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WISDOM NARRATIVES: COMMUNICATED SENSE-MAKING IN
EMERGING ADULTHOOD AUTOIMMUNE DISEASE

By

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WISDOM NARRATIVES: COMMUNICATED SENSE-MAKING IN
EMERGING ADULTHOOD AUTOIMMUNE DISEASE

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University of Nebraska, 2021

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Under the umbrellas of Communicated Sense-making (CSM, Koenig Kellas & Kranstuber Horstman, 2015), the current study explored 25 stories of illness told by assigned female at birth individuals with autoimmune disease. Using both the Theory of Memorable Messages (ToMM, Cooke-Jackson & Rubinsky, 2021) and Communicated Narrative Sense-making Theory (CNSM, Koenig Kellas, 2018), findings reveal helpful and harmful interpersonal memorable messages received across their illness journeys, as well as lessons learned and wisdom gained from disruptive chronic illness onset at a young age. Participants identified messages of belief, support, and interest as helpful while navigating disease, whereas they saw messages of dismissal, blame, and presumed psychosis as unhelpful or negative. The lessons learned from participants' illness stories (wisdom narratives) revolved around themes such as separating self from illness, creating and committing to new normals, renewing trust in self, increased empathy, and recognition of privilege and disparities in health care. Findings illuminate how to effectively support emerging adults navigating invisible, chronic illness. Limitations and directions for future research are discussed.

TABLE OF CONTENTS

Dedication and Acknowledgements	5
Chapter 1: Introduction and Rationale	7
Biographical disruption in emerging adulthood autoimmune disease onset	10
Communicated sense-making in health disruption	15
Memorable messages	17
Communicated narrative sense-making	24
Chapter 2: Methods and Procedures	29
Participants	29
Procedures	30
Data analysis	31
Chapter 3: Findings	34
Harmful messages amidst an emerging adulthood illness journey	35
“It’s all in your head”	35
“But you look healthy”	39
Messages of blame	40
Messages of dismissal	42
Helpful messages amidst an emerging adulthood illness journey	43
“I believe you. You are not alone.”	44
“Help me understand.”	47
Messages that give medical agency	48
Wisdom and lessons learned from stories of illness	51

Separating self from illness	53
Creating and committing to new “normals”	55
Rediscovering trust in self	58
Increased empathy for others	60
Recognition of privilege and disparities in medical care	62
Chapter 4: Discussion	65
“I know [it’s] coming from a place of caring, but it feels dismissive:”	
Balancing mixed messages	66
Negatively valenced messages	67
Positively valenced messages	70
“I’m going to move forward with a good life:” Wisdom and lessons learned from stories of illness	72
Limitations and future research	75
Conclusion	78
References	80
Appendices	92

Dedication

This project is dedicated to those navigating undiagnosed, invisible chronic illness and pain. Like the individuals whose vulnerable stories make up this thesis, my illness journey has tested my sense of and trust in self, relationships, and belief systems. Like poetry, my six-year diagnostic journey unfolded alongside this study, concluding the day my data collection was complete. In August 2019, I entered into University of Nebraska – Lincoln with a post-viral fatigue syndrome diagnosis. In December 2019, I was diagnosed with undifferentiated connective tissue disease. In February 2021, my diagnosis evolved to Systemic Lupus Erythematosus. To anyone reading this with undiagnosed illness: never stop advocating for your health and your access to compassionate, competent, and validating medical care. No one knows the intricacies of your body's functioning better than you and no, it isn't all in your head.

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“Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place” (Sontag, 1989, p. 3).

CHAPTER ONE: INTRODUCTION AND RATIONALE

“One day I woke up and I had this low-grade pain in my lower back and it's one of the few things I think about that I get really emotional about. I had the last pain free day of my life and I didn't even appreciate it. Like there was that one day where I wasn't chronically ill. I just ate my dinner and ate my breakfast and didn't think about pain and fatigue. I think about that a lot. That your life can just change like that in a single night and [I wonder]: What was my body up to? What was it doing? Was there one thing I did that one day that made all this happen?” –

Participant 3

I often describe it as a snap. One day I was a seemingly healthy twenty-one-year-old, and the next a storm cloud of brain fog, bone aching fatigue, and confusion blew in, and suddenly I was not. It would take five years and eleven doctors before I had a diagnosis. Visits to medical providers left me with a round chorus of “it’s all in your head,” a psychogenic diagnosis that most women and assigned female at birth (AFAB) individuals can attest to being given at least once, rooted in a rich history of the “hysterical” female patient (Dusenbury, 2018).

I have received a lot of messages on my illness journey— *“it’s all in your head,”* *“the doctor cannot help you anymore,”* *“you are always tired...”* the list goes on and on. But a message that stood out above them all was one I received at the acute onset of my disease; a stage when I was still pushing through, working overtime to conceal and perform “health” and the pre-illness self I sought to return to— *“Jacqueline only seems to not feel well when she does not want to do something.”* This one comment, which was shared with a loved one who then passed it along to me, shaped how I interacted with my

friends, family, strangers, co-workers, everyone from that day forward. It taught me to conceal, to hide what I was feeling, to perform for others, even when it was of detriment to me. It made me feel alone, and it made me feel guilty for being sick – like it was my fault; like there was something more I could be doing to fix it.

My story is not new. It is not unusual, or niche, or surprising even. Sit with any female-identifying individual with an invisible chronic illness, diagnosed or undiagnosed, and you will hear their stories of things that were said to them— memorable messages that they received from medical practitioners, friends, family members, social network members, or the media, just to name a few. These formative conversations during their illness journeys impacted the development of their identity and health behaviors.

Communicated sense-making (CSM, Koenig Kellas & Kranstuber Horstman, 2015) is integral to an individual's coping and well-being amidst difficulty, health challenges, and life disruptions. The onset of illness is especially disruptive when it occurs during emerging adulthood, a time characterized by identity formation and construction of self (Luyckx et al., 2008). This is particularly true in the case of autoimmune diseases, as they are unclear, unexpected, and often difficult to diagnose, which presents unique challenges that emerging adults with illness and few others can understand. Additionally, in instances of autoimmunity, the body itself becomes both the attacker and the attacked, blurring the lines between what is disease, what is body, and what is self, introducing multiple layers of sense-making. CSM is, therefore, critical during this time.

Through the framework of communicated sense-making (CSM, Koenig Kellas & Kranstuber Horstman, 2015), the theory of memorable messages (ToMM, Cooke-Jackson

& Rubinsky, 2021) and communicated narrative sense-making theory (CNSM, Koenig Kellas, 2018), I seek to investigate the memorable messages AFAB emerging adults with autoimmune disease receive during their diagnostic journeys, as well as the meanings, values, and beliefs that emerge from their illness narratives. The literature on communicated narrative sense-making and memorable messages in the face of health disruptions is impactful and translational, as these interpersonal conversations have the power to shape how we socialize individuals to understand their health behaviors and identities (Gunning, Rubinsky, & Cooke-Jackson, 2019). CSM impacts health management behaviors, selective disclosure and concealment, shapes belief and value systems, identity formation, and how individuals view their bodies and roles in society (Cooke-Jackson & Rubinsky, 2018; Gunning, Rubinsky, & Cooke-Jackson, 2019; Kerr, Thompson, & Rubinsky, 2019; Rubinsky, Hosek, & Hudak, 2018; Stone, 2019). Despite this foundation of research, we know little about CSM in the face of chronic illness, which likely requires differing sense-making communication, intervention, and identity reconstruction than other illness contexts because of its long-term, often evolving nature and impact across the life course.

Moreover, limited research has explored the chronic illness narratives of young adults, specifically, and when explored has most often been from the perspective of the parent, caretaker, or medical practitioner (Wicks, Berger, & Camic, 2019). In the current investigation, it is my goal to not only identify the interpersonal conversations and messages that this population recalls, but also those they *wish* they had heard, in an effort to create a translational guide for medical practitioners, family members, friends, and social support network members that instructs what interpersonal messages best support

emerging adults navigating a chronic illness diagnosis. I will begin by detailing the disruptive biographical impact of illness onset in emerging adulthood and the role agents of communicated sense-making can play in helping individuals process and cope amidst disruptive health experiences. Using ToMM (Cooke-Jackson & Rubinsky, 2021) and CNSM (Koenig Kellas, 2018), in the remainder of this chapter I argue that the juxtaposition of memorable messages and illness narratives offers a broad picture of CSM in the context of autoimmune disease and emerging adulthood illness onset, for it looks at both the messages individuals *hear* and the stories they *tell* (Koenig Kellas, 2018). In chapter 2, I propose my methods for conducting a study that seeks to explore messages received and meanings, values, and beliefs assigned to this illness experience. In chapter 3, I discuss my findings of this study as it relates to the harmful and helpful messages that this population receives, as well as the lessons they learned from their illness experiences. Finally, in chapter 4, I discuss theoretical implications and opportunities for future research as it relates to supporting emerging adults navigating chronic illness.

Biographical Disruption in Emerging Adulthood Autoimmune Disease Onset

The onset of autoimmune disease brings with it adverse physical and emotional repercussions, identity and relational disturbances, as well as a forced re-evaluation of individual priorities, values, and belief systems (Castle, 2015; Price & Walker, 2014; Wilson & Stock, 2019). Autoimmune diseases are chronic health conditions that cause the immune system to produce antibodies that attack and destroy healthy, normal body tissues, detecting these parts or processes of the body as disease (AAAI, 2020). There are over eighty autoimmune diseases, many with similar symptoms, which makes diagnosing

autoimmune disease especially difficult. Common symptoms include fatigue, joint pain, fever, dizziness, and cyclical flares of increased disease activity, caused by environmental-based sources like exposure to sunlight, stress, or hormonal changes (OWH, 2020). Because of this connection between disease activity and hormonal changes, AFAB individuals of childbearing age are at higher risk of developing autoimmune disease, making up 78% of autoimmune disease diagnoses (Fairweather et al., 2008; OWH, 2020). Because of this, I am constraining my population for the present study to AFAB individuals.

The impact of autoimmune disease is especially disruptive for AFAB individuals when onset occurs during emerging adulthood, the stage of life that includes the most developmental change (Williams, Holmbeck, & Greenley, 2002). During this time, emerging adults begin to form individual identity and social autonomy, as well as explore and orient themselves toward the future (Christie & Viner, 2005; Kroeger, 2004). Being diagnosed with chronic illness during emerging adulthood has implications on an individual's development of identity and biography, relationships, sense-making structures, trust in the medical system, and orientation toward the future (Charmaz, 2002; Edwards, 2008). Navigating these changes alongside a chronic condition presents a unique challenge for emerging adults, resulting in difficulty coping emotionally, an increased risk of developing depression and other psychological disorders (Huurre & Aro, 2002; Knight, Trupin, Katz, Yelin, & Lawson, 2018), and susceptibility to educational disengagement (Hopkins, Green, Henry, Edwards, & Wong, 2014). This creates significant barriers to individual psychosocial wellbeing and disease management (Knight et al., 2018).

The journey to autoimmune disease diagnosis is tumultuous, shaded with dismissal, invalidation, and misdiagnosis. On average, it takes an autoimmune patient seeing four doctors over the course of four years to be diagnosed and treated for an autoimmune condition (AARDA, 2017). Over this four-year journey, the majority of autoimmune patients are misdiagnosed and told that symptoms are “in their heads,” with 45% of these patients labeled as chronic complainers (AARDA, 2017). This makes an already challenging diagnostic journey that much more difficult, for repeated ambiguous, indecisive, or dismissive experiences and messages by medical providers teach individuals not to trust their diagnoses, their lived experiences, or their bodies, thrusting them into “diagnostic vertigo” (Crimlisk & Ron, 1999; Price & Walker, 2014). This has particularly detrimental implications for emerging adults, whose “identity reconstruction process is more complex and psychologically damaging... as this life stage is culturally associated with health/vitality and experiencing illness marks a biographical shift from a perceived normal trajectory” (Wilson & Stock, 2019, p. 1111, 1118).

AFAB individuals have an added layer of difficulty, uncertainty, and illness identity ambiguity to bear, as these individuals are more likely to be assigned a psychogenic diagnosis, have prior diagnoses dismissed, and have their medication under prescribed or withheld entirely by healthcare providers (Crimlisk & Ron, 1999; Norman, 2018). This is rooted in a sordid history of the presumed “hysterical” female patient, a diagnosis that can be traced to the middle ages (Dusenbury, 2018). With the development of health and illness identity intrinsically tied to diagnosis (Kirk & Hinton, 2018; Wicks, Berger & Camic, 2018), an inability to root identity in a specified illness impedes individual sensemaking abilities and development of individual identity (Price & Walker,

2014). This disorienting experience is captured by Meghan O'Rourke's (2013) retrospective editorial narrative of her years-long autoimmune diagnostic journey, which illustrates,

It wasn't just that I suffered brain fog... and it wasn't just the 'loss of self' that sociologists talk about in connection with chronic illness, where everything you know about yourself disappears, and you have to build a different life. It was that I no longer had the sense that I was a distinct person... To be sick in this way is to have the unpleasant feeling that you are impersonating yourself. When you're sick, the act of living is more act than living.

The adverse impact of chronic illness on sense-making and identity in young adulthood was further explored by Wilson & Stock (2019) whose study examined the impact of long-term chronic health conditions on young adults' mental health and identity formation, as well as what sense-making and resilience practices help them live well amidst the disruptions. Findings indicated that impact on mental health and identity include negative mood, depression, anxiety, fear for the future, and young adults' comparison of their former "well" self and "normal" others to their now "ill" or "abnormal" identity (Wilson & Stock, 2019, p. 1115). However, from these disruptions and losses, young adults with long-term health conditions noted the use of positive thinking (focusing on what they are able to do), celebrating good days and small achievements, as well as acceptance of their limitations and changed identity and lifestyle as instrumental to their coping processes (Wilson & Stock, 2019). Wilson & Stock (2019) focus heavily on participants' comparisons between "former 'well'/'healthy' self and their current 'ill'/'sick' self," as well as "distressing comparisons between 'normal'

others and ‘abnormal’ selves due to societal expectations about young adulthood” (p. 1118-1119). A call for research exploring this tension as it relates to communication is extended by Palmer-Wackerly & Voorhees (2020), who ask health communication scholars to explore “how, when, and why people shift back and forth from considering themselves as ‘healthy’ to identifying as ‘ill,’ and what effects these shifts may have on their identity, relationships, and overall wellbeing” (p. 13). As autoimmune diseases are characterized by cyclical flares in which patients experience increases, and subsequent decreases, in disease activity, AFAB patients are a fitting population to study the alternating tension between ‘healthy’ and ‘ill’ identities. Narrowing this population further to emerging adulthood adds an additional layer of identity complexity, as these individuals are still forming ‘ill’ and ‘healthy’ identities, as opposed to older populations who may integrate an ‘ill’ identity into their already formed identities.

Research findings can aid in identifying strategies and opportunities for intervention that support young and emerging adults navigating chronic illness. Wilson & Stock (2019) emphasize the need for multi-disciplinary support in helping young adults with chronic illness cope with “loss of normality, change in identity... mental health implications” and reaching acceptance (p. 1119). This is echoed by Palmer-Wackerly & Voorhees (2020) who call for work that helps individuals navigating illness “understand that ‘illness’ can be experienced in different, multiple, and contradictory ways and to [give space] to grieve their losses, negotiate new meanings about illness and health, and find new relationships and identities, thus improving their relationships and quality of life” (p. 13). Young adult AFAB individuals likely need space to communicatively make sense of their illness identity. Thus, I turn next to literature on communicated sense-

making and memorable messages in an effort to extend an understanding of interpersonal conversations that may aid in coping processes surrounding chronic illness, as well as continue to add to “the sparse qualitative research with young adults which explore similarities in experiences and management strategies across conditions” (Wilson & Stock, 2019, p. 1118).

Communicated Sense-making in Health Disruption

Communicated sense-making (CSM) is a theoretical model introduced by Koenig Kellas & Kranstuber Horstman (2015) that offers a guiding framework for how individuals process and make sense of difficulty, identity, and relationships through communication. Under this framework, six devices for communicated sense-making are offered, including accounts, attributions, communicated narrative sense-making, metaphors, memorable messages, and communicated perspective-taking. Each device offers a unique approach to understanding the role of communication in sense-making “surrounding difficult, confusing, or complex situations and experiences, such as mental health and illness” (Koenig Kellas & Kranstuber Horstman, 2015, p. 32). Thus, CSM offers a fitting framework for analyzing the illness narratives and memorable messages of emerging adult AFAB individuals navigating the disruption of autoimmune disease onset.

CSM has been used by health and interpersonal communication scholars to look at the role interpersonal conversations play in resilience, well-being, and behaviors in situations of difficulty, illness, and health challenges. Flood-Grady & Koenig Kellas (2018), for example, explored CSM in the context of mental illness, finding that the stories families tell about mental illness include lessons for younger members about how to manage and view mental illness. Horstman & Homan (2017) examined the effects of

communicated perspective-taking (CPT) on relational partners' well-being following miscarriage, noting a connection between CPT ability and relational satisfaction. This research was extended through the exploration of metaphors in the context of miscarriage, with findings indicating that metaphors are an effective sense-making device for individuals, relational partners, and medical practitioners in illustrating and evoking support in instances of illness and loss (Holman & Kranstuber Horstman, 2019; Kranstuber Horstman, Horstman, & McBride, 2017). These studies provide practical, common language that can be used with patients and families who are navigating a disruptive health experience. For example, Holman & Kranstuber Horstman (2019) noted that stories characterized by themes of *time heals* and *helpful support* were more consequential in individuals' healing processes, as opposed to stories that relayed their traumatic health experience as *factual* or evoked shame or guilt. In the case of autoimmune disease, Joyce and Jeske (2020) identified the use of war metaphors, with patients employing attack language to describe their disease activity (i.e. attack, battle, fight, killing), resulting in their invisible illness becoming more understandable and recognizable to relational others. Utilizing devices of communicated sense-making offers a path for relational connection, understanding, and subsequent effective support in the face of disruptive health experiences, both for the patient and their loved ones. By extending CSM into the realm of emerging adulthood chronic illness, health and family communication scholars can begin to identify the most effective sense-making tools, conversations, and messages for medical practitioners, family, and peers to use in supporting emerging adults navigating a chronic illness diagnosis. In the current study, I explore the CSM in participants' illness narratives (CNSM) and memorable messages.

Memorable Messages

The messages AFAB individuals receive about their health influence their perceptions of body and self, identity development, and perceived agency in medical settings and practitioner interactions. Memorable messages are short, highly impactful verbal messages that individuals can recall over a long period of time and shape identity, values, beliefs, and behaviors (Rubinsky & Cooke-Jackson, 2017; Stohl, 1986). These messages effect the way individuals manage their health (Gunning et al., 2019), impact selective disclosure and concealment (Rubinsky, Gunning et al., 2018), as well as shape their belief and value systems and how they view their bodies and roles in society (Kerr, Thompson, & Rubinsky, 2019; Rubinsky, Hosek et al., 2018). Stemming from a variety of interpersonal sources including family, friends, and socializing others, these messages can be positively or negatively valenced (Knapp et al., 1981) and impact how individuals make sense of their lived experiences.

In recent years, health communication scholars have used a memorable messages framework to study communication about stigmatized health topics and illness experiences (Cooke-Jackson & Rubinsky, 2018), thus offering a fitting theoretical framework to explore the impact that messages received by emerging adults on their autoimmune disease diagnostic journey have on identity formation, sense-making, and disease management behaviors. Cooke-Jackson & Rubinsky's (2021) theory of memorable messages (ToMM) posits that messages received during important events, situations, or episodes influence identity which in turn impacts individuals' self-concept, behaviors and actions, and subsequent formation and delivery of new messages to others. These messages can be both verbal and nonverbal and received from a variety of

interpersonal and media-based sources. Memorable messages research seeks to interrogate how early engrained messages are reinforced and challenged during the lifespan and how they may be intentionally disrupted through communication to make room for more positive understandings of self and behavior.

In line with ToMM, memorable messages received during emerging adulthood have been found to impact decision-making processes and behavior change, including identity development, health behaviors, and relationship pursuit. For example, in Nazione et al.'s (2011) study examining memorable messages that aid in navigating college life using a control theory framework, 70% participants reported a change in behavior following receipt of the message, indicating that memorable messages can result in behavioral and attitude change. The impact of emerging adulthood messages was further explored by Orrego Duneavy & Yang (2015) and Reno & McNamee (2015) who studied the role of peer messages on internalized body image perceptions and health behaviors in college-aged populations. Their findings suggest that organizations can play a powerful role in socializing emerging adults to lasting, internalized health behaviors and body perceptions (Orrego Duneavy & Yang, 2015; Reno & McNamee 2015). Heisler (2013) examined parental messages socializing gender and sexuality, finding that parents' instructive, memorable messages socialize children into societal roles and health practices. These studies reinforce the known susceptibility of emerging adults to internalizing memorable messages about health, body, and self and their impact on health behavior and identity shifts. Through these studies, we also know that family members and peers are instrumental in socializing emerging adults with negative or positively

valenced understandings of health, and thus, memorable messages are likely an important and influential form of sense-making during an individual's diagnostic journey.

Prior research on memorable messages in the context of long-term difficulty and illness offers a guide for the role memorable messages play in cultivating and enacting resilience, re-framing hardship, social support and compassionate care, and health behavior adherence. Most memorable message research on navigating long-term health conditions has been studied in the context of breast cancer prevention and detection behaviors. Lauckner et al. (2012) explored the use of framing in self-reported breast cancer memorable messages, finding that gain-framed messages, as opposed to loss-framed messages, were found among participants, suspecting that gain-framed or positively valenced messages may be more easily remembered than negative or loss-framed messages in the context of chronic illness. Smith et al. (2009; 2010) explored the impact of memorable messages on breast cancer prevention and detection behaviors, finding that messages impact and motivate health behaviors in long-term illness. Lucas & Buzzanell (2013) found that memorable messages can be used both for the cultivation of short-term or long-term resilience for individuals navigating hardship and families socializing their children. Lucas & Buzzanell's (2013) findings are especially important as they relate to the potential use of memorable messages to cultivate long-term resilience in emerging adults diagnosed with a chronic health condition.

Memorable messages have been used to explore how individuals are socialized about their health and bodies, with notable focus on women, AFAB, and individuals of diverse genders. Because the present study attends to an AFAB population, memorable messages research on female reproductive and sexual health, body image, and their

impact on health behaviors is important to note. Rubinsky, Gunning, et al. (2018) explored the impact of memorable messages of menstruation on uterine-bearing individuals' health and information seeking behaviors, as well as symptom management. Findings from this study indicate that young adults desire conversations about their health that pair instrumental and informational support with emotional support, as well as normalize reproductive processes (Rubinsky, Gunning, et al., 2018). These messages surrounding female bodies was extended by Gunning et al. (2019) who found female-identifying individuals to be socialized with predominately negative messages about their reproductive and sexual health and bodies, resulting in feelings of shame, secrecy, and expected concealment. Kerr et al. (2019) found memorable messages of body image to have an anticipatory socialization effect, with interpersonal and social influences "preparing individuals for what to expect as a result of some aspect of their identity" (Kerr et al., 2019, p. 2). If, as this body of research suggests, AFAB individuals are susceptible to both positive and negative influences of memorable message as it pertains to their health, memorable messages also likely influence the CSM of people in the context of chronic illness.

In addition to families and peers, health care providers (HCPs) are a likely source of memorable messages. Despite this, limited research has used a memorable messages framework as it relates to HCP communication. In one of the few studies, Smith et al. (2009) found that memorable messages from health care providers are the least likely to be recalled by patients and have a larger impact on health behavior change or adherence as opposed to identity formation. However, it is important for health professionals to know the topics and sources of memorable messages as they relate to long-term illness

prevention and detection outreach (Smith et al., 2009). Ford & Ellis (1998) studied messages of support and nonsupport among care providers, noting a correlation between nurses' burnout and the receipt of unsupportive messages. They found nurses often received messages of nonsupport from superiors, as a consequence of the superior's own stress and burnout, and urged scholars to further explore the impact of medical hierarchy organizational communication on patient support (Ford & Ellis, 1998). Willer (2014) explored compassionate messages from care providers in the context of infertility, finding a correlation between perceived compassion and patient's positive affect, self-esteem, and reduction of stress. This study offers translational guidance and insight into the role messages of support from medical practitioners have on long-term, disruptive health journeys and patient well-being (Willer, 2014). Willer (2014) identified supportive memorable messages from medical providers during infertility journeys as including offering hope, practicing patient-centeredness, enacting empathy, privileging patient ahead of self, and communicating nonverbals, with nonverbal communication and privileging patient perceived as most compassionate by patients. The present study seeks to extend the literature on memorable messages by investigating messages received by emerging adults on their autoimmune disease diagnostic journeys from family, friends, and HCPs. Thus, I ask:

RQ1: What are the helpful and harmful memorable messages emerging adult AFAB individuals with autoimmune disease receive during their diagnostic journeys?

Communication scholars have begun to explore the importance of desired memorable messages and the translational potential of these ideal messages to

educational programs and trainings, whether with teachers, medical practitioners, family members, relational and social supports, among others. Holman & Koenig Kellas' (2018a; 2018b) studies on real and desired memorable messages and conversations in the context of parent and adolescent sex talks illustrate the translational potential of research that explores ideal conversations about health topics. Such studies offer a path for designing conversation guides and educational materials that present behavioral health information in ways that effectively resonate with a chosen population (Holman & Koenig Kellas, 2018a; 2018b). Holman & Koenig Kellas (2018a) identified discrepancies in what adolescents recall their parents saying about sex (*memorable* conversations) and what adolescents wish their parents had said (*preferred* conversations), citing implications on risky sexual attitudes and behaviors. This finding was echoed by Holman & Koenig Kellas (2018b) who identified adolescents' perceptions of their parents' communication competence as a strong predictor of adolescents' perception of and engagement in sexually risky behavior. The importance of exploring desired or preferred conversations and messages was extended by Rubinsky, Gunning, et al. (2018) who found that women desire normalizing, emotionally supportive, and validating messages about their reproductive and sexual health.

Gunning et al. (2019) found that individuals are able to shift harmful health behaviors and perceptions stemming from early negatively valenced memorable messages to more positive understandings through communication and individual moments of intervention. Important sources of positively valenced messages and catalysts for comprehensive, positive understandings surrounding health behaviors include open dialogue, body acceptance, symptom management, and re-defining identity

(Gunning et al., 2019). This study is important in that though impactful and formative to early individual identity and health behaviors, memorable messages can shift over the lifespan, creating room for evolving and integrated identities, behaviors, and thought processes (Gunning et al., 2019). These findings are especially important in light of the translational potential of desired memorable messages in healing the tension between ‘ill’ and ‘well’ identities seen in instances of chronic illness (Gunning et al., 2019; Palmer-Wackerly & Voorhees, 2020).

A memorable messages framework has not been applied to instances of chronic illness onset or the diagnostic journey. By identifying what messages emerging adults received during their illness and diagnostic journeys alongside what they *wish* they had been told offers an opportunity to create a conversational guidebook for relational others, medical practitioners, and sources of social support to adequately and effectively support this population through their illness journeys. Thus, to extend inquiry of assigned female at birth individuals’ desired messages into chronic illness, I ask:

RQ2: What are the memorable messages that emerging adults with autoimmune disease wish they had received during their diagnostic journeys?

Kauffman et al. (2013) applied a narrative framework to consider memorable messages as narratives in the context of memorable familial messages about sex. Giving greater depth and context to memorable messages through a narrative lens allows for researchers to “[understand] *memorable messages as stories* that hold special meaning and contain important life lessons” (Kauffman et al., 2013, p. 3). The present study seeks to extend the intersection of memorable messages and narrative research through

collection of illness narratives and dual analysis of memorable messages and communicated narrative sense-making devices found within them.

Communicated Narrative Sense-Making

Narratives offer a unique and intimate opportunity to engage in an individual's illness diagnostic journey and illustrate the meanings, values, and beliefs they assign to their illness experience and individual, illness, and relational identities (Koenig Kellas, 2018). Topics of health and illness are often seen in individual and familial stories, for "illness produces stress, anxiety, worry, and depression that can be understood through narrative sense-making" (Koenig Kellas, 2018, p. 63). The sharing of illness narratives benefits the sensemaking of the individual telling the story, the individual(s) witnessing the story (Ahola Kohut, et al., 2018; Park-Fuller, 2000), aids in the development of effective, compassionate, and competent medical care (Charon, 2006), and highlights opportunities for effective sensemaking interventions (Eriksson & Lindstrom, 2005; Koenig Kellas, 2018; Martz & Livneh, 2010). Analyzing the content of narratives, such as framing devices, message content, source, among others (Kauffman et al., 2013), can offer insight into relational satisfaction and well-being of both the individual with illness and their relational supports (e.g., Holman & Kranstuber Horstman, 2019).

Identity construction is a main function of narratives and storytelling (Koenig Kellas & Trees, 2013). Though seen as a biographical disruption, the narratives of chronic illness onset and illness trajectory offer unique, translational biographical insight into the evolution and development of "philosophical and sociological concepts of identity and self" (Anderson & Mackay, 2014, p. 5). Individuals with chronic illness struggle with narrative coherence and identity (Charmaz, 1991), as the ambiguity,

physical threat, and bodily changes that come with chronic illness disrupt their life stories (Charmaz, 2002; Edwards, 2008). Narratives of autoimmune disease contradict society's master illness narrative of restitution which views "health as the normal condition that ought to be restored" (Frank, 1995, p. 77) and undermine the favored perception of illness as an event that can be valiantly overcome by the heroism of modern medicine, individual, and mind over body.

Narrative sense-making in autoimmune disease has been explored in the context of women with Systemic Lupus Erythematosus (SLE), a systemic autoimmune disease with often invisible symptomatic manifestations, shedding light on the meanings that they assign to their diagnostic journeys and illness (Castle & Koenig Kellas, 2019). Castle & Koenig Kellas (2019) found that women with SLE narrate their illness journeys "in ambivalent terms, recognizing the complexities of Lupus and the ups and downs it causes for them and their families" (p. 220), with some women even finding a sense of purpose in their diagnosis. In analyzing the narratives of women with SLE, Castle (2015) found a correlation between narrative plotline and state of an individual's physical and mental health in the face of autoimmune disease. Specifically, women whose narrative plotlines were coherent, and who engaged in open communication and perspective-taking with their families about illness, were more physically and mentally healthy and relationally satisfied (Castle, 2015). Thus, narrative-based frameworks offer an appropriate approach for exploring sense-making and well-being amidst autoimmune disease.

Koenig Kellas' (2018) communicative narrative sensemaking theory (CNSM) posits that the stories individuals hear and tell have lasting implications on their beliefs, behaviors, attitudes, values, and identities. Thus, narratives and storytelling have

implications for an individual's perceptions of their own health, as well as how they view and treat others' health conditions (Flood-Grady & Koenig Kellas, 2018). The intent of CNSM theory is to "shed light on the *communicated* content, process, and functions of storytelling as they help to explain and are explained by individual and relational health and wellbeing" (Koenig Kellas, 2018, p. 63). The communicative act of storytelling becomes the focal point, giving insight into individual narrative sense-making amidst illness and health disruptors. CNSM is guided by three heuristics which frame studies and future research, including the retrospective storytelling heuristic, interactional storytelling heuristic, and translational storytelling heuristic (Koenig Kellas, 2018). The present study grounds itself in the retrospective storytelling heuristic which inspires research rooted in the belief that "the stories we *hear* and *tell* can have significant lasting effects on our beliefs, values, behavior, and health" (Koenig Kellas, 2018, p. 64). Within the retrospective storytelling heuristic Proposition 1 of CNSM theory proposes that the content of these retrospective stories reveal "individual, relational, and intergenerational meaning-making, values, and beliefs" (Koenig Kellas, 2018, p. 64). The present study seeks to apply Proposition 1 to understanding the retrospective storytelling and meaning-making, values, and beliefs found in the stories of emerging adulthood chronic illness onset, specifically autoimmune disease. Sharing narratives can have individual and relational benefits, including improved well-being, understanding, ability to cope, make sense, and make meaning, as well as gaining control (Koenig Kellas et al., 2010). However, the role that communicated narrative sense-making plays in coping, making meaning, and improving well-being has not been explored in the context of chronic illness, especially instances as disruptive as emerging adulthood onset.

Flood-Grady & Koenig Kellas (2018) supported proposition 1 of CNSM in a study that explored lasting impacts of narratives of mental health told in families and how these stories socialized younger members to prepare, perceive, and navigate topics of mental health. Findings indicate that individuals can learn positive lessons from negatively valenced stories, as well as learn how to effectively support individuals with mental health struggles through storytelling (Flood-Grady & Koenig Kellas, 2018). These findings reinforce that “engaging in behaviors that promote understanding during conversations about difficulty... can facilitate reframing, ultimately benefitting storytellers and story listeners” (Flood-Grady & Koenig Kellas, 2018, p. 9). This is especially important as it relates to the potential of retrospective storytelling in helping individuals and family members cope with stigma, loss, and uncertainty amidst a chronic illness diagnosis.

Prior research has identified acceptance, sense-making, and identity renegotiation as integral to increasing resilience, compassion, empathy, maturity, and motivation in young adults with long term health conditions (Wilson & Stock, 2019). Similar sense-making outcomes emerge in communicated resilience processes, including forming narratives that make sense of adversity, crafting new normals, positively adapting, and experiencing growth (Buzzanell, 2018). Memorable messages have also been shown to be an effective narrative sense-making tool for fostering and enacting resilience (Kauffman et al., 2013). Thus, I believe the present study’s analysis of illness narratives of emerging adulthood autoimmune disease onset can offer further insight into what sense-making, meaning-making, well-being, and identity negotiation looks like in instances of chronic illness, which communicated sense-making scholarship has yet to

explore. Additionally, exploring these narratives through CNSM theory offers potential opportunities to later develop a translational storytelling intervention to improve health and well-being in young people navigating chronic illness, an experience disruptive to all aspects of life during a time of identity formation. Thus, I ask:

RQ3: What meanings, values, and beliefs does this population assign to their illness experience?

This project investigates the retrospective illness narratives of individuals with autoimmune disease onset in emerging adulthood in an effort to identify how communication can foster sense-making, identity reconstruction, connection, and improve wellbeing amidst an otherwise disrupting and uncertain time. By rooting this inquiry in two branches of CSM (Koenig Kellas & Kranstauber Horstman, 2015), I hope to identify specific interpersonal conversation-based messages and sense-making devices that can foster support, solace, and guidance for patients and their loved ones to not only cope, but develop resilience, positive adaptation processes, and perhaps even thrive amidst health-related difficulty and uncertainty.

CHAPTER TWO: METHODS AND PROCEDURES

Methods

Participants

To qualify for this study, participants had to be between the ages of 19-30, assigned female at birth (AFAB), and have been diagnosed with an autoimmune disease(s) between the ages of 19-30 that had gone undiagnosed for least one year. Autoimmune diseases were constrained to those listed under the American Autoimmune Related Diseases Association, Inc.'s (AARDA) list of one hundred autoimmune diseases. This criterion was used to ensure a sample who had experienced long-term, life-disrupting illness onset in emerging adulthood, and align with the average autoimmune diagnostic time of four years (AARDA, 2021).

Participants ($n = 25$) were from the United States and included predominately cisgender women ($n = 24, 96\%$) and one trans male (4%) between the ages of 19-30 years old ($M = 26.04, SD = 2.21$). Autoimmune disease diagnoses included Spondyloarthritis/Ankylosing Spondylitis ($n = 7, 28\%$), Systemic Lupus Erythematosus ($n = 5, 20\%$), Mixed or Undifferentiated connective tissue disease ($n = 3, 12\%$), Psoriatic arthritis ($n = 3, 12\%$), Celiac disease ($n = 2, 8\%$), Ulcerative colitis ($n = 2, 8\%$), Multiple sclerosis ($n = 1, 4\%$), Rheumatoid arthritis ($n = 1, 4\%$), Autoimmune encephalitis ($n = 1, 4\%$), Hashimoto's thyroiditis ($n = 1, 4\%$), Autoimmune small fiber neuropathy ($n = 1, 4\%$), Narcolepsy ($n = 1, 4\%$), Ménière's disease ($n = 1, 4\%$), and Graves' disease ($n = 1, 4\%$). The average age of autoimmune disease diagnosis was 23.12 years ($SD = 2.88$). Participants identified diagnostic journey lengths ranging from 1 year to 20 years ($M = 5.74, SD = 4.25$). Participants were Caucasian ($n = 20, 80\%$), Asian ($n = 2, 8\%$), Hispanic

Latina ($n = 1$, 4%), Black ($n = 1$, 4%), and one preferred not to identify race or ethnicity (4%). Participants were geographically dispersed around the United States, including California, West Virginia, Nebraska, Texas, New York, North Carolina, New Jersey, Georgia, Michigan, Wisconsin, Illinois, Alaska, Utah, Pennsylvania, and Tennessee.

Procedures

Following IRB approval, participants were recruited through online platforms and snowball sampling. The primary investigator (PI) recruited participants through Reddit and Instagram, where an IRB-approved script (see Appendix A) was posted to the platforms, requesting that those interested in participating in the study reach out to the PI via their university email address to schedule an interview. The participant call was shared by others to a Historically Black Colleges and Universities' (HBCU) listserv, a National Communication Association listserv, chronic illness support groups on Facebook, as well as personal social media sites.

Once recruited, almost all individuals participated in a semi-structured interview via Zoom ($n = 24$, 96%). To accommodate health constraints and access to participation, one participant responded to questions in writing, which bore equally poignant results as face-to-face interviews (see Appendix C2). Interviews took place virtually on Zoom due to the ongoing COVID-19 pandemic that was occurring during data collection. Due to the exploratory nature of the study, a semi-structured interview guide (see Appendix C1) was used to allow flexibility in asking additional questions and probing insights based on participant responses (Rubin & Rubin, 2005). Following consent to participation (see Appendix B) and collection of demographics via Qualtrics survey, participants were first asked to share their illness journey as a whole (e.g. Can you please tell me the story of

your illness journey?), then asked to identify and reflect upon memorable messages received and desired from medical practitioners, family, friends, intimate partners, and influential others during this journey (e.g. Can you identify and recall memorable messages received during your diagnostic journey and their influence or impact? What, if anything, do you wish the person who had said this message would have said instead? Why?). All interviews concluded by asking participants to share any additional information that they deemed important, relevant, or poignant to the study. Video interviews lasted between 45-90 minutes and were machine transcribed by Zoom with participant's consent.

Data analysis

Transcriptions resulted in 990 pages of double-spaced interview data. While transcribed, all identifying information linking participants was removed and each participant was assigned a corresponding number for identification of transcript and exemplar line (e.g. Participant number: transcript exemplar). Transcripts were then cleaned for accuracies and disfluencies (e.g., like, um).

Participant narratives were analyzed through two theoretical frameworks: the theory of memorable messages (ToMM, Cooke-Jackson & Rubinsky, 2021) and CNSM theory (Koenig Kellas, 2018). ToMM was used to identify salient harmful, helpful (RQ1), and desired (RQ2) memorable messages participants recalled during their diagnostic journeys. Proposition 1 of CNSM theory guided the identification of the meanings, values, and beliefs that emerged from participant stories (RQ3), operationalized as lessons participants learned. In line with CNSM Proposition 1, the stories participants told illuminated these lessons learned. Thus, instead of analyzing their

stories as a whole through Reissman's (2008) narrative analysis, I chose to analyze both CNSM and MM questions through thematic analysis to more deeply discern individual lessons learned. Based on the lessons I inductively derived from participants' stories, I refer to their stories as *wisdom narratives*. As I discuss in chapter 4, framing participants' stories as wisdom narratives offers translational guidance for others' navigating invisible chronic illness to make sense and cope with their illness experience. With participants spanning a number of years into their illness journeys, there was much wisdom to gain and lessons to learn from their cumulative experiences.

To begin, I first read through the data to gain a holistic understanding of the health and interpersonal experiences that characterized participants' diagnostic journeys, generating first-order *in vivo* and conceptual codes (Saldaña, 2014) to preserve participant language and core concepts (e.g., "it's all in your head"). Following Braun & Clarke (2012) and Owen's (1985) thematic analysis, I read through a second time and generated a codebook for memorable messages and lessons learned in wisdom narratives, confirming that the data met the criteria of repetition, recurrence, or forcefulness. Reflexive thematic analysis honors the voices of participants and focuses on meaning-based patterns across the data set (Braun & Clark, 2019). These codes identify and label commonalities in the data that are potentially relevant to the research questions (Braun & Clarke, 2012).

To answer RQs 1 and 2, I extracted each memorable message, noting who the memorable message came from (e.g., parent, intimate partner, medical provider) and its valence (negative, positive, neutral) (Voorhees et al., 2021). These memorable messages were then combined into themes and theoretical connections between repetitive,

overarching ideas expressed by participants were made. In line with Cooke-Jackson & Rubinsky's (2021) ToMM, any behavioral impacts identified by participants were noted. During this analysis, it became clear that messages that were coded as positive were very similar to the messages coded as desired. For instance, whereas some participants noted positive messages such as "I believe you" as influential, other participants who were not met with this support expressed that they desired or wish they had received a message in which someone said "I believe you." Due to this significant overlap, I have chosen to address both the second portion of RQ1 (what positive messages did participants receive) and RQ2 (what are desired messages) together in my results.

To answer RQ3, I first analyzed what the greater illness stories looked like. Similar to Koenig Kellas & Castle (2020), I found the illness stories discussed at the beginning of the interview protocol (Can you please tell me the story of your illness journey) to be medicalized, focusing almost entirely on the clinical aspects and steps involved with their medical journeys. Thus, in line with Castle and Koenig Kellas' methodology, I used not only their initial illness stories, but also questions across the interview as a whole (e.g., How has your perspective about illness changed over time?) to best understand the meanings, values, and beliefs that characterize the overall illness story. Upon generation of a codebook, I held a data conference with four scholars to confirm the validity of the data and analysis. In this conference, data themes and participant examples were discussed to ensure cohesiveness, validity, and resonance. Initial themes were validated and extended to tease out specificities in messages. Specifically, messages of blame and dismissal were changed to keep themes separate.

Members of the data conference confirmed cohesiveness and validity of the data and agreed that findings were significant and clear as initially analyzed.

CHAPTER THREE: FINDINGS

Expanding upon current literature on communicated sense-making, the intent of this study was to identify harmful, helpful, and desired messages received during an invisible chronic illness diagnostic journey, as well as beliefs gained and lessons learned from illness onset in emerging adulthood. In the current chapter, I will report on the findings of my analysis. Because there was a great deal of overlap between positive messages some participants received and desired messages that others expressed wishing they had received, I have chosen to address both the second part of RQ1 (What helpful or positive messages did you receive on your illness journey?) and RQ2 (What desired or ideal messages did you wish you had received?) together in my findings.

To answer RQs 1 and 2, I first discuss harmful memorable messages amidst an emerging adulthood illness journey, with four themes of (1) “it’s all in your head, (2) “but you look healthy,” and messages that (3) blame and (4) dismiss. Then, I discuss helpful and desired memorable messages amidst this journey, with three themes including (1) “I believe you. You are not alone,” (2) “Help me understand,” and (3) messages that return medical agency. Finally, I discuss the five salient pieces of wisdom (lessons learned) participants shared from experiencing a disruptive illness experience at a young age, including learning to (1) separate self from illness, (2) create new “normals,” (3) rediscover trust in self, (4) increase empathy for others, and (5) recognize privilege and disparities in medical care. These findings are discussed in turn.

Harmful memorable messages amidst an emerging adulthood illness journey

The thematic analysis of the harmful memorable messages participants recalled over the course of their illness journey (RQ1) revealed four themes of harmful messages. Participants received harmful messages from medical practitioners, family members, friends, and social network members. Participants identified harmful messages as having a negative impact on their wellbeing, perceptions of self and illness, and health behaviors. Themes include: (1) “It’s all in your head,” (2) “but you look healthy,” and (3) message of blame, and (4) dismissal.

“It’s all in your head.” An experience that characterizes the journey to autoimmune disease diagnosis, as well as many other “invisible” illnesses, is a dismissal or delegitimizing of symptoms due to an inability to detect disease activity on bloodwork or scans. This is often the reason the average autoimmune disease diagnosis takes four years (AARDA, 2021). In the case of systemic autoimmune diseases like Systemic Lupus Erythematosus and Ankylosing Spondylitis, the average length of diagnosis is six years (Sawah et al., 2015) and nine years (Dincer et al., 2008), respectively. In that time, many patients do not have access to proper treatment to slow disease activity or improve quality of life. Not surprisingly, then, participants in the current study recalled messages in which others attributed “invisible” symptoms to psychogenic or mental health-related causes, aligning with the permeating societal narrative of the “hysterical” female patient (Dusenbury, 2018; Gunning & Hudak, 2021). These “it’s all in your head” themed messages came from medical providers, family members, friends, and influential others in a variety of forms that boiled down to “you just haven’t taken care of your mental

health” (3). As one participant summarized, “to have pain is to have certainty, but to see or hear about others’ pain is to have doubt” (1).

This message most often came from medical providers while participants were seeking a diagnosis, often accompanied by an alternative explanation for their invisible symptoms. For example, a participant with Autoimmune Encephalitis, whose disease onset during college, recalled a doctor asking, “do you think it is just stress? The top achievers are often like this” (5). This was echoed by a participant with Autoimmune Small Fiber Neuropathy who shared, “I was told that I was making it up, that I was depressed, that I just wanted attention, that I had a conversion disorder” (1). Some participants noted receiving these messages even when physical symptoms were present, such as a participant with Ankylosing Spondylitis who shared that a medical provider

Told me that ‘the pain is just in your head’ and ‘it’s not as bad as you’re making it out to be.’ Which, I was not able to walk at that time without limping, so that really struck me. I’m showing a physical symptom that this is bad, but her thought process was that it was something related to my menstrual cycle and that it would just go away as my cycle did. I wasn’t even on my period at the time (20).

Others reiterated this experience, noting additional implications of these messages such as strategic concealment, loss of trust in self, pushing through and ignoring their symptoms altogether, or following through on medical treatment that did not ease their symptoms, such as antidepressants or physical therapy. For example, a participant with Graves’ disease noted the impact of being

[told] ‘it’s all in your head’... anytime I have any physical symptoms, it was always, every single time, attributed to stress, to my mental illness... I’m afraid to

bring up certain symptoms or certain experiences because I'm afraid is either going to be attributed to 'It's just a symptom of your mental illness' or 'It's only your head' (4).

One participant with Ankylosing Spondylitis detailed the extent that medical providers chased a mental health diagnosis, sharing:

I waited forever to see [a] cardiologist... he looks over everything and, I'll never forget, he looks at me and says, 'If you weren't so young, and you weren't so skinny, these results would be extremely alarming. But since you're not old and since you're not fat, I think you're fine. I think you should try an antidepressant'... I just remember going and sitting in my car and just, like, I couldn't even drive. I just cried because I was like, it's there. He essentially said 'on paper, something is wrong, but because of these factors that you have literally no control over, I'm not going to do anything about it, and you're probably depressed'... [So, I went] on an antidepressant for a while—I don't think it really did much for me—but that's, you know, where I ended up. They asked me if I thought it was working, and there was one point... that my doctor said 'I don't think this is strong enough for you, let's add an anti-psychotic'—which has very extreme side effects... And I mean at that point, I don't know what to believe. I've always been the kind of person [who] put my faith in science and my faith in doctors and I didn't feel like I could trust myself anymore. So, I was like, yeah, I guess I need an anti-psychotic because I knew that what I was experiencing was very real and if the doctor said it's in my head then let's treat the head, let's treat the mind here. And so I did. I went on an anti-psychotic for, gosh, a few months, and they said, 'don't

stop taking it.’ I quit taking it on my own because I realized it was just making things worse... I’ve heard really similar stories from people that I’ve met that have similar rheumatic autoimmune disorders and it’s so disappointing. It really just makes you lose faith in the whole [medical] system (15).

A participant with Hashimoto’s Thyroiditis echoed the extent that medical providers searched for a psychogenic cause, detailing:

[My doctor] asked me, ‘have you ever been abused in your past?’ and I said, ‘why are you asking?’ She said, ‘well, sometimes people who have had past abuse can create things in their mind to gain sympathy or attention’... Thankfully, I’ve been able to sort of hold it together, but there have definitely been times when I’ve doubted myself and thought, ‘*am* I just crazy? *Is* this all made up in my head? Am I *really* just lazy and I’m making an excuse for it?’ And that has been the main [message] from doctors; lots of little comments about ‘well, you’re just getting older,’ ‘well, maybe you’re not trying hard enough.’ There’s ‘all of your tests came back normal so there’s really nothing wrong with you,’ ‘I don’t know why you keep bringing this up, we’ve already tried this,’ ‘it’s just your mental health’ (16).

In summary, “it’s all in your head” messages illustrate how deeply engrained the narrative of the “hysterical” female patient is in medicine and implications of this assumption on medical care. Following ToMM (Cooke-Jackson & Rubinsky, 2021), these messages led to a variety of behavioral impacts, including patients suffering in silence, reduced trust in self and body, adherence to treatment regimens that do not

alleviate symptoms or improve quality of life, and concealment and disclosure of symptoms to medical providers and close interpersonal others.

“But you look healthy.” Participants reflected upon the harmful impact of messages that presumed health based on their outward appearance. These messages often shared an underlying tone with “it’s all in your head,” casting subtle doubt into the individuals’ symptoms and illness. Examples include, “but you look healthy” (10) and “well, you look okay” (12). A participant with Systemic Lupus Erythematosus elaborated:

I don't consider myself disabled. I work full time, I'm mobile, I socialize, and I think to some people that's confusing. So, the message that they'll send is ‘you're doing great!’ or ‘I'm so happy you're healthy,’ and not understanding that those two things can coexist. You can be chronically ill but still functioning or appearing healthy (23).

A participant whose Rheumatoid and Psoriatic Arthritis took a decade to diagnose shared the detrimental impact of these simple words on her health behaviors:

The [message] that probably did the most detriment to me as a human was ‘but you look fine.’ Because of that sentence, I was like, ‘right, I do look fine.’ And I would push through a lot of things. I completely stopped listening to my body and was angry that it was causing me to do all of these things—like miss school and whatever. So, I would tend to overexert myself to the point of exhaustion or illness... trying to prove to everyone that I can do it (7).

In the words of a participant whose symptoms took thirteen years to diagnose—during which time her illness, Autoimmune Small Fiber Neuropathy, was discovered by

the medical community, “people trust what they can see. On the medical side, if you can't see test results and it's invisible, then it's either not there or not that bad. And then in society, if you don't look sick and you can't see it, then you can't be that sick inside” (1).

In summary, messages that perceive outward appearance to reflect internal health cast doubt, resulting in individuals second guessing their lived experiences and often pushing through symptoms with detriment to their health and wellbeing.

Messages of blame. An overwhelming number of participants spoke to messages and feelings of blame and shame, as if they had done something to cause their illness. Some messages were overt in their blame, while others were covert and suggestive. When interviewing participants, the tension negotiating feelings of shame and recognition that they were not the cause of their illness was palpable; many participants were still amidst this journey to self-acceptance. One participant shared:

I would say the overall message that I have gotten from medical professionals, from family, from society, is ‘this is your fault.’ Somehow, all of the things you're experiencing, you have done that. ‘It's because you're eating too much.’ ‘It's because you're too lazy.’ ‘It's because you're doing bad in school and you just want an excuse.’ ‘It's because you have let yourself go.’ At the base of every comment, it is my fault. It is hard not to internalize, even when I know logically that is not true. [But] knowing that people think that, like, how do you separate? Just because it's not true, if everyone thinks it is then it's almost like it's true (16).

A participant whose Celiac Disease took two decades to diagnose shared:

I was often told that I was addicted to drama or needed things to go wrong because I enjoyed sabotage. I was also told that because I worked a lot at the time,

that I brought this onto myself through stress... The impact that these messages from doctors and friends alike were unfortunately influential on my decision making. Because I was not supported or believed by a few, a fear grew in my mind that those few would be everyone. I feared that no one in the entire plane of existence would ever take me seriously, and therefore, I kind of gave up. I gave up expressing how bad I felt and replaced it with that lie everyone loves so much, "I'm fine." I took refuge in reading for a while, finding new diets or cleanses here and there that would temporarily stave off feelings of physical pain. But there wouldn't be anything to keep the mental pain of rejection away. I got lost inside of it and over time, it made me bitter towards doctors, health and illness (25).

A participant with Ankylosing Spondylitis reflected upon the multiple layers of blame he faced from the medical community as a trans male seeking a diagnosis for his debilitating pain:

Two rheumatologists had basically been like, 'well, you know, he's had a lot of surgeries.' I basically was treated as like 'well, you've cut up your body, so what do you expect? Obviously, you're going to have all this pain from having top surgery and a hysterectomy.' And I'm like, tons of women have hysterectomies every year so this idea that my body inherently makes me more susceptible to pain and that it's somehow my fault for choosing to do those things (3).

These feelings of blame have a direct impact on patients' trust in self, pursuance of medical care and treatment, and management of disease. In line with ToMM (Cooke-Jackson & Rubinsky, 2021), the repetition of these harmful messages, as exhibited by participant stories, left a lasting impact on how these patients developed their illness

identity and were socialized to disease management, as well as potentially impeding sense-making.

Messages of dismissal. Feelings of blame were perpetuated by messages that participants identified as dismissive of their symptoms and lived experiences. These messages, most often from medical providers and family, dismissed their symptoms or suggested that they would be healed if they changed aspects of their lifestyle (e.g., exercise, diet). Examples of dismissive comments from family include, “‘Just have a positive attitude.’ ‘You’ve just got to be positive,’ which I know is coming from a place of caring but feels dismissive” (14). A participant recalled turning down a friend’s invitation, sharing, “‘I’m not really feeling up to that,’ was something I would say, and I got ‘well, it seems like you’re never up to anything’” (22). Other unhelpful or dismissive messages attributed symptoms or illness to lifestyle decisions or uncontrollable circumstances. For example, a participant with debilitating back pain from, at the time undiagnosed, Ankylosing Spondylitis was asked by her family, “‘well, do you think it’s your boobs?’ I’m like, ‘no, I don’t think so’” (2). Other examples include participants with Ulcerative Colitis who recall being told “‘you really need to change your food up’” (6) and “‘everyone’s telling you ‘I have a stomachache, too.’ ‘You can’t be in that much pain’ or ‘it’s probably fine.’ ‘It’s probably something else.’ ‘There’s no other explanation, so it’s probably nothing’” (9). Two participants with Systemic Lupus Erythematosus were told “‘you’re just tired’” (18) and “‘oh you’re tired? Sleep it off’” (11). A participant with then undiagnosed Ankylosing Spondylitis was told by her mother

‘You’ve been in crisis for a while.’ That really sticks with me and it’s part of the reason why I don’t tell my mom much [anymore]. It’s something that I

consciously decided to do, because no matter how much I tell her or my family, it's impossible to understand unless you see it every day (17).

Participants overwhelmingly noted covert harm in messages that offered unsolicited lifestyle suggestions, such as diet and exercise changes, or comments that were intended as empathetic but were actually dismissive (e.g., empathizing with fatigue and pain). The general experience of “being tired” or having pain and body aches cannot be compared to the intensity and unrelenting nature of symptoms experienced with autoimmune disease, and though participants recognized these comments as attempts at empathizing, they found them to be dismissive. Articulated by a participant with Ankylosing Spondylitis, “friends have been like ‘man, my back's really been hurting! I really sympathize with you, I understand.’ And like part of me is like, no person's pain is better than the others, we all hurt, and we should all be allowed to talk about that. But [also], you tweaked your back and it's going to be better in a week” (17).

Negative messages that dismiss, blame, or assign psychogenic cause were deemed harmful by participants, even those who expressed understanding that some messages did not have ill intent. In line with ToMM (Cooke-Jackson & Rubinsky, 2021), participants identified lasting impact that these messages had, whether on their health behaviors, relationships, or perceptions of self and illness. ToMM offers an avenue to examine these harmful messages and identify opportunities for intervention.

Helpful messages amidst an emerging adulthood illness journey

After recalling messages that participants found harmful, they were asked to identify messages that were helpful or supportive during their illness journey. Participants were also asked to identify desired or ideal messages that they may not have received but

wish that they had. Due to an overlap in helpful and desired messages, with participants expressing the same messages, some having received them and others wishing they had, I have presented helpful messages on this illness journey as including both real and desired. Three major themes characterize helpful messages amidst an emerging adulthood autoimmune disease journey, including (1) “I believe you. You are not alone,” (2) “Help me understand,” and (3) Messages that return medical agency.

“I believe you. You are not alone.” Upon reflection of helpful and desired messages, participants overwhelmingly emphasized the importance of messages that demonstrate relational investment, interest, support, and affirmation. These messages varied from statements of solidarity and belief, to demonstrative actions of support and aid. Participants emphasized the importance of these messages from social network members, such as family, friends, and intimate partners, especially in the face of dismissive or invalidating medical experiences. A participant whose Ankylosing Spondylitis went undiagnosed for two and a half years shared the positive impact of his mother saying,

‘I believe you. Even if we don't know what is going on, I support you and you are not alone... you cannot give up on yourself. You know your body best. Do not let anybody else tell you how you feel or that your pain is not legitimate. Keep going’ (3).

A participant whose Multiple Sclerosis was diagnosed at 19 reflected upon comfort found in a medical provider’s message, “you are not alone. A lot of women live with this” (8). Additional examples include, “I believe you. I support you. How can I help you? You are not alone” (2), “We believe you. We know you are trying your best. What you are doing

is enough” (1), and “I hear you” (17). A participant with Rheumatoid and Psoriatic Arthritis reflected on the impact of hearing “‘you are not alone.’ Even though I might be alone in my diagnosis, I’m not alone in this journey” (7). Some participants elaborated on this sentiment, sharing stories of loved ones who made them feel like they were not alone in their illness journey. For example, a participant whose Ankylosing Spondylitis took seven years to diagnose shared the impact of a friend’s belief in her:

I remember at first, before I was diagnosed with Ankylosing Spondylitis, [doctors] thought I had Lupus. And my best friend had heard about Selena Gomez receiving a kidney from her best friend and she immediately was like ‘I will give you my kidney.’ That was the first thing she jumped to. She was like, ‘I will give you my kidney if you need it. I don't need two kidneys. My kidney is yours.’ And I was like, ‘Oh my God, they don't even know if I have this but thank you. That is so kind.’ When the rest of the world is telling me to ‘be positive,’ or to ‘suck it up,’ or that I'm making it up, you are like, ‘here, take my kidney.’ So, I think the most powerful thing is you cannot always choose your family, you cannot always choose your doctors, but you can choose to surround yourself with friends that send you those positive, validating messages (15).

In the context of intimate partner relationships, two participants elaborated on the importance of action following statements of commitment and partnership. A participant with Mixed Connective Tissue Disease shared:

When we first decided to become a couple, I laid everything out for him. I was basically like, if you want to be in a committed relationship, you should know there are going to be days that I'm not going to be able to do much. It's not going

to happen all the time, but there are going to be days where I'm going to need you to put in 100% instead of 60%. He sat with that for a while and really, really thought about it and decided 'yeah, this is what I'm signing up for.' It's one thing to hear it, but then to actually see it. So, we went months together without me having a flare up and then, when I actually did have one, sure enough he was right there by my side. I remember being extremely apologetic and he was just like, 'there's no need be.' [He] chuckled a little bit, like, 'there's no need to be apologetic. This is what I signed up for.' It was just really reassuring to me (21).

A similar sentiment was shared by a participant whose Ankylosing Spondylitis onset at age 23, following her marriage:

When my husband and I got married, we actively chose wedding vows that did not make a promise 'in sickness and in health.' We went with a more traditional Celtic one that basically states, 'I make the choice to be with you every day and I know that I can leave at any time, but it is my choice.' As I've gotten sicker, I've always asked him, 'you didn't promise to stay for this. You never made that promise. Why do you want to be here?' And [he has always responded], 'I choose to be here. This is my choice. To stay with you.' Which is hard to understand because he ends up in a primary caretaker role sometimes. On the days where I'm bedridden, he brings me food and stuff. How are we sharing equal labor? And, of course, he looks at me he's like, 'well, you do all the budgeting, you do the grocery list, you do all this, you put in the grocery orders for me to go pick up, you do other stuff. Just because you can't actually scrub a shower because it hurts doesn't mean you're not doing an equal share of your labor.'... When I first got

sick, I couldn't imagine him wanting to stay because my body was literally collapsing in on itself. We had no idea what was going on. Who wants to even sleep in the same bed as someone who wakes up crying out at night from pain? It's hard to imagine that [but], in his mind, it was just, 'I made a choice to stay, I can decide not to at a time, but I'm still choosing to so'" (20).

Affirming messages of support and validation from loved ones can make the difference between patient wellbeing and resilience, and internalized feelings shame, blame, and being a burden. As exhibited by participant narratives, simple statements of support and belief go a long way. With the diagnostic journey drenched in uncertainty, patients want to feel *witnessed*—seen, heard, and not alone—in navigating their illness. This aligns with ToMM's (Cooke-Jackson & Rubinsky, 2021) claim that helpful face-to-face, interpersonal messages provide opportunity for retroactive sense-making and disruption of prior harmful negative messages.

“Help me understand.” In addition to messages of solidarity and belief, participants expressed a desire for messages from social network members that gave narrative agency and allowed them to disclose illness experiences when comfortable, without solution-oriented or comparative responses. In other words, messages that asked patients to help their loved ones understand what it was like to live inside their bodies and how to feel supported. For example, a participant with Undifferentiated Connective Tissue Disease reflected upon desired communicative support in her family, sharing:

With [autoimmunity], there are so many shades of grey and everybody's experience is different... [so], having people say 'help me understand what these tests mean' ... to ask questions to understand the illness and understand the

spectrum of what things can happen and what are the different scenarios and trying to understand the disease itself rather than ‘have a good attitude’ (14).

A participant with Hashimoto’s Thyroiditis affirmed a similar desire for her family, reflecting upon the impact of “Just being interested in what's going on. Asking me about my doctor's appointments, asking me ‘have you found anything out?’ ‘Have you found anything that works?’ ‘What has been challenging?’” (16). In the context of support and care in daily life, a participant with Systemic Lupus Erythematosus and Psoriatic Arthritis expressed desire for “messages that attend to agency like 'what would make you feel best right now?' Like, 'what can I do to help you feel best?' ‘What do you need?’ ‘I can help you.’ ‘I'm here to assist you.’ [are] really helpful” (11). Simply stated by another participant with Systemic Lupus Erythematosus, “I don't know what it is like to have Lupus, but I care about you and I want to learn more about it” (23).

Messages of interest, curiosity, and support exhibit a deeper relational investment and return agency to the individual with illness, whether in regard to disclosure or asserting their physical needs. In responding, individuals with a new diagnosis learn to confidently assert agency over their physical and relational needs, building trust in self and others.

Messages that give medical agency. A desire for agency emerged in the context of patient-provider communication, with participants appreciating messages from medical providers that admitted not knowing the cause of symptoms and returned agency to the patient during the illness journey. Participants identified the most helpful message from medical providers as a simply stated “I do not know,” in admittance that medicine does not know all but that does not mean the patient’s symptoms are not real and possibly

indicative of something deeper. Participants expressed a desire for collaborative medical inquiry and action following affirming statements. For example, “the biggest message that could change is to just have them be willing to state, ‘I don't know, but I care about you and I want to help you find an answer’” (20). Further desired messages from medical providers include, “‘I understand that you are feeling this way and let's work on how to solve it,’ rather than brushing it off” (9), and “I can see something is wrong here, I just don't know what... we will do our best to try to get you back to a good quality of life” (5). Participants expressed both real and desired messages that attend to agency in deciding treatment and focus on improving quality of life. A participant with Ankylosing Spondylitis shared:

I would love [for medical providers to] say ‘let's see if we can get you feeling better.’ ‘Let's see if we can get you back to doing what you want to do.’ Just hearing that a physician is invested in you and actually wants you to feel better (22).

This sentiment was echoed by participants who reflected on impactful, positive medical provider messages that centered collaboration between patient and provider on personal, physical goals. For example, a patient with Systemic Lupus Erythematosus and Psoriatic Arthritis recalled:

I have always wanted to run a 5k, which seems so low level to like 99% of people, but my heart rate gets super high and my [prior rheumatologist said], ‘It's just never going to happen for you.’ I went to [my new rheumatologist], and I was like, I would really like to run a 5k. She's like, ‘let's figure out a way for you to

run a 5k.’ Just that hopeful message of ‘you can do this, and I will be alongside you to help you do that’ (11).

A participant with Ankylosing Spondylitis recalled a similar experience with her rheumatologist, sharing:

When I went to see [my rheumatologist] for the first time, [she asked], ‘What do you want out of treatment? What’s our goal?’ I was kind of confused because up to this point, everyone had just been like ‘well, I can’t do anything for you’ or ‘you’re just going to have to deal with the pain and get over it.’ And so, to [have someone say] ‘what do you actually want from this, because that’s what we need to work towards. If you want to be an Olympic marathon runner then that’s going to completely change our treatment [versus] if you just want to be able to cook dinner.’ I’m like well, I just want to be able to sleep through the night and to be able to work a full-time job and come home and make food for myself and my family and actually do something I enjoy before going to bed. I want to be able to travel, if I choose to, and just kind of live a normal life without having limitations of pain or immobility.’ ‘Okay, then that’s what we’re going towards’ (20).

A participant with Rheumatoid and Psoriatic Arthritis reflected on an early interaction with her rheumatologist, sharing:

The first question he asked me was, ‘what is your biggest fear?’ and I labeled it, ‘my biggest fear is not being able to perform.’ He [said], “okay, we are going to work so that that never happens.’ I was like, great. I feel supported. I feel seen (7).

These responses exemplify the importance of medical providers giving emerging adults agency in treatment decision-making. Participants expressed feeling a loss of control

following illness onset and diagnosis, so by approaching illness collaboratively, medical providers can aid in returning bodily agency to individuals and cultivate long-term hope and optimism in the face of a chronic diagnosis at a young age.

Affirming Cooke-Jackson & Rubinsky's (2021) postulation that helpful or desired messages offer opportunity for retroactive sense-making and disruption of harmful messages and beliefs, participants shared stories of helpful messages that served as points of intervention in their health journeys, whether affirming their experience or offering hope and support moving forward.

Wisdom and lessons learned from stories of illness

The third research question, grounded in Proposition 1 of CNSM theory, asked about the meanings, values, and beliefs that emerged in participants illness journeys. Analysis of the data revealed a number of overarching lessons participants learned over the course of their illness journeys. These lessons most often emerged from my final question to participants, *how has your perspective about illness changed over time? If so, in what ways and what contributed to this change?* This final question often prompted a cumulative reflection of their interview responses and illness journey, with the most poignant lessons learned or shards of wisdom rising to the surface. Because of this, I refer to the overall corpus of illness stories in the current study as *wisdom narratives*.

Much like Koenig Kellas & Castle's (2019) stories of women with SLE, illness stories from the current study were characterized at the beginning of my interviews (in response to the question, "Tell me the story of your illness journey") by a clinical focus (e.g., medical procedures, medication, treatment plans). Participants shared the process of finding medical providers, challenging insurance claims, filling bloodwork and scans,

testing treatments, and more. Including other parts of their interviews as narrative material (see Castle & Koenig Kellas, 2019), painted a richer portrait of their illness stories.

Proposition 1 of CNSM theory states that the stories we hear and tell reveal individual, relational, and intergenerational meanings, values, and beliefs. Koenig Kellas (in press) calls for the theoretical sharpening of CNSM theory concepts, such as positivity and meanings, values, and beliefs. In the current study, I operationalized meanings, values, and beliefs by thematically analyzing the learned lessons that emerged in participants' stories. Some participants referred to these lessons as 'silver linings,' while others simply shared what they had learned throughout their years search for diagnosis. For this study, I will refer to participants' stories as 'wisdom narratives,' for the salient advice, resilience, and guiding hope they offer.

Regardless of term, these shards of wisdom, guidance, and sustaining beliefs offer solace, guidance, and hope for emerging adults navigating autoimmune disease, as well as individuals with invisible illness who are early in their diagnostic journey. This choice of analysis does not dismiss the hardships encountered during years-long illness journeys, but instead focuses on sharing perspective, coping skills, lessons, and hope for those still navigating a journey to diagnosis or early diagnosis. When reflecting on social support and coming to terms with their health, many participants noted no long-term benefits in complaining, or "com(misery)ating" if you will, with others navigating chronic illness and pain. Though commiserating offered initial or short-term solace, patients noted feeling drained or being sucked into negative thought spirals. As a result, I focus on lessons learned not to present data with a positivity bias, but to highlight what

participants found helpful or notable to their sense-making and healing, so it may offer growth-centered solace and guidance for those amidst their illness journeys. Five major themes characterize the wisdom gained from becoming sick at a young age, including: (1) Separating self from illness, (2) Creating and committing to new “normals,” (3) Rediscovering trust in self, (4) An increase in empathy for others, (5) Recognition of privilege and disparities in medical care.

Separating self from illness. Participants reflected upon the evolution of their illness identity, notably learning how to separate their illness from sense of self. Shared by a participant with Ankylosing Spondylitis, “being sick does not define you. It can shape who you are, but it does not define you as a person” (22). A participant with Systemic Lupus Erythematosus reflected upon how she learned to create this separation:

I think in the beginning, it was all consuming. From the time that my diagnosis came and even for some time after that, it infiltrated every aspect of my life. My life was Lupus. [It] impacted everything I did, and so, in that way, it was a really big part of my life and it still is now [but] after a while I was like this is too much. This is taking up my life, [so] I stopped focusing in on my symptoms. If I had joint pain, I wouldn't ignore it, I still do things to try to help it, but I wouldn't give it power or life. As I continued to do that, I noticed I felt like I was becoming more of myself and I was doing things that I stopped doing... I was getting my identity back and my life back. It's an ever-evolving thing and there are some days where I'm like, wow, Lupus is me today because it's just really bad today, but I feel like over time, my Lupus evolved from less of an identity to more of just a

part of my life that I have to deal with and engage with but that does not control me (18).

This self-defined separation was echoed by another Systemic Lupus Erythematosus participant who shared, “you should not let Lupus define you. You should not allow it to take over your personality or your life-- it is just an element of you-- to not allow it to become all encompassing” (23). A participant with Rheumatoid and Psoriatic Arthritis reflected upon her experience, sharing:

When I was first diagnosed, I thought my world was ending... that fear was really crippling. [Questions of] do I change lifestyles? Can I have children? It was really negative and really fear inducing and caused me a lot of anxiety. [But] now I feel like it no longer defines who I am. It is just a part of the definition of who I am (7).

These examples show the power in viewing self as separate from illness.

Participants noted a reduction in anxiety, obsessive-compulsive thinking, and shame when adopting a mindset of not being defined by illness. However, in saying that, I want to emphasize participant reflections that noted that this mindset is not always possible and during times of increased symptoms or disease activity, to learn to meet yourself and your body where it—as exemplified in the following section on the creation of new “normals.”

Negotiating the acceptance of illness and a new self with illness is courageous work. There is grief involved—mourning the loss of life imagined, shifting goals and aspirations, and reacquainting oneself with a suddenly unfamiliar body with an uncertain health trajectory. It can be disorienting and disheartening to say the least, but that does

not mean each individual does not still deserve “a good life” (5). The next step in acceptance of self with illness is creating and committing to new dreams, goals, and aspirations amidst this new “normal.”

Creating and committing to new “normals.” Amidst participant stories of illness were lessons about learning to meet their body where it is, through the practice of acceptance and ridding themselves of the concept of “returning to normal.” This is a lesson that that took individuals years to practice and evolves with their disease, shifting needs, and changing “normals.” A participant with Ankylosing Spondylitis reflected:

So much of dealing with the onset of a chronic illness is trying to get back to normal and wanting to be normal and wanting to conceal limitations for a lot of people. But in fact, it's actually really important for you to accept what's happening to you and to reach out to other people who might be going through the same thing because those people are going to validate you and they're also going to give you advice that is going to help you advocate for yourself... Overcoming the need to like feel 100% like my pre-onset self has been a huge milestone for me. To be like, this is the new normal and I have to accept my limitations, because that's the only way I'm going to move forward and have a good life. It doesn't mean that I'm accepting defeat and it doesn't mean that I'm being a downer or giving into my illness. It's being realistic. Accepting that you have a disability is the first step to getting the accommodations that you deserve (3).

Within this acceptance came empowerment and individual recognition of worth and deserving amidst their newfound disability. A participant with Autoimmune Encephalitis shared:

I've tried to look for other ways to still have a good life. With the people that really love me, I don't feel like I need to be at my peak condition in order to have a good time with them or to have a connection with them. I can enjoy yoga or activities without needing to have all my health in order. I think that's something I've slowly learned to accept more and more of (5).

This acceptance took the form of re-evaluating and adjusting prior goals to fit their new abilities and aspirations, encapsulated by a participant with Ankylosing Spondylitis who learned the importance of “being willing to say ‘okay, these things will never happen... let's change the dream.’ Instead of traveling for a year straight, let's start hitting the countries I really want to and change how we travel to make it be” (20). Another participant with Ankylosing Spondylitis illustrated this lesson in shifting perspective, sharing:

Chronic illness isn't static for most people, it's dynamic. You have days where you might seem normal, you might seem perfectly fine, but you're also going to have days in between that are bad, and I think, knowing that there is a variance... I love to run, and I love to get outside and push myself and so, when I received my diagnosis, my first thought was, ‘does that mean I can't run anymore?’ And the answer is, some days, no, I can't run. But other days, yes, I can. I watched a video of an ultra-marathoner who has what I have and that really strengthened me because I was like, okay, it's possible to do things. There are days where it's not possible but listening to my body and gauging how things are is how I will take the next step (22).

Participants found resilience, empowerment, and self-worth when they shifted their perspective toward gratitude and “[appreciation] of the things that you can do” (23). As one participant noted, “having a disability is not a bad thing. [Disability] is not a bad word” (15). Identifying dreams, goals, and aspirations amidst newfound diagnoses, bodies, and new “normals” is critical, as it instills feelings of worthiness, deservedness, and hope that may have been tempered by illness and the journey to diagnosis. As noted with other themes, there is an ongoing grief process that comes along with this acceptance. It is the continual cultivation of resilience, a commitment to continuing through symptomatic inhibitors, a commitment to living a life of meaning, fulfillment, and beauty amidst disease. I have chosen the word *commitment* because this grief process ebbs and flows with the ebb and flow of disease, stunningly articulated by a participant navigating a new Ankylosing Spondylitis diagnosis that has left her nearly immobile at twenty-five:

I feel like when you are chronically ill, one of the things that is hard for people to understand is that you go through a grief process almost every day. Because almost every day can be different, you can do different things on different days. One day, you can do the dishes and be fine and the next you can do the dishes and be crying afterwards because it hurts so bad. And that makes you grieve because you're like, ‘why could I do it yesterday and not today?’ ... Sometimes it can be overwhelming... I think about my grief over being sick as a giant well or a long cave that goes into the earth and I am the rock climber. When I feel sad or I feel triggered by something, I repel down a little bit to think about the things that make me sad and things that I have lost the ability to do. But I have to come back

out kind of quick because if I stay in there too long, or if I go down too deep, I can lose hope and become engulfed by the grief... I am rational [in that I] have to keep holding on to my harness so that I don't go down too deep into the sadness, because the truth is there is always something to be sad about in the world, it's kind of a sad place. But on the flip side, in my life at least, there is usually at least one thing to be happy about. So, I try super, super hard to not go all the way down the well and come back up and just appreciate the good things that I have in my life. I was not able to do that at first, but it has become more like a skill (24).

Creating and committing to new normals helped participants make sense and find new meaning in their lives following illness onset. Within this, participants began to find acceptance and re-imagine dreams in the context of their shifting abilities.

Rediscovering trust in self. Within the present study, participants' autoimmune diseases took an average of 5.74 years to diagnose, which aligns with the average autoimmune diagnostic journey of four years (AARDA, 2021), the shortest diagnosis taking one year and the longest taking twenty. Within these years-long journeys are recurrent messages shared above and multiple medical provider interactions; thus, it is no surprise that an overwhelming number of participants noted that dismissive messages and being told "it's all in your head" impacted their trust in self. However, amidst this common sentiment, participants who had been diagnosed and treated for an extended period of time identified rediscovery or newfound trust in self in the period that followed diagnosis.

The development of trust in self was a result of having dismissive and invalidating medical and interpersonal experiences that diminished or cast doubt into

individuals' trust in self. In response, patients slowly built back their mind-body connection and learned to validate their own symptomatic experiences, as well as more confidently advocate in medical and interpersonal settings. For example, a participant who shared a three-year journey to a Graves' Disease diagnosis, shadowed by assumptions that her symptoms were attributed to a prior Bipolar disorder diagnosis, noted, "I've just learned to trust myself more and look at my health in a more holistic way in general" (4). A participant whose Systemic Lupus Erythematosus took four years to diagnose shared, "I'm not saying that my position has evolved to 'don't trust your doctors,' but trust your body. You can be the person to validate what is going on. It's not in your head" (10). A participant whose diagnosis of Ankylosing Spondylitis took three years reflected upon the disorienting and harmful impact of being told "it's all in your head" on self-trust:

The problem is when you get enough doctors not helping you, you start to feel like you're losing credibility with people in your life because even if they love you, how could they not be like, 'well, maybe he has an anxiety disorder.' 'Well, maybe he has a panic disorder.' How could they not think that? I've thought that about people... [but] that's not how being a person with mental or physical problems works. Sometimes it takes a really long time to get the help that you need, and it doesn't necessarily mean that you don't have a serious issue (3).

A renewed sense of trust in self is important as individuals learn to advocate for themselves with their newfound illness and/or disability. Family members and friends can support this pursuit by offering messages that affirm and validate individuals, as discussed.

Increased empathy for others. Participants expressed the development of empathy, notably learning to not making assumptions based on others' outward appearances. For example, a participant with Systemic Lupus Erythematosus shared, "my perspective about illness changed over time [in that] I don't like to make assumptions about other people's health or illness, because I don't like when people do that to me" (23). This sentiment was echoed by a participant with Narcolepsy and Unspecified Inflammatory Arthritis who shared:

It's definitely [made] me have more like empathetic thoughts... realizing that like there is legitimacy to feeling sick. You don't have to go to a doctor to tell you that you're sick, necessarily. And then not as much jumping to conclusions about how someone feels or the thought 'they need to suck it up'... Whereas without this experience, I would fall into the assumption that people are like overreacting to a sick day or something (12).

A participant with Hashimoto's Thyroiditis shared a similar outcome:

[This experience] has made me much more empathetic... A lot of times what we see as a failing or personal inconvenience to us from another person, I have had to realize [that] you cannot pin everything that a person does just on themselves. Sometimes it's not their fault, it just isn't, and it's not fair to just assume that you know everything about them and [that] you can pinpoint why they do what they do. That's not fair at all... I want to be really honest and open with the people that I meet because I want them to then go forward and if they meet a woman who they think is 'crazy' and 'always has health problems,' I want them to remember me and remember that I still tried really hard. I was trying to get treatment. I'm

still a person. I still have worth. I'm still doing things that are worthwhile, but I have something at the base of it all that makes it much more of a struggle for me than it might be for other people (16).

A number of participants reflected on the importance of developing larger societal empathy, acceptance, and recognition of illness and disability, for “you do not have to have a chronic illness to be empathetic and to care for someone with chronic illness” (3). A participant with Systemic Lupus Erythematosus reflected on empathy and the role of community in chronic illness support:

When I was younger, [illness] seemed more like an individual problem, [but] when I look at it now, I see so many more systemic things that have caused illness in people's lives. It's not so much an individual problem as it is a result of someone's environment. It's not something that they necessarily did to themselves, it's something that [has] generally been influenced by the world around them. So, it's frustrating to me that illness [is viewed as an] individual responsibility rather than something that we all have to carry, because it happens to literally everybody and maybe not to the extent that some people have it, but we all get sick sometimes [so] it's weird that there's the lack of empathy... In most cases it's a social problem. Health is very community-oriented (19).

These examples illustrate the importance of empathy, for self and others, in the face of chronic illness. Without empathy and understanding, society, both knowingly and unknowingly, perpetuates a system that does not create space for differently abled bodies, instead shaming and ostracizing them. Many participants spoke to an experience of shame, blame, and feeling like the onset of illness was their fault, or something they

could have avoided. This couldn't be farther from the truth. Autoimmunity can be genetic, it can be environmental, thus individuals do not always have control over their health outcomes. This disparity was discussed by participants in the context of access to care, medicine, and disease information.

Recognition of privilege and disparities in medical care. With autoimmune disease disproportionately affecting women of color, White participants discussed a recognition of privilege in their access to medical care. A participant with Systemic Lupus Erythematosus noted:

I think one of the bigger takeaways for me throughout this whole process was also reflecting a lot on my privilege and my access to medical care [and] health insurance. I spend a lot of money, even with health insurance, on my medications each month. In Lupus in particular it's mostly ethnic minority women who are disproportionately likely to have it, so through having Lupus, I have met a lot of those women because of where I live. A lot of them are in disadvantaged situations and their outcomes are so much worse... We think of illness as objective—you have it or you don't, and it's mild or severe—but really there is a lot environmentally that goes into your outcomes. Your access to care, your knowledge base. Are you willing to advocate for yourself? Are you able to? Do you have social support systems? Do you have job flexibility to make your appointments? So that's been another major takeaway for me (23).

Another participant with Systemic Lupus Erythematosus also reflected on the “hysterical” female patient and disparities in care, elaborating:

There is a general stereotype that the medical field is working to move away from that still surrounds women's bodies and how they try to advocate for themselves. So that is an awareness that I carry with me and try to keep in consideration the privileges of medicine and the privileges White people have to medicine that a lot of marginalized communities don't have. Most people who have Lupus are women of color. But these tests, and the samples, and all these medical journals that are coming out aren't including those voices of people who have lived with these conditions for their whole lives and arguably have worse conditions. So that's something that really impacts how I think about autoimmune diseases and chronic illness (10).

A participant with Ankylosing Spondylitis adds:

I feel really grateful for having the financial means to be able to drop a doctor and say I'm not going to see you anymore. I'm going to look elsewhere. I know that is not the norm. Even having health insurance, period, is expensive and even with health insurance the medical bills really stacked up. Knowing that if I can't pay one, my parents can help me out, I know that's not the norm and I think about the women, especially women of color, who don't have that and go undiagnosed and in pain, it just absolutely kills me (17).

Autoimmune diseases occur more often and go undiagnosed longer in women of color. This disparity is particularly staggering in Systemic Lupus Erythematosus, a systemic autoimmune disease in which the immune system mistakenly attacks and destroys healthy tissues, systems, and organs (CDC, 2021). African American women are three times more likely to get Lupus than White women and often manifests as a more severe

form of disease, followed by Hispanic, Asian, and Native American and Alaskan Native women (CDC, 2021). Underneath the medical narrative of the “hysterical” female patient is a far more sinister and permeating history of dismissal and abuse of the Black female body (Roberts, 2017). White participants in this study spoke of barriers to medical care, including insurance denials, long waits for providers, and financial constraints.

Navigating systemic barriers with an invisible chronic illness is exhausting when you have access and support. Any additional environmental, physical, financial, access or transportation-based barriers make the journey to diagnosis arduous and sometimes impossible. For each diagnosed autoimmune disease, there are many more women who just think they are tired or do not have the means to inquire about health concerns. The population interviewed for this study has privilege and access not only to medical care, but to space and time to participate in this study.

These lessons learned from the stories participants told about their illness experiences offer guidance for navigating a chronic health condition at a young age. Upon reflection of their illness stories, participants shared newfound beliefs, lessons, and shards of wisdom, making sense and meaning out of their difficulty, affirming Koenig Kellas’ (2018) postulation that retrospective storytelling reveals individual meaning-making, values, and beliefs. These lessons learned offer both solace and guidance for individuals navigating autoimmunity, whether at the beginning of their journey or years in.

CHAPTER FOUR: DISCUSSION

As illuminated by the twenty-five participants who shared their stories of illness in emerging adulthood, autoimmune disease often prompts a reverberative reckoning of body, self, and illness, as acute physical, emotional, and relational changes disrupt an individual's life course. This swift loss of a life-long definition of health often thrusts patients into a state of fight or flight, as autoimmunity prompts their bodies to adopt new roles as both the attacked and attacker. Suddenly, these emerging adults have to negotiate unforeseen and evolving (dis)abilities while fielding questions and messages of doubt and blame that undermine their perceived physical and mental realities. Though a small sample representing unique experiences, this study seeks to prompt scrutiny of larger societal narratives that cast doubt and blame into chronic illness, pain, and disability, and the extent that these already marginalized populations must suffer and defend themselves. At the heart of the experience of doubting chronic illness is a problematic societal narrative of "normal" and "should." Participants shared stories of dismissal and invalidation that did not focus on witnessing and validating who they are and what they are experiencing, but instead who they should be. Because they are young, female, trans—the list of marginalized identities goes on—they should not be experiencing what they say they are, and thus, it must be attributed to a lifestyle choice they have made, not a reflection of environmental, genetic, and societal factors or otherwise. In spite of these challenges, participants in this study move forward, holding stories of invisible and quiet resilience, deep pain and wisdom, hope in its purest form, and interpersonal lessons that can teach us how we can support loved ones navigating chronic illness and pain.

Expanding the body of literature of communicated sense-making (Koenig Kellas & Kranstuber Horstman, 2015) and applying ToMM (Cooke-Jackson & Rubinsky, 2021) and CNSM theory (Koenig Kellas, 2018) to the experience of chronic illness, this study sought to capture the disorienting and depersonalizing experience of autoimmune disease onset in emerging adulthood through the focus of messages individuals receive about their illness and the lessons that emerged in their illness stories. The goal of this study was twofold: first, to identify harmful and helpful interpersonal messages amidst in emerging adult invisible chronic illness experience, and second, to share the meanings, values, and beliefs developed through storytelling that can offer guidance, support, and solace for other emerging adults at various stages of their illness and diagnostic journeys. In this final chapter, I conclude by discussing implications and future research that can come of this study.

“I know [it’s] coming from a place of caring, but it feels dismissive:” Balancing mixed messages

The present study sought to extend memorable messages research into the experience of chronic illness through the focus of emerging adulthood autoimmune disease. In doing so, the present study identified helpful, harmful, and desired messages received both on the medical journey to diagnosis and following diagnosis. These messages came from a variety of interpersonal sources, most often medical providers, family members, friends, and intimate partners. Grounded in ToMM and addressing Cooke-Jackson & Rubinsky’s (2021) call for research that examines the implications of memorable messages on health behaviors and identity formation and how harmful

messages can be interpersonally disrupted, the present study identifies helpful and desired messages for autoimmune disease in emerging adulthood. Juxtaposing negative or harmful messages to desired and positive messages offer a script for social support others and “healthcare providers to encourage more constructive message delivery” in the face of autoimmune disease diagnosis, as well as ongoing undiagnosed, disruptive chronic illness and pain (Cooke-Jackson & Rubinsky, 2021, p. 96).

Negatively valenced messages

As evidenced by the emergent themes, young adults navigating autoimmune disease are influenced by a variety of memorable messages about their illness, presumed cause, behaviors, and opinions from others. Seeing as this study sought to identify the most helpful, and in turn harmful, memorable messages received during their illness experiences, it comes as no surprise that a variety of negative or harmful messages rose to the surface. Participants identified negative memorable messages that fell into three salient themes including “it’s all in your head,” “but you look healthy,” and messages of blame and dismissal. These messages confirm prior research that AFAB individuals are socialized with messages of blame and shame in regard to their health (Rubinsky, Gunning, et al., 2018; Voorhees et al., 2021) and are prone to receiving messages that equate their symptoms of illness to psychogenic cause (Dusenbury, 2018; Gunning & Hudak, 2021; Hoffman & Tarzian, 2001). These findings align with Flood-Grady, Starcher, & Bergquist’s (2018) study which found that young adults with mental illness receive harmful and invalidating messages about their illness, including “it’s not real” and “get over it and try to be happy,” affirming that psychogenic cause is attributed to invisible chronic illness, both physical and mental.

In line with ToMM's (Cooke-Jackson & Rubinsky, 2021) postulation that memorable messages influence health behaviors, participants in the present study noted that messages such as "it's all in your head" and "but you look healthy" undermined their trust in self and often made them question whether their physical symptoms were truly psychogenic. In many instances, this led to secrecy, concealment, and consenting to undergo unnecessary medical treatments that did not relieve symptoms. Other participants reflected upon years of suffering or "just pushing through" because no one believed them, an undermining medical experience studied by Hoffman & Tarzian (2001) and Dusenbury (2018) in the context of females with chronic pain and illness. This experience of "just pushing through" permeated the negative memorable messages shared, as participants spent years of their young adult lives searching for a diagnosis; the shortest diagnostic journey in this study was one year while the longest was twenty. This aligns with the average timeline of autoimmune disease diagnosis of four years (AARDA, 2021). For diseases such as Systemic Lupus Erythematosus and Ankylosing Spondylitis, of which nearly half of participants had diagnoses, the average length of diagnosis is even longer—six years and nine years, respectively (Dincer et al., 2008; Sawah et al., 2015).

During their diagnostic journeys, participants discussed strategically presenting their symptoms to medical providers in attempt to evade a psychogenic diagnosis, including emphasizing certain symptoms over others in an attempt to receive autoimmunity bloodwork. The strategic revealing and concealing of autoimmune disease has been discussed by Defenbaugh (2013) in the context of Ulcerative Colitis, however, her reflections position hospitals and medical care as a validating safe haven for those

with invisible chronic illness, which begs the question of the difference in medical care and diagnosis depending on the autoimmune condition. Other participants shared that they stopped visiting medical providers altogether, attributing feeling traumatized, disbelieved, and violated by the medical system, returning only when their symptoms became unbearable. This speaks to the innumerable number of women walking this earth with undiagnosed autoimmune disease, suffering in silence because they were dismissed by medical providers and chose not to return or lack access to necessary health care and treatment.

As memorable messages are part of the socialization process and influence health identity formation (Cooke-Jackson & Rubinsky, 2021), behavioral outcomes such as these are especially concerning as they have the potential to result in active disease going untreated for longer periods of time. In line with Charmaz's (1983) findings of physical and psychological suffering in chronic illness, these messages became increasingly harmful on identity with repetition or repeated discrediting events, as "the ill person either feels forced to accept the discredited definitions and/or feels that these definitions further weaken the foundation of an already shaky self" (p. 182). The harmful messages shared by participants in this study further affirm the potential for physical and psychological distress in the journey to autoimmune disease diagnosis and asks us to explore the role of messages and storytelling in sense-making and identity (re)construction in the face of chronic illness and pain.

ToMM (Cooke-Jackson & Rubinsky, 2021) paired with CNSM (Koenig Kellas, 2018) offers a path for harmful message disruption and sense-making, as telling stories of illness prompts individuals to engage in retrospective sense-making. Charmaz (1983)

discusses how the repetitive layering of messages in the context of chronic illness can be harmful if left undisrupted. Proposition 3 of ToMM offers a guide for how to disrupt those repetitive memorable messages, offering opportunity to assess and change behavior. This can be seen in participants' illness stories and the impact that one medical provider believing them can have on their illness trajectory. This retrospective storytelling study offers insight into the role of message disruption, for though dismissive messages characterized these participants' journeys, they each ultimately received diagnoses and competent care. In the words of a validating medical provider whom one participant encountered during their search for diagnosis, "diseases do not read the textbooks... Just because your disease does not check all these boxes, does not mean that it is not real" (3). As a result, this study offers concrete examples of disrupting and helpful health messages as well as the impact that message disruption and retrospective sense-making can have on behavioral, identity, and lifestyle changes in experiences of autoimmune disease.

Positively valenced messages

With the unpredictable and disorienting nature of autoimmune disease, messages that express support, care, and attend to agency offer a stabilizing force in the face of uncertainty; individuals in the current study expressed that even though they are alone in their physical symptoms, they are not alone in their illness experience and journey. These messages also support the development of healthy sense-making and coping in emerging adults, shaping how they view themselves, their health and diagnosis, and their abilities. To extend prior research exploring desired and ideal health messages (Gunning et al., 2019; Koenig Kellas & Holman, 2018b), the present study sought to identify what

emerging adults navigating an invisible, chronic illness would have liked to hear both during their journey to diagnosis, and in the face of ongoing disease and symptom management. Three message themes emerged, including simple statements of support such as “I believe you” and “you are not alone,” learning-centered messages that express interest and investment such as “help me understand,” and messages that return medical agency and allow patients to have a say in disease management and treatment.

Participants expressed a desire for these messages from all interpersonal sources, sharing examples of family members, friends, intimate partners, and medical providers.

Nearly all participants expressed the messages “I believe you” and “you are not alone” as having a profound impact in the face of undiagnosed chronic illness, notably during the earliest stages of disease. Participants identified supportive messages from medical providers as those that offer medical agency, belief, and center the patient in the treatment decision making process, which affirms and extends Willer’s (2014) research on supportive patient-practitioner messages during disruptive health experiences. Like Willer (2014), patients in the current study identified compassionate medical provider messages as those that allow them a voice in treatment plan and connect them with an alternative care provider if the current provider is not able to give the necessary care. The present study also extends Gunning et al.’s (2019) findings that women benefit from messages that allow them to define what agency over their health behaviors looks, feels, and sounds like. These messages affirm the impact of message disruption theorized by Cooke-Jackson & Rubinsky (2021), as validating messages, sometimes received for the first time, marked a change in individuals’ behavior and trust in self, with some recalling renewed faith in their search for diagnosis and treatment. In the words of one participant,

these messages of support offered comfort and solace during an uncertain time for “even though I may be alone in my diagnosis, I am not alone in this journey” (41).

“I’m going to move forward and have a good life:” Wisdom and lessons learned from stories of illness

The present study asked participants to share the stories of their illness journey in line with the retrospective storytelling heuristic, or proposition 1, of CNSM (Koenig Kellas, 2018), which is interested in the “significant and lasting impact of the stories people hear and tell” (Koenig Kellas, in press). Similar to Koenig Kellas & Castle (2019), the stories told in this study were predominately of a clinical nature, thus, to extend CNSM theory’s proposition 1 (Koenig Kellas, 2018), I chose to analyze the meanings, values, and beliefs that emerged from participant stories through a focus of lessons learned in what I call *wisdom narratives*. As narratives can hold memorable messages (Kauffman et al., 2013), conceptualizing the meanings, values, and beliefs of proposition 1 of CNSM as lessons learned offers opportunity to weave ToMM and CNSM together by excavating the memorable messages, disrupting messages, and lessons learned from retrospective stories, offering insight into retrospective sense-making in the context of a health journey. Prior CSM (Koenig Kellas & Horstman, 2015) research has identified lessons learned as an outcome of retrospectively storytelling, including Flood-Grady & Koenig Kellas (2018) who found familial stories of mental illness to hold socializing lessons for younger members perceptions and understandings of mental health and stigma. Lucas & Buzzanell (2017) found lessons for building long-term resilience in the face of hardship in familial memorable messages and stories. This study further tests the

potential of CNSM theory's retrospective storytelling heuristic for identifying salient lessons learned in the context of ongoing health experiences.

This chosen analysis sought to identify relatable and translational lessons for those navigating an autoimmune diagnostic journey or otherwise invisible illness journey. With participants at varying stages of their illness journey, from those recently diagnosed to those who have been managing their condition(s) for years, there is a great deal to be learned from their stories as it relates to coping, making sense, and finding meaning and hope amidst this disruptive health experience. These wisdom narratives offer solace and support for those currently navigating an autoimmune diagnosis in emerging adulthood, as well as individuals navigating simply an invisible, yet-to-be-diagnosed chronic illness or pain, as well as a guidebook of lessons from those who have come before.

Five salient lessons emerged from the stories participants told about their illness journeys, including learning to separate self from illness, create new "normals," rediscover trust in self, as well as noting an increase in empathy for others, and recognition of privilege and disparities in medical care. These findings affirm Flood-Grady & Koenig Kellas' (2018) and Buzzanell's (2018) findings that storytelling can facilitate reframing, as well as foster resilience in the form of creating new normals, positive adaptation, and personal growth. Additionally, these results align with Wilson & Stock's (2019) findings that acceptance, sense-making, and identity renegotiation are integral to increasing resilience, empathy, compassion, and maturity in young adults with chronic health conditions. The present study supports Wicks, Berger, & Camic's (2018) narrative study of identity formation in chronic illness onset at a young age, with similar findings including locating trust or power in self, contradicting health and illness, and

forging a new path, offering insight into parallel developmental tasks following disease onset in adolescence and emerging adulthood.

Participant story themes of learning to separate themselves from their illness, as well as a noted increase in empathy and recognition of disparities in medical care reinforces that storytelling has implications on an individuals' perception of their own health, as well as how they treat the health conditions of others (Castle, 2015; Flood Grady & Koenig Kellas, 2018). Many participants reflected upon a shift in how they viewed health, ability, and access to medical care, expressing having a linear view of illness and disability (e.g., disability equates to being bedridden or in a wheelchair) prior to themselves becoming disabled, as well as recognition that their access to medical care and treatment, whether based on financial means, locational access, or other, was not available to everyone.

Something striking from these stories was the inner peace and acceptance that came from creating new normals and rediscovering their trust in self, which speaks to the importance in disrupting harmful memorable messages of blame and shame. These findings reinforce Buzzanell's (2010, 2018) adaptive-transformational tensions amidst the process of resilience and offer further avenues to explore resilience scholarship in the face of chronic illness, as participant reflections of moving forward with illness "[looked] beyond conventional ways of thinking about and doing life by putting alternative logics to work" (2018, p. 14). Instabilities, such as onset of autoimmune disease, "produce capacities to persist and encourage ongoing constructions of the 'new normal' or the post-crisis vision" (Buzzanell, 2018, p. 15). Participants spoke of wading through anger, frustration, and resentment—from the whys of not being believed, genetic or

environmental pre-disposition to disease, loss of relationships, time, and mobility due to a long diagnostic journey and treatment being withheld, the list goes on—to reach a point of recognition and acceptance of health and youth as fleeting and learning to live with the uncertainty of illness.

Though this study could certainly focus on those frustrations, being young and sick is not fair, doing so would diminish the strength, resolve, and patient resilience of this inspiring population. Alongside many harmful memorable messages were expressions of empathy, understanding, and release for the sender of the message; next to stories of trial or tribulation were reflections of its placement as a steppingstone to healing and growth; with expressions of loss came something that was gained, whether a new sense of self, relationship, or otherwise. Within these stories which told of losing parts of self were greater roadmaps leading participants back to themselves; more accepting, empathetic, and grateful selves who recognize the limitations of body, medicine, and relationships and learned to care for their bodies and souls in ways they did not prior to falling ill. For while one hand held darkness, the other held light. This aligns with McAdam's (1993) work on redemptive stories of illness and presents an opportunity for future research to explore proposition 2 of CNSM theory as it relates to story framing and wellbeing. The wisdom narratives in this study offer further insight into the process of meaning making and sense-making in the face of ongoing chronic illness.

Limitations, future research, and practical implications

This study sought to extend communicated scholarship into the experience of ongoing chronic illness by studying the illness narratives of emerging adults with autoimmune disease. These stories were analyzed through two theories within CSM

(Koenig Kellas & Kranstuber Horstman, 2015), ToMM (Cooke-Jackson & Rubinsky, 2021) and CNSM theory (Koenig Kellas, 2018) with the intent of offering insight into the role messages about illness play in identity development and health behaviors, as well as meanings, values, and beliefs that emerge from the experience of communicating to make sense of illness.

Although the interpretive and qualitative nature of this study offered depth and insight into how this population and their relational supports makes sense of chronic illness, as well as the role that messages from interpersonal others play in shaping perceptions of illness, this is just one experience of chronic illness in emerging or young adulthood. The current population was constrained to those who had received a diagnosis and asked them to reflect upon the years of experiencing undiagnosed, invisible illness in an effort to speak to the experience of invisible, chronic illness at a young age. To more effectively capture the chaotic narrative of chronic illness (Frank, 1995), scholars may consider populations who are in the middle of undiagnosed invisible illness. Additionally, this study captures multiple autoimmune diseases, each with their own disease manifestations, characteristics, and parallel narratives. This study acts as an introduction into narratives of autoimmunity and asks scholars to more deeply explore specific autoimmune disease diagnostic journeys and how those narratives and messages may differ, like Castle (2015) has explored in the context of Systemic Lupus Erythematosus. Additionally, there are multiple layers of identity that play into medical treatment, including gender, race and ethnicity, age, among others. Though this study includes diverse participants, including women of color and a trans male, studies that focus on

specific identities and demographics can more effectively tease out biases and barriers that may be at play in medical diagnosis and treatment.

This study offers practical implications for family members, friends, intimate partners, and medical providers to support an emerging adult navigating autoimmunity or invisible chronic illness in general, as well as opportunity to explore future narrative interventions. The messages identified in this study offer a preliminary guide for interpersonal social supports to most effectively convey messages of support and solace in the face of chronic illness. With avenues for sense-making identified in the form of beliefs and lessons learned, this project offers a guide to develop translational storytelling interventions (Koenig Kellas, 2018; in press) for this population, perhaps through the creation of social support friendship pod conversations, story witnessing (Koenig Kellas et al., 2020), peer mentoring (Faith et al., 2018), or arts-based interventions such as writing (Koenig Kellas et al., 2015), drawing (Willer, 2012; Willer et al., 2018), or photography (Mizock et al., 2015).

Beyond practical applications, this study holds theoretical implications for ToMM (Cooke-Jackson & Rubinsky, 2021) and CNSM theory (Koenig Kellas, 2018), as well as insight into the important links between CSM constructs (Koenig Kellas & Kranstuber Horstman, 2015), such as stories or narratives as encompassing memorable messages¹. Both CNSM and ToMM posit that retrospective reflection of stories and messages offer avenues for sense-making, meaning-making, and identity (re)construction (Cooke-Jackson & Rubinsky, 2021; Koenig Kellas, 2018). This study touched upon memorable messages, disruptive messages (such as helpful or desired messages), and lessons learned

¹ See p. 37 for Participant 15's quote, an example of narratives housing memorable messages)

in participants' retrospective stories of illness, shedding light into how retrospective storytelling can offer insight into the impact of initial or repetitive messages, the identification and role of disruptive messages in socializing health, and their implications in the form of behavioral changes, lessons learned, or otherwise.

Conclusion

In line with Cooke-Jackson & Rubinsky's (2021) claim that memorable messages about health influence decision-making processes and behavior change, this study has identified that the messages emerging adults receive about their illness from medical providers, family members, friends, and influential interpersonal others influence their perceptions of self, illness, and health behaviors. With messages emerging from participant stories, this study also extends Kauffman et al.'s (2013) claim that memorable messages can be an effective narrative sense-making tool, by showing the intertwining relationship between memorable messages and meanings, values, and beliefs that emerge from participant narratives. Results suggest that interpersonal conversations and storytelling are instrumental in an individuals' development of illness identity, sense-making structures, and coping in the face of disruptive autoimmune disease onset. I began this thesis by reviewing literature on communicated sense-making in the face of health and illness, then detailed the methods that were used to complete the study, and reported analysis of the data and findings. In conclusion, I discussed the role that this study places in advancing CSM, CNSM, and ToMM and our understandings of messages and stories that shape perceptions of body, self, health, and ability in the face of emerging adult illness onset. Opportunities for future research, practical implications, and potential narrative interventions were discussed. These findings call for scholars to more deeply

explore the stories of young and emerging adults with chronic illness, for they hold lessons that can be applied to those with and without illness; lessons about resilience, resolve, and mortality, the profound impact of simple statements, and the deeply healing power of loving relationships and conversations.

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APPENDIX A: RECRUITMENT SCRIPTS

A1. Social Media and Listserv Announcement

Autoimmune Disease Onset in Emerging Adulthood

Hello! My name is Jacqueline and I am a graduate student at the University of Nebraska – Lincoln conducting a study on narratives of autoimmune disease onset in assigned female at birth (AFAB) emerging adults (e.g. women, gender non-conforming individuals born female, male-identifying individuals born female). During my early 20's, I experienced a debilitating health journey that left me nearly bedridden for three years. It took four years and eleven doctors before I was diagnosed with an autoimmune disease. Frustrated by years of misdiagnoses, dismissal, and invalidation, I have dedicated my Master's thesis to studying the firsthand narratives of autoimmune disease onset in emerging adulthood (19-30 years old) with the goal of identifying effective means of support and making sense for these individuals, as well as shedding light on an experience not often discussed. If you have experienced a disruptive autoimmune disease experience, I would love to interview you for this study.

I invite you to participate in this study if:

- you are between the ages of 19-30 years old
- you identify as assigned female at birth
- you identify as having a life-disrupting autoimmune disease that developed during emerging adulthood (19-30 years old) and went undiagnosed or inconclusively diagnosed for over one year

This is a research project that focuses on understanding (helpful and harmful) messages received on the diagnostic journey, desired messages, and effective devices for sense-making amidst illness disruption. Participation in this study will require approximately 45-90 minutes. You will be asked to complete a video interview via Zoom in which you will answer questions about demographic information and share your illness experiences. You will complete the interview via your own personal computer. Participants will receive a \$10 gift card for their participation.

If you are interested in participating or receiving more information about participating in this study, please email the primary investigator at the following email address:

Jacqueline Gunning
jgunning2@huskers.unl.edu

Thank you!

A2. UNL Department of Communication Studies Listserv announcement

Autoimmune Disease Onset in Emerging Adulthood

Hello! My name is Jacqueline and I am a graduate student at the University of Nebraska – Lincoln conducting a study on narratives of autoimmune disease onset in assigned female at birth (AFAB) emerging adults. I invite you to participate in this study if:

- you are between the ages of 19-30 years old
- you identify as assigned female at birth
- you identify as having a life-disrupting autoimmune disease that developed during emerging adulthood (19-30 years old) and went undiagnosed or inconclusively diagnosed for over one year

This is a research project that focuses on understanding (helpful and harmful) messages received on the diagnostic journey, desired messages, and effective devices for sense-making amidst illness disruption. Participation in this study will require approximately 45-90 minutes. You will be asked to complete a video interview via Zoom in which you will answer questions about demographic information and share your illness experiences. You will complete the interview via your own personal computer.

You will receive a \$10 gift card for completing this interview.

If you are interested in participating or getting more information about participating in this study, please email the primary investigator at the following email address:

jgunning2@huskers.unl.edu

Thank you!

APPENDIX B: INFORMED CONSENT



IRB #: 20835

Participant Study Title: Autoimmune Disease Onset in Emerging Adulthood

Authorized Study Personnel:

Principal Investigator: Jacqueline Gunning
 jgunning2@huskers.unl.edu

Email:

Secondary Investigator: Jody Koenig Kellas, Ph.D.

Email: jkellas2@unl.edu

Key Information:

If you agree to participate in this study, the project will involve:

- Assigned female at birth (AFAB) individuals ages 19-30 who identify as having a life-disrupting autoimmune disease that developed during emerging adulthood (19-30 years old) and went undiagnosed or inconclusively diagnosed for over one year, and you live in the United States.
- Procedures will include completing a 45-90 minute Zoom interview about your illness experiences on your personal computer.
- You will receive a \$10 gift card for your participation in this study.
- There is minimal risk involved in this study and you may opt out at any point in time.
- You will be provided a copy of this consent form upon request.

Invitation

You are invited to take part in this study about making sense of the experience of autoimmune disease onset in emerging adulthood. The goal of this study is to better understand the experience of emerging adulthood autoimmune disease onset as well as identify effective means of support and sense-making for emerging adults seeking a diagnosis.

Why are you being asked to be in this research study?

You are being asked to be in this study because you are an AFAB individual between the ages of 19-30 who identifies as having a life-disrupting autoimmune disease that developed during emerging adulthood (19-30 years old) and went undiagnosed or inconclusively diagnosed for over one year, and you live in the U.S.

What is the reason for doing this research study?

Experiencing the onset of autoimmune disease in emerging adulthood can be disruptive experience, but storytelling and narratives about difficult experiences can help people make sense of stressful events. The purpose of this study is to (1) better understand the experience of autoimmune disease onset in emerging adulthood, and (2) to identify

effective devices for sense-making and support during a disruptive chronic illness experience in emerging adulthood.

What will be done during this research study?

Participation in this study will require approximately 45-90 minutes. You will be asked to complete an interview in which you will be asked to reflect on your illness experience, memorable messages and conversations received during the diagnostic journey, and means of making sense and coping. You will complete this interview through Zoom via your own person computer.

How will my data be used?

Your data will be shared amongst the members of the research team but will be kept confidential. De-identified survey responses or written responses may be used for educational purposes in the classroom and will be written up in academic presentations and manuscripts for academic publication. Any personal information that could identify you will be removed from the data and any written reports. Subjects information collected as part of the research, even if identifiers are removed, will not be used or distributed for future research studies.

What are the possible risks of being in this research study?

This research presents risk of loss of confidentiality and emotional and/or psychological distress because the interview will ask you to reflect on difficulties you have faced during your illness journey. You can share as much or as little information about yourself that you feel comfortable with. If you want to end your participation in the study *at any time*, you may do so.

What are the possible benefits to you?

Reflecting on your illness experience may help you make better sense of it and reframe in a more beneficial or positive way, as well as provide catharsis. However, you may not get any benefit from being in this research study.

What are the possible benefits to other people?

Results obtained from this study will be used to design supportive interventions for emerging adults navigating the onset of chronic illness. The benefits to science and/or society may include better understanding of how to effectively support emerging adults navigating a disruptive illness journey.

What will being in this research study cost you?

There is no direct cost to you to be in this research study. You will need to provide your own technology to access Zoom for the interview.

Will you be compensated for being in this research study?

You will receive a \$10 gift card for your participation in the interview.

What should you do if you have a problem during this research study?

Your welfare is the major concern of every member of the research team. If you have a problem as a direct result of being in this study, you should immediately contact one of the people listed at the beginning of this consent form.

How will information about you be protected?

Reasonable steps will be taken to protect your privacy and the confidentiality of your study data. Data collected in this study including electronic survey files, audio files, and video files will be stored on a secure server (i.e., Box) and will only be seen by members of the research team. All research records, including audio and video data, will be kept indefinitely by the research team in the secure server.

The only persons who will have access to your research records are the study personnel, the Institutional Review Board (IRB), and any other person, agency, or sponsor as required by law. The information from this study may be published in scientific journals or presented at scientific meetings but the data will be reported as group or summarized data and your identity will be kept strictly confidential.

What are your rights as a research subject?

You may ask any questions concerning this research and have those questions answered before agreeing to participate in or during the study. For study related questions, please contact the investigator(s) listed at the beginning of this form.

For questions concerning your rights or complaints about the research contact the Institutional Review Board (IRB):

- Phone: 1 (402) 472-6965
- Email: irb@unl.edu

What will happen if you decide not to be in this research study or decide to stop participating once you start?

You can decide not to be in this research study, or you can stop being in this research study (“withdraw”) at any time before, during, or after the research begins for any reason. Deciding not to be in this research study or deciding to withdraw will not affect your relationship with the investigators or with the University of Nebraska-Lincoln. You will not lose any benefits to which you are entitled.

Documentation of Informed Consent

You are voluntarily making a decision whether or not to participate in this research study. By clicking on the I Agree button below, your consent to participate is implied. You should print a copy of this page for your records.

Name: _____

APPENDIX C: INTERVIEW PROTOCOLS

C1. Interview Protocol for Zoom Interviews

Before we begin, I would like to thank you for agreeing to talk with me today about your experience with chronic illness. My name is Jacqueline Gunning and I am a graduate student at the University of Nebraska – Lincoln, and I am studying the illness narratives and diagnostic journeys of assigned female at birth individuals with autoimmune disease. Before we begin, let's review the informed consent form you received.

[Review informed consent]

I am going to begin recording. Any information recorded in this interview will remain private and confidential, and any identifying information will be removed upon transcription.

[Start recording]

Part 1 (Demographics)

I would like to begin with some general questions about you.

1. How old are you?
2. What gender do you identify with?
3. What is your diagnosis? What age were you diagnosed?
4. How long did it take from onset of initial symptoms to diagnosis?
5. What is your geographic location?
6. How do you identify in terms of your race and ethnicity?

Part 2 (CNSM)

1. To begin, please tell me the story of your illness journey.
2. How do you define health? How do you have define illness?

Part 3 (Memorable Messages)

I am interested in the memorable messages that emerging adults with autoimmune disease receive during their diagnostic journeys. Memorable messages are short, highly impactful verbal messages that individuals can recall over a long period of time and shape identity, values, beliefs, and behaviors (Rubinsky & Cooke-Jackson, 2017; Stohl, 1986). These messages can come from doctors, medical practitioners, family members, friends, intimate partners, influential others, etc. and can be positive, negative, or neutral, as long as they are long lasting. Does this make sense to you? (ADD VISUAL MESSAGES TO DEFINITION)

1. Can you recall, and then describe, a memorable message(s) you have received your diagnostic journey? This can include what it meant, how you felt, its influence, etc.
 - a. Can you recall who you received this message(s) from?
 - b. Can you recall how it made you feel and/or left you feeling?

- c. What, if anything, do you wish the person who said this message would have said? Why?
2. Have these memorable message(s) about illness impacted your behaviors? If so, please explain in what ways.
3. How has your perspective about illness changed over time? If so, in what ways has your perspective changed and what contributed to this change?

Conclusion

That concludes our interview. Thank you again for participating and sharing your experiences with me. It helps move research forward so we can better understand how to support emerging adults navigating autoimmune disease. Do you have any questions, comments, or insights about this study or the interview?

The last thing I would like to discuss is future research. Would you be interested in being contacted about future research opportunities?

[Ask for email]

[End recording]

C2. Interview Protocol for Written Response

Dear [name],

Before questions, I want to thank you again for being a part of this study. I am so grateful for your time, honesty, and vulnerability in sharing your stories navigating autoimmune disease diagnosis. A bit of background: My name is Jacqueline Gunning and I am a Communication Studies master's student at the University of Nebraska – Lincoln studying the illness narratives and diagnostic journeys of assigned female at birth individuals with autoimmune disease. My goal of this study is to identify effective messages of support for individuals navigating autoimmune disease diagnosis, as well as highlight the wisdom from this population and experience. I want emerging adults navigating disruptive, undiagnosed invisible illness to know that they are not alone in their experiences and to encourage self-advocacy in medical settings, as well as talk about an experience not often discussed—being young and sick.

Before answering questions, please fill out the Informed Consent document on Qualtrics: (LINK); this gives consent for participation in the study, as well as collecting a few demographics (which will also be collected on this page to ensure I have them in two places). I have emailed you a copy of the Informed Consent for your records, as well. If you have any questions at all, please message or email me! The heart of the informed consent is that you do not have to share any information that you do not want to, and to know that any information shared will remain private and confidential, as well as de-identified upon transcription (so no one will be able to track you back to this study).

There are three parts to this study's interview questions—1) demographics, 2) your illness story, and 3) “memorable messages” received. You are welcome to answer the questions on this document, or on a separate document; whichever is easiest for you. If you have questions as you answer them, please feel free to message/email me.

Part 1 (Demographics):

First, I would like to begin with some general questions about you and your diagnosis:

7. How old are you?
8. What gender do you identify with?
9. What is your diagnosis?
10. What age were you diagnosed?
11. How long did it take from onset of initial symptoms to diagnosis?
12. What is your geographic location?
13. What is your race and/or ethnicity?

Part 2 (Illness Story/Narrative):

1. In as much detail as you would like to share, could you please tell me the story of your illness journey.
2. With your experiences in mind, I have a two-part follow up question: 1) How do you define “health?” And 2) How do you define “illness?”

Part 3 (Memorable Messages):

I am interested in the “memorable messages” that emerging adults with autoimmune disease receive during their illness/diagnostic journeys. “Memorable messages” are defined as short, highly impactful verbal messages that individuals can recall over a long period of time and shape identity, values, beliefs, and behaviors (Rubinsky & Cooke-Jackson, 2017; Stohl, 1986). These messages can come from doctors, medical practitioners, family members, friends, intimate partners, influential interpersonal others, etc. and can be positive, negative, or neutral, so long as long as they are long lasting and specific. An example of a memorable message would be, during my diagnostic journey, I was told by a doctor “we can’t help you anymore.” Which made me feel guilty and like I had control over my illness; like I wasn’t doing enough to heal or fix it. An example of a memorable message from a friend would be “you’re tired all the time.” With memorable messages in mind, please respond to the following memorable message prompt (you can include multiple memorable messages; please include as many as you can think of, from as many interpersonal sources):

4. Can you recall and then describe memorable messages that you have received from **medical providers** on your diagnostic journey? This can include what it meant, how you felt, its influence, etc.
 - a. Can you recall how it made you feel and/or left you feeling?
 - b. What, if anything, do you wish the person who said this message would have said instead? Why?
5. Can you recall and then describe memorable messages that you have received from **friends, family, and/or intimate partner(s)** on your diagnostic journey? This can include what it meant, how you felt, its influence, etc.
 - a. Can you recall how it made you feel and/or left you feeling?
 - b. What, if anything, do you wish the person who said this message would have said instead? Why?
6. Have these memorable message(s) about illness impacted your behaviors? If so, please explain in what ways.
7. How has your perspective about illness changed over time? If so, in what ways has your perspective changed and what contributed to this change?

Thank you again for taking the time, thought, and care to respond to these questions—I am so appreciative! Please let me know if you have any questions about this project; I am happy to stay in touch as the data is published, as well, if you are interested.

Wishing you continued healing and peace,
 Jacqueline
 jgunning2@huskers.unl.edu

APPENDIX D: DATA CONFERENCE DOCUMENT

“You’re Not Alone:” Wisdom Narratives & Communicated Sensemaking in Emerging Adulthood Autoimmune Disease Codebook

Jacqueline Gunning

“One day I woke up and I had this low-grade pain in my lower back and it's one of the few things I think about that I get really emotional about. I had the last pain free day of my life and I didn't even appreciate it. Like there was that one day where I just never was chronically ill and I just ate my dinner and ate my breakfast and didn't think about pain and didn't think about fatigue. I think about that a lot. That your life can just change like that in a single night and I'm like, what was my body up to? What was it doing? Was there one thing that I did that one day that made all this happen?” -Participant 3

RQ1: *What are the helpful, harmful, and desired memorable messages that emerging adult assigned female at birth individuals with autoimmune disease receive during their diagnostic journeys?*

Harmful:

Presumed health based on outward appearance. Examples include, “but you look healthy” (10), “well, you look okay” (12), and “but you look fine, I don’t understand why you’re going to all these doctors” (7). A participant with Systemic Lupus Erythematosus elaborated:

“I don't consider myself disabled. I work full time, I’m mobile, I socialize, and I think to some people that's confusing. So, the message that they'll send is ‘you're doing great!’ or ‘I'm so happy you're healthy,’ and not understanding that those two things can coexist. You can be chronically ill but still functioning or appearing healthy” (23).

“It’s all in your head.” Participants expressed medical providers and interpersonal others attributing symptoms to the state of their mental health, prior mental health diagnoses (e.g. depression, bipolar disorder), or lifestyle decisions. For example, a participant with Graves’ Disease noted the behavioral impact of being “[told] ‘it’s all in your head’ ... anytime I have any physical symptoms, it was always, every single time, attributed to stress, to my mental illness... I'm afraid to bring up certain symptoms or certain experiences because I'm afraid is either going to be attributed to ‘It’s just a symptom of your mental illness’ or ‘It’s only your head’” (4). A participant with Ankylosing Spondylitis echoed this experience, sharing a medical provider “told me that ‘the pain just in your head’ and ‘it's not as bad as you're making it out to be.’ Which, I was not able to walk at that time without limping, so that really struck me. I'm showing a physical symptom that this is bad, but her thought process was that it was something related to my menstrual cycle and that it would just go away as my cycle did. I wasn't even on my period at the time” (20). A participant with Autoimmune Encephalitis, whose disease onset during college, recalled a doctor saying, “do you think it is just stress? The

top achievers are often like this” (5). A participant with Hashimoto’s Thyroiditis recalled recurrent medical dismissal, sharing:

“[My doctor] asked me, ‘have you ever been abused in your past?’ and I said, ‘why are you asking?’ She said, ‘well, sometimes people who have had past abuse can create things in their mind to gain sympathy or attention’... Thankfully, I’ve been able to sort of hold it together, but there have definitely been times when I’ve doubted myself and thought, ‘*am* I just crazy? Is this all made up in my head? Am I really just lazy and I’m making an excuse for it?’ And that has been the main [message] from doctors; lots of little comments about ‘well, you’re just getting older,’ ‘well, maybe you’re not trying hard enough.’ There’s ‘all of your test came back normal so there’s really nothing wrong with you,’ ‘I don’t know why you keep bringing this up we’ve already tried this,’ ‘it’s just your mental health’ (16).

One participant with Ankylosing Spondylitis detailed the extent that medical providers chased a mental health diagnosis, sharing:

“I waited forever to see [a] cardiologist... he looks over everything and, I’ll never forget, he looks at me and says, ‘If you weren’t so young, and you weren’t so skinny, these results would be extremely alarming. But since you’re not old and since you’re not fat I think you’re fine. I think you should try an antidepressant’... I just remember going and sitting in my car and just, like, I couldn’t even drive. I just cried because I was like, it’s there. He essentially said ‘on paper, something is wrong, but because of these factors that you have literally no control over, I’m not going to do anything about it, and you’re probably depressed’... [So, I went] on an antidepressant for a while-- I don’t think it really did much for me-- but that’s, you know, where I ended up. They asked me if I thought it was working, and there was one point... that my doctor said “I don’t think this is strong enough for you, let’s add an anti-psychotic”-- which has very extreme side effects... And I mean at that point, it’s like, I don’t know what to believe. I’ve always been the kind of person [who] put my faith in science and my faith and doctors and I didn’t feel like I could trust myself anymore. So I was like, yeah, I guess I need an anti-psychotic because I knew that what I was experiencing was very real and if the doctor said it’s in my head then let’s treat the head, let’s treat the mind here. And so I did. I went on an anti-psychotic for, gosh, a few months, and they said ‘don’t stop taking it.’ I quit taking it on my own because I realized it was just making things worse... I’ve heard really similar stories from people that I’ve met that have similar rheumatic autoimmune disorders and it’s so disappointing. It really just makes you lose faith in the whole [medical] system” (15).

Dismissal of chronicity and symptomatic impact of diagnosis. Participants expressed frustration when family members, friends, or influential others dismissed or invalidated the severity of their symptoms, diagnosis, or the impact their illness has on their lives. Messages ranged from seemingly helpful but inadvertently harmful, such as “just have a positive attitude,” “you’ve just got to be positive,” which a participant with Undifferentiated Connective Tissue Disease and Celiac Disease said, “which I know is coming from a place of caring but feels dismissive” (14), to tone deaf such as “you’re just tired” (18) or “you’re tired? Sleep it off” (11), to outwardly harmful such as “get over it”

(13). A participant with Ankylosing Spondylitis detailed the evolution of her family's support throughout their her journey, sharing:

“At first, your family takes you very seriously... and then, when you don't get answers immediately and you're going from doctor to doctor and trying medications and nothing's working then they're kind of like okay, we're tired of putting up with this. I know, at least in my family, a message that has been persistent is ‘just be positive’ and ‘just believe that everything's going to work out.’ ‘Just believe you're going to get better.’ ‘Just believe some doctor is going to figure it out.’ And that's how you keep going and so that really, really started to get to me when I was working every day, and just the act of getting up and putting on clothes was making me sick. The act of going to work and doing the bare minimum was making me so sick. And then I call my mom and I'm like, ‘mom, I just I can't do this anymore. I am serious, I'm making myself sick by doing this every day.’ And she [said], ‘just keep your head up. Just be positive.’ ‘Just keep going.’ It's this idea of just keep pushing and eventually it'll get better. But I kept pushing for years and years and it only got worse. In the beginning, family was pretty supportive... but as time goes on, the message has been ‘alright, at some point, you have to get over it, and at some point, you have to just kind of suck it up and keep going’ (15).

Helpful and desired:

“I believe you. You aren't alone” Participants expressed a desire for social support others to acknowledge their symptoms without action or solutions. Examples include “I hear you” (17), “I believe you. I support you. How can I help you? You are not alone” (2), “We believe you. We know you're trying your best. What you are doing is enough” (1). A participant with Systemic Lupus Erythematosus and Psoratic Arthritis expressed a desire for “messages that attend to agency like 'what would make you feel best right now?' Like, 'what can I do to help you feel best?' ‘What do you need?’ ‘I can help you.’ ‘I'm here to assist you.’ [are] really helpful” (11). Affirming, validating messages of support are important when seeking a diagnosis, for as a participant with Rheumatoid and Psoriatic Arthritis reflected on the impact of hearing “‘you're not alone.’ Even though I might be alone in my diagnosis, I'm not alone in this journey” (7).

Messages of interest and investment. Participants expressed a desire for messages from support others that expressed interest in learning more about their diagnosis. Examples include, “I don't know what it's like to have Lupus, but I care about you and I want to learn more about it” (23). A participant with Lupus recalled a friend who asks, “‘How are you feeling today?’ ‘What does [Lupus] look like for you?’ [Messages that are] not pointed, per se, just curious. It creates a safe environment for me to disclose whatever. And I feel like if she doesn't understand any part of it, she says ' I don't really understand that. Can you tell me a little bit more about that?' [She shows a] genuine interest in it” (11).

Returning medical agency. Participants expressed a desire for messages from medical providers that admitted unknowing and returned agency to the patient. Multiple participants expressed a desire for medical providers to admit that they may not know

what is going on during the diagnostic journey. For example, “the biggest message that could change is to just have them be willing to state ‘I don't know, but I care about you and I want to help you find an answer’” (20). Further desired messages include “I can see something is wrong here, I just don't know what... we will do our best to try to get you back to a good quality of life” (5) and “‘I understand that you are feeling this way and let's work on how to solve it,’ rather than brushing it off” (9). Participant 22 shared, “I would love [for medical providers to] say ‘let's see if we can get you feeling better.’ ‘Let's see if we can get you back to doing what you want to do.’ Just hearing that a physician is invested in you and actually wants you to feel better” (22).

*Include positive messages where doctors said this

Wisdom Narratives:

RQ2: *What meanings, values, and beliefs does this population assign to their illness experience?*

Increased trust in self. Participants noted an increased trust in self following their diagnostic journeys. For example, “I've just learned to trust myself more and look at my health in a more holistic way in general” (4) and “I'm not saying that my position has evolved to ‘don't trust your doctors,’ but trust your body. You can be the person to validate what is going on. It's not in your head” (10).

Being sick does not define you. Participants shared the evolution of their illness identity, notably learning how to separate their illness from sense of self. A participant with Systemic Lupus Erythematosus shared, “I think in the beginning, it was all consuming. From the time that my diagnosis came and even for some time after that, it infiltrated every aspect of my life. My life was Lupus. [It] impacted everything I did, and so, in that way, it was a really big part of my life and it still is now [but] after a while I was like this is too much. This is taking up my life, [so] I stopped focusing in on my symptoms. If I had joint pain, I wouldn't ignore it, I still do things to try to help it, but I wouldn't give it power or life. As I continued to do that, I noticed I felt like I was becoming more of myself and I was doing things that I stopped doing... I was getting my identity back and my life back. It's an ever-evolving thing and there are some days where I'm like, wow, Lupus is me today because it's just really bad today, but I feel like over time, my Lupus evolved from less of an identity to more of just a part of my life that I have to deal with and engage with but that does not control me” (18).

Increased empathy for others. Participants expressed the development of empathy, notably not making assumptions based on others' outward appearances. For example, a participant with Systemic Lupus Erythematosus shared, “my perspective about illness changed over time [in that] I don't like to make assumptions about other people's health or illness, because I don't like when people do that to me” (23). A participant with Hashimoto's Thyroiditis shared, “[This experience] has made me much more empathetic... A lot of times what we see as a failing or personal inconvenience to us from another person, I have had to realize [that] you cannot pin everything that a person does just on themselves. Sometimes it's not their fault, it just isn't, and it's not fair to just assume that you know everything about them and [that] you can pinpoint why they do

what they do. That's not fair at all... I want to be really honest and open with the people that I meet because I want them to then go forward and if they meet a woman who they think is 'crazy' and 'always has health problems,' I want them to remember me and remember that I still tried really hard. I was trying to get treatment. I'm still a person. I still have worth. I'm still doing things that are worthwhile, but I have something at the base of it all that makes it much more of a struggle for me than it might be for other people." (16).

Creating new "normals." Participants expressed learning to meet their body where it is through acceptance of self, illness, and ridding themselves of the concept of returning to "normal." For example, a participant with Ankylosing Spondylitis shared, "so much of dealing with the onset of a chronic illness is trying to get back to normal and wanting to be normal and wanting to conceal limitations for a lot of people. But in fact, it's actually really important for you to accept what's happening to you and to reach out to other people who might be going through the same thing because those people are going to validate you and they're also going to give you advice that is going to help you advocate for yourself" (3). A participant with Autoimmune Encephalitis shared, "I've tried to look for other ways to still have a good life. With the people that really love me, I don't feel like I need to be at my peak condition in order to have a good time with them or to have a connection with them. I can enjoy yoga or activities without needing to have all my health in order. I think that's something I've slowly learned to accept more and more of" (5).

Recognition of privilege and disparities in medical care. With autoimmune disease disproportionately affecting women of color, white participants discussed a recognition of privilege in their access to medical care. A participant with Systemic Lupus Erythematosus noted, "I think one of the bigger takeaways for me throughout this whole process was also reflecting a lot on my privilege and my access to medical care [and] health insurance. I spend a lot of money, even with health insurance, on my medications each month. In Lupus in particular it's mostly ethnic minority women who are disproportionately likely to have it, so through having Lupus, I have met a lot of those women because of where I live. A lot of them are in [city] and disadvantaged situations and their outcomes are so much worse... We think of illness as objective—you have it or you don't, and it's mild or severe—but really there is a lot environmentally that goes into your outcomes. Your access to care, your knowledge base. Are you willing to advocate for yourself? Are you able to? Do you have social support systems? Do you have job flexibility to make your appointments? So that's been another major takeaway for me" (23). Another participant with Systemic Lupus Erythematosus elaborates, "There is a general stereotype that the medical field is working to move away from that still surrounds women's bodies and how they try to advocate for themselves. So that is an awareness that I carry with me and try to keep in consideration the privileges of medicine and the privileges White people have to medicine that a lot of marginalized communities don't have. Most people who have Lupus are women of color. But these tests, and the samples, and all these medical journals that are coming out aren't including those voices of people who have lived with these conditions for their whole life and arguably have

worse conditions. So that's something that really impacts how I think about autoimmune diseases and chronic illness" (10).