Master's Thesis

Exploring the Diagnostic Journeys of Women with Systemic Lupus Erythematosus in New York City: A Qualitative Research Proposal

Thesis Type: Research Proposal

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Abstract

Despite being a relatively common autoimmune disease that physicians are trained to recognize, the average time to diagnosis for patients with systemic lupus erythematosus (SLE) is approximately 6 years. In addition to this troubling overall diagnostic delay, women typically wait almost two years longer than men to receive a diagnosis, and there is also emerging preliminary evidence of racial/ethnic disparities in time to diagnosis. Approximately 90% of SLE patients are women, and the prevalence of SLE is higher among racial and ethnic minorities than among white people in the United States. Despite this, the literature regarding the factors that contribute to diagnostic delay is not robust, and there is a significant gap when it comes to examining gender and racial disparities in particular. The proposed study will utilize qualitative research methods informed by narrative inquiry and grounded theory to examine the diagnostic journeys of women with systemic lupus erythematosus in New York City with a focus on the ways in which gender and race shape patient-provider interactions and time to diagnosis. Data collection will occur in two phases. The first phase will involve conducting 20 key informant interviews with medical providers, social service providers, and employees at patient advocacy organizations as well as observing patient support group sessions. The second phase will consist of semi-structured in-depth interviews with 12 women with SLE. Drawing from a narrative approach, each woman will be interviewed three separate times. These diagnostic journey narratives will be analyzed using thematic analysis.

Statement of the Problem

Systemic lupus erythematosus (SLE) is a chronic, oftentimes debilitating autoimmune disease that can affect any organ in the body (Pascoe et al., 2017). The most commonly-experienced symptoms are fatigue, joint pain, muscle pain, and skin and mucous membrane lesions, but without proper intervention and treatment, organ damage such as kidney failure can occur (Wallace & Gladman, 2019). The average time between the onset of symptoms and receiving a diagnosis is approximately 6 years (Lupus Foundation of America, 2019; Morgan et al., 2018). Women typically wait almost two years longer than men to receive a diagnosis, and while it remains understudied, evidence also points to potential racial/ethnic disparities (González et al., 2013; Morgan et al., 2018). While SLE is a complex illness with a wide array of potential symptoms and presentations, it is a relatively common autoimmune disease that all

physicians are trained to recognize and that rheumatologists are well-equipped to identify and treat. In addition, unlike other conditions with non-specific functional symptoms such as fibromyalgia, chronic pain, and myalgic encephalomyelitis, SLE has standardized diagnostic criteria that include laboratory tests (Wallace & Gladman, 2019). This suggests something else may be influencing time-to-diagnosis, but the literature regarding the factors that contribute to diagnostic delay is not robust, and there is a significant gap when it comes to examining gender and racial disparities in particular. Approximately 90% of SLE patients are women, and the prevalence of SLE is higher among racial and ethnic minorities than among white people (Pons-Estel et al., 2010). Research shows that physicians are less likely to believe physical complaints and pain ratings from women and racial/ethnic minorities, which leads to their complaints often being dismissed. Previous studies of similar conditions found that women presenting at physicians' offices with non-specific symptoms like pain and fatigue face gender-specific barriers to diagnosis. These barriers include providers believing women are exaggerating or inventing symptoms, dismissing their concerns, and suggesting their symptoms are psychological rather than physical (Swartz, 2018; Werner & Malterud, 2003). Additionally, sexism in patient-provider relationships is racialized, as examinations of maternal morbidity and mortality have illuminated (De Marco et al., 2008). The purpose of this study is to examine the diagnostic journeys of women with systemic lupus erythematosus in New York City with a focus on the ways in which gender and race shape patient-provider interactions and time to diagnosis.

Background and Significance

Background

Systemic lupus erythematosus (hereafter referred to as SLE or lupus) is estimated to affect between 300,000 and 2 million people in the United States, making it the second- or third-most common rheumatic autoimmune disorder (Wallace, 2008, p. 11). Prevalence estimates vary widely but tend to fall between 20 and 150 cases per 100,000 people, though this differs by race/ethnicity, gender, and country of residence (Schur & Hahn, 2019). While the mechanism for racial disparities in incidence and prevalence of SLE is unknown, it does not appear to be related to genetics or geographic ancestry. For example, SLE is quite rare in Africa, but people of African descent in the United States and Europe are significantly more likely than white people to be diagnosed (Pons-Estel et al., 2010, pp. 258–259). In Manhattan, the estimated age-

standardized prevalence (per 100,000) is 64.3 for non-Hispanic white women, 91.2 for non-Hispanic Asian women, 138.3 for Hispanic women, and 210.9 for non-Hispanic Black women (Izmirly et al., 2017, p. 2009). While the gender gap in time to diagnosis is more well-documented, studies examining racial disparities in the overall time to diagnosis have been mixed, with Black women in one study in the UK reporting a shorter diagnostic delay than white women but no current evidence of similar patterns in the US (Morgan et al., 2018). However, there is data from the US demonstrating that women of color in general, and Black women in particular, have accumulated more organ damage and have more severe symptoms at the time of diagnosis, suggesting the potential of a greater delay (González et al., 2013). One factor contributing to this appears to be an increased wait time in receiving a specialist referral; African American, Hispanic, and Asian women with lupus are all significantly more likely than white women to wait longer than three months for a referral (Gaynon et al., 2018). This is likely a result of racism in the medical system. Racial discrimination in patient-provider interactions is well documented across a variety of health conditions and may have an impact on women of color's ability to have providers take their symptoms seriously enough to warrant further action (Smedley et al., 2003).

SLE is frequently difficult to diagnose because it is a complex illness with a wide variety of presentations that often mimic the symptoms of other conditions (Oglesby et al., 2014). Estimates of patients receiving a misdiagnosis of another condition prior to being correctly diagnosed with SLE range from approximately 50-75% (Kent et al., 2017, p. 1097; Morgan et al., 2018, p. 682; Sloan, Harwood, et al., 2020, p. 3). There is no one definitive test for the disease. Instead, clinicians draw from a combination of laboratory tests, exam findings (i.e. physical signs), and symptoms to determine if a patient meets the criteria for SLE (Hatfield-Timajchy, 2008, p. 113). There are three major sets of criteria for diagnosis: the American College of Rheumatology criteria (ACR 1997), the Systemic Lupus International Collaborating Clinics criteria (SLICC 2012), and the European League Against Rheumatism / American College of Rheumatology criteria (EULAR/ACR 2019) (Aringer et al., 2020, p. 17). The 1997 ACR criteria are by far the most commonly used (with some physicians using them in combination with the 2012 SLICC criteria), and the 2019 EULAR/ACR are so new that it is not known how they are being used in practice (Wallace & Gladman, 2019). All three sets of criteria were developed using primarily white patients in academic settings, which is a significant

limitation (Aringer et al., 2019; Wallace & Gladman, 2019). With the 1997 ACR criteria, a patient simply needs to meet any four out of the eleven possible criteria, while to differing degrees, both the 2012 SLICC and 2019 EULAR/ACR criteria use a weighted scoring system (Aringer et al., 2020). The 1997 ACR criteria are reproduced below in Table 1.

Table 1: American College of Rheumatology Revised Criteria for the Classification of Systemic Lupus Erythematosus (SLE) [1]

A person can be diagnosed with SLE if four of the eleven criteria are present at any time:

Skin criteria 1. Butterfly or "malar" rash (lupus rash over the cheeks and nose) 2. Discoid rash (a thick, disk-like rash that scars, usually on sun-exposed areas) 3. Sun sensitivity (rash after being exposed to ultraviolet A and B light) 4. Oral ulcerations (recurrent sores in the mouth or nose)
Systemic criteria 5. Arthritis (inflammation of two peripheral joints with tenderness, swelling, or fluid) 6. Serositis (inflammation of the lining of the lung (or pleuritis) or the heart (pericarditis)) 7. Kidney disorder (protein in urine samples or abnormal sediment in urine seen under a microscope) 8. Neurologic disorder (seizures or psychosis with no other explanation)
Laboratory criteria 9. Blood abnormalities (hemolytic anemia, low white blood cell counts, low platelet counts) 10. Immunologic disorder (blood testing indicating either a positive LE cell[2] preparation, anti-dsDNA[3], false-positive syphilis test[4] or positive anti-Sm[5]) 11. Positive ANA[6] blood test

[1] Table and footnotes reproduced from Table 3.1 (p.114) in Hatfield-Timajchy, K. S. (2008). *Delayed diagnosis: The experience of women with systemic lupus erythematosus in Atlanta, Georgia* (2008-99130-448; Issues 1-A). Emory University.
[2] Specific cell found in blood specimens of most lupus patients.
[3] Antibody and double-stranded DNA (Anti-dsDNA): Antibodies to DNA; seen in half of those with systemic lupus and implies serious disease.
[4] False-positive serologic test for syphilis: A blood test revealing an antibody that may be found in patients with syphilis and that gives false-positive results in 15 percent of patients with SLE; associated with the lupus anticoagulant and antiphospholipid antibodies.
[5] Anti-Smith (anti-Sm) antibody; this type of antibody is found only in lupus patients.
[6] Antinuclear antibodies (ANA): Proteins in the blood that react with the nuclei of cells. Seen in 96 percent of those with SLE, in 5 percent of healthy individuals, and in most patients with autoimmune diseases.

Symptoms of note that are not included in the ACR criteria but are present in either the SLICC or EULAR/ACR criteria include fever, non-scarring alopecia, expanded neurologic symptoms, and lupus nephritis (as opposed to only generalized kidney disorder) (Aringer et al., 2020). While fatigue is not included in any of the three sets of criteria, 80-100% of SLE patients

experience fatigue and patients frequently mention it as one of the most significant inhibitors of their quality of life (Pettersson et al., 2010; Wallace & Gladman, 2019). Similarly, muscle pain (as opposed to joint pain from arthritis, which is included) is another frequent, debilitating symptom that is not detailed within any of the diagnostic criteria (Sloan, Harwood, et al., 2020; Sutanto et al., 2013). It is likely that these two symptoms, while extremely common, are not in the official diagnostic criteria because they are more subjective and non-specific. However, these are also the symptoms that most commonly prompt a patient to first seek medical care, so it is crucial for doctors to be aware of their role in the presentation of SLE (Hatfield-Timajchy, 2008, p. 20). Patients frequently see their primary care provider or a dermatologist before realizing their symptoms are manifestations of a larger, multi-system condition and being referred to a rheumatologist and/or nephrologist for treatment (Hatfield-Timajchy, 2008, p. 123).

For the purposes of this study, the term "diagnostic journey" will refer to the experience of attempting to obtain a diagnosis starting from the onset of symptoms. Some qualitative studies of SLE include the diagnostic journey as part of their focus, but very few studies focus exclusively on this period and its significance. Patient-provider interactions across the entire illness course for SLE have, however, been examined more frequently using qualitative methodologies (Sutanto et al., 2013). Because of the non-specific nature of many of SLE's symptoms and the fact that it is characterized by flare-ups and periods of remission, patients often have difficulty communicating their symptoms to their doctors, which strains patient-provider relationships (Hatfield-Timajchy, 2008; Sloan, Naughton, et al., 2020). Another factor contributing to difficult patient-provider interactions is the frequently-reported disparity between patient and provider priorities. Patients often want more care and treatment for their quality of life symptoms, while providers are more focused on observable findings such as laboratory tests, joint damage, and organ damage (Sloan, Naughton, et al., 2020, p. 4).

Currently, there are four published studies focusing specifically on patients' perspectives of their diagnostic journeys, two of which are journal articles and two of which are doctoral dissertations (Hatfield-Timajchy, 2008; McNeil, 2018; Mendelson, 2009; Price & Walker, 2014). Hatfield-Timajchy's (2008) dissertation was a mixed-methods medical anthropology study that examined diagnostic journeys and the impact of diagnostic delays for African American and white women in Atlanta using interviews, participant observation, and surveys. Half of her participants experienced a diagnostic delay of four or more years, and she identified limited

access to specialists as a major structural barrier (Hatfield-Timajchy, 2008, p. 126). In addition to struggling to get a referral or find an in-network specialist, participants sometimes saw multiple specialists at a time who focused on separate organ systems and frequently disagreed with each other and failed to piece together the patient's systemic illness (Hatfield-Timajchy, 2008, pp. 126–127). One of the factors that contributed to participants' frustration with being disbelieved by their providers was the transience of their symptoms. Their appointments would not always line up with a disease flare, and they struggled to have their symptoms taken seriously when they could not be directly observed (Hatfield-Timajchy, 2008, p. 128). McNeil's (2018) dissertation utilized a phenomenological approach to look specifically at the diagnostic journeys of women of color throughout the US. Her participants struggled with ambiguity throughout the diagnostic journey and sought the validation of an official diagnosis (McNeil, 2018, p. 146). Once they received a diagnosis, though, they framed the journey as something extremely difficult that they "pushed through" and felt they came out stronger on the other side of it (McNeil, 2018, p. 156). Mendelson (2009) explicitly examined the gendered nature of the diagnostic journey in her feminist analysis of written narratives submitted by women with lupus recruited from online support communities. She theorizes the diagnosis journey as a liminal state, and many of her participants struggled with their symptoms being dismissed or misattributed to mental health conditions before they received the correct diagnosis (Mendelson, 2009, p. 397). One of the major themes that arose was women being told that what they were experiencing was "all in [their] head" and the ways in which this negatively impacted their sense of self (Mendelson, 2009, p. 398). Price and Walker (2014) utilized a variety of qualitative methods including focus groups, artistic representations, and narrative interviews to explore the diagnostic journey as a state of "vertigo" characterized by uncertainty and insecurity. For their participants, receiving a diagnosis was often not a discrete moment but rather an ongoing, distressing process (Price & Walker, 2014, p. 229). They argue that physicians dealt with their own uncertainty during a difficult diagnostic process by falling back on explanations of mental health (Price & Walker, 2014, p. 230). While many of the women used the internet to research their symptoms and gain clarity about their condition, they still faced an uphill battle when trying to convince their providers to consider an SLE diagnosis, and this often further strained the patient-provider relationship (Price & Walker, 2014, p. 233).

Significance

Gaining an understanding of women's diagnostic journeys is particularly important because of the negative health outcomes and psychological consequences that arise from diagnostic delays. The longer it takes to receive a diagnosis of SLE and initiate treatment, the more likely it is that organ damage will occur or worsen (Sebastiani et al., 2016). At all levels of disease severity, patients diagnosed within six months of symptom onset have less frequent flares, lower all-cause and SLE-related healthcare utilization, and lower healthcare costs compared to those who wait at least six months to receive a diagnosis (Oglesby et al., 2014). The presence of social support is linked to improved health outcomes in people with chronic illnesses, but social support can wane during a protracted journey to diagnosis as friends and family begin to doubt the veracity of a person's experience when it is continually not validated by medical professionals (Brennan & Creaven, 2016; Meghani & Green, 2018; Sloan, Naughton, et al., 2020). In the context of endometriosis, which is similarly characterized by years-long diagnostic delays, Ballard et al. (2006, p. 1299) found that receiving a diagnosis "sanction[ed] access to social support" and legitimized women's inability to perform work and social duties because women could finally "prove" that what they were experiencing was medical in nature. It is reasonable to assume that a similar process may be occurring for women with SLE.

In a recent series of studies, Melanie Sloan and colleagues identified a number of mechanisms through which the experience of having a protracted journey to diagnosis negatively impacts SLE patients' interactions with the healthcare system even after they receive a diagnosis (Sloan, Harwood, et al., 2020; Sloan, Naughton, et al., 2020). Participants' interactions with providers during the diagnostic journey shaped how they approached their medical relationships going forward and frequently led to an ongoing lack of trust, even when seeing new or different providers (Sloan, Naughton, et al., 2020, p. 3). Approximately half of their participants initially received a misdiagnosis of either a mental health problem (including "health anxiety" and hypochondria) or medically unexplained symptoms before being correctly diagnosed with SLE (Sloan, Harwood, et al., 2020, p. 3). "Medically unexplained symptoms" (MUS) is a broad category describing subjective symptoms (e.g. fatigue, pain) that cannot be traced to any underlying pathology or clear cause and encompasses conditions such as fibromyalgia and chronic pain (Samulowitz et al., 2018). Sloan, Naughton, et al. (2020, p. 4) found that these mental health and MUS misdiagnoses frequently led to self-doubt and insecurity, particularly

when a participant's family members sided with the provider. After being diagnosed, some patients continue to underreport their mental health and cognitive symptoms even though these symptoms are well documented in SLE because they fear their providers will then misattribute their physical symptoms to mental illness (Sloan, Naughton, et al., 2020, p. 6). This complements prior research that patients frequently underreport disease flares, and, importantly, that physicians are typically unaware of this phenomenon (Kent et al., 2017). In addition to underreporting symptoms, Sloan, Naughton, et al. (2020, p. 5) also found that patients often avoid seeking care altogether as a result of previous negative experiences with providers, particularly those that occurred during the diagnostic journey. Given these long-lasting impacts, uncovering the complexities of the diagnostic journey, including the ways in which gender and race shape women's experiences, will have an impact above and beyond shortening the diagnostic delay itself.

Theoretical Lens

The proposed study will be grounded in feminist theory with a specific emphasis on intersectional feminism and feminist approaches to diagnostic uncertainty and chronic illness. Developed by feminist legal scholar Kimberlé Crenshaw in her seminal 1991 article, intersectionality provides a framework to describe the ways in which individual social identity categories like race, gender, socioeconomic status, and sexual orientation intersect at the individual or micro level to reflect larger, interlocking sociostructural systems of privilege and oppression such as sexism, racism, and classism (Bowleg, 2012, p. 1267; Crenshaw, 1991). Crucially, this theory posits that experiences of privilege and oppression are not additive (e.g. straight white women experience only sexism, queer white women experience sexism + heterosexism, and straight Black women experience sexism + racism) but are rather mutually constitutive (Bowleg, 2012, p. 1271). This theory helps illuminate the ways in which the type of sexism experienced by women is influenced by their race, and the type of racism experienced by women is influenced by their gender. Because SLE is a disease that affects almost exclusively women, and because the prevalence is higher among women of color than in white women, intersectionality will provide an important framework for understanding the ways in which micro-level patient-provider interactions during the diagnostic journey are reflective of macro-level interlocking sociostructural forces like racism and sexism.

Because women are disproportionately affected by conditions with non-specific symptoms like pain and fatigue and because studies have consistently shown that men and women receive disparate treatment for these conditions, there is a growing body of feminist theoretical literature focusing on the role of sexism and gender norms in the treatment of women with chronic illnesses. In a review of the literature on gender bias in healthcare, Samulowitz et al. (2018, p. 9) found that women receive less pain medication, including opiates, compared to men and also are more likely to be given antidepressants and mental health referrals rather than pain relief. Drawing a through line from nineteenth-century conceptualizations of hysteria, feminist scholars emphasize dismissive and incredulous attitudes by providers who tell women that they are exaggerating, imagining, or overreacting to their symptoms and/or that their symptoms are a physical expression of psychological distress (Samulowitz et al., 2018; Swartz, 2018; Werner et al., 2004). Because of the subconscious, entrenched nature of sexism, these experiences are not limited to male providers, although in some studies the provider's gender has been found to impact interactions and treatment (Samulowitz et al., 2018, p. 9). It is also important to note here that, in addition to the aforementioned gender disparities, there is a robust literature on racial disparities in pain management. Black people in the United States, who are at an increased risk of SLE, are disproportionately more likely to have their pain both underestimated and undertreated (Meghani & Green, 2018, p. 827).

The majority of these frameworks have been developed for conditions such as fibromyalgia and chronic pain that don't have standardized diagnostic tests or criteria. However, based on the few available studies that explore this phenomenon, women with SLE seem to face the same gendered obstacles as women with MUS throughout their diagnostic journeys (Hatfield-Timajchy, 2008; McNeil, 2018; Mendelson, 2009). Currently, Mendelson (2009) is the only scholar who has both focused explicitly on the diagnostic journey and done so through the lens of gender. She found that prior to diagnosis, women were frequently told their symptoms were simply a result of stress and depression, and that they were sometimes offered antidepressants rather than pain medication (Mendelson, 2009). While this study examined the role of gender, it did not also examine race, and all of the participants were recruited from online support groups, limiting analytic generalizability. This leaves plenty of unexplored territory for the proposed study, which can also serve to strengthen her conclusions. Swartz's (2018) "feminist bioethics approach to diagnostic uncertainty" will be particularly applicable for the

proposed study. In providing a framework for the experiences of women with contested illnesses, she highlights the role of providers as gatekeepers or experts, the vulnerable and subordinate position of female patients attempting to obtain answers and care, and the ways in which societal "views about the credibility of women and the seriousness of their complaints" permeate the diagnostic process (Swartz, 2018, p. 38). Another relevant theory for the proposed study is Malterud's (1999) "gendered construction of diagnosis." Arguing from a semiotic constructivist perspective, she emphasizes the role of social and cultural context in medical interpretation and views the diagnostic process as one of "perception, interpretation, narration, and negotiation" influenced by the male gaze rather than an objective reporting of medical facts (Malterud, 1999, pp. 282–283).

Specific Aims

1. Elicit provider and patient advocate perspectives on women's diagnostic journeys and the factors that may contribute to protracted diagnostic journeys.
2. Explore women's journeys from symptom onset to obtaining a diagnosis of systemic lupus erythematosus.
    a. Examine women's experiences interacting with medical and social service providers throughout their diagnostic journeys.
    b. Explore women's experiences with implicit and explicit sexism and racism on these diagnostic journeys.

Research Methodology

Overview of Study Design and Approach

The proposed study will achieve the above aims by utilizing qualitative research methods informed by narrative inquiry and grounded theory. Qualitative methods are best suited for this study because of the limited preliminary research on diagnostic journeys for women with SLE, particularly when it comes to experiences of implicit and explicit racism and sexism. Using qualitative methods will allow previously unexplored or underexplored key concepts and themes to emerge through semi-structured interviews and periods of observation. The study will be carried out in two phases, described below.

Phase I: In order to gain a better understanding of the salient issues and concepts and facilitate triangulation, the first phase will involve conducting key informant interviews with medical providers, social service providers, and employees at patient advocacy organizations as well as observing patient support group sessions. Speaking with medical providers will elucidate their own struggles to make a timely diagnosis of this complex illness as well as their perceptions of what patients are experiencing during the process. People with SLE frequently have difficulty working, may receive disability benefits, and/or may generally be in need of social services, and social workers will have intimate insights into the challenges their clients face (Schudrich et al., 2012). Similarly, patient advocates will be familiar with patients' most pressing concerns and be able to provide insight into which issues and experiences are most common. During support groups, patients will build off of each other's comments, make connections, and perhaps feel more comfortable sharing difficult experiences because they will be in a space with others who understand their struggles.

Phase II: Using an interview guide informed by the preliminary findings of Phase I, Phase II will consist of semi-structured in-depth interviews with women with SLE. Drawing from a narrative approach, each woman will be interviewed three separate times to elicit a complex and comprehensive account of her diagnostic journey. Utilizing multiple interviews will allow the interviewer to build trust and rapport with the participant and understand the intimate details of their diagnostic journey. The interviews will focus on the diagnostic journey as a whole and emphasize the nature and role of interactions with providers. A narrative approach is well-suited to an exploration of diagnostic journeys, which are a bounded period that begins with the onset of symptoms and "ends" with obtaining a diagnosis. Additionally, narrative inquiry emphasizes "sensemaking," which is the process by which people make sense of their lived experiences within their social and structural contexts (Ntinda, 2019, p. 411). Because diagnostic journeys are often characterized by prolonged periods of uncertainty, using a narrative approach will help elucidate how participants grappled with and understood this uncertainty throughout the various phases of the diagnostic journey.

Sampling and Recruitment

Phase I: There will be 20 key informant interviews: 5 with patient advocates, 5 with social service providers, 5 with primary care providers (physicians and/or nurse practitioners), and 5 with specialists (rheumatologists as well as nephrologists and/or dermatologists). Rheumatologists will be located through the Manhattan Lupus Surveillance Program's registry of hospitals, private rheumatology practices, and specialty clinics (e.g. NYU Langone's Lupus Center) that serve patients with SLE (Izmirly et al., 2017). Using online searches, a selection of private and health system-affiliated (e.g. Mount Sinai, New York Presbyterian) nephrology, dermatology, and primary care practices from a variety of neighborhoods in New York City will be identified and contacted. Patient advocates and social service providers will be located and contacted via online searches for relevant organizations and agencies within New York City such as the Lupus Foundation of America's northeast regional chapter. Connections to support groups for observation will be made through patient advocates with a goal of observing at least two support group sessions.

Phase II: The sample of SLE patients will be 12 women ages 25-60 in New York City who have received a diagnosis of systemic lupus erythematosus within the past year. This will facilitate detailed accounts of participants' diagnosis journeys as they will have been "completed" quite recently. This recency will also allow participants to focus in on the diagnostic journey itself, with less emphasis on their potential difficulties obtaining adequate treatment once they did get a diagnosis. Selecting a relatively small sample size for the in-depth interviews, with each participant being interviewed multiple times, is characteristic of narrative inquiry (Sharp et al., 2019). The interviewer and participant will build rapport over the course of the interviews, and interviewing fewer people multiple times (as opposed to more people only one time) will allow for an exploration of the diagnostic journeys in all of their detail and complexity. In addition, the comprehensive first phase of the study, with key informant interviews from multiple perspectives and observation of support groups, will allow for triangulation of the data from these narratives. This study's age range was selected to be within approximately one standard deviation of the mean age at diagnosis for women of all races in Manhattan. Nationally, most diagnoses occur between the ages of 37 and 50 for white women and between the ages of 15 and 44 for Black women (Schur & Hahn, 2019). In Manhattan specifically, Izmirly et al. (2017, p. 2011) found

that from 2007-2009, the mean±SD age at diagnosis was 40.1±16.6 for women, 42.2±17.7 for non-Hispanic whites, 39.2±16.3 for non-Hispanic Blacks, 39.6±17.0 for Hispanics, and 37.9±16.0 for Asians.

Women will be recruited via flyer/ads from a variety of sources within New York City to facilitate obtaining a sample with a variety of perspectives. These include support groups, lupus specialty clinics, rheumatology, dermatology, and nephrology practices, primary care practices, and online forums such as Facebook groups and message boards (e.g. LupusConnect). The four existing studies that focus specifically on the diagnostic journeys of women with SLE (described in detail above) all recruited primarily from in-person and/or online support groups (Hatfield-Timajchy, 2008; McNeil, 2018; Mendelson, 2009; Price & Walker, 2014). Women who had less arduous diagnostic journeys, or who perhaps feel adequately supported by friends and family, would be less likely to seek out these groups (Price & Walker, 2014, p. 228). Including non-support-group settings in the sampling frame will ensure that these women will also have an opportunity to tell their stories, as it is important to have an understanding of what factors positively impact women during the diagnostic journey. Women will first be recruited purposively based on race/ethnicity. In qualitative research, this type of sampling is used to ensure that the people in the sample will be able to provide relevant information based on a study's specific questions and goals (Maxwell, 2012, p. 97). Race/ethnicity was selected as a criterion because one of the goals of this study is to elucidate women's experiences of implicit and explicit racism during the diagnostic journey (see Aim 2b). Even though women of color are more likely to be diagnosed with SLE than white women, many studies still have samples that are primarily white and are therefore unable to adequately explore experiences of implicit and explicit racism in the medical system. Following purposive sampling, as themes begin to emerge during the iterative data analysis process, we will draw from grounded theory and employ theoretical sampling to refine concepts and fill in any gaps (Charmaz, 2007, pp. 11–12).

Data Collection Methods

Phase I: The principal investigator and a research assistant trained in qualitative interviewing will each conduct key informant interviews. These interviews will be face-to-face and last approximately 60 minutes. During the interviews, interviewers will make brief notes and then write up a full memo directly following the interview. Memos will include key points, what did

and did not go well during the interview, and proposed alterations to the interview guide. The interviews will be semi-structured, with interview guides modified to include questions based on the specific expertise of the key informant. Questions tailored to the different types of key informants will include:

- Patient Advocates and Social Service Providers
    - What major challenges do your clients face when attempting to obtain a diagnosis?
    - What types of support systems (e.g. government assistance, online and in-person support group communities) are available to your clients?
        - How does this change before and after they receive an official diagnosis?
    - How does SLE impact your clients' quality of life during the diagnostic journey? After they receive a diagnosis?
- Primary Care Providers
    - What sort of symptoms make you suspect the patient may have SLE?
    - What typically leads you to refer the patient to a specialist and/or order testing?
    - What factors might lead you to believe that what the patient is experiencing is actually the result of stress and/or mental health issues?
    - Describe an example of a patient where you were skeptical about the presence or severity of their symptoms and/or whether or not they truly had lupus.
- Specialists
    - Which set(s) of diagnostic criteria do you use?
    - How do you translate what a patient is saying about their lived experience (e.g. mentions being more tired than usual) into symptoms?
    - How do you decide to run tests?
    - Describe an example of a patient where you were skeptical about the presence or severity of their symptoms and/or whether or not they truly had lupus.
    - What frustrates you most about the diagnostic process?
    - What makes for a successful patient-provider relationship?

For support group observations, the principal investigator will solely be observing the session and will not ask support group members specific questions. As described in detail under "Protection of Human Subjects and Data Management," support group participants will be made

aware that a researcher is coming to observe their session and will consent to observation. During the support group, the researcher will write brief notes (e.g. key quotes, major concepts). Immediately following the observation, the researcher will write up detailed field notes and make note of any specific topics they want to follow up on during the in-depth interviews.

Phase II: In-depth interviews will be conducted by the principal investigator. All interviews will be face-to-face. Each of the twelve participants will be interviewed three times, with approximately one month between interviews and interviews lasting on average between 60 and 90 minutes. The interviews will be semi-structured, with an interview guide that is informed by the key informant interviews and observed support group sessions from Phase I. Over the course of the three interviews, the goal will be to build trust with the participant and elicit a detailed, comprehensive account of their diagnostic journey. It may be that the participant will not feel comfortable sharing some of the most difficult or distressing aspects of this journey until the second or third interview. For example, participants may want to establish themselves as reliable and/or build credibility with the interviewer before sharing how a provider attributed their symptoms to mental illness or said what they were experiencing was "all in their head," which participants in previous studies frequently experienced (Mendelson, 2009). All interviews will be tape-recorded and transcribed. As with the key informant interviews, the interviewer will jot down brief notes during the interview and then write up a memo following the interview. The consent process, including procedures for making participants feel safe and comfortable, is described in detail below under "Protection of Human Subjects and Data Management."

The first interview will aim to elicit more of a basic chronology of the diagnostic journey so that subsequent conversations can delve further into how participants felt during each phase of the journey, what factors were important in shaping their experience, etc. (Creswell & Poth, 2016, p. 69). Questions establishing this basic chronology will include:

- When did you first start experiencing symptoms of SLE?
- What initially made you seek out care?
- How long was the gap between the onset of symptoms and seeking care?
- How did you decide that what you were experiencing warranted medical attention?
- What was the trajectory of seeing various providers and obtaining referrals up until you received your diagnosis?

    - (E.g. “I first saw my primary care provider, who referred me to a dermatologist for my rash, who referred me to a rheumatologist who ultimately diagnosed me”)
- How many total providers did you see?
    - What were their specialties?
- How did you describe your symptoms to providers?
- Once you sought medical care, how long did it take to receive an official diagnosis?
- What sort of diagnostic tests and/or physical exams were performed?
- How was the diagnosis ultimately made?

After establishing this basic outline of the diagnostic journey, subsequent conversations will focus in on topics such as patient-provider interactions and social support. There will be a semi-structured interview guide with questions to cover during the second and third interview, and the interviewer will have leeway to jump around the guide and probe based on what direction the conversation goes in and what the participant brings up. Questions during this phase of interviews will include:

- How was your ability to work and engage in social activities impacted throughout the diagnostic journey?
- What was the response of your friends and family when you first started experiencing symptoms? What about when you initially sought care?
- How did friends and family support you during periods of uncertainty?
- Did friends and family ever question or discount your experience?
- How did levels of support from your loved ones change over the course of the diagnostic journey?
- During periods of uncertainty, what impact did the lack of a diagnosis from your medical provider have on levels of support from your loved ones?
    - Probes: Were they angry on your behalf? Did they accept what the providers said and agree that nothing was medically wrong?
- How did providers respond to you when you explained your symptoms?
- What was your relationship like with your various providers?
- How did your providers support you? What could they have done to better support you?
- What were some of the most difficult parts of the experience?

- What made things harder?
- What made things easier?
- Who did you go to for support (e.g. friends, family, support groups, online communities)?
- How did you feel when you received your diagnosis?

Data Analysis Plan and Methods

All interview transcripts will be uploaded to Dedoose for analysis. Themes and concepts that emerge from the memos written following key informant interviews and support group observations will inform the creation of the in-depth interview guide. Diagnostic journey narratives will be analyzed using thematic (rather than structural or discourse) analysis as the goal will be to identify common themes, salient concepts, turning points, and areas for further exploration (Creswell & Poth, 2016, p. 200). Data analysis of the in-depth interview transcripts will be an iterative process that is concurrent with data collection to facilitate theoretical sampling. As themes begin to emerge, additional participants will be identified based on concepts that need to be clarified and/or require different perspectives (Rapley, 2016).

To develop the codebook, the principal investigator and the research assistant will each read the same three transcripts, which will be selected based on their conceptual diversity (i.e. with the goal that they will together incorporate a wide variety of the relevant themes and concepts). The researchers will immerse themselves in the data by closely reading the transcripts and making margin notes (Rapley, 2016). Next, they will come up with a preliminary list of codes. These will include a combination of *a priori* codes (generated through theoretical and background literature as well as the key informant interviews and interview guide) and codes that emerge from the data. The researchers will meet to compare their lists and create the codebook. Next, they will begin individually applying the codebook to transcripts. Protocols for maintaining validity and reliability during the data analysis process, including ensuring that each member of the team is consistently and reliably applying the codebook, are discussed in detail below. Codes will be applied to short segments of text (rather than line-by-line), and more than one code may be applied to a given segment (i.e. double-coding). These overlaps will facilitate the identification of emerging themes. Throughout the coding process, the researchers will write memos in Dedoose whenever thoughts, questions, emerging themes, or suggested alterations to the codebook come up. After all of the transcripts are coded, the researchers will then create a

matrix-style data display to group the codes into themes and identify representative quotes from the transcripts. The data display will also allow for comparisons of experiences across axes of difference, such as race and time to diagnosis. The analytic tools within Dedoose, memos written during the analysis process, and frequent team meetings will all facilitate this process.

Validity and Reliability

The research team will employ a number of different safeguards to maintain validity and reliability. It should first be noted that unlike quantitative research, which seeks a representative sample that will allow for statistical generalizability, in qualitative research the goal is *analytic* generalizability. Despite the small, non-random sample, the employment of purposive and then theoretical sampling (facilitated by an iterative data analysis process) will ensure a representativeness of concepts and themes relevant to this specific research question and allow for an analysis of the consistency of these themes (Corbin & Strauss, 1990, p. 421). The two-phase structure and multiple methods of data collection (i.e. observation, key informant interviews, and in-depth interviews) will also facilitate data triangulation. Conducting key informant interviews with stakeholders from multiple perspectives and observing support group sessions will inform and contextualize the subsequent in-depth interviews. It will also allow for the interrogation of discrepancies between the key informant and patient perspectives. During the data collection process for the in-depth interviews, the interviewer will pay close attention to how a participant's narrative may change over the course of multiple interviews (Lewis, 2014). This will include probing to elicit more information or clarifications, especially in cases where there are gaps in participants' narratives or they contradict themselves. In addition, we will pay close attention to any "negative cases," (i.e. participants whose experiences do not fit into and/or directly go against emerging themes) in the in-depth interviews. These may support our findings if participants deliberately position themselves as "exceptions to the rule," or they may require us to re-evaluate or amend our findings (Rapley, 2016). Regardless, they will help us strengthen the validity of our findings.

Prior to conducting data analysis, researchers will write subjectivity memos. These will include a discussion of how their personal lived experiences, including the identities they hold and any prior training and experiences, may impact their interpretation of the data. In particular, the researchers will think critically about their own experiences with chronic illness and/or the

medical system. After laying out their potential biases in the subjectivity memos, the researchers will make plans for deliberately attending to this bias throughout the analysis process. This will include making use of the "memos" feature in Dedoose to make notes throughout the coding process whenever they have a strong emotional reaction to an interview (surprise, sadness, connections to personal experiences, etc.) or have trouble understanding what a respondent is trying to communicate. To maintain reliability, two members of the research team (the principal investigator and the research assistant) will use the codebook to separately code a subsection of the same transcript. They will then calculate an inter-coder agreement (ICA) as the number of agreements divided by the total number of agreements and disagreements. Next, they will discuss and resolve disagreements by going code by code, talking through their thought processes, and referring back to the codebook. After resolving all disagreements that can be resolved, they will re-calculate the ICA and also make any needed changes to the codebook. The codebook will be continually refined as new concepts and themes emerge, and previously coded transcripts will be re-examined to apply these new codes, if applicable.

Protection of Human Subjects and Data Management

Prior to data collection, all research materials, including interview guides, recruitment flyers, and consent forms, will be reviewed and approved by the Columbia University Institutional Review Board. Support group facilitators will notify members that a researcher will be coming to observe the next session. They will explain the general purpose of the study as well as the processes in place for keeping information confidential and de-identified. This way, support group participants who do not want to be observed will know in advance and can choose not to attend that session. Consent and confidentiality information will then be repeated at the beginning of the session being observed. Research participants for the key informant interviews and in-depth interviews will all be given randomly assigned numbers (e.g. KIP01 for a key informant interview with a patient advocate), and transcripts and memos will only be identified with this number and the date of the interview. Signed IRB-approved consent forms will be stored separately from transcripts and memos. Consent forms will be read aloud to participants, and they will have an opportunity to ask questions and clarify any points of confusion. The only identifying information collected will be participants' gender, race, age, and years of experience (for key informants). During the consent process, interviewers will explain to participants that

their names will not be used in connection with the data, and that all information will be kept confidential. For key informants, the consent process will also involve explaining that the information they provide will in no way be connected with or shared with their employers. All study information will be stored on encrypted, password-protected computers. Recordings and transcripts of interviews and support group sessions will only be shared with members of the research team for the purposes of data analysis. As noted above, we will use Dedoose for data analysis. Security settings within Dedoose will be configured so that only members of the research team will be granted permission to view and code transcripts.

Sharing their diagnostic journeys may be emotionally taxing for in-depth interview participants, and every effort will be made to create a safe, comfortable, and confidential space for them to share their stories. As discussed in more detail above, conducting multiple interviews with each participant will help build rapport and allow them to feel safe sharing difficult experiences. Interviewers will make it clear to participants that they can choose not to answer any question, and that they may end the interview or ask to have the recording stopped at any time. Additionally, resources will be made available to all participants following the interviews. These will include information about local and online support groups, resources regarding obtaining disability benefits and other social services, and referrals to local therapists who specialize in treating patients with chronic illnesses. Following key informant and in-depth interviews (even if the participant chooses to stop the interview early), all participants will receive remuneration.

Conclusion

Diagnostic delays and their associated negative health consequences are well documented among SLE patients. Despite this, there are very few studies that focus specifically on how people with SLE experience and make sense of their protracted journeys to diagnosis. SLE almost exclusively affects women, and its prevalence is higher among people of color than white people. However, the studies that do exist fail to grapple with and adequately examine the impact of implicit and explicit sexism and racism during the diagnostic journey. The proposed study will fill an important gap in the literature by using feminist theory to explicitly frame the diagnostic journey as a gendered and racialized experience as well as utilizing qualitative methods to explore how women make sense of and are impacted by this experience. This study will also

have the benefit of examining this issue from multiple angles. It will utilize key informant interviews with a variety of stakeholders, including providers, as well as interviews and periods of observation with the patients themselves, which will elicit complex and robust accounts of their diagnostic journeys. Given that SLE is such a complex disease, there will invariably be periods of uncertainty while patients and providers work together to find the correct diagnosis. The proposed study will help elucidate the specific challenges women face during these prolonged periods of uncertainty and identify areas to focus on in future interventions.

References

Aringer, M., Costenbader, K., Daikh, D., Brinks, R., Mosca, M., Ramsey-Goldman, R., Smolen, J. S., Wofsy, D., Boumpas, D. T., Kamen, D. L., Jayne, D., Cervera, R., Costedoat-Chalumeau, N., Diamond, B., Gladman, D. D., Hahn, B., Hiepe, F., Jacobsen, S., Khanna, D., … Johnson, S. R. (2019). 2019 European League Against Rheumatism/American College of Rheumatology Classification Criteria for Systemic Lupus Erythematosus. *Arthritis & Rheumatology*, *71*(9), 1400–1412. https://doi.org/10.1002/art.40930

Aringer, M., Leuchten, N., & Johnson, S. R. (2020). New Criteria for Lupus. *Current Rheumatology Reports*, *22*(6). https://doi.org/10.1007/s11926-020-00896-6

Ballard, K., Lowton, K., & Wright, J. (2006). What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. *Fertility and Sterility*, *86*(5), 1296–1301. https://doi.org/10.1016/j.fertnstert.2006.04.054

Bowleg, L. (2012). The Problem With the Phrase Women and Minorities: Intersectionality—an Important Theoretical Framework for Public Health. *American Journal of Public Health*, *102*(7), 1267–1273. https://doi.org/10.2105/AJPH.2012.300750

Brennan, K. A. M., & Creaven, A.-M. (2016). Living with invisible illness: Social support experiences of individuals with systemic lupus erythematosus. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *25*(5), 1227–1235. https://doi.org/10.1007/s11136-015-1151-z

Charmaz, K. (2007). *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. Sage Publications.

Corbin, J. M., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Zeitschrift Für Soziologie*, *19*(6), 418–427. https://doi.org/10.1007/BF00988593

Crenshaw, K. (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review*, *43*(6), 1241–1299. JSTOR. https://doi.org/10.2307/1229039

Creswell, J. W., & Poth, C. N. (2016). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. SAGE Publications.

De Marco, M., Thorburn, S., & Zhao, W. (2008). Perceived Discrimination During Prenatal Care, Labor, and Delivery: An Examination of Data From the Oregon Pregnancy Risk Assessment Monitoring System, 1998–1999, 2000, and 2001. *American Journal of Public Health*, *98*(10), 1818–1822. https://doi.org/10.2105/AJPH.2007.123687

Gaynon, L., Liu, N., Laura Trupin, Jing Li, Ishita Aggarwal, Patricia Katz, Maria Dall'Era, Lindsey Criswell, Cristina Lanata, Louise Murphy, & Jinoos Yazdany. (2018). Diagnostic Delays and Disparities in Access to Care in Systemic Lupus Erythematosus [abstract]. *Arthritis & Rheumatology*, *70*(Suppl. 10). https://acrabstracts.org/abstract/diagnostic-delays-and-disparities-in-access-to-care-in-systemic-lupus-erythematosus/

González, L. A., Toloza, S. M. A., G McGwin, J., & Alarcón, G. S. (2013). Ethnicity in systemic lupus erythematosus (SLE): Its influence on susceptibility and outcomes: *Lupus*. https://doi.org/10.1177/0961203313502571

Hatfield-Timajchy, K. S. (2008). *Delayed diagnosis: The experience of women with systemic lupus erythematosus in Atlanta, Georgia* (2008-99130-448; Issues 1-A). Emory University.

Izmirly, P. M., Wan, I., Sahl, S., Buyon, J. P., Belmont, H. M., Salmon, J. E., Askanase, A., Bathon, J. M., Geraldino-Pardilla, L., Ali, Y., Ginzler, E. M., Putterman, C., Gordon, C., Helmick, C. G., & Parton, H. (2017). The Incidence and Prevalence of Systemic Lupus Erythematosus in New York County (Manhattan), New York: The Manhattan Lupus Surveillance Program. *Arthritis & Rheumatology (Hoboken, N.J.)*, *69*(10), 2006–2017. https://doi.org/10.1002/art.40192

Kent, T., Davidson, A., Newman, D., Buck, G., & D'Cruz, D. (2017). Burden of illness in systemic lupus erythematosus: Results from a UK patient and carer online survey. *Lupus*, *26*(10), 1095–1100. https://doi.org/10.1177/0961203317698594

Lewis, P. J. (2014). Narrative Research. In J. Mills & M. Birks (Eds.), *Qualitative Methodology: A Practical Guide* (pp. 161–180). SAGE Publications, Inc. https://doi.org/10.4135/9781473920163

Lupus Foundation of America. (2019). *Lupus Facts and Statistics*. Lupus Foundation of America. http://www.lupus.org/resources/lupus-facts-and-statistics

Malterud, K. (1999). The (gendered) construction of diagnosis: Interpretation of medical signs in women patients. *Theoretical Medicine and Bioethics*, *20*(3), 275–286. https://doi.org/10.1023/a:1009905523228

Maxwell, J. A. (2012). *Qualitative Research Design* (3rd ed.). Sage Publications.

McNeil, J. N. (2018). *"I noticed something wrong": Lived experiences of women of color who faced a protracted journey to diagnosis with lupus* (2017-23163-157; Issues 8-B(E)). ProQuest Information & Learning.

Meghani, S. H., & Green, C. (2018). Disparities in Pain and Pain Care. In R. J. Moore (Ed.), *Handbook of Pain and Palliative Care: Biopsychosocial and Environmental Approaches for the Life Course* (pp. 821–834). Springer International Publishing. https://doi.org/10.1007/978-3-319-95369-4_41

Mendelson, C. (2009). Diagnosis: A Liminal State for Women Living With Lupus. *Health Care for Women International*, *30*(5), 390–407. https://doi.org/10.1080/07399330902785158

Morgan, C., Bland, A. R., Maker, C., Dunnage, J., & Bruce, I. N. (2018). Individuals living with lupus: Findings from the LUPUS UK Members Survey 2014. *Lupus*, *27*(4), 681–687. https://doi.org/10.1177/0961203317749746

Ntinda, K. (2019). Narrative Research. In P. Liamputtong (Ed.), *Handbook of Research Methods in Health Social Sciences* (pp. 411–423). Springer. https://doi.org/10.1007/978-981-10-5251-4_79

Oglesby, A., Korves, C., Laliberté, F., Dennis, G., Rao, S., Suthoff, E. D., Wei, R., & Duh, M. S. (2014). Impact of early versus late systemic lupus erythematosus diagnosis on clinical and economic outcomes. *Applied Health Economics and Health Policy*, *12*(2), 179–190. https://doi.org/10.1007/s40258-014-0085-x

Pascoe, K., Lobosco, S., Bell, D., Hoskin, B., Chang, D. J., Pobiner, B., & Ramachandran, S. (2017). Patient- and Physician-reported Satisfaction With Systemic Lupus Erythematosus Treatment in US Clinical Practice. *Clinical Therapeutics*, *39*(9), 1811–1826. https://doi.org/10.1016/j.clinthera.2017.07.039

Pettersson, S., Möller, S., Svenungsson, E., Gunnarsson, I., & Welin Henriksson, E. (2010). Women's experience of SLE-related fatigue: A focus group interview study. *Rheumatology*, *49*(10), 1935–1942. https://doi.org/10.1093/rheumatology/keq174

Pons-Estel, G. J., Alarcón, G. S., Scofield, L., Reinlib, L., & Cooper, G. S. (2010). Understanding the Epidemiology and Progression of Systemic Lupus Erythematosus. *Seminars in Arthritis and Rheumatism*, *39*(4), 257. https://doi.org/10.1016/j.semarthrit.2008.10.007

Price, E., & Walker, E. (2014). Diagnostic vertigo: The journey to diagnosis in systemic lupus erythematosus. *Health (London, England : 1997)*, *18*(3), 223–239. https://doi.org/10.1177/1363459313488008

Rapley, T. (2016). Some Pragmatics of Qualitative Data Analysis. In D. Silverman (Ed.), *Qualitative Research* (4th ed.). SAGE Publications.

Samulowitz, A., Gremyr, I., Eriksson, E., & Hensing, G. (2018). "Brave Men" and "Emotional Women": A Theory-Guided Literature Review on Gender Bias in Health Care and Gendered Norms towards Patients with Chronic Pain. *Pain Research & Management*, *2018*, 1–14. http://dx.doi.org/10.1155/2018/6358624

Schudrich, W., Gross, D., & Rowshandel, J. (2012). Lupus and community-based social work. *Social Work in Health Care*, *51*(7), 627–639. https://doi.org/10.1080/00981389.2012.683694

Schur, P., & Hahn, B. (2019). Epidemiology and pathogenesis of systemic lupus erythematosus. *UpToDate*. https://www.uptodate.com/contents/epidemiology-and-pathogenesis-of-systemic-lupus-erythematosus?sectionName=EPIDEMIOLOGY&topicRef=4668&anchor=H1&source=see_link#H1

Sebastiani, G. D., Prevete, I., Iuliano, A., & Minisola, G. (2016). The Importance of an Early Diagnosis in Systemic Lupus Erythematosus. *Israel Medical Association Journal*, *18*, 4.

Sharp, N. L., Bye, R. A., & Cusick, A. (2019). Narrative Analysis. In P. Liamputtong (Ed.), *Handbook of Research Methods in Health Social Sciences* (pp. 861–880). Springer. https://doi.org/10.1007/978-981-10-5251-4_106

Sloan, M., Harwood, R., Sutton, S., D'Cruz, D., Howard, P., Wincup, C., Brimicombe, J., & Gordon, C. (2020). Medically explained symptoms: A mixed methods study of diagnostic, symptom and support experiences of patients with lupus and related systemic autoimmune diseases. *Rheumatology Advances in Practice*, *4*(1). https://doi.org/10.1093/rap/rkaa006

Sloan, M., Naughton, F., Harwood, R., Lever, E., D'Cruz, D., Sutton, S., Walia, C., Howard, P., & Gordon, C. (2020). Is it me? The impact of patient–physician interactions on lupus patients' psychological well-being, cognition and health-care-seeking behaviour. *Rheumatology Advances in Practice*, *4*(2). https://doi.org/10.1093/rap/rkaa037

Smedley, B. D., Stith, A. Y., & Nelson, A. R. (2003). Assessing Potential Sources of Racial and Ethnic Disparities in Care: The Clinical Encounter. In *Unequal Treatment: Confronting Racian and Ethnic Disparities in Health Care*. National Academies Press. https://www.ncbi.nlm.nih.gov/books/NBK220340/

Sutanto, B., Singh-Grewal, D., McNeil, H. P., O'Neill, S., Craig, J. C., Jones, J., & Tong, A. (2013). Experiences and perspectives of adults living with systemic lupus erythematosus: Thematic synthesis of qualitative studies. *Arthritis Care & Research*, *65*(11), 1752–1765.

Swartz, A. K. (2018). A Feminist Bioethics Approach to Diagnostic Uncertainty. *American Journal of Bioethics*, *18*(5), 37–39. https://doi.org/10.1080/15265161.2018.1447046

Wallace, D. J. (2008). *Lupus: The Essential Clinician's Guide*. Oxford University Press.

Wallace, D. J., & Gladman, D. D. (2019). Clinical manifestations and diagnosis of systemic lupus erythematosus in adults. *UpToDate*. https://www.uptodate.com/contents/clinical-manifestations-and-diagnosis-of-systemic-lupus-erythematosus-in-adults

Werner, A., Isaksen, L. W., & Malterud, K. (2004). 'I am not the kind of woman who complains of everything': Illness stories on self and shame in women with chronic pain. *Social Science & Medicine*, *59*(5), 1035–1045. https://doi.org/10.1016/j.socscimed.2003.12.001

Werner, A., & Malterud, K. (2003). It is hard work behaving as a credible patient: Encounters between women with chronic pain and their doctors. *Social Science & Medicine*, *57*(8), 1409–1419. https://doi.org/10.1016/S0277-9536(02)00520-8