

# CHRONIC ILLNESS NARRATIVES THROUGH FACEBOOK

by

Katrina Layton Hinson

January, 2014

Director of Thesis/Dissertation: Dr. Donna Kain

Major Department: Department of English

The Internet has changed the process by which illness meanings are created and brought into the everyday lives of those who struggle with a chronic condition. More importantly the rapid rise and use of electronic groups created through social media outlets like Facebook allows for the chronic illness experience to be shaped by multiple others and also results in the formation of a new discourse and a new discursive genre. An increasingly available discursive form is that formed through or as a result of virtual space. Virtual support groups have the potential to modify how patients perceive their condition, how they manage their illness and how they communicate within the doctor-patient relationship. Social media provides people who have survived and now live with the effects of a post traumatic event such as pulmonary emboli a place to share their story, to learn from others, to relay information, to communicate with others and to be validated as patients. Given the increase in the number of patients who experience a pulmonary embolism and survive, stronger evidence about the use of social media such as Facebook and the associated virtual support groups which form around the traumatic event is needed.



CHRONIC ILLNESS NARRATIVES THROUGH FACEBOOK

A Thesis/Dissertation

Presented To the Faculty of the Department of English

East Carolina University

In Partial Fulfillment of the Requirements for the Doctorate of Philosophy in

Technical and Professional Communication

by

Katrina Layton Hinson

January, 2014

© Katrina Layton Hinson, 2014

CHRONIC ILLNESS NARRATIVES IN FACEBOOK

by

Katrina Layton Hinson

APPROVED BY:

DIRECTOR OF  
DISSERTATION/THESIS:

\_\_\_\_\_  
Donna Kain, PhD

COMMITTEE MEMBER:

\_\_\_\_\_  
Michelle Eble, PhD

COMMITTEE  
MEMBER:

\_\_\_\_\_  
Daniel Goldberg, PhD

COMMITTEE MEMBER:

\_\_\_\_\_  
Andrea Kitta, PhD

CHAIR OF THE DEPARTMENT  
OF (Put Department Name Here):

\_\_\_\_\_  
Jeremy Johnson, PhD

DEAN OF THE  
GRADUATE SCHOOL:

\_\_\_\_\_  
Paul J. Gemperline, PhD

## Dedication

I dedicate this dissertation to my husband James, and our children, Brittany Elaine, Jourdan Kelley, Connor Shea and Noah Jayden. They have all diligently stood beside me as I walked the path toward completing my doctoral degree. They have held me up and pushed me forward when I wanted to give up, and they never let me use them as an excuse for not meeting my deadlines. They refused to let me give up when I felt like that was all I could do. I got hugs and kisses and reminders that this, the writing of the dissertation, was but a momentary journey in the larger picture of life. My husband has listened to my ideas just as much as my kids and while they never really commented, their being my sounding boards is what got me this far.

I also have to acknowledge my mom and my dad. My entire life, my parents always instilled in me all that I could do and never focused on anything I could not do. I was taught that nothing was impossible, and all the things in life worth having required hard work, time, commitment and sacrifice. My parents, like my husband and children, always told me that they were proud of me no matter what. To my mother-in-law Brenda, I owe my undying thanks because she gave me her son in marriage twenty-three years ago. Little did she know how much of his strength I would need as I walked through life.

I also acknowledge my friends Barbara Daly, Cindy Asbell, Dr. Rochelle Mabry, Lori Ann Priest, Helen McGee and Dr. Amelia Davis. Whether it was sharing a cup of coffee while letting me vent, driving to work and discussing how we could fix the worlds problems, having a positive attitude and a smile to share, or sharing your own struggles as a doctoral student, you sometimes provided me with the distraction I needed to refocus on the writing that often became so difficult to get on paper. The laughter you shared with me outside my office door – being

always there when I needed you most—gave me strength on the hardest days. I knew I could always count on you. To my colleagues at Appalachian State who met me at the end of this journey, I also owe my gratitude for the constant encouragement given and the friendship you offered. You have all made the end of this journey an attainable outcome.

Finally, I have to acknowledge the people that saved my life -- my medical team from Physician's East. On January 14, 2008 I went to the doctor for a simple cut on my finger which had not healed only to find myself a few hours later in the emergency room(ER) fighting for my life due to a pulmonary embolism with infarct in my right lung. Had my physician assistant (PA) that day not asked one last time if I had anything else that needed her attention, I would have gone home, and as the doctors have told me, I would not have awakened the next morning. There are no words to describe that moment. Dr. Thomas Hodgins,(Internal Medicine), Dr. Richard Fogarty (Pulmonary) Dr. Richard Croskery (Internal Medicine) and Dr. Jeffrey Alloway (Rheumatology) have been a part of this particular journey from the beginning of the dissertation process and every visit I was asked about my progress, not just my health but also my academic work. I also had a great team at Vidant Medical Center's Cardio-Pulmonary Rehabilitation facility. Sylvia White-Ramos and Beth Shane and all the others that worked with me to help me to find my "new normal" so that I could address the physical challenges I faced as my body healed. I learned that healing comes in its own time and not mine. There is also a mental and emotional part that has to heal along with the physical. It is sometimes the unseen pain, the loss and the grief one feels at all the "what might have beens" that takes the longest to heal and while navigating what felt like a helpless space for me, Alison Brodeur reminded me frequently that I was not a broken individual in any way and that a physical limitation did not have to define who

I was or how I chose to live. In my darkest moments, she reminded me that I had lived for a reason and to give up now would simply dishonor the blessing of life I had been given.

Additionally, an amazing team of physician's at Duke University Medical Center composed of Dr. Njira Lugogo (Pulmonary) and Dr. Carlos Bagley (neurosurgeon) also saved my life because they never quit listening. Dr. Lugogo kept her promise to not give up on me until we knew what was going on with my body and to try to determine why every breath for me was a battle. She embodies the ideal physician when it comes to patient care. I was never a chart number and always a person. Because of her, I ended up in the skillful hands of Dr. Carlos Bagley. Dr. Bagley is probably the reason I am even able to type this dedication. Had he not found the damage to my spinal cord and corrected it, I could have been paralyzed or dead. Considering that I was born in 1971, at 28 weeks, weighing 2lbs, 15ounces, I feel totally blessed to have faced death three times and survived. I count each day as a gift. Each page I have completed is a testament to the importance of excellent communication between patient and the health care provider

## **Acknowledgement**

I would like to express my special appreciation and thanks to my advisor, my colleague, my friend, Dr. Donna Kain. You have been a great mentor for me, encouraging me to follow my ideas and critiquing my work when it was necessary. You pushed me to exceed the boundaries I had set for myself and like my family, you never allowed me to give up. You often took my frustration and turned it into something worthwhile. You have been an excellent role model as a professor and as you so often remind me, as a colleague. I can only hope to live up to the example you have set for me. I hope I always make you proud that you have accompanied me on this journey in this part of my life and I look forward to the time we can collaborate together as peers.

I would like thank Dr. Andrea Kitta, Dr. Daniel Goldberg, and Dr. Michele Eble for serving as my committee members and offering comments, suggestions and encouragement while preparing this dissertation for defense. I appreciate the guidance you have given me throughout this process.

I would like to thank Mary Jo Brubaker for taking the time to proofread my work. When my mistakes had blurred into obscurity, she brought clarity to the picture. I am indebted to her keen eyes.

## Table of Contents

<b>Dedication</b> .....	<b>i</b>
<b>Acknowledgement</b> .....	<b>iv</b>
<b>LIST OF TABLES</b> .....	<b>vii</b>
<b>Chapter 1: Introduction</b> .....	<b>1</b>
<b>Research Questions</b> .....	<b>10</b>
<b>Background</b> .....	<b>11</b>
<b>Chapter 2: Theoretical Frameworks</b> .....	<b>25</b>
<b>Social Constructivism and Chronic Illness</b> .....	<b>26</b>
<b>Knowledge, Power, and Narratives of Chronic Illness</b> .....	<b>28</b>
<b>Stigma and Chronic Illness</b> .....	<b>37</b>
<b>Social Media and Chronic Illness</b> .....	<b>38</b>
<b>Researching Online Spaces</b> .....	<b>40</b>
<b>Chapter 3. Methods</b> .....	<b>45</b>
<b>Rationale</b> .....	<b>45</b>
<b>Participants and Procedures</b> .....	<b>51</b>
<b>Data Collection</b> .....	<b>53</b>
Survey.....	54
Interviews.....	55
Observations.....	57
Coding and Analysis.....	58
Ethical Considerations.....	60
<b>Chapter 4. Data Analysis – Survey Results</b> .....	<b>63</b>
<b>Participants</b> .....	<b>64</b>
<b>The Survey</b> .....	<b>66</b>
<b>Results</b> .....	<b>68</b>
Who Participates in illness related Facebook groups?.....	68
How do these groups impact individual empowerment?.....	81
<b>Chapter 5. Pulmonary Embolism and DVT Virtual Groups in Facebook</b> .....	<b>86</b>
<b>Background</b> .....	<b>86</b>
<b>Framing illness in virtual support groups</b> .....	<b>88</b>
The Group Frame.....	89
Awareness as a framework.....	90
The Survivor Framework.....	98
<b>Power, Stigma, and Othering</b> .....	<b>102</b>
Power.....	102
Stigma and Othering.....	104
<b>A “New” Normal</b> .....	<b>111</b>

<b>Health Care Perceptions.....</b>	<b>113</b>
Confrontations .....	113
Listening .....	114
Dismissive Behavior .....	117
Self Advocacy .....	118
<b>Chapter 6: Conclusions .....</b>	<b>124</b>
<b>Introduction .....</b>	<b>Error! Bookmark not defined.</b>
<b>Summary of Key Findings .....</b>	<b>127</b>
Frames and Framing .....	127
A “New” Normal .....	129
Othering and Stigma.....	131
Constructions of Chronic Illness and the Doctor Patient Relationship .....	132
<b>Future Research .....</b>	<b>134</b>
Technical and Professional Communication and Social Media in Medical Contexts.....	135
<b>REFERENCES.....</b>	<b>137</b>
<b>APPENDIX A: Survey Introduction .....</b>	<b>150</b>
<b>APPENDIX B: Informed Consent to Participate in Research .....</b>	<b>151</b>
<b>APPENDIX C: Participant Survey Questions.....</b>	<b>154</b>
Survey .....	154
Demographic data. ....	159
<b>APPENDIX D: Interview Questions.....</b>	<b>163</b>

## LIST OF TABLES

1. Table 1: How long has it been since your initial diagnosis? .....	71
2. Table 2: Perceived health status .....	74
3. Table 3: Did/Do you exercise? .....	75
4. Table 4: Group membership numbers .....	77
5. Table 5: How long have you been a participant in a health related online virtual community? .....	77
6. Table 6: Having had a PE/DVT event.....	79
7. Table 7: As a result of your PE or DVT, do you feel excluded?.....	80
8. Table 8: Participation in a health related virtual community has empowered me (check all that apply) .....	81
9. Table 9: Participants in a health related online community (check all that apply) ...	82

## LIST OF SYMBOLS OR ABBREVIATIONS

CDC	Center for Disease Control .....	1
CDMC	Center for Disease Management and Control.....	1
PE	Pulmonary Embolism .....	5
DVT	Deep Vein Thrombosis.....	5
VTE	Venous Thrombolytic Event.....	12
PEA	Pulmonary Embolism Awareness.....	51
PES	Pulmonary Embolism Survivors.....	51
PEAP	Pulmonary Embolism Awareness Project .....	51
TPC	Technical and Professional Communicator.....	135

## Chapter 1: Introduction

Chronic illness as explained by the Center for Disease Control (CDC, 2013) and the Center for Disease Management and Control (CDMC, 2013) refers to a collection of diseases that manifest over a period of time and that may or may not go away on their own. Any individual with a chronic illness may find his or her day-to-day activities limited. For many with chronic illness, interactions with others decline because well-meaning individuals may comment, “you don’t look sick,” or “why can’t you just get over it?” especially when there is little outward sign of an illness or disease. Those with a chronic illness may suffer alone, in silence, in an effort to maintain relationships or avoid having to explain their illnesses at every turn.

The Internet, however, has changed the process by which people make meaning of their illnesses and how these illness meanings are created and brought into the everyday lives of those who struggle with a chronic illness. The rapid rise and use of electronic support groups created through social media outlets like Facebook allow for the chronic illness experience to be shaped by sufferers and multiple others. Virtual support groups have the potential to modify how individuals perceive their condition, how they manage their illnesses, and how they communicate within the doctor-patient relationship. Virtual support groups may also modify the self-care practices that individuals choose to adopt to cope with their illnesses. Vasilev et al. (2011) write, “Social networks are recognized as relevant to supporting self care but little attention has been given to social context and the role of others in shaping and supporting self care practices” (p. 60). Virtual support groups become a means by which the participants tell their illness story and live their illness experience. In the telling of his or her story, “the ill person who turns illness into story transforms fate into experience; the disease that sets the body apart from others, in the story

becomes the common bond of suffering that joins bodies in their shared vulnerability” (Franks, 1995, p. i). The ill person, the wounded, becomes the narrator of his or her narrative, a storyteller who can actively engage in caring for others, and “all those who suffer can also be healers. Their injuries become the source of the potency of their stories” (Franks, 1995, p. iii).

Discourse created by individuals who seek out virtual support related to their medical diagnosis is not only shared but also reshaped by responses from others with similar experiences to the story. The participants’ narratives within the virtual space of the support group “are stories of marginality from a perspective not present in expert [physician-centered] views” (Kangas, 2002, p. 303). The physicians’ views are not ignored; rather, they may be actively used “to legitimate and explain pain and suffering, to make it morally and politically more acceptable” (Kangas, 2002, p. 303). The participant’s narrative created within the virtual support group invites others to share in the illness experience. This virtual support group narrative also increases the need for physicians and others involved in a person’s treatment, to, as Charon (1994) states “allow [their] own injuries to increase the potency of [their] care of patients, to allow [their] personal experiences to strengthen the empathic bonds with others who suffer” (as cited in Franks, 1995, para. 3). Virtual support groups may also provide an avenue for individuals to have a more equal voice in the doctor-patient, lay person-expert dyad that may help all involved, from the health care professionals to the patient, to have shared empathic experiences that may lead to improved treatment plans for the chronically ill individual.

Clinical psychologists, medical sociologists, medical anthropologists and folklorists have all acknowledged the importance of understanding the individuals’ perceptions of their illnesses and the relationship of others to successful long term self-care management. Past research studies by Conrad and Barker (2010), the narrative histories of Kleinman (1998) and Franks (1995), or

the dialogue regarding the place of narrative in medicine discussed by Charon (2006) present primarily a medical sociological or medical anthropological point of view. Folklorists Briggs (2013), Briggs and Mantini-Briggs (2003) and Diane Goldstein (2004) have researched the narrative power of the stories people tell, especially those who are ill. The former studies looked at a broad array of illnesses: cancer, diabetes, depression, chronic fatigue syndrome and more, all of which can occur/recur in the life of the individual, but the research is presented from the physician-centered point of view, not that of the individuals experiencing illness. On the other hand, folklorists capture the social lives of stories, capture the narratives and legends around illnesses for example HIV/AIDS, that have embedded in them the narrative of patients; but, the narrative is not always easily discernable amidst the lore. Briggs (2013) points out that “the study of folk medicine is seldom celebrated as an endeavor that offers galvanizing new concepts or theories that become necessary reading for all folklorist” (p. 320) and yet folklorists might be the best ones to tell the stories of those who are ill. Goldstein (2004) writes “the narrative informs the listener in ways that not only affect thinking but also becomes enacted as the listener expresses belief or concern” (p.24). For the person who is ill, all he or she has is his or her story and for many, the story is only ever heard in part.

Researchers, doctors, and other medical personnel all speak about the individual as “a patient,” the “I” of a first person narrative is often absent. Dr. Rita Charon (2006), director of the program in narrative medicine at Columbia University’s College of Physicians and Surgeons, addresses the importance of the individual patient’s medical narrative and the role of others in patient care in, *Narrative Medicine: Honoring the Stories of Illness*. In the preface, she writes “patients have found new allies in their search for health, notably in advocacy groups and

support groups, in the readership of published and electronic ‘telling of illness stories’” (Charon, 2006, preface, para.5). She goes on to describe the individual patient’s narrative as a

clinical cousin of literature-and-medicine and [as] a literary cousin of relationship-centered care, narrative medicine provides health care professionals with practical wisdom in comprehending what patients endure in illness and what they themselves undergo in the care of the sick (para.6). Narrative medicine is “a form of health care that recognizes suffering, provides comfort and honors the stories of illness” (Charon, 2006, para.6).

The narrative is also based on the physician’s interpretation of what an individual has reported as well as what the physician has witnessed that remained unspoken by the patient. Missing, however, from the medical file, is the individual’s own first person telling/writing of his or her narrative in his or her own words.

Face-to-face health-related support groups or related advocacy groups are venues in which illness narratives can be told and heard; but, as Internet technologies have grown, health related virtual communities and associated advocacy groups have also become mediums in which an individual’s personal illness narrative can be not only told, but written by the individual. Health care professionals and periphery service workers, including social workers who often deal with chronically ill people, may benefit from reading illness narratives created within the confines of a virtual support group, but first must come to understand the context in which they were written. Diane Goldstein (2004), writing of her work with HIV/AIDS patients in Newfoundland, stresses that the stories told to her “are best understood, in situ, as responses to real world situations taking place in local cultures” (p.xiv). A person’s official medical record becomes a document written by multiple authors across spans of time with its own narrative structures to support it and, combined with the narrative written by the ill person and told in a virtual space, could become a means by which those working with the chronically ill “look with

refreshed eyes at what it means to be sick and to help others to get well” (Charon, 2006, preface, para.20). Within the health-related support groups created within the boundaries of social media, patients generate their illness narratives and update them regularly with almost every wall post shared with the group. The information shared on the wall could potentially be the missing piece of information a health care professional needs in order to better understand the chronically ill person that may become his or her patient.

My research explores the discourse shared through social-media created virtual support groups related to participants’ experiences of having been diagnosed with or having survived a pulmonary embolism (PE) or deep vein thrombosis (DVT). To investigate the role of discourse created through such groups, I identify types of narrative frames that emerge within such groups and what, if any, impact these groups may have on the individual beyond the group exchange.

Goffman coined the term “frame analysis” in relationship to discourse as the process of deconstructing individuals’ organization of experience ( Goffman, 1974, p.11). He goes on to say “linguistics provides us with the cues and markers through which such footings become manifest, helping us to find our way to a structural basis for analyzing them” (Goffman, 1981 p. 157). For Goffman (1974), an individual’s primary framework is the first point of his or her organization of experience. He writes “we tend to perceive events in terms of our primary framework and the type of framework we employ provides a way of describing the event to which it is applied” (Goffman, 1974, p. 24). One recent study by Gayatri (2008) defines framing as “an organizing principle that is socially shared and persistent over time, which works symbolically to meaningfully structure the world” (p. 2). Tannen and Wallat (2008) reference Kendon’s (1979) work related to context analysis which

presumes that participants are not isolated senders and receivers of messages. When people are in each other's presence, all their verbal and non-verbal behaviors are potential sources of communication, and their actions and meanings can be understood only in relation to the immediate context, including what preceded and may follow. (p. 332-333)

Tannen (1993) explains that Goffman intended to illustrate "how people use multiple frameworks to make sense of events even as they construct those events" (p.60). Individuals are always framing events in a variety of ways in order to negotiate day-to-day relationships in context of some event. Tannen and Wallat (2008) state "the interactive notion of frame, then refers to a sense of what activity is being engaged in, how speakers mean what they say" (p. 334).

The discourse of the virtual illness narrative may affect an individual's perception of his or her illness and self-care management, and his or her relationship with family, friends and coworkers. At some point, it may even influence the physician-patient relationship. Murphy et al. (2001) write that "the quality of physician-patient relationships alters health outcomes, affects patients' willingness to comply with medical advice or treatment and influences patients pursuit of malpractice suits" (p. 126). Discourse created within the virtual support group may also empower or enable participants to become more proactively involved in self-care management, illness prevention or illness awareness. Membership in a virtual support group may also alter how the ill person views the physician or other health care provider as the physician or health care provider may no longer be the sole purveyor of 'expert' knowledge within the doctor/healthcare practitioner-patient, lay-expert dyad. Kleinmann (1988) hoped to use his research to expand "academic medical discourse beyond molecules and drugs" (p. 266). Discourse created within virtual support groups devoted to lesser-known chronic illnesses may

prove to be a means by which medical discourse can be bridged with social media discourse to enhance the doctor-patient, lay-expert health care experience.

Groups that form around a specific illness or condition may also contain certain expertise, expertise gained through experience. My research specifically focuses on the discourse associated with recovery after a pulmonary embolism (PE) or other thrombotic events such as a deep vein thrombosis (DVT). These virtual support groups are deliberately chosen in part because of my own personal involvement with them. At some point, illness, disease becomes personal for each of us in some way. For me, it was 6 years ago, in January 2008, when I was quite literally told during a routine doctor's visit, that were I to leave the office, I would not live through the night because I had, what would later be determined, a massive unprovoked pulmonary embolism in the right lung, so severe that it caused tissue death (infarct) and lung function loss. Other than a bad night's sleep the night before, there had been no warning. There is nothing so traumatic as having a doctor, or in my case, several doctors, look at you and throw your own mortality in your face. This one event would be the trigger for one symptom after another and six years later I am still learning to cope, learning to live with and understand my diagnosis.

My decision to examine the discourse associated with chronic illness, social media, and virtual support groups arose from a review of the literature when I began searching for the answer to 'why did this happen to me.' I learned that there was little information associated with a pulmonary emboli and its after effects as a chronic illness and even less about pulmonary emboli related, social-media support groups situated within Facebook such as the ones chosen for this study.

In 2008, when I began searching an answer to my question, the idea of virtual support groups was relatively new and there were few direct studies that examined the narrative structures of virtual support groups created by individuals who had experienced one or more pulmonary emboli and whose lives had been forever altered. These persons, like me, seemed to be invisible everywhere but in the virtual support group and yet there seemed to be many affected. Multiple studies from anthropological and sociological points of view examine the doctor-patient relationship (Conrad & Barker, 2010; Barker, 2008; Beacco et al., 2002; Charon, 2006; Franks, 1995; Kleinman, 1988), but few studies exist that attempt to explore the relationship of virtual support groups and patients' experiences following a pulmonary embolism (PE) or deep vein thrombolytic (DVT) event.

More broadly, the narrative discourse created through virtual support groups available through social media needs to be examined to better understand the illness stories participants tell others and how participants use others' stories to enable their own self-care practices. The individual illness narrative told within the virtual support group's master narrative, which might be considered a group's collective interpretation of illness, may enable a person to feel he or she controls his or her own illness experience and may encourage individuals to live with rather than suffer through the illness experience.

The objective for my study is to explore whether support groups created via social media like Facebook could possibly be used in a patient's health care plan in order to encourage positive self health care practices, to address patient questions and concerns, and to connect or network patients with similar illnesses to avoid isolation that may sometimes occur when dealing with a chronic illness. Using discourse analysis as well as narrative analysis, my study will attempt to identify different frames for the illness experience of those affected by a PE or DVT,

different definitions of ‘chronic illness,’ and representations of otherness and stigmatization based on the chronic illness experience caused by or as a result of a PE or DVT.

This research will also address how the individual’s virtual illness narrative impacts the recovery process that occurs after the initial pulmonary event. By providing an avenue for the creation of what Kleinman (1988) calls the “illness narrative” (preface, para. 5) and what Charon (2006) refers to as “narrative medicine” (para. 2), virtual support groups created through social networking sites such as Facebook may help legitimate the illness experience for the individual and his or her family and give voice to those who would be silenced because of the stigmatization associated with their illness experience. Physicians try to respect an individual’s “ethic of voice” and the individual’s “right to speak her own truth in her own words” (Franks, 1995, preface, para.8) but the individual affected, in the moment of an event, may feel unheard and ignored or even dismissed.

Taking a qualitative approach to this research may also highlight information about the doctor-patient dyad that reveals the power of the individual’s patient narrative as a privileged experience that becomes “. . . the basis for developing a sensitive, client-focused response that takes into account the wider social context of people's lives as well as the medical aspects” (Telford, Kralick, & Koch, 2006, p.458) and in turn becomes a means through which the individual’s illness narrative can become heard and acknowledged in an effort to strengthen patient-health care professional communication.

In the remainder of this chapter, I present my research questions, provide background about chronic illness, specifically pulmonary embolism (PE) and deep vein thrombosis (DVT); discuss current thinking on the state of the doctor-patient relationship, and the emergence of

information technologies as sources of patient information; and forecast the subsequent chapters of the dissertation.

### **Research Questions**

To more fully understand the post- PE, post-DVT experience as a chronic illness expressed through Facebook created virtual support groups, I address the following questions:

1. Within virtual support groups created through Facebook, what frames become defined by people post-PE, post-DVT to understand/explain illness, relationships, the chronically ill self, self-care?
2. How is "otherness" and stigmatization expressed in the virtual support group?
3. What does the discourse within the virtual support groups reveal about the individual's constructions of chronic illness and doctor-patient relationship?

Future studies may attempt to address how health care professionals may or may not react to patients who bring knowledge gained from the virtual support group into the provider/patient relationship. This may prove to be the most difficult question to explore and is beyond the scope of this current study because it crosses a boundary that is considered sacred, the doctor-patient dynamic. Doctors may not yet be willing to disclose their discomfort, if any, with social media and its direct impact on individual behaviors.

Before we can determine the impact, if any, virtual groups may have on the doctor-patient relationship, we must first seek to understand the narrative discourse created within the virtual space and what impact it has on the participants in and out of the group. My research is an opportunity to develop a deeper understanding of the participants who enter such virtual support groups, why they enter the groups, and what types of questions have led them to initially seek

out virtual support groups. It is possible that the narratives shared in virtual space by these participants demonstrate “the natural world and the cultural world share the burden of creating disease realities” (Goldstein, 2004, p.xiii). Ortega y Gassat (1959) states, “Before understanding any concrete statement, it is necessary to perceive clearly, ‘what it is all about’ in this statement and ‘what game is being played’”(as cited in Tannen and Wallat, 2008, p. 334). The narratives developed within virtual support groups available through social media like Facebook becomes a means for better understanding about the PE & DVT recovery process.

## **Background**

Technological advancements and improvements to health care have had a direct impact on increasing the longevity. Quite simply, people are living longer; however, that does not mean they are living free of illness or disease. The increase in life span also increases a person’s likelihood of developing chronic illness or illnesses. According to the Centers of Disease Control and Prevention (CDC), “in 2005, 133 million Americans—almost 1 out of every 2 adults—had at least one chronic illness.” Although not everyone will develop a chronic illness, many people become the caregivers to those who do have a chronic illness. The caregiver is often as impacted by the chronic illness as the patient, sometimes more so.

Heart disease, cancer and diabetes are recognized as chronic illnesses more quickly than lesser-known illnesses such as pulmonary embolism (PE) or deep vein thrombosis (DVT). The impact of these well-known illnesses on patients and caregivers is frequently discussed in brochures found in doctors’ offices, advertised in commercials for medications on television, and voiced by prominent spokespeople. Patients affected by well-known illnesses such as heart disease, cancer, or diabetes are also supported by national organizations such as the American Heart Association, the American Cancer Society and the American Diabetes Association that

hold and maintain a very real presence through multi-media outlets, print publications and television commercials. Such organizations actively promote awareness and prevention as well as treatment plans. Ironically, despite such awareness, individuals comment that they feel less cared for than in previous decades (DeVita, 1995, p.64).

Deep vein thrombosis (DVT) and pulmonary embolism (PE) are not as well known or as widely recognized. As individuals age, there is an increased likelihood of developing a blood clot in the legs (DVT) or blood clot in the lungs (PE) or both. When both occur, as Raskoub et al. explains “deep vein thrombosis (DVT) and/or pulmonary embolism (PE) are referred to collectively as venous thromboembolism (VTE) (S502). The National Heart, Lung and Blood Institute identifies a pulmonary embolism as occurring when a clot forms in the deep veins of the leg or pelvic area and travels to the lung [via the heart] where it can then cause pain in the chest, decreased oxygen saturation in the blood, and damage to other organs. If a blood clot forms in the deep veins (Deep Vein Thrombosis or DVT) of the legs or pelvic area, and if the clot breaks, it can enter the lungs causing a PE (pulmonary embolism). Delays in diagnosis or misdiagnosis can be lethal. Death by pulmonary embolism is second only to cardiac arrest as a sudden cause of death (Ouellete & Harrington, 2013). Since 2003, there has developed

a growing awareness of VTE as an important public health problem. . . [which] had raised the question of whether a systematic national approach to surveillance of VTE should be taken to provide more generalizable data on disease incidence, refine the current understanding of risk factors and the impact of changes in clinical practice on disease incidence” (Raskoub et al., S503, 2010).

By 2010 when Raskoub et al., were publishing their findings, the discussion of national surveillance was still being undertaken and the “silent killer” continued to claim unknowing victims. In recent years, the incidence of pulmonary embolism being covered by the media, has risen as a result of high profile personalities including Regis Philbin (2010) who underwent

surgery (pulmonary thromboembolitic surgery, PTS) to remove a blood clot; Serena Williams (2011) and Hilary Clinton(2012) whose recoveries were documented in the news media both on television and through social media, or rap musician Heavy D (Dwight Myers) (2011) who tragically died as a result of his PE that occurred after a long flight. Former police officer turned actor, Dennis Farina (2013) also passed away as a result of a blood clot in the lung (PE) and late in 2013, Nascar driver, Brian Vickers was sidelined from racing due to pulmonary emboli in both lungs. Because of the treatment available, including the advances in technology, individuals who once would have died from a pulmonary embolism now have a higher incidence of surviving but never quite the same as before their venous thrombolytic experience; an awareness of innocuous symptoms previously ignored develops and otherwise healthy people find themselves not only surviving the PE but also facing the aftereffects, shortness of breath, increased fatigue, pain, and anxiety, which may or may not be a chronic in nature, as they learn to live life as PE survivors.

People who have had a pulmonary embolism or a DVT and who participate in various online social groups, such as those accessed via Facebook, or who visit blogs looking for information about what has happened to them, report that their daily activities are directly affected by the pulmonary event. They report decreased activity levels and decreased social interaction with others. This self-reporting in virtual support groups about decreased activity levels, echoes findings discussed in the Patient Education Blog at [clotconnect.org](http://clotconnect.org) (Waldron, 2012). The blog report states that people who have survived an embolism in the lung(s) often have a decrease in activity level that could lead to a recurrence of a clot or multiple clots, and the fear of a recurrence is at the very heart of chronic illness for PE survivors. Individuals want to

know the answer to “why me” as much as health care professionals. The fact that an individual survives a PE sometimes leaves physicians as confounded as it does the patients.

Health care professionals also want to know why. Like all great detectives, they attempt to identify the root cause of pulmonary events. However, sometimes health care professionals can only diagnose a pulmonary embolism by ruling out other related medical possibilities. An individual may be diagnosed with a pulmonary embolism without ever being given a specific reason for an embolic event; all the while, he or she may be experiencing shortness of breath, chest pain, and fatigue noted by the health care provider in the individual’s medical record. People often undergo a complete and sometimes intrusive ‘workup’ involving blood tests, CT Scans, pleural effusion scans, and MRI’s etc., in an effort to rule out a pulmonary event (Ouellete & Harrington, 2013, Overview). Individuals may walk away frustrated without an answer that clearly explains “why me” just as the health care professional may be frustrated when he or she watches an otherwise healthy person leave still experiencing symptoms that can be traced back to the onset of the pulmonary event but that no medical test can clearly explain. Each pulmonary event, like each survivor, is different.

Pulmonary embolism (PE), deep vein thrombosis (DVT) or both (VTE) are not illnesses in and of themselves, although Raskob et al. (2010) noted, both pulmonary embolism and deep vein thrombosis are referred to as disease; however, both are often a cause or a symptom of illness; many who experience PE’s do not survive, and those who do struggle to put into voice what they may be experiencing subsequently. For many, a pulmonary embolism is only found upon autopsy. Knowing nearness of death is often just as frightening as the pulmonary embolism (PE) or deep vein thrombosis (DVT) incident. It is also difficult for others, inclusive of the health care practitioners involved with someone’s care, to truly understand the trauma and chronicity of

surviving an embolism. Health care practitioners follow the science of the diagnosis but may be deaf to the individual's story. A disconnect occurs because the science may indicate one thing while the individual experiences another. There is often no outward sign that someone has had a pulmonary embolism other than shortness of breath, which in and of itself can have many causes. People who have suffered such an event may look healthy, be healthy, and live a healthy, active lifestyle. Survivors do not lose their hair, like those who undergo chemotherapy; they may not wear oxygen cannulas when being active, like individuals with emphysema; and they are not bruised and scarred, like people who have undergone open-heart surgery. The body is intact and whole—normal. There is nothing for others to identify and label, no scarlet PE emblazoned like a crest on a vestment. People who have survived a pulmonary embolism appear, at first glance, just as healthy as any other individual; yet, though these persons look normal from the outside, they may feel physically unwell and struggle to maintain a 'normal' life. Maintaining a normal life is not easy for some pulmonary embolism survivors.

Some PE survivors report being unmotivated, misunderstood, and overlooked (Turner & Kelly, 2000, p. 124). With increasing regulations, and mounting costs of health care and lower reimbursement rates by insurers, clinicians find themselves sometimes processing individuals like cars on an assembly line that then leads to a decline in the doctor-patient relationship. More and more frequently "health care decisions are made not by or even for patients..." (Charon, 2006, Preface, para.4). If hospitalization occurs, people are often treated by "hospitalists, who are strangers to the patients. . ." (Charon, 2006, Preface, para.4) with no knowledge beyond the medical record. Doctors are sometimes only passive voyeurs in the acute care of individuals, especially those who are hospitalized and surrounded by strangers. The chronically ill person is seen in the physician's office by multiple others, from the nurses who draw blood to the

physician assistant who may come into the exam room in lieu of the doctor, or he or she may be seen by an “urgent” care physician or an emergency room doctor if the person has to go to the hospital unexpectedly. These health care professionals may have little contact with the person before such an incident and little contact afterwards. The physician may delegate health care to others in an effort to control associated costs, but, in doing so, also may create a divide between the primary care physician and the chronically ill individual. In some instances, the primary health care provider makes decisions based on second hand information gained from various others involved in the chronic person’s care but not based on his or her own physical examination. Charon notes that the “passivity of health care that began in the 1980s” is endemic of the medical profession and has only grown stronger with the passage of time and increased involvement of “... corporate executives and shareholders in the practice and art of medicine”(Charon, 2006, Preface, para.4).

To address this passivity, virtual support groups in which individuals and healthcare professionals all participate could prove to be a cost effective means of rebuilding the doctor-patient relationship that such passivity has weakened. The long held belief within Western medicine that locates the doctor as the vessel of medical knowledge, the one with power in the doctor-patient relationship, is shifting. According to Kangas (2002), “there has been a “drive towards more equality between ‘lay’ and ‘expert’ knowledge within healthcare” (p. 302) in part as a result of sociological and anthropological critique of the medical profession. At no other point in time has medical knowledge been so easily accessible by the ‘layperson’ who can find information with a mouse click. In the evolving and changing nature of the doctor-patient relationship, people may become “actors and agents creatively making sense of their illness” (Kangas, 2002, p. 303).

Tension between medical discourse about chronic illnesses and the layperson discourse about chronic illness; however, is amplified when an individual feels alienated from his or her medical practitioner. Danzinger (1981), as quoted in Beisecker, writes, “conflict may arise when doctor and patient do not share similar expectations of their mutual roles” (1990, p. 108). Beisecker goes on to reiterate the comments of Krepps (1988) stating “that an unspoken, implicit contract develops between relational partners, such as doctors and their patients, directing participants to behave according to the boundaries of each other’s role expectations”(1990, p. 108). Those with a chronic illness often want answers that simply may not exist. The individual seeks knowledge from the one individual who is expected to have it, but the physician’s lack of information or inability to relay information can be costly as demonstrated by

[a] 1973 government report that concluded that most malpractice suits result from poor communication between doctors and patients. More recent statistics [at the time of the article, 1995] indicate that of those patients who win malpractice suits, 80% of the patients questioned said they sued because they felt humiliated and shamed by their doctors. (DeVita, 1995, p. 66)

Health care professionals responded to the increase in malpractice claims by distancing themselves from individuals and relying more and more on the irrefutable facts of science and technology (DeVita, 1995, p. 66). The result is further erosion of the doctor-patient relationship and a lessening of trust in the expertise of physicians. Hippocrates, the Greek physician credited with being the ‘Father of Modern Medicine’ instructed those who would follow his art:

But it is particularly necessary, in my opinion, for one who discusses this art to discuss things familiar to ordinary folk. For the subject of inquiry and discussion is simply and solely the sufferings of these same—ordinary folk when they are sick or in pain. If you miss being understood by laymen, and fail to put your hearers in this condition, you will miss reality (NYAM, 2012)

Hippocrates held the belief that the body must be treated as a whole rather than the sum of his or her parts or symptoms (Greek Texts and Translations, 2012). He left such an impression on the field of medicine that those entering the medical field as doctors still take the Hippocratic Oath promising to carry on the tradition began centuries ago.

Today, practitioners swear to, “remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug” (Greek Texts and Translations, 2012). The empathy that Hippocrates aimed for has slowly slipped away as business practices and not the *art of medicine* increasingly shape medicine. For many chronically ill individuals, modern medicine seems to attempt to reduce the doctor-patient relationship to nothing more than the clinical, scientific, record: a reiteration of symptoms, a recitation of medicines taken, a review of any new changes between visits, a recounting of one's blood pressure and weight and finally the ‘interview’ or “patient encounter” recaptured through the health care professionals' notes. Franks (1995) writes of this loss of voice in *The Wounded Storyteller* that “in post-modern times, pressures of clinical practice, including the cost of physicians' time and even greater use of technologies, less time is available for patients to speak” (p. 13).

In an article about the decline of the doctor-patient relationship, health and science journalist, DeVita (1995) writes, “ask just about anybody and you will hear a doctor-patient horror story, a tale that reflects the indignation with which Americans have come to view their healers” (p. 63). The once sacred relationship between the doctor and the individual has devolved into a mechanized, industrialized conveyor belt practice. Individuals are not much more than their numerical identifier. The pedestal upon which society once placed doctors has gotten shorter as “the public (including patients) have relegated them, along with lawyers, politicians

and yes, journalists, to the pool of suspect religion” (DeVita, 1995, p. 63). Good and Good (1999) quote David Mechanic (1997), a leading twentieth century sociologist, “there has been a continual erosion of ‘trust’ between the doctor and patient over the course of the latter part of the twentieth century (p. 243). For much of modern medicine’s history, the traditional role of the physician has been that of paternalistic authority over the patient (Wilson, 1980). Talcott Parson’s work in the late 1970s noted that the physician was becoming “responsible more to professional codes than individual patients” (Franks, 1995, p. 15). The health care professional in the latter part of the twentieth century placed more emphasis on “adherence to the profession before the particular demands of any individual patient”(Franks, 1995, p. 15).

Consequently, the individual patient’s narrative voice has been forced to surrender to the business of medicine (Franks, 1995, p. 16) in which the person’s only responsibility is “get well, cease to be patients, and return to their ‘normal’ lives” (Franks, 1995, p. 9). Within the hard science of medicine, some “thing” has been lost within the doctor-patient relationship, a relationship once based on the character of the doctor but now resting more on his or her credentials, his or her ability to do well on tests, than on his or her ability to care. That is not to say this is true of all doctors for as DeVita notes, “there will always be doctors who are able to shrug off the dehumanizing pressures of modern medical practice to provide skilled empathetic care” (p. 63). The Hippocratic Oath also calls the practitioner to “remember that (he/she) does not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person's family and economic stability. The physician’s responsibility includes these related problems, if (he/she) is to care adequately for the sick” (NYAM, 2012).

The practice of modern medicine, however, does not allow physicians the time or capacity to actively listen to the individual before them nor to truly empathize with people

because doctors are constrained more by the business of medicine rather than the art of medicine (Charon, 2006; Franks, 1995; Kleinman, 1988; and DeVita, 1995). At the turn of the twentieth century, the doctor-patient relationship guided an individual's treatment, but that has now been "subverted by technology, by the medical education system and more dramatically by the intrusive demands of managed health care" (DeVita, 1995, p. 63). Physicians unintentionally miss the reality of the person living with a chronic illness because they do not hear; there is a delineated difference between the doctor's attention to disease and the individual's experience with illness. The professional medical perception indicates that if one is not sick in a socially acceptable, recognizable manner then the person does not meet the expectations about behavior of a known illness (the science of the illness). As a result, medical professionals may perceive that there is no disease or no illness despite actual symptoms on display. Such perception breeds the stigmatization of the one who is suffering as a hypochondriac, a paranoid and delusional individual. Nothing is wrong because one's symptoms do not 'fit' a readily accepted or expected pattern. Arthur Franks (1995) references the work of Parson who observed, in the 1950s

that a core social expectation of being sick is surrendering oneself to the care of a physician . . . the physician becomes the spokesperson for the disease [not the patient]; the ill person's stories come to depend heavily on repetition of what the physician has said. (p. 5)

The ill person is not in control of his or her own illness. His or her only job is that of "getting well" (Franks, 1995, p. 13). But according to Kleinmann (1988), "human problems cannot be reduced to simplistic formulas and stereotyped manipulations that treat patients as if they were overly rational mannequins" (p. 228). Additionally, Kleinmann (1988) states, "chronic illness is more than the sum of many particular events that occur in an illness career...illness becomes inseparable from life history" (p. 8). As the accepted authority over illness, the physician assumes a very paternalistic stance towards the person and may nod politely yet may

never truly hear or understand, only furthering the growing divide between doctor and patient (Wilson, 1980, p. 1712). Unless the individual objects, he or she “accepts having the particularity of his individual suffering reduced to medicine’s view” (Franks, 1995, p. 11).

With increasing demands from insurance companies and government agencies, medicine’s view is less about medicine and more about business-profit and loss. There is a demand on physicians that leaves less time for a physician to meet the physical or emotional needs of the person passing through the exam room. Such encounters often leave both people frustrated and even estranged (DeVita, 1995, p. 64). This is especially true for the individual with a chronic illness who may be in and out of an exam room numerous times over a short period. Kleinman (1988) writes, “the care of chronic illness is not one of the great success stories of contemporary medicine” (para.8). He identifies that modern medicine is flawed because “one intended outcome of modern medicine is that it does just about everything to drive the practitioner’s attention away from the experience of illness...to the alienation of the chronically ill...” (p. 20). Decisions about patient management are driven by profit and decided not necessarily by physicians but by health care management company policies that require doctors “to see more patients in the course of a day, which means less time spent with the patient” (DeVita, 1995, p.66). Less time with the individual leads to less time spent on effective communication.

External influences by insurers and government bureaucracies that have little to do with the direct care of the person only deepen the decline of the doctor-patient relationship. DeVita (1995) refers to Dr. Allen Mondzac’s comments when she writes in *American Health* “it’s very demoralizing...you strip away everything and you’re left with someone sitting behind a desk with a prescription pad. It’s assembly line medicine” (p. 67). A connection between the doctor

and his or her patient is necessary to establish trust necessary to maintain quality of care. As medical information related to types of illness, causes of illness, symptomology, and treatment options becomes more dispersed within the public realm through the use of Internet technologies, that need to reestablish trust between doctor and patient is more urgent. The reassurance that one is getting credible information through technological sources also needs to be established. Just as information can be useful, it can also be misused, misunderstood, and misrepresented more easily as a result of growing access to information that technology affords the twenty-first century person.

In spite of what seem like glaring problems within the health care system, there is also hope through narrative medicine. Charon (2006) writes:

There is impressive vitality and creativity in health care. The movements for quality improvement in health care are beginning to be felt in palpable and measurable ways. We are making meaningful progress in understanding and teaching communication skills, professionalism, cultural competence, team-building, and patient-centered care. (Preface, para. 5)

The more easily health care professionals can communicate with patients, the better the quality of care may be. The narrative developed within a virtual support group available via social media may provide health care professionals with the means by which to make healthcare practices more patient-centered. Such a model will only be successful if both patient and health care professional participate. However, the focus of medicine from the person to the disease has continued a major shift begun in the 1950s and 1960s –the business of medicine, rather than the science or art of medicine has continued to grow more important than the patient or doctor-patient encounter and continues to grow more depersonalized as it becomes more profitable (DeVita, 1995, pps. 64-66).

Medical practice has been structured “to drive attention away from the illness experience” (Kleinman, 1988, Preface, para.6) and is stagnating in the physician centered, physician focused approach to medicine that rewards doctors for being successful, not necessarily compassionate. Bedside manner has lost its value. Success and compassion may not coincide nor does one preclude the other. The concern arises when success nudges compassion and empathy out of the patient-doctor relationship in a way that could potentially be detrimental to the relationship and the patient’s health. It is entirely possible “that a successful doctor could actually be least helpful in providing empathetic care but skilled in the treatment of disease” (DeVita, 1995, p. 64). Attempting to act in the persons’ best interest, a “domineering physician may feel the need to act as an authority, give advice” [or provide treatment] (Wilson, 1980, p. 1712). A physician may also act dismissively of an individual’s problem, dismissing a complaint and similarly dismissing the individual (Wilson, 1980, p. 1712). As a result, individuals may seek out others who are “like them” in an effort to validate who they are and what they are experiencing, to avoid feelings of isolation and alienation, and to discuss treatment options and concerns about care. Thus, identifying how chronic illness narratives are developed in virtual support groups can provide knowledge for the development of new ways of thinking about the illness experience and lead to more effective, patient centered treatment strategies.

Illness discourse outside the medical setting is increasing along with use of technology and is developing through online spaces such as web forums and social media groups on Facebook. People seek each other out at various points of the illness experience, whether it is during the early aftermath of diagnosis or years later when an individual finds a group by coincidence while searching for illness related information. Additionally, family members of individuals who have died as a result of chronic illness also find groups for similar reasons: to be

validated, to share the story, to make others aware, to discuss treatment options, and for other intangible reasons. An online forum can empower individuals and may even dampen symptoms for a time, but participation in the virtual support group can also be a barrier to effective medical care when misinformation is conveyed, when it divides the patient and doctor relationship, and when stigma is attached to the ‘virtual’ medical world.

There is much to learn about illness narratives created in virtual space through social media. Social media and virtual support groups may be necessary to move current academically-centered medical discourse beyond mere molecules (Kleinman, 1988, p. 266) to a more patient-centered, empathic doctor-patient relationship.

The chapter has provided a rationale for exploring the discourse associated with health related online virtual support groups related to recovery from a pulmonary embolism or deep vein thrombosis incident. It also discussed the need for moving beyond the current sociological and anthropological studies toward examining the content and context of how people are using virtual support groups through social media. Chapter 2 will review theoretical frameworks related to this study while Chapter 3 will discuss the methodology used in this study. Chapter 4 addresses the quantitative results of the survey administered to the participants and Chapter 5 addresses the qualitative results obtained through observation of the Facebook wall posts of selected virtual support groups related to pulmonary embolism (PE) and deep vein thrombosis (DVT) and interview responses obtained from volunteers from with the selected groups. The last and final chapter, Chapter 6 draws conclusions based on the research obtained and looks ahead to future related studies.

## **Chapter 2: Theoretical Frameworks**

Advancements in technology allow individuals to interact more readily, to more quickly discover information and to more quickly disseminate knowledge. Trust that was lost between the doctor and patient is re-established, re-created, or transferred to individuals with no credential other than the shared illness experience. Social media provides people who have survived and who now live with the effects of a chronic illness a place to share their story, to learn from others, to relay information, to communicate with others and to be validated as individuals. Additionally, involvement in the virtual support group may encourage the person to cooperate with therapeutic plans like getting an X-ray, taking medication as prescribed, or making necessary lifestyle changes (DeVita, 1995, p. 66). Given the increase in the number of people who experience a pulmonary embolism and survive, stronger evidence about the use of social media such as Facebook and the associated virtual support groups that form around the traumatic event is needed in order to identify the impact, if any, on the person.

In this chapter, I review literature suggesting notions of illness are socially constructed through interactions and that the institutional power of the medical profession has been and perhaps continues to be, the primary force in shaping modern ideas about illness. Framing my work along the lines of Bourdieu's theory of distinction, I highlight the transformative agency of a type of knowledge capital that may be gained from participation in virtual support groups. I also review work on illness-related stigma, which as noted by Goffman (1963), reduces the individual "from a whole and usual person to a tainted, discounted one" (p.3) but that within the illness group may be avoided or overcome. In the final section of the chapter, I discuss some

affordances and challenges of online activity, including research approaches to online interactions.

### **Social Constructivism and Chronic Illness**

Research conducted in the 1960s by Dr. Alvan R. Feinstein created a clear distinction between illness that is socially constructed and disease that is scientifically explainable. In the intervening decades, the dichotomy between illness and disease has been further strengthened by the research of others, especially in the fields of medical sociology and medical anthropology (Banks & Prior, 2001, p. 11). As technology continues to develop and shape how the medical community interacts with those who are ‘ill’ or ‘diseased,’ the dichotomy between illness and disease remains a site of struggle. The medical community grounds itself in the idea that “disease (is) a natural, though pathological (abnormal) process in the human body, whilst ‘illness’ (refers) to a sufferer’s subjective experience of such pathology” (Banks & Prior, 2001, p. 11).

Sociologists such as Goffman and Kleinman moved away from Parson’s modernist “sick role,” which “carried with it the expectation that ill people get well, cease to be patients and return to their ‘normal’ obligations” (Franks, 1995, p.9). Goffman, Kleinmann and others began to focus on the idea that illness is socially constructed. Such a framework emphasizes “the cultural and historical aspects of phenomena widely held to be exclusively natural” (Conrad & Barker, 2010, p. S67). Medical sociologists found that “individuals and groups contributed to producing perceived social reality and knowledge” (Conrad & Barker, 2010, p. S67) which echoes the earlier research of folklorist, Diane Goldstein (2004) who stated “the natural world and the cultural world share the burden of creating disease realities” (p.xiii). In the decades since Feinstein’s original work, much has changed in regards to how people produce and perceive illness. In an update to his published work, Feinstein acknowledges what has been done by

others and also notes that there is work still to be done in the evaluation of patient care practices (Feinstein, 1994, p. 804). Conrad and Barker (2010) also note that “the social construction of illness has become a major research area” (p. S67). There is something to be found in the relationship between virtual support groups created via social media, a clearly socially constructed, albeit, virtual space like Facebook and the recovery from illness as experienced by those who have survived a pulmonary embolism (PE) or a deep vein thrombosis (DVT).

A social constructivist approach to illness “foregrounds how illness is shaped by social interactions, shared cultural traditions, shifting frameworks of knowledge and relationships of power” (Conrad & Barker, 2010, p.S69). Social groups now coalesce around illness in addition to the more traditional formation of groups around socio-economic status, gender, or age. Newly formed illness-related groups often shape and define illness related behavior and often have deeply ingrained beliefs about what is normal or abnormal for their particular illness. In many respects, members of such groups take ownership of the illness, constructing their own social world and constructing individual self-hood through ongoing interactions (Conrad & Barker, 2010, p.S68).

For the chronically ill person “real and tangible” social consequences of their illness label are mitigated by the social group that affords a sense of empowerment. The illness group, for the chronically ill, may be the only space where the individual feels ‘in control.’ Virtual support groups demonstrate Goffman’s ideas of how individuals today take control of their ‘illness world.’ The individual posts in virtual support groups provide “evidence for the fairness or unfairness of his (her) situation and other grounds for sympathy, approval, exoneration, understanding or amusement (Goffman, 1974, p. 503). Social media thus helps “individuals make sense of their illness” (Conrad & Barker, 2010, p. S68).

## **Knowledge, Power, and Narratives of Chronic Illness**

The illness group formed when participants join an online health related virtual support group is very much a ‘field’ as explained by Bourdieu (1989) in that the illness group reinforces specific social positions and power relations (p. 101). Members share their individual stories, symptoms, and treatment regimens—the habitus (Bourdieu) of their illness—in an effort to understand, to gain knowledge, and therefore have power over the illness rather than the illness controlling them. Often this shared information within the illness social group diverges from accepted and expected medical discourse that Foucault noted, “constructs knowledge about the body including disease” (Conrad & Barker, 2010, p. S68). Well-intended medical professionals provide the illness label which in turn “influences patients’ behaviors, impacts their subjective experiences, shapes their identities, and legitimates medical interventions (or lack of)” (Foucault qtd in Conrad, 2010, p. S69). But, the individual sufferer, as a result of the knowledge gained in the illness group, becomes a “lay expert” of his or her illness. The more the person learns, the more he or she adjusts or modifies his or her own agency and the habitus in which he or she is a patient, the more likely a contested space between physician and patient develops.

The illness group allows participants to further and maintain “ideas that are often in conflict with those of medical professionals” (Banks & Prior, 2001, p. 12). Such lay experts, as these individuals become, define their illness differently than accepted medical professionals potentially leading to clinical consultations that become contests between doctor and patient (Banks & Prior, 2001, p. 12). Individuals may face contested illnesses as well as a contested treatment plans leading them to seek out validation from like-minded individuals of an illness group. An illness group may validate individuals’ symptomatology and etiology; the members of such groups tend to recruit evidence, expertise, and enthusiasm (Banks & Prior, 2001, p. 12) that

align with the groups' definition of illness and "arises out of the interaction between mind, body and patient's social world" (Banks & Prior, 2001, p.13) as created within the virtual support group. As a result of their individual involvement in an illness group, virtual or face-to-face, participants have the potential for transformative agency to affect the quality of health care and a change in institutional practice that promotes people being actively involved in the decision making processes involving their care rather than maintaining a role of passivity and quiescence (BèHague et al., 2008, p. 491). Though at first an individual's health habitus may be one of compliance, the knowledge capital acquired from the external habitus of the illness group may transfer back to the clinical environment of the hospital or physician's office and may cause changes within the doctor-patient relationship. Virtual support groups may enable individuals to develop a more proactive response to medical encounters. The response developed by the individual who is also a participant in an online illness related social media group may be shaped not only by the patient's individual experiences (habitus), but also the experiences (habitus) of others.

In *Birth of the Clinic*, Foucault (1973) explores the relationship of power and knowledge within health care practices. He reinforces the idea that, like history itself, the field of medicine is mutable. The virtual support group may actually redistribute the power once held solely by the medical professional. The virtual support group, like the doctor-patient relationship, is a site of struggle and power and possibly a means to critically evaluate health care relationships and practices that lead to subsequent changes in how the person and health care professional relate to one another. There is a need for examination of the narratives created in virtual support groups to better understand how individuals tell their story or don't tell their story to others, including to the doctor or other health care providers. Also, such examination may highlight how individuals

use others' illness narratives to enable individual self-care practices or to control his or her illness rather than being controlled by illness. The virtual support group affords a space for an individual to narrate, to author, to reveal his or her illness experience which in turn allows the individual to take ownership of his or her diagnosis in such a way that may improve overall quality of life.

Traditional literary studies often relate narrative to setting, plot, conflict, climax, resolution, theme, and point of view. In short, a narrative tells a story about something that has already happened; narrative relates a temporally ordered past experience. A story can be told for the sake of the story or it may be told with some grander 'point' or purpose in mind. As a narrator, as a storyteller, an individual may narrate the story, events or episodes, all smaller versions of the whole, of his or her life or the life of another. In his work with inner city black youth, Labov (2008) defined narrative as one method of recapitulating past experience by matching a verbal sequence of clauses to the sequence of events which (it is inferred) actually occurred and the sequence of events were to be temporally ordered in such a way that to change the temporality of the occurrence was to change the occurrence completely and thus make it something it is not. Labov identified five elements that must be present for an exchange to be considered narrative. For Labov, a narrative must have an abstract (What is this about?), an orientation (who, when and where is this?), a complicating action (then what happened?), an evaluation (the "so what?" moment), the result (what finally happened) and the coda (which returns the participant to the present (p.218- 219). Labov (2008) placed particular emphasis on the coda as the sign that demarcates the beginning and end of a narrative and stated "a complete narrative begins with orientation, proceeds to the complicating action, suspended at the focus of

evaluation before the resolution and concludes with the resolution before returning the listener to the present with the coda” (p. 219).

In the opening introduction to *The Discourse Reader*, Jaworski and Coupland (2008) state, “telling stories is a human universal of discourse. Stories or narratives are discursive accounts of factual or fictitious events that take place, have taken place or will take place at a particular time” (p. 25). Jaworski and Coupland make no immediate distinction between storytelling and narrative. Indirectly, the difference between narrative and storytelling is an implied difference in that narratives [not stories] are “constructed in a particular temporal order” (Jaworski & Coupland, 2008, p. 25). The primary difference between narrative and storytelling then becomes primarily a difference of sequential order. Narrative and storytelling are mutable and often combine a variety of modalities and voices in a single event or become a single event told by multiple storytellers who have the common aim to inform, to entertain, to persuade, to build communal bonds, to strengthen relationships, to preserve self or to heal (Jaworski & Coupland, 2008, p. 25). However, some see narrative as a privileged genre over story because a story may lack plot and coherence and embody a certain familiarity and closeness not evidenced in a narrative (Boje, 2001, p. 1). Narrative and storytelling share the same basic structure and the same adherence to plot. If any distinction can be made, it is perhaps in understanding that individuals’ stories are told to create, advance, forward, or develop a master narrative or life story. Narrative thus becomes a collection of stories told over time that represent ‘self’ in and across various spaces and narratives “are not inherently objective or impartial ways of representing events . . . but are rather intimately tied to the narrator’s point of view” (Jaworski & Coupland, 2008, p. 27). Understood this way, the narrative, the “performative domain of social action” (Edwards, 2008, p. 227) is the whole of an individual’s life while ‘stories’ represent the

often informal and uncontrollable episodes of that life as an individual attempts to bring order to chaos. Stories are the (re) enactment of “important aspects of our identities and relations to others” which compose the narrative of self (Jaworksi & Coupland, 2008, p. 27).

The illness-narrative, then, becomes a sub-genre of narrative as events, in particular, illness, are told and retold through the lens of the sufferers or those who have had to share the suffering of another; as a result, the re-telling is not an “an objective mirror image of reality” but rather a perception of how the narrator sees him or herself in relationship to the illness event (Jaworksi & Coupland, 2008, p. 27). Goffman’s (1974) definition of narrative—“a tale or anecdote, that is, a replaying . . . of a past event . . . the personal perspective of an actual or potential participant . . . [is also] something that listeners [readers] can empathetically insert themselves and vicariously (re) experience what took place” (p. 504)—is evidenced in the postings that occur in virtual support groups formed through social media outlets such as Facebook. The illness narrative developed within the framework of a social media outlet is a distinct form of narrative, “distinct from say, a sermon, lecture, scientific explanation or any other discursive category” (Edwards, 2008, p. 229). Like other narrative forms, illness narratives “(1) value an end point or goal, (2) an ordering of events (3) stable identities, (4) causal links and explained outcomes, and (5) demarcation signs marking the beginning and ending” (Edwards, 2008, p. 228). The illness narrative is a category of narrative on par with comedy, tragedy, romance, satire, and irony, and shares a close association with irony in that illness narratives, like irony, understand “that comedy, romance and tragedy are mere schemes of mortals to control experience: individuals are not so pure, nor is the social order so healthy” (Murray, K., qtd in Edwards, 2008, p. 229). The illness narrative can at times be humorous, tragic, ironic while still

highlighting individual awareness of one's own mortality as well as heightening the awareness of the mortality of others through the shared experience of illness.

Boje (2001) states that “story is an account of incidents or events [while] narrative adds ‘plot’ and ‘coherence’ to the storyline” (p.1) and that narrative comes after story and provides plot and coherence. Boje goes even further, developing a new term that he refers to as the *antenarrative*, “the fragmented, non-linear, incoherent, collective, unplotted, and improper storytelling” which may more accurately describe what often happens in virtual support groups developed around illness. Whether fragmented, non linear, or at times incoherent, virtual support groups become a means by which individuals tell their illness story and live their illness experience. Sontag (1978) noted in *Illness as Metaphor* that “everyone who is born holds dual citizenship in the kingdom of the well and in the kingdom of the sick [and] sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of the other” (p. 3). For individuals who seek out and join an online health related virtual support group, the support groups become Sontag's *kingdom of the sick* and allow participants to be ‘sick’ within the confines of virtual space even if unable to fully express sickness, illness when in the *kingdom of the well*. Individuals can exist simultaneously in both but may feel they truly only belong, or ‘fit in’ with one. This illness narrative posted in virtual space allows for the enactment of Burke's (1950) theory of identification and consubstantiation whereby illness becomes the common space of identification for those who would otherwise have nothing in common (Burke qtd in Herrick, 2009, p.225-226)

Postings shared in spaces such as Facebook, or in the more concise venue of Twitter, allow people to express their lived experiences. Facebook postings, more than Twitter, may share many of the same features of narrative-storytelling in which the speaker/narrator/story-teller

demarcates the beginning and end of the ‘story’ or episode; events are sequenced to reveal an overall plot and involve the actions of characters, diverse others who are as much a part of the narrative being retold as the narrator-storyteller. These posts are often more than what occurs naturally in conversation and evoke a certain shared empathy. Acknowledging the common bond between storytelling and research, Riessman (1993), states “Storytelling, to put it simply, is what we do with research and clinical materials, and what informants [participants] do with us . . . [the story/narrative] does not assume objectivity, but, instead privileges positionality and subjectivity” (p. 3). Illness is a disruption in an individual’s master narrative or life story and it fundamentally alters the individual (Riessman, Analysis, 2000 p. 332). Illness may be a one-time disruption, or as with chronic illness, may be an ongoing disruption marked by various episodes that flare and resolve from onset of illness to either cure or death is achieved. The ill person, the wounded, becomes the narrator of his or her narrative, a storyteller who might also actively engage in the caring and healing of others. The discourse created by individuals who seek out virtual support for their illness is not only shared but also shaped and reshaped by responses to that story.

Narratives from within the virtual support group share many of the same characteristics as any other narrative. If a narrative is, as Charon (2006) noted, a clinical cousin of literature, the implication is that, like any literary narrative, the narratives created in virtual space are likewise structured. In their article, “Small stories as a new perspective in narrative and identity analysis,” Bamberg and Georgakopoulou (2008) identify what they call “small stories,” narratives which exists on the fringe (p. 379). Illness narratives in virtual space may exists on the fringe but “they can be used as a point of entry into identity analysis. . . privileged forms/structures/systems for making sense of self. . . (Bamberg and Georgakopoulou, 2008, p. 378). The illness narrative

within a virtual support group such as those found through Facebook can be identified by its beginning, usually marked by the onset of illness, and then marked again by entrance into the virtual support group.

Illness narratives are a form of health care that “recognizes suffering provides comfort and honors the stories of illness” (Charon, 2006, p. 17) whereas the narrative that is heard and retold by the physician is based on the physician’s interpretation of what a person has reported to him or her as well as what the physician has witnessed or observed that remained unspoken by the individual. The exam room silences many individuals who are “wounded not just in body but in voice” (Franks, 1995, Preface, para. 5). Although told by the individual, the medical record is the clinical record of the individual as interpreted or translated by the physician and transcribed often by some unknown other. Danish medical informatics researchers, Dr. Troels Mønsted et al., (2011) write about medical records stating:

These documents have a strong narrative aspect because narratives supply a workable medium for representing knowledge that is time- and context-dependent—and often uncertain or ambiguous as well. They are created to organize, record, and capture practical experience (p. 81).

Additionally, according to Mønsted et al., “a medical record embodies multiple intertwined representations of the patient” (p. 81). But, the personal ‘story’ is subsumed, surrendered to the business of medicine (Franks, 1995, p.7). The physician-centered narrative created by health care professionals revolves around a person’s symptoms and diagnosis, but it may never tell the whole story from the individual’s point of view. A person can be reduced, anonymized, to nothing more than clinical notations of symptoms and billing codes. Peters and Gillette (2012) discuss the ways by which people are categorized as “good” or “bad” patients based on the individual’s ability to meet discursive norms placed upon them by the health care practitioner.

Their work looked at the “good patient narrative” as reported in social media used by health care professionals (HCP’s) with a particular focus on weblogs (blogs). Participants within the online health-related virtual support group form or coalesce around critical health care phenomena and their virtual patient narratives define the “good or bad” health care professional (Peters & Gillette, 2012, p. 2).

By contrast, in the virtual support group, the individual, the patient, becomes the narrator, the storyteller of his or her own story in order to inform, to persuade, to heal those who also share the same illness experience. Though an individual has the choice to lurk or the choice/chance to speak, virtual space allows for, encourages even, the interaction between many and is a space in which the individual participant’s anecdotal knowledge privileges the person as an ‘expert’ of a “discourse [that] can be taken to represent a voice within a text or a speech position” (Mills, 2004, p. 8) that might otherwise be silenced in the larger, more clinical, physician driven narrative. The story is also shaped by the stories of others. This ‘storytelling’ of the self-created narrative empowers and enables participants to become more proactively involved in self-care management and illness prevention and awareness. The multiple ‘stories’ of one person’s narrative may affect the choices another person may make while also providing a certain amount of legitimacy to the illness experience that might be otherwise stigmatized. The narrative within virtual space is a collection of fragmented, disjointed, non-sequential stories created simultaneously by the story-telling practices of multiple narrators and story-tellers.

Virtual space may be the only place a chronically ill person feels he or she is ‘in control.’ Unlike a face-to-face group aligned with a specific illness that may meet with a facilitator, virtual spaces may have no facilitator, no set time or day in which the virtual group ‘meets’. The group is fluid and organic, always on and rarely, if ever, off. Through storytelling, individuals may

have the potential for their own transformative agency to affect not only their own health care, but also the quality of health care for others as well as institutional practices and policies related to health care. Participants not only develop responses to their individual medical encounters based on their own individual experiences (*habitus*) but also base their responses on the experiences of those within the online virtual support group. The virtual support group may aid an individual in creating a new patient narrative in which he or she is an active agent/actor rather than a passive agent/actor that is acted upon. There may even be redistribution of power within the doctor-patient relationship.

### **Stigma and Chronic Illness**

Chronic illness narratives are a means to reclaim the silenced patient's voice; virtual support groups provide a vehicle by which these otherwise silent stories, autobiographical narratives, can be expressed in such a way as to "preserve face" and to manage "potentially spoiled identities" (Goffman, *Stigma*, 1963, p.3). Outside of the group context, an individual may feel stigmatized by illness. Whether, the stigmatization is personal perception or whether it is felt in the interactions one has with others, the stigma of chronic illness—the sense of being less whole, in some way broken, incomplete, or spoiled—is lessened within the virtual support group context because the individual finds empathetic others who share in his or her illness experience. Illness is a 'thing' to be avoided. Some illnesses are more acceptable than others; whether it is cancer instead of TB or heart disease instead of cancer, the disclosure of illness "can be a scandal that jeopardizes ones love life, one's chance of promotion, even one's job" (Sontag, 1978, p. 8).

## **Social Media and Chronic Illness**

In the 21st century, chronic illnesses bare the stigma once given to TB or cancer often because a chronic illness “implies a weakness, trouble, failure that is mechanical” (Sontag, 1978, p. 9). The dread of cancer has lessened as individuals have become emboldened and empowered by awareness of the disease. Survivors are warriors in the battle between life and death, ennobled by a disease that once would have shamed them. Chronic illnesses consume and ravage the once healthy body, mind or both (Sontag, 1978, p. 10). Illness narratives are a means by which participants negotiate how they want to be known within the stories they develop collaboratively within the virtual support group. These narratives may also help define how they shape their lives of illness in relationships outside the context of the virtual support group. The Internet provides fertile ground for illness narratives to grow, especially those of marginalized voices that might otherwise not be heard.

Internet usage among individuals of all ages continues to rise. The increased availability of readily-accessible information related to disease and illness is often what makes the Internet wary active online. In her article about Electronic Support Groups (ESG’s), Barker (2008) writes that as of 2002 “approximately 93 million American adults went online to search for information about their health (Fox and Fellows qtd in Barker, p. 20). Today, that number has increased to “billions of people around the world” (Boughin, et al., 2011, p. 5); but, electronic support groups are not a new idea. According to a 2012 study by Galit Nimrod, “the phrase ‘virtual community’ was first used by Rheingold (1994) describing his experiences in an early online community called WELL (Whole Earth Lectronic Link)” (p. 1246). From that 1994 experience to today, it is easy to see how integrated the Internet has become in everyday lives in a relatively short amount of time. Bughin et al’s 2011 report on Internet technologies states:

Online search technology is barely 20 years old, yet it has profoundly changed how we behave and get things done at work, at home, and increasingly while on the go. It empowers people and organizations in every corner of the world. A world without search technology has become unimaginable—so much so that we take it for granted and underestimate its value. (p. 1)

Bughin et al. support Barker's (2008) earlier work which states "a key component of what is known as e-health is electronic support groups (ESG's) for illness sufferers" (20). Information for sufferers is "accessed as bulletin boards, news groups, listservs and chat rooms" (Barker, 2008, p. 20). This description is similar to Rheingold's in 1994 when he defined a virtual community "as a group of people who may or may not meet one another face-to-face, and who exchange words and ideas through mediation of computer bulletin boards and networks" (Rheingold qtd in Nimrod, 2012, p. 1246). Additionally, Nimrod (2012) notes that much of the communication research related to online support groups "focused on email, distribution lists, chat rooms, or forums/bulletin boards" (p. 1247). Noticeably absent is any mention of Facebook or any other social media outlet. Barker's article was published in 2008 and Facebook was barely four years old, having been launched in February 2004, though it was not generally accessible until 2008. In 2008, Barker noted that thousands of ESGs already were available for illness sufferers; but, in spite of the large number of ESGs, little is known about them. Barker's findings echo that of Eysenbach et al. (2004), who stated

no robust evidence exists of consumer led peer to peer communication, partly because peer to peer communication has been evaluated only in conjunction with more complex interventions or involvement with health care professionals. Given the over abundance of unmoderated peer to peer groups, research is required to evaluate under which conditions and for whom, electronic support groups are effective and how effectiveness in delivering social support can be maximized (p. 1).

Social media is still evolving and as a result, methodologies to study the results of social media on the individual are still developing. Information, especially the information that is

oriented towards a more scientific discourse like medicine is no longer passed from expert to layman, doctor to patient, in a linear fashion because “science is no longer ‘enclosed’ within identifiable discursive forms but circulates within many ordinary discourses, whether in the media or not” (Beacco, Claudet, Doury, Petit, & Reboul-Toure, 2002, p. 279).

### **Researching Online Spaces**

Research in online spaces is relatively new and is constantly changing. The individual’s daily lived experiences are now carried out or cross over into these online spaces, especially with the widespread use of social media outlets such as Facebook. Online researchers regardless of discipline, whether social science, linguistics, communication, or technology have had to adapt and modify existing methodologies for use in the online space as well adapt a variety of theories, based on the researchers discipline, to online research practices. Methods used to study online environments entail a certain amount of uncertainty; even if much anecdotal evidence identifies the value of virtual space, there is much “uncertainty about how, or even if they can be evaluated in accordance with the clinical standards of evidenced-based [traditional] medicine (Eysenbach et al. qtd in Barker, 2008, p. 20). But social media such as Facebook is “after all a social phenomena [which] must be studied, at least in part, using tools and methods of social science” (Barker, 2008, p. 20).

The social constructivist approach to research “examines how individuals and groups contribute to producing perceived social reality and knowledge (Berger & Luckman qtd in Conrad & Barker, 2010, p. S67). The social constructivist approach to studying medicine was also shaped by Goffman’s work as a symbolic interactionist. Goffman identified “patienthood” as distinct from any biological condition . . . [because] individuals actively participate in the construction of their own social worlds” (Goffman qtd in Conrad et. al., 2010, p. S68).

A certain level of intimacy in the social constructivist approach lends itself to conducting fieldwork in the environment under investigation by immersing the researcher in the setting being studied (Barker, 2008, p. 24). Illness related virtual support groups are “organically occurring” and there is “much to be gained using methods that capture how they function day to day” (Barker, 2008, p. 23). Although “field research (e.g. ethnographic, participant observation, or non-participant observation) can provide thick description of a natural social environment (Barker, 2008, p. 24), there are of course, ethical concerns related to whether the researcher should or should not disclose his or her presence in the setting being studied (Barker, 2008, p. 24). The decision should be carefully made after weighing the risk involved. If the researcher is an active participant in the group from which research data will come, he or she must also consider the relationship of trust that has been established and decide whether or not he or she is going to risk that relationship in order to conduct the necessary research.

One consideration is that if the researcher chooses to participate “the online researcher [may] fundamentally change the peer to peer environment” (Barker, 2008, p. 24). This also assumes that the researcher does not naturally “belong” and overlooks the fact that the researcher may also be a patient participant within the setting being studied. There is little evidence available that discusses the patient-participant-researcher observation may alter research setting’s content and structure (Barker, 2008, p. 24). Online researchers struggle with the issue of public versus private information and do everything in their power to gain informed consent while maintaining subject anonymity. The argument can be made that once information is posted online, the individual forfeits any privacy; in contrast, the argument can be made that a reasonable expectation of privacy be maintained, especially within group discussions (Barker,

2008, p. 24). One way to address this sensitive ethical concern is to establish a collaborative relationship between the researcher and the community in which one wishes to collect data.

Ethnographic observation is one choice for methodology; however, it is not “true” ethnography as would be applied in the social sciences but modified for online research. Denzin and Lincoln demonstrate how ethnographic practices have been modified to work with online spaces, arguing that “computer-mediated construction of self and social structure constitutes a unique phenomena of study” (2005, p. 646). Computer mediated construction of self is made more unique as we consider that the virtual self does not have to be ill, even if the physical self is. Individuals could create a healthy virtual self when they log onto social media sites like Facebook; but, the ill self is clearly evidenced by the large number of illness groups developed through social media such as Facebook. These groups are more patient driven than those created by health care professionals (HCP’s). Virtual illness groups coalesce “out of a particular intersection of forces, discourses and institutions” (Denzin and Lincoln, 2005, p. 647) and in a manner become a genealogy that “maps the complex contradictory ways in which forces and processes come together to produce a certain set of effects...they are histories of effects of consequences” (Denzin and Lincoln, 2005, p. 647). According to Peräkylä (2005) “many scholars working with written text have drawn insights and inspiration from the work of Michel Foucault”(871) and because he provided no definite method for textual analysis, for subsequent scholars, “a primary concern is...how a set of ‘statements’ comes to constitute objects and subjects (Peräkylä, 2005, p. 871). To illustrate the effective use of Foucauldian analysis, Peräkylä references Armstrong’s application of Foucauldian methods to a study of how “rules defining the difference between dangerous and safe or between pure and dirty, have changed during the past two centuries. . . . Armstrong explored the evolution of the spaces in which

individual identity is located” (Peräkylä, 2005, p. 871). Armstrong believed that “texts and practices are inseparable . . . texts in question act as guidelines, instructions even, for actual social practices” (Armstrong qtd in Peräkylä, 2005, p. 872). A Foucauldian approach to text generated by the participants in the virtual groups might first consider how the groups are formed (archeology), secondly, explore the relationships built (genealogy) and third determine how the groups impact care of self (Foucault, 1973).

It is care of self that unfolds within the virtual space with which I am concerned. Foucault’s work in *The Birth of the Clinic* emphasizes the way medical knowledge had, at the time of its writing, become a space of power, power that was often used to inappropriately label the “normal” and the “abnormal” and the ways such labels would adversely affect the individual. Today, individuals are labeled in a variety of ways, such as “sick,” “ill,” “well,” “unwell,” “able” or “disabled.” Such labels need to be deconstructed, taken apart to be fully understood. Each individual’s venture into what Sontag (1978) refers to as the “kingdom of the ill” (p.3) is different and the landscape is created by the words written and shared by the individual participant in the group. As the individual writes out his or her experience in the “kingdom of the ill”, he or she is also forced to encounter his or her understanding of their label – sick, well, able, disabled, bereaved, or even victorious. Virtual support groups constructed through social media may give the individual the power to deconstruct his or her illness and to resist the label of being “ill.”

Participants in virtual support groups are collectively shaping a new discourse, “writing seen from the point of view of the beliefs, values, and categories which it embodies . . . a way of looking at the world” (Mills, 2004, p. 5). Illness narratives are a discourse of multiple utterances “which are regulated in some way and which seem to have coherence and force to them in

common (Mills, 2004, p. 6). For Foucault, medical discourse (illness narratives) shapes how an individual understands both the body and the body in relationship to illness. Because virtual support groups and social media have the potential to modify how patients perceive their condition, manage their illness, and communicate within the doctor-patient relationship, the narrative stories told in virtual space need to be examined if we are to fully understand how that discourse shapes the illness experience for individuals in relation to self and others, including health care professionals.

## Chapter 3. Methods

In this chapter I discuss the rationale for the methodologies used in this study. I also discuss the participants and procedures, the data collection and the coding and analysis of information collected during this study.

### **Rationale**

Grounded theory (GT), developed in the School of Nursing at University of California in San Francisco by sociologists Glaser and Strauss (1967), is well suited to discuss the social processes which occur as a result of social media, particular to this study, the social processes of virtual support groups related to some type of venous thrombotic event (VTE). According to Glaser and Strauss this methodology is built around “the discovery of theory from data systematically obtained from social research” (Glaser and Strauss, 1967, p.2). For the participants of these groups, collaborative relationships are socially constructed as a result of having survived the VTE. The diagnosis of a VTE is inseparable for the participants ongoing social processes on or off line. Vygotsky(1978) stated that knowledge is collaborative and socially constructed; “learning,” he said, “could not be separated from its social context”(1978, p. 57), neither can illness or disease be separated from its social context of the virtual support group which may present itself as a space in which participants construct a self that is chronically ill or a self that is a survivor. Vygotsky (1978) argued that

cognitive function originated in, and therefore must be explained as products of social interactions and that learning was not simply the assimilation and accommodation of new knowledge by learners; it was the process by which learners were integrated into a knowledge community. (Vygotsky, 1978, 57)

For Vygotsky, linguistic abilities impose a culturally defined meaning on an otherwise chaotic world. Cognitive development is for Vygotsky (1978) primarily socially constructed but knowledge is not. Knowledge is co-constructed, (39). In the virtual support group, knowledge about individual PE or DVT experiences is continually shaped and defined by other participants within the group. A purely constructivist approach “denies the existence of an objective reality, ‘asserting instead that realities are social constructions of the mind, and that there exist as many such constructions as there are individuals (although clearly many constructions will be shared) (Guba & Lincoln, 1989, p.43)” (Mills, Bonner and Francis, 2006, p. 2). Grounded theory, in its origins as advanced by Glasser and Strauss, Strauss and Corbin and others,

consists of simultaneous data collection and analysis, with each informing and focusing the other throughout the research process. . . Grounded theorist portray their understandings of research participants’ actions and meanings, offer abstract interpretations of empirical relationships, and create conditional statements about the implications of their analysis (Charmaz, 2005, p.508).

Work by Charmaz and others (Seale, 1999; Bryant, 2002, 2003; and Clark, 2003, 2005) begins to move grounded theory towards a more constructivist approach that “emphasizes the studied phenomenon rather than the methods of studying it”(Charmaz, 2005, p.509). Grounded theory becomes ever more focused on the exploration of a topic with the goal of generating a richer understanding of phenomena because “constructivist grounded theorists take a reflective stance on modes of knowing and representing studied life. That means giving close attention to empirical realities and our collected renderings of them—and locating oneself in these realities”(Charmaz, 2005, p.509). For Charmaz and others (Clarke, 2003, 2005; Maines, 2001, 2003) “‘grounded theory’ refers both to a method of inquiry and to the product of inquiry” (Charmaz, 2005, p. 507). Using grounded theory “encourages the researchers to remain close to their studied worlds and to develop an integrated set of theoretical concepts from their empirical

materials that not only synthesize and interpret them but also show processional relationships” (Charmaz, 2005, p. 508) and in this case, being close to the studied worlds involves being a participant in the groups studied.

Grounded theory as a methodology is suited to analyzing chronic illness narratives as a means to reclaim the individual’s voice, to make sense out of the chaos of life (Charmaz, 1990, p. 1161). Charmaz argued that justice and injustice are “enacted processes, made real through actions performed again, and again” (p. 508), so too can the labeling of sick, well, healthy, unhealthy, abled, disabled also be “enacted processes,” and the silencing of the person when they become ‘a patient’ also a social injustice. Charmaz (2005) advances a theoretical framework which blends grounded theory with social constructivism in order to broaden the scope of inquiry to allow the researcher to “offer theoretical statements about the conditions under which injustice or justice develops, changes or continues” (Charmaz, 2005, p.508). A constructivist grounded theory approach recognizes the role of the researcher as well as that of the participants, acknowledging the fact that the researcher is neither impartial nor without prior interpretive frames. Charmaz (2005) writes “in short, we[researchers] share in constructing what we define as data” (p.509)

Because of the textual nature of a virtual support group, critical discourse analysis(CDA) is another important perspective for this research. CDA as referenced here “sees discourse (semiosis) as a social process” (Fairclough, et al, 2011, p.357). CDA allows the researcher to “approach (the research) less with aims of ‘constructing knowledge’ and more with hopes of ‘negotiating encounters’” (Santos, 2011, p. 1). CDA recognizes that discourse is “socially constituted as well as socially constructed” (Blommaert & Bulcaen, 2000, p.447). CDA analyzes the real and often extended social interactions that represent “opaque as well as transparent

structural relationships of dominance, discrimination, power and control as manifested in language (Wodak, 1997 as cited in Blommaert & Bulcaen, 2000, p.447). CDA draws attention to “(a) the relationship between language and society, and (b) the relationship between analysis and the practices analyzed (Wodak, 1997 as cited in Blommaert & Bulcaen, 2000, p.447).

Blommaert and Blucaen (2000), also quote Chouliaraki & Fairclough (1999) who wrote

discourse is an opaque power object in modern societies and CDA aims to make it more visible and transparent. It is an important characteristic of the economic, social and cultural change of late modernity that they exist as discourses as well as processes that are taking place outside discourse, and that the processes that are taking place outside discourse are substantively shaped by these discourses (p.4)

The illness narratives which are shared within the virtual support groups can sometimes highlight the invisible and transparent as individual participants discuss economic, social and cultural changes as a result of their pulmonary embolism or deep vein thrombosis. Within the confines of the group, the societal inequities faced by those who sojourn too long in the ‘kingdom of the ill’ become evidenced in the stories of lost jobs, lost relationships or lack of access and even loss of access to health care.

Critical discourse analysis allows for the study of meaning making within a virtual support community. Individuals in virtual support groups negotiate encounters every time they enter the virtual support group. Encounters in the virtual support community open a space for the examination of negotiation between participants and what Levinas called the “need for, and potential disruption caused by others and their narratives” (Santos, 2011, p. 7). Virtual support groups, virtual support communities, are a space in which stories collide not only because of the participants’ need to tell the story but also the need to hear another’s story as a means of validating their own. Virtual support group participants need the space in which to voice their on stories but also need to accept that their stories often may be disrupted by the stories of others.

Santos argues that “digital technologies awaken a desire for something that is missing in the atomistic Modern life; they rekindle a desire for others” (Santos, 2011, p. 1). CDA is a tool by which to examine the space where this disruption of the narrative occurs, as well as the space before and after the disruption and allows for, even encourages examination of the disruption itself. For the participants of the selected groups in this study, the disruption is the pulmonary embolism or deep vein thrombosis event.

Groups created through social media may enable individuals to take proactive steps in their post pulmonary embolism or post thrombolytic health-care decision-making processes. The purpose of this study is to better understand the way in which virtual support groups help define the chronically ill self for the PE/DVT survivor, to better understand the way in which stigma and othering are conveyed in virtual support groups related to specific diagnoses, and final, to better understand individual healthcare decision-making practices as a result of participation in the virtual support group.

In this study, I used a mixed methods design with the “intent of mixing quantitative and qualitative data in a single study (or a program of study)” (Creswell, 2003, p. 208) to develop a more complete understanding of the research questions. Using mixed methods reflects “the situation today [that] is less quantitative versus qualitative and more [about] how research practices lie somewhere on a continuum between the two (e.g. Newman & Benz, 1998)” (Creswell, 2003, p. 4). Mixed methods also provided room for multiple points of view and varying levels of insight (Creswell, 2003, p. 16). There are many advantages and disadvantages to using a mixed methods approach. Mixed methods are increasingly familiar to researchers and “can result in well validated and substantiated findings” (Creswell, 2003, p. 217) in a much shorter time period. Additionally, mixed methods may also allow for multiple perspectives

within one study or may allow for two types of data collection whether of equal or unequal priority to the study (Creswell, 2003, p. 218). On the other hand this type of research requires more effort and expertise (Creswell, 2003, p. 217) because of the use of different methods for data collection and analysis. Discrepancies that arise may also be much more difficult to resolve (Creswell, 2003, p. 218). In this research, I collected data using surveys, interviews and analysis of posts to Facebook.

Participants were members of selected virtual support groups created through Facebook (FB) that were designed around pulmonary embolism (PE) and deep vein thrombosis (DVT) recovery. The survey and the interview was developed to gather information about the group members' self-perception of the illness-related online virtual community and its connection to health related decision-making practices. The goals were to identify participants' attitudes about virtual support group as well as basic demographic data about the membership of the groups. The survey and interview questions about attitudes were developed from topics discussed in Facebook communities. The survey results were not used to gauge statistical significance among variables but to consider participants' attitudes about topics. The survey questions were first developed through conversations with my dissertation advisor to make sure that my questions reflected the direct response sought. The survey questions were also presented to my dissertation committee for content review. Each member of my dissertation committee was uniquely qualified to provide appropriate guidance about the survey questions. My committee was composed of individuals with research backgrounds in bioethics, public health and law; discourse analysis, health and medical rhetoric, and rhetoric and professional communication. Any suggestions given regarding the design of the survey questions were addressed prior to submitting to the Institutional Review Board which was subsequently approved.

Also during the research window, narrative discourse was explored through the collection and analysis of participant posts to three illness related online communities specifically related to pulmonary embolism and deep vein thrombosis accessible through Facebook. Combining the qualitative data gained through the collection of the participant posts with the quantitative data collected from the survey “offers another means to understand the social meanings which are constitutive of and reflected in human behavior” (Mann, 2000, p. 84).

### **Participants and Procedures**

Participants were solicited for the study from the members of three different Facebook groups related to pulmonary embolism. First, Pulmonary Embolism Awareness (PEA) the largest of the three groups selected as well as the largest VTE related support group on Facebook, is an open group. In August 2013, membership of the group was approximately 2949 members and 3 months later this number has grown to 3,224, a 9.3% increase in membership. PEA is an open group that anyone can join and anyone can see posts shared in the participants’ newsfeed.

The second group selected was the Pulmonary Embolism Survivors (PES) group that had approximately 594 participants when data collection began in August 2013 and 3 months later had a membership of 1,256, a 111.4% increase. This group is a closed group meaning that anyone can see the group but only members can see the posts of the participants. Privacy of membership is important and the administrators of the group reiterate this in their explanation when they state “This is a support group for people who have suffered from Pulmonary Embolism(s). Only Members can post to this wonderful group!”

The third group selected was the Pulmonary Embolism Awareness Project (PEAP). When data collection began in August 2013 there were only 175 participants. This has since

grown to 328 participants, 87.4% increase. This group is also closed and is strongly focused on awareness. This sense of awareness is represented in the group's strong site description which states in part, "Pulmonary embolisms kill 100,000 people each year!! They do not discriminate based on age, race, or sex!! KNOW what you are looking for! This is a silent killer!" (PEAP, 2013).

Once IRB approval was attained for the research, a letter of explanation was posted to each group and volunteers were requested for this study. Participants for this study were selected from the three groups because they are:

1. impacted personally by a pulmonary embolism
2. the family member of a PE victim or survivor
3. between the ages of 18 and 80
4. are willing to provide written consent.

Participants were asked to complete a survey/questionnaire (see Appendix C). Once the survey window had closed, a request for participants who were willing to be interviewed was then posted to each of the groups.

Eighty participants completed the survey and twenty consented to the interview. Response to the request for interviews was much better than I had anticipated. Originally, I had planned on interviewing only six participants, two from each Facebook group. Due to the positive response to the request for interviews, I decided to interview participants at various intervals of membership to ensure I had a range of viewpoints represented. Fifteen participants were selected. Interview times were arranged and all interviews were conducted utilizing the Facebook chat feature. Three volunteer participants were selected from 0-3 months since their

VTE experience, one participant from 3 to 6 months, two participants from 6 to 12 months, three participants from 1 to 3 years, two participants from 3-5 years and four participants whose VTE event was over 5 years past. I would have interviewed all 20, but one declined after having initially given consent and the remaining five were not available during the research window. The participants chosen for, and who agreed to participate in, this more qualitative part of the study are members in one or more of the three groups as well as members of groups not selected for the study but also related to PE/DVT recovery. I had hoped to use length of time participants had been members of the individual groups as a factor of consideration; however, because group membership is fluid, participants were selected based on his or her most recent VTE experience

Participants could opt out at any time and participants of the group could request that I not use all or any part of their postings as part of this research study. Participants indicated their consent to complete the survey, their permission to use their online posts and comments in my research, as well their consent to be interviewed. Additionally, at the time of interview, all 15 participants were asked to reiterate their consent to participate in the study and this was captured in the chat transcript. Participants were reassured that their names or other online identification would not be used in the research and would only be used to identify and collect data from their activity within the group in associated observations of their wall postings to the group.

### **Data Collection**

Data for this study includes results of a survey of 80 participants of the three online social media groups identified previously, postings collected from these same three groups over a 4-week period, and interviews with selected participants.

### *Survey*

An invitation to participate in the quantitative survey (see Appendix 1) was distributed to all participants via posts to the online groups. Prospective participants were provided with an explanation of the research study and my role as both a participant within the group and as the researcher. The importance of the study and the importance of their responses were also explained.

The survey was web based and accessed via a URL provided to participants. An informed consent document was posted as the first page of the web survey. Clicking “I agree” was taken as a participants’ consent to participate in the research plan. The survey was made available for 2 weeks. A reminder post was posted at the end of the first 5 days, again 3 days later, and 24 hours before closing the survey.

The first part of the survey asked participants about their perceptions of how participating within the virtual group has affected how they deal with their illness in areas outside of the group. Some questions on the survey were open ended “other” type questions that allowed the participant to input his or her own responses. Participants also had the chance to select “not applicable” when necessary. This part of the survey posed questions related to participants’ activity within the virtual health community. The final question on the survey was open ended to allow the participant to include any additional comments not addressed through the preceding questions. The last part of the survey instrument asked questions related to participant demographics. These questions provided information on age, gender, employment, education, and other questions connected to illness-related online communities.

## *Interviews*

For this study, qualitative data was collected through interviews with selected participants. Many methods enable researchers of online spaces to develop a better, stronger understanding of the social activities that coalesce in virtual spaces; research methods associated with the study of spoken and written records of human experience tend to be more qualitative than quantitative. Qualitative researchers often rely on the use of interview data that are used to gain insights about general characteristics of the participants of a specified online community and their motivation for participating in the community under investigation (Silverman, 2011, p. 103). Using a structured interview approach and seeking answers to specific questions (see Appendix 2) allowed me to focus on individual perception of illness as well as individuals' perception about how they are seen by others including health care practitioners in and out of the virtual support group. In a sense, the virtual support group frames the illness narrative for a participant in a virtual support group.

To further understand the survey data, I developed interview questions that would allow me to gather more nuanced information than that collected via the survey instrument. I chose to develop interview questions because as stated in *Analyzing Text and Talk*, by Annsi Peräkylä, interviews are the “accounts given to the researcher about issues in which he or she is interested” (Peräkylä, 2005, p. 869). Interview questions (Appendix D) were developed in such a way as to flesh out the information provided on the survey. Where as the survey collected information about attitudes and demographics, the interview provides space to better understand the attitudes expressed in the survey. The data collected for my study comes from the participants of the online communities, whereby they are able to provide feedback based on their own personal experiences, activities, thoughts, and suggestions. Through the interview “the researcher can

reach areas of reality that would otherwise remain inaccessible” (Peräkylä, 2005, p. 869). For Peräkylä (2005), the textual information gained from an interview is treated as a narrative account rather than true pictures of reality (p. 869). Texts generated through interview methods are social artifacts that are produced, shared, and used in socially organized ways both online and off.

In their work with patients suffering from Chronic Fatigue Syndrome, Banks and Prior (2001) noted that CFS patients, like many other chronic illnesses patients, account for their disorder and manage their disorder in different ways in different environments, which in turn affects how “doctors and patients seek to position themselves vis-à-vis various debates about symptoms, causes, and symptoms” (Banks & Prior, p. 14). Their work involved face-to-face interviews, whereas the interviews in this study will be virtual, but their technique of structured interviewing with very specific questions can be adapted to work within the online space and can potentially address the same questions from the point of view of individual empowerment gained as a result of involvement in a virtual support group.

Participants for the interviews were selected once the survey had closed. Eighty participants completed the survey and of those, 20 indicated consent to be interviewed. In addition to the previously stated criteria (impacted personally by a pulmonary embolism (PE), deep vein thrombosis (DVT), or both (VTE), the family member of a PE victim or survivor, between the ages of 18 and 80, and willing to provide written consent), I attempted to select individuals who were at varying junctions of their venous thrombotic experience (VTE) from newly diagnosed, to those who were three to 6 months from their VTE, 6 to 12 months from their VTE, 1 to 3 years from their VTE, 3 to 5 years from the VTE and more than 5 years from their VTE. Choosing the participants by date of their VTE allowed me the opportunity to identify

trends that may emerge over the duration of member participation in the virtual support groups as well as to acknowledge that participants who experienced his or her VTE over a year ago could still be new to the online support community. Through interviews, the researcher can glean insights and deepen understanding of responses to the survey instrument. Interviewing participants allowed participants to “exercise agency in the following ways: by reframing the question, by answering the question, by being purposefully terse (or verbose), by being silent, by setting limits on what they are willing to say, and—in the ultimate act of free will—by quitting the interview” (Kauffman, 1992; Knapik, 2006 qtd in Silverman, 2011, p. 187). As Silverman (2011) notes, the more the researcher can get the participants to “buy in” to the interview process, the more likely the participants are to produce “the information, stories, and accounts that aid the researcher’s quest” (p. 187). Asking structured interview questions and leaving room for individuals to expound on their experiences helped establish rapport and illicit a more developed narrative related to the attitudes expressed through the survey instrument alone.

### ***Observations***

I also collected data in the form of the consenting participants’ postings to one or more of the groups for a period of 4 weeks in 2013. Observation of the wall posts during the specified time frame allowed me to examine posts for the narrative frameworks that might emerge. Information from open group did not need consent as the design of the open group is to promote awareness. However, wall observations from within the closed groups were only used if consent was given. Additionally, anyone who had previously told me that he or she did not want their information used, was excluded from the observations.

### *Coding and Analysis*

Data collected was coded in various ways including conversation analysis, or applying strategies of critical discourse theory, or strategies of narrative analysis. The textual documents' themes or threads that emerged were sorted as the document unfolded.

Coding and analysis of data from surveys was done using Qualtrics. Data was analyzed to see if any noticeable trends emerged within the four illness-related social media communities. Some questions on the survey used a 5 point (rating) Likert scale where 1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often or 5 = All the time. Data conveyed information related to how the participants use illness related communities created through social media outlets like Facebook.

The data collected through qualitative methods were coded by hand and analyzed for themes. Before this could be accomplished, I conducted a preliminary review of existing posts to the three illness related groups available during the research period; I coded and labeled the texts; attempted to identify themes that developed through the coding process; connected related themes; and finally, analyzed the narratives.

There are a variety of approaches to analyzing interview texts once collected, but the most common forms of analysis are derived from conversation analysis (CA), discourse analysis (DA) and narrative analysis (NA). Each form of analysis provided a means for the researcher to develop an understanding of the significance of virtual spaces in relationship to the larger space of the world. To understand the way in which words and text shape one space is to understand the way in which words and texts shape the other.

A distinction between naturally occurring material (such as the posts collected from the groups) and interview with volunteers must also be noted. An interview is focused on the

speaker/writer of the text whereas naturally occurring material is focused more on the topic of investigation rather than the participants. With naturally occurring material there is a sense of historicity of the text being analyzed whereas an interview has more of a sense of immediacy and ‘in the now’ aura. But, as with anything else, there is a grey area in which interviews and naturally occurring material blend or overlap, which is seen in ethnographic fieldwork when “people describe their practices and ideas to the researcher in circumstances that are much closer to ‘naturally occurring’ than are the circumstances in ‘ordinary’ research interviews (Peräkylä, 2005, p. 869). In this study, interviews were conducted with fourteen participants. Nine questions were asked of each participant with the first one having to do with collecting background information on the interview subject. In all fourteen interview scenarios, questions were asked in the same order and in each interview respondents were often asked to explain or clarify his or her response. Interview subjects were eager to have someone listen to their story and often, the interview drifted into that crossover blend between structure and naturally occurring and.

Data collected from observation of wall posts being were analyzed using grounded theory in the manner of those qualitative researchers “who use written texts as their materials” and “who do not try to follow a predefined protocol” but rather “try to pin down their key themes, and, thereby, to draw a picture of the presuppositions and meanings that constitute the cultural world of which the textual material is derived” (Peräkylä, 2005, p. 870). This approach “may be the best choice as a method in research focusing on written texts” (Peräkylä, 2005, p. 870). During the 4 week observation period of this study each group generated hundreds of wall posts and responses each week with some groups being more active than others. Wall posts were collected using Safari’s ‘export to PDF’ feature so that they could be converted to word documents and analyzed both by hand and using NVivo. Once all the wall postings were

collected and all postings before or after the collection period were excluded, postings were sorted and catalogued initially by type: administrative, informational, emotional. Next posts were studied with regard to the topic that generated the most data. The cataloging of text into a variety of categories and topics allowed various narrative frameworks to emerge over the course of the analysis phase. These narrative frameworks could also be identified in participant interview responses and even in survey responses where individuals could add ‘other’ comments as permitted. Virtual support groups are unique in that they occur in real time just as a face-to-face interaction might but without the physical presence of the body, and live through the text typed and shared even if the texts are bound to the confines of the screen, the apparatus which allows for its creation. Yet, the empathic bonds formed as a result of membership in the virtual support groups reiterate the need that individuals have for contact with others and the need to maintain that contact with one another, a contact that is at the very heart of our social and personal being (Peräkylä, 2005, p. 874).

### ***Ethical Considerations***

Online research, like any other research that involves human subjects, brings with it many ethical challenges. Many web forums, blogs, online chats, and other instant messaging avenues are available through the online space. Like forums or blogs, information on Facebook is primarily a text based platform even though individuals can upload photos and other pictures as part of their profile or cover photo and even create individual albums to share publically or only with selected individuals. The individual Facebook participant chooses how little or how much information to disclose. A qualitative approach to this space allows for observation and analysis of data collected. According to Banks and Eble (2007), “traditionally, humanities

research has dealt with written or spoken texts rather than the individuals who write or speak them” (p. 35).

Research conducted in online spaces forces a researcher to consider how existing policies to protect research subjects can be or should be applied to the online space. As online research has continued to grow, the Association of Online Internet Researchers writes that, “the literature of internet research ethics has grown considerably, providing us with a far more extensive range of theoretical resources and practical examples to help recognize and guide ethical reflections”(Markham and Buchanan, 2012, pg. 2). Researchers in digital spaces are just as obligated to demonstrate “respect for persons, beneficence, and autonomy” (Banks and Eble, 2007, p. 31) as any other researcher; researchers in online spaces “have to be aware of these regulations and the problematic transfer from “real life” to the “virtual” realm (Banks and Eble, 2007, p. 32). Too often, “digital spaces . . . are often referred to as ‘virtual,’ suggesting ‘not real,’ yet we can’t always agree about the implications of this real-ness, nor are we clear about what constitutes public or private space in these environments” (Banks and Eble, 2007, p. 36). As a result, “researchers must go to great lengths to articulate possible risks to human participants and must justify their interactions with participants in ways that will reduce these risks as much as possible” (Banks and Eble, 2007, p.36).

Whether online or not, the individual participant was never far from the researcher’s mind. The participant’s right to dignity and anonymity were carefully considered alongside the potential benefits to others and risk to the participant (Markham, 2012, p. 4). Ethical considerations were addressed in each phase of this research study. The Institutional Review Board permission for conducting research was completed and submitted for review before any research was conducted. The online survey included a consent form that clearly stated the aims

of the research study, and explained that participants are guaranteed certain rights and explained that their participant rights are protected throughout the study and afterward. Participants could opt out of the research study at any time. In this study, every attempt was made to de-identify information as much as possible. Real names, exact locations and any reference to specific employers were not disclosed unless expressly stated by the participant. Participants were identified by pseudonyms only unless the participant gave consent to use a real name. All information recorded was confidential and online survey responses were assigned numeric identifiers keeping participant identification anonymous. The Qualtrics survey software was used to administer and maintain the survey results. Qualtrics was made available to me as a student of East Carolina University faculty who has met the guidelines established by the institutional review board. Data was stored on a secure sever.

The methodologies discussed in this chapter informed my decision making processes as the researcher for this study and different aspects from multiple methodologies were utilized as the project developed. The survey allowed for solid data collection on participants that could be quantified and also yielded qualitative data through ‘other’ comment spaces provided at various points on the survey instrument. The observation of the wall post and the interview responses yielded individual and group narratives which were examined with both narrative analysis and critical discourse analysis. In Chapter 4 I will discuss the survey results and in Chapter 5, I will discuss the observations of the Facebook wall postings and interviews in much more detail.

## **Chapter 4. Data Analysis – Survey Results**

Data from my current study consists of the results obtained from a survey instrument, follow-up interviews with selected group members, and analysis of posts within the selected health related support group(s) on Facebook. In this chapter, I discuss the data obtained from a survey of pulmonary embolism (PE) and deep vein thrombosis (DVT) survivors and explore what the data says about health related online support groups such as those created within Facebook. This survey was conducted to determine if there were identifiable trends among the participants in the selected online support groups related to PE /DVT recovery that would more clearly illustrate who the participants of the online support groups were, why they sought out an online support group and what benefit, if any, was gained as a result of membership. The survey instrument was used to gather demographics and other descriptive data such as length of time within the online virtual support group and length of time since diagnosis.

Participants who completed the survey instrument belong to one or more of the following groups: Pulmonary Embolism Survivors (PES) formed around survivorship; Pulmonary Embolism Awareness (PEA) formed around awareness; or the Pulmonary Embolism Awareness Project (PEAP) group that was formed as a way of remembering a lost loved one. Each group has been part of Facebook for at least five years. Why does it matter? It matters because these individuals survived when over a third of those who experience a PE, DVT or both do not. Survivors are often reminded of this by health care professionals who state “You’re lucky to be alive.” Of those who survive, over half live with long term (chronic) complications and also live in fear of being part of the third who develop a recurrence in 10 years (CDC, June 2012).

## Participants

Individuals who participate in online support groups vary greatly depending on their personal illness experience as well as what they are searching for or hope to gain from the group.

Griffiths et. al., (2012) state

social networks enable individuals to exchange information on behalf of themselves or others on such subjects as the experience of bodily symptoms, clinical diagnosis, and treatment options, adverse treatment effects, sources of medical evidence, experience with individual providers and options about their quality (2234).

The three groups chosen for this study coalesce around having survived either a pulmonary embolism (PE), deep vein thrombosis (DVT) or both. Individuals who compose these groups are themselves survivors, friends or family of survivors, or loved ones of those that tragically, did not survive. Information worldwide varies related to the number of people affected by a venous thrombotic event or VTE, a term that refers to the occurrence of PE and DVT, (Raskoub et al., 2010, S504). Outside of the United States there are few databases that store information about the occurrence of VTE's, but what is known is that mortality rates increase. In the United States, the Center for Disease Control (CDC) indicates that approximately 300,000 to 600,000 people each year are affected by a VTE. Raskoub et al.(2010), report

the disease burden from VTE is major. Each year there are an estimated 900,000 patients with clinically evident VTE in the US., resulting in an estimated 300,000 deaths from PE. The estimated 600,000 nonfatal cases of VTE result in several hundred thousand primary hospitalizations or extended hospital stays in patients who develop VTE while hospitalized. (S502).

Of those who suffer a PE or DVT, 10 to 30% die within the first month while 25% of this number die suddenly and without warning – the cause only detected during autopsy. Of those who do survive, the CDC estimates that half will have long term, chronic complications while a third of the survivors will experience a recurrence within 10 years. Additionally, according to

the CDC, 5% to 8% of the population at large has one or more genetic factors that put them at an increased risk of developing a PE or DVT, and yet they may not know this.

After any tragedy, people often seek answers. For those in the groups chosen, the groups are an informative platform to learn about what has happened, to come to terms with the diagnosis, or to encourage one another through difficult days. Hyun Jung Oh et al., (2013) quotes Fox (2011a) stating “[u]sing the Internet as a tool for health is increasingly common. Six in ten U.S. adults have gathered health information online and one in five have gone online to find other individuals that share similar health concerns” (2012). Individuals who participate in these three groups are in some instances driven by fear, by anger, by grief, by confusion and by doubt as they struggle to understand what it means for them to be a survivor of a PE or DVT. The groups are comprised of men and women from all walks of life from around the globe. PE’s and DVT’s affect all genders, all ages, and ethnicities; although, certain risk factors such as smoking, immobility, or oral contraception can increase the risk or threat of a PE or DVT. For survivors, some instances of PE or DVT can be identified, “[y]et in about 50% of the cases there is no acquired risk factor identified (idiopathic) and in 10% to 20% there is no acquired or genetic risk identified. . .” (Raskoub et al., 2010, S505). The event happens and one may never know the origin or cause. The not knowing often adds to feelings of isolation and may increase the tension between patient and doctor because there is no answer to the ‘why me?’ Virtual support groups created through social media like Facebook may help mitigate that sense of isolation and may actually prove to have a positive effect on individual self care practices as noted by H.J. Oh et al., (2013) who states “[a]s of today, online health information seeking has been associated with various positive outcomes . . .” (2013), what he terms as “self-efficacy.” H.J. Oh et al., refers to prior studies by Clark & Dodge (1999), Bandura (1977, 1986, 1990 and 1997) and O’Leary

(1985) which all recognized the value of social support and desired medical outcomes related to medication, diet, exercise and stress management (2073). Today, that social support is frequently found not face-to-face but rather from online support groups such as those created through social networking sites like Facebook as “[o]ne in four Internet users who have chronic conditions indicated that they go online to seek for others who have similar issues (Fox, 2011b)” (H.J. Oh, et al., 2013, 2073). Online virtual support groups are important when one considers that there is no world wide data warehouse, similar to the CDC, available on the incidence of pulmonary embolism (PE) or deep vein thrombosis (DVT) and groups like the ones in this study may give its participants a voice and a presence where otherwise there would be none.

### **The Survey**

On August 7, 2013, the survey instrument (Appendix C) for this study was made available to potential respondents in the previously described pulmonary embolism (PE) and deep vein thrombosis (DVT) related Facebook groups. An announcement that explained the purpose of the survey was posted to each of these groups. The announcement included a link to the survey introduction (Appendix A), the informed consent document (Appendix B) and a link to the Qualtrics created survey instrument. Before participants could start the survey, they had an opportunity to review the reasons for the research and to provide informed consent when they answered question 1 on the survey. The survey was divided into two sections. The first section composed of questions 2 to 27 addressed participants’ pulmonary embolism and/or DVT experience and their participation in the online groups related to these events. These questions allowed me to identify potential trends that might emerge related to participation in an online health related virtual support group and a positive PE / DVT recovery experience. These questions might also be used to help identify gaps in the health care literacy of participants that

could be used to develop new communication practices for the dissemination of information to patients. The second section of the survey, composed of questions 28 to 46 contained questions concerning general demographic information related to country of origin, age, income and health care access. These descriptive elements of the survey helped define the participants, demonstrated variety in the participant pool and allowed me to see if other factors, such as income and access to health care, were driving participants to online health related virtual support groups.

The survey was opened on August 7, 2013 and remained open until August 21 at midnight Eastern Standard Time (EST) when it was closed. The survey was submitted by 83 participants and completed by 79 (95%) of the participants. The participants completing the survey were members in one or more of the groups that form this study. Participants who were interested in being interviewed or who would consent to allow me to use their wall posts were asked to provide their online contact information. Twenty respondents (25%) did so in the survey while an additional seven people contacted me via private message through Facebook. Two individuals reviewed the survey but did not consent to participate, one for unknown reasons and one because of perceived religious overtones as a result of several questions that asked about the relationship between individual's health status and his or her religious activities. No specific religion was specified but the questions made the respondent uncomfortable and he indicated via message in Facebook (FB) that he would not do the survey because of this. Participants were not required to answer all the questions and could choose to complete one section and not the other. Additionally, participants had the option of opting out at any time.

## Results

### *Who Participates in illness related Facebook groups?*

Research question #1 focused on gathering data related to “who” the participants of illness related online support groups might be. Responses from the survey indicate that participants within the three groups represent six countries including the United States. Other countries include Australia, Canada, Hong Kong, Mexico, the Netherlands, and the United Kingdom and Northern Ireland. Age of participants represents the span of individuals affected by a PE or DVT, demonstrating that it is not just a risk of aging. The respondent pool included 92% (73) females and 8% (6) males. Out of 79 respondents, 3% (2) were 18-25 years of age; 23% (18) were 25-35 years of age; 33% (26) were 35-45 years of age; 25% (20) were 45-55 years of age; and, 16% (13) were over the age of 55. Past studies indicate that “Venous thromboembolism is predominantly a disease of older age” (Raskob et al., 2010, S504). Another study indicates the “incidence ranges from 1 per 100000 in the young and increases to 1 per 100 in people aged  $\geq$  80” (Beckman, et al., 2010, S495). The breakdown of age in this study shows that the possibility for having a PE or DVT occurs at a much younger age than previously considered, in part due to the increase risk for women during their reproductive years. Beckman et al., (2010) writes “Men have a slightly higher overall incidence rate than women, but women have a slight increase during the reproductive years” (S495). Observation of all three groups demonstrates that although men may have a slightly higher rate of incidence overall, men are not as vocal or participatory within the online virtual support groups as are the women mirroring the survey results with a 1 to 4 ratio of men to women.

Having been diagnosed with a DVT or PE may impact one’s ability to continue working due to increased health related absences or the debilitating nature of the PE or DVT event itself.

Of the participants, only 20% (16) indicated that they were unemployed; 13% (10 ) worked part-time; 54% (43) continued to work full time work, and 13% (10 )identified themselves as disabled. Of the 43 who reported working full time 58%, (25) commented that they worked 40 or more hours. The remaining 44% (18) indicated that they worked between 15-38 hours each week. The ability for one to continue to work impacts participants' ability to seek adequate medical care and directly impacts participants' socio-economic status in the long run.

Being diagnosed with a PE or DVT or both (VTE), can be costly. The income one has can shrink drastically due to the financial burden surviving either a DVT or PE or VTE may cause. Raskob et al., (2010) state “The direct medical costs for patients with nonfatal VTE are estimated to be between 5.8 to 7.8 billion dollars (based on 2004 provider payments)”(S503). When asked “What is your annual salary (including bonuses and commissions) in US dollars, 87% (69 out of 79) participants answered the question and their responses varied with 33% (23) of the participants making less than \$25,000 a year; 43% (30) participants making more than \$25,000 but less than \$75,000 a year, and 23% (16) making over \$75,000 per year but less than \$200,000 per year. One participant indicated yearly income over \$200,000 per year. An additional question asked participants about insurance coverage, and 78% (62) indicated they had some sort of medical insurance while 22% (17) indicated no insurance at all. When asked whether or not insurance was provided by an employer 52% (33 out of 64) indicated the employer provided a PCP or HMO based insurance. 48% indicated the employer provided no coverage. When asked if participants received Medicaid or Medicare benefits, 77 participants responded with 18% (14) indicating ‘yes’ and 57% (44) replying ‘no’ while 25% (19) indicated the question was ‘not applicable.’ Knowing that the participant pool was global, the survey asked participants if they had insurance as part of a national health care program and 78 respondents

replied with either a ‘yes’ or ‘no’ answer; 22% (17) indicated that they were part of a national health care system and 78% (61) indicated in the negative. The 22% that did respond reflects in part, those ‘not applicable’ responses in the previous question about Medicaid, This survey occurred before the now publicized Affordable Care Act requirements took effect in the United States. Because one’s insurance or lack of insurance may determine if one seeks specialized medical care specifically related to the pulmonary or thrombolytic event, participants were asked if referrals to specialists were covered under their insurance. Referrals were noted as being covered by 75% (54) participants though 14% (10) indicated they were not. Eleven percent (8) indicated “other” because being referred to a specialists was not applicable to them either because they paid out of pocket or were in a foreign country and covered under a different medical insurance structure. Respondents were also asked to indicate which types of specialists they had seen if referrals were covered. Of the 43 respondents who indicated they had been referred to a specialist, 19% (8) saw only a pulmonary specialist; while 40% (17) respondents saw only a hematologist; 16% (7) respondents indicated they had been referred to both a hematologist and a pulmonary specialist; 26% (11) respondents indicated they had seen more than two specialists, inclusive of a hematologist and pulmonologist. The remaining participants indicated they had seen some “other” type of specialists such as an internist, cardiologist, vascular surgeon, or neurosurgeon, or indicated it was not applicable to them because they were outside the US and such referrals were not needed under their health care coverage.

Another question asked respondents about where they were diagnosed. Out of seventy-nine respondents, 73% (58) were diagnosed in the emergency room and 15% (12) respondents were diagnosed either during a ‘normal’ visit to the doctor’s office or an unexpected urgent care visit. The remaining 11% (9) respondents indicated that they were diagnosed while in the

hospital for something else prior to developing or experiencing a pulmonary embolism or DVT. Upon diagnosis, 68 of the respondents were seen by a specialists within the first two weeks while 8 were seen within the first four weeks. The remaining respondents were seen within the first six months immediately following their event. Respondents were also asked how much time had passed between their pulmonary or deep vein thrombosis event at the time of the survey. Seventy eight participants responded to this question. Table 1 below indicates the length of time between event and participant’s response to survey question. The provided answers show that involvement in the group can occur in close proximity of a PE, DVT or VTE and can be maintained over a long periods of time.

#	Answer	Response	%
1	0 - 2 weeks	3	4%
2	2 weeks - 1 month	2	3%
3	1 - 3 months	9	12%
4	3 - 6 months	6	8%
5	6 months - 1 year	13	17%
6	1 - 3 years	23	29%
7	3 - 5 years	5	6%
8	over 5 years	17	22%
	Total	78	100%

**Table 1: How long has it been since your initial diagnosis? (Question 43)**

Beckman et al., (2010) state “about one third of all VTE patients experience a recurrence within 10 years of the initial event, with the highest risk occurring within the first year, yet

individuals remain at risk throughout their lives” (S496 ) Because there is a possibility of recurrence, the participants of this survey were asked if they had developed a recurrence after their original diagnosis of a pulmonary embolism (PE) or deep vein thrombosis (DVT) or both (VTE), and if they had, to specify the length of time between events. Of the 79 respondents, 23% (18) indicated that they had had a subsequent event in as little two weeks to as long as 10 years from the initial event and 75% (59) indicated no recurrence. Additionally, 2 marked “other” and explained that they had “two separate DVT’s then a PE” while another person commented “Been back to the A&E 5 times with related complications.” Although the response to the question elicited less than the expected one-third recurrence rate, the data shows recurrence is a very real fear for participants’ within the online health related support group created within Facebook. In summary, this data helps to create a picture of the individual who has suffered from and survived a PE or DVT and shows the prevalence of PE and DVT as a real health concern for anyone and that more awareness is needed. As Beckman noted (2010), “Without the important knowledge of why, where, and among whom VTE occurs, it is difficult to understand where to focus research and target prevention measures” (S498). The data from this survey instrument helps to identify why, where and among whom.

From the beginning, responses to question 2 indicated a contradiction between self perception and the stark reality of one’s day to day life. Respondents were asked whether they viewed themselves as either “Healthy” or “Unhealthy;” 56% (45) of the 80 respondents said they viewed themselves as healthy while 44% (35) said they were unhealthy. The 80 respondents here reflect the fact that participants completing the survey could answer one question and not answer others. Individuals were then given the chance to provide additional information (Question 3) related to their responses; 88% (70) chose to give more information, which yielded

a somewhat contradictory picture than what was self reported in the survey or in their wall posts on Facebook. In spite of their health care crisis, 43% (30) of the participants indicated they still viewed themselves as healthy; some even indicated that as a result of their health care crisis, they were now healthier than they had been prior to the incident while 57% (40) of the respondents indicated that they viewed themselves as “ill,” “sick,” “unwell,” and “unhealthy” not only as a result of their healthcare incident but also because of other associated issues such as diabetes and obesity and cancer. For individuals who have survived a PE, DVT or VTE and consider themselves “unhealthy,” the event can signal other health concerns that need to be addressed along with PE, DVT or VTE recovery. The virtual support group in Facebook “can serve as a source of support and interaction” (H.J. Oh et al., 2013, 2073) as individuals address not only the recovery from a PE or DVT but also as individuals make other lifestyle changes to reduce the risk of recurrence and to become “healthy” in a self-fulfilling positive manner.

Respondents were next asked in question 4 if they felt others perceived them as either healthy or unhealthy. Results were almost evenly divided with 51% (40) participants indicating that others viewed them as healthy while 49% (39) indicated that they were viewed as unhealthy by others. Again respondents were given a chance to elaborate on their responses. Fewer participants, 60 out of 79, chose to elaborate, with 52% (31) people indicating that others viewed them as “unhealthy” because they often witnessed the respondent being “short of breath,” “taking medication,” “being in pain,” or “missing work.” On the other hand, 38% (23 ) participants indicated that they felt that others saw a “normal” person, while 10% (6) respondents felt that it depended on who they were being viewed by. Responses indicate that close friends and family may be more likely to see an unhealthy person but acquaintances, co-workers or

people in passing, would never know anything was wrong because outward appearances indicate a “healthy” individual.

Table 2 shows the difference between how the individual respondents see themselves compared to how the respondent believes others perceive his or her health. Respondents perceive themselves as healthier at a higher rate than they see themselves as unhealthy. Respondents, however, indicate that others perceive them as unhealthy at a higher rate than they are perceived as healthy by others.

	Self Perception	Other’s Perception
Healthy	56.25%	37.5%
Unhealthy	43.75%	50.0%
Total	100%	87.5%
Missing		12.5%
Total		100%

**Table 2: Perceived health status**

Probing further, the participants were asked whether they see themselves as chronically ill and whether they thought that others would see them as chronically ill. Participants identify as chronically ill because the PE or DVT alters their entire lives from the moment of the event until one’s demise at some future time. Survivors must, because of the nature of the PE or DVT, be constantly aware of what they eat or drink if on long term anticoagulant medication like Warfarin. They must also be constantly vigilant about sitting in one position for too long such as a long air flight across the country or an extended car ride. Additionally, symptoms may not disappear; pain lingers in the chest; a twinge here or there that once would have gone unnoticed, isn’t, and the survivors finds themselves struggling to breathe, carrying an inhaler everywhere they go, or becoming easily fatigued after the most mundane of tasks. Of the respondents 53

participants indicated that see themselves as chronically ill and 38 participants indicated that they believe others also viewed them as chronically ill.

A common characteristic of those with chronic illness is a decline in activity, especially exercise. Beckman et al. state

one third to one half of lower-extremity DVT patients develop post-thrombotic syndrome and chronic venous insufficiency, lifelong conditions characterized by pain, swelling, skin necrosis and ulceration. Quality of life has been reported to be adversely affected up to four months after DVT and for those with post-thrombotic syndrome, quality of life actually declines further during this period, with changes similar to those seen in individuals with chronic heart, lung or arthritic disease (S496).

However, the data gathered from this survey indicates a different connection with activity and illness. Participants were asked about their level of exercise before and after their pulmonary or DVT event. 80 participants responded on a scale of Never, Rarely, Sometimes, Often, and All of the Time. The larger number of participants were grouped in the Often and All of the Time categories representing 43% of the responses. Ironically, post-PE exercise was noted for the same 43 (34) responses as indicated in Table 3 related to exercise.

#	Question	Never	Rarely	Sometimes	Often	All of the Time	Total Responses
1	prior to your pulmonary embolism or deep vein thrombosis	2	17	27	26	8	80
2	post pulmonary embolism or deep vein thrombosis	7	15	24	26	8	80

**Table 3 Did/ Do you exercise?**

A decline was noted in those who indicated Sometimes and Rarely between their pre and post exercise routines which corresponded to an increase in the number of people reporting that they “never” exercised post pulmonary event.

In the previous responses where participants could elaborate on their answers, exercise was often noted in individual responses. Two individuals had even indicated that as a result of their health care incident they had become more proactive in their exercise regimen and had lost more than 10 pounds and had kept it off. Obesity was also often noted as a contributing element to respondents’ seeing themselves as unhealthy, or as perceiving that others would see them as unhealthy not only because of their pulmonary event but also because of their obesity. More clear results might have been obtained if I had asked for specific information such as frequency or type of exercise. The data demonstrates that those who were active before their pulmonary event, tended to continue to be active post pulmonary event.

Participants were also asked whether they were involved in face-to-face support groups related to their pulmonary embolism or DVT, with 6% (5) participants indicating “yes” and 94% (75) indicating “no”. Participants were also asked if they were involved in a Facebook community related to their pulmonary event or their DVT event and 98% (77) respondents answered “yes.” Participants were then asked to indicate their involvement in three particular groups: Pulmonary Embolism Survivors (PES) , Pulmonary Embolism Awareness (PEA), Pulmonary Embolism Awareness Project (PEAP), with a selection to indicate Other if they were involved in other PE or DVT related groups not cited. Table 4 shows the distribution of membership in the 3 groups as well as membership in other VTE related groups on Facebook.

#	Answer	Response	%
1	Pulmonary Embolism Survivors	52	67%
2	Pulmonary Embolism Awareness	43	55%
3	PEAP	13	17%
5	Other	47	61%

**Table 4: Group membership numbers**

Table 5 shows the length of time participants have been part of Facebook groups related to their VTE. The question did not ask how long people had been involved specific groups, but rather looked at online involvement as a whole.

#	Answer	Response	%
1	0 - 2 weeks	7	9%
2	2 wks - 1 month	2	3%
3	1 - 3 months	11	14%
4	3 - 6 months	12	15%
5	6 months - 1 year	14	18%
6	1 - 3 years	28	35%
7	3 - 5 years	2	3%
8	5 + years	4	5%
	Total	80	100%

**Table 5: How long have you been a participant in a health related online virtual community? (Question 11)**

A combined 46 respondents have been members of a group for at least 1 year while 30 have been members for more than one year but less than five, and 4 indicated that they have been members

for five or more years. At the time of the survey, 7 participants indicated that they had been members for two weeks or less. The number of new members grows daily as individuals continue to find their way to one or more of these Facebook communities related to a VTE experience. Questions about whether individuals were members of one, two, or all of the groups, along with specific information related to length of time within each group, was not attained but should be in future research studies to explore the benefits of group membership over time and to explore whether or not there is a specific time in the recovery process where exchange of information is important for the participants' perceptions of themselves.

There were also questions in the survey which were designed to have participants consider how their PE or DVT event had impacted various elements of their lives: day-to-day activities, relationships with family, work, social commitments or religious activities. Once again, with the exception of not being excluded from activities within an individuals' religious community, participants report being excluded from some aspect of home activities, work activities, and social activities approximately 50% of the time as a result of the PE or DVT. Having had a pulmonary embolism or deep vein thrombosis often leaves no outward sign and the chronic symptoms that remain are also associated with other medical or lifestyle issues. Participants in this survey indicate that they often are short of breath, fatigued, and anxious as a result of their pulmonary or DVT event. Additionally, respondents indicated that they still continued to experience chest and back pain post pulmonary event or post-DVT. All of these symptoms are difficult to explain to family, friends or health care providers. Shortness of breath, increased fatigue at a quicker rate, and anxiety-related issues can be reasons that work is often impacted for the pulmonary or DVT patient. Sometimes these symptoms persist to a point that leads to the loss of a job and increases the need for individuals to apply for disability benefits.

Often, these symptoms can be misunderstood by observers. Shortness of breath and an increased level of fatigue can be the result of someone being out of shape while anxiety related symptoms are often just dismissed as being “in ones head.” Not only did I ask about the impact on work, I also asked about whether social obligations or religious obligations were impacted by the pulmonary or DVT event. Respondents indicated that their social lives were impacted but, regarding religion they indicated there had been no change at all.

Table 6 reflects how the respondents to this survey feel their VTE, whether it was a PE or DVT, has affected their day to day lives. Of the respondents, only 2 who indicated that their VTE had “Never” impacted their lives.

#	Question	Never	Rarely	Sometimes	Often	All of the Time	Total Responses
1	impacts my day-to-day life	2	13	22	18	24	79
2	has affected my relationship with family	13	16	30	13	7	79
3	has affected my relationships at work	19	17	18	6	14	74
4	has affected my social relationships	15	22	19	9	11	76
5	has affected my relationships within my religious community	52	10	2	2	7	73

**Table 6 Having had a PE/DVT event . . .(Question 13)**

The other responses indicated that the VTE impacted some element of their lives whether it was day to day, relationships with family, colleagues or friends. Religious activities were the least affected by an individuals VTE with 52 of 73 respondents indicating relationships within his or her religious community were “Never” impacted. A follow-up question asked whether participants addressed not just impact, but feelings of exclusion as a result of the VTE experience. Table 7 shows how the participant responded. Participants were also asked whether they felt excluded from certain areas of their day to day lives: work, family, social obligations and religious activities.

#	Question	Never	Rarely	Sometimes	Often	All of the Time	Total Responses
1	from activities at home	32	17	22	5	3	79
2	from activities at work	33	14	10	7	9	73
3	from activities with your social, face to face, community	26	15	17	13	6	77
4	from activities with your religious community	55	7	2	2	4	70

**Table 7: As a result of your PE or DVT, do you feel excluded . . .?(Question 15)**

While people felt that their lives had been impacted by their pulmonary emboli or DVT, few indicated any sense of exclusion from activities or groups, instead they indicated the exact

opposite. This could be due in part to respondents not having disclosed their ongoing recovery from a PE or DVT to the various groups in their day to day lives.

***How do these groups impact individual empowerment?***

Data indicates that participants in the online virtual support group may talk very little about their PE or DVT with those they see face-to-face; but, the online virtual community is full of others just like them and participants find validation of what they are going through. That sense of “I’m not alone” also seems to empower individuals outside of the group. H.J. Oh et al., (2013) state “an individuals beliefs about his or her capabilities affect the way he or she reacts to a given situation. . . self efficacy can play a significant role for different desirable outcomes” (2073). Survey participants were asked if they felt that membership in the online groups had empowered them in various areas of their lives. This question did not address how participation empowered them, asking about particular areas of their lives.

#	Answer	Response	%
1	at home	57	85%
2	at work	21	31%
3	at school	3	4%
4	in my social community	20	30%
5	in my religious community	5	7%
6	with my health care professionals	50	75%

**Table 8: Participation in a health related virtual community has empowered me (check all that apply)...? (Question 16)**

Of the 79 responses, 72% (57) felt empowered at home; 63% (50) felt more empowered when talking to his or her health care professional; 27% (21) felt empowered at work; and, 25% (20)

felt empowered within his or her social group. An additional question asked if participants trusted the information shared in the online support community. On a scale of Never, Rarely, Sometimes, Often and All of the Time, 92% (73) respondents indicated that they trusted the information sometime or often; 5% (4) rarely and 8% (2) trust “all of the time”. None of the respondents indicated a lack of trust. More needs to be learned as it relates to just how these individuals feel empowered. What is it from the online group that gives one that sense of empowerment when at home, with family, or out publically, at work, or with friends?

Participants were also asked to explain the benefits gained from their participation in the online communities related to PE or DVT. Table 9 shows participant responses.

#	Answer	Response	%
1	helps me cope	51	65%
2	provides encouragement	64	81%
3	leads to friendships	23	29%
4	explains causes and effects of a pulmonary or thrombolytic event	45	57%
5	provides answers related to insurance, coding and billing	3	4%
6	validates me as a patient/person	37	47%
7	helps me through the process of applying for or fighting for disability	6	8%
8	provides information related to alternative treatment options	27	34%
9	provides information related to dietary concerns	35	44%
10	provides information related to medication related concerns	53	67%
11	provides information related to physical activity concerns	43	54%
12	Other	19	24%

**Table 9 Participation in a health-related online group . . . (Question 25) (check all that apply)**

Those who answered “other” were asked to elaborate and responses included a wide variety of benefits. Several indicated that the online support community had helped them to make the

decision about pregnancy post VTE, or to “accept my problem”, or that the group “reminds me that I am not the only one going through this.” But, not all were positive. One respondent, explaining why he/she selected “other,” stated that rather than being fully helpful, participation in the group

makes me believe that hypochondriacs who crave attention are the key members of these groups. There is useful information but much of it is sensationalized and a different personality to mine could think they are about to die with what some people tell them!

While this view represents only a single participants’ point of regarding participation in the Facebook groups related to PE or DVT, it is a point of view that serves as a reminder that great care must be used when one navigates the vast amount of information that can be found from within the health related online support groups..

Before asking about the demographic information which the survey instrument collected, there was also a question (Question 27) on the survey that was an open ended question asking participants if there was anything they wanted to add that they felt I had not covered in the previous survey questions. Of 79 participants in the previous question (26), 29% (19) participants chose to provide comments ranging from short concise comments like “Medication routines and side effects,” or “I plan to become involved in DVT/PE Awareness” to providing a rather long comment questioning what I meant when I asked about exercise (in question 6). The respondent provided the following:

What constitutes your exercise? ...extensive walking for purposes of aerobic/cardio/lung ? household chores? minor walking in home? ..or as little moving as possible? would evaluate just what patient is capable of.. Have you found medical advisor to be knowledgeable on blood clots...or is pulmonary doctor interested in apnea/sleep studies? Part B: Is your medical advisor knowledgeable of current research...or resistant to your health suggestions? Have you continued working upon health issues? Have you received employer accommodations/work load reductions regarding your health issues?

The responses to the open ended question echoed a sense of concern and compassion such as the following response:

Online support groups are there for you most of the time, we cheer together, encourage each other and grieve together when another member loses their battle to live;" or, "The online group also allows one to share success .... Celebrate milestones. These positive reinforcements are something family and friends have no clue of how important these milestone celebrations are to the well being of the recovery of the patient. We need to have support for the good and the bad.

Yet others expressed concerns as noted with:

There is a lot of panic that happens in these groups. I have had to learn how to check info to make sure that it is valid and reliable. I wish that there were more doctor led groups so that I would know more about the reliability of information;" or "Often people post medical questions that they should be asking a health care provider. This is scary. This is a support group, not a medical provider.

Concern was demonstrated with the following:

More people on virtual media should give less advice that starts with "I went through the same thing it was nothing " You got a concern see the CORRECT Doctor. Be aware of the disorder, don` t live in it, live in spite of it.

What emerged in the 19 responses from these individuals are the diverse opinions of those who seek out online virtual support groups, why they seek the group and what benefits and drawbacks exist as a result of one`s membership. What was also gleaned from these results was the need for more information about PE and DVT awareness, the need for better communication practices between patient and doctor, using social media as a means to do so and the need to educate patients to effectively discern the credible versus non-credible information from within an online virtual support network.

The results posted in this question also support the need for health care professionals to be more involved in online virtual support groups available through social media. Responses to this question show that participants wish more health care professionals were present both to

stem the panic that can sometimes arise and also to learn about the varied ways a PE, a DVT or both really impact those who survive day to day. Chapter 5 will discuss the results of observations of the groups during a 4-week interval as well as discuss responses gleaned from follow-up interviews.

## **Chapter 5. Pulmonary Embolism and DVT Virtual Groups in Facebook**

The survey results presented in Chapter 4 provided a description of the participants who form the groups that are part of this study. This chapter will discuss discourse created by participants in these groups, and how, through that discourse, frames emerge that illustrate ways participants come to define their chronically ill selves in relationship to pulmonary embolism and deep vein thrombosis recovery. This chapter will also illustrate how the discourse is used to ‘other’ participants within the group or to mitigate stigma from outside of the group. Finally, this chapter will explore how individuals’ constructions of their chronically ill selves shape participants’ views about the doctor-patient relationship.

### **Background**

Research from this study demonstrates that users who have suffered a pulmonary embolism, a deep vein thrombosis or both form groups through Facebook because it affords them a space through which to vocalize their experiences. In the article “Social Media and Health Promotion,” Cameron Norman (2012) states “social media realizes [Edmund] Carpenter’s vision by placing participation and co-production at its core”(pg. 4). Individuals are no longer simply talked to as in a lecture, but are rather invited to engage in the conversation(s). Facebook and its associated applications encourage this co-production and has changed the way in which individuals create and value knowledge. People use their social networks to organize information both on an individual and collective level in order to share similar experiences and gain new insight from persons with similar circumstances. Individuals who now have access to information in a larger, quicker capacity than ever before can exchange that information on a scale unlike anything society has previously experienced. Social media is to modern society what

the printing press was to the Medieval Period. Technological advances related to social media increase the need for understanding how individuals now create social networks around health related concerns that exist almost exclusively in virtual environments like Facebook.

Applications that enable online communities to form have steadily increased over the last few years and the impact on physical and emotional well being has become fertile ground for researchers from varied disciplines. Good et al.,(2013) state “Facebook usage in particular, is reported to increase a sense of well being amongst its users” (417) and that “users were more easily able to form relationships, provide companionship and emotional support. . .” (417). People who once would have never had an opportunity to meet one another, now meet regularly via Facebook and its associated applications, in particular, Facebook Groups. Individual users create new social networks faster than ever before and these networks “operate at many levels from the level of families, levels of specific population groups to the level of nations” (Masic et al., 2012, p.48). According to the article “Connecting to patients via social media: A hype or a reality” by Edgar Huang and Christina Dunbar (2013) “as of April 2012, Facebook had 900 million active users. Researchers estimate that by 2015, more than three billion people will own social media accounts”(p.13). Although social media has been a prevalent part of Western culture since 2004, the increasing availability of mobile Internet enabled devices such as the iPhone or Android, now makes social media platforms available to people who previously would not have access to the Internet because of location, the lack of a computer, or lack of an internet connection (Norman 2012, pg. 3). The world is now an interconnected networked space where the audience is not simply a passive element but rather an involved participant and co-producer.

## **Framing illness in virtual support groups**

Social networks often develop around a common point of origin or some shared, common ground. In the case of the virtual support groups that compose this study, the common ground is the onset of or the survival of a pulmonary embolism (PE), deep vein thrombosis (DVT) or both (referred to as a venous thrombotic event, VTE). Participants in all three groups are connected by what Goffman (1974) called an “astounding event.” Individuals may join a group right after diagnosis, or days, weeks, months, even years later. Some have even logged on from their ER bedside in an attempt to make sense of the moment they are then experiencing, an unexpected breaking of their existing frame of reference.

In *Frame Analysis*, Goffman (1974) forwards his ideas related to frames and frameworks and states “when the individual in our Western society recognizes a particular event, he tends, whatever else he does, to imply in this response (and in effect employ) one or more frameworks or schemata of interpretation of a kind that can be called primary” (20). An individual’s primary framework is that which serves as his or her reference point for understanding events from the mundane and daily to the extraordinary. According to Goffman the individual’s primary framework “is seen as rendering what would otherwise be a meaningless aspect of the scene into something that is meaningful” (20). When an individual experiences a PE or DVT, the individual’s primary framework is not just disrupted but broken. The primary framework, in short, explains the rules, be it the rules for one’s life or the rules for a game of checkers, by which an individual understands his or her circumstance. For the PE/DVT survivor, the prior framework before the PE/DVT event no longer functions and a new frame of recovery takes its place, becoming a scaffold upon which all other frames are built.

The three Facebook groups selected for this study demonstrate multiple levels of framing encompassing the group, individual and shared experience. The frames “provide background understanding for events that incorporate the will, aim, and controlling effort of an intelligence, a live agency, the chief one being the human being. Such agency can be coaxed, flattered, affronted and threatened” (Goffman, 1974, p.22). First, there is the group frame that is established through the group’s site description. The site description provides the primary framework, the structure, in which the individual users act. The second frame created is the individual user’s frame developed through his or her wall posts and shared with the group. A third frame emerges as a result of participants’ similarly shared experiences. These frames bind the activities enacted through the virtual support group by all members.

### ***The Group Frame***

This study is limited to the study of three groups directly related to pulmonary embolism and deep vein thrombosis. The groups chosen have somewhat distinct and sometimes overlapping frameworks that participants within collaboratively build with each shared post. Each groups’ frame is clearly explained not only through each group’s chosen name but also from the information posted on the group’s “about” page. In order to understand the group’s frame, “one must try to form an image of a group’s framework or frameworks—its belief system, its cosmology. . .” (Goffman, 1974 p.27). For the groups chosen for this study, Pulmonary Embolism Awareness Project (PEAP), Pulmonary Embolism – Awareness (PEA) and Pulmonary Embolism – Survivors (PES), the groups belief systems and cosmologies begin with what is posted as their site description. The groups’ site descriptions in turn become the framework for posts shared within the group. For two of the groups in this study, awareness of the risk of a PE

or DVT or related hypercoagulable disorders is a dominant frame through which information is exchanged, while for the third group surviving as an ongoing process is the dominant framework.

### *Awareness as a framework*

Two of the groups, Pulmonary Embolism Awareness Project (PEAP) and Pulmonary Embolism-Awareness (PEA) both use the word awareness in the name of the group, setting the stage for the frame that develops in the site description. To be aware is to perceive or to be conscious of some ‘thing.’ For these groups and their participants the primary frame is being personally aware and making others aware of pulmonary embolism and deep vein thrombosis as potential risks as well as increasing awareness of the difficulties often involved with recovery from a PE or DVT.

PEAP, the smallest of the three groups with only 337 members at the time of this study is perhaps the strongest advocate for awareness. During the month of August when this group was observed, there were 109 parent posts not including new member addition notices. Of these 109 posts, 82 were posted by the moderator and included embedded hot-links to news articles, web blogs, and research material relevant to people post-PE /DVT. The group was founded by the moderator and her family following both the death of a relative and the occurrence of PE in a second. The site’s description contains an imperative “Know what you are looking for!!!!” statement that directs the participant to gain knowledge, to seek knowledge, and to understand the dangers of not knowing what a PE or DVT is or not knowing the characteristic symptoms associated with each. The site description also states “We try to post the most current info and answer all questions pertaining to DVT’s/PE’s and medication” (PEAP, 2013). The site description also includes a disclaimer that states “We do not diagnose; we recommend contacting your doctor” (PEAP, 2013). This mention of the physician shows that although the group shares

much information based on personal experience, such posts should not take the place of the physician or other health care provider. This statement, in its simplicity, privileges the doctor even in his or her absence.

The posts shared within this group, unlike the other two, are more informational in nature and generate less conversation. The group acts like a data warehouse of information related to pulmonary embolisms and deep vein thrombosis along with associated information related to diet, medication and research. Early in the period in which I was collecting data for this research, the moderator of the group addressed group participants stating:

We have a wonderful mix of people here! I learn much from everyone, we have people from around the world & most of us had no idea treatments varied so much! I try to stick with my standard sources because I get the same info all doctors have available to them online. They send me e-mails daily, and I sort through searching for info useful to anyone on here. Feel free to request any info, I'll try to get the answer to your questions (PEAP 2013).

The posting above demonstrates the depth of commitment and the level of seriousness that this particular moderator feels for the participants within the group. With this post, she establishes herself as a sieve of information from which the group membership may benefit. She references standard sources, and a review of her postings show consistent reporting from ClotConnect.org, The Blood Clot Recovery network, the CDC and other media content. She takes her role as moderator with a sense of survivor's guilt, having herself survived when her son did not and is on a mission to help prevent anyone else from having to experience what she and her family have undergone. The group is a means by which she has re-framed the negative experience of loss in an effort to make sense of events for herself and for others. She takes the time to welcome each new member personally to the group as seen in the exchange below:

**Moderator-PEAP** added [name] to the group.

**Moderator-PEAP** Welcome [name] August 27 at 10:19am ·

[name] Thanks for excepting me!! August 27 at 10:27am via mobile ·

**Moderator-PEAP** Any questions or concerns? We'll find someone to help!

While such an exchange sometimes occurs in the other groups when someone new is added, often, the add is automated and the group is simply notified with an automated “someone was added to the group” notice. In PEAP, the moderator demonstrates her commitment to awareness by personally welcoming each new member with a “Welcome!”

Also in the site description for PEAP, the group’s moderator invites individuals to view her story which can be found under the ‘files’ section for the group. This sharing of personal narrative is also an act of awareness. The moderator shares that she lost her 19 year old son, her seemingly healthy son, to an unprovoked PE. Her son had been healthy and had only developed symptoms in the seven days prior to his death. She had taken him to the ER and within four days her son had been diagnosed with pleurisy in spite of her informing them that she had suffered from multiple pulmonary emboli as had other family members. Three days later, her son was dead at age 19. She drives home the awareness framework of the group with the statement “stupidity cost me my son...now, we want to make sure this does not happen to you or your loved ones...Please learn the signs and symptoms – and above all else, when in doubt, **GET HELP!!!!**(emphasis hers)”(Anglebrandt, PEAP, 2012). From time to time as new members join and read of this experience, they will posts condolences and expressions of sympathy. Participants have asked if they could share the moderator’s story to which the moderator has responded with “Yes, you may. I wrote it so people will understand, ignorance is not bliss” (Anglebrandt, PEAP, 2012). During an interview I conducted with the moderator, the moderator explained that when the group first started it was a collaborative effort among her, her daughter and her sister. Over time, the other two began to participate less. Regarding her sister and her

daughter, the moderator commented “My daughter & sister have baled on PEAP, I solely handle it now. My sister told me she felt for me & my loss, but didn't know how I could get up everyday and check posts & answer questions until 10 PM everyday, that it must be painful!” When I followed up and asked if she indeed found her work with PEAP to be painful, she replied “No, I actually think his death gave me a purpose, and many have said he would be proud I have educated so many people.” She also added “I wanted to make people aware of the symptoms . . . I figured if I could help just one person, our son did not die in vain” (Anglebrandt, Interview, 2013). As moderator of the group, she creates a frame of ongoing awareness around available treatment options, self care practices, and other related concerns participants might have.

Based on posts shared on the group’s wall, new members participate in the awareness framework the moderator has constructed for this group; for example, one wrote “I love this sort of page as it helps raise awareness, find examples of new treatments, support systems. I run an exercise referral scheme for the National Health Service (NHS) commissioning and find these [posts] give me a chance to find out opinions of those who matter (you all)” (PEAP, August 4, 2013). From PEAP’s site description to the shared posts made by the moderator and other participants, PEAP promotes and advocates raising awareness by encouraging participants to learn more. As a result, PEAP is full of relevant news articles, treatment plans and miscellaneous articles related to health care providing no excuse for not learning more.

Information exchange to raise awareness is evident with each post including those posted by participants other than the moderator as evidenced by this post shared by one of the groups participants on August 8, 2013 that provides an explanation of blood clots:

## **Everything You Ever Needed to Know About Blood Clots**

[www.stoptheclot.org](http://www.stoptheclot.org)

Part One: This segment defines: Hemostasis = normal blood clotting, Thrombosis = excessive blood clotting, Thrombophilia = predisposition to thrombosis, DVT = deep vein thrombosis (clot in leg)

A participant seeking information about exercise post-PE recovery shared

Apparently, very few studies have been conducted to investigate how physical training affects blood clots. According to the NBCA (National Blood Clot Association) site ‘blood levels of the clotting protein Factor VIII INCREASES with exercise and the elevation persist post workout during muscle recovery’(PEAP, August, 2013).

For those group members with a Factor VIII clotting disorder, such information may be useful in guiding their decisions related to beginning a new exercise regime or altering an existing regime and serves as a reminder to ask physicians about potential risk. This post also indicates that little research has been done on the connections between physical activity and blood clots in those with Factor VIII clotting disorders and yet physical activity is encouraged post-PE or DVT event as a means of prevention. The participant who raised the question about exercise not only got an answer to his own question but the response helped to bring an awareness to a problem that might otherwise be overlooked.

PEAP participants sometimes have questions about tests to be performed or physicians to be seen and what to expect from the encounter. One such instance occurred when a participant asked if she should seek a second opinion regarding her health care concerns. The moderator suggested the participant seek a hematologist that might help her find the answers she was seeking. Other participants, especially newly diagnosed, will have lots of questions and seek advice such as this new participant to the group:

Thank you! I am very newly diagnosed—less than a week. I'm trying to adapt as best I can to the new normal, but any advice that you could provide would be greatly appreciated (PEAP, 2013).

The poster's question generated 15 responses, the majority of which were posted by the moderator with a second respondent being another newly added participant. It is unusual for this group to have such lengthy discussions as a result of the parent posts, but in response to the request for information, both the moderator and others provided the information requested by the parent post. Awareness is constantly advocated in this group by making participants aware of all their options, making participants aware of symptoms and treatments and providing suggested questions for the participants to ask their physicians. PEAP also attempts to provide support and encouragement when requested or indicated within an individual's wall post but support and encouragement are secondary benefits of participation in this group whose mission is providing the most current and up to date information related to pulmonary embolisms and DVTs.

Awareness also emerges as a framework in the Pulmonary Embolism – Awareness (PEA) group. This group is the largest of the three selected for this study. At the time of the study, the group was composed of 3,223 members and currently the group has a membership of 3,425 and growing. Of the three selected for this study, the PEA group is the only group that has an 'open' forum which means that anyone can post within the group and posts shared on the group's wall show up in that participants' Facebook newsfeeds. Awareness as a framework for this group is less about the simple exchange of information and more about the personal narratives that reveal risk factors, symptoms and day-to-day life of a PE/DVT survivor.

The site's description states "Please note this is an open group to make people aware of the risks factors and symptoms of pulmonary embolism and blot (blood) clots. Additionally, this group is a support system for those who have a similar diagnosis" (PEA, 2013). The discourse of

moral support and encouragement developed through the wall posts of those with similar experiences raises awareness both for the PE/DVT survivor and others. The open nature of the group also indicates the groups' focus on awareness because information posted within this group is also visible in the newsfeed of those 'friended' by the participant but who are not members, thereby increasing the number of people who are made aware of risks, symptoms and daily struggles or victories the participants may experience. Through this passive observation by secondary non-group members, awareness of what it means to be a PE / DVT survivor grows. The site's description also includes a list of the common risk factors associated with the development of pulmonary embolisms and DVT's as well as the associated symptoms. This group—unlike PEAP which has a single moderator—has 3 administrators whose activity levels vary from time to time. One admin posted as a reminder to the group “Just want to remind members: This is an open group in the hope of spreading awareness. Your posts and comments will be visible in your friend's newsfeeds . . . It's so much better to share information on the page...” (PEA, 2013). Awareness and information as expressed in this group focuses less on embedded links to articles or blogs and more on the individual participant's illness experience and making others aware of that experience, both good and bad.

Dialogue between participants is much higher in this group than in PEAP and participants will ask questions of one another quite often. During the period of this study, of 148 parent posts, 62 posts were questions related to some aspect of post-PE, post-DVT recovery. For example, one participant wrote

Since I have to get a spinal injection soon, my Doctor wants me to stop the Coumadin and start giving myself Lovenox shots. I'm not sure if I can stick needles into myself. I just might throw up. ☹ Is there some other alternative to this?? O\_o (PEA, 2013)

Participants responded with encouragement and expressed mutual dislike for having to self inject medication, as demonstrated in responses such as “I hated Lovenox shots!!!” or “You’ll get used to it after the first day or two”(PEA, 2013). The conversation ended on an up note with “glad we can laugh about it” (PEA 2013). Although maintaining an upbeat and positive tone is encouraged with comments such as “Oh, [name], keep smiling”; “Just know you’re not alone. We are all sending positive thoughts your way;” “Hang in there, stay strong” and “keep your eye on the prize. Hang in there.” The phrase “Hang in there” appears 13 times over the four week period and emphasizes to participants to not give up, even on the difficult days. Participant discourse also shows that participants may express and are able to freely express negative experiences, as in this post shared by one of the PEA participants; “Ended up at the A&E [accident and emergency] again last night (was in last week) I couldn’t breathe & was on oxygen. . . How long can this keep happening?! 2.5 years post-PE ☹” (PEA, 2013). This post generated 8 responses from 6 different people. The responses were sometimes apologetic such as this one “So sorry you’re having problems,” and “Oh so sorry. I know how frustrating it is. 2.5 yrs for me too” (PEA, 2013). Sometimes respondents shared their similar experience through a comment such as: “That just happened to me” (PEA 2013) establishing camaraderie and identification to demonstrate to the original poster that she’s not alone. There are others just like her with similar experiences.

Wall posts shared within the PEA group can generate large numbers of responses. Through the struggles and triumphs shared on the wall of the group, participants become aware of what may lay ahead in their own recovery process, and so too do the Facebook ‘friends’ of participants who also see these exchanges unfold. With each exchange, awareness is increased.

The importance of this group to its members is conveyed in posts such as this: “Thanks everyone who posts and whoever created this group. It’s reassuring to hear that my experience, if frustrating, is typical. . . Maybe we can all get that little mental boost when we see someone else had a good day or bounced back from a bad day” (PEA, 2013). Another post received 19 ‘likes’ by others: “Life has knocked me down a few times. It has shown me things I never wanted to see. I have experienced sadness and failures. But one thing for sure . . . I always get up!”(PEA, 2013) Members in this group openly express their need for reassurance as well as openly give reassurances to others. Such openness lends itself to creating a frame in which sharing ones personal narrative becomes part of the routine discourse created in the group. Post shared within this group can be as long as 7 paragraphs and 245 words to short comments of one or two lines and few words. This group also frequently uses emoticons within the context of their posts to provide emphasis on how good or how bad their circumstances are. Responses to parent posts can be equally as long as the parent post, sometimes longer, or can be quite concise with only an “☺” as the reply. The sharing of personal narrative posts encourages participants to become aware of the differences in treatment, differences in diet restrictions, the frustrations during recovery and the differences with which PEs and DVTs are approached by health care professionals. These posts bring awareness to those outside of the group when they appear in the newsfeeds of the participant as well as the participants’ friends.

### ***The Survivor Framework***

The Pulmonary Embolism-Survivor’s (PES) group, at the time of this study, was composed of 1,285 members and develops a framework of survivorship more so than awareness. This group’s site description indicates:

    this is a support group is for people who have suffered from Pulmonary Embolism(s)/DVTs/Blood Clots. Only Members can post to this support group! . .

*This group is supposed to help one another - in our journey of why we had a PE, are we going to have another one, and helping those who have questions..... some of us are farther along than others- so I hope we can all help each other (PES, 2013).*

In spite of a somewhat smaller size compared to the Pulmonary Embolism – Awareness group (PEA), the PES group generated nearly 278 parent post, 89% more parent posts than the PEA group which has nearly triple the membership. Participants of the PES group, having survived a PE or DVT share comments such as this “. . . Almost losing our lives was one of the most traumatic things that can and could happen to someone! . . . Good luck to you and know your a Survivor!” (PES, 2013); “It’s a battle, a hard one but at least we are warriors and better yet Survivors!” (PES, 2013); “That’s my [name]. I see that fighter, warrior, survivor!” (PES, 2013); or this one, “ Some medical professionals have no idea what it is to be a PE survivor with all the physical and emotional scarring . . .” (PES, 2013) and “I am glad to be part of this special group of PE Survivors!” (PES, 2013) to which another responded “. . . we are survivors and tougher than some of the toughest...”(PES, 2013).

Individuals identify themselves as survivors as well as in “I am a twice PE survivor” (PES, 2013). Others provide encouragement by reminding participants of their survival as in this response “. . . you are strong and a survivor...” (PES, 2013) This same respondent had in a previous post responded “We are tough survivors!” (PES, 2013) A new member joined what he/she called “this family of PE Survivors!”(PES, 2013) In response to a parent post, this respondent stated “You are a survivor of this horrible experience that all of us went through. . . .” (PES, 2013). Survivors are defined by their ability to go forward – their strength, their difficulties but most of all, survivors are framed as individuals who “survived for a reason and that gives us the hope, all will be well” (PES, 2013). Sometimes survivors are shaken out of their own pain by that of another. For example, one participant of this group shared his/her anxiety

and the gratitude he/she felt at finding a group like the PES. In response to this parent post and the subsequent responses from others, one respondent wrote

I am not sure whether you have heard my story. My wife [name] went to sleep on 10.10.10 and never woke. . . Although having read many stories about what you survivors go through, given the choice, are you not happy to have survived rather than what happened to my wife?(PES, 2013).

Being a survivor is not easy and as one respondent put it “honestly, we would love to stop talking about it and carry on with life’ but it just is not that easy!” (PES, 2013) Survivors depend on one another, because no one else understands quite what it is like to be a survivor as demonstrated in this response to a parent post

. . . this group has helped me so much more than any doctor could I get the reassurance and knowledge here that I do not get from gp, and this group is for P.E. Survivors so we do talk about it a lot to help each other, to support each other, it doesn’t mean for one minute mean we are not grateful to be alive, it means that this is our way of getting through it day to day...”(PES, 2013).

New members, especially those who are anxious about re-clotting even while on medication find reassurance from those who respond to their anxiety. The following posts illustrate reassurance:

. . . but you are a survivor . . . You will come out of this well and a survivor!”  
“PAMPER yourself! Take time to extend your life. We are survivors. We deserve it!” Survivors are encouraged and reminded to “Be strong [they] are a survivor!” (PES, 2013)

Throughout numerous post and responses, individuals may be collectively addressed as “my fellow PE survivors” and may individually self identify “I am a survivor.” Survivorship might mean strength but it can also bring with it survivor’s guilt as expressed in this parent post by a participant “. . . there are some times where I am paralyzed by the mental/emotional aspect of what happened. I keep thinking ‘am I broken now? Was that a sign that I might not be here

much longer?’ and all the survivor guilt that goes along with it. . .” (PES, 2013). Guilt that one life was spared when others are not can be paralyzing for some, but participants are encouraged to move past it, as this response demonstrates:

It’s part of the process, but you have to realize “You are alive and you are living.” You gotta move. Guilt? I understand that but you have to snap outta that one or its going to defeat the recovery process. . . (PES, 2013)

The discourse of survivorship demonstrated through this group is perhaps best summed up this way. Survivors are “Broken. But not destroyed. [we are] survivor(s)” (PES, 2013) Survivors are courageous individuals who will get through this, the post-PE/DVT recovery, because they have already proven that they are survivors. The hard part, the living with the event is difficult and through the discourse of this group, which frames PE/DVT events through survivorship, that many participants find the motivation and encouragement to not just survive, but live. The individual voice can proclaim “I am proud to say I am a survivor. . .” (PES, 2013) and the group can proclaim WE are survivors who offer support and help to others when it is needed.

The group frames presented by each of the three groups in this study, establish for the participants a primary framework of awareness and/or survivorship which the individual uses “to locate, perceive and identify, and label a seemingly infinite number of concrete occurrences defined in its terms” (Goffman, 1974, p.21). Individual frames emerge in and across three groups that comprise this study. Frames created by the individual poster either as a parent post or in response to a parent post may forward the group’s primary frame or may create a primary frame for the poster. Individuals may frame their experience through awareness, survivorship, fear, his or her self-care choices, his or her symptoms, or his or her emotional state. Goffman commented that once the individual can answer for him or herself the question “what is it that is

going on here?” they can then “fit their actions to this understanding and ordinarily find that the ongoing world supports this fitting” (Goffman, 1974, 247). The group becomes the “frame of activity” through which individuals can develop their own frame(s) in an effort to understand and/or explain their present position post pulmonary or DVT event and in doing so this “framing activity establishes meaningfulness for him (or her)” (Goffman, 1974, p. 345). PEAP, PEA, and PES all have varying levels of activity and the content created can sometimes come at individuals in a flurry all at once or it may dribble in and seem that the group is not active at all.

Goffman (1974) also argues that “Frame, however, organizes more than meaning; it also organizes involvement” and all three groups demonstrate how “during any spate of activity, participants will ordinarily not only obtain a sense of what is going but will also (in some degree) become spontaneously engrossed, caught up, enthralled” (p. 345). This is not to say that every post gets a response because many do not. Although it is impossible to say with absolute certainty that certain posts will elicit a reply and others will not, looking at the wall observations for all three groups across the month of August, some generalizations can be made. Posts that elicit a response are often those in which a question is asked or those in which a participant expresses some type of emotional response (i.e. fear, victory, sadness, frustration or any version thereof). Individual posts by the same participant when collectively reviewed often reveal multiple frames at work.

## **Power, Stigma, and Othering**

### ***Power***

Power is a strange thing within all three groups and in most instances is self regulating. Facebook allows individual users to block posts they dislike but within a group individual users only have the ability to approach the moderator or group administrator, assuming he or she is

still active in the group and on Facebook. In the groups where leadership is carefully exerted by the moderator, such as in PEAP, such heated exchanges like those in PES are rare but when they do occur are quickly addressed. The moderator(s) or group admins become the de facto leader of the entire group unless he or she distributes the power among other individuals in the group. Within the virtual support group, a leader is one “who has the ability to trigger feedback, spark conversations within or even shape the other members of the group” (Huffaker, 2010, p.594). Although there are designated admins in the all of the groups, the admins in PES and PEA are more for administration than leadership, with the exception of the moderator of PEAP. When asked about group management, the moderator for PEAP replied “If there is a post I do not agree with, I simply remove it” (PEAP, 2013). Additionally, in an exchange on the group wall, the moderator posted “Any spam messages I find will be deleted. We are not interested in who's looking us up! And the second time you post it - I will delete you from the group” (PEAP, 2013). She further explained “I try to protect our members from malware, spyware, etc. & only use trusted sources” (PEAP 2013). The admins in all the groups moderate interactions, observe exchanges and keep the group on track should it get lost in a heated debate, and on occasion, acting as the law enforcement, removing participants who violate either the explicit or implicit rules of the group.

Those “who can set agendas by causing or facilitating dialog focused on a particular topic or frame discussion by shaping the way a particular topic is talked about” (Huffaker, 2010, p.595) become the leaders in the group in the moment that a conversation is occurring. Leadership is fluid often passing from one person to another as the topic of the conversation changes and evolves.

### *Stigma and Othering*

The group frame and the individual frame are the means by which individuals within the group, can, for themselves, begin to deconstruct and resist the labels that they have been given or reinforce labels that individuals might deem positive. Participants within health related virtual support communities are

members who interact online to satisfy a certain need and/or perform a specific role. These people have a shared purpose, such as an interest, need, or service. To achieve that purpose, the community develops formal and informal policies in the form of implied assumptions, rituals, rules, or guides, and it relies on computer systems to support the online interaction” (Nimrod, 2012, pg. 1246).

However, the informal policies of the group may at times create a certain amount of tension between the individual and the group. The virtual support group is a “kingdom of the ill”(Sontag, 1978, p.3) in which individual participants, whether passively observing or actively engaging in the group, are forced to encounter their own understanding of the event that has occurred.

The virtual support groups do not often engage in such verbal skirmishes but at the same time, there are people with strong opinions and sometimes those opinions can grate on the patience of either another individual or the group as a whole. At times, the group can close ranks against an individual to the point that the participant will leave the group or become silent. In these moments, individual participants may feel very stigmatized much like the tainted, discounted individual described by Goffman (Stigma, 1963, p.3). One participant made this comment during the interview when asked about the negative aspects of belonging to an online virtual support group:

Only to us that continue to smoke. I can't say I blame them but we DO struggle with it and I don't think there is one of us who wouldn't love to quit, but still are unable to at this point I have read from others their posts in regards to smoking so

I don't post about it because there seem to be a very few who seem to go "on the attack", which does nothing for our self esteem. Other than that all is positive (Respondent 02032011).

Another respondent shared

There are personality clashes just as in "In-Real-Life" groups and there are people who think they know more than they really do. This is a forum of life experiences and we have been to many doctors and hospitals and have taken in a lot of information but we are not doctors ourselves and I do believe sometimes that point gets confused (Respondent 09042013).

Sometimes, participants feel quite strongly about their point of view and their well meaning intent gets lost in the passion. One of the interview subjects shared the following, which quite accurately sums up what sometimes occurs: "there are some who take it too far and do focus on the "if you don't do this u will die" mantra" (Respondent 09032013).

One topic that often generates tension and othering is the issue of medication post-PE/DVT. The standard course of treatment for years has been Coumadin/Warfarin but over the last 18 months, other medications have been approved for use, Xarelto and Eloquis. Participants in all three groups can take sides for and against and express their opinions vehemently without always considering the impact such 'discussion' has on the whole group. Below is an exchange that occurred within the PES group during the observation period that demonstrates the 'othering' such exchanges can cause. The conversation started on August 1st when a participant posted a question about Xarelto in comparison to Coumadin/Warfarin. The parent post generated 67 responses from 18 group members including the parent poster. For the first part of the conversation, people simply posted their experiences with either drug. About halfway into the first day of the conversation, everything changed when PESSP0801 posted:

Xarelto lover for 4 months now! All my Coumadin side effects were gone within the first 7 days of the switch. No vision problems. **I feel like myself** on this med and certainly don't mind being on it forever (might be an issue when I'm an old woman, but that's a long time from now, so enjoying life now and I'll cross that bridge when I come to it).

Two participants replied to that comment with no reaction. The third reply, however, was the start of rising escalation.

**PESJB0801 -1** I have been on it for 2 months now. A few weeks ago had blood drawn and it clotted in the needle/ tubing. And again the next week. I was immediately sent to a Hematologist **who told me he is not a fan of Xarelto**. I guess I'm concerned since I don't know what my INR is and if I am therapeutic since I'm clotting abnormally! I also banged the heck outta my leg and had minimal bruising. **I am talking to him about switching back to Coumadin so I feel I have more control**

This same participant added an additional comment:

**PESJB0801-2** My hematologist said I am the 3 case this month with problems while on Xarelto. He is notifying the FDA. I also have numbness and tingling in my hands that started after I started taking Xarelto.

The response stating that the hematologist was not a fan of the medication along with the comment about blood clotting in the needle generated multiple responses blaming the phlebotomist drawing the blood and dismissing the fear about Xarelto as a lack of understanding on the part of PESJB0801. Other participants provided a couple of additional comments against Xarelto advocating “Get informed everyone. If on Xarelto...you find yourself in an emergent situation .....they can't reverse it like Coumadin” (PESJM0801) and then PESSP0801 responded to both expressions of concern with a rather long narrative justifying her faith in the new medication and somewhat dismissing comments of distrust as ‘horror’ stories:

After 4 months I couldn't be happier with my decision to start Xarelto. There will always be people who will tell you horror stories, but you really have to do the research yourself (thank God for the Internet), talk to your doctors, and make **an**

**educated decision for YOURSELF.** For me, my *godfather (who is an ER doctor)* was the one who urged me to look into it, and his stamp of approval means a lot to me and I'm grateful he saw the hell I was going through and offered a solution.

The response ended with a reminder that any decision comes back to personal choice.

PESJM0801 comes back with a response that at first expresses agreement about being informed and making informed decisions, but the somewhat dismissive tone from PESSP0801 related to the 'godfather (ER doctor)' led PESJM0801 to push back with

*But ask your godfather dr....if you came into his ER with a trauma or say a BRAIN bleed....how is he going to treat you when you are on Xeralto? Please come back to us with the answer. Xeralto is still a drug for patients with afib. I am truly curious at his answer to how he would save your life*

The push back from PESJM0801 was taken as hostility by PESJM0801

PESJM0801, I don't completely understand *why you're being so hostile toward me.* I was simply answering a question and relaying my experience. But, yes, I have asked *my godfather* and we've had lengthy conversations on the issue, and the answer (which I was typing before you even asked it) is above, in addition to FFP and a consult with Hematology as well as Neurosurgery. Xarelto has a half-life of 7-9 hours, and both the PCC and Xa have been shown to decrease that significantly. *I'm a medical transcriptionist by profession (21 years) and have access to much research and work with many physicians I've brainstormed with.*

PESSP0801 also responded to previous posters, other than PESJM0801, highlighting her professional experience and training, her access to research, and her access to physicians which referenced her credibility and the trustworthiness of her information while dismissing and othering PESJM0801 as naïve and unaware. Several other posters responded in support of PESSP0801's comments with "You go [name]!!!"

Similarly, another respondent in the same conversation thread is perceived as having a condescending manner. Respondent PESJB 0801 expressed agreement with PESJM 0801's

concern over the efficacy of Xarelto to which PESRC 0801 repeatedly tells PESJB “If you need numbers to make you feel better, that’s your call. But some of us are not new to this game and have made a very informed decision to move to this drug and it has improved our quality of life greatly” (PES, 2013). PESRC 0801 takes on the plural ‘we’ speaking for more than herself. The result led PESJB0801 to respond

[name], I welcome your knowledge and education from your experience, **but I reject your condescending and scolding comment.** The clotting has happened on 2 separate blood draws within a week. At separate labs with different phlebotomists. It caused significant concern with both my physician and hematologist.

My comment in this post was to express my experience. This is what has happened to me. That was the initial question right???. **I'm sorry it rubbed you the wrong way. Have a good night!**

The use of the multiple question marks after the question and the exclamation point at the end of the post emphasizes the frustration this participant was having with the conversation. With that, poster PESJB0801 left the conversation which continued until August 3.

When exchanges like this occur, participants sometimes withdraw not just from the conversation but from the group because it only reinforces the idea that no one is listening. If one has come to the group seeking common ground and shared experiences as well as understanding, such exchanges make it difficult to identify. It should be noted here that this conversation also highlights the difficulty that exists in keeping up with who has made which comments. The comments below were posted after PESJB0801 had left the conversation. PESSP0801 responded to PESJM0801 not realizing that the previous two comments did not come from that PESJM0801 but rather came from PESJB0801, a different participant.

**PESSP0801** PESJB0801, (*PESJB0801 is not the person who had commented to PESRC0801*) ***I hear that you're new to this*** and many of us on here are (I'm 6 months out from my DVT/PE). We are here to learn together. ***I'm giving you the benefit of the doubt that your comments to me were made out of naiveté and passion.*** Perhaps you've misread PESRC0801 frustration as attitude? While the rest of us shut down, she took the opportunity to teach. I hope we can all start over on friendly terms because the bottom line is that we need each other for support, education and even celebration.

The phrase “I hear that you’re new to this...” is received as an excuse for what PESSP0801 has already determined to be hostile behavior by PESRC0801. PESSP0801 then follows this up with the patronizing phrase beginning with “I’m giving you the benefit of the doubt. . .” as if PESJM0801 had actually done something improper.

***I'm very sorry you haven't experienced the benefit many of us have found with Xarelto,*** and I hope you can switch to something you feel more comfortable with. ***I have noticed that treatments on here are a touchy subject because it's the basis for our health and survival.*** I can assure you that every person on here has researched their treatment options and heard all the arguments and the last thing they want is to have to defend their choices to other survivors. With our medical histories, we all deserve peace of mind and quality of life and not feel a need to be on the defense.

PESSP0801 makes a second apology which reads more like a backhanded reprimand indicating that PESJM0801 just needs to keep looking or keep working on finding a medication that affords her the same benefit others have expressed. Ironically, she follows this up with a comment that also acknowledges that medications work differently for everyone and that such discussions cause tension. PESJM0801 responds with

I am really not being hostile. I really want to know the answer. When I have asked many drs i was told that with a history of blood clots the last thing they want to do is give you plasma and they cant wait out the Xarelto and have no way to test to see if you can be treated.

At this point, PESRC 0801 rejoins the conversation in support of PESSP0801. PESRC0801 also feels it necessary to justify her stance by referencing her credentials in an effort to fortify the

stance that Xarelto is good and that any negative experience PESJM0801 has experienced was due not to the medication but human error.

**PESRC0801** Amen PESSP.

Just FYI. *As a trauma RN, I've dealt with hundreds of dvts and PEs over the years. I've drawn labs on thousands of patients.* I've never had blood clot in the tube or the needle. Ever. A misdraw or not treating the tube correctly can cause these issues, or you can have a specimen come back hemolyzes, but you won't SEE that.

Just as PESSP0801 had done in an earlier comment, PESRC0801 also used her professional training and experience in that profession to shape her comments. And that ended the somewhat tense exchange between the 4 participants but did not end the conversation thread as a whole which continued for another day and a half with somewhat more neutral comments and questions but no further hostility. This would not be the last conversation or tension over the use of Xarelto or Coumadin. Similar conversations developed 9 times over the course of the observation period with tension flaring at some point during the conversation.

In spite of such exchanges highlighted here, the overall perception of the groups is one of positivity where the benefits outweigh such negative moments. It is also in the negative exchanges that the power of the group can be exerted. One interview participant commented that the only negative he/she had witnessed was “once when people were being a little unkind about a member who was very outspoken” (Respondent 03002011). The previous conversations from the PES group highlight how individuals can be stigmatized in a negative manner if they are deemed too outspoken or have a different view than the dominant voice at the time.

## A “New” Normal

Virtual support groups created within social media spaces allow for the participants’ “subjective experience of pathology” (Banks and Prior, 2011, p.11) and participant contributions to the three groups contradicts the idea that an ill person gets well and returns to normal (Franks, 1995, p.9). Participants often indicate not a return to normalcy in their lives as they had known it prior to their PE or DVT but the developing awareness of a what group members collectively refer to as a ‘new normal, such as in this post:

**[Respondnet Name]** [Parent Poster’s Name] - allow yourself to experience the grief, but don't dwell on it! You SURVIVED. You are here to tell us about it, and more importantly, to continue to experience the life you are meant to lead. Focus on THAT -- the pain will subside and you will have a new normal. (PES, 2013).

Achieving an awareness of one’s new normal also brings added stress as seen in this post which states “Anyway, stress always makes me read my new normal physical symptoms as potential signs of a new PE. I kinda just want to laydown for days on end” (PES 2013). When a new member to the group expressed frustration and feelings of uselessness, the group quickly responded. One respondent attempted to explain ‘new normal’ in an effort to reassure the new participant. The respondent wrote:

**[Respondnet Name]** I know what you mean and it's a normal way to feel right now. It's all very surreal. It will take time to adjust to the new normal. I'm 35 and was just diagnosed a little over 1 week ago. At first I could hardly do anything without getting really out of breath, but I'm noticing day by day small improvements. Thus group has been really great for support, info, and advice. Keep sharing and hang in there! (PES, 2013)

The parent poster followed up, writing, “I was just so active before this. I'm trying not to get depressed. I just wonder if I'll ever be able to do everything again” (PES, 2013). The respondent commented again stating “I guess there may be some things that will have to change for you, a new normal so to speak. Time will tell” (PES 2013). As participants reach their new normal, they

in turn encourage others that they too will reach that point in the recovery journey and that it is different for every person.

For participants in all three groups, the recovery process is constructed as a journey that can be undertaken successfully, even if there are detours, just as it is often constructed as a battle with the participant the warrior who overcomes. Mankoff et al. (2011) states “patients explanatory models of illness are in part social constructs and may be developed and refined in online settings” (p.1). Instead of a habitus created with the realm of the sick, participants in these virtual support groups create a new habitus in which symptoms and side effects are addressed and acknowledged; confusion and questions are brought clarity and participants find encouragement and support. For the participants in the virtual support groups “when standard medical information did not fit the patients’ experiences, they moved to community based resources and adopted new theories and practices for managing their illness” (Mankoff et al., 2011, p.1). Participants within the group act as interpreters of medical information relying on practical experience rather than scientific fact always forwarding the idea that the individual participant needs to be and should be his or her own best advocate in his or her health care relationships. Anecdotal evidence, for the participants in these groups, evidence from other individuals who know through first hand knowledge in many cases trumps the physician centered view of PE/DVT survivorship. Participants, for good or bad, have developed deeply ingrained beliefs about what is or is not normal for one who is a post-PE/DVT survivor. Through the posts shared within the group, participants construct a new social world and find their individual self-hood as PE/DVT survivors. For example, one interview subject responded “it's great to be able to see that my worries (for example, worrying about each and every pain) are totally normal for someone who's been through what I have. It's also great to feel taken

seriously” (Respondent 07052013, 2013) or the comment from one participant who spoke about how the support from the group led her to ask the physician questions which might have otherwise gone unasked; the interview respondent stated “it's given rise to questions that I've asked the doc about”( Respondent 05002013).

### **Health Care Perceptions**

The observations of the three groups during this study also revealed information about perceptions participants develop related to health care professionals, most often physicians. Some participants are more willing than others to confront their health care providers while others express frustrations with physicians in particular, failing to hear and being dismissive of patient concerns. In response to the struggles expressed by PE and DVT survivors in all three groups, self-advocacy is strongly encouraged both as a means to be heard and a means to educate.

### ***Confrontations***

Few people actively seek out confrontations, but when one's life is at stake, confrontation may be necessary. Often, if participants do not confront the health care professional in question, nothing changes for the relationship involved and quality of care can suffer. The exchange below reveals the importance of confrontation as a new member seeks guidance from the group as a result of a confrontation with a physician.

**PEAP0817-1:** Thanks. **I am in transition with my doctor.** My former PCP diagnosed me with asthma and gave me an inhaler. The ER doc. said that the inhaler made me worse

**PEAP0817-2** You are very lucky!

**PEAP0817-1** I am lucky, ***but I did not hesitate to tell my former PCP how badly she screwed up and to fire her.*** She attempted to do "damage control" by saying

that the PE wasn't so bad because the tests didn't show any heart damage. *That just reinforced my decision that I don't want that person to have any part of my care again.*

**PEAP0817-2** *4 years after our son died, I wrote a letter to his doctor & told him what we thought of him and how he destroyed our faith in all doctors to keep us healthy.*

**PEAP0817-1** I'm very sorry to hear of your loss, [name]. But I applaud your courage. *Some doctors do not realize that the consequences of their actions can be devastating.* My ex-PCP's *efforts to minimize the significance* of her misdiagnosis showed that she was one of them. I did not let her get away with it. *If you are going to apologize for making a mistake, it should be done without reservation and without saying "it could have been worse."* Thankfully, it wasn't worse, but it was no thanks to that doctor.

Participants in this exchange confronted their physicians but often, that is not the case regardless of the number or times participants are encouraged to be their own best advocate when it comes to their health care exchanges.

### ***Listening***

Sometimes group members' frustrations with their health care professionals are directly related to changes that a physician is making in regard to individual self-care practices and the perceived lack of listening to the participant's concern. In the exchange below, the issue of the patient's need to lose weight was met with skepticism by the individual and then supported by others in the group:

**(Parent Post) PEAP0805-1** My experience with Dr's in my little city are that this type of thing is no big deal. *My ex family Dr said to me when I told him that I was terrified of going off the Warfarin that he would be terrified too.* Not comforting at all. Then he was saying the pain was from my back. Not sending me for tests or anything like that. *Well I quit going to him because he also made comments saying I needed to lose weight because my butt was getting bigger.* He had noticed it. Um yeah I gained a bit of weight because I was on B/C and going through with PE and Pleurisy of course I gained weight. *I have an new Internal*

*Med's Dr who is very good and basically told me to take it easy, to not over exert myself and to try things like yoga or swimming.*

**PEAP0805-2** They *fail to realize pain* & breathing problems make it impossible to exercise. Glad you switched!

**PEAP0805-3** Agree. I switched hematologists as well. *My doc gave me a lecture about how overweight the people in the western world are and how i need to lose weight.*

She considered taking me off Coumadin. Like any other professions, *not all doctors are good.*

**PEAP0805-4** I have been told by a lot of my docs ( both gi's, pulmonologist, endocrinologist & cardiologist ) that I need to lose some weight because it will help control my breathing, and possibly get rid of my ongoing pain in the stomach area .. *what some of them fail 2 remember is* that I am on Coumadin and I also have a genetic disorder called turner syndrome that one of the symptoms/ side effects is obesity.

The first response to the parent post sums up an overall impression expressed by many participants in all of the groups – the idea that the physician doesn't understand how the participant feels. The physician or other health care provider just doesn't "get it" – they don't know or can't know what it means for the individual PE/DVT survivor. As noted in the first exchange from PEAP0817-2, a bad experience can destroy the trust relationship between physician and patient because "doctors also influence us in our decisions" (PEAP0811-7). In order to be successful, the relationship between doctor and patient must be developed and maintained; trust develops over time but is easily broken in an instant.

The tenuous relationship between participant and physician is also seen in this comment "But he's a doctor, so he knows what he's doing I hope" (PEAP0821-1) which shows the implicit trust given to a doctor simply because he or she is a doctor. This sentiment is also seen in the PEA group when a participant wrote "Opinions thoughts advise... I feel I need one but have gotten very mixed messages from different doctors" (PEA0826-1). Within the group however,

when questions emerge regarding participants with new or ongoing symptoms or changes in symptoms, the physician is the first course of action as evidenced by the PEAP moderator's response to a participant's question about diet. The moderator stressed not just once, but several times in the conversation that "When in doubt, call your doctor - that is what they are for!"(PEAP0817-2) because "your doctor should be able to answer according to your personal medical history" (PEAP0812-2). This same reference to the physician is seen throughout the conversations in the PEA group especially when it seems that a participant might be jumping to conclusions based on exchanges within the group as happened with this participant in the exchange below:

**(ParentPost)PEA082411** Please someone tell me what is SOB, and D-dimer? I have PE in my lungs

**PEA0824-2** Short of breath and d-dimer is a blood test to see if you have clots in your body

**PEA0824-1** thanks always SOB then, never had the D-dimer "given enough blood to keep a couple of vampires alive thou !

**PEA0824-1** Is it always like this „even years later, *I'd rather ask here then Dr's BS ..bullshit* lol ! no seriously this really stinks, along with my Fibromyalgia ugh!

There were multiple responses at this point related to PEA0824-1's question of "Is it always like this, even years later. . ." and the responses were not reassuring as evidenced as the conversation continues:

**PEA0824-7** *You guys scare me.* PE two years ago and been off Coumadin after 6 months. Supposed to be on an aspirin a day and don't take it. I see reoccurring clots YEARS later is obviously common. :0(

**PEA0824-8** PE's stink...I've had them twice and been on Coumadin for 13 years..

**PEA0824-7** U had them while on Coumadin?

**PEA0824-1** I'm going to tell my Dr. I'm going to stay on the Coumadin *be my own advocate* like the lady before said, *it's our lives and our bodies, we are just a number per se !!!*

**PEA0824-9** I agree with [name], seems like lots of people have had a second round of clots so that is scary

At this point in the conversation, another participant who also serves as one of the group administrators entered the conversation and tried to remind the participants that there is, in short, no one size fits all approach when it comes to the post-PE/DVT recovery process. She states:

**PEA0824-10:** To PEA0824-7 and PEA0824-9 just because others have had second episodes doesn't mean you will. If there was an obvious one time cause for your experience, it may be perfectly safe to come off blood thinners. *Each person's case is different. I wouldn't just trust one doctor's opinion, though.* My family doctor wanted me to have the IVC filter removed after I'd had knee surgery even though I'd previously had a PE of undetermined origin. Luckily I listened to my vascular surgeon and it was in place when I had another round of DVT a few weeks after surgery when he was sure the danger had passed. *In the end we must get as much information as possible and then go with our gut feeling. It is \*our\* life, after all.*

Even after reassurances however, the original poster replied the next day with “I'm a ticking time bomb” (PEAP0824-1).

### ***Dismissive Behavior***

Participant frustration with health care is a dominant theme from participants who want information or want answers as to “why me?” only to encounter dismissive behavior as this participant expressed during an exchange in the PEA group on August 18. The participant’s frustration and feeling of betrayal are clearly noted when he/she writes

As brilliant as my pulmonologist is, *I think he is missing something* and *I feel a bit betrayed that he dismissed me* back to the general pulmonary clinic with the fellows, who, by the way, thought my echo with the enlarged heart was normal!

So I just don't see a pulmonologist anymore. *The hell with it*. I mean, what is the point. . . Whenever *docs dismiss things* just because they can't diagnose it with all their tests and use something lame like weight loss, I feel like they are unwilling to admit their limits in knowledge

Another participant writes “Yet, doctors don't warn patients and don't seem to understand when we report what is happening” (PEAP, 2013) which once again echoes the idea that the health care professional is not listening to the individual. In post across all three groups, participants indicate a lessening of trust in the person they most need it from, their physician. Physicians are often characterized as dismissive and uncaring which intensifies feelings of alienation between doctor and patient. In an already weakening relationship between doctor and patient, indicated earlier in this study, dismissive behavior only widens the gap.

### *Self Advocacy*

In spite of evidenced mistrust in health care professionals, especially physicians, when questions or concerns arise, the physician is the first course of action recommended by the group with comments like “Yep, always call your doctor if you're worried” or with cautious reminders:

None of us are doctors. What might manifest as a symptom for one person may not for another person. *You know your body, if concerned seek medical attention*. While asking strangers questions may help you emotionally, nothing will help you better than an in-person medical evaluation (PEA0812, 2013).

However when interviewed about whether or not health care professionals should be part of any of the groups, reactions were mixed. One interview respondent shared the following:

**Respondent 09032013:** From reading some of the threads it seems many *people have drs who don't take them seriously*. I think *it would be beneficial for them to be apart of a group like this to see how we all relate to one another and we all have similar symptoms and feelings*. This helps *to validate what we feel* and may *make the drs more aware* of the symptoms *to take them more seriously*. I think it would also benefit the group in the sense that, again my post 3 days ago, to have a dr say go to the er now would be concrete. The drs would also be able to interact with us and *alleviate some fears* we may have. A detriment may be

too much [doctoring] and not enough listening. *They need to come in with a bystander mentality and not a dr patient clinical mentality.*

In contrast, another interview respondent brought up the fact that having the health care professionals be part of the group might have negative results with “I think the group would become a two-tier system, with the health care professionals "Lording it" over the patients... that said, they might see things from our point of view more” (Respondent 07052013). Another respondent expressed the concern that group members might not speak up. The interview subject shared “Not sure about that it would be good in some ways perhaps but I would fear it may stop people from opening up and talking freely” and then followed up with the benefits stating

The good I could see from it and have seen this mentioned over and over again. Is that Dr's just do not understand the effects of the drugs and *if they could see enough people saying the same thing as I do in this group may be they would get it* that it is not all in our heads that these things a really happening to us (Respondent 00002010).

The health care professional’s influence is part of the group even if there are no physicians or other professionals participating (other than those participants who themselves have experienced a PE or DVT and are also in the healthcare field) due to the primacy that the role of physician has even when the actions are questioned. The physician is still the single most referenced to individual within any of the three groups. For every negative or frustrating comment shared by an individual there are an equal number of comments that direct someone to see a doctor, find a physician, seek a second opinion, and to get help. Along these lines is the idea that the individual participant should also be his or her own best advocate – the physician acts on what he or she sees and is told and if a participant doesn’t ask questions or question decisions, the physician cannot know what is undisclosed and in turn follows the science of medicine. The patient must advocate for him or herself in such a way that the health care professional does hear.

When a new member joined the Pulmonary Embolism Survivors(PES) group and was seeking advice, one of the first things the new member was told was “Be your own self-advocate”; and later in the conversation the new member was reminded “You have to be your own advocate” (PES, 2013). Advocating for oneself can be a daunting task for a PE/DVT survivor, especially when there are sometimes conflicting opinions. For example, patients taking the traditionally prescribed blood thinning medication, Coumadin/Warfarin, are often told to adjust their diet and watch their intake of vitamin K rich foods. Some participants are told to outright avoid Vitamin K rich foods and this brings up advocating for oneself in a different way – self care and the importance of being informed. The exchange below highlights the importance of being an informed advocate:

**(Parent Post) PES0828-1** *Here is some information I put together.* I hope you all have seen the article floating around about vitamin K and heart health. ***I have written a post about why vitamin K is important and needed*** - even if you are on warfarin. I have included a link to the article in the post if you have not read it yet.  
<http://bloodclotrecovery.net/warfarin-and-vitamin-k>

**PES0828-3** This is very well put. I avoided vit k for the first month on warfarin, then upon doing my own research advocated for maintaining the recommended daily value because I was breast feeding. It changed my dose from 5mg to 11mg daily (which I stayed on for nearly 3 years) and all I had to do was measure the same amount of broccoli and spinach to consume daily. ***My doc resisted until I had a dietician weigh in at the hospital.***

***I'm surprised how often I see on here that people completely avoid it,*** and are lifers on warfarin. There is simply no way to remain healthy if you don't consume greens, ever, in your whole life.

Thanks for posting!

**PES0828-1** Thank you PES0828-3 I also greatly appreciate you sharing your experience- ***this is what I mean by being your own advocate!*** You nailed it when you said "there is simply no way to remain healthy if you don't consume greens ever...." I am equally surprised and concerned when I hear about people avoiding them completely. And ***nowhere in research*** does it actually say "avoid it," but as

you and I have seen, it's easier to treat someone without having to worry about possible fluctuations relating to diet. Then, it just starts to disturb me! I am really hoping to get the word out and change this way of thinking. Thank you for your input!!

**PES0828-4** Thnx PES0828-1. Im planning on living a long time. I will not eat or avoid foods simply because i take warfarin. Life's to be lived and surely most of us luv to eat. *I want to look after myself* and i try to. I also try to take the emphasis of having "Had" clots out of my life. Im alive and life goes on. *You can move past it all if you think positive.*

Being an advocate for oneself often means having a certain level of confidence in oneself. This can be difficult for the PE/DVT survivor who may be struggling to create a new framework for his or her life during recovery. In contrast, being your own best advocate can also have its own reward, as demonstrated in this response “I know how to be my own advocate, I do agree that nobody knows your body like you do. I've educated myself and know I'm doing the right thing. I encourage everyone to do the same” (PES, 2013). Another participant acknowledged the importance of self advocacy and the difficulty with doing so when he/she wrote “If you feel something is wrong-go with your instinct and advocate for yourself. It is hard sometimes because we don't want to upset people or cause a problem or a fuss--sometimes we need to for our own piece of mind” (PES, 2013). Self advocacy also involves not giving up and always questioning.

Participants are encouraged by posts like this one in which the participant shared, “I would advocate that if something showed up on your blood work don't let doctors dismiss it....bug them until you get the information you need” or this one, “If you're really concerned over it, ask why they came to their conclusions and if you don't agree, ask for more. It is your body and you have to be its best advocate” (PES, 2013). In the Pulmonary Embolism Awareness group, advocacy is related to increasing awareness. A new member shared with the group the

numerous trips made to the ER prior to being diagnosed with PE and the frustration she felt because the ER physicians had not validated her concern on a previous ER visit when she had explained that she had recently lost her father to a PE and felt she was herself experiencing the effects of one. Instead, the individual had been told it was probably acid reflux and sent home, only to return a few days later when the symptoms intensified and she nearly lost her life. This led to many posts of supports and an almost immediate expression of advocating awareness as expressed in this post:

**PEA0824-4** They still sent you home even after learning about your father's history?! *This is why we have to spread the word about the symptoms of PE.* Even emergency *physicians* tend to see only a certain demographic when they're looking for PE and *fail to realize* how many otherwise young and healthy people are affected. I'm glad you're here to tell your story. *We need to educate the public and the medical community that deadly PE can strike anyone, anytime!*

**PEA0824-1** They also knew I had factor V and

**PEA0824-4** *Then they are seriously incompetent! This is why we must be our own advocates.*

The conversation generated 30 responses from 14 individuals in less than a 24 hour period which demonstrates the passion with which participants view the challenge of being heard. As the conversation above continued, PEA0824-12 advocated for physician education when he/she wrote “I think all dr"s should re educate on PE"s its someone's life . . . People can die don't they realize this ?” to which PEA0824-13 replied “Thankfully you survived. Of those who have died from a PE, I wonder how many complained to deaf ears before they died” (PEA, 2013) which only strengthens the need for participants across all three groups to heed the advice when told to be their own advocate and in doing so, educate the physicians and other health care professions encountered by PE&DVT survivors.

When asked in the interview about health care professionals, one individual responded with perhaps a reason for the deaf ears stating “I think there are a lot more people having DVT and PE's. I also think there is a great deal still to be learned about the cause and effect of DVT/PE” (Respondent 0000200708). There is still much to be learned on all sides and technology only increases the demand for continued growth and education. Information is readily available but not always understood and warrants the sometimes skeptical view represented by one of the interview subjects who stated “I asked my Dr. The same? They told me basically stay off the Web. The primary Dr. I go to says she surfs the groups all the time. Didn't have much to say Like they know it all” (Respondent 00002007). Social media has become an active venue, as these 3 groups demonstrate, for illness sufferers to find common ground through sharing their experiences. Social media could also be the solution to improved communication which participants in the groups clearly feel is lacking. The participants in these three groups collectively narrate a story of survival and awareness, power and control and self-advocacy as each participant navigates his or her own PE/DVT recovery.

## Chapter 6: Conclusions

This chapter discusses the key findings of the study as they relate to the research questions presented in Chapter 1:

1. Within virtual support groups created through Facebook, what frames become defined by people post-PE, post DVT to understand/explain illness, relationships, the chronically ill self, self-care?
2. How is "otherness" and stigmatization expressed in the virtual support group?
3. What does the discourse within the virtual support groups reveal about the individual's constructions of chronic illness and doctor-patient relationship?

Addressing these research questions helps to fill a research gap that includes social media studies, discourse studies and health care communication practices. The gap exists in part because of the quickly changing technological advancements of social media platforms like Facebook and the increasingly profit driven, clinically distant health care arena which privileges the science of a diagnosis that seems sometimes far removed from individual experience and lacks an empathetic understanding of the individual sufferer's voice.

In particular, I focus on the narrative frameworks of discourse created in pulmonary embolism (PE) and deep vein thrombosis (DVT) related virtual support groups created within the social media platform of Facebook (FB). The chapter also discusses how the findings contribute to discourse studies and healthcare communication practices. Finally, the chapter concludes with suggestions for future studies. In particular, for this study, I could find no research that explores the narratives of pulmonary embolism or deep vein thrombosis survivors that are created through

social media platforms like Facebook. This research seeks to close that particular gap and addresses the discourse of the narratives told by PE and DVT survivors in Facebook.

Individuals dealing with the effects of a pulmonary embolism (PE) or deep vein thrombosis (DVT) have learned how to leverage social media in order to address not only their illness but also their relationship with various others, including health care professionals. For some survivors, health care continues to be perceived as more bureaucratic and cost-conscious, and empathy from the health care professional perceived to be lacking. Finding health care to sometimes be cold and clinical, impersonal and bureaucratic, individuals who have suffered a PE or DVT search out other avenues for understanding, for empathy, for hope. Social media, leveraged well, could be a means to improve patient understanding of chronic illnesses while at the same time providing narratives from individuals that help to educate health care professionals on plights of individuals recovering from pulmonary embolism and deep vein thrombosis events. Individuals affected by PE or DVT use social media to better understand what has happened to their life frame.

Chapter 2 discussed the existing literature and theoretical frameworks that act as a foundation for this study. This chapter examined the social constructions of illness, the power of the institution of medicine, the role of the physician, and the narrative structures of texts, including the texts of virtual space. This chapter explored prior work that theorizes how the individual with an illness, in particular chronic illnesses, understands the body and the body in relationship to illness and connected that work with the growing urgency to understand the impact of text created in virtual spaces like Facebook on perceptions of the body and illness. Chapter 3 presented the methodology for this study and the rationale for using a mixed methods approach. Chapter 3 also introduced the participants of the study and the setting in which the

study occurs. The methodology chosen for this study attempted to bring together multiple methodologies across a wide array of disciplines in an effort to gain a deeper understanding of research of social media discourse specifically associated surviving a VTE. The methodologies used in this study pulled from a variety of behavioral studies, communication studies and discourse studies and became an ethnographic tool by which to study a virtual support group as an embedded member of the community. Additionally, chapter 3 examined the data collection process related to the distribution of the survey, the observations of Facebook wall posts and interview responses.

Survey results are discussed in more detail in chapter 4 and the observational and interview data are discussed in chapter 5. The data from the survey helped to more clearly understand the individuals who choose to join online support groups related to pulmonary embolism and deep vein thrombosis events as well as to examine how these virtual support groups impact individual perceptions of empowerment. The results of the survey indicated that for the participants in the groups in this study, there is a need for stronger, more personal communication between health care professionals and the individual PE/DVT survivor. The majority of the survey respondents felt that social media is a platform that should be further explored as a means of closing perceived communication gaps between survivors and healthcare professionals.

Chapter 5 examined the data from Facebook wall posts of the groups involved in this study and follow-up interviews with volunteers from these same groups. Data from the posts and the interviews indicated that individuals who have survived a pulmonary embolism or a deep vein thrombosis event and who join an online virtual support group related to PE or DVT create frames of understanding around awareness and survival. It is in the creation of these two larger

frames that individuals also create new frames of understanding for their individual self post-PE/DVT event. Observations from the wall posts and interviews also examined how othering and stigma are sometimes conveyed and finally, this chapter examined how group affiliation impacts perceptions of the health care professional-patient relationship.

### **Summary of Key Findings**

This section presents a summary of findings as they relate to the research questions that framed the focus this research about how the discourse created in VSG's impacted self-perception of illness post-PE or DVT event, self-care practices, and perceptions of the doctor-patient dyad.

#### ***Frames and Framing***

The first key finding of this study was to identify the frames created by individuals in virtual support groups related to pulmonary embolism and deep vein thrombosis. What developed through the survey results, the wall observations and the interviews is that framing occurs on multiple levels. An individual's PE or DVT experience has, at the least, disrupted, and at worst, completely broken an individual's reference point by which events are understood. The frame of what the individual considered 'normal' that existed prior to the PE or DVT no longer works. Charon (2006) notes "patients exist within a temporal ceasure—the experience of pain or suffering indivisible into 'then' and now"—states of suffering erase all distinction in time except for 'before it started' and 'since'"(p. 121). For the PE and DVT survivor in these groups, the "after" can sometimes be so different from expectations and alien territory because the individual has no frame of reference for the event. The virtual support groups provide the necessary framing that helps to move the individual from a space of loss created by the breaking of the prior frame

as a result of the PE or DVT to forming a frame of awareness and/or survival created after the PE or DVT event.

At the group level, two frames in particular seem to dominate, awareness and survival. While two of the groups in this study have awareness as their dominant frame, the awareness frames are both different by design. In the PEAP group, a closed group in which only members can participate in the discussion, awareness is directed inwardly towards the participants themselves. The PEAP group frames awareness as an information exchange in which the individual participants are constantly gaining knowledge about their pulmonary or deep vein event in order to make more informed decisions about their post- event recovery process. The second group that creates a frame of awareness is the PEA group. This group differs from the other two in that it is an open group in which anyone can view the discussion and comment and the discussions will appear in individual members' newsfeeds. As a result, awareness is not directed purely inward toward the individual participants, but is also focused externally toward those who observe the exchanges second hand through the newsfeeds. The PEA group creates a heightened awareness in the day-to-day lives of pulmonary embolism and deep vein thrombosis survivors.

Within the third group the Pulmonary Embolism Survivors (PES) group, the frame of survival and the individual survivor emerged. Interactions within this closed group encourages individuals to move forward because they are able, because they survived. The group frame of survivorship frames the onset of a PE /DVT as the beginning of a battle in the grander scheme of one's life. It is a moment in which individuals affected by a PE or DVT cannot allow themselves to become paralyzed, but must instead find the strength to move forward. The PES group is all

about survivorship, with each day a different battlefield for the PE/DVT survivor, the PE/DVT warrior and victor.

All three groups provide a space in which participants can narrate their post-PE/DVT event. Charon (2006) writes “so, narrative acts by definition engage reader and writer in the process of discovery and transformation” (p.125). Individuals affected by PE or DVT use the group to re-create, re-frame their overall life narrative as they gain understanding about what has happened to themselves. Patients construct their post PE/DVT event lives by using Facebook (FB) support groups focused on their illness event to help them narrate their chronically ill self. Participants work through the creation of a new narrative built out of, or around, having survived a pulmonary embolism or deep vein thrombosis. Patients use FB to tell and retell their illness story seeking understanding and validation for what is happening to them, encouragement and moral support, and a sense of unity, as if to reinforce the idea of ‘normalcy’ when normal is the very thing that has been shaken and altered.

### *A “New” Normal*

A second key finding of this research examines how the support of others in their moment of need is evidenced throughout the posts shared either as a parent post or in response as a child post. Participants move from being seekers of something within the group to being givers within the group – giving information that individual participants have gained about their post-PE/DVT experience to others who join the virtual support-The ‘givers’ in the group share their experiences in an effort to help someone else have a different experience than he or she has had; in an effort to help someone else suffer less from illness and focus more on surviving and moving from surviving only to living life with a “new normal.” The shared experience of surviving when others did not, and living with that knowledge every day, is sometimes difficult

for many of the participants and it is that common ground of survival that unites the members within the group. Participants alternate between interactive frames of surviving/living on one hand and acceptance/encouragement on the other. The online virtual support group becomes a means to navigate toward 'normal' once more as this participant indicated when he/she replied "I've had to accept the fact that I now have a "different" normal but that's ok because I'm alive & blessed!!"(PEAJS0822, 2013). Additionally, the validation participants feel aids in the participants' arrival at a "new" normal post-PE/DVT recovery as witnessed in this response from a member in the survivors group who stated "I try not to consider my limitations as disability. I decided long ago that it would be my new normal" (PES0818, 2014). For the individual who has experienced a PE or DVT or both, the virtual support groups "provide unusual opportunity for information exchange and mutual support among people who face special health interests and vulnerabilities"(Sharf, 1997, p.66).

Social support is evidenced in each of the illness related virtual support groups selected for this study. Social support unfolds within the group alongside the constant exchange of information that occurs. Social support develops in a moment of need in response to either a parent post or in response to a response given to a parent post. For example:

**PSJD08221248 (Parent Post)**

About to have my ablation procedure done! Wish me luck!

**PSLH08221250** Good luck (name) x

**PSRH08221257** Good luck! I was so glad I had mine!!

**PSLLH08221305** good luck!!!

The above parent post generated 27 posts sending well wishes, kind thoughts and hopes for a speedy recovery to the participant who posted they were about to have a surgical procedure done. It is quite common across all three groups in this study for people to show affection and demonstrate concern for other members. Members share virtual hugs, send prayers, send good

thoughts or positive energy. Participants comment on their shared experiences with reminders that “We’ve all had those days....” Or “I know what you mean” or “You’re not alone” comments. While Facebook is very much an asynchronous environment, when social support is needed, someone from within the group is always available, regardless of the time. Individual members connect with one another in this virtual space and provide support for one another that the individual participant may not feel anywhere outside of the online support group.

### ***Othering and Stigma***

A third key finding identifies areas of power within the groups and how, with this power, stigma and ‘othering’ are enacted within the online virtual support groups.

Power is a somewhat ambiguous ‘thing’ within the groups. Both the PEA and PES groups exhibit that power is distributed among the membership in the sense that whoever starts the conversation is, for that moment, the leader. While there are moderators for both of these groups, moderators stay in the background and only speak up or act when the implied or stated rules of the group are broken. Power in the PEAP group is a bit more tightly controlled. PEAP has an active moderator who shapes the entire group and whose goal is to protect members from any sort of ‘bad’ behavior. The moderator of PEAP wields power much like a parent would with a child. There are rules, such as respect for one another, and when those rules are violated, there are consequences such as removal from the group.

One aspect in which the membership has more direct control, or power is in ‘othering’ those with whom one does not agree. While tension overall within all three groups is minimal, there are moments when participants can be stigmatized because of their viewpoints on an issue is being discussed or because of life choices they disclose, such as continuing to smoke post-PE event.

Members can be also accused of being hostile when they express dissenting views other than those of the parent post and members will attempt to shout down those with whom they disagree.

Participants across all three groups have instances where individuals have felt so stigmatized and ‘othered’ that they chose to leave the group completely, sometimes moving to one of the other groups available.

### ***Constructions of Chronic Illness and the Doctor Patient Relationship***

The fourth key finding of this research identifies recovery as an ongoing process of negotiation with self and others: family, friends, acquaintances and especially health care providers. The health-care provider relationship can become a point of tension for the individual who has experienced a PE/DVT and continues to experience symptoms long after the event.

Participants in the groups expressed an overall dissatisfaction with their health care providers because providers failed to validate participants’ health concerns or they exhibit dismissive “it’s all in your head” behavior toward the patient. As a result, the virtual support group also becomes a place in which an individual can ‘doctor’ shop.

In virtual environments such as the ones which are part of this study, the missing element is the health care professional. Huang and Dunbar (2013) write “. . . healthcare providers are essentially using social media to disseminate information to consumers as a means for marketing, advertising and fundraising” (p.15). Physicians and other health care professionals, from studies reviewed by Huang and Dunbar (2013), utilize social media personally but “ ‘one thing that hasn’t changed . . . is the lack of patient-physician communication on social media’ ”(p.15). Some health care professionals are divided over the legal and ethical concerns of communicating with their patients outside of the traditional medical environment. Others, however, disagree.

According to Huang and Dunbar “National Health Information, LLC, refers to social media opportunities as ‘Health 2.0’ and sees social media as empowering, engaging, and educating both health care consumers and providers” (p.15) a sentiment also demonstrated by participants of this study. During the interview phase, participants were asked whether or not health care professionals should become part of the three groups. Responses were divided, just as those from health care professionals in Huang and Dunbar’s study, with some participants advocating the positives the group could experience from having physician interaction while others highlighted the negatives that could potentially occur. Interview respondent 09032013 stated

I think it would be beneficial for them (physicians) to be a part of a group like this. . . may make drs more aware of the symptoms to take them seriously. . . drs would also be able to interact with us and alleviate some of our fears. The detriment could be too much dr-ing and not enough listening.

Another respondent shared “would love my GP & other medical practitioners to read posts- maybe they would realize the after effects of PE are very real!!! They would learn loads!”

(Respondent 03002011)

But, as with the Huang and Dunbar study, interview respondents were mixed with regard to whether it would be beneficial for health care professionals to become part of the social media support group. Responses show concern that health care professionals may in some way silence the group as indicated in this response; “Not sure about that it would be good in some ways perhaps but I would fear it may stop people from opening up and talking freely” (Respondent 00002010). Another respondent stated “I think the group would become a two-tier system, with the health care professionals "Lording it" over the patients... that said, they might see things from our point of view more”

(Respondent 07052013). More research needs to be done regarding health care professionals participation in virtual support groups created in such spaces as Facebook.

### **Future Research**

The group feature in Facebook allows people to connect around nodes of similarity, in the case of this study, illness, disease and trauma. For almost any experience, an individual seeker can probably find a group and if there isn't one, with a few keystrokes can start one and within minutes can grow from a group of one or two, to a group of hundreds or thousands.

For health care professionals, social media could be a solid, stable platform to grow patient education programs and increase patient awareness about illness prevention, effective treatment plans, alternative treatment plans, symptom management and an overall better quality of life for the individual. Future studies need to address the health care professionals' perceptions of such virtual support groups such as the ones researched in this study—those that survivors create to share stories and support. But, clear ethical and professional guidelines for health care professionals in virtual spaces like Facebook need to be established. Additionally, future studies need to explore creating a collaborative relationship between health care professionals and virtual support groups to investigate how these virtual support groups could be used to improve patient-provider communication practices, self-care practices and feelings of more control over their condition. Many issues need to be addressed, from the time involved, and monetary costs associated with establishing such spaces, to ethical and legal limitations, and boundaries.

Future studies of virtual support groups through Facebook need to more closely examine the ongoing narrative that the participants create – from the moment of joining the group forward. Understanding how individuals reconstruct narrative coherence post PE or DVT as

advances are made in healthcare that lead to more people surviving. The narratives identified in these virtual support groups could be quite useful to the healthcare professional in terms understanding how the individual affected re-constructs not just the medical narrative but also the post-PE/DVT identity. As healthcare communication continues to change and evolve as a result of emerging technologies, there will continue to be a need for ongoing strategies for improvement.

### ***Technical and Professional Communication and Social Media in Medical Contexts***

Technical and professional communicators (TPC) needs to be involved in such a way as to help show that the discourse created through social media outlets, especially those related to little talked about illnesses such as pulmonary embolisms (PE) or deep vein thrombosis (DVT), are not just “backchannels, which serve mainly to spread ‘misinformation and rumor’” (Keller, B. et al., 2014), but are also spaces in which patient education in an informed manner can occur. Social media encourages increased participation by users, provides stronger connections to others with similar experiences and increased levels of interactivity among users. TPC’s can help identify the ways in which participants communicate in virtual support groups like those in FB that encourage or promote positive self healthcare practices and improved healthcare overall.

Discourse analysis (DA) may be used to identify the varied discursive frames related to how participants’ interactions influence behaviors and decision making processes. As scholars and practitioners, we bring our ability to identify the nuanced way in which language is used and how that language impacts the most mundane of and the most extraordinary of circumstances. Language play in virtual support groups moves towards creating a medical narrative fully developed through participant interchanges. Analyzing these interactions could help provide healthcare professionals with a tool that affords better empathy with PE and DVT survivors.

Virtual support groups like those in this study offer a space in which health care providers and participants in the groups can learn from one another. TPC students and healthcare professionals can be and need to be educated about the manner in which social media influences healthcare choices, constructing meaning for both the participant in the group as well as the healthcare professionals involved. This study provides insight into how participants in virtual support groups available as a result of social media frame and co-construct life post-PE/DVT. Technical and professional communicators, working with healthcare professionals could help individuals impacted by a PE or DVT co-construct a space in which the group participants negotiate their post-PE/DVT experience supported not just by other survivors but also supported by healthcare professionals trained to pay attention to the nuanced interactions which occur in virtual support groups as participants negotiate meaning and strive for ‘normalcy.’ The discourse analysis that can be done in such a space would provide valuable data as to how individuals make sense of their VTE event and how these individuals create new narrative frames as they cope with the outcome of survivorship.

## REFERENCES

- American Medical Association. (2006). Improving Communication-Improving Care: An Ethical Force Program Concensus Report. American Medical Association.
- Antiphospholipid Syndrome Foundation of America. (2010, November 13).  
*Antiphospholipid Antibody Syndrome*. Retrieved August 25, 2012, from APS Foundation of America: <http://www.apsfa.org/aps.htm#6>.
- Bamberg, M. & Georgakopoulou, A.(2008). Small stories as a new perspective in narrative and identity analysis. *Text & Talk*, 377-296.
- Banks, J., & Prior, L. (2001). Doing Things with Illness: The Micropolitics of the CFS Clinic. *Social Science and Medicine*, 11-23.
- Barker, K. (2008, March). Electronic Support Groups, Patient-Consumers and Medicalization: The Case of Contested Illness. *Journal of Health and Social Behavior*, 20-36.
- Beacco, J.-C., Claudet, C., Doury, M., Petit, G., & Reboul-Toure, S. (2002). Science in media and social discourse: new channels of communication, new linguistic forms. *Discourse Studies*, 277-300.
- BèHague, D., Kanhonou, L., Fillipi, V., Ronsmans, S. L., & Kanhonou, L. (2008). Pierre Bourdieu and Transformative Agency: A study of how patients in Benin negotiate blame and accountability in the context of severe obstetric events. *Sociology of Health and Illness*, 489-510.

- Beisecker, A. E. (1990). Patient Power in the Doctor-Patient Communication: What Do We Know? *Health Communication*, 105-122.
- Berkley, University of California at Berkley (2005). *Teaching Guide for Graduate Instructors*. Retrieved April 28, 2013, from Theories of Learning: Social Constructivism: <http://gsi.berkeley.edu/teachingguide/theories/social.html>.
- Blommaert, J. &. (2000). Critical Discourse Analysis. *Annual Review of Anthropology*, 29, 447-466.
- Boje, D. M. (2001). *Narrative Methods for Organizational & Communication Research*. Thousand Oaks, CA, US: SAGE.
- Boughin, J., Cobb, L., Manyke, J., Mottenbohm, O., Chui, M., Barbat, B. d., et al. (2011). The Importance of Information Technology: Search. *McKinsey's Technology, Media and Telecommunications Practices Report* .
- Bourdieu, P. (1989). *Distinction: A Social Critique of the Judgement of Taste*. (R. Nice, Trans.) Cambridge, MA: Harvard University Press.
- Bourdieu, P. (1986). The Forms of Capital. In P. Bourdieu, *Handbook of Theory of Research for the Sociology Foundation* (R. Nice, Trans., pp. 241-258). Greenwood Press.
- Briggs, C. (2012). Towards a New Folkloristics of Health. *Journal of Folklore Research*, 49:3, pp. 319-345

- Briggs, C., & Mantini-Briggs, C., (2003). *Stories in the Time of Cholera: Racial Profiling during a Medical Nightmare*. Los Angeles: U of California Press.
- Calman, L. D. (2006). What is grounded theory? *Nurse Education Today*. School of Nursing, Midwifery and Social Work.
- Center for Disease Control and Prevention. (2012, August 13). *Chronic Disease*. Retrieved August 25, 2012, from Center for Disease Control and Prevention: <https://www.cdc.org>.
- Centers for Managing Chronic Disease. (2011). *What is Chronic Disease*. (U. o. Michigan, Producer) Retrieved August 25, 2012, from Center for Management of Chronic Disease.: <http://cmcd.sph.umich.edu/what-is-chronic-disease.html>.
- Charmaz, K. (1990). Discovering Chronic Illness Using Grounded Theory. *Social Science and Medicine* , 1161-1172.
- Charon, R. (2006). *Narrative Medicine: Honoring the Stories of Illness*. New York, New York, USA: Oxford University Press. Kindle Edition.
- Conrad, P., & Barker, K. (2010). The Social Construction of Illness: Key Insights and Policy Implications. *Journal of Health and Social Behavior*, S67-79.
- Creswell, J. (2003). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (2nd ed.). London: Sage.
- Demeris, G., Afrin, L. B., Speedie, S., Courtney, K. L., Sundhi, M., Vimarlund, V., et al. (2008). Patient-Centered Applications: Use of Information Technology to

- Promote Disease Management and Wellness: A White Paper by the AMIA Knowledge In Motion Group. *Journal of the American Medical Association*, 8-13.
- Denzin, N., & Lincoln, Y. S. (2005). *The Sage Handbook of Qualitative Research*. Thousand Oaks, California, USA: SAGE.
- DeVita, E. (1995). The Decline of the Doctor-Patient Relationship. *American Health*, pp. 62-67.
- Edwards, D. (2008). Narrative Analysis. In A. Jaworski, N. Coupland, A. Jaworski, & N. Coupland (Eds.), *The Discourse Reader* (pp. 227-238). New York, New York, CA: Routledge.
- Ellison, N. B., Steinfield, C., & Lampe, C. (2010). Connection Strategies: Social Capital Implications of Facebook-Enabled Communication Practices. *New Media and Society*, 1-20.
- Eysenbach, G. &. (2001). Ethical Issues in qualitative research on internet communities. *BMJ*, 323, 1103-1105.
- Fairclough, N., J. Mouldering & R. Wodak (2011). Chapter 17: Critical Discourse Analysis. In T. Van Dijk (Ed.), *Discourse Studies: A Multidisciplinary Introduction* (pp. 357-378). Thousand Oaks, CA, USA: SAGE.
- Feinstein, A. (1994). Clinical Judgement Revisited: The Distraction of Qualitative Methods. *Perspective*, 799-805.
- Ferguson, T. M. (2007). *e-Patients: how they can help us heal healthcare*. Retrieved August 25, 2012, from e-patients: <http://www.e-patients.net>.

- Foucault, M. (1973). *The Birth of the Clinic*. (R. D. Laing, Ed., & A. M. Smith, Trans.) New York, New York, USA: Pantheon Books. Kindle Edition.
- Foucault, M. (1984). *The Foucault Reader*. (P. Rainbow, Ed.) New York, New York, USA: Pantheon Books.
- Franks, A. (1995). *The Wounded Storyteller: Body Illness, and Ethics*. Chicago, Illinois, USA: University of Chicago Press. Kindle Edition.
- Frost, J., & Massagli, M. (2009). Patients Like Me: The case for a data-centered patient community and how ALS patients use the community to inform treatment decisions and manage pulmonary health. *Chronic Respiratory Disease*, 225-229.
- Fuchs, C., & Bolin, G. (2012). Introduction to the Special Section: Critical Theory and Political Economy of the Internet. *Triple C: Cognition, Communication and Co-Operation*, 30-32.
- Gayatri, S. A. (2008). Advertising Appeals in Magazines: A Frame Study. *SJSU Scholar Works*.
- Glaser, B. & Straus, A. (1967) *The Discovery of Grounded Theory*. Hawthorne, NY:Aldine.
- Goffman, E. (1961). *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. New York, New York, USA: Anchor Books.
- Goffman, E. (1974). *Frame Analysis*. Boston, MA, USA: Northwestern University Press.

- Goffman, E. (1981). *Forms of Talk*. Philadelphia, PA, USA: University of Pennsylvania Press.
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. New Jersey, USA: Prentice Hall. Kindle Edition.
- Goldstein, D., & Shuman, A. (2012). The Stigmatized Vernacular: Where Reflexivity Meets Untellability. *Journal of Folklore Research*, 49:2, 113-126.
- Good, M. &. (1999). Clinical Narratives and the Study of Contemporary Doctor-Patient Relationships. In G. F. Albrecht (Ed.), *The Handbook of Social Studies in Health and Medicine* (pp. 242-258). London: SAGE.
- Graham, S. S. (2009). Agency and the Rhetoric of Medicine: Biomedical Brain Scans and the Ontology of Fibromyalgia. *Technical Communication Quarterly*, 376-404.
- Greek Texts and Translations*. (2012). Perseus Digital Library at Tufts University.
- Griffin, J. (2011). Double Edged Sword of Communicating via Social Media. *Journal of Chartered Secretaries, Australia*, 659 - 663.
- Griffiths, F., J. Cave, F., Boardman, F., Ren, J., Pawlikowska, T., Ball, R., Clarke, A. & Cohen, A. (2012). Social networks – The future for health care delivery. *Social Science & Medicine*, 2233-2241.
- Heritage, J., & Maynard, D. (Eds.). (2006). *Communication in Medical Care: Interaction between Primary Care Physicians and Patients*. Cambridge, United Kingdom: Cambridge University Press.

- Herrick, J. A. (2009). *The History and Theory of Rhetoric: An Introduction*. (J. Zalesky, Ed.) Boston: Pearson.
- Hess, R. D., Jo Ann Weinland, M. C., & Kelly Beebe, B. R. (2012). I Am Not Alone: A Survey of Women With Peripartum Cardiomyopathy and Their Participation in an Online Support Group. *CIN: Computers, Informatics, Nursing*, 215 - 221.
- History*. (2012, June 15). Retrieved August 25, 2012, from The New York Academy of Medicine: <http://www.nyam.org/about-us/history/>.
- Jaworski, A., & Coupland, N. (2008). Introduction: Perspectives on Discourse Analysis. In A. Jaworski, & N. Coupland (Eds.), *The Discourse Reader* (2nd ed., pp. 2-37). New York, New York, US: Routledge.
- Kangas, I. (2002). Lay and Expert: Illness Knowledge Constructions in the Sociology of Health and Illness. *Health*, 301 - 306.
- Keller, B., Labrique, A., Kriti, M.J., Pekosz, A., & Levine, O. (2014) Mind the Gap: Social Media Engagement by Public Health Researchers. *Journal of Medical Internet Research*.
- Kielmann, T., Huby, G., Powell, A., Sheikh, A., & David Price, S. W. (2010). From Support to Boundary: A Qualitative Study of the Border Between Self-Care and Professional Care. *Patient Education and Counseling*, 55-61.
- Kietzmann, J., Silverstre, B. S., McCarthy, I. I., & Pitt, L. (2012). Unpacking the Social Media Phenomenon: Towards a Research Agenda. *Journal of Public Affairs* .

- Kleinman, A. M. (1988). *The Illness Narratives: Suffering, Healing and the Human Condition*. New York, New York, USA: Basic Books. Kindle Edition.
- Krupa, C. (2012, February 13). *AMA Association*. Retrieved August 25, 2012, from Amednews.com: <http://www.ama-assn.org/amednews/2012/02/13/hlsa0213.htm>.
- Labov, W. (2008). The Transformation of Experience in Narrative. In A. Jaworski, & N. Coupland (Eds.), *The Discourse Reader* (pp. 218-226). New York, New York, US: Routledge.
- Lorber, J., & Moore, L. J. (2002). *Gender and the Social Construction of Illness* (2nd ed.). (B. R. Judith Howard, Ed.) New York, New York, USA: Alta Mira Press.
- Magnussen, L., Hanson, E., & Borg, M. (2004). A Literature Review Study of Information and Communication Technology as Support for Frail Older People Living at Home and their Family Carers. *Technology and Disability*, 223-235.
- Mann, C. &. (2000). *Internet Communication and Qualitative Research: A Handbook for Researching Online*. London: Sage.
- Markham, A., & Buchanan, E. (2012, August). *Ethical Decision Making and Internet Research: Version 2.0*. Retrieved 2013, from Association of Internet Researchers: <http://aoir.org/>.
- Mills, S. (2004). *Discourse*. New York, New York, USA: Routledge.
- Monsted, T. M. (2011). The Use of Narratives in Medical Work: A Field Study of Physician-Patient Consultations. In S. B. Bodker (Ed.), *Proceedings of the 12th*

- European Conference on Computer Supported Cooperative Work* (pp. 81-100).  
Denmark: Springer.
- Murphy, J. C.-S. (2001). The Quality of Physician Patient Relationships. *The Journal of Family Practice*, 50 (2), 123-129.
- Nguyen, H. e. (2004). Internet-Based Patient Education and Support Interventions: A Review of Evaluation Studies and Directions for Future Research. *Computers in Biology and Medicine*, 95-112.
- Nimrod, G. (2012, 6). Membership Lifecycle in Online Social Groups. *International Journal of Communication*, 1245-1261.
- Ouellete, D. M., & Annie Harrington, M. (2013, January 18). *Pulmonary Embolism*. (M. Zab Mosenifar, Editor) Retrieved August 25, 2012, from Medscape Reference:  
<http://emedicine.medscape.com/article/300901-overview>.
- Owen, J., Goldstein, M. S., Lee, J. H., Breen, N., & Rowland, J. H. (2010). Use of Health Related Online Support Groups: Population Data from California Health Interview Survey Complimentary and Alternative Medicine Study. *Journal of Computer Mediated Communication* .
- Pagani, M., Hofaker, C. F., & Goldsmith, R. E. (2011). The Influence of Personality on Active and Passive Use of Social Networking Sites. *Psychology and Marketing*, 441-456.

- Peräkylä, A. (2005). Analyzing Talk and Text. In N. K. Denzin (Ed.), *The SAGE Handbook of Qualitative Research* (pp. 869-886). Thousand Oaks, California, USA: SAGE.
- Peters, A., & Gillette, D. J. (2012). Health Professional Narratives and the Patient: An Analysis of Meaning in Online Medical Blogs. *2nd Global Conference: The Patient* (pp. 1-12). Prague: Inter-disciplinary.net.
- Phoenix, K. H., & Coulson, N. S. (2011). Developing a Model for Online Support Group Use, Empowering Processes and Psychosocial Outcomes for Individuals Living with HIV/AIDS. *Psychology and Health*, 1-15.
- Pitts, V. (2004). Illness and Internet Empowerment: Writing and Reading Breast Cancer in Cyberspace. *health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 35-58.
- Poulsen, S., Hvitfeldt, N. K., Moller, J., Knudsen, T., & Frandsen, J. L. (2011). Clinical Outcome of Patients With Suspected Pulmonary Embolism: A Follow-Up Study of 588 Consecutive Patients. *Journal of Internal Medicine*, 137-143.
- Powell, J. A., Darvell, M., & Gray, J. A. (2003). The doctor, the patient and the world-wide web: how the internet is changing healthcare. *Journal of the Royal Society of Medicine*, 74-76.
- Pulmonary Embolism Awareness Group. (2013). *Facebook*.
- Pulmonary Embolism Awareness Project Group. (2013). *Facebook*.
- Pulmonary Embolism Survivors Group. (2013). *Facebook*.

- Raskob, G., Silverstein, R., Brattler, D., Heit, J., and White, R. (2010) Surveillance for Deep Vein Thrombosis and Pulmonary Embolism: Recommendations for a National Workshop. *American Journal of Preventive Medicine*, S502-S509.
- Reissman, C. K. (1993). *Narrative Analysis*. Thousand Oaks, CA, US: SAGE.
- Robardet, C. (2011). Data Mining Techniques for Communities' Detection in Dynamic Social Networks. In B. K. Daniel, & B. K. Daniel (Ed.), *Handbook of Research Methods and Techniques for Studying Virtual Communities: Paradigms and Phenomena* (pp. 88-102). Hershey, PA, US: IGI Global.
- Roundtree, A., Dorsten, A., & Reif, J. J. (2011). Improving Patient Activation in Crisis and Chronic Care Through Rhetorical Approaches to New Media Technologies. *Poroi*, 1-15.
- Santos, M. (2011). How the Internet Saved My Daughter and How Social Media Saved My Family. *Kairos: A Journal of Rhetoric, Technology, and Pedagogy*.
- Seale, C., Ziebland, S., & Chateris-Black, J. (2006). Gender, Cancer Experience, and Internet Use: A Comparative Keyword Analysis of Interviews and Online Support Groups. *Social Science and Medicine*, 2577-2590.
- Silverman, David (2011). *Qualitative Communication Methods*. Thousand Oaks, CA, USA: SAGE.
- Smith, J. (2001). *English Paper*. Retrieved 2013, from [www.google.com](http://www.google.com)
- Sontag, S. (1978). *Illness as Metaphor*. New York, New York, USA: Farrar, Straus and Girouy.

- Stoop, A. a. (2004). Using Information Technology for Patient Education: Realizing Surplus Value. *Patient Education and Counseling*, 187-195.
- Sublet, V., Spring, C., & Howard, J. (2011). Does Social Media Improve Communication: Evaluating the NIOSH Science Blog. *American Journal of Industrial Medicine*, 384-394.
- Tannen, D. & C. Wallat (2008). Chapter 24: Interactive Frames and Knowledge Schemas in Interaction: Examples from a Medical Examination Interview. Adam & Jaworski (Ed.), *The Discourse Reader* (2nd ed., pp. 332-348). New York, NY, US: Routledge.
- Tannen, D. (1993). Introduction. In D. Tannen (Ed.), *Framing in Discourse* (pp. 1-13). New York, NY, USA: Oxford University Press.
- Tannen, D., & C. Wallat (1986). *Medical Professionals and Parents: A Linguistic Analysis of Communication Across Contexts*. Cambridge, MA, US: Cambridge University Press.
- Telford, K., Kralick, D., & Koch, T. (2006). Acceptance and Denial-Implications for People Adapting to Chronic Illness: A Literature Review. *Journal of Advanced Nursing*, 55 (4), 457-464.
- Thompson, J. B. (1995). *The Media and Modernity*. California, USA: Stanford University Press.
- Turner, J. & Kelly, B. (2000). Emotional dimensions of chronic disease. *Western Journal of Medicine*, 172 (2), 124-128.

- Vasilev, I., Rogers, A., Sanders, C., Kennedy, A., Blickem, C., Protheroe, J., et al. (2010, October 4). Social networks, social capital and chronic illness self management: a realist. *Chronic Illness* .
- Vitak, J., Ellison, N. B., & Steinfield, C. (2011). The Ties that Bond: Re-Examining the Relationship Between Facebook Use and Bonding Social Capital. *Proceedings of the 44th Hawaiian International Conference on System Sciences*.
- Vygotsky, L. (1978). *Mind and Society*. Cambridge, MA: Harvard University Press.
- Waldron, B. (2012, March). *Patient Education Blog*. Retrieved August 25, 2012, from Clot Connect: <http://patientblog.clotconnect.org/2012/02/28/psychological-impact-of-having-a-blood-clot/#more-1457>.
- Waters, R., Canfield, R. R., Foster, J. M., & Hardy, E. E. (2011). Applying Dialogic Theory to Social Networking Sites: Examining How University Health Centers Convey Health Messages on Facebook. *Journal of Social Marketing*, 211-27.

## APPENDIX A: Survey Introduction

Title of Research Study: Chronic Illness in Virtual Spaces

Principal Investigator: Katrina Hinson

Institution/Department or Division: East Carolina University, English Dept.

Address: 600 Moye Blvd., Brody School of Medicine, 4N – 70, Greenville NC, 27858

Telephone #: 252 – 744 - 2914

---

Date: June 7, 2013

Dear Facebook Group Member:

My name is Katrina Hinson and I am a Ph.D. candidate at East Carolina University. For my dissertation, I am studying virtual support groups created within Facebook for individuals with a diagnosis related to pulmonary emboli, deep vein thrombosis or other clotting disorders. Because you are a participant in a virtual support group, I am inviting you to participate in this research study by completing a survey at [link to survey]. I am also asking for permission to use posts from the virtual support group and for volunteers to participate in follow-up interviews about their experiences in the virtual support group.

The survey instrument should take no more than twenty minutes to complete. There is no compensation for completing the survey. There are no known risks for participating, but you can stop participating at any time if any questions make you feel uncomfortable. All survey responses will be anonymous. You may, however, include your online identifier so that I can contact you for an interview. Additional information about this research and instructions for completing the survey are available on the landing page of the survey at [link again].

Thank you for considering this request to assist me in my research. The information you provide may enable better self-care practices for patients involved in the group and who have or have had a pulmonary embolism, deep vein thrombosis or other clotting disorder. Upon your request, I will provide a copy of the study once it is complete.

If you require additional information or have questions please contact me at the phone number or e-mail address provided below.

Sincerely,

Katrina L. Hinson  
(252)702-2571 or [hinsonka91@students.ecu.edu](mailto:hinsonka91@students.ecu.edu)  
Dr. Donna Kain, Advisor  
(252) 328-6023 or [kaind@ecu.edu](mailto:kaind@ecu.edu)

## **APPENDIX B: Informed Consent to Participate in Research**

Title of Research Study: Chronic Illness in Virtual Spaces  
Principal Investigator: Katrina Hinson  
Institution/Department or Division: East Carolina University, English Department  
Address: 600 Moye Blvd., Brody School of Medicine, 4N-70, Mail Stop 682,  
Greenville, NC 27858  
Telephone #: 252-744-2914

---

Researchers at East Carolina University (ECU) study problems in society, health problems, environmental problems, behavior problems and the human condition. Our goal is to try to find ways to improve the lives of you and others. To do this, we need the help of volunteers who are willing to take part in research.

### **Why is this research being done?**

The purpose of this research is to identify perceptions and attitudes related to chronic illnesses and virtual support groups. The decision to take part in this research is yours to make. By doing this research, we hope to learn how individuals use virtual support groups to inform or shape their coping with chronic illness. We also hope to identify how language is used by individuals within a virtual support to shape their personal identity and self-advocacy.

### **Why am I being invited to take part in this research?**

You are being invited to take part in this research because you participate in an online virtual support group. Please note that this research will be conducted only in English.

### **What will I be asked to do?**

You are being asked to (a) allow permission to collect postings to the online virtual support group to be analyzed by the researcher; (b) complete a survey that contains approximately 50 questions; and (c), if you volunteer, agree to a follow-up interview with the researcher. You may allow me to use posts without completing the survey. You may complete the survey without giving permission for me to collect your posts.

### **Where is the research going to take place and how long will it last?**

The survey will be conducted online. Participants will be sought from 3 separate illness related virtual support groups on Facebook. The survey will be made available online and should take no more than 20 minutes to complete. Follow-up interviews if needed will be conducted at the discretion and availability of the participant. The total amount of time for this research study will be approximately one month.

**Are there reasons I should not take part in this research?**

Interested individuals should not volunteer for this study if they are under the age of 18.

**What other choices do I have if I do not take part in this research?**

You can choose not to participate. Participation is completely voluntary.

**What possible harms or discomforts might I experience if I take part in the research?**

The risks associated with this research are no more than what you would experience in everyday life. If any questions make you uncomfortable, you can skip them or stop the survey at any time.

**What are the possible benefits I may experience from taking part in this research?**

There may be no personal benefit from your participation but the information gained by doing this research may help others in the future. This research might help us learn more about how virtual support groups could be utilized in a manner that enables better health care practices related to chronic illness.

**Will I be paid for taking part in this research?**

We will not pay you for the time you volunteer while being in this study.

**What will it cost me to take part in this research?**

It will not cost you any money to be part of the research.

**Who will know that I took part in this research and learn personal information about me?**

To do this research, ECU and the people and organizations listed below may know that you took part in this research and may see information such as your online identifier and Facebook profile. With your permission, these people may use such information to do this research:

- Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections
- The University & Medical Center Institutional Review Board (UMCIRB) and its staff, who have responsibility for overseeing your welfare during this research, and other ECU staff who oversee this research.

**How will you keep the information you collect about me secure? How long will you keep it?**

All identifying information about you will be removed. You do not have to provide your name or contact information unless you agree to an interview. Every attempt will be made to keep participants anonymous in any publication present or future. Data collected from this research project will be kept on a secured server in a password protected file. Data will be kept for no less than 3 years and no more than 5 years in order to be used with future research projects not part of this current study, in teaching presentations, or in related conference presentations.

**What if I decide I do not want to continue in this research?**

If you decide you no longer want to be in this research after it has already started, you may stop at any time. You will not be penalized or criticized for stopping.

**Who should I contact if I have questions?**

The people conducting this study will be available to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator at 252-702-2571 (days, between 8 A.M. – 5 P.M.). You may also reach the Principal Investigator by email at [hinsonka91@students.ecu.edu](mailto:hinsonka91@students.ecu.edu). If you have questions about your rights as someone taking part in research, you may call the Office for Human Research Integrity (OHRI) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director of the OHRI, at 252-744-1971.

**I have decided I want to take part in this research. What should I do now?**

By clicking the submit button, you agree to the terms of this research study. Clicking submit means that as a participant you agree that:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By agreeing to continue, I am not giving up any of my rights.

**I agree to allow you to use my online posts.** [Yes] [No]

If yes, please provide your Facebook group user name [box for username here]

**I am willing to be interviewed.** [Yes] [No] If yes, please provide your Facebook group user name [box for username here] Click **HERE** to participate in the survey.

## APPENDIX C: Participant Survey Questions

### Survey

1. In thinking about yourself, do you consider yourself healthy or unhealthy? Healthy / Unhealthy . Please elaborate on your response?

2. Do others consider you healthy or unhealthy?  
Healthy / Unhealthy. Please elaborate on your response?

3. Prior to your pulmonary embolism or deep vein thrombosis, did you exercise  
Never                      Somewhat                      Frequently                      Always

4. Post pulmonary embolism or deep vein thrombosis, do you exercise  
Never                      Somewhat                      Frequently                      Always

5. Are you a participant in an health related face-to-face group? Yes/ No.  
If yes, how long:

0 - 2wks    2 wks - 1 month    1 - 3 mos    3 - 6 mos    6 mos - 1year  
1 - 3 years    3 - 5years                      5+ years

6. Are you a participant in an health-related online virtual community through Facebook? Yes or No.

If yes, which of the following groups do you participate in (check all that apply):

Pulmonary Embolism Awareness (PEA);  
Pulmonary Embolism Survivors (PES);  
Pulmonary Embolism Project (PEAP);  
Thrombosis Group (Clots, DVT, PE or Stroke);

None of the above

Other \_\_\_\_\_

7. How long have you been a participant in a health-related online virtual community:

0 - 2wks    2 wks - 1 month    1 - 3 mos    3 - 6 mos    6 mos - 1year

1 - 3 years    3 - 5years    5+ years

8. How active are you within a health-related online community:

Very Active    Often    Somewhat    Never.

9. Having had a pulmonary embolism or deep vein thrombosis event impacts my day-to-day life:

Never    Somewhat    Frequently    Always.

10. Having had a pulmonary embolism or deep vein thrombosis has affected my relationship with family:

Never    Somewhat    Frequently    Always

11. Having had a pulmonary embolism or deep vein thrombosis has affected my relationships at work:

Never    Somewhat    Frequently    Always

12. Having had a pulmonary embolism or deep vein thrombosis has affected my relationships socially:

Never    Somewhat    Frequently    Always

13. Having had a pulmonary embolism or deep vein thrombosis has affected my relationships within my religious community:

Never    Somewhat    Frequently    Always

14. I perceive myself as an individual with a chronic illness:

Never    Somewhat    Frequently    Always

15. Others perceive me as an individual with a chronic illness:

Never                      Somewhat                      Frequently                      Always

16. Do you feel excluded from activities at home as a result of diagnosis of a pulmonary embolism or deep vein thrombosis:

Never                      Somewhat                      Frequently                      Always

17. Do you feel excluded from activities at work as a result of having had a pulmonary embolism or deep vein thrombosis:

Never                      Somewhat                      Frequently                      Always

18. Do you feel excluded from activities within your social face to face community as a result of having had a pulmonary embolism or deep vein thrombosis::

Never                      Somewhat                      Frequently                      Always

19. Do you feel excluded from activities within your religious community as a result of having had a pulmonary embolism or deep vein thrombosis::

Never                      Somewhat                      Frequently                      Always

20. Participation in a health-related virtual community has empowered me (check all that apply):

- At home
- At work
- At school
- In my social community
- In my religious community
- With my health care professionals
- Other: \_\_\_\_\_.

21. Describe your access to competent health care professionals:

Problematic                      Moderate                      Quick                      Very quick

22. How frequently do you seek care for your pulmonary or thrombolytic event:

Annually Bi-annually

Monthly Bi-monthly

Bi-weekly Weekly

23. Which of the following symptoms related to your PE or DVT do you experience.

Select all that apply:

shortness of breath

fatigue

chest pain

pain in your leg

experience anxiety

24. Who do you see most frequently for pulmonary or thrombolytic illness related concerns:

General Practitioner

Family Doctor

Nurse Practitioners

Physician's Assistant

Nurse

Lab Technician

Respiratory therapist

Physical therapist

Occupational therapist

Psychiatrist

Psychologist

Social worker

Counselor

Pulmonologist

Oncologist

Hematologist

Other (Please specify \_\_\_\_\_.)

25. Have you engaged in awareness and prevention as a result of your diagnosis:

Never

Somewhat

Frequently

Always

26. How much do you trust the information you learn as a result of your participation within a health related online community?

Never                      Somewhat                      Frequently                      Always

27. Participation in a health-related online community (check all that apply) :

- helps me cope
- provides encouragement
- leads to friendships
- explains causes and effects of pulmonary or thrombolytic event
- provides answers related to insurance, coding and billing
- validates me as a patient/person
- helps me through the process of applying for or fighting for disability
- provides information related to alternative treatment options
- provides information related to food related concerns
- provides information related to drug related concerns
- provides information related to physical activity changes
- Other \_\_\_\_\_.

28. Participation in a health-related online community provides a non-judgmental audience that listens:

Never                      Somewhat                      Frequently                      Always

29. As a result of your participation in a health-related online community, do you feel more equipped to discuss your health care concerns with a health care professional:

Never                      Somewhat                      Frequently                      Always

30. In the space provided, please include any information you feel is not covered in the questions above.

**Demographic data.**

1. From the list below, please provide your country of origin (US, Canada, Mexico, Great Britain, Scotland, Ireland, Australia, New Zealand....etc.)

2. From the list below, please provide your age range:

Under 18            18-25            25-35            35-45            45-55            55+

3. Male/Female/Other

4. Are you:            Unemployed            Part Time            Full Time

5. If #4 is “Unemployed”, do you receive disability benefits or other governmental assistance? Yes or No

6. If #4 is part time or full time, please provide the number of hours worked. \_\_\_\_\_

7. From the list below, please provide your annual household income (OPTIONAL):

below    \$10,000        \$10,000-20,000        \$20-30,000        \$30-40,000  
          \$40,000-50,000        \$50,000 -60,000        \$60,000-70,000  
          \$ 70,000-80,000 \$80,000-90,000        \$90,000-100,000        \$100,000+

8. Do you have health insurance? Yes/No.

9. Does your employer provide your health insurance? Yes or No.

    If yes, is it a PCP or HMO plan?

10. If, in the US, Do your receive Medicaid or Medicare or Neither?

11. Do you have insurance as part of a national health care program? Yes or No

12. Does your insurance cover referral to a specialist: Yes or No. If yes, which of the specialists below have you been referred to (check all that apply):

- Pulmonologist
- Hematologist
- Pulmonary rehabilitation
- Counseling

13. Where was your first pulmonary or thrombolytic event diagnosed in the:

- Emergency room
- Physician's office
- Other (Please specify)\_\_\_\_\_.

14. Length of time between first event and visit with a pulmonary specialist:

- 0 - 2wks      2wks - 1 month      1-3 mos      3 - 6 mos
- 6 mos - 1yr      1year+

15. How long has it been since your first pulmonary or thrombolytic event?

- 0 - 2wks      2 wks - 1 month      1 - 3 mos      3 - 6 mos      6 mos - 1year
- 1 - 3 years      3 - 5years      5+ years

16. How long has it been since your most recent pulmonary or thrombolytic event?

- 0 - 2wks      2 wks - 1 month      1 - 3 mos      3 - 6 mos      6 mos - 1year
- 1 - 3 years      3 - 5years      5+ years

17. Which of the following explanations was given for the cause of your pulmonary embolism(PE) or deep vein thrombosis (DVT)? You may select more than one.

Factor V Leiden

Deficiencies of natural proteins that prevent clotting

Elevated levels of homocysteine

Elevated levels of fibrinogen or dysfunctional fibrinogen

Elevated levels of factor VIII or other factors including factor IX and XI

Abnormal fibrinolytic system, including hypoplasminogenemia, dysplasminogenemia and elevation in levels of plasminogen activator inhibitor (PAI-1 )

Cancer

Lupus

Multiple Sclerosis

Scleroderma

Recent trauma or surgery

Obesity

Pregnancy

Birth Control Pills

Hormone replacement therapy

Prolonged bed rest or immobility

Heart attack, congestive heart failure, stroke and other illnesses that lead to decreased activity

Lengthy airplane travel, also known as "economy class syndrome"

Antiphospholipid antibody syndrome

Previous history of deep vein thrombosis or pulmonary embolism

Unspecified Autoimmune Disorder

OTHER: \_\_\_\_\_



## APPENDIX D: Interview Questions

Possible interview questions could be related to the participant in the virtual support group. Open ended interview questions allow for the participant to reflect on his or her experiences within the group(s) and as a result, this may lead to additional questions, not listed below.

1. How did you first find out about the virtual support communities related to pulmonary and thrombolytic events?
2. Why did you first become involved with the (name(s) of virtual support groups here)?
3. If you were going to describe the name(s) of virtual support groups here) to someone else who was considering joining, how would you describe the group?
4. Has being a member of a virtual support community provided positive results for you and if so, will you elaborate?
5. Has being a member of a virtual support community had negative results for you and if so, will you elaborate?
6. What do you feel you have contributed to the group(s)?
7. What kind of information do you seek most frequently from the virtual support group? Have you shared this information with others? If so, who and how did others react? Can you recall an incident that you can share with me?
8. Do you feel that health care practitioners could benefit from being a part of the virtual support groups related to pulmonary embolism or DVT? What would they gain from the group and what could they bring to the group?

