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Performing Narrative Medicine: Understanding Familial Chronic Illness through Performance

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Performing Narrative Medicine: Understanding Familial Chronic Illness through Performance

by

Alyse Keller

A dissertation submitted in partial fulfillment
of the requirements for the degree of
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Department of Communication
College of Arts and Sciences
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DEDICATION

For my grandma, Jean Keller. The original funny girl.
We keep laughing thanks to you.

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Thank you to my committee members Chris, Carolyn, Sara and Lori for helping me realize my own capabilities and guiding me through this long, long journey. To Heidi, thank you for introducing me to this crazy academic world as a mere undergraduate. And most of all, thank you Chris for seeing in me the potential I couldn't see in myself, for lending a 'front row' office seat when I needed it, and for sending me reminders that this dissertation would/must come to an end—it's over!!

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TABLE OF CONTENTS

Abstract.....	iii
Chapter One: Introduction.....	1
Rationale.....	7
Chapters.....	10
Chapter Two: Framing my Performance of Narrative Medicine: Theoretical Commitments and Contextual Literatures.....	13
Theoretical Commitments.....	14
Models for Understanding Disability.....	15
Medical Model of Disability.....	16
Social Model of Disability.....	18
Cultural Model of Disability.....	20
Contextual Literatures.....	22
Chronic Illness and Disability in Families.....	22
Performing Family Illness Narratives.....	26
Narrative Medicine.....	30
Performing Narrative Medicine.....	34
Chapter Three: Creating and Questioning: Introduction to Method and Ethical Considerations..	37
Performance Ethnography.....	39
Ethical Considerations: A Practice of Reflexivity.....	42
Performance as Process.....	45
Questions and Purpose.....	47
Chapter Four: Laughing with you Always: Humor as Narrative Medicine.....	53
Interviews.....	55
The Cast of Characters.....	60
Denise Keller.....	61
Jana Keller.....	61
Barbara Keller Yendall.....	62
Loren Keller.....	62
Robert Keller.....	63
Kathy Keller Otto.....	64
Jim Keller.....	64
Alyse Keller.....	65
Humor and Family Communication.....	69
Disability Humor.....	71
Theories of Humor.....	72
Humors as Reframing.....	75

Humor as Resistance.....	77
Humor as Relief.....	81
Humor as Relational.....	83
Humor as Narrative Medicine.....	86
Chapter Five: Rehearsal and Production: Performance as Narrative Medicine.....	91
An Ethnographic Exploration of a Performance Ethnography.....	93
Choosing Narratives.....	98
Rehearsal and Production.....	101
Everyday Life Performance and Performance Art.....	105
Close Reading and Creativity.....	108
Intersubjectivity and Relationality.....	115
Embodiment and Personhood.....	122
Performing Narrative Medicine: A Heuristic for Families Living with Chronic Illness.....	130
Chapter Six: Imagination First: Conclusion and Contributions.....	133
Understanding Performing Narrative Medicine.....	136
Aesthetic Action Toward Justice.....	140
Performing Narrative Medicine for Me.....	141
References.....	144
Appendix A.....	155

ABSTRACT

This study presents the process of creating a performance ethnography of my family's narratives about familial chronic illness and disability. I label this process *performing narrative medicine*. By documenting and granularly analyzing the process of my performance ethnography, the following chapters provide a step-by-step discussion of how families communicate about chronic illness/disability through storytelling and humor, and how/what performance does as a method, metaphor and object of study to further our current communicative practices and understandings of chronic illness and disability in families. I argue that *performing narrative medicine* is a heuristic for families living with chronic illness and disability, and a method that may be used and applied outside the context of my own family.

The chapters in my dissertation directly address the following questions: How does my performance work as embodied knowledge to gain greater understanding of the lived experience of familial disability/chronic illness? How does the use of humor as a communicative construct, and performance ethnography work as a practice of “performing narrative medicine?” What are our scholarly stakes in performing narrative? How too might binding narrative medicine to performance inform how we do qualitative research? How do the respective motions of narrative medicine and research practices/principles of performance ethnography converge and cross-fertilize each other? Does a work like narrative medicine endow storytelling and performance with a consequentiality?

This performance ethnography of familial disability and chronic illness contributes to understandings of families dealing with chronic illness/disability, extends narrative medicine as a

theoretical construct, and speaks to a long tradition of the practice of performance ethnography. Overall, *performing narrative medicine* reveals the underlying communication competencies at work in families living with chronic illness and disability. Through the use of humor and performance as a communication practice, I reveal the power of empathy. The power in realizing our own human capacities to relate to one another across differences, and continue the work of “living well.” This dissertation emphasizes the power of performance to constitute alternative ways of performing and understanding familial chronic illness, by emphasizing the work of creating, implementing and studying performance.

CHAPTER ONE:

INTRODUCTION

If we accept the notion of human beings as homo performans, and therefore as a performing species, performance becomes necessary for survival
-Madison (2005, p. 149)

They say she is sick, weak. She says that her body is different from yours. So, you come to know her body as different from your own. Because she says so. Because everyone says so. Everyone says so because your mother and grandmother are/were afflicted with Multiple Sclerosis.

Multiple Sclerosis is a chronic autoimmune disease that attacks the central nervous system and often manifests itself as a physical disability. Approximately 400,000 Americans and nearly 2.5 million people worldwide suffer from it (Hoops, 2008; Olsson, Lexell, & Soderberg, 2008). MS is an incurable chronic illness with symptoms such as visual loss, cognitive impairment, lack of coordination, fatigue, and diminished ability to walk (Olsson et al., 2008). Yet to reduce MS to a list of symptoms and statistics doesn't do its extensive impact justice. In this dissertation, I look at how MS impacts families by studying and performing the narratives told by my family members, all of whom have had a mother with MS.

I frame my dissertation as a project of *performing narrative medicine*. My dissertation documents the step-by-step process of creating, rehearsing and producing my performance of family and personal narratives. The project works to “promote complex knowledge of disability [and chronic illness] as a valued element of human diversity” (Jarman, Monaghan, & Harkin,

2017, p. 6), and a valued element of my family's experience. My performance is a heuristic, a way to create meaning and understanding for families living with chronic illness and disability.

"Can you find my perfume and spritz a little on me, honey?" my mother slurs, each laborious word harder to produce than the next. Her left hand lies shriveled next to her against the sterile white sheets. Her frail body, thin and limp, disappears beneath the covers.

I begin to search the drawers of the plastic oak night table, nestled against the hospital bed. Her shared room is divided by a flimsy off-white cloth, separating her from Janice, a stroke victim snoring a mere three feet away. The television quietly buzzes with the monotonous sounds of "Jeopardy," or "Wheel-of-Fortune," or "The Price is Right," drowning out the moans of patients in surrounding rooms.

She's here because they don't know why, she's here because they never seem to know why or when or how. They, being the doctors. They, being our family. We are at a loss for how this happened and how this same thing happened to my grandmother. Urinary tract infection is what they say, but how did we not find this out until now? Why did my mother wait so long to tell anyone? Why did my father wait so long to take her to the hospital? Why did I wait this long to visit her?

It was a brief phone call four weeks prior. My sister's voice timidly emerges on the other end of the line.

"I'm scared."

I don't respond immediately. We sit in silence. I know I shouldn't agree, but I do. I'm scared too. Too scared to tell her. This is the first time my sister and I acknowledge the gravity of

our mother's situation. My mother was diagnosed with MS before I was born, but now, 30 years after her diagnosis, it feels like for the first time in our lives the disease is winning. For nearly two weeks now, our mother has been hospitalized. The doctors claim it's a urinary tract infection, but no one is communicating with us or with each other very well. All we know is our mother can't walk, can barely talk and is stuck in a hospital room with no end in sight.

I finally reply with trepidation, "I know. I'm scared too."

"I found it," I proclaim. I bring the perfume to her, spritzing her wrists. The aroma of my mother's perfume wafts around me, scarcely masking the scent of urine that fills the space. Urine is a scent I all too often associate with this disease. They say sense of smell is the strongest indication of memories.

I remember back to my grandmother's nursing home. It always smelled of urine. Urine and processed food products. My grandmother's room was sandwiched between the room of a woman whose toothless, despondent smile haunted me every visit, and one in which a gentleman screamed for his family every few hours.

We turn the corner into her room, my sister and I clasping my father's hands tightly. She waves at us, her tiny wrists twirling around motioning for us to enter. As she struggles to pull her upper body erect, her linen white hair remains matted to the back of her head and her oval glasses fall onto the bridge of her nose. We march in, filling the corners of her tiny living quarters, with one window and an off-white curtain to feign a sense of privacy. As usual, her television is humming, tuned into "Jeopardy," or "Wheel-of-Fortune," or "The Price is Right."

She speaks slowly, each word strung together in one long slur, "Hi girlllsss."

My body tenses up. I never feel comfortable around my grandmother. People talk to her differently. Treat her differently. So, I speak to her differently. Slowly. More methodically. Distanced and tentative to get too close. My gaze is curiously fixed on her motionless body beneath the covers. My sister and I respond reluctantly in unison, "Hi Grandma."

As I begin this project, I am cognizant of the fact that this is a story about my family, my mother, my grandmother, and all our experiences with Multiple Sclerosis. At the center of all my family's narratives are two women who I hope you get to know better by the end of this project. They are two women I hope I get to know better by the end too.

My mother, Denise Keller, is cool. I am fairly convinced that she is, in fact, the true hipster of our generation. Moreover, I am not particularly biased. I spent years, I mean years, of my angst-ridden adolescence in total opposition to her. Puberty made us mortal enemies. So why say she is cool? Aside from her ability to bleed both sass and compassion at the same time, she is the most authentic human you will ever meet. She wakes up every morning, no matter how she feels that day, dresses in trendy shirts, with yoga pants, and color coordinated earrings, rings, bracelets and necklace sets because she will show up that day. She will keep doing what makes her happy. She could care less if you're not interested in her. She's smart, funny and self-deprecating.

She also happens to have Multiple Sclerosis, a disease I accuse of dimming her feisty Bronx attitude. A disease I blame for keeping her from dancing her heart out and being the mother she wants to be. But as her body and mind degenerate with this illness, she/we as a family adapt to a new normal. We become used to constantly changing, ever shifting norms. And still, she remains cool as a cucumber.

My father also had a cool mom. A mom described by her children as “an exceptional mother.” A mother whose children chose to hang out with her on Friday nights instead of going out with their friends. A mother who was the fun mom on the block. A mother they each had undying respect for and didn't want to disappoint or let down. She was described by each of her children as one of the funniest people they knew and their best friend.

My father's mother also had Multiple Sclerosis. A disease which eventually took her life far too young, and far too soon. A disease which influenced my perception of her. She was foreign to us, someone my sister and I didn't know and frankly never came to know during her lifetime. It wasn't until the stories my family told about her, after her death, that I learned about my grandmother, a woman that was so much more than her disease.

When my mother and grandmother became prisoners in their bodies, they also became prisoners to the stories told by, and especially about them. MS marked my mother and grandmother as aberrant. I saw how people communicated and treated them differently as their bodies became less able. I saw how chronic illness and disability permeated their perceptions of themselves and my perception of them. I saw how my family became hostage to similar disabling narratives of illness and disability. But I have also witnessed how my family uses storytelling to escape prescriptive narratives as well.

My family has always communicated by telling stories. We are a family who breaks into song and dance at the dinner table and who tells the same stories repeatedly every Christmas. We're a family who uses humor to poke fun at ourselves, each other, and our situation. I recognize performance and narrative theory as a fundamental and important entry point for my project because storytelling is an integral component of the way my family communicates and interacts. In the same way disability and chronic illness are just one “way of being” in the world,

I contend performance and narrative theory provide just one way of seeing disability and chronic illness differently.

Life with illness is frustrating. It is frustrating for my mother and grandmother, and it is frustrating for our family. Communicating about and through everyday experiences of living with chronic illness and disability has been a challenge for my family, and I imagine a challenge for many others. The experience is hard to explain and hard to reduce to a two-sentence elevator speech when people ask in a dejected tone, "How is your mother doing? How is your family doing?"

Ultimately, as a communication/performance studies scholar, and someone with several family members with Multiple Sclerosis, I engage with performance and narrative theory in this project because, as Ellis (2000) states, "[arts-based forms of research] open important avenues to exploring the intricacies of intimate communication that are left out or ignored in most social science research" (p. 287). Performance allows access to embodied knowledge of disability and illness for me and my audiences.

In my dissertation, I draw on disability, health communication, family communication, narrative medicine, and performance studies literature to interrogate how our communicative practices, metaphors, identities, and societal (mis)understandings influence the lived experience of disability in families (Harter, Scott, Novak, Leeman, & Morris, 2006). By documenting and showcasing the ethnographic performance of my family, and putting a reconceptualization of Langellier's (2009) "performing narrative medicine" into practice, I highlight the power of performance and storytelling to constitute alternative ways of performing and understanding chronic illness in families for myself and for others. I argue that *performing narrative medicine*

is a heuristic for families living with chronic illness and disability, and a method that may be used/applied beyond the context of my own family.

And so, this is where my dissertation story begins.

Rationale

In my dissertation, I gain an embodied understanding of disability and chronic illness in family systems through the method of performance ethnography. Performance, as a process and an aesthetic text, possesses the ability to “explain human action, and how people communicate with themselves and others” (Pelias & Shafer, 2007, p. 5). I interrogate how my family’s communication and the performative rendering of such communication, influences my lived and learned experience of familial chronic illness and disability.

Performance is the catalyst for this dissertation because of my firm conviction that performance, in all its iterations, possesses the potential for change and reflexivity. Through the performance of my family members’ narratives and the replication of their language and actions, I engage with questions such as, “Could language also be a photograph of what was unseen about society just as it reflects what is unseen in an individual? Does the inability to empathize start with an inhibition, or a reluctance to see? Does prejudice instruct those inhibitions?” (Smith, 1993, p. xxxiii). And furthermore, how do these words force me to see things I might not have otherwise?

My emphasis on the process of creating performance ethnography is a move away from privileging the product of performance and instead places the focus on the process of creating, rehearsing and implementing as a mode of inquiry. This is important because the labor and work that goes into creating a performance constitutes ways of knowing and understanding that are often neglected and unaccounted for in research. My performance functions as a step-by-step

process of seeing and unseeing. It is about seeing and unseeing chronic illness and disability at an explicitly individual and implicitly societal level. It is about seeing and unseeing how cultural and social constructions of illness, disability, and disease can be reified but also challenged through our familial communication practices.

Madison's (2005) "performance of possibilities" is defined as a staged, cultural performance which is an:

Active, creative work that weaves the life of the mind with being mindful of life, of merging the text with the world, of critically traversing the margin and the center, and of opening more and different paths for enlivening relations and spaces. (p. 172)

I develop a performance of my family's narratives with these possibilities in mind. My performance ethnography highlights how chronic illness and disability is understood and reproduced in families through narrative storytelling. I claim that the experience of illness is felt not just by a single body; it is a communal experience which influences the entire family structure. The performance of my family narratives provides the space to counter/critique/extend and challenge my own and other's understandings of disability and chronic illness.

Performance opens conversations with audience members outside my lived experience and provides a space for me, as performer, to create new understanding or meaning for my own experience. Jarman et al. (2017) discuss *radical belonging*, the idea that we should make experiences public in order to create understanding across difference. So rather than families experiencing chronic illness and disability in isolation, performance can create community. I believe that performing and showcasing the narratives and lived experiences of my family creates a space of belonging. I reimagine my own family through performing family narratives; through performing narrative medicine.

In accord with Huber and McRae (2014), I am "committed to engaging in performance as a means of coming to understand the ways our communicative practices are always marked by culture, power, and ideology...[and] engaging in performance [is] a means of transforming the ways we communicate and move through the world" (p. 266).

Performance theory asserts "three indispensables of performance" (Conquergood, 1985, p. 10), which include "energy, imagination, and courage." These three indispensables are arguably essential tools for "intercultural understanding:"

Scholars need energy to gather enough information to create full portraits. They need imagination to enter between facts, to feel what it is like to be, to think, and act as another person. They need courage to face alternatives, comparing different experiences to help their fellows locate themselves. (Conquergood, 1985, p. 10)

I unite these indispensables of performance and the theoretical underpinnings of narrative medicine to bring together two seemingly disparate conversations. I show through my dissertation how uniting these two conversations can also enhance understandings of families living with chronic illness/disability. I do this by creating a performance of narrative medicine to show how performance theory and medical theory can unite to create understandings about families living with chronic illness/disability. Ultimately, I show on the page and the stage what performing narrative medicine is and means.

The chapters in my dissertation directly address the following questions: How does my performance work as embodied knowledge to gain greater understanding of the lived experience of familial disability/chronic illness? How does the use of humor as a communicative construct, and performance ethnography work as a practice of "performing narrative medicine?" What are our scholarly stakes in performing narrative? How too might binding narrative medicine to

performance inform how we do qualitative research? How do the respective motions of narrative medicine and research practices/principles of performance ethnography converge and cross-fertilize each other? Does a work like narrative medicine endow storytelling and performance with a consequentiality? (Charon et al., 2016; Langellier, 2009).

By documenting and granularly analyzing the process of my performance ethnography, the following chapters provide a step-by-step exploration of how families communicate about chronic illness/disability through storytelling and humor, and how/what performance does as a method, metaphor and object of study to further our current communicative practices and understandings of chronic illness and disability in families. This performance ethnography of familial disability and chronic illness will contribute to understandings of families dealing with chronic illness/disability, extend narrative medicine as a theoretical construct, and speak to a long tradition of the practice of performance ethnography. This dissertation emphasizes the power of performance to constitute alternative ways of performing family, by emphasizing the work of creating, implementing and studying performance.

Chapters

In the next chapter I review my theoretical commitments and the contextualizing literature for this dissertation. I discuss and cover scholarship on disability and chronic illness, family communication, humor and disability, performance and storytelling and narrative medicine. I make a case for my project's relevance in the fields of disability studies, narrative medicine, family communication, health communication, and performance studies. The chapter provides a framework and foundation for the conversation that my study will enter and advance.

My third chapter introduces my method of performance ethnography, as well as the ethical questions and concerns that may arise, guided by Conquergood's (1985) ethical pitfalls of

performance. I begin outlining my performance process by discussing my experiences creating questions and a purpose for my overall performances.

The fourth chapter serves as an account of how humor functions as narrative medicine for my family. I start with an explanation of the “cast of characters” that are featured in this dissertation project as well as my performance. I analyze narratives derived from my “participant observation” and interviews I conducted with all my family members. I use theories of disability humor to understand my family’s communication and how this eventually translates into a performance. This chapter continues to illustrate my process of creating and performing narrative medicine and provides the background for why I ultimately chose the humorous narratives I did for my performances.

In the fifth chapter, I illustrate the process of crafting and embodying my performance script and an analysis of this process. I argue for what Pineau (1995) calls “production as research,” and make a case for using my production, the process, and performance itself, as research. This chapter narrates choices I make throughout the iterative process of embodiment and writing, and since my performance script has gone through many different drafts and presentations, I show how and why those changes occur. I demonstrate this by creating a “performance on the page” and an aesthetic rendering of these changes. I discuss and continue to analyze the rehearsal and production process. Ultimately, I perform on the page what I work to perform on the stage.

In the sixth and final chapter, I provide a conclusion and accompanying contributions of my dissertation project. I discuss how my performance ethnography contributes, adds to, and extends what we know about performance ethnography, narrative medicine, and current literature on disability and chronic illness in families. This chapter also culminates in a section

on contributions to the field and how I (re)conceptualize the idea of “performing narrative medicine.”

This dissertation reimagines how families can look, feel, and be. But most of all, I am passionate about how this performance dissertation project opens conversations for my family and me about how MS has impacted our family unit. I view the performance of family storytelling as just one way of “doing family” that allows me access to the nuances and ways chronic illness has shaped my family. I end this project with a personal narrative, similar to how I began, to show how this process has transformed my understandings of this disease, and my family, as well as how this project might continue beyond the page and stage. In sum, as Arthur Frank (2013) states, this dissertation is "a project of living differently" (p. 187).

CHAPTER TWO:

FRAMING MY PERFORMANCE OF NARRATIVE MEDICINE:

THEORETICAL COMMITMENTS AND CONTEXTUAL LITERATURES

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place

-Sontag (1978, p. 3)

It was the first day of fall in Florida.

Each year there is one day in Florida where autumn finally arrives. It's not quite as drastic as the seasonal change in the Northeast, where temperatures suddenly drop and foliage reveals itself through the gradient reds, browns, and yellows. Rather it's very discrete. It's a subtle drop in temperature, a light breeze in the air, a slight relief from humidity. You can feel it creeping for weeks. The winds start to kick in, the cloud formations are less ominous and dreary. Without notice, you wake up one morning and step outside, and things have changed.

I received a curt but panicked text from my father reading, "I'm quite upset right now as some members of our family informed me that I can't drop mommy off anymore. They can't handle it." I picked up the phone and immediately dialed my father. He spoke quickly, without much break between thoughts.

"They said they can't watch your mother anymore. 'Watch' is the language they used. Your mother answered their call and they asked to speak with me, as if your mother has no voice or ability to speak for herself. I had a pit in my stomach because I knew what was coming. I knew they were going to give me bad news."

“What did you say back to them?” I reply, with shock and concern in my voice.

“I said, ‘Okay’ and hung up,” he defeatedly states.

I’m angered by the level of selfishness in my own family. I’m mad for my mother whose entire adult existence has been dictated by this disease and the mandates of other people who think they understand her illness better than she does. I’m mad for my father, who is my hero. I’m selfishly anxious that I act as an intermediary because I realize I am not ready for this change to come. I act as an intermediary between the illness and my family, between my family members, and frankly an intermediary with myself. Because, sometimes you’re not as ready as you think.

He cries into the phone and the other end of the line cuts off.

Subtle or not, this is a shift.

Fall has crept up on us without warning.

Theoretical Commitments

I understand theory as the tool I, as researcher and performer, use to illuminate social and communication phenomena. It guides the questions I ask, the arguments I make, and becomes the underlying framework for my project. I employ disability and performance theory to understand how disability and chronic illness function in families. I am reliant on these epistemologies because I commit myself to the idea, first proffered by Henderson and Ostrander (2008), that "disability studies is always in some sense a form of performance studies...but... that all performance studies is a form of disability studies" (p. 2).

To understand how seemingly unrelated disciplines are, in fact, theoretically interdependent, I first outline how various models for understanding disability inform this dissertation project. I then situate my project within several relevant bodies of literature, and

conclude with a focus on performance and narrative medicine as necessary theoretical and methodological approaches for this project.

Models for Understanding Disability

MS is discussed and defined in disability studies literature as both a chronic illness and disability (Berger, 2013; Wendell, 2001). As a discipline, disability studies works to address the social barriers that perpetuate negative stereotypes of people with disabilities (PWD) and to gain equity for PWD. Disability studies is concerned with the embodiment of difference, and reframes disability as a "byproduct of social, environmental and biological forces" (UIC Department of Disability and Human Development, 2015), or something that is constructed rather innate. The goal of communication scholars studying disability is then to focus on how the lived physical and material experiences of PWD are constituted through communicative and discursive actions and policies. I explore how families contribute to and challenge this construction and meaning-making through family narratives and the (re)performed iterations of these narratives.

I deliberately define chronic illness as a category of disability. This is often-contested in disability studies literature, since "identifying disability with illness fosters the myth that people with disabilities are globally incapacitated, which in turn contributes to the social devaluation of disabled people" (Wendell, 2001, p. 17). This tension exists because the very essence of chronic illness is in direct contrast to the underlying intentions of the disability rights movement, "which seeks to mark systems of oppression as the problem, not individual bodies" (Wendell, 2001, p. 18).

The experience of chronic illness must consider individual bodies because undeniably, chronic illness is very much a lived experience in which people can have both physical/cognitive malformities and be severely sick. It is important then to categorize chronic illness as disability,

so those with disabilities due to chronic illness can still benefit from the support of the disability rights community, a community working to mobilize equality, resources, and rights for people with disabilities.

The disabled body is the central focus of disability rights movements. Disability studies scholars, such as Davis (2006), encourage us to rethink and create alternate readings of the disabled body, compelling those with and without disabilities to understand the world through the point of view of disability. This disability studies consciousness “is a lens through which ideas, individuals, and relationships are newly viewed” (Katzenstein, 1987, p. 8). I understand chronic illnesses as not merely suffering from pain, but rather as unique ways of living in the world. Unfortunately, MS is viewed as abnormal because of its status as a disability and is often framed through master medical narratives which seek to cure disability, rather than find ways to make it a “normal” societal experience.

Medical Model of Disability

A master or grand narrative is defined as a totalizing narrative which provides universal order to lived experiences (Lyotard, 1984). Meta- or master narratives are woven into the fabric of society and become constitutive of dominant discourse about disability. Narrative scholars argue that all social structures can be conceived of as narrative threads of this broad discursive form (Harter et al., 2006; Tracy, 2004). Langellier (2009) believes that “when we make and do stories, we “make do” with what is available, legible, intelligible” (p. 153). Master narratives become what we ‘make do’ with, while inadvertently ignoring local and diverse experiences and stories. The lack of personal stories about chronic illness and disability in dominant discourse, are examples of this inadvertent ignorance.

The medical model of disability is a master narrative that reduces disability to impairment and calls for medical treatment to normalize patients (Grue, 2011). Impairment is defined as “the physiological loss of physical, sensory, or cognitive function” (Berger, 2013, p. 145), whereas disability is defined as “the inability to perform a personal or socially necessary task because of impairment or the societal reaction to it” (Berger, 2013, p. 145). Historically, people with disabilities were condemned as “bad luck” (Berger, 2013), or placed on display in freak shows or circuses. The medical model was originally developed as a response to the stigmatizing mistreatment of PWD, an attempt to humanize the experience of PWD and provide a definitive medical diagnosis. Though the intentions of the medical model were good, ultimately it still frames PWD as social burdens or outcasts. Through the use of referential language such as “cripple,” “retarded,” and “handicapped,” the medical model of disability becomes a prominent model used to describe, define, and label PWD based solely on impairment.

When we assign only medical meanings to a disability, we lose sight of the person behind the disability. Per Linton (2006), “the medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit...rather than ‘treating’ the social processes and policies that constrict disabled people’s lives” (p. 162). We end up treating individual medical concerns, as opposed to the social processes that have created disenfranchisement for PWD. For instance, doctors treat incontinence, a major symptom of MS, through prescription drugs. This is crucial since incontinence causes UTI's and can lead to further systemic infections, or even death.

When we focus solely on individual medical concerns though, we then forget to address social barriers such as inaccessible or handicapped accessible bathrooms, which are an essential

part of being able to easily relieve oneself. Thus, the medical model becomes a major setback for the disability community.

Social Model of Disability

In response to the rampant medicalization of disability, a variety of models were created to destabilize the hegemonic force of "normal" and "institute alternative ways of thinking about the 'abnormal'" (Davis, 2006, p. 15.) The most widely adopted counter-model is the social model of disability. This model "posits that it is not an individual's impairment, but the socially imposed barriers—the inaccessible buildings, limited modes of transportation/ communication, prejudicial attitudes—that construct disability as a subordinate social status and devalued life experience" (Berger, 2013, p. 27).

The social model, in contrast to the medical model, focuses on the construction of disability in areas such as communication, language, and discourse. The social model moves away "from an emphasis on the primacy of material factors in the creation of disability, toward a more nuanced focus on culture, language and discourse," which puts communication studies in conversation with the social model of disability (Oliver & Barnes, 2012, p. 180). As with the medical model of disability, the social model also receives criticism, since according to Siebers (2008), "the medical model pays too much attention to embodiment, whereas the social model in its purest form leaves the body out of the picture altogether" (p. 25).

Ironically, with a move away from the medical model of disability and toward the social model, the disability community loses sight of the embodied experience of disability. As a result, numerous scholars have continued to build off these important models in an attempt to complicate notions of disability through cultural, economic, political and materialist frames.

Shakespeare (2014) and Siebers (2008) propose the interactionist approach, which focuses on embodiment, while not leaving out the medical experience. The interactionist approach to disability studies emphasizes that “disability is always an interaction between individual and structural factors” (Shakespeare, 2014, p. 74). In other words, “people are disabled by society and by their bodies” (Shakespeare, 2014, p. 75).

Within the broad spectrum of disability theories and models, there are other theoretical dispositions which address this tension between the medical and social models of disability. A tradition referred to as the “phenomenology of the body” stresses "the lived experience of embodied human beings as the starting point for understanding disability" (Berger, 2013, p. 28). Rather than distinguish between the medical and social experiences of disability, the phenomenology of the body asserts that both are important to focus on. As a result, Siebers (2008) calls for the theory of complex embodiment:

Which illuminates the effects of social environment, including the subjection of disabled bodies to the dictates of medical-rehabilitative practice, but also the pains and pleasures that derive from the body itself. It acknowledges the chronic pain and secondary health effects that may be associated with physical impairment...and [that] there are practical disadvantages to impairments that “no amount of environmental change can entirely eliminate. (p. 28)

The theory of complex embodiment values disability as one form of human variation in much the same way that the cultural model of disability does as well.

Cultural Model of Disability

The cultural model of disability disrupts dominant narratives of chronic illness and disability and combines arguments from both the social and medical models of disability. As a framework, the cultural model:

Recognizes disability as a site of phenomenological value that is not purely synonymous with the processes of social disablement...such an emphasis does not hide the degree to which social obstacles and biological capacities may impinge upon our lives, but rather suggests that the result of those differences come to bear significantly on the ways disabled people experience their environments and their bodies. (Snyder & Mitchell, 2006, p. 6)

In other words, the disability and illness experience cannot solely be described as a social or medical experience. Both experiences influence and inform each other. The cultural model supports Wendell's (1996) desire to ameliorate the sharply made "distinction between the biological reality of a disability and the social construction of a disability" (p. 35). Wendell (1996) suggests that we examine both experiences to gain a greater appreciation for the nuances of living with chronic illness and disability. Jarman et al. (2017) would define this approach to disability as a "sociocultural approach," or one that focuses on communication and the communication produced in relationships.

Since this framework involves both the individual and social perspectives, it provides an all-encompassing account of disability. Disability "is both individual and social; both biological and cultural. It is a complex, nuanced, embodied and socially contextualized experience in which social and cultural oppression interacts with bodily experience" (Green, Darling & Wilbers,

2013, p. 160). Stories of chronic illness fit seamlessly into this framework, as such, this model/approach foregrounds my work in this dissertation.

By situating my work within the cultural model of disability, my dissertation provides a holistic view of chronic illness. The cultural model of disability allows me to mark “disability as a site of resistance and a source of cultural agency” (Snyder & Mitchell, 2006, p. 10) and incorporate both the medical and social narratives of my family’s experiences. This means the cultural model permits for a redefinition and reshaping of chronic illness and disability by creating new ways of framing chronic illness which is “both/and” rather than the restrictive “either/or.” The cultural model foregrounds chronic illness as both a product of social disablement as well as of biological forces. Diseases, like MS, have material consequences in the everyday lives of those living with it.

It is typical that “the paradigmatic person with a disability is healthy disabled and permanently and predictably impaired,” but those living with a chronic illness, in particular those living with Multiple Sclerosis, experience a disease which is not static or predictable (Wendell, 2001, p. 21). It is a disease that can have recurring periods of debility acute episodes of permanent loss or functionality, but also extended periods of health. The social experience of disease and disability is important, and one must understand that these physical and medical conditions are intrinsically linked to the social experience, impacting one’s ability to work, perform normal everyday tasks, socialize, and even communicate.

The cultural model allows for a more nuanced picture of chronic illness. This model guides and informs my choices as I begin to examine my family’s communication and explore what “performing narrative medicine” means.

Contextual Literatures

Chronic Illness and Disability in Families

Chronic illness and disability are marked in medical, cultural and social discourse as disruptions. Chronic illness itself can have myriad effects within family units, often shifting family's performances, roles, relationships, and changing established norms. Rehm and Catanzaro (1998) assert that "when illness or disability occurs in a parent, both children and parents participate in negotiating and constructing the meanings that illness has for the family" (p. 22). The changing roles become a family issue, not just an individual problem.

Dudevany, Buchbinder and Yaacov's (2008) study explores the impact disability has on the parenting role of fathers with SCI (spinal cord injury). By examining the experiences of fathers with SCI, Dudevany et al. (2008) examine the father's relationships with their children. The study contributes to a growing understanding of how fathers with SCI define their parenting role, their relationship with their children, and if/how the children accept their father's disability (Dudevany et al., 2008).

It is important to note that society's dominant negative attitudes and treatment of persons with disabilities shape the parenting experience of people with SCI, as well as what and how they communicate. The study underscores how dominant negative attitudes towards disability make the fathers more nervous to communicate about their disability with their children, for fear their children will "adopt society's negative attitudes toward persons with a disability and a sense of shame would create an emotional distance between them and their children" (Dudevany et al., 2008, p. 1030).

Findings from the study show that there are clear communicative implications to parenting with a disability, and that often when fathers open up to their children and demystify

the disability experience, it makes the child more confident and comfortable--even prompting the children to teach their fellow peers about their father's disability.

Further research also focuses on the role of motherhood and disability. Mothers with disabilities experience a complicated relationship toward parenting. Extant literature on disabled motherhood illustrates a prevalent view that disabled women should not become mothers (Kocher, 1994; Malacrida, 2009). Many women are "trapped in a discourse of disability that makes it extremely difficult to be looked upon and treated as a mother since the mainstream discourse of disability does not blend easily with the mainstream discourse of motherhood" (Grue & Lareum, 2002, p. 672).

This is because "the ideal mother in western culture is positioned as a woman who mothers naturally, who is always and immediately present to care for her baby, and who does this mothering selflessly and seamlessly" (Malacrida, 2009, p. 99-100). As such, typical constructions and discourses of motherhood promulgate a specific way of being and "doing mother" that frequently neglect to include the voices, concerns, and experiences of mothers with disabilities (Kocher, 1994; Malacrida, 2009).

When women with physical disabilities choose to become mothers, they are typically scrutinized or examined much more meticulously than their able-bodied counterparts (Grue & Lareum, 2002, p. 674). Mothers with disabilities feel an exceeding amount of pressure to prove their motherhood to the general public and even loved ones (Grue & Lareum, 2002). They often feel pressure to overcompensate for their disability by being "supermoms" that can do everything, while still having a disability. Studies find that mothers with disabilities "often go to great lengths to 'present' themselves and their children as managing 'normally'" (Thomas, 1997, p. 622), in order to prove they are capable.

Mothers with disabilities also "can have a more complicated relationship to ideal motherhood because they are perceived either as asexual, and inappropriate to the role of motherhood, or conversely are seen as at risk" and in need of nurturing themselves (Malacrida, 2009, p. 99). Motherhood is associated with ideas of maternal femininity, nurturing and authority. These qualifications stand in antithesis to the way our society frames women with disabilities. Therefore, mothers with disabilities are forced to work against these stereotypes and societal images. Mothers with chronic illness have even reported that medical professionals were noticeably indifferent toward discussing motherhood with them, or often failed to understand the implications of illness or disability on their role as mothers (Thorne, 1990). This underscores the marginalization and stigmatization that mothers can experience while still trying to navigate the parental role.

Unfortunately, studies which focus specifically on the effects of parental Multiple Sclerosis provide inconsistent and overgeneralized conclusions about the effects of parental chronic illness on children and family members (Anderson, Huth, Garcia, & Swezey, 2014). Perpetuating many of the same claims about disability and motherhood, Sarah Arnaud's (1959) research argues that parents with Multiple Sclerosis have a negative influence on their children because their disability limits their abilities to parent, causing subsequent negative effects on their children. She contends that the negative psychological and behavioral traits children develop are "body concern, high anxiety, dysphoric feelings, hostility, constraint in interpersonal relations, dependency longings, and a higher incidence of "false maturity"" (Arnaud, 1959, p. 9).

Yet, more recent studies have contrarily argued that children can develop "normally" despite the "profound atypical stressors" (Anderson et al., 2014, p. 5) to which Arnaud (1959) refers. What is most important about these findings is that existing literature makes assumptions

about the effects of parental chronic illness or disability on children and family members, frequently without the children or extended family member's actual perspectives (Anderson et al., 2014).

One rare study which does include children's perspectives about living with parental Multiple Sclerosis is Turpin, Leech, and Hackenberg's (2008) study which looks at the everyday experiences of children who have a parent with MS. Their study finds that "parental MS affects the roles and responsibilities of all family members...and provide[s] both pride and stress" (Turpin et al., 2008, p. 155). They argue that children experience conflicting feelings of both pride and stress because of the extra caretaker responsibilities they must adopt.

In their study, many children required additional sources of support to discuss their experience with parental MS, and children possessed general anxiety about their parent's well-being. The study suggests that social and pragmatic support for the parent with MS could in turn reduce their children's anxiety. Turpin et al. (2008) argue that open communication, outside support systems, and outlets are essential for children of parental MS to understand and work through the disease experience. They argue, as I do, that further studies should explore the perspectives of multiple family members since the impact of illness and disability "happen to a family, not the individual alone" (Anderson et al., 2014, p. 3).

The onset of chronic illness/disability incites feelings of hopelessness and confusion for all family members (Kuyper & Wester, 1998). Families are an important influence in the lives of those with chronic illness and disability, frequently acting as caregivers and emotional/physical support systems (Braithwaite & Thompson, 1999; Skar, Folkestad, Smedal, & Grytten, 2013). The way families communicate with and/or about chronically ill or disabled family members, shapes continued perceptions of PWD. Families play a significant and influential role in how

people with disabilities and individual family members view each other and themselves (Canary, 2008).

With the aforementioned studies in mind, I add to these conversations by focusing my research and efforts on how the entire family unit communicates through the illness experience, with particular focus on how performance enhances understandings of these experiences.

Performing Family Illness Narratives

Family communication is one area of study that privileges the historically private voices and experiences of families. Critical family communication scholar Suter (2016) calls for "seemingly private familial practices to be conceptualized anew as capable of not only reifying normative practices, but also as potentiating resistance, critique, or even transformation of existing arrangements in both private and public domains" (p. 3). Suter (2016) calls family communication scholars to engage in critical work since "families are sites of power struggles that constrain inequities and hegemonic patterns of discourse, that reify dominant belief structures, material realities that constrain communicative interactions, and contain silenced voices that are in need of being heard" (p. 2). Communication scholars focus on examining the communication patterns, models, and behaviors that construct and constitute families living with chronic illness/disability.

One must understand that "no family is natural, and that all families are constructed. Family is a set of discursive practices, storytelling one among them" (Langellier & Peterson, 2004, p. 124). The practice of family storytelling functions as an organizational structure and framework that helps families interrogate "how individuals construct notions of ability and disability within their families" (Canary, 2008, p. 437). As Kleinman (1988) offers, "patients order their experience of illness—what it means to them and to significant others—as personal

narratives,” (p. 49) which helps provide structure and coherence to the illness experience (Canary, 2008). Stories are important because they can be perceived as “social artifacts that can tell us just as much about society and culture as they can an individual or family unit” (Riessman, 2008, p. 105). From a communication studies perspective, performance and narrative provide the power to transform and challenge how we look at our interpersonal, discursive and cultural communication about Multiple Sclerosis in families.

The "performative turn in narrative theorizing privileges the situated embodiment of otherwise bodiless voices and assumes that narrative performances (re)construct identities" (Harter et al., 2006, p. 6). By using performance, I contribute to a continued expansion of the "varied forms [in] which narratives bestow visibility on illness, suffering, hope and resiliency" (Harter, 2009, p. 148). Harter (2009) encourages "interdisciplinary scholarship [to] be enriched by bringing aesthetic sensibilities more fully into narrative theorizing about the communicative accomplishment of health and healing" (p. 148). In particular, "in performing narrative, families become visible and audible both to themselves and others" (Langellier, 2009, p. 148). Families use stories to construct and relearn what it means to be ‘family.’

Langellier (2009) states that “the performative power in storytelling—embodied and precarious—materializes a horizon of possibility and hope” (p. 157). I argue that the performance of my family narratives allows for a creative reshaping of family where possibility is born; where the family might become a site of resistance and reinvention; and where I might embody these resistive ideas and extend notions of narrative medicine as a practice.

Health-related performances created by performance scholars have explored health and illness in a range of contexts and from the vantage point of difference diseases/disabilities such as HIV/AIDS (Howard, 2013) and inflammatory bowel disease (Defenbaugh, 2013). Each

performance individually has a different agenda, but all work toward greater awareness of how health and illness is communicated and constructed.

Howard's (2013) "performance project was an intervention, a disruption of and opposition to stereotypes about HIV/AIDS and those living with the virus" (p. 147).

Defenbaugh's (2013) project discusses her personal experience of living with inflammatory bowel disease and provides a space for others who have lived with IBD or illness to share their stories. Defenbaugh (2013) states, "I textually perform these memories, so others who feel shame or stigma have a model to narrate their ill experiences" (p. 168).

By aligning my performance with a health-related agenda, I too have "the potential to embody how illness stories reflect personal and social experiences, and communicate them to the public to ensure a richer understanding of those illnesses...thus providing an opportunity for transformation by shifting illness narratives from an interpersonal frame to one that is more public" (Howard, 2013, p. 134).

Scholars such as Lindemann (2011), Davidson (2016), and Scott (2016) speak more specifically to the importance and benefits of performance ethnography as a mode to understand communication and disability. Lindemann (2011) argues that performance ethnography is beneficial for disability studies because, first, it "engenders a self-reflexivity about ability and the body" and "performance functions as social critique of the discourse of disability," a way to access empathy in order to dialogically engage with disability and difference (p. 298). Scott (2016) explores similar themes in *Crippling*, a performance ethnography about disabled professional identities.

Scott's (2016) work argues that the performance of disabled bodies is an important way to communicate about the disability experience. Through her scripted performance, Davidson

(2016) looks at how communication about disability and health influence family systems.

Davidson investigates how the U.S. healthcare system is ostracizing and frustrating for families to navigate. Using a literal "hospital map" as a metaphor, Davidson (2016) questions "how patients and their families violate the map produced by the hospital" and argues that "this map, and the institution that produces it, "stage-manage" the performances of families and govern their "performance choices" and expectations" (p. 31). Her performance encourages families to share and perform their individual experiences with illness in order to create public expressions of the lived experiences of illness and disability.

Davidson (2016), Scott (2016), and Lindemann's (2011) performance ethnographies raise questions about disability, family, reflexivity and the performance of difference. I too bind disability studies to performance studies because I argue that "disability is something we do, rather than something we are" (Henderson & Ostrander, 2008, p. 2). Disability is performative, something which is created, (re)produced and reified through communication, and therefore necessitates close examination (Henderson & Ostrander, 2008). With this in mind, my project incorporates both the stories of my family as well as my personal narratives of my research experiences. Not only do I examine my personal journey and process of conducting and implementing this performance ethnography, but include personal narratives of my experience with my mother's and grandmother's illness.

Narrative Medicine

As previously noted, I approach chronic illness from the theoretical perspective of the cultural model of disability. By focusing on the cultural model and its "account of the world negotiated from the vantage point of the atypical," patient-oriented counter-narratives become

one way in which accounts of resistance and "atypicality" gain traction (Berger, 2013, p. 29).

Counter-narratives, by nature, subvert prevailing dominant narratives and social norms (Corker & French, 1999). The term counter-narrative is used "to describe a cluster of histories, anecdotes, and other fragments woven together to disrupt stories of domination" and replace an oppressed identity with one that elicits respect (Harter et al., 2006, p. 6).

My project works as a counter-narrative to the predominant medical narrative about disability and illness. Master medical narratives offer little room for individual stories and experiences of living with chronic illness. As Corey (1998) notes, "the personal narrative is one way of disturbing the master narrative and, through the performative dimensions of the personal narrative, the individual is able to disrupt—and, dare I say *rewrite*—the master narrative" (p. 250). A counter-narrative thus compels scholars to engage the conditions that create disenfranchisement, specifically for people living with disability and chronic illness.

The current health care system in the United States pathologizes human difference. For example, diagnostic categories label patients as "abnormal," and communicate an 'other' status to the patients themselves. Additionally, antiquated paternalistic communication practices that emphasize "protocol over emotion" (Davidson, 2016, p. 33) are still widely observed by doctors who neglect to focus on what is important in the patient-doctor interaction--the patient. These practices are a result of doctors who are captive to insurance company mandates, and to a health care system which views patients as numbers in a database, and more importantly, as capital.

An issue for many patients with chronic illness and disability is that they feel neglected by doctors. Much of the literature on communication about illness "describes dyadic exchanges between doctors and patients and usually presents patients as the passive recipients of messages sent by powerful and knowledgeable providers" (Ellis, 2000, p. 288). Often when patients with

chronic illnesses explain to doctors how their illness influences parts of their life outside their immediate health issues, for instance, their families, doctors are unwilling or unable to address these concerns (O'Dell, 2007). The communication practices that occur in these doctor/patient exchanges can also inform the way families communicate with one another and become a model of how to talk about the illness/disability experience for families.

In response, efforts have been made to “humanize medicine,” and provide the medical field with the tools to recognize the worth and lived experience of patients and families (Charon, 2006, p. 7). The philosophy of patient-centered care imbues the medical field with a humanistic focus. In other words, an emphasis on empathy and a focus on communication. Patient-centered care, also known as person-centered care, is defined as "the therapeutic relationship between health care providers and recipients of health care services, with emphasis on meeting the needs of individual patients" (Dabney & Tzeng, 2013, p. 359). This approach to medical care has been theorized by a variety of scholars and practitioners, but most notably Stewart, Brown, Weston, McWhinney, McWilliam, and Freeman (2003) champion a focus on patient-centered care in family medicine.

A focus on patient-centered care in family medicine includes six dimensions of patient care, "(1) exploring both the disease and the illness experience; (2) understanding the whole person; (3) finding common ground; (4) incorporating prevention and health promotion; (5) enhancing the patient–physician relationship and (6) being realistic" (Hudon, Fortin, Haggerty, Loignon, Lambert, & Poitras, 2012, p. 170).

Others have built off this model and focus on how patient-centered care is used in cases of chronic disease management (Dabney & Tzeng, 2013; Hudon et al., 2012; Stewart et al., 2003). The model considers the person or patient's whole illness experience by "knowing about

the patients' life context (family, work, religion, culture, social support, etc.), as well as personal development stages (life history and personal and developmental issues)" (Hudon et al., 2012, p. 173). Patient-centered care becomes the foundation for an approach to illness and medicine which focuses on the person first.

Physician and literary scholar Charon (2006; 2016) extends on the idea of patient-centered care with her theory of narrative medicine. She states that medical practitioners should approach the practice of medicine and health care with a specific set of narrative skills. These skills broadly include:

The ability to perceive suffering, to bring interpretive rigor to what they perceive, to handle the inevitable oscillations between identification and detachment, to see events of illness from multiple points of view, to envision the ramifications of illness, and to be moved by it to action. (Charon, 2006, p. 8)

Listening to and for patients' stories is an important practice which doctors habitually neglect because of the unfortunate demands and pressures placed on practitioners and the medical field as a whole. Charon's reframing of the United States health care system through narrative, reestablishes dignity, nourishment, and respect for patients. Charon (2006) argues that "only when the doctor understands to some extent what his or her patient goes through can medical care proceed with humility, trustworthiness, and respect" (p. 3-4). In other words, doctors must engage empathy to treat patients in ways that are humanizing.

Narrative medicine works in tandem with the cultural model of disability to highlight counter-narratives of illness and disability. The practice of narrative medicine teaches and enables physicians and medical professionals "to practice with empathy, trustworthiness, and sensitivity toward individual patients" (Charon, 2006, p. 7). Though established in the medical

field, narrative medicine requires a refined appreciation and application of communication in order to achieve individualized, vulnerable, and interpersonal treatment of patients.

Several scholars in the field of communication studies have theorized how narrative medicine may be situated in our field. Studies which look at the intersection between communication and narrative medicine range from a discussion of its reflexive qualities, its application in end-of-life scenarios, and the ethical questions it conjures.

Bochner (2009) looks at the autoethnographic qualities of narrative medicine to focus on how reflexivity is achieved through the relational act and connection demanded by narrative medicine. Thompson (2009) believes that “creating shared narratives, and the closeness that this brings, lead to better care provision than the oft-prescribed distancing” (p. 193) many physicians practice. Last, Rawlins (2009) and Roscoe (2012) exemplify the importance of stories as a way to communicate end-of-life experiences. Overall, communication scholars bring necessary and important perspectives to the practice of narrative medicine (Charon, 2009).

Harter and Bochner (2009) assert that “by invoking narrative practices, narrative ethics, and narrative theory to healing practices, [we] offer images of how to live well in the midst of inescapable suffering, trauma, and disability associated with the lived experience of illness” (p. 114). Furthermore, communication scholars demonstrate the power of narrative medicine to counter paternalistic medicine practices, and give voice to patients again. My project works to merge the power and essential principles of narrative medicine with performance in order to bring-to-life the marginal experiences of families living with chronic illness.

I offer “into circulation alternative storylines for medical encounters,” by showing how performance enables and constrains greater understandings of families living with chronic illness and disability (Harter & Bochner, 2009, p. 115). Binding performance to narrative medicine

brings performance into conversation, as both metaphor and materiality, with discourses of medicine that often neglect arts-based epistemologies for more rational and logical modes of thought.

By merging narrative medicine with performance, I argue that performing narrative medicine can be an instructive framework for understanding communication about chronic illness and disability in families. Performance becomes another way of knowing and understanding medical and illness experiences.

Performing Narrative Medicine

I am committed to the use of performance as a mode of understanding and evaluating chronic illness and disability in families. Performance also informs my (re)understanding of narrative medicine in relation to conversations of chronic illness and disability. Performance theory necessitates the belief “that we come to simultaneously recognize, substantiate, and (re)create ourselves as well as others through performance” (Madison, 2005, p. 149). By understanding both communication and performance as generative, I argue both possess the ability to make realities and relationships. Performance offers a metaphor, object of study, and method for understanding communication, in particular the communication that occurs in families living with chronic illness/disability (Pelias & Shaffer, 2007; Lindlof & Taylor, 2011).

Narrative performance theory allows for “a way to understand both family communication practices” and “locate variations in what particular stories are told, how they are told, and what identities they constitute” (Langellier & Peterson, 2005, p. 100). The concept of performing narrative is not only about the telling of a story, but as a communicative act it “combines the performative ‘doing’ of storytelling with what is ‘done’ in the performance of a story” (Langellier & Peterson, 2004, p. 2). Harter (2009) argues that “aesthetic renderings of

experience” (p. 147) may extend or amplify textual understandings of patients' narrative experiences.

Performing narrative medicine is, therefore, an important way to understand contexts and relationships outside the patient-doctor encounter, such as the lived illness experiences of families. By binding narrative medicine to performance, narrative medicine becomes marked as “both embodied and discursive, a site where vulnerable bodies are textualized as stories” (Langellier, 2009, p. 152).

My performance becomes defined as a performance of narrative medicine. I argue that to perform narrative medicine enables bodies and their stories to become “palpable and visceral...the conventions they reiterate become visible, discussable, and potentially revisable” (Langellier, 2009, p. 153). This is important to note since performing narrative medicine can allow for revision and understanding of the experience of families communicating about disability/chronic illness for both me and my audience members.

An embodied form of narrative medicine is important for my project because I am engaging with ideas of disability and chronic illness, both of which are lived experiences that are body-centered and performative. As Langellier (2009) poses, “how might binding an interaction or event to the name ‘performance’ affect the way we live in that world?” (p. 151). Langellier (2009) posits that we should “consider what it might mean to call narrative medicine a performance” (p. 151). I extend Langellier’s conceptualization by studying what it might mean to call a performance narrative medicine. I intend to explore how performance may inform qualitative research, and inversely how qualitative and performative research practices, such as performance ethnography, can inform narrative medicine.

The use of these various models of disability and performance lend themselves to “dialogic engagement” (Conquergood, 1985) within my family, with my audience, and with self as a performer and researcher. These models allow me “to question points of difference, to understand new ways of seeing the world, and to feel what perhaps cannot be articulated” (Pelias & Shaffer, 2007, p. 17). The cultural model, performance theory, and narrative medicine are committed to understanding the intricacies and nuances of ‘others.’

In the next chapter, I detail the specifics of how my method of performance ethnography, some of my ethical commitments, and begin to document the process of creating my performance.

CHAPTER THREE:

CREATING AND QUESTIONING:

INTRODUCTION TO METHOD AND ETHICAL CONSIDERATIONS

I am looking at the processes of the problems, not for solutions to social problems. [Performance] is a constant process of being something. I am first looking for the humanness inside the problems or the crises. The spoken word is evidence of the humanness. Perhaps the solutions come somewhere further down the road

–Anna Deveare Smith (1992)

It's now been six months since she was released from the nursing facility. Six months of recalibration, re-understanding how to navigate my mother's (normally) pristinely decorated home. MS is mechanical and messy. My parents' house has become a repository of machines, assistive devices, and pills. Living with MS is a disordered experience. It's sloppy, leaky and trying. It tests your patience, but you adapt. It's six months and sometimes things still aren't easy, but you must always adapt.

"Alyse," she quietly whispers. "I need to go."

"Nooooo," I whine. "Can't you hold it? It's three in the morning, Mom."

"No. I need to go now," she calmly replies.

I turn over to face her. I'm lying next to her, a guest in her quarters. My twin size mattress nestled against her hospital-style bed. Through the slivers of my eyes, I see her lying next to me, patient and still. She looks so small in relation to the rigid bed and hand rails surrounding her.

Being testy, I say, "You still sure you need to go?"

"Alyse," she firmly responds.

“Okay, okay.” I flop my lifeless body out of bed and shuffle over to her side. My eyelids struggle to lift, swollen shut, I murmur, "You must move now, Mom. Work with me here."

Her eyes are also sealed shut, as she lifts the upper half of her body, and attempts to swing her legs around to the side of the bed. She ends up collapsing back on the bed again.

“Try once more,” I utter, exhausted.

This time my mother draws her upper body up and over, by leaning on the hand rail attached to the right side of her bed. I pull her legs, tense and crooked, out from under the covers and place them on the ground. Her left leg involuntarily shakes from fatigue and her right leg refuses to bend at all. After I coax her right leg to move, I decide to put both my feet on top of hers, firmly placing them on the ground. She puts her hands around my neck and finally lifts herself off the bed. We swing her around in one swift movement, plopping her down into her chair.

“Oh, Lisa would not be pleased with that transition,” my mother mumbles. Lisa is her physical therapist, a woman who is constantly coaching my mother to make sure her technique is on point, or else she can hurt herself or the person helping her transition.

I reply, “Well, don’t tell Lisa. We can work on it later. Let’s just get you to the bathroom.”

Transitions are an art form. A dance where we are totally in sync some days, and others days, stepping on each other's feet...literally.

We make our way to the bathroom. Once we transition her on to the toilet, I collapse on the floor next to her, closing my eyes for just a moment. It’s not until my mother whispers “Alyse,” that we both realize that we fell asleep again--she on the toilet and I on the ground.

“I mean we could just sleep here too,” she laughs at the absurdity of the situation. I get up and we dance our way back to our beds.

Adaptation and transitions, such as those I experience with my mother, are techniques and an art form that help prepare me for entering the field. Being flexible with the absurdity of any given moment, but also sensitive and keenly aware of all that is going on around me are just some of the skills I must employ, as a researcher and daughter of maternal chronic illness. I am an observer/researcher entering a “field” with which I am very familiar. A field with “participants” whom I care about deeply.

Representation through qualitative research will always be a contentious and risky endeavor. The researcher/performer’s interpretation of their participants weighs heavily on how people perceive the “other” or others they study, and subsequently how they may end up being treated. Thus, it is important to remain diligently aware of the theoretical, methodological and ethical commitments that remain the foundation of qualitative research and my project. In this chapter, I outline a brief introduction to performance ethnography as my method, as well as the ethical questions and concerns that accompany my project. I then begin to document my process of creating my performance.

Performance Ethnography

In my dissertation project, I use performance ethnography as my method. Though it is a method which possesses rigor and discipline, it simultaneously embraces fluidity and adaptation. Jones (2006) describes performance ethnography as a method encouraging scholars, performers and audience members alike to unlearn ingrained ‘truths.’ Performance is both the lens through which researchers understand what they study, as well as the ultimate product of research.

Performance ethnography is a method which stems from the qualitative research tradition of ethnography. Ethnographic inquiry “is the systematic study of another culture using fieldwork methods such as participant-observation, interviewing, and journaling” (Pelias & Shaffer, 2007, p. 52). Ethnography “aims to reveal elements of empirical reality that are not amenable to statistical representation” (Berger & Lorenz, 2016, p. 5). Performance ethnography, an extension of ethnography, demands that I, as researcher, put culture into action and expose the lived experiences and communicative behaviors of those I am researching through embodied performance. Performance ethnography situates my body as the means of data collection, analysis and transmission of data. As Norman Denzin (1997) emphasizes, this method “exists not merely to describe or even explain culture, but instead exists to advocate for specific people, positions or ideas” (p. 343).

Approaching qualitative research with performative sensibilities allows ethnographers, like me, to transform their role from authoritative social scientist or observer to an interpersonal and invested member of the culture being observed. With this shift, I replace the traditional ethnographic terminology of participant-observation with the more accurate term “co-performance,” which is a “doing with that is a deep commitment” (Madison, 2005, p. 168). I am not looking for a specific objective meaning during my interview sessions; rather I seek to understand the meaning making that occurs during the storytelling event---the symbols and metaphors that construct our co-performance with one another.

Performance ethnography as method is the performative (re)presentation of research, gathered through co-performative fieldwork and interviews. Through the interview and immersion process, performance ethnographers are asked to enact culture through the body. Performance becomes both a product and/or theatrical event, but also “a heuristic tool that

illuminates the presentation and representational elements of culture” (Hamera, 2006, p. 5).

Performance as a heuristic enables me and my audience to view performance as a metaphor for the lived experience of familial chronic illness.

For both audience and ethnographer, the live performance allows for an intimate learning experience and exchange through the practice of performance as communication. Performance creates a forum in which the public can interact with the performer and question or challenge them. Performance also reveals different perspectives, enabling both performers and audience members the ability to challenge their own identities and presuppositions. As I perform the narratives of my family members, this method allows the audience and me to challenge our own identities and assumptions pertaining to disability, family, and communication.

An integral component of performance ethnography is that as a researcher and performer, I am actively aware that I am influencing the process and outcomes of my research. I intend to use my own personal narratives and autoethnographic experiences to situate the research and performance I do with/of my family. Autoethnography is defined as “a form of self-reflection and writing that explores the researcher’s personal experience and connects their autobiographical story to wider cultural, political, and social meanings and understandings” (Ellis, 2004, p. 37).

Considering this approach, I understand self by beginning with the other. As Smith (1993) states, “the activity of reenactment could tell us as much, if not more, about another individual than the process of learning about the other by using the self as a frame of reference” (p. xxvii). My personal experiences as a daughter of maternal chronic illness and my family’s conversations with me about these experiences connect to my project’s larger cultural concerns about the power of communication to shape understandings of disability and chronic illness.

Performance is a vehicle of emancipation from cultural and familial identity scripts that have structured my identity personally and professionally, and a way of reflexively showing me, my research participants, and audience, that I account for my story and body in this research.

Ethical Considerations: A Practice of Reflexivity

Reflexivity is an essential component of my dissertation project for two reasons. One, it is important since my performance showcases the voices of my family members. And two, I intend to embody my mother. This is an ethically fraught endeavor, since my able body, a body in a position of privilege, is performing my mother's disabled body. I must/do reflexively question how I respect the phenomenal experience of disability.

I “work to move away from studying culture, to inhabiting culture, with all of the messiness and vulnerability and aliveness that such inhabiting demands” (Jones, 2006, p. 341). Greater awareness of self and other is what ethnographers and qualitative researchers alike call reflexivity (Berry & Clair, 2011; Madison, 2011; McRae, 2015). Boylorn (2013) discusses the importance of sharing one's work with their participants. She encourages other researchers to be cognizant of the people they are writing or performing about, especially if they are one's own family members.

I am always mindful of the ethical implications of performing my family members since they are vulnerable to my interpretations of them and critique from audience members, with whom they have never interacted or may never meet. I must be extremely diligent and well-rehearsed when I perform them through my body.

McRae (2015) documents "critical reflexivity" as both "a performance that attempts and works to recognize the ways the self is (and can be) constituted," and "second, reflexivity is also an act of constituting the self in and through communication" (p. 57). In essence, as a researcher

embodying and researching disability and chronic illness, an experience foreign to my own, I recognize my body as a site of “cultural production” influenced and “embedded in larger social structures and systems” (McRae, 2015, p. 57). I recognize my body as constantly negotiating what it means, feels and looks like to perform other bodies.

As Conquergood (1985) discusses, performance ethnography can catalyze social change and create open dialogue. However, it also demands a willingness for "listening out loud" (Langellier, 2009, p. 155) and to engage in the act of “performative listening” in which researchers like myself “demonstrate the ways listening can function to create connections with others across a variety of differences” (McRae, 2015, p. 65). The performative acts of listening to and with, compel a practice of empathy and fine-tuned ethical commitments. These ethical commitments and a readiness to listen openly and actively are important because of the many moral repercussions that are possible when embodying the other.

Conquergood (1985) addresses these moral implications through his four performative stances towards the other, or what he calls ethical pitfalls. These performative stances are "the Custodian's Rip-Off," "The Enthusiast's Infatuation," "The Curator's Exhibitionism," and "The Skeptic's Cop-Out" (Conquergood, 1985, p. 4). Conquergood (1985) calls performance scholars and researchers to enact dialogic engagement in order to be reflexive researchers and performers.

"The Custodian's Rip-off" is a performative stance that focuses on the inherent selfishness of the ethnographer. It argues that an ethnographer approaches their research with the sole goal of finding material to produce a successful performance. The ethnographer is only viewing culture in a detached way and using said culture solely for performance material. This stance resonates with my project since I must be wary of not exploiting my own family for

performance material. I ensure that my family is informed, throughout all steps of my process, of the transformations that the script and performance undergoes.

"The Enthusiast's Infatuation" emphasizes a superficial approach to the other. This superficial stance produces a performance that is simplistic and trivial. This position views the other in a naïve way, only focusing on generic similarities and not allowing for growth of the ethnographer or other. This stance is a warning to ensure my performance is not sheer entertainment, but seeks critical/cultural critique, particularly in terms of disability and illness experiences.

"The Curator's Exhibitionism" only focuses on the difference between ethnographer and other. The goal of the performer/ethnographer is to amaze and entertain the audience, making a spectacle of the other. As I perform my mother's disabled body, I keep this pitfall in mind, since concerns of "Crip face" are always present when an able body performs a disabled body.

Lastly, Conquergood considers, "The Skeptic's Cop-Out," a stance that creates dissonance between the other and the ethnographer. It is an ignorant stance in which the performer or researcher refuses to acknowledge any similarity or solidarity between themselves and the other they perform. This is the most dangerous stance because it eliminates any chance of dialogue or growth. Though generally believe I avoid this stance, based on the inherent intentions of my performance, it is still important to be cognizant of this.

The final performative stance that Conquergood discusses is "Dialogical Performance." This is the central and balanced stance that is composed of elements from all four of the performative stances. Conquergood (1985) feels that "this performative stance attempts to bring together different voices, world views, value systems, and beliefs so that they can have conversation with one another...it brings self and other together so that they can question, debate

and challenge one another" (p. 9). He believes this is the very essence of performance ethnography. The ethnographer should strive to create dialogue and open opportunities for both other and ethnographer to learn and grow. It challenges all involved to be reflexive as well as accountable for their actions as ethnographer and performer, and resists coming to any hasty or ill-informed conclusions—which is an important call for all researchers.

In conclusion, my dissertation performance works theoretically, methodologically, and ethically to provide an expansive view of how chronic illness and disability function aesthetically and communicatively in family units. By documenting my performance process, I argue for performance as research. Next, I detail the first steps in the process of creating my performances.

Performance as Process

I consider the entire process of interviewing my family, rehearsing, and producing my performance as data for my dissertation. The written reflections of my experiences performing and embodying my family members in various contexts and settings, as well as my systematic documentation of the process and labor of embodying my family members, become data for this dissertation. I make a case for "production as a form of research" (Pineau, 1995, p. 45). The rehearsal and preparation process for my performance became key sites for analysis as I detail my struggles, failures, and triumphs. I view the documentation of my process of interviewing, rehearsal, and production all as ethnographic data.

I, as the performer, director, researcher, and audience to myself become the informant, and my rehearsal process, becomes reframed as 'fieldwork.' As Pineau (1995) states, "performance methodology explicitly privileges process over product; rehearsal is the site of research, the space of fieldwork, and the means of data collection and analysis. The public

production, therefore, is reframed as the presentation or communication of research “findings” and as an act of engaging the public in scholarly dialogue” (p. 49). Since my performance was presented several times and changed with each iteration, the production of each iteration also becomes data.

This performance project began in January of 2016, with the first iteration of my performance at the Patti Pace performance festival in Georgia, titled “Disabling Mother.” I gave a performance which layered the narratives of my mother, father, and sister acquired from previous interviews, against medical narratives performed by a fictional doctor character. Through the presentation of this first performance, I gained insight and feedback from scholars in the field which helped me expand the performance as I continued to conduct further interviews with family members. I also decided to remove the fictional doctor character in order to focus more meticulously on the stories of my family members.

Once the performance was revised to include the voices of my extended family members, I presented it three more times. I gave it once within the larger University of South Florida community, as a part of Disability Awareness Week, and again at the National Communication Association conference with an audience of disability studies, performance studies, family and health communication scholars. Last, I presented it as a part of my department’s annual “Comm Day” performance event titled “Expectations.” Though I view the witnessing audience in all these performances as an essential part of the performative relationship, written audience feedback or formal surveys are not incorporated within the scope of this project. This is one way I intend to expand my research after the dissertation is complete. Ultimately the performance as a text, as well as the documentation through narrative, audio and video recordings, journal entries,

and field notes of my personal process of preparation and presentation of the performance, serve as data to be analyzed for this project.

I use Pineau's (1995) questions about process and creation as a step-by-step guide to keep structure and coherence as I create this performance. With this in mind, I ask:

What were the motivating questions or issues? How did pre-production concepts evolve through rehearsal? What did the director or actors come to know by engaging the text on an intimate, physical level? What images and insights did audience members carry away with them? (p. 44)

As Madison (2005) states, creating a performance becomes "a matter of translating those layers and layers of witnessing—written, spoke, lived, and remembered---that surrounded me and then "mak[ing] them into art" (p. 399). In the following section, I analyze my steps of creating questions and finding a purpose for my performance because these are essential and informative components in the process of "making art," and research.

Questions and Purpose

We sit in my office, pen and paper between us, handing articles back and forth.

"What do you want to do with this project?" he asks. This is the dreaded question for which I am never prepared. The initial phases of this performance began back when I was an undergraduate, back when I first witnessed Anna Deveare Smith perform at my alma mater, and realized the power of performance to shed light on matters of social justice. As an audience member I saw first-hand the power in performing multiple voices or multiple others through the body of one performer. I knew ever since I witnessed her performance that I wanted my dissertation research to be performative. I knew that performance ethnography was the method I needed to explore my own family's communication practices. Specifically, I needed performance

to discover more about my relationship with this disease and my family. I wanted to understand the embodied implications of performing and how that impacts how I relate to this disease and my family. But, also, I intend to use performance as a mode to educate people outside my family about this experience. Some people don't need research to access these understandings about themselves or others. But I do. And I feel compelled to educate others because that is how change occurs, or at the very least the seeds of change. Yet, to condense these goals into a question, or series of questions is far more difficult than I'd imagined.

I tentatively respond, "I'm not sure right now." I refer to the articles, neatly stacked in front of me. I've been using Langellier's (2009) concept of performing narrative medicine to guide my questions up until this point and right now I can't let go of my literature safety net. All I know is that I feel that there is importance to working with these narratives of my family members, and there is importance in the performance and embodiment of these narratives.

I continue, "Well, I wrote these questions down earlier as I was reading through the article, so maybe we can start with these: How does performance change how we talk about disability in scholarship? What does performance reveal about families living with chronic illness? How/what does it communicate?"

"Cool," he replies, "That sounds great. That gives me a better understanding of your goals. But I wonder how you might show your audience what this looks like. What does it look like to be a family living with chronic illness/disability? How are you going to show performing narrative medicine on the stage and in your body? What does that look like?"

"Those are really good questions," I answer. "I need to figure out through movement what that means to me? Maybe we should start there? Should we get up and test it out?"

"Yes let's!" he replies.

Coming up with a focus and questions began with the back and forth process of referring to literature, immersing myself in my interview data, and getting up and moving. By “playing, testing, choosing, repeating, and presenting” (Pelias & Shaffer, 2007, p. 89) the narratives of my family members, my questions and purpose began to develop and narrow, bringing me to questions such as:

- How does performing this piece of familial narratives work as a performance of narrative medicine, opening conversations with myself and the witnessing audience about the larger communication surrounding disability and chronic illness?
- How can performance be used to better understand the ways that chronic illness/disability are reified or communicated about in families?
- How does familial chronic illness become a performative “stylized repetition of acts” and how does performance theory help understand this better?
- How do I get from humor to the value of narrative medicine?

“Purpose and ethical obligation” (Madison, 2005, p. 397) are essential for taking these guiding questions and making a performance out of them. The purpose for my project evolved over the course of my three performances, and it also emerged from my personal experiences. The back and forth between creating my performance and reflecting on my personal experiences guided me toward developing a purpose, which I struggled to fully grasp during the first few iterations of my performance.

The room clears out and the performance event is over before I have time to process that it began. I gather my belongings, glancing back at the large lecture hall repurposed as a

performance space and turn to leave. I am not sure what has just occurred. I am thoroughly exhausted, a little delirious, and not entirely ready to mentally unpack it all. It is my second time performing a drastically different script from my first performance, which I now title “(Dis)Abling Family.” After my first performance, I received positive feedback from my audience, which made me feel excited and certain. But this time, unlike with my first performance, I am left feeling utterly confused.

After the performance, the talk-back session begins and during it an audience member asks, “Is there an overall message you want to convey to the audience? Why did you choose the narratives you did? Was there a specific process or purpose?” I choke up. I can’t respond. Caught completely off-guard I have no concrete answer to his question. I know that performance ethnography is my method of choice. I know that I strategically employ this method, but I can’t articulate how or why.

Instead of frankly answering his question I steer the conversation in another direction by saying, “Well, what do you think it is?” It feels wrong not to be able to answer this honest question, and cowardly to put the spotlight on him, but I panic.

As I walk back to my car, I think about it. I think about why it was that I couldn’t respond to his question.

My friend turns to me and says, “I have all these thoughts about your performance, but I’m mostly interested in why you didn’t respond to that student. I want to hear your response. I want to know what this performance was about from your perspective and why you chose the narratives you did.”

I respond, “Yeah, I guess I got choked up.”

“Right,” he responds. “I assumed that, but the audience and I were still left wondering what was going on? I think that he is probably making a point. If he’s confused, then maybe others are confused about your focus as well?”

I sigh and reply, “Yeah, I didn’t think about it that way”

He is right. I wasn’t ready to address what I was doing with this performance, mainly because I don’t know. I want to believe that the performance speaks for itself. Here were the narratively woven words of my family members living with chronic illness/ disability. Here were their obvious perspectives, different as they may be, layered to create a holistic view of the lived experience of family members of chronic illness/disability. Couldn’t the audience see that? Art should just speak for itself, right?

As Madison (2005) notes, “Moving from the field to the script, it is purpose that energizes will; then, it is politics and beauty that energizes performance” (p. 401). Without a clear purpose or method, there is not a clear message. I know I must be able to distinctly articulate the purpose of my performance, or else its meaning and importance will get lost not only for my audience, but especially for me.

The lights shut off, and the applause begins. My third performance at the National Communication Association conference has finally ended. The talk-back session begins, a routine component of conference presentations, and a member of the audience states, “I loved being able to meet your family through this performance. Humor works well to show why these stories need to be shared, and what specifically it says about family.” This was the “lightbulb” moment I’d been waiting for. Her comment sticks with me. It sticks with me because I had

known humor was something I would incorporate in my performance, I just didn't realize that my audience had picked up on the humor as well. Her comment/question left me thinking:

- What about humor and MS is happening specifically for my audience?
- How does humor work well to share these stories, and what does it say about family?

It was after this comment I realized that my performances must be framed by humor, and as such I must reflect about how humor works medicinally in my family as a way to communicate with each other, myself, and my audience members. Incorporating humor as a frame for future performances happened organically through the process of performance. Humor works for my audience to reveal and conceal the particularities of families living with chronic illness, and so I work to discover how humor works for me and my family as well. My family's entire illness experience has been framed by humor and laughter, and so in the next chapter I explore how this emergent purpose and frame works for my family members as I conduct interviews and begin performing their voices and narratives.

CHAPTER FOUR:
LAUGHING WITH YOU ALWAYS:
HUMOR AS NARRATIVE MEDICINE

If you analyze humor for too long, it isn't funny anymore

-Keller (2016)

My family has always been close, but there's been a glaring lack for me. That glaring lack is the presence of my grandmother. After her passing, I slowly felt that I knew so little about a woman that meant so much to my family members.

What remained were the repetitive stories my family told about her during holidays or family celebrations. Of the stories they told about her, there was a clear understanding that she was funny. And not only that she was funny, but that humor was an essential part of who she was and the way her children and loved ones talked about her. So, as I sat down to interview my extended family members about their experiences with my grandmother and her illness, it should have come as no surprise that they too used humor to understand their own and her lived experience with illness.

In the context of chronic illness and disability, stories provide structure and coherence to the often-chaotic illness experience and storytelling manifests itself as illness narratives, or narratives about what it's like to live with a chronic illness. Storytelling becomes a meaning and sense-making entity, which "is a vehicle for fashioning a world that is plausible and intelligible, the means by which we 'do family'" (Jorgenson & Bochner, 2004, p. 518). Since there aren't

many examples of how “to live well” with Multiple Sclerosis, many families are left to their own devices to make up their own understandings or stories of the illness experience.

Specifically, since MS is chronic, families must adapt to the ongoing nature of accommodation. Families also become responsible for creating an “alchemy of inclusion and promot[ing] a sense of self-worth, pride, and genuine belonging” (Jarman et al., 2017, Location No. 1084), within the family unit. Communication and specifically performance is at the root of these shifting experiences/feelings and key to constructing a sense of belonging.

The performance process has enabled new possibilities for viewing my mother and grandmother’s illness, my relationship with them/toward MS, and my understanding of the unique, contributory and individual ways all my family members are involved in these possibilities. As Arthur Frank (1995) notes:

Broyard, a writer of some fiction and much literary criticism, presents living with rapidly progressing prostate cancer as a problem of style: “It seems to me that every seriously ill person needs to develop a style for his illness.” I understand telling stories as an especially important medium through which we discover what that style might be. Storytelling is less a work of reporting and more a process of discovering. (p. xvi)

Humor becomes a metaphor for larger discursive understandings of disability and lived experience in our family, as well as a method or way we communicate about and through these experiences. This chapter serves as an account of how humor as narrative medicine emerged throughout my interview and performance process. I concentrate on how humor is used by my family members, and how that ultimately informs the continual construction of my performance in Chapter 5.

I start this chapter with a brief reiteration and explanation of the method I employed to conduct interviews with my family. I narrate my way through the experience of interviewing and performing my family members by using humor to understand our communication. I argue that humor functions primarily as narrative medicine for my family. I focus on the use of humor in instances which highlight the communicated experience of illness and disability. This chapter acts to clarify again how the performance process revealed humor as a valuable communicative pattern that subsequently can be viewed as a health competency or as a form of *narrative medicine*.

Interviews

My research participants are my family members, which includes my nuclear family in Connecticut, comprised of my mother, father and sister, and my extended family in New York, consisting of my Aunt Barb, Aunt Kathy, Uncle Bob, and Papa Keller. I chose this population because my family poses a unique site for research. All the children in my nuclear family and my father's side of the family have had a mother with Multiple Sclerosis. This situation is a rare phenomenon since research on MS is still inconclusive about the hereditary origins and manifestations of MS.

The interviews with my nuclear and extended family members were conducted over the course of several years. The interviews with my nuclear family began at the start of my doctoral program, predominantly through skype and phone calls, and as contributions to my classes on Performance Theory and Compassionate Interviewing. I've spent the last year, most intensively this summer/fall, interviewing my family members. I conducted face-to-face informant interviews, which are in-depth, qualitative interviews, with all my family members.

I include my entire extended family on my father's side to gain a well-rounded view of various familial perspectives on the lived experience of chronic illness/disability. With each family member, I conducted two to three face-to-face interviews, some skype interviews, and engaged in ethnographic interviewing in order to frame my interviewees "not as an object, but a subject with agency, history, and his or her own idiosyncratic command of a story" (Madison, 2005, p. 25).

During these interviews, I took copious notes on the setting and context, as well as my participants' mannerisms. I also video and audio taped these interviews to add to my performance's embodiment and the vocal quality of each individual. These interviews are an important way to access the aesthetics and patterns of how my family communicates about chronic illness and disability.

All my family members were asked to tell me stories. Most of the questions I asked guided the conversation toward a holistic understanding of the ways chronic illness impacts my family, and how it is communicated about in my family. With an interview guide to create structure, I posed questions such as "Can you recall a moment when MS was particularly challenging for Grandma and the family? Can you recall a story when the family used humor as a way to communicate in the face of her illness? What influence do you think Grandma's illness had on the family unit as a whole?"

The questions were there to "guide" the conversations, and I pushed myself to let go of the interview guide and allow the conversations and stories to emerge naturally as I became more comfortable with the process.

Communication about the project began unofficially even before I conducted my interviews:

Hi Aunt Barb, Aunt Kathy, Uncle Bob, and Papa,

I'm not sure how much my dad has told you about my dissertation project, (I've cc-ed him on this e-mail so he can help with planning too), but one of the intentions of my dissertation is to focus on how chronic illness/disability functions in family units. Since communication is my area of interest, I specifically focus on the way chronic illness is talked about within families. Our extended family poses a unique "site" for my research since obviously both my mom and grandma Keller were diagnosed with Multiple Sclerosis. I've already conducted interviews with my mom, Jana, and dad (though I intend to conduct more), but the ultimate goal of my project is to interview all our extended family members and gain insight and stories about Grandma as well. Hopefully through these stories I will gain a better understanding of how MS impacted our family and work to better understand communication practices in families where parental chronic illness exists.

The cool part about my project, which I'm nervous to tell people since it makes me feel vulnerable, but I'm also excited about, is that I will be creating a solo performance out of these narratives/interviews and performing (with your permission) these (your) individual voices in conversation with one another. The performance will use performance ethnography to try to blur the lines between theater and journalism, using text from real-life encounters and interviews to create gripping portrayals or stories surrounding a theme.

With all of this in mind, I want to come up to Buffalo this summer to interview you all. I can always call and skype in for additional interviews if necessary, but I think it's important to conduct these interviews face-to-face. I hoped July would be the month

where I could come up to Buffalo for a week or so and interview you all. I was thinking sometime between the start of July 1st and July 18th. I think it would be important to talk to you individually, but also cool to have one session with all of you together. I'm not sure if this would be feasible, etc. so if you could let me know that would be great!

This e-mail has been good practice in trying to concisely explain my dissertation—clearly I still need to work on the “concise” part! ;)

I'm really excited about this project and what it might do beyond the limits of our family.

Okay talk soon!

Love,

Alyse

Almost immediately I started hearing back with responses from my family members which ranged from Uncle Bob:

We would love to be a part of this important project, and for you to pick this sensitive family subject just shows what a wonderful person you are and how important family is to you... We love you and hope that we can help in some way.

Love your favorite uncle,

Bob

To extremely organized Aunt Barb:

Alyse,

Of course, you know I will do my best to meet with you when you are in town. The more notice I have the better, so I can try to reschedule quartet practice if necessary, etc. Will you be here for 4th of July weekend with your family? I'm planning

on having the family over (plus some friends) to our house on Sunday 7/3, so that might give you the chance to get all of this together (that is if everyone will be able to make it).

A few thoughts that came across my mind as I read your email about your dissertation--factors that I think have made a difference in how your family handled your mom's MS as compared to how we handled the same diagnosis years before:

- Information (they knew so very little about it when my mom was diagnosed and lack of computers made any independent research difficult),
- Treatment availability (no matter what, MS leaves the family members feeling somewhat helpless/hopeless, but when the doctors have NO suggestions for any treatments at all, it's frustrating for all involved),
- The tightness of the family unit (both my mom and yours were lucky here to have loving, supportive families)

There are other factors that made the experiences similar and a lot that made them different. I just wanted to express those to you while they were in my head.

I'll look forward to talking to you more about it.

Love you lots,

AB

And an extremely long e-mail exchange with my Papa, who seemed both nervous and excited about the prospect of being interviewed about his former wife:

ALYSE, I'M STILL HAVING TROUBLE JUST USING THIS MACHINE, BUT I'M EXCITED ABOUT BEING PART OF YOUR PROJECT. A LOT OF THE LONG CONVERSATIONS I HAD WITH JEAN WHEN SHE WAS IN THE NURSING HOME I THINK YOU'LL FIND FIT INTO YOUR PLAN VERY WELL. IF YOU

HAVE A COPY OF MY NOVEL, YOU"LL FIND SEVERAL SEPARATE SECTIONS WHERE THOSE TALKS WE HAD UNDER THOSE CONDITIONS SHOULD GIVE YOU INSIGHTS THAT WILL HELP YOUR STUDY, ESPECIALLY WHEN YOU AND I DEAL WITH THAT KIND OF SPECIAL SITUATION. I'M LOOKING FORWARD TO WORKING WITH YOU.

all my love, papa

Ultimately, the formal interviews with my family members comprised nearly 12 hours of formal audio. The performance itself wound up being around 30-minutes worth of narratives, which I derived from my formal interviews, as well as numerous other informal interactions and stories.

In my own interviews with my nuclear family, I always knew that humor was a way we discussed my mother's illness with her and with each other, but it wasn't until I interviewed my extended family members that it became obvious that humor was a way they communicated about my grandmother's illness as well. There are many narratives which developed throughout the interviews which were humorous by nature, but the following is an explication of the humor used in several selected narratives, thematically categorized by how the humor functioned. By creatively approaching family communication from the lens of humor, I create/allow space to reimagine what family means in the context of chronic illness/disability, and how humor functions as narrative medicine for my family.

The Cast of Characters

Since each member of my family possesses narratives within my larger performance, a "thick description" (Geertz, 1973; Ryle, 1949) of my individual family members is important for both my reader and audience members to understand each of their "characters" better. A detailed

description of each of these characters and my relationship with them provides the interpersonal context and background for why I chose to interview my family, as well as personal perspective on how they understand Multiple Sclerosis and its impact on our family.

Denise Keller

Denise is my mother. Denise grew up in the Bronx, NY. The star of her high school's basketball team, lead in the school plays, straight A student and a beauty pageant queen. She was an overachiever all around. My whole life I've heard I inherited her Type A personality. It's true. She was my age, 27, when she first started noticing symptoms of MS--fatigue, irritated nerves, and balance issues. Doctors misdiagnosed her many times, from Fibromyalgia, to Lyme's Disease. It was a process of elimination by the time they finally concluded that her symptoms were, in fact, a result of Multiple Sclerosis.

She is also an extremely talented listener. Always keenly observant and actively listening, she will often whip out information you didn't realize she knew because she was paying attention. She is always paying attention. In our nuclear family, we have fondly named her 'Queen Denise,' and she not so secretly loves it.

Jana Keller

My younger sister Jana and I both grew up with a mother and paternal grandmother with Multiple Sclerosis. Though our mother has had MS our whole lives, neither my sister nor I were told she had MS until middle school. Our mother's symptoms waxed and waned over the years, but the year I left for college, with my sister still in high school, was the year my mother became the sickest. With my dad working full-time and traveling often, my sister was left to help care for my mom, whose physical and cognitive abilities were rapidly diminishing. Jana remembers many instances in which she was called out of school early to help our mother at home, or days

on end where my mother didn't leave her room. My sister is an empath, a beautiful soul who connects easily with others. She has often become the translator for my mother when she herself can't articulate what she needs or feels. She has established numerous inside jokes with my mom that help make showering her or bringing her to the bathroom less burdensome for my mother and our family.

Barbara Keller Yendall

Aunt Barb is the youngest of my father's siblings. Her mother, my grandmother, was diagnosed with MS when she was around 5 years old. Similar to my sister and I, she too grew up with a mother with MS for most of her life. The most prominent difference between her upbringing and mine is that she grew up in a single-parent household on a single parent income. As far back as I can remember she has always expressed concern about my mother's illness and its impact on me and my sister. As a pre-teen, I recall visiting the mall with her, an activity I distinctly didn't do with my mother by that point because it made her too exhausted. While on our trip I recall discussing my mother's illness with her and comparing our experiences. During my interviews with my Aunt Barb she revealed to me that she brought me on that mall trip because my father had asked her to, a fact I never knew. He was concerned how my mother's illness would or was impacting me and my sister. Her and I learned a number of things about each other during this process but most specifically we learned we are both "fixers," much like my father and me. We like to solve situations and provide some semblance of closure, a very difficult feat in the face of MS.

Loren Keller

Loren Keller, also fondly named Papa Keller, is my paternal grandfather. He refers to my grandmother as "the mother of his children." My Papa and Grandma Keller divorced years ago,

back in the 60s, a time when divorce was supremely taboo and not a frequent occurrence. Their divorce left my grandmother trying to raise four children, living off alimony, and attempting to hide a chronic illness which was only growing increasingly worse with each passing day. He is frequently cited as saying he would have never left her had he known she had an illness. A quiet and soft spoken man, he was an English teacher and published author in the Buffalo area his whole life. Some of his poetry discusses my grandmother and their family. But his book directly addresses their divorce, his guilt, and their eventual friendship. When my grandma was finally admitted to a nursing home at the young age of 57, he visited her regularly. So regularly, in fact, the nursing home staff thought he was her husband. To which my grandmother would emphatically proclaim, “No, this is my EX husband, isn’t that a hoot?” During our interview, he continually read from passages which highlight how spectacular he thinks my grandmother was. Since his memory tends to slip sometimes, he uses the book as a resource in front of him during our interview, a way to prompt and relive his memories of my grandmother.

Robert Keller

Uncle Bob, aptly described by his siblings as “the favorite child,” was by all accounts the closest with my grandmother. He, like my sister, is an extremely empathetic and compassionate person. He is always willing to lend a helping hand and sacrificed a lot of his teen years and early 20s to be present for his mother, and to let his other siblings live their lives. All of his siblings cited instances during their interviews in which Uncle Bob sacrificed his own time or social life for them. He is also the most quietly funny member of the family. He will often slip in jokes without anyone expecting it and have the whole room in stitches. Undoubtedly my interview with my Uncle Bob was the most emotional, but our outward displays of emotion were

also an indication of just how close he was with my Grandma, and the indelible impact she had on his life. The indelible impact both of our mothers have had on our lives.

Kathy Keller Otto

Aunt Kathy is the eldest sibling of the Keller “Krew.” She explains her relationship to my grandmother as strong during her teenage years, but one that waned as her adult life progressed. As the oldest child, she took the brunt of my grandmother’s divorce and illness diagnosis, when it first happened. She explains that during her teenage years she stayed home a lot with her mother because she felt guilty leaving her. She acknowledged that in her adult life she did not visit my grandmother as often as she would have liked.

Jim Keller

Jim Keller, the second child and son of Jean and Loren Keller, grew up in Buffalo, New York with his three other siblings. He is a man who has been surrounded by MS most of his life. His mother, my grandmother, was diagnosed with MS when he was 11 years old, and ten years later he met my mother, the love of his life, who would also end up being diagnosed with the same exact illness. My father is a man of many words and few outward displays of emotion. Yet I’ve watched my father’s unwavering love for my mother for the last 27 years of my life. When my mother became very sick again in the fall of 2015, he sat by her bedside at the assisted living facility every feasible day. He was there the moment visiting hours began and left when he was kicked out. Every day my father could be there, he was. He seamlessly transitioned into her caregiver overnight, without any question. I see the ways this disease brings my parents together; I also see the ways it enrages them both, sending them into fits of anger or silence. I’ve listened to his guilt-ridden tears on the other end of the line when he is asking for permission to get away

for the weekend, to take a break for himself, to escape for just a moment of reprieve. And yet always, I try to see love through this disease.

Alyse Keller

My father and I share numerous similarities. Mainly we share our desire to create connection through likeness. We poke, prod, and pry until we find something in common with new people we've met. We even do it with each other. But that also means we don't listen particularly well. We listen for something, for keywords, a sentence, or a phrase. We listen for trigger words that will create a connection, but we do not always listen with-- a very different active listening practice. We really like to solve and resolve our own and other people's problems. We have a tendency to find a solution or a logical reasoning for everything. Obviously, this is flawed. And so, frustration ensues when we can't solve the problem at hand. That's why, in our way, illness is hard for us both to understand. It's a process, much like this dissertation. We are fixers and fixers don't always do well with unresolved problems.

As I embark on this dissertation journey my voice is always present. Every narrative and performance is my interpretation. It is imbued with my own subjective understanding of the situation or words at hand. The detailed descriptions and biographical stories of my family members provide an understanding of each of them in relation to Multiple Sclerosis. I emphasize these relationships in order to contextualize the importance of each of these "characters," as I begin to explore the importance of humor as narrative medicine for us as a family.

My mother doesn't often drink. For years, she said it was because the doctors told her it was bad for her MS. This was in addition to the myriad other suggestions doctors made like

avoiding heat, not overexerting herself, and she may have at one point alleged the doctors told her “doing laundry” was also bad for her. Smart, smart woman.

When she does drink now, it’s usually with me, her most responsible and positive influence of a daughter. It is usually five small sips of sweet, sweet white wine, before her head cocks forward, mouth agape, and she’s out for the night.

It was Christmas break and our family was gallivanting around the city (“New York is obviously the only city”-Denise Keller), and we stumbled upon a restaurant with all American cuisine and an extensive drink menu. My father and I ordered beers from a local brewery, my sister got her usual “Dirty Shirley, hold the dirty,” and in the last inning, after oscillating back and forth between a Moscato and a Moscato, my mother shocked us all with an unexpected cocktail order called “The Gypsy”, a bright pink concoction of vodka and unidentified neon pink liquor.

We were 30 minutes into our dinner, my mother was about half-way through her whimsical pink drink, and she looked at my sister and me, softly whispering, “I need to go.” “I need to go,” is code in my family for help me to the bathroom immediately. I stood up, unlocking my mother’s wheelchair, and rapidly rolled her into the bathroom with my sister in tow.

In the timeline of my mother’s disease, this was probably a week after she was released from the assisted living facility. A week into us learning how to transport her from the chair to the toilet. A week into all of us getting used to the process of bringing our mother/wife to the bathroom. A week into showering my own mother for the first time. A week into learning how to properly wipe my own mother after she goes to the bathroom. And 30 minutes into realizing we’d all had one drink too many.

Now let's fast forward to the moment of truth. We started the normal transition. Lock the wheelchair at an angle adjacent to the toilet. Allow enough room to wiggle into the space between the toilet and the chair. Hold onto mom's waist and have her place her arms around your neck or shoulders, or using the bar on the wall, lift together. Once she's standing, if there is another person there to help, pull the wheel chair out from behind her to ensure that she doesn't trip on the wheelchair. Pull her pants and diaper (we call them adult underpants in our family) down, rotate her 45 degrees and sit her on the seat, as smoothly as physically possible.

Well this time, things didn't go as they should have. We had mom standing at this point. My sister Jana had pulled the chair from behind her, but we're not sure what combination of absurdity contributed to the next series of events. It could have been the angle of the wheelchair, we might have been a little too far from the toilet seat, her legs might have been too tired by 8:30 pm that night. But what I do know wholeheartedly contributed to the next move, the goddamn Gypsy drink.

Before we knew it, my mother was laughing, I was laughing, and Jana was laughing. But we weren't laughing in place, we weren't strong enough for this kind of laughter. None of us, my mother included. As the laughter grew, so did our inability to support our mother, or for her to support herself. And so, she started to sink to the floor-- a very dirty, Manhattan bathroom floor, mind you. And there was nothing we could do. The sink was shipping, and we were going down with it. Not only did her laughing fit weaken her ability to stand, it also prompted her bladder to run loose like ol' faithful.

So there we were, three gals out on the town, sprawled on a bathroom floor, surrounded by our mother's urine. If you too have ever been stranded on a bathroom floor with your mother and her urine, you know that it's a funky position to be in. Mostly because you must dead lift a

grown woman off the floor, and neither Jana nor I fully passed any of our physical fitness tests in elementary school P.E., so that made the situation significantly more difficult.

There were several ways to approach this situation. I'm not sure any of them were right, but I decided the best approach to a situation in which we were stranded on a bathroom floor with our mother and her urine—we must share secrets.

So I started, “Mom, I guess there is no better time to tell you, but both Jana and I also have been incapacitated on bathroom floors during college, surrounded by our own liquids.”

Jana chimed in, “Yeah, mom if it makes you feel any better, we've all been there... especially, Alyse.”

My mother sarcastically chimes in, “Ah, you girls clearly know how to make a mother proud.”

She takes a deep breath and says, “Okay, I think I'm ready to get up.”

And like a NASCAR support crew, my sister and I worked my mother back on to the toilet, cleaned the floor and our mother, without skipping a beat. Luckily for us, none of the humans that entered the bathroom while we were sprawled on the floor asked if we needed help, so we didn't have to deal with other people inquiring why three grown women were relaxing on a bathroom floor. This New York scenario was evidently not out of the ordinary for them. And this, my friends, is why I love New York.

When we returned to the table, all three of us giggling, my father who had been waiting a while for us to return, smiled and said, “I won't ask.” We gathered up our belongings, my mother completely silent up until this point. And as we rolled out of the restaurant, my mother motioned for us to pause, and laughing at herself dramatically stated, “Okay, so who's ready for round two?”

Now some might find the moral of this story to be something related to alcohol consumption. This is a valid assumption. Yet, I would argue that it's because of our ability to find the humor in this situation that we made it out nearly unscathed. Humor makes the experience digestible and livable and vulnerable and real. As my mother says, "It's the only way to live." But let's be honest, the real moral of this story--never order a cotton candy colored drink called "the Gypsy."

Humor has always been a natural antidote for my family, but also a way of communicating through our experiences. I frame humor as an important element of communication, as a part of everyday interaction and a tool for social navigation. Humor provides a special context to engage in transformative dialogue and to discuss taboo topics. Through humor, there exists an ability to "encourage, even force, others to view an aspect of the human experience from a perspective with which they may not be personally familiar or to consider sides of an issue to which they usually stand in opposition" (Bingham & Green, 2016, p. 2).

Throughout the process of interviewing my family members and performing them, I learned humor functions as a mode of critique, role-taking, and processing. By narrating some of my family's interviews and experiences, I show the variety of ways that humor functions to help my family communicate about the experience of disability.

Humor and Family Communication

Family is a term which incites myriad definitions and understandings. Family can be most succinctly described as "an interactional and cultural product," a system of relationships, "resulting from complex connections and encounters with significant others as well as with canonical narratives of family circulating through culture" (Jorgenson & Bochner, 2004, p. 514-

515). Families learn how to be and act through the relational and cultural constructs we (re)produce through communication. As Jorgenson and Bochner (2004) assert, “to believe in the importance of family communication is to heed the call of stories” (p. 515). The call for stories reemphasizes the power and resonance that storytelling has to construct “family.”

Humor not only acts as a communicative practice among families living with chronic illness and disability, but becomes a way to challenge normalized notions of what a family should be or act. It is a way of talking back at what society perceives to be the "norm" for families, and instead creates dialogue about alternative ways to understand the experience. I conceive of “humor and comedy as sociocritical tools that can be used to reorder, disorder, question, and reconstruct traditional narratives of disability [and chronic illness]” (Bingham & Green, 2016, p. 94). Therefore, I work to comprehend humor as a form of “narrative medicine,” by understanding how it works as a subversive and empowering mechanism in families and contributing to my overall project of performing narrative medicine.

Scholars Bingham and Green (2016) thematically categorize humor as working in three ways. First, humor is understood as a part of social interaction, an integral part of our everyday lives. Humor provides the context to engage in transformative dialogue and to discuss taboo topics, such as living with a chronic illness or disability. Humor can also be used to navigate situations that others identify as awkward. In this way, humor has the power to shape perceptions. Humor possesses the ability to shape perceptions because it "builds on an understanding of cultural norms, values, and practices” by displaying the mundane through the absurd (Bingham & Green, 2016, p. 17). It pushes one to have a keen contextual awareness and understanding of the other.

Traditionally, humor has been framed as a coping mechanism within families. I redefine the way coping is defined in family units. In line with Bingham and Green (2016), I believe humor is an active process, instead of a passive term. Therefore, to conflate humor with coping is narrow and limiting. It forces lived experiences to be viewed through a tragic frame. Instead of using the word “coping,” Bingham and Green use the word “encounter” and state that “using humor as a way to encounter an environment provides a different frame, one that takes into account the complexities of interpreting, analyzing, and navigating situations” (Bingham & Green, 2016, p. 19). By reframing humor as an active process of encountering and a way to communicate through experiences, humor becomes a relational process and one that has an important influence on the way that families define themselves.

Humor also possesses the ability to “be an important vehicle for revealing feelings about illness to the larger family group and for communicating about other sensitive subjects...in addition...it assists with creatively integrating illness into the family experience” (Bingham & Green, 2016; Brooks, Guthrie, and Gaylord, 1999; Rieger, 2004; Rieger, 2005). With these perspectives on humor in the family, I move next to an exploration of how the illness and disability experience converge with theories of humor.

Disability Humor

In disability studies, disability is understood as one way of being in the world. My study also shows one way of moving through the experience of living with chronic illness. Humor is the most prominent way that my family communicates through the illness experience. Humor possesses the ability to communicate about serious disability issues with subversive power. The international disability organization Kolucki and Duncan (1994) says:

Humor is a universal bridge over the awkwardness many people feel when approaching a new or unfamiliar situation. It can often quickly convey a message that, given in a more lengthy and serious way, would be didactic and uninteresting. Messages received through humor are remembered longer. (p. 9)

Yet, sometimes humorous stories about disability are told by people without disabilities, and used in oppressive or disabling ways (Bingham & Green, 2016). With this in mind “humor narratives carry significant cultural power. Humor can be (and often is) used to oppress. It may, however, also be used to empower and counter the tragedy narrative of disability, to resist and fight back against disabling humor” (Bingham & Green, 2016, p. 95). In this way, disability humor can “function as a mediator of social experience, a method of social analysis, and a strategy of social activism” (Bingham & Green, 2016, p. 95).

Bingham and Green (2016) look at how comedians with disabilities have used their performances as an avenue for discussing topics of disability through a comedic lens. Yet, both Bingham and Green (2016) note that their book and current research is limited to comedians and so pose the question to other scholars, “What about the use of humor in everyday interactions by individuals with disabilities who are not comedians?” (p. 159) Tending to and extending off this question I ask specifically, how do family members use comedy and humor in their everyday interactions to communicate about the illness experience?

Theories of Humor

Bingham and Green (2016) connect general theories of humor to lenses of disability to understand how humor functions within the lived experience of disability. Their focus is on the staged performances of disabled comedians. My chapter applies these very same concepts, but in the context of everyday experiences of families living with illness and disability. The four

theories of disability humor that Bingham and Green (2016) explore are: Superiority theory, Relief theory, Inferiority theory, and Incongruity theory.

Superiority theory is described as the type of humor or joke that pokes fun at the inferiority of others, and “positions the source of blame or liability at the personal level, rather than blaming broader ideals and norms” (Bingham & Green, 2016, p. 96). In the context of disability, this is the type of humor in which someone laughs at the impairment of another, and perceives their disability as failure rather than variation. Yet, superiority humor also enables those with disabilities to push back, and many comedians have used superiority humor “to turn the tables by framing not disability itself, but traditional able-bodied interpretations of disability as morally inferior” (Bingham & Green, 2016, p. 99).

Inferiority theory on the other hand, is very much the opposite of superiority theory. It manifests itself as self-deprecating humor. This type of humor attempts to get others to laugh with, as opposed to at, someone with a disability. By creating humor based on relatability or universal experiences, inferiority theory refocuses on the shared experience at hand, rather than the person’s disability.

Incongruity theory and Relief theory are the two most common lenses for understanding disability humor. Incongruity theory relies on the idea that “when expectations aren’t met, hilarity can ensue” (Bingham & Green, 2016, p. 109). Laughter or comedy is a way of highlighting the absurdity of a potential circumstance, and relies on the disparities between “human ideals and realities.” In some ways, it “creates a cognitive shift by pointing out the paradoxical, ironic, or inconsistent aspect of social life” (Bingham & Green, 2016, p. 109).

Relief theory is “directly connected to the medical lens [of disability], through the assumption that people who experience tragedy use humor as a coping mechanism” (Bingham &

Green, 2016, p. 100). The main focus of relief theory is to counteract pity by using humor as an outlet or source of empowerment.

Most existing literature on humor and disability discusses humor as a way of coping or normalizing the family experience, attempting to create a “regular” family and sense of normalcy in the face of “chaotic” disability experiences (Rieger, 2004). I argue that humor does not necessarily function as a way to cope, but rather as a way to move through the disability experience. It is not about making the illness experience normal, or regular, rather making the experience *a* norm and *a* regular experience. Since disability is often perceived as a tragedy and limitation, humor becomes a way to counter this tragic frame and creatively adapt to the lived experience of chronic illness/disability. Based on the four theories of humor, I derive four major themes or intentions of humor, as they are used in my family, a family that has lived with chronic illness/disability. These four major themes or functions are humor as relational, humor as reframing, humor as resistance and humor as relief.

Each of these four functions of humor, work together to “serve as active agents in the creation of new narratives of disability” (Bingham & Green, 2016, p. 94). And with new narratives of disability, I too might “illustrate new relational formations,” (Bingham & Green, 2016, p. 16) new ways of being “family” in the face of chronic illness/disability.

These four R’s of humor are not mutually exclusive, rather work in tandem with one another, often overlapping and informing each other. I use Bingham and Green’s (2016) theories of disability humor as a start to understand how humor is used in families communicating about chronic illness and disability. Again, I pose the four “R’s” of humor: Reframing; Resistance; Relief; and Relational, as the four major intentions and communicative uses of humor in families living with chronic illness.

Humor as Reframing

We sat in my Aunt Barb's living room, Kathy, Bob and Jim squished together on the forest green couch. Barb and I sit separately on respective dining room chairs, each anchoring either end of the couch. My computer and iPhone are placed on the coffee table in between us all, used as recording devices for this session.

"I've brought you all together today because I think it will be great to hear more stories from you and hopefully you can fill in some of the gaps in each other's stories and tell me more of..."

"The lies?" my Uncle Bob sarcastically interjects as the rest of the siblings laugh and sigh, as if to acknowledge, "Oh Bob."

I giggle and reply, "Yes, the lies you've told. And so, we begin our interviews with lies. A perfect place to start."

I continue, "Can you think of examples or stories in which humor was a part of the way that Grandma and maybe the family dealt with her illness? I know being funny was inherently a huge trait of hers..."

My dad chimes in, "Well you know Alyse, I will say it's so much the same as you and Jana relate to your mom, exactly the same. You know the self-effacing kind of humor? My mother was exactly the same way. Some of the things that your mom does are exactly like my mother. You know sort of saying strange things she knows are funny, that she probably shouldn't be saying, but goes ahead and says them anyway? Grandma would do that too. Just like throw something out there. I think when my mom knew she was sick she threw zingers in there every once and a while that were like, nobody is expecting this and don't take this too seriously."

"Really? Like what?" I ask.

“Well,” he pauses to think, “My mother didn’t lie very much, but I remember this person coming to the door this one time. She must have been selling Avon or something and your grandma was already turned off by her because she kept pronouncing potpourri as POT-pourri,” we all start laughing. “And Grandma tried to correct her by saying, it’s potpourri if you must know. But the woman ignored her and continued trying to sell her items, and grandma said, you know she was thinking to herself I just don’t have the energy for this. So, she interrupted the Avon lady and said, “You know, I’m so sorry, but I have a terminal disease and so I need to go back in the house,” and closed the door on the lady. She came back inside and was like, well I feel bad but I got rid of her by telling her I was dying. And then she proceeded about her regular business. So, zingers like that.”

Aunt Barb continues, “You know our mom never liked to be a burden on people, and sometimes she’d just get to the point where she just had to complain because it got bad you know. She would say something and then follow up with something funny afterwards because I think she didn’t want us to feel bad. You know she’d say “I’m just so tired of hurting” and I’d say “I know mom, I wish I could make it better” and then she would make some sort of comment like “You know God says he doesn’t give you more than you can handle, but he’s pushing it,” and make me laugh. I think partially it was to make herself feel better but also because she didn’t want to make us feel awful and she knew we did, so she would often do that, say something sad and then immediately have a joke after.”

Humor as reframing focuses on the shared ability for families to reframe a difficult experience and make it into something which they can laugh about. As my Dad notes, his mother’s ability to add “zingers” at moments redirects the focus of conversations or the focus away from her. Additionally, as Aunt Barb mentions my grandmother would often use humor to

make her children feel at ease with the disease. This type of humor is more stereotypically used amongst people with disabilities because they often take the burden of others on as their own (Goffman, 1963). One could view my grandmother's use of humor in this situation as accommodation, but I view this as a way to take control and agency of the situation at hand, and to reframe it on her own terms.

Rather than allowing an experience or story to take control of the way that my grandmother or mother define themselves, or my family defines them, humor works to reframe the focus. To reframe the way they themselves, and the way my family approaches the illness. The use of absurd "zingers" and joke-telling, show the power of humor to reframe painful situations and experiences for my family.

Humor as Resistance

My father continues, "Well, we went to some MS stuff with mom. What was it--the MS luncheon or whatever, remember?" Jim asks the group. "Remember we'd joke around with mom?" His voice lowers, "Oh, we're going to get MS for lunch today."

Uncle Bob swiftly interjects, "No, it's the suicide picnic you're thinking of." Everyone begins to laugh uncomfortably, and my dad replies, "No, no it was MS."

Uncle Bob assuredly states, "We did go to that too though. To the suicide prevention picnics."

Aunt Barb nods in agreement and continues, "Yeah, we called it the last supper."

The entire group bursts out in laughter, simultaneously awkward but relieving laughter.

The family uses humor to resist the potentially tragic framing of the experiences they've had with their mother. By diverting the conversation away from the literal facts that they were at

luncheons for people suffering from illness and depression, they poke fun at the experience to resist the way it functions for them personally and communally.

This is the type of joke that could be perceived as politically incorrect, but I see power in the politically “incorrect” joke. As Bingham and Green (2016) note, “politically correct control of language can detract from [a joke’s] dynamism. The more practical concerns of disabled people—such as demeaning treatment, inadequate or discriminatory public policy, devaluation of disabled lives, and other real-world issues—can get lost when there is an overemphasis on surveillance of language” (p. 134).

There were and are many moments where MS has become too much for both my mother and grandmother. My mother very frankly will state, “I’m just sad. I’m just depressed.” And I learned that my grandmother also vocalized numerous times that she wanted to die, but it was her children that kept her alive. Yet, in the face of this, both my mother and grandmother, as well as my family members have used humor to resist sadness, rather than define the illness experience only through tragedy or hardship.

I have also personally found that I use humor to resist on behalf of my mother. I am defensive for my mother, and act in protective ways. This possesses the potential to hinder my mother’s voice and to perpetuate stereotypes of the passive disabled person who can’t speak for herself. Yet, I also know this resistance can often be productive. I see humor as resistance, as a communal way that my family pushes back against reductionist stereotypes and pushes back against people who sympathize, rather than empathize.

I am surrounded by dozens of 50-something women, self-identified “Ladies of Luxury.” I’m lost in a sea of bright pink and green dresses, with patterns akin to the curtains at my grandmother’s house. My mother, sister and I all fake a sense of comfort as we enter the party.

I park my mother’s wheelchair at her designated seat, and walk away from the table for what seems like a millisecond, before I’m intercepted by a woman in one of the curtain dresses, “OH MY GOD!! Alyse, is that you?”

With absolute false certainty in my voice I respond, “Yes! Hi...” My voice trails off. I have no clue who this woman is.

In a slow, slurry response, one that seems either Chardonnay or Xanax induced, “It’s meeee, So-And-So’s Mom! I haven’t seen you in yearssssss. You look wonderfulllll. How are youuuu?”

“Oh yes!” (Still no recognition. Don’t remember So-And-So. Don’t remember the Mom.)

I quickly plaster a smile on my face, “How is So-And-So?”

She begins to slur out more words, as I begin to drift off, when she suddenly interjects in a tone of forced compassion, “Oh, (long pause), how is your motherrrr doingggg?”

Ah, here we go. This is the moment of truth. The infamous question. A question I don’t entirely blame people for. It’s always well-meaning. But the subtext of “How’s your mother doing?” is always a desire to know about her health, never the human things she does with her life. And rarely, rarely are they looking for honest answers like, “Oh, well she can’t really walk or drive anymore, and holding her bowels is a big struggle.” Or even, “Well now that you ask, she has read three books this month, booked the venue for my sister’s wedding, and had more of a social life than all of us in this room combined.”

But I know this lady of luxury is a waste of breath. So, I courteously but ambiguously respond, “She’s doing well.”

“Oh good, good, good. You know she is just so lovely. I ran into her and your sister helping her into the bathroom. Your mother is just so sweet. What a nice woman.”

Holding my laughter in I respond, “Yes, she is. She is just such so, so...sweet.”

I return to my mother and sister, intelligently keeping to themselves and I sarcastically whisper, “That lady over there said she thinks you are just the sweetest, Mom.”

My mother smirks at me and sassily replies, “Well I just am, Alyse.”

My mother, a woman who is genuinely kind and compassionate, is also the sassiest person I know. Sweet and demure are not two words I would ever use to describe Denise Keller. Yet, they are two words I often hear people use to describe my mother, grandmother and many folks with disabilities, who become reduced to innocent creatures without a backbone or opinion.

I continue, “I’ve decided my new response to people when they say “Your mother is so, so sweet” is to respond ‘Really? That’s funny because that’s not what the inmates said about her before she got released from jail.’ What do you think?”

We laugh, my mother takes a sip of her drink looks back at me and says, “Make sure you say my name was Big D in jail”

I smirk and say, “Deal!”

In these specific instances, humor resists the idea that my mother is merely a “sweet” disabled woman, and defines her as more. As Garland Thomson (2011) notes, "female, disabled, and dark bodies are supposed to be dependent, incomplete, vulnerable, and incompetent bodies....Women and the disabled are portrayed as helpless, dependent, weak, vulnerable, and incapable bodies. Women, the disabled, and people of color are always ready occasions for the

aggrandizement of benevolent rescuers, whether strong males, distinguished doctors, abolitionists, or Jerry Lewis on his telethons" (p. 20).

Again, the point is that these utterances of pity, masked as kindness, are often discursive disassociations from people like my mother, those they see as living a less desirable life than their own. Humor as resistive provides our family a sense of agency in the face of stereotypical constructions of disability. For me it becomes a way of defending my mother, but also a relational way for my mother and me to use humor to push back together.

Humor as Relief

We both sat in a back room of his house, him on the brown couch and I in a burnt orange chair, a side table nestled between the two of us. Uncle Bob was already crying before we even started the interview.

He sniffled, "Well this was a given, I cry at everything. Hallmark commercials, every wedding I've ever been to..."

He and I laugh and he continues, "Okay my mother, she'd laugh at herself sometimes too. I was at one of my many different points where I ran. So at one point I was preparing to go out running, and her MS wasn't terrible yet, but her equilibrium wasn't good, and she said 'I'm so jealous you can go out running, I would just like to go out running.'

So I said "Well come out running with me, we don't have to go far." And she said "Really?" I said "Yeah yea we don't have to go far." So I gave her one of my sweat suits and she put it on and got all dolled up in running attire and we went out. I don't think she'd ever tried running in her life, but of course she wanted to try running with Multiple Sclerosis-- but that's okay! So, we got out there and she was all excited. Of course we were running a slow pace anyway, and so we'd run, and she'd start going off the sidewalk. She never fell, just sort of

veered off. And she'd go again and then go off into the grass. Eventually she goes 'This is really ridiculous!' She would just continue going off the side of the road until we reached the end of the block and she proclaimed, 'I think I must retire from my running career!' We laughed and we both walked back home."

When humor becomes a tool for relief, it refocuses the purpose of humor as an outlet. It becomes a way to communicate through the experience. Instances of humor as relief were common amongst the stories told by my nuclear and extended family members.

Uncle Bob restarts, "You kind of worried when she went out. She went to a high school reunion over at Holy Angels, and she was in a wheelchair at the time. But she trusted the people that were going with her and stuff. So she went and it was all these friends she hadn't seen in many, many years and these people were pushing her in the wheelchair. These were probably people who weren't very familiar with a wheelchair. People think that they know wheelchairs and sometimes they don't. I don't know what exactly happened, I wasn't there, but whomever was wheeling her, they went and hit either a step or a bump or something and tried to get her up it and the wheelchair started going back, and the whole thing went backwards and she hit her head. She must have got a concussion because about twenty minutes later at the party she threw up, all over her dress."

Laughing Uncle Bob says, "Yeah it was not a good scenario, I think it's the only reunion she ever went to. No surprise. But she came back home, and was telling me the whole story and got to the end and said, "Other than that, I had a great time!"

Humor functions as an outlet, to share and process experiences. This type of humor "can be used to put others at ease with the issue of disability in order to get them to move past the impairment to other things" (Bingham & Green, 2016, p. 101). This type of humor counteracts

pity by showing my grandmother's ability to poke fun at herself and the ability for her family to embrace this type of self-deprecation. This is just one way in which our family uses the power of humor as an outlet in the face of disability experiences. Laughter and humor allow for moments of relief, the ability to take a break from the emotional chaos of disability and chronic illness (Wooten & Dunkelblau, 2001).

Like Bingham and Green, I re-conceptualize what coping means in the context of my family. I define coping as a way to communicate through experiences, as a way to "encounter" said experiences.

Humor as Relational

My sister Jana's pixilated face slowly emerges on the screen as she giggles, "I'm a whole lot of face right now! Hellooo from the other side!" she sings and waves at the camera, as the pixilation fades in and out.

"We're recording now, can you hear me?" I slowly scream at the computer screen, as my voice reverberates off my office walls.

Jana joyously repeats herself, "Hello!"

Growing irritated at the seemingly unreliable Wi-Fi I reply, "Can you not hear me? Are you there?"

Jana exclaims, "No, I can hear you, I'm just trying to be as formal as possible for our future audience," Jana grins, bleeding sarcasm. She knows I have to transcribe every word and utterance she makes.

"Stop wasting my transcription time, please. Are you ready now?" I retort.

"Mhmmmm. Yup. Mhmmmm. Wait, Alyse how are you going to transcribe "mhmmmm? Two m's, or three m's?"

“Jana Maria!”

“I’m kidding, I’m kidding!” she giggles, her voice purposefully lowering, “Let’s do this.” My sister and I have lived our entire lives with a mother with Multiple Sclerosis. A phenomenon that intrigued some people, didn’t faze others, and elicited pity from many. Our relationship towards one another has always been one which relied on humor, but throughout the course of our interviews we realized it was the most integral part of how we communicate about our mother’s illness with each other and those outside of our family system.

I look down at the nearly illegible pre-prepared questions I jotted down on a stray sticky note. I suddenly feel entirely unprepared for this interview. I know this is ridiculous since my “interviewee” is my sister. This isn’t some stranger. Yet, nerves take over as I start, “Welcome, Jana. Today I want us to talk about a variety of topics.”

Jana begins to laugh.

I defensively respond, “What? What did I do?”

“I’m glad I came to this business meeting. Let me formally introduce myself. I’m your sister, Jana.”

I giggle, realizing the absurdity of my formality, “Sorry, you’re right, we don’t need introductions. Okay, let’s just talk!”

Jana replies, “Perfect.”

“Interview” never feels like the appropriate word to describe our sessions with each other. Each discussion becomes its own comedy sketch, full with wildly inappropriate humor, and witty banter. Any time we err on the side of formality, we whip each other back to our shared, very informal reality. Using humor in our interviews provides a space to discuss experiences, which are often otherwise too difficult to talk about. This is not just about one

sibling's life event, rather a narrative of our shared familial experiences and how we are interconnected.

“Okay, where to begin,” Jana starts, “Well you know I always say, you wipe your own mother's ass and the word awkward doesn't apply to your life anymore.”

Rolling my eyes, I respond, “Right, naturally the perfect place to start our dissertation interview, Jana.”

Humor as relational means, really relating. This may seem redundant, but so often we sterilize experiences in interviews. We sterilize our emotions, or the stories we tell. That never happens with my sister, a point proven by the beginning of our “interview session.” And I firmly believe that humor is a catalyst for this relationality.

“Well, I think one of the most difficult stories I can remember about mom was at our cousin's wedding. Mom had another accident. I knew it was going to happen though because she was wearing tights and mom only has accidents when she's wearing tights. That way it gets nice and messy,” Jana sarcastically affirms.

“I don't find those incidences frustrate me so much as they hurt my heart. Like we were in the photo booth having such a fun time and she said “I have to go,” and then her face was so defeated and then we all smelt it. No one cared, but she did, and that's what I hate. I hate when she apologizes when you clean her up afterwards. Or how when she got on the toilet she put her face in her hands. Those moments are awful. She's a grown woman who doesn't want her children to have to clean her up and she wants to just enjoy a party without having to have a complete outfit change. I think that's reasonable, it's not too much for her to ask and it's in those moments I hate MS the most. I hate that it makes her put her face in her hands. I hate that it makes her apologize because she has nothing to apologize for and no one to apologize to. If

anything, she deserves to have more accidents. Every parent on this planet should after their children are grown. Then their kids can clean and change them like they had to do for us thousands of times. It's like pay back for all the times we screamed "I hate you!" as teenagers. Parents can turn around and be like, 'Remember when you were 15 and you said you hated me and acted like a child when I didn't allow you to go to that inane movie, well you're definitely going to hate what you see in my undies in a minute.' And then the circle of life would be complete! And that's where you would cue the Lion King music, Alyse."

People have often accused my sister and me of using humor as a crutch, or a way of covering up how we feel. A coping mechanism if you will. But I've never thought humor hindered our ability to communicate, rather humor has enabled, not only me and my sister, but my entire extended family to communicate about what it's like to live with MS.

Through our collaborative interviews (Ellis & Rawicki, 2013), and use of humor as a communicative mechanism, we realize our capacity to empathize with each other. This allows us to share experiences by "being with and allowing ourselves to be in communion with the other" (Ellis & Rawicki, 2013, p. 376-378). Both my sister and I lean into the idea of uncertainty and doubt as an integral part of the familial illness experience. Humor has the ability to break the sometimes harshness of reality. Embracing laughter and humor creates possibility, when sometimes it feels like there is only impossibility.

Humor as Narrative Medicine

The interviews and narrated experiences with my sister, mother, father, and extended family members exemplify how humor functions to point out societal misunderstandings or misconceptions of the disability experience, to poke fun at each other and the experience as a whole, to critique and counter the political correctness of humor, and to understand that political

correctness has a time and place. Humor becomes narrative medicine because it functions as a form of relief, resistance, a relational tool, and a way of reframing experiences for my family. All four of these functions contribute to the idea of humor as a form of narrative medicine.

Overall, each interview is unique and drastically different. What's particularly salient is that both my grandmother and mother utilized similar approaches for communicating about/through their illness. This isn't to say this is the only way, but it is one way, that given their lived experiences, they chose to embrace. Two women with very different backgrounds and personalities, very different families at the time, chose to use humor to communicate with others and themselves. Additionally, my nuclear family and extended family also use similar forms of humor to communicate about their experiences.

The chronicity of Multiple Sclerosis has the ability to fracture, fracture relationships and fracture stories. As we piece together the fragments of our narratives, we use humor as the glue which binds us and our stories together. As we de/re/co-construct illness experiences in relation to one another, we use humor as a way to understand how Multiple Sclerosis functions in our family and how it has impacted our experiences. Through comedic vignettes and "sketches" of traumatic incidences in our lives, we rewrite our understandings of those events and each other. We see laughter as a way to move through these experiences, and as an alternative space to explore the "normalcy" of our familial dynamic within the particularity of our lived experience.

These examples of humor used in my family can be viewed as "tools in the arsenals available [to family members] who seek to use humor to push back against the disabling assumptions, beliefs, and actions of people living in an ablest world" (Bingham & Green, 2016, p. 116), as well as tools for living well. Humor is not a way to mask sadness or suffering, rather it does productive work (Lanphier, 2016). It points one in a new direction, allowing those living

through difficult or confusing experiences “to work on the tragic in the present moment.”

Therefore, humor can help us perceive in ways previously unavailable to us.

In many ways, reframing the disability/illness experience from a comedic rather than tragic frame is hard. Tragedy is too easy, it’s too easy to depict the stereotypical tragic patient, or disabled person. The tragic frame is the dominant narrative that presupposes how we imagine disability and how it should be interpreted socially. People with disabilities or chronic illnesses are always already introduced as tragic figures who come to serve as a reminder and reaffirmation of ablebodiness. As a result, we are used to the tragic frame and assume it to be the norm.

Comedy counteracts this assumption, and becomes a counter-narrative to the tragic construction of the disabled person. Comedy is where hard work is done. I “employ humor as an index and epistemological tool to examine disability in social context. [I] also reverse the lens, using disability as a way to better understand humor” (Bingham & Green, 2016, p. 6). Humor becomes a way to step back and provide a mode for families living with chronic illness/disability to reimagine family, for themselves and those outside the experience. The four R’s also become integrated into the construction of my performance and influence its overall purpose and intent.

All four of these “humor paradigms provide an interpretive lens through which individuals can be encouraged to bear witness to the unexperienced and to reframe their previous ideas of normality” (Bingham & Green, 2016, p. 116). Humor relies on an understanding of context, a relational sensitivity towards the other and a keen ability to listen. As such, an analysis of humor as narrative medicine becomes an exemplar for how to understand the ways that empathy, understanding, and compassion are practiced communicatively in families living with chronic illness. These humor competencies work together to form new narratives for disability

and chronic illness, which in turn can open up new possibilities for families faced with chronic illness and disability. Humor becomes a comedic counter-narrative, a *counter-narrative medicine* for my family and me.

In the next chapter, I explore the process of crafting performance script(s) out of the many humorous stories I derive from my interviews and document the labor of embodying those narratives.

Each time I return to my parents' home, is a marker of time passed and maturity gained. It is also an indicator of the toll MS takes on my mother's body. She/we change each time. The scents of oregano and fresh basil swirl throughout the house.

Over the buzz of the television set, I cry uncontrollably. I lie across her chest, and sink into her. My whole body shakes. My broken heart keeps beating.

"I'm sorry, Mom. I'm not a human right now."

We lie on her bed, the View, or Oprah, or Good Morning America playing in the background.

She softly replies, "Don't be sorry. I'm sorry. I wish, as your mother, I could do more for you. I'll just sit here and listen as long as you need, Jana-Alyse-Jana."

I look up at her, a smirk creeps across my face, "I'm Alyse, Mom," correcting her commonplace confusion about which daughter I am. At least I'm not the ever exhausting Alyse-Jana-Alyse-Jana, as my mother so fondly calls my sister, Jana.

"Right, honey. I know"

"Okay," I muffle into her chest.

Minutes go by and she finally breathes a long sigh and whispers, “Well, I know why you’re this upset. You’re this upset because,” she hesitates, “because he touched you, isn’t it?”

I look up at her, and we both erupt in laughter. I was waiting for this, waiting for some “zinger” from her.

Composing myself I respond, “Well yes, he certainly did touch me. We dated, mother.”

Still laughing, and covering her mouth in embarrassment she lets out an, “Oh no! Why did I say that?”

I giggle, “I really don’t know, Mom. But I think it’s perfect. I loved it”

“Well good. At least there’s that.”

“Yes,” I reply, “at least there’s that.”

We continue to lie there, my head rising and falling on her chest with each breath, and I think to myself, “Frankly, I hope we continue laughing, but with each other, always.”

CHAPTER FIVE:
REHARSAL AND PRODUCTION:
PERFORMANCE AS NARRATIVE MEDICINE

Ethnographic performance can do the labor of making local work a global issue. It hopes to re-imagine Otherness. It hopes to disturb and invoke. It hopes to always and already make Others known, real, and memorable, not only in what they say, but in what they do
– Madison (2005)

If you say a word often enough, it becomes you
-Smith (1993, p. xxiv)

My hands shake and my heart races. My caffeine buzz pulses through my body as I sit in the audience waiting for the performance to start. I feel underprepared and overly caffeinated. I've been rehearsing for over a month now, memorizing whole narratives, and working on embodying each character. I've rehearsed with colleagues, with faculty, and especially on my own. I spent this entire 6-hour car ride to Statesboro, Georgia listening to my own recorded voice on repeat, reciting performance narrative after narrative. I sometimes reiterated them quietly under my breath, sometimes screamed them above the sound of my car radio until my voice was hoarse, or sometimes silently in my head at stoplights where passersby gave me funky looks. But even now, even after all these preparations, I don't feel ready.

I enter the stage, a large black box theatre, the floor surrounded by bleacher seats on one side and a stage on risers behind me. I move to the stage situating myself on the edge. Facing my audience, I wait for my audio to begin. It starts with, "Okay, so I've gathered you here today..." I cringe at the sound of my own voice, which ricochets off the walls and ceilings, but I know finally indicates the beginning of my performance. The audio ends and now my video, which

provides some educational information about MS, should begin on a projector behind me. As I sit literally on the edge of my seat, I wait for the video with accompanying audio to indicate my transition into the next phase of my performance. But...

there is no audio.

“Just wait, Alyse,” I think to myself. My heart starts racing again.

Silence. Still, no audio.

“Keep waiting,” I think. “Practice patience. You suck at it, but try.”

Still there is no audio.

“Okay, now it’s time. Now you can panic, Alyse.”

I break character for a moment, and look back at the projector behind me to check that the video has begun. The video is running, but there is still no audio. The video provides my audience with an explanation of the anatomical and medical effects of MS. The video’s narrator is a stern and authoritative voice. His robotic intonation begins with a medical description of Multiple Sclerosis. He uses words such as “attack,” “infiltrate,” “unpredictable,” and “loss” to describe and frame MS. His language use makes MS seem like an eerie warzone, with video images showing ethereal and otherworldly nerves and cells. Subtle hues of purple and blue make the whole video sequence seem dream-like and unrealistic.

The video is important for this performance because it provides the audience a foreshadowing of the “Sergeant” doctor character who will perform alongside me in a moment. I create the doctor character as a symbolic manifestation of these very same medical narratives of chronic illness. Medical narratives which are limiting, authoritative, aggressive and pathologizing. The same medical narratives that force people with chronic illness to feel they have limited options for performing self. Later in the show, I will weave the doctor character’s

lines with my family's narratives to illustrate a holistic view of the voices family members are bombarded with on a daily basis. But in this moment, all that matters is that the audio for my video isn't working.

Obviously, this wasn't supposed to happen. I prepared the script as perfectly as possible, working to ensure each audio and video transition was distinctly noted on the script. The show ran without any issues during rehearsal. Yet, sometimes as much as you rehearse and prepare, things don't always work out the way you expect them to. But as always, the show must go on.

An Ethnographic Exploration of a Performance Ethnography

Multiple Sclerosis is progressive by nature. It is an illness which is continually changing, making those living with it or in its presence, exhausted and uncertain. Performance, by nature, is also a fluid process which shifts and changes each rehearsal and production. As with the lived experience of chronic illness, performance is a process that is fatiguing and has ambiguous outcomes/trajectories. I argue there exists an explicit parallel between the performance process and MS as ever shifting and changing phenomenon. Again, I continue to argue that *performing narrative medicine* is a heuristic tool. I use my performance process as an analogy or instrument for understanding what it means to be a family and family member living with chronic illness and disability.

In this chapter, I merge my experiences during each of my three performances as one "site" of analysis. As with traditional ethnography, I explore the work that goes into each of these performances and the iterative meaning making and shift over time which occurs because of the relationships amongst performer, audience, and text. Voice and body work as analytical tools, "as instruments for examining the aesthetic texts of others" (Pelias & Shaffer, 2007, p. 77). As Madison (2006) notes, "ethnography is as much, or more, about bodily attention—performing

in and against a circumscribed space—as it is about what is told to you in an interview” (p. 401). In other words, a focus on the embodied nuances and non-verbal cues can communicate just as much as the words during performances.

I enter this chapter with an understanding of the performance process and use of narratives as pedagogical and medicinal. As Pineau (1995) notes, “Performative research, whether it takes the form of ethnographic fieldwork or formal productions of aesthetic texts, insists that living, breathing, speaking, and moving bodies are invaluable sites of inquiry and understanding,” (p. 46). In this way, performance is an embodied form of criticism and knowledge, a way of bringing culture and personal experience/expression into conversation with one another.

As my performance develops and grows, as I endure the trials and tribulations of rehearsing, creating, and producing, I realize the similarities this process has with the process of being a family member living with chronic illness/disability. Warren (2010) notes, “performance has been used as a productive metaphor for subjectivity, calling on us to conceive of nuanced ways of seeing identity” (p. 218). In many ways, my performance calls on me to see my family members and their stories/identities in a new light. But predominantly the performance of their narratives calls on me to reflect on my own identity as a daughter and family member of maternal chronic illness.

Over the last year, my performance has taken many different forms and I presented in a variety of contexts. This was not accidental, rather it was an active decision I made for this project. My performance and performance scripts must shift and change in the same ways that life with chronic illness revises and changes itself on a constant basis. As I continue to grow and change as a scholar, daughter, and performer learning about this disease’s relationship with my

family, so must my performance. My performance is a dialogic act of inquiry, and my way of communicating with myself and others about the lived experience of illness in families.

I mark my performance as aesthetic communication. Campbell (1971) broadly defines aesthetic communication as “the dimension of language in which we create and recreate ourselves in relation to the ‘real’ world around us and in which we use those imaginative or artistic events (originated by others or by ourselves) to become new beings or personae” (p. 9). My performance as aesthetic communication works to help create new ways of talking about “family” or being a “family member.” It starts by creating open dialogue about the illness experience between my family members and me, and the audiences who witness the performance. Performance possesses the potential “to educate and transform, to unify and heal” (Pelias & Shaffer, 2007, p. 170). It possesses the ability to “unify” and “heal,” to working medicinally as a cathartic way to bring together my family members and those outside our lived experience. The performance process itself creates a space to learn what it means to be a family member living with chronic illness, and to educate others about this experience as well. It brings people one step closer to understanding our experiences.

On one level, my performance becomes public pedagogy since it works to communicate with audiences about health and illness in the context of family systems. The use of performance to communicate about health with the public has been used by both performance and health communication scholars as a means of educating and progressing justice-oriented agendas (Conquergood, 1988; Harter et al., 2016).

By putting the stories of my family members on display, I give voice to the traditionally private stories of families, making them political and public. Family communication studies have traditionally been a private sphere and "disconnected from seemingly more profound matters of

the public sphere" (Suter, 2016, p. 5). A reconceptualization of family communication, particularly from a critical communication lens, places the "daily affairs of the family as political sites, embedded within broader societal systems and discourses and underscores the mutual interdependence of macro-level cultural concerns and micro-level familial matters" (Suter, 2016, p. 1). My project is a public form of research which exposes my interpretations and analysis of family communication through my body and voice.

Public forms of research, such as performance, allow for messages to be disseminated more widely but also for audiences to immerse themselves, if only briefly, in the stories that are being performed for them. As Frank (1995) suggests, "To think about a story is to reduce it to content and then analyze that content... To think with a story is to experience it affecting one's own life and to find in that effect a certain truth of one's life" (p. 363) I invite my audiences to think with me and my family by speaking directly with them and performing my family's narratives from the individual interpretations/characters of each of my family members, rather than an omniscient narrator. To think with the stories and performances of these narratives that I portray.

As Geist-Martin (2016) notes, "Storytelling is one of the most potent medicines at our disposal" (p. 363). As I perform the stories of my family, I also think with and "become" the words and stories I perform. Through performing I am inherently exercising the qualitative process of empathy. Therefore, this form of narrative medicine does not only work for witnessing audiences, but for me as well.

To infuse narrative medicine with performance sensibilities, and inversely performance ethnography with principles of narrative medicine, I push discussions of family communication surrounding disability/chronic illness towards dialogical performance. Conquergood (1985)

defines dialogical performance as a “performative stance [that] struggles to bring together different voices, world views, value systems, and beliefs so that they can have a conversation with one another” (p. 9). The emphasis here is on the “struggle.” It is not easy to empathize with others or to create open and genuine dialogue, but I cite Conquergood’s dialogical performance because it foregrounds performance as one way to understand how families living with chronic illness/disability communicate or create conversation amidst the push and pull of various and often competing narratives and models of “how to live well.” Dialogical performance and narrative medicine provide theoretical frames to understand how my aesthetic performance functions as a sense-making endeavor.

I document my rehearsal and production process by using five of Charon et al.’s (2016) six principles of narrative medicine to frame my analysis: intersubjectivity, relationality, close reading, creativity, and personhood & embodiment. I explain how each step of the performance process, as a site of analysis, works “medicinally” for me and possibly for my audience. By weaving together narratives of my performance experiences and lived experiences as a family member living with chronic illness, I show and perform on the page how performance is narrative medicine.

My choice to create disjointed narratives also correctly reflects the chaotic and often confusing relationship loved ones have to illness and disease. I move to include both the voice of tragedy and comedy in my narratives because that more fully reflects our lived experience. By granularly looking at the step-by-step process that occurs in the creation and presentation of my public performances, this chapter becomes an act of questioning, probing, creating, embodying, challenging, and working toward greater understanding of how performing narrative medicine works as a heuristic tool.

Choosing Narratives

After posing questions, creating a purpose and interviewing my family members, the process of choosing narratives comes next. The process is never linear. I listen and write, listen and write, constantly moving back and forth between the audio/video of my family and their written words. I begin by extracting narratives that resonate with me emotionally, comically, and informatively. Ultimately, I want the whole of my script to tell a story, a story which is as fluid as it is disjointed, and one which depicts the many facets of living with MS. With my purpose of showing “humor as narrative medicine,” I want the performance to show how family units communicate as a whole but also how this system is comprised of individual voices.

Listening to the interview audio of my father and his siblings, a cacophony of voices invades my headphones. At this point I’m not certain how I will distinguish between each, or how I will perform all these different characters. They are telling important stories, many of which I find especially poignant. But how do I decide which to use and which to save for later? I return to my father’s interview audio, in which we discuss his experience living with my grandmother.

He starts, “There were kind of like big picture things, like she loved to dance. She always said that, you know. I know she loved to sing and she always did sing, but I guess I didn’t realize it because as a kid your mom doesn’t dance with you that much. She taught me to dance but it’s not like I spent a lot of time dancing with my mother. I didn’t realize how much she liked to dance until she couldn’t, and that’s what she used to say. She used to say you know, I really miss dancing.”

I sit with his words. My eyes well up, swollen red. Every time I hear him say she couldn't do the things she loved, I become angry, upset, and sad. "Get it together, Alyse," I think to myself. This must stop. I can't keep crying in public places. Well I mean I can, but by God this is getting exhausting. It's been weeks, no months of this same routine, and I keep coming back to some of the same narratives over and over again, some of them hilarious, others informative about MS, and many deeply poignant and powerful. I know that I keep returning to these same ones for a reason. This must mean something. These must be the ones I need to tell, but know I can't tell them all.

My dad continues, "I remember many times her saying I miss dancing, or I miss driving. Anyway, she had come home from the hospital that first time, and I remember when she came home, she was home permanently, and we decided to drive to see her sister and our cousins in Rochester. I just remember that that being very special, very upbeat. We were all together and happy. We were driving up there and I think Kathy was driving, so it was probably the first time Kathy had driven to Rochester. I'll always remember Stevie Wonder's song, "You are the Sunshine of My Life" played on the radio. It was just becoming popular then, and so that's always been my song for my mother ever since then."

My father takes a long pause. I can hear through the audio, as I remembered living it during the interview. He and I both struggle to gain composure. He starts up again, "It was, it was a hit at that time. It played at least, at least once while we were on that ride. I remember it just seemed very apropos, her kinda coming out of the hospital and being you know, our sunshine."

I sit down with all their words on the page and listen to their audio recordings, trying to figure out which stories to communicate to an audience. Unfortunately, “choosing brought about its own brand of worries. There were narratives that were eloquent and deeply poignant, yet beyond my purpose” (Madison, 2005, p. 400). One of the most difficult decisions during this process was figuring out which narratives to keep, and which would remain filed away to be told later, or never because “even the discarded [narrative] is instructive” (Pelias & Shaffer, 2007, p. 77).

With each story I chose not to use, I felt I was concealing a voice that could be/should be heard. I had the power to choose which to tell, and frame why these stories are told. This power makes me feel anxious and feels burdensome. I want to make sure my family is portrayed in the best light but also don't want to leave out the gritty details of our lived experiences.

Though a difficult process, I found that I was still able to incorporate the essence of some of the omitted narratives. For some narratives, including symbolic elements was more important than the actual words being spoken. For instance, though I was not able to incorporate the narrative of my father discussing his mother's love of dancing and driving, or that “You are the Sunshine of My Life” is the song that reminds him of her, I made sure during my second performance event that I played “You are the Sunshine of my Life” while my audience was filling the room. Though not overtly a part of my script, there was a part of this story that I was able to integrate into my performance event. It is important to understand that performing narrative medicine is more than the words that come to life in my script, it is a practice which draws numerous elements, including the sometimes “hidden” aspects of the qualitative research process.

After mining the interview narratives and audio recordings I'd acquired, the next part of the process:

Was then ordering and juxtaposing them for the stage. It is at this point in the scripting process where it feels like you are both a social critic, building an argument of logic and persuasion, and an artist creating an object of imagination and beauty. (Madison, 2005, p. 401)

I had to figure out a way to sort the narratives and tell the stories that address my main questions. I extract the narratives that resonate with me and layer them together on a word document. It is through the layering of each of these individual voices that I ultimately create an object of "imagination and beauty," and one that weaves my family's narratives together to create a whole story. As Pelias & Shaffer (2007) assert, "One of the most important aspects of creating aesthetic stories for the stage is the shape of the stories themselves...stories should be creative and clear" (p. 55). With this in mind, I make sure to highlight the distinctly individual voices that comprise the community of my family members living with chronic illness, as my script(s) finally come to life.

As my scripts begin to take shape, so does my ability to see the resonances I have with each of my family members' experiences and stories. My process of selecting narratives for my performances and my surprising emotional reaction to feeling like I was concealing narratives all link to my performance as a heuristic for understanding the experiences of families living with chronic illness/disability.

Rehearsal and Production

"Stars shining bright above you, night breezes seem to whisper I love you. Birds singing in the Sycamore tree, dream a little dream of me." Ella Fitzgerald's "Dream a Little Dream of

Me” quietly fills the room, creating a background serenade to my seemingly never ending writing session. Ella was one of my grandmother’s favorite artists, a detail I learned from my Papa during our interview session. Ella has accompanied me now throughout most of this rehearsal process. The vibrato of her voice feels familiar and commonplace while I work to memorize my script. It feels like a piece of my grandmother is always with me, ever so subtly nudging me along.

Pacing back and forth I recite the same line over and over. I am struggling with my Aunt Kathy’s narrative today. For some reason, I am having a hard time creating a performative distinction between her and my Aunt Barb. They are very different humans, with drastically different mannerisms, but when it comes to performing them I am having a lot of difficulty.

“You know you can do this,” I mutter to myself.

I start with her line, “I really didn’t do a lot in high school.” Nope, not right. I start over again.

“I really didn’t do a lot in high school.” My tone isn’t high enough. Try again.

“I really did do a lot in high school.” Not even close. Now you’re making lines up.

“Come on Aunt Kathy!” I scream out at no one, but myself.

“Are you okay in there?” I hear my roommate ask.

Laughing and slightly embarrassed I reply, “Yes! Just rehearsing. I’ll be talking to myself all night. I’m sorry!”

“No apologies,” she yells back. “You do you.”

I try again, “I really didn’t, umm…” but the line won’t come to me at all this time. I’m growing increasingly more frustrated with each iteration. Why can’t I just remember this?

I know this frustration. It's familiar. It's the same frustration I feel for my mom when I've told her the same thing several times in a row and she keeps asking me what I said. Or when she calls three times consecutively, not remembering that she just called me two times prior. Or when she can't remember my name when we talk. It's the frustration I imagine my grandmother felt --after being diagnosed with MS-- during the infamous ground beef incident, a story my family tells often.

She kept repeating "ground beef," over and over again as she walked down the stairs to make sure she remembered to bring ground beef up from the basement and save herself from having to descend the grueling steps again, only to find herself upstairs, without any ground beef in hand, and still repeating the words, "ground beef...ground beef".

I take a deep breath and return to the script. "Take your time," I say to myself, "Just be patient. You can do this." I start over again, as Ella continues to push me along.

In this section, I break down the rehearsal, and production process with Charon et al.'s (2016) guiding principles of narrative medicine. I start by explaining a bit more about my method of performance ethnography, then move on to explicate her principles of intersubjectivity, relationality, close reading, creativity, embodiment & personhood, since I find that these principles coincide with the steps and practices I employ during my production process. With this, I literally merge performance with the practice of narrative medicine, showing how I *perform narrative medicine*.

As Pineau (1995) asserts, "The play is already written. The ethnography is not. It is always writing and rewriting itself through the rehearsal process" (p. 402). As a result, the rehearsal is "an act of data-making," (Pineau, 1995, p. 48) and therefore I pull excerpts from the

three performances to show how my production process is an act of narrative medicine and ethnography. By breaking down my process into three sections: first, close reading and creativity; second, intersubjectivity and relationality; and last, embodiment and personhood; I ultimately reveal how these principles become the foundation that contribute to my understanding of *performing narrative medicine*.

The five principles were formulated by Charon et al. (2016) in order to provide an educational framework for how patients and physicians should approach the practice of narrative medicine, specifically in the context of the patient/physician interaction. Yet, I extend these principles beyond this context. My performance, as a practice of narrative medicine, adds performative understandings to what is deemed a historically medicalized theoretical approach. I argue these principles help my performance because they provide a sense making and organizing structure to understand the ways that performance is a form of narrative medicine. To heed the words of Charon et al. (2016):

The idea that one person can understand what another person says or means is the deepest part of science and the deepest part of art. This idea is the ground spring of language, of beauty, of knowledge, of government, of culture, and of love. In the shadow of that meta-perspective of human experience, we place our work in narrative medicine at a series of boundaries, realizing that the effort is always to bridge the divides, to seek the permeability, to unlock the channels that might provide unexpected benefit to both sides. Whether the two sides of the divide are psychopharmacology and psychoanalysis, a doctor and a patient, a war veteran and a nurse, or two readers reading one poem, the effort is to transcend the partisan or defensive, toward contact with one's partner not in

argument or agreement but in paradox, a contact that will not nail answers but will craft vessels for thought. In the process of the craft comes relation. (Location No. 4196-4202)

Everyday Life Performance and Performance Art

My performance is guided by the method of performance ethnography, but more specifically by the methods of Everyday Life Performance and Performance Art. I derive inspiration from performance work like Anna Deveare Smith's. In her work, she uses the words of her interviewees to create a performance, which largely works to critique and create commentary about race in America. Smith individually embodies each character in her performances and performs verbatim what the character said to her during the interview.

In her one-woman show *Twilight: Los Angeles, 1992*, Smith discusses the period of riots immediately following the Rodney King beating. Her play takes the form of a series of monologues created through interviews she conducts with those involved, affected by, or concerned with the L.A. riots. Again, what is distinctive about her work is that she performs these perspectives from her body, and her body alone. Ultimately my own, and "Smith's research goals are 'to become the Other' ...through listening to their recorded voices, then "wearing" their words" (Stucky, 1993, p. 172).

Deveare's approach to performance is what Hopper (1993) calls Everyday Life Performance, and Stucky (1993) calls Natural Performance. Everyday Life Performance is a method that calls for performers and researchers to perform the words, dialect, volume, pronunciation, and rate of those with whom they are researching (Hopper, 1993). Everyday life performance is a method which asks researchers "to collect and replicate in performance the conversations of others" (Pelias & Shaffer, 2007, p. 54). I engage Everyday Life Performance to achieve deep engagement with the narratives of my family members.

In order to do this I video and audio record conversations and interviews, then type up a transcript of the interview with notations and cues for my vocal and embodied performance. The goal of this model is to perform a memorized and close-to-verbatim version of the performance. Stucky (1993) extends this perspective and calls it natural performance. He similarly argues that “natural performance involves engagement in the artistic re/performance of something which was, at first performance, an ordinary event” (p. 168). The performance is heavily process oriented and requires careful attention to and repeated rehearsal of my scripts.

I also integrate performance art into my performances by using specific elements such as media, body as text, and culture as text (Pelias & Shaffer, 2007). Performance art is defined as a live performance in which the performer is the focal point, and text and performer become fluid. Performance art focuses on expanding traditional notions of what constitute aesthetic texts and contexts. I use my body, culture, and media as texts, to enhance the embodied and political manifestations of chronic illness and disability. I do so by experimenting with the use of video, incorporating other characters to highlight the medical establishment, and by breaking the traditional proscenium theatre format.

Ultimately, I use performance art because “it draws attention to the process of performance rather than the finished product” (Pelias & Shaffer, 2007, p. 177). Performance art allows me to experiment with character, context, and language. Though traditional performance ethnography typically replicates the exact context of the interview, I use performance art to expand context; to place the words of my family members in different scenarios that might highlight themes or messages that the original context may not do.

Victor Turner (1986) claims that “man is a self-performing animal—his performances are, in a way, *reflexive*, in performing he reveals himself to himself and the actor may come to

know himself better through enactment; or one set of human beings may come to know themselves better through observing /participating in performance generated by another set of human beings” (p. 81).

Everyday life performance and performance art, are immersive, intimate and risky. They are precisely the methods I feel are appropriate for my dissertation project. It is through the labor of living in and as these characters, of coming to know my own family members by “wearing their words,” and embodying them, that I see performance ethnography working for me and towards greater reflexive awareness. It is how I perform narrative medicine. My performance is “a quest that moves back and forth between the self and the other” (Smith, 1993, p. xxvii), and provides a greater awareness and understanding of the experiences of families living with chronic illness and disability.

It is in the process of crafting my performance that I find understanding across difference, specifically with the words and lives I perform. My performance works toward dialogic engagement, which is to work toward balanced conversation and understanding of self and other through the use of performance (Conquergood, 1985). The end goal of dialogical performance is intrinsically infused with the similar principles and practices of narrative medicine. I consider my own performance as dialogic. Just as I find parallels between my memorization process and my lived experience as a daughter of maternal chronic illness, I argue that documenting my process of performance ethnography becomes a heuristic for understanding the lived experience of families with chronic illness/disability, and thus a heuristic for *performing narrative medicine*.

Close Reading and Creativity

After performing the entire script in front of my director for the first time, I quietly murmur, “Okay so what do you think?” Do you feel like I was really embodying the characters? Was it believable?”

This is my second performance, but my first time presenting this piece entirely on my own, without the addition of the doctor sergeant character. One of the many concerns I have with this performance is my ability to make each of these characters believable to my audience. I do not want it to come off as if I’m mocking them. I’ve voiced this concern before, but with 24 hours to go before the performance, I feel the pressure even more now.

He sits silently nodding and says “Maybe we should bring it back to the videos. I think we need to look at each of these characters again and figure out how to distinguish between them.”

I respond, “You mean like come up with a signature move for each of them, like an identifying characteristic?” I know exactly what he means. I’ve been struggling to create a specific movement or series of movements for each of my characters so that it becomes easier for my audience members to identify who I am performing at that moment. I also need these movements for myself to help connect with who I am performing as well.

“Yes, that’s perfect. You are not performing *them* remember, you are performing your *interpretation* of them.”

My performance(s) begin with an understanding that close reading of my family members and creativity must merge to create art as social commentary. Close reading is a fundamental pillar of Charon’s narrative medicine, but also a fundamental pillar of the practice of performance ethnography. I define close reading as “attentive listening and observation of

details” (Charon et al., 2016). Close reading is necessary during the rehearsal process because through close reading and a concentrated understanding of the disability experience, I hope to creatively open new ways to reimagine my family experiences through performance. Charon et al. (2016) defines creativity as “an openness to uncertainty and doubt, an expansion of the mind, a welcoming of the unexpected” (Location No. 354). But most importantly, in line with Liu and Noppe-Brandon (2009), I argue that “creativity is imagination applied” (p. 19).

Both these principles are essential to crafting a performance which balances respect for the individualistic characteristics of my family members, and takes creative liberty to make art out of their words and stories. Close reading of these characters is conducted via multiple solo rehearsals and memorization sessions; Be it talking to myself in my mirror at home, to screaming out loud in my car, or rehearsing lines while running through Tampa. I made sure the recordings came everywhere with me. But even with the solo rehearsals, I found that collaborating and showing the recordings to colleagues also helped me figure out the appropriate mannerisms to use.

As Pineau (1995) says, “When we rehearse a performance, we allow our bodies to be manipulated by teachers and directors, choose between multiple ways to voice a text, and polish the subtlest nuances of timing, gesture and inflection, [with this] we accumulate evidence of the rigor and precision of our method” (p. 46).

My director and I open my laptop. Sitting in a common area of our department we start watching the videos of my family members. As we watch family member, after family member, we both take notes on specific movements, accents, and tones each of the individuals employs.

“What do you think about this for Aunt Barb?” I stand up, and start waving my hands around, creating wide open gestures with my arms.

“Yeah, that’s good,” he replies. “She really has more open body language, and she also enunciates very clearly. She’s very animated, both vocally and in her body.”

“I agree. What do we think about Uncle Bob?”

“I really think that when it comes to Uncle Bob, you should probably have more closed off body language, and maybe a quieter tone.”

“Oh yeah, that’s so Uncle Bob. So maybe making my movements subtler? Rather than open body language like Aunt Barb, perform more refined gestures and movements that remain close to my body?”

“Yes, yes that’s good. I feel like you have your father, sister, and mother down at this point, but what about Aunt Kathy?”

“I want to make her movements more focused. Her gestures are less exaggerated, but her voice is more amplified than Uncle Bob’s.

“Okay, yes, let’s play with that.”

Character development continued throughout the entire performance process. Again, voice and body work requires close reading infused with creativity. With each rehearsal, my family members came to life in conversation and movement. As they came to life, I also came closer to an understanding of who they are in relation to one another, and who they are in relation to this disease. Close reading and creativity became a way to gain access to these understandings. Attention to the details of each character, as well as the feedback from my director, advisors, and audience members became “the necessary equipment for coming to envision and comprehend the meaning-making” that was happening in my family (Charon et al.,

2016, Location No. 3100-3105). And, with an understanding of each character, I then entered the performance and production phase with muscle memory, since “the body has a memory just as the mind does” (Smith, 1993, p. xxv-xxvi).

An embodied understanding of my family members and their experiences also continued through my use of performative transitions. My first performance, at the Patti Pace performance festival, works as a woven piece of oral history, using symbolic and repetitive movements as transitions between each of the large narratives. I show the family experience of chronic illness represented as a drill, with a Sergeant doctor character guiding the movement through his lines. Guided by the doctor character’s lines, I implement symbolic transitions into my performance to creatively achieve an embodied understanding of my family’s experiences.

As I still sit, on the edge of the stage, the doctor character emerges from stage left. He marches out in military precision, pauses and begins:

“Hello there Ms. KELLER. We have identified a series of prescription medication treatment option strategies, what we call,” his voice lowers emphasizing the next phrase in a guttural projection, “PMTOS! to infiltrate your MS. A full assault will not work here, but interdiction, or what we call *shoot and scoot*, should help to contain the threat. These PMTOS will provide the artillery you need to endure the battle Ms. KELLER.”

He rotates his body directly toward the audience and screams out, “ATTENTION!” On “Attention!” I stand up and move several steps toward the audience, who are sitting on bleacher seats in front of me. I stand erect and frozen, ready to take my next “orders.”

He continues, “Managing Disease Course!” I click my heels together, and rotate my body stage left. I begin to march in place to the beat of “Script, script, script, rest, script. Script, script,

script, rest, script.” As he begins the next part of his monologue, I begin the series of embodied drills. He starts:

“Injectable Medications

Copaxone Betaseron

Oral Medications

Rebif & Gilenya

Pharma-ceuticals

Prescription refills

Syringes, and pills and pills

AND REST!”

As I move through the sequence, the kinesthetics I employ are akin to military drills including side steps, lunges, and jumping jacks. But with each iteration of this transition, my performance of the drill-like movements becomes increasingly more dragged out and less crisp. I literally feel the physical exhaustion of having done the same transition sequence, over and over again. I am figuratively portraying this exhaustion through the symbolic movements during each transition, but also literally feel the effects during the live performance. I use the routine to symbolize the exhausting pattern of routines families must endure while living with chronic illness. The series of embodied drills I perform act as a metaphor for the patterned and routine actions that my family must repeat on a daily basis. It feels real. It feels like my own experiences.

I wheel my mother into the bathroom, where we find a note on the counter top. On a yellow notepad, scribbled in blue ink, I read my father’s handwriting aloud, “Every morning

take: Fluoxetine (green capsule), Nitrofurantoin (yellow capsule), Baclofen (white tablet-remember to cut in half), and eye drops. Every Evening take: Oxybutynin (purple tablet), Baclofen (White tablet-cut in half), and Eye drops. On Alternate Evenings take: Amitiza (pink capsule)—M,W,F,Su, and Gilenya (gold capsule) Tu, Th, Sa.”

“Well, Mom,” I sarcastically start, “at least we’ve got a pill for you to take in every color of the rainbow. Makes the experience more...colorful.”

She looks up at me rolling her eyes, “Yeah, I’m not in the mood to take those today.”

I look at her. She’s of course sitting in her wheelchair, her body slouched off to one side. She’s tired. I get it. I mean, I don’t get it. Cause really, I’ll never get it. But I get that she’s just tired of the routine. She’s tired of not having control over her mornings, or days, or even nights. She’s at the disposal of her family members to clean her, and dress her, and take her to the bathroom. And well, she just doesn’t want to have to endure that routine today.

I empathetically respond, “Well, I wish we could avoid them, Mom, but these are doctor’s and dad’s orders, so you must take them.”

She looks up at me, wide eyed and pouty.

I laugh, “Your pouting won’t work on me, missy. I’ll stand here with you to keep you company while you take them, but you must take them.”

I wait in the bathroom with her as she sticks one after the other onto her tongue, and with a swig of tap water, struggles to swallow each. Her MS has started to affect the muscles in her throat now, so sometimes she chokes on things.

I watch with even more resolve. I’m a nervous human generally, but when it comes to my mother swallowing things my body feels like it’s on fire with fear. I hate seeing her struggle to

swallow a simple pill and though she always remains calm, even when she chokes on something, I'm ready to pounce down her throat and grab the pill right out of her.

Before I know it, she is opening her mouth wide and sticking out her tongue at me.

"Mom, why are you doing that?" I inquire.

"Well, I wanted to prove to you that I took them all, and I'm also just sticking my tongue out at you."

"Oh good," I respond, "I'm glad you're feeling extra sassy this morning."

With our pill routine complete, I wheel her into her bedroom to start getting her dressed for the day. Before we know it the evening routine will have begun, and we'll have to start it all over again.

My performance works as metaphor, linking the symbolic movements and stories of performance to my lived experience. Performance provides me the space to reflect on my own lived experience as a daughter of maternal chronic illness as I perform my family's narratives. The labor I endure as a performer becomes "a communal labor and conceptual shift" (Jarman et al., 2017, p. 6) for me and my audience members as well. I implicate my audience members in my performance to ensure they endure the same emotional and physical journey that I do as well. The literal exhaustion I feel through embodying these characters becomes a representation of the labor of performing a daughter off maternal chronic illness, and the labor of performing and reimagining family for myself and others. Specifically, "close reading not only bears on the complexities, contradictions, and secrets of bodies as texts; it also produces corporeal realities" (Langellier, 2009, p. 154). Close reading and creativity merge to allow me and my audience an

experimental place where I create new bodily and conceptual realities about my lived experiences.

Intersubjectivity and Relationality

In the following quotation, I take the words of Charon et al. (2016) as they apply to literary texts, and merge their words with the language of performance. As I theoretically blend narrative medicine and performance, I use their words as a guide:

Reading [performance] texts with a focus on relational dynamics awakens us to the social, structural, professional, and personal relationships in our lives. Thinking and writing about the co-constructed and dialogic nature of human exchanges as represented in [performance] texts brings readers into a more finely grained awareness of their own effect on others...Just as [performance] enriches and deepens stories, doctors, patients, nurses, family members—all who work together in caring for the sick—can thicken the telling and listening, can learn to sit comfortably with ambiguity and multiple perspectives. (Location No. 871)

Charon et al.'s (2016) principles of relationality and intersubjectivity, as they apply to performance, work in tandem to frame experiences from a relational perspective. I contend that we “as readers and as listeners—take in the relationships between characters, between narrator and character, narrator and reader, and between an individual and society” (Charon et al., 2016, Location No. 458), and from those relationships create greater understanding and awareness of different lived experiences. Both principles of intersubjectivity and relationality are intrinsically linked to the practice and performance of empathy. I define empathy, in the context of my performance, as “a qualitative process in which individuals understand and share the feelings of others” (Pelias & Shaffer, 2007, p. 99). In other words, relationality works in the act and process

of performance as way to feel and learn with the experiences of others. Whether that be me as performer understanding and feeling with the characters I perform, or my audience understanding and feeling with the characters I perform. Relationality and intersubjectivity help construct *performing narrative medicine* as a practice which relies on one's relationship with self and others, and on the act of empathy.

I've been practicing in the room all day. The space is an auditorium, likely used for large lectures or small banquets. Chairs and tables are scattered everywhere in no particular order. I've made the decision to push the chairs into a U formation for this second performance. This is very different from my first performance where the audience was distinctly separate from my performance area, on raised bleacher seats above the stage. The audience above me looked down on my performance, creating a power dynamic that wasn't conducive for engagement. It wasn't conducive because the audience seated above me looked down on me, creating a distancing effect between performer and audience. The change I've made for this performance, having the audience at my level and wrapping the chairs around my "stage," makes my audience members a "part" of the stage and a part of the performance.

I want to intimately engage my audience and perform with them, rather than at them, in order to implicate my audience in the conversation and performance. By shifting my focus from talking at them to talking with them, my performance becomes a conversation, a dialogical performance (Conquergood, 1985). In much the same way my family navigates the illness experience; we, as audience and performer, became a collaborative unit, a community that is in conversation with each other and open to dialogic engagement.

As the doors open and the audience members start rushing in, I start to realize that this performance will be a much bigger experience than I anticipated. People keep filing into the room, and with five minutes to go before the performance there is an audience of over 50 people. Students, faculty and members of the Tampa community begin to set up more seats as the original set-up isn't large enough to cater to the crowd. My audience became so large that not everyone was going to be part of the conversation exactly as I anticipated.

With this unexpectedly large audience, I start to panic. What if I forget my lines? What if it doesn't translate the way I intend? What if they can't hear me? There is something about an audience this large that makes me exceedingly nervous to perform. It makes the stakes feel greater, possibly because I am communicating with more bodies in a room, but mostly because I am vulnerable in front of more people. I try to ease my nerves, take a deep breath, and let myself start the performance. I enter the stage.

As I take a seat on stage right, I sit among my audience members. This is a distinct and deliberate change from my first performance. I begin to move into Aunt Kathy's narrative with the line, "I think I had umm probably an unusual teenage life." I realize at this moment I'm not ready to make eye contact with my audience members like I initially planned to. I'm looking down at the ground instead of at my audience. I am far too nervous to commit to the character. Nerves get the best of me and it's too difficult to fully immerse myself in the mannerism and accent I've previously rehearsed.

I can see audience members in my periphery, looking directly at me and ready to engage, but I can't make eye contact. I set out to make this distinct change in my performance, and was incapable of doing so. Both a lack of confidence in my memorization and fear of interaction contribute to a less than interactive performance. I finish the performance feeling utterly

disappointed in myself. This experience though allows me to make connections to the ways this performance functions as a heuristic for my own family experience.

I am disappointed in ways I've felt when I can't live up to or be the daughter I wish I could be for my family. The inability to do as planned, or to live up to my expectations is an everyday feeling/occurrence in my family. The unexpected nature of familial chronic illness lends itself to feelings of disappointment, when my mother can't achieve the things she wants to, or our family can't attend gatherings or events because it's too exhausting or too much work. Feeling or living this way is a common occurrence, but one that pushes us all to be okay with what we can do, and what we do have.

Ultimately my experience with the second performance makes me more motivated to achieve a more intimate interaction with my audience for my third performance. To accomplish a more engaged performance, one where I speak with the audience, I ensure that during subsequent rehearsals I speak directly with those witnessing my rehearsal. I practice one-on-one with my director, and speak only to him, guaranteeing that we make eye contact the whole time. I figure that every bit of awkwardness or discomfort I feel with him one-on-one will help me get over the fears that I have when speaking one-on-one with audience members.

With the practice of any art form, be it narrative medicine, teaching, or performance, the more practice one has the more comfortable one becomes with the material at hand. I want to feel and live in each of these characters to my greatest ability each time I perform them. Though this is a grand expectation, since sometimes I can't help but let nerves get in the way, it's an important expectation. Reframing each performance and iteration as a new way to understand these characters, as a new way to understand the audience's reactions, and a new way to

understand myself, makes the experience more empowering and constitutes my practice of narrative medicine.

As I set up the room for my third performance, with only 15 minutes until show time, I realize we have no speakers or projector cable available. “Oh good,” I think to myself. No matter how prepared I may be, this never seems to go as planned. I set the room up in a U formation again. With only 20 seats total, it is a much smaller room than during my second performance. The stage is set up again to create inclusivity and allow for movement. After repeated rehearsals and a continued emphasis on the relationship with my audience members, I am excited but nervous about this performance. I want this one to achieve the immediacy and intimacy that my first and second performances did not. I need to finally engage directly with my audience members.

After scrambling to find speakers and cables, the lights finally dim and I begin. I’ve made it to the second half of the performance, where my extended family members are introduced. I transition into my Aunt Barb’s character, seated on the left-hand side of the U, and start her narrative, “But I saw the difference in them.” During her narrative, my Aunt addresses the ways others have treated her mother because of her disability. She also discusses her own personal relationship with her mother—a relationship her and I know has many parallels to my relationship with my own mother. She begins:

But I saw the difference in them, she became a pain with her group of friends that she hung out with. They would say, “Well wait a minute, what happens if she needs to go to the bathroom once you leave.” We’d respond, “She can step. She can make a few steps and get on the toilet. And if you’ll bring the toilet seat in you can help her raise the toilet up.” We would try all these ways and I think in the very beginning they were still picking

her up, but then she had an accident in one of their cars and that's when they asked if we could transport her. And you know that was fine, but it changed things.

They would say to us, "Oh no, we want her to come, we want her to come, we want her to come, you know, anyway YOU can do it." You know there were certain ones that wanted her to come, and there were others who were like oh geez this is gonna be hard. I don't know that your Grandma knew that they felt differently, but she was embarrassed. She was very, very worried about the incontinence. That was the worst part for her. She'd get really embarrassed on the toilet when I had to wipe her and she'd say, "I don't want you to have to do that." And I'd say "Ma, I think I owe you a couple hundred."

As I work my way through the narrative I remain composed and feel confident about how far I've come with Aunt Barb's mannerisms and accent. I am making direct eye contact with my audience members, making sure I don't just focus on one person the whole time. I transition eye contact during several points in the narrative to create relationship with different members of my audience. But it's not until I get to the line, "I don't want you to have to do that," that something changes for me. As I make direct eye contact with one of my audience members, for the first time during my whole performance process, I begin to cry. I realize that at this moment, it's not my Aunt Barb or me saying the line, "I don't want you to have to do that"; it's my own mother saying these words.

I am called down to the office. An angst ridden 17-year old, I care too much of what my classmates think, and too little of myself. It is customary that I am called down to the office to help my mother walk in and out of the building to help in the College and Career Center. It is also customary that I do it with an attitude.

I begrudgingly meet her at the entrance to the school.

“Come on Mom, let’s make this quick,” I whisper so as to draw less attention to us. She reaches for my hand to steady herself. I draw my hand away.

“Mom, why don’t you just take my arm.”

She looks at me inquisitively, but obeys. I’m embarrassed. What teenager has to walk her mother into school holding hands, I think. I lower my arm as we enter the school, hoping to conceal us both. I try to rush us through the lobby as quickly as possible. I know I am walking too fast for my mother, but she never complains, merely struggles to keep up with my pace. I rush her to her office and into her seat.

She looks up at me, clearly realizing my unwarranted embarrassment and says, “I’m sorry you had to do that, honey.”

I look at her and without saying goodbye, I run away to class. I run away from her.

Something about performing my Aunt Barb’s line, something about the human connection that occurs at the very moment of speaking, something shifts for me. I’ve performed this line many times in rehearsal and previously during my second performance. Yet, during this performance I/we relate to one another. It was in communion and connection with my audience member, in connection and communion with my Aunt, my grandmother, and my mother, that I found empathy. I realize that I was connecting with my Aunt Barb’s words in ways I never had before. The (re)performance of them and the audience interaction made me empathize on a visceral level.

There is something fundamentally different about saying a line over and over again to yourself, when you are rehearsing on your own or in a safe space with a director, than when you

look another person in the eyes and say the line. The resonance completely changes. My performance of this narrative is the first time I feel a relationship with my audience members and with her character. This enables an understanding of my performance's power to create connection and a relationship to and towards my audience members.

There is a relationship and reflexivity that occurs when I say lines directly to another person that doesn't necessarily exist when I read their text on a page. Vulnerability and the ability to fail all contribute to the power of this type of performance. Performance enables and makes a person and a community. It possesses the power to create relationality and intersubjectivity through vulnerable bodies in a space. My decision to break the fourth wall in my performance and speak directly with audience members is a more specific way that I create intersubjectivity, and relationality literally with my audience members. This move toward more direct interaction also allows me to engage empathy with my family members and maybe even understand myself a bit more.

Embodiment and Personhood

As Pineau (1995) states, “embodied knowing” is not a theoretical abstraction of performers, it is the everyday established practice that defines our discipline. Performance methodology is a process of intimate, somatic engagement, a means of “feeling on the pulses” the rhythms, nuances, and kinesthetic idiosyncrasies of human communicative experience” (p. 47). Embodiment of values, ideals, and principles is also at the core of narrative medicine theory as well. As Charon et al. (2016) notes:

The creative acts of representation—in writing or telling or painting or composing—do not merely reflect something real, but create something real...once form has been conferred onto the unformed the chaos is discernible both by those who witness it and

those who hear accounts of it. Once represented, the chaos is at least potentially comprehensible. (Location No. 3951)

It is through the creation of form and structure in the face of experience that both narrative medicine and performance engage one another. By creating structure around the often chaotic illness experience and putting that chaos on my body, I am able to communicate human experience and access “personhood” at the root of it all.

My first performance comes to an end and the assigned respondent opens the conversation with a talk back session. After I hear several comments from the audience, it is an unexpected comment that resonates with me the most. The audience member says, “The embodiment of your Dad seems the clearest. Why is that? What is it about this character that enables this clear connection for empathy? Something that you are otherwise unaware of? Gender? His feelings/approach/role? Are there similarities between you and your Dad? What did embodying these people teach you? What did you learn?”

At first I react poorly. I don’t know this woman, she doesn’t know me. Why is she trying to psychoanalyze me or my father? But once the talk back session is over, and I’m processing the event and performance, I realize I have already grappled with these same questions. Prior to the first performance I had journaled my fears of performing my father, which made her comments that much more powerful:

“I am frustrated. It could be because I’m not off book yet and as always have found myself with a lack of confidence and days to go before the performance. Or it might be that I feel weird performing my family members who are my everything, and being told how to perform them is rubbing me the wrong way. Why is it so hard to perform/embody my father? He mentioned prior to his interview that he was sensitive about me

performing a mock version of him, so I think I am hyperaware of not hurting or insulting him. I'm also concerned about performing my mother in a way which perpetuates stereotypes of disability and chronic illness, which I'm deliberately trying to challenge or complicate in this performance. Rehearsing them in my body has been much, much harder than I thought it would be. How will watching the audience's reactions impact my understanding of each of these characters as well as myself as researcher and performer?"

In conjunction with Smith (1993), "I am interested in how inhibitions affect our ability to empathize. If I have an inhibition about acting like a man, it may also point to an inhibition I have about seeing a man or hearing a man. To develop voice one must develop an ear" (xxviii). By interrogating my own inhibitions and fears of performing my father, by questioning my defensive reactions to my audience members, I realize there must be a reason I feel these inhibitions or fears. There must be a reason I need to listen to this intuition.

"Alyse, please come here!" my father screams from across the house.

Ignore.

"Alyse, I know you can hear me. Answer me."

Ignore.

"Alyse Anna Keller, this is the last time I'm going to ask you. Come to my bedroom immediately!" his voice echoes through the halls.

I finally reply, with nothing but sixteen-year-old sass in my voice, "FINEEEEE! I'm coming."

I slowly trudge across the house, dragging my feet along the linoleum floors, making sure each forcefully laborious step is audible to him. I enter the room with a smirk, which creeps its

way up the left side of my mouth. I know if I'm bitchy I'll piss him off. I know that eventually he'll burst. All the while I'm in control of the situation. I'm in control of whatever complaint or outburst is about to ensue.

I'm extra ordinarily mad at him today. The impetus for which doesn't really matter, and probably isn't rational. I always seem to be mad at him lately. My sister and I know my mother and he are keeping secrets from us. Why do casseroles keep showing up on our doorsteps? Cards attached with rotating messages of, "Get well soon!" "Feel better!" "We're praying for you!" Why do people keep asking us, "How's your mom doing?"

Yet, before I can even let out a peep, my father's eyes well up. A man who stands for strength and stability in our household is unraveling before me. I'm frozen. We don't cry. My father and I, that's not what we do. That's not what we've ever done. His most quintessential "fatherly" advice to me in the past was, "Alyse, you should really stop wearing your heart on your sleeve."

Words are hard to muster for us both. He sees the fear in my eyes and coughs.

He stutters, "Alyse, your mother is very sick."

His voice cracks. His eyes divert.

"She's not getting any better. This is what happened to your grandma, what happened to my mom when I was your age and I regret..." he pauses. "I regret a lot, Lysy. I know you butt heads with her sometimes and I know you are stubborn just like her, but I need you to try harder, Alyse. I need you to be strong. Can you promise me you'll try?"

He looks back at me. The liquid that veils his eyes magnifies the deep blue of his pupils. Why is he telling me this? Why are we having this conversation now?

I'm stunned and sad, taken by the purity of his pain and frightened by the helpless quality in his voice. My father is a person who absorbs. He absorbs feelings and emotions, but doesn't display. Yet, he is allowing me in, if only for a moment.

We sit with the weight of his worry. I realize I haven't responded, so I muster up the words, "Yes dad, I can do that."

"Okay, okay good." He straightens his posture and lowers his voice, "Now go finish your homework."

He turns towards the door and, without any further acknowledgment of what just occurred, we both retreat to our corners of the house. We retreat back into ourselves.

My fears, which I was initially afraid to admit, are that I connect most to the stories and words of my father. We are/were both children that left home after our mothers became ill. We were/are the children that come back to visit during breaks for school or from work, but we weren't/aren't always present. We are the children that had to re-acclimate to the family dynamic, the jokes, the conversations, and the transitions each time we return because we weren't always there. As a result I/we feel some residual guilt. I realize that in embodying my father, I am already in some way, embodying myself—my own fears, guilt, frustrations, and hopes.

As I continue to work through the embodiment of my characters, it is my mother's character that I worry about performing as well. Embodiment of any character is inherently linked to ethics of choice. And the choices I make must always keep, first and foremost, the sanctity and dignity of the person(s) I'm performing and embodying in mind. These "persons" are my family members, who have willingly volunteered their stories and voices for the sake of

my dissertation project. It is a project they are on board with, a project they are passionately excited about, but also a project which makes both them and me vulnerable to a public and audience of anonymous others.

We sit in our department's black box performance laboratory. I am mostly off book at this point, and know that as I continue to rehearse these narratives I will continue to feel with and understand the nuances of each character. But as of right now it's too hard to think about anything but the lines. As I start up again, my advisor stops me and says, "Wait a second, before we start again, I really think you need to go bigger." I must have made a questionable face in response because he continues, "I know you are scared to go there, but you have to go bigger or your audience won't be able to distinguish between each of your characters."

With my face likely still contorted, I nervously respond, "But I don't want to mock any of them. I already feel like I'm going big, like I'm over the top, and I'm afraid if I push any further it will be a parody of them, as opposed to a realistic performance."

He nods, "You mean you don't want to mock your mother, right?"

I sigh and reply, "Yes."

"Well," he responds, "I think that is valid, and you should be wary of that. But understand that you aren't mocking her, at least not from my perspective, and you should keep pushing to fully embody her, which you can't do if you don't 'go there.'"

I have always been confused about my body in relation to my mother's and confounded by its relationship to hers. MS, the disease I now loath as an adult, is the same disease that I longed for as a child. I would frequently self-diagnose tingling in my hands, feet, and legs as

early on-set symptoms of MS in order to identify with my mother's experience. My choice to embody my mother is always a risky endeavor. As noted, embodying people with disabilities holds the potential for mockery. But as I address with myself, with my committee, and often during my performance talkback sessions, there is something to be said for "going there."

I perform my mother for both my audience and for myself. If I do not perform her, it is a disservice and an absence to her voice. An audience member once noted, "Is it ableism to deny doing it?" or as Smith (1993) questions, "does privilege mean one shouldn't see? (xxviii). I firmly believe these questions get directly at the root of my desire to perform her. It is a privileged position to deny performing her, and it's a disgraceful omission if my mother, in all her embodied glory, is not a part of this project. To omit her means to omit one of the main intentions of this performance, which is to normalize the disability experience; to show variations of ways to live as families and as "health citizens."

As Smith (1993) continues, "these questions, this uneasiness, are sometimes judgments about performance, but they are also indications of the uneasiness we have about seeing difference displayed. Mimicry is not character. Character lives in the obvious gap between the real person and my attempt to seem like them. I try to close the gap between us, but I applaud the gap between us. I am willing to display my own unlikeness" (p. xxxviii). So, to omit my mother, a disabled body, is to omit her voice and her story. It is an omission of her ways of living and my own "unlikeness" with her. Madison (2005) notes, "we come to simultaneously recognize, substantiate, and (re)create ourselves as well as Others through performance" (p. 150).

Every time I enter her character I contort my body. I tense up all my muscles, making my movements slight and purposeful. I twist my legs as one unit, off to the side, slouching down in my seat, and craning my neck as hers often does. My left hand lies tense next to my body. As

early as the proposal stages of my project, I was hearing concerns about how the performance of my mother could be received by audiences, and how I would negotiate the fact that I was an able body performing a disabled body. Reflexivity and empathy are necessary functions of embodiment and again, “if only a man can speak for a man, a woman for a woman, a Black person for all Black people, then we, once again, inhibit the *spirit* of theater, which lives in the *bridge* that makes unlikely aspects *seem* connected. The bridge doesn’t make them the same, it merely *displays* how two unlikely *aspects* are *related*” (Smith, 1993, xxix). Every time I perform her, I come closer to understanding what it means to be her daughter and reflect on what her illness means to me.

Embodying another human contains a myriad of ethical questions and contentions. As I embody my mother, I follow Pelias and Shaffer’s (2007) guidelines for a performer’s tasks to empathize through performance:

The performers’ first obligation in using empathy as an investigate method is what we might call a process of imaginative entry. Here, performers move through the recognition, convergence, and adoption steps of the empathic process. Recognition calls for questioning, a process of careful scrutiny of the other’s perspective. Convergence necessitates identification, adjusting oneself to the world of another. Adoption demands that the other’s unique qualities be incorporated, felt, taken on as one’s own. Each step takes performers closer to others as they attempt to enter the others’ worlds. (p. 107-108)

In the context of embodying and performing my mother, I must always push back and not ever enter the life/world of another person without interrogating and questioning what my intentions and approaches/methods are. I alone am responsible for the embodiment of all characters I portray. Though this is only an interpretation of my family members, not an actual

documentary rendering of them, I still must honor that they are humans that can and will see this performance and particularly individuals that I respect and love. This distinction is important because I am responsible and accountable for the interpretations that I then perform to an audience outside of my family.

After one of my performances, an audience member familiar with my mother says, “I feel like I just witnessed your mother in the room. That was so, Denise.” This is certainly a flattering comment, but I also understand that it isn’t my mother in that room. There’s something about performing my mother each and every time that will never be my mother, and never be the lived experience of disability. I will always try to empathize with my mother’s experience, while realizing I will never fully grasp what she endures on a daily basis. And that’s okay. Because I will keep trying to learn and grow from this experience.

Performing Narrative Medicine: A Heuristic for Families Living with Chronic Illness

The intimate embodiment, relationality, and close reading I conduct and achieve with each performance mirrors the experiences that I have with my own family members. I grow closer and closer to my family members and to their experiences and words with each iteration. As Conquergood (1983) notes, “performance of another living person’s story is a humbling experience. When the ethnographer becomes a performer, he or she comes closest toward entering the world of the other, while being aware simultaneously that he or she will never be that other (p. 154). The documentation of multiple iterations of my performance are a heuristic for my lived experience as a family member living with chronic illness. Heuristic significance, in the context of qualitative communication research, “moves people to further explore, research, or act on research in the future” (Tracy, 2010, p. 846).

I recognize that there are potential outcomes or contributions to the process of performance as narrative medicine. Many of the long-term outcomes of performing narrative medicine are like the “long-term outcomes” of Charon et al.’s (2016) practice of narrative medicine, including: “Recognition of emotion, perceptual sharpness, tolerating uncertainty, decreasing burnout, improving [familial experience], and deepening knowledge of patient/familial situations” (Location No. 252).

Performing my family multiple times, I imaginatively access their lived experiences and words in multiple ways through improvisation, failure and empathy I grow as a daughter of maternal chronic illness. Performance first acts as a practice of imagination and improvisation. Allowing me to improvise on the stage, and reflect on how I’ve improvised in real life with my family. Performance offers the visceral and lived practice of failure and success, the same failure and success I experience as a daughter of maternal chronic illness.

With every performance, failure was inevitable because I rely on flawed others and myself. With each day as a family member of chronic illness and disability, failure is also inevitable and at this point anticipated. My performance also opens me up to practicing empathy over-and-over again. Empathizing with the words I perform, but also empathy incited by the physical performance in front of an audience.

In the next chapter, I synthesize the overall arguments of my entire project of *performing narrative medicine*. By documenting my reflexive experience performing in this chapter, I continue to explain what this project of performing narrative medicine means and its overall contributions.

I sit at another coffee shop, on another day. Each one blending into the next at this point. I continue the repetitious cycle of typing, reading, and figuring out how I'm ever going to finish this performance. Ella sings her/my staple "Dream a Little Dream of Me" into my headphones. I decide, for just a moment to take my headphones out to readjust the pile of papers scattered across the granite counter table top. My frustration and confusion are mounting and I need a quick break.

Among the clamoring of coffee cups, espresso machines buzzing, and Floridians complaining about humidity, ever so subtly, I hear Ella in the background. "Dream A Little Dream" plays above the ambient coffee shop noises. Her music is all around me at this point. It is exactly what I need. A little nudge, a little reminder of why I'm doing this, and who I'm doing this for. A little piece of my Grandma. And maybe, just maybe, it isn't a coincidence.

I put my headphones back in and return to the work.

CHAPTER SIX:
IMAGINATION FIRST:
CONSLUSION AND CONTRIBUTIONS

Life imitating art imitating life
-Flaherty (2011)

The semester has been rather turbulent. As I continue prepping for my performances, job applications, and eventual (fingers crossed) graduation, the most pressing issue at hand seems to be the trouble I'm having with my Senior Capstone class. I've found that this semester my students and I aren't connecting. A small classroom of 12 students, I can't figure out if it is the way I am teaching the material, the fact that it is 9:30 in the morning, if our personalities just don't mesh, or if all my students, including myself, have been plagued with the dreaded "Senioritis." Yet, we still have moments of clarity and levity, fleeting as they may be. Today is one of those days, but one that is colored by fear and confusion.

The presidential candidate, Donald Trump, has recently mocked a disabled journalist on national television during one of his many rallies, a mockery which highlights the potential for ablest and discriminatory practices to become naturalized, once again, in our country. This mockery instilled in me a sense of fear for our country, for my students, but most of all, for my mother.

I decide to cater our activity of the day, what I call a "Communication Challenge," to the recent Trump event. I decide the challenge should focus on empathy. If we aren't going to see empathy practiced by the man who may hold the most powerful and revered office in the nation,

then I will make sure my students practice empathy in our classroom, to save themselves and to save me. The challenge itself asks students to consider the follow scenario:

You were recently hired as the Assistant Human Resources director for Women's Wear Daily, a fashion magazine in Manhattan. This is one step closer to your dream job of Director of Human Resources at a large fashion magazine. Within the first few weeks of being hired, you are assigned to interview your first potential employee for the position of summer editorial intern, with the supervision of your boss, the Director of Human Resources, who will be in the room at all times. After hours of potential candidates, you meet a woman, Talia, who you think is perfect for the position. She is an English major at NYU, and the fashion editor at NYU's school newspaper *The Washington Square News*. Her writing samples are strong, she came prepared with diligent research on the organization, and her work ethic fits with the work culture at the magazine. At the end of the interview you thank her for her time and tell her that they will be in touch with her soon. Talia promptly interjects and tells you that she needs you to know that she has a chronic illness and she wants you to know in advance just in case she is hired. She feels she needs to be honest so that you are all aware of her abilities. She discloses to you that she has Multiple Sclerosis, a degenerative autoimmune disorder which makes her fatigued, weak and often impacts her short-term memory. You thank her for being honest and send her on her way.

After the woman walks out of the office, your boss says, "Well that's too bad," and throws Talia's application in the trash. You ask her why such a qualified candidate would be thrown away. Your boss tells you, "This is normal hiring practice, and this is just an unwritten part of the organization's policy. She is a liability and we have to think about productivity--bottom line." How do you plan to address this situation? Discuss multiple ways you understand

the situation, including specific messages and delivery methods, and an analysis of ethical and political implications.

After giving students time to discuss the challenge in their groups, we begin presentations of how they plan to address the situation. The first three groups are unanimously in agreement that a hiring practice that uses Talia's disability against her is discriminatory and is not only a company they don't want to work for, but also a scenario that should be addressed immediately. Yet, even after each group presents their disgust and concern, I can see one student in the back rolling his eyes and glaring at me. So, I point my attention to him.

"Samuel, you don't seem to agree with the conversation we're having. I would love to hear your perspective on this challenge."

Reluctantly he sighs and starts, "For me it just comes down to productivity, plain and simple. Clearly her disability is going to get in the way of her productivity as an employee, and so they would be better off hiring someone without a disability. I mean I don't see why this is even a question? Why we are wasting our time on this challenge?"

My face turns fiery red and my insides begin to burn. I have never come face-to-face with someone like this, someone who unabashedly believes people with disabilities are incapable. I mean, let's face it, many people subconsciously or inadvertently are discriminatory towards people with disabilities. Or some people say something they don't realize might be hurtful or offensive. But it is rare that you come across someone whose fundamental value system completely neglects people with disabilities as equal members of society.

I am hurt and shocked and not sure how to respond, so I turn the conversation to my students. The eleven other students step in and begin to defend the woman in the communication challenge. They say they believe Samuel is wrong, and that there is more nuance to the situation.

They reiterate that this scenario isn't just about productivity, though the facts should speak for themselves, it's about what you believe is right and wrong. "Use your moral compass," they say. Though their support and advocacy means something, means a lot, I can't shake the fact that Samuel isn't a lone wolf. He isn't alone in his belief system. There are more Samuels out there than I'd like to believe.

Though just a character created for an in-class Communication Challenge, Talia in many ways represents my mother and my grandmother. The challenge and its reception ignite a desire, a need, a want, and a realization of the importance of my performance. The importance of my performance as public pedagogy is to speak back to the Samuels of the world and to fight back in my own way.

But it also and maybe more importantly, emphasizes the significance of creating alternative and creative ways to communicate about and through the disability/illness experience for me and for my family. Because it isn't always about fighting back. Sometimes you will never get your point across to the Samuels of the world. Rather, it is about coming together and somehow communicating across difference. That is where my performance comes into play.

Understanding Performing Narrative Medicine

Health communication is defined as "the symbolic processes by which people, individually and collectively, understand, shape, and accommodate to health and illness" (Geist-Martin, Ray, & Sharf, 2011, p. 3). My dissertation in its entirety works as a practice of performing narrative medicine and a mode of health communication. This dissertation moves narrative medicine and its essential principles and intentions beyond the realm of the doctor's office, and into the family's and patients' everyday lives. By putting "narrative medicine" on my body, by performing the narratives of my family members, I make its medicinal "uses" and

“functions” public, revisable, and real. My dissertation works to move performance beyond the stage and to incite change in myself and those witnessing my performance. Performance works on many levels in this project. It works as a form of healing, as a way of knowing, as a way of challenging, and as a form of advocacy.

Therefore, I return to the questions I pose at the start of this dissertation project: How does my performance work as embodied knowledge to gain greater understanding of the lived experience of familial disability/chronic illness? How does the use of humor as a communicative construct, and performance ethnography, work as a practice of “performing narrative medicine?”

Though this project is not necessarily a call for all researchers, practitioners, and families to begin performing and embodying their own and other narratives of health and illness, it is a call for scholars, practitioners, and health citizens to understand performance as a legitimized way of knowing and understanding the experience of illness and disability. It is a form of research which allows greater access to the nuances of lived experiences. As Parrott, Roxanne, Thompson, & Nussbaum (2011) state, “current research looks to cultural health narratives as conduits for transforming viewers/listeners, shaping their understandings, feelings, attitudes, and perhaps behaviors in particular ways” (p. 42).

As I move through the motions of questioning, probing my interview data and creating my performance, I contend that my performance acts as “a heuristic tool that illuminates the presentation and representational elements of” my family (Hamera, 2006, p. 5).

My dissertation uses performance as both method and metaphor for understanding chronic illness and disability within families. Performing narrative medicine, “produces theory that begins with the experiential before it enters the printed stage” (Jones, 2006, p. 55). Many areas of health communication focus on how external forces, such as cultural, institutional and

political narratives about health, illness and disability, impact one's conception of self. This performance instead focuses on how my experience performing my family's narratives and experiences of disability and chronic illness can foster health-related consciousness and action.

At one of my performances, a disability and performance studies scholar approached me and mentioned that there are many conclusions one can draw from my work, but at the end of the day this is "hearts and minds" work I'm doing, and that's what truly matters. To a certain degree, I concur. This is hearts and minds work. This is the kind of work that can shift our conceptual and empathic feelings. But, I also argue that it's constructive, resistive, and productive "hearts and minds" work.

My process of performance ethnography becomes a productive analogy and provides insight into the lived experience of families living with chronic illness/disability. To cite my performance as a heuristic is based on the idea that "we are constantly theorizing from the stories we tell, hear and see about every day health practices" (Yamasaki et al., 2016, p. 7). My performance pushes me and my audience members to become more knowledgeable "health citizens" (Yamasaki et al., 2016). I "use the term health citizen to convey [a] sense of universality among all members of a society, as well as the rights, responsibilities, and privileges that accompany such participation" (Yamasaki et al., 2016, p. 22). As such, my performances and analysis of my performance process provide a glimpse of familial chronic illness and the communication that occurs about said family experience.

Humor specifically contributes to my practice of performing narrative medicine because it possesses transformational qualities. Performing humorous narratives, performing humor as narrative medicine acts "to change the shape of" (Bingham & Green, 2016) how I understand my own family and how I actively practice communication in my family. Though it's already

common for many families to use humor as a way to communicate, by taking these humorous stories in the context of familial illness and putting them on my body and on display, I seek to mark humor as a specific way to perform narrative medicine.

Overall, *performing narrative medicine* works to reveal the underlying communication competencies at work in families living with chronic illness and disability. Through the use of humor and performance as a communication practice, I reveal the power of empathy. The power in realizing our own human capacities to relate to one another across differences, and continue to work toward “living well.” In some ways, I hope that it pushes audiences toward “the recognition of disability as a unique way to experience the world [and] a crucial part of creating communities and making “affirming spaces”” (Jarman et al., 2017, Location No. 5262). My emphasis on my family and “a concentration on relationships is closely connected to a call to come together for social and political reasons” (Jarman et al., 2017, Location No. 5285). I view performance as a way to create “a more inviting, inclusive social fabric.”

Performing narrative medicine is a project of being a better individual and scholar. Muscle memory enables this craft/practice to be employed in the future. Performing narrative medicine is a practice that can be applied in other contexts and by other health practitioners, performers, or families. It is a learned/embodied experience that can enable others outside of my family to understand their own or others lived illness experiences as well.

As Conquergood (1988) asserts, “Experience is known through embodied performance. Instead of the idea of experience pressing out to expression, we must remember that we know experience through the body. It is the embodied expression that organizes experience” (p. 85). Performance is a way to learn how familial and individual failure and triumph feels on my body and how I’ve learned to be okay with that. Like with most qualitative methods and practices,

performing narrative medicine is about relying on intuition first and foremost. Performing narrative medicine is a method which hones the skills we already possess and the skills that are already available to us all.

Aesthetic Action toward Justice

In the previous chapter, I only employ five of Charon et al.'s (2016) six principles of narrative medicine. The last of Charon et al.'s (2016) six principles of narrative medicine is Action toward Justice. The goal of action toward justice is to “creative inclusivity of those who do and those who do not feel ‘at home,’” (p. 318). By applying the principle of action toward justice to the aesthetic functions of my performance, I examine the social, political and cultural implications of my work, and hope to create a space or “home” for other families living with chronic illness/disability.

To create action toward justice, “health communities, where ordinary citizens communicate with one another, [must] create a movement to focus their advocacy on a particular health issue, [which] often end up influencing health policy” (Geist-Martin, 2016, p. 374). I use my work of performing narrative medicine, to create a space of “radical belonging.” By this I mean I “wish to underscore the idea that integrating people with disabilities into the broad social fabric—is a shared responsibility” (Jarman et al., 2017, Location No. 5262). This integration is a shared responsibility for my family members and me. It is also a shared responsibility for the witnessing audience members and larger community as well, because at its core performance generates community (Warren, 2010).

I never imagined when I started this project that I would be living during a political administration where simply fighting to acknowledge disability rights would be a reality. But here we are. And though this complicates life and the world, it makes these discussions that

much more important. So, I tell the stories I know and the stories I deem important because “personal stories can raise social awareness, destigmatize disease, inspire or affect policy decisions, and highlight the many identities and roles that we can play as we embrace our role as health citizens” (Jarman et al., 2017, p. 361). I firmly believe that this type of work can be constructive and productive for individuals, but also can drive public advocacy and policy.

Though my work doesn’t explicitly discuss policy change, my dissertation brings awareness, through performance. I never want the work I do to remain on the page or stage. I want this work to spark conversations and continue discussions about the experiences of families and people living with chronic illness and disability.

I argue that performing one’s own or another’s story can bring people together and create understanding; “simply, stories make us who we are and offer us the chance to remake ourselves again and again. (Pelias & Shaffer, 2007, p. 57) With this, I invite “you to consider [my] collection of [communication] competencies that may improve your own sense of empowerment and activism across health contexts” (Geist-Martin, 2016, p. 366). I invite you to consider how the creative analysis and reconceptualization of family through my process of performing narrative medicine creates possibility and becomes a site for resistance and reinvention.

Performing Narrative Medicine for Me

For me, this practice of performing narrative medicine was not just a therapeutic journey; it was a reflexive, difficult, and confusing process. I mustered the courage within myself to talk with my family and conduct research about issues that were beyond what many of my colleagues and friends vocalized they were even willing to do. It’s true on many levels that we can study people in cultures far different from our own, or even study people in our very own community, but to study or simply communicate with our own families comes with its own set of difficulties.

And maybe that's where this dissertation project comes into play. Maybe that's where imagination and creativity and performance and humor help us and help me.

As Liu and Noppe-Brandon (2009) state, "How might we free ourselves if we just imagine?...The general assumption is that a will to act must precede imagination—that you decide to do something before you imagine what it is. The reality is that imagination comes first. It must" (p. 7-8). My project of performing narrative medicine attempts to imagine possibilities. It tries to reimagine familial chronic illness through humor and performance.

Though, for all its intentions and subsequent contributions, this project was about my need to understand how communication practices have consequences and create realities. It was about my desire to contribute something to the fields of health communication, narrative medicine, disability studies and performance studies. This project was also about my wish to communicate more richly with my family and others, and to understand my own lived familial experience of chronic illness and disability

Maybe I'm the one that needs this narrative medicine. Maybe my family needs it. Maybe we all need it. Maybe we all need a little laughter in the face of stark realities that we face each and every day. Or maybe we need performance to show us and save us from our own lived experiences. So, I will continue to perform and I will continue to laugh. I will continue this project of *performing narrative medicine*.

I sit in the black box theatre of our department, the same department in which I got my first taste of the "Samuels of this world," nearly 6 months ago. The same department I have created, rehearsed and performed in for years. The same department walls I cried in when I found out my mother was sick, again. But this time really sick. The same department I felt safe enough in, four years ago, to create my first performance about my mother's illness, about our

relationship with one another, and how we as mother and daughter have danced through life together and will continue to do so.

I sit on a black box in the center of the stage, waiting to begin my final performance. The lights come up. All eyes are focused on me. I am the only one up here.

I begin to *perform narrative medicine*.

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APPENDIX A:

PERFORMANCE SCRIPTS

SCRIPT 1: (DIS)ABLING MOTHER

Bring lights up

(Alyse stands at rear stage right with notebook in hand.)

Play (1 Introduction) audio file:

Bring lights down

Play (2 MS Video) video file

After movie is finished, turn off projector light

Bring lights up

Doctor (audio) while Alyse traverses obstacle course:

Hello there Mrs. KELLER. We have identified a series of prescription medication treatment option strategies, what we call PMTOS to infiltrate your MS. A full assault will not work here, but interdiction, or what we call *shoot and scoot*, should help to contain the threat. These PMTOS will provide the artillery you need to endure the battle Mrs. KELLER

ATTENTION!

Managing Disease Course!

Script, script, script, rest, script

Script, script, script, rest, script

Injectable Medications

Copaxone Betaseron

Oral Medications

Rebif & Gilenya

Pharmaceuticals

Prescription refills

Syringes and pills and pills

AND REST!

Cue to play file – Alyse will stomp her feet (right then left), then hang her head.

Play (3 Jana) audio file

“So I remember going to Disney world in first grade and mom had the motor scooter and I thought that was awesome!”

Jana (Alyse):

So I remember going to Disney world in first grade and mom had the motor scooter and I thought that was AWE-some, cause I was like this is so handy that we can put all our bags in the cart and we can cut every single line. I was like we are SO lucky. But then I don't

really remember her being sick again until the fourth grade when she just stopped coming out of her bedroom and all the neighbors started dropping off all those casseroles and that's when she stopped making my lunches because she would try but her mind wasn't with it and one time she sent me to school with moldy bread. And fourth grade Jana was really afraid that day that the paraprofessional that sat next to me at lunch was going to think that I had neglectful parents because I came to lunch with moldy bread and expired yogurt which is like, let's just talk about the fact that when I went home last weekend there is still expired yogurt in our parents fridge because that's evidently still what our parents eat. So I started making my own lunches and I just remember her not being there. She never came out and then every day after school because I would get home first I'd always answer the door and there would always be food. There would be casseroles and weird stuff and then when we'd go to church they would pray for her during the sick and shut-ins. I don't know if you remember that? That's how I learned what the word shut-in was because before I knew that I thought they were praying for the sick and shutters (laughter) and I used to think, why are all these wasted prayers going towards shutters. And then I thought, shut-ins, oh mom never leaves her room. And then grandma passed away the same year. Yeah, and umm I don't know how I knew that she had Multiple Sclerosis. I mean no one ever told me, no one ever sat me down, I mean I'm still waiting for them to give me the official birds and the bees talk...

Doctor (audio) while Alyse traverses obstacle course:

Script, script, script, rest, script

Script, script, script, rest, script

Injectable Medications

Copaxone Betaseron

Oral Medications

Rebif & Gilenya

Pharmaceuticals

Prescription refills

Syringes and pills and pills

AND REST!

Cue to play file – Alyse will stomp her feet (right then left), then hang her head.

Play (4 Mom) audio file

"I think that when I was first diagnosed the doctors said to me..."

Mom (Alyse):

I think that when I was first diagnosed the doctors said to me, Dr. Scheinberg, said to me at that time, "Denise I don't ever see you in a wheel chair. Umm, I don't see you in a wheelchair." And I took that to heart. Here I was twenty something years old, and I was not gonna be in a wheelchair... (with emphasis in her voice) I was NOT going to succumb to that" So that had a lot to do with the fact that I was still teaching obviously for many years after I was diagnosed, so everything seemed normal to you and to the rest of the family. I was still going out to work and doing all of that stuff, until the disease got to a point where, the fatigue, I couldn't do it anymore. But why I wanted, I didn't want to scare my children. I didn't want you to have negative thoughts. I was really big on positive thinking. And I think that positive thinking has a lot to do with everyone in everyone's life. You want to have that positive energy in your life. There's too much negativity in our lives,

and I couldn't deal with that. So that's why I chose not to say anything to my girls, until such time I couldn't hide it many years later, about MS.

Doctor (audio) while Alyse traverses obstacle course:

Script, script, script, rest, script

Script, script, script, rest, script

Injectable Medications

Copaxone Betaseron

Oral Medications

Rebif & Gilenya

Pharmaceuticals

Prescription refills

Syringes and pills and pills

AND REST!

Cue to play file – Alyse will stomp her feet (right then left), then hang her head.

Play (5 Dad) audio file

“Your mother was very private about it.”

Dad (Alyse):

Your mother was very private about it. And one of the reasons she was so private about it was because my mother had had it. Clearly it had influenced her way of looking at the disease, she clearly went into it like, this isn't going to beat me, I'm not going to be like your mother was but also she didn't want people feeling sorry for her because when she came along Grandma Keller was well into it, and she did say I don't want to tell your family and it was mainly because my family had gone through it, was going through it.

I always thought we should have told them way before we did. Because I thought if anyone's gonna understand it's gonna be them, but I do understand Mommy's thinking because her feeling was because they have a member of the family with it, I don't want them feeling sorry for me, I don't want them taking care of me. This was way back long before she was bad, or where she really couldn't get around and she really didn't want them to start asking that.

I think now I see a change where they don't include her in a lot of decision making and I think that's going back to what you said about this perception of weakness I clearly see it. I clearly see it. And I discussed it with your mother weeks ago. People make decisions without her opinion all the time. And I can only attribute that to one thing, and it's that they don't think she is capable. And that's just not true.

Doctor (audio) while Alyse traverses obstacle course:

Script, script, script, rest, script

Script, script, script, rest, script

Injectable Medications

Copaxone Betaseron

Oral Medications

Rebif & Gilenya

Pharmaceuticals

Prescription refills

Syringes and pills and pills

AND REST!

Cue to play file – Alyse will stomp her feet (right then left), then hang her head.

Play (6 Mom) audio file

“It was at that time in my life when I was into positive thinking and meditation.”

Mom (Alyse):

It was at that time in my life when I was into positive thinking and meditation. I didn't want to have an aura of negativity around me because I really do believe that negative thoughts and stuff would affect my disease and can affect my health but umm, I was so into that, and umm I should have just said to you girls that....and that's why I didn't really tell people. I didn't really tell anyone. Until such time that I had to.

I never told my school that I had MS. I said I had Lyme because that was more acceptable at that time. But if I would have said that I have MS they would have thought the same thing that I was going to be in a wheelchair and that I couldn't go to work again and duh duh duh duh duh. People's perceptions of words are very different and so I held it back for those reasons. That's pretty much what I did. It's just now bringing back all those memories

So, my colleagues, people I've taught with for twenty/ thirty years, they couldn't understand what that meant when I finally came out, said I did have MS they didn't know what to say to me, they thought that I was going to be in a wheelchair...And they were afraid to call me. No one called me. No one said anything. These were people that were really close to me and they just clammed up because they were embarrassed and they didn't know what to say or what to do. And I didn't want to put them through that. I was thinking more of them then myself because I knew how it was going to effect them. That's how people are. They really don't know how to deal with people with disabilities

Doctor (audio) while Alyse traverses obstacle course:

Script, script, script, rest, script

Script, script, script, rest, script

Injectable Medications

Copaxone Betaseron

Oral Medications

Rebif & Gilenya

Pharmaceuticals

Prescription refills

Syringes and pills and pills

AND REST!

Cue to play file – Alyse will stomp her feet (right then left), then hang her head.

Play (7 Jana) audio file

“When I was home last week she was really struggling getting into bed.”

Jana (Alyse):

When I was home last week she was really struggling getting into bed. But she does this thing where she puts her upper body on the bed and you just push her butt. And it is so intimate. But she's become really good humored about it. And then I put my upper body on the bed and push out my tush, and say, “All right mom, now my turn’ But she never does it. She can be selfish like that. It made me think that we should get a harness and put it on mom and have it attached to a belt on the back of me, and put mom on roller blades...okay do you see where I'm going with this, and as i walk she gets towed behind

me. One, I think it would reconnect us in an umbilical sort of way and make us closer as mother and daughter and two I just think it's more efficient for everyone and it would help her get around. So the first time I suggested that she was obviously on board and very excited!

Doctor (audio) while Alyse traverses obstacle course:

Script, script, script, rest, script

Script, script, script, rest, script

Injectable Medications

Copaxone Betaseron

Oral Medications

Rebif & Gilenya

Pharmaceuticals

Prescription refills

Syringes and pills and pills

AND REST!

Cue to play file – Alyse will walk back to rear stage right and stand

Play (8 Conclusion) audio file

“OK, well if that's all for today...”

At end of Audio file, bring lights down

SCRIPT #2:(DIS)ABLING FAMILY

LIGHTS OFF

Cue MS Video with accompanied audio- 0:00-1:20

Bring Lights Up and AUDIO 1 begins

Hello there Mrs. KELLER. We have identified a series of prescription medication treatment option strategies, what we call PMTOS to infiltrate your MS. A full assault will not work here, but interdiction, or what we call *shoot and scoot*, should help to contain the threat. These PMTOS will provide the artillery you need to endure the battle
Mrs. KELLER

ATTENTION!
Managing Disease Course!

Script, script, script, rest, script
Script, script, script, rest, script
Injectable Medications
 Copaxone Betaseron
Oral Medications
 Rebif & Gilenya
Pharmaceuticals
Prescription refills
Syringes and pills and pills
 AND REST!

AUDIO 2- Keller Siblings (0:00-0:28)

Cue to play file – Alyse will hang her head.

AUDIO 3

“So I remember going to Disney world in first grade and mom had the motor scooter and I thought that was awesome!”

Jana (Alyse):

So I remember going to Disney world in first grade and mom had the motor scooter and I thought that was AWE-some, cause I was like this is so handy that we can put all our bags in the cart and we can cut every single line. I was like we are SO lucky... Oh, I'm Jana Keller. Devoted and favorite daughter of Denise Keller. Okay okay, so I don't really remember her being sick again until the fourth grade when she just stopped coming out of her bedroom and all the neighbors started dropping off all those casseroles and that's when she stopped making my lunches because she would try but her mind wasn't with it and one time she sent me to school with moldy bread. And fourth grade Jana was really afraid that the paraprofessional that sat next to me at lunch was going to think that I had neglectful parents because I came to lunch with moldy bread and expired yogurt which is like, let's

just talk about the fact that when I went home last weekend there is still moldy bread and expired yogurt in our parent's fridge because evidently that's still what our parents eat. So anyway I started making my own lunches at that age and I just remember her not being there. Then when we'd go to church they would pray for her during the sick and shut-ins. I don't know if you remember that? That's how I learned what the word shut-in was because before that I thought they were praying for the sick and shutters and I used to think, why are all these wasted prayers going towards shutters. And then I thought, shut-ins, oh mom never leaves her room.

Yeah, and umm I don't know how I knew that she had Multiple Sclerosis. I mean no one ever told me, no one ever sat me down, I mean I'm still waiting for them to give me the official birds and the bees talk...

AUDIO 4 while Alyse moves to next position:

Script, script, script, rest, script

Script, script, script, rest, script

Cue to play file – Alyse will then hang her head.

AUDIO 5

"I think that when I was first diagnosed the doctors said to me..."

Mom (Alyse):

I think that when I was first diagnosed the doctors said to me, Dr. Scheinberg, said to me, "Denise I don't ever see you in a wheel chair. Umm, I don't see you in a wheelchair." And I took that to heart. Here I was twenty something years old, and I was not gonna be in a wheelchair...this was NOT going to come to that.

So that had a lot to do with the fact that I was still teaching for many years after I was diagnosed, so everything seemed normal to you and to the rest of the family. I was still going out to work and doing all of that stuff, until the disease got to a point where, the fatigue, I couldn't do it anymore.

But why I didn't tell you girls, I didn't want to scare my children. I didn't want you to have negative thoughts. I was really big into positive thinking. And I think that positive thinking can do a lot in everyone's life. You want to have that positive energy in your life. There's too much negativity in our lives, and I couldn't deal with that. So that's why I chose not to say anything to my girls, until such time I couldn't hide it many years later

AUDIO 6 while Alyse moves to next position:

Script, script, script, rest, script

Script, script, script, rest, script

Cue to play file – Alyse will then hang her head.

AUDIO 7

"Your mother was very private about it."

Dad (Alyse):

Your mother was very private about it, Alyse. And one of the reasons she was so private about it was because my mother had had it. Clearly it had influenced her way of looking at

the disease. She clearly went into it like, this isn't going to beat me, I'm not going to be like your mother was, but also she didn't want people feeling sorry for her and she did say I don't want to tell your family

I always thought we should have told them way before we did, because I thought if anyone's gonna understand it's gonna be them. But I do understand Mommy's thinking because her feeling was because they have a member of the family with it, I don't want them feeling sorry for me, I don't want them taking care of me.

I think now I see a change where people don't include her in a lot of the decision making and I think that's going back to what you said about this perception of weakness. I clearly see it. I clearly see it. And I discussed it with your mother weeks ago. People make decisions without her opinion all the time. And I can only attribute that to one thing, and it's that they don't think she is capable. And that's just not true.

AUDIO 8 while Alyse moves to next position:

Script, script, script, rest, script
Script, script, script, rest, script

Cue to play file – Alyse will hang her head.

AUDIO 9

“It was at that time in my life when I was into positive thinking and meditation.”

Mom (Alyse):

It was at that time in my life when I was into positive thinking and meditation. I didn't want to have an aura of negativity around me because I really do believe that negative thoughts and stuff would affect my disease and can affect my health. That's why I didn't really tell people. I didn't really tell anyone. Until such time that I had to.

I never told my school that I had MS. I said I had Lyme's because that was more acceptable at that time. But if I would have said that I have MS they would have thought the same thing that I was going to be in a wheelchair and that I couldn't go to work again and duh duh duh duh duh. People's perceptions of words are very different, Alyse.

So, my colleagues, people I've taught with for twenty/ thirty years, they couldn't understand what that meant when I finally came out, said I had MS. They didn't know what to say to me, and they were afraid to call me. No one called me. These were people that were really close to me and they just clammed up because they were embarrassed and they didn't know what to say or what to do. I was thinking more of them than myself. That's how people are. They really don't know how to deal with people with disabilities

AUDIO 10 while Alyse moves to next position:

Script, script, script, rest, script
Script, script, script, rest, script

Cue to play file – Alyse will then hang her head.

AUDIO 11

“When I was home last week she was really struggling getting into bed.”

Jana (Alyse):

When I was home last week she was really struggling getting into bed. But she does this thing where she puts her upper body on the bed and you just push her butt. And it is so intimate. But she's become really good humored about it. And then I put my upper body on the bed and push out my tush, and say, "All right mom, now my turn" But she never does it. She can be selfish like that.

But it made me think of this genius idea! Did I tell you about it? It made me think that we should get a harness and put it on mom and have it attached to a belt on the back of me, and put mom on roller blades...okay do you see where I'm going with this. As I walk she gets towed behind me. One, I think it would reconnect us in an umbilical sort of way as mother and daughter and two I just think it's more efficient for everyone and it would help her get around. So the first time I suggested this to Mom she was obviously on board and very excited about this idea!

AUDIO 12 while Alyse moves to next position:

Script, script, script, rest, script
Script, script, script, rest, script

Cue to play file – Alyse will then hang her head.

AUDIO 13- Dad's Interview-(1:13:49-1:13:55)

"Yeah I mean I guess the difference with you guys from us, from my family is"

Dad (Alyse):

Yeah I mean I guess the difference with you guys from us, from my family is that we knew your mom had MS before you guys were born, so there was never this moment where we're like "Okay at five years old we gotta tell the girls that you have MS" Because it was always there, and I think we kind of you know sort of never made that happen and we probably should have, but it was like, it's just part of what we are...

AUDIO 14-Keller Siblings- (1:21:09-1:21:44)

AUDIO 15-Dad's Interview- (6:15-6:18)

"By the time she was diagnosed I guess I was 14"

Dad:

By the time she was diagnosed I guess I was 14. I remember friends, relatives, and doctors saying you know, this is in your mind. You can't possibly be having all these symptoms, that just doesn't make sense. You know you're telling me that you're having trouble seeing, and you're having trouble walking, and you're having trouble remembering, and you know those don't make sense, those all don't go together.

I mean did we talk about my mom having MS, yeah a little bit... but it was painful. You kind of kept it to yourself mostly. And then as you heard from the group of us we had this lady down the street who had had MS so we were familiar with it and umm, ummm, she was in a wheelchair, so my first impression was Mom's gonna be in a wheelchair some day that's just kinda how it went.

I didn't know anybody else with it, there was no ads about it, there was no fundraisers for MS, there really wasn't most anything about it. I heard two things about it, one was they called it the Crippler of Young Adults, a real classy moniker for the disease and the other was, Mrs. Kennedy had it down the street, that was all I knew about MS.

AUDIO 16-Aunt Kathy- (4:57-5:03)

"I think I had umm probably an unusual teenage life"

Aunt Kathy:

I think I had umm probably an unusual teenage life. I didn't do a lot of stuff in high school because I felt bad. I didn't want to leave her. I mean she never asked me to stay home, but I just always felt bad and honestly wanted to hang out with her. She was just a cool mom. She was the cool mom you brought all your friends home to meet. She was the cool mom that danced in the living room when we had the music on. You know. Taught us how to jitterbug. She was the kind of person that if someone wasn't going to do it she was going to do it by herself

AUDIO 17-Uncle Bob and Auntie Ellen- (13:07-13:10)

"We've always been the odd ball family"

Uncle Bob:

We were always been the odd ball family anyway, where as siblings we were always so much closer than other siblings you know. And all of us were really attentive to her. I think others might have thought it impacted me more because I was there more than a lot of the others because just the way everybody's lives kind of were then, you know, I was kind of a Mama's boy anyway so it worked out better that way. **(giggle)** But ummm, it didn't affect me in a negative way at all it made it closer with her.

She didn't like to complain you know, I mean she did but almost like an explanation of why she can't do this or why she can't do that. But I always felt like she was missing out on something more than we were.

LIGHTS FADE

AUDIO 18- Papa- (29:40-32:35)

LIGHTS COME BACK UP

AUDIO 19-Uncle Bob and Auntie Ellen- (23:08-23:10)

"This is one story you've probably heard before"

Uncle Bob:

This is one story you've probably heard before. I came this one day, it was just one of these days that she was kind of feeling bad for herself. She was laying in bed, which she did a lot, like your mom, cause they just have to, and umm she was just kind of laying there and I was sitting next to her talking to her and I said something stupid like, "Oh you know it could always be worse, it could be worse you know like what other people have, some people could say it's a gift from God you didn't get something worse." **(giggle)** And she looked away from me and said "A gift from God," and then looked back at me and said, "I would have rather gotten a sweater."

AUDIO 20-Aunt Barb- (24:45-24:49)

“But I saw the difference in them, she became a pain”

Aunt Barb:

But I saw the difference in them, she became a pain, with her group of friends she hung out with and they would say, “Well wait a minute, what happens if she needs to go to the bathroom once you leave.” We’d respond, “She can step. She can make a few steps and get on the toilet. And if you’ll bring the toilet seat in you can help her raise the toilet up.” We would try all these ways and I think in the very beginning they were still picking her up, but then she had an accident in one of their cars and that’s when they asked if we could transport her. And you know that was fine, but it changed things.

They would say to us, “Oh no, we want her to come, we want her to come, we want her to come, you know, anyway YOU can do it.” You know there were certain ones that wanted her to come, and there were others who were like oh geez this is gonna be hard.

I don’t know that your Grandma knew that they felt differently, but she was embarrassed, she was very very worried about the incontinence. That was the worst part for her. She’d get really embarrassed on the toilet when I had to wipe her. And she’d say “I don’t want you to have to do that” And I’d say “Ma, I think I owe you a couple hundred”

AUDIO 21-Uncle Bob and Auntie Ellen-(47:23-47:25)

“She was a terror with the wheelchair”

Uncle Bob:

She was a terror with the wheelchair. We got her an electric wheelchair at the nursing home and they’d call us all the time and be like “You’ve got to do something your mother is hitting people, she’s going too fast” and you know going from not having any independence to all of a sudden having independence with the electric wheelchair (**race car noises**) she was all over the place, it was a little scary.

Several times they called us. “You’ve gotta talk to her. You’ve gotta talk to her. She’s clippin’ people on the corners.” It was not good.

AUDIO 22-Aunt Kathy-(38:44-38:47)

“Somebody said to me once or I read it”

Aunt Kathy:

Somebody said to me once or I read it, it’s like you’re telling your foot, “Okay now heel toe, heel toe” and it won’t move. It just doesn’t work that way and that’s what people don’t understand. That’s when I remember thinking back and thinking, “Gosh all those times when I was kinda like, Come on Mom!”

She did get frustrated. There were times when she was in a lot of pain, and she would take a dive in the pity pool like we all do every once and a while, but then she would shake it off. I would say she probably used humor more to deal with it.

AUDIO 23-Dad Interview- (30:18-30:20)

“She always did that, she uhh umm”

Dad:

She always did that, she uhh umm you know she always used to you know act like she was drunk, even though she hadn't had a drink because she was stumbling and slurring her words, so she'd be like "I'm not as thunk as you drink I am" or something like that. think the idea was umm, they think I'm drunk anyway based on my mannerisms, I may as well play along or you know I can kinda joke with them about it, so that happened quite a bit cause I think that was her coping mechanism. You know she just kinda did this you know, **(raises glass)** she'd raise this fake glass, you know here I am.

Brings Lights Down

AUDIO 24-Alyse from Uncle Bob Audio- (58:58-1:00:40)

AUDIO 25-Adolfo

Alyse walks off stage

SCRIPT #3: (DIS)ABLING FAMILY

AUDIO N.W 1

LIGHTS OFF

AUDIO N.W. 2

Cue MS Video with accompanied audio- 0:00-1:28

LIGHTS UP

AUDIO 1

Cue to play file – Alyse will hang her head.

AUDIO 3

“So I remember going to Disney world in first grade and mom had the motor scooter and I thought that was awesome!”

Jana (Alyse):

So I remember going to Disney world in first grade and mom had the motor scooter and I thought that was AWE-some, cause I was like this is so handy that we can put all our bags in the cart and we can cut every single line. I was like we are SO lucky... Oh, I’m Jana Keller. Devoted and favorite daughter of Denise Keller. Okay okay, so I don’t really remember her being sick again until the fourth grade when she just stopped coming out of her bedroom and all the neighbors started dropping off all those casseroles and that’s when she stopped making my lunches because she would try but her mind wasn’t with it and one time she sent me to school with moldy bread. And fourth grade Jana was really afraid that the paraprofessional that sat next to me at lunch was going to think that I had neglectful parents because I came to lunch with moldy bread and expired yogurt which is like, let’s just talk about the fact that when I went home last weekend there is still moldy bread and expired yogurt in our parent’s fridge because evidently that’s still what our parents eat. So anyway I started making my own lunches at that age and I just remember her not being there. Then when we’d go to church they would pray for her during the sick and shut-ins. I don’t know if you remember that? That’s how I learned what the word shut-in was because before that I thought they were praying for the sick and shutters and I used to think, why are all these wasted prayers going towards shutters. And then I thought, shut-ins, oh mom never leaves her room.

Yeah, and umm I don’t know how I knew that she had Multiple Sclerosis. I mean no one ever told me, no one ever sat me down, I mean I’m still waiting for them to give me the official birds and the bees talk...

Cue to play file – Alyse will then hang her head.

AUDIO 5

“I think that when I was first diagnosed the doctors said to me...”

Mom (Alyse):

I think that when I was first diagnosed the doctors said to me, Dr. Scheinberg, said to me, “Denise I don’t ever see you in a wheel chair. Umm, I don’t see you in a wheelchair.” And I took that to heart. Here I was twenty something years old, and I was not gonna be in a wheelchair...this was NOT going to come to that.

So that had a lot to do with the fact that I was still teaching for many years after I was diagnosed, so everything seemed normal to you and to the rest of the family.

But why I didn’t tell you girls, I didn’t want to scare my children. I didn’t want you to have negative thoughts. I was really big into positive thinking. There’s too much negativity in

our lives, and I couldn't deal with that. So that's why I chose not to say anything to my girls, until such time I couldn't hide it many years later

Cue to play file – Alyse will then hang her head.

AUDIO 7

"Your mother was very private about it."

Dad (Alyse):

Your mother was very private about it, Alyse. And one of the reasons she was so private about it was because my mother had had it. Clearly it had influenced her way of looking at the disease. She clearly went into it like, this isn't going to beat me, I'm not going to be like your mother was, but also she didn't want people feeling sorry for her and she did say I don't want to tell your family

I always thought we should have told them way before we did, because I thought if anyone's gonna understand it's gonna be them. But I do understand Mommy's thinking because her feeling was because they have a member of the family with it, I don't want them feeling sorry for me, I don't want them taking care of me.

I think now I see a change where people don't include her in a lot of the decision making and I think that's going back to what you said about this perception of weakness. I clearly see it. I clearly see it. And I discussed it with your mother weeks ago. And I can only attribute that to one thing, and it's that they don't think she is capable. And that's just not true.

Cue to play file – Alyse will hang her head.

AUDIO 9

"It was at that time in my life when I was into positive thinking and meditation."

Mom (Alyse):

It was at that time in my life when I was into positive thinking and meditation. I didn't want to have an aura of negativity around me because I really do believe that negative thoughts and stuff would affect my disease and can affect my health. that's why I didn't really tell people. I didn't really tell anyone. Until such time that I had to.

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Cue to play file – Alyse will then hang her head.

AUDIO 11

"When I was home last week she was really struggling getting into bed."

Jana (Alyse):

When I was home last week she was really struggling getting into bed. But she does this thing where she puts her upper body on the bed and you just push her butt. And it is so intimate. But she's become really good humored about it. And then I put my upper body

on the bed and push out my tush, and say, “All right mom, now my turn’ But she never does it. She can be selfish like that.

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Cue to play file – Alyse will then hang her head.

AUDIO 13- Dad’s Interview-(1:13:49-1:13:55)

“Yeah I mean I guess the difference with you guys from us, from my family is”

Dad (Alyse):

Yeah I mean I guess the difference with you guys from us, from my family is that we knew your mom had MS before you guys were born, so there was never this moment where we’re like “Okay at five years old we gotta tell the girls that you have MS” Because it was always there, and I think we kind of you know sort of never made that happen and we probably should have, but it was like, it’s just part of what we are...

AUDIO N.W. 3

AUDIO 14-Keller Siblings- (1:21:09-1:21:44)

AUDIO 15-Dad’s Interview- (6:15-6:18)

“By the time she was diagnosed I guess I was 14”

Dad:

By the time she was diagnosed I guess I was 14. I remember friends, relatives, and doctors saying you know, this is in your mind. You can’t possibly be having all these symptoms, that just doesn’t make sense. You know you’re telling me that you’re having trouble seeing, and you’re having trouble walking, and you’re having trouble remembering, and you know those don’t make sense, those all don’t go together.

I mean did we talk about my mom having MS, yeah a little bit... but it was painful. You kind of kept it to yourself mostly. And then as you heard from the group of us we had this lady down the street who had had MS so we were familiar with it and umm, ummm, she was in a wheelchair, so my first impression was Mom’s gonna be in a wheelchair some day that’s just kinda how it went. I didn’t know anybody else with it, there was no ads about it, there was no fundraisers for MS, there really wasn’t most anything about it. I heard two things about it, one was they called it the Crippler of Young Adults, a real classy moniker for the disease and the other was, Mrs. Kennedy had it down the street, that was all I knew about MS.

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AUDIO 17-Uncle Bob and Auntie Ellen- (13:07-13:10)

“We’ve always been the odd ball family”

Uncle Bob:

We were always been the odd ball family anyway, where as siblings we were always so much closer than other siblings you know. And all of us were really attentive to her. I think others might have thought it impacted me more because I was there more than a lot of the others because just the way everybody’s lives kind of were then, you know, I was kind of a Mama’s boy anyway so it worked out better that way. **(giggle)** But ummm, it didn’t affect me in a negative way at all it made it closer with her.

She didn’t like to complain you know, I mean she did but almost like an explanation of why she can’t do this or why she can’t do that. But I always felt like she was missing out on something more than we were.

AUDIO N.W. 4

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having independence with the electric wheelchair (**race car noises**) she was all over the place, it was a little scary.

Several times they called us. “You’ve gotta talk to her. You’ve gotta talk to her. She’s clippin’ people on the corners.” It was not good.

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Somebody said to me once or I read it, it’s like you’re telling your foot, “Okay now heel toe, heel toe” and it won’t move. It just doesn’t work that way and that’s what people don’t understand.

That’s when I remember thinking back and thinking, “Gosh all those times when I was kinda like, Come on Mom!”

She did get frustrated. There were times when she was in a lot of pain, and she would take a dive in the pity pool like we all do every once and a while, but then she would shake it off. I would say she probably used humor more to deal with it.

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Brings Lights Down

AUDIO 24-Alyse from Uncle Bob Audio- (58:58-1:00:40)

AUDIO N.W. 5

SCRIPT #4: LAUGHING WITH YOU ALWAYS: A PERFORMANCE OF NARRATIVE MEDICINE

**Chairs set up in U shape. Projector 1 on. Music playing.
(Lights Down) (Music Fades)**

**Slide 1: (keep for 30 seconds)
Start with power point slide displaying text explanation of my performance**

**Slide 2: (keep until lights go on)
Laughing with you Always: A Performance of Narrative Medicine**

(Lights On)

**Slide 3:
Alyse Keller
Performer/Researcher
AUDIO 1**

“Well I can start with this story about Mom...”

Slide 4: black screen

Alyse:

Well I can start with this story about Mom. So my mom doesn't often drink. For years, she said it was because the doctors told her it was bad for her MS. This was in addition to the myriad other suggestions doctors made like avoiding heat, not overexerting herself, and she may have at one point alleged the doctors told her “doing laundry” was also bad for her. Smart woman.

When she does drink now, it's usually with me, her most responsible and positive influence of a daughter. It is usually five small sips of sweet, sweet white wine, before her head cocks forward, mouth agape, and she's out for the night.

So it was Christmas break two years ago and we were out to dinner in the city (New York City is the only city- Quote Denise Keller) My father and I ordered beers from a local brewery, my sister got her usual “Dirty Shirley, hold the dirty,” and in the last inning, after oscillating back and forth between a Moscato and a Moscato, my mother shocked us all with an unexpected cocktail order called “The Gypsy.” A bright pink concoction of vodka and unidentified neon pink liquor.

We were 30 minutes into our dinner, my mother was about half way through her whimsical pink drink, when she looked at my sister and me, softly whispering, “I need to go.” “I need to go,” is code in my family for help me to the bathroom immediately. I stood up, unlocking my mother's wheelchair, and rapidly rolled her into the bathroom with my sister in tow.

In the timeline of my mother's disease, this was probably a week after she was released from the assisted living facility. A week into us learning how to transport her from the chair to the toilet. A week into showering my own mother for the first time. A week into learning how to properly wipe my own mother after she goes to the bathroom. And 30 minutes into realizing we'd all had one drink too many.

Now let's fast forward to the moment of truth. We started the normal transition. Lock the wheelchair at an angle adjacent to the toilet. Hold onto mom's waist and have her use the bar on the wall to lift herself. Then lift together. Once she's standing, pull the wheel chair out from behind her to ensure that she doesn't trip. Pull her pants and diaper down, rotate her 45 degrees and sit her on the seat, as smoothly as physically possible.

Well this time, things didn't go as they should have. what happened next is all a blur. It could have been the angle of the wheelchair, we might have been a little too far from the toilet seat, her legs might have been too tired by 8:30 pm that night. But what I do know wholeheartedly contributed to the next move, the goddamn Gypsy drink.

Before we knew it, my mother was laughing, I was laughing, and Jana was laughing. But we weren't laughing in place. As the laughter grew, so did our inability to support our mother, or for her to support herself. And so, she started to sink to the floor-- a very dirty, Manhattan bathroom floor, mind you. But not only did her laughing fit weaken her ability to stand, no that's too easy, it also prompted her bladder to run loose like ol' faithful.

So there we were, three gals out on the town, sprawled on a bathroom floor, surrounded by our mother's urine. If you too have ever been stranded on a bathroom floor with your mother and her urine, you know that it's a funky position to be in. Mostly because you must dead lift a grown woman off the floor, and neither my sister Jana nor I fully passed any of our physical fitness tests in elementary school P.E., so that made this situation significantly more difficult.

There were several ways to approach this situation, I'm not sure any of them were right, but I decided the best approach to a situation in which we were stranded on a bathroom floor with our mother and her urine—we must share secrets. So I started by telling Mom "I guess there is no better time to tell you, but both Jana and I also have been stranded on bathroom floors during college, surrounded by our own liquids." After admitting how proud she was of us she said she was ready to get up.

And like a NASCAR support crew, my sister and I worked my mother back on to the toilet, cleaned the floor and our mother, without skipping a beat. When we returned to the table, all three of us giggling, my father who had been waiting a while for us to return, smiled and said, "I won't ask." And as we rolled out of the restaurant, my mother motioned for us to pause, and laughing at herself dramatically stated, "Okay, so who's ready for round two?"

Slide 5:

Denise Keller

Alyse's mother

AUDIO 2

"I think that when I was first diagnosed the doctors said to me..."

Slide 6: black screen

Mom:

I think that when I was first diagnosed the doctors said to me, Dr. Scheinberg, said to me, "Denise I don't ever see you in a wheel chair. Umm, I don't see you in a wheelchair." And I took that to heart. Here I was twenty something years old, and I was not gonna be in a wheelchair...this was NOT going to come to that.

So that had a lot to do with the fact that I was still teaching for many years after I was diagnosed, so everything seemed normal to you and to the rest of the family.

But why I didn't tell you girls, I didn't want to scare my children. I didn't want you to have negative thoughts. I was really big into positive thinking. There's too much negativity in our lives, and I couldn't deal with that. So that's why I chose not to say anything to my girls, until such time I couldn't hide it many years later.

I didn't really tell anyone. Until such time that I had to. I never told my school that I had MS. I said I had Lymes because that was more acceptable at that time. But if I would have said that I have MS they would have thought the same thing that I was going to be in a wheelchair and that I couldn't go to work again and duh duh duh duh duh. People's perceptions of words are very different, Alyse.

So, my colleagues, people I've taught with for twenty/ thirty years, they couldn't understand what that meant when I finally came out, said I had MS. They didn't know what to say to me, and they were afraid to call me. No one called me. These were people that were really close to me and they just clammed up because they were embarrassed and they didn't know what to say or what to do. I was thinking more of them than myself. That's how people are. They really don't know how to deal with people with disabilities

Slide 7:

Jana Keller

Alyse's sister

AUDIO 3

"So I remember going to Disney world in first grade and mom had the motor scooter and I thought that was AWE-some..."

Slide 8: black screen

Jana:

So I remember going to Disney world in first grade and mom had the motor scooter and I thought that was AWE-some, cause I was like this is so handy that we can put all our bags in the cart and we can cut every single line. I was like we are SO lucky. But I don't really remember her being sick again until the fourth grade when she just stopped coming out of

her bedroom and all the neighbors started dropping off all those casseroles and that's when she stopped making my lunches because she would try but her mind wasn't with it and one time she sent me to school with moldy bread.

And fourth grade Jana was really afraid that the paraprofessional that sat next to me at lunch was going to think that I had neglectful parents because I came to lunch with moldy bread and expired yogurt which is like, let's just talk about the fact that when I went home last weekend there is still moldy bread and expired yogurt in our parent's fridge because evidently that's still what our parents eat.

So anyway I started making my own lunches at that age and I just remember her not being there. Then when we'd go to church they would pray for her during the sick and shut-ins. I don't know if you remember that? That's how I learned what the word shut-in was because before that I thought they were praying for the sick and shutters and I used to think, why are all these wasted prayers going towards shutters. And then I thought, shut-ins, oh mom never leaves her room.

Yeah, and umm I don't know how I knew that she had Multiple Sclerosis. I mean no one ever told me, no one ever sat me down, I mean I'm still waiting for them to give me the official birds and the bees talk...

BUT did I tell you about my genius idea I came up with the other day? Okay, I think that we should get a harness and put it on mom (**pause**) and have it attached to a belt on the back of me, and put mom on roller blades...

Okay do you see where I'm going with this. As I walk she gets towed behind me. One, I think it would reconnect us in an umbilical sort of way as mother and daughter, and two I just think it's more efficient for everyone and it would help her get around. So the first time I suggested this to Mom she was obviously on board and very excited about the idea

Slide 9:

Jim Keller

Alyse's father

AUDIO 4

"Your mother was very private about it."

Slide 10: black screen

Dad:

Your mother was very private about it, Alyse. And one of the reasons she was so private about it was because my mother had had it. Clearly it had influenced her way of looking at the disease. She clearly went into it like, this isn't going to beat me, I'm not going to be like your mother was, but also she didn't want people feeling sorry for her. She she did say I don't want to tell your family

I always thought we should have told them way before we did, because I thought if anyone's gonna understand it's gonna be them. But I do understand Mommy's thinking because her feeling was because they have a member of the family with it, I don't want them feeling sorry for me, I don't want them taking care of me.

Oh god I see so many similarities between my mother and mommy, your mother. I mean more than I'd like to because sometimes I look at my wife and I'm like, you know it's my mom, and you don't want that... There's so many things that they say and do and their actions and their movements, uhh the stuff that you guys joke about with mom, are the same things we joked about with Grandma Keller. You know the hand gestures you know that she does, Grandma Keller did all that same kind of stuff and I think it's because you're using your hands to do things that your legs used to do maybe, I don't know but they both did it. They both had the same self effacing humor. You know they're both willing to be laughed at and you know laugh along. But your Grandma would always ask, "Are you laughing at me or with me?" And we'd respond, "With you, Always"

Slide 11:

Barbara Keller Yendall

Alyse's Aunt

AUDIO 5

"But I saw the difference in them, she became a pain"

Slide 12: black screen

Aunt Barb:

But I saw the difference in them, she became a pain, with her group of friends she hung out with and they would say, "Well wait a minute, what happens if she needs to go to the bathroom once you leave." We'd respond, "She can step. She can make a few steps and get on the toilet. And if you'll bring the toilet seat in you can help her raise the toilet up." We would try all these ways and I think in the very beginning they were still picking her up, but then she had an accident in one of their cars and that's when they asked if we could transport her. And you know that was fine, but it changed things.

They would say to us, "Oh no, we want her to come, we want her to come, we want her to come, you know, anyway YOU can do it." You know there were certain ones that wanted her to come, and there were others who were like oh geez this is gonna be hard.

I don't know that your Grandma knew that they felt differently, but she was embarrassed, she was very very worried about the incontinence. That was the worst part for her. She'd get really embarrassed on the toilet when I had to wipe her. And she'd say "I don't want you to have to do that" And I'd say "Ma, I think I owe you a couple hundred"

Slide 13:

Bob Keller

Alyse's Uncle Bob

AUDIO 6

“This is one story you’ve probably heard before

Slide 14: black screen

Uncle Bob:

This is one story you’ve probably heard before. I came this one day to visit your Grandmother. It was just one of these days that she was kind of feeling bad for herself. She was laying in bed, which she did a lot, like your mom, cause they just have to, and umm she was just kind of laying there and I was sitting next to her talking to her and I said something stupid like, “Oh you know it could always be worse, it could be worse you know like what other people have, some people could say it’s a gift from God you didn’t get something worse.” **(giggle)** And she looked away from me and said “A gift from God,” and then looked back at me and said, “I would have rather gotten a sweater.”

Your grandmother was also a terror with the wheelchair. We got her an electric wheelchair at the nursing home and they’d call us all the time and be like “You’ve got to do something your mother is hitting people, she’s going too fast” and you know going from not having any independence to all of a sudden having independence with the electric wheelchair **(race car noises)** she was all over the place, it was a little scary.

Several times they called us. “You’ve gotta talk to her. You’ve gotta talk to her. She’s clippin’ people on the corners.” It was not good.

Slide 15:

Alyse Keller

Performer/Researcher

AUDIO 7

“I mean I don’t know, I mean this interviewing everybody has been really good for me..”

Slide 16: black screen

Alyse:

I mean I don’t know, I mean this interviewing everybody has been really good for me because I think that it’s a really unique situation and there aren’t a lot of people that understand the experience so it’s pretty special to have all of you to talk to about this and to share these stories that are very similar to the experiences my sister and I had, but it’s been really good and really important too. Because all the things you’ve all been saying are all the things I’ve felt before like having a sensitivity toward people with disabilities and that’s really important because I see people treating my mom differently all the time.

Her group of girlfriends, friends have dropped off left and right because it’s too much work for them and I think like how can you do that to somebody that you call your friend and so for me it’s important to share these stories I think because it normalizes it. It makes it a norm.

(Lights Off)