mikhail Bakhtin. Dialogue, or conversation in action, has the capacity to generate additional dialogue, and therefore additional meaning (Frank, 2005). In a formal engagement setting, this function was and is crucial in generating feedback for researchers as patient participants engage in roundtable discussion that informs and critiques the researcher and his or her project. Further, according to Frank (2005), “dialogue depends on perpetual openness to the other’s capacity to become someone other than who she or he already is” (p. 967), or rather, in the PES setting, that the researcher allows dialogue to generate a perspective beyond just a patient’s vulnerable identity.

Given the variety of meanings of engagement perceived by patients, administrators, and care providers (Gallivan, Kovacs Burns, Bellows, & Eigenseher, 2012), it is also necessary to establish a concrete definition for this specific project. In a study conducted by Gallivan et al. (2012), many of the assumed definitions submitted by participants had little to do with research endeavors at all. PCORI is a premier source of patient engagement terminology and serves as the source of the definition applicable to this study. PCORI defined engagement as “meaningful involvement of patients, caregivers, clinicians, and other health care stakeholders throughout the research process—from topic selection through design and conduct of research to dissemination of results” (PCORI, n.d., para. 1).

The context of this study features a large health system and academic health center in the Southeast, consisting of a multi-campus hospital system, a medical school, a

nursing program and three academic partners. In the health system's fiscal year 2017, there were approximately 3.8 million outpatient visits and over 52,000 hospital discharges. The engagement studio within this organization consists of one governing board of approximately 16 members, which includes patients, clinicians, and researchers. Consisting of approximately 30 additional individuals, several sub-boards exist depending on medical condition, which provide a means of disease-specific patient input.

To help understand the communicative transactions involved in a PES, I will first offer an explanation of how a studio operates. I will then explore the context of a PES and a patient's identity within that setting by applying identity negotiation theory. Additionally, I will discuss principles of intercultural communication as they apply to patients and researchers while drawing parallels to the patient-physician relationship. I will then examine the function of the PES by applying co-cultural theory and Dutta's (2007) culture-centered approach to health communication. Finally, I will discuss dialogue in general health care settings to make the case for the necessity of an intentional format such as a PES.

CHAPTER TWO  
LITERATURE REVIEW

The Function of the PES

To effectively apply the subsequent theoretical discussion, an understanding of how an engagement studio functions is necessary. A flagship example of formalized patient and community engagement is the Community Engagement (CE) Studio model at Vanderbilt University (Joosten et al., 2015). The CE Studio staff facilitates the recruitment of patients, community individuals, and other stakeholders, aiding the researcher in this task. This model largely resembles their Clinical and Translational Research Studio, a program that connected researchers with academic experts and specialists related to researchers' specific projects (Joosten et al., 2015). Researchers can submit a request for a CE Studio, which the CE Studio team then reviews. Based on the request, the team then assembles an expert panel from their pool of stakeholders that they have identified either through community organizations or clinical practices. Researchers receive instruction on communicating their research effectively to nonexperts, and then, a facilitated meeting is conducted where stakeholders can provide feedback based on the researcher's presentation (Joosten et al. 2015). Based on Joosten et al.'s (2015) study, stated outcomes of CE Studio participation for both researchers and stakeholders included new knowledge and perspectives, while stakeholders experienced feelings of worth and significance.

Joosten et al. (2015) stated emphatically that participants in the CE Studio are not subjects but consultants, recruited specifically for their "lived experience" (p. 1647). This

distinction is crucial to the function of a studio and demonstrates a horizontal working relationship. Studio participants are not being observed or quantified, but rather sought after for their personal expertise. Examples of specific patient populations that have participated in Vanderbilt's CE Studio model include survivors of the ICU, African-American adults, smokers, and individuals who use opiates to relieve chronic pain (Joosten et al., 2015). The PES at the center of this study was formatted based on the Vanderbilt studio. Unfortunately, quantitative data regarding the prevalence of engagement studios, both nationally and internationally, is not readily available. A champion of engagement, PCORI itself is less than a decade old, although an aspect of its mission is to continually expand the presence of engagement studios in health care settings.

Generally speaking at this specific health system, research has occurred in pockets for many years, although its more robust, formal engine has only begun to initiate in recent years. This particular studio was advocated for by the chief science officer at the health system, a crucial stamp of approval from leadership. When first introduced, and even now, this PES lacked publicity, and therefore relevant stakeholders were and are not aware of its existence or its function. According to the director, some who utilize it do so to fulfill a requirement, versus understanding its intrinsic value. It is my intention that this study provide a presentation of the robust value and tremendous positive ripple effect of formal patient engagement. With this example established, I will now explore identity negotiation theory as it relates to patients in a general health care setting and studio setting specifically.

## Identity Negotiation Theory

Ting-Toomey's identity negotiation theory provides an effective lens through which to assess both how a patient can feel more affirmed in a health care or research setting, and more specifically, how the dynamics in a setting such as the PES are a conduit for beneficial dialogue. According to Ting-Toomey (2016), *identity* in identity negotiation theory can mean all manner of identities of an individual, including social class, religious, cultural, ethnic, professional, sexual orientation, gender, and family. Beyond some of these foundational attributes, other identities can include various qualities and characteristics individuals assume of themselves, termed *personal identities* (Ting-Toomey, 2016). In the context of the PES, patient identities can be all of these. In fact, it is preferred that there be a number of these attributes that comprise an individual who is participating in the PES. *Negotiation* in this theory is "the role of verbal and nonverbal message exchanges between the two or more communicators in maintaining, threatening, or uplifting the various sociocultural group-based or unique personal-based identity images of the other in situ" (Ting-Toomey, 2016, p. 1).

A core assumption of the theory is that an individual's perceived identity will influence his or her communication patterns (Ting-Toomey, 2016). Patients', researchers', and, as indicated above, physicians' communication patterns will all be shaped by each of their respective perceived identities. A certain consistency of personal identity is both expected and needed, the spectrum of which is emotional security and emotional insecurity. As such, environments that are familiar will produce identity emotional security, and environments that are not familiar will produce the opposite

(Ting-Toomey, 2016). If interacting with individuals from a different group, understanding the various aspects of their identity is conducive to a positive interaction (Ting-Toomey, 1999). Feelings of inclusion are fostered from the positive endorsement of identities (Ting-Toomey, 2016), which is a benefit of a formal platform such as the PES.

Understanding patients as members of a group, based on the tenets of intergroup communication (IGC), aids in implementing the function of identity negotiation within the PES setting. Individuals will have expectations of interaction based on their group identity, and consequently, will experience unpredictability when interacting with individuals outside of their group (Ting-Toomey, 2016). Of course, the risk here is that a negative interaction will polarize the two groups. In contrast, meaningful interpersonal interactions can foster a trust in individuals from different groups (Ting-Toomey, 2016), a benefit already demonstrated by formal patient engagement.

Additionally, individuals in a situation or setting that is unfamiliar to them are more likely to undergo an identity transformation, whether that be positive or negative (Ting-Toomey, 2016). Although, for the purpose of this study, a positive identity transformation is in question in terms of how the patients view themselves. Because successful identity negotiation relies on “integrating the necessary intercultural identity-based knowledge, mindfulness, and interaction skills to communicate appropriately, effectively, and adaptively with culturally dissimilar others” (Ting-Toomey, 2016, p. 4), positive implications of formal patient engagement could be compounded as researchers and physicians further understand their patient populations and are able to address them

and their needs more appropriately. As such, at the conclusion of the identity negotiation process, patients will feel “understood, respected, and affirmatively valued” (Ting-Toomey, 2016, p. 4), the markers of effective identity negotiation.

Most likely without realizing she was almost perfectly defining the PES, Ting-Toomey (2015) discussed the importance of creating opportunities for different groups to associate with each other in intentional educational contexts, “to see the ‘human face’ beyond the stereotypic group membership identity labels” (p. 10). This kind of structured gathering should include joint learning opportunities as well as a “mutual sharing process” (Ting-Toomey, 2015, p. 10). She also suggested that these group meetings should be advocated by key leaders within an organization and have adequate funds, incidentally, both necessities for the success of a PES. This setting encourages reliance on each other, or each group, to reach a common goal (Ting-Toomey, 2015), which, for the PES, is patient-informed, translational research that transforms patient care.

Frank (2001) warned that within research, “whatever cannot be reinscribed as an instance of some extralocal category must be rejected and censored” (p. 359). For health researchers, this may mean that the communication of the patient is filtered through the lens of an exact medical diagnosis and systemic health care, and thus the patient’s personal account of his or her suffering is stricken from the record if not given the opportunity to negotiate otherwise. This scenario is quite the sterile contrast to the intricacies of identity negotiation, which is why the opportunities provided by a PES are so valuable: a formal, inviting space for patients to challenge broader, categorical medical literature (Frank, 2001). To build on the concepts of identity negotiation, the identities of

both patients and researchers will be explored with comparisons to the patient-physician relationship, along with examples of how the rejection of additional dialogue in a health care setting can stunt a patient's care.

### Patient and Researcher Identities

Broadly speaking, intercultural communication (ICC) is an exploration of the interpersonal communicative habits between individuals of different cultures (Kim, 2010). The definition of culture has expanded since the inception of the study of ICC to include more than just societies and nations based on geography (Kim, 2010). For clarification, Ting-Toomey and Oetzel (2001) stated that culture is “a learned system of meanings that fosters a particular sense of shared identity and community among its group members” (p. 9). Relatedly, IGC is about the significance of an individual's enactment of communication because of his or her association with a particular group identity apart from his or her individual traits (Harwood, Giles, & Palomares, 2005). For both groups and cultures, characteristics of identity can expand beyond ethnicity and race to also include identifiers such as age, gender, political affiliations, academic backgrounds, and more (Harwood et al., 2005; Giles, 2012; Watson & Giles, 2009).

In a setting such as the PES, both cultural and group identity communications perspectives of ICC can be applied. While the labels of “patient” and “researcher” are broad in their own right, within a formal setting, specific identities crystallize. As such, within a PES, a formal setting for patient culture and researcher culture to interact is created, as well as the opportunity for a more horizontal communicative relationship. From an intergroup perspective, within a PES setting, participants are invited to offer

their input precisely because their identity as a patient is applicable to overall discussions of health care and salient to the researcher's specific study at hand. Additionally, amongst each other, patients share a common identity either as a general member of a patient population, or as a patient with a specific health condition or disease.

To give context to a patient-researcher model, one might consider the patient-physician relationship, which Ishikawa, Hashimoto, and Kiuchi (2013) stated is defined by power and a top-down approach. The physician, in his or her elevated position, is the individual in this model with more access to knowledge, technology, and resources (Ishikawa et al., 2013). As such, the patient-physician relationship is sometimes at risk of dominance, which might manifest itself in a format such as a patronizing tone from a physician, or of discourse management, which would not allow a patient sufficient dialogic room to appropriately converse about his or her condition (e.g., an interruption; Watson & Gallois, 1999).

Examples of prior research on patient-physician communication include studies on underprivileged parents of children with asthma who utilized the emergency department for medical care for their child/children (Wissow et al., 1998). Results indicated that if communication from physicians was highly medically specialized, the child, who was the actual patient in question, would provide little feedback or interaction (Wissow et al., 1998). Incidentally, the study also indicated that a more patient-centered approach resulted in both parents and children participating more in the communicative process (Wissow et al., 1998).

Another study examined the comparison of effective patient-physician communication between patient populations of a different race (Johnson, Roter, Powe, & Cooper, 2004). The study assessed verbal dominance by comparing the amount that the physician spoke versus the amount that the patient spoke (Johnson et al., 2004). Then, verbal dominance was compared to patient centeredness, which was evaluated based on the amount of socioemotional conversation and a patient's inquiries compared to the actual scientific information conveyed by the physician (Johnson et al., 2004). The unfortunate results revealed that patient-physician interactions possessed a greater level of verbal dominance by the physician when the patient was African-American (Johnson et al., 2004).

An apt assessment of both examples referenced above, Frank (2001) stated that a "person is transformed into a patient when the diagnostic category is appended to his or her name" (p. 358), after which that person becomes a clinical case, reliant on the greater knowledge and expertise of a health care team and a bottom member of a vertical relationship. Specialized language and medical jargon are markers of this different culture, so it becomes necessary for a patient to negotiate his or identity in this setting. Obviously, this is only effective if allowed the room to speak. Thus, it is relevant to consider the various communicative behaviors of nondominant groups as explicated by Orbe's (1998) co-cultural theory and the power of conversation as a root of those behaviors.

### Employing Dialogue in Co-Cultures

Drawing from muted-group and standpoint theories, Orbe (1998) devised co-cultural theory as a means of exploring the communicative processes and theoretical backgrounds of communication by non-dominant groups with groups that society deems more powerful or superior. He developed the term “co-cultural” to avoid using paternalistic language that implied one group was inferior to the other (Orbe, 1998). Examples of non-dominant group members include members of the LGBTQ community, individuals with disabilities, women, and minorities, incidentally, all qualities of patients in the studios I observed. Although the identity being explored here is solely that of a patient, Orbe (1998) does address this phenomenon with the admission that a simplistic definition of co-cultural theory is nigh impossible. Individuals can be members of both dominant and non-dominant groups simultaneously, and can therefore be recipients of and contributors to oppressive communication (Orbe, 1998). In his work on co-cultural theory, Orbe (1998) delineated these cases of non-dominant group members’ oppressive communication contributions with the term “co-cultural oppression” (p. 51). While this concept is not crucial to this specific study on patient populations, it is relevant to mention in order to indicate Orbe’s (1998) intricate thought and attention to detail regarding the complexities of co-cultural communication. I also acknowledge it to demonstrate my awareness of the potential for this phenomenon to occur, although it did not in this study.

As previously mentioned, co-cultural theory is built on the principles of standpoint and muted-group theories, both very relevant to the concept of a PES. Shirley

and Edwin Ardener's muted-group theory, simply put, posits that dominant group members "at the top of the social hierarchy largely determine the dominant communication system of the entire society" (Orbe, 1998, p. 20). This principle applies to the often dismissive and sterile communicative processes adapted by physicians toward their patients, thereby often muting the patient voice.

According to Smith (1992) standpoint theory could be considered more of a "method of inquiry" (p. 88), instead of a "totalizing theory" (p. 88). Orbe (1998) expounds on this by explaining its tenets, the first being that the researcher's own personal experiences should be the starting point for "an inductive, open process of discovery" (p. 27). This statement both captures my intent in this study, and offers a benchmark for researchers who participate in a PES. Additionally, this format of discovery should feature the perspectives of non-dominant groups "within the process of research inquiry in meaningful ways" (Orbe, 1998, p. 27), an apt description of a PES. Ultimately, this perspective liberates dominant group members from the status quo of social norms, and offers a robust perspective of non-dominant group members that isn't filtered through a dominant communication structure.

Several assumptions of co-cultural theory apply when discussing the patient-physician/patient-research relationship, including that dominant group members express their influence, either intentionally or unintentionally, to enforce communication patterns that are informed by dominant group members' experiences (Orbe, 1998). In turn, this can "impede the progress of those persons whose lived experiences are not reflected in

the public communicative systems” (Orbe, 1998, p. 11), or in this context, a health care setting.

Additionally, in order to effectively navigate a setting controlled by a dominant group, the non-dominant group members adapt a series of various communication behaviors, which include “censoring self,” “developing positive face,” “bargaining,” “mirroring,” and “communicating self” (Orbe, 1998, pp. 16-17). Relatedly, non-dominant group members adapt behaviors amongst themselves, a concept Orbe (1998) refers to as “intragroup networking” (p. 74). This activity can provide a source of education and understanding amongst group members to encourage them in their interactions with dominant group members. Orbe (1998) also takes into consideration the context and influential factors of these intercultural interactions and responsive behaviors. One must consider the setting and approach of these exchanges, as well as the potential and desirable outcomes (Orbe, 1998).

The PES is unique in that it provides a setting for the specific purpose of engaging with different cultures, and for giving a non-dominant culture member the platform to share their input based on their experiences, with the desired outcome of patient-informed and/or guided research. Thus, one might assume that an empowering setting such as the PES will incite positive communicative behaviors, specifically “communicating self” and “educating others” (Orbe, 1998, p. 17).

Orbe’s (1998) framework for examining co-cultural non-verbal and verbal communicative behaviors provides a foundation for Frank’s (2005) explication into the power of dialogue between dominant and non-dominant groups and the negotiating

power of verbal communication. In his explication, Frank (2005) calls upon dominant groups' "recognition of the other's unfinalizability" (p. 967), because the power of dialogue in this case hinges upon the dominant group's allowance for non-dominant group members to break down the barriers of their perceived identities through dialogue. Sourcing the dialogic leanings of Bakhtin, Frank (2005) compared Bakhtin's description of a character in a work by Dostoevsky to the calculated, sterile exaction of patient identity in health care settings and research.

Deshuvkin had glimpsed himself in the image of the hero of "The Overcoat," which is to say, as something totally quantified, measured, and defined to the last detail: all of you is here, there is nothing more in you, and nothing more to be said about you. He felt himself to be hopelessly predetermined and finished off, as if he were already quite dead, yet at the same time he sensed the falseness of such an approach (Bakhtin, 1984, p. 58).

To assume that the end of an understanding of an individual has been reached is both wrong in description and in ethics (Frank, 2005). Here the opportunity for patient dialogue presents itself, since, according to Frank (2005), dialogue is only the natural result of and logical next step after understanding the complexities that comprise a person, and that truly, no human can reasonably be finalized. To clarify though, Frank (2005) stated that his argument is not that academia should eliminate specialized language or jargon within research, but rather the finalization of humans within research.

Within Orbe's (1998) co-cultural theory, dialogue defines and communicates the self. Frank (2010) terms this as *narrative identifying* (p. 49), and emphasizes yet again

that “no identity is ever final” (p. 49). He explains narrative identifying as beginning with a concept from philosopher Louis Althusser called *interpellation*, which, at its most basic level, means “calling on a person to acknowledge and act on a particular identity” (p. 49). Thus, for a patient, the exercise of communicating self through dialogue because they are a patient affords the opportunity to express his or her point of view, although in such a way where the complex identity of that patient is not sacrificed for a one-dimensional perspective of the particular group as a whole (Orbe, 1998). Frank (2010) described “point of view” as having “the capacity to make one particular perspective not only plausible, but also compelling” (p. 31), thus enabling a patient to interrupt the status quo perspective of a dominant group. The platform of the PES allows for a patient to communicate his or her point of view and the opportunity to incite affinity between groups (Frank, 2010).

Additionally, the opportunity for dialogue allows the patient, as a member of a non-dominant cultural group, to educate others of his or her personal identity and experiences, as well as attributes of the patient population he or she is representing (Orbe, 1998). This crucial role of education by non-dominant group members can be tedious, although it is tremendously valuable for its ability to impact change for the group as a whole (Orbe, 1998). There is a danger for non-dominant group members’ educational stories and information to stereotype other members of the group (Orbe, 1998), although studios are designed to intentionally include an array of perspectives. Many types of patients whose cultural attributes intersect with other identities are invited to the literal and proverbial table to engage in dialogue and feedback.

The potential for impact of dialogue between dominant and non-dominant groups is extensive, only if given the opportunity though. To emphasize the idea that patients and researchers are members of two different cultures, and also to bring forth the health system's role in helping to foster more effective communication, consider Dutta's (2007) two contrasting approaches to health communication: the cultural sensitivity approach and the culture-centered approach. Briefly, the cultural sensitivity approach, similar to the traditional patient-physician relationship, is a top-down relationship in which cultural qualities and needs of groups are determined by the researcher (Dutta, 2007). As such, all aspects of communication from a culturally sensitive approach are developed and evaluated by members outside of that particular culture. While goals of culturally sensitive health communication are to provide health messaging that adapts to the various specific aspects of that culture, the health organization and/or professional are deeming what health needs are worthy of attention without actually consulting the obvious experts, members of the culture itself (Dutta, 2007).

In contrast, the culture-centered approach invites members of those cultures and groups to the proverbial (or literal) table as a means of "presenting voices of the marginalized sectors through engagement in dialogue" (Dutta, 2007, p. 310). Dutta (2007) argued that it is crucial to engage the actual culture in discussion to understand far more thoroughly their health-related needs and issues. Similarly, it is crucial to give patients the dialogical space for thorough communication regarding their overall health care experiences and specific conditions, both in a formal engagement setting and with their physician. These are the voices that will challenge the traditional medical ideology

discussed previously, providing a basis upon which to better understand and help usually silenced people, and, ideally, ensure patients have successfully negotiated their identity and feel “understood, respected, and affirmatively valued” (Ting-Toomey, 2016, p. 4). Thus, I posit that a PES is an engine for change in health care, fueled by a culture-centered approach and the patients themselves. Considering the contrast of these two approaches, it is pertinent to consider how dialogue often presents itself in a health care setting. As such, an understanding of the typical context of patient-physician communication will indicate the tremendous value of creating a specific space such as the PES for dialogue between dominant and non-dominant groups.

#### Communication in a Health Care Setting

Similar to Frank, Geist and Dreyer (1993) stated that the traditional tenets of medicine tend to deny the rich dialogue within a patient-physician relationship, and that the “ideological hegemony” of medical sciences “establishes a system of values, attitudes, and beliefs that restricts the layperson’s participation in scientific decision-making” (p. 233). Considering the patient-physician relationship examples presented previously, a more in-depth look at the role of dialogue in a health care setting is relevant.

Also drawing from Bakhtin, as well as the false unities of relationships by communication scholar Leslie Baxter, Geist and Dreyer (1993) compared and contrasted communication within the patient-physician relationship through both a traditional medical lens and a dialogic lens. One of Baxter’s false unities (as cited in Geist & Dreyer, 1993), self, presents a conundrum within the patient-physician relationship because of the failure to recognize the value of a patient’s dialogue beyond assessing a medical

condition and diagnosis, and therefore the patient's portrayal of self is at the direction of the provider. In opposition to this traditional view, a dialogic approach would call for a more horizontal means of creating a portrayal of patient's multidimensional self, and also account for other social contexts that affect the patient, including their professional and personal lives (Geist & Dreyer, 1993).

Another false unity examines the perceived closeness of the patient-physician relationship and the supposed joint efforts to reach a diagnosis (Geist & Dreyer, 1993). Traditionally, while it might appear the patient and physician are a team dedicated to improving health, the aim of this relationship for the physician is a precise diagnosis, or a "singular interpretation couched in scientific language" (Geist & Dreyer, p. 235). Such a sterile goal tends to eliminate the need for a relationship beyond diagnosis, therefore eliminating opportunities for richer dialogue from the patient.

Contrary to this, a more varied assessment of the patient's condition is reached via detailed feedback from the patient regarding his or her personal characteristics, mental makeup, and personal story within a broader context. This more storied approach provides the physician with a richer understanding of the patient's preferences, struggles, and opinions, which enriches the relationship and contributes to their overall diagnosis.

An additional false unity that pertains to the patient-physician relationship, information transmission refers to the passing of knowledge from provider to patient, which, as can be imagined, is an active sender-passive receiver relationship (Geist & Dreyer, 1993). Physicians are acting in a familiar environment, disseminating information they are already accustomed to understanding, and they filter a patient's

contribution to the discussion into the knowledge that already exists medically speaking. Within a dialogic perspective, both physicians and patients would be more open to “balanced communication (Geist & Dreyer, 1993, p. 236). More than just the exchange of rote medical information must be the goal of the relationship.

Of course, the concepts of identity negotiation and the opportunity to combat finalization are ideal if actually given the opportunity for dialogue. Unfortunately, the traditional patient-physician communication model leaves little room for negotiation, as demonstrated previously, since physicians often dominate the conversation, and patients are not often given the opportunity for meaningful discussion beyond what is considered necessary for diagnosis. Thus, the practical application and operationalization of encouraging patient dialogue is found within formal patient engagement and in an organized framework such as the PES.

Based on the above theoretical assumptions, my research asked the following questions:

RQ1: What benefits (if any) do participants gain from their experience in the PES?

RQ2: How do patients build upon these benefits in other types of health care settings and beyond?

## CHAPTER THREE

### RESEARCH METHODS

The nature of the PES demanded a qualitative methodology that allowed for participants to share their own perspectives and experiences within formal patient engagement (Warren, 2002). I was and am interested in the human experience within patient engagement and its benefits beyond, which was why a qualitative approach was more appropriate. I did not want to quantify the human experience but rather present the varied responses from and nuanced understanding of participation in the PES. Frank (2005) stated that dialogic research instigates the “task of representing individual struggles in all their ambivalence and unfinalizability” (p. 972). As discussed previously, the PES is already a means for this type of research. Like the patient, dialogue and research are unfinalizable and are capable of building upon themselves (Frank, 2005). The intent of this study was to continue the engagement platform for patient participants to understand the potential for change and development within them caused by participation in the PES.

I conducted an ethnographic study to understand both the direct feedback of patients via interviews, and to observe their communicative and adaptive interactions within a studio setting (Johnson, 2002). Discussing ethnography, Berry (2011) cites a flexible definition of culture when he states that he is “drawn to how culture and cultural identity (sexuality, race/ethnicity, gender, socioeconomic, and difference generally) impact and get reconciled through social interaction, and the ways those processes impact self-understanding” (p. 169). He then explains that ethnography both celebrates variety

and diversity, while also acting as a lens for identifying themes and patterns in communication, a two-pronged goal I strove for in my study (Berry, 2011). Conquergood (1991) compared ethnography to more traditional research approaches by highlighting ethnography's embodiment of the human perspective, of alternating from the gaze to the experience of research, from the sterile observation to the illustrious portrait of another human through his or her own means of communication. The PES is already a platform for sharing perspective, thus this study is my extension of this “embodied practice” (Conquergood, 1991, p. 180).

I turn to Geertz who was foundational in establishing ethnography as a legitimate form of study. He described ethnography as “a kind of intellectual effort” (Geertz, 1973, p. 6). This is an apt term for an exercise that is far less about observation and more about the interpretation of the observation (Geertz, 1973). It is not a simplistic process but rather like reading a “manuscript—foreign, faded, full of ellipses, incoherences, suspicious emendations, and tendentious commentaries, but written not in conventionalized graphics of sound but in transient examples of shaped behavior” (p. 11). This description instilled in me an almost frightening realization of the responsibility that was upon me to do these patients’ experiences justice, and to serve their futures by contributing accurate research in the present.

Continuing the topic of responsibility, Van Maanen (1988) emphasized the uniqueness of ethnography in that it is very much an individual journey that is still collective as a whole in its depiction of various societies and cultures. Thus, Van Maanen (1988) explained that both the observations themselves and how they are explicated and

written are of equal importance, emphasizing again the responsibility of the researcher in all aspects of the study. Thus, it was my intent to present the results of this study in a way that embodies the mission of the PES itself: an enthusiastic invitation to patients to participate in and contribute to the jargon-free conversation surrounding translational research, and, more broadly, their health care.

### Approach

I was excited to stand at the intersection of knowledge and power with these participants, but I did and do not take the role lightly, nor can I continue without acknowledging my connection to the PES at the center of this study. Two of my colleagues are directors of this PES, and through my own job responsibilities, I learned of this specific studio and its design. To my knowledge, formal patient engagement is largely, if not solely, driven by population health scholars. Through my graduate education in communication, I came to understand the opportunity for connecting communication theory to the study of patient engagement, both for the sake of escaping the silos that so often plague corporations and academia, and for the possibility of replication in other health care settings. I had already been exposed, via anecdotes, to various positive outcomes of this specific PES, thus, I strove to be continuously aware of my own assumptions from the very beginning of this study. According to Guillemin and Gillam (2004), “reflexivity involves critical reflection of how the researcher constructs knowledge from the research process—what sorts of factors influence the researcher’s construction of knowledge and how these influences are revealed in the planning, conduct, and writing up of the research” (p. 275), indicating that reflexivity should

permeate the entire research study, versus just the examination of knowledge. Therefore, I was cognizant throughout this whole process regarding my prior exposure and how it could have potentially affected what I observed and how I perceived what interviewees were expressing to me. I was prepared to hear responses that did not fit my preconceived notions (Pillow, 2003) by including in the interview protocol (See Appendix A) an opportunity for patients to suggest how to improve future engagement experiences.

### Characteristics and Assumptions

A PES is in itself representative of qualitatively inspired research—there is a method and intentionality to the weekly meetings and an organization in the agenda, yet the goal of meeting is for the patients to each add their own interpretation of, and input to, the discussion at hand, ultimately concluding in one assemblage of experiences. The three characteristics of qualitative research as stated by Tracy (2012)—self-reflexivity, context and thick description—can be aptly embodied in a study of this nature. My prior exposure to the studio piqued my curiosity and caused me to wonder about patients’ experiences in a unique context such as a PES, as well as the intercultural interactions at hand. These exchanges allowed for a rich thick description that transcended the physical setting, although the physical setting itself often lended its own contributions of robust observation. I strove to be the reflexive researcher that Ellingson (2009) describes here: “Qualitative research benefits significantly from embodied writing by reflexive researchers who implicate their bodies as essential components of research design, data collection and analysis, and the creation of representations” (p. 36).

I would consider myself to be a social constructionist on the qualitative continuum (Ellingson, 2009). In this regard, I believe that each participant's experience is his or her own truth, grounded in this specific context. I was prepared to encounter varying realities and recognize them all as truth for each respective individual, especially considering my previous exposure to the studio. Although my mind might crave a positive or post-positive outlook for simplicity's sake, generally speaking, I have to believe this world is too large and varied to have anything other than an interpretive perspective of individuals' accounts of their experiences (Tracy, 2012; Creswell, 2013).

#### Commitment to Quality

Broadly speaking, it was my intention to resemble in some small way the dedication of my employing health system to patient-centered care by instituting a format such as the PES. Additionally, it was and is my commitment to establish tangible grounds for replicating studio formats, as well as to understand the reasons and communicative behaviors behind why a model like this works, so that members of dominant groups in a co-culture can adapt those practices to endorse the non-dominant group.

Touching back on what I said earlier about being a reflexive researcher (Ellingson, 2009), I must reiterate my commitment to having listened wholly to a participant and not just considering the parts of his or her stories that aligned with my positive assumptions about patient engagement. It is important to consider Ellingson's (2009) use of words: "entrusted their stories" (p. 40). To do anything but be reflexive would be to revert to the traditional mode of communication between a patient and physician in a health care setting. Frank (2005) states that in dialogical research, the

researcher and the participant, in this case, the patient, are on the same team; they are working together to create change through dialogue that builds upon dialogue. Through my studying of individual responses, whether or not they aligned with my original assumptions, I was able to identify themes that created a greater common understanding of all participants in the studio (Frank, 2005).

Tracy (2010) lists eight criteria for qualitative research, and I believe this study exhibits all of them: worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethical, and meaningful coherence. To reiterate, up to this point, patient engagement has largely been the work of population health scholars. As such, I believe this is a worthy topic for its implications in health care. A range of reflections from participants contributed a variety of takeaways from the study, which exudes credibility. Additionally, this study provides a multidimensional representation of a PES for those unfamiliar with it (and potentially even for those who are involved). I have stated my commitment above to acknowledge all of the data that was presented to me despite my positive assumptions about a PES. From my first day in the field and with each participant, I intended that the sincerity of this project was apparent in both my self-awareness of my past experiences and how those influenced my role as the researcher, and in the entire construct of the study and its methods.

#### Discourse Collection

After obtaining IRB approval and permission from studio leaders, this study commenced with both studio function observation as a focused participant observer

(Tracy, 2012) for a total of 16.75 hours over the course of two months, and semi-structured, in-depth interviews with 10 patients in person.

The field for my observation included scheduled meeting rooms for the studio's bi-weekly board meeting on Tuesdays at noon. Fieldwork also included condition-specific studios, such as diabetes and rheumatoid arthritis. Sites for these meetings were in a church meeting room, hospital conference rooms at the main campus, and facilities further afield in a more rural setting, as well as at midway points for both rural and urban studios to meet together. Notes from fieldwork were recorded on a notepad and then transcribed into formal field notes, while interviews were audio recorded and then transcribed verbatim. I attended 11 total studio sessions, including three main, one rheumatoid arthritis, three rural diabetes, one urban diabetes, and three combined diabetes studios.

Individual semi-structured, in-depth interviews were held face to face in a variety of locations including medical school meeting rooms, a hospital cafeteria, Starbucks, and a hospital lobby. I interviewed 10 individuals using the semi-structured interview protocol listed in Appendix A and then transcribed verbatim their recorded interviews. The average interview time was 35:30. Three men and seven women comprised my interviewee pool, and they ranged in age from 27 to 76.

I made my research intent known to the co-directors of this PES for transparency's sake and for the potential for snowball sampling (Creswell, 2013). I asked for their recommendation of patients who might be interested in participating. One co-director connected me via email with all seven of the main studio's patient participants,

six of whom I interviewed. This same co-director also leads the rural diabetes board, so she recommended three potential interviewees, two of whom I spoke to. She then connected me with the rheumatoid arthritis board leader who also recommended a patient. I reached out to the director of the urban diabetes board to connect me with a specific patient I had noticed during my field observation. I contacted participants directly by email to request an interview.

To ensure that proper attention was given to all types of participants in the PES, my intent was to reach a maximum variation sample through specific recruitment efforts that include individuals with unique demographic qualities, such as a rare medical condition or a minority status (Tracy, 2012). With the inclusion of an African-American participant, a transgender participant, and patients with varying conditions such as diabetes, rheumatoid arthritis, blood disorders, and digestive disorders, I believe a diverse sampling was accomplished. Interview and field note files are stored on my student Google Drive account, accessible only by me and the principle investigator, Kristen Okamoto, PhD. Files will be destroyed after three years.

Table 3.1 (Names changed to protect privacy)

<b>Patient</b>	<b>Age</b>	<b>Gender Identity</b>	<b>Studio</b>	<b>Interview Length</b>
Eric	76	M	Main	38:37
Nick	27	M	Main, Rural Diabetes	36:44
Gladys	69	F	Main, Rheumatoid Arthritis	47:28
Amanda	33	F	Main, Diabetes	31:42
Gina	66	F	Main	34:50
Elyse	57	F	Main	36:51
Madeline	55	F	Rheumatoid Arthritis	39:28
Etienne	70	M	Urban Diabetes	31:52
Nadia	41	F	Rural Diabetes	28:55
Tatiana	61	F	Rural Diabetes	31:08
<b>Average</b>	<b>56</b>			<b>35:30</b>

Participants were provided a copy of the consent form via email at least 24 hours in advance, so that they could read the document ahead of time and not feel rushed to sign it when actually meeting with me. For the interviews, participants first signed the consent form and were then made aware that they would be recorded and would remain

anonymous in the study. Interview questions were open-ended and inquired as to how the individual initially became aware of this PES, and what prompted them to continue returning. Additionally, I inquired as to why they think a concept such as patient engagement is meaningful, both for themselves and others (See Appendix A for full interview protocol). The nature of the questions allowed for more conversational discussion as opposed to rote questions and answers (Harrington, 2003). Frank (2005) discusses the intricate relationship between interviewer and interviewee and how there should be a “reverberation” and “further reverberations” (p. 968) based on their dialogical interactions. It is my belief that the interviews operated like so. After all of the interviews were complete and transcribed, participants were provided a copy of their interview transcripts.

#### Site Description

At the time of the completion of this study, the main studio consisted of seven members, although discussions were in place to add more based on an increased awareness of a need for more demographic variety. The main studio met biweekly, although sometimes meetings were canceled or added on an as-needed basis. The meeting spaces were either in medical school study rooms or in hospital meeting rooms. It should be noted that all participants in all studios received a small stipend for each studio they attended.

The rheumatoid arthritis studio, under the direction of a researcher at a partner institution, was working on an app designed to help track symptoms and flare-ups of rheumatoid arthritis. I only attended once, and that day a graphic designer professor from

a local university was in attendance. The discussion was largely about the user experience and the correct flow of design, with input from patients on what information and functions mattered most to them.

The co-directors of the main studio were also the directors of both an urban and a rural diabetes board, funded by a grant from the health system. The purpose of each of these studios was to aggregate what one of the directors termed as “wonderings” about diabetes as a disease, life with the condition, and education surrounding reducing symptoms and actual occurrences of the disease itself into formal research questions to present to potential researchers. Additional grant money was provided to support the actual project, thereby encouraging researchers to tackle an already-funded study. (To clarify, my study was not a part of this grant and did not receive funding of any kind.) The rural and urban studios met both separately and together, and, according to the director of the studio, while a lot of their conclusions about research interests were similar, the rural group placed a greater emphasis on their desire for increased education on nutrition and exercise and better access to these educational resources once created.

The urban studios were hosted in the same settings as the main engagement studio, while the rural studios were further away. In fact, I posit that my field observation of the rural studios started before I ever arrived at the actual location. I remember driving by these verdant fields and farmlands and the John Deere tractor that sat just off the highway exit, on my way to the meeting places, first a church in the small town, and then at the community hospital. While the scenery was beautiful almost to the point of being distracting, I had to remind myself that people live there, and many of them without

ready access to physical health care or health education and resources. Over the course of the few times I met with the rural studio, I wondered how, in the 21st century, just some tens of miles could separate people that are just as entitled as others to research and access to care that could very well preserve their lives.

### Discourse Analysis

Lindlof and Taylor (2002) provide a three-pronged goal regarding data analysis: “data management, data reduction, and conceptual development” (p. 211). This simple but thorough outline directed me during both the data collection and initial coding phases and as I commenced with a more thorough manual analysis process (Lindlof & Taylor, 2002).

First, I transcribed all interviews shortly after conducting them, as well as wrote formal field notes after each observation period. I managed my data by first storing my interview transcriptions, totaling 118 pages; my field notes, totaling 36 pages of single-spaced, typewritten formal notes; and any artifacts from field observation, such as PowerPoints, meeting agendas, and patient handouts, on my secure student server, a cue I took from Tracy (2012). From the very start—the first interview and the initial opportunity to witness a studio—I employed the constant comparative analysis method (Glaser & Strauss, 1967; Charmaz, 2006). After transcribing each interview and writing formal field notes, I reread each document and first-level coded broadly, capturing ideas I deemed relevant to the overall direction of the study (Tracy, 2012). I simultaneously created a digital coding key that included a range of coordinating colors that helped me attach participant input to various ideas and themes (Lindlof & Taylor, 2002). I attempted

to view each interview independently and thus adapted my methods to the complexities of the data by continuing to develop additional codes (Rubin & Rubin, 1995), or modifying existing categories, according to the constant comparative method (Tracy, 2012). Additionally, throughout this data management process, I wrote separate notes on a master notes sheet, also on my secure server, that captured my thoughts on the various points and ideas that were emerging from my reviewing each interview transcription. I then printed out hard copies of each interview and of each entry of formal field notes to reread and make notes in the margins. These documents were placed in a locked shredding bin at my place of employment once I had utilized them to their fullest capacity and had springboarded into the next stages of analysis.

The data reduction portion of my analysis was more difficult than I anticipated since a number of interviews contained discussions on a variety of topics relevant to health care and life in general, although in the interest of maintaining focus in my study, I had to commence with eliminating content. Some initial codes included topics such as self-deprecating humor, sarcasm, and the concept of patient engagement versus patient experience. While relevant ideas to explore on their own, I ultimately had to set them aside to allow for the more universal threads amongst all participants to take shape. I began my data reduction process and secondary-cycle coding (Tracy, 2012) by creating five separate documents on my secure student server that allowed me to cull quotes with similar themes from my hard copies, both field notes and interviews. This process segued into the final stage of my analysis with each document serving as an organizational and visual tool for understanding emerging themes.

The conceptual development portion of analysis (Lindlof & Taylor, 2002) commenced with my inputting structure to my five documents that became holding places for each of my data entries. These served as the basis for the outlines for each theme described below as axial coding was occurring (Charmaz, 2006). While the very nature of an engagement studio demands openness to the patient perspective without finalization (Frank, 2005), I was confident that themes were emerging and replicating themselves in the patients' responses and that saturation had occurred (Bowen, 2008).

After the analysis portion of my study, I opted to conduct a member check session with the main studio members. Of the seven patients present, four of them had also been interviewees. I was thrilled for the project to come full circle and present my study about the studio to the studio itself.

I shared a high-level look starting with my research questions and a brief definition of ethnography. I proceeded by sharing each theme and its subpoints, as well as quotes that supported each theme. This portion segued into the implications section, where I discussed the topics of thematic relationships, obesity, framing, and implementation of better communicative practices in health care settings. Finally, I opened it up for questions and comments. I also presented a series of three graphs that posited the potential relationship between the three themes, centralized around the identity of the patient expert. This segment of the member check session is explained further below and includes all three illustrations.

After my presentation, the studio had the chance to comment. The first patient to respond stated, "I wasn't interviewed, but all of those quotes seem like something that

might have come out of my mouth” (Studio participant, presentation feedback, October 16, 2018). This began a discussion on how the patients related to the various quotes and themes presented with thoughts on their affirmation that someone is actually listening to them, that they’re making a human connection, and that they have a right to ask questions and obtain information about their health care. I was confident that the patients were understanding and supportive of the results of the study.

One patient did indicate her discomfort regarding the idea of impacting change leading to empowerment. She stated her concern that the patient’s horizontal identity as a co-investigator was at risk, since the studio is already created to allow patients to impact change, thus there being no question that they actually will. As such, I included additional language in that section that delineated between the studio’s practical structure that enables patients to impact change, and the feeling of empowerment they benefit from when impacting change.

## CHAPTER FOUR

### RESULTS AND DISCUSSION

#### Themes

Building on identity negotiation and co-cultural theories (Ting-Toomey, 2016; Orbe, 1998), this study sought to identify any benefits for a patient who participates in formal patient engagement, and, if there are any, how these benefits transfer to other settings, both health care-related and non. The results both coincide with and build on Joosten et al.'s (2015) study, which stated that outcomes for Vanderbilt studio participants, who were general community members and not necessarily patients, included new knowledge and perspectives, as well as feelings of worth and significance. This study springboards off of those concepts and utilizes qualitative interviews and field observation to affirm the effectiveness of formal patient engagement and understand its impact through rich examples. Additionally, on a broader level, the outcomes address health communication issues at large for patients specifically. I will present three major themes: education, empathy, and empowerment; that became apparent after my interviews with patient participants and my field observation, identifying how each of these themes is relevant to both research questions:

RQ1: What benefits (if any) do participants gain from their experience in the PES?

RQ2: How do patients build upon these benefits in other types of health care settings and beyond?

Additionally, I will explore how these themes were interrelated and catalysts for each other and often did not exist as a siloed result. Finally, I will discuss the dialogic

implications of patient/physician communication as it was addressed in both the studio meetings and in patient interviews.

### An Educated Patient

A feature of participating in a formal engagement studio that many patients acknowledged was the opportunity for education on a variety of levels. At the very least, many patients shared that they simply enjoyed the opportunity to learn, indicating a general willingness to receive and enthusiasm surrounding knowledge. During my field observation, I attended a variety of presentations on research topics such as developing walking programs for cancer-surviving senior citizens, understanding best practices for creating a diabetes instructional video on injections, and creating a symptom-tracking app for rheumatoid arthritis flare-ups. In 2018 so far, the main studio has witnessed presentations on virtual reality and pain control, cellular health, access to opioids addiction resources, care for families with children who have autism, and improvement of care pathways for surgical cancer patients, all avenues of study that general patient populations aren't aware of or don't have access to.

Tatiana said that she has “learned so much that I didn't know and so much that I would like to know” (Tatiana, personal communication, August 18, 2018). When asked what she found most meaningful about the studio, Gina responded, “The opportunity to hear all the things that you get to hear and to be able to ask questions of people who are doing some pretty cutting-edge things in their work” (Gina, personal communication, July 3, 2018).

### *Exposure to Health Systems and Research Processes*

Patients also attributed to the studio a basic education on the workings of a health system, especially at a teaching hospital, a term that might generally be recognizable by the public but not understood to its fullest degree. Nick had stated, “I think there's a misconception, you know, as to what is a teaching hospital” (Nick, personal communication, June 28, 2018). Asked if being involved in the studio had changed the way she viewed health care, Amanda had said:

If we're in-patient in the facility, you know, knowing and understanding and even structuring of, like, OK, this is a fellow, this is a resident—no, I need the actual doctor. You know, it's kind of helped me understand some structuring that, um, if I wasn't so connected to all this, I probably wouldn't have understood or been so aware of (Amanda, personal communication, July 2, 2018).

As stated previously, the diabetes studios worked on formulating research questions to present to researchers within the health system and the system's academic partners. Thus, the studio participants underwent education on the research process, and then performed the complex task of whittling down a series of ideas into formal questions. Of this experience, Nadia said:

It's been really interesting to go through, seeing what the process of coming up with research topics and how you—you know, we've just had to debate every single thing about the topics and things to be presented, and um, it's been really interesting to see different—other patient experts' takes on what we're supposed to be doing, and their, you know, where they're coming from. But, um, getting to

listen to the different doctors and all that have come in to help us think about honing the research topics. I've loved that. It's been really interesting (Nadia, personal communication, August 18, 2018).

As members of a non-dominant group (Orbe, 1998), it might be assumed that patients are incapable of understanding complex medical information, or the various complicated avenues of research studies. However, considering the breadth of research studies that the main studio has critiqued, and that the diabetes studios are actually charged with formulating the research questions, a greater faith and trust in a patient's capacity to understand is warranted, allowing them to counter typecasts of general patient populations (Orbe, 1998).

### *Health Advice*

While not a support group by definition, these studios often offered the opportunity for patients to discuss various personal disease experiences with each other, especially on the rheumatoid arthritis and diabetes studios. A function of their group identity in a co-cultural setting (Orbe, 1998), these relationships served as a form of “intragroup networking” (p. 74), and as a source of tips and encouragement for one another in their own respective health journeys and experiences. Madeline said, “It's not a support group, but you learn some things, you know?” (Madeline, personal communication, August 10, 2018). She proceeded to explain how she wasn't familiar with the potential side effects of rheumatoid arthritis, such as hair loss and weight gain, but attending the studio had helped her learn what to expect from the illness due to other studio participants' experiences.

I observed a number of conversations about tips and tricks that diabetes patients shared with each other, regarding benefits of a vegan diet, best places to buy inexpensive test strips and other diabetes supplies, and grocery store recommendations. A patient recounted how she thought she was doing well by eating carrots instead of candy, until another participant had pointed out that there was a lot of sugar in carrots. This same patient even took the time after a studio meeting to ask a visiting physician a question about her medications:

I always wondered why I had so many medications for the diabetes itself, and when I was able to talk to her after the meeting, she explained each one to me, and it made perfect sense. Because I knew how this one was helping this one was helping this one, where before I didn't understand that. I thought, You know, why am I taking all of this? (Tatiana, personal communication, August 18, 2018).

Etienne shared with me that after learning he was pre-diabetic, he set out on a health journey, an aspect of which was his joining a diabetes studio. On being a participant, he said, “It just gave me more options, and it gave me, um, more insight on things I should be doing for specific areas” (Etienne, personal communication, August 14, 2018).

#### *Patient/Researcher Communication*

Because of the purpose of presenting patient-designed research questions to researchers, the diabetes studios underwent various training sessions on patient-researcher communication and how best to share feedback with researchers. I attended both the rural and urban diabetes studios on the day that a director was giving a

presentation on best practices for communicating between patients and researchers. The director had commented that to her knowledge, little research existed on such a topic. Components of the presentation included actively listening, making the researcher feel at ease, and understanding the variety of modes of communication, including verbal and nonverbal cues, text, and body language. The term “communication negotiation” was used in the context of building and sustaining trust and respect to maximize the mutual working relationship. Without realizing it, the director was directly referencing the components of identity negotiation and comfort-building between co-cultures (Ting-Toomey, 2016). Jargon was also addressed as a characteristic of researcher culture (Orbe, 1998). Patients in both studios compared medical lingo to examples such as texting language, unfamiliar acronyms at a new job, and lawyer speak. The director encouraged participants to not be intimidated by unfamiliar terminology.

During the urban diabetes studio session on this topic, the participants extended the discussion on modes of communication by exploring the variety of characteristics that could affect communication. The discussion was initiated by a participant who shared how her ethnicity often affected her interactions with her own physicians, although her physician took the time to learn her cues, which subsequently built her confidence when seeing him. The other patients then shared other cultural features that might impact the effectiveness of communication, such as gender, age, and disability, echoing Harwood et al. (2005); Giles, (2012); and Watson and Giles (2008), that characteristics of identity in intercultural communication should extend far beyond ethnicity.

The overall topic of patient-physician communication will be addressed later in this study, but I wanted to remark on this particular presentation as it helped me understand that communication education goes both ways, in that we can educate both physicians (and researchers) and patients to communicate effectively with each other. Encouraging patients to put researchers at ease and to actively listen bolsters patients' position as a very crucial member of the health care or research team. Patients' opinions are so important that researchers might actually feel nervous upon presenting. Just as it is imperative for health care providers to actively listen to patients and be curious, so is it for patients to do likewise.

#### An Empathetic Patient

A remarkable note about the following theme of empathy is that patients were the non-dominant group (Orbe, 1998) in this studio setting, yet they still gained new levels of understanding of each other and of patient populations as a whole. First though, it should be noted that the patients did not lack empathy before joining the studio and then suddenly gain it after participating. In fact, many of the reasons given for joining the studio discussed wanting to positively impact the future of health care for patient populations or as a general community benefit, implying an already existing empathetic motive, and an understanding of the potential impact of their role as representatives of patient populations (Orbe, 1998). When asked why she agreed to become a participant, a diabetes studio participant, frustrated with her own experiences and lack of diabetes education, said, "Just the idea of making a change. I wanted something to do, but I wanted something that made a difference. And this made me feel like I was doing

something for my community” (Nadia, personal communication, August 18, 2018).

Continuing the broad communal thinking and how it applies to patient populations, Nick stated:

I'm very outcome driven, and I love being a part of things that are going to progress not only what we're doing as a society but as an industry, and so, as a patient, in all your experiences, there's good and bad, there's always good and bad, and so, if we have the opportunity to change someone's experience—you know, one bad experience to a good experience is a win to me (Nick, personal communication, June 28, 2018).

Another participant said:

My whole focus, I mean my personal focus is what can I, at this time in my career, contribute in some little way to improving health care in the United States. And continue to drive it toward ultimately the well-being of the patient, you know? I mean, your total margin and revenue, and all of those things are important, but ultimately how does it impact the individual patient? (Eric, personal communication, June 27, 2008.)

In the anticipation of empathetic opportunities, some cited specific health care experiences as reasons for joining, such as having had a specific surgery, a chronic illness, or a social issue, or as having to advocate for family members in the system, again identifying participants' willingness to speak on behalf of others who have had similar health care experiences (Orbe, 1998).

That's one of the things that excites me about being part of the studio is that I've been a patient for—kind of in a major way for a number of things, and, um, and I consider the patient status along with the counseling that I've had that goes along with weight loss surgery, that goes along with addiction, that goes along with changes I've made recently, and um, so, I like being able to talk from my perspective (Gina, personal communication, July 3, 2018).

Referring to his experiences helping both his elderly parents and his in-laws navigate the health system, Eric stated:

I learned a lot vicariously more than personally, but you know, how the system worked, and sometimes the system worked very well, and sometimes it was disastrous, and depending on the individual, you know, it comes down to the individual physician or the individual nurse or the receptionist, for that matter. So that has kind of framed what works and what doesn't work from a patient standpoint. That's kind of the thinking I bring to the Patient Engagement Studio (Eric, personal communication, June 27, 2018).

One patient mentioned her children as a reason for participating in the studio: “My children will grow up in this system, and this health care arena, so I want to leave it better than we found it” (Amanda, personal communication, July 2, 2018). Madeline recounted how it was when she had received the medication she needed to effectively control her pain, she began to wonder about opportunities to help future patients with the same condition prepare themselves for the aspects of her condition that they weren't expecting or didn't feel knowledgeable enough to know how to handle:

If I can do something or be a part of something that helps educate someone else for this, I want to be a part of that, because it's just like, this thing was painful. I could have a baby better than I could deal with some of that stuff, so, um, and you could just get no relief (Madeline, personal communication, August 10, 2018).

Nadia is on the diabetes studio on behalf of her mother, and because she noticed a rising trend of juvenile diabetes:

I am a special education teacher. I work in a, um, a school in a historically poverty-stricken area. So one of the reasons that I kind of was interested in is that we do have a lot of students who have, especially type 2, but also type 1, diabetes and a lot of that is attributed to, um, you know, the diet that they're typically exposed to mainly because they're high poverty. Um, I also—my mother is a type 1 diabetic and has been since she was 21. I think hers was considered juvenile onset. Um, I've never been diagnosed, believe it or not, but I know that as I go through and get older, and she gets older, I'm going to be a primary caretaker for her, so the interest was there for that (Nadia, personal communication, August 18, 2018).

### *Fostering Empathy*

As identified above, the participants already had community- and others-focused motives for joining, although the consistent exercise of examining research projects from a patient perspective has conditioned the participants to think more empathetically. One patient stated:

I'm interested in doing things for the betterment of patients, and I like to think that as I look at these research projects, I'm thinking of, not necessarily of myself in those settings, but of real people in those settings, and how one might make communication better with the doctor or the PA or whomever it was going to be, uh, so that everybody gets better at letting the other party know what's happening with them (Gladys, personal communication, June 29, 2018).

I witnessed examples in some of the studio gatherings of participants thinking for patient groups who couldn't actually be present. One particular session was a presentation about a walking exercise program for cancer patients who had recently underwent chemotherapy. Several participants addressed potential social and safety issues, such as physical condition after chemotherapy, access to transport and a safe exercise environment, weather conditions for the elderly, and patients' negative feelings about themselves after just finishing treatment and therefore not being capable of effective exercise.

Elyse, a member of the main studio, had mentioned that her participation had "deepened my awareness that there are a lot of people dealing with a lot of stuff. And there are a lot of people who have overcome a lot." She went on to elaborate that, while each person has their own share of health struggles, and that the perspective of the possibility that conditions could be worse, each individual's own personal experiences are worth considering. "I think it's important if you're having a hard time to feel validated in that," she said (Elyse, personal communication, August 1, 2018).

Eric, a 76-year-old male, described his lifelong journey in fostering and expressing empathy, especially given his mindset and personality. His words echo Frank's (2005) charge to clinical professionals to not finalize the patient, as he or she is a living, breathing person with complexities and unending personal attributes that any caretaker would do well to understand in order to assess the larger context of an individual's personal health.

You know, each of us have different—you know, I mean, I've had to learn to be, to be able to express, not that I don't feel it, to be able to express empathy. I mean, that was part of my growth. My focus all my life has been, All right, we've got a problem, let's fix it. You know, well, the problem involves a human being that has feelings and so on. So how do you fix it, while recognizing that you're dealing with a whole person? So that's been something I've personally had to learn, and the Patient Engagement Studio has been one element of that process. (Eric, personal communication, June 27, 2018).

### *Group Identity*

Many patients referred to the camaraderie and group identities that were formed among all studios, especially the main one. Listening to the evolution of these studios provided insight into how patients grew in their empathetic understanding of each other and their respective individual perspectives, especially considering the differing backgrounds of main studio members, and also how an identity around a condition, such as diabetes, fostered sensitivity. Orbe (1998) alludes to this in his assumption that a

communicative function of co-cultural theory is that intragroup members will search out relationships with each other.

Several patients had mentioned that when they were approached to be a part of a studio, they did their research but still considered it to be more like a focus group. Because the concept of formal engagement is relatively new, it is not often understood, and so it was only after they had attended several times that they understood its function. Still, they had not formed a cohesiveness as a group, echoing the unpredictability of, and uncertainty surrounding, interactions among different groups, or in this case, different individuals, that Ting-Toomey (2016) refers to in identity negotiation theory. For the main studio, without a chronic condition as a binding characteristic, the members felt especially uncertain about their purpose and identity. Amanda said about the main studio:

We were trying to figure out what we were. And who we were. We didn't have an identity. We knew we had all these people in a room and that we were all very different, but what is our goal? We kind of knew our goal, or what's our dream statement or what's our purpose. So we had these loose ideas, so we spent months trying to figure out who are we and what are we and what do we want to do. So I think one of the reasons why the patients are so invested as we are, is because we got to help build the identity of the studio (Amanda, personal communication, July 2, 2018).

Ting-Toomey (2016) offers a resolution though, when she posits that meaningful interpersonal interactions will foster trust. One patient equated the studio to a trust-building model, using the YMCA's Big Picture Deck as an example.

The model of—was the trust-building model... I did a little research on, you know, where the Big Picture Deck came from and talking about, um, how it came from the YMCA, and how it was built to build communities—to bring communities together. And, um, people from different backgrounds, and people from different upbringings, so that's how I feel about the studio model. I feel like we're all different ages, we all come from different ailments, or chronic conditions. We all come from different health systems we've had experiences in, and you know, being able to bring a perspective that's totally different than everyone else's is very unique, and it's interesting when I see people come in with their perspective, you really get an idea and see where they're coming from (Nick, personal communication, June 28, 2018).

Their differences ended up serving Orbe's (1998) charge well—that when speaking on behalf of a patient population, that individual's complex identity was not sacrificed, to the researcher and even amongst the group. As alluded to above, not only did they get to educate researchers about their identities, they had the opportunity to educate each other. As trust and identity began to form, participants learned to recognize the various perspectives and backgrounds of their fellow studio members, and even who would speak from a specific point of view:

First off is the quality of the people involved in the studio. You know, they—it feels like such an honor to be able to be engaged with those folks, and um, hear them ask their questions and to—you know, you get to a place where you begin to realize, OK, I know who's going to answer that question. I don't even

need to go there because [Patient] is going to take care of that stuff. And, we also have different levels of expertise and things that we get excited about—group thinking is always fascinating to me. It's truly experienced there, and it's positive (Gina, personal communication, July 3, 2018).

For the diabetes and rheumatoid arthritis studios, empathy was perhaps a little more obvious in the cultural identity of a specific health condition (Harwood et al., 2005; Giles, 2012; Watson & Giles, 2008). This manifested itself in a variety of ways, through the sharing of tips with each other, and more significantly, the understanding that others are facing worse diagnoses, pain, or complications, again demonstrating Orbe's (1998) "intragroup networking" (p. 74) function. Madeline said, "Seeing friends that have become friends now, you know, like OK, this is what you're dealing with. That's a lot worse than what I'm dealing with. Or, you know, I can relate more to that I guess. And more understanding" (Madeline, personal communication, August 10, 2018), while another said something similar: "I'm trying to sympathize. I tell by my mediocre problems against their large problems. It makes me feel very insignificant about it when we talk because I have no reason to be complaining at all" (Etienne, personal communication, August 14, 2018).

### An Empowered Patient

The theme of empowerment builds on Joosten et al.'s (2015) study that participants experience feelings of significance and worth, as well as affirms that Ting-Toomey's (2016) effective identity negotiation ends in participants feeling "understood, respected, and affirmatively valued" (p. 4). As stated previously, the engagement studio

is a springboard for patients to experience a horizontal relationship in the mostly top-down structure of health care, thus empowering them to speak. Additionally, the process of understanding their potential for impact has expounded on their empowerment both in the studio and outside of it in other settings. Important to note, participants are referred to as patient experts on the studio's website and in grant applications. According to one of the directors, this designation elevates the patient as more than just a faceless cog in a complex health system, for the benefit of the patients and researchers to understand the value of patient input.

### *Impacting Change*

First, it should be noted that a PES' design is intended to enable patients to impact change. Their identity as patient experts and co-investigators in a study is already upheld simply by their involvement as a studio member. To understand the significance of this model, some context would be helpful. While patient involvement and input has existed and does exist in health care, it has not always been apparent to patients that their contributions made a difference. A patient had recounted to me that several years prior to being a studio member, she had participated in a facilities committee for the hospital. She said, "It was checking a box, because they listened to what we said but it really was like, OK we're checking the box. It was very apparent that's what that was" (Elyse, personal communication, August 1, 2018).

Nadia compared her engagement studio experience to a similar "box-checking concept" but compares it to their current work in the diabetes studio:

This is not just show up so we can document that we're doing this. You know, so that [health system] can just say we're, you know, we did this. Here's where all these people met. Here's our data that we're trying to do something. That this is going to a foreseeable end goal and then it will carry on from there (Nadia, personal communication, August 18, 2018).

Another patient used the word “empowering” to actually describe her involvement in the studio and the potential for impact that they have:

The idea of getting to be a part of something that was bigger, you know. I think everyone thinks, OK, I'll just go to my doctor and go through the motions, so that when you can detach from that and get to look at something big picture, it almost is a little empowering to know, OK, well, maybe this, that whatever we reviewed, maybe in a year or down the road, it's going to be something we actually do, and use and be productive. Um, and that matters to my health care and to my children, and to everyone, so to me, it's just getting to be a part of the bigger picture, um to be able to help (Amanda, personal communication, July 2, 2018).

Attached to the concept of impacting change is the feeling of hope in the actual ability to improve the complexities of health care, and in the ideas that individual patients do not have to feel lost at sea in the complicated inner workings of a health system, and that their own care is in their hands:

I think health care is probably the most important thing that we can all impact today. There are many other things that are important that we can't impact. And I'm not going to have any impact at all on who the next Supreme Court Justice is

even though I might like to. But nothing I can do about that, but there are things I can do about health care, which is an area where there is a great deal of opportunity for progress, and there's certainly a great need for progress, so it's my little place where I can help with that and help my community (Gladys, personal communication, June 29, 2018).

For patients to speak for themselves and positively negotiate their identity left them feeling “affirmatively valued” (Ting-Toomey, 2016, p. 4): “I think it is definitely a, um, a positive hope that things aren't going to stay the same. That people are working to, you know, start from the ground up, which is the research,” said a patient (Nadia, personal communication, August 18, 2018). For diabetes studio patients especially, the structure of their involvement in creating research questions and that researchers would care to investigate what’s most important to patients was promising, as was the idea that they are capable of self-improving:

I used to think, Well, you can't do anything about it. You can't say anything about it because there's nothing you can change. This has made me think that I can make a change. That I can contribute to, um, something that will improve diabetic lives. And so that's—it's made me feel good about myself (Tatiana, personal communication, August 18, 2018).

### *Speaking Up*

As patients told of their early experiences in the studio, many discussed the uncertainty about the function of the studio and the unfamiliarity with each other. Since the format of a studio creates a springboard for input and participation, participants grew

in their confidence and in their responsibility of educating dominant group members (Orbe, 1998). When asked of any “aha” moments Gina said, “Most of my ‘ahas’ were, Oh, did I really just ask that question? You know, it was, like, kind of a surprise. I kind of made a little bit of a leap” (Gina, personal communication, July 3, 2018). Another shared her reluctance to participate when first attending but then offered insight into her personal evolution:

When I first went, I wasn't sure about speaking out, but as other people started talking, I felt like I had things in common, so then I think it's, you know, uh, it's made me want to speak out more. I feel safe. In that group, I feel safe about what I say. Where like in other places I'm not quite, I don't say what I think or mean, because I don't feel quite as safe letting it out. So I think that's what attracted me is that I felt safe in that meeting that I could say what I was thinking and in how I was feeling, and not worry about somebody looking at me funny, making fun of me, or you know, just going like that [makes eye roll gesture]. I didn't feel that (Tatiana, personal communication, August 18, 2018).

I heard multiple patients relay stories of empowerment in physician settings, and how they've learned and are learning to advocate for their own care, which is another manifestation of validation (Ting-Toomey, 2016). One patient said, “It makes me more apt to say, ‘Hey doc, can you take a minute and answer this for me?’” (Tatiana, personal communication, August 18, 2018). Another had increased in his awareness “that I had the right to be in charge of my own health” thanks in part to his involvement with the studio (Etienne, personal communication, August 14, 2018). When asked if the involvement in

the PES had changed her view of health care, a patient answered affirmatively and followed it up with this statement:

Everyone in the room has definitely already had a voice prior to being involved, but now I think our voices are just strengthened, and we're more—I can't speak for everyone, but I am definitely more assertive in how I communicate in general from a health care perspective (Amanda, personal communication, July 2, 2018).

She followed this statement with an account of a recent surgery she had scheduled, when a health professional recommended she not go through with it. She then found herself in an uncertain situation, unsure of the correct path forward.

Beforehand I would have been completely torn, you know, like, OK, I have someone saying this, and I have someone saying that. There's multiple ways to hopefully get to the same goal. Um, but I was pretty clear already, like, No, this is what the doctor said. This is the direction I need to go. I don't need to be detached from this idea. The way that I'm going is fine (Amanda, personal communication, July 2, 2018).

Elyse relayed a similar experience when talking with her anesthesiologist before a surgery, and how she felt more empowered to communicate her strong dislike for anesthesia. She was able to negotiate a different dosage for herself so she didn't feel as out of control when she woke up from her surgery:

I think it has, because of that, it has made me feel empowered. I mean, I'm not really a wallflower anyway. I'm pretty much going to stand up for myself. But I would say that conversation with the anesthesiologist came a little bit out of this,

just because he opened the door, and I thought, Well, I'm going to tell you exactly what I think (Elyse, personal communication, August 1, 2018).

### Relationship of Themes

While each of these themes are significant on their own, I'd like to explore with examples how these benefits influenced and can influence each other, especially for application's sake. While the topic of patient/health care system communication will be addressed further below, I would like to briefly comment on the educational intersection of patients and a health care system, and their individual health care providers, and how vital it is that patients have access to correct information. Understanding the relationship between these three themes might aid in connecting opportunities to maximize communication channels amongst patient populations, allowing for health information to reverberate. Additional consideration should also be given to what a patient actually wants to know, whether that be general research knowledge, more specific information related to their health condition, and more practically, the structure and organization of their local health care provider. I touch back to Dutta's (2007) culture-centered approach, versus a culture-sensitive approach: the opportunity lies with the health system to outreach to patients to inquire as to what they need and want most, versus just relying on their own data and expertise.

First, patients' desire to understand and encourage each other can result in educational opportunities, and with already existing knowledge gleaned from a studio, empower that interaction. Etienne, a diabetes studio participant and who is pre-diabetic,

emphasized the power of group identity and the mutual understanding of each other's health concerns, as well as tips on how to improve, when he said the following:

I mean, I've been listening to everyone else talking about the things that people with full-blown diabetes and got all the problems they got and going through, it makes me want to do better. And we talk about what we're doing and what we're eating. Um, the trials and tribulations they have, and it just inspires me to do better, and I am doing better...We look forward to seeing people come in and say, "How did you do last week? What happened with this and what you did last week?" They come in and say, "My medicine did this." And we all talk about that person's medicine. And if somebody cried, we all have to—we all have to stop and almost cry. And we all gather around that person, and we tell them, "We understand! It's not your fault." And I knew it was going to happen, and that's probably why I can't wait to get there. Because I know when I get there, I got folks that are going to know what my problems are, and my problems are very minute to some of the other folks' problems. But they'll still tell me, "[Patient], you need to eat more of this. Do this. Do that. Eat more of that. Or put those chocolate chip cookies away." Stuff like that. So, I love the support I get from the group, and then I also learn a lot from others that have already been to places I haven't got yet. And they telling me, they help me try not to get there. That's why I love it so much (Etienne, personal communication, August 14, 2018).

A rheumatoid arthritis studio participant had shared with me an empathetic moment with a family member who was recently diagnosed with rheumatoid arthritis.

Gladys, also in the main studio, does not have rheumatoid arthritis but is a member to maintain a connection to the PES. She shared the following opportunity with me:

I knew nothing about RA [rheumatoid arthritis] before. To think, I was actually having a conversation with somebody who had just recently been diagnosed with RA and was a family member of mine, and I said, “Well, you know, you need to be sure and talk to your doctor about ya-da-da-da-da. And there are different kinds of medications based on this, and you will undoubtedly get this sheet of info that you're going to have to fill out, it's called the Rapid Three. It has to do with your symptoms, and your medication and that sort of thing, and you should do that and pay attention to it because it'll help you make good decisions about your medication.” And she's like, “Do you have it?” And I said, “Oh no. I just happened across some information on this.” So, I don't know if that is exceeding my authority, but I'm sorry. It was very useful to this woman—my cousin (Gladys, personal communication, June 29, 2018).

Additionally, the same participant remarked on the phenomenon of formal patient engagement and how knowledge can lead to choice in who is providing your health care. If physicians differ in how they care for patients, wouldn't a patient want to see the physician that has a more established rapport and more effective way of communicating? Education and understanding that physician communication is being examined and critiqued, and now taught in medical schools, would incentivize and empower a patient to be much more intentional about their health care choice.

I mean, it's fascinating to think that people in the medical world want to do it, that medicine has gotten competitive, that health care has gotten competitive, and thus people can have a choice. People can make a choice, but they have to have some knowledge in order to do that (Gladys, personal communication, June 29, 2018).

Finally, I was especially intrigued by a story a diabetes studio participant relayed to me about how he is now in charge of the Health Minute portion of his church's weekly service, which incorporates health tips, terminology, and information on conditions such as diabetes, because his pastor knew he was a studio member: "At first, I said, 'Why me?' And he said, 'Because you're in the studio. You can do it.' And so, I do it" (Etienne, personal communication, August 14, 2018). The ripple effects of his education and that he feels empowered to lead it, paired with the communal impact of a faith-based organization, are worth considering and emulating. The congregation members are now indirect recipients of formal patient engagement.

I cannot definitively say how these themes appear, whether in steps, a cycle or simultaneously. During the member check session referenced above, I reviewed the three main themes and then discussed the potential relationship between the three with examples. A co-director had suggested that the patient expert could be the central entity of the relationship, thus I presented the following visuals and asked the studio participants to indicate which one was the most accurate:

Figure 4.1

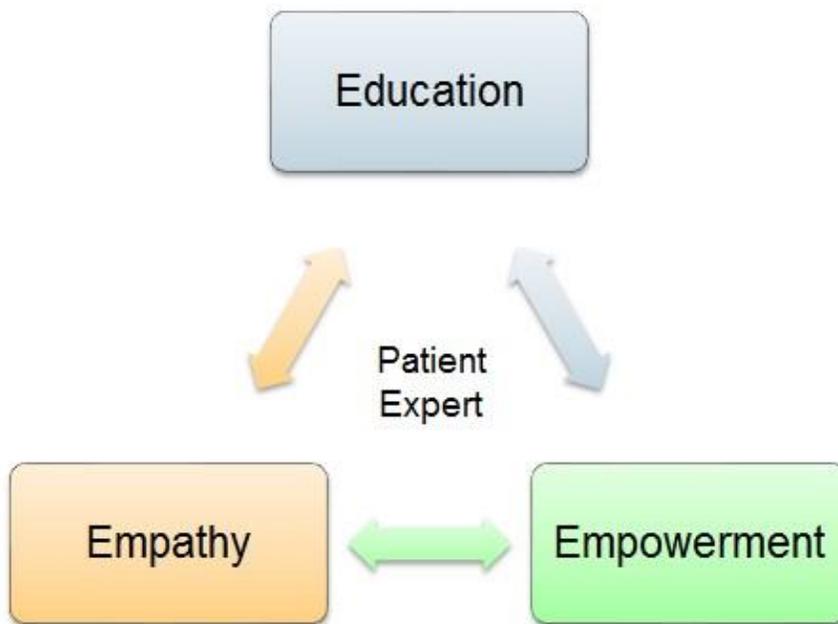


Figure 4.2

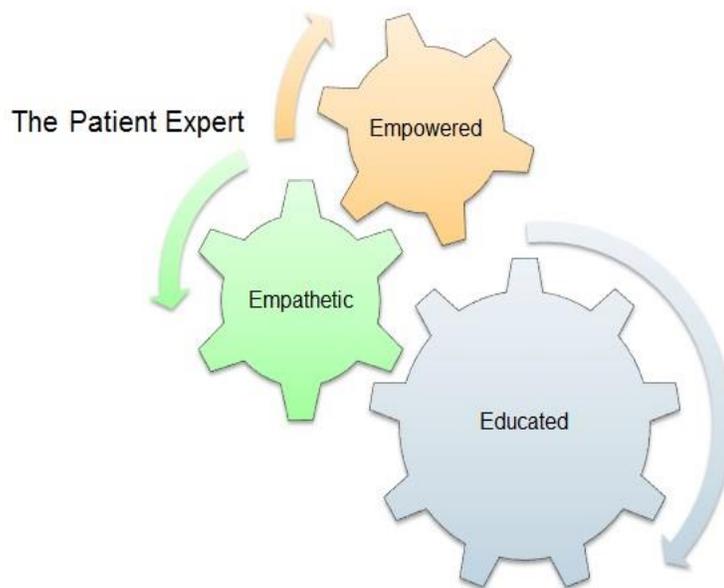
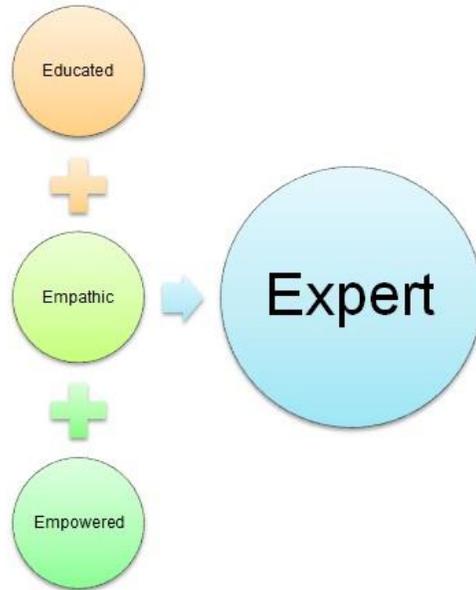


Figure 4.3



The third option was the least accurate according to the studio, and was too calculated. Thus the discussion mostly centered around comparison of the first two. Some appreciated the constant patient identity represented in the first graph, while some identified with the gears in the second graph, particularly how education was a larger gear, and thus the basis for their transformation. Referring back to the first graph, several patients suggested that the graph be more circular, versus suggesting that education was a pinnacle of the relationship. Overall, I was impressed with the feedback, although I was not surprised, given my familiarity with these patients and their attention to detail and thinking for others. While I still cannot definitively say that one graph is more accurate than the other, save for the third, which can be entirely eliminated, I believe these diagrams present a basis for further exploration, as these themes relate to both the studio setting and patient-physician communication patterns in general.

### Applied Dialogic Implications

The topic of patient/physician communication served as both a basis for my study and was a constant theme throughout both my interviews and my field observation. Also, as a student already in the workforce, I want to emphasize my attempt to contribute scholarship that is practical in application, so I turn to Dempsey and Barge (2013) who offer three characteristics of engaged scholarship, which they define as: (1) “committed to utilizing the resources of academic inquiry for practical concerns and useful ends,” (2) “functions as a mode of scholarly inquiry,” and (3) “brings sustained focus to the relational, communicational dynamics that define the research process, seeking to democratize knowledge production” (pp. 6-7). I submit that this study in its entirety, and this specific discussion, are examples of engaged scholarship. In the literature review, I shared some examples of negative patient/physician relationships and communicative interactions. Below, I provide additional accounts, as well as implications of the above three themes.

I have learned throughout this study and from my professional experience that there is a constant and continual compromise and concession required in health care from a health system’s financials and the responsibilities and schedules of a clinician, to the resources available for actually producing educational materials for both patients and physicians, and then establishing effective communications channels for those resources. I understand that I can offer only one perspective—that of a communications grad student who works in health care communications—but from my own professional experience and through the course of this study, I believe it is possible to cull together a variety of

perspectives, much like the function of an engagement studio, to effectively serve all parties involved, the most important being the patient.

### *Obesity*

A number of patients shared their dialogue experiences on the topic of obesity, and how often, the reason for any doctor's visit was hurriedly trumped up to their weight. Ting-Toomey (2016) touches on this when discussing the third and fourth assumptions of identity negotiation theory: these patients feel vulnerable in an environment they are unfamiliar with, and their vulnerability is taken advantage of when their cultural identifier, in this case, obesity, is disgraced. Additionally, no effort is made to understand these patients' contexts, and thus, they are finalized (Frank, 2005). Nadia, a diabetes studio participant shared:

About three years ago, I had a knee go out, and basically just ended up with cartilage gone. And the first doctor I went to said, "You know, there's no way you'll have a knee replacement. We won't touch it until you go on a 900-calorie diet and lose 200 pounds." It's just easy for doctors to say things like that with no support and no understanding of what each individual patient goes through (Nadia, personal communication, August 18, 2018).

Another shared of her struggle with joint pain, and again, a dismissive experience because of her weight:

I was having pain in my joints. And I was having real bad pain in my elbows and hands. And I went to a family doctor and he—the only thing—he didn't really check me over. He told me I was fat. I needed to lose weight and that's all. That

was my problem. That was my only problem was that I didn't know how to push away from the table. And you know, of course I never went back to him. I just left. I didn't do anything. You know? I kept thinking to myself, Well what does that have to do with my elbow or my hands? And I felt so ashamed that I didn't ask about it anymore. I'd just handle it (Tatiana, personal communication, August 18, 2018).

Her reaction coincides with two of Orbe's (1998) behaviors of non-dominant group members: "censoring self" (p. 16), a brief description of which is "remaining silent when comments from dominant group members are inappropriate, indirectly insulting, or highly offensive" (p. 16); and "avoiding (p. 16), which is "maintaining a distance from dominant group members (p. 16). Of course the point of these examples is not to assess whether this participant was a viable candidate or not for a knee replacement, or that the other's joint pain was not connected to her weight, as I certainly cannot make these calls from a medical standpoint. What could be addressed though is the approach to a weight loss conversation and the importance of ensuring a patient has the appropriate education and encouragement to feel empowered to make a change for themselves. Tatiana continued:

I think that's a lot of experiences with especially those who are overweight and stuff is that, you know, we don't talk about it. Because it's not that we're not trying. I mean, I've tried diets galore, you know? And I've lost some weight now and kept it off. I've lost about—I was 270 and I'm down to 240 now, but what I'm saying is even that doesn't make me feel good because people still look at me like,

She's not doing anything about it. And you feel that way when a doctor won't even address it in a way that—like I told mine that I've been drinking water, and then what I get from him is that I can drink too much water. He only sees when I gain. Not when I lose. And I have to look and say, “Did you see?” (Tatiana, personal communication, August 18, 2018.)

The patient touches on the importance of approach in her account and how crucial it is that health care providers address topics in a more effective, empathetic, and even empowering manner. Connected to this discussion on obesity is the topic of framing, which I will proceed with below.

### *Framing*

Similar to the theme of empowerment, the method of how illnesses and lifestyle changes are framed impacted a patient's perception of themselves and their ability to adjust their lifestyle choices. Again, the diabetes patients offered excellent insight into their struggles with how the disease is discussed both in the public and medical spheres. During one particular field study, I listened as patients talk about blame and guilt in regards to the disease:

“I get really upset when they say it is a lifestyle disease. ‘If you hadn't done all those bad things in your life...’”

“Quit blaming me.”

“Everything I eat makes me feel guilty on some level.”

““You caused your own disease. You created your own problem.””

The physician present in the room at the time carefully took notes and let each patient speak who wanted to, validating them and their experiences (Ting-Toomey, 2016). She commented that perhaps diabetes could be discussed in such a way that “lifestyle modification could help control the disease, versus that being what caused it.”

Touching on lifestyle modification, this is what the diabetes patients often stressed that they lacked the most: proper education on lifestyle choices such as diet and exercise. The following is a long passage from Tatiana, a rural diabetes studio participant, but it is worth posting in its entirety as her words sum up her experience from initial diagnosis to now, and why her involvement on the studio is so important to her, from both an educational and empathetic standpoint, and to illustrate the lack of empowerment she felt:

They sent me to one diabetes education class, and you were there for like two hours and that was all the education you got. That's why going through this group here, I mean I have learned so much that I didn't know before just from being around diabetics. But also, that's why I'm so keen on education because I just didn't get any. I didn't know how to shop. I didn't really understand good carbs versus bad carbs. I thought, Well, you know, this is a vegetable. It's good for me. I can have all I want. This is fruit. It's good for me. I can have all I want. And that's not how it works. But in my mind, if I was eating from the food groups and just watching the amounts that I ate, that I was doing good. Because I figured that's what I had to do. And for a while it did do that. I kept my A1C down, I had medication but I kept my A1C down, and you know, everything was going good.

Now, I've had to go on more medications and it's going up, because I really didn't make enough changes to really affect it, but I wasn't really aware of that. I thought I was doing good. You know, in my mind, I thought I was doing good. Coming here, I realized, going to these meetings and stuff, that I'm not. I'm not even on enough-level plane. So I'm having to rethink a lot of things that I'm doing, and that's why I like being involved in this to try and get out there that more education is what's needed. Especially with rural hospitals and people who live in rural areas, small towns. We don't have the support system that big cities have, so, you know, we don't have, we either don't have access or we don't know about the things that we could do or go to to learn more. So, that was one of my big things about being involved with this survey and what I kept stressing was nutrition training and basic education and just like a support group. I always thought when I looked at cancer and heart disease, you know, two of our biggest ones, they have a whole concept around them. And even though diabetes is becoming one of, um, the biggest ones in the country affecting a lot of people, we don't have that same support system. They don't have genetic testing, or nutritional training or you know, when you come in and you're diagnosed with heart disease or cancer, they automatically send you out to all these different things. All these different people to get the support and the education that you need. When you're diagnosed with diabetes, it's like, Well, just take this pill. Watch what you eat, exercise and that's about it. And there's nothing there to encourage or really push anyone (Tatiana, personal communication, August 18, 2018).

Her last statement about lack of encouragement is telling in that, as mentioned above, education, filtered through empathy, can be framed in such a way that empowers patients to appropriately modify their lifestyles. Another diabetes studio participant had commented that education on nutrition must be framed in such a way that expands the scope of a patient's awareness of food, versus be themed around deprivation. From this particular studio, and from the others I witnessed, as well as through my own interpersonal interactions, I am struck by how it is in these moments of sharing that patients are unfinalized (Frank, 2005), sharing their perspectives to interrupt the status quo.

*"Just Five Minutes"*

A concept I want to briefly touch on is the idea of "just five minutes," or that positive patient/physician interactions do not need to burden both parties or the scheduling functions of the practices and health systems. Also, I'd like to counter the above negative examples with a positive one, to demonstrate the power of positive patient/physician dialogue. Elyse, the same patient who shared the story about the anesthesiologist also told me about an interaction with another physician who took a few minutes to spend time with her as she was experiencing dangerously high blood pressure.

He said, "OK, I'm going to sit up and just talk a minute. So tell me what's going on in your life and tell me what you're thinking right now." So we kind of talked about that. And I said, "I've got this trip coming up," and he said, "Oh, where are you going?" And I said, "I'm going to Spain." And he said, "Oh! Where are you going in Spain?" Anyway, he spent, I don't know how many minutes, but we

talked about Barcelona, and we talked about Madrid, and we talked about the Familia—the Sagrada Familia, we talked about—you know, we talked about everything other than my blood pressure. And, so it just—anyway, that was such a positive thing, because in that moment, number one, he needed me calm, and number two, I need to not be flipping out. So, I just felt like that was, that was a seize-the-moment, that was probably five minutes he didn't necessarily have to spend, but it was a priority, and I won't forget that, you know? Um, so that was a really positive thing (Elyse, personal communication, August 1, 2018).

Thus we see again an example of a patient unfinalized (Frank, 2005), and a physician who took a brief amount of time (five minutes) to physically and mentally calm a patient by trying to understand the context of her life.

#### *What are Best Practices for Patient/Physician Communication?*

As said previously, I believe best practices for patient/physician communication should not be decided by one entity or one body, but can only be effectively assessed by all involved parties: clinicians, patients, and the departments in a health system such as marketing and/or public relations, patient relations, physician practice schedulers, and any other entity that touches the patient experience as it relates to their health care specifically.

At a studio session on designing a tool that effectively communicates a patient's colorectal screening options, I was introduced to the concept of shared decision making, the goal of which is “to empower the patient to be ready to participate in the conversation,” said the director of the rheumatoid arthritis studio who was present that

day. I felt a surge of energy listening to that statement as it encapsulated so much the ideas that were already forming in my head after having attended a number of studios and interviewed several patients at this point. Again, knowledge is power to ask, and to ask again. The cyclical effect of additional education can only breed more inquiry for patients, who become increasingly empowered to advocate for themselves.

This same researcher introduced me to thinking of patient educational opportunities in light of the clinician burden, which helped me understand the greater context of implementing any sort of health campaign or educational materials. As such, there is not a simple solution, just as there is not a homogenous patient population. In prior projects at work, what has helped me to make sense of the complexity of health care is to evaluate an organization chart. Understanding the functions of the departments helps me to question a) what sorts of educational materials or communications pieces have already been created and can be used again? and b) what sorts of channels already exist to communicate? If the health system's population health research and enablement engine is working on a communications piece about colorectal screening options to increase colon cancer screenings in their populations, how can they utilize the channels that the marketing and public relations departments have already established through social media, through online resources, such as a health blog, or through community summits? Additionally, how can these materials and educational opportunities be enabled in a physician practice without burdening the clinician? What are the optimal points of contact for a patient to receive information? Interestingly, several patients commented that they don't know what they don't know. So if the materials already exist, how can a

health system increase awareness of the available channels? In an academic health center setting, what are opportunities to expand the scope of communication education, especially to students before they become practicing physicians or providers of any kind? This section is titled with a question on purpose, as I don't have definitive answers. What I can definitively say though as I ponder these questions and next steps is that the patient perspective is invaluable, insightful, and worth chasing after.

### Limitations

While I feel confident in the results of this study and its implications, I must address its limitations. First, I myself need to continually learn to not generalize patient populations, and this study was certainly a good exercise. However, that being said, I can't say that I speak for all participants when listing the beneficial themes of studying in a studio. Also, a larger number of interviewees at different points of their involvement in the studio may have contributed contradicting data. Practically speaking, a greater window of time would have allowed for patient input across the spectrum of a project and to understand impact even further as research results were disseminated. Specific attention to group identity formation could be implemented into a study that could initiate at the start of a studio with a greater time window.

Of course, my bias is a limitation in this study. I do acknowledge my positive viewpoint and anecdotes of the PES above in my commitment to quality, though, while I did adjust the research questions and interview protocol to account for the possibility of there being no benefits and even negative experiences, I still feel compelled to allow my self-awareness to identify this limitation.

Additionally, the functions of the studio were different, and although they follow largely the same structural design, their end goals were unique. While in some ways this added breadth to my data, in other ways, it may have skewed it. This study may look entirely different if a certain cultural identifier was examined, such as gender identity, age, and geographic location.

Finally, the more I engaged with this study, the more overwhelmed I became with its implications, and the more I felt I could not possibly effectively touch on every single important topic that was communicated to me by the patients I interviewed. While I struggled with the magnitude of representing real people with real perspectives, I began to understand the opportunities for future study, which are addressed below.

#### Future Directions

First, I believe this study could be flipped, in that researchers could be interviewed on how their understanding of patient populations has changed because of their involvement in the studio. One could apply co-cultural communication theory to understand the influence and power for change of a non-dominant group dispelling their stereotypes and communicating themselves (Orbe, 1998). Also, by understanding the assumptions of Ting-Toomey's (2016) identity negotiation theory, physicians and other members of dominant groups can understand the communicative functions necessary to help patients feel validated. As previously stated, Woolf et al. (2016) stated that patient engagement models are impacting researchers' approaches to their work, and it would be valuable to capture specific anecdotes and procedures of how this is occurring.

The relationship of the three themes could certainly be explored to assess if

causation is present and to better understand the flow of these particular attributes. A better grasp on the interworkings of these three themes could contribute to both future studio design, as well as health system education and communication. For example, Cross, Davis, and O'Neil (2017) argue for health campaigns to be designed with appropriate education, communication, and psychological theories so that they are robust and effectively framed. I believe that these benefits could be further informed and explicated with theories from a variety of disciplines.

Additionally, a closer examination of the group dynamics and intergroup identities established in the main studio and in the disease-specific studios separately would be warranted. Continuing to assess identity forming through identity negotiation theory (Ting-Toomey, 2016) and subsequent social systems through structuration theory (Giddens, 1984) might give additional insight into the power of the function and design of a formal engagement studio and its implications for further use, both in and outside of health care.

Finally, as per my discussion above, I am slightly flummoxed by where to start in addressing effective means and methods of communication for patients as produced by complex health organizations. In an information-overloaded world, I believe it is vital for health systems to inform as much as possible the education that patients are receiving, so that they are not misinformed. Additionally, a range of types of audiences should inform both the need for specific education and the best way to distribute it. These types of endeavors could take on the form of a research project, similar to the patient-informed

research questions of the diabetes studios, or the endeavor of the health system through already existing resources.

### Conclusion

In many ways, this study encapsulates the most impactful lesson that graduate school in its entirety has taught me: that every person's life has its own swirling contexts of reality, and therefore each person's own perspective is valid. Last year, I sat in a fifth-floor boardroom that overlooked the health system's home city for a meeting that I actually don't remember much about, other than a variety of topics related to community outreach. A gentleman in the audience raised his hand and asked if any of the representatives of those communities we were trying to reach were present, which they weren't, of course. The PES format is here to not only combat this top-down approach, but continually inform health system outreach and education as a whole, and potentially, in the future, transfer into other arenas.

Here I stand at the end of this study, humbled to have met these patients and attended their studios to understand membership in a co-cultural, non-dominant group, and to synthesize their responses effectively to uncover themes that point to the benefits of intentional engagement. I think of my own health journey, normal by any standards, although not without my own struggles as they relate to the very basics of self-care—nutrition and exercise. Yet, I hear of the treks of others and know that health is within my reach and capability. I am grateful for the education that I have received from a variety of different outlets, such as the patients who relayed their varying experiences and the studio presentations themselves. I find myself considering the empathy necessary to effectively

understand the complexities of patient populations and the unique individuals that comprise those audiences. While change may seem out of reach or overwhelming, I am empowered to know that even the slightest impact is still an alteration from the status quo. We all must remain continually engaged, leaning in to the challenges that face ourselves and others.

## APPENDIX: Interview Protocol

### **Demographic Information**

**Age:**

**Gender Identity:**

**Length of time in the PES:**

1. Tell me a little bit about yourself.
2. What have been some of your prior health care experiences?
  - a. Is there one that stands out to you in particular? Why?
3. How did you get involved in a Patient Engagement Studio.
  - a. What prompted you to get involved in the PES?
  - b. Could you describe what your first (or early) experience was like?
4. Were there any “aha” moments or stories of significance for you where you felt like you were making a difference?
5. What are some of the things that you find most meaningful or significant about the PES?
6. How has your participation in a Patient Engagement Studio affected you?
  - Outlook on self?
  - Others?
  - Life?
7. How would you, or do you, explain the PES to others?
8. What conversations have you had with family and friends about the PES?

9. Has your understanding of health care changed since you began participating in the PES? How so?

10. In what ways, if at all, do you feel empowered to communicate with those living with your same condition?

11. What recommendations for improvements or adjustments would you make to the PES to improve future experiences?

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