

RUN FOR YOUR LIFE: AN AUTOETHNOGRAPHY

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A handwritten signature in black ink, appearing to read "Stephanie L. Young". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

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*For my people.*

**Table of Contents**

1. Acknowledgements .....5

2. Abstract.....7

3. Introduction.....9

4. Review of Literature.....12

    a. Storytelling.....12

    b. Narrative Medicine.....17

5. Methodology.....26

    a. Autoethnography.....26

    b. My Process: Collecting, Reflecting, and Writing .....31

6. Autoethnographic Reflections.....35

    a. Diagnosis.....35

    b. Making Sense of My Illness: Emplotment and the Quest Narrative..38

    c. “It’s All I Got. I Run”: Recrafting My Identity as a Runner.....59

    d. Back into My Body and Svelte: Running Again .....72

    e. “It’s Cold.” – Culmination and the Final Race.....74

7. Conclusion.....77

    a. Future Directions.....79

    b. Final Thoughts.....80

    c. Epilogue.....81

8. References.....84

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### **Abstract**

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Run for Your Life: An Autoethnography. Major advisor: Dr. Stephanie L. Young.

This thesis is an autoethnographic analysis of congestive heart failure and recovery. Everyone gets sick, and sickness becomes a central part of the ill person's identity. Illness is a fundamental part of being human. Advancements in medical techniques and technology allow more and more people, people who would have otherwise been dead or unable to function, to enjoy living in the world of the healthy, even if their health may be fleeting or fragile (Frank, 1995). Congestive heart failure and severe cardiomyopathy are such illnesses and are a perfect ground for a narrative approach to medicine due to their fluctuation between periods of clinical stability and exacerbation (Volpe & Testa, 2019).

Arthur Frank (1995) establishes the narrative genre of automythology as a medical journey and highlights the importance of storytelling in medicine, develops the idea of the body as a text - and that of the sick body as a story to be told in order to heal - and that the story of the sick is worth telling. Medicine is organized and communicated through storytelling events (Hunter, 1991) and through medical narrative, humans can come to better understand themselves, their illness, each other, and the world around them (Cousins, 1979).

Volpe and Testa (2019) state that storytelling is a pivotal tool for healing in many cardiovascular conditions such as heart failure and cardiomyopathy (2019). Through trials and tribulations, death and eventual rebirth, a transformation can occur that provides a new approach to living. Through an automythology composed of journals, lived experiences, stories, and analysis applied to the structure of Joseph Campbell's Hero's Journey, I utilize the healing power

of narrative. Through the reclamation of my identity as a runner, I come to better understand my own condition and journey while assisting others on theirs.

*Keywords: Communication, Identity, Autoethnography, Running, Automythology, Recovery*

## Chapter 1: Introduction

*December 14, 2018*

*I look how I feel. I feel terrible. I look terrible. I've got extreme bags under my eyes from not being able to sleep at night. My feet are fat. My ankles are swollen. My knees hurt. The skin on my thighs is tight and makes it tough to walk. My stomach has gotten considerably fatter. I feel like I'm constantly out of breath, even when I'm just walking around normally. The symptoms have been getting worse, but I am stubborn and trying to hold out. I'm trying to hold out in hopes that they go away. I'm trying to hold out until health insurance kicks in so that I can actually afford to go see a doctor. I look at myself in the mirror, wiping away the steam from the shower I'd just taken. I don't recognize myself. This isn't me. This person is sick.*

Sickness is a transformative experience. Illness not only impacts the body, but also one's identity. Despite medicine's incredible technological progress in diagnosing and treating illness, the inability to listen, understand, and empathize those suffering is a persistent problem. Sick people attempting to make meaning of living with illness tell stories to cope with and better understand their pains and experiences. Narrative enables individuals the means to "organize a host of random emotional, perceptual, physical, and social experiences into a meaningful account of their situation" (Babrow, Kline, & Rawlins, 2005, p. 34). Through storytelling, individuals can reinvent who they are and what it means to be sick. The experiences of deep suffering through illness causes the sick to want to share their enlightenment with others, not only to tell their stories just to tell it, but to guide others who are going through similar experiences (Frank, 1995). Sick people's stories, then, can provide breadth and depth in navigating illness and health in humanizing ways (Nosek et al., 2012).

One growing area in qualitative health communication research is that of narrative medicine (Eggly, 2002; Harter, 2013; Kellett, 2020). At the center of narrative medicine is the valuing of patient narratives and their experiences. Medicine is organized and communicated through storytelling events (Hunter, 1991). Narrative medicine services to bridge the gap between scientific knowledge of medicine and the experiential knowledge contained in patients' stories (Charon, 2001). Through the sharing of narrative life stories, meaning and identity can contribute to a sense of self-worth and purpose (Moore et al., 2006). Storytelling can be a pivotal tool for healing (Volpe & Testa, 2019). In fact, "individuals can use narration to (re)create a sense of where one is in light of bodily malfunction and change" (Harter et al., 2005, p. 16). As Frank (1995) argues, stories are told *through* the body, for

the stories that ill people tell come out of their bodies. The body sets in motion the need for new stories when its disease disrupts the old stories. The body, whether still diseased or recovered, is simultaneously cause, topic, and instrument of whatever new stories are told. (p. 2)

Telling one's embodied journey of illness can be a way to "provide catharsis, testimony, identity restructuring, and the ability to connect to others" (Japp & Japp, 2005, p. 107). Specifically, Arthur Frank (1995) in *The Wounded Storyteller* argues that one approach for the sick person to make sense of their survival and transformation is through the framework of the quest narrative. According to Frank, "quest stories meet suffering head on; they accept illness and seek to *use* it" (p. 115).

Specifically, this autoethnography is about heart failure, *my* story about heart failure and a quest for understanding, meaning, recovery and wellness. It is also an examination of the myriad of changes that occurred along the incredibly long and winding road of illness, serves as

a first-hand account of my experiences with cardiomyopathy inside the modern medical apparatus, and documents my trials and tribulations. This autoethnography is a map of one route through sickness. Through my autoethnography, I seek to resist the image of a sick person, specifically a cardiac patient. I provide storied moments in my life to resist dominant discourses about cardiac patients, constructing a personal quest narrative that is “characterized by self-reinvention, individual transformation, and metaphorical rebirth following traumatic illness (France et al., 2013). In doing so, I hope to not only aid in my own healing process, but also provide guidance for those who live with chronic illness and those who can only survive with medical technology. As Langellier (1989) argues, “telling personal narratives *does something* in the social world” (p. 261). Through medical narratives, humans can come to better understand themselves, their illness, each other, and the world around them (Cousins, 1979).

First, I provide a review of the literature on autoethnography and health communication, primarily through the lenses of storytelling and identity. Specifically, I introduce the concepts of the quest narrative (Frank, 1995) and emplotment - the act of locating oneself on a narrative arc (White, 1973; Mattingly, 2008) - both of which provide the theoretical framework for the following autoethnographic reflections. Next, in chapter three, I describe my methodological approach to autoethnography and look at how autoethnography as a research method can be beneficial to addressing illness and healing. In chapter four, I provide my narrative accounts and memories of my journey through heart failure. I focus on my identity and transformation from “heart patient” to “distance runner,” as well as my position on a greater narrative quest story arc. Finally, I conclude with how my autoethnographic reflections can impact health communication, narrative, and recovery.

## Chapter 2: Literature Review

### Storytelling

Human beings are storytelling creatures (Bochner, 2002; Fisher, 1984; Frank, 1995). Lives are made up of stories and humans use stories to interpret, imagine, and make decisions throughout their existences. Narratives *matter* in that they provide us with ways of self-understanding (Freeman, 2016). Narrative “gives shape to things in the real world” (Bruner, 2002, p. 8). As Brody (1987) observes, “The primary mechanism for attaching meaning to human experience is to tell stories about them” (p.5). Through stories, humans come to know themselves and each other. Not only do humans tell stories, but we are storied and “live stories in and through our being” (Harter et al., 2006, p. 6). Human lives are guided by internalized narrative plots complete with narrative arcs, central characters, and action sequences, and humans rely on their abilities to generate and interpret stories to survive and grow in a complex world (Sarbin, 1998; Sunwolf, Frey, & Keranen, 2005). Stories offer a way of knowing and sharing experiences and knowledge, and they function to stitch together unrelated or unexpected events in a meaningful way so that both storyteller and listeners can make sense of and find meaning in their lives while plotting their experiences along said familiar narrative structures and acting accordingly (France, Hunt, Dow, & Wyke, 2013; Harter et al, 2005; Sunwolf & Frey, 2001). Essentially, humans give meaning to experience through narrative (Bruner, 1990; Herrmann, 2011). As Langellier (1989) explains, “personal narrative is a storytelling performance” of the self (p.249). This act of meaning-making constitutes the fundamental creation of an identity balanced between internal thoughts and feelings and an outer world of observable states and actions (Garro & Mattingly, 2000). The story is not simply a collection of rote information, but an exploration of human variation and its holistic meaning (Hunter, 1991)

with the capacity to elicit emotional responses, making narrative particularly effective at altering perceptions and behaviors (Dunlop et al., 2008).

In fact, “telling personal narratives *does something* in the social world” (Langellier, 1989, p. 261, italics in the original). Personal stories exist within larger social processes, continuously shaping the self and others. Stories can configure personal identities and are capable of reidentification by having a certain authority, as they influence and define the only person who has any moral capacity to make decisions: the storyteller (Nelson, 2001). That is, we make and re-make ourselves through stories (Bruner, 2002).

Furthermore, as Nelson (2001) notes,

Personal identity is a system of meaning - a semiotic representation of the things that contribute importantly to one’s life over time... consisting of a fluid and continual interaction of the many stories and fragments of stories that are created around the things that seem most important about a person’s lifetime (p. 92).

We continuously create ourselves, and “self-making is a narrative art” (Bruner, 2002, p.65). Identity is essential to being human and making sense of who one is through dialogical relation and communion with others (Frank, 2009). According to Hecht and Choi (2011), our identities are formed and managed in “an ongoing process of communication with the self and others rather than as a simple product of communication” (p. 139). Specifically, communication identity theory observes that identities are layered and interconnected, personal, enacted, relational, and communal (Hecht, 1993), and “posits that individuals internalize social interactions, relationships, and a sense of self into identities through communication” (Hecht & Choi, 2011, p.139). The stories we share about ourselves with others, then, is part of this ongoing process of identity making.

By depicting and characterizing the elements of our lives that either we or others find most significant, stories help us to better understand who we are and give weight to our own narratives through connection (Nelson, 2001). Being human is in essence the ability to reveal one's identity through one's actions, and through knowing which actions are worth contributing to our own identities. In fact, "stories are the narrative frames within which we make our experience meaningful" (Bochner, 2002, p. 73). The narrative construction of who we are is dependent on how we see ourselves as well as what others see in us, and our self-concept requires more than one person for its construction, maintenance, and expression; it is relational (Frank, 2009; Hecht, 1993). This co-authoring of identity and narrative forms the base for a human understanding of reality itself; narrative activity embodies the self and its actions, ideas, and place in the world. Narratives define who someone is, the knowledge of what to do, and through the act of doing produces new narratives that can create even more new actions (Brockmeier & Carbaugh, 2001).

Since identity is co-authored, stories passed down among families and communities constitute some of the earliest memories and identities that people have (Hatem & Rider, 2004). As MacIntyre (1981) states, "the story of my life is always embedded in the story of those communities from which I derive my identity" (p. 218). That is, our individual narrative selves exist within communal identities and stories (Hecht, 1993). Communities and groups look to stories to offer insight, understanding, imagination, and new perspectives, and the acts of hearing and telling stories bond people together through a shared thread of experience while constructing the identities of self and the community within which people are embedded (Nelson, 2001; Sunwolf, Frey, & Keranen, 2005). Narrative tradition among community members subtly shapes what its members know and value (Nelson, 2001). Narratives draw meaning from their relation

to other texts. Individuals' stories exist amid various cultural elements derived from communal and societal narratives. These intersecting social systems that form stories at large provide a wider circle of narrative patterning, called master narratives, that shape personal and public narratives on a grand scale (Harter, Japp, & Beck, 2005).

Master narratives are the archetypal cultural stories circulating that summarize basic rules of social interaction and understanding through stock characters and plots. As McLean and Syed (2015) explain, master narratives are “culturally shared stories that guide thoughts, beliefs, values, and behaviors” (p. 323). Many master narratives are either unobjectionable or even necessary, as they assist us in our ability to make sense of ourselves and each other. Other master narratives, however, are either morally malignant or actively damaging through their negative depiction of particular social groups as lacking in virtue or as existing merely to serve others ends.

Additionally, counterstories are stories that attempt to resist stories of domination and replace these oppressive identities with ones that command respect through resistance, serving as tools that repair identities damaged by abusive power systems or master narratives and re-identify individuals on their own terms (Nelson, 2001). Narratives, then, can provide us with the tools to “help us deal with the problems of society” (Rorty, 1982, p. 198).

According to Nelson (2001), the point of a counterstory or counter-narrative is to systematically repair the damage done to the identity from a first-person perspective. Counterstories are depictive, but they are selective in what they depict; they are interpretive and they are connective, relating their own elements to each other and to other stories. Counterstories can repair identities through the redefinition of a past that has been incorrectly characterized and allow damaged individuals to feel a greater sense of moral worth through seeing themselves as

competent moral agents. In doing so, one becomes less likely to accept the oppressive views that others might have of them and to exercise their agency more freely (Nelson, 2001). In fact, counter-stories are a way to resist dominant master narratives and provide alternative ways of making sense of the self. They are about the possible, about creating new ways of living. As Freeman (1998) states, “we need to understand lives and indeed to *live* lives differently if we are to avoid further fragmentation, isolation, and disconnection from each other” (p. 46). These personal narratives function to enact recognition and understanding by asserting a right to define one’s identity and the need to define one’s story as relevant, while describing the act of operating within the dominant cultural narratives available (Harter, Japp, & Beck, 2005).

Much in the same way that master narratives can be narrowed to apply negatively to specific individuals, so too can the counterstory of an individual be generalized to revise the incorrect understanding of a group to which that person belongs. Counterstories resist hegemonic narratives, allowing the individual to be depicted as “morally worthy,” and opening possibilities for the person to “attain, regain, or extend her freedom of moral agency” (Nelson, 2001, p. 150). Especially with stigmatized identities, counter-stories can provide individuals with a sense of empowerment by humanizing their experiences (Harter et al., 2006; Lippert, 2019). As Harter (2013) argues, storytelling is “a necessary survival strategy as individuals adjust to personal expectations and reidentify priorities in the face of once unimaginable circumstances” (p. xvii). People need counterstories that both they and the people around them can endorse to understand their position more fully, both in terms of how others see them and how they see themselves, and to obtain the necessary resources for healing through community (Nelson, 2001); the only way to get out of an old story is to tell a new one (Frank, 2009).

## **Narrative Medicine**

The modern experience of illness involves monolithic, vast, and complex organizations that view healthcare as a quantifiable resource to be allocated in the most efficient and profitable way possible. The newly diagnosed, often scared, and devastated by the interruption of illness, faces an overwhelming set of challenges as they set out on their healing journey (O’hair, Scannell, & Thompson, 2006). People now go to nurse practitioners and clinicians, specialists and diagnosticians, electrophysiologists and physicians to have their symptoms reinterpreted into a diagnosis whose language is often seen as unfamiliar and overwhelming. Advancements in medical technology allow more and more people, people who would have otherwise been dead or unable to function, to enjoy living in the world of the healthy, even if their health may be fleeting or fragile (Frank, 1995). Patients are often provided with everything diagnostically or mechanically necessary in the event of illness or emergency except for comfort, security, ease, and human interaction (Cousins, 1979).

Navigating the myriad of interconnected contexts involving identity, family, providers, healthcare organizations, and society at large throughout the healing process is exceedingly important, as the starts and stops along the journey may impact the outcome of their illness experience. Sick individuals need to exact agency through defining their narrative identities to successfully manage their healing journey (O’hair et al, 2006). Modern medicine, however, has lost its human elements; advances in technology speed up medical work, interrupt continuity with patients, and erode autonomy derived from physician-patient interactions. Medical informatics and modern data collection strategies complicate matters further, with necessary human interactions such as the medical interview being replaced with cut-and-paste functions on digital medical records (Johna & Rahman, 2011). What is missing in modern medical

interactions is fundamental, humanizing practices of medicine, “face to face encounters between people who are suffering bodily ills and other people who need both the skills to relieve this suffering and the grace to welcome those who suffer” (Frank, 1995, p.1).

Health communication, likewise, has rapidly grown as a field of study, especially in response to advancements in medical technology and growing interests in addressing problems such as poor health habits and pandemics (Hinyard & Kreuter, 2007). Specifically, emerging research has focused on narrative health communication - from using stories in the construction of effective health campaigns (Balint & Bilandzic, 2017; Lee, H. et al., 2016, Fitzgerald et al., 2020; Shem Sheer, & Li, 2015) to examining narrative medicine within patient-provider interactions (Denniston, Molloy, & Rees, 2018; Pinto et al., 2021) to narrative theorizing within the health-related context (Harter, Japp, & Beck, 2005). Narrative storytelling is being explored more and more as an effective way to provide useful information to populations of patients (Baezconde-Garbanati et al., 2014). Storytelling that advocates for positive health outcomes through detection and prevention can have significant effects on patient’s behavior (Shen, Sheer, & Li, 2015), and effectively delivered narratives may have the potential to make major contributions towards the health outcomes of unhealthy and aging populations (Suggs, 2006). Hearing or reading about successful health interventions can lead to greater engagement and encourage individuals to take up their own cause (Han et al., 2012) which reduces disparities in engagement in typically underserved populations (Baezconde-Garbanati et al., 2014). Storytelling, when used effectively, has the powerful potential to positively influence health outcomes on both a personal and macro scale (Baezconde-Garbanati et al., 2014).

The master narrative of modern medicine is one of technology (Frank, 1995; Harter & Japp, 2001; Morris, 2007). Technology does not simply refer to the tools of doing medicine,

MRIs and EKGs, robots and computers, but rather technology encapsulates the dominant ways of thinking, talking, and acting that involves an evidence-based medicine approach that places biological fact and objectivity at the center of effective medicine (Harter & Japp, 2001; De Vincentis et al, 2018). A strictly scientific view of medicine encourages physicians and patients to solely focus on the diagnosis of disease rather than the care of the person who is ill.

Individuals do embody physical manifestations of disease and disability, but they also embody the meanings and messages of the disease and its impacts on their emotional, spiritual, and relational situations (Harter et al., 2008). An understanding of medicine as a narrative process enables physicians and patients to shift away from the relatively simpler matter of the diagnostics to the care of healing the patient, as a condition must be described narratively before being discussed in any useful capacity. The mistaken idea of medicine as a body of objective, scientific knowledge and facts and rules to be mastered to produce reliable results leads to poorer health outcomes and care for patients and produces physicians who have been deprived exposure to and appreciation for the case-based and skeptical methodology that has produced so much of modern medicine's success (Hunter, 1991). As Charon (2001) argues, narrative medicine informed by the biopsychosocial and patient-centered approaches to caregiving proposes an ideal of care that emphasizes narrative connections, "practiced with the competence to recognize, interpret, and be moved to action by the predicaments of others" (p. 83).

Narrative medicine is an informative tool in providing a deeper understanding of how patients and their families think, feel and act. Patient-centered care through understanding their lived experience is one of the pillars of narrative medicine, and the stories surrounding treatment, the patient's journey, are just as important as the illness being treated. Integrating clinical data with the lived experience of patients and their caregivers, including both the emotional and

psychological aspects of the journey, can positively influence the healing process (De Vincentis et al., 2018). Narrative medicine and empathy are inseparable. If patients' narratives are respected and understood, caregivers can respond with empathy to the patients' suffering and recognize them as individuals to collaborate with rather than solely as patients. "Moreover, narrative medicine can provide meaningful support to patients in clinical practice and breaks new ground in compassionate healthcare" (Yang et al., 2018). Narrative medicine is a contemporary effort to rehumanize medicine, an answer to the problems of a strictly biological view of medicine that recognizes the value in stories of illness. For medical professionals, a "narrative stance towards practicing medicine [means] committing oneself to understand patients' health concerns and observable symptoms in and through the contexts of their own lived stories" (Rawlins, 2005, p. 213). Understanding the meaning and significance of stories is critical for effective medical practice, as storytelling provides some comfort to both physicians and patients; patients can find stability in words to contain and endure the chaos of illness, while physicians may find that telling stories about patients and themselves allows them new perspectives on treatment and patient interaction (Johna & Dehal, 2013).

Narrative is how humans communicate, learn, and grow, and as such, narrative is an important communicative process in influencing health ideals (Hinyard & Kreuter, 2007). Teaching through narrative has been shown to be especially useful when concerning morality, religion, personal values, meaning in a person's life, complex social relationships, and other issues for when traditional empirical approaches may not work well, i.e., most situations that would arise in a healthcare setting (Howard, 1991; Lutrell, 1989; Polkinghorne, 1988). Stories have been shown to increase the ability for practitioners to connect with marginalized

populations through culturally grounded narratives and affect change in behavior and attitudes towards health practices (Lee, Fawcet, & DeMarco, 2015).

Medicine is an interpretive activity (Frank, 2009). As Hunter (1991) explains, it is a learned inquiry that begins with the understanding of the patient and ends in a therapeutic action on the patient's behalf. Far from being objective, a matter of hard facts, medicine is grounded in subjective knowledge - not of the generalized body in textbooks, which is scientific enough - but the physician's understanding of the patient. Despite its reliance on dozens of heavy and expensive textbooks and thousands of scholarly journals, medicine is passed on as a traditional practice: interpretive, diagnostic, concerned with the identification and treatment of disease.

A divide exists between the logical empiricist approach to medicine that relies on objectivity, moral neutrality, and the objective search for facts and the interpretivist approach of narrative medicine that seeks empathy, subjectivity, and an understanding of what it means to be human (Bochner, 2002). While medical success draws on and applies the fundamental principles of chemistry, biology, and physics, clinical diagnosis appears more related to the work of anthropologists as an investigation in which hypotheses are shaped by fact (Hunter 1991). Diagnoses not only consist of biological details, but also include word choice, sentence structure, and prosody; all of which carry clinical significance. A patient's story is more than just dry facts told in a sequence, and interpreting, and responding to a patient's narrative requires a special skill set. The skill to recognize story structure and appreciate and interpret literary devices is known as narrative competence. Narrative competence in a medical setting means centering and unpacking the patient's storied experiences. By developing narrative competence, "physicians can better understand a patient's experience and thereby be better equipped to help him or her"

(Alcauskas & Charon, 2008, p. 826). Likewise, a narratively competent patient is one who is more educated and capable of understanding and interpreting their own symptoms and illness.

Healthcare providers listen to and tell stories every day. The medical day is organized around telling stories: at morning report, on rounds, at case conferences, patient histories, and when signing out in the evenings. Stories in a medical setting are constantly told, revised, and retold, and these narratives form the foundation of effective healing and serve as the currency of healthcare interactions (Alcauskas & Charon, 2008). The body is a text to be interpreted, the medical history of a patient is a story to be read, and the medical chart is a cumulative manuscript of observation to be analyzed and translated. Illness is subjective and diagnoses are fundamentally narrative in nature (Hunter, 1991). Narrative medicine is a patient-centered approach to medicine that repairs the patients' stories and integrates elements they deem important into decisions regarding their health care, which enhances the doctor-patient relationship and contributes to greater healing interactions (Hatem & Rider, 2004; Rian & Hammer, 2013). Increasingly, medical professionals recognize the value of the illness story beyond that of the medical narrative represented by the medical chart (Rian & Hammer, 2013). Ill persons are experts on their own illness and speak with a voice that is their own (Frank, 1995), and narrative medicine teaches doctors how to hear the voices of their patients. It improves the ability to hear and interpret stories more fully, to act on behalf of the voice that is heard (Nowaczyk, 2012), and to truly see and understand the patients.

Furthermore, Nowaczyk (2012) argues that the goal of narrative medicine is to better understand and honor the life stories of the sick. Sickness and healing are narrative acts, and effective healing requires an empathetic understanding of being sick, through a combination of mindfulness, acute observation, and a library of past narrative situations that is both broad and

deep (Charon, 2007). Both patients and physicians write about their experiences in healthcare with increased frequency, as doing so may provide an understanding of illness and being that is otherwise unobtainable (Charon, 2001). The growing number of texts being written about both physician and patient medical experiences also highlights the link between medicine and literature (Barber & Moreno-Leguizamon, 2017).

Interestingly, writing about illness and traumatic experiences has been shown to have positive health and psychological benefits, such as increased immune response and medication efficacy, as well as a decrease in negative symptoms from certain ailments (Alcauskas & Charon, 2008) and may also lead to a better sense of self and meaningful relationships with colleagues and society at large (Milota et al., 2019). Indeed, “Stories are antibodies against illness and pain,” and narrative medicine provides insights into what it means to be an effective healer (Broyard, 1992, p.20).

At the center of narrative medicine is the wounded storyteller (Frank, 1995). The body’s suffering during illness creates a need for stories, and different wounds cause need for different stories. Medicine in the modern era has become central to our understanding of what it means to be alive, and medical narrative has seen an increasing demand from the public in the form of fiction, autobiography, drama, and reportage (Frank, 1995); stories are about the failure of control and the threat of the end, which enable us to consider the value of life and death, the meaning of pain, what it means to be human, and our own feelings towards any number of topics depicted therein (Hunter, 1991). Stories of illness teach the listener and the teller that “if the body is falling, the mind does not have to fall with it” (Frank, 2009, p. 37) and serve to teach, to guide, to motivate, and to reinvent individuals as better persons (Nelson, 2001). These stories have the capacity to influence both the teller and the listener through understanding, and the

experiences of others often speak to us even stronger than our own experiences. Through telling stories that run counter to the perceived notions about a person or group, challenging notions that one is sick, frail, weak, or incapable (Frank, 2009), people can influence and improve the world around them (Nelson, 2001). Through deciding what to allow disease to mean in their lives, sick individuals overcome the initial representation of their illness through separating what they can control from what they cannot. Only in doing so and suspending judgments about what illness means are they able to accept a spiritual freedom and live fully in the present, and through changing their beliefs about their situation, they find healing through reclaiming their own identities (Frank, 2009).

In addition, the public discourse of health and healing, like any story, is narratively constructed. The master narrative serves to reinforce the dominance and legitimacy of the biomedical narrative, which reduces disease to a biological simple mechanism of cause and effect that can be overcome through science and technology, and in doing so privileges medicine and marginalizes the voice of the patient (Mishler, 1984; Japp & Japp, 2005). Developing a counternarrative involves rejecting the perspective that humans are either sick or well and embracing the idea of living well despite an inescapable illness or experience of trauma. Through telling stories, individuals can renegotiate their self-image, plot their life path, and repair the damage caused by the master bio-medical (Harter, Japp, & Beck, 2005; Gwyn, 2002; Sharf & Vanderford, 2003). Through authoring a new story, the sick may create new understandings of what it means to be sick (Frank, 1995).

In summation, much narrative scholarship has focused on storytelling, identity formation, and an interpretivist approach to learning. Storytelling plays a crucial role in how humans experience the world, learn, grow, and understand who and where they are in life. Additionally,

health communication scholars have looked to narrative as a valuable tool for effectively communicating health information and holistically understanding patients and have explored narrative in the context of healing through the redefinition of what it means to be sick. My autoethnography, then, extends this research by providing an interpretive look at a severe heart condition and my holistic, narrative approach to the healing journey.

### Chapter 3: Methodology

Autoethnography is a qualitative research method that combines ethnography, biography, and self-analysis to gain understanding of the connections between self and others within a larger social context (Ngunjiri et al., 2010). According to Adams et al. (2017), autoethnographers combine the research approaches of autobiography and ethnography. Autobiographers examine historical texts, journals, and utilize memory and hindsight to reflect on past experiences, then utilize storytelling devices to assemble a text out of those experiences to create a representation to give audiences a sense of how the lived experience feels. Ethnographers observe and participate in a cultural experience for an extended amount of time to understand how members of the culture think, feel, and live, to condense the cultural practices into something familiar to cultural outsiders in the form of descriptions that offer a sense of experience. Together, the processes and practices of autobiography and ethnography contribute to both the act of doing autoethnography and the goals and purposes of autoethnographic work.

As Reed-Danahay (1997) notes, “autoethnography is a form of self-narrative that places the self within a social context. It is both a method and a text” (p. 6). Similarly, Muncey (2010) argues that “autoethnography is a research approach that privileges the individual” (p. 2). That is, autoethnography focuses on the researcher’s lived experiences to better understand a social phenomenon in lieu of traditional scientific approaches which require researchers to minimize their selves through qualitative and experimental methods (Wall, 2006).

Approaching research in this way, by centering the researcher’s experiences, challenges the traditional social scientific ways of doing research and treats the act of doing research as a socially conscious act in and of itself (Ellis et al., 2011). Some qualitative researchers have increasingly identified the limitations of traditional research practices and instead have embraced

the concept that a researcher's perspective should inform and facilitate the process of research (Holman Jones, Adams, & Ellis, 2013). Within communication studies, autoethnography has become a primary method of choice for using lived experience to examine key cultural experiences (Adams et al., 2017).

Specifically, Chang (2013) argues that autoethnography as a research method can be characterized by three features: (1) autoethnography uses personal stories and experiences of the researcher as primary data; (2) autoethnography attempts to illuminate a social phenomenon; and, (3) the autoethnographic writing process varies by individual. The first step is to decide on the topic and finding stories within one's personal life to illuminate the topic. As Linn observes, "whether autoethnography starts from the researcher's professional interests or from personal experience, it is helpful to keep a running list of compelling experiences, professional curiosities, nagging issues, and intense emotions (p. 110). Then, collecting autobiographical data is needed. This can be done through "recalling, collecting artifacts and documents, interviewing others, analyzing self, observing self, and reflecting on issues pertaining to the research topic" (p. 113). The third step is to attempt to make meaning of the fragments, searching for "recurring topics, dominant themes, unusual cases, and notable statements" (p. 115). Finally, one writes the autoethnography, which can take on different styles— from performative and creative autoethnographies to confessional-emotive forms of writing to descriptive-realist accounts.

Communication scholars have used autoethnographic inquiry as a method to examine numerous topics from mundane lived experiences to more traumatic and extreme topics (Rambo & Ellis, 2020), from personal experiences to global cultural phenomenon (Ellis et al., 2011). For example, numerous scholars have autoethnographically explored familial relationships (Hermann, 2005; Jago, 2015; Poulos, 2009; Stern, 2015), abuse (Tamas, 2011), sexual violence

(Mingé & Zimmerman, 2008), eating disorders (Tillmann, 2009), and grief (Doshi, 2014; Paxton, 2014).

For my autoethnography, I take up an autoethnographic style that is “analytical-interpretative writing” in which “narration tends to support researchers’ socio-cultural analyses and interpretations” (Chang, 2013, p. 119; see also Reed-Danahay, 1997). According to Anderson (2006), there are five features to analytic autoethnography: “(1) complete member research status (CMR), (2) analytic reflexivity, (3) narrative visibility of the researcher’s self, (4) dialogue with informants beyond the self, and (5) commitment to theoretical analysis” (p. 378).

First, complete member researcher status (CMR), specifically opportunistic complete member researcher status means that the researcher be born into or has acquired intimate enough knowledge about the group being researched, such as in the case of illness, that they are fully immersed and integrated into the social world. CMRs exceed other researcher types because they come closest of all to the experiences and peoples that they study (Adler & Adler, 1987). Second, analytic reflexivity requires the researcher to be aware and introspective of the reciprocal influence of their research on the culture and peoples being studied, as they themselves both influence and are influenced by their research. Third, the researcher must be a highly visible social actor within the text with the vital contributions of their feelings and experiences captured in the narrative. Fourth, analytic autoethnography requires engagement with outside subjects and data in order to maintain its relational construction. Finally, a commitment to an analytical agenda necessitates the use of empirical evidence to glean an understanding of a greater social phenomena.

Denzin (2013) defines the approach of interpretive autoethnography as one that grounds life in a historical moment, then works backwards in time to interrogate the historical, cultural,

and biographical occurrences that encouraged the experiences being studied. By taking up this analytical interpretative approach, I can share my personal stories to engage in a conceptual discussion on recovery, employment, and identity. Specifically, what it is like for an otherwise healthy male in his early thirties to experience a rapid and severe decline in health, then go through the extremely long and multifaceted recovery process. In this way, I hope to shine light on a marginalized story in the context of the greater social understanding of recovery and illness.

The autoethnographer is “both the author and the focus of the story...the observer and the observed” (Ellis, 2009, p. 13). This process requires the autoethnographer to engage in rigorous self-reflection to identify and investigate the intersections between the personal and social life (Adams et al., 2017). In fact, one central characteristic of autoethnography is that of reflexivity (Anderson & Glass-Coffin, 2013; McCorkel & Myers, 2003; Muncey, 2010). As Atkinson, Coffey, and Delamont (2003) note, autoethnographers-as-authors frame their accounts with a reflexive view of the self by situating their ethnographic data within their personal experience and sense making, and in doing so form part of both the experience in which they are engaging and as part of the story being told.

Reflexivity through an analytical interpretative autoethnographic approach means being aware of one’s connection to the research topic, as well as making a conscious effort to be introspective in one’s storied experiences. Strong reflexivity means reflecting on one’s experiences at different times (Anderson and Glass-Coffin, 2013). Therefore, throughout my autoethnography I plot my journey of recovery along Arthur Frank’s (1995) quest narrative and routinely take stock of my progression towards the ultimate goal of wellness. I use running as a tool for recovery and repeatedly reflect on where I’m at in my own narrative arc, how far I’ve come, and where I am going to.

Furthermore, personal accounts offered by autoethnographers can provide important nuances of cultural issues and norms from an insider perspective. As stated before, conducting autoethnography allows the self to become a part of the experience being studied, and autoethnographers can write about private contexts that would be impractical to study in traditional social scientific ways. In fact, one purpose of autoethnographic inquiry is to “break silences surrounding experiences as they unfold within cultures and cultural practices” (Holman Jones, Adams, & Ellis, 2013, p. 35). That is, autoethnography can provide a space for addressing understudied, confusing, and painful topics.

In addition, autoethnographic researchers may provide stories that run counter to dominant cultural scripts, resist stereotypes, and take up critical perspectives (Adams et al., 2017; Boylorn & Orbe, 2021; Toyosaki & Pensoneau-Conway, 2013). For example, Norman Cousins (1979) challenges the notion that patients aren’t responsible for their own recovery, or that sick people are incapable of having a sense of humor. Arthur Frank (1995) repeatedly challenges the idea that ill persons are victims who are frail and without the ability to productively contribute to society. Barbara Scharf (2005) presents a counter narrative on patient power and decision making in the face of the traditional medical model.

Autoethnographers can also seek to create texts that are accessible to an audience outside of an academic setting and engaging to both academic and nonacademic audiences (Adams et al., 2017), which further promotes autoethnography as a key method of research for marginalized groups (Wall, 2008). Autoethnography can provide us with stories to “live with rather than only just think about” (Holman Jones, Adams, & Ellis, 2013, p. 35; see also Bochner, 2002).

Finally, autoethnography can provide health communication scholars with opportunities for exploring illness and health that center the individual’s experience (Chang, 2016; Doshi,

2013; Ettore, 2010; Pohl, 2014; Frank, 1996; Cousins, 1979; Scharf, 2005). As Chang (2016) argues, the self is the focal point of autoethnography and functions as a member of the greater social context to be explored, and in the case of illness can provide health care researchers with valuable information that may not be gained in any other context while allowing for a more critical and interpretive understanding of the impact of illness on persons and their environments. Illness autoethnographies may have multiple purposes; to expose personal struggles in life as a result of illness, to explain the relationship between the experiences and context of sickness, or to provide an understanding of the interruptive effect of illness on life. Whatever the purpose, “illness autoethnographies bring the readers to awareness and consciousness about health issues” (Chang, 2016, p. 446).

### **My Process: Collecting, Reflecting, and Writing**

The first step of my autoethnographic journey was to collect qualitative data. I gathered journal entries, archived medical notes and reports, recalled conversations, collected electronic text messages and emails, documented memories, and journaled personal accounts of events and interactions that occurred throughout my personal illness journey. Specifically, I started to take notes on my experiences after I’d gotten out of the hospital and was healthy enough to write, but journaling in earnest began about a year after my diagnosis on February 11, 2020 - three days before I was scheduled to have surgery. I think something about the danger of surgery coupled with the determination for recovery that I felt was what encouraged me to start documenting things in earnest. My journal was always with me, since it was just a note document on my phone, so I wrote often. Most of the time I was writing about how hard it was to eat or cook healthily, other times it was about frustration with progress or setbacks. In total, about 32 pages

of thoughts taken over the years contributed to what would ultimately form the narrative portion of this project.

I am fortunate enough to be able to read lab results, and I also operate from a privileged position as someone who comes from the healthcare world and as such has access to records and information. My entire healthcare journey was thankfully cataloged in the form of a patient portal that allowed for easy browsing and reading. Through a combination of conversations with my health care providers, connecting test results to my lived experiences, and interpreting lab results, I was able to piece the hospital portions of my illness back together well enough, starting with my initial diagnosis and testing on December 21, 2018 and ending with the last time I had labs drawn on September 9, 2021. In total, sixty-three instances of an electronic medical record were used to reconstruct my illness journey.

I was also thankful that most of my conversations are digital in nature, so going back and looking at specific exchanges that occurred around important events along the journey was not particularly hard. I spoke with my friends about my recovery online, so remembering how something happened was as easy as scrolling through chat logs or revisiting a specific post on a forum. Looking back at photos from the time was also beneficial, as I took pictures of myself before each milestone that was then cataloged and dated, and the pictures were often the topic of conversation. Between Discord, Facebook Messenger, and text messages, a consistent digital record of conversations was available.

Data was originally organized chronologically. Milestones were easy to identify as they coincided with increased journaling, conversations, and oftentimes marked by a test or procedure in the medical record. Over time, a narrative arc started to develop which informed the overall structure of the story. Events were organized chronologically, but were also plotted against an

established quest narrative structure, which also further informed the project by being a central conceit to the concept of emplotment. Additionally, while journaling, the theme of running kept appearing. I found myself writing more and more about running, conversations started to turn more towards my exercise and running, and my test results and medical notes showed improvements alongside my training. Ultimately, the journey of health directly coincided with my journey through running, and I decided that finishing a distance race would be both my real life goal and serve as the end to the narrative arc. I signed up for multiple races, three of which were canceled, eventually competing in and finishing the Run of Luck 7k on March 12, 2022.

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*Steph told me to journal, but she didn't tell me I would eventually have to make sense of all these journals! She just said to keep writing. So, I did. I wrote about food, I wrote about how scared I was of surgery, and I wrote about how sad I was when I had to restart my journey time and time again. Somehow, I ended up writing about running a lot. I wrote, and I ran, and I wrote about running, and while I was running I was thinking about what I would write. Running served as a central concept to the narrative arc of the project, and it also served the practical function of giving me time to dissect and organize thoughts in my head so I could put them down to paper.*

*Sifting through charts and medical notes was significantly more difficult. They were better organized in the form of an electronic medical record, and I knew how to read them since I'd spent years in the medical field, but every attending and specialist had their own way of saying my heart sucked. It was neat, though, seeing test results coincide with milestones in my recovery. It was objective evidence that what I was doing was working, and that progress was*

*being made. Even still, I knew that data without context was useless, and my job was to provide the context that would hopefully bring those numbers to life.*

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Once all these narrative fragments were collected, I attempted to make meaning of the pieces, looking for themes. Specifically, through examining my own illness and recovery, I was able to better understand illness narratives as a whole and harness the healing powers of storytelling to provide meaning to my struggles and repair my identity. Through this analytical process, I was able to identify recurring elements in my own narrative and found several major themes: the concept of therapeutic employment, Frank's (1995) quest narrative, the body as a text, and the act of running as a function of recovery and identity repair. Therefore, in the next section, I explore these themes through my autoethnographic reflections.

## Chapter 4: Autoethnographic Reflections

### Diagnosis

“Well, your heart sucks.”

I was extremely sick. I was extremely sick for a long time, but I didn't always know that I was extremely sick. In fact, I spent most of my adult life sick, but I was so unaware of being sick that “sick” was just my normal. I had what a lot of people would probably describe as a normal young adult phase; I was on the track team in high school, I worked an active job on weekends for the hospital, and I did well enough in school. When I went to college, not much had changed. I took electives like hiking and fencing. I partied like any red-blooded college student would. I stayed active mostly through biking trails and walking around campus. I stayed active in the workforce after graduation, mostly traveling to other states and doing conventions where I was on my feet. Eventually, I found myself running two extremely successful coffee shops that kept me busy from open to close, six days a week. The point being, I was always in motion. I was always active, and I was always doing something. I never really thought of myself as being particularly sick because, well, look at everything that I was busy doing. How could somebody who did everything that I did be considered “sick”? It happened fast. One day I was fine, the next day I wasn't.

*December 21, 2018*

*I am working for a sub-contractor for Sam's selling cell phones and DirectTV subscriptions. This job has me standing on concrete for upwards of six hours at a time. I am exhausted. My body aches. There is pain in my joints. I can feel the accumulation of fluid in my body. I am struggling again with depression. The holidays have inflamed my stress. I am desperately trying to provide for my family. I'm eating terrible food-court food. I can't take care*

*of myself, and I feel like crap. I feel terrible about myself. The weight gain and eating terribly. Depression and unable to sleep. I am exhausted. Standing. Standing. Six hours. Seven hours. Seven hours. Eight hours. Standing on my feet with no real breaks for nine hours at a time.*

I distinctly remember praying every night as I fell asleep, hoping that I would make it to the point that I could land a new job with health insurance. I found myself out of breath and struggling to walk up the stairs to our apartment. I found myself having a hard time getting in and out of my jeep because my legs and abdomen had gained so much weight in the form of what I now know was excess fluid in my tissues. I found myself almost falling asleep on my hour plus commute to work because of a complete lack of energy and now horrible circulation.

*I call my mom. We had spoken earlier in the week about trying to hold out on anything health related until I was able to get insurance from a new employer. “Mom,” I plead...*

*“What do you need?” She knew.*

*“Remember how I was going to wait to go to the hospital?”*

*“Yes.”*

*“I need to go to the hospital.”*

*“Do you want to take yourself or do you want me to pick you up?”*

*I am crying, sobbing. The pain is too much. My mother picks me up and takes me to the hospital, and I barely fit in her little Honda Civic because of all the excess weight. I walk in the front doors while my mom parks the car. The nurses at the desk take one look at me and immediately tell me to sit down in a wheelchair. They, like many people after them, are baffled by the fact that I was able to walk into the hospital under my own power. They quickly check me in and get me to an emergency room. Tests come quickly: x-ray, blood draw, oral history, and report. Each time someone asks me how I go to the hospital, each time I tell them that I walked*

*in the front door, and each time they give me a look of confusion. I start to get the inkling that something bigger might be wrong, but I fight the urge. I'd been in this situation before, and I know that the symptoms fit only a handful of diagnoses. I narrow it down to liver failure, which it couldn't be because I hadn't had a drink in ten years, or heart failure, which it couldn't possibly be because I'm not a heart patient. I am suffering from pneumonia, I convince myself. Maybe it's potassium deficiency, I think. All the symptoms fit. But it's not. The diagnosis comes back: Heart failure. Severe cardiomyopathy.*

I was diagnosed with severe cardiomyopathy and late-stage congestive heart failure. Put simply, my heart had been extremely weak for quite some time and was in the process of failing. All of my symptoms were a direct result of an inability to pump fluid through my body.

*I told the doctor that my symptoms had been pretty severe for a few weeks, but that I was trying to hold out for health insurance from a new job. "Well, it's a good thing you came in, because if you hadn't, someone probably would've found you dead in the next 48 hours," the doctor informs me. My mind is racing what if. What if I had not decided to come to the emergency room that day. What if. My girlfriend likely would have found me dead on the floor of the shower within 48 hours. What if... I could be dead.*

*I am in shock. I am trying to process it all. Heart transplant. Medication. Shock vest. My world has turned from "probably just pneumonia" to "emergency transplant list while getting fitted for something called a 'shock vest.'"*

"Well, your heart sucks." This was the diagnosis that they gave me. There was no mincing of words, no formalities, and no confusion on the part of what was wrong with me. The doctor gave me the exact diagnosis that I needed to hear; blunt and succinct. It was oddly comforting to have it presented in such a direct way after being involved in an environment so

full of jargon, technical lingo, and unfamiliar concepts. My heart sucked, and there was no two ways about it. Thankfully, the rest of me was in relatively good health, and I was determined enough to see the story through to the end. I was caught in the chaos of illness, adrift at sea, but I at least knew what I was up against.

According to Arthur Frank (1995), illness is an interruption to the stories of our lives. In a span of fifteen minutes, my life, my story had been interrupted. I was devastated by the news and scared of what lay ahead, as newly diagnosed tend to be (O’hair, Scannell, & Thompson, 2005). What I needed was a guide, a sense of direction, a story that I could follow to help me through my new and frightening reality (Sarbin, 1998; Sunwolf, Frey, & Keranen, 2005). I also needed to make sense of who I was within this new context, to regain and repair some sense of my identity (Harter, Japp, & Beck, 2005; Nelson, 2001).

### **Making Sense of My Illness: Emplotment and the Quest Narrative**

*I am sick and afraid.*

How does one make sense of one’s life? If we are the stories we tell ourselves, then diagnosis of an illness becomes a turning moment, a jarring experience, that thrusts one’s life off course. I was lost, but I had to persevere. I knew that to make sense of my illness and find coping mechanisms for recovery, I had to take control of my story.

*I am sick and afraid.*

Sick people strive to make sense of their illness within the prevailing social conversations, either directly related to their illness or to sickness in general, for “the need to narrate the strange experience of illness is part of the very human need to be understood by others” (Mattingly, 2008, p. 1). In fact, telling stories helps us to navigate through illness and health (Frank, 1995). I had to recontextualize my recovery, and I knew that I was on a journey to

get better. According to Frank (1995), the quest narrative provides a structure for the storyteller to make sense of illness itself. Quest stories allow the ill individual to meet illness head on, not only to overcome it, but to use it to a greater end. Resilient identities developed from a narrative of survival can counter traumatic events and buffer psychosocial stress (Ramirez & Hammack, 2014). Autobiographical retellings are shown to relate to interpretations regarding health and aging among relevant groups (Ianello et al., 2018; Valtonen, 2021). Through the sharing of narrative life stories, meaning and identity can contribute to a sense of self-worth and purpose (Bass et al., 2006). Storytelling repairs and restores what has been lost to the sick: identity, community, meaning, and control (Nosek, et al., 2012).

I'm no hero. I'm not a warrior or knight in shining armor. But I am the author of my life. I'm taking control of my life. My illness became the occasion of a journey, the call to an adventure, a quest (Frank, 2005). To make sense of everything, I centered myself as the protagonist in my own adventure. This is the only way that I was going to survive. As humans, storytelling is a way of making sense of a chaotic world. All great stories take us on a quest, a journey (Ryan, 2004). We all know these stories – tales and mythologies of heroes overcoming trials or adventurers slaying dragons. In fact, Joseph Campbell (2017) describes this narrative pattern of the “monomyth” in which, “a hero ventures forth from the world of common day into a region of supernatural wonder: fabulous forces are encountered and a decisive victory is won: the hero comes back from this mysterious adventure with the power to bestow boons on his fellow man” (p. 23).

*I'm going to get through this. I need to fight this.*

The quest narrative became a way for me to structure what was happening to me. How do I overcome the challenges set out before me? Quest storytellers write of their own pains and

experiences, and their personal understanding of illness allows them to feel and to see the pain that others may be going through. The experiences of deep suffering through illness causes the sick to want to share their enlightenment with others; not only to tell their stories just to tell it, but to guide others who are going through similar symptoms (Frank, 1995). Illness is seen as a quest that gives a greater meaning to their lives as a whole (Nelson, 2001). These quests represent an attempt to find meaning in change through a journey of understanding, and the resulting exploration of self results in transformation on some other level. Indeed, “Something is to be gained from suffering that only can be achieved by hitting the depths and rising anew” (Nosek et al., 2012, p. 1005). The journey of health and illness allows the sick to experience a physical, psychological, and spiritual transformation (Frank, 1995).

*I am a fighter.*

Central to the quest story is a three-stage schematic of departure, initiation and return (Campbell, 2017; Frank, 1995; Nosek et al., 2012). Departure is what begins the story, a call to adventure that is oftentimes first refused. Through a denial of symptoms, the sick person avoids the suffering that lies ahead. Eventually, the call becomes too great and can no longer be refused, in the form of serious symptoms and concrete diagnoses, and the ill person crosses the first threshold and is initiated into the world of the sick. The initiation serves as a series of tests composed of the various sufferings that illness involves, transforming the sick and granting them insight to be passed on to others. Finally, the return occurs as the hero returns to the world of the living, marked by illness and fully transformed from the journey. Additionally, the figuring out of one’s position on a narrative arc is a process called emplotment (White, 1973). According to medical anthropologist Cheryl Mattingly (2008), emplotment is the process of realizing what life plot or story one is enacting in a specific moment in time. Emplotting allows individuals to

discern common narrative occurrences as signposts that give direction to the larger narrative that they may find themselves in. More important than just providing a map of the surrounding narrative landscape, emplotment can itself have therapeutic properties, as it allows individuals not only to identify where they are on a narrative arc but to do something about it. Through recognizing their position on a narrative arc, actors can either follow said arc to its conclusion or change their actions to better suit a different narrative with a different outcome. Indeed, the only way to get out of a bad story is to tell a good one (Frank, 2009).

### I. Departure

*I'm not sick. I'm fine. This isn't happening to me. This is NOT happening to me. Severe heart failure?! Why is this happening to me? I don't want to die. I don't want these tubes in my arms. I don't want to have to ask for help to use the bathroom. I don't want to sleep in this terrible bed with people coming and going every hour. I don't want to eat hospital food. I just want to go back to being normal.*

I realized very early on that I was in a classic illness story. My options: be sick or get out of being sick. I knew that I could overcome sickness, and to do so, I would have to turn what I was doing into a quest. The first stage of the quest narrative, departure, was characterized by my call to illness. I'd inadvertently checked all the boxes that come with presenting a new hero with a chance at a life changing adventure; I'd denied that I was sick, I'd refused the reality of the quest being presented, and I'd come very close to simply giving up and resigning myself to fate. I'd turned away from illness and recovery because I knew that recovery was not going to be easy.

*Everything is happening too fast. There must've been some mistake. I can read an EKG. I can understand a blood test. Even if those levels are high, someone must've screwed something*

*up. I'm too young and too healthy to be sick. Heart failure patients are supposed to be old and frail, not like me.*

Quest narratives and recovery from illness are characterized by a great deal of suffering, trials, and tribulations, and ultimately either success or failure in the form of death. I knew what road I was going to have to walk if I wanted to get better. Again, there was no mincing of words from the doctor; I needed to change practically everything about my life, and even then, there was no guarantee that I would be one hundred percent healthy. I would have to completely reinvent myself and fight tooth and nail against the reality that was presented to me every day. I had to take the road less traveled in the form of diet, exercise, medication, social support, and personal wellness. Any disruption or half measure would prove to be potentially fatal; the transformation had to be complete for it to work. For the first time in my life, however, I was being given the opportunity to be the master of my own future. No longer would activities and motivations be driven by some insidious, undiagnosed illness. My struggle had a name - severe heart failure - and my path had a destination - get healthy. All I had to do was change almost everything about the way I'd been living for the entirety of my adult life.

## II. Initiation

When you cross the threshold, you become initiated into the world of illness. What I faced now was my road of trials that stood between illness and rebirth. For the first time, it was my actions, my choices, that were going to dictate the outcome of my story.

*Okay, Kyle. Let's do this. Gonna fix myself. Gonna fix this. Let's do this. Diet. Exercise. Medication. I'm going to be responsible. Nobody else but me. Work out. Eat right. Take your vitamins, Hulk Hogan style. He's been telling kids to do that for years. It can't be that hard to put into practice, right?*

In reality, to transform everything about the person who you thought you were, is a monumental task. You need support, and I had help. I was determined to conquer this illness, and I had some of the best medical staff on the planet looking out for me.

*“You’re like the poster child for heart failure.”*

I had a partner who was willing to aid me.

*“We’re in this together.”*

I had a family that was supportive of me.

*“You’ve got this.”*

I had a social circle that was going to motivate me to do what needed to be done.

*“You’ve always been there for us, man, so we’re here for you.”*

*My dad hates hospitals. My whole life, my dad has wanted nothing to do with hospitals, which is funny because both his wife and son have spent so much time working at them. Still, every day, he’s at the hospital. He drives three hours up to check on me, looking like he wants to crawl out of his own skin the whole time. I’m the one in the hospital bed with tubes in my arms, but dad always looks like the most uncomfortable person in the room. Still, he wants to be supportive. My mother, on the other hand, takes to the hospital like a fish to water. She knows where everything is, she knows who everyone is, and she makes sure her son is getting taken care of. The doctors reassure her that I’m in good hands, and if she’s willing to believe them, so am I. Everyone wants to see me make it out of here.*

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*Stop eating so much sodium. Stop drinking so much fluid.*

I repeat the simple instructions from my cardiologist over and over again. It sounds quite simple.

*Just don't eat salt and watch how much water you drink, dummy!*

“You’re going to have to train your body to not be thirsty” explained my cardiologist. I quickly learned that water always follows salt. If you have too much salt, you retain more water. But my heart was bad. It was a failed pump. It couldn’t do the work. So, I would retain water more easily, and retaining more water meant I would start swelling up again, constricting my veins and arteries, and ultimately forcing my heart to work harder than it had to.

*Two thousand milliliters. That's all I can have. Two thousand milliliters.*

My body is in a constant state of thirst. Going from drinking six to eight thousand milliliters a day down to two thousand milliliters is agonizing. I am craving my two cups of coffee in the morning. I miss drinking tea and water. Working at the coffee shop, I drank all day long. And now? Cottonmouth became my standard state of being. I became acutely aware of just how much liquid people normally take in. Big gulps. Drinking multiple coffees at cafes. Unlimited refills at restaurants, to say nothing of all the beer and wine and mixed drinks one could consume at a bar - all of it contributed to a culture of excessive fluid intake that I could no longer participate in. The shine was off the apple, and I had to measure out exactly what I was going to drink and when throughout my days. No longer could I idly sip a soda or spend a good few hours drinking cup after cup of coffee on the patio of my local cafe. I had to be measured in all things and developing a drinking regimen was part of it.

*I measure the water going into my coffee. Every time. I weigh the ice going into my glass. Every time. I drink one beverage when going out to dinner. Every time I am thirsty. So thirsty. Don't drink anything extra. Keep 500mls of my daily allotment free for a post workout glass of water. Strict fluid intake. Keep myself from puffing up.*

Up to 60% of our bodies are composed of water (Mitchell, Hamilton, Steggerda, & Bean, 1945). The brain and heart are composed of 73% water, the lungs 83%, the skin 64%. We need water to survive, yet too much water could kill me. Water is vital to the life of every cell in your body, but my heart is too weak to pump the blood into my kidneys to flush out my system. So, what do I do?

Adapt. Adapt to drinking less. Live in a world where it is entirely possible to go through the day without consuming too much fluid. Train your body to not be thirsty. It's fascinating how our bodies can adapt. And slowly, you don't have to think too much about fluid limits to survive the day. I know that I'm going to drink 800ml of coffee across two cups and have another 400ml of water after I work out or before I go to bed, which leaves approximately 16oz of wiggle room on an average day. Rarely, if ever, do I butt up against the 2000ml hard cap imposed on me. The only time I become extremely aware of my fluid intake anymore is when I go to a restaurant and they want to keep refilling my drink after every sip, and even then, I just mentally stick myself to one glass and skip the water before going to bed so as not to upset the balance. After doing it for a few years now, it is hardly noticeable. The same cannot be said for trying to avoid salt.

*Salt is everywhere.*

According to the FDA (2022), the average US citizen consumes about 3400 milligram of sodium per day - more than one and half times what my maximum intake of 2000 milligram was. Unlike excess fluid, excess sodium is extremely difficult to get away from. Nutritional values are not always available, and when they are, they are not always accurate. Measurements and values are purposely obfuscated or listed in such a way as to give the best possible impression of the food on the shelf. The amount of salt in some things is absolutely staggering, and after becoming aware of it, there was no turning back. Reading the nutritional value and sodium content of

snacks - not even salty snacks, just snacks - is an absolute life-ruiner of a practice. It felt like every single piece of food I ever enjoyed was just made of salt. Even foods that shouldn't be salty sometimes had unusually high sodium content, and things like fast food and restaurant foods were absolutely stuffed to the brim with salt. Gone were the days of being able to go through a drive-thru on the way home and just pick up something to eat. I had to change my fundamental approach to how I ate and prepared food, but luckily I had help.

*We've started cooking together. Amanda. God bless her. She has done more for me in these first few months than I could possibly ask of anyone. She's made sure that everything coming into the kitchen is acceptable for my diet. We've thrown out all of the food and snacks that don't meet our new requirements for salt content. Sacrifices have been made, and she has been willing to make them alongside me to ensure that I'm maintaining my sodium intake. I've cut out cheese almost entirely, which has seemed almost impossible. I've cut carbs almost entirely out. No bread. No tortillas. They have a sneaky way of being packed with sodium. No breakfast meats, cured and loaded with salt. No condiments or sauces stuffed with preservatives or snacks coated in salt. No more chips or fast food or low tier dine-in restaurants. I've changed everything about the way I eat.*

*It has been incredibly hard. I am so thankful for the lengths of experimentation that Amanda is willing to try to bring some sense of normalcy into my diet. We have tried five different recipes for ranch this past weekend. We scoured aisles to find the one bottle of sauce that works for us. We have happily dug through mountains of cheese to find a single type of parmesan that wasn't terrible, or taste tested five different salsas after a trip to the store to see if any of them would work for me. She's helped me chase down elusive and near impossible targets, things like bacon or sausage for which there seemingly is no low sodium substitute.*

*Our kitchen has grown by leaps and bounds. We've added several new appliances so we can create low sodium alternatives. Trying, failing, and trying again and again. We've chased down complex creations like Thai green curry or multi-layer lasagna without using salt. Searching for recipes has become how we spend time together. I've cooked for the better part of my life, mostly out of necessity from being single and too broke to order take out or eat at restaurants. But now. Now, I have started to really enjoy my time behind the grill and the stove. I'd been a flavor chemist for years, and what is cooking other than food science and flavor chemistry with a bit of artisanal flair? Cooking has become an escape. It has become a solution to a problem. Most importantly, it has become something where progress is measured and victories celebrated. If you can stick the landing on a perfectly grilled single-flip hamburger, then people need to know about it.*

Cleaning up my diet and cutting out salt and fluid helped me start my weight-loss journey, but it was only half the equation when it came to dropping the weight and getting healthy. If I wanted to come out the other side, I would have to fix my activity level.

*Working out is hard. Yes, I know. Exercising is supposed to be difficult. But finding the time, finding the place, and knowing what to do at the beginning—it's been tough. I am trying to make small changes, the sort of things that commercials for a revised food pyramid tell you to do. I am taking the stairs instead of the elevator. I'm doing push-ups or squats from time to time in my office. I'm making sure to get my steps in. Reaching at least a minimum level of activity hasn't been too difficult. Working at the hospital, I cover five floors plus the basement, herding employees like cats all night across the entire campus. That's plenty of walking. But, I have to do more.*

*Thankfully, Amanda has been so supportive. She's signed me up for a gym membership. I'm not totally lost around a gym as I was athletic in high school and college, but having just come off a lengthy hospital stay made getting started difficult. The gym seems to have the answer to my prayers—a pool. I'd grown up on the beach. I'd always joked that it was tradition in my family to toss kids into the Pacific Ocean and if you made it back then you got to stay. I had spent a great deal of my time growing up swimming in any body of water: the ocean, a lake, a river, a creek, a pool, a mud hole, it didn't matter to me. It's time to go back to my roots, go back into the water, and swim.*

The gym is open 24/7. Since I get off work just after midnight every day during the week, I start the 1AM Swim Club. The club has a single member, me. I am dedicated to going to the pool at least three times a week to swim laps and do general pool-based workouts. I am extremely self-conscious of my body, doubly so after going through such a profound weight gain and weight loss period due to excess fluid on my body. Swimming when there aren't people around helps. I have the pool to myself most of the time. Swimming allows me to focus on my body and mind.

*I can feel my lungs expand with air. I can feel my arm muscles stretch forward and my legs kicking. I imagine myself as a shark cutting through the water. Stroke. Glide. Stroke. Glide. Deep breath in and out. Swim, I tell myself. Just keep swimming.*

I spend about an hour swimming laps and using underwater dumbbells. Sometimes, I just float around and think about the day. I process the projects that I have going on at work, I walk myself through conversations and meetings that I know are coming up, or I think about what I'm going to cook over the weekend. Sometimes, I think about what getting healthy will be like. I wonder what it's like to be in shape and firing on all cylinders. I think about what I'm going to

look like in six months, a year, multiple years down the line if I keep this up and keep improving. Other times, I don't think about anything at all, which is wonderful. It was a good wind-down from work. After a while, I get more comfortable with myself and the idea of working out, so I start doing other things.

*There is this little room with a clock that tells you when to move from one workout station to the next. There is the arm curl machine and the calf raise machine. Next. Legs. Next. Glutes. Breathe, set the weight, rack'em. Do it, do it, do it, stop, switch. Breathe, set the weight, rack'em. Circuit training with weights is a nice supplement to swimming. I'm really proud of myself. I've been keeping a schedule and working out three or four nights a week. I feel better. Between my diet and running around at my job and swimming and weight training, I feel healthier. But I know. I need more. There is always more.*

Between diet, exercise, and medication, medication is the most frustrating. I had control over my diet; it was my choice whether to stick to it, it was my decision what to eat or not eat, and it was my effort that went into obtaining and preparing food that led to results. I had control over my activity levels; it was my choice to be more or less active, it was my decision to go to the gym throughout the week and actively work on myself, and it was my effort that went into doing the workouts and showing up at the gym that led to results. With medicine, I had no control over it. I had no control over how my body was going to respond to increasing doses of blood pressure medicines. I had no control over the diuretic effects that came with taking some of my heart pills. I couldn't really do anything to combat the fact that my doctor was giving me the maximum dose that I could tolerate, because pushing the boundaries of what I was able to tolerate was the only way to get healthy at the speed I needed to.

Nearly passing out from blood pressure medication was the point because it meant I wasn't passing out and could function at that dose. Once my body would get acclimated to a dose and stop nearly passing out, my doctor would prescribe a larger dose to push me right back to that threshold. I had to learn to stand up slowly. I had to learn to balance myself even when my field of vision would start to narrow, and I'd want to sit down. Getting healthy wasn't taking place inside a vacuum; I had to learn how to deal with medication while I was at work or while I was driving somewhere or while I was trying to work out. At times it felt like the medication was actively fighting against me—blood pressure bottoming out when I was trying to be more active at work or in the middle of a strength training circuit. Yet, I had to keep it up. I had to keep a schedule. I had to know what to take when and with what else for it to work. I had to endure, and I had to push myself to keep up with it, because that was the only way I was going to get better. With all three facets figured out, diet and activity and medication, I figured I was on the fast track to good health, and for a while, I was. Eventually, though, I had an appointment with my doctor that would once again change everything.

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According to Aristotle (ca. 350 B.C.E./1967), *peripeteia* is “a change by which the action veers round to its opposite, subject always to our rule of probability or necessity” (p. 344). In Greek, it means reversal. As Sukhia (2020) explains, *peripeteia* is “the moment a story halts going in one direction and takes off in the opposite one” (para. 3). I had been following the recovery story arc up until this point, marching ever forward along the familiar path of a restitution narrative. I knew who and where I was, and what direction I had to go towards through the process of emplotment (Mattingly, 1998). Emplotting gave context to the unfamiliar landscape of illness, but the last thing I expected was to have my recovery journey halt and veer

another direction. Yet, peripeteia forces one to move forward even when you are smacked in the face.

On some level, I knew what was coming. Emplotment told me everything that I needed to know before it happened. Every quest has the hallmark of a brush with death. I knew that I had not yet plunged the darkest depths of suffering necessary for total transformation. As hard as everything I'd gone through was, it was about to get a lot harder. I needed surgery.

It had been a year since I'd been initially discharged and I needed life altering, dangerous surgery. I needed surgery that you might-not-come-back-from surgery, and even if I did come back, I would be marked. My cardiologist informed me that, while my heart was getting better, it wasn't getting better quick enough or well enough. Even though I'd been out in the wild for a year, my condition was still extremely fragile. My condition was such that, at any given moment, my heart could simply stop working and that would be the end of my story. Every day I spent without surgery was another day when, suddenly, the sword could drop, and the end would come. The only solution and safeguard that existed would be surgery for the installation of a defibrillator and pacemaker to hopefully prevent my heart from stopping.

*I am crushed. I am devastated. I feel useless. I feel hopeless. I AM TRYING. I am trying to make meaning. I can't. I can't. I can't. WHAT IS THE POINT!? Why on earth spend all of these hours at the gym or in the kitchen? What is the point of eating right and working out if, ultimately, I still find myself here?! All of the hard work I've put in, all of the weight I've lost, every pill I've swallowed only to endure nearly blacking out from loss of blood pressure. IT'S ALL FOR NOTHING! IT'S ALL FOR NOTHING!*

Rage can be a powerful emotion. Moving through one's rage and acknowledging that you cannot control everything is part and parcel of the recovery process (Parrott & Hess, 2014). In

fact, health communication scholars explain how rage and anger can help return feelings to normal after venting their emotions, and failure to do so can result in cognitive deficiency and dysfunction. Proper display of anger can lead to better interpersonal interactions, understanding, and the reduction of tension and anxiety to name a few (Andersen et al., 2007).

This was tough. Moving towards acceptance of my body and situation and illness. This was painful. Anger becomes a coping mechanism when one feels powerless. I didn't really have a choice - my options were either have surgery or have the potential to just be dead at any given point in time. All the autonomy and control that I'd been given over my health outcomes was taken away from me. Again.

*I am so tired and angry! My brief window of being the master of my own body has ended. I thought I could do this. I thought I could solve this. And now the only solution is staring down a knife while laying on a table. ANGER!!!*

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My personal narrative diverged in one of two ways—I could either accept my lot in life and go quietly into the good night, or I could stand in defiance and claw my way back up out of the pit for a second time. But this time, I'd have to do it with one arm tied behind my back. There was no guarantee that I'd even make it to the other side, and if I did make it, I would lose a great deal of the progress I'd made. The recovery process from surgery was long. I would have to pause all the successes that I'd achieved up to that point and functionally start over. There was not a lot of debate. There were no long conversations with my family. I never drew out a list of pros and cons and weighed the advantages and disadvantages of the procedure. There was no planning or getting my affairs in order prior to going under. There was simply an extremely brief conversation with Dr. Wagneister, my cardiac surgeon.

“When do you want to do this?” he asked.

“I don’t know, whenever,” I replied.

“Well, how does Friday sound?”

“This Friday?”

“Yeah. Or we can wait.”

“No, if we wait then I’ll have time to worry about it. I guess Friday works.”

“Awesome. We’ll get the room booked. See you then.”

And that was that. I was committed. Dr. Wag and I went through the general flow of the procedure. *It’s just a “routine,” I think.* But it’s not. This is cardiac surgery. Cardiac surgery, no matter how routine, still carries risks. It’s just a routine procedure, I keep telling myself. *Yeah, if you mean cutting a human open and screwing two electrodes into a still beating heart, and then implanting an electronic device inside someone’s chest.* It may be routine for a cardiac surgeon, but for me it would most assuredly be a red-letter day.

How does one prepare for cardiac surgery?

*The days have been flying by. I’ve announced to my team at work that I’d be getting surgery. Trying to keep a stiff upper lip when talking about it. I’ve underplayed the risks and assured them that I would be back to lead them once again within a few days. I’ve made sure things are taken care of at home—write down all my passwords and bank information in the event something goes wrong. Tell all the people that I care about that I care about them. Now, I wait. I still have a job to do. I still have my 1AM Swim Club to attend to. I’m going to keep active.*

*But I’m afraid. Genuinely afraid. It’s the night before the surgery. Admit it, Kyle. You’re terrified. You don’t know what is going happen or if you’re going to ever wake up after they put*

*you under anesthesia. You don't know what your life is going to be like, or how long it's going to be. I know this is my best chance at getting better. I have no issues with having a device implanted inside me. I mean, I've been wearing contacts for years, and I have a permanent retainer on my bottom teeth, so from a functional standpoint this doesn't seem any different.*

*Right? Right? Sure, getting something screwed into your heart and cut into your chest is a considerable step up from a metal bar to keep your teeth straight, but the idea is the same. Right?*

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*Anagnorisis* comes from the Greek meaning “recognition” or “to make known again.” Aristotle (ca. 350 B.C.E./1967) explains how *anagnorisis* is the moment a protagonist in a story has an epiphany, that moment when one realizes one's identity or situation. It's that moment of illumination. I think the night before my surgery was my *anagnorisis*. That moment when I knew that this was it. The scales fell away from my eyes. I realized that, by all accounts, I should be dead. I'd been 48 hours away from death. For a whole year, I clawed my way back from the brink of oblivion. All that work and effort wasn't wasted. It had gotten me to this point in my healing journey. This was the real test. Everything prior to it had just been to set the stage. I'd proven that I could make the changes necessary to my life and to become stronger than I'd ever been. I wasn't being punished. I was quite literally being given a second chance. More importantly, I'd given myself a second chance by putting in the long hours in the gym and in the kitchen. This was the start of the climb, but I was going to have to not only survive the procedure, but crawl my way back out of the hole that it was going to put me in. Just like that, the conditioning was broken. I understood myself and the path ahead of me on a fundamental level, and I was ready to face it with every fiber of my being. This was therapeutic employment at

its most basic level. Mattingly (1998) defines therapeutic emplotment as a way of redefining one's illness experience to find a new way to tell one's story, "a way of framing a practical decision about what to do (p. 72). For example, Sharf (2005) discusses how therapeutic emplotment empowered her to construct an alternative narrative to resist the traditional medical model of illness. This was the same for me.

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*I know what's going to happen, but I'm still terrified. Today's the day. I can always back out. I can always give up. Just let things happen. But this surgery. As terrifying as it is, I know I'm going to come out the other side stronger. Ten. Nine. In. Eight. Seven. Out. Six. Five. Breathe. Four. Anesthesia. Three... Two...One...*

For a time, I touched oblivion. No thoughts, not stimuli, no dreams, no reaction to the world. I couldn't tell how long I'd been out, but eventually it all started to come back to me. I found myself in the recovery ward with a dull pain in my left shoulder. I'd survived. I remembered my name, I knew where I was, and now it was time to start the long road of recovery.

*March 2020. I'm beginning to regain function in my arm. I look down at my chest and see the scar. I'm beginning to return to a normal life. But I'm hearing about this new and highly infectious virus that is highly lethal when it comes to individuals with cardiac or respiratory issues, especially those with compromised or weakened immune systems. It's spreading like wildfire, particularly in healthcare settings. I must be extremely careful given my condition.*

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*So, it happened. Leadership decided that COVID-19 was a perfect cover to cut out someone who physically couldn't perform to the level that they wanted. So, they "eliminated my*

*position due to rising health concerns” which is functionally different than firing someone for a temporary disability. I mean, I was always a “lead from the front” type of worker who felt the best way to learn anything was to be on the front lines and participate in the work. But post-surgery, I was confined to desk duty due to doctor’s orders. Of course I wasn’t able to perform my job in the same way that I’d been able to prior to surgery. In a perfect world, accommodations would be made, and there would still be plenty of usefulness for a person who is temporarily, I repeat, temporarily unable to use one of their arms. Yeah, the world I inhabit is not perfect. Fuck them. I’d always excelled at my work, I’d never had a negative review, I’d constantly educated and bettered myself within the institution, and I’m sent packing because I’d had the gall to have surgery and attempt to get healthy.*

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Losing my job, being unable to work on myself physically, and a lack of social outlets due to quarantine and lockdowns led me to a dark place. I was an extroverted person before all of this happened, and I was increasingly finding it difficult to locate any avenue with which to interact with other people. I couldn’t physically go to the gym for a long while, and once I’d gotten the all-clear from the doctor, the gym I was a part of was either closed or too crowded to comfortably go without fear of getting even more sick.

*I’m sick of being sick. I’m sick of this pandemic. I’m not me. I’m so lonely and tired. Everywhere is dangerous. The gym. The coffeehouse. Along with public space restriction my fluid restrictions don’t allow me to sit and sip multiple cups of tea anyway. I’ve lost my sense of taste and smell. I can’t even find joy in a cup of coffee. I am trapped. I am struggling. COVID-19 has created this horrible Groundhog Day. Day after day. The same. I can’t sleep. I can’t expend extra energy through working out. My food schedule is all messed up. I am deteriorating. Why*

*can't I take care of myself? I'm spiraling. I'm so afraid to ask for help. No one can help me. Not even my family or friends or Amanda. All that progress. It's all gone. It's all evaporated. All that work and growth that I made over the last year and half. I'm so scared. I'm spiraling. Heart transplant. I hear the words in my head. I have to help myself or else I am gonna need a new heart. And I ain't gonna qualify for a new heart based on my current physical and mental condition. Whose gonna a waste of a perfectly good heart on a depressed fat guy?*

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If things couldn't get worse. Amanda and I broke up. We had grown apart. We had started out eating well together, exercising together, and getting healthy together. Now, those things faded away. There was a time when we'd both hit the gym and then go home and cook some good food. Now, I found myself working out on my own. I was still eating well, but she was gravitating back to fast food and ice cream by the pint. I spent my days off road running and doing yoga. She spent her time off sitting on the couch scrolling infinitely through Netflix and Facebook. I thought that by getting healthy, it would help the two of us. I felt like everything I was doing was for the both of us. I wanted to be healthy and alive for the wedding. I wanted to look good so she would be attracted to me, and I wanted us to take care of ourselves and spend time together doing it. Everything was falling apart. I was losing my reason for living.

It happened so fast. I lost my family. I lost my house. I found myself once again sleeping on a box spring mattress on the floor. I was severed from my social circles. I quickly found a place to stay and moved more than 45 minutes away from everything. I lost my kitchen. I lost my motivation. I'd lost my spark. My brain was wrapped in a fog, and even things that I'd once been driven to do seemed impossibly hard to pick back up. I couldn't summon any power to think critically or creatively. I lost my enjoyment in everything and just started going through the

motions. Working in tech at a job that I'd held with pride and genuinely enjoyed going to every day, became rote execution. I grew cold and distant, exacerbated by the actual physical distance between myself and the groups of people that I'd grown close to. I was trapped back in the Groundhog's Day loop of quarantine, but this time I was completely isolated from anything that could help me. Wake up, drive, work, drive, sleep, repeat. It felt like months were going by every week. I'd completely lost my way, and I didn't really have anyone to turn to for help.

Things happen to us, but we also make choices. We are the authors of our life stories. I found myself once again at a crossroads of my health narrative. Somehow, somewhere I had to find motivation. *Drag yourself out of this nightmare of your own creation, Kyle.* Money was short but time was long. The silver lining of the pandemic—time. I had functionally nothing going on and was doing absolutely nothing. When you're doing nothing, doing anything is something, a positive change. Anything is better than nothing. My health, my life, is in my hands. If I was going to move forward, I needed to move. *Move. Find that tiny spark of determination. Grab it with both hands.* One morning, I made a simple online order—a pair of running shoes. In some ways, I was going to literally run out of the story of decay towards recovery.

### **“It's All I Got. I Run”: Recrafting My Identity as a Runner**

“It's all I got. I run,” I texted my dear friend Lauryn.

This was the truth. I had nothing: no home, no family, no direction, no motivation, no desire. What I did have, though, was a pair of shoes. It was a cold dreary day in January when I decided to put my bright orange trainers back on for the first time in what seemed like weeks since Amanda and I had split. I didn't know where I was going, but running was how I was going to get there. I was going to fight back against these feelings of loss and uncertainty. The

first few steps were stiff. It felt like it'd been forever since I ran when in reality it may have just been a week. Time stopped making sense a long time ago.

First one foot, then another. Even though it was below freezing, it didn't matter. I'd always joked that the temperature became irrelevant anyway once you got about a mile and half in. My nose went numb around the first half mile, and after that I stopped caring. I found myself running through long forgotten neighborhoods, up a gravel trail in the woods, and past rundown houses. Everything started to blend together, and the world fell away until it was just me and the road.

I found my way back into the good headspace that had eluded me for what felt like ages. Through a combination of what was probably endorphins and dopamine, I found a little spark of something that I was looking for. I poured everything I had into that run. I left it all on the road and went full sprint as I came around the last corner. Something had clicked. Running was the thing that was going to keep me sane and functional in these tough times. Running was all I had, but it was going to be the thing that brought me what I needed.

*Inhale. Left foot. Exhale. Right foot. In and out. I can feel my lungs expand, my muscles stretching, pavement under my feet. Inhale. Exhale. In. Out. The rhythm of the road. One mile at a time.*

I kept at it. I started rebuilding, again. Running became everything in my life. I ran to cope with my loss. *I'll show you how strong I can get and how wrong you were about me.* I ran to get myself healthy; every step, every lap, every mile, and every day contributed to a stronger heart. I ran to unwind after a long day at the office. I ran to rehearse pitches and went over contracts in my head. Since I was cut off from my social circles, I used running to connect with more like minded people. It started small. *Hey, you run too?* a conversation at a coffee shop

added a single person to my running crew. Now I wasn't going it alone. I could build on that. I even went one step farther; I signed up for a race. I'd gone from sick and barely able to climb stairs to running as a sport. I wasn't just running, anymore. I *became* a runner. My whole sense of self had shifted.

The only way to get out of a story is to tell another one. As Sharf (2005) explains, telling one's story is making sense of one's experiences and "re-gaining a sense of control that was often lost" (p. 340). I can "use narration as a communicative means in order to become the active interpreter, organizer, and negotiator of the meaning" of my illness (O'Hair, Scannell, & Thompson, 2005, p. 415). I shifted my identity away from "sick" and "helpless." I didn't want to be a heart patient, so I became a runner. Running became more than an activity, but a dominant part of who I am. Being ill became less and less important. I put "runner" before "heart patient" on my Instagram page. I introduced myself as a runner, but I only revealed that I had a defibrillator and pacemaker implanted if I felt connected enough to a person to reveal that information. I put "runner" on everything that I did. I started to feel like a runner.

People have been running for about as long as they've been telling stories, and stories about running are in no short supply. From the Tarahumara of Mexico and the African plains runners, to the famous story of Pheidippides at Marathon, stories about running permeate human culture. These stories share common themes of perseverance, endurance, and struggle against the elements. When it comes to narrative and autoethnographic research on running, Allen-Collinson and Hockey (2001) unpack the process of injury and recovery in reconstructing the athletic runner identity. In Fisette's (2015) autoethnography, she shares her journey in overcoming a spinal injury and crafting her new embodied identity as a runner. Scarfe and Marlow (2015) narrate how epilepsy impacted the first author's identity as a runner while Ronkainen, Harrison,

and Ryba (2014) look at how transmigration shapes a runner's identity within different running subcultures. Gross (2021) takes an ethnographic approach in trying to understand how runners engage in corporeal and sensual experiences that create a hyperawareness of their bodies. In fact, running long distances can be liberating (see Ronkainen, Shuman, & Xu, 2018).

If emplotment let me find my position in a particular story, then running allowed me to find my place in my grand character arc. My recovery mirrored the progression of my running, and I used running as the most powerful tool in my arsenal for recovery. Running provided me with everything that illness had taken away from me. I grew as a runner by following the narrative arc established by all the runners before me: start slow, build up speed, hit your stride, and finish strong.

The first steps, in recovery and in running, are always the hardest. To even get to those steps, so much had to be overcome. I had to have a desire to press forward, a want to get better, and a capacity to deal with discomfort and pain. In recovery, one must want to heal. My condition, having congestive heart failure and severe cardiomyopathy, like many other health conditions, presented me with two options: (1) I could either follow the recovery process and get better or (2) I could surrender to inaction and eventually drown in sickness. The choice is an entirely personal one. I chose to recover, to survive. That choice was made every time I chose to lace up my shoes every day and hit the pavement.

*Why is this always the hardest part of running? That first step. Gotta get up. Gotta lace up. Rain or shine, you are putting on those shoes, Kyle. There are nine different ways and reasons and excuses for why you shouldn't run. Don't let it get in your head. Running is tough. Recovery is tough. Yes, it's easier to stop trying. You can't go back to eating garbage. You can't*

*go back to not caring and taking care of yourself. The first step of breaking bad habits. The first step of changing. That's the toughest one. Lace up, Kyle. Run!*

I always knew that if I could just get stretched and put my shoes on, I'd be good for the day. When things weren't working out or when life was throwing me curveballs, I would at least have a schedule, a ritual, of stretching, putting my shoes on, and hitting the road. I found comfort in the repetition, despite how hard it got sometimes. Likewise, I found some comfort in the repetition of taking medicine. At first, medicating was difficult. I didn't really have a schedule. Prior to my diagnosis, I'd never been in a situation where I had to consistently take medicine. Medicine, like running, is challenging at first because your body must adjust. It's tough to handle blood pressure drops. It's tough to handle muscle cramps and soreness. It is for dang sure tough to handle both of them simultaneously. I found a way, though, to stick to it day after day. Slowly, both got easier over time. Eventually, I got used to the medicine, and I got used to the distance.

"I'm going to prescribe you Entresto," my doctor said. "If you can tolerate it, we can go from there." *Of course, as soon as you get used to something, that's when things change.* "You've made progress with the blood pressure meds, but we are going to have to increase the dosage." *Every time I find a stable footing, he turns my prescription up, and I have to relearn all the ins and outs of taking them again.*

This was the same with running. Every time that I'd get used to running a distance, sure enough, I'd find myself pushing further or faster and end up having to go through muscle soreness. Time and time again. It was progress, however, and the progress was producing progress. Getting used to medication let me time out my meals and runs better. This, in turn, allowed me to get better at running, which in turn helped my heart and body get stronger so that they could advance farther down the recovery path.

*I can feel everything working together. Left foot, medicine, right foot, exercise. Inhale, social life, exhale, professional success.* I ran to get healthier, and the healthier I got the more I could run. I built up distance quickly, always looking to add on another lap just so I could tell someone that I'd run farther today than I'd ever run before. My pace increased, and I was able to handle more frequent workouts. Likewise, I adjusted to my medicine time and time again and the numbers were bumped up higher and higher. It was all good for me, even if it was difficult.

Each aspect of my life started to feed into every other aspect, providing me with the holistic approach to healing that I had so desperately needed. My body, my mind, my heart, my health. I knew, and repeated many times to anybody that would listen, that no one aspect of my recovery could be credited with the lion's share of healing. A holistic approach to healing meant taking responsibility of my healing process and bringing my body-mind into balance through medicine and diet and exercise and time and support (see Geist-Martin, Becker, Summer, and Slauta, 2008). In fact, I couldn't have possibly been on the path of recovery if I'd neglected even a single element of the greater picture. Just taking medicine wouldn't have healed me, just exercising wouldn't have healed me, and doing anything without support would have proved to be a fruitless endeavor. I needed every aspect of recovery to work together in the same way that I needed every part of me to work together to run.

Running isn't just feet, running is legs and arms and core strength and breathing and diet and emotion. If I didn't have everything working together when I was running, then I wasn't running. If I didn't have everything working together when I was healing, then I wasn't healing. My holistic approach to running and to my recovery were two parts of the same ideal; the effort must be complete to succeed, with no one part taking precedence over the others. I know because days where I couldn't run for whatever reason, whether I was forcing myself to take a day off

and recoup or the weather was crummy, or I had some sort of social or professional obligation, my healing felt incomplete. I felt the same way when I didn't run that I felt if I forgot to take my meds, both of which were thankfully rare occasions. These narrative acts of running and recovery were starting to form a single concurrent story, my story, of healing.

I became obsessed with running, and then I hit my stride. Things were seemingly coming together. A holistic approach led to a holistic result. I found success in my healing, my running, and my life. By staying consistent with exercise and eating right, I'd lost upwards of 120 lbs. I was putting in mile after mile, night after night, with no end in sight. I wanted to run, and I was able to run nearly as often as I wanted. I even snuck in some trail running and some two-a-days every now and again to keep things fresh. I found myself running new routes to new locations to discover new things. I introduced myself to new people as a distance runner. I bought clothes and accessories specifically designed for running. I had multiple pairs of running shoes for different occasions, and I had opinions about all of them that I would gladly share with random people I met. I talked about running with old friends and new friends alike. Part of me even wanted to put "distance runner" on my resume to see if anyone asked about it in interviews.

I used the time I spent running to sort out my mental situation, and it allowed me to think through difficult situations or process information that I'd been studying. In fact, research has looked at the mental health benefits of running, specifically with depression and anxiety (Oswald et al., 2020). Running cleared my head. I studied for the MCAT, and every time I'd finish a chapter, I'd go out for a few miles so that I could really digest what I'd just read. I'd find myself running through chemical structures or biological concepts while running. Muscle contraction. Electron transport chain. And it worked because I found myself on the receiving end of an excellent MCAT score. I ran to unpack difficult customers at work, or to negotiate a contract in

my head before presenting it to a client, and success started to follow at the office. I even argued with the owner that it was in his best interest if I worked less and ran more, since running allowed me to get my head on straight enough to solve problems and, most importantly, make him and me considerably more money. I wrote text messages in my head while I was running to ask cute girls if they wanted to get coffee. I thought my way through difficult interactions. I ran to find my center, and I even pre-wrote chapters of my autoethnography in my head before getting home from running and sitting down to write. Without running, none of this would have been possible. I had most certainly hit my stride. I just had to finish strong and conquer one final obstacle if I wanted to truly earn the mantle of “runner” and finish the quest that I’d initially started. I had to prove it.

### **The Body as a Text**

When someone is ill, they can become disconnected from their body (Sontag, 2002). Illness disrupts one’s relationship between body and self, challenging one’s identity (see Charmaz, 1995). The body, then, is the central text of the illness narrative (Frank, 1995). More than just a collection of organs and symptoms, the body communicates the story of the sick to the world at large, sometimes intentionally and sometimes unintentionally. The story of the sick is told through words and actions, but also through and with the body. Sometimes overt, sometimes subtle, the messages communicated by the sick body are extremely important to the healing process. When it comes to understanding and interpreting the healing journey, the body is essential.

My own body has changed a great deal over time, rubber banding to either end of the extremes. Looking back at pictures from before my diagnosis, it’s almost comical how obviously sick I was, but how hard I wanted it. My mother swears that she could tell that I was sick before I

was actually sick. I genuinely believe her, but I've always been stubborn. She's tried to tell me for years to take care of myself, but I wouldn't listen. It wasn't that I didn't want to take care of myself, it was that taking care of myself first would require me to admit that I was sick. Indeed, in the grand narrative of quest stories, rejection of the call to adventure is often coupled with the first time the hero hears the call (Campbell, 2017). I feared what "being sick" might entail, so I ignored the messages. I wasn't listening to my body. I didn't want to admit that there was anything wrong with me. And denial is a powerful thing. I held out for as long as I physically could. In my instance, per numerous doctors and nurses, if I'd held out any longer there was a good chance that I would be dead.

My body communicated to the outside world that I was sick long before I acknowledged it. I rapidly gained weight. The pictures from before I was admitted to the hospital show a staggering transformation—I ballooned up over a hundred pounds over the course of a month. Trouble with sleep, primarily due to discomfort, also manifested itself in the form of a weather-worn face and bags under my eyes. I had to walk carefully, gingerly almost, due to the pain in my joints from excess fluid accumulation. My hands and feet were swollen. My abdomen was full of fluid. and I wore ill-fitting clothing most of the time. I was out of breath nearly every time I climbed the stairs to my house. I would wince in pain when I'd have to get in and out of my car. I flat out could not participate in activities that I once found enjoyable due to my exhaustion and inability to move. Sickness invaded every aspect of my life, not just my physical self. Functionally, I was a stranger in my own body. One night, I remember crying and grabbing part of my fluid filled stomach fat and proclaiming to my girlfriend at the time that "This isn't me."

My body was doing everything it could to communicate to me and others that I was sick. But nobody was listening. I didn't have health insurance, so I couldn't just go to a doctor and

have my symptoms interpreted. Even then, I would have flatly rejected the diagnosis. Because I was sick, I was less social. I retreated into my own world and my friends and family and the people who cared about me were less likely to see me and the condition my body was in. Others at work seemed to ignore that I was sick. In a capitalistic society, a sick worker is a bad worker, an unproductive worker. Sick people need time off from work to get better. That would mean that I wasn't working and making money for the company. That would mean others would have to cover my shifts. Nobody wanted that, and we most certainly can't provide universal healthcare. I mean, let's just work everyone to death. My girlfriend at the time, too, whether for better or for worse never said anything. I was the only one working in the family, and my terrible job was the only way that we were keeping a roof over our head and food on our table, so whether she meant to or not, she never mentioned it. She also might have just felt uncomfortable having the conversation that her boyfriend was getting really fat and looked terrible, and I don't begrudge her for either outcome .

My failing body full of fluid was going to speak to the medical professionals, to be read by them and help me to understand what was going on. This time, I was receptive to the message: heart failure. I had to reconcile my embodied sick self with the "factual" medical information (see also Sparkes, 1996). I listened and was no longer in the dark. I had to listen and work and heal in the hospital. I lost 80lbs of fluid over the course of about a week and a half. The treatments—diuretics, ACE inhibitors, antiarrhythmics, and blood pressure medication —were working. I could stand and walk again. For the first time in months, I wasn't violently ill. I slept on my back and got a relatively decent night's rest. I was a far cry from being healthy, but I could feel my body changing. Eventually, the test results and physical responses to medication

sufficiently communicated to the attending health care workers that I was healthy enough to go home. Being able to go home meant that I was on the right path to healing.

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*These first weeks at home have been extremely hard. My body aches. I'm still exhausted from the hospital stay. So thankful that I can just lay and fall asleep in my own bed. I've gone back to work, probably too quickly. But at least this new job includes health insurance and other benefits. I'm probably pushing myself too hard. I'm so afraid that people are going to know. I pretend I'm okay, but the other day, I was myself bracing against the handrail out of breath in the stairwell. I'm pretending to be healthy, but I'm not. I'm constantly having to sit down to have a conversation without passing out. I think folks know something's up. Am I just fooling myself?*

*"You look kind of pale."*

*"If this is too much, just let me know, and we can stop."*

*"Why don't you just take some time, and we'll get back to it in a bit."*

*I'm so overwhelmed. I know I'm capable, but I'm exhausted. If I'm going to be honest with everyone, I've gotta be honest with myself. Just tell them you're sick.*

*"So, I've got a bad heart."*

The identity that I was trying so hard to fight against was now mine. Self-disclosing my medical condition meant being honest with myself. I was sick. I would have to learn how to share my private information with others, figuring out when and with whom to share with (see Petronio and Durham, 2008). It wasn't necessarily a bad thing to admit that I was sick and share it with others. Yet, in doing so means managing all the cultural and social baggage that comes with "sick." Even if I didn't want to reveal that I was sick, my body would happily do it for me.

*"Oh, wow, you've lost a lot of weight."*

“You look good for someone who just got out of the hospital.”

There was always a tinge of concern in their voice. I was sick and frail, not healthy and lean. While well intentioned, the comments just reminded me that I was sick. Slowly, however, I began to accept this new identity—just another guy who took medicine and had blood pressure spikes. Everything was going well until my body communicated it needed more.

“So, Kyle. Here’s the situation: lab tests came back. It’s better, but it’s not where we want you to be.”

It was a year after I’d initially been discharged, and I listened intently to Dr. Patel. While I’d been doing well, I hadn’t been doing well enough. Tests and diagnosis that had once told me that I was well enough to go home now communicated that I needed more help. My doctor had seen all that he needed to see. My heart was getting better, but it wasn’t getting better enough. Despite all the medicine and activity, my heart needed more.

“I’m very pleased with your progress. Your weight loss and dietary changes seem to have positively impacted you. Looks good. But, your heart is still very weak. I think we need to take some precautionary measures. That’s why I’m going to recommend that we do..”

I was doing everything I was supposed to be doing.

“...surgery.”

Surgery. The words rang in my ears. I didn’t want to listen. I didn’t want to listen to him. I didn’t want to listen to my body, but I caught myself. What happened the last time you didn’t listen, Kyle? This time, I decided to listen

“Okay. Surgery. Best course of action, I guess,” I reluctantly replied.

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*Pain.* Recovering from surgery meant rest and copious amounts of acetaminophen. Again, I found myself back at work but this time there was no hiding what I'd been through. A large bandage covered my left shoulder and neck. *Don't use your left arm for any lifting or pushing or pulling.* Yeah, because my arm really, really hurts. When the bandage came off, I looked down and saw an incision line and a pronounced lump about two inches in diameter just under my clavicle. This was where the device had been implanted under my skin. Forever marked by illness, my body told a story through my scar and my device, a story of endurance and recovery.

Eventually, I returned to a relatively normal life. I was mildly thankful that my scar and device were usually hidden by whatever shirt I was wearing, and my sickness started to fade into the background. Occasionally, I'd reveal my scar and device in order to move through public places and social events. Whenever I went to a concert or live event, I'd signal to the attendant that I couldn't walk through the metal detector. They would motion that they had no idea what I was talking about, and then I'd pull out my little card from my wallet that said I had an implanted device. The attendant would still have no idea what I was talking about, so I'd have to pull down the collar of my shirt and point at the scar and the device so they would reluctantly let me into the event. This happened time and time again. My illness was relatively invisible until it wasn't. I would thrust myself back into the world of the sick only long enough to get through the door, and then I would go back to being "normal". Aside from the two times a day I had to take medication and the occasional times when I'd stand up too fast and have to wait for my blood pressure to catch up, I was functionally normal. "Normal" wasn't good enough, though. I wanted to be healthy.

**Back into My Body and Svelte: Running Again**

Running allowed me to become more comfortable in my own body. I could feel the weight falling off, my muscles growing stronger. I became more self-aware and less self-conscious.

“That was the first time in my life that I didn’t have to wear a fat guy shirt while I was running!” I shouted as I walked into the house.

“You look svelte,” my best friend Bruce replied.

I had never been called svelte before. It felt good. I no longer felt like a stranger in my own skin. Running gave me what my illness had initially tried to take from me—my own sense of self. Little by little. Step by step. Time after time, I would run into someone who hadn’t seen me in a while, and the positivity would be overwhelming. “Wow, you look great!” and “You look healthy!” were comments that I started chasing. I wasn’t afraid of seeing people that I used to know. I just didn’t look healthy. I felt it. I felt it in my bones and muscles and lungs and heart.

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The idea to run a race came while attending a social event for a local tech company and having a conversation with an attractive woman about running shoes.

“What are your splits?” she asked.

Splits? I knew when she said “splits” she meant mile times, but I’d never actually measured mine because I’d never competed.

“Oh,” she said. “I just figured you ran races.”

Me? Race? I had never thought about running a race before. But the seed was planted. I had a new goal. I was going to compete.

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*Faster. Farther.* I trained, and my body took to the training like a fish to water. *You can go harder. Run!* I listened. Two runs a day, trail running, running in adverse weather, road running, track running, yoga. Farther and farther and faster. I *consumed* running. I *drank* training. *I wanted more.* I wasn't thinking about being sick or having a medical device in my body. Sick people don't train so they can run distance races. Sick people don't do two-a-days. Sick people don't get pretty cybersecurity girls to call them hot. My body and I were firing on all cylinders. I wanted everyone to know that I was, in fact, a competition runner, and the only way to achieve such a thing was to finish a race. *What race?* I looked and found a race near me—The Run of Luck 7k. I quickly signed up and eagerly anticipated the day when I could line up at the starting line. Everything was coming together.

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Three days before the race, I laced up my running shoes and made my way up to the elementary school where I had been training. It was just me, a clear March night, and the distance before me. I started running with the intention of completing the full distance for the race, seven kilometers. I don't know if there's some sort of runner's code that disallows you from practicing the full course, or if it goes against the spirit of the final act of the quest narrative if you practice the ordeal before you undertake it, but I didn't care. I wanted to make sure that the distance wouldn't kill me. The sky was clear, and I had plenty of time to reflect on everything that had brought me to this point.

This race, this run, would be the final ordeal of my quest. To complete the race would symbolize me overcoming illness. This would be how I could accomplish my narrative arc. I also knew that I had to finish the race to rightfully claim the identity of the runner. I knew runners ran, and to be a runner you had to run with runners. Completing the race would unequivocally

put me in the company of other runners. I would be a real runner. Finally, finishing the race would symbolize my bodily transformation and I had materially changed myself.

There were no crowds. There were no other runners. There was nothing but myself and the distance in front of me lit by the stars and the moon. You are who you are when nobody else is around. This was me. I finally felt like me. I survived the distance. I was ready to run.

### **“It’s Cold.” – Culmination and the Final Race**

There was a winter storm the night before the race. The universe had decided to make things interesting.

*It’s fine. I’m fine. I run this distance just fine. It’s fine. Everything is fine. Gonna lace up in the grandest fashion possible. Running shoes, running socks, a second pair of running socks, running tights, running shorts, running pants, running gloves underneath regular gloves, running shirt, race shirt, trusty hoodie, new running sunglasses, running mask, and a hat because, well, I want a hat.*

I wanted to communicate to the world that I am a runner! Also, I wanted to be warm. I pinned my number to my chest and drove to the course. I parked a few blocks away and was pressed for time, so I ran. I ran to my race.

Suddenly, I was there. I was in it. I was amongst competitors and fellow runners. I stood shoulder to shoulder in six-degree weather with people who had been doing this their whole lives, presumably. The field had already been thinned considerably by the weather conditions. Only a serious runner or a lunatic would get up this early to run in single-digit temperatures. There was no question that the people who stood around me were true diehards. The crowd, likewise, was also considerably thinned out because the only person more crazy than the guy who gets up early to run in single-digit weather is the guy who gets up early to cheer him on in

single-digit weather. Surprisingly, my best friend Bruce was already waiting for me. He had gotten up extra early and driven an hour and a half so that he could stand outside in single-digit weather and cheer me on. He'd been supportive of me through everything, and he knew how much this meant to me.

"You're insane, dude!" Bruce gave me a big hug before retreating to the warmth of the bar that was hosting the event.

*This is it.* I watched the clock near the starting line tick down while the organizers explained the course to the gathered runners. All I heard was "four laps" because that's all I needed to hear. *Follow the signs. Look for the arrows. Four laps until freedom.* Four laps in six-degree weather was all that separated me from the end of my quest. Suddenly, I found myself lining up near the front of the pack. *There must be some mistake. I shouldn't be up front, right?* There was no time to argue. The clock counted down to zero. The band struck up a chord. The announcer shouted for the race to begin.

*It's cold.* This was the message my body was telling me as I took the first arduous steps. It most certainly was, and it only got colder when we rounded the first corner directly into the wind whipping off the river. Some people had started to pass me, but I was keeping pace and warming up as best I could. My extensive layering of clothing held against the biting winds, and I started to get my legs under me. I could at least breathe because of my facemask, and everything else was warm enough to function.

As I made my way down the first straightaway, I saw it. It was just a small group, but there they were—my friends and family had gathered to cheer me on. My mom had even made a sign, "Let's Go Kyle" Everyone knew how important this was, and I had the support that I

needed to endure the rest of the race. I found my stride, and as I came around the first corner, I started to pass people.

*Holy shit, I passed people?* Me, a heart patient, had started to pass people. Only runners pass people in races. I watched it happen, almost in slow motion. The cold had already started to sink its teeth into the other racers, and they were dropping out before the end of the first lap. Not me, though. I had smashed through the first wall. I had a pace, I had a goal, and I had a target about half a mile ahead of me. My rabbit. I didn't know his name, or even why I picked him, but I was determined to pass that guy. I threw a casual thumbs up to the photographer as I rounded out the first lap and started to race in earnest.

Layers started to get shed. I had warmed up enough, and now it was time to put some real mustard on it. The gloves came off, both literally and figuratively. *Left foot, right foot, just like we practiced. Tight turns on the corners, but not so tight that you lose momentum or put too much strain on your knee. Maintain pace, watch the lines on the road. It's only four laps.* Everything was working in tandem, just like it was supposed to. *Arms pumped, legs stepped, and lungs kept breathing.* Every lap, I'd hear a cheer and a yell from my personal fan club and catch another small burst of speed. I took my mask off so I could breathe better. I took my hat off because I wanted my beautiful hair to flow in the wind. I was honestly just having fun at this point. "Last lap!" shouted the timekeeper. *Wait, seriously? I'm on my last lap? This is easy.*

It wasn't easy. Icicles had started to form on my beard and in my hair. I was literally starting to freeze. My sunglasses had fogged slightly, which normally wouldn't be a problem, but the fog had frozen and now it was tough to see. Still, I was able to make out one thing. I was right on the tail of the guy that I'd sworn to pass. I could hear him breathing. Somehow, passing this guy was the only thing that mattered to me. Then, it happened; he stopped running. The cold

had gotten to him, and he stopped running with less than a mile to go. It was time. I put all my energy into running and kicked with all my might, just like in practice. Every time I practiced, I poured everything I had into the last 800 or so meters. It was a sort of cleansing ritual to leave everything I had on the track or road as I finished a run. This was no different. I took off, hauling ass towards the last turn.

“Good job!” the timekeeper shouted.

“Four more?” I jokingly responded before accepting a fist bump and tearing down the last straight away towards the finish line. I could see the numbers on the clock. I could see all the racers and fans gathered at the end cheering us on. This was it. Shockingly, I didn’t hotdog my way across the finish line. Just like in practice, I finished strong. I ran through the finish line. I had done it. I had successfully completed an endurance race in freezing temperatures. The ordeal was over. As people gathered around to congratulate me, I knew that I had done what I had set out to do. The little medal of a shamrock that they put around my neck was all the proof that I needed. I was a runner, and everyone knew it.

## Chapter 5: Conclusion

In this autoethnography, I shared my personal journey of congestive heart failure and recovery, sharing moments when I was forced to focus on my body—from exercising to the surgery to becoming a runner. Arthur Frank’s (1995) quest narrative provided me with a narrative structure me to make sense of my illness. Additionally, my illness story exists within a larger context of stories about health and healing, enabled and constrained by larger medical discourses and public narratives of illness. In fact, “personal stories are vital to healing across a spectrum of health and illness experiences, but as stories migrate into public dialogue, they can no longer be understood solely as personal expressions of experience” (Japp, 2005, p. 55).

Chang (2016) describes three reasons that people share illness autoethnographies. First, there is the desire to bring previously unknown information to light (Denshire, 2010). Second, it is to build a sense of belonging through shared experiences (Spieldenner, 2014). Finally, illness autoethnography can heal and transform through therapeutic storytelling (Gingras, 2012; Jones, 2012). In this section, I connect my own writing to these three reasons, as well as describe some possible future directions for further examination.

First, autoethnography in health research has grown to cover a vast array of perspectives and topics (Chang, 2016; Doshi, 2013; Ettore, 2010; Frank, 1996; Pohl, 2014; Scharf, 2005). Even then, I initially found it difficult to find familiar voices among the mountains of published literature. This may be because young and otherwise healthy individuals do not typically experience severe heart problems. I know from my own experiences that the number of people under forty years old who I interacted with during my seven years in the cardiac units of a major hospital could be counted on one hand. I stuck out like a sore thumb every time I went to my cardiologist for a checkup as I didn’t fit the bill of a “typical” heart patient. Never once did I see

another patient whose age was likely within twenty years of mine. The rarity of someone experiencing severe heart issues in their thirties, surviving, recovering, and then writing about it meant that this story was relatively untold. In telling my story, I hoped to have shone light on what was a unique and previously unheard voice in the medical autoethnography field.

Second, this autoethnography details my initiation into what Albert Schweitzer (1974) called a fellowship of those who bear the mark of pain, or what Arthur Frank (1996, 2004) describes as an invitation into the world of the sick. In traversing that boundary and answering the call of illness, I found myself in a strange world that everyone will one day be forced to inhabit. Through the telling of my story and subsequent analysis, I have grown closer to other members of the fellowship. I better understand not only my own sickness and journey towards health, but also the perspectives of people who may be sick with a myriad of other conditions. Regardless of whether the sickness is labeled as heart failure, cancer, fibromyalgia, or any number of other ailments, I better understand what it means to be sick. I can empathize with Norman Cousins (1979) and his struggle against a collagen illness, and I better understand Barbara Sharf's (2005) battles against arthritis, fibromyalgia, and her healthcare practitioners. I *get* where my coworkers are coming from when they talk about their serious back pain or their post-surgery digestive issues. I hope, too, that my stories of heart failure and recovery resonate on some level with other members of the fellowship. I hope that I have provided even the most basic map to allow someone to find their way after they are shipwrecked and wind-tossed by illness. At some point, everyone becomes initiated, and I hope that they at least realize they aren't alone.

Finally, the last stage of the quest narrative is one of returning to the world of the living. I told this story to heal and transform. Frank (1996) describes the quest narrative as an adventure

that you go on to find out what kind of adventure you've been on, and that was exactly what this autoethnography served as for me. I started this journey, and this project, as a sick person.

Through repeated introspective analysis, the synthesis of knowledge, perseverance in the face of extreme hardship, and a desire to heal, I emerged from the other side as a changed person. I succeeded in what I set out to do, and the proof of my journey is written all across the central text of this story—my body. I have been initiated, and now seek to use my illness journey to aid those who find themselves lost among the chaos of their illness. Telling this story allowed me to better understand myself and my adventure on a fundamental level, something that I wouldn't have been able to do otherwise.

### **Future Directions**

While there is growing scholarship in narrative health communication research and autoethnography (Chang, 2016; Cousins, 1979; Doshi, 2013; Ettore, 2010; Frank, 1996; Pohl, 2014; Scharf, 2005), it was difficult to find a similar voice even though health autoethnographies have become increasingly popular. Stories are how we discover and make sense of the world around us. More voices help us to understand the human impact of health and healing as well as validating individuals' experiences so they can see themselves in tales of illness and recovery. More stories contribute to the breadth and depth of our understanding of what it means to be sick and to heal. More information, more data, more stories, and more experiences could only be a positive thing.

In addition, a greater number of documented experiences could also lead to a greater understanding of therapeutic employment. The narrative construction of employment has the potential for positive results in health outcomes, and as such, further research into employment and more personal narratives to which someone can be employed against, can result in more

positive health outcomes. More stories and “maps” for different illnesses and conditions would allow for more people to navigate their way through their narrative arc, find comfort in stories that seem familiar, and potentially emerge victorious on the other side. It would remove some of the uncertainty and fear that is inherent in modern-day biomedical model of health care and provide the uninitiated with much-needed information on how to navigate a chaotic new world.

Finally, autoethnographic scholarship can continue to explore identity and how the synthesis of personal information can lead to growth, healing, and re-identification of the self. How autoethnography contributes to how a person sees themselves and how the world sees their story are topics essential to understanding the therapeutic qualities of storytelling. Even beyond plotment, stories have the capacity for healing, and further understanding this quality could lead to more effective health practices and a reimagining of the traditional health care model. Storytelling and a more holistic approach to health care both remain important topics that could be explored further.

### **Final Thoughts**

This project, my recovery, and my evolution as a runner and person all happened simultaneously. I practice what I preach when it comes to a holistic approach to healing and living, and I don't think that any one of these elements would have been possible without recognizing how the elements interconnect. Running gave me the drive to press forward in healing and in writing, actively contributed to the story I was writing and the health outcomes I was working towards and provided me with time to synthesize and process information pertaining to both. Writing allowed me to understand who I was and the journey that I was on, and through that understanding I discovered things about my illness and healing process that I might not have thought about under normal circumstances. Telling the story contributed to

healing, and the story itself gave me a reason to train and press on and get healthier. I had to complete the narrative arc, driving me to get better and work harder. Everything came together to bring me where I am today and make me the person that I am.

Beyond autoethnographic research, I also hope to have provided at least one person with some sort of guidance on their recovery journey. I hope that even just one new member of the fellowship can look to my story and see some sort of familiarity. Illness is terrifying for so many reasons, and if I can positively impact even just one person's journey, I call it a victory. I also hope that healthy individuals might be able to better understand the struggles and tribulations that ill people face, and that I have dispelled even a little bit of the myth that all heart patients are old, sick, frail, and incapable of hard work. I hope that, if nothing else, somebody somewhere enjoyed the story that I put out into the world. That's all anyone can really ask for.

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## **Epilogue**

*The immediate aftermath of the race was one of elation. I was standing shoulder to shoulder with giants, heavily breathing the extremely cold rarified air. My mother gave me my medal for finishing, and there were hugs all around from my supportive friends. It was far too cold to stand around and talk outside, so we went inside with the rest of the runners to warm up. The warm air inside the bar was much better for hanging out, but I found myself sweating to a comical degree and trying to catch my breath. The change in temperature caused a blood rush, so I took a bit to sit down and drink in the atmosphere. All around me, runners were congratulating each other. There was a celebratory mood, and every time someone else would walk in they would add to it with a "Woo!" or a cheer or some clapping. I couldn't really talk, since the effects of the run all seemed to hit me at once, but still people were walking up to me*

*and congratulating me or asking me how I had felt about it, what I had thought about this being my first race, etc. I could feel it. These were my people. We had survived a trial together and came out the other side. We were united in our triumph, and it felt good.*

*Eventually, I got my legs back under me and found enough strength to make the call to go to the coffee shop. While I was running, one thing that kept me going was knowing that I got to drink a cup of brew and all I had to do was finish the race. The faster and farther I ran, the quicker and closer I got to a cup of coffee. I had earned it. The drive was short, and I arrived as a conquering hero—sweat soaked running clothes, number pinned to my chest, a victory medal draped around my neck. Immediately, the people behind the bar started to congratulate me and ask the same questions the runners had. Once again, I was amongst my people. I didn't have to order, they knew what I wanted. I drank in the good vibes and the good coffee as more and more of my friends showed up to join the congregation. We drank and made merry. We went across the street and ate sushi, truly a feast fit for a conqueror. Eventually, we found ourselves in the parking lot saying goodbye. I returned home with my medals, took a very long and very warm shower, and had myself a nice restful day.*

*The next day, I went for a run, because I am an insane person. Honestly, for the first time in a long time, I wasn't running for any reason other than the fact that I wanted to. There wasn't a race to train for, there was no milestone of distance or time looming around the corner, and I didn't have an appointment coming up that I was trying to drop weight for. I just ran. The weather was about sixty degrees warmer, so I found myself enjoying the sun and the breeze. I tried to reflect on everything that had happened, the long road that had led me to where I was now running, but mostly I just cracked myself up. I suppose the hallmark of a good journey is one that you can look back on and laugh at. I'd really ran, not 24 hours prior, in freezing*

*temperatures with a laser focus on success, but here I was in a t-shirt and shorts having to slow down every now and again because I was laughing so hard at the absurdity of it all. I'd already started to think to myself about what I could conquer next. There were greater distances out there. There were harder courses looming just over the horizon. There was a whole world out there to run, and I was just getting started. I did not come this far to only come this far. I ran home, cleaned up, and before I knew it, I was signed up for another race. Just like that, I had another goal to work towards.*

*Beyond running, the following weeks were filled with progress. I was finally able to seriously sit down and focus on my writing. I had completed the narrative arc, and now it was time to make sense of everything. I also made the decision to finally put myself back out there and try meeting more people. Sure enough, the first line of my online dating profile read "distance runner" in big letters, and my photos were all taken at halfway points on runs that I'd gone on just to enjoy the scenery. It worked, I guess, because people seemed to like the transformed me, and I made sure to mention running at least half a dozen times in every conversation so that they really got the picture.*

*From a health perspective, things had improved greatly, too. I'd started to push myself further and further on runs, and the results were starting to show; blood pressure spikes were all but gone, I'd lost about 180lbs and started to develop musculature that I'd never had before, and there were conversations about taking my pacemaker defibrillator out. They were only whispers but, again, I found myself with something to work towards. I knew that the battery had to be changed eventually, and what a victory it would be to instead progress to the point where we just took it out. It was doable. After everything I'd been through, anything was doable.*

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