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Beyond the Skin: Women’s Lived Experiences with Hidradenitis Suppurativa

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Beyond the Skin: Women's Lived Experiences with Hidradenitis Suppurativa

By

Kenzie Tapp

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Beyond the Skin: Women's Lived Experiences with Hidradenitis Suppurativa

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June 3, 2024

DECLARATION OF ORIGINALITY

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ABSTRACT

Hidradenitis Suppurativa (HS) is a chronic, recurrent inflammatory skin disease, categorized by inflamed regions in follicular areas (i.e., hair follicles) located in the body (Jemec, 2012). Common psychological comorbidities include elevated levels of anxiety, depression, and suicidality, as well as body image disturbances, poorer quality of life, and diminished self-esteem and self-worth as a result of symptom impacts (Chernyshov et al., 2021). Due to the increased incidence rate of HS in women, coupled with the societal and medical expectations surrounding women's bodies, these comorbidities are even more prevalent for women (Sabat et al., 2020). The purpose of this qualitative study was to gain a deeper understanding of the lived experiences of women diagnosed with HS by amplifying a more integrative, strength-based understanding of the condition. A total of 25 HS-diagnosed Canadian women (age range 20 to 63 years old; M = 36.16, SD = 10.61) were interviewed about the challenges they faced with HS and how they overcame them through strategies of resilience and meaning-making. Reflexive thematic analysis techniques (Braun & Clarke, 2019), situated with a feminist social constructionist lens, were employed to explore these accounts. We generated four major themes relating to how women reflected on their experiences living with HS, including (1) *Developing Agency in the Diagnosis Journey*, (2) *Cultivating Methods to Cope*, (3) *Harnessing One's Voice for Advocacy and Change*, and (4) *Gaining Insight and Growth Through Life-Long Learning*. The findings from this study have direct implications for future research about HS, including considerations for how to improve the well-being and quality of life of this population through more active and advantageous strategies that can inform more holistic treatment practices (e.g., resilience-focused training and support groups).

DEDICATION

This thesis is dedicated to my participants, as well as my fellow HS warriors. Thank you all for showing me what true resilience and growth really is, and for entrusting me with your stories. You have reignited a flame in me to continue this work and push to make the HS field, as well as other chronic illness areas, better for future generations to come. I truly hope that this thesis does justice to the incredible accounts you all have shared with me. I am eternally grateful for the kindness and support that I have been shown from this community.

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CHAPTER I

Introduction

Hidradenitis Suppurativa (HS) is a chronic, recurrent inflammatory skin disease, categorized by inflamed regions in follicular areas (i.e., hair follicles) located in the body (Jemec, 2012). Individuals with HS develop painful and deep-seated pus-filled nodules, abscesses, sinus tracts, and/or fistulas (i.e., tunneling) that typically develop in skin folds located in the armpits, groin, buttocks, and perianal areas (i.e., pelvic) of the body (Sabat et al., 2020). Global prevalence rates are estimated to be between 1% to 4%, with a female to male ratio of 3.3:1 (Margesson & Danby, 2014). Common physical comorbidities include obesity, metabolic syndrome, diabetes, arthritis, Crohn's disease, and polycystic ovary syndrome (Revankar et al., 2021). Individuals with HS can also experience elevated levels of anxiety, depression, and suicidality, as well as body image disturbances, poorer quality of life, and diminished self-esteem and self-worth as a result of symptom impacts (Chernyshov et al., 2021).

Diagnosis urgency is crucial to mitigate these potential lifelong comorbidities. However, HS is frequently misdiagnosed and under-diagnosed, and is relatively unknown to practitioners within the general medical system (Margesson & Danby, 2014; Patel et al., 2017). Dermatologists are generally the most well-suited clinicians to recognize, diagnose, and treat HS, but patients are often not able to access this specialized form of care until a referral is made, which is typically after a diagnosis has been secured following many reoccurring medical visits (Alikhan et al., 2009). HS has a reported diagnostic delay of an average of 10 years from the time the first symptom is experienced and is often misdiagnosed as boils, which are mistakenly assumed to require the short-term treatment of lancing (i.e., surgically draining the pus-filled nodules; Jemec, 2012; Willems et al., 2022). Patients with HS often report frustration due to a lack of awareness of HS, fragmented care, insufficient educational and supportive resources post-diagnosis, inadequate guidelines for symptom management, and barriers in accessing practitioners specializing in HS diagnosis and treatment (Collier et al., 2021; Margesson & Danby, 2014; Willems et al., 2022). Treatment plans often focus on the biomedical aspects of the disease, and very rarely incorporate elements that address the persistent psychological and psychosocial impacts of HS across the lifespan.

Due to the increased incidence rate of HS in women, coupled with the societal and medical expectations surrounding women's bodies in relation to their function and gender expression, nearly all comorbidities are heightened in women with HS (Sabat et al., 2020). HS for women is implicitly framed as a condition that disrupts femininity both physically and socially. This concept has further encroached the medical institutions that govern Western societies, which frequently results in women's symptom concerns being dismissed, invalidated, and pathologized (Hesse-Biber, 2007). Thus, this overarching lack of support, dismissiveness, and judgment can exacerbate the stigma and shame surrounding HS, as well as lead to a potential worsening of symptoms and health outcomes (Frings et al., 2019; Howells et al., 2021; Koumaki et al., 2021; Krajewski et al., 2021). It is not surprising then that the literature surrounding HS, especially regarding women with HS, is largely negative and painted as inevitable, irreversible, and irreconcilable.

The purpose of this qualitative study was to broaden the HS literature by moving away from a deficit perspective and instead amplifying a more integrative, strength-based understanding of HS. Furthermore, while capturing women's experiences with HS are rare, so are feminist interpretations of these experiences, which was a crucial aspect of this project. Our goal was to capture experiences of resilience and meaning-making as women reflected on and made sense of their experiences living with this complex, life-long heterogenous chronic health condition. We also aimed to understand how women overcame oppressive structural systems (e.g., health care) and advocated for better care and support.

In line with feminist methodology (Wigginton & Lafrance, 2019), we captured, through a semi-structured qualitative interview, various domains related to how women embraced and reflected on their experiences of living with HS, in their own way, through their own language, stories, and perspectives. We also captured elements of self-advocacy and empowerment, as well as strategies that shifted the narrative from deficits to perspectives of strength. Reflexive thematic analysis techniques (Braun & Clarke, 2019), situated within a feminist social constructionist lens, was our primary analytical strategy to explore women's lived experiences, while also acknowledging the broader social inequities that systematically disadvantage women with this condition.

To our knowledge, this project is the first study of its kind to amplify participant-centered, strength-based avenues of health and wellness in women living with HS. It also emphasizes the development of participant-centered and inclusive frameworks to advance research and advocacy for women with HS, as well as inform health equity practices for women more broadly. Additionally, HS research has been almost exclusively studied using quantitative analyses from clinical samples. In this study, we used qualitative methodology to capture a larger range of women's experiences living with HS in ways that are not possible within quantitative paradigms. We also advance this literature with a feminist theoretical lens, which has yet to be incorporated into this work. Ultimately, the importance of amplifying the patient experience is necessary to raise awareness and education of HS, and to improve the well-being and overall quality of life of this unique population through more active and advantageous strategies that can inform more holistic treatment practices (e.g., resilience-focused training and support groups).

CHAPTER II

Literature Review

Hidradenitis Suppurativa

Hidradenitis Suppurativa (HS) was first documented in the 1830s by a French surgeon, Alfred Armand Louis Marie Velpeau, when he identified unusual and unfamiliar abscess-like formulations in axillary, sub-mammary, and perianal regions in some of his patients (Von der Werth & Williams, 2000). Later, in the 1850s, his colleague, Aristide Auguste Stanislas Verneuil, coined this phenomena Hidradenitis (i.e., inflammation of the sweat glands) Suppurativa (i.e., containing pus), which reflected its initial conceptualization as a pathogenic form of acne (Dhaou et al., 2013). With this conception, it was suggested that HS was associated with the sweat glands due to the distribution of the condition (Von der Worth & Williams, 2000). It took many decades after this initial conceptualization for the medical field to determine that HS was associated with follicular occlusion (i.e., blockages) rather than a disease of the sweat glands (Von der Worth & Williams, 2000). Even after these advancements, however, HS was still mistakenly defined by most medical practitioners as a disease of the sweat glands due to its name and initial conceptualization and, consequently, did not have a universal definition or diagnostic classification system until 2009 (Dhaou et al., 2013).

The current state of the literature defines HS as a chronic, recurrent inflammatory skin disease, categorized by aggravated regions in follicular areas (i.e., hair follicles) located in the body (Jemec, 2012). Individuals with HS often develop painful and deep-seated pus-filled nodules, abscesses, sinus tracts, and/or fistulas (i.e., tunneling) that typically develop in skin folds located in the armpits, groin, buttocks, and perianal areas (i.e., pelvic) of the body (Sabat et al., 2020). HS is not a rare disease, as global prevalence rates are estimated to be between 1% to

4%, with a female to male ratio of 3.3:1 (Margesson & Danby, 2014; Sabat et al., 2020). The onset of HS typically occurs after puberty but can develop at any point during adolescence or young adult development (Kouris et al., 2016).

The exact cause of HS is relatively unknown, but it is postulated to be related to a combination of genetic (i.e., HS tends to run in families), environmental (i.e., abnormal cellular activity provides an appropriate environment for HS), and immunological characteristics (i.e., immunologic response to normal skin flora; Fisher & Ziv, 2022). Originally, it was thought that factors such as poor hygiene, deodorant use, and shaving, including both mechanical and chemical methods, contributed to the likelihood of disease development due to its mistaken association with sweat glands (Slade et al., 2003). These hypotheses have since been challenged, including the thought of obesity and smoking being causal factors as well (Sabat et al., 2020; Slade et al., 2003). Instead, weight, smoking, deodorant type, and clothing choice (i.e., tight clothing) have been identified as factors that can potentially exacerbate the experience of HS, rather than directly cause its development (Alikhan et al., 2009).

As a whole, HS is a condition that is frequently misdiagnosed and under-diagnosed and is relatively unknown to practitioners within the general medical system (Margesson & Danby, 2014; Patel et al., 2017). Dermatologists are usually the most well-suited clinicians to recognize, diagnose, and treat HS, but individuals are often not able to access this as a first line of care until a referral is made, which is typically after a diagnosis has been given following many reoccurring medical visits (Alikhan et al., 2009). HS has a reported diagnostic delay of an average of 10 years from the time the first symptom is experienced (i.e., 10.0 ± 9.6 [mean ± SD] years; Kokolakis et al., 2020), and is often confused as boils, which, mistakenly, are assumed to require the short-term treatment of lancing (i.e., surgically draining the pus-filled nodules; Jemec, 2012; Willems et al., 2022). Individuals with HS often report frustration regarding fragmented care, insufficient educational and supportive resources, inadequate management techniques and guidelines, and barriers in accessing practitioners specializing in HS diagnosis and treatment (Collier et al., 2021; Margesson & Danby, 2014; Willems et al., 2022).

Once identified though, the diagnosis of HS can be made by a trained practitioner through reported history and physical presentation during an examination; no confirmatory tests exist (Revankar et al., 2021). General diagnostic criteria for HS includes typical lesions and distribution patterns, as well as reported chronicity and reoccurrence of these experiences (Collier et al., 2021). The severity of the disease is then usually classified using Hurley's staging system, involving stage one as temporary nonscarring lesions, stage two as recurrent lesions with tunneling and scarring, and stage three as mass lesions with tunneling, scarring, and inflammation (Saunte & Jemec, 2017; see Table 1). Upon diagnosis, most individuals are identified as having stage two due to the likely diagnostic delay (Collier et al., 2021). Very rarely are individuals identified as having stage three, with only about 1% of the patient population progressing to this severity level (Jemec, 2012).

Table 1

Hurley Staging System for Hidradenitis Suppurativa Diagnosis

Stage	Characteristics
I (mild)	Solitary or multiple isolated abscess formation(s) without scarring or sinus tracts
II (moderate)	Recurrent single or multiple abscess formation(s) that are widely separated with sinus tracts
III (severe)	Diffuse or broad involvement across a regional area with multiple interconnected sinus tracts and abscesses

Note. This table was adapted from Menderes et al. (2010).

Currently, there is no cure or successful preventative care for HS, with treatment plans often providing temporary relief from symptoms until their eventual reoccurrence (Fisher et al., 2020). In more mild cases, topical antibiotic treatments are first prescribed (e.g., clindamycin, dapsone, etc.), followed by oral antibiotics with anti-inflammatory properties (e.g., retinoids, etc.) and/or steroid injections (e.g., corticosteroid injections, etc.; Jemec, 2012). In individuals with ovaries specifically, anti-androgens and/or birth control are often prescribed, in addition to the above-mentioned treatments, as HS 'flare-ups' can reportedly occur around menstrual cycles for some due to fluctuating hormone levels (Collier et al., 2020). In more severe cases, various biologics (e.g., Humira, etc.) and surgical interventions (e.g., incision and drainage, deroofing, wide excision, laser surgery) will be recommended for lesions that are unresponsive to alternative methods (Altenburg et al., 2011). It must be noted though that simply draining lesions is discouraged since reoccurrence is more likely, and more persistent lesions typically do not drain easily or fully (Ritz et al., 1998). As such, most surgical methods involve removing the site altogether, as well as surrounding tissue that may be damaged from tunneling, which sometimes requires skin grafting techniques to adequately close the site (Ritz et al., 1998). The scarring that comes along with HS is, unfortunately, not responsive to treatment, and thus is not a common treatment goal or consideration (Howells et al., 2021).

Impacts of HS

Overall, HS is a condition that is associated with many comorbidities, both physically, psychologically, and socio-culturally. Common physical comorbidities include obesity, metabolic syndrome, diabetes, arthritis, Crohn's disease, and polycystic ovary syndrome (Fisher et al., 2020; Revankar et al., 2021; Saunte & Jemec, 2017). Furthermore, HS is associated with a markedly increased mortality rate, especially due to associated cardiovascular implications (i.e., ischemic stroke, cardiovascular-related mechanisms of death, and major adverse cardiac events; Nguyen et al., 2021; Revankar et al., 2021; Sabat et al., 2020).

However, chronic pain seems to be the most distressing and pressing concern reported by individuals with HS (Chernyshov et al., 2021). Pain, as it pertains to HS specifically, has been categorized into two potential forms: acute and chronic. Acute pain arises from nodules which are typically characterized by “burning, stinging, shooting, and stabbing” sensations (Horváth et al., 2015, p. 75), whereas chronic pain experiences arise from more advanced and persistent nodule formations that are characterized by “gnawing, aching, tender, and throbbing” sensations (Horváth et al., 2015, p. 75). It is these chronic pain experiences that are associated with forms of disability and interferences with activities of daily living (Tait et al., 1990). For example, individuals with chronic pain due to HS often cite interferences with work, social and leisure activities, sleep, movement, and daily grooming activities (i.e., dressing, showering, etc.) as a result of chronic pain (Esmann & Jemec, 2011). This burden leads to secondary complications, including missed appointments and scheduled shifts at work, social isolation, perceived helplessness and dependency, and the feeling that HS is all-consuming (Esmann & Jemec, 2011; Patel et al., 2017).

Limitations in daily functioning are not restricted to experiences of chronic pain only; rather, there are many psychological and psychosocial complications associated with HS. The most common psychological impacts reported by individuals with HS involve elevated levels of depression, anxiety, suicidality, and body image disturbances (Koumaki et al., 2019; Machado et al., 2019; Patel et al., 2020); diminished sexuality, self-esteem, and self-worth (Sisic et al., 2017; Weigelt et al., 2022); and a sense of hopelessness towards the self and future (MacMahon et al., 2020). These experiences contribute to the reduced quality of life and increased morbidity observed in individuals with HS (Dufour et al., 2014). This is especially so for women with HS, who tend to score higher on all domains assessing overall distress in relation to quality of life (i.e., all domains of the Dermatology Life Quality Index [DLQI]: daily activities, work, leisure activities, personal relationships, and treatment; Howells et al., 2021; Krajewski et al., 2021; Revankar et al., 2021).

Gendered Implications. In particular, HS has been reported by women as affecting the various social identities and roles associated with womanhood, such as being a mother, wife, and provider, as well as their overarching sense of femininity and gender adherence (Fisher & Ziv, 2022; Revankar et al., 2021). Women tend to experience more impactful and heightened threats to their gender expression, especially in the context of illness, as their bodies have historically been characterized as their sole way of operating in the world (i.e., for the purpose of childbearing, to attract a husband, etc.; Cash & Henry, 1995). This perspective has thus been embedded in the institutions that govern society as a means to uphold such standards and to systematically devalue those who deviate from these expectations (Condon, 2004; Hesse-Biber, 2007). This is especially so within the medical institution, as women's bodies and their natural functions have historically been pathologized (i.e., menstruation, childbirth, and menopause were placed outside of the control of women), where the conception of the 'healthy body' has inherently been masculine and unrepresentative of other genders (Moore, 2010). Furthermore, women's health conditions that produce symptomatology that deviate from societal standards (e.g., polycystic ovary syndrome, endometriosis, amenorrhea, post-partum depression, etc.) are often more readily dismissed by providers, where products to 'correct for' such deviations are suggested as 'treatments' to realign them with the ideal female body (Fernley, 2021; Gruen, 1990; Soucie et al., 2021; Wren & Mercer, 2022). As such, the gendered nature of HS is embedded in most institutions, and particularly in medicine, which results in a limited understanding of HS, as well as women's concerns being more readily dismissed, invalidated, and pathologized (Collier et al., 2020; Hesse-Biber, 2007). As a whole, this can exacerbate the stigma and shame surrounding HS, as well as lead to a distrust of medical institutions, and a potential worsening of symptoms, which can negatively impact both physical and psychological health outcomes (Krajewski et al., 2021).

Overall, experiences surrounding both physical, social, and personal appearances affect individuals who identify as women more readily than men due to the harsher and more direct societal implications that arise when gendered norms or expectations are broken (Condon, 2004; Hesse-Biber, 2007). However, when faced with such repercussions, women tend to show greater strategies of resilience than their male counterparts, especially in the face of chronic illness (Charmaz, 1995; Kesavayuth et al., 2015; Matheny et al., 2005). Men reportedly view these enduring chronic health experiences through an ‘all-or-nothing’ lens and struggle through the process of grappling with their identities and regaining previous control, whereas women, due to their historical experiences with societal pressures, are able to reconstruct their identities and find growth and meaning in the face of disease burden and illness-related impacts (Charmaz, 1983; Vlassoff, 2007).

Resilience

The term resilience originated from the field of technical science and was used to describe the occurrence of a material reverting to its original form, despite being bent, compressed, or stretched (Babić et al., 2020). Put simply, it encompassed the incidence of ‘bouncing back’. This idea was later adapted into psychology and psychiatry respectively, where the term shifted to the general definition of positive adaptation in the face of significant adversity (Luthar et al., 2000). More specifically, resilience involves recovery from stressors through implementing certain characteristics and resources to overcome distress and remain stable (Elam

& Taku, 2022). Within psychology, researchers use this term to describe three distinct phenomena, including the result of a positive state despite potential risk, maintaining a positive state despite chronic circumstances, and recovery from an event of trauma (Babić et al., 2020). It should be noted though that resiliency is a dynamic process that changes over time and can be specific to certain aspects of one's life (Fletcher & Sarkar, 2013).

Despite this concept formation, the definition of resilience has been debated throughout time, where a consensus still has yet to be reached. In commenting on these issues, Masten (1994), as well as other more recent works (Ye et al., 2020; Hughes & Bushell, 2013; Standish et al., 2014; etc.), recommended that the term strictly be used to describe these instances of adaptation and limit the notion or description of it in terms of representing a personality trait. Through this latter view, it could lead others to assume that some people just simply do not possess the natural ability or initiative to overcome adversity, which could lead to additional pathologizing and blame. Further, this perspective does not consider the idea that resilience can be present in some situations but not others, that it can strengthen or weaken over time, and that some simply do not face significant adversity to warrant such a reaction. It thus limits the ability to examine the underlying processes and influential factors that contribute to resilient acts, as well as the design and implementation of interventions and strategies to foster its development, maintenance, and use (Luthar et al., 2000; Masten et al., 1990; Reynolds, 1998; Tarter & Vanyukov, 1999). As such, the definition of resilience as a state-based concept or process, rather than a trait-based concept, will be used throughout this study.

When considering the construct of resilience in this form, it is important to reflect upon the factors that are interconnected to it, including both exogenous and endogenous factors. Firstly, exogenous factors, or characteristics or processes outside of oneself, include risk factors and resource factors (Obradovic et al., 2012). A risk factor is concerned with exogenous agents related to the increased probability of a negative outcome (Masten & Wright, 1998; Obradovic et al., 2012), whereas a resource factor is concerned with exogenous agents related to the decreased probability of a negative outcome by mitigating those associated with risk (Yates et al., 2015). As a whole, both risk and resource factors directly influence adaptation, and can be affected by various endogenous factors, such as vulnerability and protective factors (Yates et al., 2015). A vulnerability factor is concerned with endogenous agents related to the increased probability of a negative outcome, whereas a protective factor is concerned with endogenous agents related to the decreased probability of a negative outcome by mitigating those associated with risk (Ledesma, 2014). What is important to note is that these factors are not static over time and are instead highly dynamic and can be dependent upon the specific situation that arises (Johnson & Wiechelt, 2004).

There are multiple sources that contribute to resiliency, including biological, psychological, social, and dispositional characteristics, as well as elements from various social systems (e.g., friends, family, school, work, community; Herrman et al., 2011). Within a macroenvironmental level, community factors, including spirituality, access to appropriate resources (e.g., high quality schools, healthcare, and extracurricular opportunities), cultural factors, and overall safety contribute to resilience (Herrman et al., 2011; Luthar & Cicchetti, 2000). Within a microenvironmental level, social support, which encompasses both familial and peer interactions, is a main factor contributing to resilience (Trivedi et al., 2011). Furthermore, resiliency has been associated with a variety of personality traits, including openness, extroversion, and agreeableness, as well as high self-esteem, cognitive flexibility, resourcefulness, an internal locus of control, adaptability, and active coping (Ledesma, 2014).

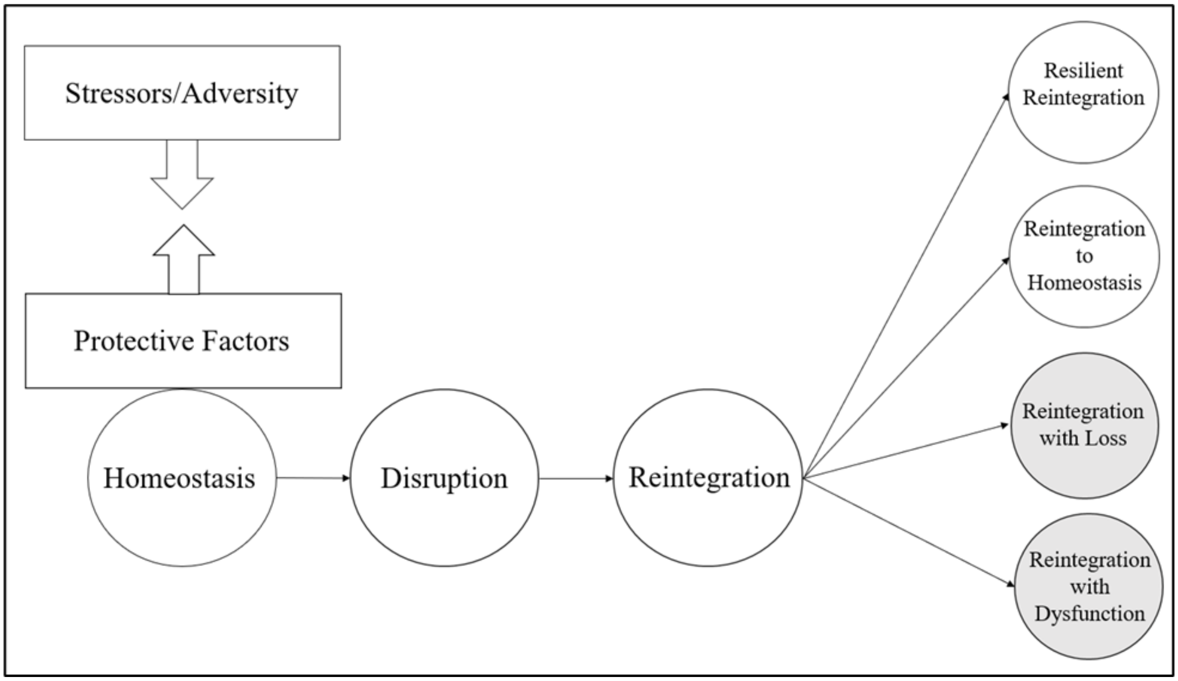
All of these above processes were eventually combined and further illustrated in the creation of various classes of resilience models, including compensatory, protective, and challenge models (Fleming & Ledogar, 2008). A compensatory model represents a situation where a factor of resilience counteracts the effect of a risk factor, where it has an independent effect on the outcome. In a protective model, various resources reduce the effects of a negative outcome, including neutralizing the effects of risks, weakening the effects of risks, and/or enhancing protective factors to produce a more positive outcome. Lastly, a challenge model posits that the relationship between a risk factor and an outcome is curvilinear in nature, where exposure to either low or high levels of risk factors leads to negative outcomes and exposure to moderate levels of risk factors leads to less negative, and more positive, outcomes.

One of the most well-known and accepted resilience theory, which represents an application of a *challenge model* of resilience, was developed by Richardson et al. (1990) and has received minimal alterations since its conception (see Figure 1). Although other models of resilience have been posed (Brown, 2006; Hadfield & Ungar, 2018; Ledesma, 2014; Mullins et al., 2015; Seligman, 1990), the model developed by Richardson and colleagues (1990) has been a frequently used model within a variety of applications (Galli & Vealey, 2008). Additionally, it is the most relevant model for the current study as it has been applied to many health and illness populations successfully (Fletcher & Sarkar, 2013; Richardson, 2011).

This model reflects the occasion where people must respond, either unconsciously or consciously, to disruptions or adverse life events that occur and disrupt their state of biopsychospirtual homeostasis (i.e., now currently called biopsychosocial homeostasis within the literature). This homeostatic state is continually bombarded with both internal and external stimuli or forms of change. To cope with these stressors, humans elicit various resilient strategies to minimize the disruption of these interactions. The interaction between these resilient qualities and the stressor at hand can then provide the opportunity for growth and development.

Figure 1

Resiliency Model by Richardson et al. (1990)



If a disruption occurs, various primary emotions will begin to transpire, such as loss, fear, self-doubt, and confusion (Richardson et al., 1990). This is deemed as the ‘poor me’ phase of the model, which often requires assistance from others through active listening and sympathy. The individual ultimately may question their ability to learn new skills and accept the likely change that may ensue from this disruption. Eventually, after reflecting upon these thoughts and emotions, the individual will begin to actively question what they can do to eliminate or overcome the disruption and either reintegrate resiliently, return to their original homeostatic point, reintegrate with loss, or reintegrate with dysfunction.

The overall act of resilient reintegration is the most favourable and beneficial form of adaptation for an individual (Richardson et al, 1990). It encourages forms of introspection, while using the resilient qualities and tools one has. It ultimately allows for growth and insight through the disruption, thus increasing and strengthening these resilient qualities. The individual does not return to their original homeostatic level and instead returns to a newer, higher quality state. Although this form of adaptation overlaps slightly with the newer concept of posttraumatic growth (PTG), where transformative changes can occur as a result of distress, this pathway still highlights the use of characteristics and resources to overcome stressors that is essential to the conception of resilience and the concept of growth that is central to PTG that is still present throughout this thesis (Elam & Taku, 2022). As such, although this model may conflate these two terms based on current definitions of resilience and PTG, this study aims to explore both of these constructs in tandem and will consider their current definitions in order to represent them appropriately (please see below for section detailing PTG and meaning-making).

This same resilient reintegration process is not evident within those who wish to return to their original homeostatic state (Richardson et al., 1990). These individuals are said to hold on to their ‘comfort zones’, where they actively avoid opportunities to grow to prevent any further disruptions or challenges. In some situations, this homeostasis path is not available as some disruptions are more permanent in nature (e.g., the death of a loved one, permanent physical injury, etc.), and thus an alternative solution must be developed. Although reintegration to homeostasis is not necessarily the most ideal, it is not as harmful as some of the other potential pathways within this model.

The final two solutions, namely reintegration with loss and reintegration with dysfunction, are much more damaging in nature to the individual (Richardson et al., 1990). Reintegration with loss essentially describes situations in which people give up hope or lose motivation to overcome the disruption, whereas reintegration with dysfunction occurs when an individual resorts to other detrimental coping methods, such as substance use or maladaptive behaviours, to deal with the disruption. In both instances, individuals may need professional assistance to remedy their introspection skills and thoroughly overcome the disruption.

Although this specific resilience model was designed to be applicable to a variety of different stressors, adversities, and life experiences, and is one of the only resilience models to incorporate theoretical ideas from physics, psychology, and medicine, there are potential drawbacks to its use (Fletcher & Sarkar, 2013; White et al., 2008). Firstly, it is a linear model that only considers how one event can contribute to this process, where most individuals are likely to experience multiple, competing stimuli at one point in time (Richardson, 2002). Secondly, the model does not explain how emotional and cognitive factors affect the reintegration process as well, which is an important aspect in the processing of stressors and one’s functioning (Efkildes, 2008; Fletcher et al., 2006; Jager & Bartsch, 2006). Lastly, the model mainly frames this process as a reflection of coping (i.e., thoughts and behaviours used to manage stressful events; Wu et al., 2020), even though the concepts of resilience and coping are considered conceptually distinct (Brown, 2006; Connor & Davidson, 2003). Despite these potential drawbacks, this particular model is still largely used and has been applied to situations relating to health and health promotion with great success (Fletcher & Sarkar, 2013).

Resilience and Chronic Diseases

There has been a growing interest in examining resilience within the realm of health and illness more precisely, especially regarding the development and maintenance of chronic diseases (Cal et al., 2015). Chronic diseases are defined by the World Health Organization (WHO) as conditions of ‘poor’ health (e.g., produce incapacity or disability) that can fluctuate and last for an extended period of time, which thus produces negative symptomology or forms of disability that require rehabilitation and continued follow-up. Global prevalence rates estimate that over 125 million people have at least one chronic disease or illness, with at least 75 million of these individuals having two or more (Gheshlagh et al., 2017). It should also be noted that millions more are impacted by chronic diseases, as those persons diagnosed with a chronic disease often rely heavily on the support and care of family and other loved ones (Tecson et al., 2019).

This concept of lifelong care and treatment is essential to the management of chronic diseases, where patients' own care efforts are particularly important (Kim et al., 2019). Due to the high demands of self-care required, individuals with chronic diseases often report symptoms of psychological stress, social isolation, reduced self-esteem, depression, and anxiety, and thus a general worsening of disease-related symptoms (Babić et al., 2020; Gheshlagh et al., 2016). Chronic diseases also tend to threaten overall welfare, physical integrity, financial stability, future-oriented planning, and the ability to act in and fulfill desired social roles (Cal et al., 2015; Gheshlagh et al., 2016). As such, patients facing such instances may not be able to aptly apply typical coping strategies and must instead consider new strategies that incorporate various elements of resilience as mentioned above (Sells et al., 2009).

Chronic diseases ultimately disrupt one's identity, as well as the connectedness one feels between the body and self (Charmaz, 1995). One way to unify these elements, once again, is to alter one's conception of life and self to accommodate such losses experienced. This supposed adaptation, or process of resilience, must often occur in a progressive and cyclical manner during ongoing episodes, flare-ups, or complications. This means that one must consistently and actively resolve tension experienced between the body and self, as well as living with the disease and not just living for it. As such, chronic diseases offer an opportunity to develop a deeper connection to the body and self, as well as uncovering more hidden and implicit meanings within life, if one is open to such experiences through resilience, as well as PTG, processes.

Resilience within individuals with chronic diseases is especially important as it allows for better adaptation to the various changes that come along with disease development (Kim et al., 2019). Specifically, in patients with chronic disease and resilience, reported increases in self-care, treatment adherence, self-empowerment, self-efficacy, and overall health-related quality of life have led to vast improvements in disease severity, pain, and management (Böell et al., 2016; Stewart & Yuen, 2011). Furthermore, reductions in more negative disease symptoms, such as depression, anxiety, stress, and pessimism surrounding the future, lead to accelerated recovery and remission status (Tecson et al., 2019). Ultimately, resilience allows for patients to feel more in control and capable of managing and living with their disease, rather than engaging in negative and ruminative responses (Robottom et al., 2012).

These findings were further exhibited in two studies examining resilience and HS within the current literature. Specifically, in a study by Kirby and colleagues (2017), it was found that resilience moderated depression in HS, thus contributing to better quality of life and disease maintenance. Similarly, in a study by Butt and colleagues (2020), it was found that resiliency and quality of life in those with HS was partially mediated by social support, where levels of resiliency increased over time through repeated use of either in-person or online HS support groups. Both studies ultimately suggested that resiliency aids in protecting and/or increasing overall quality life in individuals with HS, where resiliency-based interventions should be implemented to provide a more holistic form of support and care.

Overall, individuals with chronic diseases tend to have lower levels of resilience when compared to the general population (Tecson et al., 2019). Nevertheless, those individuals who have a stable source of social support, active roles that they need to continue to fulfill (e.g., parent, spouse, employee etc.), a willingness and flexibility to complete tasks differently, optimism, and higher self-rated health (i.e., less severe disease and thus less disability) seem to exhibit higher levels of resilience and subsequent adjustment than those patients that do not (Robottom et al., 2012). However, various resilience-based training programs have been created and implemented to increase such factors within various chronic disease populations and have demonstrated overarching success in the development and maintenance of resilience (i.e., trained attention, adaptive coping, spiritual connectedness, self-control, etc.) across disease persistence (Manning et al., 2016; Trivedi et al., 2011).

Many of these programs have incorporated the works of Denz-Penhey and Murdoch (2008), as well as Richardson and colleagues (1990), through their conception of a grounded theory of personal resiliency in those with chronic diseases. They largely highlighted five major components or dimensions for participants to demonstrate resilience and thus access the quality of life they desired, which included connectedness to one's social environment (e.g., friendships, community, belonging), physical environment (e.g., a sense of home, appreciating and connecting with nature), family (e.g., belonging, commitment to duty, sharing values), experiential inner wisdom (e.g., wisdom of the body, life changing insights), and strong psychological self (e.g., resolution of personal issues, self-acceptance, positive attitudes). Individuals must exhibit all these elements, as all have been found to be central and necessary to various positive outcomes in relation to chronic disease development.

Furthermore, through the influential works of Charmaz (1983; 1995) and Carver (1998), individuals with chronic diseases, including HS, adapt to the changes that ensue through the successful reintegration of one's concept of self. This adaptation occurs in three stages, including experiencing and defining loss or impairment, assessing such losses and changing one’s concept of self, and finally, surrendering control and opening the self up to learning from such experiences (Charmaz, 1995). As such, individuals learn to function with their illnesses and/or diseases by regaining control and coping with changes by surrendering to these experiences, allowing for conditions to arise in which they can discover clarity and purpose, as well as redemption and transcendence of self (Charmaz, 1995). Thus, this provides the possibility of resolution and renewal in the form of posttraumatic growth (PTG) and meaning-making processes and practices.

Posttraumatic Growth (PTG)

Posttraumatic growth (PTG) is a relatively newer term used to describe experiences of growth arising from experiences of distress (Tedeschi et al., 1998; Yu et al., 2014). This terminology captures four essential phenomena that are key to this experience: (1) PTG is more likely to occur in situations that result in severe crisis or distress (e.g., natural disaster, death of a loved one, chronic health diagnoses and conditions, etc.), (2) PTG involves a transformation of the self that goes beyond surface-level components of the distress, (3) PTG is an outcome rather than a coping mechanism, and (4) PTG challenges basic assumptions about the self and the world (Tedeschi et al., 2015). In short, conceptions of PTG involve a certain level of existential struggle and challenges to beliefs and/or worldviews that can lead to reconstruction and growth as an outcome (Westphal & Bonanno, 2007). This conception of PTG then involves five core positive transformations as a result of distress, including improved relationships, new possibilities in life, greater appreciation of life, personal strength, and spirituality (Dekel et al., 2012; Tedeschi & Calhoun, 1996; Tedeschi et al., 2015).

Although this concept is somewhat similar to resilience, and is often conflated with it, it is important to note that although PTG and resilience are both ‘outcomes’ of distress, they are distinct: PTG does not necessarily develop as a consequence of distress, but rather can develop in the aftermath of it, whereas resilience involves the general ability to navigate and overcome distress and maintain normalcy throughout (Greup et al., 2018). In short, resilience is associated with adaptation and adjustment to distress without significant change, whereas PTG involves transformative change due to various psychological struggles (i.e., shattered beliefs, worldviews, concept of self, etc.; Elam & Taku, 2022). Nonetheless, resilience and PTG have been found to be positively associated with one another; however, it cannot be assumed that resilience leads to PTG or vice versa (Bensimon, 2012; Duan et al., 2015; Sexton et al., 2010). Rather, it is the overall experience of emotional turmoil that leads to the possibility of maintenance and/or growth and development, rather than the mere exposure to a distressing circumstance (Dekel et al., 2012).

PTG has typically been measured in various works by examining benefits that have been found in the aftermath of distress (Helgeson et al., 2006), implementing self-report instruments that encompass perceived growth and change (e.g., Post-traumatic Growth Inventory [PTGI]), and/or through the process and theoretical framework of meaning-making (Park, 2010). Ultimately, the process of finding meaning is essential to PTG, as growth is fueled by efforts to make sense of traumatic and/or distressing events through examining philosophical and existential consequences and learning from them (Joseph & Linley, 2006). This can then lead to a re-evaluation and potential transformational change of various aspects within one’s life, thus resulting in the re-conceptualization of one’s beliefs and worldviews to result in a positive development of the self (Elam & Taku, 2022).

Meaning-Making

The concept of meaning is fundamental to the human experience as humans have a natural tendency to make meaning from their lived experiences (Krauss, 2005; Postman & Weingartner, 1969). It helps to make up an individual's formulation and experience of reality, thus influencing the definition of actions and behaviours (Lofland et al., 2022). People ultimately have the freedom to formulate their own meaning, which influences the underlying motivations within thoughts, emotions, and actions (Lofland et al., 2022). However, meaning is more involved than just simply describing these concepts, rather it actually defines, justifies, and interprets these instances as well (Ostafin & Proulx, 2020).

The process of meaning-making specifically depicts how individuals interpret, understand, and make sense of various life occurrences, relationships, and their concept of self (Park, 2010). In particular, it refers to perceptions of significance, and how one confronts discrepancies with the aim of reducing subsequent distress and disparity (Park, 2010). It is a central aspect in recovering from highly stressful and/or traumatic experiences, including those within the healthcare domain, such as chronic diseases, terminal illnesses, and bereavement (Park & George, 2013). In short, it is an intrapersonal mechanism or skill that is highly related to and predictive of the process of resilience and/or PTG, which generally increases life satisfaction (Anum & Dasti, 2016; Gerson, 2018; Porter et al., 2017).

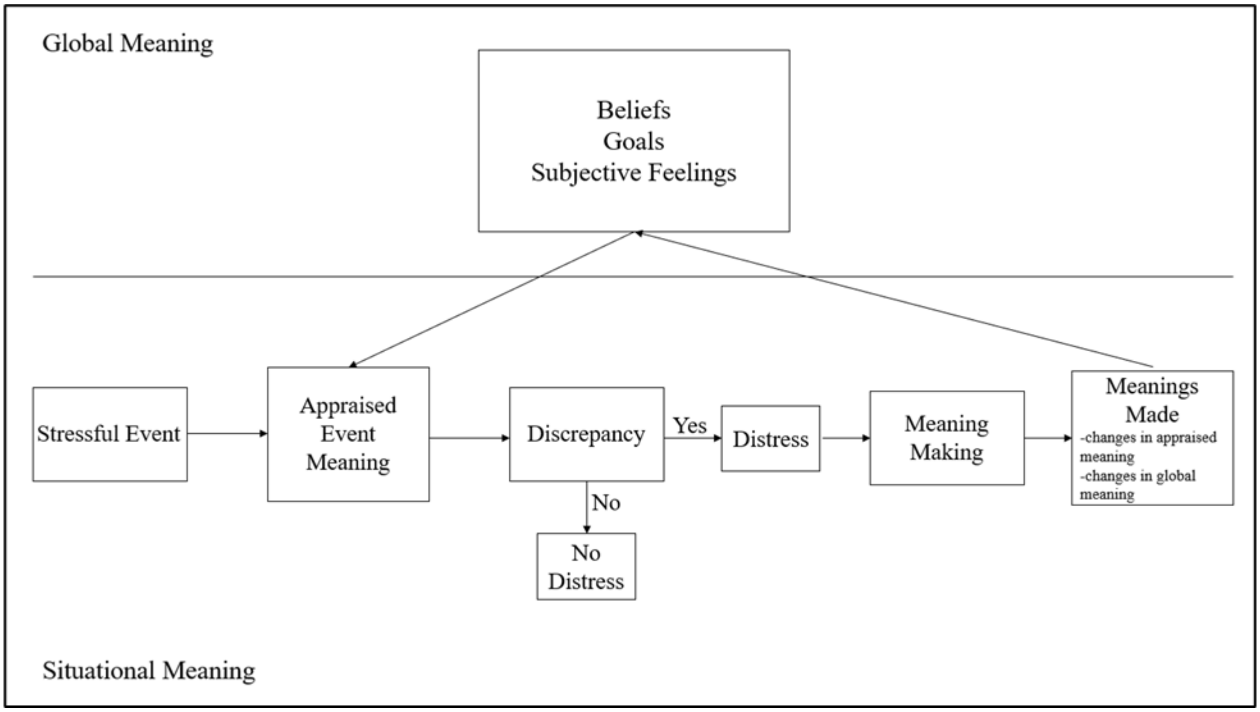
This concept has largely been depicted through the Meaning-Making Model by Park and Folkman (1997), which identifies two levels of meaning: global and situational (see Figure 2). First, global meaning refers to a general orienting system that is comprised of beliefs about the world, the self, and the self in the world; goals (i.e., outcomes that one desires to obtain or maintain); and subjective feelings (i.e., a sense of purpose and meaningfulness regarding a specific direction or goal). It is generally constructed early in life through an accumulation of life experiences and is modified on the basis of these experiences.

Situational meaning, however, refers to meaning garnered from a specific experience. It ultimately involves the interaction between components of one's global meaning (e.g., beliefs and goals) and the circumstances within a person-environment interaction, thus influencing how one copes with potential demands and their corresponding outcomes (Park & Folkman, 1997). One's situational meaning is therefore compared to one's global meaning to examine whether discrepancies persist. This consists of three components, including appraisal of meaning (i.e., the initial evaluation of the personal significance of a situation), searching for meaning (i.e., coping processes used when a situation has been appraised as stressful), and meaning as an outcome (i.e., the meaning or resolution that is made in the aftermath of the situation).

As an example, an individual, prior to their diagnosis of HS, may have the belief that they are a very physically strong and healthy person; this is a part of their global meaning. This meaning becomes challenged though once they receive a diagnosis of HS, a chronic condition. This event may tell the individual that their previous global meaning may not be entirely correct; they may not be as physically healthy as they thought, which is their situational meaning. Within this example then, this individual's global meaning and situational meaning are not aligned and are instead discrepant. This discrepancy can lead to subsequent distress where a resolution needs to be sought out to relieve this conflict. Through this, the opportunity to engage in meaning-making can be encountered. For instance, through this process, the individual may conclude that despite having been diagnosed with HS, their body is still physically strong for fighting through it and that they are mentally strong and healthy to overcome the hurdles presented to them. So, in this case, the individual's situational meaning changes (i.e., they are a strong and healthy person and can handle this condition) to align with their global meaning (i.e., they are a physically strong and healthy person).

Figure 2

Meaning-Making Model by Park and Folkman (1997)



As such, the Meaning-Making Model is discrepancy-based, where distress arises when one perceives inconsistencies as occurring between one's global and situational meanings (Park & Folkman, 1997). This potential experience of distress then gives rise to the need to remediate the discrepancy and reduce experiences of distress. This can be solved through problem-focused and emotion-focused coping strategies; however, in more low-control situations, such as chronic illnesses and diseases, meaning-making is the most adaptive approach. This ultimately involves intrapsychic efforts to reduce the discrepancy, through either changing one's situational meaning to fit with one's global meaning, or vice versa. This rebuilding process can lead to improved adjustment in the extent that a satisfactory outcome is produced so that meaning can be made.

This then aids in the growth and transcendence of self, where a better, more adaptive, state of self is formed, rather than simply returning to baseline. This concept directly reflects the principles outlined in post-traumatic growth, and thus depicts the ways in which one grapples with adverse events and how one can subsequently demonstrate growth and development.

In this context, it can be postulated that the greater the discrepancy is between one's perception of one's illness and one's global meaning, the greater the amount of distress one will experience, thus resulting in poorer health outcomes (Ferreira-Valente et al., 2021). It is then essential for one to integrate one's conceptualization of the illness and one's global meaning to reduce this distress, and engage in stress-related growth (i.e., positive changes experienced from a stressful encounter; Park, 2013). This adversarial growth can then lead to positive changes in social relationships, resources, spirituality, and coping, as well as better lifestyle management and adherence to treatment (Ferreira-Valente et al., 2021; Park, 2013; Park & George, 2013). Thus, the practice of meaning-making can lead to more adaptive health behaviours and outcomes.

Purpose of the Study

Currently, HS is framed as having detrimental effects to one's physical body and psychological well-being. Most often, the literature surrounding this condition purports that quality of life with HS is unanimously poor and that this is inevitable, irreversible, and irreconcilable. This is especially true for women with HS, as this disease is often associated with violations to femininity (e.g., hairlessness, perfect skin, thin, etc.), and has the potential to impact the ascribed social roles of mother, wife, and caretaker. Despite these societal pressures, women with HS can and do live fulfilling lives with this condition while finding ways to cope with its impacts and navigate oppressive institutions. However, a more strength-based outlook on HS in relation to resilience and meaning-making across the lifespan have yet to be explored within the current literature. Additionally, capturing the lived experiences of HS through qualitative methodology has rarely been explored as most studies are conducted with either quantitative and/or biomedical frameworks which rarely highlight the psychosocial and experiential impacts of the disease. We also advance this literature with the inclusion of a feminist theoretical lens to acknowledge the social inequities that systematically disadvantage women with HS.

The purpose of the present study was to gain a deeper understanding of women's experiences living with HS over their lifetime. We also aimed to understand how women navigated the daily, and sometimes shifting, symptoms and impacts related to HS across various domains (e.g., physically, psychologically, socially), and how they reflected on the stigma surrounding the condition. As our focus was also on understanding resilience and meaning-making, our intent was to capture the various ways in which women with HS overcame challenges within each of these domains and reflected on the broader impacts of HS on their lives and their identities as women. The following research questions guided this qualitative inquiry: (a) what do women's lived experiences reveal about managing the day-to-day symptoms and impacts of HS, (b) what are the main challenges women with HS face across various life domains and how do they overcome these challenges, and (c) what have they learned about themselves through their experiences with HS, and how have they found meaning in their condition?

It is anticipated that this study will gain insight into the process of resilience and meaning-making in women with HS, and how one can maintain or even improve overall quality of life despite any potential challenges or setbacks faced with this condition. It is our hope that the results gleaned will illuminate how women navigate and overcome the negative aspects of

HS, as well as what strategies they apply when faced with various challenges to lead a fulfilling life. This may, in turn, aid others with HS, as well as others facing similar illness-related impacts, in using tangible and evidence-based strategies to support themselves. Furthermore, these strategies can be implemented more directly within patient care and treatment plans of this condition, where psychosocial resources and/or resilience training programs can be more aptly developed and used in order to provide a more holistic form of care. Ultimately, this has the potential of impacting long-term outcomes of disease maintenance, treatment management, and overall quality of life.

CHAPTER III

Methodology

Qualitative research is a type of research inquiry that aims to gather in-depth data on a person's lived experiences and realities, including understanding their attitudes, beliefs, motivations, and the context in which they live (Hesse-Biber & Leavy, 2011). Qualitative knowledge is interpretive. It involves a shared understanding of how individuals ascribe meaning through language, to themselves, to others, and to the larger social world (Denzin & Lincoln, 2011). The researcher is a co-producer of knowledge and remains reflexive and critically attuned to their own experiences in the process (Hesse-Biber & Leavy, 2011). There are four dimensions within qualitative research, particularly related to interpretive paradigms, including ontology, epistemology, theoretical perspectives/orientations/frameworks, and methods (Hesse-Biber & Leavy, 2011). Each of these four dimensions greatly influence how a study is ultimately conducted, with ontological and epistemological views specifically informing theoretical perspectives and method considerations (Hesse-Biber & Leavy, 2011). As such, it is important that one is transparent in reporting such dimensions to provide context for the data collected, as well as to allow researchers and readers to better understand the meanings derived from the data.

Ontology

Ontology is a concept within qualitative research that defines a philosophical belief system about reality and being (i.e., what can be known and how; Hesse-Biber & Leavy, 2011). This is largely divided by two different approaches, although they exist on a continuum, including realism and relativism (Denzin & Lincoln, 1994). Realism posits that research can uncover and understand reality because it is objective and independent of the human experience (Denzin & Lincoln, 1994). Whereas relativism posits that research constructs various views of reality, as multiple views of it are inherently possible and subjective since they are based on differing combinations of social, cultural, and historical backgrounds, and lived experiences (Denzin & Lincoln, 1994).

It was the intent of this study to understand how women with HS framed their subjective realities based on their varying characteristics and world views, as well as how they interacted with mine. This study was not concerned with the accuracy, or a universal ‘truth’ of participants’ stories pertaining to HS and was rather interested in the construction of participants’ stories based on their own unique perspectives and perceptions. As such, a *relativist* approach was implemented within this study to explore such constructions.

Epistemology

An epistemology is a philosophical belief system detailing how knowledge is gathered and how it is related to reality (Guba & Lincoln, 1998; Hesse-Biber & Leavy, 2004). Ultimately, as posited by Merriam (2009), there are four main epistemological approaches, including positivist/post-positivist, interpretive/constructivist, critical, and post-modern/post-structural. Firstly, a positivist/post-positivist approach relies heavily on objectivity, rather than considering individuals’ subjective experiences. An interpretive/constructivist approach is concerned with subjectivity and a co-construction of meaning, wherein there are multiple realities, schemas, and representations of knowledge. A critical approach dismantles taken for granted truths and invites alternative ways of being in the world, while also allowing for empowerment, reconstruction, and the identification of freeing information and solutions. Lastly, a post-modern/post-structural approach aims to deconstruct previous truths or knowledge formulations that largely underlie social and cultural institutions.

One of the primary assumptions adopted within this study was that the ways in which women with HS experience their symptoms and demonstrate acts of resistance in relation to them does not solely depend on these women's individual characteristics and personalities. More accurately, these experiences are shaped by dominant socio-cultural standards in relation to their various identifying factors (e.g., gender, race, socioeconomic status, etc.), resulting in multiple inherent truths to exist. These standards constitute the beliefs, values, and practices that are present within a particular historical time, and thus influence how people are socialized (Griscti et al., 2016). The differences between people are not only due to their attitudes and attributions towards a social object or event but can rather be attributed to the object or event itself (Willig, 2008). As such, an *interpretive/constructivist* approach was the most well-suited epistemology for this study as the main goal was to understand the lived experiences of women with HS from each participants' individual experience.

Theoretical Framework

According to *feminist social constructionism*, the main theoretical framework implemented throughout this study, 'reality', and therefore knowledge, is socially constructed (Campbell & Wasco, 2000). As such, various social factors, such as gender, sexuality, race, ethnicity, culture, and class are agents that construct how we view and interpret our own realities (Crawford & Marecek, 1989). There is ultimately no single reality or truth, but instead multiple truths that are individually constructed to form our own unique realities (Campbell & Wasco, 2000). Additionally, how these constructs and their subsequent practices and conceptualizations function within society as a means of oppression is at the forefront of this framework to dismantle the belief that they are inevitable and unchanging (Friedman, 2006).

Feminist social constructionism involves making implicit assumptions that are deeply rooted within social constructs explicit (Cosgrove & McHugh, 2000). However, all knowledge, even those derived from feminist social constructionism research and work, is never completely objective and always serves some form of interest (Fiaccadori, 2006). As such, there is essentially an inescapable relationship between knowledge and the functions of power and marginalization (Fiaccadori, 2006). Thus, conducting such work is not about actively re-constructing these inherent truths, but instead identifying and shining a spotlight on both dominant and marginalized experiences so that individuals are able to incorporate them into their realities and potentially challenge and change them (Wigginton & Lafrance, 2019). This can enable the ability to critique dominant hegemonic conceptions of such constructs as ‘natural’ or ‘essential’ and leads to the re-conceptualization of these identities through action (Wigginton & Lafrance, 2019).

Within medical and illness-related institutions specifically, feminist social constructionism aims to bring to light how knowledge within these spaces supports social inequality and further benefits those in power (Conrad & Barker, 2010). Particularly, in regard to gender, inherent and dominant gender norms are readily assigned to women’s bodies through medical discourse and practices in order to naturalize and further enforce gender inequality (e.g., symptoms of menstruation violate societal norms and thus are pathologized; Markens, 1996). Such ideals result in the social control and policing of women’s behaviours and bodies, which further enforces societal beliefs, knowledge, and oppressive structures, as these beliefs justify inequalities within other institutions as well (Conrad & Barker, 2010).

This theoretical positioning thus reflects how women with HS are consistently subjected to power struggles from a vast array of social constructions that systematically disadvantage them and lead to their marginalized status. Additionally, their experiences and their individual lenses are constructed based on their own knowledge formulations which are a function of their historical timeframe and unique identifying factors and social locations (e.g., race, gender expression, class etc.). These experiences were analyzed through this study, as well as through any potential readers, which leads to subjectivity and alternate meanings being construed. As such, it is essential to acknowledge that objectivity could never be possible within this analysis and that different analyses and conclusions can arise from those with various backgrounds and realities. Instead, it was the aim of this study to engage participants in an interactive dialogue to break down these socially constructed realities and identify those concepts that were inherently disadvantaged to provide the opportunity for further change and resistance.

Participants

Once clearance from the University of Windsor's research ethics board (REB) was received in July of 2023 (REB# 23-085), a total of 25 women diagnosed with HS by a Canadian practitioner were recruited to participate in this study. To be eligible, participants had to be a Canadian or permanent resident of Canada, English speaking, over the age of 18, self-identify as a woman, and self-report as having received a formal diagnosis of HS from a Canadian practitioner due to differences in healthcare systems. It was important to provide participants with the opportunity to self-identify with recruitment criteria as it could allow for the right to control sensitive personal information (e.g., health records confirming a diagnosis) and encourage more diverse recruitment for those within marginalized groups (e.g., women identifying as transgender; Gelinas et al., 2017). Despite these potential restrictions, our goal was to recruit a diverse sample regarding identifying factors outside of gender, such as race, ethnicity, class, sexuality, and dis/ability status. In order to capture a diverse range of experiences, purposeful and maximum variation sampling strategies were employed to ensure that our sample included individuals from these diverse social locations and various diagnosis profiles (Ellard-Gray et al., 2015). These strategies included, but were not limited to, inclusive study advertisements, iterative sampling procedures (e.g., if a particular group was overrepresented in the sample, we used a wait list), and prioritizing interviews with individuals with more diverse demographic identities. Additionally, participants needed to have access to a computer or mobile device that had the capacity to conduct videoconferencing if they were unable to attend an interview in-person (e.g., due to transportation restrictions, residing outside of the geographic region of Windsor-Essex, etc.).

This sample size was determined based on a variety of factors following new qualitative sampling recommendations. Saturation (i.e., the point in data collection at which no new information or themes are produced from the data) has traditionally been the gold standard for determining when to stop data collection in qualitative research (e.g., Guest et al., 2006). However, recent critiques of this concept posit that this is a logical fallacy as new insights are always theoretically possible as meaning requires interpretation, which can vary based on a researcher's subjectivities and theoretical lenses (Braun & Clarke, 2019). Recent discussions suggest that sample size is instead determined through interpretive judgement practices about when to stop, which includes considering the researcher's goals, purpose, timeline, and resources (Braun & Clarke, 2021a). This approach also aligns with Maltreud et al.'s (2016) emerging discussions of information power sample size guidelines, where sample size is dependent on the relevance of data, with more relevant information requiring fewer participants. As such, our final sample size was based on an interpretative judgement.

Ultimately, participants (*N* = 25) ranged in age from 20 to 63 years old (*M* = 36.16, *SD* = 10.61), with an average time to diagnosis of 11.10 years since the time their first symptom(s) began (see Table 2 for demographic information of participants). Additionally, this sample consisted of 68% of White women, followed by Black (8%), East Asian (8%), Indigenous (8%), Middle Eastern (8%), South Asian (8%), and Biracial (4%) (please note that participants were instructed to select all options that applied to them). Most participants were married or in a civil union (32%), while others reported being single (32%), partnered/non-married committed relationship (24%), casually dating (12%), separated (4%), or widowed (4%) (please note that participants were instructed to select all options that applied to them). Furthermore, most women had completed an undergraduate degree (36%), followed by the completion of a graduate degree (20%), a vocational degree/certificate (20%), a high school diploma or equivalent (12%), some college or university (8%), or some high school (4%). Lastly, the majority of participants reported part-time employment (i.e., 1-39 hours per week; 52%), followed by full-time employment (i.e., 40 or more hours per week; 32%), self-employment (8%), unemployment and looking for work (4%), and unemployment and not looking for work (4%).

Table 2

Participant Demographic Profiles

ID #	Age	Ethnicity	TTD	Severity of HS	Relationship Status	Education Status
01	30	White	6 years	Stage 2	Partnered/NCR	Undergraduate degree
02	44	White	20 years	Remission	Married/Civil Union	Graduate degree
03	43	White	27 years	Stage 2	Single & Casually Dating	Graduate degree
04	30	White	7 years	Stage 1	Partnered/NCR	High school diploma
05	30	Middle Eastern & White	5 months	Stage 1	Partnered/NCR	Graduate degree
06	46	White	25 years	Stage 2	Married/Civil Union	Vocational degree
07	31	South Asian	9 months	Stage 2	Casually Dating	Undergraduate degree
08	21	White	1 year	Remission	Single	Some college/university
09	20	Black & Middle Eastern	7 years	Stage 3	Partnered/NCR	High school diploma
10	50	White	22 years	Stage 2	Married/Civil Union	Graduate degree
11	54	White	10 years	Stage 1	Widowed	Vocational degree
12	63	Indigenous	34 years	Stage 2	Single	Undergraduate degree
13	33	White	12 years	Remission	Separated	Vocational degree
14	35	White	22 years	Stage 2	Partnered/NCR	High school diploma
15	42	White	33 months	Stage 2	Single	Vocational degree
16	33	Black	6.5 years	Stage 3	Married/Civil Union	Undergraduate degree
17	30	White	8 months	Stage 2	Married/Civil Union	Undergraduate degree
18	43	White	12 years	Stage 2	Single	Vocational degree
19	43	White	17 years	Remission	Married/Civil Union	Undergraduate degree
20	25	White	11 years	Stage 3	Partnered/NCR	Some college/university
21	27	South Asian	8 years	Stage 1	Married/Civil Union	Some high school
22	43	East Asian	14 years	Stage 1	Married/Civil Union	Undergraduate degree
23	34	Biracial	1 year	Stage 2	Single	Undergraduate degree
24	24	Indigenous & White	30 months	Stage 2	Single & Casually Dating	Undergraduate degree
25	30	East Asian	8 years	Stage 1	Single	Graduate degree

Note. Age is shown in years, TTD stands for Time to Diagnosis, Severity of HS represents the severity at the time of the interview, and NCR stands for Non-married Committed Relationship.

Procedure

To recruit participants, a general study advertisement was created and included the above-mentioned eligibility criteria (see Appendix A). The advertisement was posted and circulated virtually through social media platforms using an account for the study (i.e., Facebook and Instagram; see Appendix B) and online HS support groups based on permissions from group moderators, as well as posted physically in local dermatology clinics (see Appendix C). Interested participants were asked to scan the QR code contained in the study advertisement or to click on the hyperlink included in the description for online posts to complete a pre-screener questionnaire to express their interest to participate (see Appendix D). Once this was completed, participants were contacted through the email address they provided in the pre-screener questionnaire by a study-specific email address (i.e., hsstudy@uwindsor.ca), or they were contacted by telephone using a secure phone contained in the lab space of my supervisor. This screening information was not used for any research purposes and was only used to determine eligibility and to ensure that we collected experiences from diverse individuals in terms of age, class, ethnicity, sexuality, and diagnosis timeframes.

Once eligibility was determined, participants were asked about their preference regarding completing the interview session online via Microsoft Teams or in-person on the University of Windsor campus. Participants were given this choice to ensure their comfort regarding public health occurrences (i.e., ongoing effects of the Covid-19 pandemic), as well as transportation considerations (i.e., some participants did not reside in Windsor, Ontario). However, all participants that were recruited preferred to conduct their interviews online via Microsoft Teams. As such, an electronic calendar invitation through Microsoft Teams was sent to the participant to confirm the date and time agreed upon through email or telephone correspondence, as well as a meeting link to conduct the interview on Microsoft Teams. Additionally, an informed consent form to participate in the study was sent electronically through email for participants to review (see Appendix E), as well as post-study educational and mental health resources, prior to participation in the interview session (see Appendix A). All of the interviews were completed by the student principal investigator (KT) as no conflicts of interest arose that would have required an alternate interviewer.

The present study consisted of three components for participants to complete during a single session that was approximately 90 minutes in length. First, the consent form was reviewed with the participant and any questions or concerns they had about anything contained within this document were addressed. Additionally, a brief overview of the study was provided, where participants were encouraged to ask or modify questions or refuse to answer any questions they did not wish to discuss at any point in the interview. Participants were then asked to provide verbal consent to participate in the study, to be audio recorded through Microsoft Teams for transcription purposes, and to use anonymous quotes from their interview to be used in any reports, publications, or presentations associated with the study. If participants decided to revoke their participation, they were free to leave the interview session without consequence.

Second, a semi-structured interview was used to guide the interview sessions, while also still encouraging participants to express themselves freely (see Appendix F). This interview guide focused on four domains: (1) women’s health care experiences, such as their diagnostic experiences and the impacts of trying to secure a diagnosis; (2) the lived and day-to-day experiences managing HS, with a focus on daily impacts, managing good/bad days, coping, and mental health and body impacts; (3) conversations with others, such as disclosures, social support, and challenging stigma; and finally (4) ending reflections, which included holistic understandings of growth and meaning as a result of HS. Since the interview session was based on a semi-structured format, follow-up questions were posed in order to capture self-reflection and meaning-making within each domain. The interview concluded by asking participants to share anything that was not covered in the interview that they felt was important to share.

Once this interview process was completed, participants were directed to complete a brief survey to contextualize the sample on the basis of demographic and diagnostic information (see Appendix G). Since all of the interviews were conducted virtually, participants were sent a Qualtrics link to complete this survey through the Microsoft Teams chat function. KT was accessible to participants while they completed this survey in case they had any questions or experienced any technical issues, which was ensured by staying in the Microsoft Teams meeting space with the participant. Upon completion of the study, participants received a $20 e-gift card to a place of their choice that was sent to their preferred email address. This process of data collection occurred from July 2023 to September 2023.

Within 24-hours of each interview, the Microsoft Teams platform provided a preliminary auto-generated verbatim transcript, which was saved in a password protected folder on KT's University of Windsor OneDrive account. All of the interviews were then orthographically transcribed and were checked for accuracy by five trained undergraduate research assistants, all of whom signed confidentiality agreements. Each interview was assigned a unique identifier code and any potentially identifying information was removed during this process, which included participants' names, locations, and any other personal information mentioned throughout their interview (e.g., names of friends or family, names of doctors, etc.). All de-identified transcripts were then reviewed and verified for accuracy by KT, where the original audio files were then deleted after this process was completed from the Microsoft Team's server to ensure continuous anonymity.

Approach to Data Analysis

Braun & Clarke's (2019; 2021b; 2022) reflexive thematic analysis (RTA), situated with a feminist social constructionist lens, was employed as the main analytical strategy of this study. Although thematic analysis, as outlined by Braun and Clarke (2019), consists of three core approaches, including coding reliability (i.e., analysis that begins with theme development and identifying a pre-determined codebook), codebook analysis (i.e., application of a structured codebook or coding framework), and reflexive analysis, the reflexive approach was deemed to be the most suitable for this study as it is used to explore the experiences, perspectives, and behaviours of participants given a particular topic of interest. Essentially, it allows for participants to tell their stories, where the researcher interprets and creates meaning out of these accounts rather than discovering truths embedded within them (Clarke et al., 2015). Furthermore, the use of thematic analysis in general was chosen over other qualitative analysis techniques (e.g., discourse analysis, interpretative phenomenological analysis, grounded theory, etc.) as it is a more accessible and flexible technique, it distinctively considers the corpus of data as a whole (e.g., shared meanings), it is the most suitable method for larger (i.e., *N* greater than 10) and heterogenous samples, and it can produce more clear implications for practice (Braun & Clarke, 2021b).

As such, RTA involves identifying, organizing, and interpreting patterns of meaning within a given dataset that is guided by the underlying purpose of the study (Braun & Clarke, 2012). This involves the fundamental construction of themes, which are conceptualized as patterns of shared meaning that are connected by a core concept (Braun & Clarke, 2012; 2019).

It should be noted though that themes are not obvious and are not summaries of the dataset, nor are they reflective of data collection questions (Braun & Clarke, 2019). Although these conceptualizations can be helpful in the process of theme development, they do not represent thorough theme development and would constitute under-developed themes and concepts (Braun & Clarke, 2019; Connelly & Peltzer, 2016). Furthermore, themes do not ‘emerge’ from the data and are rather actively constructed by the researcher(s) and their subjective lenses, thus requiring extensive analytic labour (Braun & Clarke, 2016; 2022; Terry et al., 2017).

This coding process is recursive, non-linear, and bends back on itself (Braun & Clarke, 2019). It is expected that RTA be implemented with theoretical knowingness and transparency, where the researcher strives to be aware of their theoretical assumptions and subjective lenses that guide their coding and analytical processes (Braun & Clarke, 2021b; 2022). This includes the researcher being aware that decision-making will need to occur, where they must knowingly and truthfully engage in this (Braun & Clarke, 2019; Terry et al., 2017). All of these processes must consistently and transparently occur throughout the analytical process, as well as during report writing (Braun & Clarke, 2022).

RTA consists of six phases, including data familiarization, generating initial codes, generating themes, reviewing themes, defining and naming themes, and finally, producing the report (Braun & Clarke, 2006; 2019; 2022). The analytical team for this study consisted of the student principal investigator, Kenzie Tapp (KT) (i.e., a second-year master’s student in child clinical psychology), the research supervisor, Dr. Kendall Soucie (KS) (i.e., a psychology faculty supervisor in applied social psychology), and a secondary coder, Jasmine Kobrosli (JK) (i.e., an upper-level undergraduate research assistant serving as a secondary coder and data analyst).

These roles ultimately contributed to the validity and trustworthiness of the qualitative analysis at hand (please see Table 3).

Phase One: Data Familiarization

Phase one involves the general step of immersing oneself in the collected data, which is completed by reading and re-reading the transcripts of the data (Braun & Clarke, 2012; 2019). It is further recommended that if audio and/or video files are available to listen to and/or watch, these should be used in addition to textual data to provide further meaning and context. This review of the data should be completed at least once, although it is recommended that this be repeated numerous times until the researcher feels they know the data intimately. Furthermore, casual and observational notes should be made on the entire dataset, as well as individual transcripts, to document any initial thoughts.

As such, within this first phase, KT and JK read through all of the interview transcripts, while listening to their corresponding audio files, in one sitting to gain an initial understanding and appreciation of the participants' accounts. After this initial immersion, any initial thoughts were recorded in separate, designated research journals. Two additional reading sessions were completed where initial patterns or reoccurring ideas that seemed to be shared across the transcripts were recorded. Within this process, questions related to how participants were framing their experiences as related to their worldviews and characteristics, and how these unique factors were potentially shaping their realities and constructions of meaning, were raised. Additionally, KT's and JK's own worldviews and characteristics were recorded to determine how these were potentially influencing their interpretations of these experiences. These journal entries were shared with KS, where the three researchers met to discuss these entries in debriefing meetings.

Phase Two: Generating Initial Codes

Phase two marks the beginning of the systematic analysis of the data through the use of coding, which can be completed at the semantic or latent level of meaning (Braun & Clarke, 2012; 2019). A code is a word or brief set of words that capture the "essence" of the data (Braun & Clarke, 2013, p. 207). Generally, codes provide a label for a specific feature present within the data that is relevant to the underlying purpose of the study. Codes are not meant to be fully developed explanations but are rather meant to be succinct and work as a form of 'short-hand' that the researcher understands. This process is complete when the data relevant to each code has been identified, and the codes generated capture the diversity and patterns within the dataset. Ultimately, there is no minimum or maximum number of codes possible; however, a code should appear in more than one transcript or piece of data.

Within this iterative phase then, KT and JK began the process of line-by-line coding, wherein they examined segments that represented single meanings that were related to the research questions. Detailed records about each of the codes generated were kept, as well as how they related to the research questions and how they could be clustered to form themes and/or subthemes. Additionally, debriefing sessions were conducted between KT and JK throughout this phase to compare the codes that were generated to ensure that the data was being represented in its truest form (please see Appendix H for an example of one of KT's journal entries and an audit trial log).

Phase Three: Generating Themes

Within phase three, the analysis begins to shift from code generation to the development of themes, which essentially represents something important and some form of patterned response within the data (Braun & Clarke, 2012; 2019). In general, this largely involves reviewing the codes generated and identifying any patterns of similarity between them and clustering codes together that seem to share a unifying feature. Additionally, the researcher should begin to explore the underlying relationship between the themes, and potential subthemes, generated and how they tell a coherent ‘story’ of the data. Again, there is no minimum or maximum number of themes and/or subthemes possible; however, a theme should display sufficient depth and detail to represent the richness present within the dataset.

Within this phase, KT and JK referred back to notes made in phase two, where the codes and their possible shared meanings were examined. This process was iterative, as considerations were made about how accurately the themes and subthemes conceptualized represented an organizing concept, as well as how they related to the research questions posed and to the other potential themes developed (please see Table 4 for a representation of codes, subthemes, and themes). If a dispute arose between KT and JK about theme development and/or the organization of codes and subthemes, a meeting was held between them and KS to resolve any major discrepancies.

Phase Four: Reviewing Themes

Phase four involves the notion of quality checking, where the developed themes are reviewed in comparison to the generated codes and the dataset as a whole (Braun & Clarke, 2012; 2019). If potential discrepancies are found with the themes generated, then various codes may need to be discarded or relocated, boundaries of a theme may need to be re-conceptualized, and/or a theme may need to be discarded entirely and the prior phases revisited. The overarching point of this phase is not to ‘force’ the specific analysis to fit within the dataset, but rather create an analysis that is distinctive and coherent in representing the dataset. This generally involves re-

reading the dataset in its entirety, sometimes more than once, to determine whether the themes generated accurately capture the experiences present within the dataset as a whole.

During phase four, KT and JK refined the themes generated in phase three to determine whether they represented the data appropriately. To refine the themes generated, the transcripts were reviewed in their entirety, as well as the codes, subthemes, and themes generated from phases one to three, to ensure that they captured participants' stories accurately and represented a fully developed concept. If a code, subtheme, or theme did not appear to represent the data, or it did not represent an organizing concept, a series of options were assessed, including reorienting the theme, reorganizing codes, collapsing themes, discarding themes, or developing new themes. KT and JK discussed these options in debriefing meetings when representation was an issue to assess different perspectives and determine the most appropriate course of action.

Phase Five: Defining and Naming Themes

Phase five entails defining the final set of themes generated, which involves clearly stating what is unique and definitive of each specific theme (Braun & Clarke, 2012; 2019). Overall, themes should ideally represent a singular idea, concept, or focus, be related to one another but not overlap, and directly address the research question(s) posed. This also involves selecting extracts of data to quote and analyze, thus providing the structure of the analysis. It is important to note that data cannot tell a story solely by itself but requires an analytic narrative to express interpretations and depict why it is important to the research question(s) at hand.

Within phase five, KT and JK first determined what each theme represented or how it was defined through highlighting the focus and unique contribution of each theme by collaborating on written descriptions of each theme and subtheme. Then, each theme was evaluated based on its relevance to the research questions, as well as its connection to the other themes generated and its contribution to the overall story told by participants. This process was reviewed by KS to determine whether this conception fit with the data and if the themes could be interpreted in a different way. Once consensus was reached, the themes were named to summarize their key concepts, which was again reviewed by KS for continued agreement.

Phase Six: Producing the Report

Finally, phase six involves producing a report that represents a clear, convincing and compelling story of the dataset (Braun & Clarke, 2012; 2019). Themes should be presented to represent a logical and meaningful connection, where they build on previous themes to tell this story in its most relevant form. It should be noted though, as mentioned briefly above, that this phase does not mark the ‘end’ of the RTA process. Writing and analysis are an interconnected processes that can be completed at various stages and in tandem throughout a study; there is no specific order of how this must be conducted.

During phase six, KT and JK discussed how to present the themes in a purposeful order for the current report to tell the story of participants in the most truthful and accurate way possible. Additionally, exemplar quotes were selected to represent each theme and to provide the reader with evidence and further description. Exemplar quotes were selected based on how well they reflected the depth and breadth of each theme, as well as how they related back to the research questions posed. While writing the results section of this report, KT considered the implications of the themes presented, along with the quotes used, for participants and others with HS. This guided KT in presenting results that are logical, meaningful, and compelling, which were reviewed and approved by both JK and KS to ensure continued agreement.

Table 3

Phases of RTA Data Analysis

Phase of Analysis	Means of Implementing Phase
Phase One: Data Familiarization	-Completed initial reading of all transcripts in one sitting -Recorded any initial thoughts from first reading in a designated research journal -Completed two additional reading sessions and recorded initial patterns or reoccurring ideas that seemed to be shared across the transcripts -Asked questions while reading through the transcripts
Phase Two: Generating Initial Codes	-Began line-by-line coding by examining segments that represented single meanings that are related to the research questions -Continued reflexive journaling by noting down codes and describing the coding process -Compared the codes generated to those of a secondary coder through audit trials
Phase Three: Generating Themes	-Examined codes and their possible shared, higher-order meanings -Conducted audit and debriefing trials with secondary coder about theme development -Kept detailed notes about the development of themes
Phase Four: Reviewing Themes	-Refined themes by reviewing the transcripts, and the codes and themes generated -If a code or a theme did not appear to represent the data, tried to reorient the theme, reorganize codes, collapse themes, discard themes, or develop new themes
Phase Five: Defining and Naming Themes	-Defined themes by examining their unique focus and contribution -Evaluated themes based on their relevance to the research questions and their connection to the other themes generated -Conducted debriefing trials with the secondary coder and the thesis supervisor -Named the themes to summarize their key concepts
Phase Six: Producing the Report	-Organized the data analysis to tell a coherent story -Reported on reasoning behind theoretical, analytical, and methodological choices made throughout the entire study -Used exemplar quotes to show the breadth and depth of the themes

Note. Audit trials involved KT keeping a transparent description of the research steps taken from the start of the coding process to the end (i.e., through this report, through a coding diary), whereas debriefing trials involved discussing experiences and findings as a coding group (i.e., KT, JK, and KS) throughout the analytic process to enhance self-reflection and build confidence in the themes generated.

Table 4

Clustering of Codes, Subthemes, and Themes

Codes	Subthemes	Themes
-Listening to the body's limits -Trusting what the body is communicating -Re-framing the label of chronic	Becoming In-Tune with the Body	Developing Agency in the Diagnosis Journey
-Having a plan in place/knowing there are resources -Surrendering the rigid definition of control -Not letting HS get in the way of life (perseverance) -Symptom management (finding what works for you, being your own researcher)	Regaining a Sense of "Control"	
-Relying on others for mental and emotional support -Relying on others for physical forms of support -Finding community in online support groups for HS	Engaging Social Supports	Cultivating Methods to Cope
-Using movement to make physical symptoms better -Using movement to make psychological symptoms better -Modify movement to align with current HS symptoms	Engaging the Body	
-Reminding self HS is temporary/it will get better -Counting blessings (seeing the positive, appreciating the good days) -Finding humour -Focusing on the present	Engaging Psychological Practices	

-Using formal methods (grounding, mindfulness, therapy) -Distraction		
-Standing up for self in healthcare settings related to HS -Standing up for self in healthcare settings not related to HS -Communicating boundaries to others	Asserting One’s Needs	Harnessing One’s Voice for Advocacy and Change
-Feeling comfortable going against societal norms -Questioning societal norms -Pushing back against backlash for not adhering to societal norms	Challenging Stigma and Societal Norms	
-Spreading awareness about HS -Dispelling misinformation about HS -Wanting to help others with HS (generativity)	Passing on Knowledge to Others	
-Feeling strong to have dealt with previous HS challenges -Feeling strong to face upcoming HS challenges due to previous experiences -Feeling strong to face any life challenges because of HS	Newfound Strength	Gaining Insight and Growth Through Life-Long Learning
-Being gentle with the self -Knowing limits (balance) -Taking away blame and guilt about HS -Self-love	Journey to Self-Acceptance	
-Feeling more empathetic towards others with HS -Feeling more empathetic towards others with chronic illness in general -Feeling more empathetic towards everyone (approach the world with kindness)	Deeper Empathy Towards Others	

Trustworthiness

As a whole, the notion of trustworthiness is an important concept to uphold while conducting qualitative research in order to ensure validity and reliability (Cope, 2014). Trustworthiness ultimately entails the supposed rigor of a study, which involves the overall confidence in the methods, data, and interpretations presented in a study (Connelly, 2016; Polit & Beck, 2009). Various criteria outlined by Lincoln and Guba (1985) were implemented to uphold standards of trustworthiness within this study, which include credibility, dependability, confirmability, transferability, and authenticity.

Credibility

Credibility of the study is concerned with the truth of the study and its subsequent findings (Connelly, 2016; Lincoln & Guba, 1985; Polit & Beck, 2009). As such, a qualitative study is considered valid and credible if the experiences or information presented in a given study are easily identified and recognized by individuals who share in that experience (Cope, 2014). To ensure this standard, various methods of engagement and observation, as well as audit trials, can be employed (Cope, 2014).

Within this specific study, KT and JK documented their thoughts while reading through the transcripts, as well as their thoughts during the coding and theme development processes. Debriefing trials were also conducted throughout the coding and theme development phases, as well as debriefing trials with KS to review progress. The HEAL lab members at the University of Windsor, led by KS, were also consulted after every completed phase of the RTA process to receive any further feedback about the journal entries of KT and JK, or code and theme development.

Dependability

Dependability refers to the stability of the data over time and how it compares to similar conditions (Connelly, 2016; Lincoln & Guba, 1985; Polit & Beck, 2009). To ensure this standard, the maintenance of audit trial or peer-debriefing logs can be employed (Connelly, 2016), as well as noteworthy agreement with a secondary researcher after each stage of the research process (Cope, 2014). Within this study, KT and JK completed logs or journal entries detailing the events and discussions had within each debriefing session, including those with KS and the members of the HEAL lab. Additionally, the data analysis was completed using a team approach (i.e., a primary and secondary coder) to ensure that KT was not inherently biasing or misrepresenting the data. Any disagreements had between KT and JK were resolved in a meeting with KS to safeguard agreement.

Confirmability

Confirmability involves the impartiality of the findings, including the degree to which the findings are consistent and could be replicated (Connelly, 2016; Lincoln & Guba, 1985; Polit & Beck, 2009). This can be exemplified through the detailed conclusions and interpretations implemented throughout the study, allowing for the findings to be accurately derived from the data (Cope, 2014). This is often achieved through including rich quotes provided by participants to accurately portray these themes and conclusions (Cope, 2014).

This specific criterion was applied in the final write-up stages of this study, where the most accurate and representative quotes were included to thoroughly depict results, as decided by KT, JK, and KS. As mentioned previously, exemplary quotes were selected based on how well they reflected the depth of each theme, as well as how they related back to the research questions posed. The implications of such quotes were also considered to determine their relevance to the research questions posed, as well as to the participants and those with HS in general.

Transferability

As a whole, transferability refers to the extent to which findings can be useful or applied to individuals in other settings (Connelly, 2016; Lincoln & Guba, 1985; Polit & Beck, 2009). This is upheld when researchers provide sufficient information regarding the context, location, participants, methods of analyses, and trustworthiness (Cope, 2014). This study, and its final write-up, displays transparency by providing detailed descriptions and explanations of all these essential components. This has been achieved by providing demographic information of participants to contextualize the data gathered and the quotes presented, which was done in a way that ensured the privacy and anonymity of participants was still protected. Additionally, this write-up provides a thorough description of the methodology used, but it is also acknowledged that the materials not presented within the write-up (i.e., journal entries, debriefing logs, etc.) are available for readers to review upon request.

Authenticity

Authenticity involves the extent to which the researcher has accurately and faithfully represented a complete range of the data collected (Connelly, 2016; Lincoln & Guba, 1985; Polit & Beck, 2009). Through using a descriptive approach, readers are more inclined to grasp the experiences and information present in a study (Cope, 2014). As such, the selection of participants to include within a study sample, as well as the inclusion of an assortment of quotes from these individuals, aided in ensuring this criterion (Connelly, 2016).

The richest sample possible was thoroughly sourced and assessed by implementing various sampling techniques as explained above to represent those with diverse identities.

Additionally, a variety of rich exemplary quotes from participants to showcase each theme's true depth and scope were selected. This process was reviewed in debriefing trials with all team members present to ensure agreement and accuracy of reporting.

Reflexivity

Due to this study's use of reflexive thematic analysis, coupled with a feminist social constructionist lens, it is important to acknowledge that the findings constructed from this study represent one interpretation of the data based on the co-construction of meaning between the research team and participants. Throughout this study, the research team constantly reflected on how their own experiences and identities may have contributed to our analysis to adhere with this reflexive aspect. The reflections below are presented for readers to consider as they review this work and to situate the research team within the context of this study.

As such, I (Kenzie Tapp; she/her) am a white, cisgender, bisexual woman who was diagnosed with Hidradenitis Suppurativa (HS) by a Canadian practitioner at the age of 14. HS has been a central part of my identity, even though it has fluctuated between stage one and remission for an extended period of time. I find myself thinking about my HS constantly, and find it extremely debilitating, painful, and embarrassing at times. However, I also find power in my HS and seek to connect with others, both in personal and academic means, to share in the ways that HS can bring positivity and specialized teachings to my life. Working on the conceptualization of this study has brought both of these elements forward and has highlighted the need for myself to focus on the intersection of both positive and negative elements of this condition and how they can both be equally present in one's experience of HS. I acknowledge that my experiences with HS, both personally and professionally, will influence my subjective interpretation and analysis of the dataset collected.

My supervisor (Dr. Kendall Soucie; she/her) is a white, cisgender, heterosexual woman who has an interest in understanding chronic health conditions that are socially and culturally stigmatized, as well as highly gendered. Her research interests centre around understanding the lived experiences of polycystic ovary syndrome (PCOS) in various spaces, such as in health care and relationships, and its intersections with various physical (e.g., HS) and psychological comorbidities (e.g., mental health, quality of life, etc.). She enters this project as someone who has lived experiences with a chronic illness, specifically PCOS, and understands the daily struggles and barriers associated with a syndrome that is all-encompassing. Her research and advocacy efforts have centered around incorporating resilience and strength-based approaches into women's health literatures that have historically been medicalized and pathologized. She embraces new avenues of inquiry by amplifying counter narratives and frameworks and brings this perspective into this work.

My secondary coder (Jasmine Kobrosli; she/her) is a Middle Eastern, cisgender, heterosexual woman who is interested in chronic health conditions and their impacts on psychological wellness and identity. Her research interests centre around individuals' lived experiences with inflammatory bowel disease (IBD), as well as other chronic health conditions (e.g., PCOS, diabetes). She enters this project as someone who has lived experiences with several chronic health conditions, including IBD, primary sclerosing cholangitis (PSC), immune thrombocytopenia (ITP), and PCOS. Through these conditions, she understands first-hand the difficulties individuals with chronic conditions encounter. Her focus in research and clinical work is to provide a platform for individuals to share their experiences and to further recognize the routes in which individuals take to understanding their condition and its impacts.

CHAPTER IV

Results

Four main interconnected themes were constructed throughout the analysis of participants' accounts in relation to their lived experiences with HS, and specifically, how they overcame challenges. Participants first detailed the strategies they used to develop initiative with managing their condition upon receiving a diagnostic label, often without any guidance from practitioners, within theme one, *Developing Agency in the Diagnosis Journey*. They then described various coping strategies they implemented to relieve frustration with their condition and its negative symptomatology, as well as the lack of formal support they received within theme two, *Cultivating Methods to Cope*. Participants then expressed finding a new sense of empowerment and advocacy, both for themselves and others, throughout their experiences within theme three, *Harnessing One's Voice for Advocacy and Change*, in response to being silenced in health care settings and by others in their lives. Lastly, this trajectory resulted in participants finding meaning through the many lessons they learned about themselves through managing their condition within theme four, *Gaining Insight and Growth Through Life-Long Learning*.

1. Developing Agency in the Diagnosis Journey

The first theme captured a part of the process of receiving a formal diagnosis of HS and the struggle to receive adequate care from practitioners, often leading to the self-management of symptom concerns. Despite these negative experiences with health care providers and institutions, such as being brushed off, having rushed appointments, and not listening to participants' symptom concerns, participants described a sense of relief in receiving a diagnosis of HS as they finally had an explanation for their symptoms. However, participants described how they were often left without any guidance or support from practitioners, which made them feel lost and confused about their HS, reflecting the duality of the diagnosis. This sparked a sense of agency and empowerment within participants to find ways to manage their symptom experiences by themselves, especially regarding the uncertainty and fluctuations of their HS.

1.1 Becoming In-Tune with the Body

Once they received a diagnosis for their symptom concerns, participants realized that their bodies had been "right" all along in informing them that something was truly wrong; that it had not been "all in [their] head" like they were frequently led to believe. This often resulted in participants feeling more in tune with and connected to their bodies. They became more inclined to use them as a tool and listen to them (e.g., in future healthcare scenarios), where they pushed past just evaluating their bodies based on their physical characteristics or appearances. As an illustration, Participant 01 stated, "I learned that I know my body best. And all those doctors or nurses saying, like, 'It's nothing. It's hormones.' The fact that I, like, kept it in the back of my mind, like, 'No, this is worse than everyone's saying it is.'" Participant 24 also went on to explain how her negative healthcare experiences led to a greater sense of trust towards her body:

> Yeah. And kind of trust myself that, you know, it is something, you know? I mean, some people, I was thinking at first, you know, like, "Oh, maybe I just need to do different cleaning. Or maybe I'm just not, uh, you know, the way, you know, maybe it's just, you know, that's the issue." But kind of feeling, like, no, that's – I think there's actually something, you know, going on. So, kind of getting that trust in, you know, my gut I guess did, uh, come out of that as well.

Although participants often described many negative interactions with healthcare professionals, which often led them to question their symptom accounts and sense of certainty, they eventually recognized how reliable their bodies were in communicating their needs. To further exemplify this, Participant 05 stated, "So, I think one of the biggest things is that despite feeling like they kind of broke my trust in a way, had it not been for those experiences, I wouldn't have found myself in a place where I actually trust myself more and listen to my body."

This newfound connection to their bodies led to perseverance and agency within other healthcare settings that even extended beyond HS-specific care (e.g., dentist appointments, regular check-ups with their family doctor, reproductive health care).

Additionally, this closer bond permitted participants to recognize how their bodies were doing their best in managing their symptoms, and in fostering healing and recovery, dismantling the idea that their bodies were fighting against them or were unruly or felt out of their control. Their bodies were trying to protect them by sending them signals, alerting them to attend to their needs, and to take better care of themselves. Participants reflected on how they appreciated these reminders. For instance, Participant 03 recounted how listening to and interpreting her body's signals has expanded her insight into what she needs:

> I think I became more aware of my body and my body's signs and symptoms, and the way it was trying to tell me to listen. "You're not listening. You need to slow down." So – even if it's not directly related to HS symptoms. So, you know, if, maybe I, sometimes I get tension between my shoulder blades when I'm working too much. I think I've learned a lot more about listening to my body and trying to address what it's trying to communicate to me. Um, my [therapist] always says, "Your body is always communicating. You just have to listen to it and know how to listen to it." So, I think I've gotten a lot better at listening to my body overall, as well as directly related to HS.

Participant 05 further articulated her deep appreciation for her body's signals and how by opening up dialogue with her body, she learned to feel more at home in her body:

> And another thing I've learned from the experience, which has become even more and more louder in the last four years for me, is, um, I've opened up dialogue with my body . . . Inflammation is your body's way of articulating to you that something is wrong, and you need to address it and-and learning that I-I heard – learning to reinhabit my body and trust it. Because once you start shutting that communication down and things become a little more unpredictable, you know, you're not necessarily learning and-and listening. So, I've been - I feel like my voice, it's like my body has a-a bigger voice now.

She goes on to reflect about how this deep connection and appreciation allowed her to feel more comfortable with and trusting of her body again, despite having the chronic label of HS:

> And I'm learning to listen more to my body, uh, and listen in ways that I never have before . . . And for people with chronic conditions, your body doesn't really feel like home. It becomes a place that's unpredictable, unreliable. You can't really trust it. You don't really understand it. And just to kind of work through confronting inflammation with that kind of reframing has allowed me to feel safer in my body . . . I feel like our body - there's also a new appreciation for how intelligent our body is and how it can heal itself. And it's just your own, like, your own belief in that, and allowing your body to heal itself. So, I think I'm in a place now in my healing, because of all these experiences, where there's this nice surrendering knowing that while I'm trying to take authority over it, uh, I trust my body enough that it can heal itself. And I just need to allow it the space to do that.

As a whole, participants began to recognize how powerful their bodies were to fight against their HS symptoms, despite the 'chronic' label ascribed to this condition. They felt reassured knowing that their bodies were "looking out" for them, where they felt a greater sense of confidence in their body's ability to manage the uncertainty of HS. However, participants also recognized a balance with this mindset, where they acknowledged that sometimes their bodies "can only do so much" and accepted this messaging in order to find a "better balance" in their lives. Participants recognized the importance of being connected to and appreciating what their bodies could do, rather than scrutinizing their bodies for not adhering to 'normal' functioning standards.

1.2 Regaining a Sense of "Control"

Participants also often articulated how they "took back the reigns" (Participant 06) from their HS through enacting a sense of ownership and empowerment over the symptom management of their condition. This often resulted in participants taking initiative outside of their professional healthcare experiences by doing their own research on at-home or more accessible symptom management techniques. For example, Participant 21 explained that she "found a lot of the relief that [she has] now is because of things that [she] had to figure out on [her] own." Participant 13 also added that,

> For me, I've just really learned, like, you know what? Take your health into your own hands because depending on the physician you have, or different things . . . And also, just like, do your own research. Because there's so much on the Internet that you can find on it or realize. I mean, some of it's not always the best advice, but sometimes it does lead you down the right path.

Not only did participants incorporate this independent research approach within their day-to-day routines outside of their healthcare visits, but they also used it to navigate the medical approaches presented by their physicians during their appointments. For instance, Participant 16 went on to describe how she incorporates her own research into her professional care:

> I, like, kind of don't exactly trust what [physicians] say, so I do a lot of my own research. Um, and, like, even, like, when they recommend – like, even my dermatologist now, if he recommends, like, a treatment, like, a drug or whatever, I'm just like, "Okay, cool. But, like, I'm gonna go do my own research. Talk to, like, my own, like, HS connections and see, like, what they say because I can't just go with what you say anymore." [Laughs]

Although participants highlighted how valuable it was to complete their own research about HS symptom management techniques, they also described how important it was to test and evaluate the effectiveness of these techniques on their own. They described this process as an "experiment" (Participant 21) to determine what could work for them due to the varying presentations and subsequent needs of HS. Participant 10 stated that this process for her was about "finding your thing", where Participant 09 discussed the value of trial and error: "it really is just a matter of trying everything out all at once." Participant 25 described this process further:

> Yeah, so for a long time I had to-I had to make sure, like, I had to develop a system for when I had these flare ups. I tried, like, anything you could think of under the book that, like, could help with this. I did, you know, I did, like, antibiotics, systemic antibiotics, topical antibiotics. Um, I tried, like, Korean skin care in those areas. When I showered, like, you know, I was, like, I used to do physical exfoliation 'cause, you know, it came with, like, discoloration and things like that . . . Like, I've tried everything under the sun.

Furthermore, Participant 03 went on to explain how meaningful and impactful this experimentation was for her:

> And I guess everybody's different, everybody with HS. So, for me that was my way of saying, “Okay, I'm in charge of this,” I think. You know, “I'm going to do whatever I can to track this and figure out what's wrong with my body and what I can do” . . . So, I think you find what works for you and whatever that is, it's okay.

Once participants found the methods that worked for their HS management, they often constructed a management hierarchy, wherein they would approach their symptom presentations in a stepwise and methodical manner. This empowered participants to feel more at ease when experiencing flare-ups with their HS, as they felt reassured by having a plan in place and knowing the options they had at their disposal before needing to become more deeply concerned and potentially access more formalized care. For example, Participant 01 said:

> It's very comforting to know that if I'm in pain, then I can go and talk to somebody or, like, do something about it. It gives me that action plan. And that there's . . . just understanding it more, like, the fact that there's phases and that there's different treatments. Like, you can go to surgery, you can have de-roofing done, you can try this medication. If that doesn't work, try a different medication. Like, there's so many possibilities for something to help.

These sentiments were reflected by Participant 24 where she described having a “routine” to tackle her symptom presentations before letting herself “spiral”, as well as Participant 02 who said she “finds refuge in making it a routine” to make herself feel “in control of something that is uncontrollable.” Ultimately, participants felt that they were able to adequately manage HS with the methods they had accrued over their HS journeys, which seemed to mitigate more anxious or catastrophic thought patterns. This, in turn, made participants feel more in control of their HS and the steps they needed to take to overcome the symptomatic hurdles often presented to them.

This was typically coupled with participants engaging in various perseverance strategies, despite the difficulties they were presented with. Participants frequently detailed how they would not let their HS get in the way of them living out their lives and being present in the moments they wanted to enjoy or partake in. For instance, when talking about the pain associated with her

HS, Participant 06 expressed, “I really try to not let it stop me from doing other things. So, I think – I mean the best approach I’ve had, is just mentally, ‘Yes, there’s an issue. Yes, it hurts. But I’m not going to let this ruin whatever it is that I have going on for the day.’” Other participants echoed this sentiment by saying they try to “push through” (Participant 08), “fake it till you make it” (Participant 02), and “not let it hold [them] back” (Participant 03) as they “don’t want it to take [them] out completely” (Participant 16). Participant 09 stated that she even uses a specific phrase or motto to remind herself to persevere through her HS flare ups:

> And I think that's just something that I keep telling myself. Like, you just keep it pushing. That's my motto. All my friends know that I say that. I'm like, “Gotta keep it pushing, keep it pushing, keep it pushing.” Like, that is just something that . . . you just kind of have to do when you have any sort of condition really, or you're going through anything. It's, like, it can be so easy to want to take the easy way out and just lock yourself in your room and do whatever. But, like, I mean, if you do that, then you're missing out on so many, like, potential great experiences. So, I don't know, I just I think the outlook that I have on life right now is just to keep it pushing.

Despite this notion that participants felt they re-established a sense of control over their condition through the tactics detailed above, they also maintained a realistic view of what this ‘control’ truly meant when living with an unpredictable chronic condition like HS. Specifically, participants acknowledged that they did not need to, nor could they have, absolute and total control over their HS, and they were comfortable with acknowledging this. Participants described knowing that HS has it's “ebbs and flows” (Participant 05) and that they can “only do what [they] can to take care of [themselves]” (Participant 21) as there are “things [they] can do to help it and reduce it, but there’s also stuff [they] can’t do” (Participant 11). Participant 02 highlighted this concept further:

> I often refer to the “let it go” kind of phrase or “let it be” – I'm a huge Beatles fan. So, I always say to myself, “Just let it be, like, let it be.” It is what it is, you know? And I think that, you know, probably as I think about it, probably HS, I mean, it's a small piece of my life, but I think it's certainly added to that ability to understand what it means to just let things be and let it be and just, it is what it is, right? So, yeah, I think just that experience

> has probably just built that understanding for me a little bit more because I can't change it, right? So, I'm just like, well, it is what it is, right? Yeah.

Ultimately, participants redefined what ‘control’ was to them regarding their HS, which resulted in a sense of authority over their condition, while also reducing their anxiety about non-responsive flare ups due to certain elements being out of their hands. They created a balance for themselves, or as Participant 05 called it, a “nice surrendering”:

> I think the best thing you could do is find it – find something that empowers you. Uh, because in a situation where you feel like you've lost a lot of control, um, I think the greatest amount of control you could have – I don't wanna necessarily say *over* something, but to sit in that would be to surrender. And I feel like you could only surrender if you're reframing the experience a little more, not better, but reframing it to be something that is teaching you something, rather than you just bargaining with not wanting to have it.

2. Cultivating Methods to Cope

To better deal with their HS symptom experiences outside of Western medical practices, and due to a lack of formal support options, participants sought out and experimented with a variety of coping strategies until they found the ones that worked for them. In a way, participants formed a toolbox of strategies that they could use when they were struggling, which prevented them from engaging in a negative, self-perpetuating cycle of worry, frustration, and hopelessness. They approached their coping in a holistic, all-encompassing way in which they often, unknowingly, used a biopsychosocial model of support, where they sought strategies to use to engage all three of these aspects (i.e., biological, psychological, and social) to better address their needs.

2.1 Engaging Social Supports

Every participant described how important and beneficial it was to develop and rely on close social supports during more difficult times with their HS. Participants usually relied on immediate family members and close friends, but also found that connecting with colleagues and/or employers was sometimes necessary too. They explained how conversations with others provided them with a sense of “validation” and “relief”, where “people checking in with [them] really helps. It really goes a long way” (Participant 01). Participants highlighted how they often used their social supports to talk things out, to vent, to help them stay positive, and to “help [them] push through” (Participant 09). Participant 23 further explained how important her family’s support was during difficult times with her HS:

> But the thing that has helped me the most is the fact that my family knows about it, and they've been with me since I was 13-14 years old. Uh, so, they kind of understand the pain because they saw me when I had my initial surgery with, like, the bandages; my mom took me to the clinic every day to get them clean. So, I think she understands how it can really, like, affect me. And I feel less judgments from them as well because I trust them 100%. . . I guess what brings me a little bit of peace is knowing that my family is here if I really need to, like, take care of me, go buy stuff for me at the pharmacy. Uh, and just, I don't know why, it's just having, like, I feel people that you trust 100%, that have compassion and understanding. I think that's how I kind of help myself in a way. Knowing that although it's me, that I have all of these symptoms, I feel deep inside of me that I'm not alone.

Furthermore, participants described how their supports would not only provide them with emotional support, but that they also frequently helped them with the physical care of their HS if they were unable to complete it themselves. For instance, Participant 20 stated that her “partner actually gives [her] [her] Humira injection weekly because [she’s] scared to do it”, while Participant 21 explained how her spouse would “come in to [the shower] and help [her] or sit in the bathroom with [her] and just talk to [her] while [she] did what [she] needed to do.” Participants highlighted how valuable this type of support was to them as they were able to better listen to and respect their bodies, while also still completing day-to-day tasks needed to continue to care for themselves and manage their condition.

Participants also frequently found care and support through connecting with others with HS, as well as those with other chronic health conditions, often through online support communities and/or forums. They described how important it was to connect with others who are "going through the same thing as [them]" in order to feel "not so alone" (Participant 07) in managing their condition, and often highlighted how they "found [their] people" (Participant 04) through these communities. Participant 18 added that connecting with HS support groups "has been helpful in the sense of not feeling so alone in it. And then, also, getting some, you know, great ideas of how they've been managing it or different things that are available for treatments", which, in turn, helped her to feel less overwhelmed about different medical management strategies for HS. This further added to participants feeling more hopeful about their future with HS, where Participant 16 stated:

> They really, like, just share their stories. And just me being able to relate, um, is, like, so helpful. Um, and a lot of the times it's, like, it's hopeful too because, you know, they've gone through this and they're still here. They're still doing, you know, whatever it is that they do. So, it's, you know, you feel hope that, you know, you can still have, like, a full life and, like, do the things that they've done while you're working through this whole HS thing.

Overall, social support was the main coping strategy that participants employed when dealing with the challenges associated with their HS, where they often found the most impactful benefits from this coping source. They highlighted how important it was to rely on those that they trusted the most to not feel so alone in their journey with HS and to bring positivity to difficult times. They often urged others in their lives with HS, or future generations of HS patients, to do the same in order to avoid further hardship with this condition.

2.2 Engaging the Body

Although not as accessible for some, a few participants (i.e., seven) described how they engaged their bodies by using various physical strategies to relieve their symptoms and/or provide distractions from the physical sensations associated with their HS. Specifically, participants often used walking to cope and engage in exercise, as other physical methods were more difficult for them to implement. For example, Participant 07 stated, “Like if you're feeling miserable all the time, it's just, like, you know what, go for a walk.” Participant 24 also added how she modifies her exercise needs based on her HS symptoms to ensure she still receives the benefits of physical movement, “I guess adjust based on the symptoms that are present. Um, whether that be clothes or, you know, not going to the gym that day and going swimming instead or, you know, doing different things in that way.”

However, participants also used more unconventional ways to physically engage with their bodies, which still addressed their physical coping needs. For instance, Participant 05 explained that she uses an infrared sauna to “sweat it out”, while Participant 10 uses reiki to feel attuned despite stating that, “it's probably not a thing. Most definitely not a thing. But if it helps, it helps. That's what I'll do.” Furthermore, Participant 15 explained how important horse back riding was for her when she was healing after a major HS surgery she had:

> P15: The nurses said, “You're not supposed to ride your horse.” So, I didn't ride my horse for two weeks. And then after that, I was like, no, I'm – and I got up and I mounted, and I just walked. Like I didn't do, like, I didn't do anything. But I was like, no. I found things to do to, you know, to get me to move a little bit. So, I didn't feel so, like, “Oh god, here we go. This is just taking longer than if I had just left it.” I need to know how to deal with it, but I just finally had better ways to get rid of some of that stuff [i.e., mental health impacts].
> Interviewer: Yeah. Yeah. But it sounds like you still were able to, like, find that connection, like with your horse that you mentioned, to really kind of help you through that time. Like you said, kind of get yourself moving.
> P15: Yeah, I had to. And I was like, I know that it's against the rules, but you got to do it.

Participants highlighted how important it was to “prioritize [themselves]” through “going for more walks and doing more gardening or engaging in other things” to move their bodies (Participant 13). For those that engaged in it, they noticed that “physical exercise, any type of it, was the best for [them]” (Participant 23), where they found different ways to support this need through the ups and downs of their HS symptoms. Though at times HS made it difficult for participants to be physical in various capacities, they realized how important it was not only for their physical symptoms, but also their mental state, to continue to be active in whatever capacity they could.

2.3 Engaging Psychological Practices

Lastly, participants used various cognitive strategies to relieve the more psychological impacts of their HS, such as symptoms of anxiety, depression, and low self-esteem. Although at times participants described how difficult it was to remember to use such techniques, they found them extremely impactful, as well as applicable to other challenges within their lives. More specifically, participants described how they reminded themselves that the challenges with their HS are temporary, to focus on the positive, to find humour, to focus on the present, and to use more guided mental health practices, such as grounding, mindfulness, and therapy.

Firstly, participants often tried to remind themselves during flare-ups that the physical symptoms of their HS, namely pain and discomfort, were temporary and that they would recover soon. They described challenging their negative thought patterns in the moment by recalling that their physical symptoms “won’t last forever” (Participant 11), that they just have to “wait it out” (Participant 03), and “let it run its course” (Participant 12), and that “tomorrow is a new day” (Participant 07). Participants 01 and 12 described how they used these phrases as a “mantra” to “make it through” their flare-ups. Participant 18 highlighted this concept further:

> There have been some changes, like positive changes, related to, like, how often I have symptoms and things since I've started different treatments. And so, I mean that has been certainly helpful. Like, just reminding myself that, you know, things are getting slightly better, which means they can continue to get better. So, it may not always be like this, and that can be kind of helpful to, like, pull myself up a little bit when I'm having, like, a lower mood about things.

Participants also tried to restructure their mindset by focusing on the positive things going on in their lives and fully appreciating when they had good days with their HS symptoms.

For example, Participant 09 explained, “And so I guess being able to accept the fact that I do have HS, but also being able to know that, like, there are good moments and there are good days. And I've experienced those fully.” Participants explained that they aren’t “comfortable with being negative [people]” (Participant 10) and instead want to “see the bright side” (Participant 17), which “puts things into perspective” (Participant 08). They further explained how they need to be grateful for what they have in order to fully appreciate the good in their lives and reinstate their quality of life with HS. Participant 03 explained this by stating:

> I mean, you know, there's some things about my life, sure, I'd like to change if I could. But if something happens, I'll be like, “Okay, so this is happening. Let's think of three ways this could be worse. Okay. What would make this worse? So, uh, you know what? I still have full function of my legs. I can go out and I can walk around, do whatever I want. I have a roof over my head. Many people don't have that. And you know what? Even though it hurts, for the most part, I am healthy. And I am independent. And living in my home by myself without help.” So, I find that kind of grounds me a little bit and I'm like, “Okay, you know what? It would be really easy to get into a tailspin and really get stuck in something. And have that pity party” – and it's okay to have that pity party sometimes, I think. But as long as you check yourself and take it back down to perspective. “Okay, really, let's think about this in the grand scheme of things.” So, I find for me, that's something that helps.

In relation to this, participants also tried to use humour to reframe their HS experiences through using laughter as a form of positivity. They not only used humour as a form of coping for themselves, but they also used it to “normalize” their HS experiences and show others that their “life doesn’t end because of this” (Participant 02). They further explained that they want to “always find a reason to smile and laugh” (Participant 04) despite pain or discomfort and that they enjoy being “the shocker trying to make a joke” (Participant 10). Participant 05 explained how humour permits her to not only cope with the discomfort and embarrassment of her HS, but also how it leads to an exploration of humility:

> My sister will joke sometimes, which adds some comedy to it. And, you know, if it's a closer circle, we'll kind of all chuckle ‘cause, you know, if it's – right now it's affecting my cheek, as you can see. It's looking much calmer than it did in the days that preceded

> this interview. But she'll show me pictures of certain characters that look like me, um, and I'll kind of laugh it off. And it brings some humility to the experience, where, like, you know what, I have enough humility to kind of laugh with it because it's very easy to get me to laugh. So, I kind of lean on laughter as a way to kind of reframe an experience where, like, had it not been for this, we wouldn't be laughing, so.

Furthermore, participants often reminded themselves to focus on the present moment to prevent themselves from “spiraling” about their flare-ups. They used phrasing, such as “one step at a time” (Participant 02), “one foot in front of the other” (Participant 06), or “cross that bridge when you get there” (Participant 03) to redirect their attention to the current presentation of their flare-up and “treat what’s right in front of [them]” (Participant 03). At times, they also had to push their worries about HS out of their minds completely to better attend to other tasks within their lives. For instance, Participant 06 stated that “mentally [she has] to put it in the back of [her] head because [she’s] not gonna be able to do what [she has] to do everyday if that’s all [she] can think about. So, [she has] to just put it in the back of [her] mind and work around it.”

Similarly, participants sometimes tried to use various distractions to divert their attention away from their HS symptom experiences, especially when experiencing heightened pain or discomfort. Specifically, participants described how they would try to watch their favourite television shows, listen to music, draw or paint, read a book, or really use “anything that’s enjoyable” (Participant 08) to try to reduce negativity. Participant 18 described how she even uses her dog as a source of distraction and support because “he's good company and [she has] to take care of him. So, it gives [her] something else to focus on other than just laying around and being in pain.”

Participants also sought out more formal mental health services and strategies to better equip them to overcome challenges. They often cited that they used grounding techniques, such as deep breathing or the 5-4-3-2-1 sensory method, as well as mindfulness-based techniques, such as guided meditation and gratitude journaling. For example, Participant 14 said that she "writes down what she's feeling now" in a journal to ease her anxiety and stress about HS, as well as listening to self-help podcasts to "build [her] mind." Additionally, some participants (i.e., 11) also reported that they sought professional therapy services to better process and understand their HS experiences, which was otherwise challenging for them to attempt to accomplish on their own. Participant 13 highlighted how impactful her therapeutic relationship was to her:

> So, that's why I think, like, therapy, for me, was really important, and stuff like that, for sort of an outlet to express how I'm feeling and have understanding. And take care of the other issues in my life that could cause me stress or anxiety that would attribute to me having a flare-up again, and stuff like that, so.

Overall, participants were quite resourceful in finding different psychological strategies to cope with their HS experiences. They often used a trial-and-error process to find which techniques worked the best for them and their personal experiences, and surprisingly did not become discouraged through this discovery phase. They ultimately realized how important it was to truly take care of themselves across various dimensions and realized that their HS often improved or at least was not as burdensome if they continued to put themselves first and approach their needs using a holistic form of care.

3. Harnessing One's Voice for Advocacy and Change

Once participants felt more confident in themselves and their abilities to manage their HS symptoms, they often sought out strategies to advocate for themselves and their HS to receive better care and support, not only from the medical field, but also from close others and society in general. Participants felt that they needed to develop and exercise their voices in order to incite change for themselves and others managing HS. They realized that they needed to be their strongest advocates as only they could truly represent themselves and potentially advance the field of HS care and research through sharing their personal experiences.

3.1 Asserting One's Needs

Through their difficulties with HS, participants began to realize that in order to receive the proper care and support from medical professionals and close others, they needed to voice their needs and push back against any resistance they faced in doing so. They understood that in order for others to try and best support them, they needed to communicate their needs openly. Within medical settings specifically, participants described how they prepared themselves for their appointments by making notes and having talking points, and how they used their own research to inform their medical decisions. When faced with backlash or a lack of support from providers, participants described pushing back, not leaving until they got an answer, and standing up for themselves and their needs. As Participant 08 explained, "There is a time when you gotta fight for yourself. I feel that no one is going to look out for my health but me."

Participants took up space and reclaimed their voices within a system that historically made them feel small. For example, Participant 20 stated, "Oh yeah, I don't take no for an answer now if I know there is something wrong," while Participant 10 expressed, "It's not just standing up for yourself and advocating, it's doing it in a loud voice. I'm not taking this anymore." When asked what she learned from her diagnostic experience with HS, Participant 21 shared the following sentiment:

> Vouch for yourself. You're own spokesperson. You're your own hero. You're your own everything. Like, you have to vouch for yourself. If one person doesn't listen to you, don't give up. Don't just take what someone says and run with it. You know what I mean? Or don't just say, "Okay, there's nothing I can do. This is my life. That's it." Like, that's what I wanted to do a few times; just accept it. But I was like, I can't live like this. You shouldn't live like this . . . So, you know, I – yeah. Just always fight. Like, I just realized that I literally have to fight for myself every time or feel unheard.

Participant 17 reflected a similar outlook when asked about how her diagnostic experience with HS has changed how she approaches providers now:

> I think through this process I have realized that I need to stop assuming that providers know what I want, and I need to start telling them. I guess moving from more of, like, that paternalistic relationship to a team-based approach because I know that in the past, I've been dissatisfied with what a doctor has wanted or prescribed, or whatever. But then realizing now that I can actually advocate for myself and tell them what I need or want, because it's my body and they don't know what I'm thinking or what I'm hoping for. So, I need to speak up.

Though participants learned these strategies through their own medical experiences and applied them within their own interactions, they also tried to encourage others in their lives to do the same. For instance, Participant 15 stated, “I would probably tell people now to, like, don’t be written off…just keep pushing,” while Participant 01 added, “No matter what a doctor says, if you’re not satisfied, just keep looking. Look for another doctor until you get the answers you’re looking for or if you have some type of relief.” Whether an individual they came into contact with was trying to receive a diagnosis for HS or another medical condition entirely, participants would support them and encourage them to advocate for their own care as well. For instance, when asked about what she would tell others dealing with HS, Participant 13 stated:

> What I've learned from it, especially, is that you just, you need to be an advocate for your own health one hundred percent. Like [sighs], and even just conversations I have nowadays with other people that I'm friends with, and I'm like, “Get a second opinion, or push for more information, or ask for that referral. Like, don't be afraid.” Um, so, for me, I've just really learned, like, you know what? Take your health into your own hands.

This advocacy often extended outside of healthcare spaces and into other aspects of participants lives as well, especially with close others, where participants learned to inform their social circles of their HS experiences in order to receive the support they needed. When these close others were confused or not listening to participants, however, they continually reiterated their needs and established boundaries to ensure their well-being. For example, Participant 07 described how she communicates her boundaries to her friends during a flare-up: “If I can’t do it, I just say, ‘Please don’t take it personal. This is what I kind of have to follow for my life to be normal and I need you to respect that.'" As well, Participant 01 further explained how she reinforces boundaries concerning intimacy with her partner when she is experiencing a flare-up:

> Once I have the courage to bring it up and say, "Hey, like, this is how I'm feeling, I'm having a flare up, it really sucks." You know, he's in, like, fix it mode and I have to again tell him like, "No. Right now this is what I need. I need to just stop and do nothing. I need you to, like, just don't touch me. Don't come – don't come near me. Try again tomorrow." [Laughing].

Participant 14 added that informing others in her life reduced guilt and shame surrounding her condition where she used these conversations to make sure that "people understand and appreciate the reasonings behind [her] approach." She later went on to explain why this was important to her and her HS journey:

> And so, making sure that everyone in my life understands what's going on with me so that they are supportive, and they don't see it as, like, she's just being lazy or, you know, she just doesn't want to do anything. They understand that when I'm in those positions that I just need that space. And so, I think just like looping everybody in that is around me and having the support gives me the opportunity to just take the whole night and not have to worry about anything else.

Participants ultimately highlighted how important it was to continually put themselves first and ensure this by taking the responsibility to communicate this to others. As Participant 09 expressed about her family, "If I don't say anything, then they won't know what to do. And it's not fair to them and, like, expect them to know what to do when I'm just, like, kind of sheltering myself." As a whole, participants recognized how important it was across multiple areas of their lives to reclaim their voice and use it as a strategy to have their HS needs respected and met by others.

3.2 Challenging Stigma and Societal Norms

Additionally, HS caused participants to face the "rules" of womanhood and what this meant to them and their disease management more acutely. This was often connected to experiences of stigma, especially in relation to weight, hair growth, and scarring. Through these largely impactful and distressing experiences, participants would challenge themselves to fight back and to not unknowingly accept these implicit rules enforced upon them by questioning their reliability and validity. For example, Participant 11 explained how she challenged weight stigma imposed by her family members when they hypothesized that weight loss could reduce the severity of her HS:

> I think there's, you know, obviously lots of stigma and lots of embarrassment, and it's related to weight . . . You know, some of the stuff talks about, you know, well, “If you just lose weight, it gets better.” And it's like, “Well, I was a lot thinner, and it wasn't better.” So, no thanks. Like, I’m good. [laughs]

Participant 03 further commented on this issue where she began to question the labels that are often assigned to specific body types, and ones that are especially looked down upon within the HS sphere, where she reclaimed these labels to remove the negative connotations often associated with them:

> I am a person who is fat. And oh, three years ago, I would have never said I’m a person who's fat. Holy cow. I would have run away from that word. Now I'm like, “No. Short, fat, tall, skinny, bald. It's just a label. Whatever.” So, I've really done a lot of work on trying to let go of what other people may think of me. I can't control what people think of me, so why waste energy on that? Life’s too short, let go.

To further communicate and stand up for their various symptom management decisions, especially those that were more cosmetic in nature (e.g., not shaving, not wearing tight clothing, etc.), participants began to challenge the status quo and social expectations imposed on women. Specifically, they became more likely to outwardly show and verbalize this disdain by wearing certain clothing to “show off” their “hairy armpits” or express how “sexy” they felt in loose clothes that did not exacerbate their HS, finding a balance between self-expression, confidence, and comfort (Participant 04). For example, Participant 23 stated, “I would put comfort over how I'm going to look, because of sometimes how intense the pain is. So, I'm like, I know they'll see maybe the scars under my arm.” Participant 04 commented further on this issue:

> But that really has helped me just to realize too, like, everything is all about society, and it's like, someone now – when someone will be like, “Oh, like, you got a little bit of hair on your arms.” Now for me, I'm just like, well, where in society does it say you have to? Right? Um, like, so now, I'm kind of like, pushing the boundaries to show, like, everyone that this is how, like, society has made it seem. And as well too, like, to kind of touch on the mental health aspect, like, we might think, like, even from reading books, like, “women should do this.” And like, that whole “should” thing. Where did we get that “should” thing from? Like, there's no such thing as a “should,” right? So, like, even that has kind of helped me with realizing like, okay, so if someone says like, you know, “you should wear this,” and it's like, well, “that's you, not me.” You know?

This resulted in participants trying to find the deeper meaning of these messages from society and find ways to grapple with the idea of them being labelled as “abnormal”. More specifically, this often resulted in participants questioning the value that society places on aspects of women’s appearances and re-evaluating their own values regarding this. For instance, Participant 05 realized that she has “much more to offer than my appearance. And you know, realizing that if somebody's gonna judge, that's on them, not me. And just realizing that being confident is the best thing you could show up as.” Participant 16 further echoed this sentiment when she reflected on how her experiences with HS changed her perspective and priorities in life:

> I think it's made me not as, like, superficial, I think. Like, nothing about, like, looks and all of that. Like, it's just that those really aren't my priorities anymore. I’d rather just be a caring and compassionate person . . . instead of always worrying about how you look or how others look and judging them off that.

As a whole, this questioning led participants to feel more confident with themselves and how they chose to present to others. This further led to their acceptance of their symptoms and made them reconsider how they framed and interpreted them (e.g., not using the word ugly to describe HS scars). Participants chose to show up as their true, authentic selves despite the negative messaging they were receiving from society, which allowed for a more impactful connection with themselves and their bodies:

> I would say that, like, I rebel against – so, this is now the feminism part of it. Like [laughing], I reject a lot of, like, just, like, society's, um, I guess views on beauty. Um, and this was, like, part of my self care journey as well. Like, you know, now, like, I don't care if I, you know, if I wear – or if I have hair somewhere, or if I have scarring. I'm just like whatever, like, this is me. (Participant 25)

3.3 Passing on Knowledge to Others

Participants then began to use their voices and newfound wisdom about HS to talk more openly about their experiences with it in order to educate others and spread awareness of and dispel myths about HS. They did so most frequently in more personal spaces where they knew people better, such as at work, school, and family/peer social events. However, some participants (i.e., 12) also felt quite open and shared information about HS in any setting they felt they needed/wanted to. For instance, Participant 15 shared how HS came up in a visit to the dentist:

> Yeah, and I think people are – once they kind of, like, know that I have something, people get curious. Like randomly at the dentist last week, they had to update my file and I was like, "I'm on doxycycline." And so, they were like, "Well, why?" So, I told the hygienist and she just started googling it, which I don't mind because you know what, yeah, not a lot of people know about it. But half the time, like I would say, one in three people that I tell I have HS, they'll be like, "Oh, I know somebody who has that too or has the same symptoms," or something and like, "They should go to see their doctor" . . . I don't mind, learn a little bit more information. Go for it.

In a similar instance, Participant 20 explained how she carries around a book about HS with her and uses it to broach conversations with people about HS, especially within medical settings, because "if they don't understand" she's "gonna educate them about it." Participants ultimately expressed how being open with others resulted in less room for misunderstanding. However, other participants felt uncomfortable sharing the "nitty gritty" of their condition and simply stated that they encouraged individuals to "look it up" and conduct their own research. Through these interactions, they hoped to still de-stigmatize the condition and spread awareness, without sacrificing personal details about their experiences.

Interestingly, many participants (i.e., 16) decided to be more open about their HS to try and help others with the condition, especially future generations, to prevent them from "going through what [they] had to go through" (Participant 14). The notion of helping others not only assisted others with their HS, but it also gave participants a sense of purpose with their condition. For example, Participant 03 described how her advocacy efforts led to others finally receiving an HS diagnosis and how impactful this experience was for her:

> I'm not afraid to talk about my HS. I'm an open book. It doesn't bother me at all. So, I post on Facebook during Awareness Week, even when it's not Awareness Week. I posted all about my treatment journey, what I went on. And actually because of that, I'm very proud to say that a friend of mine from undergrad, her daughter was showing symptoms, and sure enough, she has HS. Um, I found out that six other people I know personally have HS and have never talked about it with anyone . . . And just recently, uh, someone from my small hometown got in touch with my mom because – high school chum. She's seen me posting and she's like, "This sounds exactly like what my niece is going through." So, they got in touch. So, I'm very glad that I'm able to help raise awareness about HS and hopefully help people understand what's going on with their bodies. Perhaps a little sooner than they might have otherwise. So, I think that's the biggest thing. So, I think all of those skills that I've learned are being put to really good use to help people in a very different way, a personal way. That's important to me.

As such, participants realized that being more vocal and open about their HS experiences not only potentially helped them with their symptoms by advancing awareness about HS and making them feel more purposeful, but it also potentially helped others with their own HS experiences. They began to notice the "ripple effect," which motivated them to continue to share their HS journeys. Participants felt that this could help advance research and clinical practice of the condition and potentially reduce misdiagnoses, underdiagnoses, and delays in diagnoses. In fact, some participants explained that they agreed to partake in this study for the purpose of advancing the field to help others:

> I think the reason why I agreed, and why I wanted to do this study, is because I think that because I've had it for so long and I got – I had it from such an early, early age. If I can help, you know, whether it's like in clinical research or in, like – at the place that I'm at, where I had surgery, I also signed up for their clinical research program. 'Cause if I can

> help one person just make diagnoses or make breakthroughs in mental health or physical health, sign me up for it. Because, you know, I – as someone who's gone on and had it for so long, and had such a late diagnosis, I would love for that to not happen to somebody else. So, uh, yeah. Yeah, something good has come from that ‘cause I'm willing to, like – I want to help people. (Participant 15)

4. Gaining Insight and Growth Through Life-Long Learning

Once participants felt better equipped to manage, cope with, and advocate for their HS symptoms, they were able to find meaning within their diagnosis and learn lessons through their HS experiences to better themselves. Participants viewed these opportunities as important and meaningful life lessons and often communicated that they were thankful that they were able to experience them through their HS, despite the negative challenges they also faced. Overall, participants felt that they had adequately incorporated HS into their lives and identities for the most part and felt that their HS contributed to their growth and development, which led many to express that they would not change their experiences with HS because of this. Participants truly felt at peace with their HS and felt that they could apply their teachings to other aspects of their lives to continue their journey through personal growth.

4.1 Journey to Self-Acceptance

Ultimately, participants began to accept their bodies for how they were, including their HS symptoms, and began to engage in self-love and appreciation. Participants felt that they were able to reach this lesson by first removing the self-blame and guilt they had related to their HS. They expressed how receiving a diagnostic label of HS was important to begin this process, and how this provided a sense of relief that there was a medical reason behind how their bodies were acting. As Participant 14 explained:

> But just knowing what it is and that, you know, it's not something I'm doing to myself. Because I spent so many years, like, maybe it's the soap or maybe it's the underwear or maybe it's, you know, the food I'm eating. And nothing I have ever done has helped, like I – changing my diet hasn't helped. And [my doctor] just made it clear that sometimes

> there's just nothing you can do. And that made me feel a lot better about myself. So, I'm far more confident and I don't hide under layers and layers of clothes anymore like I used to.

Participants, especially during flare-ups, often tried to remind themselves of this to help reduce the “whoa is me mindset” (Participant 06), which aided them in finding pieces of solace within their experiences. For example, Participant 01 stated, “I think just talking about it or putting, like, a name to it and saying, ‘This is a flare up’ or ‘I am in pain’ or, you know, like, kind of separating it from me and saying, like, ‘It's not my fault.’ Again, like, taking away the blame, there's a reason for this.” Participant 11 shared in this technique as well during challenges with her HS, “There's a lot of telling myself, like, ‘it's okay,’ and ‘it's just an illness,’ and you know, ‘you're doing everything you can.’”

With the self-blame and guilt associated with their condition removed, participants were then able to exhibit more kindness towards themselves when they were experiencing flare-ups or challenges associated with their HS. Specifically, participants often expressed how they “give [themselves] grace” when they are having a difficult time with their HS and are generally more understanding towards themselves. For instance, Participant 02 said, “So I try to be kind to myself and realize, hey, if I'm in a lot of pain and the Advil or whatever isn't working, then I just go lay down. Like, I go lay down and watch a movie in my bed.” Participants explained that they “try not to push [themselves] or force [themselves] through anything” (Participant 08) and give themselves “twice the extra grace to focus on [themselves]” (Participant 07). As such, although in other themes participants were able to cope with and persevere past their symptom experiences, they also felt that in order to accept their HS, they also needed to be okay with allowing themselves to simply rest as well. They ultimately found “a delicate balance” (Participant 06) and understood their “limits” with HS:

> I think I've given myself more grace. If I need a day, if I'm feeling tired, if, you know . . . You know what? If I'm tired, it's okay to take a day. It's okay. So, I think that I've learned that, as well as part of this from those bad days. You know what? Taking one day is a lot better in trying to stop this now, nip it in the bud, than getting into a gigantic flare and missing five days or three days or that type of thing. So, yeah. (Participant 03)

This then resulted in participants being more accepting of their HS and how they could live with this in a harmonious way. They explained that HS "is a part of [their] life, [their] stories, and who [they are]" (Participant 13), where they have had to "come to the conclusion that this is a part of [their] lives" (Participant 17). This helped participants to more readily grapple with the changes that often occurred to their bodies because of their HS and pushed them to move past any discomfort they felt both physically and mentally about these impacts:

> I don't feel like there's anything I can do to change the situation or what my body looks like. So, I just – I try to be accepting of it as much as I can . . . I just try to tell myself my body is fine the way it is, you know? Can't really change the scars or the abscesses or anything about it. It just is what it is. So, I guess I just try to be my best self and look at myself like I don't have those issues. I don't know, I don't know. (Participant 20)

However, this bodily acceptance, once experienced with HS, often pushed participants to apply this to other aspects of their appearance that were not necessarily caused directly by HS, such as weight. Participants truly began to "appreciate" their bodies, be "comfortable with [themselves]" (Participant 04), "gain more confidence back" (Participant 15), and "wholeheartedly love [themselves]" (Participant 25). Participant 04 expressed how impactful her HS was on this journey of self-love and acceptance:

> 'Cause now, like for me, like, the way I share – and I'm so open and so vocal, and more confident, and care less about what people think, right? It's like...without HS, like I said, not that I was like, "Oh, yay! Having HS is a good thing," but without it, I would probably still be, not even, like, in other appearance aspects, with just my weight itself—I would probably still be like, "Oh, you know, I don't look sexy and skinny, like everyone else." But from just having HS, like, weight, like, I was like, "Okay, that's not even something on my radar anymore." So, now it's just, like . . . I don't know, I just embrace everything. So, you'll see me, bikini on the beach, armpits all out, flares all out. I really don't care.

As a whole, participants expressed how empowering and meaningful this particular lesson was for them and how it pushed them to be more accepting of themselves as a whole and truly embrace their physical appearances as they were. Participants explained how “relieving” this experience was for them, as well as how it eliminated social pressure and stress to constantly fit in and worry about their appearance and ‘abnormal’ features. They often tried to share this lesson with others in their lives and felt that this was one of the most important aspects for HS warriors to consider in overcoming their experiences more adaptively:

> I think honestly, it's, like, for me, it's just it's okay to be who you are, and, like, you need to accept who you are. Just like we do with any other illness. Like, again, when we come back to, like, a broken leg or somebody who was born without a hand, like, you learn to have that be part of your life. And my biggest push for anybody with HS is just to learn that it's part of you and that it's okay. And to just try to learn different coping mechanisms because, yeah, I mean, it is who you are. And if you continue to hate yourself and hide away and not deal with it, you're never gonna be happy and you're never gonna be able to grow in life. So, just be who you are and fuck the haters. (Participant 14)

4.2 Deeper Empathy Towards Others

Participants not only developed acceptance and kindness towards themselves, but they also applied this to others. Participants described how their experiences with HS led them to have a greater understanding of chronic health conditions, where they developed greater levels of compassion and empathy towards those with such conditions. This understanding of the chronic experience extended even beyond others with HS and was applied to all individuals with some type of health condition. Participants explicitly stated that they “gained more empathy for people with chronic health conditions” (Participant 18) where they were able to “fully see other people’s experiences in ways that maybe people without chronic conditions might not necessarily see” (Participant 05). More specifically, the unseen nature of HS made participants especially appreciate “hidden disabilities or conditions” (Participant 15). Participant 13 echoed this view by stating:

> I'd say, like, perspective-wise it's, like, just because you can't always physically look at somebody and tell that they're having issues or health problems, doesn't mean that they're not. I think a lot of people suffer in silence, so it's just to go a little easier on people. And just, like, there are things that people don't wanna talk about or disclose or that they try and hide . . . So, I just think for others, like, just don't always take them at face value. Like, there could be things going on that you don't know about or that you don't recognize, or they don't wanna disclose. And just trying to be just, in general, just, like, a nicer, more understanding person.

Some participants even explained how this lesson of greater empathy and compassion towards others even extended beyond those with chronic health conditions and was applied to others more broadly. For instance, Participant 13 explained how she has used this teaching with her employees, which has strengthened the team dynamic at her workplace, whereas Participant 14 described how she fosters this perspective with her friends and family and is known as the “person to go to” for support, regardless of the issue at hand. As a whole, participants really highlighted that “you never know what someone is going through” (Participant 20) and so it is “always better to approach things with love and kindness” (Participant 14). Participant 09 expanded on this sentiment:

> I would say the last kind of thing that I've gained is, like, a lot more compassion towards people. I've been able to, like, even if it's not, like, someone going through a chronic condition, like, I think just in general my approach towards, like, the whole entire world and, like, every person that I interact with is, like, just a lot more compassionate.

4.3 Newfound Strength

Lastly, through the challenges they faced with their HS, participants reflected on how strong they must be in order to overcome such adversity, which often helped them to keep a more positive frame of mind when thinking about the likelihood of other future challenges with HS. Participants described this new development as a “superpower” (Participant 21), where they felt like “Spartacus” (Participant 15); they felt that they truly embodied what it meant to be a “HS warrior” (Participant 01). Specifically, Participant 20 stated, “I learned that I must be pretty damn strong if I can make it through those bad days," while Participant 03 said, "I think too, knowing in the face of adversity, I am stronger than I think." Participant 02 described how this strength helped her to persevere through her bad days with HS:

> And really, it's a matter of, like, I can get through it, right? I mean, I'm again pretty fortunate that even through the, you know, turmoil of adolescence and early adulthood, like, I never felt like I ever pitied myself. I was never like, "Oh my God, I can't get through this." I've, you know, I mean, sure, I've been frustrated and questioned like, "Oh my God, why is this happening to me?" But I never felt defeated. Like, I never felt like I can't get through this, or I can't do this. So again, I've been pretty fortunate that way. But it just taught me I'm a pretty strong person, strong personality, and nothing's gonna take me down. Nothing's gonna take me down, you know?

Interestingly, participants often did not take note of their strength until they reflected more specifically on their challenges with HS. HS provided participants with the opportunity to grow and develop within this context, with many crediting their HS experiences as the driving force behind this characteristic. With strength being brought to the forefront during their HS experiences, however, participants were able to recognize this newfound ability more clearly, acknowledge their efforts, and use this to overcome challenges with a more positive re-framing of their situation. For instance, Participant 17 stated, "I don't think I always give myself enough credit. Like, I have been through a lot," while Participant 13 added, "I guess I've just learned that I'm more resilient and stronger than I initially thought." Participant 14 explained how HS fueled this growth for her more explicitly:

> I would just say that I'm, like, I don't know, just much stronger of a person. I feel like I look for solutions to solve problems, whereas before it was just, like, if I had a problem or a frustration, I would just get madder and madder and, like, there was no figuring things out. I've grown into somebody who's, like, when there's something wrong, it's like, "What can we do to fix this?" Like taking baby steps, setting mini goals, so that I always feel like I'm hitting those goals and I'm not feeling overwhelmed or like I'm not being successful.

This strength eased participants worries about the future, not only regarding their HS, but also other challenges that could come their way. Participants felt like "HS is the toughest thing [they've] had to deal with so far" (Participant 16), where they "can overcome anything that happens . . . if [they] just hang in there" (Participant 13). Participants ultimately highlighted that "any other problems just [don't] seem as severe" (Participant 09) in comparison to the challenges they faced with their HS; that they "grew thicker skin" (Participant 24). As Participant 21 stated, "I feel like anyone with HS is invincible. I feel invincible." Participant 24 explained this further:

> Yeah, it's definitely kind of built a little bit of resilience in me, I guess. More so if I didn't have it. You know, because it is a lot to deal with at certain times and it is – especially when you're young and still learning and not really knowing what's going on. And kind of thinking, "Well, if I could overcome that," and I overcame that. Then, you know, this little thing here I, you know, it's nothing. Whereas if I didn't have overcome or dealt with those things previously, then this might have been a bigger deal.

As a whole, participants embraced this newfound strength with pride, where they not only applied this lesson to their HS experiences specifically, but also to other life stressors. With this new characteristic in mind, participants felt more equipped and at-ease when thinking about the uncertainty of their HS, which often resulted in more success with managing their symptoms. Participants were no longer bogged down by the chronic nature of their HS, despite the messaging that was constantly presented to them. Instead, they became more active problem solvers, where they sought out solutions rather than allowing negative emotions to prevent them from doing so.

CHAPTER V

Discussion

This study provides novel and unique insights as to how women diagnosed with HS manage and make sense of the many challenges associated with their condition, which highlights a more integrative and strength-based understanding of HS. How women overcame oppressive structural systems (e.g., health care) and advocated for better care and support was also explored, which highlighted elements of advocacy, strength, and empowerment. Through employing a feminist social constructionist framework throughout this analysis, this study not only captured women's lived experiences with HS, but it also exposed and interrogated the dominant social inequities that are ever-present within Western society that systematically disadvantage women, and especially women who defy 'normal' expectations of womanhood and femininity. In line with this perspective, we highlighted these experiences by asking our participants to reflect on their experiences of living with HS in their own way and through their own language, stories, and perspectives. This gave us an opportunity to further explore and understand their experiences, while also prioritizing space to actively challenge the deficit-based, patriarchal, and dualistic frameworks that are often implicitly and explicitly superimposed on them. The findings of this study suggest that most women with HS find meaning within their diagnosis and engage in acts of resiliency and/or post-traumatic growth to overcome the challenges that are presented to them. In our RTA, four major themes characterized the strategies and approaches women with HS used when trying to reach this result, including (1) *Developing Agency in the Diagnosis Journey*, (2) *Cultivating Methods to Cope*, (3) *Harnessing One's Voice for Advocacy and Change,* and (4) *Gaining Insight and Growth Through Life-Long Learning*.

The path towards resilience and growth often began with participants feeling alone and unsupported in the management of their HS symptoms. Although receiving a diagnostic label was extremely validating and relieving for participants, which has similarly been reported throughout the HS literature (Collier et al., 2021; Hsiao et al., 2022; Kokolakis et al., 2020), participants were frequently left on their own to try and navigate the healthcare system to receive proper care and management strategies. Participants reported a sense of frustration with this insufficient care from formal medical systems, so they took initiative to better understand and manage their HS. This manifested through two interconnected sub-themes, including (1) becoming more in-tune with their bodies and listening to its signals and (2) becoming more empowered to find balanced control over their HS and the requirements of their day-to-day lives. This latter component of flexible control has been reported throughout the literature as an important attribute for chronically ill individuals to engage in to result in acceptance of their condition, thus contributing to more positive health outcomes (Lee et al., 2004; Stewart & Yuen, 2011). Specifically, an internal locus of control in such situations is important to maintain; however, there must also exist a willingness and ability to find modifications to balance the needs of the chronic condition and the steps to complete the daily task (Sells et al., 2009), which participants in this study also demonstrated.

However, the former finding of becoming more in-tune with one’s body as a means for participants to trust themselves with what they were feeling and thus persevere through negative healthcare experiences, while also fighting against the ‘chronic’ label imposed on them, is a relatively nuanced finding within the resilience literature. Despite postulations that trust in the body is disrupted for chronically ill individuals (Charmaz, 1995), the chronic illness literature has also observed this phenomenon of body connectedness (Cooper et al., 2010; Herre et al., 2016), yet it has not been linked to the process of resilience and/or post-traumatic growth within this particular population. Participants in our study reported that they “pushed back” against the idea that their bodies were broken, unruly, or fighting against them, thereby challenging persistent labels that are often ascribed to the chronic illness community (Cal et al., 2015; Gheshlagh et al., 2016). Through this, they were able to find meaning and appreciation towards what their bodies were doing for them (i.e., protecting them and providing them with signals to learn how to better take care of themselves), which contributed to a more adaptive and strength-based outlook on their HS management and outcome.

Furthermore, with the management of their HS underway, participants then began to explore and experiment with different coping strategies that they could rely on in times when their HS was flaring. The toolboxes that participants created were holistic in nature, often representing a biopsychosocial model of support, to address the psychological, social, and physical implications of their HS. Most notably, participants highlighted how important it was for them to rely on their close social support networks, such as family members, friends, and significant others, during more difficult times, whether for emotional, psychological, or physical support. This finding is not at all surprising as social support is one of the most widely studied and impactful protective factors that contribute to resilience overall, and especially for those with chronic illness (Maguire et al., 2021; Trivedi et al., 2011). Specifically, social support alone has been associated with improvements in psychological health, benefit-finding, endurance, self-esteem, and overall success in disease management (Singer & Lord, 2020; Stewart & Yuen, 2011).

This reliance on social support was not only present within participants’ in-person relationships, however, as they frequently accessed HS online support groups to connect with others who better understood their perspectives and to share symptom management strategies, coping mechanisms, and encouragement. These virtual community spaces have become increasingly popular for HS individuals to access, especially for those who feel extremely unsupported by medical professionals and/or by close others within their lives (Butt et al., 2020; Shukla et al., 2020). Most HS individuals who access these spaces, as well as those who are surveyed about the needs of HS individuals, express how impactful these online support groups are for HS persons and how more formal and well-established groups should be recommended for individuals to join at the outset of their HS journey (Chadha et al., 2023).

In addition to this, some participants within this study reported using physical exercise as a way to mitigate their physical pain and reduce their psychological distress associated with their HS. The benefits of physical activity have been extensively examined within the HS literature, with resounding evidence supporting the benefits of activity in mitigating both physical and psychological symptoms, and thus improving quality of life (Bouwman et al., 2023), but not necessarily improving HS physical symptomatology overall (Pascoe & Kimball, 2014). Within the resilience literature as well, engagement in physical activity has been associated with more resilient outcomes in those with chronic illness (Gheshlagh et al., 2016; Lenti et al., 2020).

A final coping domain that participants employed included various cognitive strategies to relieve the more psychological impacts of their HS. They described how they reminded themselves that their challenges with HS are temporary, to focus on the positive, to find humour, to focus on the present, and to use more guided mental health practices, such as grounding, mindfulness, and formal therapy supports. Overall, the use of positive cognitive appraisals and positive psychological coping has been connected to resilience in individuals with chronic illnesses more broadly (Aizpurua-Perez & Perez-Tejada, 2020; Stewart & Yuen, 2011), but more specific strategies are often not explored within the literature and have yet to be explored more thoroughly amongst HS individuals in particular. However, the use of humour to cope, as well as the use of more guided mental health practices, have been reported within other chronic illness populations outside of HS (Lenti et al., 2020; Tecson et al., 2019; Trivedi et al., 2011). The other cognitive reframing strategies reported by participants within this study though, including reminders that HS symptoms are temporary, and re-directing themselves to focus on the positive and the present moment, are more nuanced and are not explicitly present within the current literature.

Once participants felt more confident with their abilities to manage and cope with their HS symptoms, they often sought out strategies to advocate for themselves and their HS to receive better care and support. This was evident through participants being assertive with healthcare professionals and close others, educating others about HS to spread awareness about it and to help future generations, and challenging social norms that were posed on them due to their HS symptoms causing ‘abnormalities.’ Although many of these subthemes are present within the current chronic illness literature, especially the concepts of advocacy (Kirby & Zaenglein, 2021; Kralik et al., 2004; Soucie et al., 2021) and generativity (Hannum et al., 2017; Kooij & Van De Voorde, 2011), they have yet to be explored within the HS literature more explicitly. As well, incorporating the intersection of gender to explore these concepts, especially through employing a feminist lens, is largely lacking in HS research, and in chronic illness literature more broadly. This lens is crucial as women report needing to increase their advocacy efforts to push back against oppressive systems and institutions within society (Hesse-Biber, 2007; Krajewski et al., 2021). Interestingly, however, we found that women in our sample were more willing to make social contributions (e.g., advocacy and education) to aid future generations so that they do not have to experience these same oppressive systems that halted their care (Blatny et al., 2019). The women within this study expressed how impactful these advocacy and education efforts were for themselves as well, which often led them to feel a greater sense of purpose within their lives, which is an inherent factor that is associated with resilience and post-traumatic growth (Maguire et al., 2021).

Furthermore, the detailed reports of participants actively challenging societal norms placed on them about their ‘abnormal’ bodies and their subsequent violation of the Western feminine ideal has yet to be explicitly documented within the HS literature. Much of the current research on this concept generally highlights the negative body image and reduced quality of life that often ensue with HS, especially for women (Anderson et al., 2020; Fisher & Ziv 2022). This continues to support a long-standing deficit-based framework within the literature and does not provide an avenue for these perspectives to be confronted and changed, and thus help women with HS overcome this major stressor on their quality of life.

Although understanding the deficits and problems related to these societal pressures can aid with the identification of risk and vulnerability factors, by focusing instead on women’s empowerment and integration of their HS into their gendered identities, the strengths and methods used to reach this more positive outcome can be better understood and applied by other women with HS. The women within this study highlighted the idea that the avenue of resistance and acceptance must be actively pursued as they are continuously confronted with these obstacles and are forced to grapple with the inherently gendered and ableist values that are placed upon them. To live more freely within society, the women within this study had to engage in these acts of resistance themselves; there were no other adaptive strategies they could employ to address this conflict they were experiencing.

Lastly, participants were also able to find growth and meaning within their diagnosis and learn lessons through their HS experiences to better themselves, leading to the concepts of meaning-making and post-traumatic growth more broadly. These included lessons about self-kindness, empathy, and strength, which were applied in both HS-contexts and more general life contexts by participants, as well as being shared by participants to others in their lives. Through this last major theme, participants exhibited the concept of post-traumatic growth, and meaning-making more specifically, where they exhibited an ultimate transcendence of self and found solace within their HS experiences. Participants reported being more enlightened, value-based individuals, leading to an all-encompassing acceptance and appreciation of these experiences.

These higher order concepts are still relatively new within the chronic illness literature, but the dearth of studies examining the concepts related to post-traumatic growth and meaning-making do highlight the correlation between all three of the subthemes mentioned above (Elam & Taku, 2022; Henson et al., 2021). Again, however, this study presents these findings within the HS literature specifically, with the added layer of examining this process through female perspectives, thus providing greater insight into these processes for chronically ill women, and especially so for those with HS. Qualitatively, it was these teachings that really encouraged participants to overcome their HS, while also integrating it into their lives in a balanced way, thus reinstating their overall quality of life. By identifying these processes, future research can more readily assess whether fostering these teachings more directly in other HS individuals can result in similar transcendent outcomes (Blatny et al., 2019).

HS Extensions to the Resiliency Model

Overall, these findings can be related back to the Resiliency Model posed by Richardson and colleagues (1990). This model reflects the idea that individuals must choose how to respond to disruptions or adverse life events that occur and disrupt their state of biopsychospirtual homeostasis. The interaction between the strategies employed and the stressor(s) experienced will determine whether a disruption to this homeostasis will occur and potentially allow for growth and development through resilient strategies.

Firstly, when a disruption occurs, like the onset or diagnosis of a chronic condition, emotions such as loss, fear, self-doubt, and confusion will occur (Richardson et al., 1990). Participants within this study often described that prior to their diagnosis, they felt frustrated, confused, and hopeless, as they did not have an answer or a diagnosis for what was causing their homeostatic disruption. For participants, their HS symptoms caused severe disruptions to their lives, with most reporting pain as the most debilitating symptom, which impacted many facets of their lives, such as school, work, relationships, intimacy, and daily living; all findings that have been reported previously in the HS literature (Chernyshov et al., 2021; Esmann & Jemec, 2011; Patel et al., 2017). Eventually after receiving a diagnosis, often after many years of trials and tribulations with healthcare providers leading up to the diagnosis, participants began to actively question what they could do to eliminate or overcome the disruption their HS caused them, propelling them towards the paths of reintegration that are present within this model.

Most participants within this study demonstrated the outcome of resilient reintegration, which results in the individual experiencing a disruption to return to a newer, higher quality state (i.e., a process that would now be considered as post-traumatic growth; Richardson et al, 1990). This process encourages forms of introspection, which allows for growth and insight to occur (e.g., through meaning-making). Participants within this study specifically exhibited acts of resilient reintegration more explicitly in theme four, where they reflected on their journey with

HS more acutely, thus resulting in deeper meanings and lessons to arise, which led to participants becoming more introspective and transcendent individuals.

However, participants also used strategies that are often present within the reintegration to homeostasis path (Richardson et al., 1990), which would be considered as a form of resilience based on definitions in the current literature (Elam & Taku, 2022). This path, although resolves the disruptions, results in individuals returning to their original homeostatic level through employing different coping mechanisms, rather than through deeper meanings being made. Participants within this study used these various strategies to maintain their homeostasis on a day-to-day basis, which can be seen in themes one, two, and three, and although most reached the previous path of resilient reintegration more broadly, looking for a deeper connection was not necessarily sustainable or applicable to every challenge that their HS presented to them. Participants did not necessarily hold on to their 'comfort zones' or avoid opportunities to grow as this model describes this path, but rather they titrated between the two paths of resilient reintegration and reintegration to homeostasis depending upon the challenge presented to them and the resources that were available to them. This balance between resilience and post-traumatic growth has been reported previously within the literature (Seiler & Jenewein, 2019; Serpa-Barrientos et al., 2023; Wheeler et al., 2020), with resilience being cited as a mediator between post-traumatic growth and distress.

The last two pathways within this model, including reintegration with loss and reintegration with dysfunction (Richardson et al., 1990), were not evident within the sample that was interviewed for this study. Participants described that at other points in their lives and HS journeys that they may have experienced elements of these two pathways, such as losing motivation to overcome HS at times and/or using more detrimental coping methods, but these were not lasting solutions for them as these approaches often did not resolve their life disruptions due to the chronic nature of HS. Although participants within this study who experienced elements of these more detrimental pathways at some points in their HS journeys were able to switch to resilient reintegration and/or return to homeostasis through their own efforts, some individuals with HS may not have the resources to do so without additional interventions, which should be kept in mind as a future consideration.

HS Extensions to the Meaning-Making Model

As well, the findings from the present study, especially those garnered from theme four, can be compared to the Meaning-Making Model by Park and Folkman (1997). The process presented within this model largely highlights how one confronts discrepancies through interpreting, understanding, and making sense of these occurrences, with the aim of reducing distress (Park, 2010). Specifically, if there exists a discrepancy between one’s global meaning (i.e., comprised of beliefs about the world, the self, and the self in the world; goals; and subjective feelings) and situational meaning (i.e., meaning garnered from a specific experience) then distress will ensue, which can lead to deeper lessons being made to resolve this (i.e., through modifying one’s situational meaning to match one’s global meaning, or vice versa).

Within this study, participants exhibited this meaning-making process while discussing the lessons they learned from their HS, including self-compassion, empathy, and strength. Though their HS caused them moments of distress through discrepancies between their global and situational meanings, they actively sought to resolve these discrepancies through searching for and understanding the greater lessons associated with their challenges. At times participants tried to solve these more deeply rooted discrepancies through problem-focused and emotion-focused coping strategies that they often used for more typical challenges of HS (e.g., the pain caused by HS); however, they readily switched to the more adaptive approach of meaning-making in more low-control situations presented by their HS (e.g., being classified as chronically ill). This then allowed participants to adapt their situational and/or global meanings to find the greater lessons within their HS experiences, which often led to positive changes in their social relationships, resources, and coping, a finding that has been supported in previous meaning-making literature (Ferreira-Valente et al., 2021; Park, 2013; Park & George, 2013). Thus, the meaning-making demonstrated by participants in this study broadly led to both growth and resilient behaviours and outcomes.

Implications

The findings from this study provide important contributions and means towards promoting resilience and meaning-making to allow for an overall acceptance of and enhanced quality of life for those with HS, especially for women with HS. Within the current chronic illness literature, much of the work is framed using a deficit-, disorder-, or problem-based framework, which tends to emphasize risk and vulnerability factors associated with a given condition (Kralik et al., 2006; Trivedi et al., 2011). While understanding these impacts is important to consider at times, especially when considering long-term implications and further health considerations, viewing chronically ill individuals exclusively through this type of lens highlights their ‘problems’ rather than providing them with a more holistic framework where more active strategies to better address and overcome challenges are available to them (Aizpurua-Perez & Perez-Tejada, 2020). Specifically, a resilience or post-traumatic growth lens, as demonstrated through this study, recognizes possibilities rather than problems by identifying the antecedents of this more favourable outcome (e.g., coping strategies, how to challenge oppressive messaging, etc.), which can offer a more prevention-based approach instead of the correction-based approach that dominates current Western medicine practices (Trivedi et al., 2011).

As such, through sharing these participants' experiences of resilience and meaning-making through their own narratives, a strategy often associated with participatory action principles (Kindon et al., 2007), this perspective can be strengthened and can also allow for others with HS to be exposed to such strategies to potentially bolster their own resilience and growth (Kralik et al., 2006). There is growing evidence that the burden on health care systems, as well as the burden placed on patients within these systems, can be most readily reduced if these patients engage in more active approaches to cope with their own health care experiences due to stagnant structural systems, which is often fueled by resilience and meaning-making (Manning et al., 2016; Trivedi et al., 2011). In order to achieve this outcome, and after identifying the various strategies employed by resilient individuals in particular contexts, these can be used in various intervention programs to determine whether these strategies truly foster resilience, which can help those struggling with this process successfully navigate through hardship and adversity (Cal et al., 2015; Manning et al., 2016). In fact, various meta-analyses have been conducted and have provided support for the significant outcomes that can result from resilience intervention programs (Kim et al., 2019; Tecson et al., 2019), although none have been conducted within the HS realm. By highlighting the strategies that the participants of this study used to result in transcendent outcomes, the various antecedents that should be considered in those with HS can be easily identified and considered within such efforts as a next step. As a whole, improving resilience within the HS population, especially for women with HS due to the heightened impacts they frequently experience (Sabat et al., 2020), should be an essential consideration to optimize HS care and patient outcomes.

However, it should not go unnoticed that the participants within this study often reported that they felt “abandoned” by the medical system and were given very little guidance as to how to adequately integrate HS into their lives, cope with and overcome its challenges, and maintain their quality of life, where they had to take control and guide themselves. Although participants within this study exhibited growth and reached a resilient outcome themselves, many participants did struggle to initiate and maintain their plight on this pathway while anticipating and waiting for this reintegration. As well, by providing more adequate sources of supports to reinforce resilient outcomes, such results can be achieved more readily and much easier by individuals with chronic conditions (Kim et al., 2019). The quite obvious need for more support for individuals with HS, especially women with HS, is still alarmingly present, even though countless studies within the literature suggest that support needs to be considered (Collier et al., 2021; Margesson & Danby, 2014; Willems et al., 2022). Ultimately, the onus should not be placed solely on the individual to exhibit resilience and growth when subjected to a broken social system. Rather, corrective-based strategies to address issues that are present within these systems must be considered in tandem with the prevention-based strategies that individuals are often encouraged to engage in.

More specifically, the state of abandonment reported by participants within this study suggests that there is a prominent gap in the care continuum for HS individuals that must be considered. Firstly, more comprehensive guidance and support at the time of diagnosis may be beneficial, which could be achieved through more individualized/personalized care plans. Personalized care planning involves the collaboration of clinicians and patients to create a treatment plan(s) and is often a strategy that is recommended for patients who have more complex needs, such as those with chronic illnesses and diseases (Edwards et al., 2017). This strategy has been associated with improvements in the quality of patient care, self-efficacy, self-care, and psychological and physical health indicators (Coulter et al., 2015). However, many personalized care initiatives still only consider more physical health mechanisms, rather than approaching patient-centered care more holistically (Edwards et al., 2017). Participants within this study highlighted the importance of developing personalized care plans that consider the many social and psychological obstacles they faced in tandem with their physical experiences of HS. To address this more acutely, the unique coping strategies and resilience-building practices identified by participants of this study can help to provide an initial conceptualization of the types of skills, supports, and resources that could be implemented. As well, using an interdisciplinary team approach to address these needs (i.e., a biopsychosocial model of support), especially those that involve mental health professionals, can better address the social and psychological disruptions often expressed by participants in this study, which can promote psychological well-being alongside physical health management.

Furthermore, healthcare providers can play a more active role in correcting the medical system for their HS patients. For instance, in considering the themes of resilience and growth found within this study, healthcare providers can play a crucial role in supporting patients to develop such skills through self-advocacy efforts by offering resources and training to help patients prepare for medical appointments, including making notes, completing their own research using appropriate resources, and understanding their treatment options. As well, providers can actively work to destigmatize and improve the quality of life of those with HS by incorporating education about the condition into public health campaigns and patient education materials to spread awareness and dispel misinformation.

In relation, higher-order changes should be considered in addition to the above-mentioned approaches. Firstly, based on participants' experiences, there appears to be a need for better training and education of healthcare providers on HS and its psychosocial impacts. This could include workshops on empathy, patient communication, patient centered care, and a biopsychosocial model of chronic illness, while also taking into consideration an intersectional approach to understand the nuances that can be associated with such impacts (e.g., gender impacting receipt of care and functioning within society). As well, it should be a more prominent goal for healthcare institutions and policymakers to consider funding and supporting HS research and practices to better understand its impacts and to develop more effective treatment and support strategies (e.g., ensuring appropriate coverage for physical and psychological treatments). This could reduce the fragmented and delayed care that individuals with HS currently receive, and that our participants reported, while simultaneously improving access to HS care and support. As a whole, although individuals with HS can engage in various strategies and supports to overcome the challenges presented to them, the medical system's involvement in such challenges, and the actions they can take to reduce them, cannot go unnoticed.

Limitations and Future Directions

Overall, the main limitation of this study involves the lack of demographic variability of participants in relation to their ethnic identity, socioeconomic status, and education level. Though it was an aim of this study to follow purposeful and maximum variation sampling strategies to consider other diverse social locations aside from gender (Ellard-Gray et al., 2015), more than half of our sample consisted of those who identified as white (i.e., 68%), middle-class (i.e., 88%; total household income between $50,000 and $100,000), and educated (i.e., 56%) despite our best efforts to recruit a more diverse sample. This homogeneity amongst participants prevents further considerations to be made about how participants' experiences were shaped by their diverse identities (i.e., intersectionality), which is an integral part of feminist social constructionism. As well, these results may not be entirely transferable to all women with HS, especially those from more diverse social locations. Specifically, the composition of the sample of this study goes against research purporting that individuals who identify as women (Margesson & Danby, 2014), black (Vaidya et al., 2017), and low in socioeconomic status (Choi et al., 2022), comprise the majority of the HS population. As such, future studies may benefit from examining the interplay between such intersectional factors to not only ensure greater transferability, but to also ensure needs from all potential HS-diagnosed individuals are not being overlooked, especially those that are often further oppressed within the same systems as women with HS (e.g., ethnic and racialized groups, individuals of various socioeconomic status).

In relation to this, although women diagnosed with HS was the intended sample of this study, it could be potentially advantageous to consider HS-diagnosed men and/or HS-diagnosed individuals who do not identify as a woman. The results of this study, though providing a baseline of potential antecedents in the process of resilience throughout the HS journey, may not be fully representative or transferable to individuals with HS who do not identify as women, due to the possibility of this intersection causing differences between subgroups. Comparisons should be made to assess whether the themes found throughout this study are unanimous across genders or whether those with different gender identities require different resources and considerations.

It should also be noted that although recruitment strategies occurred through multiple online forums and in-person dermatology clinics, all of the participants that were interviewed had indicated that they had seen the study advertisement through an online HS support group. It is possible that the sample of participants that were recruited potentially represented a particularly resilient group of individuals since these online support groups generally require individuals to seek out this support by themselves, with many groups supporting and encouraging very solution-oriented content (e.g., individuals often share the treatment strategies and coping mechanisms that worked for them). Although this allowed for the study to interview participants across Canada more readily, it would potentially be beneficial to interview a more community-based sample of HS-diagnosed women who are not a part of online support groups and compare the strategies that they frequently employ without this potentially influential source of support present.

Lastly, based on the findings of this study, as discussed above, various future directions within the HS literature should be considered. Firstly, the finding that our participants developed a greater connectedness to their bodies should be explored more explicitly with individuals with HS to better understand the impacts that result from this due to conflicting reports being presented in the current literature. As well, exploring the impacts of a more formal and regulated online HS support group, and how this relates to resilient and PTG processes for HS individuals, could be a meaningful endeavour to consider based on how impactful this source of support was for our participants. Finally, exploring the more nuanced coping strategies reported by participants in this study should be explored further within the resilience literature to further understand their role in the process of resilience, especially for individuals with chronic conditions, such as HS.

Conclusion

The purpose of this qualitative study was to broaden the HS literature by amplifying a more integrative, strength-based understanding of HS through capturing elements of resilience and meaning-making as women discussed their experiences with their HS. We generated, through reflexive thematic analysis, four major themes relating to how women overcame and reflected on their experiences of living with HS, including (1) *Developing Agency in the Diagnosis Journey*, (2) *Cultivating Methods to Cope*, (3) *Harnessing One's Voice for Advocacy and Change*, and (4) *Gaining Insight and Growth Through Life-Long Learning*. The findings from this study amplify participant-centered, strength-based avenues of health and wellness in women living with HS, with the purpose of advancing research and advocacy for women with HS, as well as informing health equity practices for women more broadly. This has direct implications for future research about HS, and other chronic health conditions more broadly, including considerations to improve the well-being and overall quality of life of this population through more active and advantageous strategies that can inform more holistic treatment practices (e.g., resilience-focused training and support groups).

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APPENDIX A: FLYERS

Recruitment Flyer:

PARTICIPANTS NEEDED FOR RESEARCH ON HS

INTERVIEWS WILL BE APPROXIMATELY 90 MINUTES LONG & PARTICIPANTS WILL RECIEVE A $20 E-GIFT CARD

Participant Requirements:

- CANADIAN
- CONFIRMED DIAGNOSIS OF HIDRADENITIS SUPPURATIVA
- AT LEAST 18 YEARS OLD
- SELF-IDENTIFY AS A WOMAN
- SPEAK ENGLISH
- ABLE TO COME IN FOR AN INTERVIEW OR HAVE ACCESS TO A COMPUTER FOR A VIRTUAL INTERVIEW

Research Team:

KENZIE TAPP
DR. KENDALL SOUCIE
HEAL LAB UWINDSOR

This study has Research Ethics Board clearance.

CONTACT INFORMATION
hsstudy@uwindsor.ca

Scan the QR Code to Sign Up

Resources Flyer:

Health Resources

Government of Canada Mental Health Support

Wellness Together Canada

Good2Talk (Ontario)

Good2Talk is a free, confidential helpline providing professional counselling and information and referrals for mental health, addictions and well-being to post-secondary students in Ontario, 24/7/365.
Phone: 1-866-925-5454

HS Resources

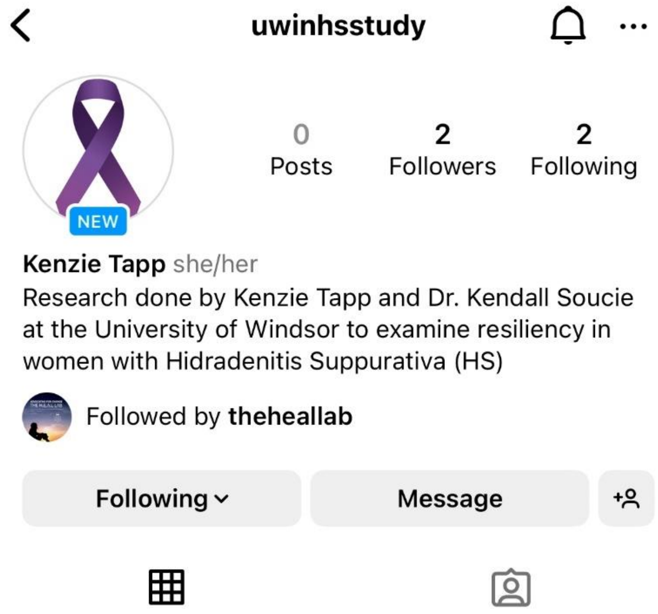
About HS

HS Support

HS FAQs

APPENDIX B: SOCIAL MEDIA ACCOUNTS

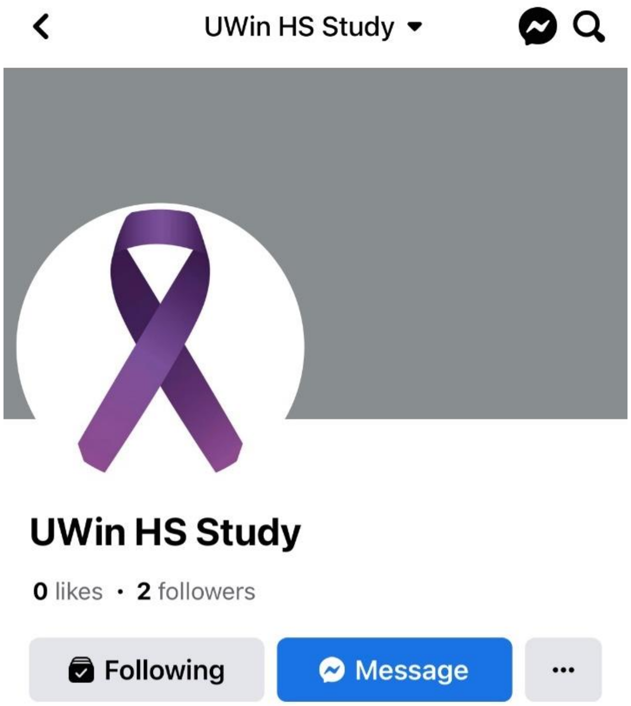
Instagram:



Kenzie Tapp she/her
Research done by Kenzie Tapp and Dr. Kendall Soucie at the University of Windsor to examine resiliency in women with Hidradenitis Suppurativa (HS)

Followed by **theheallab**

Facebook:



Email: hsstudy@uwindsor.ca

APPENDIX C: DISSEMINATION OF STUDY ADVERTISEMENT

Instagram

-Hidradenitis & Me (1,906 followers)

-HSF.Org (1,720 followers)

-HS Heroes (3,698 followers)

-Derm Effects (932 followers)

-Healthy Image Windsor (1,674 followers)

-WeSpark Health Institute (808 followers)

-Womxn’s Centre (983 followers)

Facebook

-Hidradenitis Suppurativa Canada (2,000 members)

-HS Connect (10,600 members)

-HS Global (6,700 members)

-Hidradenitis Suppurativa Warriors (19,400 members)

Reddit

-r/Hidradenitis (29,051 members)

-r/HidradenitisAIP (1,951 members)

Dermatology Clinics

-Derm Effects (London, Ontario)

-The Healthy Image Centre (Windsor, Ontario)

-PureSkin Dermatology (London, Ontario)

APPENDIX D: PRE-SCREENER QUESTIONNAIRE

1. What is your age in years? (open-ended)
2. What province do you currently reside in? (open-ended)
3. With which gender do you identify? Select all that apply.
    a. Female
    b. Male
    c. Trans female
    d. Trans male
    e. Non-binary
    f. Two-spirited
    g. Intersex
    h. Prefer not to answer
    i. Please specify: _______________
4. What is your ethnic background? Select all that apply.
    a. Black
    b. East Asian
    c. Indigenous (e.g., First Nations, Metis, Inuk/Inuit)
    d. Latinx
    e. Middle Eastern
    f. Southeast Asian
    g. South Asian
    h. White
    i. Please specify: _____________________
5. How would you describe your sexual orientation? Select all that apply.
    a. Straight or heterosexual
    b. Lesbian or gay
    c. Bisexual
    d. Pansexual
    e. Omnisexual
    f. Asexual
    g. Unsure
    h. Please specify: _________________
6. Have you been diagnosed with hidradenitis suppurativa (HS)? (Y/N)
7. Were you diagnosed in Canada by a Canadian practitioner? (Y/N)
8. How old were you (in years) when you were diagnosed with HS by a Canadian practitioner? (open-ended)
9. How may we contact you to set up a date and time for an interview? Select all that apply.
    a. Email: _______________
    b. Phone: _______________
    c. Other: ______________
10. Are you able to attend an in-person or virtual interview? Select all that apply.
    a. I can attend in person at the University of Windsor (Chrysler Hall South, Rm. 282-2)
    b. I can only attend virtually
11. Do you require any accommodations to complete an interview for the study? (open-ended)
12. Where did you hear about this study? (open-ended)

APPENDIX E: INFORMED CONSENT FORM

CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: The Lived Experiences of Women with Hidradenitis Suppurativa

You are asked to participate in a research study conducted by **Kenzie Tapp** and **Kendall Soucie** from the **Psychology Department** at the University of Windsor.

If you have any questions or concerns about the research, please feel to contact **Kenzie Tapp** at tappk@uwindsor.ca, or **Kendall Soucie** at ksoucie@uwindsor.ca (519-253-3000 ext. 2222).

PURPOSE OF THE STUDY

The purpose of this study is to explore the lived experiences of women with Hidradenitis Suppurativa (HS), specifically in how they overcome common challenges associated with HS in various life domains (e.g., health care, relationships, etc.).

PROCEDURES

To capture your experiences with HS, we will interview you about your HS diagnosis and symptoms, how HS has impacted various life domains (e.g., relationships, mental health, relationship with your body, etc.), and coping strategies. We will primarily ask you to talk about how you overcome any challenges you face due to HS, as well as how this can be applied to future research and care initiatives. We will then ask you to fill out a brief survey comprised of demographic information. Interviews will take approximately 90 minutes and will be conducted by Kenzie Tapp, a graduate student in the Child Clinical Psychology program at the University of Windsor.

POTENTIAL RISKS AND DISCOMFORTS

The questions in the interview contain questions about both positive and negative experiences with HS. You may find that the challenges and barriers that you may have experienced in relation to HS are difficult to think about and disclose. This may result in some minimal discomfort. If you feel any discomfort at any time, you are free to withdraw from the study with no negative consequences. You are also free to refuse to answer any questions that make you feel uncomfortable. We will provide you with the contact numbers of several local and on-campus counselling services. You may also contact the principal investigator for the study, Kenzie Tapp, if you have any questions or concerns, or require assistance.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

By participating in this study, you may learn new insights about yourself and your experiences with HS, as well as how HS can be viewed in a more positive lens. Your experiences can help inform us of methods that can be used for other women with HS to overcome various barriers and/or challenges. As well, it may help to establish more integrated forms of care for HS (e.g., resiliency training, formal support groups etc.).

COMPENSATION FOR PARTICIPATION

You will receive a $20.00 e-gift card for your participation in this study within 24 hours of your interview date. Examples of common gift card locations include Starbucks, Amazon, Tim Hortons, Walmart, Sephora, Lulu Lemon, and Roots.

CONFIDENTIALITY

Your package of completed questionnaires and audio recorded interviews will each be given an identifier code. This code can in no way be traced back to you. Signed consent forms which do not contain an identifier code will be stored separately from questionnaires. Typed interviews will be stored in a password protected file located on the principal investigator's computer. The interview sessions will be video and/or audio recorded and subsequently transcribed by trained research assistants who will ensure that any identifying information will not appear on the finalized transcripts. The only individuals with access to the audio recordings will be the principal investigator, research supervisor, and trained research assistants. Once the audio recordings have been transcribed, they will be deleted. Transcribed data will be de-identified and only the principal investigator and trained research assistants who have completed research ethics training will have access to the transcribed data. As the interview data is intended to capture participant responses at specific moments in time, participants will not have the opportunity to review and/or edit their responses post interview. All data, coding procedures, instructions, and the interview protocol will be retained in password protected files for a minimum of 10 years after completion and/or publication of the study. After this time, all material will be destroyed (i.e., transcripts will be deleted, questionnaire data will be deleted, and computer files with typed responses deleted). Raw data will be stored and identified only by the ID number. Furthermore, study participants will not be individually identified in any publications or presentations that may stem from this research; only aggregated data will be presented.

PARTICIPATION AND WITHDRAWAL

You will receive full compensation if you chose to withdraw from the study at any point without penalty. If you wish to withdraw your data, please email Kenzie Tapp (tappk@uwindsor.ca) on or before 3 weeks following your interview. You may also refuse to answer any question that you do not want to answer and still remain in the study. The investigator may withdraw you from this study if circumstances arise which warrant doing so.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE PARTICIPANTS

If you would like to be informed about the findings of this study, you may go to: www.uwindsor.ca/reb

SUBSEQUENT USE OF DATA

These data may be used in subsequent studies, publications, and presentations, but only aggregated data will be presented.

RIGHTS OF RESEARCH PARTICIPANTS

If you have questions regarding your rights as a research participant, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario, N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: ethics@uwindsor.ca

Please indicate your answer with an "X":

I am willing to participate in an interview about my experiences with my HS diangosis.

☐ No ☐ Yes

I consent to the video-taping or audio-taping of interviews. I understand these are voluntary procedures and that I am free to withdraw at any time by requesting that the viewing be discontinued. I also understand that my name will not be revealed to anyone and that viewing will be kept confidential. I understand that confidentiality will be respected and the viewing of materials will be for professional use only.

☐ No ☐ Yes

I consent to the use of direct and anonymous quotations from my interview responses to be included in any reports, publications and/or presentations that arise from this study.

☐ No ☐ Yes

I consent to be contacted again involving further research opportunities related to my experiences with HS (e.g. follow up interview).

☐ No ☐ Yes

SIGNATURE OF RESEARCH PARTICIPANT/LEGAL REPRESENTATIVE

I understand the information provided for the study titled "The Lived Experiences of Women with Hidradenitis Suppurativa" as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

____

Name of Participant

______________________________________ ____________________

Signature of Participant Date

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

____ ____________________

Signature of Investigator Date

APPENDIX F: SEMI-STRUCTURED INTERVIEW GUIDE

Hi, _____. Thank you for your interest in our study and for agreeing to participate. My name is Kenzie and I'm currently a master's student at the University of Windsor. Today I would like to talk with you about your experience living with HS and how you overcome any challenges you may face in relation to it. Since I am going to be asking you questions about your own diagnosis, I'd also like to share a little bit about mine. I also am a HS diagnosed woman and have been living with HS for about 9 years now – I was diagnosed when I was 14 years old. A lot of my research interests have come from my own experiences with the disease, and it's where the idea for the interview we're doing today came from.

We'll start by re-confirming your consent. As you know, the purpose of this study is to learn more about your experience with HS, specifically to learn about how you overcome any challenges in relation to it. Your identity will not be revealed at any point and your responses will not be tied back to you. As we do the interview, please feel free to modify or decline to answer any questions; you also may suggest any questions you think I should be asking. If you need to take a break at any point, please let me know. This study has received ethics clearance from the University of Windsor REB.

We will start with our camera on, but if the internet connection gets poor, we may need to switch off our cameras (if participant only consented to audio recording, omit this line; if in-person, omit this line). Can you please confirm that you are willing to participate, and you consent to being video-taped (or audio recorded)? Please remember that you may withdraw from this study at any point during the interview and for any reason. Following the interview, you'll have two weeks to withdraw your data for any reason.

Thank you! Do you have any questions for me before we begin (also ask if they have any requirements, like needing extra breaks etc.)? I am going to start the recording now.

(START RECORDING)

Interview Questions

Health Care Experiences

1. How old were you when you were diagnosed with HS? /How long have you had HS for?
    a. What issues led you to seek care?
2. Can you tell me a little bit about how you came to be diagnosed with HS?
3. What were some challenges you faced when you were trying to get diagnosed?
    a. What challenges or concerns do you have now?
4. How has this experience changed you (prompt for positive and negative; what have you learned from it)?
5. How do you typically approach your medical needs with providers now?

Daily Impacts

1. What symptoms have been the most distressing for you and why? How do you manage or navigate these experiences?
2. What successes have you had in managing symptoms? What helps and what doesn't help?
3. What does a bad day with HS look like for you?

    a. How do you deal with a bad day?
    b. What have you learned about yourself on the bad days?

4. Have you found any coping mechanisms or self-care strategies the help you manage flare-ups and symptoms?

Mental Health and Body

1. How does HS affect your mental health or emotional well-being?
2. What are the main challenges you have faced in relation to your mental health as a result of HS? How have you worked through these challenges?
3. How does HS impact how you feel about yourself and your body (prompt for positive and negative)?
4. Does HS make you feel different from others (or the way you are supposed to look)?
5. Does HS make you feel different in relation to your gender (do you feel less feminine)?

Conversations with Others

1. How does having HS affect your relationships (family, friends, romantic, etc.)?
2. Do you feel like you can talk to others about HS? Why or why not?
    a. What do you feel like you need from others?
    b. Have others met these needs? If yes, how have others supported you? If no, what can they do to better support you?
3. Have you ever felt misunderstood because of HS?
4. Have you ever been treated differently because of HS?
    a. Do you think there is stigma surrounding HS? If so, how do you navigate feeling this way?

Ending Reflections

1. What do think you have lost because of HS? What have you gained?
2. Has anything positive come out of your diagnosis (can you share a specific example with me)?
3. How has HS changed your perspective on life?
4. How has HS influenced your priorities and goals in life?
5. How has your experience with HS shaped who you are today? In what ways have you found meaning in your life since being diagnosed with HS?
6. How have you integrated HS into your life story/who you are?
7. In what ways do you hope to see greater awareness and advocacy for HS in the future?

Ending Remarks

Thank you for taking the time to meet with me today. Is there anything that we have not covered in this interview that you feel is important for me to know? Do you have any questions for me?

(STOP RECORDING)

APPENDIX G: DEMOGRAPHIC QUESTIONNAIRE

Please enter your unique identifier code: ____________________

Please respond to the following questions:

1. What is your age in years? (open-ended)
2. Were you born in Canada? (Y/N)
    - If no, in what country were you born? (open-ended)
3. Which province do you currently reside in? (open-ended)
4. With which gender do you identify? Select all that apply.
    a. Female
    b. Male
    c. Trans female
    d. Trans male
    e. Non-binary
    f. Two-spirited
    g. Intersex
    h. Prefer not to answer
    i. Please specify: ______________
5. What is your ethnic background? Select all that apply.
    a. Black
    b. East Asian
    c. Indigenous (e.g., First Nations, Metis, Inuk/Inuit)
    d. Latinx
    e. Middle Eastern
    f. Southeast Asian
    g. South Asian
    h. White
    i. Please specify: ____________________
6. How would you describe your sexual orientation? Select all that apply.
    a. Straight or heterosexual
    b. Lesbian or gay
    c. Bisexual
    d. Pansexual
    e. Omnisexual
    f. Asexual
    g. Unsure
    h. Please specify: ________________
7. What is your current relationship status? Select all that apply.
    a. Single
    b. Casually dating
    c. Partnered/Non-married committed relationship
    d. Married/Civil union
    e. Separated
    f. Divorced

    g. Widowed
    h. Other (Please specify)
8. Do you have children? (Y/N)
    - If yes, how many children do you currently have? (open-ended)
9. What is your total combined annual household income?
    a. $0 – $9,999
    b. $10,000 – $19,999
    c. $20,000 – $29,999
    d. $30,000 – $39,999
    e. $40,000 – $49,999
    f. $50,000 – $59,999
    g. $60,000 – $69,999
    h. $70,000 – $79,999
    i. $80,000 – $89,999
    j. $90,000 – $99,999
    k. $100,000 or more
10. What is the highest level of schooling you have completed or the highest degree you have received?
    a. Some high school
    b. High school diploma or equivalent (e.g., GED)
    c. Some college/university
    d. Vocational degree/certificate
    e. Undergraduate degree (Bachelor's)
    f. Graduate degree (Master's)
    g. Professional degree (e.g., MD, JD)
    h. Postgraduate degree (Doctorate)
    i. Prefer not to say
11. Are you currently a student? (Y/N)
    - If yes, what is your current status as a student?
        a. Full-time
        b. Part-time
        c. Other (Please specify)
12. Which of the following categories best describes your employment status? Select all that apply.
    a. Employed, working 1-39 hours per week
    b. Employed, working 40 or more hours per week
    c. Not employed, looking for work
    d. Not employed, not looking for work
    e. Self-employed
    f. Support from government program (e.g., ODSP, etc.)
    g. Retired
    h. Other (please specify)
    i. Prefer not to say
13. How would you describe your current living situation? Select all that apply.
        a. Alone
        b. Spouse/Partner(s)

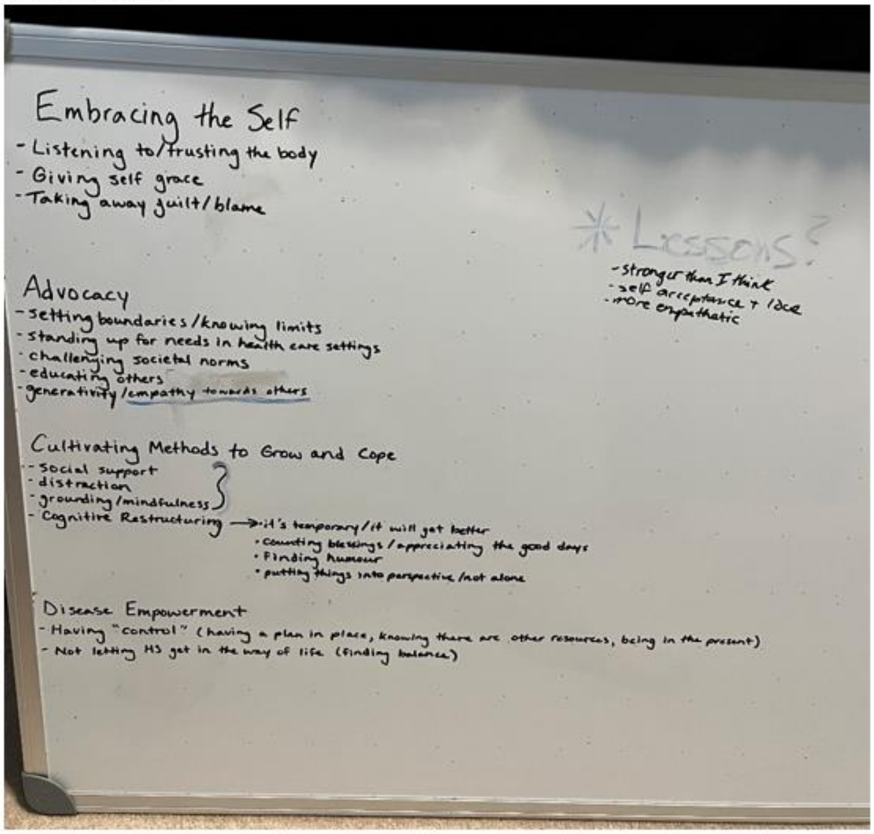
    c. Child(ren)
    d. Sibling(s)
    e. Parent(s)/Guardian(s)
    f. Group setting
    g. Personal care attendant
    h. Other (please specify)
    i. Prefer not to say

14. Which of these spaces best describes where you live?
    a. Urban
    b. Suburban
    c. Rural
    d. Prefer not to say
15. Approximately how old were you (in years) when you first started experiencing symptoms of HS? (open-ended)
16. How old were you (in years) when you were diagnosed with HS? (open-ended)
17. What provider or medical practitioner provided you with a diagnosis of HS?
    a. Family Doctor
    b. Dermatologist
    c. Emergency Room Physician
    d. Gynecologist
    e. Please specify: ____________
18. How long did it take for you to receive a HS diagnosis (in months) since your first symptom experiences? (open-ended)
19. Approximately how many providers did you see for your symptoms before receiving an official diagnosis of HS?
    a. 1 provider
    b. 2 providers
    c. 3 providers
    d. 4 providers
    e. 5 providers
    f. Please specify: ____________
20. How would you describe the current severity of your HS?
    a. I'm in remission
    b. Mild (stage 1)
    c. Moderate (stage 2)
    d. Severe (stage 3)
    e. Please specify: ____________
21. What symptoms of HS do you currently experience? Please list them all.
22. Have you noticed what causes a flare-up of your HS symptoms? Select all that apply.
    a. Clothing (fabric choice, fit, etc.)
    b. Food/Nutrition
    c. Exercise
    d. Weather (humidity, heat, etc.)
    e. Stress
    f. Friction
    g. Other: ___________

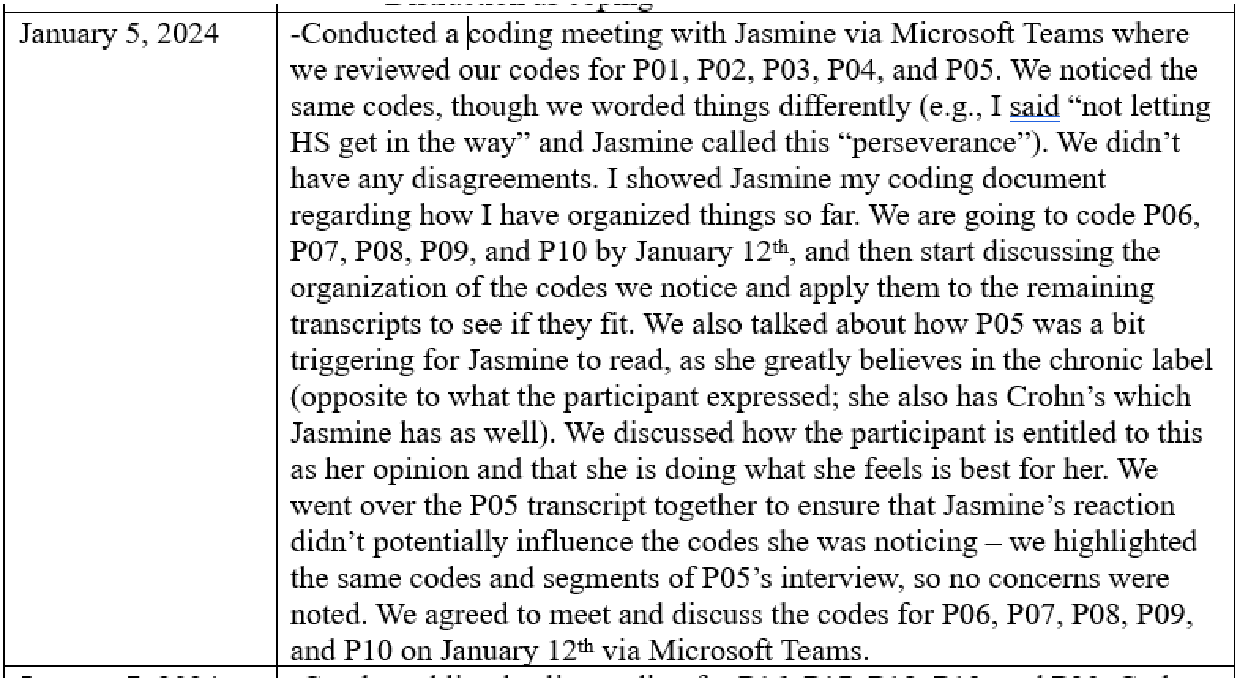
23. What types of therapies/treatments are used to take care of your HS currently? Please list them all. (open-ended)
24. What previous therapies/treatments have been used to take care of your HS? Please list them all. (open-ended)
25. Have you been diagnosed with any other chronic health conditions? (Y/N)
    - If yes, what other chronic health conditions have you been diagnosed with? (open-ended)

APPENDIX H: KT ENTRIES

KT Journal Entry

December 18, 2023	-Reviewed the codes noted from the session on December 16th, 2023 and played around with their organization, naming, and conceptualization on a whiteboard.  Embracing the Self - Listening to/trusting the body - Giving self grace - Taking away guilt/blame * Lessons? - stronger than I think - self acceptance + love - more empathatic Advocacy - setting boundaries/knowing limits - standing up for needs in health care settings - challenging societal norms - educating others - generativity/empathy towards others Cultivating Methods to Grow and Cope - social support - distraction - grounding/mindfulness - Cognitive Restructuring → • it's temporary/it will get better • Counting blessings/appreciating the good days • Finding humour • putting things into perspective/not alone Disease Empowerment - Having "control" (having a plan in place, knowing there are other resources, being in the present) - Not letting HS get in the way of life (finding balance) -Need to revisit the idea of having a separate theme regarding lessons learned; it potentially overlaps with other subthemes. Also need to revisit the organization of "having more empathy for others" as a combination with generativity – not sure this fits. Need to consider how to lump different coping methods together – consider renaming the larger organizing concept.

KT Audit Log



January 5, 2024	-Conducted a coding meeting with Jasmine via Microsoft Teams where we reviewed our codes for P01, P02, P03, P04, and P05. We noticed the same codes, though we worded things differently (e.g., I said “not letting HS get in the way” and Jasmine called this “perseverance”). We didn’t have any disagreements. I showed Jasmine my coding document regarding how I have organized things so far. We are going to code P06, P07, P08, P09, and P10 by January 12th, and then start discussing the organization of the codes we notice and apply them to the remaining transcripts to see if they fit. We also talked about how P05 was a bit triggering for Jasmine to read, as she greatly believes in the chronic label (opposite to what the participant expressed; she also has Crohn’s which Jasmine has as well). We discussed how the participant is entitled to this as her opinion and that she is doing what she feels is best for her. We went over the P05 transcript together to ensure that Jasmine’s reaction didn’t potentially influence the codes she was noticing – we highlighted the same codes and segments of P05’s interview, so no concerns were noted. We agreed to meet and discuss the codes for P06, P07, P08, P09, and P10 on January 12th via Microsoft Teams.

VITA AUCTORIS

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