

ILLNESS AND AGING: A BIOLOGICAL AND SOCIAL INTERPLAY

Lane Stonecipher Nelson

A THESIS
in
Critical Illness Studies

Presented to the Faculty of the Independently Designed Major at

Colorado College

In Partial Fulfillment of Requirements for the
Degree of Bachelor of Arts.

Under the Supervision of Dr. Eryn Murphy and Dr. Krista Fish

Colorado Springs, Colorado
May 2024

Table of Contents

List of Tables and Figures	4
1 Introduction	5
2 Literature Review	12
2.1 Introduction to Social Constructionism and Social Identity Theory	12
2.2 Illness as a Social Construct	15
2.3 Shortcomings of the Field	20
2.4 Disease vs. Illness, and the Cyclical Relationship Between the Biological and the Social	23
2.5 The Biopsychosocial Model	26
2.6 Introduction to Loneliness and the Elderly	28
3 Methods	30
3.1 Study Design and Procedure	30
3.2 Materials	33
3.2.1 The Duke Social Support Index	33
3.2.2 The Health History Survey	34
3.3 Quantitative Analysis Design	35
3.4 Qualitative Analysis Design	36
4 Quantitative Results	38
4.1 The Duke Social Support Index	38
4.2 The Health History Survey	39
4.3 Statistical Analysis	40
5 Discussion	43
Acknowledgements	56
References	57
Appendices	
Appendix A Recruitment Email	
Appendix B Consent Form	
Appendix C Health History Survey	
Appendix D 11-Question Duke Social Support Index (DSSI)	
Appendix E Interview Question Template	

List of Tables and Figures

Table 1	Mean scores for the Duke Social Support Index (DSSI) and it's social interaction (DSSI-soci) and subjective support (DSSI-supt) sub-scales when administered to the surveyed population of older adults	39
Table 2	Percent incidence of chronic illness and cardiovascular disease (CVD) among the surveyed sample population of older adults	40
Table 3	Duke Social Support Index (DSSI) Mean Loneliness Scores and Sub-scores as a Function of the Incidence of Self-Reported Chronic Illness	40
Table 4	Incidence of Self-Reported Chronic Illness as a Function of the full 11-Question Duke Social Support Index (DSSI) Scores (split into upper and lower 50%) . . .	41
Table 5	Incidence of Self-Reported Chronic Illness as a Function of the Duke Social Support Index Social Interaction Sub-Scale (DSSI-soci) Scores (split into upper and lower 50%)	42
Table 6	Incidence of Self-Reported Chronic Illness as a Function of the Duke Social Support Index Subjective Support Sub-Scale (DSSI-supt) Scores (split into upper and lower 50%)	42

1. Introduction

The summer before my senior year of high school, for the first time, I found myself in severe, sudden, and persistent pain, engulfing my entire lower abdomen and back. Endless blood tests, IVs, samples, scans, and exams characterized the following months, before finally rendering a diagnosis: Crohn's Disease. A subsection of Inflammatory Bowel Disease, this condition is characterized by a thickening of the wall in the terminal ileum of the small intestine. Caused by my immune system treating the healthy bacteria inside my gastrointestinal (GI) tract as unhealthy invaders, this disease was chronic. And in my case, out of control. Despite being on a laundry list of antibiotics, steroids, biologics, and painkillers, my doctors discovered not just one, but a "bird's nest" of fistulas and abscesses that were branching off my colon and grasping towards my ovaries and rectum. By December of that same year, I was on the operating table. Surgery was the last resort to control my disease progression and alleviate my chronic pain. One foot of intestines later - and a four-inch scar running down my stomach, and I was finally pain free. While the metaphorical knife that had been constantly digging into my side, twisting and turning, was gone, I underestimated the changes that would accompany this experience.

In the months of pre-surgery chronic pain, life went on around me; I went to school and saw my friends and did my homework and applied to college. I also took my medications and visited specialists and argued with insurance companies and struggled to sleep. A second part of my life had emerged overnight, an alternate identity that endlessly consumed my time and energy, separating me from my life and myself. Despite my robust support system of friends and family and clinicians, I often felt isolated by my pain. The knife in my side was a perpetual reminder that I was unable to engage with life as I had before. At my best, I was worried I wasn't

joyful enough to be a positive addition to my social groups, leaving me feeling burdensome, lonely, and angry.

A successful surgery didn't erase the burden of my illness, it just changed its form. I am fortunate enough that my daily symptoms are mild and largely pain-free, and I am almost entirely able. My digestive system is intact and functional (mostly), I can eat without restriction (mostly), and my chronic illness doesn't slow me down (mostly). I have a team of clinicians that believe me, support me, and respect my opinions and my pain; and I have quality health insurance and parents with the mobility to support me. But as with most chronic illnesses, that doesn't mean it goes away, it just softens the blow. I still experience pain and troublesome bowels and increased risk for a laundry load of other conditions, and I always will. The *chronic* part is relentless and inescapable. And this is one of the biggest burdens of a chronic illness: the unspoken mental toll.

The diagnosis process violently ripped away my cloak of invincibility, forcing me to reconcile with my (lacking) health and never-before-questioned mortality. As a child, illness and death was something that happens to others, non-real experiences that seem inapplicable to me. However, the diagnosis process and illness experience shattered that mental conception and made real the scary consequences of life. All of a sudden, there was a new and undeniable truth about myself, thrust upon an unwilling me with consequences that will last a lifetime. It wasn't just coping with a change in health, it was coping with a change in mental framework and worldview, forcing significant self-evaluation and re-worldbuilding. The way we each choose to move forward is deeply personal and wholly unique to the individual. This project is part of how I cope.

During my first semester at college, I took a sociology class called “Sociology of Health and Medicine,” which first introduced me to this depth of thought on health and illness. Before this class, I had never read anthropological or sociological literature, and had no idea that the field of medical anthropology even existed. The assigned readings and recommended chapters focused on illness as a social construction, the social determinants of health, personal experiences of chronic illness, biological embedding, sociopolitical policy, pushback against the hegemony of Western biomedicine, amongst a host of other topics. Reading from authors who had expertise on, and oftentimes lived experience with, chronic illness was the first time I learned from people whose experiences had mirrored mine. Even further, these individuals had been brave enough to push against the status quo to make their voices and their stories heard.

There was one piece that struck me in particular: “Welcome to Cancerland,” written by a writer and breast cancer ‘survivor,’ Barbara Ehrenreich. Although I don’t, and have never had cancer, her piece stood out for its outright and unapologetic anger and frustration. Rejecting the passive and accepting monolith of the sick patient, she utilized an intersectional feminist lens to challenge the toxically positive and exclusionary “cult of pink” she found within breast cancer community. Her voice was a dagger, slicing through the layers of sociocultural padding that had been built around her illness with illuminating precision. I cried like a baby reading her piece.

In high school, I was heavily encouraged to join the Crohn’s and Colitis Foundation, where I acted as an “honored hero” to encourage patients and families to walk 5Ks, buy t-shirts, and donate to fund research to “find a cure.” Within this space, I found myself frustrated by the overly positive outlook of the organization, which glorified the illness experience and focused only on ‘survivors,’ abandoning those who had not “overcome” their disease. Crohn’s Disease and Ulcerative Colitis were effectively painted as positive and transient incidents in a person’s

life, something that could be overcome with proper medical care and mental fortitude, leaving you stronger than before your diagnosis. I found that the community never left space in which to address and acknowledge the feelings of anger and frustration at limited treatment options, the sadness and isolation brought on by chronic pain, and the struggles of living with the stigmatized representation of a mostly invisible illness within society.

Where it felt like everyone else had reached the acceptance stage, I was left floundering alone with a foreign, deep-seated internal rage, seemingly alone in the community that was supposed to understand me. But Ehrenreich verbalized her anger, so like mine. Her writing put words to experiences and frustrations I hadn't yet consciously acknowledged, teaching and validating as she wrote. She screamed of what it meant to be sick, forcing acknowledgement of the whole experience of illness. Her writing created a space that expanded patients beyond their physical ailments and predetermined role as passive receivers of treatment, finally acknowledging us as active agents that *feel*. It was only then that I realized there was a place within academia that not only centered patient narratives, but more importantly believed them – and I wanted to be a part of it.

I hope this project can act as a validating force, contributing to the medical humanities discourse and bolstering research surrounding biopsychosocial entanglement. I am not presumptuous enough to assume that sharing a few stories will resolve the ailments of others, but I do believe that narratives carry power. After all, “stories are critical to challenging equity and access” (Villarosa, 2024). By sharing and engaging with stories, humans build connections and develop empathetic understandings with and of one another. Individuals and communities thus have opportunities to influence the larger discourse and bring critical attention to areas of lived experience, encouraging positive change in the eternal march forward.

I designed my major around listening to these voices and surrounding myself with new ones, hoping to learn from them and find a sense of community and belonging. This project focuses on a specific group of older adults, all of whom belong to a fitness class for retirees from Colorado College. These older adults have long since had their “cloak of invincibility” torn away, experiencing the realities of aging and for many, chronic illness too. They have been forced to reconcile with their bodies and their limitations. Through a series of ethnographic interviews and surveys, I hoped to explore each of their experiences with health and illness, learning about biopsychosocial entanglement, but also about how they adapt, cope, and practice resiliency. This project is not solely about contributing to the literature, but also about creating a space for the wide range of emotions that accompanies one of the more challenging parts of the human condition. Like the hoard of forceful and poignant researchers who have come before me, I hope to provide a raw and innately human voice within this conversation.

Despite this project having its conceptual origins at the individual level, it is important to acknowledge the wide-reaching impact of patient-centered narratives to not just individuals, but also to the field of health and medicine. Narratives are powerful tools in world-building, shaping cultural narratives and policy through their powerful messages and empathy-arousing influence. And there is a distinct need for such impact.

While the importance of understanding and addressing issues related to the health and wellbeing of the human population need not be justified, a focus on the cultural components of illness is now necessary as rates of disability grow (World Health Organization [WHO], n.d.) and modern understandings of chronic illness evolve. Currently, over one billion people around the globe live with some form of a disability, making them the largest minority group (WHO, n.d.). However, disabled populations face some of the most significant discrimination barriers in

almost all facets of their lives, including employment, education, and physical accessibility (United Nations [UN], n.d.). And, as medical advances give rise to longer lifespans for the average person, the number of elderly people who disproportionately experience disability is growing rapidly ([UN], n.d.). While there has been increased focus on studying the social model of disability and the patient experience within the biomedical field (van Gennip et al., 2013), the literature largely focuses on the young and the middle-aged. Understanding and documenting both the social and biological aspects that inform the illness experience among the elderly is an area of research that has only recently gained critical attention.

While important, this area of research is vast in its coverage, and cannot reasonably be addressed by even a lifetime of research. I thus want to hone in on one social experience in particular, one that every reader has felt intimately and is so heavily researched that it has an entire body of research devoted to quantifying it: loneliness. Crucial to the defining of our individual social realities, feelings of loneliness might come and go or become a chronic force. Regardless, our sense of belonging and purpose within our social circles, unsurprisingly, shapes and is shaped by our biological health status. For those who are less than able-bodied, feelings of loneliness tend to accumulate as you are physically or mentally hampered from participating as you normally would, often to the extent that social realities are certifiably different (Conrad and Barker, 2010). There are also heavily documented causal connections between loneliness and certain negative health outcomes (Bu et al., 2020; Christiansen et al., 2021; Courtin & Knapp, 2017), proving what many may intuitively know: loneliness is bad for your health. I want to explore this connection within the context of older individuals, and so loneliness among chronically ill elderly persons will thus be the focus of my thesis. Specifically, how do the social relationships and resulting feelings of loneliness among an older-adult health-focused group

impact the biological and social wellness of its members? Inversely, how does biological health status impact the social relationships and feelings of loneliness among members of this group? And while these two lines of research are valuable, they do not capture the complexity of the social-biological relationship. Thus, what can be learned when we complicate the relationship between loneliness and chronic illness among older adults?

This past research and literary background will be further explored in the literature review, a scaffolding that will provide the theoretical and methodological framework through which I can interrogate my research question via a mixed methodological approach.

2. Literature Review

The medical humanities, and the vast array of disciplines that are housed within its broad reach, first gained critical attention in the 1970s. Disabled activists rejected the one-sided understanding of disability as solely a physical impairment, turning a critical lens to the society that actively disabled them via exclusionary institutions and practices (Peruzzo, 2020). Feminist scholars expanded these criticisms, advocating for a “more subjective and embodied experience of disability” (Peruzzo, 2020, p. 33). The publishing of works like Audre Lorde’s groundbreaking *The Cancer Journals* in 1980, put voice and experiences to these critiques, a testament to the power of narratives. Soon after, Black and minority clinicians and patients were advancing concepts of “weathering,” advancing critical research on how stressors in the social environment gets under the skin, and inequitably so (Geronimus, 1992).

Since this conception of the medical humanities and its sub-fields, scholars and activists have been forever pushing forward and expanding literature on the topic. As this literature review is developed, you must keep this activism in mind. There are generations of people who fought for such recognition from an ableist literary body, despite having lived these “discovered” truths daily, who have contributed to the state of the field now. We owe our knowledge to their consistent and considerable efforts, and it is because of them that we have the existence of all research that follows.

Introduction to Social Constructionism and Social Identity Theory

The term “social constructionism” was first introduced in 1966 by Berger and Luckmann in their book “*The Social Construction of Reality: A Treatise in the Sociology of Knowledge*,” engaging philosophical and sociological thought to challenge the perceived objectivity of ‘reality’ and ‘knowledge.’ Their treatise posited that reality is an inherently shared and subjective

experience, co-created by humans in their interactions with one another. No one can experience or construct reality in isolation. We, as a social group, fashion our understandings of the world via shared meanings, language, and cultural norms, thus answering questions about what is normal, what is true, what is right, what is known. This confluence of societally shared beliefs and histories shapes individual perceptions of reality, coloring viewpoints and influencing how we present ourselves. In short, the individual's understandings of reality are a product of the societal beliefs, norms, and life experiences present within the social context from which they originate. "The reality of everyday life is shared with others" (p. 43).

Since the publishing of this text, Berger and Luckmann's work has become a foundational tenet within the discipline, continuing to challenge binary views of reality and informing evolving understandings of social constructionism. Foucault famously expanded upon social constructionism in a series of texts by tying this understating of formation of systems of knowledge to power structures, providing an explanation of, and mechanism for, social control (1966, 1975, 1976). Foucault argued that socially constructed political narratives "had caused us to misunderstand the way that power operates in modern societies" (Pollard, 2019), pointing out the specific social order of repression and marginalization that were normalized via the constructed nature of social reality rather than some natural order (Foucault, 1976). Foucault emphasized that it was knowledge and power that acted as the inseparable agents of enforcement for this prescribed social order, leaning significantly on established social constructionist theory is his defense, yet moving such theory forever forward (1976).

In modern sociology and psychology, the work of Berger and Luckmann, Foucault, and countless other sociological thinkers have expanded social constructionism to new contexts and generated new genres of theory. One such theory is known as social identity theory.

Social Identity Theory (SIT; Tajfel, 1978; Tajfel & Turner, 1979) begins with the premise that individuals define their own identities with regard to social groups and that such identifications work to protect and bolster self-identity. The creation of group identities involves both the categorization of one's "in-group" with regard to an "out-group" and the tendency to view one's own group with a positive bias vis-à-vis the out-group. The result is an identification with a collective, depersonalized identity based on group membership and imbued with positive aspects (e.g., Turner, Hogg, Oakes, Reicher, & Wetherell, 1987). (Islam, 2014, p. 1781)

Drawing upon in-group, out-group sociology, SIT bolsters social constructionism by speaking to how individuals create and reify the identity of themselves and some "other." This represents a shift in thinking within the literature, moving away from the focus on how the social context defines *reality*, instead focusing on how it defines *identity*. A series of texts published by Tajfel over the span of two decades marked the start of the literature exploring this theory.

The social identity perspective has its conceptual origins in research by Henri Tajfel on perceptual accentuation effects of categorization (Tajfel, 1959), cognitive aspects of prejudice (Tajfel, 1969), effects of minimal categorization (Tajfel, Billig, Bundy, & Flament, 1971), and social comparison processes and intergroup relations (Tajfel, 1974). (Hogg et al., 2004, p. 248)

Following this foundational research, and in collaboration with his graduate student, Turner, in the 1970s, Tajfel integrated his research around the familiar concept of social identity. They drew upon the social constructionism work of Berger and Luckmann (1966) to inform their groundbreaking 1989 article that identified the theory by name for the first time, marking the start of the literature on the topic (Hogg et al., 2004).

Research on social constructionism and the social identity perspective has since expanded in an explosive fashion, playing "a key role in the burgeoning revival of social psychological research on group processes" (Hogg et al., 2004, p. 249). While still housed firmly in sociological thought and processes, such theory has both informed and faced resistance among a wide array of other disciplines, including psychology (Burr & Dick, 2017; Gergen, 1985, 2011),

sexuality and gender studies (Green, 2007; Nagoshi et al., 2014), feminist studies (Kang et al., 2017; Weisstein, 1993), and even domestic violence case studies (Mahmood, 2005), among others. This literature review and thesis will focus on another field of study that has been heavily influenced by these wide-reaching theories: health and illness.

Illness as a Social Construct

Patients, practitioners, and philosophers alike have long known that the physical manifestations of disease bear the significant burden of the cultural and social experience of living with them. Intellectuals like Foucault, so far back as his 1976 work, *The Birth of the Clinic: An Archaeology of Medical Perception*, have acknowledged the social facets of the illness experience, the medical system, and medical knowledge in general. And yet, Western and modern biomedicine often fails to consider such social implications. Biomedical patients often find that the medical model posits that illness is a straightforward process, “in which disease is viewed in terms of deviation from normal biological functioning, and where the experience and etiology of illness are understood solely in terms of biological factors, such as genetic predispositions or physiological dysfunctions” (Miles, 2020, p. 259). This bodily ‘malfunction’ can then be cured by following a piece of medical advice (White, 2017). However, current research and advocacy within the fields of medical anthropology, health sociology, narrative medicine, health psychology, disability studies, ethnomedicine, abolition medicine, and more have brought critical attention to the dynamic, often cumbersome, and downright discriminatory social sphere that is constructed around illness and disability. These studies exemplify a truth that many patients and practitioners profoundly feel: the biomedical model is incomplete.

To address this lack, a problem-centered interdisciplinary lens is slowly being deployed, and experts are beginning to acknowledge that the experience of disease is not entirely

segregated from time and place, but is heavily influenced by the cultural and social systems surrounding a patient. Theories such as social constructionism and social identity theory have thus often been utilized within related disciplines to legitimize and intellectualize the experience of illness and disability.

“Phenomenological tenets (Berger and Luckmann 1966; Schutz 1967) were appropriated by medical sociologists to showcase how individuals make sense of their illness, how they cope with physical and social restrictions, and how they deflect self-erosion in the face of those restrictions (Bury 1982).” (Conrad & Barker, 2010, p. 68)

The highlighted excerpt speaks to an emphasis within the discipline to understand the reality of illness for those individuals who may experience it. By interrogating the experience for individual patients, or categories of patients, researchers are empowered to explore the extrinsic forces that shape illness. Researchers have begun to dive into the worldbuilding, reality-bending impact of illness, realizing that the diagnosis and experience of disease constructs an entirely different existence for patients. A medical diagnosis has the power to create the specific social experience of ‘patienthood,’ distinct from the biological condition that created it (Goffman, 1961, 1963). Thus, the literature is firm: illness is socially constructed. However, the forms of this social constructionism are multifaceted, and the most relevant lines of research will be briefly introduced here.

Many cultural analysts contend that some illnesses are imbued with a host of cultural meaning. This means that certain illnesses carry certain connotations, both consciously and unconsciously inherited and passed forward by people in the never-ending process of history making. This process results in “illnesses have[ing] particular social or cultural meanings attributed to them. These meanings adhere to the illness and may have independent consequences on patients and health care” (Conrad & Barker, 2010, p. 69). And predictably, not all illnesses are

treated the same in the public image and biomedical sphere. Much of the research surrounding cultural meaning of illness thus focuses on stigmatization.

For instance, some illnesses are stigmatized, and others are not; some are contested, and others are not; and some are considered disabilities, while others are not. What is important about these distinctions is that they exist for social rather than purely biological reasons. As we will see, sociologists are keenly interested in examining these distinctions because they bring into sharp relief the cultural landscape that ordinarily eludes us; or, as the anthropologist Ralph Linton (1936) once quipped, “The last thing fish would notice is water.” But more than mere sociological curiosities, these cultural meanings have an impact on the way the illness is experienced, how the illness is depicted, the social response to the illness, and what policies are created concerning the illness” (Conrad & Barker, 2010, p. 69).

Conrad and Barker speak directly to the process and lived reality of enculturation, positing that the perceived social reality and knowledge of illness is produced by the individuals and groups that have come before, creating distinct cultures surrounding health and illness. Illnesses are thus “embedded with cultural meaning - which is not directly derived from the nature of the condition - that shapes how society responds to those afflicted and influences the experience of that illness” (Conrad & Barker 2010, p. 76). By looking at the reactions to and experiences of illness and disability, investigators can better understand a culture and the ways in which it operates to generate the lived social context for each individual.

Not only is illness instilled with significant cultural meaning, but the illness experience can be thought of as socially constructed not just by society, but by the individual. Applied in this context, the social constructionist approach acknowledges the subjective experience of illness, delving into the personal and social facets of such illness for the individual. It also investigates how individuals navigate illness within their social environments. The preliminary strands of this research acknowledged that people who experience illness are not passive entities that detachedly experience disease and treatment, instead they are agents of their own health. They

engage in meaning-making activities to understand and process disease and experience a rich and multifaceted life beyond an illness and/or disability (Conrad & Barker, 2010). Such research acknowledges the crucial role that agency and resistance play in the coping process and widen the narrow scope through which researchers have historically understood people who experience illness (Conrad & Barker, 2010; Charmaz, 1991).

Additionally, this research differentiates between the patient experience and the illness experience. The experience of a patient within a biomedical context, though important, is not the only experience for someone experiencing an illness. Most individuals do most of their living and coping outside of the doctor's office or any other clinical setting, living with illness but not necessarily as a patient. The two experiences create distinctly different, though sometimes overlapping, realities (Strauss & Glaser, 1975). This distinction was understood only through largely qualitative and ethnographic work that interrogated the illness experience. Researchers pieced together individual accounts of the day-to-day lives of those living with chronic illness, for the first time creating rich descriptions of their lives and making legitimate their mindsets and realities (Charmaz, 1991). Such individual focus also provided insight into how individuals struggled to understand themselves within the context of illness yet found avenues through which they can reclaim a sense of self.

People endeavor to endow their illness with meaning within the context of their personal and social relationships, employment status, health insurance coverage, religious and cultural beliefs, and the like. Individuals may abate an erosion of self by engaging in identity reconstruction. Said differently, when illness becomes a "biographical disruption," individuals recast themselves in terms of new and unexpected plot developments (Bury 1982). Chronic illness can prompt a reevaluation of one's former life and identity, and, in some cases, the creation of a new illness identity (e.g., cancer survivor)... In sum, individuals actively shape the parameters of their illness and the meaning of selfhood in relationship to those parameters. (Conrad & Barker, 2010, p. 72).

At its worst, illness can degrade identity and reduce personhood to management of symptoms. However, people have proven, and research has found, time and time again, that resiliency is a common theme throughout the experience of illness. Individuals find themselves confronted with a changing reality and often demoralizing worldview, but more often than not, empower themselves to stand firm and actively redefine their personhood despite the reductionist toll of illness. Many people lean on existing communities or create new ones, in search of a sense of belonging (Banks and Prior, 2001; Brown et al., 2004; Kroll-Smith & Floyd, 1997). This speaks not to the ease of disease, but rather to the enduring strength and tenacity of those who experience it, and their significant community-building efforts.

Conrad and Barker (2010) have also posited that medical knowledge itself is socially constructed. While it might be easier to consider an individual's experiences as shaped by their environment, the knowledge base itself is not immune from social and political forces.

Medical knowledge sometimes reflects and reproduces existing forms of social inequality. Rather than being value-neutral, some medical knowledge, implicitly or explicitly, shores up the interests of those groups in power. Upon close inspection, some medical ideas have been shown to support gender, class, and racial-ethnic inequality. (Conrad and Barker, 2010, p. 73).

For instance, what does and does not qualify as a biological disease is not determined by some divine or inherently natural power. Rather, experts and the field decide via social negotiation (Conrad & Barker, 2010). This process is referred to as medicalization, whereby issues or experiences of human life are reclassified as medical conditions via a process of diagnosis development, medical validation, and implementation to define and treat patients. What is considered medically "normal" and "abnormal" is thus decided by some authoritative medical body operating within a specific sociocultural space. This has generated historical patterns of finding women, queer individuals, racial minorities, and specific groups of others to be medically

aberrant in some way, thus requiring biomedical treatment to “fix.” Feminist scholars often cite pregnancy, childbirth, and menstruation as examples of such medicalization (Barker, 1998; Riessman, 1983; Riska, 2003).

This construction of the medical body of knowledge goes further than just medicalization. Medical practice not only defines what is medically aberrant, but also reflects societal fears and enables modes of social control, inscribing cultural meanings and stereotypes into the bodies themselves. This is often reflected in treatment protocols and more subtle medical overtones.

For example, embedded within medical knowledge about pregnancy, premenstrual syndrome (PMS), childbirth, and menopause, one finds clear ideas about women’s “proper” (i.e., subordinate) place in society, as well as moral assumptions about women’s sexuality and femininity more generally. In the early twentieth century, pregnant women were advised against driving an automobile or dancing, on grounds that these activities threatened the health of their unborn child. Today, pregnant women are endlessly warned about the risks of drinking alcohol (Armstrong 2003). In both periods, the medical advice reflects marked cultural anxieties about women’s sexual and social freedoms; and, in both periods, when pregnant women follow the prescribed medical advice, they enact the dominant cultural ideals of femininity (Conrad & Barker, 2010, p. 73).

In this way, social constructionists challenge the purely factual and unbiased perception of medical knowledge, calling into question its concrete nature and introducing the multitude of ways in which the sociocultural sphere shapes even the most seemingly definite of realities.

Shortcomings of the Field

I find this social constructionist lens to be particularly compelling. The perspective that it proffers shifts the onus away from the individual and their affliction, instead acknowledging the role that the historical and social systems of our society have in creating the standards that stigmatize and ostracize those deemed as “other.” This places the blame of discrimination on society itself, forcing a reevaluation of how and why we perceive illness and disability as we do,

and how such categories intersect and overlap with other modes of discrimination. However, social constructionism is not without its criticisms.

One such criticism comes from the disability community itself, challenging the labels that I find validating, instead emphasizing the reifying, and thus nefarious, power that naming things truly has.

Political and medical definitions such as disabled, invalid, and ill, while being crucial to access resources and services, were also individualizing, divisive, and performative: they constrained and allowed for recognition and self-recognition of individuals in those specific definitions (Slee 2013; Youdell 2006)... Butler's nominalist position contributed to highlighting the performative nature of power and language, in that "discursive performativity appears to produce that which is names, to enact its own referent, to name and to do, to name and to make." (Peruzzo, 2020, pp. 35-36).

The world-building power of labels, and their use as tools to enable stratification and discrimination becomes apparent within this argument. The conversations that aim to acknowledge the systems of power through which disabled subjects are created actually reify the "other" category, further separating the disabled body from the able one and unintentionally contributing to its own marginalization via discursive performativity.

Such labels not only separate disabled bodies from able ones, but separate disabled individuals from other disabled individuals. By distinguishing the social experience from the individual one, the overlap of individual and society is neglected. This seems to forget philosophical and sociological research that posits that there is no such thing as individuality, and that a person cannot be separated from or defined outside the bounds of their larger culture and society (Glăveanu, 2011). This counteracts the express goal of this research, which aims to integrate the biological and the social, understanding both within the context of one another, even going so far as to irrevocably tie them together and blur their distinction. However, I have

decided that only by separating and naming these confluent terms can I truly describe their intertwining.

My final critique is one of the most foundational within this project and addressing it will be one of the express aims of this project. The three previously discussed applications of social constructionism to illness, including the cultural meaning of illness, the illness experience as socially constructed, and medical knowledge as socially constructed, are an acute example of research moving unidirectionally. While deeply important and foundational to an understanding of the illness experience, these three applications explore only how a biological event of disease is experienced, and how sociocultural forces manipulate the reality and reputation of an illness and its sufferers. In this fairly typical model for the social construction of illness, almost no space is attributed to the reverse: how a social reality can imbed itself to create a distinct biological reality. That line of study falls exclusively under the public health and biomedical disciplines, creating a divide among the relevant literature. This critique is one of the most foundational within this project and will be further explored and addressed in the following sections.

Disease vs. Illness, and the Cyclical Relationship Between the Biological and the Social

This construction of illness, imbued with significant depth of sociocultural meaning by both society and the individual, is only one half of the picture. Sociologists largely focus on this one facet of illness, leaving the biological intricacies to public health experts and human biologists. This lack of interdisciplinary integration leaves a gap in the literature, exemplified by the distinction between vocabulary like “disease” and “illness” (Seidlein & Salloch, 2019). In response, there is a growing focus on critical integration, exploring not just the social experience of illness, but how the social and the biological interact to produce the biological outcomes and lived realities for those with chronic illnesses and/or disability, texturizing the illness experience.

I will explore this core conversation within what little relevant literature exists, assembling the knowledge base that will prepare me to address my inquiry, which has gone largely unexplored within this field.

As related fields have emerged to explore the social context and construction of illness more deeply, they have often clashed with Western biomedical line of thought, requiring distinctions to be made to elucidate their assertions. One such distinction that is common among sociocultural explorations of illness is a specification between the terms “illness” and “disease.” These two definitions are crucial to understanding the literature within the field, and will be commonplace throughout my analysis, so I will summarize them here. Disease is something that is diagnosed and treated by a medical professional (Kleinman, 2020), presenting as “abnormalities in the function and/or structure of body organs and systems” (Eisenberg, 1977, p. 9). Illness, then, is the host of experiences that a patient and their family then undergoes in companionship with the diagnosis of a disease. These experiences cannot be separated from the social world in which they originate. Thus, disease is a biomedical experience, whereas illness is a social one.

These two terms, often used interchangeably in medical discourse, have become the subject of scientific controversy as conceptions of health have evolved (Seidlein & Salloch, 2019). Because, after all, “language is never innocent” (Fleischman, 1999, p. 7). The distinction between these terms was first introduced by Twaddle in his senior thesis at Brown University in 1968, laying out the conceptual triad of disease, illness, and sickness (acute sickness will not be addressed in this paper). This framework has been co-opted throughout the related literature and is often utilized to “capture fundamentally different aspects of phenomena related to human ailments and healthcare” (Seidlein & Salloch, 2019, p. 1). By defining and differentiating the

vocabulary surrounding health and illness, the more abstract ideas surrounding the social construction of illness are linguistically validated and made real for researchers, academics, practitioners, and those living with chronic illnesses.

By defining the biological existence of disease as distinct from the social experience of it, this naturally encourages conversation between the two: how do they influence one another? The literature addresses this inquiry in two lines of thought, sharply separated by discipline. In what capacity does the biological reality color the social experience for both sufferers and society? And how does the social context imbed itself to create or alter the course of disease?

The first has largely been explored in the *Illness as a Social Construct* section, exploring how a biological event, like disease, is experienced within and constructed by the social sphere. The second is often researched within the sociological context of the social determinants of health (Centers for Disease Control [CDC], 2022). This theory finds the social world, with its deeply inequitable distributions of power and privilege, largely responsible for the disparities mirrored within the healthcare system and occurrence of disease among Americans (Egede & Walker, 2020; Link & Phelan, 1995; Woolf & Braveman, 2011). Most simply speaking, the social context of an individual or a group *physically causes* disease. The cited mechanism for such biological embedding is the stress that these lived experiences illicit, and the epigenetic and hormonal changes that are thus provoked. Woolf and Braveman (2011) summarize this process: people living with inadequate resources often experience stress levels that can cause the brain to stimulate endocrine organs to produce hormones, such as cortisol and epinephrine, at levels that may alter immune function or cause inflammation. Repeated or sustained exposure to these substances may produce “wear and tear” on organs and precipitate chronic diseases such as diabetes and heart disease. They suggest that the most profound health effects to impact living

conditions are delayed consequences that unfold over the span of a lifetime. “Experiences in the womb and early childhood, including stress, can have lasting effects that do not manifest themselves until late adulthood - or even in the next generation” (Woolf & Braveman, 2011, p. 1855).

It is critical to acknowledge that much of the weight of this biological embedding has been long and most profoundly felt, and robustly written about, by communities of color. Black Americans consistently face the worst health outcomes of any racial group, an insidious legacy of generations of continued racial and social injustice (Graves and Goodman, 2023; Noonan et al., 2016). This depression of minority health by the societal forces of structural racism and its consequences has been critically written and spoken about by Black American and indigenous scholars and advocates more and more in recent years. Experts have coined terms such as “weathering,” which describes the premature aging of Black Americans due to the undue stresses of living within a racist society, burdened by racist policies, racist treatment, and fear. Black writers and scientists have engaged with the concept of allostatic load, meaning “the cumulative burden of chronic stress and life events” (Guidi et al., 2020), expanding the term to account for the detrimental toll of inequitable and discriminatory sociopolitical structures, further emphasizing the critical intersection of racism and health. Indigenous communities and associated scholars have begun pushing for trauma-informed healing practices that acknowledge intergenerational trauma which might be transmitted through epigenetic mechanisms, legacies of oppression, and ongoing modes of modern health depression (Oldani & Prosen, 2021) sanctioned by the US government and executed largely by White medical professionals. Highlighting the history of invasive and nonconsensual medical research within these communities, indigenous communities call for a strengths-based lens (Kennedy et al., 2022) and culturally competent

healthcare providers that accept and engage traditional healing practices (Tanta-Quidgeon, 2023). Such ideas and coined terms bring critical attention to, and push back against, centuries old, abhorrently racist, and plainly ignorant aspects of medical knowledge and practice – something that we desperately need.

While these biological imbedding of broader social conditions are widely recognized and broadly researched, the literature only more quietly acknowledges that an individual's social relationships can also benefit or depress health. Umberson and Montez (2010) argue that behavioral, psychosocial, and physiological pathways allow a person's social relationships to have significant effects on health throughout their life course and have a cumulative impact on health over time. Similarly, Smith and Christakis (2008) interrogate how a social network facilitates the spreading of health constructs and knowledge, social support, access to resources, and even a contagion itself, arguing that people's health is just as interconnected as the people themselves.

These research avenues are fruitful and provide validating evidence to what many intuitively know: that the prescribed conditions of our lives, and society's response to them, are an important factor in our health. However, I argue that the literature is incomplete and underdeveloped, addressing the biological and the social discretely, and almost never in conversation with one another. The one exception to this rule, it appears, is the biopsychosocial (BPS) model.

The Biopsychosocial Model

First conceptualized in 1977 by Engel, the biopsychosocial model challenged the commonplace. Engel criticized the narrow lens of the biomedical model and complicated the prevailing Western modalities of health, drawing critical attention to the relevance of

psychosocial factors (Miles, 2020). Engel argued that health and disease are a product of a combination of physiological, psychological, and sociocultural factors, rather than solely physiological ones. More importantly, he emphasized the interconnectedness of these three factors. The BPS model posits that only by acknowledging and integrating physiological, psychological, and sociocultural effects can illness be understood; and, that these variables can influence the course and experience of illness. “In other words, the biopsychosocial model suggests that both the etiology and the expression or prognosis of illness are best understood as the result of an interaction between biological, psychological, and sociocultural variables” (Miles, 2020, p. 259).

This integrated nature of the BPS model made it a valuable resource for my study. Rather than replicating the unidirectional and linear nature of models that characterize much of the research on social constructionism or biological imbedding, the BPS model demands a sophisticated interweaving of interdisciplinary conversations. Within this new model, a wide array of literature can be taken and applied in a *cyclical* direction, allowing all factors to influence one another in a series of positive and negative feedback loops. This allows us to model the complexity of health and illness and acknowledge the interconnected experience felt by many patients, expanding ideas of causality to be non-linear and labyrinthine.

By adopting the biopsychosocial model, informed by these related sociological and biomedical research avenues, I hope to engage this topic in a new way, combining a variety of theory and methodology to address a glaring gap in the literature. While research on social constructionism and biological embedding and the BPS model exist, it only rarely comes together to inform my chosen topic: loneliness and aging. We will explore the few examples of this specific research below.

Introduction to Loneliness and the Elderly

Though abundant, the academic writing on loneliness remains stratified between multiple disciplines and areas of focus, disjointedly interrogating a wide variety of the causes and experiences of loneliness. There is, however, a growing application of the BPS model, focusing on the sociological, anthropological, and psychological experience of loneliness, and how they converse with illness to cause or be caused by disease. Macdonald et al. summarizes this research among the elderly well:

This biomedical interpretation of disability, referred to as the biopsychosocial approach (see Shakespeare et al. 2016), has dominated contemporary studies concerning loneliness and disability. This conceptualizes the relationship between disability and social isolation from an individualized perspective, which subsequently pathologizes disability in order to explain the experience of loneliness. This relationship is explained by either: the experience of loneliness causing health issues which can progress into a long term disability; or the experience of disability disrupting social participation and exacerbating the occurrence of loneliness and isolation. (2018, p. 9)

But critical sociological and anthropological perspectives are not the only ones contributing to the conversation. Clinicians are beginning to recognize and acknowledge how a patient's chronic illness can contribute to feelings of loneliness, and how loneliness can physically and mentally negatively contribute to a patient's biological health. The research published by Özkan Tuncay et al., a team of registered nurses working with chronic illness patients in a clinical setting, is one example of this. They are exploring personal perceptions of one's illness and how it "not only affects all dimensions of a person's life but also plays an important role in his/her coping with the complications and consequences of the disease" (2018, p.1). Drawing upon their 206-person study sample of individuals that had each had a chronic illness for at least one year, they found that "the participants perceived their loneliness level as moderate and that their illness perception was negatively affected as their loneliness levels

increased” (p. 1). However, data were collected via short interviews and lacks the depth typical of an ethnographic study, which I believe would yield more personal and detailed information.

Though such application of the BPS model is fruitful, it is still largely discipline centric. Clinical perspectives remain discrete from anthropological/sociological perspectives, no matter how similar the subject matter. Simply, they lack the depth that a mixed methodological and interdisciplinary approach can yield. Additionally, studies continue to reference the cyclical nature of the BPS but rarely engage both qualitative and quantitative methods to *prove* it. Unidirectional analyses dominate the academic landscape. The few instances of research that are both interdisciplinary and mixed methodological are far and few between, and I hope to contribute to this small collection and help address the gap in integration, as will be described in the following section.

3. Methods

In order to both understand and document the cyclical interplay of social and biological factors in the illness experience, I took a multidisciplinary and mixed-methodological approach in this study. Collecting and analyzing survey data provided a means of quantifying the social experience of loneliness and putting it into a quantifiable conversation a clinical diagnosis. However, surveys alone can never fully address the research question. To truly get a glimpse at the multifaceted experience of illness undergone by each individual that participated in this study, a more qualitative perspective was required. I employed long-form ethnographic interviews to more thoroughly understand the cultural and social components that accompany the biomedical experience, specifically concerning how social groups are formed and personal identities are constructed/reconstructed among those who are chronically ill. It is through this mixed methodological approach that I will challenge the directionality of pre-existing research, correcting the common oversight of the field and acknowledging the cyclical interplay of both social and biological factors.

Study Design and Procedure

I obtained Institutional Review Board (IRB) approval for this data collection process through the IRB at Colorado College. My research consisted of two components, including survey and ethnographic interview portions. I recruited older adults, aged 65 and older, through a Colorado College affiliated, on-campus exercise program in Colorado Springs, Colorado that specifically caters to maintaining fitness levels for people of their advanced age group, called Fit4Life. I sent a recruitment email (Appendix A) and stopped by their group classes to encourage participation in my study, though I had previously established personal connections with many of them. I welcomed all individuals, regardless of ability levels or health

backgrounds, into the study, so long as they were able provide informed consent. I confirmed eligibility as participants were required to provide their date of birth upon intake, ensuring they belonged to the target age range.

All participants voluntarily chose to participate, cognizant of their ability to refuse participation with no repercussions. I assured participants that their contributions would be anonymous, their data would be de-identified, and they would be assigned a pseudonym for all interview data and quotations. I did not use deception during the study.

I began with the goal of recruiting between 5-20 participants to complete the surveys. Sixteen participants were eventually recruited, and from that pool I interviewed 10 individuals on a first-come, first-serve basis. Participants reached out via email, or in-person at Fit4Life classes, to sign up. Participants who did not participate in the interviews were provided copies of the consent form and two surveys at one of the tri-weekly Fit4Life classes at the Colorado College campus fitness center, or via email.

I first guided participants through a consent form (Appendix B), provided time to review it, and offered the opportunity to ask clarifying questions prior to participation. After providing their express informed consent, participants were asked to complete two brief surveys, including a health history form (Appendix C) and the 11-question Duke Social Support Index (Appendix D). The second part of the study consisted of an ethnographic-style interview, where I drew from a list of predetermined questions (appendix E), adapting them and following up as needed to best ask the questions and most effectively interrogate the guiding themes of this research.

For those who participated in the ethnographic interviews, I recorded our conversation and then used the audio recording to generate a transcript. I removed names from the surveys and transcripts and assigned participants a pseudonym. I took these precautions to ensure the data

remained anonymous, reducing the risk that a participant might be identified by other members of the small Fit4Life group. Ensuring the confidentiality of the respondents was paramount, protecting the participants from potential social risks and ensuring they felt safe and able to be vulnerable. I transferred the collected data into data processing software, namely NVIVO and Excel, which I used to conduct the majority of the analysis.

I administered the ethnographic interview in the Human Biology and Kinesiology (HBK) Department's conference room, in Olin Hall on Colorado College's Campus. Looking out over Tava quad, the heavily windowed conference room contained a large table where all but one of the interviews was conducted. The room is located next to the HBK faculty offices and a student study space, ensuring it is generally quiet and undisturbed. Participants were offered refreshments and encouraged to make themselves comfortable before I began the surveys and interviews. I had an audio recording running on my smartphone throughout the duration of each interview, and I took notes on a notepad throughout. Necessary equipment thus included a tape recorder, paper copies of administered materials, and a notepad and pen for my notetaking.

Due to individuals' differences in experience and willingness to share, I expected that the time required to participate in the study would vary. I scheduled each participant for a 1.5-hour time slot, but there was no expectation that all that time would be filled. The participant and I talked until they felt they were ready to stop, or until I had exhausted all guiding and follow-up questions. I communicated to participants that if this time was not sufficient for them to share all that they would like to, they could stay slightly longer, or they may sign up for an additional time slot. No participants required significantly extra time. For those who only completed the surveys, their time commitment was approximately 15 minutes and completed on their own time.

Additionally, I engaged in participant observation in Fit4Life classes. This observation included participating in fitness classes, engaging in unscripted conversations, and general notetaking with a notepad and pen, or with an electronic device. By spending time with the participants and occasionally immersing myself in the social group, I intended to observe their behaviors, practices, and interactions, hopefully providing insight into their group dynamic and larger social cohesion. In preparation for such research, I could not predict the direction that participant observation will take me and I committed to exploring the specific avenues that become available to me, continuing to follow ethical guidelines.

Materials

The Duke Social Support Index

I chose the Duke Social Support Index (Appendix D) from the vast collection of social support surveys due to its rare and tailored focus on elder-specific loneliness, resulting in its extensive use in studies of aging (Koenig et al., 1993; Powers et al., 2004; Woods et al., 2021). For this study, I used the 11-question version of the DSSI. While the scale has a larger, 35-question counterpart, the 11-question version was developed in response to the exhaustive nature of such long-form surveys and the undue burden it places on the already over-interviewed patients (Koenig et al., 1993). Despite its shortness, this scale has been confirmed to be reliable and valid in older, and often chronically ill, populations (Goodger et al., 1999; Koenig et al., 1993; Wardian et al., 2013).

Within this 11-question DSSI, there are two identified sub-scales: the 4-question social interaction sub-scale, and the 7-question satisfaction with social support (subjective support) sub-scale (Powers et al., 2004). These sub-scales quantify different and unique aspects of social support, bolstering the level of detail accounted for within the full 11-question scale (Koenig et

al., 1993). While these sub-scales will be referenced throughout this analysis, the results that they render often parallel (or are identical to) the overall score of the full 11-question survey. Thus, the 11-question, DSSI score is the one that I most often reference and utilize in this analysis.

The sub-scales scores are generated by summing the scores for the relevant questions, while the total DSSI score is generated by summing the scores from the two sub-scales. Items 1 to 4 are re-coded and summed to generate the social interaction sub-scale score, with a potential score range from 4 to 12. For this subscale, higher scores indicate more *social interaction*. Items 5 to 11 are summed to generate the subjective support sub-scale score, with a potential score range from 7 to 21. For this sub-scale, higher scores indicate more *social support*. The total score for the full 11-Question DSSI is generated by calculating the sum of the 11 items. Mean imputation may be used for up to two missing items. This generates a potential score range of 11-33 for the DSSI, with higher scores indicating greater levels of social interaction and social support (Powers et al., 2004).

The Health History Survey

I administered a brief, 9-question health-history survey to determine the incidence of chronic illness among the participants. Created specifically for this project, this survey contains six yes-or-no questions aimed to screen for risk factors of cardiovascular disease (CVD) or active cardiovascular disease, as well as three open-ended questions aimed to screen for any other forms of chronic illness (Appendix C).

Given the open-ended and self-reported nature of the chronic illness screening questions, I regarded almost any positive response to the “do you have any other medical diagnoses?” question as an instance of chronic illness. The unrestrictive nature of this question was intentional, rejecting the rigid and severe survey format that is commonly utilized to screen for

chronic illness within Western biomedicine. Instead of solely listing conditions and having participants check a “yes” or “no” box for each condition, the health history survey left space for participants to describe their health in a more open-form way, defining for themselves what a medical diagnosis or chronic illness looks like.

I did not regard risk factors and precursory conditions, including hypertension, high cholesterol, pre-diabetes, and osteopenia, as chronic illnesses within the bounds of this study. However, it is important to note that many experience such risk factors and precursory conditions as chronic illnesses and engage in self-redefining and coping all the same.

Quantitative Analysis Design

I performed paired t-tests to compare the means of DSSI scores by incidence of chronic illness, as well as to compare the mean incidence of chronic illness by DSSI scores. By determining if there is a statistically significant, non-zero difference between both of these paired measurements, I can develop the quantifiable bidirectional relationship between loneliness and incidence of chronic illness amongst this group of older adults.

I first split the response based on incidence of chronic illness. I conducted three t-tests to compare the means of the full DSSI, the social interaction (DSSI-soci) sub-scale, and the subjective support (DSSI-supt) sub-scale between the chronically ill and non-chronically ill groups.

I then split the responses into an upper and lower 50% of full DSSI scores, an upper and lower 50% of the social interaction (DSSI-soci) sub-scale scores, and an upper and lower 50% of the subjective support (DSSI-supt) sub-scale scores. I conducted a t-test to compare the mean incidence of chronic illness between each of these three DSSI data splits.

The results of these quantitative analyses will be detailed in the following results section, and their implication in the discussion section.

Qualitative Analysis Design

After I collected the audio data, I transcribed and coded the recordings using NVIVO software, creating thematic nodes to organize the data. These nodes helped to group responses and find themes among the data, preparing the data for narrative analysis.

I utilized multiple types of narrative analysis to draw data (both quantitative and qualitative) from the interview responses. Content analysis provided insight on the themes, patterns, and motifs present throughout the interviews, enabling a breakdown of the discussion topics and analysis of recurring themes. Discourse analysis and critical analysis engaged the discourse, language, and implications present within the interviews, situating them within the larger sociocultural and political sphere. This type of analysis questions the motivations, assumptions, and values behind certain words or phrases, tone, and style of speech, providing insight on how larger social narratives are absorbed and performed by individuals. Finally, I engaged in phenomenological analysis to understand the subjective experience of the individual, and the meaning-making and coping that accompany such experiences. By “analyz[ing] the language used to describe experiences, the emotions expressed in the narrative, or the ways in which the narrator constructs meaning from their experiences” (Hassan, 2024), I can better understand how participants interpret and make sense of their lives and experiences.

I will, somewhat unconventionally, include the results and discussion for the ethnographic interview data in the discussion section only. This organization facilitates the generating of a more ethnography-style discussion section, which introduces and discusses

qualitative, quote-based results more effectively than the typical structure for presenting results and findings does.

4. Quantitative Survey Results

Sixteen individuals completed the surveys, and 10 of those individuals chose to participate in the interview portion. Inclusion criteria included being 65 years or older with the ability to provide informed consent. Participants reported moderate-to-high activity levels and engagement, involved in the triweekly Fit4Life classes and oftentimes engaged in other social opportunities. The sampled population had a mean age of 77.3 ± 7.12 years.

I did not include explicit questions about race or gender in the surveys or interviews. Though the interview context provided a space for participants to discuss their identity with me if they chose to, no participants explicitly shared their racial or gender identities. Thus, participants were sorted into categories for my analysis based on my observations, including how they presented themselves and how those presentations fit into the sex/race categories that are commonly constructed in the US. From these observations, 9 participants presented with “typical female” traits and 7 participants presented with “typical male” traits, placed within the normative gender binary. The surveyed group's observed racial composition was largely white, reflecting the homogenous racial composition of the entire Fit4Life group.

The Duke Social Support Index

In this analysis, the 16 collected responses yielded DSSI scores that ranged from 24.5 to 33. The average DSSI score was 29.2, while the average score for the social interaction sub-scale was 9.50 and the average score for the subjective support sub-scale was 19.7 (Table 1). Only one participant failed to answer a question. In this case, mean imputation was utilized as directed to generate the DSSI score for that participant (Powers et al., 2004). Another participant circled the space between the 2. *Somewhat Dissatisfied* and 3. *Very Satisfied* options, resulting in a score of

2.5 for that question and generating the only DSSI score to include a ½ point denotation. All other participants completed the DSSI completely and with presumed competence.

Table 1

Mean scores for the Duke Social Support Index (DSSI) and its social interaction (DSSI-soci) and subjective support (DSSI-supt) sub-scales when administered to the surveyed population of older adults.

	DSSI (full survey)	DSSI-soci (social interaction sub-scale)	DSSI-supt (subjective support sub-scale)
Score ^a	29.2 ± 2.54	9.50 ± 1.67	19.7 ± 1.22

^a mean ± standard deviation (n = 16)

The Health History Survey

In this analysis, among the 16 collected responses to the health history survey, 68.8% of participants had at least one chronic illness, while 31.3% of participants had cardiovascular disease (CVD) (Table 2).

All participants completed the health history survey in its entirety, only leaving boxes empty when they had drawn arrows between response spaces to indicate a redundant response. Their answers to the self-reported question aimed to elucidate chronic illness diagnoses were varied, reporting the following conditions: active cardiovascular disease (CVD), hyperthyroidism, asthma, arthritis, chronic obstructive pulmonary disease (COPD), anxiety, sleep apnea, benign paroxysmal positional vertigo (BPPV), ulcerative colitis, gastroesophageal reflux disease (GERD), and Grave's disease.

Table 2

Percent incidence of chronic illness and cardiovascular disease (CVD) among the surveyed sample population of older adults.

	Chronic Illness	CVD
% Incidence	68.8	31.3

Statistical Analysis

There is a statistically significant difference between the means of the DSSI scores between the chronically ill and non-chronically ill groups, such that DSSI scores were higher in the non-chronically ill group (28.1 ± 2.29 and 31.6 ± 0.55 , chronically ill and non-chronically ill respectively, $p < 0.001$). There is also a statistically significant difference between the means of the DSSI sub-scale scores between the chronically ill and non-chronically ill groups. DSSI-soci scores were higher in the non-chronically ill group (8.91 ± 1.70 and 10.8 ± 0.45 , chronically ill and non-chronically ill respectively, $p < 0.005$). DSSI-supt scores were higher in the non-chronically ill group (19.1 ± 1.10 and 20.8 ± 0.45 , chronically ill and non-chronically ill respectively, $p < 0.001$).

Table 3

Duke Social Support Index (DSSI) Mean Loneliness Scores and Sub-scores as a Function of the Incidence of Self-Reported Chronic Illness

Chronic Illness	DSSI (full survey)	DSSI-soci (social interaction sub-scale)	DSSI-supt (subjective support sub-scale)
Present ^a	28.1 ± 2.29 **	8.91 ± 1.70 *	19.1 ± 1.10 **
Absent ^b	31.6 ± 0.55	10.8 ± 0.45	20.8 ± 0.45

Note: higher DSSI scores indicate greater levels of self-reported social support and lower levels of loneliness.

^a mean \pm standard deviation ($n = 11$), ^b mean \pm standard deviation ($n = 5$)

* Indicates a statistically significant difference between the indicated value and the associated absent value, $p < 0.05$

**Indicates a statistically significant difference between the indicated value and the associated absent value, $p < 0.001$

Additionally, results indicate that there is a statistically significant difference between the mean incidence of chronic illness for the split-score DSSI group (see Table 4), such that incidence of chronic illness was higher in the lower 50% of DSSI scores (100% and 37.5%, upper 50% of DSSI scores and lower 50% of DSSI scores respectively, $p < 0.05$).

Table 4

Incidence of Self-Reported Chronic Illness as a Function of the full 11-Question Duke Social Support Index (DSSI) Scores (split into upper and lower 50%)

DSSI Scores	% Incidence of Chronic Illness
Upper 50% (> 30)	37.5*
Lower 50% (< 30)	100

Notes: DSSI scores were ordered and separated into an upper and lower 50%. The lower 50% had a score range of 24.5-30, with a mean and standard deviation of 27.2 ± 2.07 , $n = 8$. The top 50% had a score range of 30-32, with a mean and standard deviation of 31.1 ± 0.83 , $n = 8$. Higher DSSI scores indicate greater levels of self-reported social support and lower levels of loneliness.

* Indicates a statistically significant difference between the indicated value and the associated lower 50% value, $p < 0.05$

There is also a statistically significant difference between the mean incidence of chronic illness for the two split-score DSSI sub-scale groups (see Tables 5 and 6). The incidence of chronic illness was higher in the lower 50% of DSSI-soci scores (100% and 37.5%, upper 50% of DSSI-soci scores and lower 50% of DSSI-soci scores respectively, $p = 0.0112$). The incidence of chronic illness was higher in the lower 50% of DSSI-supt scores (100% and 37.5%, upper 50% of DSSI-supt scores and lower 50% of DSSI-supt scores respectively, $p = 0.0112$).

Table 5

Incidence of Self-Reported Chronic Illness as a Function of the Duke Social Support Index Social Interaction Sub-Scale (DSSI-soci) Scores (split into upper and lower 50%)

DSSI-soci Scores	% Incidence of Chronic Illness
Upper 50% (< 10)	37.5*
Lower 50% (> 10)	100

Notes: DSSI scores were ordered and separated into an upper and lower 50%. The lower 50% had a score range of 6-10, with a mean and standard deviation of 8.25 ± 1.49 , $n = 8$. The top 50% had a score range of 10-11, with a mean and standard deviation of 10.8 ± 0.46 , $n = 8$. Higher DSSI scores indicate greater levels of self-reported social support and lower levels of loneliness.

* Indicates a statistically significant difference between the indicated value and the associated lower 50% value, $p < 0.05$

Table 6

Incidence of Self-Reported Chronic Illness as a Function of the Duke Social Support Index Subjective Support Sub-Scale (DSSI-supt) Scores (split into upper and lower 50%)

DSSI-supt Scores	% Incidence of Chronic Illness
Upper 50% (> 20)	37.5*
Lower 50% (< 20)	100

Notes: DSSI scores were ordered and separated into an upper and lower 50%. The lower 50% had a score range of 16.5-20, with a mean and standard deviation of 18.81 ± 1.13 , $n = 8$. The top 50% had a score range of 20-21, with a mean and standard deviation of 20.5 ± 0.53 , $n = 8$. Higher DSSI scores indicate greater levels of self-reported social support and lower levels of loneliness.

* Indicates a statistically significant difference between the indicated value and the associated lower 50% value, $p < 0.05$

5. Discussion

When engaging with the results of the statistical analysis, it is important to attach them to the people they represent. This group, as a whole, is extraordinary. They do not represent the average older adult, instead exemplifying health behaviors and outcomes that most of us can only hope for. The 16 surveyed individuals had a chronic illness incidence rate of 68.8% (Table 2), lower than that seen in the comparable general population, with an incidence rate of 91.8% (Machlin et al. 2008). Additionally, they are generally more socially supported than the average older adult. The surveyed older adults in this study reported a mean DSSI score of 29.2 ± 2.54 (Table 1). This value can be compared to a study of a “general population” of older adults, which reported a mean DSSI score of 24.39 ± 3.28 , more than three points lower than the median score of the population in this study, even when using the 10-item version of the DSSI. (Wardian et al., 2013).

Keeping this in mind, it makes the results all the more surprising, given the small size of the surveyed population and their exceptionally good health. The two unidirectional avenues of statistical analysis validated the previous literature, confirming a quantifiable and statistically significant relationship between loneliness, a social condition, and incidence of chronic illness, a biological condition. And as we discuss these results, it is important to keep the group’s circumstances in mind. This group is deeply supported from many directions, a shining example of health and support. To see such significant relationships between loneliness and chronic illness, even among this group, speaks to the truly deleterious consequences of such factors, and the potentially magnifying power of their impact.

On average, participants who had one or more chronic illnesses had a *lower* score on the DSSI (Table 3), indicating higher levels of loneliness and lower levels of social support.

Inversely, participants who had no chronic illnesses tended to have a *higher* score on the DSSI (Table 3), indicating lower levels of loneliness and higher levels of social support. These results indicate that those who experience chronic illness tend to experience loneliness at higher rates and have lower social support scores. Bolstering the findings of the first comparison, the second comparison found that the top 50% of social support scores, those who are the most socially supported, had a 37.5% incidence of chronic illness, while those in the bottom 50% of social support scores had a 100% incidence of chronic illness (Table 4). These results indicate that those who are lonelier and less socially supported, as measured by the DSSI, tend to have chronic illnesses at higher rates than those who are less lonely and more socially supported.

Together, these two avenues of analysis confirm a bidirectional relationship. Loneliness and chronic illness are inherently tied, no matter how you flip the analysis. This aligns with previous literature on the topic, reinforcing findings from an array of disciplines that quantitatively support that loneliness can influence biological course of disease, and a chronic illness can influence an individual's experience of loneliness, as the literature suggests.

But statistical evidence isn't enough. Correlating loneliness with chronic illness in a unidirectional manner is nothing new within the literature. And while these unidirectional lines of research are valuable, they do not, and cannot, fully capture the complexity of this biopsychosocial entanglement between loneliness and chronic illness among older adults. Here, I thus interrogate this unidirectionality by utilizing a more sophisticated and complex model and method through which to engage and understand the biological-social relationship. Using the biopsychosocial model as a framework, the methodology of ethnographic interviews allows me to explore the intricacies of the biological-social relationship, acknowledging their intertwined nature via a qualitative and distinctly human mode of expression: human narratives.

Each interview began quite routinely. Participants set their bags and their coats on the long table in the high-windowed conference room where the interviews would take place. I sat at one end of the table, my seat marked by my notepad, folder of surveys, and cup of coffee. Everyone chose to sit across the table from me, close but not too close, distinctly professional. They often accepted a glass of water or a homemade treat when I offered, settling in as we chatted about the weather or their walk over or just how they had been. No interview was the same as another, though themes of proactivity, community, and coping emerged. Each person brought different experiences and mindsets to the table, stamping the conversation with their individuality and redirecting it to unexpected places.

Anna arrived in head-to-toe grey athleisure, short with brilliant blue eyes. She was quick to laugh and fiddled with her glasses as she spoke. Raymond had shaggy grey hair with eye contact that never wavered. He smiled when talking about harder topics, his thoughtful intention shining through his monotone and relaxing voice. He took his time to craft his thoughts. Casey shed a few tears behind his progressive glasses throughout the interview, gesturing animatedly with his hands as his deep voice spoke about the people he loved. Ella had an overwhelmingly warm personality, kindness radiating from her the second she stepped into the room. Gruff and no-nonsense, Tom was surprisingly animated as he spoke, leaning forward onto his elbows and even moving around the room as he told his stories. Michael arrived wearing a biking helmet with pockets overflowing from his bright red biking clothes. Wendy, Laurel, and Alice had matching haircuts on their greying hair. George filled the time with his words, intent and focused, leaning back in his chair as he spoke. All participants were excited to begin.

Our conversations always started with a list of guiding questions, each purposeful in their duty to interrogate one specific component of the participant's experience. I asked about

interactions with the biomedical system and times of failing health, for both themselves and for others. I asked about community and social support, about loneliness. I asked them to describe what health looks like to them, how they maintain it and what they do in the face of its breakdown. These questions not only interrogated each person's experience, but also aimed to elucidate the scaffolding of their thoughts – the mental structure they have built through which they understand their health and themselves, and cope with the aging process. As the interview process progressed, common themes emerged among the narratives of the participants.

Proactivity was a hallmark of this group. Across the board, participants placed emphasis on maintenance of ability, expressing a preference for lifestyle changes as opposed to medical interventions. “Neither of us want to go on medicine, so we will do what we need to do to change our lifestyle” claimed George, speaking of himself and his wife's reaction to abnormally high numbers on a blood test. He continued, "pills and surgery are not what we're about. And so, if we can make the changes, lifestyle changes so that we can have a happier, longer life, then that's what we want to do.” Laurel expressed similar feelings, saying “I like to do things that affirm good health.” Diet changes, consistent exercise, and increased social engagement, as will be discussed in further detail, were among the most cited lifestyle changes that participants engaged in. In this way, biological realities compelled social health behaviors.

Their reasons for being medically proactive were varied. Some had never known anything else. “I think about health quite a bit, and that's because I'm conditioned to that. I was doing athletics when I was younger, and when [my wife] and I got married, we were two years out of college, and I still worked out quite a bit and for no particular reason, except I felt like I should. And I didn't enjoy it. 62 years we were married, and she insisted in all of those 62 years that I enjoyed working out because I did work out. And so that has become very front lobe, front

lobe kind of thing. I think about that all the time,” said Casey. A mix of athletic and social pressures drove his continued commitment to physical fitness. Tom, a lifelong coach, cited his career as a motivating agent in his heart attack recovery process, helping him excel where others struggled. In his cardiovascular rehabilitation group, there were “some, maybe multiple issues with smoking, or alcohol, or an inability to adhere to a schedule, or really be conscientious about their rehab. Lacking, I guess, the willpower in old age to engage in that. I think maybe my career in coaching and working with... I mean, observing that determination that comes from survival strategies in a game, I think helped out.” Both Casey and Tom recognized the influential power of social experiences like athletics and coaching, and their tangible impact on their fitness levels and recovery process.

Others had witnessed loved ones struggle or deteriorate. George had watched his parents. “I think one of the influences was watching my mom who had horrendous arthritis and she had hips replaced and a knee replaced starting at 80. She lived to 96. Always overweight. And I watched her end of life and it wasn't pretty... And my dad had COPD, died of essentially... lung cancer, but essentially died from smoking. And from the time I was a little kid, I watched what he was doing. I said, ‘I'm never going to smoke.’... And so, I think, again, going back to my science observation [background], looking at what's going on around me and watching the people that have serious issues, they don't really deal with [them]. They get medical care for it, but that's not necessarily dealing with it... And neither of [my parents] were willing to change their lifestyle. So, I think that was really kind of a critical aspect of why I am the way I am.” This social experience colored his conception of health and directly influenced his personal health behaviors. And he wasn't the only one. Laurel watched her parents struggle too. Her mother “ultimately passed away in her mid-nineties, with super high cholesterol that she never ever

treated,” said Laurel. Both George and Laurel were pushed towards proactivity, it seems, by the experiences of their loved ones and the stubborn resistance to matching that fate.

Yet others had seen their own bodies struggle. Raymond described how his convoluted history with the medical system and early childhood illness influenced his mindset. “Well, one thing I think that is very good for me at my age, and even early on, is that [my illness] made me aware of health issues, to pay attention, to be proactive and to plan.” Raymond was a planner, deeply conscious of himself and his abilities, and hard-set on planning around his perceived limitations. And for him, this was a generally positive symptom of illness. “That’s probably what’s helped me, to be more conscious of my health and my quality of life, how I want my life to be. So I think it has helped me, that I went through all that, because like I said, I do pay attention to health issues and be proactive or preventive, anything.” Yet, such intense mindfulness is not always a wholly positive experience. “But I have also I think worries or obsessions, because, when it comes to balance, even very early on, about I think 10 years ago, if I see a handrail, I’ll go for it. If it doesn’t have handrails, like when I go to the [inaudible] Center, they have these huge steps, I just sit there and I think, okay, I have to go up. And I do go up and everything, but I think that you can also develop that kind of negative feelings or attitudes that you cannot do something.” Increased caution keeps Raymond safe, but also constructs limitations around his body and his mind that can, it seems, hold him back, limiting his social experience due to his biological realities.

For Ella, a somewhat recent fall had spurred her caution. After tripping on a rug, thankfully without any broken bones or serious injury, she became more careful. “Now I hang onto railings, and if people don’t have railings, I ask them, ‘why not at your house?’ People are older. But I try to just be careful. I have to look to see where I’m going... Even walking off a

curb, you have to be so careful because... you could slip. So anyway, I feel right now in our lives, we're doing things for ourselves to keep ourselves healthy.” Following his heart attack, Michael had a moment of self-consideration and reevaluation. "Not to the extent that [it is] in the movies, where that kind of stuff was very dramatized. It was just like I did a little mini exercise of, ‘okay, so here I am, this is my age’ ... there's only so many things you can work on and focus on and make happen.” Michael’s cardiologist had credited his physical fitness as an important factor in his survival, evidence of his previous proactivity with physical fitness and fuel for its continuance. “So then you ponder these things and it is just a cliché, stuff happens and then you get zeroed in, [realizing] I'm wasting time on these things that don't matter.” It seems that his heart attack not only affirmed his proactive physical fitness habits, but also functioned as a reset for his mind, a biological push that spurred a moment of social consideration.

Within each of these stories, despite the personal motivation towards proactivity, one of the most consistent and underlying components was medical advice. Each participant, though influenced by individual experiences, had a medical professional sitting on their shoulder, pushing them to proactively engage with their health, effectively participating in their social support system. And it seems that the participants really listened. "If the doctor says it, then I do it," was a prevailing sentiment among members of the group. Participants tended to visit their doctors regularly, each sharing anecdotes about recent or influential appointments. And though they might push back against any barrage of pills or invasive treatment, they routinely followed and took seriously the medical advice they had been given. This makes sense, given the generally positive experiences reported with the health system, personally or via close relations. “I mean, generally speaking, my experience with the healthcare [system] has been positive,” said Tom, summarizing the sentiment of the group.

But that doesn't mean no one had experienced medical challenges. Two individuals had experienced heart attacks, four had other forms of chronic illness, and everyone had felt the wear and tear of aging. And yet, only a few people felt unheard or unsatisfied in their relationships with their clinicians or throughout the treatment process. Alice expressed frustration with the doctors that recommended her treatment for Grave's Disease, which consisted of radioactive iodine that worked to destroy the overactive cells in her thyroid. "Since doctors here weren't really familiar with how to treat [Grave's Disease], I gave up after a year and took radioactive iodine. So it's kind of coming to terms with, then after that, it destroy[ing] your thyroid and you hav[ing] to take a pill every day for the rest of your life... It was just super frustrating that that was apparently the only thing that could be done." Others had watched family members or parents struggle to receive medical care. Tom reflected on his daughter's experiences: "now, she's having a tough time with the medical system, getting to see specialists. She suffered greatly during her change-of-life years and is still not quite over it... She has experienced probably more frustrating times with the system than I have had." Still others recognized the larger problems with public health administration in the United States. "I think a lot of that hinges on insurance," said Ella. George was quick to acknowledge his connections within the biomedical sphere and the impact that it had on his care. "I think it all comes down to privilege. I really do. And I count my lucky stars." They recognized the social conditions that enabled their medical treatment and biological realities, affirming the complicated relationship of the biological and the social.

Within this pattern of proactivity, another theme was interwoven: community. Community underlay decisions about health and supported the participants throughout such decisions. Each person told me about their multifaceted and robust support system, and the people that made it up. Many even directly acknowledged the importance of their community for

their health. “Health to me is social circles... My closest circle is, of course, my husband, my two daughters and I have a single sister, and we're very close... So there's that group, and then there's closest friends. And I probably have one person in there that's my absolute closest friends. We met as freshmen at CC 55 years ago... And then I have another [circle] right outside that circle of people that I know I could call on for anything I needed. And I see people in my exercise class, which is a very social thing. It's fun for me... and it's really important... But I have a significant social circle that's really important to me,” said Laurel. Laurel effectively created a model of concentric circles through which she understands her social circles and the support each person/category can provide. Intuitively, she knows this social circle is important for, and inseparable from, her health. Her social circle is a health resource, innately tied to her biological reality.

Others expressed similar appreciation for their community, citing incidences of connection and anecdotes of assistance. For George, the presence of his community made itself known during moments of medical struggle, an instance of biological realities influencing social support and community. “I mean, we've all had various kinds of, over the years, medical conditions or minor surgeries or whatever. And [people were] always there to help out, supply food if that was necessary. So, I think maybe [times of illness] makes [a community] stronger. And learning, I mean, we certainly did when [my daughter] was sick, people say, ‘let me know if you need any help.’ And we came to realize at that time that those were not empty words, that people really did or do want to help. And by not letting them help, we are denying them an involvement or a sense of being helpful. And I think that's a really important thing to have people do, to be able to help you.”

Wendy relied upon her support system in moments of difficulty too. “I was in trouble, just emotionally. And the rug that was pulled out was a significant one, and I didn’t know how to identify myself around that. I had a compassionate, loving friend... that I see pretty often, and she just said, ‘you need help.’... I was in no place to help myself, no energy... And so she went and researched for me without me knowing... And so those critical steps, I had no capacity to do that for myself. And she did that,” said Wendy. She went on to summarize the experience in a way that many participants related to, exemplifying the tie between biological health and social support, and the impact they make on one another to produce wellness. “I understand when the rug is completely pulled out from under you. The normal ways that we depend on each other and function in the world gets really shaken. And that’s when... there are support systems that we can tap into during those critical times. I’m particularly grateful for that.”

For many, community has become a domain for coping, enabling healing, whether it be from acute medical issues or simply the wear and tear of aging. Each participant had people or groups that they felt close to, and that community created a space for connection and coping. Tom described a group of friends and one of their recurring topics of conversation. “We call it organ recital, right? We talk about respective organs, right? I mean, ‘How’s your knee? Oh, you got a hip replacement.’ One guy just had a hip replacement and is coming back to Fit4Life. And so that’s another support group, albeit smaller than the others that I’ve mentioned, but I look forward to that.” The space Tom describes, not necessarily positive or negative, is one instance of a space that just is. Its neutrality made room for engagement with listening and empathetic ears, making a positive impact on Tom. By engaging socially, he coped with his biological realities. “The opportunity to meet and greet and engage, observe, chat, encourage each other is important. And these other groups do the same thing. I mean, when they relate troubles that they have

experienced maybe with medical issues or family issues or kids, I say, 'Well, we've had that too.' So, you kind of converse about things like that, and then all of a sudden it's not nearly as bad as it initially seems, and you're encouraged to plod on, right? And so that keeps us young in old age," said Tom.

Fit4Life, the glue that unites this group, was another neutral space that enabled coping. While some felt less connected to the group than others, all acknowledged its social importance. "At first, I had this negative view that I was going to join all these old people like me and they were going to be cranky, negative and all that. But I went to it, and I like it very much. It's very important for me because they're role models. Many of them, they travel together, we exercise together, some have book clubs, some go hiking together. They're very active. I see people that are 85, 89 there and balancing and doing something for their life. And that's what I would like to do too, and I admire them for that. And I get to see them, they're colleagues that I work with here at the college. So, I look forward to that, to being with them. I think it's very important for me, I don't think so much the exercises, but seeing them do it and I'm [a] part of it. And also, that it forced me to go to the treadmill afterwards," reflected Raymond. He continued, "I need to see people because people make me happy. Even when you don't tell them that you're unhappy, they come to visit and they light up your world. You didn't have to discuss your problems, but just seeing them or listening to them provides hope." Even the simple relief that comes from discussing and relating with one another lessens the biological burden of illness, a significant agent of coping.

The Fit4Life group benefitted them with more than just its exercises, as many acknowledged. The social support it provided was a powerful way to stave off loneliness, protecting their health via social means too. Raymond expresses this simply, "the most important

thing is being together. The social aspect of seeing each other just for that hour.” And Tom alludes to the scary consequences of not having such a group. “We're grateful for the opportunity to be able to gather in that setting or in other social groups. But there no doubt are people who have retired from the college who are reluctant to join and prefer isolation. And I respect that. But loneliness is dangerous. And so whatever we can do to bring others into the fold.”

Throughout these responses and among participants, the social and biological entanglement becomes obvious. As participants describe their experiences and their mindsets, they both directly and indirectly reference the connection between health and social support, an interconnectedness they intuitively feel. And the language they use to describe this entanglement lacks directionality. To them, the connection exists without motive or direction. Their testimonies push beyond the unidirectional, or even bidirectional, model, contributing to a complex web of biopsychosocial entanglement that is far more convoluted than statistical analysis can represent. Their lessons on coping and resiliency exemplify that; an unquantifiable lesson in the aging process.

They taught me that, difficult and often all-consuming, chronic illnesses demands strength and resiliency from those who experience it. It is an unrelenting consumer of ability, yet a generous producer of empathy. Many who underwent challenging diagnoses found themselves changed, sometimes positively and sometimes negatively, though always without consent. All participants had been challenged and slowed down by changes in health and ability but turned such experiences into moments of connection. Despite feelings of isolation and frustration brought on by their changing health status, participants continuously and courageously engaged in relationship-building, meaning-making and self-re-definition, seeking engagement and

community with others. Though each participant brought a wholly unique and deeply personal story to the table, they all shared the qualities of tenacity and courage.

And despite the complex nature of these lessons, this research is crucial. Much of the research in the field is insufficient, abandoning the true complexity of the topic in favor of simpler research methodologies. This project presents a different avenue for analysis, introducing a methodology that hopes to humanize our understandings of biopsychosocial entanglement, specifically concerning loneliness and chronic illness among the elderly. Further research should continue this push, bringing it back to the humans. The people behind the statistics present important perspectives and worldviews that cannot be gleaned from surveys alone, and are more than worth engaging with as we move our understandings ever forward.

Acknowledgements

I would like to express my deepest appreciation for Dr. Eryn Murphy and Dr. Krista Fish, my excellent and kick-ass power team of advisors, for not only their academic expertise, but for their fundamentally kind and overwhelmingly human voices. They continuously met my project with enthusiasm and extraordinary emotional investment, helping me expand this project past the four walls of my own mind and experiences.

To the participants – thank you for being vulnerable with me. Your courage is commendable, and your positivity is infectious. You created a loving space for me and my work, despite having some of the busiest schedules I have ever seen. As far as humans go, you are some of the most wonderful I have had the pleasure of meeting, and there isn't enough time in the world to learn all that you have to teach.

And to everyone else, I love you. You all simply light up my world, making even the grey parts of life technicolor. I owe my sanity and my happiness to your continuous support and giggly commitment to balancing life with just the right amount of fun. When you tear up at my work, I know I am moving in the right direction. I thus continue my endless march towards making you proud – my silly and exceptional humans.

References

- Banks, J., & Prior, L. (2001). Doing things with illness. The micro politics of the CFS clinic. *Social Science & Medicine*, 52(1), 11–23. [https://doi.org/10.1016/S0277-9536\(00\)00117-9](https://doi.org/10.1016/S0277-9536(00)00117-9)
- Barker, K. K. (1998). A ship upon a stormy sea: The medicalization of pregnancy. *Social Science & Medicine*, 47(8), 1067–1076. [https://doi.org/10.1016/S0277-9536\(98\)00155-5](https://doi.org/10.1016/S0277-9536(98)00155-5)
- Berger, P. L., & Luckmann, T. (1966). *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. Anchor Books.
- Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R., & Gasior Altman, R. (2004). Embodied health movements: New approaches to social movements in health. *Sociology of Health & Illness*, 26(1), 50–80. <https://doi.org/10.1111/j.1467-9566.2004.00378.x>
- Bu, F., Zaninotto, P., & Fancourt, D. (2020). Longitudinal associations between loneliness, social isolation and cardiovascular events. *Heart (British Cardiac Society)*, 106(18), 1394–1399. <https://doi.org/10.1136/heartjnl-2020-316614>
- Burr, V., & Dick, P. (2017). Social Constructionism. In B. Gough (Ed.), *The Palgrave Handbook of Critical Social Psychology* (pp. 59–80). Palgrave Macmillan UK. https://doi.org/10.1057/978-1-137-51018-1_4
- Centers for Disease Control and Prevention. (2022). *Social Determinants of Health*. <https://www.cdc.gov/nchhstp/socialdeterminants/index.html>
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time* (2. paperback print). Rutgers.

- Christiansen, J., Lund, R., Qualter, P., Andersen, C. M., Pedersen, S. S., & Lasgaard, M. (2021). Loneliness, Social Isolation, and Chronic Disease Outcomes. *Annals of Behavioral Medicine*, 55(3), 203–215. <https://doi.org/10.1093/abm/kaa044>
- Conrad, P., & Barker, K. K. (2010). The Social Construction of Illness: Key Insights and Policy Implications. *Journal of Health and Social Behavior*, 51(1_suppl), S67–S79. <https://doi.org/10.1177/0022146510383495>
- Courtin, E., & Knapp, M. (2017). Social isolation, loneliness and health in old age: A scoping review. *Health & Social Care in the Community*, 25(3), 799–812. <https://doi.org/10.1111/hsc.12311>
- Egede, L. E., & Walker, R. J. (2020). Structural Racism, Social Risk Factors, and Covid-19—A Dangerous Convergence for Black Americans. *The New England Journal of Medicine*, 383(12), e77. <https://doi.org/10.1056/NEJMp2023616>
- Ehrenreich, B. (2001, November). Welcome to Cancerland: A mammogram leads to a cult of pink kitsch. *Harper's Magazine*.
- Eisenberg, L. (1977). Disease and illness Distinctions between professional and popular ideas of sickness. *Culture, Medicine and Psychiatry*, 1(1), 9–23. <https://doi.org/10.1007/BF00114808>
- Engel, G. L. (1977). The Need for a New Medical Model: A Challenge for Biomedicine. *Science*, 196(4286), 129–136. <https://doi.org/10.1126/science.847460>
- Fleischman, S. (1999). I am ... , I have ... , I suffer from ...: A Linguist Reflects on the Language of Illness and Disease. *Journal of Medical Humanities*, 20(1), 3–32. <https://doi.org/10.1023/A:1022918132461>

- Foucault, M. (1966). *The order of things: An archaeology of the human sciences* (Vintage books edition). Vintage Books.
- Foucault, M. (1975). *Discipline and punish: The birth of the prison* (A. Sheridan, Trans.; Second Vintage Books edition). Vintage Books.
- Foucault, M. (1976a). *The birth of the clinic: An archaeology of medical perception*. Tavistock.
- Foucault, M. (1976b). *The history of sexuality. Vol. 1: An introduction* (Reprint, Vol. 1). Penguin Books.
- Gergen, K. J. (1985). The social constructionist movement in modern psychology. *American Psychologist*, 40(3), 266–275.
- Gergen, K. J. (2011). The Self as Social Construction. *Psychological Studies*, 56(1), 108–116. <https://doi.org/10.1007/s12646-011-0066-1>
- Geronimus, A. T. (1992). The weathering hypothesis and the health of African-American women and infants: Evidence and speculations. *Ethnicity & Disease*, 2(3), 207–221.
- Glăveanu, V. P. (2011). Creativity As Cultural Participation. *Journal for the Theory of Social Behaviour*, 41(1), 48–67. <https://doi.org/10.1111/j.1468-5914.2010.00445.x>
- Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates*. Doubleday.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity* (1. Touchstone ed). Simon & Schuster.
- Goodger, B., Byles, J., Higganbotham, N., & Mishra, G. (1999). Assessment of a short scale to measure social support among older people. *Australian and New Zealand Journal of Public Health*, 23(3), 260–265. <https://doi.org/10.1111/j.1467-842X.1999.tb01253.x>
- Graves, J. L., & Goodman, A. H. (2023). *Racism, not race: Answers to frequently asked*

- questions* (Paperback edition). Columbia University Press.
- Green, A. I. (2007). Queer Theory and Sociology: Locating the Subject and the Self in Sexuality Studies. *Sociological Theory*, 25(1), 26–45. <https://www.jstor.org/stable/20453065>
- Guidi, J., Lucente, M., Sonino, N., & Fava, G. A. (2020). Allostatic Load and Its Impact on Health: A Systematic Review. *Psychotherapy and Psychosomatics*, 90(1), 11–27. <https://doi.org/10.1159/000510696>
- Hassan, M. (2024, March 25). Narrative Analysis—Types, Methods and Examples. *Research Method*. <https://researchmethod.net/narrative-analysis/>
- Hogg, M. A., Abrams, D., Otten, S., & Hinkle, S. (2004). The social identity perspective: Intergroup relations, self-conception, and small groups. *Small Group Research*, 35(3), 246–276. <https://doi.org/10.1177/1046496404263424>
- Islam, G. (2014). *Social Identity Theory* (pp. 1781–1783).
- Kang, M., Lessard, D., Heston, L., & Nordmarken, S. (2017). *Social Constructionism*. <https://openbooks.library.umass.edu/introwgss/chapter/social-constructionism/>
- Kennedy, A., Sehgal, A., Szabo, J., McGowan, K., Lindstrom, G., Roach, P., Crowshoe, L. (Lindsay), & Barnabe, C. (2022). Indigenous strengths-based approaches to healthcare and health professions education – Recognising the value of Elders’ teachings. *Health Education Journal*, 81(4), 423–438. <https://doi.org/10.1177/00178969221088921>
- Kleinman, A. (2020). *The illness narratives: Suffering, healing, and the human condition* (Second edition). Basic Books.
- Koenig, H. G., Westlund, R. E., George, L. K., Hughes, D. C., Blazer, D. G., & Hybels, C. (1993). Abbreviating the Duke Social Support Index for use in chronically ill elderly

- individuals. *Psychosomatics*, 34(1), 61–69. [https://doi.org/10.1016/S0033-3182\(93\)71928-3](https://doi.org/10.1016/S0033-3182(93)71928-3)
- Kroll-Smith, S., & Floyd, H. H. (1997). Bodies in Protest: Environmental Illness and the Struggle Over Medical Knowledge. In *Bodies in Protest*. New York University Press. <https://doi.org/10.18574/nyu/9780814749234.001.0001>
- Link, B. G., & Phelan, J. (1995). Social Conditions As Fundamental Causes of Disease. *Journal of Health and Social Behavior*, 80–94. <https://doi.org/10.2307/2626958>
- Lorde, A. (1980). *The cancer journals* (1. ed). Spinsters.
- Macdonald, S. J., Deacon, L., Nixon, J., Akintola, A., Gillingham, A., Kent, J., Ellis, G., Mathews, D., Ismail, A., Sullivan, S., Dore, S., & Highmore, L. (2018). ‘The invisible enemy’: Disability, loneliness and isolation. *Disability & Society*, 33, 1138–1159. <https://doi.org/10.1080/09687599.2018.1476224>
- Machlin, S., Cohen, J. W., & Beauregard, K. (2008). Statistical Brief #203: Health Care Expenses for Adults with Chronic Conditions, 2005. *Agency for Healthcare Research and Quality*.
- Mahmood, S. (2005). The Subject of Freedom. In *Politics of Piety* (REV-Revised, pp. 1–39). Princeton University Press; JSTOR. <https://doi.org/10.2307/j.ctvct00cf.7>
- Miles, E. (2020). Biopsychosocial Model. In M. D. Gellman (Ed.), *Encyclopedia of Behavioral Medicine* (pp. 259–260). Springer International Publishing. https://doi.org/10.1007/978-3-030-39903-0_1095

- Nagoshi, J. L., Nagoshi, C. T., & Brzuzy, S. (2014). Feminist and Queer Theories: The Response to the Social Construction of Gender. In J. L. Nagoshi, C. T. Nagoshi, & S. Brzuzy (Eds.), *Gender and Sexual Identity: Transcending Feminist and Queer Theory* (pp. 15–29). Springer. https://doi.org/10.1007/978-1-4614-8966-5_2
- Noonan, A. S., Velasco-Mondragon, H. E., & Wagner, F. A. (2016). Improving the health of African Americans in the USA: An overdue opportunity for social justice. *Public Health Reviews*, 37(1), 12. <https://doi.org/10.1186/s40985-016-0025-4>
- Oldani, M., & Prosen, D. (2021). Trauma-Informed Caring for Native American Patients and Communities Prioritizes Healing, Not Management. *AMA Journal of Ethics*, 23(6), E446-455. <https://doi.org/10.1001/amajethics.2021.446>
- Özkan Tuncay, F., Fertelli, T., & Mollaoğlu, M. (2018). Effects of loneliness on illness perception in persons with a chronic disease. *Journal of Clinical Nursing*, 27(7–8), e1494–e1500. <https://doi.org/10.1111/jocn.14273>
- Peruzzo, F. (2020). I am not disabled: Difference, ethics, critique and refusal of neoliberal academic selves. In N. Brown & J. Leigh (Eds.), *Ableism in Academia* (pp. 31–50). UCL Press. <https://doi.org/10.2307/j.ctv13xprjr.8>
- Pollard, C. (2019, August 26). *Explainer: The ideas of Foucault*. The Conversation. <http://theconversation.com/explainer-the-ideas-of-foucault-99758>
- Powers, J. R., Goodger, B., & Byles, J. E. (2004). Assessment of the abbreviated Duke Social Support Index in a cohort of older Australian women. *Australasian Journal on Ageing*, 23(2), 71–76. <https://doi.org/10.1111/j.1741-6612.2004.00008.x>
- Riessman, C.K.. (1983). Women and Medicalization: A New Perspective. *Social Policy*, 14(1), 3-18. SID. <https://sid.ir/paper/554166/en>

- Riska, E. (2003). Gendering the Medicalization Thesis. In M. Texler Segal, V. Demos, & J. J. Kronenfeld (Eds.), *Gender Perspectives on Health and Medicine* (Vol. 7, pp. 59–87). Emerald Group Publishing Limited. [https://doi.org/10.1016/S1529-2126\(03\)07003-6](https://doi.org/10.1016/S1529-2126(03)07003-6)
- Seidlein, A.-H., & Salloch, S. (2019). Illness and disease: An empirical-ethical viewpoint. *BMC Medical Ethics*, 20(1), 5. <https://doi.org/10.1186/s12910-018-0341-y>
- Smith, K. P., & Christakis, N. A. (2008). Social Networks and Health. *Annual Review of Sociology*, 34(1), 405–429. <https://doi.org/10.1146/annurev.soc.34.040507.134601>
- Strauss, A. L., & Glaser, B. G. (1975). *Chronic illness and the quality of life* (1st ed). Mosby.
- Tajfel, H., & Turner, J. (1979). An integrative theory of intergroup conflict. In *Intergroup relations: Essential readings* (pp. 94–109). Psychology Press.
- Tanta-Quidgeon, K. (2023). *Understanding how the U.S. Healthcare System can Better Serve Indigenous People Through the Lived-Experiences of Five Indigenous Women*.
- Twaddle, A. C. (1968). *Influence and illness: Definitions and definers of illness behavior among older males in Providence, Rhode Island*. [publisher not identified].
<https://catalog.oslri.net/Record/155433>
- Umberson, D., & Karas Montez, J. (2010). Social Relationships and Health: A Flashpoint for Health Policy. *Journal of Health and Social Behavior*, 51(1_suppl), S54–S66.
<https://doi.org/10.1177/0022146510383501>
- United Nations. (n.d.). *Factsheet on Persons with Disabilities | United Nations Enable*. Retrieved March 12, 2022, from
<https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities.html>

- van Gennip, I. E., Pasman, H. R. W., Oosterveld-Vlug, M. G., Willems, D. L., & Onwuteaka-Philipsen, B. D. (2013). The development of a model of dignity in illness based on qualitative interviews with seriously ill patients. *International Journal of Nursing Studies*, 50(8), 1080–1089. <https://doi.org/10.1016/j.ijnurstu.2012.12.014>
- Villarosa, L. (2024, April 11). *Addressing the Crisis in Access and Equity in Health in the United States: How the Stories We Tell Matter*. MacLean Symposium on Narrative Medicine, Colorado College.
- Wardian, J., Robbins, D., Wolfersteig, W., Johnson, T., & Dustman, P. (2013). Validation of the DSSI-10 to Measure Social Support in a General Population. *Research on Social Work Practice*, 23. <https://doi.org/10.1177/1049731512464582>
- Weisstein, N. (1993). Psychology Constructs the Female; or the Fantasy Life of the Male Psychologist (with Some Attention to the Fantasies of his Friends, the Male Biologist and the Male Anthropologist). *Feminism & Psychology*, 3(2), 194–210. <https://doi.org/10.1177/0959353593032005>
- White, K. (2017). Medical Model of Illness. In *The Wiley-Blackwell Encyclopedia of Social Theory* (pp. 1–2). John Wiley & Sons, Ltd. <https://doi.org/10.1002/9781118430873.est0240>
- Woods, A., Solomonov, N., Liles, B., Guillod, A., Kales, H. C., & Sirey, J. A. (2021). Perceived Social Support and Interpersonal Functioning as Predictors of Treatment Response Among Depressed Older Adults. *The American Journal of Geriatric Psychiatry : Official Journal of the American Association for Geriatric Psychiatry*, 29(8), 843–852. <https://doi.org/10.1016/j.jagp.2020.12.021>

Woolf, S. H., & Braveman, P. (2011). Where Health Disparities Begin: The Role Of Social And Economic Determinants—And Why Current Policies May Make Matters Worse. *Health Affairs*, 30(10), 1852–1859. <https://doi.org/10.1377/hlthaff.2011.0685>

World Health Organization. (n.d.). *Disability*. Retrieved May 28, 2023, from <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>

Appendix A Recruitment Email.

Dear Fit 4 Lifer's!

My name is Lane Nelson, and many of you may remember me from this summer, where I assisted with XXXX XXXXXX's human cardiac function and balance research! I was their extra pair of hands, placing electrodes and running computers. If you joined us in the lab, you may also remember hearing my spiel about my personal interest in the sociocultural components of aging and illness. I am continuing to explore this interest in my next project: my senior thesis.

So, this email serves to officially reach out and invite you to participate in a new research project, an investigation into the cyclical interplay of both social and biological aspects involved within the experience of illness among older adults. The purpose of the research is to understand and document this interplay and fill gaps in the associated literature that lack perspectives from older adults. The only eligibility criteria for participation is that you are above the age of 65.

Participation will include the completion of two short surveys and an interview, all of which will be conducted in a singular, 1.5-hour session. You can expect me to ask you broad questions about your health, wellbeing, social life, and personal integration, but this is intended to be a conversation first! I have personal experiences with illness and how we all come to understand it, and my goal is to empathetically and holistically engage with your perspective. You can also expect to see me stopping by your regularly scheduled Fit4Life classes, where I will be participating and generally observing. If you are interested in completing only the survey portion of the research and not the interview portion, that is also a helpful possibility.

Due to the vulnerable nature of this research and the heaviness of the topics covered within in, including health, illness, and loneliness, there comes a potential risk for emotional discomfort and stress for each participant. However, I will take every reasonable measure to ensure that you feel comfortable and supported during the research process, and I am more than happy to provide accommodations at your request. The primary benefits to participating in this study is to expand the associated field of knowledge. There is a lack of research that incorporates the perspective of older adults within this field, and your inclusion can help to fill this gap.

So, I would love to hear from each of you, regardless of your decision to participate or not! And as a reminder, your participation in this research is entirely voluntary. You may decide to not participate or stop participating at any time without penalty. You do not have to have any previous involvement in any previous studies, and this study will not impact your participation or eligibility for any current or future studies.

For more information, or to sign up, contact me via email or cell phone (given below). I will be scheduling participants between November 1st and November 15th, at either an 8-9:30am or a 10-11:30am time slot. I will be available for some afternoons too. If none of these times work for you, please reach out, and I will be more than happy to find a time that does!
My information is as follows:

Lane Nelson, Critical Illness Studies Major, Class of 2024
Colorado College Departments of Human Biology & Kinesiology and Anthropology
XXX-XXX-XXXX, X_XXXXXX@coloradocollege.edu

I look forward to talking with many of you again, and hopefully seeing some new faces!

All the best,
Lane Nelson

Critical Illness Studies Thesis Research: Consent Form

Primary Investigator: Lane Nelson
Colorado College Department of Human Biology & Kinesiology + Anthropology
[REDACTED], l_nelson@coloradocollege.edu
Research supported by Colorado College's Independently Designed Major.

Supervisors: Eryn Murphy, PhD, Assistant Professor of Human Biology & Kinesiology
[REDACTED], emurphy@coloradocollege.edu
Krista Fish, PhD, Associate Professor and Chair of Anthropology Department
[REDACTED], kfish@coloradocollege.edu

Key information about this research study

The following is a short summary of this study to help you decide whether to be a part of the study. More detailed information is provided later in the form.

You are invited to take part in a research study aimed to investigate the cyclical interplay of both social and biological aspects involved within the experience of illness among older adults, specifically concerning loneliness.

What is the purpose of the study? The purpose of this study is to understand and document the interplay between cultural and social elements of a person's life and a biomedical diagnosis of disease, filling gaps in the associated literature that lack perspectives from older adults.

What will you be asked to do if you participate in the study? If you choose to participate, we will meet only once, and you will be asked to complete the following components:

- A brief health history survey
- A social support survey (the Duke Social Support Index)
- An in-depth interview, covering topics from social support and loneliness to health history and its personal impacts. I will come prepared with a common list of guiding questions, but I will pursue follow-up questions throughout the interview, tailored to each individual, that I determine to be relevant to the focus of the study. You may refuse to answer any questions with no penalty, and are encouraged to ask questions of your own!

Some individuals may be asked to complete only the survey portion of this study. If this applies to you, please disregard all information that has to do with the interview portion. Copies of the two surveys may be provided to you in a different manner than described in this form.

How long will it take you to participate in the study? It is estimated that it will take you between 1-1.5 hours to participate in this research. You will be scheduled for a 1.5-hour time slot, but there is no expectation that we must fill all of that time. If this time is not sufficient for you to share all that you would like to, we may go past time (if I am available) or you may sign up for an additional time slot.

What are reasons you might choose to volunteer for this study? The primary benefits to participating in this study is to expand the associated field of knowledge. There is a lack of research that incorporates the perspective of older adults within this field, and your participation can help to fill this gap and contribute to more holistic understandings of health, wellness, and illness. Ideally, clinicians can incorporate these testimonies regarding social support to create better and more holistic understandings (and treatments) surrounding health.

What are reasons you might choose not to volunteer for this study? Due to the vulnerable nature of this research and the heaviness of the topics covered within it, there comes a potential risk for emotional discomfort and stress. I will take every reasonable measure to ensure that you feel comfortable and supported, but I cannot mitigate all negative emotions that sometimes accompany self-expression about personal and deep topics. However, I expect this conversation to spark meaningful and deep reflection rather than simply negative emotions.

Do you have to take part in the study? Taking part in this study is completely voluntary. You should only decide to take part in the study because you want to do so. If you choose to be involved in the study, you can withdraw at any time without consequences of any kind. All surveys are self-reported, and you can withhold responses to any survey or interview question without penalty. Participating in this study does not mean that you are giving up any of your legal rights.

What if you have questions, suggestions, or concerns? The person in charge of this study is Lane Nelson. If you have questions about the research or your experience participating in this study, please contact Lane Nelson or her supervisors.

Lane Nelson, Critical Illness Studies Major, Class of 2024
Colorado College Departments of Human Biology & Kinesiology and Anthropology
~~910-227-1600~~, l_nelson@coloradocollege.edu

If you have any questions about whether you have been treated in an illegal or unethical way, contact the Colorado College Institutional Research Board chair, Dr. Amanda Udis-Kessler at ~~910-227-0177~~ or audiskessler@coloradocollege.edu.

Detailed information about this research study

Why are you being asked to take part in this research study? You are being asked to take part in this study due to your identity as an adult over the age of 65. Your participation is warmly welcomed regardless of any formal or informal health diagnoses.

What is the purpose of this study? The purpose of this study is to understand and document the cultural and social components that accompany the biomedical experience, specifically concerning how social groups are formed and personal identities are constructed/reconstructed among those who are chronically ill. Research within this field typically lacks perspectives from older adults, so this study aims to address this gap and challenge the directionality of pre-existing research, correcting the failure of the field to acknowledge the cyclical interplay of both social and biological factors.

What will you be asked to do if you participate in the study? Upon your arrival, you will be asked to first complete the following components:

- A brief health history survey
- A social support survey (the Duke Social Support Index)

The remainder of the time will be spent engaging in an ethnographic-style interview, meaning that the questions I ask will be descriptive and structural, allowing for you to describe your experiences, daily activities, feelings, and people in your life. I will come prepared with a common list of guiding questions, but I will pursue follow-up questions throughout the interview, tailored to each individual, that I determine to be relevant to the focus of the study. If at any point you do not want to answer a question or would like to ask questions of your own, you are free to do so with absolutely no penalty.

Audio from this interview will be recorded on a tape recorder, and I will take notes throughout. If you would like specific responses to not be recorded, I will honor these requests and strike all information from the record with no penalty. Your explicit consent for the collection of audio recordings will be requested at the end of this consent form. Of course, you may decline to have audio recordings collected at all, also with no penalty.

The study will take place in the Human Biology and Kinesiology Department's conference room. This is located in Olin Hall on Colorado College's Campus in room 210. This room is in the Olin Annex (Fishbowl), located on the West side of Olin Hall, just North of Shove Chapel. The Olin Annex is connected to Olin Hall via a short Sky Bridge on the West side. There are outdoor, concrete steps below the skybridge that will lead you straight to the Olin Annex. Even though the school year is underway, it may be possible that the doors around the building will be locked. I will be looking out to guide you to the space once you reach the Olin Annex.

You will receive an email with the specific details of your time slot, confirming exactly when you will come in. This email will also include notifications if any changes are made to the meeting location described above.

Will you be told everything about what is happening to you and about what you will be asked to do in the study? This study does not involve any deception. This consent form describes exactly what you will do and what will happen to you in the study.

How long will it take you to participate in the study? Due to individuals' differences in experience and willingness to share, the time it will take to participate in the study can be highly variable. Each participant will be scheduled for a 1.5-hour time slot, but there is no expectation that we must fill all that time. The surveys should take approximately 15 minutes, and we will then talk until you feel you are ready to stop, or until I have exhausted all guiding and follow-up questions. If this time is not sufficient for you to share all that you would like to, you may stay slightly longer (if I am available) or you may sign up for an additional time slot. This time estimation does not include the time it may take to park and make your way to the meeting space.

With whom will you interact during the study? Lane Nelson is a current senior at Colorado College pursuing an Independently Designed Major (IDM) in Critical Illness Studies. This research is primarily working towards her scholarly activity, specifically her senior thesis, and she will thus be the person you most frequently interact with during this study.

Interviews will be conducted on the campus of a small college, and it is therefore possible that participants may interact with other members of the campus community on their way to and from the meeting space. However, no one else will be present for the interview session, and all responses to survey or interview questions will remain protected and confidential.

Is there any way that being in this study could cause you harm or discomfort? Again, due to the vulnerable nature of this research and the heaviness of the topics covered within in, there comes a potential risk for emotional discomfort and stress for each participant. The discussion of personal experiences and feelings surrounding health, illness, and loneliness can be difficult for many and may spark some negative emotions. I will take every reasonable measure to ensure that you feel comfortable and supported during the research process, and I am more than happy to provide accommodations at your request. However, I expect this conversation to spark meaningful and deep reflection rather than simply negative emotions.

Are there any ways that being in this study will benefit you? There will be no explicit benefits to you as a participant, meaning there will be no monetary or other kind of compensation. However, I hope that all participants can meaningfully engage with self-conceptions of their own health in this safe environment, potentially reshaping their mindsets or simply finding comfort in sharing their perspectives to a listening ear.

Who will know about your participation in this research, or about what you said or did in the research? This study will take significant precautions to ensure your anonymity is protected due to the sensitive and personal nature of the topics being discussed and the information being collected. Your name will be used within this document and as part of the two surveys that are administered at the beginning of the data collection process. Additionally, you will state your name for the audio recording, but these recordings will be destroyed after transcription. The use of your name is solely to match the results of the surveys with your interview responses so as not to confuse participants' data.

As this information is transcribed and/or entered into an electronic data organization software, your name will be removed and replaced with a pseudonym, de-identifying the data. This electronic information will be stored on a password-protected personal laptop, even though your name will have been removed from it. A master list that ties pseudonyms to participants' real names will be generated. Two copies of this list will be stored: a physical copy and an electronic copy. The electronic copy will be stored separately from the data itself on a personal laptop under password protection. The physical copy will be stored with other physical documents that contain your name, including the intake surveys and copies of this consent form, in a locked room that only the primary investigator and her supervisors have access to. Any report of this research that is made available to the public will not include your name or any other individual information by which you could be identified unless you have specifically given permission to be identified publicly.

I will be the primary researcher with access to your confidential data. The only other individuals who might see your information for any reason as part of the research process are my supervisors, Dr. Eryn Murphy and Dr. Krista Fish.

This research involves a relatively small number of participants, meaning that it is potentially more likely, though still generally not probable, that you might be identified. Anywhere from 5-20 people will participate, but all possible measures to protect your anonymity will be taken.

What will happen to your information after this study is over? The collected and de-identified electronic copies of all research data will be archived and stored on the primary researcher's password-protected laptop. All identifying documents (which include the paper survey and the master list), along with the audio recordings, will be shredded/deleted at the end of this academic year. Consent forms will be filed for at least one year.

Your research information will not be shared with other researchers.

What happens if you do not want to participate in this study? Participation in this research is entirely voluntary. If you no longer wish to participate, please immediately inform the primary researcher, Lane Nelson. There will be no consequences for choosing not to participate.

What happens if you start to participate in the study but change your mind? If at any point during the research process you decide that you no longer wish to participate in this study, you may freely withdraw. There will be no penalty for withdrawing and such action will not be held against you. Your inclusion status will remain confidential, and you will not be excluded from future research opportunities that engage with the Fit 4 Life group. All of the data and testimony collected from you will be deleted and

removed from the study at your request. Please contact the primary researcher, Lane Nelson, directly if you decide to leave the study.

What happens if you participate in the study and get injured or have other problems as a result of your participation? It is extremely unlikely that your participation in this research will result in physical, psychological, or other forms of harm. However, due to the heavy nature of the topics being discussed, it is possible that some emotional discomfort or stress may result. If you feel you need additional support, do not hesitate to reach out to the primary researcher, Lane Nelson, or her supervisors as soon as possible.

Who can you talk to if you have questions about the study? If you have questions about the study or your participation in it, please contact Lane Nelson or her supervisors using the contact information provided at the top of this form. We warmly welcome all questions, so please do not hesitate to reach out.

If you have any questions about whether you have been treated in an illegal or unethical way, contact the Colorado College Institutional Research Board chair, Dr. Amanda Udis-Kessler at [REDACTED] or audiskessler@coloradocollege.edu.

Dr. Udis-Kessler can be reached by mail at the following address:

Dr. Amanda Udis-Kessler, IRB Chair
Colorado College
14 E. Cache la Poudre Street
Colorado Springs, CO 80903

Statement of Consent to Participate: I have read the above information, and have received answers to any questions. If I have more questions later, I have been told who to contact. By signing this document, I affirm that I am 18 years of age or older and I consent to take part in Lane Nelson's thesis research study. I understand that I will be given a copy of this form to keep for my records.

Participant's Signature

Participant's Printed Name

Date

This research involves audio recording. Check one of the following options.

_____ I agree that my participation in the study may be audio recorded.

_____ I do not agree that my participation in the study may be audio recorded but I am willing to participate if audio recording is not used.

Indicate here if you will be completing only the survey portion of this study, and not the interview portion. Disregard this section if you will be completing both.

_____ I am only providing responses to the two surveys and will not be completing the formal interview process. I understand that all information within this form that details the interview process does not apply to me.

I, Lane Nelson, have explained the study to the participant and have answered all of their questions. I believe that they understand the information described in this consent form and that they freely consent to be in the study.

Researcher's Signature

Researcher's Printed Name

Date

Appendix C

INDEPENDENTLY DESIGNED MAJOR IN CRITICAL ILLNESS STUDIES: SENIOR THESIS
Health History Form.

Date:	Time	Notes
Participant Name		
Informed Consent Complete	Y / N	Investigator initials:
Consent to Audio Recording?	Y / N	Investigator Initials:
Birthday		Age

HEALTH HISTORY
Please mark if you ever experienced or been diagnosed with any of the following: Please describe if relevant
<input type="checkbox"/> Hypertension
<input type="checkbox"/> Heart Attack
<input type="checkbox"/> Heart Arrhythmia (A-fib, heart block, "PVC's")
<input type="checkbox"/> High Cholesterol
<input type="checkbox"/> Peripheral Arterial Disease
<input type="checkbox"/> Stroke or "Mini Stroke" (including TIA)
Do you currently have any other medical diagnosis?
Are you currently being treated for any medical concerns?
If you are currently prescribed any medication, what is it for?

(for researcher only)

Assigned Pseudonym

Survey Only? Y / N

Appendix D

INDEPENDENTLY DESIGNED MAJOR IN CRITICAL ILLNESS STUDIES: SENIOR THESIS

Name _____

Date _____

Duke Social Support Index

Researcher
Score

Answer the following questions:

1 Other than members of your family how many persons in your local area do you feel you can depend on or feel very close to?

- 1. None**
- 2. 1-2 people**
- 3. More than 2 people**

2 How many times during the past week did you spend time with someone who does not live with you, that is, you went to see them or they came to visit you or you went out together?

3 How many times did you talk to someone (friends, relatives or others) on the telephone in the past week (either they called you, or you called them)?

4 About how often did you go to meetings of clubs, religious meetings, or other groups that you belong to in the past week?

5 Does it seem that your family and friends (people who are important to you) understand you?

- 1. Hardly ever**
- 2. Some of the time**
- 3. Most of the time**

6 Do you feel useful to your family and friends (people important to you)?

- 1. Hardly ever**
- 2. Some of the time**
- 3. Most of the time**

7 Do you know what is going on with your family and friends?

- 1. Hardly ever**
- 2. Some of the time**
- 3. Most of the time**

8 When you are talking with your family and friends, do you feel you are being listened to?

- 1. Hardly ever**
- 2. Some of the time**
- 3. Most of the time**

9 Do you feel you have a definite role (place) in your family and among your friends?

- 1. Hardly ever**
- 2. Some of the time**
- 3. Most of the time**

10 Can you talk about your deepest problems with at least some of your family and friends?

- 1. Hardly ever**
- 2. Some of the time**
- 3. Most of the time**

11 How satisfied are you with the kinds of relationships you have with your family and friends?

- 1. Very dissatisfied**
- 2. Somewhat dissatisfied**
- 3. Satisfied**

Any additional notes: _____

(for researcher only)

Assigned Pseudonym

Survey Only?

Y / N

Appendix E

Interview Question Template.

These questions are a template, not a script – I am expecting to deviate from this list, tailoring the interview process to each individual and their insight. The subject of focus (health, illness, loneliness) will remain the same, but I will pursue any line of questioning that I deem relevant which continues to follow ethical guidelines.

Make sure they are comfortable – offer coffee, tea, snacks, etc. Create a nice space!

Open with a short blurb about my experience.

- I was diagnosed with Crohn’s disease in high school – underwent treatment and was involved in an illness-based group.
 - o It was an isolating experience. I felt like I wasn’t happy enough to be adding to the social groups I was a part of - and was therefore burdensome, bringing feelings of guilt for simply being sick around friends and family. I was lonely.
 - o Being sick made me question my identity and reshape it around some new objective truth that I have no choice in creating. I felt trapped by the stereotype of a “sick person” I was surrounded by (society creates expectations, embodied by the people around me and myself) – there was no room for how I was actually feeling, frustrated and alone.
- I have experience with and empathy for being unwell, in whatever form it may present itself.
- Your experiences do not have to align with mine – everyone experiences health differently.

Now, questions:

- Do you have any immediate reactions? Does anything I said sound familiar or totally opposite to your experiences?
- Tell me about your health. I know this question is broad, but what comes to mind? What does health mean to you? (vs. illness?)
 - o Have you had any ups or downs in your health?
 - o How have you addressed these fluctuations?
 - o How have the people in your life responded to these fluctuations?
 - o How have these fluctuations impacted you?
- What have your interactions with the medical system looked like?
 - o Were you the patient, or was a close friend/family member/spouse the patient?
 - o Were your experiences positive/negative? Have they created better health?
 - o Did you have people to accompany you throughout this process? Did you have friends and family present?
 - o How was having or not having company while undergoing a medical diagnosis/treatment/appointment/etc.?
- Tell me about your social sphere. Do you feel connected and involved?

- Who are you closest too? Do you feel understood?
 - Not just in Fit4Life, but generally? With other friends and family?
 - Has illness changed that social sphere? And in what ways?
 - Do you feel, or have you ever felt, lonely?
- Do any other pieces of information or experiences seem relevant for you to share with me?
 - Do you have any questions for me?

To end:

- As a standard for this study, all responses will be entirely anonymous and your contributions will be recorded under a pseudonym. Your identity and participation will be confidential unless you specifically request for your name to be published. Do you understand?
- If you know anyone else that would be interested in participating in this study, I am open to more participants, and you are more than welcome to pass my information along to them.
- I will, or may have already, stopped by the Fit4Life class to do a bit of observing. I am always interested in spending time with the group and seeing how you all spend time together. Please reach out to me if you get together outside of class and you feel comfortable with my addition!

And then a BIG thank you.