A PARENT'S DIS-EASE WITH MARGINALIZATION FOLLOWING A GASTROINTESTINAL OSTOMY: IMPLICATIONS OF ABJECT THEORY AND NORMALCY DISCOURSES ON THEOLOGICAL CONSTRUCTS AND PRACTICES OF CARE

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To

Paul Hood-Patterson

With love, gratitude, and exhaustion.

Contents

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Chapter One

Introduction

“On the surface it's easy to observe the disadvantages, inconveniences, and stigmas associated with anyone requiring an ostomy bag. However, in Owen's case that bag represents a lifetime of opportunity.”

-Stephen, father of Owen

“Disease is a part of the dust of our bodies; we accept it when we accept life.”

-Arthur Frank, *At the Will of the Body*

Introduction

Donning a yellow gown, purple gloves, and a facemask stamped with the Cook Children’s logo (the standard personal protection equipment), I pause a few extra beats at the door of this hospital room. I am still overcome by the sights, sounds, and smells from the room—sights, sounds, and smells not uncommon from those living with a gastrointestinal ostomy. Sure enough, I was greeted at the door by the aroma of what I would come to learn was the “output” from a recently emptied ileostomy collection bag. This smell, the parents I later interviewed described as “just different” and “when you know, you know.”

“How are you?” I asked as I resisted my urge to turn around and come back when “she was feeling better.” We all knew that I only wanted to return when *I* was feeling better. She was less bothered by her own body than was I. I pushed my way through the aroma, plowed past my unbridled urge to make an excuse, and found the chair next to the bed. It was a safe distance away from her. My body would not touch hers, and I could not see what was collecting in the bag secured to her stomach just beneath the purple puppy hospital gown. I am still sometimes afraid of her body, her smell, her embodied difference. While gastrointestinal ostomies are not contagious, I sometimes forget that detail.

Our culture disparages bodies that look or function differently, particularly when it comes to the intestinal tract. Our media offers two illustrations of this: A commercial for Benjamin

Franklin Plumbing features Mike Rowe[1] standing with a plumbing technician near a hot water heater. Rowe says, “If you think about it, the plumbing system in your house is just like the plumbing system in your body. Hey Chris, How's the ‘patient?’” (Rowe is referring to the hot water heater.) “Leaky,” replies Chris. Rowe responds with, “Ugh, that's embarrassing.”[2] This theme repeats in literature.

Theodore Decker, the main character in *The Goldfinch*, experiences a depression episode and recounts in hyperbolic fashion all the perils and “hells” life could bring. He describes, “Boring jobs and ruinous mortgages and bad marriages and hair loss and hip replacements and lonely cups of coffee in an empty house and a colostomy bag at the hospital.”[3] Our cultural landscape frames a “leaky” body as embarrassing and a colostomy bag as a version of hell.

These examples illustrate our capacity to disparage, ridicule, and marginalize people living with illness and gastrointestinal ostomies. Not only do these social messages impede loving relationships with those experiencing illness and embodied differences, but it also impedes our abilities to love our own bodies. The ways societies cultivate and maintain an understanding of “normal” or even “preferred” bodies impacts the ways individuals assumes and adopt these messages about their identity. Our abilities to love our own bodies, when we experience illness or “difference,” becomes complicated.

As a pastoral theologian, I will offer theological anthropological resources to attend to the problem of disparaging messages about the body. As I reflect on anxiety about embodied fragility and finitude, I will demonstrate how anxiety prompts the marginalization of bodily

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[1] Mike Rowe is a television personality best known as the host of the reality-TV series “Dirty Jobs” which aired on the *Discovery* channel.

[2] This commercial can be accessed at: https://www.ispot.tv/ad/AmRm/benjamin-franklin-plumbing-leaking-featuring-mike-rowe#

[3] Donna Tartt, *The Goldfinch* (New York, NY: Little, Brown and Company, 2013), 476.

differences. I suggest that the *imago Dei*, understood as embodied and relational, offers an important corrective for the marginalizing potential of anxiety.

Objectives and Thesis

Pastoral theologians Bonnie Miller-McLemore[4] and Paul Jewett[5] have written about how our experience in our bodies is shaped by particular contexts and cultures. We cannot understand our bodies apart from our social and historical location.[6] The time, place, and culture in which we live shape our senses about embodiment and our body identity. Our bodies and embodied experiences, like illness, are interpreted through the lens of ideological frameworks that build and maintain definitions and assumptions about who is "normal" in reference to body appearance or function. I will argue that historical, social, and ideological contexts shape our bodies and our bodies shape our ideas, theories, and theologies.[7] This assumption guides the objectives of this study.

I will examine three principle objectives in this dissertation. First, I will explore the theological concept of the *imago Dei* as embodied and relational. I suggest that when we recognize that the *imago Dei* is irreducible, even when illness is present, this recognition enables us to resist discourses that otherwise depreciate the goodness of the body and our relationships with others, with God, and with our own bodies. Second, I will evaluate the role of anxiety as a theological construct which aids our understanding of constraints of finite societies and finite bodies. I will also suggest that anxiety can be facilitating—enabling our agency, our advocacy, and out resistance of normalcy discourses. Anxiety is also debilitating—resulting in actions that

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[4] Bonnie, Miller-McLemore, "Embodied Knowing, Embodied Theology: What Happened to the Body?" in *Pastoral Psychology* 62, no. 5 (October 2013): 743-58.

[5] Paul Jewett, "Body," in *Dictionary of Pastoral Care and Counseling*, expanded edition, ed. Rodney J. Hunter and Nancy J. Ramsay (Nashville, TN: Abingdon, 1990/2005), 101-3.

[6] Miller-McLemore, "Embodied Knowing," 744.

[7] Miller-McLemore, "Embodied Knowing," 748.

marginalize. Third, I propose practices of care for pastoral caregivers who accompany families experiencing illness. The intent of the proposed pastoral care practices are to assist pastors as they collaborate toward illness narratives that take suffering seriously while also resisting the effects of marginalization due to embodied differences.

The *imago Dei* is an undiminished good within humanity. The *imago Dei* is innate to humanity. It can never be erased, not because of a disease like necrotizing enterocolitis that results in a gastrointestinal ostomy. The ever-presence of the *imago Dei* can be overlooked because of the force of social and body narratives which compromise our abilities to see the brilliance of the *imago Dei*. Bodies, rendered abject[8] and not “normal” (because of a gastrointestinal ostomy), are often scorned and diminished within our current Western culture. The *imago Dei* is never reducible; it is always present within humanity.

Sustained attention on embodiment (its goodness and its frailty) reshapes our theological constructs of the *imago Dei*. When I say that humanity is created in the image of God, this means that humanity is created to be deeply relational, beautifully diverse, and embodied. The embodied quality of the *imago Dei* illustrates the breadth and diversity of God’s image within humanity. This assertion enlarges our perception of who is included when we say humanity is created in God’s image, and it helps us resist social discourses that demean and depreciate the goodness of the body. All bodies, including those with gastrointestinal ostomies, shape and enhance our conception and imagination of what is meant to be created in the image of God and what is meant to be a fully-human, fully-good body.

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[8] For this project, “abject” is a theoretical framework for nuancing the ways in which embodied difference is feared or reviled. The abject is a way of thinking about “othered” difference rooted in fear, repulsion, and aversion toward our own bodies. A brief definition is offered below but I will develop this concept and define this theoretic framework in the fourth chapter of this dissertation.

The constraints of our finitude are anxiety producing. Disease causes the body to fail and feel frail. Illness illustrates this embodied fragility and humanity responds anxiously to that fragility. Anxiety can facilitate our sense of compassion with those suffering. This happens when we relate to the suffering of others. Compassion invigorates hospitable, mutual, and caring relationships. Anxiety, however, can result in the marginalization of those experiencing embodied differences and illness. Illness also reveals social vulnerabilities. We are embedded in social and historical contexts, contexts that interpret bodies through a lens of "normalcy." When bodies do not coincide with our expectations and assumptions about the function or appearance of a "normal" body we marginalize those bodies.

When we marginalize and depreciate bodies—distinguishing them as disgusting, fear-inducing or distinctly "other"—this act of marginalization and depreciation toward bodies can be described as a sinful reaction to anxiety. Theologian Reinhold Niebuhr draws an important and clear distinction with regard to anxiety. He argues that anxiety is not sinful in and of itself but rather a precondition of sin;[9] meaning, our anxious reactions and feeling toward the body are not inherently problematic. This experience of anxiety does not nullify loving relationships with self, other, and God. However, when humanity reacts to anxiety by excluding and marginalizing bodies this exclusion is a sinful response to anxiety; it disrupts relationships with others, with God, and with our own ability to love our bodies. While humanity can react sinfully to anxiety it can also be a motivating force for care, as demonstrated by my co-researchers as it becomes a force for their advocacy and loving care toward their children.

Pastoral caregivers accompany individuals and communities as they resist marginalization emerging as a result of social norms about embodied difference.

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[9] Reinhold Niebuhr, *The Nature and Destiny of Man, vol. 1: Human Nature* (New York, NY: Charles Scriber's Sons, 1941), 183.

Accompanying those experiencing illness means developing new and revised illness narratives which takes into account the perpetual, constructive anxiety described by co-researchers—an anxiety that strengthens their resolve to lovingly care, tend, and advocate for their children. Pastoral caregivers reflect with parents and their children about how their past experiences resisting physical pain and marginalization strengthens their resolve for forthcoming and anticipated marginalization, exclusion, or physical pain because of the embodied difference of their gastrointestinal ostomy.

Key Terms

I want to clarify a few terms that will be used throughout this project and how these definitions impact the meaning and intent of this dissertation. I will define the terms context, illness, disease, embodiment, and gastrointestinal ostomy. I will also briefly define "abjection" and "normalcy discourse." The latter two terms I will define and develop with deeper attention and rigor in the fourth chapter of this project.

Contexts

There is no one, singular context. Most basically, context refers to the "particular social, cultural and ecological situation within which a course of events takes place."[10] Attention to context is important in that it shapes the way bodies are interpreted. Interpretations about the body always "take place within some background of beliefs and practices" like culture, language, traditions,[11] or theologies. Our social identity is impacted by our own "historical and

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[10] Sigurd Bergmann, *God in Context: A Survey of Contextual Theology* (Burlington, VT: Ashgate, 2003), 2.

[11] Thomas A. Schwandt, *The SAGE Dictionary of Qualitative Inquiry*, 3rd ed. (Thousand Oaks, CA: SAGE Publications, 2007), 43.

experiential contexts."[12] Even within a single social group, the impact of experience and location within time nuances our interpretation; generalizing experience is complicated.

My attention to contexts is not only a concern for social or historical location. I am also concerned with ideological contexts that sustain the word "normal." An ideology points to an idea or response that is "unconscious" and "instinctive"[13] within our social and historical location. Challenging an ideology is difficult[14] because an ideology, by its definition, is a part of our "shared cultural or 'commonplace' reality."[15] The idea that a body is "normal" is an ideology. In naming something as "normal" it reproduces "existing systems, structures, and behaviors,"[16] which often privileges those who more closely resemble that definition of "normal" within a given social-historical location.

Finally, I contend that the body is a specific site or context of inquiry. The body is not "problematic or coincidental to human experience."[17] The body—interpreted within social, historical, and ideological contexts—offers important insights for theological constructs and proposed practices of care. This assumption makes the body central. It also suggests that the body is both knowable and generates knowledge. Therefore, I agree with theologian Melanie May's assertion that the body is "the location of God's revelation"[18] and has the capacity to challenges and reframe our theological propositions and practices of care.

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[12] Lee Ann Bell, Barbara J. Love, Sharon Washington, and Gerald Weinstein, "Knowing Ourselves as Social Justice Educators," in *Teaching for Diversity and Social Justice*, 2nd ed., ed. Maurianne Adams, Lee Ann Bell, Pat Griffin (New York, NY: Rutledge, 2007), 383.

[13] Stephen D. Brookfield, *The Power of Critical Theory: Liberating Adult Learning and Teaching* (San Francisco: Jossey-Bass, 2005), 66.

[14] Dorothy E. Smith, *The Conceptual Practices of Power: A Feminist Sociology of Knowledge* (Boston, MA: Northeastern University, 1990) 42-3.

[15] Nancy J. Ramsay, "Intersectionality: A Model for Addressing the Complexity of Oppression and Privilege," *Pastoral Psychology* 63 (2014): 458.

[16] Brookfield, 67

[17] Angie Pears, *Doing Contextual Theology*. (London: Routledge, 2010), 118.

[18] Melanie A. May, *A Body Knows: A Theopoetics of Death and Resurrection* (New York, NY: Continuum, 1995), 103.

Illness and Disease

Disease and illness are not interchangeable terms. Disease is the "pathogenic processes that occur within the body."[19] Illness is the "experience of living through the disease."[20] Illness is a "uniquely human experience that produces not only physical and mental distress but also moral and spiritual distress."[21] Illness takes into account our social location and historical context. Illness evaluates not only our personal experiences but also the way context and relationships influence the meanings we make about our experience with disease.[22]

Arthur Frank, medical ethicist and sociologist, was one of the earliest to draw a clear distinction between the terms "disease" and "illness." Frank notes that disease "reduce[s] the body to physiology, the organization of which can be measured."[23] Since disease offers terms that are measurable, they are often seen as "objective."[24] The perceived objectivity of disease is a misnomer because measurable criteria is also dependent on interpretation and is exposed to power differentials within those interpretations. Frank, in his memoir, says that "illness" picks up the discussion where "medicine leaves off, where I recognize that what is happening to my body is not a set of measures. What happens to my body happens to my life."[25] This dissertation is a project about illness. I will use the term "disease" but only in reference to the physiological effects on the body.

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[19] Susan H. McFadden and John T. McFadden, *Aging Together: Dementia, Friendship, and Flourishing Communities* (Baltimore, MD: Johns Hopkins University Press, 2011), 18.

[20] Arthur Frank, *At the Will of the Body: Reflections on Illness* (New York, NY: Mariner Books, 1991 and 2002), 13

[21] McFadden and McFadden, 19.

[22] McFadden and McFadden, 19 and Frank, *At the Will of the Body*, 13.

[23] Frank, *At the Will of the Body*, 12

[24] Frank, *At the Will of the Body*, 12.

[25] Frank, *At the Will of the Body*, 13.

Embodiment

Pastoral theologians have attributed high regard to the body. In the history of the field, however, the body has not always held place as a central point of inquiry and epistemology. The body was often regarded as a component of a holistic view of humanity[26] rather than a source of knowing. Bonnie Miller-McLemore raises an important critique of how the term "embodiment" is used (and diffused). She argues that the term "embodiment" becomes synonymous with "*cultural embeddedness* or *cultural constructions* [sic] of the body."[27] The critique that she levied rightly points out that the body is both shaped by culture and context and also shapes contexts.[28] When I use the term "embodiment" I am pairing both ideas: the body is known within particular social, cultural, theological contexts *and* the body changes and amends same cultural contexts, social ideologies, and theological principles.

Sociologist Alan Prout argues that within his field the body is studied by means of two alternate approaches: foundationalists[29] or anti-foundationalists.[30] Neither of these offer a satisfactory-enough explanation about how society and the physical body mutually construct each other and the impact of that mutual construction. Prout ultimately argues for a "hybrid"[31] position in which humanity is both "being as well becoming."[32] He suggests that we are fully

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[26] Anton Boisen notes the relationship between body and mind yet he generally "entrusted" the care of the body to the field of medicine. Anton T. Boisen, *The Exploration of the Inner World: A Study of Mental Disorder and Religious Experience* (Philadelphia, PA: University of Philadelphia Press, 1971), 5.

Paul Jewett contends that the caring for the body is an important aspect of a "holistic" care of humanity. Paul Jewett, "Body," in *Dictionary of Pastoral Care and Counseling*, expanded edition, ed. Rodney J. Hunter and Nancy J. Ramsay (Nashville, TN: Abingdon, 1990/2005), 102-3.

[27] Miller-McLemore, "Embodied Knowing,"743.

[28] Miller-McLemore, "Embodied Knowing," 743-4.

[29] Prout writes, "Foundationalists take the view that the body is a real, material entity, which is connected with but different from the many different frameworks of meaning in which it is variously represented in human cultures." Alan Prout, "Childhood Bodies: Construction, Agency and Hybridity" in *The Body, Childhood and Society*, ed. Alan Prout, (New York, NY: St. Martin's Press, Inc., 2000), 3.

[30] He goes on to say that, taken to its extreme, anti-foundationalists argue that there is "no material body," only a representation of the body within a context. Prout, 4.

[31] Prout, 11.

[32] Prout, 9.

human at birth but we also change through time, both physically and socially.[33] Humanity is "actively involved in negotiating" the meanings (and the "implementation" of those meanings) that our bodies have within contexts.[34]

This understanding of embodiment accounts for the physical constraints of the natural world (like disease) as well as the social and relational constrains of illness (like marginalization because of disease)—both of which shape identity. This position notes that the body is "both resources and constraint" in the construction of humanity, drawing "attention to how the body and society work on each other."[35] Prout argues that under this understanding of embodiment "cultural stereotypes" of what is considered "normal" becomes very influential.[36] I agree with him on that argument. Our identity is impacted by what society deems as acceptable, shameful, or "normal" and deviations from those norms generates anxiety.[37]

The term "embodiment" itself characterizes certain assumptions about what is meant by being a "body." If we assume a narrow definition for "body" this becomes problematic for those whose bodies comprise more than bones, nerves, muscles, and sinew. Are bodies that exist with (and because of) medical apparatuses, emblematic of what is included when studying bodies and embodiment? I suggest that all bodies, including those which have been adapted by a medical apparatus, are emblematic of what constitutes and fully-good, fully-human body. The medical apparatus does not change or diminish the quality of the body. As theologian Nancy Eiesland points out, if we do not evaluate and critically examine what is meant by "body" or "embodiment" we risk reinterpreting social norms about the body.[38] We also risk excluding

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[33] Prout, 4-5 and 9.
[34] Prout, 9.
[35] Prout, 5.
[36] Prout, 8.
[37] Prout, 8.
[38] Nancy Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville, TN: Abington Press, 1994), 22.

those whose bodies do not coincide with traditional assumptions about how a body should look or function.

Since embodiment engages more that "just" the body we must be attuned to the reality that embodiment is not always "agreeable."[39] The body, a source of pleasure, can also be a source of tremendous suffering when experiencing illness. As Arthur Frank notes, "I live not only in my body but through it. No one should be asked to detach [their] mind from [their] body and then talk about the body as a thing, out there."[40] Our lives, our identities, our relationships and theologies, and our social discourses are at stake when we speak about or research about the body. Each informs and impacts the other.

Gastrointestinal Ostomy[41]

Many individuals who are not medical professionals assume that any ostomy is a gastrointestinal (GI) ostomy, and this was true for me prior to my clinical experience. Simply said, an ostomy is a surgically-created opening in the body. The actual opening, at the surface of the skin, is called a stoma.[42] Some ostomies enable breathing (tracheostomy), feeding (gastrostomy), or urination (urostomy). A GI ostomy is "a surgically created opening in the abdomen for the discharge of body waste."[43] After the ostomy is completed, the body expels or releases stool through the stoma. This definition of a GI ostomy is also incomplete. My co-

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[39] Eiesland, 95.

[40] Frank, *At the Will of the Body*, 10-11.

[41] Most of the definitions for this section came from the literature and conversations with Carol Wise who, at the time, was the nurse educator for all families and patients who would (or had) received a gastrointestinal ostomy at Cook Children's Medical Center. Carol's role was to train parents and patients about how to take care of a gastrointestinal ostomy post-surgery. Carol is now a part of the ostomy and wound care team. She helps families and patients with ongoing ostomy-related complications that arise due to the ostomy or ostomy products.

[42] United Ostomy Association of America, "What is an Ostomy?," https://www.ostomy.org/what-is-an-ostomy/ (accessed January 22, 2020).

[43] American College of Surgeons, *Pediatric Ostomy Home Skills Kit: Education for a Better Recovery* (Chicago, IL: American College of Surgeons, 2012), 1.

researchers described four different types of ostomies: gastrostomy, ACE Chait, ileostomy, and colostomy.[44] Two of these ostomies help expel bodily waste; the other two do not.

The training materials available to patients and families following an ostomy surgery at Cook Children's Medical Center, in Fort Worth, Texas, are designed to help families and patients adjust to the physical care of a newly formed ostomy addressing hygiene, equipment, and skin care. Very little attention in the materials and in general practice is given to the relational and social implications of an ostomy.[45] The training material does not offer many suggestions about how to talk about the ostomy with children, other family members, or curious strangers. The training material does not concretely address potential for marginalization[46] nor does it address how the ostomy impacts a person's relationship to their own body or the impact it may have on a person's identity.[47]

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[44] 1) The most prevalent is a *gastrostomy* or a feeding tube/g-button. Every child whose parent participated in this study had a g-button. Gastrostomies do not eliminate bodily waste; they help with feeding. The g-button is an opening that goes directly to the stomach (sometimes there are two tubes at one stoma site, this device is called a GJ button, the "G" goes to the stomach while the "J" goes to the jejunum which is part of the small intestine).

2) An ACE Chait or an Antegrade Continence Enema is a small stoma (sometimes created inside the belly button) for enema "flushes" at the start of the colon rather than end (through the rectum). This procedure is for patients who need on-going or long-term enemas.

3) An ileostomy "is the opening created by the surgeon to bring the final end of the small intestine (ileum) to the surface of the abdomen. An ileostomy may be temporary or permanent" (American College of Surgeons, 1).

4) A colostomy "is the opening created by the surgeon to bring the colon (large intestine) to the surface of the abdomen. There are various kinds off colostomies, each named for the location in the colon where the ostomy is formed. The four kinds are: ascending, transverse, descending, and sigmoid colostomy" (American College of Surgeons, 4).

[45] "Be prepared for what you will tell the people you meet about your child's operation. Tell them as much or as little as you want them to know. You can simply say that your child has had abdominal surgery." American College of Surgeons, 35.

[46] The material simply notes that the ostomy pouch can be hidden. "Modern pouches lie pretty flat against the body. Even though the pouch is very obvious to you and your child, it usually cannot be seen under most clothes." There are, however, many co-researchers who spoke about their children wanting to celebrate their ostomy collection pouch, allowing the pouch to remain visible or incorporating the bag in to the person's style and identity. Celebrating and visibly incorporating the ostomy bag was a very important aspect of identity for Hannah and Zoe (Zoe loves to match ostomy bag covers to her clothes, picking a different pattern for each day), Allison and Ava (Ava likes to let her bag hang out the bottom of her shirt or wear two-piece swimsuits), and Jasmine and Liam (Liam likes to decorate his bag with stickers).

[47] This dissertation, as well as a handful of social science articles, helps to fill this lacuna.

Co-researchers detailed experiences when their children's embodied differences were seen as terrifying or disgusting. The literature did not address how to manage these thoughts, feelings or experiences. While co-researchers admit that the look and output of the ostomy triggered a sense of fear or disgust they never defined their child as disgusting. Abjection theory examines how fear, disgust, or disdain for the body and bodily functions results in fear and disdain toward embodied lives.

Abjection Theory

Abjection is not a condition of being—no one is innately abject. Abjection theory, guided in part by philosopher Julia Kristeva, examines fear and loathing as a result of disgust about our own bodies and the bodies of others. This theory will be defined in greater detail in the fourth chapter of this project but a brief definition is warranted. The "abject" is a theoretical framework for nuancing the ways in which embodied difference is feared or reviled, fear and revulsion which is rooted in aversion toward our own bodies.

Normalcy Discourse Theory

As with "abjection theory," normalcy discourse theory will be defined in greater detail in the fourth chapter. Normalcy discourse is a theory grounded in the fusion of its two terms: normal and discourse. The word "normal" holds an ambivalent meaning; there is no objective definition and the term is applied to an array of ideas and items. The general definition of "normal" is ideological[48] and rooted in taken-for-granted assumptions about the body and context. My primary concern in this project is to demonstrate how definitions of "normal" impact our understanding about the body and the body's appearance within a context.

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[48] Stephen Brookfield notes, "When a belief seems natural and obvious and when it serves to reproduce existing systems, structures, and behaviors, it is ideological." Stephen D. Brookfield, *The Power of Critical Theory: Liberating Adult Learning and Teaching* (San Francisco: Jossey-Bass, 2005), 67.

"Discourse" is an idea adopted from critical theory. A discourse is more than language, speech, ideas, or ideology. Discourses hold the power to "constitute the subjects and objects of which they speak."[49] Discourses shape realities and meanings. Normalcy discourses form and shape human identity and perceptions about the body.

Integrating Methods: Correlating Literature and Experience

I will address the methods and methodological commitments in the third chapter of this project but a brief summary is helpful at the onset. Research within complex systems and relationships demand methodological commitments and approaches that critically engage multiple oppressions and power relations. They also demand a method that integrates, evaluates, and revises knowledge from multiple fields and wisdom garnered from lived experience.

Pastoral theological method takes as a starting point lived experience. Pastoral theological methodology accounts for complex human relationships, the impact of society, and wisdom from the body. Pastoral theological methods correlate lived experience with knowledge from disparate fields like theology, social sciences, and clinical practice. Pastoral theology is an exercise in constructive theology. Pastoral theologians do not simply place lived experience into conversation with theology to see how they correlate. Pastoral theologians listen for the theological insights and experiences that emerge in daily, embodied life and allow this experience to change our theological proposals and constructs. Pastoral theological method is inductive, a process in which embodied experience constructs and reframes theological landscapes and arguments.

This project is informed by two methods that work in tandem: this pastoral theological method and narrative qualitative inquiry. Qualitative inquiry is important when conducting

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[49] Schwandt, 73.

research in an institution unfamiliar with pastoral theological methods (like a hospital or clinic) because it offers some shared vocabulary and a commitment to the generation of knowledge from lived experience. Narrative qualitative inquiry is a helpful method to ascertain and evaluate lived knowledge and relationships within the plot of, in this case, an illness narrative.

Contribution of this Study

This project contributes to the field of Pastoral Theology and Pastoral Care in two specific ways. First, when we study bodies that function differently, bodies with a GI ostomy, we learn new ways of capturing and comprehending what is implied when we say that humans are made in the image of God. Secondly, when we uncover new ways of constructing theology, based on different bodies, it reframes our practices of care. We become more mindful of the guiding discourses that motivate our actions.

Differently functioning bodies topple assumed ideologies about what constitutes a healthy, normal, beautifully created, innately good body. Although bodies change over time, and with the impact of disease, this does not diminish the goodness of that body. Studying among parents and primary caregivers of children deemed “abject” because of their differently functioning intestinal tract will highlight how the valuation of body differences expands our understanding of the *imago Dei*. This occurs as we 1) critically engage and destabilize social and theological narratives that bolster narrow definitions of what constitutes “normal bodies” and 2) critically evaluate obstacles that impede our relationships and love with our own bodies, others, and with God.

The *imago Dei* is an ever-present[50] spark of goodness within humanity.[51] Bodies are finite and susceptible to vulnerabilities but neither illness nor a GI ostomy can diminish the brilliance of the *imago Dei*. All of humanity is endowed with the *imago Dei*; every type of body is representative of God's image. The *imago Dei* is innate and therefore not predicated on a body's adherence to a functional intestinal tract, one particular standard, or any culturally mediated definition of "normal."

The *imago Dei* is a theological category and the *imago Dei* also holds ethical implications. The *imago Dei* is relational. As theologian Douglas John Hall notes, "Being = Being-With."[52] To be human means that all the traits and characteristics of "being" are intended for relationships with others.[53] Edward Farley notes that when we act with "compassionate obligation" toward ourselves and toward others these actions form the basis of what it means to be human.[54]

Living out our *imago Dei* means that we offer hospitality, solidarity, and hope among those who experience on-going suffering related to illnesses that change the bodily and embodied experiences. I agree with child psychologist Lee Salk who notes, "The impact of a medical experience for a child depends to a great extent on how parents and a medical team deal with that child."[55] Pastoral caregivers have a responsibility, in tandem with clinical staff, children, and their parents, to foster mutual, hospitable relationships, to live the *imago Dei*. This

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[50] Wendy Farley, Wounding and Healing of Desire: Weaving Heaven and Earth (Louisville, KY: Westminster John Knox Press, 2005), xiii.

[51] Cooper-White, *Many Voices: Pastoral Psychotherapy in Relational and Theological Perspective* (Minneapolis, MN: Fortress Press, 2007), 41.

[52] Douglas John Hall, *Imaging God: Domain as Stewardship* (Grand Rapids, MI: Wm. B. Eerdmans Publishing Company, 1986), 116.

[53] Hall, 116.

[54] Edward Farley, *Good and Evil: Interpreting the Human Condition* (Minneapolis, MN: Fortress Press, 1990), 41-3.

[55] Lee Salk, "Foreword," in *These Special Children: The Ostomy Book for Parents of Children with Colostomies, Ileostomies and Urostomies*, by Katherine F. Jeter (Palo Alto, CA: Bull Publishing Company, 1982), v.

occurs, in part, with critical reflection about the past narratives of survival which enable future hope to resist marginalizing social and theological narratives that depreciate the goodness of the body. Pastoral caregivers can accompany parents and children as they consider how they survived physical pain and social marginalization in the past as they anticipate and resist the inevitable future suffering and anxiety that accompanies ongoing illnesses.

Limitations of the Study

There are two key limitation of this project. One limitation deals with a sustained evaluation of how embodied difference impacts the individual identity of the children who live with a GI ostomy. A second limitation speaks to a sustained look at how embodied differences, because of illness and a GI ostomy, intersect with other forms of differences which are treated oppressively, such as gender, race, sexuality, age, etc.

The first limitation was a self-imposed limitation. As I planned this study I was skeptical about how much access I would have to interview the minor-age patients who lived with a GI ostomy. I was unsure about what would be permissible and attainable within the constraints of the Cook Children’s Institutional Review Board (IRB). I, therefore, decided to limit my study to the parents of children with GI ostomies. It is impossible to draw concrete and specific conclusions about how embodied difference impacts the children without collecting first hand lived experience.

At the outset I assumed that embodied difference and its associated stigmas adversely impact the lives of children. While this finding is not confirmable based on the existing data, the co-researchers documented that their children had (or anticipated that their children would) encountered stigmas because of their ostomy. The co-researchers challenged my previously-held assumptions. They agreed that the stigma related to embodied difference had an adverse effect on their children but they wholly disagreed that the embodied difference *itself* had an adverse effect. All of the parents acknowledged that the ostomy made their child more healthful and increased their quality of life—the embodied difference is advantageous.

The second limitation was borne out of the limitations within the recruiting pool and the IRB. I found that the IRB had overt and hidden constraints that reduced and limited my access to potential co-researchers. I was not allowed to directly recruit co-researchers for this study. This narrowed the field and I had little control over who heard about this study. When I was able to identify potential co-researchers who would represent a wider variety of racial, ethnic, economic, sexual orientation, and gender identities I would actively recruit them. I had marginal success with that recruiting technique.

In my attempts to recruit for diversity I was successful in three attempts: I interviewed a woman living with a low income, a male co-researcher, and a Latina woman. Generalizations about the impact of gender, race, or economics were difficult to make because of the contextual similarities within my co-researcher pool. Throughout the chapters I have included footnotes and additional descriptions to specify how social location nuances and augments the findings.

Notably absent is a description of the role of fathers in the care of their children with GI ostomies. This absence is the result of two constraints. One is the access to fathers in the recruiting pool. All the recruiting for this project occurred at Cook Children's Medical Center and the majority of the patients are accompanied by their mothers. When interviewing the mothers for this project I asked if their male spouse would also be willing to contribute. Stephen was the only father willing to become a co-researcher. This first constraint is revealing about the second.

While all but one of my co-researchers were in committed relationships with the biological fathers of their children, the fathers made fewer contributions to the physical care of their children and the management of the disease. The role of the fathers and mothers generally coincided with traditional gender roles and rules—the mothers worked in the home and tended the children while the fathers worked outside the home.[56] In many cases the father was the primary income earner.[57] Some of the fathers take an active role in learning how to care for their children and contribute to their child's care when they are not at work.

As the research moves forward, I believe that evaluating the role of the fathers in the care of children experiencing illness could produce meaningful results. Another area of research could evaluate the intersection of oppressions related to a GI ostomy and ageism toward children would be a beneficial endeavor. The literature I acquired about children and GI ostomies falls into two categories: it either seeks to "normalize" the GI ostomy or it assumes a negative impact on childhood identity and development. Are these assumptions in the literature accurate? Are the assumptions beneficial, and to whom?

Personal Social Location and Co-Researcher Profiles

Fully abstracting and evaluating one aspect of our identity (like race, age, or gender) from the others is impossible. Highlighting one aspect of identity, however, can reveal new ideas and focus our attention in important ways.[58] I will challenge "normal" body identity in this project.

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[56] My co-researcher Allison suggested two videos that, in her estimation, clearly depicted the roles that she and her spouse assumed. These can be viewed at: 1) SickKids vs. Mom Strong https://www.youtube.com/watch?v=HvNF0yFUcx0 and 2) SickKids vs. Dad Strong https://www.youtube.com/watch?v=3Bw261h5rkc

[57] In a few cases the mothers had to cut back on the number of hours that they worked or stop working all together because their child required many hospital admissions and clinic visits making work outside the home less sustainable. This was specified by Sara, Jasmine, and Crystal.

[58] Patricia Hill Collin, in her notes on intersectionality as a method for evaluating multiple intersecting forms of oppression, argues that we can take three different approaches. We can evaluate a system of oppression as 1) a "freestanding" system, 2) as a place in which one system of oppression is "manipulated within" another system of oppression, or 3) as a site where one system of oppression reaffirms and "upholds multiple oppressions." As I

With that in mind, I will be looking at the way we construct and develop criterion about what it means to be a "normal" body. For the purposes of this project, I assume that being a "normal body" is a position of privilege—though defining the criteria and characteristics of "normal" are intangible and fluid.[59]

This tactic is not meant to impose a binary upon those who are socially accepted as having a "normal" body and those whose bodies function differently. The intent is to illustrate how some bodies are preferred within a given social context. Having a contextually preferred body is a position of privilege—we are given the status of having a "normal" body. A "normal" body is a body by which other (differing bodies) are measured, a body of which we do not have to be cognizant, and a body that does incite questions, curiosity, and scrutiny. This tactic should turn our attention to the way that everybody is responsible[60] for the social conditions that perpetuate "normal" as a body type and the way that, within shifting contextual landscapes, nobody has a "normal" body.

Personal social context impacts research interpretation; impacting how I analyze and report the data collected. It is important, therefore, to disclose my social location as the researcher. I am a relatively healthful, currently able-bodied, cis-gender female, white, well educated, heterosexual, middle-class adult with no children. In the context of this study I am generally thought to have a "normal" body.[61] This assumption about my body is based on my

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define and critique "normal bodies" for this project will use the first approach as described by Hill Collins: "normal" is evaluated as a freestanding system of oppression. Patricia Hill Collins, *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*, 2nd edition (New York, NY: Routledge, 2000), 128.

[59] This will be discussed in greater detail in the fourth chapter.

[60] Frances Kendall, in talking about race and white privilege, notes that in not identifying our privileged location within a social group makes us "blind" to ourselves and complicates our ability to take responsibility for the advantages that these positions allot. She notes that positions of privilege demonstrate the power and control we have in determining if we are "in" or "out" of a certain social group. Frances E. Kendall, *Understanding White Privilege: Creating Pathways to Authentic Relationships Across Race* (New York, NY: Routledge, 2006), 81-3.

[61] If the social and research context were to change and we were to evaluate weight and body mass index I would no longer be considered "normal."

current state of health, because I do not require medical equipment to live or thrive. In addition to having "normal" body privilege I occupy other social groups of privilege (age, race, sexuality, education, economic).

One other position of privilege that bears mentioning is the institutional privilege I hold as a chaplain and researcher in my place of employment. The first interviews for this research were conducted at Cook Children's Medical Center. Since I am an employee at Cook Children's I have institutional power. Although I did not review any of the medical charts for my co-researcher's children[62] I was obligated to wear a research name badge and my employee badge grants me access to most places in the hospital (both in terms of location and relationship). This access disproportionately favors and privileges me.

Co-Researcher Profiles

Some might reference the contributors of a qualitative study as participants. I use the term "co-researcher" as opposed to "participants" as a way of confirming a methodological commitment to a research partnership and trustworthy study.[63] The individuals with whom I engaged in this research enabled me to ask better questions and foster knowledge relevant to their particular contexts and situations by offering detailed descriptions about their experiences and correcting my misconceptions when I was wrong. The details of how (method) they contributed to this study are described in chapter three of this project. It is important to introduce them early on because their lives and their expertise set the stage for every aspect of this project.

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[62] This was a limitation within the Institutional Review Board oversight and a methodological commitment to not let the "medical narrative" take prominence within the data collection. Arthur Frank defines medical narrative as the story told by doctors, about patients. It is the narrative recorded in the medical chart. Arthur Frank, *The Wounded Storyteller: Body, Illness and Ethics*, 2nd ed. (Chicago, IL: University of Chicago Press, 2013), 5-6.

[63] This methodological rational is explored more fully in the third chapter, along with the definition and criterion of the term "trustworthy."

All of the names have been changed for the project. Any identifying factors were self-disclosed and obtained after informed consent. Over the course of this project I had the pleasure to get to know some of these families better than others. Each offered an initial interview on the campus of Cook Children's Medical Center. One third of the co-researchers contributed a first interview for this study when their child was hospitalized due to disease complications. This project is built on data collected from these nine co-researchers. Every co-researcher advocated on behalf of their children, challenged my perspectives, helped me ask better questions, and honestly shared their vulnerabilities. It is important to profile my nine co-researchers.

Hannah and daughter Zoe live in a small town about an hour from Fort Worth. Hannah was referred to me by the Cook Children's Gastrointestinal Clinic staff. Hannah, my co-researcher, is married to man and she has another child younger than Zoe. Zoe was nine and her other child was seven. Hannah is white, middle class, and describes herself as a Christian. Hannah works as a full-time parent. Her spouse is the sole income earner for the family. Hannah describes Zoe as funny, upbeat, smart, and "rocking" life's challenges.

Zoe had intestinal motility issues from the onset. She got an ACE Chait at age four and she eventually got an ileostomy at age five when the ACE Chait flushes were no longer working for Zoe. Since Zoe has a colon that does not move or function well-enough on its own Hannah was not heartbroken when Zoe needed an ileostomy. Hannah spoke about the ileostomy as a welcomed result after years of struggle and pain. She was expecting it and grateful that it would "take all of the pressure off of her body" to do things that her colon was not doing. I never met Zoe; she was the only child of a co-researcher who I never had the chance to meet. When Zoe is feeling well and not admitted to the hospital, she is very involved with sports and play-dates with her classmates at school.

Leticia is a single parent, Latina, heterosexual, working class-woman. I met Leticia through the gastrointestinal disease support group offered at Cook Children's. Leticia works in the medical profession outside the home. Leticia is the mother of Samuel, who was eighteen and starting his freshman year in college when I first met her. Leticia lives in a suburb of Fort Worth. She has four children, two daughters older than Samuel and one son, younger than Samuel. She is also a proud grandmother. Samuel's biological father no longer lives with the family nor does he provide financial support for the family or Samuel.

Samuel lives with "short bowel" syndrome. Eighty to ninety percent of his bowel was removed when he was a baby. He had a colostomy for a short time as an infant but he has lived with a gastrostomy for the majority of his life. Leticia beams when she talks about Samuel; she is so proud of him and his ambitions at college. It was interesting, heart-rending, and fun to hear Leticia talk about Samuel as he made his transition to college, through his first year, and into his sophomore year. Leticia contributed to this project with formal interviews as well as casual conversations that honed my insight.

Crystal and Stephen are married and they parent Owen and Oliver. Stephen and Crystal both contributed to this study. Although they were not the only couple that I recruited they were the only couple who both formally participated. Stephen is the only male contributor to this project. Owen was born with a twin brother, Oliver, who lived for one day. Stephen was the parent who shared this news with me. The family lives in central Oklahoma and they travel to Cook Children's to see specialists.

Crystal, Stephen, and Owen are a white, upper-middle class family. Stephen works outside the home and is the only income earner. Stephen travels for work. Crystal works as a full-time parent and caregiver to Owen. She manages his extensive therapy schedule and clinic visits. According to Crystal and Stephen, Stephen is attentive and active in the physical care of Owen when he is at home. When Owen is admitted to the hospital Stephen makes every effort to accompany Crystal using vacation days and paid time off from work. I met this family when Owen was just over a year old. When I met them, Owen was admitted to the hospital for something unrelated to his ileostomy.

Owen was born as a micro-preemie at twenty-four weeks of gestation and weighed one pound and six ounces. Owen spent one hundred ninety-four days in the Neonatal Intensive Care Unit after he was born. Not long after birth Owen got necrotizing enterocolitis (NEC) and this life-threatening condition resulted in an ileostomy. He had several hospital admissions after he went home from the NICU. Crystal and Stephen both express concerns about the complex medical issues Owen faces, and his GI issues are one among many. During the course of the research process Owen had his ileostomy successfully reversed. Owen also has a gastrostomy and lives with that device. He is described by his parents as a fighter and a “perfect” baby who defies odds and defines his space in this world.

Rebecca is the mother of Amanda, a twenty-one-year-old. I met Rebecca when Amanda was admitted to the intensive care unit. The days right before and right after I met Rebecca were very critical days. These days were filled with her prayers that Rebecca and her spouse would have the wisdom to know what medical decisions they should make for Amanda. There were conversations about how to correlate medical treatments and interventions with their values and definitions about quality of life. As a chaplain-researcher I observed this family weigh the costs and benefits of life-prolonging interventions in the face of likely death. Amanda survived that particular hospitalization and was discharged several weeks later.

Rebecca is married to a man and she has a son who is a couple of years older than Amanda. They are an upper-middle class, white family. Rebecca works outside the home, part-time, with her spouse at a family-owned company. Rebecca, along with school teachers and paid assistants, provides the majority of the physical care for Amanda. Amanda's father is less active in the role of physical care for Amanda. The family lives in a small, county-seat city, about two hours from Fort Worth. Amanda lives with a double-barrel ileostomy to help resolve pseudo-obstructions. Gastrointestinal disease is only one aspect of Amanda's medical history. She also lives with autism, Angelman's syndrome, hyperthyroidism, and a seizure disorder. As Amanda's body grew Rebecca realized that she did not have the capacity to fully care for Amanda at home. Amanda lives in the family home during the day and receives night-time care at a residential home.

I met Allison when she was staying at the hospital on one of Ava's many hospital admissions. The year I met Allison and her daughter Ava they had repeated hospital admissions due to complications from the ostomy. I also got to know them as a part of the GI support group and was able to learn from them when they were experiencing a crisis and during the moments when Ava was relatively well and at home.

Allison is a white woman who has four kids in total, ranging from nine to two; Ava is the oldest. She works at home caring for her children. She is married to a man and he works a job that takes him to another country for several weeks at a time. During the long times when he is out of the country for work all of the child care and household management falls to Allison. When he is in town, he is fairly active in Ava's care, though he does not like to change the ostomy bags. When he is able, he shares time with Allison when Ava is admitted to the hospital. They are an upper-middle class family. Allison lives in Southern Oklahoma near her parents, who help with the children when she has to be at the hospital with Ava. Allison also has a son who requires ongoing medical attention.

Ava was born with an imperforate anus and had a temporary colostomy while she recovered from the surgical intervention that created her anus. Ava started having medical problems when she was four months old but things seemed “manageable” until she was one year old. For the first four years they struggled off-and-on with Ava’s pseudo-obstruction motility disorder but then when Ava turned four, things “kind of went downhill again.” Ava was almost five when she had her ileostomy. Ava also has a gastrostomy. When Ava was not hospitalized, she loved swimming, collecting *Shopkins*, and going to school.

Jasmin is the mother of Liam, the older of her two children. Liam is a seven-year-old who lives with an ileostomy, gastrostomy, an autism, and ADHD diagnosis. Jasmin describes Liam as “very smart,” “stubborn,” and someone who “bats his eyelashes” to get what he wants from nurses. When Liam was nine days old, he was diagnosed with Hirschsprung’s disease which affected all of his colon and some of his small intestine. Liam acquired short bowel syndrome after much of his intestine had to be resected (removed surgically) due to Hirschsprung’s.

Liam and Jasmin are white, lower class. Their main source of income is from Social Security Disability benefits. Jasmin spoke about the challenges of “fighting with Medicaid every week” to ensure that Liam receives ostomy supplies and the medical care that he needs. This family lives about two hours from Cook Children’s medical center. Jasmin, herself “disabled,”[64] is married to Liam’s biological father and lives near her mom who helps, on occasion, with the care for two her sons. Liam’s father works part time to augment the family’s income. He is the

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[64] Disabled is the identifying term that Jasmin uses both for herself and for Liam.

primary caregiver for Liam’s younger brother, who also lives with ADHD, particularly when Liam is hospitalized. He is less involved than Jasmine in the physical care of the boys.

Liam is very proud of his ostomy and his ileostomy collection bag; he will talk about it and show it to anyone who will listen. Liam is a lover of dinosaurs and chocolate cake. Jasmin was the co-researcher who provided the most detail about how they, as a family, celebrated Liam’s embodied differences.

I met Mason, the son of Sara, when he was admitted in the hospital recovering from the surgery to create his ostomy. During the course of data collection Mason was hospitalized a number of times; some admissions were for rather extensive hospital stays. When I met Sara Mason was two years old. Mason was diagnosed, in utero, with a very large bladder. Mason, from a very early age, had to be routinely catheterized to empty his bladder. When Mason started to develop constipation issues Sara described incremental steps in interventions: they started with MiraLAX, then they tried suppositories, and when the suppositories “stopped working it was trying enemas.” As the enemas became ineffective Mason was experiencing an increased “fear of using the toilet because it was this incredibly painful and terrifying experience.” Mason’s stomach had some delays in emptying but his colon was “just useless” as stool simply collected and would not move through his body.

Sara is white; she is married to the biological father of Mason. Sara has an older daughter from a previous relationship along with two step-children. When I first met Sara, she was the primary income-earner for her family. As Mason’s health became more complicated she took a leave of absence from work and eventually decided to move to part-time work. Her spouse took a different, better-paying job to help augment the family’s income. Job transitions and monumental amounts of time committed to Mason’s hospital admissions led to a marked decrease in the family's household income. This required relocation so that Sara could be near family who helped carry the financial and child-care burden associated with all of the changes disease had created. Sara remains the primary caregiver for Mason. Sara's spouse is less involved in Mason's physical care and the management of clinic visits and hospitalizations.

Katrina is the mother of previously-conjoined twins Mia and Isabella. They are a middle class, white family of four, living near their extended family (who provide a lot of support and care for the twins). After struggling to get pregnant, Katrina and her male spouse were thrilled when Katrina was pregnant and even more overwhelmed, yet excited, when they heard she was going to have twins. After eighteen weeks of pregnancy Katrina was planning a big gender reveal party with family and friends. Katina went for her ultrasound but the technician became very silent when Katrina was expecting this to be a very jovial occasion. It was during this ultrasound that the doctors discovered that her twins were conjoined and they were given a very grim prognosis. The doctors spoke with Katrina and her husband about terminating the pregnancy. The couple decided to keep the pregnancy.

It was not until the twins were born, at thirty-four weeks, that they were able to determine what internal organs the twins shared (they did not know the biological sex of the babies until after birth). Mia was born with two sets of female-sex organs and Isabella had one; both girls were born with an imperforate anus and the girls were sharing a bladder.

Mia and Isabella were separated when they were two days old. This surgery was also when the twins each got a colostomy. They were separated and home from the hospital within nineteen days of birth. I met the twins when they were hospitalized prior to and following a two-day series of surgeries to alleviate issues related to their previously shared urinary tract and for reconstructive and repositioning surgery related to their genitalia[65] and while I only knew them during recovery from these surgeries, they were very feisty two-year-old's.

Katrina's spouse is very involved in the care of the twins. He readily changes ostomy bags and helps to manage follow-up visits with pediatricians and medical specialists. He also likes to be present at the hospital when the twins are admitted. Katrina's spouse is the primary income earner for the family.

Organization of Chapters

This project is organized into four forthcoming chapters: literature review, methods and methodology, theology and theory, and practices of care. As I map the way forward I want to briefly describe each chapter. In so doing I will describe the intent and theme of each chapter.

Literature Review

Many within the field of pastoral theology have omitted, underprivileged, overlooked, or even demonized the body as an epistemological source for theological inquiry. Particularly since the early nineties, however, the field of pastoral theology has contributed important ideas about embodiment. These contributions became particularly discernible in two ways: 1) As the voices from white women, African American men, African American women, and LGBTQI+ contributed constructive theologies rooted in their own lived experience. 2) Pastoral theologians began to pay closer attention to the interconnected nature of our context, our relationships, and

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[65] Katrina raises here daughters according to many traditional gender roles and rules. She is adamant, however, that she does not want to surgically change anything about her daughters' bodies that is purely cosmetic. Katrina and her spouse are comfortable with their daughters having "complex anatomies"—bodies that look differently and function differently than "normal" bodies. Katrina and her spouse also want the girls to be old enough to be involved in any decisions that change the look and function of their bodies. This value guided their decision about addressing the differences in the girls' genitalia but it also guides Katrina's decision about reversing the girls' colostomies. Although a colostomy reversal has been suggested, Katrina has decided that she does not want to proceed because the potential rewards do not outweigh the potential risks and, according to Katrina's assessment, the colostomy does not impede their quality of life.

the impact this "web"[66] of connection had on our practices of care. Both of these shifts brought with them a closer attention to embodiment and the contributions of embodied knowing as a source of theological insight. Chapter two will trace the trajectory of this development while also highlighting a few key pieces of literature in other theological disciplines (like historical and systematic theology), social science (like sociology and anthropology), and literature from medical fields (medical ethics, medical anthropology, and nursing).

Methods and Methodology

Pastoral theological methods and methodologies are particularly well situated to take seriously the co-constructive nature of how our body identity is informed by social narratives, ideologies, and theological constructs; as well as how bodies can reframe and reimagine our theologies, ideologies, and practices of care. My methodological commitments that guide this research are rooted in a commitment to the "critical engagement with theological issues that [arise] in the context of human reality."[67] Lived experience, experience of illness, is my point of departure for this project.

This chapter will detail the assumptions, commitments, and strategies used to evaluate illness experiences as well as put these in conversation with theologians (such as Nancy Eiesland, Reinhold Niebuhr, Paul Ricoeur, Wendy Farley, and Thomas Reynolds), while integrating and correlating these two sources (experience and theology) with literature and knowledge garnered from philosophy and social sciences (like Arthur Frank and Julia Kristeva).

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[66] Archie Smith, Jr., *The Relational Self: Ethics and Therapy from a Black Church Perspective* (Nashville, TN: Abingdon Press, 1982), 53.

Bonnie J. Miller-McLemore, "The Human Web: Reflections on the State of Pastoral Theology," *The Christian Century* 110, no 11 (April 07, 1993): 366-69.

Bonnie J. Miller-McLemore, "The Living Human Web: Pastoral Theology at the Turn of the Century," in *Through the Eyes of Women: Insights for Pastoral Care*, edited by Jeanne Stevenson-Moessner. (Minneapolis: Fortress Press, 1996), 22.

[67] Joretta Marshall, "Methods is Pastoral Theology, Care and Counseling," in *Pastoral Care and Counseling: Redefining the Paradigms*, ed. Nancy J. Ramsay (Nashville, TN: Abingdon Press, 2004), 138.

This chapter will illustrate methods not only for correlating disparate source material but will also highlight how sources amend and revise one another. Ultimately, the correlation is not the final result. This chapter will emphasize how correlation should be actionable with revised theological constructs and renewed practices of care that are useful in solving relational, institutional, and social problems.[68]

Theology and Theory

The body, while finite, is part of a good creation. Drawing on theological the assertion of the *imago Dei*, I affirm the innate goodness of the body but, as the parents in this study readily identified; this goodness *seems* compromised when their children experience marginalization because of their embodied difference. What is evident through my interviews with co-researchers is the power of social narratives that diminish the beauty of alterity. These narratives are fueled by fear and disgust about the body and the body's temporality. They have the potential to marginalize those whose bodies do not fit within cultural norms. They disrupt relationships with each other, with God, and with our own abilities to love our embodied selves.

Also evident in the data are the recognitions of co-researchers that their children are not defined by their ostomy. No one embodied trait can completely define a person. Co-researchers described a spark, a light, an intrinsic beauty within their children. They fear that this spark might dim because of the social pressures that they face because of embodied differences. I argue that there is an aspect of our identity that can never be ultimately and completely usurped by social narratives which aim to undermine the beauty within all bodies. I propose that even in the midst of normalcy discourses, which render the body as abject, every body holds the

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[68] Rubem Alves, "Personal Wholeness and Political Creativity: The Theology of Liberation and Pastoral Care," in *Pastoral Psychology* 26, no. 2 (1977): 125-7.

irreducible *imago Dei*. This theological proposal becomes an important aspect of survival in the midst of disparaging narratives about the body.

Practices of Care

When pastoral caregivers work among families experiencing life with a GI ostomy, we are called to witness illness. Bearing witness to illness holds ethical implications. To serve as a witness we are open to relationship. Bearing witness to illness means turning toward those impacted by disease to affirm and include all bodies. A witness resists the power of normalcy discourses which depreciate the innate goodness of the body.

Using the work of Arthur Frank on illness narrative typologies,[69] I will propose two specific types of illness narratives (the anxiety narrative and the bated-breath narrative) that were described by my co-researchers. The anxiety narrative recognizes the perpetual presence of anxiety in the lives of my co-researchers. I argue that anxiety, while sometimes debilitating, is also facilitating as they resist marginalizing discourses. The co-researchers described a bated-breath narrative which anticipates forthcoming moments when illness will seem debilitating *and* forthcoming moments when illness seems less apparent. The bated-breath narrative is a way of describing the cycles of illness exacerbation: families remember their past abilities to survive coupled with a hope that they have the ability to survive future suffering.

Conclusion

The literature from the field of pastoral theology will demonstrate that pastoral theologians are committed to embodied knowing. Pastoral theological methods weave together wisdom from lived experience with literature from theological disciplines and from other distinct

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[69] A typology is a tool to analyze qualitative data. Typologies help categorize "events and people into qualitatively different ideal types that are abstractions distilled from empirical evidence." Typologies can originate from the researcher or from the population they study among. Schwandt, 302.

fields like sociology and clinical practice. I will follow these methods for this project. Embodied, lived experience contributes importantly in revising and amending theological and ideological constructs. For example, I will demonstrate how the lived experience of my co-researchers help reframe the way we think about who is included when we describe the *imago Dei*. Their wisdom reaffirm that the body is both fragile and good. The fragility of the body does not negate its goodness.

Attention to the *imago Dei* also serves to reorient our commitments to "compassionate obligation"[70] as an ethical impulse. Pastoral caregivers are called to bear witness to illness. This means that we are attuned to the suffering of those experiencing illness (compassion) and join with them in their suffering (obligation) to resist the causes of pain.[71] I propose that pastoral caregivers bear witness to two types of illness narratives, the anxiety narrative and the bated-breath narrative. This means that we accompany people through the experience of illness *so that* we can collaborate toward the construction of future-focused narratives that revive hope, strengthen families for impending suffering, and resist normalcy discourses that attempt to marginalize bodies.

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[70] Edward Farley, 43.
[71] Edward Farley, 42.

Chapter Two
Review of Literature

"[Mia and Isabella] have a lot to offer and they are able to stand out, in a way. Not using [their difference] as a crutch, that whole thing, but their story is so unique that I just, I feel like people could learn from them about how they adapt to life and what they are able to achieve and accomplish throughout their life."

-Katrina, mother of Mia and Isabella

Introduction

Consistently, co-researchers reflected on how the differences in their children's body might be negatively interpreted in the world. At the same time, co-researchers saw this negativity as an occasion when they could positively influence how their child interpreted their body in potentially-marginalizing contexts. Sara notes, "I'm not going to be a doctor, I'm not going to be a president, my purpose in life is my kids it's teaching them how…" Sara pauses, cries, and then says:

> People ask me, "What if this is permanent?" I don't care. If it's permanent then [this is] how I teach Mason to look at it, "This is my ostomy and it's a part of who I am but it's saving me so much pain and suffering so it is a part of my body that is beautiful…" I think perspective is the most important thing I can teach my kids, that if I look at something in my life, if this is done *to me* or this is a negative thing, then it will be a negative thing. If I teach them to embrace it… and embrace the positive aspects of it, that's how they will look at things in life.

Similarly, co-researchers describe how their children's differences shapes their context, as suggested in the epigraph to this chapter. Sara shares a similar belief with Katrina: "I think [Mason] is this amazing little boy who is going to do great things in the world and I don't think this is going to stop that, if anything, it's going to complement that and he will be able to embrace [the ostomy]."

I have an abiding conviction that the body offers epistemological value shaping our contexts and our cultures; my co-researchers have confirmed this conviction. As noted in the introduction of this project, pastoral theologian Bonnie Miller-McLemore rightly points out that the term “embodiment” has too often been characterized as the “cultural construction” of the body or the body being “embedded” within a context.[72] While I generally agree with Miller-McLemore’s assessment, I see a shift in the way pastoral theologians incorporate embodied knowing into our constructive theological proposals. This chapter will trace that development. I will also highlight important literature that bolsters one of the underlying assumptions for this project: our theologies and practices of care are amended (and should be amendable) by embodied knowledge.

I will organize this chapter into three sections. First, I will detail the development of embodied knowing within the field of pastoral theology. I will then pivot to detail pertinent literature from theologians in other related disciplines, such as feminist practical theology. I will conclude with a brief overview of literature that describes abjection theory, illness narratives, and clinical literature pertaining to gastrointestinal ostomies. These final two sections will highlight critical literature that gives shape to this project; its assumptions, commitments, and methodologies.

The Body in Pastoral Theology

At initial glance it may seem that many theologians in the field of pastoral theology have omitted, underprivileged, overlooked, or even demonized the body. Rarely has the body been seen as *the* lived experience (the originating context of inquiry) that generated theological knowledge. With both intentional and inadvertent attention to the body and embodied knowing, pastoral theologians have a great deal to say, however, with regard to embodied experience and its contribution to constructive theology and practices of care. As the field expanded to include

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[72] Bonnie, Miller-McLemore, “Embodied Knowing, Embodied Theology: What Happened to the Body?” in *Pastoral Psychology* 62, no. 5 (October 2013): 743.

the experiences of white women, African American men and women, and LGBTQ+ theologians, the attention to embodiment also increased. I want to begin by tracing some of this history to illustrate the ways that increased awareness to embodied perspectives, rooted in particular contexts, has expanded theological arguments.

Body Omissions: When Mind, Emotions, and Soul are "Privileged"

As the field of pastoral theology emerged, many theologians engaged in close interdisciplinary dialogue with psychology. In so doing, the mind and the emotions took a more central place, and critical reflection about the body was often omitted or diminished. While taking a more diminished position in theological reflection, the body is not entirely ignored. In the classic history of the field through the early modern period, church historian John T. McNiell acknowledges that for much of church history our attention, in the care of humanity, has been attuned to the care of human souls rather than care for the body; consequently, care for the body is secondary at best.[73] Yet McNiell notes that "[H]ealing of the body is frequently associated with the healing of the soul."[74] This observation is made even earlier in the work of Anton Boisen, chaplain and clinical pastoral educator.

Boisen observes that the body and mental health are interconnected. He suggests that treating a physical condition could also remedy a mental condition.[75] However, he generally relegated physiological concerns to the care of medicine.[76] Many pastoral theologians follow this trajectory and relegate the care of the body to medical and nursing practice.[77] Even more

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[73] John T. McNeill, *A History of the Cure of Souls* (New York, NY: Harper and Row, Publishers, 1951, 1977), 21.

[74] McNeill, 76.

[75] Anton T. Boisen, *The Exploration of the Inner World: A Study of Mental Disorder and Religious Experience* (Philadelphia, PA: University of Philadelphia Press, 1971), 5.

[76] Boisen, *Exploration of the Inner World*, 23.

[77] As I will describe in chapter five, persons who experience illness want to tell an illness narrative that moves beyond the medical narratives available in their patient charts and medical records. Arthur Frank, *The Wounded Storyteller: Body, Illness and Ethics*, 2nd ed. (Chicago, IL: University of Chicago Press, 2013), 5-6. And

notable are the ways in which pastoral theologians overlook embodied knowing as a valuable contribution to theological construction.

While the field generally follows the precedent set by Anton Boisen, holding psychology as a preeminent dialogue partner, many pastoral theologians articulate a strong commitment to a holistic understanding of humanity: critically reflecting on body, soul, and mind together. They simply have not favored the "voice" of the body in their inquiry. An almost inevitable lacuna emerged around the concept of the body and embodied knowing. It is important, however, to highlight the occasions when pastoral theologians make strides to articulate embodiment and embodied knowing into their theologies.

Expanding Landscapes, Embodied Voices

During the final decade of the twentieth century, two important occurrences emerged within the field of pastoral theology. First, many pastoral theologians began to pay closer attention to the interconnected nature of our context and our relationships. They describe how these connections impact practices of care. Secondly, the field started to include a broader spectrum of voices, particularly white women and African American women and men. Both of these shifts bring closer attention to embodiment and the contributions of embodied knowing. Slowly, and seemingly inadvertently at times, the body has become a source of theological insight—a context for theological inquiry.

In "Body," for the *Dictionary of Pastoral Care and Counseling,* Paul Jewett notes the centrality of the body for theological consideration. He says the body cannot be neglected, overlooked, or ignored. Jewett critiques a classical pastoral theological paradigm, the "cure of

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Arthur W. Frank, "Truth Telling, Companionship, and Witness: An Agenda for Narrative Bioethics," *Hastings Center Report* 46, no. 3 (2016): 18.

the soul."[78] This paradigm sustains the argument that pastoral theologians have tended to the "soul" while unintentionally omitting bodies. Jewett, a systematic theologian, notes that Christian theologies have often favored a dualistic body/soul construct which prioritize the soul and overlooks and reduces the body (i.e. the *weak flesh* that humanity must overcome).[79]

Deconstructing this body/soul dualism is an important preface to the work of body theology. Jewett writes, "Greek dualism became more pronounced… in the early centuries of Christian history as devout Christians sought to escape the sinfulness and corruption of the world through ascetic subjugation of bodily needs and appetites."[80] In many cases, the body is the matter that "bogged down" the human soul. This dualism is evident, particularly, within very early pastoral care documents. The body is often considered shameful, the source of both indecent acts and sin.[81] More often than not, however, the body is simply overlooked in favor of care practices focusing on the mind, emotions, soul, and spirit.

Not until the nineties did pastoral theologians and caregivers begin their consideration as to how the body informed and corrected theology and practices of care. Larry Graham, pastoral theologian, pastoral counselor and caregiver, turns his attention to humanity's relationships within specific historical contexts and systems. Graham is astute to point out that the body is fundamental to any inquiry into the complex systems that contribute to our understanding of humanity. Graham rightly notes that "the body is the primary basis for connecting with our worlds and for generating our sense of selfhood. There would be no ability

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[78] Paul Jewett, "Body," in *Dictionary of Pastoral Care and Counseling*, expanded edition, ed. Rodney J. Hunter and Nancy J. Ramsay (Nashville, TN: Abingdon, 1990/2005), 102.

[79] Jewett, 102.

[80] Jewett, 102.

[81] For example, in "The Five Visions" of the *Shepherd of Hermas*, many of the "sins" were related to sex, drunkenness, or other "indulgences" of the body. The *Early Irish Penitential* documents call the body "shameful" and one of the prescriptions for penance is to withhold bodily pleasures; specifically, in the form of food and sex.

for us to connect with our sense of self as individual without the body and its processes."[82] The body is our means of interpreting the world and ourselves.

Graham also notes that contexts, and our relationships in those contexts, impact our sense of identity. He says, "[T]he reaction of the environment to the size, shape, and color of one's body has grave consequences for one's relation to the world in which he or she lives, and for the character of the self that emerges in the psyche."[83] Our relationships and the physical surroundings of a context have a quantifiable impact on how we understand our own bodies. This claim, that the body is known and constructed within contexts, continues to resonate in the field. Embodiment is not Graham's focus in this work; therefore, it is not surprising that he omits discussion on how the body alters or changes a context.

Douglas Purnell wonders about the role of a pastor's *own* embodied experience in the practice of pastoral care. He notes his own sense of vulnerability when he cared for others: "I became aware of important questions about the body—and how vulnerable I feel in my body when I stand beside someone whose body has been broken through accident or illness or decay."[84] In this brief article, Purnell, a pastoral theologian, raises a critical question about how pastoral caregivers' embodied feelings impact a pastoral care moment.

Awareness to a shared sense of *bodily* vulnerability shapes our understanding of empathy.[85] Purnell argues that empathy allows pastoral caregivers to come close to imagining and envisioning an experience of another.[86] This strategy of envisioning and imagining the experience of another can have a visceral effect on our own body. Though not his primary

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[82] Larry Kent Graham, *Care of Persons, Care of Worlds: A Psychosystems Approach to Pastoral Care and Counseling*, (Nashville, TN: Abingdon Press, 1992), 73.

[83] Graham, 74.

[84] Douglas Purnell, "Pastoral Ministry and the Fleshly Body," in *Pastoral Psychology* 53, no. 1 (Spring 2004): 81.

[85] Purnell, 82.

[86] Purnell, 82.

intent, Purnell highlights how the bodies of others contribute to our own self-awareness about embodiment.

Considering the body in specific contexts elevates difficult questions for pastoral caregivers. Purnell asks, "How can I, as pastor, be present to the body of the other when I was so anxious in my own body?"[87] An encounter with another body, especially one that does not function or look "normal," a person who is dying or ill, draws attention to our own embodied vulnerabilities and the frailty of the flesh. Purnell writes, "The pastor has to ask again and again, what is life? What is death? Those questions relate to the physical body of the other and perhaps, frighteningly, of themselves."[88] Purnell does not include consideration of social narratives of oppression and normalcy, which might also contribute to our anxiety about the body or the contexts that shape the body.

Paul Jewett, Larry Graham, and Douglas Purnell offer clear examples regarding how pastoral theologians now pay closer attention to the body. Since pastoral theologians take seriously the role of lived experience in our constructive theological enterprise, it is no surprise that embodied perspectives increase as African American males, white feminists, African American feminists, and Womanists contribute to the pastoral theological landscape. While most were not directly addressing embodiment or the role of the body in their theological constructs, there is little denial that a theologian's embodied interactions within their particular contexts nuance their perspectives and contributions to the field.

When white, heterosexual, usually adult, generally healthy, cis-gender men are the normative source of inquiry, perspectives from those embodying differences to that assumptive norm are often devalued or worse, used as examples of irregularity or pathology. The emergence

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[87] Purnell, 82.
[88] Purnell, 84.

of white feminist theologians, African American men, and African American feminist theologians in the field of pastoral theology brings a deliberate commitment to embodied perspectives that change the field. The following theologians demonstrate that white, heterosexual, male, cis-gender bodies cannot be the assumptive norm when we think about embodiment. They argue that gross generalizations about embodiment are inaccurate and dangerous.

Gender, Embodiment, and Pastoral Theology

Feminists[89] contribute to embodied epistemology in deep and nuanced ways. Feminist theologians draw attention to the ways gender is constructed within culture and have written from the lived experiences of women. In so doing, they have demonstrated how embodied differences (from men) change social and theological landscapes. Underlying many feminist theologians' proposals is the assumption that gender amplifies theological themes that have otherwise gone unnoticed or under-represented. Pastoral theologians have been instrumental in developing these themes.

It is dangerous to collapse all experiences of women under the category of "feminist" pastoral theology. Theorists and theologians writing from African American feminist, Asian American feminist, Womanist, gender non-conforming, indigenous, and non-Western contexts rightfully contest and problematize generalized assumptions about who is meant/included when we discuss "women" and their experiences.[90] It is problematic when the lives of white, Western,

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[89] I am using the term "feminist" as a tool to organize theological and theoretical literature that examines embodiment with a particular methodological lens. What entails "feminist methodology" remains contested but there are a couple of important aspects of "feminist methodology" which include, "particular political positioning of theory, epistemology and ethics that enables the feminist researcher to question existing 'truths' and explore relations between knowledge and power." Feminist researchers (and theologians) are described as, "politically *for* [sic] women; feminist knowledge has some grounding in women's *experiences* [sic], and in how it *feels* [sic] to live in unjust gendered relationships." Janet Holland and Caroline Ramazanoğlo, *Feminist Methodology: Challenges and Choices* (Thousand Oaks, CA: Sage Publications, 2002, 2008), 15-6.

[90] Holland and Ramazanoğlo, 3-4.

cis-gender women are considered the normative representation of "women" within our theological inquiry. While detailing the disputes around who is included when referencing "gendered lives"[91] is beyond the scope of this particular project, I want to underscore how social and historical contexts and social group identity is of vital importance when we consider the particularities of embodied knowing and embodied lives.

With this consideration, I have organized this section into two sub-categories. First, I will consider the contributions of women to pastoral theological literature. These contributions emerge from predominantly (not exclusively) white, feminist pastoral theologians and reflect on how women contribute meaningfully to the pastoral theological landscape. The second category in this section will demonstrate how gender-experience is problematized and nuanced by reflections on masculinity and sexuality.

Women's Experience and Theological Contributions

Though not a pastoral theologian, Valerie Saiving Goldstein, in a landmark article, articulates the importance of engendered voices for the theological endeavor. This article undoubtedly paved the way for feminist epistemology. Saiving Goldstein writes that her purpose is to:

> [A]waken theologians to the fact that the situation of women, however similar it may appear on the surface of our contemporary world to the situation of man and however much it may be echoed in the life of individual men, is, at bottom, quite different—that the specifically feminine dilemma is, in fact, precisely the opposite of the masculine.[92]

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[91] Holland and Ramazanoğlo, 5

[92] Valerie Saiving Goldstein, "The Human Situation: A Feminine View," *The Journal of Religion* 40, no. 2 (April 1960), 109.

Though a snapshot of an earlier time, her purpose in articulating a woman's contribution as "precisely opposite of the masculine" undergirds her argument that gender differences contribute to a new theological perspective.

Saiving Goldstein, a pioneer of feminist theology, argues that social location positively influences (even corrects) theological constructs that represent and favor the experience of men, the once assumed-to-be "normal" or "standard" representation of the human experience. Women offer distinct but variegated views of the world and, therefore, contribute uniquely to the theological enterprise. Goldstein articulates the importance of this particularity. We cannot "lump" human identity and contextual experience—embodied lives—into generalized and generalizable categories.

During the final decade of the twentieth century, feminist and womanist pastoral theologians published four edited volumes: *Women in Travail and Transition; Through the Eyes of Women; Feminist and Womanist Pastoral Theology;* and *In Her Own Time.* Each of these texts is a seminal contribution to the field of pastoral theology. These volumes highlight the work, wisdom, and theological constructs garnered from the lived experiences of women.

Women in Travail and Transition**, edited by pastoral theologians Maxine Glaz and Jeanne Stevenson Moessner, is the first collection of essays written by women with attention to the work of pastoral care and pastoral theology of women.** This work demonstrates how women's experiences necessitate new models of pastoral care. Furthermore, these essays hold together important pastoral theological constructs. As one reviewer notes, "[R]elationships and care of others [are] primary to a sense of self."[93] Authors demonstrate how women's experiences with suffering contribute, importantly, to our theological anthropology.

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[93] Vera Sinton, "Book Reviews: Women in Travail and Transition," *Scottish Journal of Theology* 48, no. 1 (1995): 100.

In a chapter in the edited collection *Women in Travail and Transition*, Mary James Dean and Mary Louise Cullen highlight ways in which women's bodies are the genesis for pastoral care moments. They suggest particular tools and tactics to offer care, specifically to women, as they address key embodied experiences. Evaluating bodily processes (like menstruation and childbirth), tragedies (like miscarriage and infant death), or the challenges of disease processes, Dean and Cullen describe how ministers can offer care in these specific moments.

Cullen and Dean recognize that, "History and cultural learning have trained us—male and female, clergy and layperson—to identify women with reproduction, to describe reproductive functions as illness and pathology, and to interpret women's roles in gynecologic treatment as passive, narcissistic, and masochistic."[94] While this volume particularly addresses issues arising from women's perspectives, this chapter delineates specific functions and challenges presented in the female body. The authors consider ways in which some women are calibrated to and by their bodies. They do not make specific argument for embodied knowing, but they produce helpful guides for clergy as a result of embodied knowing.

***Through the Eyes of Women*, a collection of essays edited by pastoral theologian Jeanne Stevenson-Moessner, captures and explores a variety of pastoral care concerns raised by women.** This collection of essays also addresses important changes taking place in the field of pastoral theology and pastoral care, such as greater attention to relationships and contexts for the construction of theology. In the second chapter of this volume, pastoral theologian Bonnie Miller-McLemore suggests that the field is shifting its attention away from the "living

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[94] Mary James Dean and Mary Louise Cullen, "Women's Body: Spiritual Needs and Theological Presence," in *Women in Travail and Transition: A New Pastoral Care*, ed. Maxine Glaz and Jeanne Stevenson Moessner (Minneapolis, MN: Fortress Press, 1991), 86.

human document"[95] metaphor and toward the "living human web" metaphor.[96] This shift illustrates greater attention to the way contexts shape humanity. This shift is also indicative of the way pastoral theologians and caregivers turn their attention toward care for communities, contexts, and social systems. Thus, care is no longer directed toward individuals alone.

Three chapters in particular discuss contextual implications of women's bodies. Irene Henderson, a pastoral care educator, takes a look at the effects of a mastectomy on the spiritual, emotional, and physical lives of women.[97] Henderson gives attention to the impact of physical changes to the body. There are consequences in bodily changes—either because of a mastectomy or an ostomy—and these changes impact our understanding of ourselves and God.

Jane Dasher, also a pastoral care educator and chaplain, examines social pressure for women to conform to a slender body type. This pressure to conform can result in eating disorders that complicate some women's relationships with food.[98] Dasher demonstrates how social pressures impact our perception of what it means to have a "normal" body type. Social

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[95] This phrase, attributed to Anton Boisen, is indicative of the important pastoral theological methodological commitment to study lived experience as a point of departure for theological inquiry and the development of practices of care. Anton T. Boisen, "The Period of Beginnings," *Journal of Pastoral Care* 5 (1951): 15. The origins of his commitments emerge in *The Exploration of the Inner World.*

[96] The influential argument, first proposed by Archie Smith in *The Relational Self*, and developed by Bonnie Miller-McLemore, suggests that the field is shifting away from concern and care for individuals alone; as described by the metaphor developed by Anton Boisen, the "living human document." Miller-McLemore develops the metaphor: "the living human web." She argues that the beloved phrase, metaphor, and guiding principle described by Boisen is no longer adequate; focusing too singularly on the individual without sufficient regard to the relationships and contexts that shape that individual. Miller-McLemore suggests that we cannot understand nor care for individuals abstract from their relationships and contexts. Bonnie J. Miller-McLemore, "The Living Human Web: Pastoral Theology at the Turn of the Century," in *Through the Eyes of Women: Insights for Pastoral Care,* edited by Jeanne Stevenson Moessner. (Minneapolis: Fortress Press, 1996), 9-26. Archie Smith, Jr., *The Relational Self: Ethics and Therapy from a Black Church Perspective* (Nashville, TN: Abingdon Press, 1982), 53.

[97] Irene Henderson, "Matters Close to the Heart: Pastoral Care to Mastectomy Patients," in *Through the Eyes of Women: Insights for Pastoral Care*, ed. Jeanne Stevenson-Moessner (Minneapolis, MN: Fortress Press, 1996), 207–21.

[98] Jane E. Dasher, "Manna in the Desert: Eating Disorders and Pastoral Care," in *Through the Eyes of Women: Insights for Pastoral Care*, ed. Jeanne Stevenson-Moessner (Minneapolis, MN: Fortress Press, 1996), 179–91.

context can change our interactions with our world, be it with the food we eat or our choices to "show" the ostomy collection bag attached to our stoma.

Beth Ann Estock, pastor, chaplain, and leadership coach, addresses embodied identities and shifts to identity following a hysterectomy. Estock poses the question, "I wonder how [women] can embody a positive and integrated sense of self with an image of a distant, male God that defines them as an object, a child bearer."[99] The initial intent of the question is to dislodge male-gendered images and pronouns that hold hostage our conception and imaginations about an all-inclusive God. The question points to deeper significance about the body. Estock's question reveals the complex and interlocking drama between embodied identities, the social representation of women's child-bearing bodies, and our imagination of who God is and who is represented within the *imago Dei*.

Estock points out how social expectations (insinuating that the male body is the "normal" body) and theological constructions (suggesting a male-God) hold women's bodies hostage. We are shaped, in part, by the bodies that we are born into, and our identities are further molded when there are changes to that body. Implicit in this chapter are two important contributions to this study: 1) the recognition that our self-understanding is impacted by changes to our bodies and 2) the opportunity to reclaim and re-orient theological and social frameworks to develop empowering and regenerative images of God for people experiencing physical changes in their bodies.

***In Her Own Time*, another volume edited by Stevenson-Moessner, features contributors who explore the lives of women as they relate to aging.** This collection is grounded on the assumption that "women develop as embodied selves; it is not feasible to talk of

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[99] Beth Ann Estock, "Hysterectomy and Woman's Identity," in *Through the Eyes of Women: Insights for Pastoral Care*, ed. Jeanne Stevenson Moessner (Minneapolis, MN: Fortress Press, 1996) 199.

their seasons of maturation without including the body and the interconnectedness of the body-mind-spirit."[100] While this underlying argument is intended to interrogate tightly structured developmental theories by exploring issues arising from women's development across the lifespan, the volume accents the importance of exploring embodied realities as they contribute to cognitive and spiritual understanding.

In the opening chapter of *In Her Own Time*, Stevenson-Moessner notes how Christian theology and traditions have historically devalued the body, further entrenching the body-mind dualism.[101] She contends that when we critically engage with bodies, particularly "violated bodies," we "alter developmental theory."[102] Developmental theory is problematized by Stevenson-Moessner because "we incorporate the impact of both culture and body on a person's progression through life's stages."[103] Time and age change our self-understanding, or embodied identity, and our perceptions about God. And while individuals experiencing illness or living with an ostomy should not be considered "violated" bodies,[104] the experience with illness and an ostomy challenges our perception of the body's innate goodness.

Three years after the publication of *Women in Travail and Transition*, pastoral theologian Bonnie Miller-McLemore published *Also a Mother.* This work illustrates how motherhood, theology, and feminist thought converge to portray learned wisdom emanating from lived experience and engendered expression. Her work germinated from wrestling with

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[100] Jeanne Stevenson-Moessner, ed., *In Her Own Time: Women and Developmental Issues in Pastoral Care* (Minneapolis, MN: Fortress Press, 2000), 1.

[101] Jeanne Stevenson-Moessner, "Incarnational Theology: Restructuring Developmental Theory," in *In Her Own Time: Women and Developmental Issues in Pastoral Care*, ed. Jeanne Stevenson-Moessner (Minneapolis, MN: Fortress Press, 2000), 8, 13.

[102] Stevenson-Moessner, "Incarnational Theology," 13.

[103] Stevenson-Moessner, "Incarnational Theology," 13.

[104] Many of the co-researchers ultimately appreciated having an ostomy because it makes them feel better, physically. In many cases, like with Hannah and Zoe, Rebecca and Amanda, Sara and Mason, and Allison and Ava, the ostomy is a welcomed "fix" to years of pain and discomfort.

unsatisfactory understandings of motherhood, work, and parenting that were written exclusively from the perspective of men.[105] She sets out to reconstruct "stories and interpretations of generativity that include the mother's voice."[106] Ultimately, Miller-McLemore illustrates how childbearing and motherhood— embodied experiences in dialogue with contextual roles and rules—are "revolutionary moments."[107] Miller-McLemore argues that we can learn new perspectives on humanity and about God from the lived experiences of women.

Saiving Goldstein, Glaz, Stevenson-Moessner, and Miller-McLemore pushed the field of pastoral theology toward deeper consideration of embodied, engendered lives. They featured women theologians, writings about women's experiences, for women and men pastoral caregivers and theologians. They challenge white, male embodiment as the normative idea within the field of pastoral theology. Each of these authors offer insight into what it means to think critically and theologically about the body. Their attention, however, is trained more particularly on body and gender identity alone. Gender is not altogether generalizable. Pastoral theologians who write from an African American and Womanist perspective further enliven and make more complex our sense of embodied knowledge within the field of pastoral theology.

Practical theologian Brita Gill-Austern co-edited a collection with Bonnie Miller-McLemore entitled *Feminist and Womanist Pastoral Theology*. In this collection they take seriously the challenges of women facing multiple forms of marginalization stemming particularly from race and gender oppression. The editors invite theological, epistemological, and pedagogical reflections from Feminists and Womanists within the field of pastoral theology. The field had turned toward a paradigm that defined "care" as a commitment and concern for the

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[105] Bonnie J. Miller-McLemore, *Also a Mother: Work and Family as Theological Dilemma* (Nashville, TN: Abingdon Press, 1994), 21.

[106] Miller-McLemore, *Also a Mother*, 110.

[107] Miller-McLemore, *Also a Mother*, 132.

contexts that shape individuals and communities. In the opening chapter of this volume, the three authors argue that gendered, raced bodies contribute important changes to the field, its literature, and the pedagogy of pastoral theology.[108] Implicit within this argument is a commitment that embodiment shapes theological constructs and practices of care.

Carroll Watkins Ali, a contributing author to this volume, specifically notes that the embodiment of Black women serves as a source for theological reflection, praising the subjective nature of that knowledge.[109] Watkins Ali, an African American pastoral theologian and community non-profit leader, points out that embracing contextually-specific functions of pastoral care can establish a "pastoral framework that is free of paternalism and the imposition of dominant cultural perspectives" necessary for the survival of poor Black women in the United States.[110] Watkin Ali raises an important observation and critique: a contextually-specific pastoral theology and its practices of care offer insights that enable those confronting marginalization a way to resist the oppressive discourses of dominant cultural norms. Her observation that context-specific, marginalized social groups generate knowledge and ways to resist oppressing social discourses is an influential argument for this project.

Problematizing Gender

Christie Neuger and James Poling, two pastoral theologians, co-edited *The Care of Men,* a collection of essays which turns attention to male embodiment. It is problematic when pastoral theologians and pastoral caregivers assume white, heterosexual, cis-gender male embodiment to be "normal." Such generalized norms limit the inclusion of those whose bodies

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[108] Kathleen J. Greider, Gloria A. Johnson, and Kristen J. Leslie, "Three Decades of Women Writing for Our Lives," in *Feminist and Womanist Pastoral Theology*, ed. Bonnie J. Miller-McLemore and Brita L. Gill-Austern (Nashville, TN: Abingdon Press, 1999), 33.

[109] Carroll Watkin Ali, "A Womanist Search for Sources," in *Feminist and Womanist Pastoral Theology*, ed. Bonnie J. Miller-McLemore and Brita L. Gill-Austern (Nashville, TN: Abingdon Press, 1999), 58 and 63.

[110] Watkins Ali, "A Womanist Search for Sources," 63.

will never conform to such a myopic definition of humanity.[111] A narrow definition of humanity is problematic when we discuss gender, race, and sexuality and continues to be problematic as I begin to discuss the function and state of health for people living with GI ostomies. As this volume points out, women are not the only ones negatively impacted by the systems and power of patriarchy; Neuger and Poling demonstrate how men are adversely affected by patriarchy, too. The editors recognize that our interpretations of self are not the only realities impacted by context. Theological interpretation occurs within a particular historical and cultural context, thus impacting our perceptions about God.[112]

David Kundtz and Bernard Schlager do not identify as pastoral theologians but their book, *Ministry Among God's Queer Folk*, is a helpful addition to this literature review. Kundt, a psychotherapist, along with Schlager, an historian of Christianity and professor of LGBTQ+ religious studies, offer an important definition of embodiment: to be embodied is to be one who is at home "both in the macrocosm of nature and in the microcosm of one's own body."[113] Embodiment is both the physical body and the contexts in which our bodies participate in the world. They go on to note that "[M]any queer people bring hard-won and keen appreciation of their embodiedness and a celebration of that embodiedness to the sexual relationships that they have with other persons."[114] The body is important to our physical relationships. Additionally, this definition of embodiment challenges embodiment as an assumed given. Though we all have a material, physical body at birth, a body is not what makes

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[111] Christie Cozad Neuger and James Newton Poling, eds., *The Care of Men* (Nashville, TN: Abingdon Press, 1997), 40.

[112] Neuger and Poling, 26-7.

[113] David J. Kundtz and Bernard S. Schlager, *Ministry Among God's Queer Folk: LGBT Pastoral Care* (Cleveland, OH: The Pilgrim Press, 2007), 184.

[114] Kundtz and Schlager, 185.

us embodied beings. Such an assumption fails to recognize that oppressions stymie embodied realities. Many must fight for the right to exist, to be seen, and to celebrate their bodies.

Straddling gender identities and expressions and/or sexual identities and orientations can offer compelling insight about embodied living. Pastor and pastoral theologian Craig Rubano notes that gender creativity rejects binary constructions of gender and sexuality.[115] Pastoral theologian Cody Sanders underscores how humanity is always changing, becoming, and straddling the binaries created within a culture.[116] He argues that God is seen "between" and "beyond" gender.[117] Gender and sexual fluidity provide invaluable insight into what it means to be embodied, but these fluidities also insinuate important constructive theological proposals about God's nature and participation in the world by considering human embodiment.

Race, Embodiment, and Pastoral Theology

An increasing number of authors write with attention to historical and cultural contexts and the ways these contexts have marginalized, violated, eliminated, and policed non-white bodies. At the risk of generalizing, the following theologians of color contribute to theological discourse with an astute awareness to the body; its significance and representation (or lack thereof) within cultural and historical contexts. These authors illustrate how studying bodies, within racist and colonized context, augment and challenge previously held theological propositions and practices of care. This list of authors is, by no means, an exhaustive one but

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[115] Craig Rubano, "Where Do the Mermaids Stand? Toward a Gender-Creative Pastoral Sensibility," *Pastoral Psychology* 65, no. 6 (December 2016): 822, DOI 10.1007/s11089-015-0680-2. And Cody J. Sander, *A Brief Guide to Ministry with LGBTQIA Youth* (Louisville, KY: Westminster John Knox Press, 2017), 15-6.

[116] Sanders, 19.

[117] Sander, 19.

their contributions demonstrate how attention to embodiment changes the field of pastoral theology.

Emmanuel Lartey, an African pastoral theology scholar, suggests that plurality—not heterogeneity—is a more realistic global norm. It is impossible to talk about practices of care from a "white, middle-class, Eurocentric" perspective when it "deliberately ignores, or else fails to realize, the normalcy of pluralism in every part of the world."[118] Lartey's approach to pastoral care values diversity and alterity.[119] While Lartey is not specifically and particularly addressing embodiment in his book, *In Living Color,* he affirms that context-specific knowledge generates important theological and pastoral care insight. Since plurality supersedes heterogeneity, pastoral caregivers cannot claim simplified, monochromatic ways of responding to the needs of this world.

Homer Ashby, Jr. highlights how the "Black church" in the United States has been/is a "home" or safe-haven of survival for those who are battered by the endemic and systematic destruction and oppression of Black persons by a "racist society."[120] Ashby, a pastoral theologian and counselor, is not directly citing embodiment as a genesis for knowledge, but he unequivocally draws upon Black-body politics and discourses to suggest a Black identity. Ashby argues that white racist contexts oppress and marginalize Black persons. Yet "conjuring" the resources of Black culture equips Black communities for the task of resistance and survival within a racist landscape.[121]

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[118] Emmanuel Y. Lartey, In Living Color: An Intercultural Approach to Pastoral Care and Counseling (Philadelphia, PA: Jessica Kingsley Press, 1997, 2003), 15.

[119] Lartey, 32-3 and 38.

[120] Homer Ashby, Jr., *Our Home Is Over Jordan: A Black Pastoral Theology* (St. Louis, MO: Chalice Press, 2003), 1-11.

[121] Ashby, 72-5 and 78-9.

Furthermore, Ashby contends that the Black church is a communal setting in which the fullness and beauty of Black persons are celebrated and strengthened in the midst of a society that suggests otherwise; becoming a place where a Black identity is strengthened. White racist cultures can usurp and essentialize Black identify. Ashby argues that Black identity lies not in "sameness or essence but in variety and difference."[122] Black identity is a celebration and reclamation of plurality. While Ashby is directly addressing systemic racism, he accentuates two important tenants: 1) No body characteristic—skin tone or an ostomy—completely defines an individual; and 2) embodied difference is a part of God's creation; created good. Social norms and systems that oppress—like racism or "normal" body discourses—attempt to dismantle our awareness of the innate goodness of the body.

Dwight Hopkins, a practical and constructive theologian, illustrates the ways in which "white supremacy" has demeaned "dark-skinned people in the United States and globally."[123] Racial disparity, though historically used to diminish the full humanity of darker-skinned phenotypes, is socially constructed and is a "shifting signifier based on cultural contexts and the power to define."[124] Hopkins suggests that all persons are created fully human[125] and should have "equal access to the communal resources to forge the fullest and most wholesome

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[122] Ashby, 80.

[123] Dwight N. Hopkins, *Being Human: Race, Culture and Religion* (Minneapolis, MN: Fortress Press, 2005), 159-60.

[124] Hopkins, 165. Similarly, "normal" is a "shifting signifier" and is based on "cultural contexts and the power to define" what is considered "normal" and is used to disparage embodied difference. Theory about "normal" will be explored in the fourth chapter of this project. Phillis Sheppard raises a similar argument in: Phillis Isabella Sheppard, "Raced Bodies: Portraying Bodies, Reifying Racism," in *Conundrums in Practical Theology*, ed. Joyce Ann Mercer and Bonnie J. Miller-McLemore (Leiden, The Netherlands: Brill, 2016), 221-2. This text will be discussed in the following section.

[125] I appreciate Hopkin's assertion that everyone is created fully human, it is an invaluable assertion given that he is writing from a cultural and historical context of "white supremacy." I cannot overstate that his assertion is a matter of life-and-death for those who have been violated and killed because of skin tone. As I argued in the introduction of this project, Sociologist Alan Prout suggests that we are fully human at birth but we also change through time, both physically and socially. Humanity is "actively involved in negotiating" the meanings and the "implementation" of those meanings) that our bodies have within contexts.

individual and communal practices possible."[126] His theological anthropology emphasizes the ways social perceptions about bodies fundamentally skew theological constructs.

I appreciate Hopkins' assertion that everyone is created fully human. This assertion is invaluable, given that he is writing from a cultural and historical context of "white supremacy." I cannot overstate that his assertion is a matter of life and death for those who have been violated and killed because of the color of their skin. As I suggested in the introduction of this project, however, I agree with sociologist Alan Prout, who argues that we are fully human at birth but we also change through time. This argument accounts for the physical and social changes that impact embodiment.[127] Prout's central argument is meant to highlight our human capacity in determining and "implementing" the meanings given to our bodies within particular contexts.[128]

For both Ashby and Hopkins, it is evident that no single physical characteristic of the body—like skin pigment—acts as a total representation or defining quality of human identity. What is certain is that contextual constraints and definitions attached to the body have a profound impact on a person's ability to survive and these constraints can impact access to power and resources. While these authors do not directly address embodiment, their work demonstrates that understanding human identity and our relationship with God is fundamentally impacted by our contexts. Likewise, our ability to love and celebrate our own bodies, each other, and God is informed by context.

African American feminists and Womanist scholars maintain a critical reflection on race and gender. Monica Coleman, a womanist theologian, summarizes the contribution of African

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[126] Hopkins, 167 and 169.

[127] Prout uses the term "hybridity." Alan Prout, "Childhood Bodies: Construction, Agency and Hybridity" in *The Body, Childhood and Society,* ed. Alan Prout, (New York, NY: St. Martin's Press, Inc., 2000), 4-5 and 9-11.

[128] I cannot assume to know how Hopkins might respond to Prout's assertion. There are systemic evils like racism that have the power to undermine human agency and self-determination but imagining Hopkin's response is beyond the scope of this project.

American Feminists and Womanists by suggesting that they confront racism in Feminist theology and sexism in Black theology.[129] I want to highlight two theologians and their contributions toward embodied knowing for the field of pastoral theology: Carroll Watkins Ali and Phillis Sheppard.

In her pivotal book, *Survival and Liberation*, Carroll Watkins Ali rightly corrects and expands the work of Seward Hiltner. Watkins Ali, a pastoral theologian and community non-profit leader, argues that Hiltner's suggested functions of pastoral care are incomplete and not representative of African American people and contexts. [130] African American individuals and communities, because of the history of slavery and cultural suppression, must focus on survival and liberation.[131] "Pastoral care" means that we must work to amend systemic injustices that do not prioritize the full humanity or equal access to power and resources for African American people. Watkins Ali suggests that pastoral caregivers must be attuned to social systems and narratives that complicate our ability to survive our embodied realities and work to dismantle those systems and narratives.

Phillis Sheppard writes about bodies and race in a chapter for *Conundrums in Practical Theology*. Sheppard, a womanist practical theologian, accentuates how "racial

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[129] Monica Coleman, *Making a Way Out of No Way: A Womanist Theology* (Minneapolis, MN: Fortress Press, 2008), 6.

[130] Healing cannot occur if the system remains oppressive and continues to wound people. Sustaining is not the same as surviving. Sustaining is a short-term solution to ongoing injustice. Guiding is only possible when the context is really known or understood, untenable to those without the privilege to know and define culture. Watkins Ali also critiques the function of reconciling; suggesting that reconciling is better understood as a public/political strategy than an interpersonal/intrapersonal strategy and previously conceived.

Carroll Watkins Ali, *Survival and Liberation: Pastoral Theology in African American Context* (Saint Louis, MO: Chalice Press, 1999).

[131] For Watkins Ali, survival means resisting systemic oppression and genocide and recover a sense of self and lost culture and values from abuse and exploitation. Liberation indicates a total freedom from oppression and transform dominant, oppressive cultures. Watkins Ali suggests nurturing, empowering, and liberating as important functions of pastoral care.

categories evolve over time and ultimately re-produce the ideology of racial superiority, generally that of whiteness."[132] Sheppard continues:

> Rather than pursue the epistemological question (what can we know from the body?) or a theological one (how do actual physical bodies shape religious and theological knowledge?), I am making an ethical inquiry: what do raced bodies require of us as individuals and communities?[133]

Sheppard argues that bodies should evoke action: actions which are not lodged in stereotypes.

Sheppard notes that the academy, when discussing embodiment, has traditionally held the assumption that all bodies and embodied experiences are the same. She says, "[W]e are reduced to discourse that considers 'the body' as if we all experience the same bodily experiences."[134] Sheppard contends that, more often than not, the generalizations and theorizing about the body do not come directly from those whose embodied experience and expertise are being reflected on. This offers a strong and challenging corrective, especially since this present project focuses on bodies with ostomies and neither I nor my co-researchers have ostomies.

Most importantly, however, is Sheppard's move to define embodiment. She is not simply concerned with body epistemology or questions about how body shapes theology—though both of these are important and true. Sheppard wants her audience to see how bodies and embodiment require us to take different actions; in other words, making embodiment an ethical commitment. This shift is informative for this dissertation. I will demonstrate that bodies offer knowledge that revises theological constructs, but I will also demonstrate how the theological category of the *imago Dei* is also an ethical category. Being made in the image of God means

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[132] Sheppard, 222.

[133] Sheppard, 244-5. Sheppard uses the work: Miller McLemore, "Embodied Knowing, Embodied Theology" to help define the ways bodies inform theological knowledge.

[134] Sheppard, 220.

that we are relational and we have an obligation to love and care for our own bodies and the bodies of others.[135]

Race, gender and sexuality are significant factors when considering embodiment. As I have demonstrated through this literature, social constructions of race, sexuality, and gender impact the way we interpret our bodies and the bodies others and these factors influence the way we think about, interact within, and are included/excluded within our contexts. Contexts and embodied characteristics mutually construct, inform, and influence each other. Now, I will turn my attention to additional authors who impact the way I interpret the body and embodied knowing.

Embodiment beyond the Lenses of Race and Gender

In particular, pastoral theologians Karen Scheib, Bonnie Miller-McLemore, and William Roozeboom discuss how other factors beyond race, gender, and sexuality deeply impact our construction and perception of the body. Karen Scheib discusses aging and gender. Bonnie Miller-McLemore challenges the method and definition of "embodied knowing." William Roozeboom expands our understandings about embodiment, its relationship with neuroscience, and its impact on anthropological, theological, and relational understandings of human beings in context. I will briefly highlight these contributors.

Karen Scheib, in her work *Challenging Invisibility*, writes about aging women and aging bodies. Central to Scheib's work is a sharp critique about the ways in which culture

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[135] Edward Farley and Wendy Farley both note that the being made in the image of God is a human ideal in which we are made for "compassion and obligation" toward each other. Wendy Farley also notes that compassion and obligation must be extended to ourselves. Compassion and obligation are foundational to what it means to be human. Edward Farley, *Good and Evil: Interpreting the Human Condition* (Minneapolis, MN: Fortress Press, 1990), 41-43; Wendy Farley, *Tragic Vision and Divine Compassion: A Contemporary Theodicy* (Louisville, KY: Westminster John Knox Press, 1990), 75; And Wendy Farley, *Gathering Those Driven Away*, (Louisville, KY: Westminster John Knox Press, 2011), 103.

constructs identity for older women and then reduces their value and visibility. She exhibits how "old" is socially constructed and ambiguous rather than rendered by a particular age, circumstance, or behavior.[136] The constructions of "old woman" are contextually variable, often negative, and are seldom self-claimed identities for the women she interviewed.[137] Her findings, with regard to age, hold important similarities to my findings with regard to the definition of "normal" bodies.

Scheib recognizes that we tell "subjective narratives" about ourselves and these narratives usually include stories about embodiment—how we feel, how we look, how we are received by others. She attests that the women she researched among share stories about their increased awareness toward the physical changes in their bodies; sharing a common awareness of the body's temporality. These changes are not just to the flesh of the body, the embodied changes are in dialogue with social, cultural, and relational perceptions about our constantly changing bodies,[138] something consistent with my findings for this project. Scheib demonstrates the emotional and spiritual realities of living life in a good, yet temporary and fragile body.

In her article, "Embodied Knowing, Embodied Theology," Bonnie Miller-McLemore discusses how to "put the physical body back into embodied knowing and theology."[139] For Miller-McLemore, the body is much more than blood and tissues. She suggests that the body can *and should* transform specific contexts and circumstances[140] because bodies fundamentally shape and influence "culture and history."[141] In this regard, Miller-McLemore's argument is parallel to the argument made by Phillis Sheppard.

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[136] Karen D. Scheib, *Challenging Invisibility: Practices of Care with Older Women* (St. Louis, MO: Chalice Press, 2004), 3, 19-22.

[137] Scheib, 7.

[138] Scheib, 59-61.

[139] Miller-McLemore, "Embodied Knowing," 744.

[140] Miller-McLemore, "Embodied Knowing," 744, 745, and 756.

[141] Miller-McLemore, "Embodied Knowing," 743.

Miller-McLemore raises two important critiques of "embodied knowing." One, she points out how the meaning of "embodied knowing" and/or "embodied theology" has often been reduced to mean that bodies are constructed within contexts[142] that inadvertently diminish knowledge garnered from the body. Two, Miller-McLemore argues that embodied knowing is difficult to capture in a written document. She asks, "Can living subjects be adequately understood when turned into linear texts?"[143] She invites theologians to incorporate more illustrations to challenge and change "the usual… academic prose of the conceptual."[144] She suggests incorporating "images" rather than "analysis,"[145] to better capture embodied knowledge. This methodological strategy is influential for this project and I include direct quotes and vignettes from my co-researchers to illustrate lived, embodied experience.

William Roozeboom uses the lens of neuroscience to demonstrate important factors about embodiment. He highlights that "our brains are literally located throughout our entire body, and that learning to listen to the wisdom of the body and utilize movement, physical activity, and other practices to story oneself, is central to living well."[146] Many of the practices of wellness he describes are specifically related to the care of our bodies.

Roozeboom describes attunement as "embodied self-awareness and connection." He argues that paying attention to the body through meditation, prayer, or rhythmic breathing are all practices of care that increase our embodied attunement.[147] Nourishment, which includes physical, emotional/psychological, spiritual, and intellectual nourishment,[148] is essential to living

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[142] Miller-McLemore, "Embodied Knowing," 745.
[143] Miller-McLemore, "Embodied Knowing," 746.
[144] Miller-McLemore, "Embodied Knowing," 749.
[145] Miller-McLemore, "Embodied Knowing," 749.
[146] William D. Roozeboom, *Neuroplasticity, Performativity, and Clergy Wellness: Neighbor Love as Self-Care* (Lanham: MD, 2017), 34.
[147] Roozeboom, 79.
[148] Roozeboom, 81.

well. As an advocate for physical activity, which is “one of the most profound ways that we can produce neuroplasticity and neurogenesis,”[149] he argues that movement is an important practice for wellness. He goes on to say, “From a Christian theological perspective, movement is built into the very fabric of the understandings of God, of life, or worship, of healing, or wholeness, and of wellness.”[150] He contends that rest and renewal balance movement and work; an idea often countercultural.[151]

Finally, Roozeboom suggests that meaningful relationships are key to wellness and “one’s ability and capacity to care for others is tied to one’s ability to connect with and care for self.”[152] Certainly, “caring for” and “connecting with” are broadly defined to ensure that those with limited embodied capacities for movement, sensation, or thought might also be included in meaningful relationship. Roozeboom clearly notes that theologians must pay specific attention to bodies in context as a way of ensuring that all bodies are valued:

> [O]ur (pastoral) theologies of embodiment should attend to contextuality and particularity and work to deconstruct systems and power structures that devalue certain forms of embodiment and/or use one’s embodiment to do harm to others (i.e. value certain skin colors, or genders, gender identities, body types, physical abilities, and so on, and devalue ‘other’ forms) and help persons reconstruct life-giving and empowering understandings of self.[153]

He proposes that our physical bodies can lead to oppression and multiple forms of marginalization. We must pay attention to the ways in which power structures function to prioritize some bodies while devaluing others.

Evident by this brief overview of literature within this field, pastoral theologians have long-wrestled with what it means to be embodied. They have contributed important theological

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[149] Roozeboom, 88.
[150] Roozeboom, 90.
[151] Roozeboom, 91.
[152] Roozeboom, 93.
[153] Roozeboom, 117.

constructs that emerge from particular embodied experiences. One could argue, like Bonnie Miller-McLemore, that embodiment has come to mean that bodies are constructed in contexts.[154] And, as Miller-McLemore argues, this is an invaluable yet partial understanding of embodiment. Though the body is not necessarily central or explicitly named in many pastoral theologians' reflections, many recognize that bodies—and their relationships to contexts—are the genesis of constructed theological reflection.

As pastoral theologian Larry Graham so rightly accounts: our bodies, and the ways they are received and constructed in society, shape the way that we view the world, the way the world views us, the way we view each other, and the way we view God.[155] Our conception of how bodies contribute to epistemology and a theological enterprise is broadened when reading pastoral theologians in conjunction with other practical theologians and theologians from the fields of feminist theology and body theology.

Theologians from Other Fields

Body theology is a discrete theological field. Feminist theologians and practical theologians writing through the lens of sexuality, illness, or from differently-abled-body perspectives all contribute to a growing understanding about how a body is shaped by and shapes a culture. Each of these theologians make the claim that the body is not simply embedded within a context, but the body becomes the context of inquiry. These theological proposals, emanating from the concept of the body, craft our knowledge about God. I will first explore what is meant by body theology and then I will turn my attention to embodiment explored through the lens of feminist theologians and practical theologians examining differently-abled bodies and illnesses.

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[154] Miller-McLemore, "Embodied Knowing," 745.

[155] Graham, 73-4.

Body Theology as Dialogue Partner

Angie Pears describes body theology as one type of contextual theology. In *Doing Contextual Theology*, theologian Pears suggests that the body serves as one (of many) contexts for understanding the world.[156] Body theologies can revise and expand our theological landscape by prioritizing the body as a specific context for theological inquiry. Body theologians highlight that the body is "fundamental" to our human experience;[157] the body is not "problematic or coincidental to human experience."[158] This assumption makes the body central, but it also suggests that the body is knowable and articulates knowledge.

James Nelson, a Christian ethicist, wrote *Embodiment* in the late seventies. While this text specifically addresses human sexuality, Nelson articulates three important ideas that influenced this project. First: bodies (our passions and functions of the bodies) are constructed within a "social order"[159] that "mirror[s] and symbolize[s] our perception of the world, and our perceptions of the world feedback upon our understandings of our bodies."[160] The body and its context are in a dialogical, mutually constructing relationship. Second: Nelson, like body theologians influenced by him, deconstructs the body/soul[161] dualism. He is not unique in pointing out how dualistic constructs privileges one to the detriment of the other. Third: Nelson argues that body alienation is the root of sin.[162] Alienation to our body, he notes, leads to the

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[156] Angie Pears, *Doing Contextual Theology*. (London: Routledge, 2010), 117.

[157] Pears, 118.

[158] Pears, 118.

[159] James Nelson, *Embodiment*: *An Approach to Sexuality and Christian Theology (*Minneapolis, MN: Augsburg Press, 1978) 22-25.

[160] Nelson, *Embodiment*, 25.

[161] For Nelson, the self is defined as emotions and mind. He sets the self in relief against the body to describe and explain the dualistic construct prevalent in Western thought. Other writers that highlight the body address this dualism but the come to it from a variety of vantage points. Some talk about body/soul, body/spirit, body/mind, etc.

[162] Nelson, *Embodiment*, 41.

rejection of self and others as we disown, disavow, and even demonize parts of ourselves and others.[163]

While several of the following theologians could also be included under the heading of body theology, I want to highlight their unique contributions for this particular project. I will first take another brief look at four feminist scholars (Beverly Harrison, Lisa Isherwood, Elizabeth Stuart, and Marcia Mount Shoop) who have revised and augmented discourses about theology and the body. I will then explore how and ethicist and four theologians (James Nelson, Melanie May, Wendy Farley, Thomas Reynolds, and Nancy Eiesland) examine their experiences with illness or differences in abilities to expand and construct new knowledge about the self, relationships within their particular contexts, and relationships with God.

Feminist Perspectives and Body

Beverly Harrison points out that women are posited into a patriarchal culture and norms. Subjected to patriarchy, women must claim a social identity and offer a critique of Christian traditions and theology—a tradition and history that perpetuates misogyny. Harrison, a feminist theologian and contributor to feminist ethics, is a proponent of embodied epistemology. She suggests that our ability to "feel" the world better enables our connection to the world. [164] Feeling takes us from simply knowing about the world and moves us into relationship(s) with/in the world.[165] She writes, "A feminist moral theology enables us to recognize that a major source of rising moral insensitivity derives from being out-of-touch with our bodies. Many people live so much in their heads that they no longer feel their connectedness to other living things."[166]

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[163] Nelson, *Embodiment*, 41-42.

[164] Beverly Wildung Harrison, "The Power of Anger in the Work of Love: Christian Ethics for Women and Other Strangers," Union Seminary Quarterly Review 36 (1981): 48, accessed February 12, 2016, ATLA Religion Database with ATLASerials, EBSCOhost.

[165] Harrison, 48.

[166] Harrison, 48.

This embodied and feeling connection to the world is the very thing that makes us moral agents.[167] She concludes that feelings, like anger, help us understand the world and motivate us to amend injustices and power differentials.[168]

Lisa Isherwood, a feminist and process theologian, and Elizabeth Stuart, a queer theologian, use the lenses of feminism, process thought, and liberation theology to construct a body theology in *Introducing Body Theology*. When theologians pay closer attention to the body, as a context for theological inquiry, it results in vibrant methods for understanding and interpreting the world, self, and God. They demonstrate that embodied experience has the capacity to reveal oppressive discourses that marginalize persons whose bodies do not fit with a heterosexual-male norm.[169] Similarly, investigations with my co-researchers, whose children's bodies do not fit "healthy" or "normal" body assumptions, uncover oppressive normalcy discourses that marginalize them. Isherwood and Stuart set body theology apart from other theological fields because it has a particular methodology that highlights the centrality of the body and offers a method that connects mind and body through the "feelings" of the body.[170] Feelings inform our experiences and cannot be separated from our interpretations, our engagement within, and our relationships to and through the world.[171]

Marcia Mount Shoop emphasizes the body's capacity to feel as her "way in" or method for theological insight. In describing her method, she writes, "We will not simply focus on an injured muscle or a nagging pain. We will be trying to move and breathe and ground

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[167] Harrison, 49.

[168] Harrison, 49.

[169] Lisa Isherwood and Elizabeth Stuart, *Introducing Body Theology* (Sheffield, England: Sheffield Academic Press, 1998), 20-23.

[170] Isherwood and Stuart 34.

[171] Isherwood and Stuart, 40. Beverly Harrison also notes, "Feeling is the basic bodily ingredient which mediates our connectedness to the world. When we cannot feel, literally, we lose our connection to the world. All power, including intellectual power, is rooted in feeling. If feeling is damaged or cut off, our power to image the world and act into it is destroyed and our rationality is impaired." Harrison, 48.

ourselves in our bodies in a way that is integrated with countless experiences, perspectives and possibilities."[172] She is not alone in using "feeling" as a method. Mount Shoop, a theologian and religious studies scholar, contends that our embodied capacities teach us that a profoundly good "human essence" is unchanged by circumstance or status.[173] An unchanged "human essence" is a theological lifeline for people whose bodies change because of disease. Changes to the body, like an ostomy, do not reduce the innate goodness of that body. She argues that the church can be a refuge and resource not just for hurting souls but for hurting bodies. She asks, "What if church was a place that healed our bodies, helped us wake up to our bodies, and gave us a way to embrace our bodies?"[174]

Isherwood, Stewart, and Mount Shoop all acknowledge the reality that bodies are fragile and temporary. The following theologians describe new theological insights garnered from bodies that are differently-abled or experiencing disease. James Nelson, Melanie May, and Wendy Farley write with illness as their starting point. Disease is a compelling discourse partner because it waits for no-body and ultimately affects every-body. Experiences with disease reveal our human capacity to survive even when our flesh has the capacity to fail. In this context, Thomas Reynolds and Nancy Eiesland explore embodied differences. Reynolds offers compelling insights into what can be learned about interdependence and relationship when we experience embodied differences. Nancy Eiesland proposes a new way of conceptualizing God—as disabled. I will briefly explore these three theologians.

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[172] Marcia W. Mount Shoop, *Let the Bones Dance: Embodiment and the Body of Christ* (Louisville, KY: Westminster John Knox Press, 2010), 7.

[173] Mount Shoop, 8.

[174] Mount Shoop, 162.

Embodied Fragility, Illness, and Differently-Abled Bodies

Illness and Embodiment

Since we do not simply have bodies, we are our bodies,[175] as ethicist James Nelson describes in *Body Theology*, we are perpetually creating meanings from our embodied circumstances.[176] In part three of his work Nelson indicates that illness forces us to give meaning to our bodies in ways that are often overlooked when one is well.[177] The meanings that we make and hold to be true about our bodies are directly influenced by the condition or health of our bodies. It is difficult to remember that the body is created good when it feels painful or uncomfortable.

Nelson correctly notes that illness causes us to simultaneously "become more aware" of our bodies while also becoming more "distanced from it."[178] Nelson suggests that suffering during illness occurs when our body is not integrated (not seen as an integral part of the "self") or when our body is overtly rejected as a part of the "self."[179] Nelson notes that society contributes to our suffering when we experience illness. He argues that society encourages those who are experiencing illness to play a "sick role."[180] The purpose of the "sick role" is to create and maintain distance between those who are "healthy" and those who are "sick."[181] He suggests, "Because sickness of any sort is a reminder of death, and serious illness is a prelude to death, we insist that those who are sick act in a certain way if the rest of us are to tolerate

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[175] James B. Nelson, *Body Theology* (Louisville, KY: Westminster John Knox Press, 1992), 124.
[176] Nelson, *Body Theology*, 9.
[177] Nelson, *Body Theology*, 170.
[178] Nelson, *Body Theology*, 128.
[179] Nelson, *Body Theology*, 133.
[180] Nelson, *Body Theology*, 129.
[181] Nelson, *Body Theology*, 129.

them."[182] Though he uses different language, Nelson is highlighting anxiety related to embodied vulnerability and defilement, concepts which I will explore in chapter four of this project.

In *A Body Knows*, Melanie May, develops theological themes that emerge from her near-death experiences, her familiarity with physical and mental illness, and wisdom about her sexuality. She constructs theology to amplify the themes of resurrection, solidarity, and self-love. May, a Christian theologian, recognizes that she is not simply in *possession* of a body but suggests, "I am my body."[183] It is through the attention to her body-narrative, or "history,"[184] that May learns not to fear bodily finitude. She recognizes that a fear of finitude has infringed upon her ability to live and feel alive.[185] She learns to live not in spite of her body but through her body; a true connection to her body.[186]

When May turns her attention to her body's communication of new (or previously ignored) insights she discovers more about who she is, who God is, and who she experiences "Others" to be. She elevates body knowledge in ways that give the body an epistemological credibility.[187] She writes:

> But believing my body has a history—and that history is interpretation of experience, is meaning making—I nonetheless tell the story of my body as the location of God's revelation in my life. So doing, I disrupt the normalizing discourses into which I was born, as I accordingly 'glorify God in [my] body' (I Cor. 6:20 NRSV).[188]

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[182] Nelson, *Body Theology*, 129.

[183] Melanie A. May, *A Body Knows: A Theopoetics of Death and Resurrection* (New York, NY: Continuum, 1995), 18.

[184] May, 101-3.

[185] May, 32.

[186] May, 68.

[187] The body is an important source of epistemology for May. She details this idea in the final chapter of this book. May, 95-109.

[188] May, 103.

God's revelation is manifest in and through the body and embodied experiences. When we embrace the body as a source of God's revelation, our bodies and embodied experiences upend normalcy discourses.

In *The Wounding and Healing of Desire*, Wendy Farley came to realize that because of severe migraines and an inability to read and think clearly her once taken-for-granted ways of thinking theologically were not accessible to her.[189] Farley, theologian and scholar of religious women and mystics, asserts that humanity is created fully-good, in the image of God. When the "Divine Eros" takes bodily form, it demonstrates the "sanctity of our own flesh."[190] The incarnation is not just a way of redeeming human flesh: incarnation gives evidence to the sanctity of the flesh as the place where the Divine dwells within this world.[191]

Writing with illness experiences in the fore, Nelson, May, and Farley all suggest that the pain and suffering that accompanies disease is cause for new theological insight. Each, in her or his own way, detail how disease, though physically experienced in the body, is made understandable in our interactions with our contexts. Most importantly, all three authors recognize that disease does not diminish the quality of the body—the body remains innately good.

Embodiment and differences in bodily abilities.

Theologians Thomas Reynolds and Nancy Eiesland write from the experience of differences in ability. Tomas Reynolds constructs his theology in conversation and from observation with his son who lives with Tourette's syndrome, Asperger's syndrome, bipolar

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[189] Wendy Farley, *The Wounding and Healing of Desire: Weaving Heaven and Earth* (Louisville, KY: Westminster John Knox Press, 2005), ix-xiii.

[190] Farley, *Wounding and Healing*, 104.

[191] Farley, *Wounding and Healing*, 104-5.

disorder, and obsessive-compulsive disorder. Nancy Eiesland develops her theology through experience with physical differences.

Thomas Reynolds, in *Vulnerable Communion*, focuses his work on emotional and cognitive differences as a source of theological reflection. Reynolds is a constructive and contextual theologian engaged in disabilities studies. He describes the "cult of normalcy," a social discourse suggesting that there is only one "normal" way of being embodied in this world.[192] He reminds his audience that no-body meets the standards of an "ideal" body.[193] These ideals are rooted in misperceptions and false representations about what it means to be fully human.

Reynolds suggests that disability is often cast as a "marring" of the image of God.[194] Discourses, which privilege "health" or "normal" bodies, benefit some bodies and bodily abilities to the detriment of others. Almost every-body is striving toward an elusive illusion about what is "normal." "Normal" is maintained as "true" because of a created and shared social imagination. This elusive illusion about normalcy impacts the ways we envision and imagine the *imago Dei*.[195] Reynolds concluded that "to be created in the image of God means created for contributing to the world, open toward the call to love others."[196] Our *imago Dei* is our capacity to love others and to participate with love and regard toward the world.

In ***The Disabled God*, Nancy Eiesland constructs a theology from her own and others' experiences with differently abled bodies.** Eiesland, a constructive theologian and

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[192] Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids, MI: Brazos Press, 2008), 59-63.

[193] Reynolds, 28.

[194] Reynolds, 177.

[195] Reynolds, 177-88.

[196] Reynolds, 177.

disabilities studies scholar, proposes that the body of Christ is a symbol of a disabled God[197] that is represented in the resurrection and in the Eucharist.[198] In this way, she disrupts the expectation that able-body symbolism and experience are the theological norm.[199] She notes that we must give "deliberate attention to the physical body" to "prevent it from becoming socially erased or subsumed into notions of normal embodiment."[200] Attention to the body is not simply a site for theological inquiry. Rather, attention to the physical body becomes a moral obligation: we are obligated to pay attention to the body so as not to reinterpret and reinstitute "normal" body ideals.

Where the body and embodied epistemologies were once disallowed, devalued, or demonized, theologians are now more willing to incorporate bodily knowing into theological propositions. Body theologians, as well as practical and pastoral theologians, have made strides in writing theology situated in embodied experience. Many even argue that the body is a specific site or context for inquiry. There are two apparent observations about the theologians reviewed thus far. First, these theologians, either explicitly or implicitly, suggest that the body concretely contributes to our knowledge. Thus, the body is a source of knowledge; telling us something about what it means to be human and how God relates to humanity. Furthermore, as Eiesland states, we have a moral obligation to include body epistemology and, as described by Harrison, our embodiment enables moral action within the world.

Second, each theologian argues that humanity is embodied within cultural and historical contexts. Our contextualized, embodied experiences shape us just as our bodies mold the

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[197] Nancy Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville, TN: Abingdon Press, 1994), 98.

[198] Eiesland, 23.

[199] Eiesland, 99.

[200] Eiesland, 22.

context. We cannot isolate bodily knowing since bodies are always experienced within particular contexts. As proposed by Isherwood, Stuart, Nelson, May, Eiesland, and Mount Shoop, our bodies are, themselves, a *context* of inquiry. The feeling and experience of being a body is a reasonable source of exploration and contributes to our overall interpretation of ourselves, our world, our relationships, and of God.

With all pastoral theological projects, the use of theological documents and lived experience is only partial to our method. Pastoral theology, being interdisciplinary, requires the use of other theories to augment and challenge our understanding about what it means to be human and to understand better God in relationship to humanity. Social, philosophical, and clinical theories bolster the theological commitments of this project. Some of these theoretical sources should be mentioned here.

Body Theory, Social Theory, and Contextually-Specific Literature

Theologians enquiring into embodiment draw upon theories derived from other disciplines to help amplify and amend theological commitments. Philosopher and literary critic Julia Kristeva (and subsequent theorists following her lead) and medical ethicist and sociologist Arthur Frank contribute important theory for this project. Kristeva develops the theory of abjection and Frank uses narrative criticism as a point of inquiry for bodies experiencing illness. This final section of the literature review will include: 1) Abjection theory followed by an examination of three specific articles that capture the use of Kristeva’s theories as they pertain to illness; 2) Frank’s use of illness narratives; and 3) Notes about literature pertaining specifically to gastrointestinal ostomies.

Abjection and the Body

Julia Kristeva's work, *Powers of Horror*, fashions a theoretical foundation for this project. Philosopher Kristeva,[201] augmented by anthropologist Mary Douglas[202] and political philosopher Iris Marion Young,[203] demonstrates how fears and curiosities, associated with difference, can incite powerful actions and prominent reactions. Furthermore, our reaction to difference can rouse fears about our own embodied vulnerabilities, temporalities, and frailties. Kristeva's work has most notably impacted the fields of literary and art criticism as well as a wide variety of other disciplines and fields. Abjection theory has been a productive avenue for those who (both explicitly and implicitly) describe and analyze fear and disgust (of self or others) in relationship to illness. Three articles illustrate a few trends that emerge across this sub-set of literature.

Pamela van der Riet, a nurse, and Dennis Waskul, a sociologist, propose that a person objectifies their own body when it becomes a source of medical and social scrutiny because of illness.[204] Studying among people undergoing treatment for cancer, the researchers found that the body was a source of personal shame as the body became increasingly less controllable because of treatment.[205] The authors argue that the body, now a source of examination and embarrassment, does not fully constitute the "self" while maintaining that the body is an inseparable aspect of the "self."[206] Participants in their study use various methods of

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[201] Julia Kristeva, *Powers of Horror: An Essay on Abjection*, trans. Leon S. Roudiez (New York, NY: Columbia University Press, 1982).

[202] Mary Douglas, *Purity and Danger: An Analysis of Concepts of Pollution and Taboo* (New York, NY: Routledge, 1966).

[203] Iris Marion Young, *Justice and the Politics of Difference* (Princeton, NJ: Princeton University Press, 1990).

[204] Pamela van der Riet and Dennis D. Waskul, "The Abject Embodiment of Cancer Patients: Dignity, Selfhood, and the Grotesque Body," *Symbolic Interaction* 25 no. 4 (2002): 506, JSTOR.

[205] van der Riet and Waskul, 489.

[206] van der Riet and Waskul, 489.

living with the stigma of illness[207] like distraction, body distancing, playing the role of "normal," or directly confronting social expectations about normalcy.[208]

These authors argue that physical pain (rather than social pain/stigma) becomes the dominant experience of illness; pain demands acknowledgement, recognition, and interpretation.[209] They imply that physical pain is a source of suffering that reduces and ultimately consumes a self.[210] I resist their anthropological conclusion. I believe that pain can be a central feeling that is unignorable and undeniable. I do not, however, believe that it can ultimately invalidate the goodness of the body or consume the entirety of human identity.

Magdalena Harris draws upon the work of Mary Douglas and Julia Kristeva to describe stigma associated with Hepatitis C. Harris, a sociologist who studies the sociology of health, conveys that stigma related to illness is experienced both as an individual phenomenon as well as a phenomenon perpetuated by social structures.[211] Any attempt to address the individual experiences of stigma, without also addressing social factors contributing to stigma, fails to produce ample results. Harris correctly attests that visible marks on the body, because of illness, often come to define an individual within some social contexts.[212] She asserts that totalizing definitions usurp important aspects of personhood.[213] Harris notes, too, that society expects those living with illness to describe their experience as "improving" or "getting better." As

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[207] van der Riet and Waskul, 491.

[208] The authors point to the reality that there is pressure to "appear healthy" even in the midst of living with cancer. van der Riet and Waskul, 490.

[209] van der Riet and Waskul, 503-5.

[210] van der Riet and Waskul, 505. This statement is directly oppositional to the position proposed by Wendy Farley, in *The Wounding and Healing of Desire*.

[211] Magdalena Harris, "Injecting, Infection, Illness: Abjection and Hepatitis C Stigma," *Body & Society* 15 no. 4 (2009): 37, DOI: 10.1177/1357034X09347221.

[212] Harris notes that the visibility of "track marks" from intravenous drug use is interpreted as a moral failure (addiction and drug use) as well as a representation of illness. Harris correctly links the fears about mortality and a fear of being marginalized because of illness. Harris, 46

[213] Harris, 37-8.

confirmed by my co-researchers, this is a particularly taxing expectation for individuals who have a chronic illness.[214] For the chronically ill, their health may never be fully restored to the pre-disease condition or, as some of my co-researchers described, health is improved *because* of a GI ostomy.

Claire Decoteau, a sociologist, demonstrates disease as both a physiological and social phenomenon.[215] She critiques the politics and privilege of rendering a disease as "manageable" by those in the healthcare profession or by anyone who is not directly experiencing the effects of illness. Decoteau contends that social stigma often renders a disease unmanageable even if medical cures, interventions, and treatments are available.[216] When we speak of "manageability" as it pertains to illness, we must consider social (not simply medical) implications. Those who experience illness are the ones that should determine what is manageable and what is not manageable. Decoteau maintains that the "haunting" feelings of "pain, chaos, and death,"[217] which often emerge when we learn about disease, act as our invitation to moral action: we are invited to reorient and resist social discourses that dehumanize those living with chronic and contagious disease.[218] I appreciate how Decoteau suggests that we should be moved to moral action because of fear (haunting) not in spite of fear.

Each of the above authors recognizes the importance of exploring embodied illness because it contributes to reshaping social discourses. These authors contest simplistic, straightforward narrative arcs. They refuse to accept the myth that persons experiencing illness narrate their lives in a linear trajectory: from diagnosis, to treatment, to improvement, and

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[214] Harris, 48.

[215] Claire Laurier Decoteau, "The Specter of AIDS: Testimonial Activism in the Aftermath of the Epidemic," *Sociological Theory* 26 no. 3 (September 2008): 235. http://www.jstor.org/stable/20453108.

[216] Decoteau, 240-2 and 245.

[217] Decoteau, 252.

[218] Decoteau, 250-2.

culminating in restored health. Arthur Frank, a medical ethicist and sociologist, helps us better see ways of narrating illness experiences.

Narrating Embodied Illness

Arthur Frank, a sociologist and medical ethicist, tackles the quandary of the narrative-stopping experiences of illness in his work *The Wounded Storyteller*. Frank applies narrative analysis to identify three narratives that "wounded bodies" need to tell: restitution, chaos, and quest. Frank contends that illness narratives occur in a larger social context that reifies four types of "ideal" bodies: 1) the "disciplined body,"[219] 2) the "mirroring body,"[220] 3) the "dominating body,"[221] and 4) the "communicative body," which is an ethical ideal.[222] Like other ideals, the ideal body types are constructed illusions and are ultimately unachievable.[223] The communicative body, as an ethical ideal, is complimentary to the theological proposal I suggest in the fourth chapter of this project: an embodied *imago Dei* is an ideal that is both a theological category and an ethical obligation for compassion toward our own bodies and the bodies of others.[224]

Frank's observations and illness narrative typologies[225] have substantially impacted both the method and the content of this project. In the following chapter I will detail aspects of his

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[219] A body that is regimented, compliant to medical treatment, or controlled. Frank, *Wounded Storyteller*, 41-3.

[220] A body that tries to "recreate the body in the image of other bodies" trying to be like other bodies and dislikes appearing different. Frank, *Wounded Storyteller*, 43 and 46.

[221] A body which tries to overpower others with aggression or force. When illness is experienced "the disciplined and mirroring bodies turn on themselves" in self-loathing while the "dominating body turns on others." Frank, *Wounded Storyteller*, 48.

[222] A body that serves as an invitation for "others to recognize themselves in it." The communicative body is a construction in relation to others. Frank, *Wounded Storyteller*, 49-50.

[223] Frank, *Wounded Storyteller*, 29.

[224] Edward Farley, 41-43; Wendy Farley, *Tragic Vision*, 75; and Wendy Farley, *Gathering Those Driven Away*, 103.

[225] A typology is a "devise for organizing qualitative data" to categorize "events of people into qualitatively different ideal types. Thomas A. Schwandt, *The SAGE Dictionary of Qualitative Inquiry*, 3rd ed. (Thousand Oaks, CA: SAGE Publications, 2007), 302.

method for narrating and analyzing bodies and illness. I will also draw on Frank's illness narrative typologies in the fifth chapter as I suggest two additional illness narratives that emerged from my interviews with my co-researchers. As I turn to this final section of literature review, I want to very briefly highlight literature specific to my context of research. This final section demonstrates the type of educational literature available to children and their parents after an ostomy surgery.

Context- and Condition-Specific Literature

The majority of the literature I have encountered about gastrointestinal (GI) ostomies is found in nursing and other related medical literature. The bulk of this literature deals with the digestive system and problems or illnesses related to the GI system. Most of the medical and clinical literature explores the reasons ostomies are needed; how they are surgically created; and the maintenance, care, and complications associated with a GI ostomy. While imperative and helpful for those practicing medicine and those physically caring for patients with ostomies, this research does not address many of the social[226] or theological implications of life with an ostomy.

The clinical staff at Cook Children's tries to equip families and patients as they learn how to care for themselves and their children. The GI clinic employs a clinical therapist and a Child Life Specialist to assist with transitions into life with a GI ostomy. These staff members address emotional concerns as they work with patients and families one-on-one. Cook Children's also has ostomy and wound care nurses to help families with questions related to the physical care

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[226] There is social science research detailing social concerns that emerge from experiences with an ostomy. One in particular describes the connection between bodily control/continence, full-adulthood, identity and a gastrointestinal ostomy. The researchers studied among adult survivors of colorectal cancer. Their populations and findings were focus on adults but the research has helpful insight to life with a GI ostomy. Andrea Altschuler, Marcia Grant, Mark Hornbrook, Robert Krouse, Carmit McMullen, and Michelle Ramirez, "'I Didn't Feel Like I Was a Person Anymore': Realigning Full Adult Personhood after Ostomy Surgery," in *Medical Anthropology Quarterly* 28, no 2 (June 2014): 242–259. EBSCOhost.

and maintenance of ostomies. The surgery nurse educators offer patient education literature during their post-operative training process. Very little attention, within the training literature, is given to potential stigma or social concerns. None of the literature addresses spiritual or theological concerns that might emerge after a change in the body.

Most parents that I interviewed said that a combination of visits with ostomy nurses, social media GI groups,[227] conversation with other parents, and learning from their own trial-and-error were the most helpful resources when learning how to physically care for their children and the ostomies. The intention and tone of the materials attempts to normalize[228] GI ostomies while also acknowledging that an ostomy involves many life changes.

I want to mention two examples of how the literature attempts to "normalize" the ostomy. One, in a picture book available to patients, the ostomy collection device is depicted as a friend or partner in their healthcare.[229] This book, written and distributed by an ostomy supply company, offers suggestions regarding how to manage going back to school and play time. They propose ways for a child to talk about their ostomy with classmates and peers. Two, the educational literature produced by the American College of Surgeons encourages parents and adult caregivers to be prepared to explain the ostomy to others.[230] Arguably, at times, the

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[227] This was a topic of discussion at the monthly GI support group I attended while working on this project. This discussion took place on October 17, 2017. This topic is explored in the article: Dennis O. Frohlich and Anne N. Zmyslinski-Seelig, "How *Uncover Ostomy* Challenges Ostomy Stigma, and Encourages Others to do the Same," *News Media & Society* 18 no. 2 (July 9, 2014 and February 1, 2016): 220-238, accessed November 1, 2017, https://doi.org/10.1177/1461444814541943.

[228] Normalizing an ostomy, in the clinical literature, is thought to have a positive meaning and is considered a worthwhile endeavor. Thomas Reynolds points out that it can be positive if it is used to reinstate or foster meaningful relationships. All too often, however, a dominant society or medical professions determine or define what is "normal" and then insinuate these ideas for persons experiencing embodied differences; rather than leaving those who embody the difference to determine and define what is "normal" for them. Reynolds, 68-9.

[229] Sanchia Patrick, *When I Met Tipster: A Child's Story about Living with a Stoma*, ed. Sandi Burnello, Teri Carwley, Marie Oren-Sosebee, and Jeannine Thompson (Minneapolis, MN: Coloplast Corp., 2013) 1-27.

[230] One source notes, "Be prepared for what you will tell the people you meet about your child's operation. Tell them as much or as little as you want them to know. You can simply say that your child has had abdominal surgery." American College of Surgeons, *Pediatric Ostomy Home Skills Kit: Education for a Better Recovery* (Chicago, IL: American College of Surgeons, 2012), 35.

literature perpetuates the stigma of having an ostomy by encouraging family members to develop code language about the ostomy as they anticipate moments when the ostomy pouch leaks.[231]

Conclusion

A child with a GI ostomy requires physical, emotional, and spiritual attention. It is evident that the context and condition-specific literature is attuned to the physical and emotional needs of children, and their parents, as they live with GI ostomies. They are less attuned, however, to the manner in which a person living with an ostomy is embedded in a complex system of relationships and contexts—each informing how they experience not just the disease but also the illness.

Arthur Frank offers important typologies to critically analyze narratives told though embodying illness. He suggests important tools to analyze illness narratives but also offers methods for evaluating disease within social and historical contexts. The theory of abjection developed by Kristeva and illustrated by Decoteau, Harris, van der Riet, and Waskul demonstrates our human capacity to loathe, fear, or find disgusting our own bodies and the bodies of others when disease is present. These theorists amplify a human tendency to marginalize bodies and bodily matter that incite our fear and anxieties.

These clinical, philosophical, and social scientific resources are remarkable in demonstrating obstacles to mutual, caring relationships. They demonstrate the challenges of loving our own bodies and the bodies of others when we experience illness. They are incomplete, however, in their capacity to demonstrate the human potential to love and tend to bodies in the midst of illness. It is evident that pastoral theologians have helped to pave the way for such conversation and critical analysis.

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[231] American College of Surgeon, 36.

Pastoral, constructive, and practical theologians like Dwight Hopkins, Homer Ashby, and Carroll Watkins Ali have demonstrated that bodies are constructed and known within particular social and historical contexts that can be oppressive and dangerous to our survival. Yet our embodied lives have the capacity to disrupt theological and social norms and amend practices of care.

Other feminist theologians like May and Farley, along with pastoral theologians like Miller-McLemore, Stevenson-Moessner, and Scheib, increasingly trust the wisdom of the body and incorporate that wisdom into theological proposals. Mount Shoop, Isherwood, and Stuart demonstrate the body's capacity to "feel" as a way to narrate realities about the human condition and understandings about God while Harrison notes that our feeling capacity enables us to be "moral agents" in the world. Phillis Sheppard notes that being a body is akin to being an agent of ethical change in oppressive historical and social contexts. Theologians Eiesland, Reynolds, and ethicist Nelson all demonstrate how illness and embodied difference is a valuable and integral context for knowing and re-imagining God. Illness and differences in abilities do no diminish our embodied goodness. Our bodies, and the bodies of my co-researchers' children, are instructive. Bodies can never be evaluated apart from a particular context but bodies are revealing of those contexts and have the capacity to amend our social discourses and theological propositions. Thus, bodies have the capacity to uncover theological lacuna, oppressive social discourses, and even demonstrate our capacity and obligation to care for ourselves and each other.

Chapter Three

Methods and Methodology

> For me, writing is a gesture of the body, a gesture of creativity, a working from the inside out. My feminism is grounded not on incorporeal abstraction but on corporeal realities. The material body is center, and central. The body is the ground of thought.
>
> -Gloria Anzaldúa, *Preface: Gestures of the Body*

Introduction

Pastoral theological methodology is particularly well situated to take seriously the co-constructive nature of how our body identity is informed by social narratives, ideologies, and theological constructs, as well as how bodies can reframe and reimagine our theologies and ideologies. Pastoral theologians elevate concrete, lived experience; it is our point of departure. Nancy Ramsay writes, "In contrast to systematic theology or ethics, pastoral theology… begins with the concrete particularity of experience and intends a useful response for that situation."[232] Pastoral theologians have developed multiple approaches to the study of varied and particular contexts.

A pastoral theological approach is not an exercise in applied theology. It is an exercise in constructive theology. This study, like others within the field, does not simply assume that theological understandings garnered elsewhere address lived experiences; but emerge out of contexts of care. Pastoral theologians also do not simply place lived experience into conversation with theology to see how they correlate. Pastoral theologians listen for the theological insights and experiences that emerge in daily, embodied life. Our method is inductive, a process in which embodied experience constructs and reframes theological landscapes and arguments. Pastoral theologians *expect* that lived experience will change and

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[232] Nancy J. Ramsay, "Contemporary Pastoral Theology: A Wider Vision for the Practice of Love," in *Pastoral Care and Counseling: Redefining the Paradigms*, ed. Nancy J. Ramsay (Nashville, TN: Abingdon Press, 2004), 157.

modify our assumptions, our theories, and our theologies. These changes will refine and modify our approaches to care.

The methodological commitments that guide this research are rooted in a commitment to the "critical engagement with theological issues that [arise] in the context of human reality."[233] But engaging with human realities requires attention to the politics and questions of "how" we arrive at knowledge generated from lived experience. I will pay particular attention to the source materials that guide this project. My inquiry will focus on integrating and critically evaluating multiple sources. These sources will be woven together in a spiral. Thus, my approach is not linear. While a linear approach to integrating source material is easy to read, it limits the fluctuating, tentative, and often incomplete nature of a lived narrative. I will describe this spiral technique at a later point in this chapter. To begin, we must first consider a few methodological commitments that shape the sources I will engage through this project.

This chapter will unfold in five sections. First, it is important to give credence to embodied knowledge. I will demonstrate how some researchers incorporate embodied knowing into research as viable and reliable source material. Second, I explore the politics and challenges of integrating multiple sources into theological argument. Third, I will engage two parallel methods to integrate multiple, interdisciplinary sources for the construction of a theological proposal. These methods will ultimately work in tandem to highlight and incorporate different facets of my source material. Fourth, I will describe my commitment to developing a "trustworthy" study as a way of representing the lived knowledge from co-researchers,[234] my

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[233] Joretta Marshall, "Methods is Pastoral Theology, Care and Counseling," in *Pastoral Care and Counseling: Redefining the Paradigms*, ed. Nancy J. Ramsay (Nashville, TN: Abingdon Press, 2004), 138.

[234] I will used the term "co-researcher" as opposed to "participants" a way of reiterating my commitment to a collaborative and trustworthy study. Patricia Hill Collins and Sirma Bilge use the term "co-investigator" as a way of denoting that the persons with who we engage in research help us ask better questions and foster knowledge that is relevant to their particular contexts and situations. Sirma Bilge and Patricia Hill Collins, *Intersectionality* (Malden, MA: Polity Press, 2016), 164.

embodied knowing, and knowledge garnered from theological and clinical literature. Finally, I will discuss a few of the particularities about the study structure pertaining to my research with Cook Children's Medical Center in Fort Worth, TX.

Both pastoral theological method and qualitative inquiry offer important research strategies for this project. Qualitative inquiry presents an important supplement to the methods of pastoral theology. I would like to briefly highlight my rationale for working in close association with qualitative researchers (from a variety of non-theological disciplines) to uphold, define, and nuance the method and methodology[235] of pastoral theologians. Insights gained from qualitative research serves my purposes in two specific ways.

One: combining wisdom from qualitative inquiry helps to demonstrate the interdisciplinary strength of a pastoral theological methodology. When researching across disciplines it is important to understand the methods, assumptions, and principles of source materials. Many of the source materials I incorporate from the fields of medical anthropology, sociology, philosophy, and clinical practice emerge from qualitative research methods and methodologies. It is evident that qualitative inquiry and pastoral theological methodology share important similarities, such as a commitment to developing knowledge from lived experience.[236]

Two: qualitative inquiry offers a shared vocabulary and methodological commitments from which we can depart as pastoral theologians, particularly when researching among healthcare professionals. Within my research setting, proficiency in translating and explaining theological methodological concepts is essential. Qualitative inquiry offers a "way in" (so to

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[235] Method means the "procedures, tool, or technique used by the inquirer to generate and analyze data." Methodology denotes "a theory of how inquiry should proceed" giving attention to "assumptions, principles, and procedures." Method and methodology "display a synergistic relationship: a particular method (or set of methods) is employed (and given meaning within) a methodology that defines the object of study and determines what comprises an adequate reconstruction of that object." Thomas A. Schwandt, *The SAGE Dictionary of Qualitative Inquiry*, 3rd ed. (Thousand Oaks, CA: SAGE Publications, 2007), 190-93.

[236] Qualitative inquiry seeks to understand the "meaning of human action." Schwandt, 248.

speak) to the conversation. Qualitative research methods provide institutional credibility. I have found that the vocabulary, concepts, and methodological commitments of qualitative inquiry, though still somewhat unfamiliar within my particular context, were more approachable to clinicians familiar with quantitative inquiry. My use and understanding of qualitative research have been invaluable when communicating with members of my research team and the Cook Children's Institutional Research Board. This research language and foundation has provided me with much needed credibility in the context of my research.

Experiential and Embodied Epistemologies

The question of epistemology is of upmost importance. I believe that reflection on and construction from lived experience requires serious inquiry into embodied experience as a source for the knowledges that we generate. More specifically, we must incorporate the voice of the body to authentically claim that we are taking embodied lived experience seriously. This incorporation poses a few challenges. Sociologist Arthur Frank reminds us that while the body is "mute," it is not inarticulate.[237] How, then, do we fashion words out of the wordless moaning of the body? Theologians, sociologists, and qualitative researchers have been exploring that question. I will begin by describing techniques theologians use to write lyrics for the body's melodies. I will describe how illness narratives require careful consideration for the voice of the body, with particular emphasis on the "feeling" nature of the body. Next, I will explore some of the challenges to incorporating the voice of the body into research while suggesting forms of writing, data collection, and data representation as a way to mitigate (not eliminate) these challenges.

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[237] Arthur Frank, *The Wounded Storyteller: Body, Illness and Ethics*, 2nd ed. (Chicago, IL: University of Chicago Press, 2003), 27.

Feeling as Methodological Technique

"Feeling" is a methodological technique described alike by theologians and social science theorists. Theologians Melanie May, James Nelson, Marcia Mount Shoop, Lisa Isherwood, and Elizabeth Stewart share a commitment to "feeling" as a way of embodied knowing. For May, feeling seems more of an intuition rather than a specific method of research. May does not specifically address "feeling" as a methodological enterprise, as does Marcia Mount Shoop or James Nelson. She does, however, incorporate narrative descriptions of how her body *felt* at various moments. These feeling motivated her theological inquiry and construction.[238]

For James Nelson, specifically in his work *Embodiment*, feeling is arguably the preeminent way of four methods for understanding and interpreting "body language" in theology. (Nelson also describes desire, communion, and incarnation[239] as important methods.) Feeling, as a method, is amplified in the work of Marcia Mount Shoop. Feeling is made explicit and central in her approach to body theology. In *Let the Bones Dance*, Mount Shoop addresses the ways in which Christian theology generally ignored the body. Her methodological commitments honor the body and the feeling nature of the body as site and source for theological discovery. She notes, "This theological category of feeling is complicated and primal; it is not emotion, not thought, not sensation, but instead the most primary and the most embodied mode through which we navigate all experience, including but not limited to emotion, thought, and

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[238] May does not specifically address "feeling" as a methodological enterprise, as does Marcia Mount Shoop or James Nelson. She does, however, incorporate narrative descriptions of how her body *felt* at various moments, which inspired her theological inquiry and construction. Melanie A. May, *A Body Knows: A Theopoetics of Death and Resurrection* (New Yok, NY: Continuum Publishing Company, 1995), 13-26.

[239] James Nelson, *Embodiment*: *An Approach to Sexuality and Christian Theology* (Minneapolis, MN: Augsburg, 1978), 30-36.

sensation."[240] She underscores the reality that feeling connotes many and varying ideas, a significant contribution to body theology.

Lisa Isherwood and Elizabeth Stuart note that body theology not only privileges the body but does so in a way to deconstruct and challenge the mind/body dualism that remains prevalent in Christian theology. These authors insist that "feeling" is a connection between mind and body.[241] These feelings inform our experience which, in turn, cannot be separated from the ways in which we interpret, engage, and form relationships in and through the world.[242] May, Nelson, Mount Shoop, Isherwood and Stewart all suggest that feeling is a "way in," so to speak, of listening to the body.

It is notable that feeling is interpreted both through experience and context but feeling also informs the way we view the world. Arthur Frank says that bodily stories are always personal and social.[243] This personal and social aspect is particularly evident when disease is present. Disease can make our bodies hurt, create exhaustion, or cause other discomforts. When our bodies are a constant, present, uncomfortable, or painful reminder of disease we will likely interpret our surroundings differently than when our bodies are relatively well. Frank notes, "The body, whether diseased or recovered, is simultaneously cause, topic, and instrument of whatever new stories are told."[244] Thus, Frank argues that disease demands a different story, even if "health" has been restored.[245]

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[240] Marcia A. Mount Shoop, *Let the Bones Dance: Embodiment and the Body of Christ* (Louisville, KY: Westminster John Knox Press, 2010), 12.

[241] Lisa Isherwood and Elizabeth Stuart, *Introducing Body Theology* (Sheffield, England: Sheffield Academic Press, 1998), 34.

[242] Isherwood and Stuart, 40.

[243] Frank, *The Wounded Storyteller*, 2.

[244] Frank, *The Wounded Storyteller*, 2.

[245] Frank, *The Wounded Storyteller*, 2.

I want to point out two specific aspects when we talk about "feeling" as a method of inquiry. With the exception of Mount Shoop, often when hearing and incorporating the "voice" of the body there is no detailed delineation or distinction about what is meant by "feelings." This lack of distinction is important, especially when we place embodied lives into conversation with diseases that change or affect the body. To begin, there are somatic feelings that the body communicates. These come in the form of deep groaning pain, butterflies of excitement, or the rush of adrenaline, itching, nausea, etc. I think of these as phenomenological properties of the body. There is another type or source of "feeling." These are constructed as our bodies engage with our contexts. I say "constructed," but not to insinuate that they are without somatic interpretation. When I speak of constructed feeling I am speaking of concepts like fear, disgust, hope, or happiness. These feelings are certainly situated in the body and have somatic sensations, but they are informed by outside stimuli and are understood through the lens of constructed social order. Feelings of loathing, fear, or disgust that accompany an encounter with the abject would be an example of a constructed feeling. I make this distinction about feelings because I want to honor the somatic, pre-lingual "voice" of the body. I also want to reiterate how Arthur Frank acknowledges that our embodied feelings are personal but also socially informed and constructed.

Enlivened by the work of Arthur Frank, Brett Smith and Andrew Sparkes remark, "[T]he kind of body that one has and is becomes crucial to the kind of story told and analysis produced."[246] Frank has authored books and articles reflecting on his own experiences with illness, extracting meaning from both his body and his experience with illness. Sparkes and

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[246] Brett Smith and Andrew C. Sparkes, "Narrative Analysis as Embodied Engagement with the Lives of Others," in *Varieties of Narrative Analysis*, ed. James A. Holstein and Jaber F. Gubrium (Thousand Oaks, CA: SAGE Publications, 2012), 55.

Smith build upon the notion that context impacts body narration. They explore *their* embodied experience as they research; recognizing that their bodies—as researchers—react to the research context.

Sparkes and Smith demonstrate that the researcher's own body is not value-neutral in data collection or interpretation. My own body impacts the study as I react to what I see, hear and read. Some might say that it is the researcher's duty to be objective in her analysis. I will assume that objectivity is unreliable and political (more on this concept in the final section of this chapter). One can never factor out her or his own embodied subjectivity when conducting research and embodied subjectivity is assumed for this project.

Incorporating my voice and perspective into the text of this project proved challenging. I followed the suggestions of Sparkes and Smith, using autoethnographic-like inclusions as I gathered and analyzed data. Sparkes and Smith argue that autoethnographic additions "illustrate the ways in which we experience the emotional and embodied nature of our narrative work and how this might have impacted our analysis over time."[247] As I interviewed co-researchers, I took field notes regarding my feelings during the interview. I also wrote transcription memos and transcribed moments where the narrative drove me, and my co-researchers, to an embodied reaction—like laughter or tears or nonverbal expressions of fear or disgust. These notations informed my interpretation of data.[248]

Embedded within this notion of embodied subjectivity is the stark reminder that subjectivity is an asset, not a limitation. Smith and Sparkes point out, along with other autoethnographers, how researchers and audiences are also invited to participate in data analysis

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[247] Sparkes and Smith, 56.

[248] The most notable inclusion in my field notes and transcription notes were indications describing my comfort with conversations about ostomies and human excrement. Much of that is attributable to the honesty and sincerity of my co-researchers and prolonged exposure to the topic.

and interpretation. Neither researcher nor audience can control the overall interpretations of a text or a story. To do so, they argue, "[W]ould assume we actually know the definitive meaning ourselves."[249] "This would be a deceit," they say, "as our own meanings associated with the moments we have described are multiple and changing over time."[250] While Sparkes and Smith specifically address the interpretation and analysis of data, they allude to the need for different forms of writing that capture the "embodied engagements" with and among those they research.

Articulating the voice of the body demands different forms of communication. What is often overlooked within this method are the ways in which "feelings" are pre-lingual and thus challenging (if not impossible) to fully communicate. Arguably, each form of communication is incomplete. Compelling visual interpretations of embodiment are possible, specifically abject embodiment,[251] but the primary form of communication for theologians remains writing. Therefore, new methods of writing are required. Joretta Marshall notes that as the field of pastoral theology, care, and counseling diversifies, multiple voices emerge. This multiplicity impacts writing styles as first person accounts are incorporated into the construction of theological claims and care practices.[252] Evidence of this shift can be seen through the poetic inclusions of Melanie May or Marcia Mount Shoop. Additionally, evidence can be found in theologians reflecting on dance, running, pain, or other activities in which our body's movements

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[249] Smith and Sparkes, 57.

[250] Smith and Sparkes, 57.

[251] One of the most compelling series is a photographic collection by Albert Winn, "Band-AIDS." Of this series, Winn writes, "The cocktail, which was the first effective medical intervention against the virus that causes AIDS, had a secondary affect which improved the appearance of people who were infected with the illness. As one who benefited from the efficacy of new drug treatments, I soon found myself the recipient of compliments on my appearance and supposed restoration to good health. These compliments were really a form of measurement, a comparison to how I looked before. It occurred to me that I was walking around with invisible scars and determined to make my illness seen. Band-aids were placed as signifiers of illness on those areas of my body where there had once been a manifestation of illness - a lesion, a scar or a place where some medical procedure had been performed." Albert J. Winn, "Band-AIDS," http://www.albertjwinn.com/index.php?/photographs/band-aids/ (accessed May 2, 2012).

[252] Marshall, 144.

or sensations generate theological argument. I will return to the argument for a broader writing style in a moment but before I do, I want to explore some of the challenges to articulating the body's narrative.

Theologians and clinicians alike recognize the challenge of articulating the body's voice. Bonnie Miller-McLemore points out, even displays, the ways in which embodied knowing—the physical body "speaking" and "writing" its truths—is hard to capture in a written document. How do we turn the actions, inactions, feelings, and sensations derived from the body into words that adequately convey their nuanced truths? She asks, "Can living subjects be adequately understood when turned into linear texts?"[253] Miller-McLemore suggests that incorporating embodied knowledge might demand a different style of writing, one that incorporates a more illustrative narrative that changes "the usual disproportion in academic prose of the conceptual over the depictive, analysis over images."[254]

Arthur Frank and other qualitative researchers in fields related to sports and activity note similar challenges to narrating the body's "voice." For Frank, telling stories about illness is a way to give voice to the body. As such, Frank argues that the act of storytelling is a method for articulating the body narrative. Narrating illness, in particular, helps us understand our bodies and the changes we have undergone because of illness. Narrative helps us identify that which has become unfamiliar through illness and guides us as we become familiar, again, with our embodied lives.[255] Helping families narrate their illness stories is akin to what I do as a chaplain. It has important implications, as will be discussed in chapter five, for the care we offer when accompanying families through the experience of illness.

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[253] Bonnie Miller-McLemore, "Embodied Knowing, Embodied Theology: What Happened to the Body?" in *Pastoral Psychology* 62, no. 5 (October 2013): 746.

[254] Miller-McLemore, "Embodied Knowing…," 749.

[255] Frank, *The Wounded Storyteller*, 2.

Frank reminds us that illness stories take place in specific contexts. We must also recognize that a story is fluid. We must take into account and accept the audience's co-constructive contribution. Frank stresses to us that we cannot simply hear a story, analyze a story, and then directly apply another's story to our own circumstances.[256] I am joining my story (as a researcher) with the stories of others, learning from them and integrating their interpretations and meanings into ideas harvested from theory. Together we create new theory and new theology; we are not simply applying one person's experience to another situation.

Frank's methodological commitments hold some similarities to the way Joretta Marshall describes the method of pastoral theology. Pastoral theologians do not simply apply or correlate theology with other disciplines (like psychology) to discreet circumstances or contexts. Pastoral theology is an exercise in thinking theologically and constructively about lived experiences—an integration of theory and praxis.[257] Before I detail my method to synthesize various sources, from multiple disciplines, together (for the construction of my theological propositions) I want to first pause and briefly return to the idea that narrating the voice of the body demands a different sort of writing.

Writing Style as Methodological Commitment

I have argued for a change in rhetorical strategy, particularly when researching embodied narratives and experiences. I want to spend some time reflecting on what these "rhetorical strategies" might entail. I am assisted by the work of qualitative researchers to help describe writing and data representation. I will first describe the importance of first person accounts in the construction of this research. Second, I will examine how the form and structure of writing is equally important to the interpretation and analysis of data.

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[256] Frank, *The Wounded Storyteller*, 20-25.

[257] Marshall, 142-3.

First person accounts, from my co-researchers, are important and meaningful inclusions for this project. They are not included merely for illustrative purposes. I incorporated direct quotes from co-researchers as a way of resisting the "essentialism" often seen in the "we" of academic writing.[258] As Isherwood and Althaus-Reid note, for example, "[Q]ueer theology is a form of autobiography because it implies an engagement and a disclosure of experiences which traditionally have been silenced in theology."[259] My theological constructions address embodied realities that have often been overlooked by theology, the academy, and even clinical research.

First person narratives are also important in feminist methodology, which encourages reflexivity. Reflexivity is a way of evaluating the power relationships within the research and writing process.[260] Thus, first person inclusions are a reflexive strategy intended to help balance the voice of the researcher and the incorporated theory and theologies.[261] Some have pointed to the use of "third person narration" as a "shield" against the "blemishes and unsightliness" uncovered in the research process.[262] Others argue that first person voice moves us from objectivity to inter-subjectivity, providing occasion to reflect on the politics of the research, the "indeterminacy of language," or the "fallibility of human sense making."[263]

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[258] Marcella Althaus-Reid and Lisa Isherwood, "Introduction: Queering Theology Thinking Theology and Queer Theory," In *The Sexual Theologian: Essays on Sex, God and Politics*, edited by Marcella Althaus-Reid and Lisa Isherwood (New York: T&T Clark International, 2004), 6.

[259] Althaus-Reid and Isherwood, 6.

[260] Janet Holland and Caroline Ramazanoğlu, *Feminist Methodology: Challenges and Choices* (Thousand Oaks, CA: SAGE Publications, 2002/2008), 118-19.

[261] Holland and Ramazanoğlu, 119.

[262] A "next step" in this research could incorporate the first person accounts from co-researchers as well as first person accounts from the position of researcher. This tactic proved cumbersome for a dissertation and its requirements for length, clarity and tone. Margaret Anzul, Maryann Downing, Margot Ely, and Ruth Vinz, *On Writing Qualitative Research: Living by Words* (Washington, D.C.: The Falmer Press, 1997), 354.

[263] Laura L. Ellingson, "Analysis and Representation Across the Continuum," in *The SAGE Handbook of Qualitative Research*, 4th ed., ed. Norman K. Denzin and Yvonna S. Lincoln (Thousand Oaks, CA: SAGE Publications, 2011), 600.

Some researchers believe that we are able to become sufficiently acquainted with our biases and our assumptions to "bracket" these assumptions out of our projects and establish a more objective position in our research.[264] I believe that bracketing our position and assumptions is a fallacy.[265] While critical distance and personal awareness are helpful in research, I do not believe that we can ever fully bracket our assumptions. Moreover, I believe that our subjectivity should not be ignored but instead embraced.[266] It is our duty to inform our audience of our assumptions and allow our audience to point out and critique overlooked assumptions.

The form and structure of writing is equally important to the way we interpret and analyze our data.[267] The form our writing takes should be an invitation into deeper analysis of the topic. While different forms of writing can be intriguing the "aim must be to make ongoing meaning for ourselves and to communicate that meaning with people in order to involve them in thinking about and living our research experience."[268] I cannot assume control over the exact meanings of illness stories, the first person co-researcher inclusions, or the meaning that my audience makes of either. The objective of writing, then, is an invitation for the audience to become involved in the research experience.

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[264] Schwandt, 24.

[265] A couple of qualitative researchers have developed the tem "analytic bracketing" as a way of suggestion that various data could and should be brackets from each other as a way of analyzing "discursive practice" and "discourses-in-practice" or the "hows and whats" of complex "lived interplay between social interaction and its immediate surroundings, resources, restraints, and going concerns." James A. Holstein and Jaber F. Gubrium, "The Constructionist Analytics of Interpretive Practice," in *The SAGE Handbook of Qualitative Research*, 4th ed., ed. Norman K. Denzin and Yvonna S. Lincoln (Thousand Oaks, CA: SAGE Publications, 2011), 347.

[266] R. Ruard Ganzevoort likewise acknowledges that the narrator's subjectivity is important and she or he engages in "an ongoing dialogue in which the narrator engages with her or his audience." R. Ruard Ganzevoort, "Narrative Approaches," in *The Wiley-Blackwell Companion to Practical Theology*, ed. Bonnie Miller-McLemore (Oxford, UK: Wiley-Blackwell, 2011), 216.

[267] Anzul, et al., *On Writing*, 59. And Stepahnie Paulsell, "Writing as a Spiritual Discipline," in *The Scope of Our Art: The Vocation of the Theological Teacher*, ed. L. Gregory Jones and Stephanie Paulsell (Grand Rapids, MI: Wm B. Eerdmans Publishing, 2002), 23-5.

[268] Anzul, et al., *On Writing*, 61.

Theological writing should, in part, dispel the myth that we are somehow not implicated[269] in the theology that we construct. We must consider the ways in which we are all complicit in the oppressing normalcy discourses that I will discuss in this research. As the author and researcher, I am not an "admirable figure with selected human limitations that are gradually overcome as… [I] move toward understanding."[270] It should become evident that we all are implicated in and by dominant, oppressing normalcy discourses. My hope is to communicate in a way that compels the audience to examine the topic, thereby inviting further reflection and action. Rhetorical techniques, to incite action, are certainly not unique to qualitative research.[271]

The objective of many pastoral theologians is to incite action; they argue for change to practices of care and theology. There is persuasive power in the construction of our writing. It invites the reader to be a participant in the meaning of the research.[272] In the words of Stephanie Paulsell, "[I]t matters what words we choose, what voice we speak in, what tone we take. It matters both for the quality of our own thought, and for the quality of our invitation to our readers."[273] Lived experience not only guides theological construction, it affects how we write.[274] Writing, like constructive pastoral theology, is an inductive process. When necessary, my work will embrace multiple forms of writing (like personal antidotes and vignettes directly quoted from co-researcher interviews). This structure will help me better communicate multiple perspectives and emerging theories.

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[269] Ronald J. Pelias, "Writing into Position: Strategies for Composition and Evaluation," in *The SAGE Handbook of Qualitative Research*, 4th ed., ed. Norman K. Denzin and Yvonna S. Lincoln (Thousand Oaks, CA: SAGE Publications, 2011), 662. Pelias argues that researchers are always implicated by the problems they are seeing to address.

[270] Anzul, et al., *On Writing*, 354.

[271] Anzul, et al., *On Writing*, 354.

[272] Anzul, et al., *On Writing*, 65.

[273] Paulsell, 24.

[274] Anzul, et al., *On Writing*, 61 and Paulsell, 24.

I have described a few of the techniques that theologians have employed to incorporate the voice of the body as a source for theological construction. I have explored how narratives of illness require careful consideration with particular consideration for the body's feelings. I have pointed to some of the challenges to hearing the voice of the body for research and noted how forms of writing and data representation offer a way to alleviate some challenges. I will now turn my attention to my method for integrating various and diverse source materials.

Integrating Diverse Sources: Method and Politics

I have often considered research to be like a photo mosaic—an image cast by many smaller images of similar and related variety. The composite image is distinguishable and recognizable but remains pixilated. I am proposing that we hold together (with fairly equal weight and importance[275]) various source materials like the feelings/sensations of the body (somatic sensations); the lived experiences of my co-researcher; feminist, liberation and neo-orthodox theologies; clinical research; and the co-researcher's interpretation of culture and context. I take these compiled sources to see how they build upon each other, contradict each other, or overlap with each other. The result of this layering and blending is a composite picture, but the picture remains a bit pixilated. Such is the nature of investigating messy, fluid, embodied lives; the meaning is never crystal clear and always pixilated.

Combining Source Material

Pastoral theologians and qualitative researchers, alike, describe the compilation of sources as moving in a spiral form. This spiral form details how the "researcher engages in the

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[275] In the following section, I will explore the politics of source materials.

process of moving in analytic circles rather than using a fixed linear approach."[276] Pastoral theologian Christie Neuger describes this method:

> [It] begins in particular and cultural experience and then uses that experience both to critique and utilize the traditions and theories of pastoral theology. Those traditions and theories include insights from Scriptures, church traditions and doctrines, the social sciences, and clinical theories"[277]

The spiral draws multiple, related materials into one picture. When we look closely, there is some overlap and some discrepancy between the source materials but they hold together to reveal an image that portrays amended theologies and practices of care.

In qualitative inquiry, the method of blending and integrating multiple source materials is known as a *bricolage*. A *bricolage* is a quilting-together or a collage. It is a "pieced-together set of representations that are fitted to the specifics of a complex situation;"[278] much like the photo mosaic I described at the outset of this section. I appreciate the way qualitative inquiry uses the term *bricolage* because it fundamentally assumes that understanding complex lives and varied experiences demands a complex mosaic or quilting-together of theories. The *bricoleur*[279] has the potential to value data from an interview with the same importance as data from a peer reviewed journal—or a sacred text.

Critics of *bricolage* argue that this blending of data and interpretation lacks regimented purity. In a way, there is validity to such a claim. I, however, agree with Thomas Schwandt, who argues that the "practice [of the *bricoleur*] itself is relational and processual (a network of

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[276] John W. Creswell, *Qualitative Research Design: Choosing among Five Approaches*, 3rd ed. (Thousand Oaks, CA: SAGE Publications, 2013), 182.

[277] Christie Cozad Neuger, "Power and Difference in Pastoral Theology," in *Pastoral Care and Counseling: Redefining the Paradigms*, ed. Nancy Ramsay (Nashville, TN: Abingdon Press, 2004), 71.

[278] Norman K. Denzin and Yvonna S. Lincoln, "Introduction: The Discipline and Practice of Qualitative Research," in *The SAGE Handbook of Qualitative Research*, 4th ed., ed. Norman K. Denzin and Yvonna S. Lincoln (Thousand Oaks, CA: SAGE Publications, 2011), 4.

[279] "Bricoleur" is the term used for those who use *bricolage* as a method.

interlocking discourses) rather than fixed and formal."[280] I do not presuppose that the challenges and joys of complicated life can be interpreted, analyzed or represented in formal, structured categories. I will assume that blending source material will be a bit informal, dissonant, yet related.

There are added political and hermeneutical challenges when holding various source materials together in a theological project. I want to explore a few of these challenges and the ways some pastoral theologians have negotiated these challenges. One question at hand involves the role of revelation in research. John Swinton and Harriet Mowat suggest that one of the challenges between correlating qualitative inquiry and theology involves resolving questions pertaining to the prominence and influence of revelation.

While Mowat and Swinton highlight the capacity of qualitative research to revise, reframe, and construct theological propositions, interpretations, and Christian traditions,[281] they ultimately conclude that theological revision is a precarious and even dangerous endeavor. I ultimately disagree with Swinton and Mowat. Valuing lived experience—and the power these experiences offer in revising theology and Christian tradition—is the hallmark of a living and breathing faith. Ultimately, I conclude that all theology is subject to interpretation and revision based on the lived experiences of its practitioners.

Swinton and Mowat identify themselves from the field of practical theology and they embrace David Tracy's revised (or "mutual") critical correlation as a helpful method of inquiry.[282] They argue that qualitative researchers often avoid making truth claims, suggesting

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[280] Schwandt, 26.

[281] Harriet Mowat and John Swinton, *Practical Theology and Qualitative Research* (London: SCM Press, 2006), 82.

[282] Mowat and Swinton, 77-80.

that truth always remains subjective in qualitative research.[283] Additionally, Swinton and Mowat retain the argument that theologians arrive at truth, in part, through Divine revelation. They argue that God's revelation holds primacy above other source materials, including lived experience.[284] While retaining such an elevated place for revelation may carry weight for some theologians, this is not the case for me.

Revising, amending, and constructing new theology is life giving and pertinent. Not only does it reflect the fluid nature of lived experience, it also reflects a fluid nature of God and God's work in the world. Wendy Farley asks, to whom is theology accountable? Farley notes that it is not enough for theology to be accountable to the Church and/or Church doctrines. Theology must stay accountable to the people in this world, and to marginalized bodies in particular.[285] "Theology that holds itself accountable to institutions rather than persons too often reinforces behaviors that support institutional—patriarchal, racist, homophobic—power."[286] Like Farley, I conclude that theology is beholden and accountable to the people of the world, with specific attention to those who do not readily find themselves in "traditional" theological spaces or "normal" bodies.

Farley echoes important sentiments raised by Rebecca Chopp, Ruben Alves, and Peter Berger in their discussion of the politics of theology in method and institution. Chopp argues

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[283] Mowat and Swinton, 73.

[284] Mowat and Swinton, 73. Mowat and Swinton conclude that practical theologians can welcome the contributions of qualitative inquiry in a number of ways but ultimately the qualitative data is placed into conversation with Christian scriptures and traditions to revise our theology and practices of care (pp. 81-2). They argue that this method—of holding qualitative data and theological sources at equal planes—can result in renewed and new understandings of traditions, Scriptures and theological interpretations (p.82). Though Mowat and Swinton clearly and concisely outline a method for revised critical correlation, they ultimately argue that theologians should engage in a "critical faithfulness." A methodology that allows theology to be open to change and revision but ultimately retains a primacy for the role and place of revelation (pp. 93-4).

[285] Wendy Farley, *Gathering Those Driven Away: A Theology of Incarnation* (Louisville, KY: Westminster John Knox Press, 2011), 9.

[286] Wendy Farley, *Gathering Those Driven Away*, 9.

that our theological endeavor should result in "new theological substance to a new theological method that speaks to a new experience and role of Christianity in history."[287] Furthermore, Chopp contends that the application of a revised critical correlation rests on the underlying assumption that there is one common human experience and one common religious experience.[288] Which sources have power and voice within a research project? Chopp, in her critique of the revised critical correlation method, suggests that our appropriation of experience should give "power to the interpreter" in a way that "privileges emancipation and enlightenment over tradition."[289]

Rebecca Chopp argues that the "practical crises of the victims of history"[290] should propel us toward a recalibrated scrutiny of the ideological and theological foundation of our source materials and traditions. Liberation theology, Chopp suggests, is not concerned about "cognitive claims" but instead "needs a method that can critique and transform situations."[291] Chopp should be read in conjunction with the aforementioned sentiment from Farley and the assertions made by Rubem Alves.

Alves raises the question about the function of theology within particular institutions.[292] Alves argues that if we fail to pay attention to context and its usefulness in solving institutional problems, then theology becomes a self-serving ideology that often reinforces institutional norms.[293] Similar claims could be made about reinforcing social norms about the body. Too

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[287] Rebecca Chopp, "Practical Theology and Liberation," in *Formation and Reflection: The Promise of Practice Theology*, ed. Lewis S. Mudge and James N. Poling (Philadelphia, PA: Fortress Press, 1987), 125-6.

[288] Chopp, 130.

[289] Chopp, 131-2.

[290] Chopp, 131.

[291] Chopp, 131.

[292] Rubem Alves, "Personal Wholeness and Political Creativity: The Theology of Liberation and Pastoral Care," in *Pastoral Psychology* 26, no. 2 (1977): 127.

[293] Alves, 125-27.

often our theological constructs become reflections of human oppressions when we do not question who is benefiting from the theological argument.

Peter Berger, in studying sociology of religion, warns that religion (including Christianity and Christian faith) is subject to its social context and thus should be analyzed as a subjective human projection maintained and made manifest by specific institutions and structures.[294] Since religion is contextually and historically specific, Berger concludes that empirical theology is impossible. All theology becomes autobiographical or situational in nature.[295]

The political and hermeneutical challenges of evaluating the role and place of tradition, revelation, or primacy of sacred texts in theological research cannot be overstated. Other projects have taken up this debate exclusively and extensively. I conclude with this point: my methodological commitment will hold all sources, to the best of my ability, as equally revealing. I believe that the body and lived expertise generate epistemological positions with the same fervor as revelation, theory, and faith tradition. Equally, I believe that the body and lived experience have the power to refashion our theology and our social theory.

The Body and Lived Experience as Source Material

Diminishing lived experience and bodily wisdom results in a dangerous dismantling of their revelatory authority. Knowledge gained from our bodies (the physical, social construction, and social perceptions that form the body) and lived experiences are source texts. They stand shoulder-to-shoulder with theological discourses, clinical texts, and faith traditions. They hold full reciprocity of our constructed realities. Furthermore, our embodied wisdom shapes our understanding of God just as much as our understanding of God should shape our

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[294] Peter L. Berger, “Appendix II,” in *The Sacred Canopy Elements of a Sociological Theory of Religion* (New York, NY: Anchor Books, 1967), 184.

[295] Berger, 184-5.

embodied perception. They have the power to hone new ways of being, practicing, and thinking. I also reiterate that this theology takes on autobiographical, autoethnographic, and self-revealing characteristics.

Sources, like the body and lived experience from co-researchers, will be in conversation with theories garnered from peer reviewed literature from liberation, neo-orthodox, and feminist theologies; context-specific sources; social sciences (anthropology and sociology) and other clinical materials (nursing and medical ethics). These sources will be integrated in a spiral fashion to help form a photo-mosaic that serves as a pixilated portrait of constructed theological concepts and revised practices of care. I have discussed the manner in which I believe source materials come together in a research project; I also need to discuss the method for doing the work of research—a "way in" to the lived experience of parents caring for children who live with a gastrointestinal ostomy. For this, I will be using two methods in tandem.

Using Methods in Tandem

No method is complete. This project is informed by two methods that work in tandem. I will use an intersectional method and a narrative method to help me critique lived experience. Each of these methods offers a mode, or approach, of inquiry that enables me to probe my research questions. I want to explore these two approaches and demonstrate how they enable me to unpack and critically engage the experiences and narratives from my co-researchers.

An Intersectional Approach: Evaluating Power Relationships

It is widely accepted that "Intersectionality" was coined by Kimberlé Crenshaw as a way of demonstrating that poor, black, women faced multiple and intersecting oppressions.[296] Without question, this method originated in African American Feminist contexts but now has

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[296] Kimberlé Crenshaw, "Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color," in *Stanford Law Review,* 43 no. 6, (July 1991): 1241-1299. http://www.jstor.org/stable/1229039.

had far-reaching use. Crenshaw suggests that we could not isolate, even for the sake of argument or evaluation, any single oppression because each aspect of oppression overlaps with, informs, and/or build upon the others. Theory, Crenshaw argues, must simultaneously address multiple forms of oppression.

While Crenshaw is credited with raising the issues of intersectionality into academic discourse, there is an overarching recognition that intersectionality was an approach used by many on a more "grass-roots" level when evaluating multiple power structures.[297] In her seminal work, *Black Feminist Thought*, Patricia Hill Collins briefly details three methods for intersectional research. Hill Collin proposes that we can evaluate a system of oppression as 1) a "freestanding" system;[298] 2) as a place in which one system of oppression is "manipulated within" another system of oppression;[299] or 3) as a site where one system of oppression reaffirms and "upholds multiple oppressions."[300] As I define and critique "normal bodies" for this project will use the first approach by Hill Collins: "normal" is evaluated as a freestanding system of oppression. Collins continues this exploration of intersectional method in a co-authored book with Sirma Bilge, *Intersectionality*. Bilge and Hill Collins define "intersectionality" and detail its usefulness as a method for analysis and praxis.

Hill Collins and Bilge note that intersectionality is particularly useful as a heuristic device to understand and solve complex problems embedded in interlocking systems of social

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[297] Bilge and Hill Collins, 64.

[298] For example, oppression related to "normal" bodies is evaluated as a freestanding system of oppression that relates to other systems of oppression like sexism, racism, ageism, etc. This method "foregrounds" illness as a unique system of oppression while also acknowledging that illness is one, among other, forms of oppression that have an impact on lived experience.

[299] For example, one could evaluate how sexism "manipulates" the criteria and standards for what is considered a "normal" body when the criteria or standard of "normal" is based on cis-male bodies; thus rendering all other bodies "not-normal."

[300] For example, oppression related to "illness" might reaffirm sexism if people experiencing disease are labeled as weak. Patricia Hill Collins, *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*, 2nd edition (New York, NY: Routledge, 2000), 127-8.

oppression.[301] They identify four domains of power that must be evaluated in an intersectional approach: interpersonal,[302] disciplinary,[303] cultural,[304] structural.[305] A dual emphasis on analysis and praxis is a key and instrumental component of intersectionality as a method and methodology. The intended and resulting outcome of an intersectional approach is to solve problems, change practices, and/or hold a system or institution to account for social injustice and oppression. Hill Collins and Bilge point out that intersectionality's focus on analysis and praxis enables a "creative sensibility between knowing and doing."[306] This creative tension between theory and praxis coincides with the pastoral theological method.

Engaging in research within complex systems demands an approach that will critically engage multiple intersecting oppressions and power relations. Pastoral theologian Nancy Ramsay argues that intersectional theory offers us insight into complex interpersonal and systemic relationships that can unveil privilege and guide us to liberative theologies, theories, and approaches to care.[307] Ramsay says, "Intersectionality is a model that effectively addresses complex individual, relational, structural, and ideological aspects of domination and privilege arising from forms of difference treated oppressively."[308] Her work reminds me that theological constructs that only pay attention to simple systems of oppression are incomplete.

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[301] Bilge and Hill Collins, 4.

[302] Interpersonal: evaluates "how people relate to one another, and who is advantaged or disadvantaged within social interactions" (p. 7). Bilge and Hill Collins, 7-8.

[303] Disciplinary: evaluates how "power operates by disciplining people in ways that put people's lives on paths that make some options seem viable and others out of reach" (p. 9). Bilge and Hill Collins, 9-10.

[304] Cultural: evaluates how "power helps manufacture messages that playing fields are level, that all competitions are fair, and that nay resulting patterns of winners and losers have been fairly accomplished" (p. 11). Bilge and Hill Collins, 10-11.

[305] Structural: evaluates the structure of an institution or organization, questioning how intersecting power relations of class, gender, race," etc. shape an organization (p. 12). Bilge and Hill Collins, 11-12.

[306] Bilge and Hill Collins, 191.

[307] Nancy J. Ramsay, "Intersectionality: A Model for Addressing the Complexity of Oppression and Privilege," *Pastoral Psychology* 63 (2014): 453-69.

[308] Ramsay," Intersectionality," 455.

Intersectionality is a method and means by which I can garner a more objective view of power structures that undergird the theological and social discourses that maintain narratives and classifications of a “normal” body. Approaching this project with an intersectional commitment will help me evaluate and highlight the assumption that oppression and privilege,[309] visibility and invisibility[310] operate within multiple, complex, and fluid power structures.

When we consider oppression and privilege as a fluid system, we can see how we are all “complicit” and implicated in each other’s experience of oppression.[311] As an example: I, with healthy-body privilege, have both the power to resist normalcy discourses in society that oppress persons living with ostomies while also having the responsibility to consider the ways in which I am implicated in the work of oppression through the maintenance of those normalcy discourses and dominant narratives. An intersectional approach will enable me to better evaluate the social and theological ideologies[312] that perpetuate normalcy discourses that lead to oppression.

Intersectionality offers a mode for evaluating the power dynamics that enable and resist oppressive normalcy discourses that lead to the abjection of embodied individuals. In addition, I need a method that will enable me to better critique the illness narratives and stories of lived expertise that I collected from co-researchers. A narrative approach is a helpful method for this aspect of this research. “Narrative inquiry” has come to denote a plethora of methods and ideas. It is important to delineate how I will be using narrative for this project.

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[309] Ramsay, “Intersectionality,” 463.

[310] Jeannine A. Gailey, *The Hyper(in)visible Fat Woman: Weight and Gender Discourse in Contemporary Society* (New York, NY: Palgrave MacMillan, 2014), 12-19.

[311] Ramsay, “Intersectionality,” 464.

[312] Wendy Farley notes that theology must stay accountable to the people in this world, marginalized bodies in particular. “Theology that holds itself accountable to institutions rather than persons too often reinforces behaviors that support institutional—patriarchal, racist, homophobic—power.” Wendy Farley, *Gathering Those Driven Away*, 9.

Narrative Qualitative Inquiry: Collaboration for a Constructed and Embodied Story

This project will weave together the voices of three storytellers: literature (theological, social science, and clinical), the reports of my co-researchers (the parents and primary caregivers among whom I do research), and the revisions to the story as I share findings and interpretations with my co-researchers during the second interview. I will structure the explanation of this narrative method as a dialogue between qualitative inquiry and theologians who adopt, design, and construct narrative approaches. This interdisciplinary dialogue is in-step with a pastoral theological method, but it will also display and reinforce the way a narrative method enables me to approach and probe the research questions of this project.

Narrative inquiry facilitates this project in three specific ways. First, a narrative approach will help me uncover theological contributions and reflections of co-researchers, especially the implicit theological concepts embedded in the daily lived experiences of parents as they care for their children. This evaluation is pertinent as I explore the role of "anxiety" in the fourth and fifth chapters. Secondly, a narrative approach is helpful when evaluating my own sense of anxiety about bodily difference. Finally, when we evaluate a sociological/medical ethics perspective of illness stories we can see how a pastoral theological perspective bolsters the moral imperatives outlined by the sociological/medical ethics contributions.

Qualitative researchers who approach a study from narrative method are trying to learn something from the story. They want to learn about the circumstances, context, or identity of the people constructing the story or the audience hearing the story. The intent of a narrative study is not to retrieve and retell a story; that is the work of autobiographers. Researchers are looking at the details of a narrative. They might be looking at plot, speaker, content, context or audience, to name a few perspectives. A narrative may also be "the *phenomenon* [sic] being studied, such as a narrative of illness."[313] A narrative study probes a story, recognizing that we can ascertain knowledge by un-packing and examining different aspects of the story or the lives communicated through said story.[314] The narrative relationships that are important for this project are: 1) co-researcher in relationship or dialogue with context and condition; 2) the collaborative and constructive relationship between researcher and co-researcher; and 3) the relationship of bodies to illness—an illness narrative.

I am using narrative inquiry as a method to ascertain lived knowledge to access power relationships within the plot. In her work with Latin@ women, Carmen Nanko-Fernandez identifies specialized knowledges emerging out of "la vida cotidiana," or common, everyday life. Nanko-Fernandez's approach assumes that theological knowledge is embedded in the *la vida cotidiana* of those whose expertise we seek.[315] The specialized narratives, stories, and experiences of co-researchers can point out impediments to already-established theologies and social discourses about what it means to live with a "non-normal" body. Similarly, listening to the stories of daily life, as parents care for their children, should uncover broader theological concepts that might otherwise go unnoticed. The objective of narrating *la vida cotidiana* is to offer theological juxtapositions that "interrupt the norm and offer opportunities to entertain new ways of theologizing."[316] Thus, narrating *la vida cotidiana* is not simply telling a detailed life story of co-researchers. This form of narration extracts the embedded, implicit theological

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[313] Creswell, 70.

[314] Creswell, 70.

[315] Carmen Nanko-Fernandez, *Theologizing en Espanglish* (Maryknoll, NY: Orbis Books, 2010), xviii.

[316] Nanko-Fernandez, xx. Nanko-Fernandez points out that often times the stories of "la lucha" (the fight or struggle) are underappreciated and an optimistic theology permeates the theological landscape. This optimism is deceiving and can inaccurately shade our theological constructs and dispels the ambiguous and messy nature of actual daily life (p. 26).

constructs that materialize as parents care for their children—those stories which might otherwise be overlooked.[317]

It is important to note that the method and methodology of narrating *la vida cotidiana* comes from *Mujerista* theologians who assume that Latina women's reflection on their daily lives and struggle to survive is a genesis for theological construction.[318] *Lo cotidiana* is an intersectional, hermeneutical, and epistemological position and is therefore a profoundly subjective reflection on the "stuff" that makes up a "shared experience."[319] This profound subjectivity is a way of extoling difference while also resisting claims for individuality that often render us more isolated.[320]

Lo cotidiana does not simply add another layer of diversity to feminist theology, its methodological commitments "points to the need to change the social order by taking into consideration the way Latinas see and understand reality."[321] The core of *lo cotidiana* is the incorporation of the lived experiences from a Latina worldview: that which is good and ethical, as well as that which maintains systems of oppression, all with the objective of liberation.[322] While the methodological implications of a profoundly subjective epistemology and hermeneutic of telling the daily lived expertise of a group is important to this project, I recognize a few profound limitations of using a methodology situated in *lo cotidiana*. I proceed with trepidation and awareness that I cannot usurp a methodology particularly tied to a cultural *lucha*[323] for identity and survival. It is my objective to incorporate the lessons from this methodology to

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[317] Elaine Graham, Heather Walton, and Frances Ward, *Theological Reflection: Methods* (London: SCM Press, 2005) 140 and 200-2.

[318] Ada María Isasi-Díaz, *Mujerista Theology* (Maryknoll, NY: Orbis Books, 1996), 66.

[319] Isasi-Díaz, 67.

[320] Isasi-Díaz, 70.

[321] Isasi-Díaz, 69.

[322] Liberation is the criteria by which Mujerista theologians judge what is right and what is wrong. Isasi-Díaz, 69.

[323] "Fight"

guide the intent and sentiment of my research task while also recognizing that there are some parallels between *la lucha* and the struggle of those rendered abject by normalcy discourses.

I will assume that particular knowledge and lived expertise is generated from embodied experiences that emerge from the "stuff" that makes up common, everyday life when caring for a child with an ostomy. My co-researchers embody the daily practice of caring for children who have a gastrointestinal ostomy and caring for bodily differences generates unique sets of knowledge. My co-researchers offer a unique perspective about the body and the body in context. Oftentimes these experiences are so routine, a "knowing in the doing," that they are "not yet discursively appropriated."[324] It is my objective to listen for the "common" and "routine" sources of knowledge that parents bring, simply because of the tasks and labor that comes part and parcel to the close, every-day interaction with the body of their child.[325]

Elaine Graham, Heather Walton, and Frances Ward note that theological reflection emerges in specific contexts. Theological knowledge assumes the local, contextual, or "vernacular" characteristics of a particular public space or situation. This local knowledge emerges as we pay attention to the every-day life of persons in context. They also argue that these theological reflections should, "account for itself in relation to… new discourses and it is recognized that they might even exercise a corrective and renewing effect upon the Christian tradition." Thus, an objective of interacting with the daily lived experience of my co-researchers should result in a robust critique of and an amendment to our theological constructs.

A narrative approach helps analyze my own embodied experience while doing this research. Mindfulness of my own embodiment led me to this project in the first place. Why did

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[324] Holland and Ramazanoğlu, 73.

[325] This is reminiscent of "Local Theologies" as discussed by Graham, Walton and Ward. They say, "[T]his method of theological reflection requires that particular attention be given to the local traditions, material and symbolic practices that make up the 'way of life' of a people." Graham, et. al., 202.

(do) I experience such hesitance when I don my personal protection attire? Why do I have an elevated sense of awareness when I accompany a family who is facing changes in the appearance and function of their child's body? Images, feelings, sounds, and smells all impact the way I practice pastoral care in a healthcare institution. Pastoral theologians have been incorporating embodiment narratives into theology for several decades as they reflect on embodied lives, in context.

It is important to be clear about one assumption that guides this project. I hold a strong conviction that my embodied perspective leaves a valid, yet measurable, mark on this project. That is, in part, the argument that standpoint theorists take up.[326] My own embodiment, as a researcher, will impact the outcomes of this study. For that reason, it was important to reflect upon my own embodied experiences during the research process. Brett Smith and Andrew Sparkes argue that, "[I]n making sense of our experience, we not only tell stories about our bodies, we also tell stories out of and through our bodies. Here, the body is simultaneously cause, topic, and instrument of whatever story is told."[327] Smith and Sparkes suggest that while we listen for the body and illness narratives of others, we must also pay attention to our own body narrative and embodied reactions.[328]

My embodied perspectives frame the ways in which I interpret and report data. This approach assumes that my involvement is not a liability. Instead, it is an asset. Pastoral theologian Douglas Purnell reflects on the importance of embodied knowing saying, "How could

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[326] This articulation makes clear that feminist standpoint methodology encompasses five characteristics: 1) the relationship between power and knowledge must be explored; 2) the "knower" is constructed from a particular and specific social location—the researcher is always contextual and the power dynamics between researcher and researched should be made visible; 3) standpoint is rooted in lived experience that takes "emotion and embodiment" seriously; 4) pays attention to variance in experience and how power impacts experience and relationship; and 5) the knowledge generated from this position is considered "partial knowledge." Holland and Ramazanoğlu, 64-66.

[327] Smith and Sparkes, 55.

[328] This method tuned my attention to the role of anxiety when confronted by bodily and social vulnerabilities.

I, as pastor, be present to the body of the other when I was so anxious in my own body?"[329] Since I will be studying the ways in which bodies narrate knowledge, it is important to acknowledge my own body narratives and apprehension around bodies that look or function differently.

This narrative will take on an "autobiographical" method. An autobiographical method has been used by several theologians. Lisa Isherwood and Marcella Althaus-Reid suggest that an autobiographical position can both engage and disclose "experiences which traditionally have been silenced in theology."[330] The specifics of how to incorporate my own embodied knowing into this project have been informed by Smith and Sparkes who propose "auto ethnographic"[331] turns. They suggest that we can do this by paying attention to our own bodily reactions to the material, circumstances, and interviewees.[332] Journaling, drawing, and memoing should be used to incorporate embodied knowing into our research.[333]

Wounded bodies tell their own stories. Arthur Frank argues that illness invites new and different stories; ones not just "*about* [sic] illness" but stories "told *through* [sic] a wounded body."[334] Clearly, my project deviates from Frank's specific trajectory in that I will not be researching among persons who are *personally* experiencing illness. His work is informative, however, because we cannot isolate and evaluate illness within an individual. Illness is

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[329] Douglas Purnell, "Pastoral Ministry and the Fleshly Body," in *Pastoral Psychology* 53, no. 1 (Spring 2004): 82.

[330] Althaus-Reid and Isherwood, 6. Autobiographical-type reflections about embodied feelings have also been a helpful research tools for Melanie May as she evaluates death in *A Body Knows*; Marcia Mount Shoop who explores feeling as she constructs knowledge rooted in rape, pregnancy, and motherhood in *Let the Bones Dance*; and Wendy Farley who uses her experience with migraines as a guide to examine suffering and wounding in *The Wounding and Healing of Desire*.

[331] Thomas Schwandt details the aim of auto ethnographic research as a method to "keep both subject (knower) and object (that which is being examined) in simultaneous view." Schwandt, 16.

[332] Smith and Sparkes, 61-2.

[333] Smith and Sparkes, 62-3.

[334] Frank, *The Wounded Storyteller*, 2.

profoundly relational. Illness affects all aspects of a person's life: how she interprets her own body and her relationship with friends, family, and God. Thus, illness shades the way we interpret our context. Illness is also a reminder that when we are sick, we are often "under" the care of a medical team that has some control or impact on our bodies and our lives.[335]

Frank concludes that the moral imperative of telling the "wounded story" is, in part, its own conclusion—the production, sharing, and hearing of the narrative. Frank notices that stories shape human identity and understanding [336] but empathy is the concluding result of Frank's narrative engagement.[337] In multiple volumes, Frank argues that society has a moral imperative to *hear* what ill persons say.[338] He contends that illness creates specialized knowledge that should be shared. He even argues that we have a great deal to learn from this specialized knowledge. Listening to illness stories should lead to "living in communion"[339] with persons who suffer. That is Frank's moral imperative—to hear stories of illness and live in communion with those who suffer.

Frank stops short, however, from calling us to question, resist, and revise the structures that maintain the discourses of normalcy in the first place. To be clear, Frank assumes that changed praxis should emanate from narrative engagement but that is an operative assumption and he does not critically consider the costs and strategies of changing praxis.[340] Engaging illness narratives, through the lens of caregivers and autoethnographically as a researcher (once and twice removed from illness), will provide necessary critical distance. This will help me illustrate ways in which bodies and discourses are co-constructed. Our moral obligation is not

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[335] Arthur Frank, *At the Will of the Body: Reflections on Illness* (New York, NY: Houghton Mifflin Company, 1991), 12-3, 36-7, 71, 91-107, and 114.

[336] Frank, *The Wounded Storyteller*, 25 and 158.

[337] I Frank, *The Wounded Storyteller*, 158.

[338] Frank, *At the Will of the Body*, 123 and Frank, *The Wounded Storyteller*, 156.

[339] Frank, *The Wounded Storyteller*, 144.

[340] Frank, *The Wounded Storyteller*, 158.

concluded simply by hearing and disseminating illness stories, stories about the experience of abjection, or engaging in meaningful and mutual relationship with a wider array of people. Our moral obligation should move us another step further. Inclusive, mutual, and compassionate relationships should move us toward public, theological, and political change.[341]

There are limitations to every method and narrative methods are no different. The shifting and tentative nature of a narrative and its meaning is one of the challenges to generalizing meanings within narrative research. Ruard Ganzevoort, in an edited volume on practical theology, points out that when we engage a person's story we cannot assume to know or come to understand what the story tells us about the speaker. We should acknowledge that the audience plays a vital role in the interpretation of a narrative.[342] The story is an invitation to think critically about what the speaker wants her or his relationship to be with the audience, with the world, and with God.[343] Ganzevoort is suggesting that the story is an invitation for deeper reflection about the relationships within our circumstances.

Ganzevoort goes on to point out that there are two approaches to narrative analysis. We can approach a story as if it were a window into the "historical truth" of the storyteller.[344] This approach to narrative analysis suggests that the intent is to arrive at an essential truth about the story or the narrator. We can also approach a narrative as "time-, place-, and relation-specific."[345] The second approach helps uncover the way people construct meaning.[346] It also

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[341] Joretta Marshall articulates a "public theology" as one in which "academics and pastoral leaders… engage the culture in ways that bring our collective religious voices to the broader concerns of the world." Marshall, 148. Similarly, Rebecca Chopp notes that theology, particularly liberation theology, is inherently political as it "shows new ways of being in the world, new relations of power, interests, knowledge, and so on." Chopp, 135.

[342] Ganzevoort, 216.

[343] Ganzevoort, 217.

[344] Ganzevoort, 220.

[345] Ganzevoort, 220.

[346] Ganzevoort, 220.

recognizes that the truth of a narrative is ever-changing and ever-shifting. The meaning (and even the narrative itself) changes. I embrace this second approach.

These two parallel research methods, intersectionality and narrative inquiry, enable me to consider the impact of complex social and theological contexts of embodied life, consider my own embodied contribution to the research, as well as evaluate the ways in which bodies are co-constructed through social and theological realities. Using these approaches, I can critique the narratives that shape our understanding of abjection and normalcy discourses to help amend illness narratives that reiterate oppressive discourses. The work of Nanko-Fernandez and Graham, Walton, and Ward and Ganzevoort demonstrate our capacity (and the necessity) to learn from and be changed by the lived experience of those with whom we research. Intersectional and Feminist theory demonstrate the necessity to pay attention to the power relationships and dynamics embedded within a narrative and context. Frank shows us that illness narratives provide moral "opportunities" and obligations to critique, question, and ultimately amend our theological and pastoral praxis.

How, then, do we "capture" or articulate theological constructs that are representative of those with whom we engage in research? I am using narrative methods. And how do we also critique the social discourses that comprise their experience? I am assisted by intersectional methods and theory. I believe, however, that the principles used by qualitative researchers to develop trustworthy studies (particularly ensuring "credibility" and "confirmability") could further enable me to incorporate lived experience as a source of understanding while also compelling us to scrutinize the discursive vehicles that maintain oppressing theologies and ideologies. I will now turn my attention to defining and detailing components of conducting a trustworthy study.

Trustworthiness: An Alternative to Validity

One of the challenges and critiques of a qualitative method is how and when researchers can generalize meaning to make a truth claim. Howard Becker pointed out that the people we interview do not give consistent meanings and meanings themselves change.[347] Becker argues that we must first understand the power dynamics of the research process. He suggests that those who are being researched (co-researchers) often do care about the opinion of the researcher and sometimes even anticipate being judged or critiqued.[348] We have to admit that, as researchers, we are always interpreting data and our interpretations can never be exact. Therefore, the research process should be collaborative. The researcher and those she is researching are co-constructing new meaning.[349] But I, as the researcher, do a disservice to those I research if I do not pay attention to the ways in which my oversight and construction of the final report creates and maintains a power differential in the research process.

The criteria of "trustworthiness" should be clearly distinguished from the principles that aim for "accuracy" and/or "validity." The difference between a "valid" and a "trustworthy" study has less to do with semantics and more to do with methodological commitments.[350] Producing a trustworthy study requires that "the processes of the research are carried out fairly, that the product represents as closely as possible the experiences of the people who are studied."[351] A trustworthy study not only hopes to honestly capture the lived experience

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[347] Howard Becker, "Epistemology of Qualitative Research," in *Ethnography and Human Development: Context and Meaning in Social Inquiry*, ed. Anne Colby, Richard Jesser, and Richard A. Shweder (Chicago, IL: University of Chicago Press, 1996), 59.

[348] Becker, 62.

[349] Ganzevoort, 220.

[350] Margaret Anzul, Margot Ely, Teri Friedman, Diane Garner, and Ann McCormack Steinmetz, *Doing Qualitative Research: Circles within Circles* (New York, NY: Routledge Falmer, 1991), 94-5.

[351] Anzul, et al., *Doing Qualitative Research*, 93.

of the co-researchers; it seeks to demonstrate trustworthiness by critically checking findings with co-researchers to result in an *actionable* study.

Arguably, qualitative projects have a method to establish validity using triangulation,[352] data saturation,[353] and other means to suggest accuracy, validity, or credibility. While I do not adhere to the assumption that validity or accuracy are ever fully achievable, I know that there are some researchers who believe that objectivity (at varying degrees) is both ascertainable and essential for a valid report. While I believe that some objectivity is achievable, I believe that we can never fully separate ourselves from our interpretations or our analysis. This view is shared by Howard Becker.[354] Becker suggests that all researchers "implicitly or explicitly, attribute a point of view and interpretation to the people whose actions we analyze… so the only question is not whether we should, but how accurately we do it."[355] It is imperative, therefore, that I represent the information and stories gathered from co-researchers in a responsible manner. This criteria for trustworthiness are particularly useful at this point

Generally, qualitative researchers suggest four practices to ensure a trustworthy study. These practices are derived from the work of Yvonna Lincoln and Egon Guba in

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[352] I am not suggesting that triangulation is an inconsequential tactic for qualitative analysis. Triangulations is thought of as, "a means of checking the integrity of the inferences one draws. It can involve the use of multiple data sources, multiple investigators, multiple theoretical perspectives and/or multiple methods." (Schwandt, 298.) Triangulation is reminiscent, in some aspects, to the method of critical correlation used by Paul Tillich. Triangulation holds a significant role in qualitative inquiry and can be a helpful and powerful tool. The assumption when using triangulation is that "data from different sources or methods must necessarily converge on or be aggregated to reveal the truth." (Schwandt, 298.) I stop short, however, in asserting that my research is intended to be "valid" as opposed to my preferred methodological commitment of "trustworthy."

[353] The term "data saturation" comes from grounded theory (Glesne). Data saturation implies that theoretical categories are "robust because you have found no new properties of these categories and your established properties account for patterns in your data" or "'nothing new happening' in the data categories" (Charmaz). I stopped collecting data when I saw repeated themes in co-researcher's narratives. Based on these categories I developed the codes: anxiety/fear, hope, fear and hope, "normal" body, "lots of work," illness narratives (not already identified by Arthur Frank), love/care for child, and body shaped by context. Kathy Charmaz, *Constructing Grounded Theory*, 2nd ed. (Thousand Oaks, CA: SAGE Publications, 2014), 213. And Corrine Glesne, *Becoming Qualitative Researchers: An Introduction*, 3rd ed. (Boston, MA: Pearson Education, Inc., 1992, 1999, 2006), 12.

[354] Becker, 56.

[355] Becker, 58.

Naturalistic Inquiry. Aspects or practices of trustworthiness are credibility, transferability, dependability, and confirmability.[356] I will define each of these practices and describe means and methods by which I will incorporate them into my study. Before I begin: it is important to note that trustworthiness is built on the assumption that each of these four characteristics function in unison.

Credibility "addresses the inquirer providing assurances of the fit between respondents' views of their lifeways and the inquirer's reconstruction and representation of same."[357] A study is credible when the researcher does her or his best to recreate and authentically represent the lived experience of the co-researcher. This characteristic is akin to the work of a good biographer or a researcher who provides a "thick description"[358] of those she is researching. But biography and thick descriptions do not wholly suffice, especially since trustworthy studies and pastoral theology are both constructive endeavors—they are actionable. To enhance the credibility of this study I included direct quotes from the interviews and written protocols gathered with co-researchers.

Transferability refers to how the researcher deals with generalizations made about the co-researchers and data. The researcher should provide "readers with sufficient information on the case studies such that readers could establish the degree of similarity between the cases studied and the case to which findings might be transferred."[359] Thus, transferability is a type or form of generalization. Generalizability is a concept nearly usurped by quantitative researchers and has even influenced the way the term "research," itself is defined.[360] Differentiating between

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[356] Anzul, et al, *Doing Qualitative Research*, 94-95 and Schwandt, 299.

[357] Schwandt, 299.

[358] Clifford Geertz, "Thick Descriptions: Toward an Interpretive Theory of Culture," in *The Interpretation of Cultures*, ed. Clifford Geetrz (New York, NY: Basic Books, 1973/1977), 3-32.

[359] Schwandt, 299.

[360] The CITI research training program that Cook Children's requires all researchers to fulfill, annually, defines research as: "a systematic investigation including research development, testing and evaluation, designed to

transferability and generalizability is particularly important because an “empirical statistical”[361] model for generalization is often assumed in my particular context of research, which is Cook Children’s Medical Center.

Transferability invites the audience into the research project. If the researcher provides sufficient information about the lives investigated, the reader can then decide if the circumstances and learned knowledges presented can be transferred from one context to another. On a basic level, the onus of representing lived experience falls to the researcher. The interpretation, application, and implementation of the research falls to the audience. I, however, believe that researchers can (and should) offer constructive proposals to our audience. The spirit of transferability lies in the recognition that the audience of a research project is a collaborative participant in an ongoing practice.[362]

Confirmability is a process by which the researcher confirms that the “data and interpretations of and inquiry were not merely figments of the inquirer’s imagination.”[363] This will be established with a protocol contingent on follow-up interviews with co-researchers. The sole purpose of the second interview is to check findings and interpretations, a process known as member checking. Member checking is a method to solicit feedback from co-researchers and

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develop or contribute to generalizable knowledge.” The assumption is that research is considered research when it draws generalizable conclusions. Collaborative Institutional Training Initiative, “Defining Research and Human Subjects,” last modified May 1, 2016, https://www.citiprogram.org/members/index.cfm?pageID=665&ce=1.

[361] Thomas Schwandt defines empirical statistical research as gathering a sample, statistically analyzing the sample and “calculating the probability that findings based on the sample are characteristic of the population.” Schwandt goes on to acknowledge that the empirical-statistical model is the “least commonly used approach to generalization in qualitative studies.” Schwandt, 126-7.

[362] As I wrote the project I found that audience collaboration—conversations that colleagues—offered anecdotal accounts of transferability. Most reflected on their own experience (personal or with of loved one) of living with illness.

[363] Schwandt, 299.

serves as “an important procedure for corroborating or verifying findings or of assuring that they are valid and meet the criteria of confirmability.”[364]

Additionally, confirmability, while still being imperfect and incomplete, offers co-researchers the opportunity to hear and respond to the ways I am interpreting and representing their story. It also demands that I show discrepancies and disagreements (to the best of my ability) between my experience and that of my co-researchers. The intent of confirmability is to minimize power differentials between researchers and those researched. I agree with the many pastoral theologians and qualitative researchers who acknowledge that research is never fully equal. Confirmability seeks to mitigate this inequality. Reflexivity,[365] or evaluating power relationships, is always an important part of the research process. I believe that incorporating a second interview, for member checking purposes, helped me understand better some of the findings and make better interpretations of the data addressing, in part, issues of confirmability.[366]

The final criterion for a trustworthy study is its dependability. Dependability “focuses on the process of the inquiry and the inquirer’s responsibility for ensuring that the process was logical, traceable, and documented.”[367] This criterion speaks to the clarity with which I present findings, interviews, and written protocol segments. Dependability also speaks to the ways in which discrepancies between the different forms of literature are presented. I am bringing together four narratives from: 1) literature (theological, social science, and clinical); 2) the reports of my co-researchers (drawn from the first interview and the written protocol); 3)

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[364] Schwandt, 187.

[365] Reflexivity is a way of evaluating the power relationships within the research and writing process (Holland and Ramazanoğlu, 118-19). Reflexivity is a central aspect to pastoral theological methods (Neuger, 66).

[366] There were some research design flaws to this process. Those will be discussed in the following section of this chapter.

[367] Schwandt, 299.

analysis from my embodied experience[368] gathered through memoing;[369] and 4) the revisions to the stories when co-researchers interact with the data during the second interviews, which did uncover discrepancies.[370] A dependable study will trace and document the variations between my interpretations, the literature, and the insights from co-researchers.[371]

Ultimately, however, the test of trustworthiness is in its resulting action through the question, "is the research actionable?" This study is representative of parents who care for children living with GI ostomies. Representation, however, is not the end result of my approach. Qualitative researchers note that a study is trustworthy when it can guide us into new and revised "social policy and legislation"[372] grounded in its findings. Though the philosophical principles that undergird the construction of a trustworthy study are rooted in feminist qualitative inquiry, these commitments coincide with a pastoral theological methodology that aims for liberation of persons and communities, remains open to revisions of our theological constructs and practices of care, and emerges from the lived experience and knowledge of daily life.

The co-researcher's lived experience, along with my interpretations, offer compelling, specialized knowledge that will expand theology, theory, and practice of care. Co-researchers

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[368] Ronald Pelias argues that researchers are always implicated by the problems they are seeking to address. I believe that the way I feel, as the researcher, contributes to my understanding of the project. I have argued, and will continue to argue, that we cannot experience the world apart from our embodied knowing. Therefore, it would be unlikely to put my own embodied knowing "on-hold," so to speak, during the research process. It is irrefutable that conclusions will be informed by my own embodied perceptions. Rather than deny this aspect of the research I assume it to be a helpful tool in this research. Pelias, 662, see also Smith and Sparkes, 54-8 and 64-6.

[369] Memos "capture the thoughts of the inquirer while he or she is engaged in the process of analysis" and can include aspects of field settings or intentions of data code sets. Schwandt, 188-89.

[370] The most notable discrepancy occurred in my interview with Katrina who agreed with me that anxiety played a role in the illness narrative around Isabella and Mia but she vehemently disagreed with me concerning the implications of anxiety. A note about this discrepancy is included in the fifth chapter.

[371] The literature uncovers a discrepancy between Leticia, Allison, and Rebecca and their interpretation about anxiety in the lives of faithful Christians. They argue that they "should not be anxious or afraid" citing their faith tradition as rational. A note about this discrepancy is included in the fifth chapter.

[372] Yvonna S. Lincoln, Susan A. Lynham, and Egon G. Guba, "Paradigmatic Controversies, Contradictions, and Emerging Confluences, Revisited," in *The SAGE Handbook of Qualitative Research,* 4th ed., ed. Norman K. Denzin and Yvonna S. Lincoln (Thousand Oaks, CA: SAGE Publications, 2011), 120.

shed new, distinct, and nuanced light on theological claims—specifically claims about the *imago Dei*—because of the particularity of their contexts and lived experience. The specific methods used by qualitative researchers as they construct trustworthy studies can enhance the ways that pastoral theologians incorporate and "member-check" the contributions of those with lived expertise.

Therefore, the objectives and outcomes of trustworthy studies are different from those of research projects, which aim for validity, certainty, generalizable, or empirical truths. The objective of a trustworthy study is to ethically represent the lives of my co-researchers in such a way that the representations are clear, convincing, and actionable. In the final portion of this chapter on Method, I want to offer a few key aspects and details about this study.

Key Aspects of Study Structure

I interviewed nine parents who care for children living with GI ostomies. The number of co-researchers was decided based on a preliminary survey of similarly constructed narrative studies from a variety of fields. This survey revealed a widely variable number of co-researchers. When constructing this study, I decided on five to ten co-researchers because it is a manageable number while also allowing for some flexibility in the data collection process. I stopped recruiting participants, in part, when I had reached data saturation.[373]

This study was conducted at Cook Children's Medical Center (CCMC) in Fort Worth, Texas. All co-researchers have children who were receiving medical treatment and care from CCMC. This was a stipulation from the CCMC Institutional Review Board (IRB). Co-Researchers gave informed consent in order to participate in the project. All participation was voluntary. I ensured that co-researchers knew that they could withdraw from the study at any

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[373] Charmaz, 213 and Glesne, 12.

time up until the final report was published. Two co-researchers opted to not complete all steps of the research process.

I recruited co-researchers through a series of social networks at CCMC using a snowball, chain, or network method with the help of the staff at the Cook Children's Gastrointestinal (GI) Clinic, its related GI support group, and Cook Children's staff chaplains. Recruitment was difficult. For example, I found that building the relationships with GI clinic staff members was challenging because it was hard to establish trust and to gain access to the clinic.

It was equally difficult to recruit from support groups. It took four months of attendance before I had one parent decide to participate. For example, in a memo I wrote on 17 January 2017 I noted that one support group attendee came to the support group needing help filling out federal aid paperwork. I helped her fill out the forms during the support group. The forms were lengthy and redundant, but she explained how she could not financially survive without the assistance. I wrote:

> Listening to her complaints [about the paperwork], I began to feel frazzled. I didn't speak—afraid of the reality that there were no simple solutions to the whirl of complex problems. When I asked her, at the end of the night, once we had completed the paperwork together, if she would be interested in participating in my study she seemed more open and interested. But she didn't want to sign consent last night. She just didn't want to do "any more paperwork."

This parent eventually became a co-researcher and contributed to this study. The experience, along with numerous others, reminded me that I was asking parents to give their time and energy when they face already-taxed schedules and demands. Ultimately, insight garnered from the dynamic and demanding schedules of my co-researchers guided my description of the bated-breath illness narrative, described in the fifth chapter of this project.

Once recruited, I scheduled three points of contact with each co-researcher. Each co-researcher sat for two audio recorded interviews and submitted a written protocol—this was an open invitation to write about their experiences. All first interviews took place on the CCMC campus. This was a requirement of the Cook Children's IRB. I assume that the setting and the recording device impacted the narrative. I was asking people to recall, remember, and report on their customary experiences in an artificial setting.[374] This was certainly one of the limitations of this study.

For the first interview I used an "intensive interview" model, as described by Kathy Charmaz. Intensive interviews are "gently guided" conversations in which I inquired about the personal experience of co-researchers(s).[375] Each interview lasted between 60-90 minutes. For the first interview I was guided by a series of open-ended questions to gather an in-depth exploration of daily experiences. I used a panel of four chaplains from the CCMC Pastoral Care Office to help critique my guiding interview questions. While developing a list of interview questions was an IRB requirement, this exercise helped me think critically about the questions to center my project and get to the "heart" of my topic.   In listening to their stories, the narratives wove together moments of daily cares as well as moments of extreme or extraordinary circumstances that seemed to highlight the challenges that they (and their children) faced.

I also asked co-researchers to submit a written protocol. The written protocol functioned like a journal entry. The intent of the written protocol was to invite co-researchers into continued reflection and topical engagement after the first interview. Co-researchers were given a writing prompt, if they wanted one, and were invited into deeper reflections about the ideas that emerged from the first interview. I anticipated that these reflections would add an additional layer, perspective, or voice for a more robust narrative analysis. While the written protocol

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[374] One of the staff members from the GI clinic thought it would be interesting to have parents wear go-pro cameras to record a typical day. While I agree that video footage was an interesting and potentially helpful perspective, I did not have the resources or the institutional support to incorporate that sort of data into this study.

[375] Charmaz, 56.

provided a secondary narrative format to critique the data collected from the interviews, it ultimately proved a less useful feature in the research design. Co-researchers disclosed that they felt burdened by the written portion of the research protocol. Furthermore, the findings did not sufficiently critique or elaborate on the data from interviews.

The written protocol was followed by a second interview. These were conducted in person and over the phone. The primary intent of the first interview and the written protocol was data collection. The aim of the second interview was member checking. It was important to have an opportunity to clarify and report my interpretations and analysis among my co-researchers. I believe that member checking is important even if it is somewhat insufficient. Howard Becker reminds us that we cannot invent meanings. It is our responsibility, as researchers, to ask our co-researchers to help us clarify the meanings we co-construct.[376]

The member checking interviews contributed to the development of the two illness narratives I propose in my fifth chapter. These interviews were essential as I was developing the emerging "bated-breath" illness narrative typology. Co-researchers not only confirmed what I was seeing in the data but they also helped to nuance what if felt like as they expected the "other shoe to drop"[377] as they cared for a child whose health-status shifted and changed abruptly.

The second interview allotted some space and time for disclosure and clarification of findings. The second interview was less successful than anticipated. The constraints of the IRB did not permit unfettered access to co-researchers. While this IRB constrain is understandable, I found it difficult to confirm exact language and final reports with co-researchers. Ultimately, the success of this portion of the protocol amounted to a research design flaw based on unforeseen

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[376] Becker, 58 and 60.

[377] This expression was used by Jasmine and Allison.

restrictions of the IRB and protracted timelines in developing a final report. If I were to propose a study of this sort in the future, I would structure the member checking portion differently.

I collected field notes throughout this project, in the form of open-ended memos. I wrote memos as I reflected on my own body while conducting research. I collected field notes about the recruitment process. I also wrote observational field notes during the two interviews. Co-researchers consented to my collection of field notes during the interviews.

I set out to specifically pay attention to and memo about three experiences or responses. First, I wrote memos about my embodied responses to and interaction with research materials and co-participants. Second, I memoed about the visible embodied reactions of co-researchers as they engaged the interview conversation. Finally, I memoed about intersecting oppressions and stigmas after interviews and while I was analyzing data. These memos include reflections about context-specific questions that I wanted to raise and that might contribute to the way a co-researcher interprets their child's body or the reaction from others to their child's body. These memos raised specific questions about how ethnicity, gender, class, and age[378] shape the ways that parents understand their child's body or how these conditions might impact their worldviews or access to care. Some of these field note memos were discussed during the second interviews and some influenced my fourth and fifth chapters.

Data was coded[379] and analyzed by hand and with the use of *Dedoose*, a cloud-based software designed for mixed method research. Data collected from the interviews, field notes, and the written protocol was de-identified and pseudonyms used for all co-researchers and their

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[378] These questions emerged particularly in concert with interview data from Stephen (gender), Leticia (ethnicity and class), Allison (gender), Rebecca (gender and class), Jasmine (class), Hannah (gender).

[379] Coding is "the process of aggregating the text or visual data into small categories of information, seeking evidence for the codes from different databases being used in the study, and then assigning a label to the code." Creswell, 287.

children. All data was coded and analyzed after it was de-identified. I used a combination of thematic codes[380] and open codes[381] in my data analysis. The thematic coding and open coding factored into the spiral analysis as I correlate lived experience with pertinent theories and theologies discussed in Chapter Four and Chapter Five.

Conclusion

In this chapter I highlighted the importance of embodied knowing as viable and reliable source material for research. I also demonstrated techniques and discussed the challenges to incorporate and integrate multiple sources for constructive theological arguments. I also explored two parallel methods (narrative research and intersectionality) as a way of analyzing the lived experience of parents who care for children with ostomies. These two methods work in tandem to highlight and incorporate multiple voices into a constructed proposal.

Furthermore, I described the method and rational for conducting a "trustworthy" study. Trustworthiness is a method to ethically represent and transmit lived knowledge from co-researchers correlated with knowledge garnered from theological, social, and clinical literature. I concluded with a brief discussion regarding the particularities about this study's structure. In the end it is evident that pastoral theological methodology, in conversation with qualitative research methods, is particularly well-situated to take seriously the co-constructive nature of how bodies with a GI ostomy informs, and is informed by, social narratives, ideologies, and theological constructs. Understanding the criteria and assumptions of this research method will enable the theoretic correlation and theological construction of the remaining two chapters of this project.

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[380] Thematic coding uses "broad units of information that consist of several codes aggregated to form a common idea." Creswell, 186.

[381] Sometimes called free codes. These codes emerge from the data and conversation with the co-researchers. Creswell, 185.

Chapter Four

Theology and Theory

> "Christ has no body now but yours, no hands, no feet on earth but yours, yours are the eyes with which he looks compassion on this world. Christ has no body now on earth but yours."
>
> -Theresa of Avila, "Christ Has No Body"

> "I would like to think [God] doesn't think she's abnormal. I mean this is the way she's supposed to be in this world… I guess I want people to know that she's precious, just the way she is."
>
> -Rebecca, mother of Amanda

Allison told me that she holds out hope that Ava's ileostomy could, one day, be reversed. When I asked her about this hope, she described feeling caught between two realities. Allison unequivocally knows that Ava's identity is not usurped by an ileostomy; yet Allison also acknowledges that society fosters conditions which could marginalize[382] Ava. Allison simultaneously wants to celebrate Ava's embodied difference but she also knows that those same differences could be a source of stigma and marginalization. Allison shared:

> I worry the older she gets the more people will not accept her because of just the norm… [the ileostomy is] not normal. Which, I think if she's happy and positive about it you know, then I think it's fine. But I also think about: what if when she gets older, she can't find a spouse or anything because that hinders her. I think a lot of her friends are very accepting and, you know, encouraging about it. But the day before yesterday she wanted to wear a two-piece because she is doing swim lessons. Her two-pieces are tankinis so they are still longer but her bag will hang out a little bit. She wanted to wear one and I said, "You know, if you are ok with it." She wears them around family. I said, "If you are completely comfortable with that then I am too and that's fine. If you want to wear it, I am completely fine with that." She said, "Yeah, I think I do." And I said, "Well, that's fine with me, go put it on." So, she wore it. That night she was going to another swim party. My mom came over to watch my little ones and she said, "Oh, Ava, your bag is hanging out, you need to tuck that in," and all of that. I kind of hit my

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[382] Iris Marion Young defines marginalization as a form of oppression in which members of a group are restricted from participation within society (p. 53-55). Notably, the families I interviewed among also recounted experiences that can be categorized as other forms of oppression, including cultural imperialism. Young describes cultural imperialism as "the universalization of a dominant group's experience and culture, and its establishment as the norm" (p. 59). Cultural Imperialism will be discussed at further length in a subsequent section in relation to the normalcy discourses. Iris Marion Young, *Justice and the Politics of Difference* (Princeton, NJ: Princeton University Press, 1990), 53-55 and 58-61.

> mom. She was like, "What? It's showing." Ava had walked out of the room and I said, "Mom, I don't want to give her a complex about that so I'm not saying a word. If she's comfortable with it, that's fine." My mom said, "But what if the other kids say something?" I said, "Well, she can handle that."[383]

Allison is not unlike the other parents interviewed for this study. She acknowledged that the ostomy can be objectified and has the potential to become a marginalizing force. But Allison also recognizes that there are powerful social discourses, as displayed by Ava's grandmother, which have the potential to shape the way Ava regards her own body. Each parent vehemently argued that the ostomy can never nullify their child's intrinsic beauty or totalize their identity.

Theologians like Reinhold Niebuhr, Wendy Farley, and Nancy Eiesland affirm an innate beauty and goodness in the human body. They each acknowledged that the body, while finite, is part of a good creation. We can affirm the goodness of the body but, as the parents in this study readily identified, this goodness is compromised by sins that marginalize. The situation described by Allison (and experienced by many co-researchers) makes evident that body and social narratives shape the identity of children living with a gastrointestinal ostomy. These narratives are powerful forces that 1) are fueled by fear and disgust about the body and the body's temporality; 2) have the potential to marginalize those whose bodies do not fit within cultural norms; and 3) disrupt relationships with each other, with God, and with our own abilities to love our embodied selves.

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[383] Patricia Hill-Collins suggests three specific ways in which the intersections of oppression can be evaluated. These are: 1) A "freestanding system" in which the oppression is examined an evaluated individually but with the recognition that the form of oppression is intrinsically impacted by other forms of oppression. In this case, bodily difference is evaluated as a form of oppression but it impacted by sexism. 2) One form of oppression is "manipulated *within*" (emphasis original) other forms of oppression. In this case, bodily difference is examined as a form of oppression that is shaped within other forms of oppression like gender, race, or economic status. 3) One form of oppression is the "specific site" of inquiry where intersecting oppressions meet. Because of the limitations and scope of this project the first method is the ideal mode of evaluating oppression related to the body. Patricia Hill Collins, *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*, 2nd edition (New York, NY: Routledge, 2000), 127-8.

Also evident in the data are the recognitions of co-researchers that their children are not defined by their ostomy. Co-researchers described a spark, a light, an intrinsic beauty within their children. Like Allison, they fear that this spark might dim because of the social pressures they face from embodied differences. They recognize, however, an aspect of their child's identity that can never be ultimately and completely usurped by these body and social narratives, which aim to undermine the beauty within all bodies.

Introduction: Weaving Theology, Lived Experience, and Social Sciences

Theologians like Wendy Farley, Reinhold Niebuhr, Douglas John Hall, Edward Farley, and Paul Ricoeur offer ample response to the questions raised by Allison and her fellow contributors. Germane theology alone does not paint a broad enough picture of the problem or offer an adequate-enough response to the problem of embodied difference. Correlating lived experience, social sciences, and insight from aforementioned theology results in training our attention, guiding reflection, and revising previously held beliefs and practices. Correlating theology and social science with lived experience also revises theological concepts—we change our theology based on lived experience.

A theological response to embodied difference is important. Theologians Reinhold Niebuhr and Nancy Eiesland affirm the goodness of the body while attending to the anxiety that the body's temporality raises in humanity. Niebuhr also cautions against an assumption that anxiety itself is a sin, noting that anxiety is also a creative force for loving care and action. Christian philosopher Paul Ricoeur and theologians Wendy Farley, Thomas Reynolds, and Fumitaka Matsuoka tune our attention to how anxiety, related to non-normative bodies, can result in sinful actions that disrupt relationships, thereby marginalizing those who experience embodied differences.

The *imago Dei* is a human ideal and therefore can never be extinguished or eradicated by sin and anxious responses to embodied finitude. Its brilliance can be missed or overlooked because of the force of social and body narratives, which compromise our abilities to see the brilliance of the *imago Dei*. While co-researchers always identified an innate beauty in their children, few directly correlated this beauty with the *imago Dei*. When illness is the most prominent embodied experience—when marginalization and physical pain are tangible, indisputable factors—the *imago Dei* offers a counter narrative. This counter narrative gives me and my co-researchers the ability to glance through body and social narratives that depreciate the goodness of the body.

The *imago Dei* is a theological category and an ethical obligation, according to theologians Edward Farley, Thomas Reynolds, and Wendy Farley. The ethical obligation of the *imago Dei* is connected to its relational quality, as described by Douglas John Hall and Edward Farley. The *imago Dei* is inseparably linked to our incarnate, embodied, and contextual realities. These contextual realities can obscure the brilliance of the *imago Dei* but its brilliance is never completely depleted, eliminated, or invisible, as described by Wendy Farley, Pamela Cooper-White and Thomas Reynolds. Any discussion, however, about the *imago Dei* is a symbolic representation and theologians Pamela Cooper-White and Reinhold Niebuhr pay attention to the language used in describing the *imago Dei*. This attention to language is an important factor when discussing the *imago Dei* in relationship to the lived experience of my co-researchers.

Theological themes are correlated with two theories from other fields of literature. Sin, defilement, the tragic and anxious responses to embodied finitude are important theological concepts and demonstrate how humanity is unable to live and act out of the human ideal, the *imago Dei*. These theological contributions, however, are augmented and challenged by contributions from philosophy, critical theory, social sciences (like sociology and anthropology), and medical ethics. Two theories in particular, abjection theory and normalcy discourses, are pertinent and helpful contributions in understanding embodied difference. The wisdom from co-researchers, theological contributors, and the contributions from philosophy and social sciences mutually inform each other. Correlating lived experience, social science, and theology should result in revisions and augmentations of source materials. Theologian Rubem Alves reminds us that theology becomes little more than a self-serving ideology that reinforces institutional norms if we fail to modify and comprehend our theologies when we encounter embodied experiences.[384]

Abjection and normalcy discourses will be defined in forthcoming sections, but a brief definition is in order to guide the opening discussion of theological themes. Abjection theory, guided in part by philosopher Julia Kristeva, examines fear and loathing as a result of disgust about our own bodies and the bodies of others. This theory enhances the theological understanding about defilement and the human capacity to react sinfully because of an anxious response to embodied finitude. Normalcy discourses, a concept derived from critical theory, examines how the fear and loathing about the body drives notions about what—and who—is "normal." Normalcy discourses offer evidence of the tragic. Understanding normalcy discourses augments our understanding of the cumulative and shaping effects of sin on our relationship with our own bodies and the bodies of others; intensifying our ability to see how marginalization and the "negation of relationship"[385] is a sin.

This chapter will unfold in three sections. I will begin with a discussion on the

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[384] Rubem Alves, "Personal Wholeness and Political Creativity: The Theology of Liberation and Pastoral Care," in *Pastoral Psychology* 26, no. 2 (1977): 125-7. EBSCOHost.

[385] Fumitaka Matsuoka, *The Color of Faith: Building Community in a Multiracial Society* (Cleveland, OH, United Church Press, 1998), 57-9.

theological themes that speak to the lived experience gathered from my co-researchers. While there are several ways in which reading these theologians clarify, respond to, and strengthen the findings within the data collected from co-researchers, two guiding questions will provide structure for this first section: first, how do anxious responses to embodied finitude result in sinful actions that negate the full humanity and depreciate relationships of those living with a GI ostomy? And second: how can the *imago Dei*, which affirms the goodness of embodied life, offer a theological basis for resisting marginalizing narratives and compel humanity toward more loving, caring, and just relationships among persons living with a GI ostomy?

Following a discussion of the theological themes that are corrected, enlivened by, and offer responses to the lived experience of the co-researchers, I will define, examine, and correlate two theories from social sciences and critical theory: abjection theory and normalcy discourse theory. These theories form the last two major sections of this chapter. Each of these theories will be defined and then correlated with the theological themes discussed in the opening section of this chapter. As a conclusion, it is imperative to turn toward the care of humanity. The correlation between theology, lived experience, and social sciences certainly unveil, revise, and strengthen the claims that each voice or field of literature makes individually. Understanding the germane theory and theology is only part of the work of pastoral theologians. An inquiry into questions related to embodied finitude, difference, sin, and the centrality of the *imago Dei* should adjust our theological constructs and revise our practices of care.

Guiding Theological Themes

Hannah recounted this story about Jacob and her daughter, Zoe:

> Zoe was on the monkey bars and she said she had pulled her sleeves up because her hands were hurting. She was using her sleeves to not hurt her hands and Jacob saw her bag. He started calling her a robot and that she was fake and that

> she had fake body parts and all this… just nasty things.[386]

Zoe knows that her ostomy saved her life; Hannah has been teaching her that since the day she had her surgery. Yet words like Jacob's impact our relationship with our own bodies and with those whose bodies look or function differently. Why do words like Jacob's take hold? How do these narratives result in an impediment to loving relationships?

Since this chapter explores human frailty and finitude—of our bodies, our social structures, and of our relationships—it is helpful to delineate six theological themes at the opening of the chapter. I will begin by defining the role of anxiety, defilement, sin, and the tragic. These theological principles are distinct thematic categories, but each contributes toward a description of what "damages" or "hinders" our relationships with our own bodies, with others, and with God.

I will then turn my attention to defining incarnation and the *imago Dei*. Incarnation reinforces God's solidarity with humanity. The *imago Dei* suggests an ideal, one that is not fully attainable within our vulnerabilities, but one that cannot be diminished because of a GI ostomy. The *imago Dei* calls humanity into loving, moral, relational responsibility for our own bodies and for others. These guiding theological categories will be, later, correlated with the two theories from the social sciences and critical theory: abjection theory and normalcy discourse theory.

Frailty, which includes the finite body, is part of creation; one created good. While finitude is part of a good creation it can invoke anxiety; this can become personally and

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[386] Attention should also be paid to the manner in which gender roles and rules frame the interaction between Zoe and Jacob. Zoe's embodied difference and her gender can both be explored as intersecting forms of oppression. This project highlights oppression related to embodied difference as a "freestanding system" of oppression. Hill Collins, 127-8.

relationally damaging. Human and social fragility are easily overlooked or ignored when our bodies *feel* healthy. The body's temporality, however, becomes an unavoidable reality when diagnosed with a disease. Additionally, marginalization highlights the frailties of our social systems and discourses as we experience embodied differences, marginalization, or illness.

Humanity has a propensity toward anxiety about the obvious displays of finitude that manifest in the midst of disease. Anxiety is not sin in and of itself. Anxiety inclines humanity toward sinful actions, thereby marginalizing those who experience illness, embodied differences, and the marginalization of our own symptomatic bodies.

Anxiety

While the co-researchers easily identify an ever-present good within their children, they live with an ever-present anxiety about their children. The data shows that anxiety has two components. First: co-researchers understand in tangible, palpable ways the temporarily and finitude of life. Each co-researcher described a first-hand experience watching their children at the precipice between death and life. Second: co-researchers describe anxiety related to the constraints of the social and ideological contexts in which their children live. Each reported an experience (or their anticipation of an eventual experience) of exclusion, marginalization, and invisibility as a result of the ostomy.

Anxiety emerges at the convergence of freedom and finitude. While anxiety is not sin, as Niebuhr is clear to point out,[387] anxiety emerges because human freedom and human finitude coexist. It is not because of our "finiteness, dependence, weakness"[388] or creatureliness

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[387] Niebuhr writes, "Yet, anxiety is not sin. It must be distinguished from sin partly because it is its precondition and not its actuality, and partly because it is the basis of all human creativity as well as the precondition of sin. [Humanity] is anxious not only because [her/his] life is limited and dependent and yet not so limited that [she/he] does not know of [her/his] limitations. [Humanity] is also anxious because [she/he] does not know the limits of [her/his] possibilities." Reinhold Niebuhr, *The Nature and Destiny of Man, vol. 1: Human Nature* (New York, NY: Charles Scriber's Sons, 1941), 183.

[388] Niebuhr, 168.

that we stumble into sin. It is our refusal to acknowledge this finitude,[389] or our anxiety about this finitude,[390] that "tempts [humanity] to sin."[391] Anxiety is the internal precondition of sin. Niebuhr describes anxiety as the "inevitable concomitant of the paradox of freedom and finiteness in which [humanity] is involved. It is the inevitable spiritual state of [humanity], standing in the paradoxical situation of freedom and finiteness."[392]

Human freedom has two aspects. One, freedom entails our capacity, as humans, to act within history; another suggests freedom as the human capacity to transcend, or to see beyond, the finite condition.[393] Although humanity has the freedom to see, imagine, or transcend finitude, humanity cannot escape the concrete limitation of our finitude and creatureliness. Humanity is inclined to sin because the "structure of finite freedom" is in tension with an "evil infinite."[394] Humanity is both embedded within historical contexts (has freedom to act within this historical context) and has transcendence over history—this tension is the source of anxiety and a persuasion to sin.[395] We know that this life is vulnerable, that this flesh-and-bone will eventually fail. Rather than pursuing loving and just relationships, anxiety about embodied finitude incites sinful responses to the manifestation of our finitude.[396]

While anxiety has the capacity to tempt humanity into sin, anxiety is all-too-often

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[389] Niebuhr, 177.

[390] Ricoeur contends, "Even death is altered: the curse is not that [humans] shall die ('for dust thou art, and unto dust shalt thou return'), but that [they] shall face death with the anguished awareness of its imminence; the curse of the human modality of dying." Paul Ricoeur, *The Symbolism of Evil*, trans. Emerson Buchanan (Boston, MA: Beacon Press, 1967), 247.

[391] Niebuhr, 168.

[392] Niebuhr, 182.

[393] Niebuhr, 181.

[394] Ricoeur argues that humanity, by nature of being a creature, has finite freedoms. Humanity, though finite, has a "desire" for infinity. Ricoeur describes the desire as a "fascination" with always having or achieving more—becoming an "evil infinite" which drives all need for power and pleasures. The driving desire within humanity is mistaken as humanity's nature. Humanity yearns for more ("desire for desire") yet there are limits imposed by finitude. Ricoeur, 252-5.

[395] Niebuhr, 181-2.

[396] Ricoeur describes freedom as a "power to defect" from the ideal of human creation. Humanity defects from the *imago Dei*. Ricoeur, 233-4.

wrongly equated with sin. Niebuhr notes that anxiety "must be distinguished from sin partly because it is its precondition and not its actuality, and partly because it is the basis of all human creativity as well as well as the precondition of sin."[397] Two co-researchers conflated sin and anxiety:

> Allison: You always feel like the other shoe is about to drop. I have learned that there is no time that I don't have anxiety like, ok, tomorrow could be the day… Being a Christian, I know I shouldn't worry; I need to pray and have faith because if I'm worrying, I'm not trusting in [God]. So, I try not to let it bury me.
>
> Leticia: We're flesh; we are only human. I worry about my son a lot. And even my son tells me, "Mom, you believe in God?" "Yeah." "Well then, don't worry about me." But I'm a mother and I will always [feel anxious] about my child.

Allison and Leticia felt the anxiety they experienced regarding the finitude and vulnerabilities of their children was a sinful response in light of their Christian faith. Here, the theology of Niebuhr is corrective for Christians like Allison and Leticia who depreciate the value of anxiety.

Certainly, anxiety can cause us to focus singularly on the fragility of the bodies before us—paralyzing our action. Stephen told the story about how he and Crystal just sat in the NICU room after their son, Owen, was emergently transported to another, higher-acuity hospital.[398] They just sat, not knowing what step to take or how to take it. After some time, however, Stephen and Crystal decided to get up and follow Owen to the next hospital because they needed to be a good source of information at that new hospital. The parents interviewed for this project live in a state of "ready." They are always attentive, knowing that they might have to go to the hospital at any time or that their children's condition might worsen at any moment. The co-researchers describe how this anxiety is motivating. To directly equate anxiety with sin is not only wrong-headed it also erodes the way that anxiety is constructive. Anxiety about embodied

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[397] Niebuhr, 183.

[398] This story is recounted, in full, at the opening of the fifth chapter.

finitude relates, in part, to humanity's contention with defilement.

Defilement

Defilement is described as a blemish, being contaminated, or the result of contact with an external derivative that will spoil one's identity or physical body.[399] On initial glance, defilement is the violation of the boundary between what is pure and what is impure.[400] This initial observation draws a clear and distinct line between the pure (clean/healthy) and the impure (defiled/diseased). This simplistic structure makes it easy to separate the pure from the defiled. One might advocate for such a separation particularly when there is a fear of contagion. This argument is helpful when considering the transmission of infectious diseases. Such an argument, however, overlooks the ethical implications of defilement[401] when people or groups are marginalized based on these same principles of contagion.

Defilement is experienced as suffering or "misfortune."[402] Humanity fears the impure because it is closely associated with misfortune. Ricoeur argues that misfortune, "all possible sufferings, all disease, all death, all failure" is construed as "a sign of defilement."[403] Humanity avoids defilement to avoid suffering.[404] The collapse in meaning between suffering and defilement has a long history, as Ricoeur describes:

> This bond between defilement and suffering, experienced in fear and trembling, has been all the more tenacious because for a long time it furnished a scheme of rationalization, a first sketch of causality. If you suffer, if you are ill, if you fail, if you die, it is because you have sinned.[405]

At the root of defilement is a fear of embodied finitude. The vulnerable and finite body is an

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[399] Ricoeur, 29.
[400] Ricoeur, 25-9.
[401] Ricoeur, 27.
[402] Ricoeur, 27.
[403] Ricoeur, 27.
[404] Ricoeur, 31.
[405] Ricoeur, 31.

impetus for suffering. This is a particularly persuasive association when our bodies feel like they are betraying us or when another's body is deemed a source of contagion and betrayal rather than part of a good creation. As Nancy Eiesland says, "embodiment is not a purely agreeable reality; it incorporates profound ambiguity—sometimes downright distress."[406] When our bodies feel pain, Eiesland notes, "We concede the precarious position of living a difficult life and affirming our bodies as whole, good." Certainly, it is difficult to comprehend the body as good when it feels so bad.

The association between suffering and defilement seems legitimate, recognizable, even. We believe that our exclusion, and the exclusion of others from relationship, is predicated on justifiable grounds. We want avoid contagion because we do not want to become defiled ourselves. The collapse in meaning between suffering and defilement has grave consequences because it often leads to the marginalization of those suffering, and are then deemed defiled, diseased, or impure. Thus, defilement can be used as a marker of exclusion. Those who have been rendered impure are removed from community as a way of preserving the integrity of the community.[407] Fear of becoming defiled ourselves wrongly justifies the negation of full humanity to those rendered impure, contagious, or different. This sort of marginalization on the grounds of defilement is a sin.

Sin

Sin diminishes relationships within God's creation. Theologian Fumitaka Matsuoka describes sin as a "negation of relationship," or a "failure to enter into relationship."[408] Sin is the

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[406] Nancy Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville, TN: Abingdon Press, 1994), 95.

[407] Ricoeur, 40.

[408] Matsuoka uses the term "negation of relationship" in discussing the evil of racism. Though racism is Matsuoka's primary lens, naming evil as the negation of relationship, helps define evil as the "obstacle to the formation of a common peoplehood" (p. 58) which is premised on the "devaluation of life," (p. 58). Matsuoka, 57-9.

negation of relationship between 1) our own bodies and 2) with others. Negating the relationships with our own bodies occur when experiences with illness create distance between the self and the diseased body.[409] As described by Eiesland, embodied living is filled with ambiguous experiences of pleasure and pain, making it hard to experience the body as fully good,[410] so we distance ourselves from our pain-filled bodies. We believe body/self-dualisms as an attempt at preserving the "self" against the sufferings of the body—as if the body can be parsed apart from the self. As such, we begin to question bodily integrity and unity.

Sin is also the negation of relationship with each other and is the focus of Matsuoka's definition of "negation of relationship."[411] Sin, as the negation of relationship, diminishes the full humanity of the other. Negation of relationship is not simply avoiding contact, friendship, or the offer of hospitality. Negation of relationship is a depreciation of the fullness of one's humanity in a way that perpetuates social and systemic injustice.[412] Sin is not just a break in the relationship between humanity and the Divine but it is a power that traps humanity,[413] causing humanity to act in ways that are contrary to our created ideal (the *imago Dei*) and diminishes our capacity to pursue our "obligations and fulfillments."[414]

Sin is an ethical and theological category.[415] Wendy Farley describes this concept and notes that sin is "against God, but the fundamental form of sin is cruelty and injustice toward

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[409] Abjection theory expands the theological interpretation of sin at this point. Illness disrupts the relationship between our own bodies and what we consider our "self." This is a clear finding from Pamela van der Riet and Dennis Waskul and will be discussed more fully in the following section on abjection theory. Pamela van der Riet and Dennis D. Waskul, "The Abject Embodiment of Cancer Patients: Dignity, Selfhood, and the Grotesque Body," *Symbolic Interaction*, 25 no. 4 (2002): 495, http://www.jstor.org/stable/10.1525/si.2002.25.4.487.

[410] Eiesland, 95-6.

[411] Matsuoka, 57-8.

[412] Matsuoka, 57-8.

[413] Ricoeur, 70.

[414] Wendy Farley, *Tragic Vision and Divine Compassion: A Contemporary Theodicy* (Louisville, KY: Westminster John Knox Press, 1990), 41.

[415] Wendy Farley, *Tragic Vision*, 42.

God's creation."[416] Sin interjects destructive powers into the created order,[417] affecting every aspect of human existence. Humanity is caught in sin but participation in sin is not always intentional.[418] Sin is deceptive;[419] meaning the "true nature" of sin is hidden within social norms, making sin "palatable" to humanity.[420] Well-meaning, upright people participate unwittingly in sinful actions; it is not the result of a few bad actors or character flaws. This does not, however, lessen the consequences of sin for the parents I interviewed or their children.

The unwitting participation in sin breeds callousness. A callous on the skin occurs when our skin rubs in one place, time and again. Often our attention is not directed toward the accumulating effect of skin growth and may only notice the callous after it has formed. We are not attuned to the deceptive nature of sin; we rub against its deception time-and-again, which eventuates in callousness toward God's creation. Callousness is described by Wendy Farley as a "deeper level of sin."[421] Sin creates the conditions in which humanity's capacities for empathy are diminished and "indifference"[422] or apathy emerges toward God and God's creation. The relationship between humanity and God's creation is compromised by this callousness.[423] The devaluation of another human—another body—need not be hidden. It enables principled people to ignore the horrors and hardships inflicted within society.[424]

Callousness affects both individual relationships and social structures.[425] Both

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[416] Wendy Farley, *Tragic Vision,* 42-3.

[417] Wendy Farley, *Tragic Vision,* 43.

[418] Wendy Farley, *Tragic Vision,* 43.

[419] Wendy Farley, *Tragic Vision,* 44-6.

[420] Normalcy discourses expands the theological interpretation of sin at this point. Humanity is persuaded into sin simply becomes something appears normal. Normalcy discourses will be correlated with this theological concept in the following section, *Normalcy Discourse,* of this chapter. Wendy Farley, *Tragic Vision,* 44.

[421] Wendy Farley, *Tragic Vision,* 46.

[422] Wendy Farley, *Tragic Vision,* 46.

[423] Paul Ricoeur argues that the "monstrousness of the act as such is less important than the alteration of the relation of trust between [humanity] and God." Ricoeur, 248-9.

[424] Wendy Farley, *Tragic Vision,* 46-7.

[425] Social structures include social, economic, political and religious systems. Wendy Farley, *Tragic Vision,* 48.

individuals and societies have a decreased "capacity to perceive injustice, to experience compassion, and to discern right from wrong."[426] As we are deceived and grow calloused, our actions, which should be caring and loving, are "tainted and corrupt[ed]"[427] by sin. Callousness makes it difficult for humanity to carry out our moral obligations and ethical relationships. This devaluation affects our contexts and bolsters social norms that marginalize.[428] Wendy Farley notes, "Human action is located in an already corrupted environment. We begin to act in the very ways that my co-researchers fear. To this extent, sin can be understood as having a "tragic dimension."[429] Humanity is responsible, culpable for sin—humanity is not a "passive victim to original sin, corrupt social institutions, or deceptive language games."[430] Humanity is culpable in that we participate—wittingly and unwittingly—in the destruction of our own obligations and our relationships with our own bodies, others, and God.

The Tragic

Humanity's nature is not cast from a sinful mold. Since humanity is part of the created good, this goodness is ontological. Ricoeur contends, "sin is not our original reality, does not constitute our first ontological status; sin does not define what it is to be a [human]; beyond [our] becoming a sinner there is [our] being created."[431] Yet sin and humanity's created goodness are not two separate conditions; they are concurrent. In the same "instant"[432] in which humanity is

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[426] Wendy Farley, *Tragic Vision*, 48.

[427] Wendy Farley, *Tragic Vision*, 49.

[428] Sin "corrupts the environment in which human beings must act and deceives them about their real situation" (Wendy Farley, *Tragic Vision*, 48-9). As this chapter unfolds, I will demonstrate how expectations about what constitutes a "normal" body become discursive in nature.

[429] Wendy Farley, *Tragic Vision*. 50.

[430] Wendy Farley, *Tragic Vision*, 50.

Ricoeur writes that every aspect of humanity "language, work, institutions" are "stamped with the twofold mark of being destined for good and inclined toward evil." Ricoeur, 246.

[431] Ricoeur, 251.

[432] Ricoeur, 251.

created good, this goodness is "lost"[433] as sin dismantles human innocence.[434]

While humanity is created for good, humanity is only known within history. Therefore, humanity can only be seen or comprehended through this historical context.[435] Even though humanity is not ontologically evil, evil is already present within history. The introduction of evil into history is not the result of the actions of one human.[436] Evil is concurrently present and concurrently emerging through the cumulative effects of individual and systemic sin.

Anxiety about embodied finitude is prompted by the tragic. That same anxious response leads humanity to sinful actions that depreciate and devalue our relationships with each other and our own bodies. We negate the goodness of God's creation and render the finite body as a source of sin that is altogether contrary to its created purpose—good yet finite.

An "already corrupted environment"[437] does not diminish our accountability for sinful actions, nor does it diminish our responsibility for the cumulative impact of sin on our contexts.[438] Sin, as Ricoeur notes, is a collective act: "all sinners" are unified in guilt, equally contributing to and impacted by sin.[439] Sin "so deeply infects a community that every action is tainted and corrupt."[440] Our tragic context and our assent and acquiescence to sin impacts our ability to act in accordance to our created ideal—the *imago Dei*.

Defining anxiety, defilement, sin, and the tragic contribute toward a description of what "damages" or "hinders" our relationship with our own bodies, with others, and with God. But these definitions offer only a partial view of humanity. These theological propositions illustrate

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[433] Ricoeur uses the word lost to describe a "primordial nature" which remains good, yet almost hidden, in the midst of evil. Ricoeur, 250.

[434] Ricoeur, 251.

[435] Ricoeur, 251-2.

[436] Ricoeur, 257.

[437] Wendy Farley, *Tragic Vision*, 50.

[438] Humanity is "simultaneously evil's perpetrators and its victims." Wendy Farley, *Tragic Vision*, 49.

[439] Ricoeur, 241.

[440] Wendy Farley, *Tragic Vision*, 49.

that humanity is not sinful at our core—it is not an ontological condition for humanity. Humanity, however, is only known in an historical context, a context which enhances humanity's opportunity or propensity toward sinful actions. It is imperative to also define incarnation and the *imago Dei*. Defining the theological category of incarnation helps to reinforce God's solidarity with humanity. The theological theme of the *imago Dei* suggests an ideal, within our vulnerabilities, for embodied humanity. The *imago Dei* calls humanity into loving, moral, relational responsibility for our own bodies and for others.

Incarnation

Though much could be said about the theological doctrine of incarnation, for the purposes of this project, it is important to highlight two specific ideas. First, since the body is only known within social, historical, and ideological contexts, any consideration of the theological theme of incarnation must consider the limitations and implications of weighing a body within its contexts. Second, the incarnation amplifies God's solidarity with an embodied humanity. God's solidarity is not only seen in God's accompaniment and awareness of the physical suffering and pain of having a body. God's solidarity is in an embodied awareness of, and practice of resistance against, the inevitable contextual constraints that impose marginalizing forces and impede our full humanity.

Any consideration of incarnation must take into account the reality that a body is never knowable apart from its contexts. The body of Christ is no different. Any evaluation of the body of Christ must simultaneously consider the conditions and constraints of an embodied Jesus within a social location. Such a commitment emphasizes that the body is always subject to evaluation and scrutiny based on its historical constraints.[441]

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[441] M. Shawn Copeland, *Enfleshing Freedom: Body, Race and Being* (Minneapolis, MN: Fortress Press, 2010), 56-60.

Incarnation does not automatically alleviate human preoccupation with the body. An embodied God, manifest in the incarnation, is a reminder that the body (any body) is “a contested site”[442] within Christian theology. Incarnation highlights that all bodies are subject to political and power constraints that exclude some and include others.[443] Thus, attention to social location invigorates the significance of God’s solidarity with humanity.

When God becomes flesh, God demonstrates solidarity with humanity in our suffering.[444] “Solidarity” is not meant to rationalize the pain of disease or marginalization because of illness. Moreover, “solidarity” does not imply that suffering is instructive, that humans must learn how to occupy different bodies, or that suffering is meant to develop “character virtues.”[445] As Thomas Reynolds points out, this “baptizes the status quo.”[446] Rather, the solidarity of God within incarnation is a reminder that God accompanies humanity in the struggle against social norms that codify and regiment bodies. God’s solidarity restores relationships, enabling “social participation and religious inclusion.”[447] The incarnation does not depict power, perfection, or status. Such a narrow rendering of the incarnation insinuates that embodied difference and “people with disabilities lack perfection and embody un-wholeness.”[448] This perception is a distortion of beauty, alterity, and the inclusivity of the *imago Dei*.

Incarnation offers an important “reversal of expectations.”[449] We expect God to come into the world as a powerful figure, but the gospels depict Jesus’ vulnerability. This depiction

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[442] Copeland, 56.

[443] Copeland, 56.

[444] Thomas Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids, MI: Brazos Press, 2008), 203.

[445] Reynolds, 42.

[446] Reynolds, 42.

[447] Eiesland, 73.

[448] Eiesland, 72.

[449] Reynolds, 201.

reinforces the importance of vulnerability.[450] It also affirms God's solidarity in participating with humanity against oppressive forces (such as cultural imperialism) that attempt to control an embodied humanity.[451] The body becomes an "important conduit for accessibility"[452] among those whose bodies are experienced as frail or weak or who experience marginalization and exclusion.

The incarnation reinvigorates and augments the goodness of the body within imperfect historical contexts. God's alliance with humanity, in the incarnation, illustrates "that there is no contradiction between bearing God and living in a body, in the world. In Christ, not only is the soul created in the likeness of the Divine, but the Divine is created in the likeness of the human form."[453] Therefore, the incarnation links the solidarity of the Divine to the human form within our imperfect contexts.

The imago Dei: An Ideal within Human Vulnerabilities

Bodies are temporary and frail; they are susceptible to disease and will inevitably die. The parents I interviewed illustrate that a gastrointestinal ostomy, like an ileostomy, colostomy, or gastrostomy, does not diminish the brilliance of the *imago Dei* within their child. All of humanity is endowed with the *imago Dei*; every type of body, every difference in intestinal tract, is representative of God's image. The *imago Dei* is innate and therefore not predicated on a body's adherence to one particular standard. Affirming an ever-present *imago Dei* does not ultimately resolve anxieties related to embodiment. The ostomy, however, does reveal

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[450] Reynolds, 201.

[451] Here Copeland is addressing imperial rule. She argues that Jesus lived "among common people" and his praxis was to "put his body where they were." This is an act of God's solidarity against the oppressive and mortal forces of Rome. Copeland, 60-1.

[452] Reynolds, 201.

[453] Wendy Farley, *Wounding and Healing of Desire: Weaving Heaven and Earth* (Louisville, KY: Westminster John Knox Press, 2005), 105.

biological, social, and political structures that obstruct the brilliance of the *imago Dei*.[454]

The *imago Dei* is an ever-present[455] spark of goodness within humanity.[456] While not all of the co-researchers identify as Christians, each of the co-researchers identified an innate beauty within their children. Some of them shared:

> Crystal: I mean, I don't see his ostomy; it's just kind of him. Just kind of the way it is. It's just him. So, to me, he's just perfect, everything.
>
> Stephen: But when you sit there and you stare at this kid struggling for weeks and weeks, to be able to laugh and play around, it's kind of amazing, really. He's just a beautiful kid.
>
> Hannah: She just has a light about her that has never dimmed in everything she's been [through].
>
> Sara: He is just this beautiful light in the world. Regardless of what he's doing and going through, he is still this beautiful little light and it doesn't matter.
>
> Katrina: I could sit there and give you facts and facts about how daunting it is being a conjoined twin or having a colostomy… I'm excited for what they can do and what they offer the world because they have had that advantage.[457]

Each co-researcher readily identified a deep, abiding goodness within their children amid narratives that attempt to restrict, hide, and confine their child.

The *imago Dei* is relational and holds ethical obligations. The *imago Dei* is not predicated nor defined by cognitive, physical, spiritual, or emotional criterion.[458] To be is to be in relationship, as Douglas John Hall indicates.[459] Edward Farley and Thomas Reynolds each

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[454] Ricoeur notes that the *imago Dei* can become "lost." The Divine image never disappears nor is it altered but it can get lost among the tragic contexts in which humanity exists. Ricoeur, 250.

[455] Wendy Farley, *Wounding and Healing*, xiii.

[456] Cooper-White, *Many Voices: Pastoral Psychotherapy in Relational and Theological Perspective* (Minneapolis, MN: Fortress Press, 2007), 41.

[457] The advantage that Katrina talks about is their embodied uniqueness. It is evident that she sees Mia and Isabella's embodied difference as an asset, not a detriment.

[458] Douglas John Hall, *Imaging God: Domain as Stewardship* (Grand Rapids, MI: Wm. B. Eerdmans Publishing Company, 1986), 115.

[459] Hall notes, "Being = Being-With." Hall, 116.

remind us that relationship is predicated on the recognition of the other:[460] the distinctive alterity,[461] interdependent, [462] and embodied[463] other. All "attributes" that comprise a human being are to enable relationships with others.[464]

The *imago Dei*, defined as relational, is an ethical obligation. Edward Farley notes that "compassion and obligation" toward each other is the basis for what it means to be human.[465] Wendy Farley asserts that it is in our compassion that we catch a glimpse of the *imago Dei* within humanity.[466] Compassion is "being drawn toward the other's fragility"[467] and is distinct from pity.[468] Compassion and obligation are inseparably inked. While compassion evokes a response, it is obligation that turns us toward the suffering of the other.[469] This obligation can certainly be dismissed. Anxiety about our own embodied finitude can result in sin rather than "compassionate-obligation."[470] The *imago Dei* is embodied and thus embedded within conditions and contexts that shape human identity. This conditionality does not ultimately diminish the reality that humanity is made in the image of God—created good—but it

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[460] Edward Farley contends that "being-with" means knowing that the other exists. Edward Farley, *Good and Evil: Interpreting the Human Condition* (Minneapolis, MN: Fortress Press, 1990), 41.

[461] Edward Farley notes that alterity is experience in two ways. 1) "Alterity is experienced when I experience the other's gaze, an interpretation of by being from a perspective and location not my own (Jean-Paul Sartre)." and 2) "I experience alterity when I experience the other's resistance to and countering of my interpretation of her or him." Alterity is not just the experience of the other but a deep regard for the autonomous other. Edward Farley, 41-2.

[462] Reynolds suggests that we are "inescapably dependent upon creation for substance and well-being." Reynolds, 180.

[463] Reynolds reminds us that "Fundamental to human relationality is a material, bodily existence. We do not have bodies; we are our bodies." These bodies, while good "define our limits." Reynolds, 180-1.

[464] Hall, 116.

[465] Edward Farley, 41 and Wendy Farley, *Tragic Vision,* 75; *Gathering Those Driven Away*, (Louisville, KY: Westminster John Knox Press, 2011), 103.

[466] Wendy Farley, *Tragic Vision,* 51.

[467] Edward Farley, 42.

[468] Edward Farley, 42. Wendy Farley also writes specifically about how compassion is profoundly different than pity. Wendy Farley notes that Compassion is the "sympathetic knowledge of suffering that mediates dignity to the sufferer." Wendy Farley, *Tragic Vision,* 79.

[469] Edward Farley says, "Being summoned by the fragility of the other not only evokes a suffering-with (compassion) but also a suffering-for (obligation)." Edward Farley, 43.

[470] Edward Farley, 43.

fundamentally impacts the relationships with our own bodies and the bodies of others.

The *imago Dei* is inseparably linked to our incarnate, embodied, and contextual reality,[471] a reality that is never perfect. God is seen and experienced in and through the bodies that occupy the world. Perfection cannot and should not be expected. Such an expectation diminishes the brilliance and "vastness"[472] of God's diversity and beauty. Embodied differences are emblematic of God's diverse character.[473] It is undeniable that the diverse bodies of humanity have the capacity to stretch our imagination about the expansive expressions of God's nature.

The body is the dwelling of the *imago Dei*. That means that bodies with GI ostomies display the *imago Dei* to the same extent as bodies without GI ostomies. Bodies—in all forms—are full and beautiful examples of what it means to be made in the image of God. However, the relational, embodied *imago Dei* is embedded in historical and ideological contexts. This embeddedness can disguise the brilliance of the *imago Dei*.[474] Bodies do not exist apart from specific contexts that pose limitations and enhance vulnerabilities. Wendy Farley contends:

> The human form of existence always appears somewhere in particular: in a particular body, culture, place, historical time, religion, and personality. The making into meat[475] of mystery is likewise embodied in a particular culture, moment of history, religious tradition, place on the planet, and personality.[476]

Embodiment—bodies within a context—does not depreciate the goodness of the body. Nor is

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[471] Wendy Farley writes, "This sanctity [of our own flesh] is not something that is accomplished by way of perfection but is present precisely in the form of our existence: luminous, wounded, and infinitely diverse." Wendy Farley, *Wounding and Healing*, 104.

[472] Pamela Cooper-White suggests that the word "perfect" is not adequate saying, "Such a perfect, pristine God is not big enough to be God… God requires an image not of perfection but of *size*" [italics original]. Cooper-White, 85.

[473] Thomas Reynolds suggests that difference and diversity is what enables relationship. Reynolds, 181-2.

[474] Wendy Farley, *Wounding and Healing*, 30.

[475] The phrase, "making into meat" is a reference to one of Farley's early sentences: "Roberta Bondi is known to remind her students of early Christological controversies that the word *incarnation* has the same root as *carne*—as in *chili con carne*: chili with *meat*" [italics original]. Wendy Farley, *Wounding and Healing*, 103.

[476] Wendy Farley, *Wounding and Healing*, 104.

the fullness of the *imago Dei* altered because of the finitude of the body. The body remains the "dwelling" of the *imago Dei*.[477] Wendy Farley reminds us that the Divine chooses to dwell embodied—this flesh-and-bone home is intentional.[478]

Furthermore, our contextual body is an important aspect of our relationships. Relationship is predicated on our having bodies. Thomas Reynolds notes:

> Fundamental to human relationality is a material, bodily existence. We do not have bodies; we are our bodies. Human beings are living souls, not souls trapped in a material body, but organically unified, embodied creatures. And our bodies define our limits. To deny this is to deny our relationship to other creatures, for relationships depend upon the differentiation created by bodily limits.[479]

Thus, the *imago Dei* dwells within fragile flesh. It is "compassionate-obligation"[480] that draws humanity into relationship in the midst of embodied fragility.

Any discussion about the *imago Dei* is a symbolic representation.[481] No example or description is fully representative of the vastness or complexity of what it means to be created in the likeness of God. These symbolic representations, however, hold enormous power. Nancy Eiesland contends that symbolic meanings have the capacity to frame our "normative standards."[482] The bodies that populate the earth display the *imago Dei.* Thus, it is an invitation to see God as profoundly diverse. One the one hand, language describing the *imago Dei* has the capacity to expand conceptions and expectations about God. One the other hand, language about the *imago Dei* also carries the capacity to confine or diminish our expectations about God's

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[477] Wendy Farley, *Wounding and Healing*, 105.

[478] Wendy Farley, *Wounding and Healing*, 104-5.

[479] Reynolds, 181.

[480] Edward Farley, 43.

[481] Paul Ricoeur notes that symbols carry a variety of complex meaning. They are not obvious or transparent in their meanings. They often point beyond an initial interpretation to a deeper, more nuance meaning. Symbolic interpretation occurs within historical contexts and the experience of a symbol happens only within that framework. Ricoeur, 15-20.

[482] "Symbols create normative standards for human interaction. They legitimate social structures, political arrangements, and attitudinal inclinations, constitute our cultural toolkits, and offer visions of what can be." Eiesland, 91.

nature. There is a need for strategic language when discussing the *imago Dei*. Defining and describing God as "perfect" is undefinable and subjective.

Parents I interviewed recognize that their children will never be "perfect" by the standards of this world. This realization poses a theological conundrum as they rationalize 1) the known beauty of their child (whose digestive system works differently and results in a visible ostomy); 2) the ramifications of what society insinuates about perfect and imperfect bodies; and 3) the theological and faith rhetorics that describe God as perfect. Parents recognize a potent theological and cultural message that suggests that their child's body is somehow insufficient because it is not "perfect." Most parents identified this conundrum but legitimized their child's goodness by defining, for themselves and their children, that any allusion to "perfect" included their child.[483]

Allison's disclosure marks this conundrum. She says, "Ava's [gastrointestinal] problems are not going away and so you have to grieve the loss of the newborn, precious baby that I brought home and accept the child that she is now. And she is perfect to me now. [T]his is our new perfect." Allison had to weigh the power of what society says about her child's body. She also had to contend with her own sense of discomfort about Ava's bodily changes and differences. Allison came to recognize that Ava's body, which functions uniquely, is not a mark of deficiency. She also had to contend with the reality that Ava is created in the likeness of God even through that likeness lacks the distinctive qualities of earthly perfection.

What is more, Reinhold Niebuhr contests the notion of pristine and perfect as descriptors of the *imago Dei*. Niebuhr berated Luther's interpretation of the *imago Dei,* claiming that Luther magnified the pre-fallen condition of humanity as "perfect" only to justify his later argument that

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[483] This same narrative and structural format emerged as parents differentiated between "normal" and "our normal."

the Fall ushers in original sin.[484] Luther claimed that humanity was created perfect but this perfection was lost at the Fall.[485] He argues that "[Humanity] was created for a higher and better life than the temporal and bodily life, even when [their] nature was uncorrupt and perfect."[486] The premonition of a once-perfect humanity fosters an unrealistic and wry conception both of humanity[487] and of the *imago Dei*.[488]

What is implied when we say that God is perfect, and humans are created in that image? The question of God's perfection is a topic for another project. The conflation and association surrounding the description of perfection, however, is dangerous and therefore a revision in the language and theology associating the *imago Dei* with an image fixed on perfection is needed. Nancy Eiesland pointed out that "theological interpretations of the meaning of perfection have historically included physical flawlessness as well as absolute freedom. Both understandings necessarily exclude the lived realities of people with disabilities (as well as most other humans)."[489] The *imago Dei* is neither thwarted nor depreciated by embodied differences; as such, it is imperative to be mindful of the language asserted when describing the *imago Dei*. Assertions are representative of espoused theology and they bolster social expectations.

The *imago Dei*, as a portrait of a human ideal, affirms the goodness of embodied life and offers a theological basis to compel humanity toward more loving and caring relationships among persons living with a GI ostomy. Anxious responses to embodied finitude result in sin:

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[484] Niebuhr, 160-1.

[485] Martin Luther, *Commentary on Genesis: Volume 1, Chapters 1-21*, trans. J. Theodore Mueller (Grand Rapids, MI: Zondervan Publishing House, 1958.), 30-1.

[486] Luther, 28.

[487] Ricoeur asserts that "a supernatural perfection" of Adam, prior to a "fall" tends to make Adam superior and hence a stranger to our condition." He added, "the very word 'fall,' which is foreign to the Biblical vocabulary, is contemporaneous with the elevation of the 'Adamic' condition above the present human condition; only what has first been elevated falls." Ricoeur, 233.

[488] Niebuhr, 161.

[489] Eiesland, 72.

the “negation of relationship”[490] of those living with a GI ostomy and with our own bodies. Understanding theological categories like the *imago Dei*, sin, and the tragic do not paint a broad-enough picture of the problem nor do they offer an adequate-enough response to the problem of embodied difference. It is important to correlate lived experience and theology with the wisdom from social sciences and philosophy. I will correlate findings from abjection theory and normalcy discourses to the theology presented thus far. A correlation with abjection theory and normalcy discourses focuses our attention, offering deeper reflection on the problem, and enables revised practices and theologies.

The Abject

Leticia remembers when Samuel’s central line[491] was accidentally pulled out and blood ran everywhere. Hannah and Allison both recall moments speeding to the emergency room with their children in the back seat of their car, worried that the rapid, severe dehydration[492] would be their end. Crystal and Stephen remember multiple, frequent conversations with doctors about the poor chances of Owen’s survival. Rebecca had similar conversations over the years concerning Amanda. Jasmin keeps a hospital bag ready at all times with supplies handy for quick packing. Katrina recognized that she “couldn’t control if [Mia and Isabella] survive or if they weren’t.” Sara recalled the first time Mason received a nasogastric tube[493] and it took a couple of tries, Mason was screaming the whole time. The hospital staff kept saying, “It’s normal, it’s normal.” All Sara could think was, “That’s *not* normal. There’s a tube out of his mouth.”

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[490] Matsuoka, 57-9.

[491] A central line (or central venous catheter) is an IV that is placed in one of the large blood veins of the body. It is used for blood draws, IV nutrition, or giving medication.

[492] For most of the parents that I interviewed hydration and nutrition were key factors in the well-being of their child. Since the gut is the avenue for the body’s absorption of hydrations and nutrition, when there are mitigating factors that limit the intestine and/or colon’s ability to absorb, dehydration (in particular) can become life-threatening at a dangerously accelerated pace.

[493] A nasogastric tube (NG-tube) is a small tube inserted into the nose that drops to the stomach. It is used to give food (formula) and medicine directly to the stomach, bypassing the mouth and esophagus.

Bodies remain good even though they are fragile. The co-researchers know this truth in concrete ways; this is their lived experience. Each could point to multiple instances where the reality of embodied finitude was unmistakable, palpable. Each co-researcher described the accompanying anxiety in those moments—the harsh reality that their child's body may not survive the assault of disease. One might expect anxiety in the moments described above, but how is this anxiety sin-producing? Reinhold Niebuhr acknowledges that humanity is provoked toward sin because of anxiety, which arises from the limitations and finitude of embodied existence. He readily acknowledged this tendency. He also affirms the innate goodness of the finite body. Paul Ricoeur notes that sickness is conflated with evil rather than its proper association with "misfortune."[494] This misguided association compounds our inability to see the body as good even when we experience the suffering of disease and illness. While theologians like Niebuhr and Ricoeur acknowledge that anxiety is sin-provoking, we turn to sociology, philosophy, and medical anthropology to help augment these assertions.

That the body is simultaneously good and finite is true; this affirmation does not offer a deep sustained reflection of what it means to experience the pains of finitude or to live in perpetually-breaking bodies. I will use the work of Julia Kristeva, and subsequent theorists on the topic of abjection, to reflect on what it means to live in finite bodies and to expound upon the anxieties of this finitude. Kristeva's anthropological claims, when correlated with theologian Nancy Eiesland, will affirm that "embodiment is not a purely agreeable reality."[495] I will demonstrate how abjection theory identifies and better distinguishes the realities and implications of living with bodies that are broken and that will break. While the work of Kristeva reveals a less positive view of embodiment, this is set in contrast to Ricoeur and

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[494] Ricoeur, 27.
[495] Eiesland, 95.

Niebuhr's claim that the body is primarily good, a goodness which cannot be negated by finitude.

This section will unfold in three parts. First, I will define abjection theory with two concrete corollaries. Second, I will correlate the work of abjection theory with the work of Reinhold Niebuhr, Paul Ricoeur, Edward Farley, and Wendy Farley to demonstrate how abjection theory strengthens a theological understanding of anxiety (which leads to sin). Third, I will also correlate abjection theory with the work of theologians Wendy Farley, Nancy Eiesland, and Thomas Reynolds to illustrate how abjection and anxiety about embodied finitude does not nullify the goodness of a finite body. In so doing, this final section will demonstrate how the theological position of an innate, embodied *imago Dei* is an important corrective to abjection theory.

Abjection Defined

Abjection is a "feeling of loathing and disgust"[496] when encountering images that horrify, incite fear, or animate anxiety. The abject is not the object of our fear. Abjection is the reaction to that object. Philosopher Iris Marion Young describes the feeling or reaction as "aversion, nausea and distraction."[497] The visible, tangible, fluid-leaking, bodies-out-of-control is a visceral and unignorable reminder that every body is finite. No body will experience a different outcome. Fearing or loathing the sight, the feel, or the smell of a body is not a loathing for the body. It is a loathing for what the leaking, uncontrolled body represents—finitude, vulnerability, death. No *body* is abject, but abjection emerges from the fear of what that body (when failing or changing) signifies,[498] both for the person experiencing illness and for those who render the other

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[496] Young, 143.

[497] Young, 143.

[498] Julia Kristeva, *Powers of Horror: An Essay on Abjection*, trans. Leon S. Roudiez (New York, NY: Columbia University Press, 1982), 3-4.

as abject. The diseased body signifies that we are all in the process of dying, experiencing illness, or losing control of our embodied existence.

French philosopher Julia Kristeva took this notion of abjection and developed a theory about how fear and loathing for an out-of-control body eventuates into fear and loathing toward another individual or social group. This theory has been applied in a variety of fields from social sciences, medical ethics, and the fine arts. I will pursue a definition of abjection theory by developing two corollaries: 1) I will examine how the theory of abjection is rooted in fear about the body and the bodies of others and 2) I will demonstrate its impact on the identity of those living with the effects of illness.

Abjection is rooted in a fear toward the body and the bodies of others. Abjection is neither an innate human quality nor is abjection a condition of being human. The human body, itself, is never abject. An in-tact body or a body that is fully contained within the skin does not incite disgust nor is it rendered abject. Bodily fluid or matter, when inside the body, is considered a part of our body. That changes when it crosses the barrier of our skin.

Our bodies, and the bodies of others, become disgusting (they are rendered abject) when they are perceived as foreign. Martha Nussbaum says, “The disgusting has to be seen as alien: one’s own bodily products are not viewed as disgusting so long as they are inside one’s own body, although they become disgusting after they leave it.”[499] Nussbaum highlights how the body’s own properties become disgusting because they cross the border between inside the body and outside the body.[500] The out-of-control body induces abjection because it arouses and represents significant anxiety about disorder or health. The out-of-control body no longer

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[499] Martha Nussbaum, *Hiding from Humanity: Disgust, Shame and the Law* (Princeton, NJ: Princeton University Press, 2006), 88.

[500] This description is similar to those outlined by Kristeva, 2-7 and Young, 143-5.

represents an indelible good.

Abjection theory enables a deeper understanding of human anxiety related to embodied finitude and frailty. The body (or other people whose bodies represent abjection for us) becomes the scapegoat for our anxiety, fear, or loathing. The fear, loathing, and disgust that we sense are objectified by the physical body or presence of another. Our bodily matter, or the body of another person, becomes the representative (or place-holder) of anxiety. Another person or the matter which has leaked out of the body is just different-enough to simultaneously 1) remind us of ourselves and 2) remind us that it is different from us. Kristeva notes that the abject "is something rejected from which one does not part."[501] We render the body or the other person as distinctly other as a way of creating more space between what is and is not; my body or my social group. These similarities are a constant reminder of our kinship.[502]

The creation of a separation between subject and object is burdensome and tenuous.[503] Abjection disrupts borders and presumed rules of order, including norms about the body and about society.[504] The abject is not the "rule-breaker" or the "border-crosser" itself but the display of the fragility of rules and how these rules are so broken or porous that they can be crossed.[505] Abjection is disorienting because the fragility of social norms and the human body is known, yet we are frightened, horrified, or anxious when it becomes obvious. It seems so unanticipated. As described by my co-researchers, experiences like illness unveil the temporality of the body and normative claims about the body in ways that are unignorable.

Abjection, that feeling of loathing that enables and maintains a separation or distinction

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[501] Kristeva, 4.

[502] Kristeva, 5 and Young, 144.

[503] Kristeva, 7 and Young, 143-4.

[504] Kristeva, 4.

[505] Kristeva, 3-5.

between subjects from objects (i.e. what I constitute as my body as compared to no-longer my body or us versus them), is a "tenuous" separation.[506] Tenuousness is an important descriptor. The abject seems terrifying because, when scrutinized, those/that which has been rendered abject still holds the majority of its DNA[507] in common with those doing the abject-ing. There is a seed of familiarity and commonality no matter how firmly we attempt to demark the boundaries of inclusion. Because of this shared commonality, it is disorienting when we experience abjection. This disorientation is certainly true among those who experience abjection from another person or group and is compounded when the experience of abjection is related to one's own body. Therefore, abjection impacts identity.

Philosophers, social scientists, and medical anthropologists have documented how abjection impacts the identity of those living with disease.[508] Pamela van der Riet and Dennis Waskul describe abjection as a violation of "biological but also normative boundaries" within the body.[509] Disease revises not only the physiology of the body but also the expectations about how the body should function. Abjection of the body affects identity, as these authors argue, in one of two ways. People either objectify their bodies[510] or use medical language[511] to augment the distance between the "self" and the disease. In both cases, persons living with disease devise a method for distancing themselves from the disease in an attempt to shore-up the boundary of an

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[506] Young, 144.

[507] It is generally acknowledged that humans hold 99.5 to 99.9% of our DNA in common.

[508] Although the data collected for this study did not examine the direct correlation between abjection and those living with illness there have been other philosophers and social science projects have made that direct correlation.

[509] van der Riet and Waskul, 487.

[510] The "body becomes disconnected and alien to the self in personal ways." The authors discover that when a person uses "it" in reference to their body the language functions as a way of distancing the self from body that is out of control. van der Riet and Waskul, 495.

[511] The authors suggest, "By adopting the language of medicine, patients may speak of their bodies as something apart from them: distant objects described in terms that do not directly evoke any significant personal connection… Their language represents a mechanism of resistance against the implication that the self and the out of control abject body are one and the same." van der Riet and Waskul, 495-6.

encroaching contamination, debilitation, or death.

The co-researchers for this project discussed ways that their children hid their ostomies and ostomy devices to distance themselves from disease or the potential for social marginalization. Parents recognized that an ostomy, and its accompanying devices, was potential for stigma. Erving Goffman, a sociologist, defined stigma as an "attribute" that makes a person different.[512] Stigmas attempt to diminish the humanity of those stigmatized[513] and "rationalize an animosity" rooted in difference.[514] Several of the parents I interviewed discussed an array of tactics used by their children to minimize the appearance of a bag or g-tube. Most parents were primarily concerned that their children have agency to disclose their bodily difference at a time of their choosing or among the social groups of their choosing. [515]

One team of medical anthropology researchers confirmed the impact of stigma on identity as it relates to gastrointestinal ostomies. [516] Their study was conducted among adult survivors of colorectal cancer. They note that participants in their study made efforts to minimize the visibility of the ostomy appliance to minimize stigma.[517] While the avoidance of

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[512] Ervin Goffman, *Stigma: Notes on the Management of Spoiled Identity* (New York, NY: Simon and Schuster, 1963), 3.

[513] Goffman, 5.

[514] Goffman, 5. Theologian Nancy Eiesland correctly asserts that Goffman's "theory of stigma does highlight the interpersonal practices of social relations; it ignores the institutional practices that undergird them." Eiesland, 61.

[515] Jeannine Gailey, a sociologist studied the visibility politics of the body. Gailey notes that social discourses render all bodies visible or invisible to varying degrees based on context. She argues that visibility and invisibility is often determined both by the circumstances and the body being seen or scrutinized. The more "normal" a body appears the more agency the person has to choose when, where, and by whom they are "seen." Those who do not fit a "normal" body profile are invisible in some circumstances and hyper-visible in other circumstances but they have less control over when the visibility shifts occur. Jeannine A. Gailey, *The Hyper(in)visible Fat Woman: Weight and Gender Discourse in Contemporary Society* (New York, NY: Palgrave Macmillan, 2014) 12-19.

[516] The effects of living with an ostomy were so profound it fundamentally shifted self-identity. The researchers found that the adults they studied among "realize that they are never going to be who they once were but attempt an approximation of their former selves through narrative reappraisals that reposition suffering, making the threats and losses they have endured more bearable." Andrea Altschuler, et al., "'I Didn't Feel Like I Was a Person Anymore': Realigning Full Adult Personhood after Ostomy Surgery." *Medical Anthropology Quarterly* 28, no. 2 (2014), 245.

[517] Altschuler, et al., 244.

stigma was an important finding in this study, it also confirmed what my co-researchers noted: a person living with disease is never fully identified by the disease. A disease cannot usurp all of one's identity because an essence remains intact that is not diseased.[518] The co-researchers for this study were insistent that their children's identities could not be collapsed into the ostomy.[519] Ultimately, abjection theory examines how fear about the body and the bodies of others impedes social and religious inclusion and impacts the identity of those living with the effects of illness.

Abjection Theory Correlated with Theology

Co-researchers repeatedly refuted the notion that the embodied difference of their children was the exclusive identity marker for that child. They proclaimed an indelible good that was not ultimately usurped by their anxious responses or the anxious responses of others. Yet anxious responses to embodied finitude can lead to the marginalization of those experiencing disease and embodied difference and the objectification of the body. My correlation will address how 1) abjection theory augments a theological understanding of anxiety and that 2) the theological category of the *imago Dei* offers a corrective to abjection theory.

Abjection theory augments a theological understanding of anxiety.

Abjection theory highlights how the finitude of the body can be anxiety producing, resulting in sinful actions. Bodies are finite, yet humanity has the ability to contemplate beyond these concreate realities. Reinhold Niebuhr says that humanity has the capacity and freedom to critically reflect on lived experience[520] but this reflective ability or capacity does not change the vulnerability of finite human creatureliness; humanity is not God.[521] Wrestling with

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[518] Altschuler, et al., 252.

[519] Since this study did not take into account the direct experiences of the children living with an ostomy the findings from van der Riet and Waskul or Altschuler, et al. are not confirmable within the context of this study. Yet, parents shared similar themes for this research. Such a question is beyond the scope of this project.

[520] Reinhold Niebuhr says that humanity has the "ability to stand outside and beyond the world," Niebuhr, 124.

[521] Niebuhr, 124-5.

embodied finitude is anxiety-producing,[522] especially in light of a desire to escape this finitude.

Humanity experiences anxiety about the finitude of the body but anxiety, itself, is not a sin.[523] The experience of anxiety, however, can lead humanity into sin—like rendering bodies abject rather than knowing that they are created good. When we experience the pains of the body and the struggle of illness within historical and social contexts and in light of the tragic, we are inclined to malign our body and the bodies of others. We are deceived[524] into believing that the body is the source of our suffering rather than acknowledging illness as suffering's root cause. Humanity, then, has the capacity to render our bodies, and the bodies of others, as abject.

Anxiety causes humanity to fear and loath the frailty of a finite body. This anxiety undermines our ability to recognize the body's indelible goodness. Ricoeur describes freedom as humanity's "power to defect"[525] from innate goodness. He indicates that humanity is "destined for good and inclined to evil."[526] Humanity is born into the tragic and humanity acts within those conditions. Our capacity to see the body as a good gift of creation is undermined. Humanity defects: we see bodies as abject. Even if we fundamentally know that the body is good, we are snared by the tragic and swayed by the sentiment that the body is disgusting or a source of contagion. Furthermore, we begin to fear that we, too, will eventually become the object of other's abjection. This exacerbates a sinful response. We react sinfully and distance ourselves from our own bodies and the bodies of others—we render them as abject—rather than seeing the body as good gift of creation.

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[522] Edward Farley nuances anxiety with, "The term [anxiety] does not describe a momentary psychological incident of a fearful anticipation of a specific future peril but the mood that attends the agent's awareness of its own non-necessity." Edward Farley, 124.

[523] Niebuhr, 182-3.

[524] Wendy Farley describes deception as the "most ubiquitous feature of sin" (44). Deception involves humanity's ability to participate in sin because humanity is blinded by the true nature of evil. Deception obscures our commitments and abilities to recognize the goodness of the body. Wendy Farley, *Tragic Vision*, 44-6

[525] Ricoeur, 233.

[526] Ricoeur, 234.

Rendering bodies and selves as abject ruptures relationships and, therefore, illustrates a sinful response to anxiety. Julia Kristeva argues that laws of purity and defilement help define the parameters of and participation in religious practice.[527] Social and religious rules that govern filth or what is clean and unclean have little to do with the filth itself. Filth symbolizes a degradation to order and is not a condition of being. Anthropologist Mary Douglas argues that expectations about the body "mirror" social fears. [528] She suggests that organizing or cleansing filth is the same as organizing the social environment.[529] In this case, "dirt" or "filth" is not an unmitigated category. Disgust, as it pertains to the "margins" (margins of the body and of society), are context-specific. Disgust is directly related to fear and discomfort around what or who is at the margins.[530]

Martha Nussbaum, philosopher and professor of law and ethics, argues that disgust is a powerful social means of developing a criterion of inclusion. She says, the "power of disgust [acts] as a barrier to the full equality and mutual respect of all citizens."[531] Disgust is such a powerful motivator in maintaining the status quo because so much of what humans find disgusting is rooted in a disgust of the body.[532] Disgust is related to what the body and bodily matter represent within a given historical context. Exclusion becomes a means of social preservation and integrity of boundaries—social or bodily boundaries. [533] In this manner, disgust

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[527] Kristeva, 90-2.

[528] Mary Douglas, *Purity and Danger: An Analysis of Concepts of Pollution and Taboo* (New York, NY: Routledge Press, 1966), 122-3 and Lisa Isherwood and Elizabeth Stuart, *Introducing Body Theology* (Sheffield, England: Sheffield Academic Press, 1998), 53.

[529] Douglas, 2.

[530] Douglas, 122-3.

[531] Nussbaum, 115.

[532] Not only would humanity need a systematic evaluation of social disgust but the link between social marginalization and bodily disgust is conflated to the point in which an honest assessment of our disgust at the body would be a necessary precursor. "Disgust at the body and its products has collaborated with the maintenance of injurious social hierarchies. Nussbaum, 117.

[533] Douglas says, "[A]ll margins are dangerous. If they are pulled this way or that the shape of fundamental experience is altered." Those at the margins of society are the most probable to cross the boundaries of inclusion. The incorporation of those who crossed the boundary alters the overall composition of the group. Douglas, 122.

functions like defilement, as defined by Ricoeur.

Ricoeur asserts that defilement is conflated with suffering and "misfortune."[534] This conflation heightens the gravity of what Kristeva, Douglas, and Nussbaum argue. Kristeva, Douglas, and Nussbaum illustrate that disgust about the body culminates in exclusion from relationship and/or community. It is Ricoeur who insisted that humanity avoids defilement as a way of avoiding personal suffering. Relationships with those deemed defiled (or rendered abject) may hamper our own social inclusion. For example, my co-researcher Rebecca shared that when she and Amanda are together, they sometimes eats lunch in their car rather than sitting in the restaurant. Rebecca recounted how people often stare at them when out in public. She remembered that when Amanda was a toddler it was easier to "fit in." Now, people seem less willing, according to Rebecca's assessment, to accept her daughter's wheelchair, toddler-age toys, and behaviors. Ricoeur's argument illustrates how humanity, though created for good, is enticed toward a sinful reaction to anxiety about our finite inclusion within a social group. Rebecca noticed how Amanda's differences hamper her own social inclusion and Rebecca feels marginalized by association. We marginalize others so we are not marginalized by association.

Marginalization is an effect of defilement. Defilement distinguishes a boundary between what is pure and what is impure. Labeling something as defiled seemingly justifies its removal from a relationship. Not only is the person excluded from community but her or his very body is reduced and diminished—rendered abject. The interpersonal and intrapersonal relationships are ruptured when we render our body or the body of others as abject. This rendering harkens back to theologian Fumitaka Matsuoka's description of sin as a "negation of relationship."[535] Labeling somebody or some-body "impure" is an attempt at preserving the existing conditions of

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[534] Ricoeur, 27.

[535] Matsuoka, 57-9.

a community (or of the body) prior to disease.[536] Marginalization maintains the status quo and our "clean" position within it. Defilement obscures the reality that every body—even those experiencing disease—is created good.

The imago Dei corrects abjection theory.

The theological category of the *imago Dei* offers a corrective to abjection theory. The body is created, and it is good. At an initial glance, the theological claim that the body is innately good seems to be a concept derived from revelation.[537] Reinhold Niebuhr asserts that "God's creation of and relation to the world" is proof that the finite body is good.[538] The proposition that the body is essentially good is a risky one in light of compelling alternative narratives proposed within abjection theory, which asserts the contrary. While humanity is created for good, suffering and anxieties about finitude disrupt and obstruct our abilities to act in accordance with that goodness. Humanity maligns her own body and gives power to abjection, marginalizing the beautifully-created body.

The Incarnation is a central Christian theological theme that acts as a powerful symbol of the goodness of the body.[539] God took up an embodied dwelling in human form. Wendy Farley describes the correlation between the incarnation and the human body:

> The Divine Eros clothed herself with flesh and a human form, revealing that there is no contradiction between bearing God and living in a in a body, in the world. In Christ, not only is the soul created in the likeness of the Divine, but the Divine is created in the likeness of human form. The incarnation awakens us to the power of the human form to bear such intimate presence of Holy Mystery within its own body.[540]

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[536] Ricoeur, 40.

[537] Niebuhr says, "The whole Biblical interpretation of life and history rests upon the assumption that the created world, the world of finite, dependent and contingent existence, is not evil by reason of its finitude." Assumptions about the body are vast in theological literature. Niebuhr argues for the goodness of the body but such an argument rests on the assumption that the body, because created, is good—because God created and declared it to be so. Niebuhr, 167.

[538] Niebuhr, 126-7.

[539] Eiesland, 91.

[540] Wendy Farley, *Wounding and Healing*, 105.

The body is not a detriment to the Divine. In fact, the body is the mechanism that displays the diversity and complexity of God in and to this world.

Believing that the body is innately good can be quite audacious, particularly when the body feels frail because of disease. Comprehending the goodness of the body, in the midst of pain and disease, is made difficult because if goodness is not felt, it is not recognized. The goodness of the body is a reticent story or experience. When living with illness we experience suffering due to physical pain and marginalization. The narrative of brokenness becomes the central plot. Under these conditions, we fail to recognize the body as good.

The *imago Dei* refutes the degrading power of abjection. A seemingly audacious claim—that the body is ultimately good, that difference is beautiful—is self-evident to the parents I interviewed. Abjection, however, obscure this truth in one particular way. The embodied *imago Dei* is not predicated on a body's adherence to one specific standard. In fact, the *imago Dei* highlights God's creative alterity. In this regard, the theological commitment to an embodied, relational *imago Dei* corrects assertions from abjection theory.

The language used to describe the *imago Dei* has implications for the care of humanity. Thomas Reynolds contends, "Christians have often interpreted disability as a distortion of God's purpose, a marring of the image of God."[541] Nancy Eiesland argues that only after resurrection—after the body of Jesus is broken and ruptured—can we understand how Jesus is the Christ.[542] She claims, therefore, that we only know God as disabled, bearing the marks of physical and social brokenness. Reynolds suggests, "[T]he image we have of God has dramatic consequences for how we interpret the image of God in human beings."[543] An image of the

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[541] Reynolds, 177.
[542] Eiesland, 100-5.
[543] Reynolds, 179.

broken body of God-made-flesh challenges a narrow portrait of who is made in the image of God and challenges an "able-bodied bias."[544] This affirmation makes one of the most revered theological claims—humanity is created in the image of God—more accessible.

What do we expect to see in ourselves and others when we speak about or identify the *imago Dei*? Hannah, in talking to her daughter Zoe, says, "Babe, you're beautiful. That bag makes you even more beautiful because it makes you healthy. Never be ashamed of it." Are we looking for some mythical, imaginary image that is so encumbered by stories of what we think of as "normal" that we miss the beauty of alterity? Are we disappointed, or worse, persuaded toward sin, exclusion, fear, and loathing because we are surprised by the images of God that we find? To say that humanity is created in the image of God, and that this image is 1) embodied and 2) a fundamental quality of humanity, is a powerful theological commitment. If this claim is made without an awareness of the power of abjection—which depreciates the value of embodied differences and the goodness within finitude—the theological claim lacks *gravitas*.

Professing an indelible goodness of the body can act like a theological lifeline for those who have experienced the abjection of their bodies by self or others. Such a position corrects the powerful, albeit incorrect, assertion within abjection theory that diminishes the goodness of the body. Rubem Alves raises the question about the function of theology within institutional life.[545] Alves argues that if we fail to allow context and embodied experience to solve institutional problems, theology becomes nothing more than a self-serving ideology that often reinforces institutional norms.[546] Recognizing and deeply embracing the innate goodness of the body is a powerful corrective in the midst of social and theological narratives that devalue

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[544] Eiesland, 104.
[545] Alves, 127.
[546] Alves, 125-27.

and depreciate the body. It also tunes our attention to the ways that abjection is a sinful response to anxiety.

Families living with the effects of chronic illness testify to their intrinsic, lived knowledge that the body, even when it functions differently or when it is a source of suffering, is very good. This was the assertion of my co-researchers, and the stakes are high. In the midst of pervasive narratives that attempt to frame the body as loathsome, terrifying, or the genesis of sin, the theological legitimacy of a body, which is created good, is imperative! Nancy Eiesland notes, “In a society where denial of our particular bodies and questioning for a better body is ‘normal,’ respect for our own bodies in an act of resistance and liberation.”[547] Claims about the innate goodness of the body are not matters of optimism or special theological revelation. It is a matter of survival amid powerful contradictory narratives.

Niebuhr argues that evil, while inevitable and “presupposed,”[548] does not define humanity. Sinfulness is not ontological. Such a claim would challenge both the goodness of humanity and the goodness of embodied existence. This claim does not, however, negate humanity’s responsibility for choosing evil.[549] Humanity has the freedom to act within the limitations of our finitude. Humanity also has the freedom to act upon anxious responses to evidence of the tragic. A sinful response to anxiety is the human capacity to render our bodies and the bodies of others as abject. Humanity’s anxious response to evidence of the tragic distorts the possibilities of human freedom. To understand this response better I will define normalcy discourses and correlate that theory with the theological contributions toward understanding the tragic.

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[547] Eiesland, 96.

[548] Niebuhr, 254.

[549] Niebuhr, 254-55.

Normalcy Discourse

Jasmine quickly identified how her son, Liam, was subjected to social stigmas because of his ileostomy. Jasmine recognized how society framed Liam's body: "Because you have to have a bag of your poop, which you empty quite frequently, they say that you are ugly and that you are not accepted by society? No! It's society that is ugly." It is not Liam's body that is a problem; it is a collective anxiety over finitude and the maintenance of normalcy that creates a problem for individuals like Liam. An anxiety over this shared finitude and the myths around body-normalcy prompts humanity toward oppression and marginalization rather than toward love.

Social and systemic structures and narratives, which augment and perpetuate fear and loathing related to bodies, create the conditions for abjection.[550] The body itself is never abject. These social and systemic structures and narratives are called normalcy discourses.[551] Normalcy discourses shape our expectations about body function and body appearance within society. Abjection and normalcy discourses have a symbiotic relationship: 1) abjection is made to seem reasonable by normalcy discourses that perpetuate and maintain disgust about the body, and 2) normalcy discourses make abjection seem justifiable—normal.

In this section I will first define normalcy discourses. I will then correlate normalcy discourse theory with the theologies of Nancy Eiesland and Thomas Reynolds to demonstrate how normalcy discourses strengthen our understanding of the tragic. Finally, I will correlate Wendy Farley's theological definition of callousness with normalcy discourses. This correlation will augment our capacity to see how normalcy discourses influence sinful behavior. Humanity does not react sinfully (rendering our bodies and the bodies of other as abject) *because* of

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[550] Young, 145.

[551] Theorists use terms like, "discourses of normalcy," "normality discourses," or "normalizing discourses."

normalcy discourse but rather humanity becomes calloused to the effects of normalcy discourses.

Normalcy Discourses Defined

There is no unified term within the literature that defines the concept of an illusory norm and the way norms function in regulating social expectations. Authors from Sociology, Disability Studies, Medical Humanities, and Philosophy use a variation on the term "normal" in conjunction with the term "discourse" from Critical Theory to describe a common set of experiences. Although the exact term varies, the authors are describing similar criteria. I have decided to use the term "normalcy discourse" for this project.

Normalcy discourses form and shape human identity and perceptions about the body. A normalcy discourse is a theory grounded in the fusion of its two terms: normal and discourse. It is rooted in an ideology about what is normal. Saying that something is "normal" is a reference toward an ideology. Stephen Brookfield notes, "When a belief seems natural and obvious and when it serves to reproduce existing systems, structures, and behaviors, it is ideological."[552] Since "normal" is ideological we are persuaded to believe that our definitions of "normal" are correct.[553] While the cognate term "normal" is applied within social science to a vast array of ideas and items my primary concern is how the ideology of "normal" impacts our understanding about the body and the body's appearance within a context.

The word "normal" holds an ambivalent meaning; there is no objective definition. Dominant groups,[554] with the force of cultural imperialism,[555] attempt to define what is normal.

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[552] Stephen D. Brookfield, *The Power of Critical Theory: Liberating Adult Learning and Teaching* (San Francisco: Jossey-Bass, 2005), 67.

[553] Brookfield writes, "[An] ideology endures partly because it contains elements that people recognize as accurate in their experience." Brookfield, 67.

[554] A dominant group is one that has the power or social, economic, or political resources to define the parameters of inclusion and exclusion of the group.

[555] Iris Marion Young suggests that cultural imperialism is a "paradox of experiencing oneself as invisible at the same time that one is marked out as different" (Young, 60). Cultural imperialism is maintained because "the dominant group reinforces its position by bringing the other groups under the measure of its dominant norms"

Cultural imperialism is defined by Young as "the universalization of the dominant group's experience and culture, and its establishment as the norm."[556] Some groups are defined as "ugly or fearsome and produce adverse reactions in relation to members of [dominant] groups."[557] Dominant groups, or those with institutional or social power, develop normalcy discourses that delineate characteristics not only of what is "normal" but who is included within the parameters of that definition.[558] The concepts of "normal" and "normalcy" emerge from a variety of disciplines from medicine and kinesiology to sociology.

"Discourse" is a concept adopted from critical theory. A discourse is more than language, speech, ideas, or ideology. Discourses have the potential to mold and form subjects and objects. Discourses not only account for "how" and "what" is communicated but discourses also account for the politics of a context.[559] Discourses hold the power to "constitute the subjects and objects of which they speak."[560] Discourses shape realities and meanings.

Defining normal is subjective and influenced by intersecting oppressions. The very definition of normal is grounded in our own assumptions and categorizations of people. Sociologist Erving Goffman contends that stigma arises because society generates "the means of categorizing persons and the complements or attributes felt to be ordinary and natural."[561] We "lean in" (so to speak) to our expectations and anticipate certain qualities. Goffman argues that

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(Young, 59). Young goes on to suggest that "an encounter with other groups, however, can challenge the dominant group's claim to universality" (Young, 59).

[556] Young, 59.

[557] Young, 145.

[558] Medical historian, philosopher, and physician, Georges Canguilhem argues that the construction of disease and health was subject to institutional power. He suggests that disease defined as different from health and the pathological as the opposite of normal. He notes that these definitions were subject to context and institutional powers. Georges Canguilhem, *The Normal and the Pathological*, trans. Carolyn R. Fawcett with Robert S. Cohen (New York, NY: Zone Books, 1966, 1991), 40-1.

[559] Michel Foucault, *The Archeology of Knowledge: And the Discourse on Language* (New York, NY: Pantheon, 1972), 48-49.

[560] Thomas A. Schwandt, *The SAGE Dictionary of Qualitative Inquiry*, 3rd ed. (Thousand Oaks, CA: SAGE Publications, 2007), 73.

[561] Goffman, 2.

these expectations and assumptions form the basis of what is considered right, healthy, or normal.[562]

Determining criteria for "normal" is all-the-more complex and difficult because the very definition is impacted by other intersecting (and often equally ambiguously defined) categories like age, race, gender, or class. Researching specifically about masculinity and health, kinesiologist Moss Norman writes, "[D]iscourse of the normal did not give rise to one homogenous and universal way of embodying" humanity.[563] He further notes, "[T]erms like 'average' and 'normal' might conjure images of being easily attainable, almost naturally occurring."[564] He found that matching the "normal" ideal was near impossible. Having a "normal" body takes on a frustrating semblance of something easily achievable yet perpetually shifting and subject to contextual criterion. The task of becoming or being "normal" is impossible because its very definition and experience is built on an ideology. Ideologies, which reify normalcy, can also be oppressive because they include and privilege some but exclude and stigmatize others. We must pay attention to whose interests are being served and whose anxieties are ameliorated by maintaining normalcy discourses.

Normalcy Discourses Correlated with Theology

Normalcy discourses, when correlated with a theological understanding of the tragic, reveal stronger evidence of the tragic. Appreciating the force and the command of a normalcy discourse helps us understand more deeply the tragic nature of our contexts. Sinful actions like the marginalization of others, the disregard of our own bodies, or rendering others and self as

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[562] Goffman, 2.

[563] Moss E. Norman, "Embodying the Double-Bind of Masculinity: Young Men and Discourses of Normalcy, Health, Heterosexuality, and Individualism," *Men and Masculinities* 14, no. 4 (2011): 437, sagepub.com/journalsPermissions.nav DOI: 10.1177/1097184X11409360.

[564] Norman, 438.

abject do not emanate from an empty void. Sin emerges in the midst of broken contexts. Correlating a theological concept of callousness with normalcy discourses reveals how humans become "acclimated" to the broken contexts within which we live. Humanity, thus, acts in sinful ways that are contrary to our created ideal—the *imago Dei*.

Normalcy discourses strengthen our understanding of the tragic.

Normalcy discourses give evidence of the tragic. Sin and humanity's goodness coexist. Humanity is not known, however, apart from historical contexts. Part of this "historical context" is the discourses of normalcy that frame, influence, and interpret our relationships and self-understanding. We interpret our bodies and the bodies of others through lenses of normalcy. What is described as "normal" is so ubiquitous and hegemonic (making it nearly unidentifiable) and yet it shapes human identity.

Institutions perpetuate normalcy discourse. As a dominant group universalizes its "experience and culture," it establishes a norm.[565] An emergent analysis identifies how "institutional policies, beliefs, norms, and practices perpetuate ableism"[566] rather than inclusion. No body is disabled but institutional practices, social assumptions, and ideologies about what is "normal" create disabling contexts for individuals and communities.[567] It also creates the conditions by which we evaluate bodies: normalcy discourses serve as a way to maintain the

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[565] Iris Marion Young defined this action as Cultural Imperialism, one form of oppression. Those experiencing cultural imperialism are "stamped with an essence. The stereotypes confine them to a nature which is often attached in some way to their bodies, and which thus cannot easily be denied." Young, 59.

[566] Pat Griffin, Madeline L. Peters, Robin M. Smith, "Ableism Curriculum Design," in *Teaching for Diversity and Social Justice*, 2nd ed., ed. Maurianne Adams, Lee Ann Bell, Pat Griffin (New York, NY: Routledge Press, 2007), 339.

Nancy Eiesland notes that legislation of the 1960's and 70's, which was meant to augment access and resources for people, also had a powerful effect in "reinforce[ing] views of disability that highlighted the existence of a minority group whose commonality was exclusion and discrimination on the basis of disability." Eiesland, 56.

[567] Nancy Eiesland argues that "the locus of the problem of disability is neither the psyches nor the bodies of individuals with disabilities, but rather it is the system of social relations and institutions that has accomplished the marginalization of people with disabilities as a group." Eiesland, 62.

status quo and the illusion that "normal" is attainable, desirable, or even definable.

The Christian Church, its theologies and practices, is not immune to the presumptions of what is normal. Assumptions about what is "normal" informs our assumptions about what types of bodies depict a humanity that is created in the image of God. We neglect to see the *imago Dei* (which is embodied, created, relational, and good) when a body—a person—does not correspond with our perceptions of normal. This perception becomes particularly problematic when we reduce and depreciate the profound inclusivity of the *imago Dei* or when differences are regarded as anomalies, abnormalities, or deviances. Our relationships with our own bodies and with others suffer and we do not fulfill the moral obligation of being created in the *imago Dei*.

When difference is regarded as deviance it limits our capacities for mutual and moral relationships. Theologian Thomas Reynolds describes the pervasiveness and persuasiveness of normalcy discourses as the "cult of normalcy,"[568] which he defined as "a set of rituals trained upon demarcating and policing the borders of a 'normal' way of being. Bodies are regulated so as to remediate and thus neutralize their deviance."[569] The word "cult" carries a profound effect. It highlights a willingness and desire to comply, to fit in, to be "normal." It also highlights how the power of social discourses shape our perceptions about the bodies of self and others. Society bolsters the normalcy discourses and normalcy discourses interpret bodies. Reynolds correctly asserts that the consequence of the cult of normalcy is that "the different body is treated with indifference, suspicion, or revulsion."[570] This indifference impedes our capacities to love and care for our own differences and the differences of others.

When difference is regarded as deviance, institutional and systemic ideologies of what

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[568] Reynolds, 59-63.
[569] Reynolds, 60.
[570] Reynolds, 60.

constitutes "normal," incentivizes sin. Humanity does not act sinfully—rendering our bodies and the bodies of other as abject—simply because sinfulness is an ontological condition of humanity. Certainly not! Rather, humanity is enticed to sin, to marginalize others, and objectify bodies because we think we are acting in accordance to what is normal. We are persuaded to act not in accordance with our ideal—a relational *imago Dei*—but in accordance with the constraints of our historical contexts, which are guided by normalcy discourses. This contextualization is how normalcy discourses give evidence to the tragic. Normalcy discourses are "already present" and taken to be true. We attempt to bring bodies into conformity without questioning the tenants that guide the action. To understand how humanity reacts sinfully, it is helpful to examine callousness, as described by Wendy Farley.

Humanity grows calloused to normalcy discourses.

Normalcy discourse asserts that humanity is deceived by the discursive force of what is "normal." This concept, when viewed through the lens of Wendy Farley's description of callousness, highlights how humanity is susceptible to the persuasive powers of what is considered "normal." "Normal" forms a canon by which we evaluate bodies. Callousness augments our propensity to sin: to render the body as abject; marginalizing others and depreciating our own bodies. Callousness also helps describe how well-meaning individuals perpetuate ideologies about whom/what is normal.

The ubiquity of normalcy discourses increases callousness and incentivizes sinful behavior. A sinful nature is not ontological. Normalcy discourses offer humanity "occasions"[571] for sin. Normalcy discourses have a way of covering up the indelible goodness of embodied difference. Because of normalcy discourses, we depreciate the value and beauty of

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[571] Niebuhr, 167.

difference—labeling difference as deviance rather than a dazzling component of God's creativity. It becomes easier to equate conformity or sameness with "normal." We have the capacity to treat our own bodies and the bodies of others as abject because difference takes on the appearance of a depreciated version of the ideal: in other words, a depreciated version of what is normal.

We rub against normalcy discourses with such frequency that we become "calloused" to their power and messages. "Normal" seems right because it is accurate to our experience.[572] It is hard to dismantle and critically evaluate the politics of our definition of normal. It seems natural to stay away from bodies that have been rendered defiled, abject, loathsome, a source of contagion, or different. Our participation in sin—negating our relationships with our own bodies and the bodies of others—happens without our awareness.[573]

Normalcy discourses are so ubiquitous that well-meaning, upright people marginalize those experiencing disease or embodied difference. Humanity is persuaded, deceived[574] into sin by believing that "normal" is an a-political, natural, definable condition. Furthermore, normal becomes a measuring guide by which we regulate and compare ourselves and others, degrading the beauty of alterity. Humanity participates in the abjection of others and perpetuates normalcy discourses because we (falsely) protect those who more easily fit within the parameters of "normal." We fail to dismantle how sin functions as a lie within normalcy discourses because we risk upending our own position within the status quo. Disgust plays a pivotal role in maintaining barriers, limiting access, equality, and respect for every body.[575] Normalcy discourses take on a dominant group/self-serving capacity. We risk giving access to all forms of

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[572] Brookfield, 67.
[573] Wendy Farley, *Tragic Vision*, 46-8.
[574] Wendy Farley describes deception as a "willingness to be beguiled." Wendy Farley, *Tragic Vision*, 44.
[575] Nussbaum, 115.

bodies.

Since the *imago Dei*—an embodied, created, relational good—can easily be overlooked when the dwelling of the *imago Dei* does not coincide with our perception of what is normal, we miss seeing the beauty of variation. We are blinded by an insatiable, yet undefinable, desire to coincide with the normal. The statements of Allison and Rebecca describe this reality:

> Allison: I worry the older she gets the more people will not accept her because of just the norm. “That’s not normal.” Which, I think if she’s happy and positive about it you know, then I think it’s fine. But I also think about, well, you know, what if when she gets older, she can’t find a spouse or anything, because that might hinder her.
>
> Rebecca: Is Amanda normal by the world’s norms? No. She’s not. But is she ok in God’s eyes? I believe that [God] allowed her to be, that [God] created her this way. Not even allowed, but *created* her this way. I would like to think [God] doesn’t think she’s abnormal. I mean this is the way she’s supposed to be in this world… I guess I want people to know that she’s precious, just the way she is.

Many parents are worried, as demonstrated by Allison and Rebecca, about the effect an ostomy would have on their child. Many expressed concerns that their child would be marginalized because their body was not “normal.”

Normalcy discourses make abjection seem justifiable. We believe that our exclusion and the exclusion of others from relationship is based on logical criteria. Abjection can be read as a sinful response to anxiety about fragility (physical and social fragility). Those abject-ed take on the *appearance* of an “inherent disorder” that “threatens, contaminates, or pollutes the bounded system of bodies, selves, and society.”[576] It seems natural to experience disgust and fear toward the body, particularly when the body is the site of disease. We fear abjection because we fear contagion from others, we fear our own bodily fragility, and we experience the effects of social fragility in the form of marginalization. As we interpret differences in the body as abject (rather

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[576] van der Riet and Waskul, 509.

than good) we think that it is justifiable to say that embodied differences are not “normal,” and this justification reinforces normalcy discourses.

Conclusion: Reframing Practices of Care

I have demonstrated how theologians like Reinhold Niebuhr, Wendy Farley, and Nancy Eiesland affirm the innate beauty and goodness of the human body. The body, while finite, is part of a good creation. The parents interviewed for this study readily identified this embodied goodness in their children. This embodied goodness did not diminish when their children received their ostomy.

Embodied goodness is not compromised by a GI ostomy. A gastrointestinal ostomy is a visible sign and representation of the vulnerabilities and finitude of our flesh and of our social contexts. We are capable of marginalizing and depreciating the body—we render the body and others as abject. Abjection offers an illustration of humanity’s capacity to react sinfully to anxieties that emerge as we encounter these finite constraints.

Fear and disgust about the body, embodied differences, and the body’s temporality are fueled by normalcy discourses. When the body looks or functions differently, we expect these differences to be indicative of deviance because the difference appears “abnormal” to us. Our relationships with each other, with God, and with our own finite bodies are compromised as we grow calloused to these ubiquitous normalcy discourses that shape our perception about our bodies and the bodies of others. Our abilities to love the finitude of God’s creation is compromised by normalcy discourses and we do not act in accordance with our created ideal—a relational, embodied *imago Dei*.

An objective of this chapter was to better understand the experiences of my co-researchers. I also demonstrated how my co-researchers’ lived experiences, caring for their children, strengthen and revise our understanding of a few key theological concepts. Their lived experiences, in correlation with normalcy discourse theory, amplify our understanding of the tragic. Humanity callously reproduces these normalcy discourses. Abjection theory, in correlation with the lived experience of my co-researchers, demonstrates how the finitude of the body can be anxiety producing, resulting in sinful action that diminishes mutual relationships. I have argued that interpreting the *imago Dei* as a good, created, embodied ideal for humanity offers a corrective to the diminishing power of abjection.

It is incomplete, however, to simply understand the experiences of my co-researchers and their children. While their lived wisdom challenges and changes a few deeply held social structures and theological arguments, it also amends our practices of care. I will conclude this chapter by way of an introduction. In the forthcoming chapter I will demonstrate how our practices of care are revised based on the lived experience of my co-researchers.

Normalcy discourses and abjection require us to change our practices of care. Theorists who write about abjection note how anxiety about embodied finitude pushes people apart. They rightfully argue that abjection creates separations and distinctions between groups and individuals or between parts of a singular body. It becomes difficult for humanity to enact our "compassionate obligation"[577] toward each other and toward our own bodies when we have rendered them abject. Abjection, as a reaction to illness, is not a forgone conclusion.

Illness offers humanity both "danger and opportunity."[578] Danger and opportunity are mutually inclusive. Danger is the endless "self-absorption" that accompanies illness, the constant attention to all that is wrong with the body.[579] Sociologist Arthur Frank says that

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[577] Edward Farley, 43.

[578] Arthur W. Frank, *At the Will of the Body: Reflections on Illness* (Boston, MA: Houghton Mifflin Company, 1991) 143.

[579] Frank, *At the Will of the Body*, 143.

opportunity is the glimmer of a shared vulnerability.[580] This definition of opportunity is remarkably similar to Edward Farley's definition of compassion: "being drawn toward the other's fragility."[581] We catch a glimpse of the *imago Dei* in acts of compassion;[582] attitudes and actions that 1) turn us toward our own finite and vulnerable bodies and 2) turn us toward each other.

Compassion and obligation are also products of humanity's anxious creativity.[583] Sociologist Iris Marion Young describes the abject as "fascinating."[584] While Young uses this term to indicate a near-sinister curiosity about disgust, the curiosity of difference draws us toward the abject.[585] Curiosity draws us into a position of inquiry about the "other." It is an identification with the near-resemblance of the "other" to ourselves that motivates this curiosity. Curiosity has the capacity to invigorate compassion and love. Niebuhr is correct to assert that anxiety, though a precondition of sin, is not ultimately a sin. Anxiety is also the source of human creativity.[586] Curiosity about those rendered abject is also the genesis of compassionate action. Compassion evokes a response and obligation turns us toward the suffering of the other.[587] In the forthcoming chapter I will detail how anxiety narratives are not just narratives detailing various paralyzing fears. Anxiety also offers motivating potential for my co-researchers. The perpetual presence of anxiety causes them to take action to lovingly care and advocate for their

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[580] Frank, *At the Will of the Body* 143.

[581] Edward Farley, 42.

[582] Wendy Farley, *Tragic Vision*, 51.

[583] Creativity is relational. Thomas Reynolds writes, "God invites participation in God's own creative activity, giving over to human beings the task of tending to the becoming world. We are called to create from chaos, to nurture order, and provide blessing" (Reynolds, 180). Humanity's invitation is to create from chaos—from the midst of the chaos of abjection.

[584] Young, 143.

[585] Young, 143.

[586] Niebuhr, 183.

[587] Edward Farley notes, "Being summoned by the fragility of the other not only evokes a suffering-with (compassion) but also a suffering-for (obligation)." Edward Farley, 43.

children.

Anxiety is always a part of my co-researchers' illness narratives but anxiety is often seen as a productive force. Anxiety compelled Leticia to stand up to a grocery store employee when Samuel was accused of shoplifting. (He was simply carrying his feeding pump behind him in a rolling backpack.) Anxiety urged Crystal, Hannah, and Sara to notice subtle changes in Owen, Zoe, and Mason's body functions and rush to the hospital at the first signs of trouble. Anxiety compelled Stephen to be a student of Owen and his disease because Stephen knows:

> The more you are there, the more active you are in his care, the more questions you ask, and the more of a pain in the ass you are to everybody the better the resource you are when things go bad… We knew so much about him and what he had gone through, what drugs he had been on, how long, what were his feeding schedules—all that stuff helps them.[588]

Anxiety heightens awareness to notice: to notice subtle changes in the body, to notice the pervasiveness of normalcy discourses, or to notice that the body—while experiencing the suffering of disease—is still good.

Normalcy discourses diminish our capacity to enact our "compassionate obligation"[589] toward our own bodies and the bodies of others. Normalcy discourses give evidence of the tragic. They shape the way that humanity interprets and cares for bodies. Humanity grows calloused to normalcy discourses. This callousness makes it possible for well-meaning individuals to marginalize and render abject our own bodies and the bodies of others.

The terms "normalize" and "normalcy" often overlap in the literature but I want to draw a clear and specific distinction between the two concepts.[590] Normalization is thought to enable

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[588] "Them" refers to the physicians, nurses, and therapists that care for Owen.

[589] Edward Farley, 43.

[590] Rather than differentiating between the terms "normalize" and "normalcy" theologian Thomas Reynolds describes a two-edged understanding of normalization. Normalization can have a "positive connotation in that persons are directed toward rehabilitation and social reintegration" (p. 68). Yet there is an overwhelming negative connotation to the word "normalization" because it is predicated on the assumption that "normal" can be defined.

those experiencing illness or difference a way to maintain or develop a positive self-identity in the midst of compelling counter-narratives. Andrea Altschuler, Michelle Ramirez, Carmit McMullen, Marcia Grant, Mark Hornbrook, and Robert Krouse say of normalization:

> [Normalization] entails maintaining a feeling of personal worth and a "sense of coherence" or potency in the face of disruption—so that the impact of the illness and its effects on the person's identity remain relatively slight—or regarding the illness or treatment regimen as normal to incorporate it more fully into the person's identity.[591]

The intent of normalization is to maintain the intrusion of disease or corresponding marginalization because of illness and difference. We are enticed to normalize a difference. Some practices of care are constructed with the guiding principle of bringing people closer to the "normal."

Anthropologist Myra Bluebond-Langer researched the impacts of cystic fibrosis on family and sibling relationships. Bluebond-Langer notes, "[O]ne must never lose sight of the fact that well siblings and their families live in a society where chronic illness and disability are stigmatized, and normalcy, control and order are valued."[592] She describes how families developed "normal" routines and activities in the periods between disease exacerbations and hospitalizations.[593] Normalization is predicated on a shared definition and ideology of "normal."[594] Thomas Reynolds sums up the problem of normalization: "[T]he normal is an

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Furthermore, it gives "unchecked license" to social whims or dominant social and medical standards to define and cultivate the definition and characteristics of "normal" (p. 68-9). Reynolds, 68-9.

Nancy Eiesland does not specifically define "normalizing" but the most pronounced use of the term has a negative connotation. Normalizing is the attempt to marginalize, exclude, or refashion the "unconventional body" (p. 39). Eiesland, 36-9. Because these terms are rarely defined and often interchanged, I have decided to draw a specific and clear distinction between normalize and normalcy because, like Reynolds, I believe there is a positive and negative connotation that must be explored.

[591] Altschuler, et al., 254.

[592] Myra Bluebond-Langer, *In the Shadow if Illness: Parents and Siblings of the Chronically Ill Child* (Princeton, NJ: Princeton University Press, 1996), 266.

[593] Bluebond-Langer, 225.

[594] Reynolds, 69.

illusory image grounded in a phantom majority, pretending to represent a common condition that never really exists nor ever will."[595] The classification of "normal" assumes a shared experience of embodiment that is simply never the case.[596] The primary question is, who defines how an illness in normalized?

The parents interviewed for this project found that normalizing the ostomy was helpful only in that it mitigated the intrusion of illness.[597] They anticipated returns to the hospital and times when their children would be excluded. For these families, normalizing the illness was not about making the bodies of their children coincide with social expectations. Normalizing illness took on a particular *cyclical* quality. Families would anticipate moments at home (when their child felt well-enough or when they did not experience marginalization) followed by moments when the illness became the primary narrative plot. For my co-researchers, "mitigating the intrusion of illness" meant two things: 1) narratives of readiness as they anticipated disease exacerbation, and 2) future narratives of hope in their abilities to help their children resist marginalization. In the forthcoming chapter I will demonstrate how pastoral caregivers revise practices of care and frame new illness narratives in light of normalcy discourses and abjection theory.

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[595] Reynolds, 64.

[596] Rebecca Chopp contends that any inquiry resting on the assumption of a single shared human experience or religious experience can have detrimental consequences to resulting theologies and theories. Rebecca Chopp, "Practical Theology and Liberation," in *Formation and Reflection: The Promise of Practice Theology*, ed. Lewis S. Mudge and James N. Poling (Philadelphia, PA: Fortress Press, 1987), 130.

[597] This finding is corroborated in the work of Altschuler, et.al. It is also an important finding from Bluebond-Langer and van der Riet and Waskul. This finding is contested by Nancy Eiesland and sociologist Claire Decoteau who argue that HIV/AIDS activists used their experience of *not* normalizing disease as a compelling force in their advocacy work. Claire Decoteau "The Specter of AIDS: Testimonial Activism in the Aftermath of the Epidemic." *Sociological Theory* 26 (3): 230–57, (Sep 2008): doi:10.1111/j.1467-9558.2008.00327.x.

Chapter 5
Practices of Care

"All I can do is try not to isolate her; is to hold her when she is afraid; is to accept her as she is; as part of this family, without whom we would be less complete."
-Madeleine L'Engle, *The Summer of the Great-grandmother*

"The ill person who turns illness into story transforms fate into experience; the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability."
-Arthur Frank, *The Wounded Storyteller*

Introduction

Owen is Stephen and Crystal's son. He and his twin brother, Oliver, were premature and weighed one pound and six ounces at birth. Oliver's tiny body was too fragile, and he died one day after his birth. While Owen survived, like many micro preemies, he had many health complications. Owen and Oliver's birth hospital cared for Owen for a time, but his health became so critical that he was transferred to a higher-acuity NICU in a different hospital.

Stephen recalled the moments when the medical transport team came to take Owen. He and Crystal sat on the couch in the NICU for an unknown amount of time. Eventually they stood up from the couch and followed Owen to the higher-acuity hospital. Stephen knew that he and Crystal were needed at the new hospital because they were the best source of information about Owen's medical history; the medical record only told a partial narrative. As Stephen recalled that moment, he said:

> I don't know how long we sat there. Anyway, you collect yourself, you make your way out, and you figure out what the next step is, what's going on. You just got to pull yourself together a little bit. Your child has been taken by strangers. I mean, there's a nurse and an RT, they are professionals, but you've never seen them before, and he's off to some place and you have no idea, you've never met these people who are going to take care of him for the next however long. You just have to get over there, you know they have a thousand questions and you've got to be there to answer. I mean, they are basically getting this huge train wreck dumped in their lap and they don't know.

Stephen and Crystal peel themselves off of the couch in the NICU and make their way to the next hospital knowing that Owen's life is in the balance. Encountering Owen's embodied fragility only a few days after his birth, and very shortly after the death of his twin brother, Stephen and Crystal had a new, deeply felt awareness of anxiety related to embodied fragility.

When Owen finally went home from the NICU a new type of anxiety revealed itself. What emerged were the questions about Owen's adjustment to everyday life with his GI ostomy. Stephen recalled a moment when he "tested the waters," so to speak. He said:

> I would assume that there would be some teasing, some what-not, some pointing. But it's so far down the road you just kind of, it's more something for Crystal and I to talk about when we're going for a walk at night when he was in the hospital, "Gee, if he does have that bag his whole life, there will be some tough days in there, I'm sure." At the end of the day, it's just conversation, I suppose. As a matter of fact, the person I was kind of concerned about, not *concerned*, but curious to know what they would say was my little niece. She's like 10 or 11. And I just assumed that she'd be grossed out and not want to be… when I was that age, I would be I don't know if scared is the word, but kind of be like, that's different, I'm not used to that, I've never seen that before. And she actually wasn't.

Stephen anticipated that others might point at and tease Owen. Stephen anticipated that Owen might experience responses from others that seem to minimize his worth and responses to anxiety which "negate relationships"[598] with Owen. Stephen, though he did not use these terms, noted that people might treat Owen with disregard and disgust, rendering him abject. Stephen expressed a clear understanding regarding how anxiety-fueled normalcy discourses could cause Owen to experience additional suffering.

Crystal and Stephen have accommodated, to a certain extent, the ever-present anxiety in their lives. Crystal and Stephen, along with every other co-researcher, acknowledge that they

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[598] Fumitaka Matsuoka describes sin as a "negation of relationship" which diminished the full humanity of another that "devalues" the life of another. Fumitaka Matsuoka, *The Color of Faith: Building Community in a Multiracial Society* (Cleveland, OH, United Church Press, 1998), 57-9.

wait with bated-breath for the next "something" to happen. They couched this narrative in the terms of "our normal." Upon inquiry into what "our normal" entailed, the co-researchers spoke of living within a tension of peaceful moments when illness is not a central plot line followed by moments when the illness becomes the central character.[599] They wait with bated-breath for when the "the other shoe will drop."[600] But these narratives do not illustrate defeated parents. Most of the families I researched among accept anxiety as a productive tool and wait knowing that they *can* and *will* overcome future challenges.

The theological proposition of the *imago Dei*, as "compassionate obligation,"[601] bolsters practices of care among families experiencing chronic illness and GI ostomies. The *imago Dei* is a human ideal; a theological concept and an ethical imperative that compels humanity toward loving, caring relationships. Edward Farley argues that the *imago Dei* is enacted through "compassionate obligation." Compassion is an attunement to a shared fragility and recognition of suffering;[602] obligation is a "disposition to join with the other in her or his fragile struggles against whatever threatens and violates."[603] Thus, "Compassionate obligation" is a "suffering-with (compassion) but also a suffering-for (obligation)."[604]

Suffering in the midst of illness may seem meaningless but has potential as a "precondition for a new impulse."[605] Suffering draws our attention to illness experiences in a

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[599] Levinas notes that physical pain is augmented by emotional and spiritual distress which "add to the cruelty of the hurt" when we experience illness. Emmanuel Levinas, "Useless Suffering," trans. Richard A. Cohen, in *The Provocation of Levinas: Rethinking the Other*, eds. Robert Bernasconi and David Wood (London: Routledge Press, 1988), 158.

[600] This was a phrase used by Allison and Jasmine.

[601] Edward Farley, *Good and Evil: Interpreting the Human Condition* (Minneapolis, MN: Fortress Press, 1990), 40-3.

[602] Edward Farley, 42.

[603] Edward Farley, 43.

[604] Edward Farley notes, we can reject our compassionate obligation, this is described as cruelty. Edward Farley, 43.

[605] Arthur Frank, *The Wounded Storyteller: Body, Illness and Ethics*, 2nd ed. (Chicago, IL: University of Chicago Press, 2013), 177.

way that beckons us into an "interhuman"[606] space in which suffering becomes a "half-opening"[607] to the "Other." Arthur Frank describes this "half-opening" as a process in which those experiencing illness learn that "their own suffering touches and is touched by the suffering of others."[608] Thus, this "half-opening" to the other acknowledges that suffering can never be fully known or named but "suffering [does not] remain useless."[609]

I propose that the "compassionate obligation" of our *imago Dei* augments our practices of care in two specific ways. First, that bearing witness is the *work* of pastoral care among individuals and families[610] living with chronic illness and embodied difference from a GI ostomy. Bearing witness to illness and difference is not simply an observational role for a pastor, lay leader, or chaplain. A pastor-as-witness accompanies individuals and communities as they work to amended illness narratives which celebrate embodied goodness.

Bearing witness is a relational commitment. A pastor, chaplain, or lay leader becomes a witness to illness when they are drawn toward those who have been rendered abject through marginalizing normalcy discourses. We participate in this relational commitment when we collaborate in the construction of revised illness narratives that enable agency and foster hope among those who suffer. This relational commitment is predicated on hospitality; yet hospitality is not merely kindness toward those experiencing marginalization. Bearing witness to illness

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[606] Edward Farley describes the interhuman as "interpersonal relation" that is "disclosed in concrete human acts and relations." (Edward Farley, 37.) He goes on to note that the interhuman is both essential to humanity (interpersonal) and a task which he uses to describe compassion and obligation. (Edward Farley, 40-3.) The "inter-human" is a space where we become aware of each other's vulnerabilities and suffering. (Frank, *Wounded Storyteller*, 176-85.)

[607] Arthur Frank uses the work of Levinas, "Useless Suffering," 156-63.

[608] Frank, *Wounded Storyteller*, 178.

[609] Frank, *Wounded Storyteller*, 178. Levinas offers that suffering seems to leave us "impotent" or feeling "abandoned" but is actuality is a half-opening which is a "possibility that wherever a moan, a cry, a groan or a sigh happen there is the original call for aid, the curative help, for help from the other." Levinas, "Useless Suffering," 158.

[610] I will often reference "families" as opposed to individuals. I do this for two reasons: 1) I did not directly interview people living with disease and 2) it acknowledges the reality that illness is not a private, individual experience alone; illness effects a whole family or social group.

means inciting change within our relational, congregational, and social contexts. This happens when we resist normalcy discourses that dehumanize those experiencing embodied differences.

Secondly, I propose that pastors must attest to anxiety narratives and bated-breath narratives. These two illness narrative typologies,[611] or ways of interpreting illness narratives,[612] are told by families experiencing chronic illness. These two typologies were developed from interviews, written protocols, and field notes gathered among my co-researchers. These illness narratives augment the three illness narrative typologies (restitution, chaos, and quest narratives) developed by Arthur Frank in *The Wounded Storyteller*.

Understanding anxiety and bated-breath narratives help pastors, lay leaders, and chaplains provide care because these narratives offer a framework to analyze important narratives when visiting families at home, at the hospital, or at other medical care institutions. Furthermore, knowing these typologies will assist pastoral caregivers in identifying an opening to hope and "lean into their future."[613] Pastoral caregivers can foster hope as families identify and cultivate facilitating (rather than debilitating) reactions to anxiety. Pastors and lay leaders can foster hope as families resist normalcy discourses that undermine the value of the body.

Though I believe some of the content of this chapter would be helpful for the parents and caregivers I interviewed, the primary audience is intended for pastoral caregivers like chaplains, congregational leaders, and lay ministers who care for families living with the effects of a GI ostomy. Bearing witness to the lives of people experiencing a GI ostomy is a calling and work

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[611] A mechanism to analyze and group qualitative data. Typologies can originate from the researcher or from the population they study among. These typologies originated from me, as the researcher, but were confirmed by my co-researchers. Thomas A. Schwandt, *The SAGE Dictionary of Qualitative Inquiry*, 3rd ed. (Thousand Oaks, CA: SAGE Publications, 2007), 302.

[612] An illness narrative is a subset category of narratives, told by persons, families, and communities experiencing the effects of illness.

[613] Andrew D. Lester, *Hope in Pastoral Care and Counseling* (Louisville, KY: Westminster John Knox Press, 1995), 138.

that requires attention to the moral imperative of the *imago Dei*—our relational obligation toward others. As pastoral caregivers affirm the innate goodness of all types of bodies, they collaborate toward the construction of new illness narratives that offer hope in the midst of ongoing disease.

Defining Narrative Witness

Witnessing is not an observational role. The *imago Dei* compels humanity toward more loving and caring relationships; this is the moral impulse of the *imago Dei*. Moreover, bearing witness to illness is a relational engagement: we participate in the "compassionate obligation" of the *imago Dei*[614] and accompany people through illness experiences. Bearing witness also means that pastoral caregivers participate to ameliorate and resist suffering inflicted due to illness.

Bearing witness to chronic illness and embodied difference means that pastors, lay leaders, and chaplains have a responsibility to: 1) collaborate toward illness narratives that mediate hope in the midst of ongoing illness; 2) affirm the value of every body as a testament to God's compassionate, accompanying presence in the midst of illness; and 3) actively respond to the testimony of ill bodies by resisting normalcy discourses that marginalize. I will describe illness narrative typologies that pastors will encounter as they bear witness to illness. But first, I want to define and describe what it means to bear witness to illness.

Pastoral Care as Bearing Witness

Disease is an inevitable part of lived experience, one that impacts all aspects of life. Therefore, clergy, lay leaders, and pastoral caregivers serve as witnesses to illness. To serve as a witness we recognize a moral obligation, an opening to relationship, a turning toward those

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[614] The compassionate obligation of the *imago Dei* is a "suffering-with (compassion) but also a suffering-for (obligation)" others. Edward Farley, 43.

impacted by disease. Illness opens us to the experience of suffering in ourselves and in others[615] so that we can accompany persons through illness and resist its suffering. We must recognize our shared fragility as human beings[616] and realize how we are implicated and complicit in the suffering of illness as we contribute to and benefit from normalcy discourses that inflict pain.

Witnessing illness shapes our practices of care. We mediate hope among those experiencing disease. Bearing witness indicates our participation in hospitality as we promote the full inclusion of every body. Pastoral caregivers attest to God's accompanying presence. As we hear embodied testimony, pastoral caregivers help families, parents, and children identify how they have resisted suffering to help amend illness narratives so that they reflect families' future-oriented hopefulness.

Bearing witness to illness means mediating hope for those suffering. Hope is known through relationships and in community.[617] A pastor, chaplain, and lay leader can be a presence and constructor of hope for those experiencing illness. Andrew Lester suggests that hope is cultivated in pastoral care situations when the pastoral caregiver fosters "trustworthy relationships out of which hope can be born."[618] Bearing witness to illness indicates that chaplains and pastoral caregivers "hope with"[619] and listen for themes of hope embedded within illness narratives. "Hoping with" means that pastors and lay leaders celebrate past moments when families survived the intrusions of illness and their expectation for future moments when they will need to survive once more. For example, "hoping with" celebrates the moment when

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[615] Frank, *Wounded Storyteller,* 177.

[616] Nancy J. Ramsay, "Moral Injury as Loss and Grief with Attention to Ritual Resources for Care," in *Pastoral Psychology* 68, no. 1 (Feb 2019): 117, https://doi.org/10.1007/s11089-018-0854-9.

[617] Lester, 94.

[618] Lester, 98.

[619] Andrew Lester borrows the phrase "hoping with" from Karl Menninger who applied the phrase in the context of medical professionals who mediate hope to their patients in the midst of hospitalization. This intent points toward relationship in which people move away from isolation and toward a future that is more life-giving. Lester, 98-9.

Leticia stood up to the grocery store attendant who accused her son, Samuel, of stealing because he was carrying his rolling backpack with his feeding pump.

"Hoping with" indicates that pastoral caregivers highlight moments when parents resisted the marginalization of their children and collaborated toward future stories and illness narratives that highlight their agency and abilities as an ally with their children. Hannah shared her daughter's encounter with Jacob. When they were playing on the monkey bars, Jacob saw Zoe's ostomy bag and began to tease her. "Hoping with" means that the pastoral caregiver highlights how Hannah acted as an ally to Zoe when she contacted the school and Jacob's parents. "Hoping with" fosters narratives in which Zoe's marginalization is an obstacle of the story, not its plot. Hannah's action toward hospitable relationships between Jacob and Zoe became particularly meaningful when Jacob, too, experienced illness—Zoe became his ally on the playground.

Witnessing is a form of care that requires attention to God's compassionate, accompanying presence. When clergy, lay ministers, and chaplains witness illness they acknowledge that an individual or family's future includes anxiety. Pastors bear witness to ongoing crises and healthful moments. When we witness, we attend to both of these plotlines. Compassion is not pity.[620] It is the recognition of the intrinsic "value and beauty of others"[621] in the midst of conditions that foster suffering. It takes seriously the physical pain or marginalization of another person.[622] To act as a witness, as opposed to an observer of illness, the witness must find herself deeply attuned to these experiences of suffering (compassionate toward) and also be compelled by them (obligation for).

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[620] Wendy Farley, *Tragic Vision and Divine Compassion: A Contemporary Theodicy* (Louisville, KY: Westminster John Knox Press, 1990), 79.

[621] Wendy Farley, *Tragic Vision*, 79.

[622] Arthur Frank, "Knowing Other People's Stories: Empathy, Illness, and Identity" (Leslie Center for the Humanities Lecture, Dartmouth College, Hanover, NH, April 4, 2018).

Bearing witness to illness requires an engagement with the testimony of the body. This testimony is not always pleasing. We witness illness when we are attuned to the suffering attested to by the body and remain engaged in the relationship; thus, we are agents of future narratives of survival. Andrew Lester argues that the pastor should affirm that God moves ahead of us, "calling us, inviting us, into the future."[623] Pastoral caregivers confirm that "God is unquestionably here with us in the present, but God reaches into the present from the future."[624]

Bearing witness to the effects of illness is a narrative process. With each telling of an illness story, the meaning of that story changes, "gradually modifying the story,"[625] and thus modifying the person. Imagining ways to survive future crises is a collaborative effort between those experiencing illness and pastoral caregiver. Christie Neuger notes that those experiencing a problem have the "resources [they] need within [their] own narrative."[626] She goes on to say that they have "survived and struggled" within the context of the problem—or the illness—and the wisdom gained and the resources used remain "available" to them when confronting impending problems.[627] These future-oriented illness narratives can restore a sense of hope in the midst of on-going cycles of pain and fear that are emblematic of a bated-breath narrative.

In illness, the body is the testimony. When we narrate the feelings of the body, the testimony of the body becomes a witness to its suffering. First-person witnesses are those who directly experience illness and have first-hand knowledge of normalcy discourses that create the conditions for their marginalization. If they do not tell their illness narratives, the narrative is

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[623] Lester, 69.

[624] Lester, 69.

[625] Frank, *Wounded Storyteller*, 159.

[626] Christie Cozad Neuger, *Counseling Women: A Narrative, Pastoral Approach* (Minneapolis, MN: Fortress Press, 2001), 89.

[627] Neuger, *Counseling Women*, 89.

"confessional"[628] and private; or an attunement to the groans of the body.

As first-person witnesses tell the stories of their bodies, they invite others into the work of witnessing. Bearing witness motivates a public response.[629] Arthur Frank suggests, "A witness makes a witness of others; a particular quality of the word witness is its movement of outward concentric circles."[630] The witness to illness "assumes a responsibility for telling what happened."[631] The onus of witnessing illness does not solely rest on the one testifying to their experience with illness or embodied differences. When we bear witness, we turn "illness into [a] moral responsibility"[632] for suffering. We become witnesses when we respond to the moral obligation of the *imago Dei*.

Women went to the tomb to tend to the body of Jesus. They came to find a corpse. They came expecting decay. Jesus appeared after the resurrection in the upper room, side and hands still wounded. Thomas wanted to see the wounds of the body. He is invited to touch the open flesh. Decay and open wounds are rendered abject. Bodies rendered abject can seem terrifying because we live in contexts that create and maintain the conditions for abjection. The wounded body of Christ offers a testimony to the suffering caused in the world.[633]

It is true that the body testifies to the pain and discomfort of disease. Yet the body also testifies to the wounds generated within society. Henry Nouwen introduced the Wounded Healer

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[628] Judith Herman, *Trauma and Recovery: The Aftermath of Violence—From Domestic Abuse to Political Terror* (New York, NY: Basic Book, 1992, 1997), 181.

[629] A testimony is both private and public. Herman, 181.

[630] Frank, *Wounded Storyteller*, 142.

[631] Frank, *Wounded Storyteller*, 137.

[632] Frank, *Wounded Storyteller*, 137.

[633] Shelly Rambo uses the post-resurrection scene of Thomas' encounter with Jesus in the upper room. Thomas insist on touching the wounded body of Jesus. Rambo argues that this act, touching the wounds, "surface pasts" (p. 84) like the "power and privilege" and the "suffering and violence" of the crucifixion (p.75) as well as "histories of harm" like racism in the United States (75-7). Rambo suggests that "touching wounds" uncovers narratives, theologies, and social mechanisms that marginalize those whose bodies "do not fit the idyllic vision" (p.85). Shelly Rambo, *Resurrecting Wounds: Living in the Afterlife of Trauma* (Waco, TX: Baylor University Press, 2017), 84-88.

as one who recognizes the wounds of the world and from those wounds invites a “healing power” for the suffering of the world.[634] The wounded body, as described above, is not representative (only) of an individual’s pain. Wendell Berry describes the “hereditary evils” that wound society.[635] Bodies testify to the power of normalcy discourses that disrupt our ability to have loving relationships with those who are different, or those who have been abject-ed.

Bearing witness means that we participate in the uncovering and resisting of normalcy discourses that wound us and wound each other; it also makes mutual relationships possible. When the women go to the tomb or when Thomas reaches out his hand to touch the body, they defy abjection. They become witnesses to the pain of open flesh but, more importantly, to the conditions that caused the flesh to open: imperial powers that result in the crucifixion of Jesus.[636]

When we witness illness, we turn toward death and unbandage open flesh to expose normalizing powers that maim us all. Those who participate in bearing witness do not ignore the testimony of the body; they turn toward it. Shelly Rambo suggests that “collective sins,” when not uncovered, continue to inflict suffering on the world.[637] Pastors, lay leaders, and chaplains must recognize our shared vulnerability. Caregivers must tend the physical wounds, yes! But pastoral caregivers must recognize and resist our complacency and complicity in normalcy discourses that perpetuate our wounding. Bearing witness means resisting normalcy discourses

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[634] Nouwen describes the Messiah as the Wounded Healer and uses this description to describe the vocation of the minister. His interpretation endows clergy with tremendous authority at the intersections of suffering and healing. While I appreciate Nouwen’s commitments to pastoral authority I believe that it is the responsibility of clergy to engage in mutual, collaborative relationships. Henry J.M. Nouwen, *The Wounded Healer: Ministry in Contemporary Society* (New York, NY: Image Doubleday, 1972, 2010), 87-9.

[635] Wendell Berry is particularly addressing the dehumanizing wounds of racism and slavery. Wendell Berry, *The Hidden Wound* (Boston, MA: Houghton Mifflin, 1970), 6.

[636] It is Delores Williams who raised concerns about the substitutional redemption of the cross. Williams argues that the cross is not illustrative of God’s redeeming love for humanity but of a “cruel, imperialistic, patriarchal power.” God’s love for humanity is evident in the “ministerial vision;” of Jesus righting relationships between body, mind and spirit. Delores S. Williams, *Sisters in the Wilderness: The Challenge of Womanist God-Talk* (Maryknoll, NY: Orbis Books, 1993), 164-5.

[637] Rambo’s text addresses the collective wound of racism. Rambo, *Resurrecting Wounds*, 73.

that keep us from seeing the indelible beauty within a differently functioning body. To witness illness, however, we must be familiar with the illness narratives in our pastoral care contexts.

Pastoral Care and Illness Narratives

A narrative pastoral practice asserts that the stories we tell to ourselves and about ourselves carry distinct meanings that we acknowledge to be true about ourselves and about our contexts. It recognizes that "stories function to construct meaning and our sense of self." [638] Our narratives can both diminish and/or empower our sense of self. Illness narratives are a particular type of narrative. I will define and explore five illness narrative typologies that pastors, chaplains, and lay leaders will hear as they care for families living with the effects of chronic disease. Before I arrive at the description of these illness narrative typologies, I want to clarify how narrative is used in this chapter; highlighting some particularities related to illness narratives.

There is often a conflation of the term "narrative" when employed and adopted across a variety of fields. It is easy to conflate the term "narrative" within the fields of narrative inquiry,[639] narrative therapy,[640] and narrative practices of care because they share many

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[638] Karen S. Scheib, *Challenging Invisibility: Practices of Care with Older Women* (St. Louis, MO: Chalice Press, 2004), 58.

[639] Narrative inquiry is a research method and methodology. It is concerned with how stories are shared, interpreted, recorded, reported, and constructed. Narrative inquiry is a collaborative process, emerging through dialogue between researcher, participant, and audience. The outcome of narrative inquiry is information, knowledge, data for research. Narrative inquiry generates wisdom allowing us to present a better argument for action; to insight conviction for change. This method offers insight into how stories are generated which can lead to better practices of care. Narrative inquiry is not the same as practices of care—though it is methods can undergird and inspire practices of care. John W. Creswell, *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*, 3rd ed. (Thousand Oaks, CA: SAGE Publications, 2013), 71.

[640] Narrative therapy is a particular therapeutic theory and practice. Pioneered, by David Epstein and Michael White in the late 1980s and early 90s. Narrative therapy sets itself apart from other psychotherapeutic theories and practices in that narrative therapy underscoring the importance of the stories we tell about ourselves. These stories shape our identity. Narratives can never be heard, told, or understood apart from a particular context—a context of complex relationships, politics, and ideologies. Therapeutic techniques are aimed at "externalizing," examining, and challenging "problem narratives." The intent of narrative therapy is a collaboration between professionals and individuals to understand and re-narrate identity stories in a manner that differentiates between a "problem" and a person with an eye toward developing "unique outcome" narratives. Unique outcome

methodological assumptions about power, the generation of knowledge, the role of experience, and a collaborative-intent in the construction of narrative. There is an assumption, among those who practice narrative pastoral care, that humanity has the capacity to construct and generate new identity claims from the stories we tell to and about ourselves. As Karen Scheib points out, "Narrative practices of pastoral care and narrative therapy share a common goal: the generation or identification of alternative stories that allow new meanings and possibilities for action."[641] In this dissertation, I draw on narrative inquiry as a research method and methodology, but I am also informed by the methods and methodology of narrative therapy in shaping my pastoral practices of care. Thus, it is important to consider the three as distinct disciplines.

Pastors, lay leaders, and chaplains can collaborate with those experiencing illness to notice "exceptions" to the "problem narratives" [642] within illness, problems like debilitating anxiety, marginalization, broken relationships, or disdain for our own dis-eased bodies. And then pastoral caregivers help to "create a new narrative strand that thicken the exceptions that make a preferred life possible."[643] Exceptions are when Stephen and Crystal stood up from the couch in the NICU, or when Amanda encouraged Ava to wear her tankini to a pool party in spite of what her mom said about the bag being visible, or how Katrina has taught Mia and Isabella to see their embodied differences as an "advantage."

The objective of bearing witness to illness narratives is to help "integrate and

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narratives should build on a person's agency in telling more life-giving identity narratives with a deeper understanding about the matrix of influences within a problem narrative.

Stephen Madigan, *Narrative Therapy: Theories of Psychotherapy Series*, ed. Jon Carlson and Matt Englar-Carlson (Washington, D.C.: American Psychological Association, 2011), 4 and 17.

David Epston and Michael White, *Narrative Means to Therapeutic Ends* (New York, NY: W.W. Norton, 1990), 38-76

Michael White, *Maps of Narrative Practice* (New York, NY: W.W. Norton, 2007), 10-59.

[641] Scheib, 63.

[642] Neuger, *Counseling Women*, 53.

[643] Neuger. 53.

strengthen"[644] those narratives that are more life-giving and hopeful. Since illness profoundly affects a person's narrative,[645] developing future-oriented illness narratives, grounded in possibilities for survival and resistance, have the power to shape present identity.[646] Co-researchers talk about hope as their ability to survive the cyclical intrusions of illness, both the physical intrusions and the social marginalization. Pastoral caregivers can help families identify "empowering stories to resist oppressive narratives,"[647] like normalcy discourses, that undermine the innate goodness of their children's bodies.

Narratives differ from stories. Stories are woven together to form narratives.[648] Karen Scheib delineates this difference: "Individual stories describe an incident, an event, or a point in time. Narratives are larger interpretive frameworks and may be constructed from full-blown stories, as well as from short accounts occurring in conversation or interviews."[649] A pastoral caregiver should invite parents to share stories about how they cared for, advocated for, or stood with their child in the midst of illness. These stories can reflect the parent's past strengths and highlight their "capacity to hope"[650] in their abilities to survive future hospitalizations and their abilities to resist social norms that marginalize their child.

Illness narratives are a particular sub-set of narratives. Arthur Frank, sociologist and medical ethicist, characterizes the process of moving from stories to narratives, saying:

> The illness story begins in wreckage, having lost its map and destination. The story is both interrupted and it is about interruption. In the illness stories what begins as the breakdown of narrative—life's interruption by illness—is

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[644] Neuger, 53.

[645] Frank, *Wounded Storyteller*, 164.

[646] Lester, 68-9.

[647] Neuger, *Counseling Women*, 86.

[648] Herbert Anderson and Edward Foley, *Mighty Stories, Dangerous Rituals: Weaving Together the Human and the Divine* (San Francisco, Jossey Bass, 1998), xiii.

[649] Scheib, 59.

[650] Andrew Lester is pointing out that our human capacity to hope lies in our ability to "anticipate the future." For Lester, anticipating the future is a given, ontological aspect of humanity. Lester, 59.

> transformed into *another* [sic] kind of narrative.[651]

Since illness disrupts a life's narrative[652] a new form and function of storytelling and narrative is required.

A story is not just something to be heard. A story is something that shapes all the parties who participate in its hearing and telling. It is an "opening to a relationship;"[653] Thus, witnesses participate in the identity-shaping nature of narrative. Pastoral caregivers are not present to simply hear stories. We "live in" stories, "*becoming* [sic] in it."[654] Our character—our plotline—changes because of stories. A story is the mechanism by which we become a witness. As we witness illness, particularly the bated-breath narrative, we have a responsibility to participate in future-oriented narratives. The bated-breath narrative recognizes that illness remains; therefore a future-orientation does not presuppose a narrative without the ongoing effects of illness. Future-oriented illness narratives take seriously the peril and ongoing sufferings of illness and, where possible, resist that suffering.

Illness narratives disrupt past identity claims and impacts future narrative structure and identity claims. Illness disrupts not only the way we interpret the current condition of our bodies (or ourselves) but it upends the past narratives we held to be true about our embodied lives.[655] Stephen and Crystal believed (past narrative) that they would welcome two healthy boys into their family until the twins' premature birth. The future narratives were interrupted by illness; not just once but on an ongoing basis.

We rarely expect illness. The sorrow of the past and the present pain make the "future

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[651] Frank, *Wounded Storyteller*, 164.
[652] Frank, *Wounded Storyteller*, 164.
[653] Frank, *Wounded Storyteller*, 158.
[654] Frank, *Wounded Storyteller*, 159.
[655] Frank, *Wounded Storyteller*, 55.

scarcely thinkable."[656] Illness may, as the parents I interviewed described, seemingly stop the story *as they knew it* but they are not rendered hopeless. They acknowledge that the body and society remain frail,[657] and co-researchers step toward these frailties. They speak about "our normal" in the face of illness. "Our normal" is a term used by most co-researchers.[658] "Our normal" became a way for families to name, for themselves, their realities, their strengths, and their own contexts.[659] They refuse to let others define what or who was meant by "normal." Bearing witness to illness narratives means that we accompany families as they amend seemingly story-stopping illness narratives and develop stories to reflect "our normal."

While the future may seem "scarcely thinkable," narratives give us the capacity to formulate future-focused illness identities. Pastoral theologian Andrew Lester describes the need to attend to "future stories." [660] This is accomplished as individuals, societies, and institutions "imagine answers to this what-will-happen-next question by projecting our core narratives into the future."[661] This is especially true among families living with chronic disease because they are always facing the question, "What will happen next?" Thus, pastors should invite a "future tense" [662] orientation to the illness narrative. Pastors, chaplains, and congregational lay leaders have a responsibility to help families attend to the expectations of forthcoming suffering that accompany illness. Pastoral caregivers should also attend to and develop resources for families

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[656] Frank, *Wounded Storyteller*, 55.

[657] Social discourses that create the conditions for marginalization is an example of social frailty.

[658] All of the co-researchers had a way of naming and differentiating their particular version of "normal." Some spoke of their "new normal" as a reference in time: after the ostomy. Others spoke about "her/his normal" in reference to their child's body. Still others described "our normal" which was meant to describe times at home versus times in the hospital or the routines and daily tasks ("*la vida cotidiano*") of living with a GI ostomy. "La vida cotidiano" means "daily life" and signifies theological knowledge is embedded in daily, everyday life. Carmen Nanko-Fernandez, *Theologizing en Espanglish* (Maryknoll, NY: Orbis Books, 2010), xviii-xx.

[659] Neuger notes that determining what language will be used for our self or our environments is a powerful narrative tool, "claiming the right to speak" and empower positive personal and social change. Neuger, *Counseling Women*, 71-2.

[660] Lester, 35.

[661] Lester, 35.

[662] Lester, 40.

to survive those moments of forthcoming suffering. This occurs as families identify how they have resisted suffering in the past and have the ability to resist impending suffering.

Pastors and lay-leaders, who accompany families in the midst of illness, have a moral responsibility to learn about the present illness narrative. Understanding present illness narratives and attending to the stories "*from* [sic] which we live"[663] enables pastoral caregivers to collaboratively construct future narratives, "*toward* [sic] which we live."[664] Chaplains, congregational clergy, and lay leaders tend to the future-orientation of *anxiety narrative* by 1) accentuating the facilitating nature of anxiety and 2) correcting the inadequate assumption that anxiety is tantamount to sin. Pastoral caregivers tend to the future-orientation of the "bated-breath" narratives by 1) cultivating hospitality toward differently functioning bodies and 2) resisting normalcy discourses that foster the conditions for abjection and marginalization.

An embodied narrative of illness is both personal and social. It is clear that illness narratives germinate in the marrow of the body. They are intrinsically and unequivocally tied to the way a body feels when experiencing disease. Feelings are powerful; they communicate the "poetics of the body"[665] but all poetry must be interpreted. Interpreting these feelings into language is complicated by the reality that there are often no words to place in the spot of the sensation; "Psychiatrists call this phenomenon alexithymia—Greek for not having words for feelings."[666] When the body, the person, is experiencing disease these new feelings disrupt the past narrative of health. What was previously comprehensible (our "normal life," her "normal body") is now interrupted by a series of painful bathroom experiences, long hospitalizations, a

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[663] Lester, 40.

[664] Lester, 40.

[665] Marcia A. Mount Shoop, *Let the Bones Dance: Embodiment and the Body of Christ* (Louisville, KY: Westminster John Knox Press, 2010), 12.

[666] Bessel van der Kolk, *The Body Keeps the Score: Brain, Mind, Body in the Healing of Trauma* (New York, NY: Penguin Random House, 2014), 100.

sudden ostomy surgery, or marginalizing looks in a grocery store. We cannot discredit these feelings of illness because such feelings allow us to intersect with the world around us: "feeling defines us, shapes us, and conditions us on every level of experience."[667] We cannot dismiss or discredit the feeling-voice of the body. In this regard, the illness narrative is deeply personal.

The illness narrative is also profoundly social. Thus, we must not let any single illness narrative hold unilateral sway. Disease does not happen within a vacuum. Too often, the "medical narrative"[668] becomes the narrative model for those experiencing disease. Patient charts, the bleeps and buzzers of hospital equipment, the measures of colon motility, and medications take narrative precedence. Each contextual variable shapes the illness narrative and impacts a person's sense of worth and inclusion within institutions, families, and societies. When people talk about their sense of health they are "making claims about themselves as worthy individuals, as more or less 'fit' participants in the activities of the social world."[669]

The medical narrative is a privileged form of narrative. It is accessible primarily to those trained to read and interpret the collected data. The medical narrative narrows the body's voice to a monosyllabic utterance.[670] If this is the preeminent illness narrative, we are limiting the agency of the body/individual and the family in their telling of a different story—a more complex and nuanced story. Many co-researchers felt the narrative of their child was usurped by these pervasive medical narratives. They wanted me to see that their child is so much more than

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[667] Mount Shoop, 17.

[668] The medical narrative is the story told by doctors, about patients. It is the narrative recorded in the medical chart is often the illness narrative that becomes true and authoritative. It is the profile, the story, by which other stories about illness experience are compared for validity. Frank, *Wounded Storyteller,* 5-6.

[669] Michael Billig and Alan Radley, "Accounts of Health and Illness: Dilemmas and Representations," *Sociology of Health and Illness* 18, no. 2 (1996): 221. DOI: 10.1111/1467-9566.ep10934984.

[670] Arthur Frank argues, "Clinical listening that is oriented toward diagnosis and treatment decisions is intensive; it narrows what is relevant." Arthur Frank, "Truth Telling, Companionship, and Witness: An Agenda for Narrative Bioethics," *Hastings Center Report* 46, no. 3 (May 2016): 18, https://doi-org.ezproxy.tcu.edu/10.1002/hast.591.

their disease or their ostomy. While no one bodily characteristic can totally define a person, it can limit and constrain access to power and resources. As my co-researchers want me to know, the ostomy does not diminish the innate goodness of their children's bodies. Furthermore, they want to define (and help their children define) how they are included as fully embodying the *imago Dei*. They want to be reflective of inclusion, not exclusion: "Humankind was created as God's reflections: in the divine image God created them."[671]

Illness narratives are often beholden to institutional and social powers. Narrators stay silent in the face of painful procedures or undignified treatment because their lives are at stake. As Arthur Frank writes in his autobiography after experiencing cancer and its treatments, "Dependence is the primary fact of illness, and ill persons act with more or less fear of offending those they depend on."[672] Those experiencing illness seldom risk upending inter-personal, social, and institutional relationships upon which they depend, choosing instead to remain silent.[673]

Chaplains, congregational lay leaders, and pastors must listen for moments when institutional and social powers restrict the narrative agency of those experiencing illness. Furthermore, pastoral caregivers should identify when people feel like illness has rendered them powerless to those taking care of them or making medical decisions on their behalf. Pastoral caregivers should question institutional and social assumptions around illness and dependence, an important narrative task between clergy/lay leaders and those experiencing illness.

The false assumption equates dependence with full humanity and Western society wrongly assumes this independence is paramount. This is consistent with the findings of Andrea

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[671] Genesis 1: 27a, The Inclusive Bible.

[672] Arthur Frank, *At the Will of the Body: Reflections on Illness* (New York, NY: Houghton Mifflin Company, 1991*)*, 112.

[673] Frank, *At the Will of the Body*, 114.

Altschuler and her research partners who found that women living with an ostomy after colorectal cancer questioned their “full personhood” when they did not have control over their toileting or when they were dependent on others for their care.[674] Theologian Thomas Reynolds directly refutes the claim that independence should be considered a human or social ideal. Such a falsehood undermines the reality that all humans are interdependent, and this interdependence is the grounds of meaningful and mutually caring relationships.[675] Pastoral caregivers have an obligation to listen for these problematic narratives amid the pastoral care experience.

Illness Narrative Typologies

When we bear witness to illness, we are attuned to the unfolding of a specific type of narrative. It is common for those who experience illness to experience that illness as a central or prominent plot in their personal and social narrative. As clergy, we cannot underestimate the power of illness in shaping a narrative. Furthermore, when clergy and lay leaders are called to the bedside in a hospital or a home in the midst of disease exacerbation, it is apparent that the illness and its effects act as a blazing fire that consumes most of the oxygen and attention in the room. Clergy and congregational lay caregivers must come equipped to understand and deconstruct the narrative they hear. I will first describe the three illness narrative typologies developed by Arthur Frank. I will then suggest two additional illness narrative typologies (the bated-breath narrative and the anxiety narrative) that most closely resemble the narrative structure described by my co-researchers.

An illness narrative typology is a way of grouping, analyzing, and interpreting types of illness narratives told by those experiencing the effects of disease. A typology can be

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[674] Andrea Altschuler, et al., "'I Didn't Feel Like I Was a Person Anymore': Realigning Full Adult Personhood after Ostomy Surgery." *Medical Anthropology Quarterly* 28, no. 2 (2014): 242-259, JSTOR.

[675] Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality* (Grand Rapids, MI: Brazos Press, 2008), 13-14 and 118.

"indigenous," meaning that the typology emerged and was named by co-researchers; or it can be "analyst constructed,"[676] a typology that is identified and named by those conducting the research. Both anxiety and bated-breath illness narrative typologies are "analyst constructs" and confirmed by co-researchers. These typologies were confirmed by nearly every parent who contributed to this study. One co-researcher disagreed, not with my interpretation, but with its severity[677] and another co-researcher did not respond to my attempts for a member-checking interview.[678]

Arthur Frank offers three illness narrative typologies based on his qualitative narrative and autoethnographic research. These three typologies became a basis by which I compared the illness narratives I was collecting within my research context. I found that Frank's illness categories did not robustly account for the cyclical nature of chronic diseases. He acknowledges that illness is not linear and that it includes multiple interruptions,[679] but his illness narrative typologies do not anticipate forthcoming exacerbations of physical, emotional, or spiritual suffering. My two suggested illness narrative typologies anticipate perpetual anxiety and forthcoming illness intrusions.

Considering the centrality of illness narratives (when offering care among families impacted by GI ostomies), it is helpful to identify typologies that structure the narratives pastoral caregivers will encounter. Sociologist and medical ethicist Arthur Frank developed three categories of illness narratives. During my data collection interviews, Frank's typologies formed a central map by which I could analyze the stories I was collecting. It became apparent to me,

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[676] Schwandt, 302.

[677] While Katrina agreed with the other eight parents (she also lived with anticipation and anxiety of what would happen next) she did not think it was significant enough to report.

[678] Hannah was my first co-researcher therefore I did not have enough data to check this finding during the first interview and, after multiple attempts, I was unable to secure a second interview with Hannah.

[679] Frank, *Wounded Storyteller*, 56-9.

early in the interview process, that my co-researchers were telling me variations of all three typologies and two additional illness narratives. It is helpful to review Frank's three narrative typologies and augment his findings with the "bated-breath" and "anxiety" narrative typologies that were most-apparent in the data collected among families living with chronic illness.

Arthur Frank's Three Illness Narrative Typologies

In developing his three typologies, Frank did not suggest that individuals narrate their illness experiences from only one of these typologies. He acknowledged that people often narrate from a combination of all three narratives.[680] This was central within my findings as well. Of equal importance, Frank did not conclude that these three typologies were the only forms that illness narratives assume.[681] They do, however, offer a helpful framework by which I could distinguish particular narrative turns emerging from experience with *chronic* illnesses.

Restitution narratives are narrative forms that anticipate recovery and restored health. The narrator describes illness as a momentary pause or juncture in life in which current conditions of illness are temporary. The anticipation is that illness will not leave any lasting or significant impact.[682] Interventions used to treat an illness—and the effects of treatment on the person—are generally ignored.[683] This narrative asserts the availability, promise, or certainty of a remedy or cure.[684] Frank argues that this is the "culturally preferred" illness narrative.[685]

Restitution narratives were somewhat rare among my co-researchers, except when parents reflected retrospectively. Several co-researchers recalled moments when they hoped that

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[680] Frank, *Wounded Storyteller*, 75.

[681] Frank, *Wounded Storyteller*, 75–76.

[682] Frank, *Wounded Storyteller*, 77.

[683] Frank, *Wounded Storyteller*, 79.

[684] Frank, *Wounded Storyteller*, 80–81.

[685] This narrative typology is culturally preferred because it is the most succinct type and, therefore, less need to account for the suffering that accompanies illness: a person gets sick, she goes through treatment, and she gets better. Frank, *Wounded Storyteller*, 83.

their child's intestine could be "hooked back up" and they would no longer need the ostomy. During the course of this study, Owen had a surgery to reconnect his intestines and this eliminated the need for his ileostomy. Allison acknowledged that she had an early hope that Ava would have her ostomy eliminated. Allison described what it was like to come to terms with the permanency of Ava's ostomy; she mourned the improbability that Ava would ever live without an ostomy. Leticia was the most instant on telling a restitution narrative. Every time I asked about Samuel's illness she would say, "Well, I believe in miracles. I am just hoping that my son's intestines will grow. That's all I can say." But Leticia went on to describe how, ultimately, she knows that Samuel will never have a longer small intestine and an intestinal transplant was not a viable solution.

I think Arthur Frank is accurate in his assessment that the restitution narrative is culturally preferred and pastors and lay leaders should not be tempted to embrace the ease of thought that accompanies the restitution narrative. Chaplains and clergy should not placate the notion that all health will be restored. This simply is not the case for parents who have children with a chronic disease. Furthermore, it bypasses the struggle and suffering that comes with *living with* an illness. Even Owen, after his ostomy was reversed, struggled with medical complications due to his premature birth. Pastors, chaplains, and lay leaders cannot diminish the reality of ongoing illness by wishing, praying, or insinuating that a cure is around the corner—doing such neither legitimizes the present suffering inflicted because of illness nor does it anticipate future struggles when illness is ongoing.

It could be argued that the co-researchers who described their child as "normal" when they were not at the hospital are narrating a version of a restitution narrative as a way of assimilating the ostomy into cultural expectations. I argue that is not the case. Most co-researchers described their child as “normal” as a way of managing the intrusions of illness and taking agency in naming and defining the conditions and criteria for “normal.” The overarching plotline of a restitution narrative is that illness is curable and life will return to a pre-illness state. While it seemed that these parents wanted the exercise agency in naming their child’s embodied difference, they were not lured by the persuasion of a pre-illness state.

The chaos narrative is the polar opposite of the restitution narrative.[686] Where the restitution narrative assumes a cure to the illness, the chaos narrative demonstrates “vulnerability, futility, and impotence.”[687] The chaos narrative is actually a pre-narrative: the story is trapped amid the chaos. The chaos of illness cannot be put into words without some reflective distance[688]thus, the chaos narrative is told in stops and starts having “no narrative sequence.”[689] This narrative is told in embodied gestures and acts; it is seen, felt, and experienced more than told.[690] The chaos narrative sets into relief two factors: the desire to control symptoms and disease set in contrast to the uncontrollable nature of that disease.[691] Chaos narratives are difficult to witness because they lack narrative structure and content rarely points to resolution.

In my research, this narrative emerged most readily when the co-researcher was at the hospital because of an exacerbation of disease or when our encounter was early in the

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[686] Frank, *Wounded Storyteller*, 97.

[687] Frank, *Wounded Storyteller*, 97.

[688] Frank, *Wounded Storyteller*, 98.

[689] Frank, *Wounded Storyteller*, 99.

[690] As a chaplain, the most common and obvious form of chaos narrative within my hospital context comes in the form of tears and incomplete sentences. I have also seen parents and guardians, upon receiving bad news from the doctor, get up and walk out of the room, go for a smoking break, start feverishly cleaning and tidying the room, pace the halls, and even throw furniture and punch cushions. My experience has taught me that it is often futile to inquire about the sentiment and thought behind the action because, as Arthur Frank reminds us, this narrative is pre-lingual; words cannot be spoken.

[691] Frank, *Wounded Storyteller*, 100–101.

diagnosis.[692] Many of my recruiting memos documented this narrative typology as an obstacle in obtaining consent.[693] Chaos narratives also emerged as co-researchers recalled the scariest moments of their child's illness. The chaos narrative is distinguishable because the plot lines of the narrative are disrupted by tears, abrupt changes in subject, or phrases that simply trail off without completion.

When the pastoral caregiver is called to bear witness to the chaos narrative it may seem that "acts" or "practices" feel minimal. This is where the practice of "hoping with"[694] is vitally important. Hoping with means: 1) the pastoral presence (where witnessing changes one through the unfolding relationship and the unfolding chaos) can lead to important relational bonds that aid future conversations and 2) pastors, lay leaders, and chaplains should take note of and remember the resources that families use to "carry on" in the midst of a chaos narrative.

A parent's non-verbal expression of terror, sadness, and pain (which are illustrative of the chaos narrative) point to important relational commitments. Co-researchers tell chaos narratives because they feel compassion for their child and a desire to stop their suffering. These relational commitments are important "resources"[695] available within the chaos narrative. For example, Stephen and Crystal stood up from the couch in the NICU because they were committed to Owen and his survival. Since some reflective distance is required to foster narrative construction, building toward future-oriented narratives are difficult (if not impossible) in the midst of chaos narratives. Once families gain reflective distance, however, pastoral caregivers help remind parents of the relational commitments that enabled their survival. These reminders foster the

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[692] Hannah and Leticia were the only co-researcher whose first interview for this study were done when neither Hannah's daughter Zoe nor Leticia's son Samuel were hospitalized. It is assumed that these variations impacted their interviews.

[693] Notably, my pre-consent/pre-interview conversations with Rebecca and with Allison were marked by chaos narratives; to the extent that informed consent could not be signed or an interview obtained.

[694] Lester, 98-9.

[695] Neuger, *Counseling Women*, 89.

construction of new illness narratives.

The quest narrative is the final typology that Arthur Frank outlines. According to Frank, those who tell quest narratives describe illness as "the occasion of a journey that becomes a quest."[696] Whereas the chaos narrative is pre-narrative, the "quest" [697] indicates that the narrator has the capacity and reflective distance for meaning-making.[698] I want to note, however, that Arthur Frank understands the quest typology in a nuanced and particular way: we should not assume that the narrator finds resolution, conclusion, or the proverbial "silver lining." The quest narrative does not assume that illness culminates in the building of character or a sense of overcoming; rather, quest narratives highlight the narrator's *capacity* and *agency* to tell her or his story of illness. Pastoral caregivers, when bearing witness to quest narratives, should accentuate the narrator's capacity and agency. These become the "exceptions"[699] for future illness narratives of survival and resistance. Elements of the quest narrative were present in my co-researchers' contributions. Each co-researcher had some reflective distance from certain aspects or moments within the illness. And yet, chronic illness does not end. Co-researchers were always anticipating the next cycle of hospitalizations, the next occasion for marginalization, and the next cycle of peaceful moments.

There is a bit of juggling that must occur when Frank's narrative typologies are placed in conversation with the data collected for this study. Frank's typologies describe stories told by

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[696] Frank, *Wounded Storyteller*, 115.

[697] Frank details three types of quest stories: memoir, manifesto, and automythology. The memoirist simply details the experience of illness but with the recognition that illness offers an occasion for pause and reflection. The manifesto is the narration in which illness forces us to "social action" to critique and question the social constructs and discourses that perpetuate suffering related to illness. Arguably, this dissertation falls into the manifesto category. The automythology is one in which the author sees her- or himself as "reborn" from the experience of illness. The emphasis is individual. Whereas the manifesto seeks social change, the automythology expects individual change. Frank, *Wounded Storyteller*, 119–26.

[698] Frank, *Wounded Storyteller*, 115–16.

[699] Neuger, *Counseling Women*, 53 And

those directly experiencing the effects of disease. While the data collected for this study recount stories from parents (once-removed) from disease, elements of Frank's typologies appeared across all interviews and written protocols collected for this study. There is a lacuna in the three typologies that Frank proposed. He never allots for the *anticipation* of forthcoming and on-going illness intrusions. My co-researchers narrated perpetual cycles of illness and these cycles were characterized by moments when their child felt relatively well followed by illness exacerbation. This shifting narrative landscape of chronic illness caused me to develop the "Bated-Breath Narrative" and the "Anxiety Narrative." All typologies have limitations and Frank is clear about his own, [700] suggesting that he limited the typologies to three to better enable people to use these as "listening devices."[701]

Pastoral theologians and caregivers are not tasked with listening alone. The work of pastoral caregivers is to: 1) attest to God's hospitality for those facing marginalization; 2) collaborate with families toward future-oriented illness narratives that affirm their courage so that they can resist normalcy discourses; and 3) construct narratives that affirm the innate goodness of the body, and in so doing, affirm the *imago Dei* within those who find themselves abject-ed because of embodied difference.

Parents living in the midst of chronic illness live without resolution to the illness. This can be a tiring experience. Clergy, congregational lay leaders, and chaplains have an obligation to accompany families through the cycles of illness. This means ongoing participation as a witness to illness. Since families report underlying anxiety throughout chronic illness, pastoral caregivers remind families of their strength and courage when anxiety seems to debilitate and fog

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[700] Frank proposed three additional typologies in the conclusion of this volume. He suggests "life-as-normal," "borrowed," and "broken" narratives. Frank, *Wounded Storyteller*, 193-204.

[701] Frank, *Wounded Storyteller*, 76.

their hope in seeing beyond the chaos of the current crisis. Since families report waiting with bated-breath for the next “shoe to drop,” pastoral caregivers offer hospitality and build hospitable communities that celebrate a child’s embodied goodness. I will structure the next two sections in parallel: I will first define and describe the anxiety and bated-breath narrative typology. I will then describe what it means to witness that type of narrative.

The Anxiety Narrative: An Underlying Narrative Theme

The anxiety narrative is “through-line” that is always present in the midst of other forms of illness narratives. The anxiety narrative is felt and acknowledged to varying degrees. In particular, anxiety narratives are sensed in varying degrees based on the point in the cycle of the bated-breath narrative. When the illness is experienced as more intrusive, the anxiety narrative is more recognizable. In our opening story, for example, Stephen and Crystal clearly recognized their anxiety when the transport team came to transfer Owen to the next NICU and when they contemplated what life would be like if Owen needed his ostomy bag indefinitely. When the co-researcher’s child is feeling healthier, the anxiety narrative can be ignored. When at home with a more healthful Owen, Stephen and Crystal did not overtly describe anxiety but they acknowledged its presence when I specifically asked about it.

Defining and Describing Anxiety Narratives

While it can be briefly halting, anxiety is not altogether paralyzing for my co-researchers. It is true that anxiety about embodied finitude fuels abjection, but my co-researchers have also demonstrated how anxiety compels them to advocate for their child’s well-being. They see through the distortions of normalcy discourses and train their vision on an embodied, stoma-ed image of God within their children. Over and over again, parents illustrated and remembered occasions when, gripped by anxiety, they were proactive in the care they provided.

In the parallel stories at the opening of this chapter, my co-researcher Stephen spoke about what it meant for Crystal and him to leave one NICU and go to a higher acuity hospital. He described it was a way to contribute to the care of his son Owen:

> Instead of just staring and worry[ing], at least you feel like you are contributing, you know. Because there really is nothing you can do other than be a source of information.

Stephen was not the only co-researcher who interpreted his actions, because of anxiety, as a meaningful contribution to the care of their child. Many co-researchers described how anxiety compelled them to stand up to people who disparaged their children because of their ostomy.

Co-researchers reported feeling powerless when their children's bodies failed or when their children encountered stigma. Every co-researcher reported a tension of living with their own anxiety and confronting the social stigmas that accompanied the anxieties of others. Yet each co-researcher described occasions in which their relational commitment to their child did not let anxiety (theirs or others) get the better of them. Parents knew that their child's fragility did not undermine the innate goodness of their child and their child's body. They used anxiety, like Stephen, as a good source of information at a critical time. Or, like Hannah, when confronted by a playground bully, to remind her daughter Zoe that she is beautiful *because* of her ostomy—not in spite of her ostomy.

If we recognize that anxiety about vulnerability is an inevitable factor within illness, we must embrace the anxiety narrative. As discussed in the previous chapter, anxiety is not the same as sin. But we must confront the very real, perpetually present anxiety experienced within chronic illnesses. Anxiety cannot be ignored or dismissed as easily as quoting scriptures that seemingly signal "Do not be afraid."[702]

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[702] This scripture was quoted to me by Rebecca, Allison, and Leticia. They said, "I know I should not be afraid."

In her book, *Counseling People with Cancer*, Jann Aldredge-Clanton wrote about caring for people living through a cancer diagnosis. Aldredge-Clanton recognizes the lingering anxiety among individuals even after their treatments and while they were in remission. Anxiety was present as they waited for their next appointment, follow-up scans, and news regarding their remission. Individuals felt anxious even when they were relatively healthful;[703] thus, they lived with the specter of disease. Although remission and chronic illness are not identical, the question Aldredge-Clanton raises is similar to my own: how do we keep living in the midst of the anxiety that accompanies a future that anticipates disease? Anxiety does not always halt a life narrative. To assume so is a misconception of the lived realities of illness.

Bearing Witness to Anxiety Narratives

I cannot ignore that my co-researchers describe a future story that anticipates another exacerbation of disease. We will likely witness the re-emergence of the chaos narrative. Anxiety is an honest and viable plotline within that illness narrative. We misrepresent God's presence in the midst of anxiety when we do not offer adequate space for those chaos moments. Clergy and lay leaders, because of their own anxiety within the moment, may rush too quickly toward a resolution of the chaos. But anxiety is not a problem in need of a solution. The problem is in dominant theological and social narratives that forget the positive potential of anxiety narratives.

Clergy and lay leaders must attest to the creative and motivating potential of anxiety. Are we allowing the lived experience to shape our theological positions and practices of care or does our theology hold live experience captive? Anxiety is complex. It is deeply influenced by our anticipation of stress, our circumstance, our emotional state, and

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[703] Jann Aldredge-Clanton, *Counseling People with Cancer* (Louisville, KY: Westminster John Knox Press, 2010), 55-57.

personality;[704] however, "anxiety can have both debilitating and facilitating effects."[705] It is imperative to acknowledge the debilitating effects of anxiety. It should not seem surprising that people, in reaction to anxiety, marginalize those who illustrate the vulnerabilities of this world and the fragility of the human body. We see this when people are marginalized, ridiculed, or ignored because they have a GI ostomy. These debilitating effects of anxiety are only one dimension of the anxiety experience.

Social psychologists Ptacek, Raffety, and Smith found that "facilitating anxiety was positively correlated with creative performance."[706] Psychologists Glenn Little and Karl Wuensch found within their research that "the happiness state of the participant does not act as a moderator in the observed relationship between facilitating anxiety and creativity."[707] They discovered that people could use anxiety in creative, rather than destructive, ways regardless of their contentment. This was true for my co-researchers as well and many recounted ways that they took constructive, creative action in the face of dire—even life-threatening—circumstances.

My co-researchers describe ways of inviting the anxiety to join the narrative of daily living. Their past history of surviving a physical crisis or the marginalization of their child gives them hope. Living in the midst of anxiety—understanding its sway and force—affords my co-researchers a way of surviving the current crisis and gives them the courage and hope to survive the inevitable crises to come. They know that for all the moments that paralyze them in fear they have a trove of examples in which they took concrete actions in the midst of those fears to build

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[704] J.T. Ptacek, Brian D. Raffety, and Ronald E. Smith, "Facilitating and Debilitating Trait Anxiety, Situational Anxiety, and Coping with an Anticipated Stressor: A Process Analysis," *Journal of Personality and Social Psychology* 72, no. 4 (1997): 892-3, DOI: 10.1037/0022-3514.72.4.892.

[705] Glenn B. Little and Karl Wuensch, "Is the Relationship Between Anxiety and Creativity Moderated by Other Emotional States?" *Psi Chi Journal of Psychological Research* 20 no. 3 (Fall 2015): 144, DOI: 10.24839/2164-8204.JN20.3.143.

[706] Little and Wuensch, 148.

[707] Little and Wuensch, 148.

a more helpful future story.

Co-researchers described in overt and subtle ways how anxiety and hope were rarely separate concepts. As I analyzed data, words like: “fear,” “anxious,” or “worry” appeared alongside the word or concept of “hope” (within the same pericope of dialogue) on ninety-seven occasions. It was significant enough for me to make “fear and hope” one of my thematic codes. This coupling of concepts was manifest in data from all nine co-researchers. Crystal illustrates this experience with the simple phrase that she repeated, “It’s a worry. We will figure it out.” Pastoral caregivers should pay attention to moments when anxiety and hope appear in the same pericope of dialogue because it points to the facilitating potential of anxiety in fostering hope.

For example, Stephen described how he and Crystal sat paralyzed on the couch in the NICU, unable to move until they stood to make their way to the next hospital. When I asked Stephen, “What motivated you to get up?” Stephen responded with, “You just have to get over there; you know they have a thousand questions and you’ve got to be there to answer.” Stephen is right; the staff would have a multitude of questions once they arrived because no one had experienced every step of Owen’s life like he and Crystal. Furthermore, Stephen admitted that their knowledge about Owen gave him the comfort that they were contributing to Owen’s care.

As pastoral caregivers, we must tend to our own anxiety about embodied and social vulnerabilities. Henry Nouwen suggests that to pay attention to the needs of others a minister must “be at home in their own house,”[708] attentive to how anxiety sways them. Douglas Purnell notes, “I became aware… how vulnerable I feel in my body when I stand beside someone whose body has been broken through accident or illness or decay.”[709] We are embedded in social

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[708] Nouwen, 97-8.

[709] Douglas Purnell, “Pastoral Ministry and the Fleshly Body,” in *Pastoral Psychology* 53, no. 1 (Spring 2004): 81.

structures that marginalize differently functioning bodies and we must be honest about how this situation produces anxiety within us. Witnessing chronic illness requires that pastoral caregivers become more self-aware about anxiety. Clergy should lean in to our own feelings[710] about anxiety. Our own experience with anxiety should make us inquisitive about the role of anxiety and hope for Stephen and Crystal.

When I directly inquired why Stephen "got up from the couch," I learned that the anxiety was also facilitating his actions. Chaplains, clergy, and lay leaders should learn to identify and address both parts of the anxiety and hope pericope described by Crystal. When we hear "It's a worry" clergy should be willing to question how parents interpret the role of anxiety.[711] Do they assume that all anxiety is problematic or an obstacle they must overcome? Do they have a troubling theological connotation about anxiety; ones that equate anxiety to sin? Likewise, pastoral caregivers should recognize phrases like "We'll figure it out" as a window into a parent's hope in their abilities to withstand the current or future crisis.

Clergy, chaplains, and lay leaders must deconstruct problematic theology related to anxiety. As clergy witness illness they should not demean the reality or potential of anxiety. Chaplains, clergy, and lay leaders have an obligation and a duty to listen for and build upon "unique outcomes" or "alternative storylines"[712] within the anxiety narrative. Pastoral caregivers should be particularly inquisitive about the creative potential of anxiety. These moments can point to a way forward. Theologian Shelly Rambo described the persistent presence of the Spirit

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[710] Beverly Harrison notes the powerful capacity of humanity to "feel their connectedness to other living things." Beverly Wildung Harrison, "The Power of Anger in the Work of Love: Christian Ethics for Women and Other Strangers," in *Union Seminary Quarterly Review* 36 (1981): 48, ATLA Religion Database with ATLASerials, EBSCOhost.

[711] Pastoral caregivers have a role in educating, not from an "expert position," but as a conversation partner that can help evaluate "the dominant discourses of the culture that serve as a framework for problem-saturated narratives." Neuger, *Counseling Women*, 88-90.

[712] White, 219.

of God that remains through the dire moments and anticipates new life.[713] She says, "This presence is an oscillation between death and life, tracking what remains and sensing a way ahead."[714] Witnesses do not retreat from the anxiety that accompanies the oscillation between life and death. Witnesses remind us of God's presence in the midst of those oscillations and sees the creative potential of anxiety in sensing a way forward.

It is not the obligation of clergy to pacify the anxious heart, minimize the presence of anxiety, or off-handedly vilify anxious thoughts. What message is conveyed if a chaplain or a lay leader cannot withstand the pre-narrative pressure of the chaos narrative and rush too quickly toward meaning-making? Do we reinforce an idea that God is somehow not present in that chaos? What is the clergy or chaplain's response when they hear Christian families spout the misconception, "I know I shouldn't be afraid," as did my co-researchers Rebecca, Leticia, and Allison? Do we even see this as a misconception in the first place?

Sermons are preached, co-researcher recall, and well-meaning lay leaders recount the words: "Fear not, I am with you, do not be afraid, for I am your God."[715] All too often our attention is trained only on the first segments of the repeated pericope. We hear and we repeat, "fear not," and "do not be afraid." This is a wholly imbalanced misrepresentation of the scripture. The emphasis is not on the fear; the emphasis within the pericope is on the accompaniment in the midst of the fear. When we bear witness to illness, we mediate the hope of God's presence in the midst of the illness. God's presence is with you: oscillating between

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[713] Shelly Rambo, *Spirit and Trauma: A Theology of Remaining* (Louisville, KY: Westminster John Knox Press, 2010), 160.

[714] Here Rambo is speaking specifically about the death-dealing traumas of life. While some of my co-researchers describe moments with their children in similar terms other describe the evolution of their child's disease as a slow, painful process of discovery. In both cases, however, all co-researchers mark life as "before" and "after" the arrival of disease. In that way, the lives of the co-researchers correlate with the marking of life described in Rambo's book. Rambo, *Spirit and Trauma,* 160.

[715] Isaiah 1:10, The Inclusive Bible.

life and death, between healthful times and disease intrusions, anticipating a way toward facilitating anxiety.

How should clergy and lay leaders remind families of God's presence in the midst of the chaos of disease exacerbation? Imagine the anxiety of Stephen and Crystal as they watched strangers whisk Owen away to a higher-acuity NICU. Pastoral caregivers should host families and parents on the couches of NICUs and hospital wards. We should sit with them for whatever time is necessary. This may mean that we keep quiet and allow the sacred silence of God's presence to come in that stillness. This may mean that we slow down hasty hospital cleaning crews and bed-monitoring staff who are trained to clean and prepare a room in a timely manner for its next occupant. This may mean that we buffer well-meaning clinical staff (that recognize how dire Owen's condition remains) and, in their own anxiety, hasten the departure of the parents.

An anxiety narrative acts as a foundation for the bated-breath narrative. Anxiety is overtly experienced to varying degrees based on the ebb-and-flow of the bated-breath narrative. When the co-researcher's child is experiencing an exacerbation of disease or hospitalization the anxiety narrative is more prominent. When the co-researcher and their child is at home and care is more routine the anxiety narrative is easier to ignore. I will now describe and define the bated-breath narrative as a cyclical illness narrative.

The Bated-Breath Narrative: The Narrative Cycle of Illness Intrusions

My co-researchers narrate from the vantage point of a perpetual precipice: "What will happen next?" When I asked about this, co-researchers described living with looming anticipation of illness intrusions. At the opening of this chapter, we heard two parallel stories from Stephen; each story illustrates a form of illness intrusion. The first illustrated how Owen's physical condition had worsened. The second illustrated how Stephen and Crystal anticipated stigma related to Owen's embodied differences. Co-researchers described two prominent expectations within the bated-breath narrative: 1) the expectation that the disease could worsen at any moment and 2) the anticipated conversations with their children, knowing that they would likely experience curious looks and exclusion. Both of these promptings of the "bated-breath" are rooted in the perpetual anxiety discussed in the above section.

Defining and Describing Bated-Breath Narratives

While rooted in anxiety, my co-researchers describe something akin to ambivalence. They discussed what it meant to live in the midst of the inevitable changes that accompany chronic illness and embodied difference. The bated-breath narrative illustrates a cycle of illness intrusion. Co-researchers anticipate the next hospitalization as they anticipate always having to explain, confront, and tend to inexperienced people's reactions to their child's difference. My co-researchers live with bated-breath that "the other shoe will drop."[716] Co-researchers also describe living with anticipation that their child will not always be at the hospital, that they will be back at school, and that they will have meaningful relationships with peers, family and friends. Both of these senses of anticipation are simultaneously true.

The bated-breath narrative is a future-oriented narrative: guided by past experiences of survival to enable hope. Co-researchers hope that the periods between hospitalizations will be extended. They also hope that their children will be received and welcomed within their congregations, families, and social groups. This hope is not founded on an end to the illness, that their child will be cured, or that their child's body will blend in with the

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[716] This was a phrase used by Allison and Jasmine.

bodies of others; those are “finite hopes.”[717]

Co-researchers express hope by remembering their past survival with the anticipation that they *can* survive future suffering. They hope that they can survive and weather the occurrences when illness is a prominent plot. They hope for days when illness is a secondary plot because they will catch their breath in anticipation of the next wave of illness intrusion. This is more akin to what Andrew Lester calls a “transfinite hope” or a hope that “embraces the mystery and excitement of open-ended future and the not-yet.”[718]

For the most part, co-researchers have forgone the restitution narrative. They neither live in the midst of chaos narratives—though chaos narratives occur; nor do co-researchers fall into the “quest” category. This, however, is an almost-deliberate choice: co-researchers make meaning of the illness narrative but only with the clear expectation that the meaning will be upended. Co-researchers dare not draw conclusions from the illness, because as soon as they do, the story shifts altogether. Changes happen as their child’s body, the disease, or the social context transforms. Arthur Frank notes, “Disease interrupts a life, and illness then means living with perpetual interruptions.”[719] This is true for co-researchers as they described the need to sort through new ostomy supplies, different styles of clothing, nutrition and hydration, conversations about not getting invited to the sleepover, new pain management regimens, and talking to a whole new set of teachers, school counselors, school nurses, and administrators.

Even when their child was experiencing good days, co-researchers developed routines that incorporate hospitalizations and disease exacerbations into their daily lives and family plans.

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[717] Andrew Lester describes “finite hope” as a hope built on attaining a goal, or hope in people or in things; it is a hope connected to “activity, event or object.” Lester, 64.

[718] Lester, 65.

[719] Frank, *Wounded Storyteller*, 56-59. See also: Myra Bluebond-Langner, *In the Shadow of Illness: Parents and Siblings of the Chronically Ill Child* (Princeton, NJ: Princeton University Press, 1996), 12–13.

Allison and Ava's family only took vacations if they were within driving distance of Cook Children's Medical Center. As Jasmine said, "I don't go to an ER without a week's worth of stuff packed." My co-researchers also routinely consider and anticipate how to support their children when they experience marginalization.[720] Both are essential aspects of caring for their child; just as essential as ensuring that they have food to eat, clothes to wear,[721] and meaningful relationships.

When pastoral caregivers are called to bear witness to the bated-breath narrative we affirm the moments of survival to help build their hope for the future. All of the daily tasks—planning food and clothes, having a hospital bag packed, and talking to their child about which swimsuit to wear[722] to a swim party—are examples of parents celebrating survival. The daily tasks—celebrating what their children *can* accomplish,[723] the restful moments at home, and the affirming moments when they recognize that the brilliance of their children's lives are not dimmed by an ostomy—are examples that pastors can use to point toward hope.

Bearing Witness to Bated-Breath Narratives

Pastors, lay leaders and chaplains proclaim the abiding goodness of the body. We celebrate with families because an ostomy provides tremendous relief from painful, embarrassing, and uncomfortable conditions. We celebrate along with Hannah because the ostomy *makes* Zoe healthy. We bear witness to these moments because they offer important

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[720] Stephen, Allison, Crystal, Hannah, Rebecca, Jasmine and Katrina have each thought about conversations with their children concerning exclusions from play dates, sleep overs, and other forms of marginalization.

[721] All of the parents I interviewed shared their concerns about and tips for the foods that their children ate and the clothes that their children wore. Both food and clothing are impacted by having a GI ostomy.

[722] This is a conversation Allison had with Ava, the story is described in the fourth chapter of this dissertation.

[723] These was a very important and satisfying reflections for Katrina (who talked about Mia and Isabella surviving multiple surgeries); Crystal (who imagined Owen walking or talking someday); Hannah (who proudly recounted all of the sports that Zoe played); and Leticia (who beamed when she talked about Samuel starting college).

reminders of courage and strength that enable families to survive the more difficult or debilitating moments. Pastoral caregivers affirm memories of survival so they can become ingrained narratives. Pastoral caregivers help families identify and construct narratives that invigorate hope—a hope founded in the innate, irreducible goodness of the body.

Lay leaders and clergy bear witness to bated-breath narratives with four concrete practices of care. First, bearing witness requires attention to privilege. Pastoral caregivers must pay attention to how privilege impacts an illness narrative. Pastoral caregivers must evaluate their own "health-privilege" in the construction of new illness narratives. Attention to privilege enables hospitality. Secondly, bearing witness is predicated on hospitality. Being a witness is not a one-sided relationship. Since bearing witness occurs as we recognize a shared *imago Dei* the pastoral caregiver is drawn toward others because of the ethical and relational obligation of the *imago Dei*. Hospitality is a compassionate, mutual relationship among those who are rendered abject. A shared concern for the way some bodies are rendered abject calls us, compassionately, *toward* abjection—not to be repulsed or scared away.

Thirdly, a pastoral caregiver resists normalcy discourses. Assurance that the body is good gives witnesses the ability and insight to see past the lies of normalcy discourses. A wounded, abject-ed body offers testimony to disease but it also opens our eyes to the oppressing function of normalcy discourses. Once visible, normalcy discourses must be resisted. Resisting normalcy discourses occurs as we validate the indignation described by parents when they see others attempt to reduce the full humanity of their children. Parents, pastoral caregivers, and the children themselves, resist normalcy discourses when they refuse to believe that their bodies are abject. When we resist normalcy discourses our pastoral practices of care are attuned to the contexts that shape human identity.

Finally, bearing witness to illness demands an affirmation that the body is irreducibly good. Co-researchers express a dissonance between the reality of social stigma (as a result of the ostomy) and the reality that their children's bodies (because of the ostomy) are good. Pastoral caregivers accompany families in that dissonance. Our assurance of the body's goodness offers parents hope that they (and their children) can withstand the pressures and lies of normalcy discourses that attempt to diminish the full humanity of their children.

Bearing witness and privilege

Bearing witness demands attention to privilege. We identify ourselves as "healthy" or "sick" based on our self-interpretation and this interpretation within a context. Alan Radley and Michael Billig suggest that our sense about "health" is "part of [an] ongoing identity in relation to others."[724] Claims made about "health" or "illness" (just as claims made about "normal" or "different") are socially constructed[725] and are not static. Health claims impact our social inclusion or marginalization. This is one reason that my co-researchers insist on using a variation of the term "normal" (they use "our normal") in describing their illness narrative. Parents want to avoid the labels of "different" or "unhealthy" because they resist marginalization[726] and the narrowing of identity within those labels. But co-researchers also recognize that to modify these labels given to their children and their illnesses means they must combat deeply ingrained assumptions.

Since our "state of health" is constructed within social contexts,[727] it is vital to pay attention to privileges carried in our witness. More often than not, those visiting the homes and

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[724] Billig and Radley, 221.

[725] Frank, *Wounded Storyteller,* 2-3.

[726] Co-researchers resist marginalization within their child's peer groups, families, and in society. Co-researchers resist, to an equal degree, the way their children marginalize their own bodies and bodily differences.

[727] Billig and Radley, 221.

hospital rooms of persons experiencing illness are assumed healthy. Lay leaders, clergy (even clinical staff like physicians and nurses) are never asked to disclose the details of their health status.[728] Additionally, (particularly for clinical staff) it is assumed that they have access to details of the medical chart of a patient, creating an imbalance in information and power. When pastoral caregivers enter a room (and are understood as “healthy” or “normal”) it is pertinent to remain aware of this privilege. Privilege is seldom lost on those with whom we visit.[729]

Attention to privilege requires commitment to fostering trusting relationships.[730] Clergy and lay leaders must establish a trusting relationship to receive and build new illness stories.[731] When clergy and lay leaders overtly acknowledge their own health privilege, it can enable the relationship with those who directly experience illness. Pastoral caregivers can remind families that their understanding of the illness experience remains partial. Pastoral caregivers should avoid pitying others, minimizing, or placating their suffering and anxiety.

When witnessing from a position of privilege one must “study, to learn, to refine what [they] know and what [they] need to know.”[732] Learning requires the ability identify and understand our own position of privilege but also the intricacies of an illness narrative. Lay leaders and clergy should learn to identify illness narrative typologies and recognize normalcy discourses. These two elements could be easily included in orientation training for leaders who

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[728] Billig and Radley, 225.

[729] Frances Kendall writes specifically about white privilege. While the insight and examples are not fully transferable to the concept of health-privilege her examination of race in the context of privilege, power and systemic injustice offers tangible insight into understanding any privileged social position. Frances E. Kendall, *Understanding White Privilege: Creating Pathways to Authentic Relationships Across Race* (New York, NY: Routledge, 2006), 22.

[730] Frank, “Knowing Other People's Stories.”

[731] Establishing trust with co-researchers was the most time-consuming aspect of the data collection process. Only one of the nine co-researchers agreed to speak with me before meeting me and she was one of the two who did not complete the entire protocol. I visited with most co-researchers numerous times before they consented to collaborate in this research.

[732] Here Kendall is describing the work of an ally. Kendall argues that anyone wanting to be an ally must be “willing to do deep personal introspection about my role and experience as a person with privilege.” Kendall, 145-6.

visit hospitals, who work as Stephen Ministers, or for those who participate in a congregation's home-bound care ministry.

It should be said, however, that establishing trusting relationships does not mean that chaplains, clergy, and congregational leaders relinquish their personal knowledge or values. Pastoral caregivers bring with them their own wealth of experience and expertise. These are valuable when examining and challenging normalcy discourses, the status quo, the power of abjection. Pastoral expertise is important in thinking theologically within a context of care. More often than not, the clergy, chaplains, and lay leaders are the ones that bring sufficient narrative distance and theological insight to ask important questions about the body and illness. Pastoral expertise should not be undervalued, and it should not overpower the expertise and experience of those directly experiencing illness.

Bearing witness and hospitality

Hospitality is not merely an invitation of inclusion to those whose bodies look and function differently to ours. Hospitality is "the practice of God's welcome by reaching across difference to participate in God's actions bringing justice and healing to our world in crisis."[733] Hospitality is a "relation of reciprocity"[734] in which all parties are transformed by God's welcome. Hospitality toward those experiencing embodied difference and the stigma of a GI ostomy enables us to break through the "narrowness of our own fears" [735] of fragility and "open our houses" to those whose bodies do not coincide with social norms.[736]

Hospitality is an openness to another in response to God's transforming work[737] in the

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[733] Letty Russel, *Just Hospitality: God's Welcome in a World of Difference*, eds. J. Shannon Clarkson and Kate M. Ott (Louisville, KY: Westminster John Knox Press, 2009), 19.

[734] Reynolds, 245.

[735] Nouwen, 95.

[736] Nouwen, 95.

[737] Russell, 50.

world. Hospitality requires that we "learn" from those who are different from us through mutual regard.[738] Hospitality is akin to the role of the witness, as described by Arthur Frank; witnessing requires a "process of learning that [our] own suffering touches and is touched by the suffering of others. The 'inter-human'[739] opens when suffering becomes the call and response implicating self and others."[740] When we witness, we are aware of the suffering and vulnerabilities of the other—they point us to our own vulnerabilities. Witnessing takes seriously the wounding power of normalcy discourses. We learn how they inflict confining and controlling pain on every-body. We question the constraints of "normal" as a qualifier for bodies and see how normalcy discourses shape the way bodies are rendered distinctly other, fear-inducing, repulsive—abject.

Hospitality occurs when we restore dignity to a body that has been rendered abject. When in the hospital, pastoral caregivers can invite families to touch[741] and tend the bodies of their children and loved ones. Pastoral caregivers can invite patients to reconnect with the body of their loved one in new ways. This is a concrete, tactile way to restore dignity to a body rendered abject. As a chaplain I have invited countless patients and family members, paralyzed by debilitating anxiety, to learn how to safely touch their bodies or the bodies of their children.

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[738] Russell, 20.

[739] Edward Farley, 37-43.

[740] Frank, *Wounded Storyteller*, 178.

[741] It is very important, when we are touching anyone, to ask permission. I always ask a person admitted to the hospital for permission to touch them, even when I say a prayer. If the child's age or condition does not allow for assent to touch, I find it important to ask consent from parents and guardians. In the hospital, in particular, it is assumed by physicians, nurses, and therapists that the body will be touched or examined. Clergy should not operate with that same assumption. Clergy, asking for consent to touch, may be one of the only times that people admitted in the hospital have the agency to give such consent.

There will also be times when, because of the fragile and delicate condition of a trauma or disease, the person admitted as a patient needs minimal stimulations. In such cases touch should be limited. Such moments offer important opportunities to talk to guardians, family, and parents about how this impacts their perception about embodied fragility. In my experience, these conversations invite families into reflective moments about the sorrow and fear about embodied fragility in concrete—tangible—ways.

Touching can restore a sense of inclusion,[742] humanity, and the sanctity of life.[743] All too often, those who experience many hospitalizations have experienced intrusions upon their bodies. As Nancy Eiesland recalls, “Our bodies have too often been touched by hands that have forgotten our humanity and attend only to curing us.”[744] Touch can be the “physical mediation of God’s grace” which helps people relate to and become reacquainted with their own bodies or the bodies of their loved ones.[745] Usually children and their caregivers need to touch new stomas as a way of learning to live in bodies (and with bodies) transformed by ostomies.[746] Having an ostomy may alleviate some physical pain and enable people to live rich lives. A new ostomy, however, is an unknown—until it becomes recognizable. Patients and families need time to touch and learn how their bodies and the bodies of their loved ones have changed.

Hospitality includes learning how to care for different types of bodies both in the hospital and in our congregations. In the hospital, parents and families are afraid that they will hurt the person who is admitted to the hospital as a patient. Other times, they do not want to get in the way of clinical staff members. At times the very image of their loved one connected to machines, in distress, or with a new stoma can cause parents and families confusion regarding how to comfort and care for their children. Once routine tasks, like diaper changing and feeding, have to be modified to accommodate an ostomy.

Chaplains, clergy, and congregational lay leaders can play a key role in inviting nurses and therapists to help families and patients learn how to safely touch, hold, change, and care for their body or the body of their child. It is possible, because handling bodies is routine (or clinical

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[742] Nancy Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville, TN: Abingdon Press, 1994), 117.

[743] Rambo says that touch is an “affirmation of bodies.” Rambo, *Resurrecting Wounds*, 105.

[744] Eiesland, 116.

[745] Eiesland, 117.

[746] Almost every co-researcher spoke about the first time they saw their child’s ostomy after the surgery. Many recounted that they felt intimidated until they learned how to care for this new body part.

staff experience their own reaction to anxiety), that even well intended staff may not be aware when a parent or family member is afraid or uncertain about how to touch and care for their own body or the body of their loved one.

Congregational clergy and lay leaders who visit congregants in a hospital or other medical institution should take time to familiarize themselves with some of the possibilities that they may encounter. These reflective and educational moments can help lay leaders and clergy develop better awareness regarding how their own personal anxiety impacts these specialized care moments. Clergy and lay leaders should prevent their anxiety from becoming distracting. Hospital chaplains can be helpful resources for training congregational ministers and lay leaders who will be paying hospital visits.

Similar lessons about tending various types of bodies can be adapted within congregations. One co-researcher shared how her congregation extended hospitality by paying attention to the different needs of her son, Mason, and his GI ostomy. Sara recognized that her congregation cared deeply for her family when they committed to learn how to change ostomy bags and run Mason's feeding pump. According to Sara:

> Our church family is this amazing network of people that they call and check on Mason. They have kept updates about him for our Sunday school class; our pastor came to visit to pray with us here, with him. They have a plan to bring meals to us when we get home, they are going to meet with us to see what needs to happen for him to stick with the nursery at church. "Despite everything," they said, "regardless of what you need us to do, if you need us to do any ostomy care or any feeding stuff."

When I met Sara, Mason had just gotten his ileostomy. Sara felt supported by her congregation. This support came in the form of their generous and warm welcome to Mason's changed body and changing needs.

Sara recalled how the church said, "[The ostomy] a part of who he is and he is still a part of our church family so we will learn right along with you." The church's embrace of Mason's differences reminded Sara that they were with her, bearing witness to the illness. They, collectively, reminded Sara that God accompanied them through the illness. They demonstrated, with the physical act of caring for Mason's body, that he was included in their community—his body was not abject to them. They demonstrated the meaning of bearing witness: their moral obligation toward and relationship with Mason. They turned toward a child and his family when they were impacted by disease.

Hospitality is a call to participate in God's justice. Hospitality is "the practice of God's welcome by reaching across difference to participate in God's actions bringing justice and healing to our world in crisis."[747] Certainly, hospitality toward discreet bodies is an invaluable gift that congregations and clergy can offer to families who find themselves in the midst of bated-breath narratives of chronic illness. Witnessing bated-breath narratives does not end with attention to individual bodies. Those witnessing illness offer hospitality in a world shaped by normalcy discourses. Historically within Christian tradition, hospitality restored "persons on the margins" to relationship within community life.[748] Thus, hospitality means the "recognition and inclusion" of individuals and groups to restore their "life and hope."[749] Pastors, lay leaders, and chaplains who recognize (and help others recognize) that bodies signify much more than an ostomy or illness are offering hospitality intended to restore "life and hope" when they remind us that every body is created good and is worthy of love. Pastoral caregivers who are attentive to the contexts that shape our self-understanding are offering hospitality intended to restore "life

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[747] Russel, 19.

[748] Christine D. Pohl, "Hospitality and the Mental Health of Children and Families," in *American Journal of Orthopsychiatry*, 81, no. 4 (October 2011): 483, DOI: 10.1111/j.1939-0025.2011.01111.x. Christine Pohl points out how in the Hebrew Bible and New Testament early church this was the primary teaching about hospitality but that diminished as the Christian church gained in social power and resources. Pohl, 484.

[749] Pohl, 485.

and hope" when they challenge normalcy discourses (and help others to challenge them) because they recognize that normalcy discourses diminish the full humanity of those experiencing illness.

Bearing witness and resisting normalcy discourses

Witnessing is a moral reckoning; a moral response to suffering. While listening itself is a moral act,[750] illness narratives turn our attention to the way that society inflicts suffering on individuals within contexts. Our moral response, our moral obligation[751] toward the other, is to resist normalcy discourses that create the conditions that render bodies abject. At the opening of this chapter, Stephen anticipated the stigma and marginalization that Owen would face when living with a GI ostomy. He recognized that his son may be rendered as abject (disgusting, fear-inducing, other) because of his ostomy. Witnessing life among those with a GI ostomy is the recognition of a shared responsibility for that abjection rendering—for the conditions of suffering brought on by normalcy discourses.

If we do not resist normalcy discourses, we are complicit in our own wounding and the wounding of others. Complicity harms society[752] and disrupts our relational obligations toward each other and toward our own bodies. Normalcy discourses shape expectations about body function and body appearance in society. Normalcy discourses reveal evidence of the tragic. As described in the previous chapter, institutional and systemic ideology about what

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[750] Frank, *Wounded Storyteller*, 25.

[751] Arthur Frank called this "narrative-deontology," arguing that moral obligation or an "ethical life" within a healthcare setting "requires more than stories." We must recognize generalizable "ought's" or obligations toward others. These obligations are always rooted in particular narratives; our narratives convey and comprise our moral obligations—whether these are personal or familial narratives, cultural narratives, scientific narratives, or religious narratives. Narratives convey and construct our moral vision. Arthur Frank went on to explain, "Hyphenating 'deontology' with 'narrative' reminds us that the core of any mediation or negotiation [revolves around] conflicting parties telling the stories that compel their values, and each hearing the stories that give each other party's values their compelling force. Shared storytelling will not, I'm afraid, resolve all health care disputes. But as people hear the stories that ground others' values, they can become better enabled to live with outcomes that they do not prefer." Frank, *Truth Telling*, 20.

[752] Wendell Berry is particularly addressing the "hereditary evils" of racism and slavery. Berry, 6.

defines “normal” complicates relationships. Marginalizing definitions of who or what is “normal” make it possible to negate our relationship[753] with our own bodies and the bodies of others. We think we are acting in accordance to what is “normal” but a marginalizing response to normalcy discourses should be understood as a sinful response.

How are we complicit to normalcy discourses? Do we hide behind normalcy discourses, considering ourselves part of the “normal” group? Do we wrap normalcy discourses with a Band-Aid and pretend that they do not exist or that they do not cause us or others harm? A witness confronts the myth of “normal.” Witnesses must overtly point out when they see and when they hear people trying to inflict definitions of normal on discreet bodies. Since normalcy discourses have a way of covering up the indelible goodness of alterity, to ignore these discourses maintains the status quo. A witness illustrates how normalcy discourse diminishes our capacities to act lovingly toward our own bodies and the bodies of others.

How, then, do pastoral caregivers confront and resist normalcy discourses? Stephen was concerned about how Owen would be treated because of his ostomy. Stephen said, “I would assume that there would be some teasing, some what-not, some pointing… ‘Gee, if he does have that bag his whole life, there will be some tough days in there, I’m sure.’” After the initial surgical bandages are removed from an ostomy, once the stoma is healed, co-researchers ask questions like: Who will think their child’s body is disgusting? Or when will my child not be invited to the next swim party or sleepover? Parents are considering how their child’s body will inevitably unbandage sinful responses from family members, peers, and society. Co-researchers anticipate, with bated-breath, the inevitable questions, scrutiny, and marginalization that come when their child does not fit the norms of society.

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[753] Matsuoka, 57-9. But this is not just a rupture to the relationship it is a negation of the full humanity and inclusion of others (and ourselves).

When I asked my co-researchers questions like: "What does normal mean?" and "Who gets to define normal?" most responded with a recognition that there was some unsubstantiated, abstract notion of "normal" that created disabling contexts for their children. Though the co-researchers of this study did not use the language of "normalcy discourse," each considered how their child would live in a world that classified their child as "different" or "not normal." Pastoral caregivers should be attuned to these moments when parents and guardians distinctly dispute the untruths embedded in the descriptions and labels given to their children.

Pastoral caregivers can ask questions that unmask power dynamics embedded within the definitions of "normal." They should ask direct questions like: 1) Who has the power to define what is normal? 2) Is there a clear, generalizable definition of normal? 3) Is that definition of normal to the advantage of someone/something? 4) Who/what holds that advantage?

These questions emphasize how "normal" is a straw-man ideology. Too often we assume "normal" without questioning the power and privilege that determines "normal." We are not witnessing illness if we fail to "decenter" normative claims.[754] Resisting normalcy discourses includes a new, future-oriented way of narrating the bated-breath narrative. Clergy and lay leaders can help families, narrating with bated-breath, remember the goodness of the body.

Bearing witness to the goodness of the body

The body is good and this is our hope. Arthur Frank argues that the body is the testimony to illness. The body is also the testimony of hope in the midst of illness. Disease and normalcy discourses confound our understanding of an embodied goodness. As the parents interviewed for this project readily identified, the bodies of their children do not cease to be good because of the ostomy—they remain good because of the ostomy. Thus, the goodness of the body does not end

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[754] Reynolds, 246.

at the construction of the ostomy. When parents, clergy, and lay leaders recognize and embrace the innate goodness of the body, they create a theological life-line of hope in the midst of powerful narratives that, otherwise, depreciate the value of the body.

Differently functioning bodies, at times rendered abject, testify to the goodness of alterity and embodiment. Parents know that the body, even when it functions differently or when it is a source of pain, is good. The body gives testimony to a hopeful reality. Loving our own bodies and tending to the bodies of others *is* an act of resistance against normalcy discourses.[755]

Neither the women at the tomb nor Thomas turn away from the potential of decay, open flesh, or of becoming defiled themselves.[756] They see abjection for what it is: a rendering by normalcy discourses. The women are drawn to the tomb in defiance of a government that washed their hands of Jesus and crucified his body; Thomas balked at norms that suggest that a risen, still wounded, body could not and should not be touched. The opening of flesh, the body itself, is an "opening" [757] (an invitation) into a relationship.

Families survive the disparaging renderings of their children (as abject) and the force of normalcy discourses by trusting in the alternative testimony that their child's body is good and should be loved. The women at the tomb witnessed that same embodied testimony. Families love the bodies of their children and are thankful that their difference allows them to live. Witnesses are present and do not turn away even in the face of anxious impulses that disrupt relationships. Witnesses turn toward the body and the bodies of others. This "compassionate-

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[755] Eiesland, 96.

[756] In the previous chapter I discussed Ricoeur and his interpretation of defilement. Ricoeur describes defilement as a separation between what is pure and what is impure. These categories act in a way to delineate the margins of society. Defilement emerges as humanity contends with suffering that accompanies embodiment. As a way of avoiding the suffering of others, Ricoeur notes, we label them as defiled and, therefore, their inclusion within a community can be limited. Paul Ricoeur, *The Symbolism of Evil*, trans. Emerson Buchanan (Boston, MA: Beacon Press, 1967), 25-9.

[757] Frank, *Wounded Storyteller*, 176-77.

obligation"[758] is evidence of our shared *imago Dei*.[759] Witnesses attest to God's ongoing presence and call toward hospitable relationships.

Conclusion

Pastoral care in the midst of chronic illnesses and embodied difference demands a narrative witness. A narrative witness is an attunement to, an accompaniment through, and a change by the varied landscape of illness experiences. Life in the midst of chronic disease recognizes that illness is always a factor in the narrative. Working among people experiencing life with a GI ostomy requires that we bear witness to the anxiety narratives and the bated-breath narratives that form the narrative landscape of chronic illness. Thus, a narrative pastoral practice asserts that the stories we tell to ourselves and about ourselves carry distinct meanings. We acknowledge that these distinct meanings say something about ourselves and about our contexts. As people tell stories through illness, they are turning illness into a call for moral responsibility. This is what it means to witness: to be become relationally and morally responsible within the experience of illness and the way it shapes identity and contexts. The onus of a narrative witness rests on all who see, touch, experience, attend, and feel illness. Witnessing is not the responsibility of the sick, alone. The call to witness is a responsibility we all share.

Pastors, chaplains, and lay leaders are called to witness anxiety narratives. It is true that anxiety about embodied finitude fuels abjection. Clergy should recognize that anxiety is not altogether paralyzing. We must hold two truth simultaneously: 1) anxiety about embodied finitude fuels abjection and fear of difference but 2) anxiety also compels us to advocate for right relationships. We must look to the facilitating potential of anxiety to draw us into relationships of care among those experiencing embodied difference and abjection.

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[758] Edward Farley, 43.

[759] Wendy Farley, *Tragic Vision*, 51.

Clergy, lay leaders, and chaplains also witness bated-breath narratives. The bated-breath narrative holds together two expectations: the expectation that a disease can worsen at any moment and the expectation that people who have a GI ostomy will experience curious looks and marginalization. Pastoral caregivers accompany families through the perpetual illness changes as families live with bated-breath. While the body offers testimony to suffering, it also offers testament to ongoing life amid illness. The body is our testimony to an enduring goodness that diminishes the capacity and power of normalcy discourses in shaping human identity. For all the ways that illness is injurious it is also an invitation to loving, mutual relationships of care.

Conclusion

I was enlivened by the experience and wisdom of my co-researchers. Their thoughtful reflection about common, everyday life caring for their children with gastrointestinal ostomies reveals important questions about how we, as pastoral theologians and pastoral caregivers, approach the frailty of embodied life. I have demonstrated that embodied, lived experience contributes importantly in revising and amending theological and ideological constructs. Although suffering because of illness persists, my co-researchers confirmed an innate goodness in the body of their child. They did not think of the ostomy as a detriment; most reflected on the ostomy as enabling the lives of their children. They are not unaware, however, that the ostomy also uncovered potential for marginalization—something that increased their child's suffering within their particular contexts.

In reflecting on co-researcher experiences with a gastrointestinal ostomy, I was able to reframe the way we think about and imagine who is included when we describe the *imago Dei*. The *imago Dei* is embodied, it is relational, and it is a force that can never be subverted by illness or bodily changes. In this dissertation I reaffirm that the body is simultaneously fragile and good; its fragility does not negate its goodness.

When I argued that the *imago Dei* is relational, that commitment illustrates that the *imago Dei* is both a theological proposition and an ethical impulse. I suggest that pastoral caregivers are called to bear witness to illness. Bearing witness means that we are attuned to the suffering of those experiencing illness (we have compassion) and join with them in their suffering (we have an obligation) to resist the cause of suffering. When we bear witness to illness we accompany families as they describe a variety of illness stories and experiences. I suggested that the conditions of chronic, on-going illness illustrate, for pastoral caregivers, two specific illness narratives: the anxiety narrative and the bated-breath narrative.

In bearing witness to anxiety narratives, pastoral caregivers recognize the perpetual presence of anxiety. They challenge the ways that anxiety can result in a break in our relationships and the marginalization of our own bodies and the bodies of others. Pastors, lay leaders, and chaplains affirm the moments when parents use anxiety as a resource to advocate for their children. When pastoral caregivers witness the bated-breath narrative they accompany families through the ongoing cycles of illness. They celebrate the moments when children are feeling well and included; the moments when families catch their breath. Pastoral caregivers remind families, during the times when the illness is exacerbated, of the ways they have survived these moments in the past to enable hope for future survival.

When pastors bear witness to illness this does not connote a passive, observational role for the pastoral caregiver. Pastors affirm and highlight the agency and hope already present in the illness stories told by families. We affirm these qualities to then collaborate toward the construction of future-focused narratives that enable our hospitality toward others and love for our own embodied differences. Pastoral caregivers affirm the goodness of the body so that we can ally with families to resist normalcy discourses that attempt to marginalize bodies.

This project and the contributions from co-researchers open new questions for research. I want to suggest two. First, I am aware that this research project is limited to data collected from the parents of children living with a GI ostomy. I believe it to be imperative to examine first-person accounts of children and adults living with ostomies. How would their experience with the pain of disease and the marginalization form illness challenge my theological propositions? This present research would serve as a helpful starting point for a project of that nature.

Finally, I am aware that this research project is bookended by two global health crises: Ebola virus outbreaks that started in West Africa and the Coronavirus outbreaks that began in

China. I believe that the contagious nature of these viruses, coupled with its global impact, have the potential to challenge my theological proposals and cause us to reexamine my proposed practices of care. Not only do we see a fear of contagion arising in the midst of these crises, but we can speculate about how this fear of contagion and embodied difference contribute to and amplify xenophobia related to the countries, cultures, and populations where these viruses originated. This present research could contribute to research related to global health crises.

When the body feels pain and when this pain is compounded by an emotional and mental pain of marginalization it is difficult to read past the pain receptors and see that the body, though fragile, is good. When sociologists like Pamela van der Riet and Dennis Waskul propose that physical pain is a source of suffering that reduces and ultimately consumes a self,[760] and when co-researchers acknowledge that their children endure physical and social suffering it is tempting to believe that when the body fails our identity and our humanity fails as well. This argument cannot be true. This dissertation affirms that the brilliance of the *imago Dei* is irreducible, even in the face of illness and marginalization.

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[760] Pamela van der Riet and Dennis D. Waskul, “The Abject Embodiment of Cancer Patients: Dignity, Selfhood, and the Grotesque Body,” *Symbolic Interaction* 25 no. 4 (2002): 505, JSTOR.

Bibliography

Aldredge-Clanton, Jann. *Counseling People with Cancer*. Louisville, KY: Westminster John Knox Press, 2010.

Althaus-Reid, Marcella, and Lisa Isherwood. *Controversies in Body Theology*. London: SCM Press, 2008.

__________. "Introduction: Queering Theology Thinking Theology and Queer Theory." In *The Sexual Theologian: Essays on Sex, God and Politics*, edited by Marcella Althaus-Reid and Lisa Isherwood, 1-15. New York: T&T Clark International, 2004.

Altschuler, Andrea, et al. "'I Didn't Feel Like I Was a Person Anymore': Realigning Full Adult Personhood after Ostomy Surgery" in *Medical Anthropology Quarterly* 28, no 2. (June 2014): 242-59. JSTOR.

Alves, Rubem. "Personal Wholeness and Political Creativity: The Theology of Liberation and Pastoral Care." *Pastoral Psychology* 26, no. 2 (1977): 124-36. EBSCOHost.

American College of Surgeons. *Pediatric Ostomy Home Skills Kit: Education for a Better Recovery*. Chicago, IL: American College of Surgeons, 2012.

Anderson, Herbert and Edward Foley. *Mighty Stories, Dangerous Rituals: Weaving Together the Human and the Divine*. San Francisco, Jossey Bass, 1998.

Anzaldua, Gloria. *Light in the Dark/Luz en lo Oscuro: Rewriting Identity, Spirituality, Reality*, edited by AnaLouise Keating. Durham, NC: Duke University Press Books, 2015.

Anzul, Margaret, Margot Ely, Terri Friedman, Diane Garner, and Ann McCormack Steinmetz. *Doing Qualitative Research: Circles within Circles*. New York, NY: Routledge Falmer, 199.

Anzul, Margaret, Margot Ely, Maryann Downing, and Ruth Vinz. *On Writing Qualitative Research: Living by Words.* Washington, D.C.: The Falmer Press, 1997.

Ashby, Jr., Homer. *Our Home Is Over Jordan: A Black Pastoral Theology*. St. Louis, MO: Chalice Press, 2003.

Becker, Howard. "Epistemology of Qualitative Research." In *Ethnography and Human Development: Context and Meaning in Social Inquiry*, edited by Anne Colby, Richard Jesser, and Richard A. Shweder, 53-72. Chicago, IL: University of Chicago Press, 1996.

Bell, Lee Ann. "Theological Foundations for Social Justice Education." In *Teaching for Diversity and Social Justice*, 2nd edition, edited Maurianne Adams, Lee Anne Bell, and Pat Griffin, 1-14. New York, NY: Routledge, 2007.

Bell, Lee Ann, Barbara J. Love, Sharon Washington, and Gerald Weinstein. “Knowing Ourselves as Social Justice Educators.” In *Teaching for Diversity and Social Justice*, 2nd ed., edited by Maurianne Adams, Lee Ann Bell, and Pat Griffin, 381-93. New York, NY: Rutledge, 2007.

Berger, Peter. “Appendix II: Sociological ad Theological Perspectives.” In The Sacred Canopy: Elements of a Sociological Theory of Religion, 179-85. New York: Anchor Books, 1990.

Bergmann, Sigurd. *God in Context: A Survey of Contextual Theology*. Burlington, VT: Ashgate, 2003.

Berry, Wendell. *The Hidden Wound*. Boston, MA: Houghton Mifflin, 1970.

Bilge, Sirma and Patricia Hill Collins. *Intersectionality*. Malden, MA: Polity Press, 2016.

Billing, Michael and Alan Radley. “Accounts of Health and Illness: Dilemmas and Representations.” *Sociology of Health and Illness* 18, no. 2 (1996): 220-240. DOI: 10.1111/1467-9566.ep10934984.

Bluebond-Langer, Myra. *In the Shadow if Illness: Parents and Siblings of the Chronically Ill Child.* Princeton, NJ: Princeton University Press, 1996.

Boisen, Anton T. *The Exploration of the Inner World: A Study of Mental Disorder and Religious Experience*. Philadelphia, PA: University of Philadelphia Press, 1971.

_________. “The Period of Beginnings,” *Journal of Pastoral Care* 5 (1951): 13-16.

Brookfield, Stephen D. *The Power of Critical Theory: Liberating Adult Learning and Teaching*. San Francisco, CA: Jossey-Bass, 2005.

Canguilhem, Georges. *The Normal and the Pathological*, translated by Carolyn R. Fawcett with Robert S. Cohen. New York, NY: Zone Books, 1966, 1991.

Charmaz, Kathy. *Constructing Grounded Theory*, 2nd edition. Los Angeles, CA: SAGE Publications, 2014.

Chopp, Rebecca. “Practical Theology and Liberation.” In *Formation and Reflection: The Promise of Practice Theology*, edited by Lewis S. Mudge and James N. Poling, 120-38. Philadelphia, PA: Fortress Press, 1987.

Collaborative Institutional Training Initiative. “Defining Research and Human Subjects.” Accessed January 19, 2017. https://www.citiprogram.org/members/index.cfm?pageID=665&ce=1.

Coleman, Monica. *Making a Way Out of No Way: A Womanist Theology*. Minneapolis, MN: Fortress Press, 2008.

Coloplast Corporation. *Life after Your Child's Ostomy*. Minneapolis, MN: Coloplast Corporation, 2011.

Cooper-White, Pamela. *Many Voices: Pastoral Psychotherapy in Relational and Theological Perspective*. Minneapolis, MN: Fortress Press, 2007.

Copeland, M. Shawn. *Enfleshing Freedom: Body, Race, and Being*. Minneapolis, MN: Fortress Press, 2010.

Crenshaw, Kimberlé. "Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color." *Stanford Law Review*, 43 no. 6, (July 1991): 1241-1299. http://www.jstor.org/stable/1229039.

Creswell, John W. *Qualitative Inquiry and Research Design: Choosing among Five Approaches*, 3rd edition. Thousand Oaks, CA: SAGE Publications, 2013.

Cullen, Mary Louise and Mary James Dean. "Women's Body: Spiritual Needs and Theological Presence." In *Women in Travail and Transition: A New Pastoral Care*, edited by Maxine Glaz and Jeanne Stevenson Moessner, 86-108. Minneapolis, MN: Fortress Press, 1991.

Dasher, Jane E. "Manna in the Desert: Eating Disorders and Pastoral Care." In *Through the Eyes of Women: Insights for Pastoral Care*, edited by Jeanne Stevenson-Moessner, 179-91. Minneapolis, MN: Fortress Press, 1996.

Decoteau, Claire Laurier. "The Specter of AIDS: Testimonial Activism in the Aftermath of the Epidemic," *Sociological Theory* 26 no. 3 (September 2008): 230-57. JSTOR.

Denzin, Norman K. and Yvonna S. Lincoln. "Introduction: The Discipline and Practice of Qualitative Research." In *The SAGE Handbook of Qualitative Research*, 4th ed., edited by Norman K. Denzin and Yvonna S. Lincoln, 1-20. Thousand Oaks, CA: SAGE Publications, 2011.

Douglas, Mary. *Purity and Danger: An Analysis of Concepts of Pollution and Taboo*. New York, NY: Frederick A. Praeger, 1966.

Eiesland, Nancy. *The Disabled God: Toward a Liberatory Theology of Disability*. Nashville, TN: Abingdon Press, 1994.

Ellingson, Laura L. "Analysis and Representation across the Continuum." In *The SAGE Handbook of Qualitative Research*, 4th ed., edited by Norman K. Denzin and Yvonna S. Lincoln, 595-610. Thousand Oaks, CA: SAGE Publications, 2011.

Emens, Elizabeth F. "Shape Stops Story." *Narrative*, 15 no. 1, (January 2007): 124-132. doi: 10.1353/nar.2007.0003.

Epston, David and Michael White. *Narrative Means to Therapeutic Ends*. New York, NY: W.W. Norton, 1990.

Estock, Beth Ann. "Hysterectomy and Woman's Identity." In *Through the Eyes of Women: Insights for Pastoral Care*, edited by Jeanne Stevenson Moessner, 192-206. Minneapolis, MN: Fortress Press, 1996.

Farley, Edward. *Good and Evil: Interpreting the Human Condition*. Minneapolis, MN: Fortress Press, 1990.

Farley, Wendy. *Gathering Those Driven Away: A Theology of Incarnation*. Louisville, KY: Westminster John Knox Press, 2011.

__________. *Tragic Vision and Divine Compassion: A Contemporary Theodicy*. Louisville, KY: Westminster John Knox Press, 1990.

__________. *The Wounding and Healing of Desire: Weaving Heaven and Earth*. Louisville, KY: Westminster John Knox Press, 2005.

Foucault, Michel. *The Archeology of Knowledge: And the Discourse on Language*. New York, NY: Pantheon, 1972.

Frank, Arthur W. *At the Will of the Body: Reflections on Illness*. New York, NY: Houghton Mifflin Company, 1991.

__________. "Knowing Other People's Stories: Empathy, Illness, and Identity." Leslie Center for the Humanities Lecture, Dartmouth College, Hanover, NH, April 4, 2018.

__________. "Truth Telling, Companionship, and Witness: An Agenda for Narrative Bioethics," *Hastings Center Report* 46, no. 3 (May 2016): 17-21. https://doi-org.ezproxy.tcu.edu/10.1002/hast.591.

__________. *The Wounded Storyteller: Body. Illness and Ethics*, 2nd edition. Chicago, IL: University of Chicago Press, 2013.

Frohlich, Dennis O. and Anne N. Zmyslinski-Seelig. "How *Uncover Ostomy* Challenges Ostomy Stigma, and Encourages Others to do the Same." *News Media & Society* 18 no. 2 (July 9, 2014 and February 1, 2016): 220-238. https://doi.org/10.1177/1461444814541943.

Gailey, Jeannine A. *The Hyper(in)visible Fat Woman: Weight and Gender Discourse in Contemporary Society*. New York, NY: Palgrave MacMillan, 2014.

Ganzevoort, R. Ruard. "Narrative Approaches." In *The Wiley-Blackwell Companion to Practical Theology*, edited by Bonnie Miller-McLemore, 214-23. Oxford, UK: Wiley-Blackwell, 2011.

Geertz, Clifford. "Thick Descriptions: Toward an Interpretive Theory of Culture." In *The Interpretation of Cultures*, edited by Clifford Geertz, 3-32. New York, NY: Basic Books, 1973/1977.

Glaz, Maxine and Jeanne Stevenson Moessner, eds. *Women in Travail and Transition: A New Pastoral Care*. Minneapolis, MN: Fortress Press, 1991.

Gleson, Corrine. *Becoming Qualitative Researchers: An Introduction*, 3rd edition. Boston, MA: Pearson Education, 2006.

Goffman, Ervin. *Stigma: Notes on the Management of Spoiled Identity*. New York, NY: Simon and Schuster, 1963.

Graham, Elaine, Heather Walton, and Frances Ward. *Theological Reflection: Methods*. London: SCM Press, 2005.

Graham, Larry K. *Care of Persons, Care of Worlds: A Psychosystems Approach to Pastoral Care and Counseling*. Nashville, TN: Abingdon Press, 1992.

Greider, Kathleen J., Gloria A. Johnson, and Kristen J. Leslie. "Three Decades of Women Writing for Our Lives." In *Feminist and Womanist Pastoral Theology*, edited by Bonnie J. Miller-McLemore and Brita L. Gill-Austern, 21-50. Nashville, TN: Abingdon Press, 1999.

Griffin, Pat, Madeline L. Peters, and Robin M. Smith. "Ableism Curriculum Design." *Teaching for Diversity and Social Justice*, 2nd ed., edited by Maurianne Adams, Lee Ann Bell, Pat Griffin, 335-8. New York, NY: Routledge Press, 2007.

Guba, Egon G., Yvonna S. Lincoln and Susan A. Lynham. "Paradigmatic Controversies, Contradictions, and Emerging Confluences, Revisited," In *The SAGE Handbook of Qualitative Research*, 4th ed., edited by Norman K. Denzin and Yvonna S. Lincoln, XX-XX. Thousand Oaks, CA: SAGE Publications, 2011.

Gubrium, Jaber F. and James A. Holstein. "The Constructionist Analytics of Interpretive Practice." In *The SAGE Handbook of Qualitative Research*, 4th ed., edited by Norman K. Denzin and Yvonna S. Lincoln, 341-58. Thousand Oaks, CA: SAGE Publications, 2011.

Hall, Douglas John. *Imaging God: Domain as Stewardship*. Grand Rapids, MI: Wm. B. Eerdmans Publishing Company, 1986.

Harris, Magdalena. "Injecting, Infection, Illness: Abjection and Hepatitis C Stigma," *Body & Society* 15 no. 4 (2009): 33-51. DOI: 10.1177/1357034X09347221.

Harrison, Beverly Wildung. "The Power of Anger in the Work of Love: Christian Ethics for Women and Other Strangers." *Union Seminary Quarterly Review* 36 (1981): 41-57. ATLA Religion Database with ATLASerials, EBSCOhost.

Henderson, Irene. "Matters Close to the Heart: Pastoral Care to Mastectomy Patients." In *Through the Eyes of Women: Insights for Pastoral Care*, edited by Jeanne Stevenson-Moessner, 207-21. Minneapolis, MN: Fortress Press, 1996.

Herman, Judith. *Trauma and Recovery: The Aftermath of Violence—From Domestic Abuse to Political Terror*. New York, NY: Basic Book, 1992, 1997.

Hill Collins, Patricia. *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*, 2nd edition. New York, NY: Routledge, 2000.

Holland, Janet and Caroline Ramazanoğlu. *Feminist Methodology: Challenges and Choices*. Thousand Oaks, CA: SAGE Publications, 2002/2008.

Hopkins, Dwight N. *Being Human: Race, Culture and Religion*. Minneapolis, MN: Fortress Press, 2005.

Isasi-Díaz, Ada María. *Mujerista Theology*. Maryknoll, NY: Orbis Books, 1996.

Isherwood, Lisa, and Elizabeth Stuart. *Introducing Body Theology*. Sheffield, England: Sheffield Academic Press, 1998.

Jewett, Paul. "Body." In *Dictionary of Pastoral Care and Counseling*, expanded edition, edited by Rodney J. Hunter and Nancy J. Ramsay, 101-03. Nashville, TN: Abingdon, 2005.

Kendall, Frances E. *Understanding White Privilege: Creating Pathways to Authentic Relationships Across Race*. New York: Routledge, 2006.

Kristeva, Julia. *Powers of Horror: An Essay on Abjection*. New York, NY: Columbia University Press, 1982.

Kundtz, David J. and Bernard S. Schlager. *Ministry Among God's Queer Folk: LGBT Pastoral Care*. Cleveland, OH: The Pilgrim Press, 2007.

L'Engle, Madeleine. The Summer of the Great-grandmother. New York, NY: Farrar, Straus and Giroux, 1974.

Larty, Emmanuel Y. *In Living Color: An Intercultural Approach to Pastoral Care and Counseling*. Philadelphia, PA: Jessica Kingsley Press, 1997, 2003.

Lester, Andrew D. *Hope in Pastoral Care and Counseling*. Louisville, KY: Westminster John Knox Press, 1995.

Levinas, Emmanuel. *Totality and Infinity: An Essay on Exteriority*. Translated by Alphonso Lingis. Pittsburgh, PA: Duquesne University Press, 1961/1969.

__________. “Useless Suffering,” translated by Richard A. Cohen. In *The Provocation of Levinas: Rethinking the Other*, edited by Robert Bernasconi and David Wood, 156-67. London: Routledge Press, 1988.

Little, Glenn B. and Karl Wuensch, “Is the Relationship Between Anxiety and Creativity Moderated by Other Emotional States?” *Psi Chi Journal of Psychological Research* 20 no. 3 (Fall 2015): 143-150. DOI: 10.24839/2164-8204.JN20.3.143.

Luther, Martin. *Commentary on Genesis: Volume 1, Chapters 1-21*, translated by J. Theodore Mueller. Grand Rapids, MI: Zondervan Publishing House, 1958.

Madigan, Stephen. *Narrative Therapy: Theories of Psychotherapy Series*, edited by Jon Carlson and Matt Englar-Carlson. Washington, D.C.: American Psychological Association, 2011.

Marshall, Joretta L. “Methods in Pastoral Theology, Care, and Counseling.” In *Pastoral Care and Counseling: Redefining the Paradigms*, edited by Nancy J. Ramsay, 133-154. Nashville, TN: Abingdon Press, 2004.

Matsuoka, Fumitaka. *The Color of Faith: Building Community in a Multiracial Society*. Cleveland, OH, United Church Press, 1998.

May, Melanie A. *A Body Knows: A Theopoetics of Death and Resurrection*. New York, NY: Continuum, 1995.

McFadden, Susan H. and John T. McFadden. *Aging Together: Dementia, Friendship, and Flourishing Communities*. Baltimore, MD: Johns Hopkins University Press, 2011.

McNeil, John T. *A History of the Cure of Souls*. New York, NY: Harper and Row, Publishers, 1951, 1977.

Miller-McLemore, Bonnie. *Also a Mother: Work and Family as Theological Dilemma*. Nashville, TN: Abingdon Press, 1994.

__________. “Embodied Knowing, Embodied Theology: What Happened to the Body?” *Pastoral Psychology* 62, no. 5 (October 2013): 743–758. https://doi-org.ezproxy.tcu.edu/10.1007/s11089-013-0510-3

__________. “The Human Web: Reflections on the State of Pastoral Theology.” *The Christian Century* 110, no 11 (April 07, 1993): 366-69.

_________, “The Living Human Web: Pastoral Theology at the Turn of the Century.” In *Through the Eyes of Women: Insights for Pastoral Care*, edited by Jeanne Stevenson Moessner, 9-26. Minneapolis: Fortress Press, 1996.

__________, ed. *The Wiley Blackwell Companion to Practical Theology*. West Sussex: Wiley Blackwell, 2014.

Mount Shoop, Marcia W. *Let the Bones Dance: Embodiment and the Body of Christ*. Louisville, KY: Westminster John Knox Press, 2010.

Mowat, Harriet and John Swinton. *Practical Theology and Qualitative Research*. London: SCM Press, 2006.

Nanko-Fernández, Carmen. *Theologizing en Espanglish*. Maryknoll, NY: Orbis Books, 2010.

Nelson, James B. *Body Theology*. Louisville, KY: Westminster John Knox Press, 1992.

__________. *Embodiment: An Approach to Sexuality and Christian Theology*. Minneapolis, MN: Augsburg Press, 1978.

Neuger, Christie Cozad. *Counseling Women: A Narrative, Pastoral Approach*. Minneapolis, MN: Fortress Press, 2001.

__________. "Power and Difference in Pastoral Theology." In *Pastoral Care and Counseling: Redefining the Paradigms*, edited by Nancy Ramsay, 65-85. Nashville, TN: Abingdon Press, 2004.

Neuger, Christie Cozad and Poling, James Newton, editors. *The Care of Men*. Nashville, TN: Abingdon Press, 1997.

Niebuhr, Reinhold. *The Nature and Destiny of Man, vol. 1: Human Nature*. New York, NY: Charles Scriber's Sons, 1941.

Norman, Moss E. "Embodying the Double-Bind of Masculinity: Young Men and Discourses of Normalcy, Health, Heterosexuality, and Individualism." *Men and Masculinities* 14, no. 4 (2011): 430-49. sagepub.com/journalsPermissions.nav DOI: 10.1177/1097184X11409360.

Nouwen, Henry J.M. *The Wounded Healer: Ministry in Contemporary Society*. New York, NY: Image Doubleday, 1972, 2010.

Nussbaum, Martha. *Hiding from Humanity: Disgust, Shame and the Law*. Princeton, NJ: Princeton University Press, 2006.

Patrick, Sanchia. *When I Met Tipster: A Child's Story about Living with a Stoma*, edited by Sandi Burnello, Teri Carwley, Marie Oren-Sosebee, and Jeannine Thompson. Minneapolis, MN: Coloplast Corporation, 2013.

Paulsell, Stephanie. "Writing as a Spiritual Discipline." In *The Scope of Our Art: The Vocation of the Theological Teacher*, edited by L. Gregory Jones and Stephanie Paulsell, 17-31. Grand Rapids, MI: Wm B. Eerdmans Publishing, 2002.

Pears, Angela. *Doing Contextual Theology*. London: Routledge, 2010.

Pelias, Ronald J. “Writing into Position: Strategies for Composition and Evaluation.” In *The SAGE Handbook of Qualitative Research*, 4th ed., edited by Norman K. Denzin and Yvonna S. Lincoln, 659-68. Thousand Oaks, CA: SAGE Publications, 2011.

Pohl, Christine D. “Hospitality and the Mental Health of Children and Families.” *American Journal of Orthopsychiatry* 81, no. 4 (October 2011): 482-88. DOI: 10.1111/j.1939-0025.2011.01111.x.

Prout, Alan. “Childhood Bodies: Construction, Agency and Hybridity.” In *The Body, Childhood and Society,* edited by Alan Prout, 1-18. New York, NY: St. Martin’s Press, Inc., 2000.

Ptacek, J.T., Brian D. Raffety, and Ronald E. Smith. “Facilitating and Debilitating Trait Anxiety, Situational Anxiety, and Coping with an Anticipated Stressor: A Process Analysis.” *Journal of Personality and Social Psychology* 72, no. 4 (1997): 892-906. DOI: 10.1037/0022-3514.72.4.892.

Purnell, Douglas. “Pastoral Ministry and the Fleshly Body.” *Pastoral Psychology* 53, no. 1 (Spring 2004): 81-85. DOI: 10.1023/B:PASP.0000039328.48171.34.

Ramazanoğlu, Caroline and Janet Holland. *Feminist Methodology: Challenges and Choices*. Thousand Oaks, CA: SAGE Publications, 2002/2008.

Rambo, Shelly. *Resurrecting Wounds: Living in the Afterlife of Trauma*. Waco, TX: Baylor University Press, 2017.

__________. *Spirit and Trauma: A Theology of Remaining*. Louisville, KY: Westminster John Knox Press, 2010.

Ramsay, Nancy J. “Contemporary Pastoral Theology: A Wider Vision for the Practice of Love.” In *Pastoral Care and Counseling: Redefining the Paradigms*, edited by Nancy J. Ramsay, 155-76. Nashville, TN: Abingdon Press, 2004.

__________. “Intersectionality: A Model for Addressing the Complexity of Oppression and Privilege.” *Pastoral Psychology* 63, no 4 (2014): 453-69. EBSCOHost.

__________. “Moral Injury as Loss and Grief with Attention to Ritual Resources for Care.” *Pastoral Psychology* 68, no. 1 (Feb 2019): 107-25. https://doi.org/10.1007/s11089-018-0854-9.

Reynolds, Thomas E. *Vulnerable Communion: A Theology of Disability and Hospitality*. Grand Rapids, MI: Brazos Press, 2008.

Ricoeur, Paul. *The Symbolism of Evil*, translated by Emerson Buchanan. Boston, MA: Beacon Press, 1967.

Roozeboom, William D. *Neuroplasticity, Performativity, and Clergy Wellness: Neighbor Love as Self-Care*. Lanham: MD, 2017.

Rubano, Craig. “Where Do the Mermaids Stand? Toward a Gender-Creative Pastoral Sensibility.” *Pastoral Psychology* 65, no. 6 (December 2016): 821-34 DOI 10.1007/s11089-015-0680-2.

Russell, Letty. *Just Hospitality: God’s Welcome in a World of Difference,* edited by J. Shannon Clarkson and Kate M. Ott. Louisville, KY: Westminster John Knox Press, 2009.

Saiving Goldstein, Valerie. “The Human Situation: A Feminine View.” *The Journal of Religion* 40, no. 2 (April 1960): 100-12. https://www.journals.uchicago.edu/action/showCitFormats?doi=10.1086/485231

Salk, Lee. “Foreword.” In *These Special Children: The Ostomy Book for Parents of Children with Colostomies, Ileostomies and Urostomies*, by Katherine F. Jeter. Palo Alto, CA: Bull Publishing Company, 1982.

Sanders, Cody J. *A Brief Guide to Ministry with LGBTQIA Youth*. Louisville, KY: Westminster John Knox Press, 2017.

Scheib, Karen D. *Challenging Invisibility: Practices of Care with Older Women*. St. Louis, MO: Chalice Press, 2004.

Schwandt, Thomas A. *The SAGE Dictionary of Qualitative Inquiry*, 3rd edition. Thousand Oaks, CA: SAGE Publications, 2007.

Sheppard, Phillis Isabella. “Raced Bodies: Portraying Bodies, Reifying Racism,” in *Conundrums in Practical Theology*, edited by Joyce Ann Mercer and Bonnie J. Miller-McLemore, 219-49. Leiden, The Netherlands: Brill, 2016.

Sinton, Vera. “Book Reviews: Women in Travail and Transition” in *Scottish Journal of Theology* 48, no. 1 (1995): 101-4 EBSCOHost

Smith, Jr., Archie. *The Relational Self: Ethics and Therapy from a Black Church Perspective*. Nashville, TN: Abingdon Press, 1982.

Smith, Dorothy E. *The Conceptual Practices of Power: A Feminist Sociology of Knowledge*. Boston, MA: Northeastern University, 1990.

Sparkes, Andrew C. and Brett Smith. “Narrative Analysis as Embodied Engagement with the Lives of Others.” In *Varieties of Narrative Analysis*, edited by James A. Holstein and Jaber F. Gubrium, 53-74. Thousand Oaks, CA: SAGE Publications, 2012.

Stevenson-Moessner, Jeanne, editor. *In Her Own Time: Women and Developmental Issues in Pastoral Care*. Minneapolis, MN: Fortress Press, 2000.

_________. "Incarnational Theology: Restructuring Developmental Theory." In *In Her Own Time: Women and Developmental Issues in Pastoral Care*, edited by. Jeanne Stevenson-Moessner, 7-18. Minneapolis, MN: Fortress Press, 2000.

Tartt, Donna. *The Goldfinch*. New York, NY: Little, Brown and Company, 2013.

van der Kolk, Bessel. *The Body Keeps the Score: Brain, Mind, Body in the Healing of Trauma*. New York, NY: Penguin Random House, 2014.

van der Riet Pamela and Dennis D. Waskul, "The Abject Embodiment of Cancer Patients: Dignity, Selfhood, and the Grotesque Body." *Symbolic Interaction*, 25 no. 4 (2002): 487-513. http://www.jstor.org/stable/10.1525/si.2002.25.4.487.

Watkin Ali, Carroll. "A Womanist Search for Sources." In *Feminist and Womanist Pastoral Theology*, edited by Bonnie J. Miller-McLemore and Brita L. Gill-Austern, 51-64. Nashville, TN: Abingdon Press, 1999.

__________. *Survival and Liberation: Pastoral Theology in African American Context*. Saint Louis, MO: Chalice Press, 1999.

White, Michael. *Maps of Narrative Practice*. New York, NY: W.W. Norton, 2007.

Williams, Delores S. *Sisters in the Wilderness: The Challenge of Womanist God-Talk*. Maryknoll, NY: Orbis Books, 1993.

Winn, Albert. "Band-AIDS." Albert J. Winn. Accessed May, 2 2012. http://www.albertjwinn.com/index.php?/photographs/band-aids/

Young, Iris Marion. *Justice and the Politics of Difference.* Princeton, NJ: Princeton University Press, 1990.

APPENDIX A: Interview Protocol

All interviews will be conducted in-person and on the property of Cook Children's Medical Center or Dodson Specialty Clinic. To maintain the privacy and anonymity of the participant, the Investigator will ensure that the interview is conducted in a private location. The Investigator will interview parent participants individually. A list of possible interview questions will be available to the participants, **upon request**, prior to the first interview. The list of questions **will not be overtly offered** since it would alter the outcomes of the research. This list of questions will not be exhaustive but is intended to offer an idea about the types of questions that will be asked. The interviews will be audio-recorded for transcription purposes, only. All audio recordings will be permanently deleted after the completion of transcriptions. Interview transcripts will be de-identified. All electronic data and will be stored on a password-protected Cook Children's computer (simultaneously backing up data on Cook Children's M drive) before locking all hard copies in a locked cabinet in the PI's office.

"Intensive interviews," as described by Charmaz (2014), will be used for data collection. Intensive interviews are "gently guided" conversations in which the Investigator will be inquiring about the personal experience of the research participant(s). The Investigator will conduct two (2) interviews, each 30-90 minutes in length. For both interviews the Investigator will be using open-ended questions to gather in-depth exploration of experiences. The Investigator will ask for detailed responses (Charmaz, 56).

First/Initial Interview:

The questions for the first interview are organized into three categories. This serves as a **representation** of the types of questions that will be covered during the interview. This is not an exhaustive list of questions. Follow-up questions may be asked for clarification and to check for understanding. Questions may also be asked in a different order.
This first category of questions is an introduction to the parent, her/his child and the circumstances of their lives. The purpose for these questions is to get a feel for the background, context and particularities of the parent's experience caring for this child. Examples of questions include, but are not limited to:

1. Basic demographic information: Current age of child, age of child at time of ostomy surgery, race/ethnicity of participant and child, gender of participant and child, and age of participant.
2. What were the circumstances around your child's illness and the stoma surgery?
3. Tell me about your child; who they are and what they are like.
4. What would you tell a parent who is just starting a similar journey?
5. Tell me how you decided to sign up for this study.

This second category of questions reflects the Investigator's interest in how the parent participant understands and relates to God/the Divine/mystery/Uniting Power in the midst of their circumstances. Examples of questions include, but are not limited to:
1. Tell me about spiritual, religious, or theological resources that have been helpful or hurtful to you as you think about the changes in your child's body and her/his appearance?

2. How has caring for your child changed your understanding about the Divine/God/mystery/Uniting Power?
3. Does the stoma and/or ostomy and the care for your child changed the way you picture your child in relation to a divine image or mystery (the *imago Dei*, God within us, the uniting mystery of the universe)? If so, how?

This third category of questions reflects the Investigator's interest in how parent participants think about stigma and oppression in relation to their child's body and an ostomy. Examples of questions include, but are not limited to:
1. Describe your thoughts and feelings concerning your child's body after the surgery.
2. Does your child's body indicate or say something about your child? If so, what does her/his body communicate?
3. Have you ever been afraid or repulsed as you cared for your child and her/his body? If so, what made you afraid/repulsed?
4. Do you imagine what people will say about your child when they see her/him? What do you imagine other people might think about your child now that she/he has an ostomy?
5. Have others expressed fear or repulsion when they see the changes to your child's body? What is your reaction to this expression? Are there spiritual or faith resources that inform the way you approach these encounters with others?
6. What do you want your child would to think about her/his body after the surgery?
7. How do you talk with your child about her/his body after the surgery? How do you/would you talk to others (family, teachers, friends, classmates) about your child's body?
8. What do you want others to know about your child and her/his body?
9. Are there any images or stories that illustrate the way that you think about your child's body?
10. What story do you wish to tell yourself about your child's body?
11. What images or illustrations help communicate more about your child beyond her/his current capacities?
12. What do you wish I had asked you about your child?
13. If you had to make the decision, again, to have a stoma surgery, would you?

Second/Follow-Up Interview:
The second interview will be conducted at least three (3) month after the first interview. The intention of the second interview is to check for understanding and clarification based on the data collected during the first interview. The primary focus for this interview will be for **member checking**.

Comments about Interview Protocol:
The Investigator will also be collecting field notes. The intent is to pay attention to the following three things as the Investigator interviews participants.
1. Body reaction of Investigator and participant.
2. The participant's reaction to the questions.
3. Listen for intersecting oppressions/stigmas and contextual resources for resistance that contribute to the how a parent interprets their child's body or other's reaction to their child's body. (For example, how does race, ethnicity, sexuality, gender, poverty, age, etc. shape the ways that parents understand their child's body?)

APPENDIX B: Written Personal Reflection Protocol

The research team is interested to learn what you do when you hear stories or comments about your child and her/his body. We also want to know if stigmas (or the way society talks about your child's body looking "different") impact the ways you think about or talk about your child.

It might be helpful to think about specific times or experiences when you felt that your child might have been looked at or treated "differently" from other kids because of her/his body.

Write a description, with as much detail as possible, about your experience caring for your child after the surgery. Please pay close attention to the way(s) you thought about your child's body in these moments. Please try not to evaluate how successful you felt at parenting in these moments. Some guiding questions may include, but are not limited to:

1. What was the hardest adjustment to make, concerning the care of your child, after surgery?
2. How has the decision to have the surgery changed the way you think about health and illness?
3. Do people talk about or look at your child differently?
4. What has changed about the daily care you give to your child after the surgery?
5. Has your faith changed because of this surgery?

Upon completion of this written narrative you may hand deliver it to Dawn Hood-Patterson, email, or mail a printed copy of the narrative to:

Dawn Hood-Patterson
Cook Children's Medical Center
Pastoral Care Office
801 Seventh Avenue
Fort Worth, TX, 76104

To send an electronic copy:
dawn.hood-patterson@cookchildrens.org

APPENDIX C: Data Coding and Analysis

The method of data analysis will follow thematic coding and spiral analysis. Thematic coding uses “broad units of information that consist of several codes aggregated to form a common idea” (Creswell, 2013, p. 186). Coding is “the process of aggregating the text or visual data into small categories of information, seeking evidence for the codes from different databases being used in the study, and then assigning a label to the code” (Creswell, 2013, p. 287.) The “data bases” will be the narratives of daily lived experience from interviews and written protocol submissions (*la vida cotidiana*, as described in the Method and Methodology section [Nanko-Fernandez, 2010, xviii.]), field notes, theological traditions and theories, as well as theories from clinical and the social sciences.)

This method of analysis follows a spiral in which the “researcher engages in the process of moving in analytic circles rather than using a fixed linear approach” (Creswell, 2013, p. 182). This is similar to the spiral approach to analysis argued for by pastoral theologian Christie Neuger (2004) who suggests that this method “begins in particular and cultural experience and then uses that experience both to critique and utilize the traditions and theories of pastoral theology. Those traditions and theories include insights from Scriptures, church traditions and doctrines, the social sciences, and clinical theories” (p. 71).

Data will be coded and analyzed by hand and by using Dedoose. Data will only be coded and analyzed after it has been transcribed and de-identified. No data will be coded or analyzed prior to being de-identified. All hard-copy data will be stored in a locked cabinet in the PI’s office. Hard-copies of data, collected during this research process, will be shredded upon completion of this study using a cross-cut shredder. All electronic data, collected during this research process, will be stored on a password-protected Cook Children’s computer (simultaneously backing up data on Cook Children’s M drive) and will be permanently deleted upon completion of this study. Data will be coded with major narrative themes which include:

Initial Coding Themes:

1) Type of illness narrative: (based on Arthur Frank’s (1995/2013) three “wounded body” archetypes)
* Restoration
* Chaos
* Quest
* Are there other archetypes beyond these four?

2) Narrative moves and thematic coding: (The phrase in parenthesis is the code I plan to use)

* What is the co-researcher saying about their child’s body? (person about body) What descriptors or assertions does the co-researcher make about their child’s body? How do they describe the body? Look for descriptor words

* How does the body shape the person? (body shapes person) How are they identifying their child in relationship to the body that the child has during illness/after an ostomy?
What assumptions are the co-researchers making about their child’s ability/beauty/health/identity

based on how **they** (parents/caregivers) interact with their child's body? How does this shape their view of their child's body and/or view of their child's identity?

* What does the co-researcher say about God/the Divine/a uniting power? (person about "God") How do they describe their spirituality, religion, and/or faith? Does "God" exist for them? Who/what is "God" to them? Does "God" act? What is the purpose of "God"?

* How do these stories shape theology? (body shapes theology) Is there a correlation between how **they** (parents/caregivers) view their child and how they view God/the Divine/a uniting power? What is congruent? What doesn't match up?

* What does the co-researcher say about society? (person about society) What stigmas do they see/experience their child facing? Do they sense oppressive discourses? Do they feel marginalized or feel that their child is marginalized? Where does this happen? Where do they feel safe/at "home"/comfortable?

* How does the body shape society? (body shapes society) How do my co-researchers challenge or resist body normative discourses? How do my co-researchers live into or reify normative discourses?

3) Untold Stories/Resistance to storytelling: It is assumed that there is a place for productive discovery in speculating about when a participant resists the telling of a story or when a participant refuses to answer a question. Elizabeth Emens (2007) says, "Ultimately, together, they alert us not only to the importance of telling new stories, and of telling challenging stories, but also to the occasional, yet vital, need to stop the stories. They call our attention to the overlooked moment when identity shapes itself by resisting the demand to tell stories" (p. 131).

4) Stories told from different sources but same person: What changes in the narratives between the written protocol, interview one, and interview two? What can be learned from analyzing these different source materials?