HIDRADENITIS SUPPURATIVA: AN EXAMINATION THROUGH PSYCHOSOCIAL VARIABLES

A THESIS SUBMITTED TO
THE GRADUATE SCHOOL OF SOCIAL SCIENCES
OF
MIDDLE EAST TECHNICAL UNIVERSITY

BY

BERFİN GÖKKAYA

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR
THE DEGREE OF MASTER OF SCIENCE
IN
THE DEPARTMENT OF PSYCHOLOGY

SEPTEMBER 2024

Approval of the thesis:

HIDRADENITIS SUPPURATIVA: AN EXAMINATION THROUGH PSYCHOSOCIAL VARIABELS

submitted by **BERFİN GÖKKAYA** in partial fulfillment of the requirements for the degree of **Master of Science in Psychology, the Graduate School of Social Sciences of Middle East Technical University** by,

Prof. Dr. Sadettin KİRAZCI
Dean
Graduate School of Social Sciences ____________________

Prof. Dr. Bengi ÖNER-ÖZKAN
Head of Department
Department of Psychology ____________________

Assoc. Prof. Dr. Leman KORKMAZ KARAOĞLU
Supervisor
Department of Psychology ____________________

Examining Committee Members:

Assoc. Prof. Dr. BANU CİNGÖZ-ULU (Head of the Examining Committee)
Middle East Technical University
Department of Psychology ____________________

Assoc. Prof. Dr. Leman KORKMAZ KARAOĞLU (Supervisor)
Middle East Technical University
Department of Psychology ____________________

Assoc. Prof. Dr. Gökhan ARSLANTÜRK
Selcuk University
Department of Psychology ____________________

I hereby declare that all information in this document has been obtained and presented in accordance with academic rules and ethical conduct. I also declare that, as required by these rules and conduct, I have fully cited and referenced all material and results that are not original to this work.

Name, Last Name: Berfin GÖKKAYA

Signature:

ABSTRACT

HIDRADENITIS SUPPURATIVA: AN EXAMINATION THROUGH PSYCHOSOCIAL VARIABLES

GÖKKAYA, Berfin
M.S., The Department of Psychology
Supervisor: Assoc. Prof. Dr. Leman KORKMAZ

September 2024, 150 pages

Studies on Hidradenitis Suppurativa (HS) have shown its impact on patients physically, psychologically, and socially. However, past research has not examined patients' experiences within a Biopsychosocial (BPS) model or focused on their relationships with close others. Our study explored the post-diagnosis experiences of HS patients in Türkiye, focusing on the psychosocial effects of the disease within the BPS model. We examined the relationships among the biological (disease severity), psychological (well-being and illness cognition as helplessness, acceptance and perceived benefits), and social (perceived stigmatization and relationships with close others, including mother, father, siblings, romantic partners, and female/male friends) components. We also investigated the impact of gender and romantic partner presence and provided the disease’s clinical presentation.

Analysis of data from 70 participants revealed that HS patients experience similar levels of well-being, helplessness, acceptance, perceived benefits, and perceived stigmatization, with their various relationships with close others similarly affected regardless of disease severity. There were no significant differences between female and male patients across any variables. Having a romantic partner was positively associated with well-being. Greater acceptance, less helplessness, and good relationship with a partner was associated with higher positive affect. Negative affect was only linked to helplessness. Perceived stigmatization was positively correlated with helplessness and negatively correlated with relationships with fathers and female friends. Good relationships with female friends were associated with higher acceptance and perceived benefits. This study is the first quantitative-correlational research of its kind in Türkiye, offering a comprehensive understanding of the psychological and social effects of HS.

Keywords: Hidradenitis Suppurativa, well-being, illness cognition, stigmatization, relationships

ÖZ

HIDRADENİTİS SUPPURATİVA: PSİKOSOSYAL DEĞİŞKENLER ÜZERİNDEN BİR İNCELEME

GÖKKAYA, Berfin
Yüksek Lisans, Psikoloji Bölümü
Tez Yöneticisi: Doç. Dr. Leman KORKMAZ

Eylül 2024, 150 sayfa

Hidradenitis Suppurativa (HS) üzerine yapılan çalışmalar, hastalığın hastaları fiziksel, psikolojik ve sosyal yönlerden etkilediğini göstermiştir. Ancak, geçmiş araştırmalar hastaların deneyimlerini Biyopsikososyal bir çerçevede incelememiş ya da yakın ilişkilerine odaklanmamıştır. Çalışmamız, Türkiye'deki HS hastalarının tanı sonrası deneyimlerini, hastalığın psikososyal etkilerine odaklanarak Biyopsikososyal model çerçevesinde araştırmıştır. Bu kapsamda biyolojik (hastalık şiddeti), psikolojik (iyi oluş ve hastalık bilişi olarak çaresizlik, kabul ve algılanan faydalar) ve sosyal (algılanan damgalanma ve anne, baba, kardeşler, romantik partnerler, kadın/erkek arkadaşlar gibi yakın kişilerle ilişkiler) bileşenler arasındaki ilişkileri incelenmiştir. Ayrıca, cinsiyetin ve romantik partnerin varlığının etkileri araştırılmış ve hastalığın klinik sunumu da sağlanmıştır.

70 katılımcıdan elde edilen verilerin analizi, HS hastalarının hastalık şiddetinden bağımsız olarak benzer düzeylerde iyi oluş, çaresizlik, kabul, algılanan faydalar ve algılanan damgalanma deneyimlediğini ve çeşitli yakın ilişkilerinin benzer şekilde etkilendiğini ortaya koymuştur. Kadın ve erkek hastalar arasında hiçbir değişkende fark bulunmamıştır. Romantik partnere sahip olmak, iyi oluşu olumlu yönde etkilemiştir. Pozitif duygular, daha yüksek kabul, daha az çaresizlik ve partnerle iyi

ilişki ile ilişkili bulunmuştur. Negatif duygular ise yalnızca çaresizlikle bağlantılıdır. Algılanan damgalanma, çaresizlik ile pozitif, baba ve kadın arkadaşlarla olan ilişkilerle ise negatif korelasyon göstermiştir. Kadın arkadaşlarla iyi ilişkiler, daha yüksek kabullenme ve algılanan yarar ile ilişkili bulunmuştur. Bu çalışma, Türkiye'de türünün ilk niceliksel-korelasyonel araştırması olup, HS'nin psikolojik ve sosyal etkilerine dair kapsamlı bir anlayış sunmaktadır.

Anahtar Kelimeler: Hidradenitis Suppurativa, iyi oluş, hastalık bilişi, damgalanma, ilişkiler

In dedication to those who hath borne the torment due to malady

ACKNOWLEDGMENTS

During the process of obtaining my specialty and writing my thesis, I experienced some of the most impactful and challenging periods of my life. I want to express my heartfelt thanks to all my loved ones who showed me their support and love throughout the process. I wish to honor each of them and leave a trace of their support in my thesis. First and foremost, I am deeply grateful to my dear advisor, Assoc. Prof. Dr. Leman Korkmaz, whose constant smile and supportive approach reminded me that I was not alone on this long and arduous journey of writing a thesis, and whose experience and guidance were invaluable. Despite her busy schedule, she always made time for me and provided detailed feedback, helping me improve my work. I am thankful for her endless support in allowing me to work on a topic I was most passionate about. I could not have completed this process without her.

I would like to thank my first teachers, my mother Hanife and my father Ziya, who demonstrated the greatest effort and dedication in shaping who I am today. I am grateful to my siblings, my first and last playmates, my sister Selen and my brother Murat, who taught me that one of the strongest bonds in this world is that of siblings, and who always made me feel unique with their support. I also want to thank my dear grandmother Gülizar Şanlı, who called me every day so I would not feel lonely and always had yaprak sarması on the kitchen table because she knew I loved them.

I would also like to thank Assoc. Prof. Dr. Cahit Yavuz, who helped me collect data from his patients and reminded me not to lose hope at the most challenging points. Special thanks to Dr. Melike Merve Balya, whose sincerity I felt from the moment we

met and who assisted me significantly in collecting data from patients. I owe a great debt of gratitude to my cousin Serdar, who supported me tirelessly during the ethical approval process to collect data from various hospitals. I also want to thank my dear friend and office mate, Rsch Asst. Fatmanur Sodalı, whose friendship, office companionship, and statistical knowledge provided endless help in conducting all my analyses. Assist. Prof. Dr. Nuh Akçakaya also deserves thanks for his invaluable support and knowledge during my analyses. I am grateful to Assoc. Prof. Dr. Gökhan Arslantürk, Assist. Prof. Dr. Muhammed Şükrü Aydın, and Assoc. Prof. Dr. Banu Cingöz Ulu, for their support throughout the process.

Thanks to my confidant and desk mate Ayşenur, whose cheerfulness and energy instantly lifted my spirits in every year of my psychology journey. I also want to thank my dear friends Yağmur, Ceren, Minel, and Emre, with whom I walked this path of social psychology thesis process and who always had my back, making me immensely grateful to have walked this journey together.

I am deeply appreciative and profoundly grateful to my dear friends Mert, Elif, Cem, Rümeysa, İstemihan, Bengisu, Fehri, Beyza, Melis, Onur, Deniz, Uğur Sena, and Elif Nur, whose presence, support, and love I always felt, even if we could not be physically together. I believe I can achieve anything with your love.

Special thanks to my beloved cousin and laughter partner Elif. I also want to thank my dear students Büşra and Enes, who made me feel their presence with their friendship and from whom I always had the opportunity to learn different aspects of life.

Lastly, I would like to express my sincere gratitude to TÜBİTAK for their financial support through the BİDEB-2210 scholarship program during my graduate studies.

I am forever grateful to all of you.

TABLE OF CONTENTS

CHAPTERS

APPENDICES

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

INTRODUCTION

1.1. General Introduction

Hidradenitis Suppurativa (HS) is a visible, chronic, draining skin disease characterized by the disruption of the terminal follicular epithelium in skin areas containing apocrine (sweat) glands, progressing relentlessly and leading to immobility (Zouboulis et al., 2015). It particularly causes disfigurement, painful sores, and lesions in the axillary, genital, and perianal regions of the body (Schneider-Burrus et al., 2018). When looking at the overall prevalence of the disease, it is estimated that 1% of the general population has HS, with a higher prevalence of up to 4% in women, and its onset typically occurs in young adulthood (Jemec et al., 1996). The Hurley clinical staging system classifies HS patients into three groups based on disease severity: Hurley I represents mild severity, Hurley II indicates moderate severity, and Hurley III corresponds to severe disease (Wieczorek & Walecka, 2018). Visible skin disorders not only present physical challenges for patients but also have a detrimental impact on their psychosocial well-being (Germain et al., 2021). HS, in particular, has a profound effect on the mental health of the patients (Phan et al., 2020).

To begin with, HS has been shown to have a more significant impact on quality of life compared to all other known chronic skin conditions (Weigelt et al., 2021). Beyond the physical discomfort it causes, HS is also linked to psychological distress, feelings of embarrassment (Mac Mahon et al., 2020), poor body image (Schneider-Burrus et al., 2018), reduced quality of life (Matusiak, 2018), higher rates of depression (Onderdijk et al., 2013), anxiety, low self-esteem (Vivar & Kruse, 2018), sexual distress (Kurek et al., 2012), and difficulties in personal and intimate relationships (Mac Mahon et al., 2020).

The Global Burden of Diseases Study recently demonstrated that skin diseases are the fourth leading cause of non-fatal disease burden (Hay et al., 2014); consequently, it is of great importance to determine the psychosocial burden of skin diseases on patients and to identify the aspects in which they are affected (Weigelt et al., 2021). In this context, our main aim is to investigate how individuals with HS are affected from a psychosocial perspective post-diagnosis by framing our research around the Biopsychosocial Model (BPSM). HS is a globally recognized condition that can lead to morbidity (Yüksel & Basım, 2020); however, studies investigating the disease often do not thoroughly address the psychosocial problems it causes, even though they touch upon some psychological and social aspects alongside the physical effects of the disease. Existing research shows that, while the disease affects the emotional state, patients also face stigmatization (Revuz, 2015) and deterioration in close relationships due to the challenges they encounter (Mac Mahon et al., 2020), and significant physical, psychological, social, and emotional distress. Moreover, the difficulties experienced by patients vary with disease severity; some variables change according to the severity, while others remain unchanged.

For instance, studies conducted over the years have proven that the psychological well-being of HS patients is affected regardless of disease severity (Alavi et al., 2017; Senthilnathan et al., 2019), indicating that even when disease severity is low, the overall emotional state of HS patients is still impacted. In terms of stigmatization, disease severity and poor mental health due to HS predicted perceived stigmatization, with higher disease severity linked to greater perceived stigmatization. (Akoğlu et al., 2021).

The literature contains findings not only on the relationship between disease severity and psychological and social variables but also on the relationships between psychological and social variables themselves. As highlighted in the literature, stigmatization negatively influences patients' health by worsening or hindering various processes, such as social interactions, psychological well-being, and behavioral responses, thereby further deteriorating their health (Hatzenbuehler et al., 2013). Perceived stigma, in particular, imposes a considerable psychosocial burden on individuals with skin conditions. On relationships, a systematic review found that 71.4% of participants reported that HS negatively impacted their relationships (Howells, 2021); and previous studies have shown that patients with HS suffer from worsening in personal and close relationships (Mac Mahon et al., 2020). Although these studies have examined the well-being, stigmatization, and overall impact on relationships of HS patients respectively, they have not explored patients' cognitions and have approached relationships of the patients with their close others (family, romantic partners and friends) as a whole. In other words, previous studies did not examine patients' illness cognitions, the association of illness cognition with well-being and stigmatization, or patients' various types of relationships. Moreover, no study has analyzed patients' relationships by dividing them into familial, social, and romantic categories. Considering the literature, the significance of the current study lies in its consideration of psychological and social effects HS might have on patients. Specifically, using the Biopsychosocial model as a framework, we explore the relationships between the biological (disease severity), psychological (well-being and illness cognition), and social (perceived stigmatization and relationships with close others, including mothers, fathers, siblings, romantic partners, and female/male friends) components. Although there have been individual studies conducted in this area within the literature, to our knowledge, there is no study that examines patients' perceived levels of stigma, illness cognitions (helplessness, acceptance, perceived benefits), relationships with their close circles (mother, father, siblings, romantic partner, fe/male friends) separately, and well-being, while also investigating how these variables change according to the severity of their disease. The aim of this study is to collectively examine the aforementioned variables and assess how each individually affects the patients' experiences.

In the following sections, we first mention the history, nature, prevalence and clinical representation and psychological effects of HS. Afterwards, since our study focuses on psychosocial effects of HS, and we frame our work around the BPS model; we discuss the features of this model and explain why we chose to use it. Within this framework, we proceed by considering disease severity as the biological component, well-being and illness cognition as the psychological component, and stigmatization and relationships with close others as the social component as well as providing the relationship between the components, as biological-psychological, biological-social, and psychological-social.

1.1.1. What is Hidradenitis Suppurativa (HS)?

Hidradenitis suppurativa (HS) (known as *Acne Inversa*), first described almost two centuries ago, is one of the most challenging and devastating among hundreds of dermatological diseases (Jemec et al., 2006). HS is a chronic, recurrent, debilitating, and inflammatory visible skin disease that usually occurs after adolescence and bears apocrine gland areas (Howells et al, 2021). HS presents itself with the blockage of hair follicles, leading to inflammation, healing, and scarring in a cyclical pattern (Alotaibi, 2024). Lesions, regions in the skin tissue that have been damaged through disease, are usually seen in areas where the individual's apocrine glands are located, especially in the armpits (most common), groin, perineum (the area between the anus and vagina in females), anogenital (inner thigh) and infrequently scalp and retroauricular regions (Jemec, 2012; Slade et al., 2003; Zouboulis et al., 2015). In these areas, debilitating inflammation of hair follicles occurs, which scars the tissue and creates sinus tracts, leading to a malodorous discharge (Esmann & Jemec, 2011). Although HS is a visibly noticeable skin condition, the lesions often appear in areas that individuals can relatively conceal. For instance, a person with lesions under their arm can hide the condition by wearing a shirt that covers the underarm area. On the other hand, a patient with lesions in the genital area may be able to hide them from others but may not be able to conceal them from a sexual partner.

Looking at the history of the disease, it has been neglected over time, subjected to misdiagnosis, and consensus has not been fully reached. The lack of consensus on issues such as pathogenesis, histopathology, genetics, bacteriology, and etiology indicate that this disease deserves to be classified as "nomen dubium et confusum" meaning that ‘name doubtful and confused’ by taxonomists (Jemec et al., 2006).

Even globally published articles and disease atlases have presented primitive, surprising, ambiguous, and even misleading results regarding the disease. There may be various reasons for this situation; which are mentioned in the book ‘Hidradenitis Suppurativa,’ edited primarily by Gregor B. E. Jemec, Jean Revuz, and James J. Leyden (2006), providing us with a good starting point. Firstly, this condition is oftentimes described by both patients and doctors as a 'heart sink condition'. Patients typically find this disease as a debilitating, and embarrassing predicament that has a high level of morbidity. Secondly, physicians administering treatment often perceive it as a difficult-to-treat condition. Therefore, patients tend to suffer silently rather than seek help, and they conceal their condition. Similarly, physicians, faced with clinical challenges, often adopt a reductionist approach instead of seeking insight; sometimes, they even misdiagnose or make the diagnosis very delayed (Aparício Martins et al., 2023). Lastly, it may only be now that a sufficient number of experts have come together to thoroughly examine and explain this condition with the enormous number of sources today from different fields, including psychology.

Moreover, there are some other barriers to conducting research regarding HS and its care, which could be listed as: the limited and incomplete medical knowledge of HS among general practitioners, the difficulty in accessing specialists with expertise in HS, and the poor communication skills of practitioners with patients resulting in decreased trust in the medical community among patients, and the pain patients experience leading them to become withdrawn and isolated (Shukla et al., 2020).

1.1.2. History of Hidradenitis Suppurativa

Hidradenitis suppurativa was first mentioned in history in 1833 by Alfred-Armand-Louis-Marie Velpeau (1795-1867). According to Velpeau, HS was a type of phlegmon caused by friction, irritation, and lack of cleanliness of the sweat follicles in the armpit (Velpeau, 1833 as cited in Tilles, 2006). He mentioned that this phlegmon follows an inflammatory pathway, develops very slowly, and could be painful. He also stated that this type of phlegmon would persist throughout life and afflict patients negatively for many years. At this point, we can see that the chronic nature of HS was discussed almost 200 years ago from today.Later, in 1864, French surgeon Aristide Auguste Stanislas Verneuil stated that the phlegmonous tumors mentioned by Velpeau were not abscesses based on sebaceous follicles, but rather abscesses originating from apocrine glands. Verneuil reached this conclusion through clinical and microanatomical observations. Then, he named the disease as “hidrosadénite phlegmoneuse”. Over the years, the disease began to be referred to as ‘Verneuil's disease’. However, today the name Hidradenitis Suppurativa is used, meaning that the condition involves inflammation of a sweat gland (hidradenitis) accompanied by the presence of pus (suppurativa) (History of hidradenitis suppurativa, n.d.). Even though HS was thought to be a disease resulting from apocrine gland dysfunction for a long time, it is now accepted that it is a chronic inflammatory disease (Micheletti, 2014; Zouboulis et al., 2015).

1.1.3. Prevalence of Hidradenitis Suppurativa in the World & Türkiye and Epidemiology

The prevalence of the disease varies between 0.05% and 4.1% in the global population (Ingram, 2020). In European and United States populations, this frequency ranges from 0.7% to 1.2% (Nguyen et al., 2020). Studies based on clinical samples have revealed that the pooled prevalence of HS (1.7%) is higher compared to community-based studies (0.3%). A systematic analysis conducted quantitatively assessed 16 studies, with prevalence estimates reported from the USA, Western Europe, Scandinavian countries, and Australia, indicating a prevalence of 0.4% for HS (Gill & Gniadecki, 2019).

When considering the percentages indicated by these studies, the varying prevalence rates led us to conclude that there are almost 400.000 individuals affected by the disease in Türkiye. Considering the total population, the magnitude of this number is undeniable. It is worth remembering that since there has been no study conducted to determine the overall size of the HS patient population in Türkiye to our knowledge, our estimate of the number of patients remains speculative.

Upon examining the potential consequences of the disease, it is evident that individuals are negatively affected in physical, psychological, and social aspects (Nguyen et al., 2020). When we take a closer look at the etiology of HS, it is clear that genetic and environmental factors coexist. According to a study conducted by Fitzsimmons and Guilbert in 1985, 34.4% of first-degree relatives of patients also suffered from HS. Another subsequent study found that 30-40% of patients had a family history of HS (Pink et al., 2012). Nonetheless, research indicates that the genetic causes of the disease account for approximately 5% (Zouboulis et al., 2015).

The onset age of the disease is typically during young adulthood (Jemec, 2012). However, according to some studies, HS begins in individuals in their 30's and 40's (Cosmatos et al., 2013; McMillan, 2014), while the average delay in diagnosis ranges from 7 to 10 years (Aparício Martins et al., 2023). The average time from the onset of initial symptoms to the diagnosis of HS was found to be approximately 9.6 years, with a standard deviation of around 10.0 years (Kokolakis et al., 2020). During this extended period before diagnosis, HS patients consult more than three different doctors on average (most commonly general practitioners, dermatologists, surgeons, and gynecologists) and encounter more than three misdiagnoses. The longer the delay in diagnosis, the more severe the disease is at the time of diagnosis (Aparício Martins et al., 2023). Additionally, a delayed HS diagnosis was associated with an increased number of surgically treated areas, comorbidities, and missed workdays (Kokolakis et al., 2020). Studies in the United States and Europe have suggested that HS disproportionately affects females compared to males (Shavit et al., 2015); however, a study conducted in South Korea found a predominance of male patients (Ingram et al., 2018; Lee et al., 2018). At this point, it can be said that the epidemiology of the disease is not similar across countries, and generalization from one society to another may not be applicable. The differences and variations in epidemiologies could stem from heterogeneous measurement methods and different samples studied (Kirsten et al., 2021; Theut Riis et al., 2019). In a study conducted by Yüksel and Basım (2020) in Türkiye, the demographic and clinical features of HS patients were examined. The records of 208 patients diagnosed with HS between June 2012 and July 2017 were retrospectively reviewed. Among these cases, 68.3% were male and 31.7% were female.

1.1.4. Treatment Options for Hidradenitis Suppurativa

The management of HS is generally challenging, and evidence-based treatment options are limited (Rambhatla et al., 2012); which is largely influenced by the chronic nature of the disease and its high rate of recurrence. Despite its high prevalence around the world, there are very limited treatment options for HS, and very few large-scale randomized controlled trials have assessed the validity and safety of these treatments (Rambhatla et al., 2012).

In their review study, Rambhatla and colleagues (2012) presented three treatment categories: surgical, medical, and miscellaneous treatments. The subcategories of medical treatments include antibiotics and biological agents. The subcategories of surgical treatments include laser surgery and excisional surgery. Miscellaneous treatments encompass cryotherapy, photodynamic treatment, and the use of various drugs as solo treatments. In 2015, a European guideline was published to review treatments for HS, indicating that other treatment options have been developed, such as adjuvant therapy and intense pulsed light (IPL) therapy (Zouboulis et al., 2015).

1.1.5. Hidradenitis Suppurativa and Comorbidities

As literature grows in this area, research shows that psychiatric comorbidities are frequently common among people with visible skin disease (Colon et al., 1991; Consoli et al., 2006; Esposito, 2006; Gupta & Gupta, 2003; Lockwood et al., 2023). One study showed that having a skin disease increases the risk of developing a psychiatric disorder, particularly depression, anxiety, and alcohol use, within seven years by two to three times compared to the general population (Balieva et al., 2023). In one of the largest epidemiological studies concluded that a 25% prevalence of psychiatric morbidity was found in 2579 outpatients of dermatological diseases, while another study found this prevalence as 38% in 545 inpatients (Picardi et al., 2005). Frequency of the psychiatric comorbidities were as follows respectively: Mood and anxiety disorders (the most common ones as the major depressive disorder and general anxiety disorder) (Shavit et al., 2015), adjustment and somatoform disorders (Picardi et al., 2005). Also, visibility of the damaged skin is associated with higher risk of psychiatric morbidity (Picardi et al., 2001).

Since HS is a visible skin condition that could often be difficult to conceal, it is not surprising that psychiatric morbidity is relatively high and the most common psychiatric comorbidities of HS include depression and anxiety disorders (Shavit et al., 2015). In addition to psychiatric comorbidities, HS patients also suffer from distinct physical and chronic diseases. Firstly, there is a powerful association between HS and obesity and being overweight. More than 75% of the patients are obese (Mendonça & Griffiths, 2006). While these percentages change according to the sex of the participant in that, 77% of male patients and 69% of female patients were found to be overweight and 26% of male patients and 33% of female patients were obese (Harrison et al., 1988).

Follicular occlusion disorders, inflammatory bowel diseases (IBD) (Chen & Chi, 2019), spondylarthropathy (Vasey et al., 1984), Crohn's disease (Short et al., 2005) are considered the most common comorbidities of HS (Fimmel & Zouboulis, 2010), aside with sexual dysfunction (Garg et al., 2022; Janse et al., 2017), type II diabetes, hypertension (Schultheis et al., 2023), working disability (Matusiak et al., 2010), polycystic ovary syndrome, dissecting cellulitis of the scalp, substance use disorder (Garg et al., 2022), axial spondyloarthritis (Fauconier et al., 2018), depression, and anxiety (Machado et al., 2019; Matusiak et al., 2010). Also, HS patients have been found to have higher risk of cardiovascular death (Tzellos et al., 2015) and suicide risk (Thorlacius et al., 2018) as psoriasis patients.

Lastly, in a longitudinal study conducted in Denmark from 1977 to 2017, 1,193 out of 13,919 HS patients developed cancer within a 14-year period, which corresponds to a roughly 40% increased risk (Andersen et al., 2024). These figures indicate that HS patients face a significantly higher risk of cancer. This result echoes findings from previous studies conducted on Swedish and Korean populations (Jung et al., 2020; Lapins et al., 2001).

1.1.6. Psychological Effects of Hidradenitis Suppurativa

As suggested by some studies, psychological and social factors play a role in pathogenesis and progression of several skin diseases (Picardi & Pasquini, 2007). Visible skin disorders not only physically challenge patients but also negatively impact them psychosocially (Germain et al., 2021). Patients face the risk of depression, anxiety, low quality of life, and low self-esteem (Vivar & Kruse, 2018). HS has a tragic effect on the mental health of individuals, showing that its psychosocial difficulty may lend its relation to suicidality (Phan et al., 2020). HS has been found to negatively affect quality of life more than all other known chronic dermatoses, including psoriasis, atopic dermatitis, and acne (Matusiak, 2018; Onderdijk et al., 2013; Weigelt et al., 2021). HS can lead to depression, affecting an individual's family, social, romantic life, and career negatively (Patel et al., 2017). According to a study, depression, anxiety, sexuality, body image, and financial concerns were identified as the most important factors contributing to low HS quality of life (Weigelt et al., 2021). Patients with HS suffer from psychological distress and shame, deterioration in personal and close relationships (Mac Mahon et al., 2020), low self-esteem (Matusiak, 2018), and poor body image (Schneider-Burrus et al., 2018). In recent years, there has been a significant increase in substance use and suicide risk among individuals with the disease (Nguyen et al., 2020). Additionally, patients feel stigmatized and excluded due to physical and psychosocial problems resulting from the disease.

HS also has a profound negative impact on sexual health due to the severity of lesions (Cuenca-Barrales et al., 2021). When looking at patients with sexual partners, sexual dysfunction is often observed (Janse et al., 2017). In one study, up to 66.7% of patients reported difficulties in their sexual lives; this is three times higher than the average of those suffering from other dermatoses (Sampogna et al., 2017). Importantly, sexual distress and dysfunction in HS patients have been associated with anxiety, depression, and suicidal thoughts (Cuenca-Barrales et al., 2021). Due to the painful nature and location of lesions, dyspareunia (pain during sexual intercourse) can also occur in women (Sampogna et al., 2017). The sexual health of male HS patients is worse than that of female patients, and most suffer from erectile dysfunction (Kurek et al., 2012).

A systematic review conducted by Howells (2021) demonstrates that HS harms and restrains patients' lives. The physical, psychological, and social consequences of HS result in individuals missing multiple life events, which can have a cumulative impact on the trajectory of one's life. This phenomenon has entered the literature as '*lifetime cumulative impairment'*, referring to the irreversible and persistent burden of a chronic skin disease (Ros et al., 2014; Von Stülpnagel et al., 2021; Warren et al., 2011). Since visible skin disease patients suffer from psychosocial and physical burdens due to their condition, their burden causes a cumulative life course impairment (CLCI). In a study conducted by Warren et al. (2011), individuals with a skin disease called psoriasis were examined regarding CLCI and it has been found that psoriasis patients' life courses were negatively affected; the same negative effect was also found in a study with HS patients in 2021 (Howells et al., 2021). For example, not being able to go to work or school, and decreased functionality (reduced physical mobility, increased pain and discomfort, the possibility of sores bursting and bleeding, etc.) hinder individuals from social environments. Not being able to go to work affects one's career life, while avoiding meeting people affects both social and romantic life. Social isolation resulting from these avoidances adversely affects individuals' family, social, and romantic lives, harming their mental health (Howells et al., 2021; Perche et al., 2022).

Pavon Blanco et al., (2018) found that patients' beliefs and perceptions about their illness were more closely related to psychosocial impairment than the clinical severity of the disease for HS patients. They noted that disease perceptions (emotional responses to the disease, lack of control over the condition) are often not a function of disease severity and that depression, anxiety, and quality of life scores contribute the most to variance in HS patients. The most significant disease beliefs cited include perceived lack of treatment control, perceived negative consequences of the disease, and emotional responses to the disease. The authors suggest that physicians should target these negative perceptions and emotions to improve patients' psychosocial well-being (Pavon Blanco et al., 2018).

1.1.7. Suicidal Ideation in Hidradenitis Suppurativa Patients

Suicidality has been observed at high rates in dermatology patients, particularly those with psoriasis (Patterson, 2024), atopic dermatitis (Chen et al., 2019), and acne (Picardi et al., 2013) (Gupta et al., 2017; Lockwood et al., 2023). Picardi & Pasquini (2007) handed Patient Health Questionnaire to 466 dermatological patients and found that 8.6% of those patients reported suicidal ideation, along with experience of suicidal thoughts in 3% of them. Another study found 7.3% of 480 patients reported suicidal ideation (Gupta & Gupta, 1998). Moreover, psoriasis and atopic dermatitis patients had reported very high levels of suicidal ideation rising up to 20% (Zacharie et al., 2004). In several cases, patients did not only have the ideation but also completed their suicide, unfortunately (Cotterill & Cunliffe, 1997; Humphreys & Humphreys, 1998). As for HS patients, since HS has a dramatic and often negative impact on patients' mental health, clinicians caring for patients with HS should exercise caution considering the prevalence of psychiatric comorbidities and suicidality in this population. The psychosocial burden of the disease may explain its relationship with suicide (Phan et al., 2019). In a study conducted by Garg et al., (2017) the US population was evaluated, and a diagnosis of HS was found to be associated with an increased likelihood of suicide, with this likelihood rising with age and peaking in patients aged 60 and older. Additionally, Patel et al. (2019) examined patient databases from hospitals in the United States and found that individuals diagnosed with HS had higher rates of self-harm and suicidality compared to the control group.

Consequently, people with HS have a potential to commit and complete suicide as a result of the dramatic negative impact of the disease (Shavit et al., 2015). Markedly, compared to people without HS, people with HS are at a greater risk of completed suicide; additionally, HS patients are 2.4 times more likely to attempt suicide (Thorlacius et al., 2018).

In the preceding sections, the history, nature, prevalence, and clinical representation of HS were discussed. Additionally, the negative psychological impacts of the disease and how psychological processes influence patients' experiences were addressed, highlighting the extent to which social, psychological, and physiological processes are intertwined in this disease. The following section discusses the Biopsychosocial (BPS) Model, which forms the theoretical framework of this study and emphasizes the interaction between biological and psychosocial processes in diseases.

1.2. Theoretical Framework: Biopsychosocial Model

The study of health, illness, and general well-being dates back to ancient times, from the era of philosophical debates on the relationship between the body and mind, rather the psychological and physical systems, to the present day (Albery & Munafò, 2014). According to humoral theory by Hippocrates (c. 460 BC-c. 375 BC) and Galen (130 AD- c. 210 AD), one of the most significant principles in Western medicine from antique times into the 19th century (Robinson, 2023), the mind and body are an inseparable whole.

The state of health is determined by the balance between the four humors in the body; which are blood, phlegm (mucus), yellow bile (gall), and black bile. Each individual has a unique balance of those humors, and health is achieved through the appropriate balance of humors specific to each person. An individual's humoral balance depends on factors such as climate, geographic location, occupation, age, gender, and economic class, meaning that what is healthy for one person may not be for another. During the times when this theory was accepted, humoral treatments aimed at restoring balance by enabling the flow of fluids out of the body. Despite its effectiveness at the time, humoral theory faced substantial criticism after the mid-19th century (Robinson, 2023). The rise of modern medicine led to dualism becoming the most widely accepted view (Albery & Munafò, 2014). According to dualism, the body and mind function independently; the mind cannot influence physical matter (Moini et al., 2024). The mind is associated with abstract notions such as emotions and thoughts, while the body is linked to tangible and physical notions like bones, organs, and the brain. Changes in physical notions are independent of mental notions (Maung, 2018). Over the years, the view that embraces dualism and asserts that diseases stem from cellular dysfunction emerged and was followed for many years as the biomedical model (also known as the Mechanistic Model) (Brannon & Feist, 2010). This model remains the dominant framework in medical education and practice today. It posits that the mind cannot affect physical systems, thus considering the mind and body as entirely separate entities, aligning with the principles of dualism (Albery & Munafo, 2014). The biomedical model was developed by scientists in the medical field to study diseases (Engel, 1977).

According to this model, diseases result from deviations of measurable biological variables from the norm, such as cellular dysfunction and chemical imbalances in the body (Taylor, 1995), or viruses, microbes, and genetic predispositions (Albery & Munafo, 2014; Ogden, 1997). The model does not consider social, psychological, and behavioral dimensions in the etiology of diseases (Engel, 1977). The biomedical view that ‘diseases may have psychological consequences but cannot have psychological causes’ (Ogden, 2012) renders the model reductionist, and, as Engel puts it, it cannot escape its status as 'dogma' (Engel, 1977; Wade & Halligan, 2017). This biomedical dogma explains all diseases, including mental illnesses, as resulting from disruptions in the body's physical mechanisms, which is insufficient for explaining both the onset and progression of diseases.

The idea that the biomedical model is insufficient and that the approach to diseases should be broadened to include psychosocial variables was first proposed by George Engel in 1977. He created his model by following the basic assumptions of the general systems theory, positing that any complex system can fail even if all its individual components are functioning normally (Von Bertalanffy, 1967).

Besides, the characteristics of each higher or more complex level cannot be explained solely by the components at a lower level; they are meaningful as a whole (Kusnanto et al., 2018). Engel outlined the reasons for the need for a new medical model as follows:

1) The laboratory test results used by the biomedical model to diagnose diseases indicate a potential illness, but their accuracy is not always reliable. In other words, the biomedical model focuses more on laboratory results than on patients' narratives, thereby overlooking individual differences (psychological and social) and remaining far from being a patient-centered model.

2) The biomedical model neglects both the rigor required to ensure reliability during the initial patient interview and the necessity of analyzing the patient's history not only in anatomical, physiological, or biochemical terms but also from psychological, social, and cultural perspectives.

3) Psychological and social factors are crucial in determining whether patients with biochemical abnormalities, such as those with diabetes or schizophrenia, perceive

themselves as ill or are perceived as ill by others. While biochemical causes can determine specific physical characteristics of the disease, they may not necessarily dictate whether a person acknowledges being ill or assumes the sick role/status.

According to Engel (1977), in order to understand the causes of any disease and provide a rational treatment to the patient, a medical model must also consider the patient (psychological), the social context in which the patient lives (social), and the system designed by society for treatments (the role of the physician and the healthcare system). The boundaries between health and illness, and between healthy and ill individuals, are far from clear-cut; as these boundaries are fragmented by social, cultural, and psychological factors. The biomedical perspective, by accepting biological indices as the ultimate criteria defining disease, overlooks the relative contributions of social and psychological factors in the patient's decision to accept their illness (illness cognition) and consequently in the process of assuming responsibility for their own healthcare.

Nonetheless today, the World Health Organization (WHO) defines health not merely as the absence of disease and infirmity, but as a state of complete physical, mental, and social well-being (World Health Organization [WHO], 1958).

The biopsychosocial model is not only utilized to develop health interventions but is also considered as the foundation to the World Health Organization's International Classification of Functioning (WHO ICF) (Wade & Halligan, 2017). It is regarded as a guide in clinical practice and asserts that concepts of health and disease emerge from the interaction of biological, psychological, and social factors. Engel did not deny that the fundamentally reductionist biomedical model led to significant medical advancements and progress in diagnosing and treating some life-threatening and debilitating diseases. However, he pointed out that this model was inadequate for explaining well-known conditions such as hysteria and neurasthenia, which have no evident physical symptoms, and noted that the model was not fully understood even in the 19th century (Wade & Halligan, 2017). Engel's call and advocacy for a biopsychosocial model were addressed and utilized in many health fields. However, it was not fully embraced in the more economically dominant and politically powerful fields of medicine and surgery (Wade & Halligan, 2017).

1.2.1. Why do we use the Biopsychosocial Model?

A professor of medical anthropology and psychiatrist Kleinman et al. (2006) posited that while doctors diagnose and treat diseases (abnormalities in the body system), it is the patients who suffer due to the illness (psychologically and socially). As a result, it is important to chart a path that begins with diagnosis and extends through treatment to recovery, without neglecting the psychological and social impacts on patients throughout the process. Also, according to the results of ethnographic studies, the most common attributions for illnesses are psychological and social causes (Murdock, 1980), highlighting the deficiencies of the biomedical model in this regard (Johnson, 2013). The biopsychosocial model’s primary purpose is to provide a more comprehensive explanation of patient behaviors and healthcare services (Wade & Halligan, 2017). There are mainly four reasons why we framed our study around BPS Model. Firstly, it focuses on the individual (Wade, 2015). Secondly, BPS Model makes way for a deeper understanding of the causes and consequences of diseases, enhancing patient outcomes, and helping to reduce potentially significant costs during disease phases (Wade & Halligan, 2017). Thirdly, BPS research considers chronic diseases and functional disorders as conditions that require the application of the BPS model (Kusnanto et al., 2018).

Lastly, the model promotes and guides patient-centered care (Smith et al., 2013), which has the potential to enhance patient outcomes (Weiner et al., 2013) and is applied in both the management and research of disabling conditions. In the following paragraphs, these reasons are explored in more detail.

To begin with, the most recent version of the model (Wade, 2015) critically focuses on the individual. The individual in the model has two contexts: personal and temporal. The personal context includes the person's character, experiences, expectations, attitudes, etc., while the temporal context encompasses the stage of the patients' lives and their illnesses. Social context covers the social groups to which the individual belongs, such as family, coworkers, and friends. Individuals interact with objects and people in a goal-directed manner, and as a result, both the individual and others who observe these behaviors attribute meanings to these actions; thus, the roles that individuals carry at that moment are formed (Wade & Halligan, 2017). We see that understanding the temporal context is crucial, as it provides insight into critical life stages and transitions that might be missed or disrupted due to illness. The physical, psychological, and social consequences of HS result in individuals missing multiple life events, which can have a cumulative and negative impact on the trajectory of their lives.

Additionally, acknowledging that social interactions and societal perceptions significantly impact individuals' experiences and behaviors (Wade & Halligan, 2017) and as Engel (1977) put it, psychological and social factors are crucial in determining whether patients with biochemical abnormalities perceive themselves as ill or are perceived as ill by others.

Therefore, since we aimed to understand how patients perceive stigmatization by others and how this is associated with their overall cognition and relationship with others, believing that the biopsychosocial model would be highly beneficial in conducting our research. Considering the importance of patients' self-assessment of their illness, we did not overlook the examination of illness cognition as well.

Secondly, the budgets allocated by health institutions for chronic diseases have been steadily increasing over the years, as has the need to decrease the negative outcomes experienced by patients. In this context, the utilization of the biopsychosocial model can contribute to a deeper understanding of the causes and consequences of diseases, enhance patient outcomes, and help reduce potentially significant costs (Wade & Halligan, 2017). Thirdly, BPS research addresses chronic diseases and functional disorders as conditions that necessitate the application of the BPS model (Kusnanto et al., 2018). Long-term chronic conditions, such as diabetes, have been found to be associated with biopsychosocial processes that lead to various health issues, including depression, anxiety, and other comorbidities (Kusnanto et al., 2018). HS is also a chronic disease and has been found to be associated with a long spectrum of comorbidities (Fimmel & Zouboulis, 2010). In this context, given that HS is a chronic disease, adhering to the BPS model is of vital importance.

Lastly, the model supports and leads to individual-centered care (Smith et al., 2013), which has the ability to improve patient outcome (Weiner et al., 2013); and the model is also used while managing and researching disabling conditions. Since our research is an explorative study regarding HS, taking advantage of the BPS model provides us with the framework necessary to achieve our objectives.

Although, the BPS model emerges as an ideal representation of science and humanism in medical practice (Borrell-Carrio, 2004); medicine still predominantly operates under the biomedical model, which posits that diseases can be understood independently of the patient and explained through abnormal molecular and pathological markers observable by physicians (Weston, 2005). In clinical practice, the BPS model is often neglected or inadequately applied, particularly regarding sociocultural factors (Farre & Rapley, 2017; Hatala, 2012), and the biological, psychological, social, and spiritual dimensions of illnesses are rarely considered in an integrated manner (Katerndahl & Oyiriaru, 2007). Recent studies in the medical field have failed to employ the BPS model for HS.

While studies investigating HS advocate for using the biopsychosocial model, it has not yet been applied in research to date. Some studies have suggested that future research would benefit from incorporating the BPS model while working on skin diseases (Howells et al., 2021; Mortimore et al., 2022; Patel et al., 2017, Trialonis-Suthakharan et al., 2023). The burden of the disease is recognized as being composed of biopsychosocial processes (Howard-James & Tobin, 2023). Therefore, we believe that establishing a framework within this context would be a valuable contribution to literature. According to the results of a thematic synthesis conducted by Howells et al., (2021), it was found that people with HS are generally affected by 3 themes. First of all, HS patients fall behind in their lives by missing events due to the physical, social, and psychological consequences of HS.

Secondly, patients try to hide their disease, but this causes patients to experience fear and hesitation if others find out. Finally, delayed or incorrect diagnosis causes patients to feel that they are not understood and heard by healthcare professionals. As suggested by the researchers, a multidisciplinary approach is needed because the effects of HS are not only physical but also psychological and social. Management and research of HS should be based on a biopsychosocial model of health and disease (Howell et al., 2021).

In the following sections, the study variables are examined in detail under the framework of the biopsychosocial model. In this research, the 'bio' component of the model addresses disease severity, the 'psycho' component covers well-being and illness cognition of the patients, and the 'social' component includes perceived stigmatization and relationship with close others (family, social, romantic) of the patients. Following this, the relationship between psychological components is discussed after defining these components. The relationships between biological-psychological, biological-social, and psychological-social components are then examined in detail, following the definition of all variables, respectively.

1.2.2. Biological Component of the BPS Model in the Current Study

1.2.2.1. Disease Severity

As described before, HS manifests itself with inflamed nodules, fistulas and abscesses that occur frequently, which creates tissue damage that cannot be reversible (Schultheis et al., 2023). Generally, following the number of current lesions and their locations around the body, HS severity is classified (Scheinfeld, 2014). To determine the severity, many different tests have been developed, and the most commonly used disease severity staging system is referred to as hurley staging; first described by Harry J. Hurley, (as cited in Koerts et al., 2023); initially developed to assist in the selection of treatment for specific body areas and primarily for surgical purposes. The system divides the disease into 3 stages. According to this classification system, Hurley stage I is associated with medical treatment, stage II is compatible with local surgery, and stage III is compatible with wide surgical excision (Ovadja et al., 2019). In Hurley stage I, there are inflammation-filled nodules and abscesses without sinus tracts or scarring.

Figure 1. *Hurley Staging.* As A stands for Hurley I, B for Hurley II and C for Hurley III. From “Hidradenitis Suppurativa,” by G. B. E. Jemec, 2003, *7*(1), *Journal of Cutaneous Medicine and Surgery*, Introduction section, Figure 1. (https://doi.org/ 10.1007/s10227-002-2104-z)

In Hurley stage II, abscesses with interconnecting tracts, scarring, and multiple regions of involvement are present. Lastly, Hurley stage III is characterized by diffuse or multiple interconnected sinuses and abscesses covering an entire area (e.g., the whole armpit) (Koerts et al., 2023) (see Figure 1). According to the literature, 45.5% of patients are at Hurley stage I, 41.5% at Hurley stage II, and 13% at Hurley stage III (Schrader et al., 2014). In a study (Schultheis et al., 2023) conducted more recently, it was found that 13% of patients are at Hurley stage I, 62% at Hurley stage II, and 25% at Hurley stage III.

1.2.3. Psychological Components of the BPS Model in the Current Study

1.2.3.1. Well-Being

There are many different definitions of psychological well-being, and due to the lack of consensus on its definition, various approaches to conceptualizing well-being have emerged (Diener et al., 2003). Well-being is defined as a holistic process in which an individual is physically, spiritually and mentally well. It is considered as a lifestyle in which the individual is ideally healthy and well, shows functionality in all areas of his/her life, integrates body, soul and mentally, and lives a full life (Timur, 2008 as cited in Dündar & Demirli, 2018). Research on well-being has progressed significantly, particularly with the introduction of the PERMA model by Seligman and Csikszentmihalyi (2000). According to this model and framework, there are five principles: Positive Emotion, Engagement, Relationships, Meaning, and Accomplishment. Each principle can be independently measured and contributes to overall well-being. In our study, we used Diener et al.'s (2003) concept of well-being.

According to this conceptualization, subjective well-being is a multidimensional concept that includes an individual's cognitive and affective evaluations of their own life. Specifically, it encompasses positive and negative affect and life satisfaction (Diener et al., 1985). Greater life satisfaction, increased positive affect, and reduced negative affect are linked to higher levels of subjective well-being (Myers & Diener, 1995). In our study, we focused on the affective (positive and negative) dimension of well-being.

1.2.3.2. Illness Cognition

The concept of ‘illness cognition’ is a part of the Common Sense Model of Self-Regulation (Nur'aeni & Mirwanti, 2020). According to Leventhal et al., (2016) the Common-Sense Model describes a dynamic, multi-level process that produces individual representations of health threats, management procedures, and systems in compiling and implementing an action plan regarding treatment. The process begins and continues with the patient's perception of symptoms and changes in the normal functioning of their body. As noted by Evers et al., (2001) there are three primary illness cognitions: acceptance, helplessness, and perceived benefits. These cognitions represent various approaches to reassessing the inherently negative nature of a chronic condition. According to the authors, helplessness highlights the aversive meaning of the disease; i.e., the focus is on the hindrances the disease causes for patients, such as reduced mobility, constant pain, inflammation, and soreness in the case of HS. Acceptance lessens this aversive meaning by acknowledging the negative consequences of the stressor and adapting to live with it, and lastly, perceived benefits attribute a positive meaning to the disease by emphasizing the further positive effects of the stressor, in our context the disease. Greater acceptance cognition is associated with positive outcomes such as less anxiety, depression, and disability, and better emotional, social, and physical functioning (Aykul, 2018). Lastly, the evaluation of an illness has been proposed to be a factor in explaining individual differences in well-being (Leventhal et al., 2003; Maes & Karoly, 2005). With illness cognition, patients perceive their conditions considering both their physical and psychological health statuses. According to this theory, the extent to which a patient accepts their illness positively influences disease management and the coping strategies they employ during the process. Conversely, when a patient perceives helplessness, it negatively impacts their coping process. To put it differently, acceptance, helplessness and perceived benefits of patients that undergo a treatment determine their health status (Nur'aeni & Mirwanti, 2020).

1.2.3.3. The Relationship between Psychological Components: Well-Being and Illness Cognition

According to Evers et al., (2001), there is a relationship between disease and the well-being of the patient, and this relationship is illness cognition, which affects the way patients perceive and think regarding their disease accounting their differences in their psychological and physical health status as individuals. Since chronic diseases are defined as long-term conditions that do not resolve on their own, rarely achieve complete recovery, and often lead to functional impairment and/or disability (Brownson et al., 1998); it is really important to pinpoint the overall cognition of HS patients to comprehend their overall process and provide them with the best action plan because it is undeniable that HS puts too much burden on patients physically, psychologically, and socially as a result of its chronic nature. Pavon Blanco and colleagues (2018) discovered that HS patients' perceptions of their illness were more strongly linked to depression and anxiety than disease severity. In addition, patients with stronger emotional responses and more beliefs about negative consequences of their condition experienced higher levels of anxiety regardless of the severity of their illness. Although illness cognition studies have been conducted on various chronic diseases and health conditions (Gurková & Soósová, 2018; Nur'aeni & Mirwanti, 2020; Patel et al., 2018), while providing preliminary evidence of its general and long-term impacts on both physical and psychological well-being (Evers et al., 2001), to the best of our knowledge, there is no study regarding the illness cognition of HS patients and its association with patients' overall emotional state. With keeping the fact that patients’ cognition of their illnesses being a factor in explaining differences in their well-beings (Maes & Karoly, 2005) in mind, we hypothesize that lower levels of helplessness, and higher levels of acceptance and perceived benefits will be associated with higher well-being.

H1: Lower levels of helplessness, higher levels of acceptance and perceived benefits will be associated with higher well-being.

1.2.4. Social Components of the BPS Model in the Current Study

1.2.4.1. Perceived Stigmatization

"Stigma" is a highly discrediting and derogatory attribute introduced to literature by sociologist Erving Goffman in 1963. He posits that certain characteristics (such as manner of speaking, clothing, and personal grooming practices) cause specific individuals to stand out from normative society. These individuals are often profiled or seen as socially excluded because they do not conform to mainstream societal acceptance (Goffman, 1963). According to Goffman, a person's visible attributes, such as skin color, facial look, body size, or hidden aspects, such as a criminal record or a diagnosis of a mental illness, can lead to stigmatization if disclosed (Goffman, 1963, p.138), stating that most people experience stigma at some point in their lives and for various reasons. Goffman noted that stigma can arise from different causes and categorized stigma into three categories, which are: physical deformities (e.g., blindness, burned skin, and leprosy), tribal stigmas (e.g., race, religion and ethnicity), and individual character blemishes (addiction, mental disorder, homosexuality). Goffman asserted that stigma can be experienced by individuals in two ways: first, when a difference is noticeable or visible (discredited stigma), and second, when a difference is unknown or not immediately perceivable (discreditable stigma). Stigmatization emerges as a multifaceted construct that blends multiple factors. This process begins with the identification and labeling of a difference. Subsequently, this difference is associated with a negative stereotype, leading to social distancing between 'them' and 'us'. This process continues with rejection and exclusion accompanied by status loss, discrimination, and social and economic consequences (Link & Phelan, 2001). Although the concept of stigmatization, introduced by Goffman, is universally accepted, the traits, behaviors, and groups that are stigmatized can vary across different societies. This variation is influenced by the time period, culture, and socio-economic background of each society (Topp et al., 2019). Consequently, cultures and the values they embrace, the norms they establish, and social interactions shape perceptions of what is stigmatized (Topp et al., 2019). Stigmatization is a well-appreciated feature of HS (Matusiak et al., 2010). HS patients face two separate challenges due to stigmatization: the disease itself, which affects them physically, psychologically, socially, and mentally, and the potential or experience of stigmatization. Therefore, to appropriately and comprehensively address the psychological, physical, social, and mental challenges faced by individuals with dermatological diseases, a holistic and patient-centered approach that also encompasses stigmatization is necessary (Topp et al., 2019).

Stigmatization is considered a social factor since it is related to societal perceptions and the views of others; on the other hand, perceived stigmatization refers to an individual's awareness of negative attitudes and/or practices related to a specific condition; that is, the patient perceives themselves as being stigmatized by their surroundings, shaping their cognition in this direction; and this type of stigma refers to the awareness of stigma (Van Brakel, 2006). These stigmatizing experiences can manifest as overt behaviors (e.g., being excluded or expelled from a place) or more subtle actions (e.g., staring, grimacing, avoiding eye contact) (Van Beugen et al., 2023).

Furthermore**,** *concealable stigmatized identities* (CSI) are those that can be hidden from others but are still socially devalued and subject to negative stereotypes (Quinn & Earnshaw, 2013). People with concealable identities believe that others would react negatively regarding their situation if they knew about it (Quinn & Chaudoir, 2015; Quinn & Earnshaw, 2013). Compared with other visible skin diseases, HS appears to be somewhat concealable, suggesting a CSI, which can be hidden from other people but socially devalued and stereotyped. When HS patient worry that whether pus from their lesions would leak out and leave a stain in their clothes or whether people will notice the bad odour spreading around the air from their lesions, they anticipate a negative reaction and are in need of constantly checking others to see if they realized and they avoid those kind of situations altogether (Quinn & Earnshaw, 2013).

1.2.4.2. Relationships with Close Others

According to the *need to belong theory* proposed by Baumeister and Leary (1995), individuals have an almost universal need to establish and sustain at least some level of interpersonal relationships with others. Belongingness is an inherent trait with an evolutionary foundation, offering clear advantages for survival and reproduction. Belongingness seems to have numerous and significant impacts on emotional patterns and cognitive processes of human beings (Baumeister & Leary, 1995). Consequently, discovering how close relationships, which are so important to individuals, affect HS patients' disease process is crucial for us to more closely examine patients' emotional and cognitive processes. HS patients may experience self and social isolation due to the physical challenges posed by the disease; this, in turn, negatively impacts their familial, romantic relationships, and friendships, and thereby harming their mental health (Perche et al., 2022). Social isolation not only affects individuals' social, work, and family lives but also leads to further withdrawal from social interactions (Philot et al., 2021). Additionally, not being able to go to work or school, along with decreased functionality (such as reduced physical mobility, increased pain and discomfort, and the possibility of sores bursting and bleeding), further prevents individuals from engaging in social environments. The inability to go to work affects one's career life, while avoiding social interactions impacts both social and romantic life; which in turn affects patients mental health negatively (Howells et al., 2021).

HS, being a suppurative condition (a term used to describe a condition where a purulent exudate [pus] is formed and discharged), causes lesions that result in discharge and foul odor, particularly in areas such as the axilla and genitals. This leads to feelings of embarrassment among patients, negatively impacting their interpersonal relationships, public image perception, and self-esteem (Shavit et al., 2015). There is a very limited research in this terms; however, a systematic review found that 71.4% of participants reported HS negatively impacted their relationships (Howells, 2021), with significant deterioration in personal and close relationships (Mac Mahon et al., 2020). As a psychosocial consequence of the disease, patients tend to isolate themselves from others because they feel anxious about going out and interacting with people. They avoid social contact out of embarrassment about their condition (Thorlacius et al., 2019).

In our study, we examined whether patients have disclosed their disease with close others (mother, father, siblings, romantic partner, and fe/male friends). If they have disclosed their diagnosis with those, with three main questions we explored how they perceived this experience, the social support they received as a result, and how their relationships were affected overall. While developing the questions, we drew upon the work of Kirby et al. (2016), particularly the social support section. In this study, the authors explored the extent and manner of patients sharing their condition with their close circles and social support patients received from friends, family members, and others under the category of "supports of others." In our study, we analyzed the responses to questions about patients disclosing their diagnosis and found that perceiving a positive disclosure experience, receiving social support and experiencing positive overall relationships after disclosure are associated with higher scores in the composite analysis. For instance, if a patient discloses their diagnosis with their mother, perceives this experience as positive, receives support, and the overall relationship improves, this is reflected in a high score for "good relationship with mother."

Before proceeding, we want to briefly provide the operational definitions of disclosure and social support. Concealable stigmatized identities refer to identities that can be kept hidden from others but are often subject to social devaluation and negative stereotypes (Quinn & Earnshaw, 2013). For individuals living with such identities, the act of disclosure is a vital part of their experience (Quinn & Earnshaw, 2013). Since HS is a skin condition that can be relatively concealed, we can consider individuals with this disease as having a concealable stigmatized identity. Self-disclosure, which involves sharing personal information with others through verbal communication, is a key element of social interaction. It encompasses the act of revealing something previously unknown or the acknowledgment of a fact that has been kept hidden (Chaudoir & Fisher, 2010).

Social support is understood as either the perception or the actual experience of being loved, cared for, and appreciated by others, while also being part of a social network that provides mutual assistance and responsibilities to enhance well-being (Wills, 1991). Individuals can enhance their coping strategies for stressful events and utilize both psychological and material resources to meet their social needs and achieve their goals, thanks to support from social networks (Rodriguez & Cohen, 1998). Social support encompasses different components, including the amount of support (the size of the network of close individuals one can rely on in difficult life situations), the interest shown by others in everyday life matters, and the degree of that interest. It is important to note that in the literature, the family and friendship relationships of HS patients have not been examined separately and in detail before; although intimate/romantic relationships and sexual lives of the patients had been explored.

1.3. The Relationships between the Components of BPS Model

1.3.1. The Relationship between Biological and Psychological Components

1.3.1.1. Disease Severity and Well-being

Numerous instruments were used to measure the quality of life in HS patients, and research consistently showed that the disease has a significant negative impact on physical, social, and emotional well-being of the patients (Gooderham & Papp, 2015; Wolkenstein et al., 2007).

To illustrate, the results of the study showed that HS patients had lower positive affect and higher negative affect compared to healthy controls. Regardless of the disease severity, the positive and negative affect scores were very similar among the patients, with no statistically significant differences found between the groups (Hurley I-II-III). Researchers interpreted this to mean that even a low level of HS contributes to poor well-being (Senthilnathan et al., 2019).

As a result, we hypothesize that regardless of the disease severity, the positive and negative affect scores will be similar across groups (Hurley I-II-III).

H2: Regardless of the disease severity, the positive and negative affect scores will be similar across groups (Hurley I-II-III).

1.3.1.2. Disease Severity and Illness Cognition

Illness cognition and HS have not been studied together in the literature to our knowledge; thus, our study is the first exploring this relationship. Nonetheless, it was demonstrated that illness cognition affects the way patients perceive and think regarding their disease accounting their differences in their psychological and physical health status as individuals (Evers et al., 2001). Among the three components of illness cognition, helplessness is negatively correlated with acceptance and perceived benefits. Illness cognition studies have been conducted on various chronic diseases and health conditions (Gurková & Soósová, 2018; Nur'aeni & Mirwanti, 2020; Patel et al., 2018), while providing preliminary evidence of its general and long-term impacts on both physical and psychological well-being (Evers et al., 2001). Consequently, considering the relationship between well-being and illness cognition, when examining the relationship between disease severity and illness cognition, we ask a research question as: ‘Will higher disease severity be associated with increased levels of helplessness and lower levels of acceptance and perceived benefits in illness cognition?’.

RQ1: Will higher disease severity be associated with higher levels of helplessness and lower levels of acceptance and perceived benefits in illness cognition?

1.3.2. The Relationship between Biological and Social Components

1.3.2.1. Disease Severity and Perceived Stigmatization

To our knowledge, there are very few studies examining the relationship between disease severity and stigmatization. In a study conducted by Akoğlu and colleagues in 2021 in Türkiye, it was found that disease severity and poor mental health due to HS were predictors of perceived stigmatization. Patients with Hurley Stage III reported perceived stigmatization levels four times higher, and those with Hurley Stage II reported levels five times higher, compared to patients with Hurley Stage I. An earlier study found that individuals felt more stigmatized when lesions were on more visible parts of the body (Matusiak et al., 2010). Contrary to these earlier findings, in a study examining the relationship between perceived stigmatization and HS, patients from South and North America, Europe, Africa, and Asia demonstrated no significant correlation between disease severity and perceived stigmatization (Bouazzi et al., 2021). However, perceived stigmatization was found to be highly prevalent among HS patients, regardless of their geographical origin, indicating that experiencing perceived stigmatization is a global issue for HS patients. As suggested by researchers in the medical field, new prospective and longitudinal studies examining the effects of HS treatments and assessing patients' mental health could benefit from investigating patients' levels of stigma so that treatments can address stigmatization and its effects on patients to enhance treatment outcomes (Akoğlu et al., 2021). By considering these previous findings, we ask a research question as: ‘Will higher disease severity be associated with higher perceived stigmatization?’.

RQ2: Will higher disease severity be associated with higher perceived stigmatization? (Hurley III > Hurley II > Hurley I).

1.3.2.2. Disease Severity and Relationship with Close Others

There is evidence suggesting that as the Hurley stages of HS patients increase, the difficulties experienced by the patients also tend to increase. Studies have shown that higher Hurley stages, which indicate more severe disease, are associated with greater physical discomfort, increased pain, higher levels of psychological distress, and more pronounced social and emotional challenges, such as stigmatization and deterioration in quality of life (Akoğlu et al., 2021; Schultheis et al., 2023); and these conditions further exacerbate the overall disease burden. Due to the increased disease burden from the challenges faced by patients, we anticipate that the psychological distress experienced may exacerbate the impact of the disease on relationships, leading to low scores on good relationships with close others. As far as we are aware, there are no existing studies in literature specifically addressing this topic. Therefore, we have approached this anticipation as a research question.

RQ3: Will lower levels of disease severity be associated with patients' good relationships with close others (disclosure, perceiving the experience as positive, receiving social support, and general relationship quality)?

1.3.3. The Relationship Between Psychological and Social Components

1.3.3.1. Well-Being and Perceived Stigmatization

Dermatology patients experience various negative thoughts and emotions due to their skin conditions and the reactions they receive from society (Lockwood et al., 2023). Looking back in history, we see that people with skin diseases have been heavily stigmatized (Dimitrov & Szepietowski, 2017), likely due to fears associated with the potential for contagion (Butt et al., 2022). The World Health Organization (WHO) has called on governments worldwide to take action to reduce stigma, which imposes an additional burden on people with skin conditions (Michalek et al., 2016). Following Erving Goffman's initial elaboration of the concept, psychological and social psychological research has addressed how stigma operates at the micro level and how it restricts the well-being of stigmatized individuals (Clair, 2018). Moreover, stigmatization is found to be associated with psychological outcomes, including depression, anxiety and suicidal ideation (Germain et al., 2021).

Research conducted by Butt and colleagues (2022) documented the negative impacts of stigma on HS patients' self-esteem, physical and mental health, and academic performance. In the context of HS, the fear that the disease might be contagious is a significant factor contributing to the stigmatization of patients. In a review on stigma associated with visible skin diseases, it was found that 61% of the compiled stigmatization studies focused on psoriasis (Germain et al., 2021). Perceived stigmatization damages psychosocial functioning and lowers quality of life (Dimitrov & Szepietowski, 2017; Wittkowski et al., 2004), and leads to psychological stress, low self-esteem, and feelings of shame (Germain et al., 2021). It also hampers individuals' willingness to seek healthcare, pursue treatment, and adhere to therapy, thereby negatively affecting the overall process (Stangl et al., 2019). Perceived stigmatization was particularly high among psoriasis patients, observed in 70-90% of cases (Van Beugen et al., 2017; Wu & Cohen, 2017). However, information on perceived stigmatization in other skin diseases is very limited (Germain et al., 2021; Topp et al., 2019). There are studies in the literature examining the relationship between perceived stigmatization and well-being in various diseases such as rheumatoid arthritis, fibromyalgia, schizophrenia, and mood and anxiety disorders (Alonso et al., 2008; Tesfaw et al., 2020; Van Alboom et al., 2021). All these studies have found a negative correlational relationship between perceived stigmatization and well-being. However, to our knowledge, no study has directly investigated this relationship in HS patients. For HS patients, since lesions are often located in more concealable and less visible areas of the body (such as the armpits, genital area, etc.), they are more likely to perceive stigmatization as directed towards them rather than experiencing direct stigma (Germain et al., 2021); that is, even if they somehow conceal their disease, they still perceive stigmatization due to their concern of being stigmatized. However, as researchers put it, there is a lack of information in the literature regarding the duration of the disease and its impact on stigmatization and its effects on patients (Germain et al., 2021). Stigmatization affects patients' health outcomes by worsening or hindering various processes, including psychological state and behavioral responses, thereby further deteriorating their health (Hatzenbuehler et al., 2013). Perceived stigma imposes a significant psychosocial burden on patients with skin conditions. Even though research is increasingly diversifying, little is known about the experience of stigma across a broad range of visible skin diseases (Van Beugen et al., 2023). In a study conducted by Van Beugen et al., (2023) with the participation of many researchers across 17 countries, observational cross-sectional research was conducted. The study aimed to quantify perceived stigmatization and identify its predictors among dermatology patients. Patients experienced higher levels of perceived stigmatization compared to the control group. The highest levels of perceived stigmatization were found among patients with psoriasis, atopic dermatitis, and alopecia.

There have been studies regarding different types of stigmatization and its psychological effect on HS patients. For instance, the study by Butt et al., (2022) found that internalized stigma has a negative impact on HS patients' psychopathology and suggested that understanding the effects of internalized stigma could assist healthcare providers and institutions in developing more targeted mental health interventions to alleviate the adverse effects of HS on patients’ psychological well-being (Butt et al., 2022). Unfortunately, to our knowledge, there is no study investigating the relationship between perceived stigmatization and well-being in HS patients. As a result, we believe that investigating the relationship between perceived stigmatization and well-being in HS patients contributes to the literature and addresses the gap in this context. All in all, considering the literature, we hypothesize that higher perceived stigmatization will be associated with decreased well-being.

H3: Higher perceived stigmatization will be associated with low positive affect and high negative affect.

1.3.3.2. Well-Being, Illness Cognition and Relationships with Close Others

When people with concealable stigmatized identities (CSI) are about to disclose their identity for the first time, they especially choose people who can be supportive confidants, mostly these people are close others to the individual (Chaudoir & Quinn, 2010). The fear of stigmatization often leads patients to isolate themselves and avoid discussing their condition, even with their family (Esmann & Jemec, 2011; Zouboulis et al., 2015). Concealed stigmatized identities can adversely affect individuals' mental and physical well-being.

According to research about disclosing a concealed stigmatized identity, it was found that disclosing can have outcomes on the long-term well-being of the individuals (Chaudoir & Quinn, 2010). Positive and supportive reactions as a result of disclosure can have long-term positive psychological benefits. Individuals feel supported and accepted when they make the challenging decision to disclose their CSI to others (Beals et al., 2009). Disclosure can improve long-term well-being and foster feelings of support and acceptance (Beals et al., 2009; Chaudoir & Quinn, 2010). Prior studies suggest that supportive reactions to disclosure are linked to better psychological well-being (Quinn & Earnshaw, 2013). Furthermore, the reactions people with CSIs receive from their close others when they disclose their identities has an immense effect on their self. If the reactions they receive are not positive and supportive in nature, this reaction can be classified as an experienced discrimination (Quinn & Earnshaw, 2013). Consequently, examining whether HS patients disclose their disease with their close others is an important aspect to study.

In our study, we asked the patients whether they have disclosed their diagnosis with their close others (mother, father, siblings, romantic partners, fe/male friends) and examined how this disclosure perception and experience is associated with their well-being and illness cognition.

Social support can buffer against negative health outcomes in individuals with chronic illnesses (Kök-Eren & Demir, 2017). The progression of skin diseases, such as psoriasis and vitiligo, has been found to be associated with social support (Picardi & Pasquini, 2007). Healthy and strong social and close relationships are linked to better health, with social support serving as a protective factor in the connection between close relationships and health (Cacioppo & Hawkley, 2003; Cohen et al., 2000). Conversely, poor social support is correlated with increased skin morbidity (Dalgard et al., 2005). A study by Evers et al. (2005) highlighted the buffering effect of social support, particularly in dermatological patients with atopic dermatitis and psoriasis, showing that psychological distress was more strongly associated with poor social support than with the physical symptoms and clinical status of the patients. Additionally, perceived social support provides individuals with essential emotional and practical resources, making it a crucial component linked to both physical and psychological health and well-being (Nabi et al., 2013). Having a supportive social environment can act as a preventive factor against health problems and enhance mental well-being (Singh et al., 2023).

Considering the literature, it is important to investigate the experience of disclosure and different sources of social support that HS patients receive during the post-diagnosis process. To observe the impact of perceived social support, it is necessary for the disease to be shared with the surrounding environment (Kirby et al., 2016). Kirby et al. (2016) explored the extent and manner of patients regarding disclosing their condition with their close circles and social support patients received from friends, family members, and others under the category of "supports of others." The responses indicated that patients generally found it helpful to share their condition with their close circles, which aided them in overcoming difficult times and elicited positive reactions from those individuals.

In our study, we ask patients whether they disclosed their condition with their close others, how they perceived this disclosure experience, the level of support they receive from them and how their overall relationship is affected. We believe that the support patients receive after sharing their condition influences both their illness cognitions and their emotional state. To our knowledge, there has been no study looking at the disclosure experiences, different sources (familial, social and romantic) of social support and the how the overall relationship is affected in HS patients. Given the impact of strong social support on maintaining healthy and close relationships, as well as on preserving patients' mental health, examining the effects of different relationships separately will allow us to compare how the support received by HS patients influences their overall health processes. To our knowledge, none of the studies divided relationships into familial, social and romantic relationships; as a result, we will be the first study to examine and explore these relationships separately in this manner. By considering all findings from the literature, we hypothesize that:

H4: Having a good (higher scores will be corresponding to a better relationship with close others) relationship with close others (mother, father, siblings, romantic partners, fe/male friends) will be associated with higher well-being, increased perceived benefits, and acceptance as well as decreased helplessness and perceived stigmatization.

Lastly, as part of our research, we aimed to explore certain variables. To do so, we identified the disclosure experience of the participants; i.e., we examined how many individuals disclosed their diagnosis with their mother, father, siblings, romantic partner, and female/male friends, and how many did not. Also, we explored gender differences and the association of having a romantic partner with the variables we are analyzing among HS patients in an exploratory manner. Finally, we explored whether patients without a current romantic partner would disclose their diagnosis to a future partner and asked all patients if they would share their diagnosis with a new friend after having been diagnosed.

1.3.3.3. Romantic and Sexual Relationships

Having HS negatively influences patients' romantic relationships, especially single patients' (Esmann & Jemec, 2011). When examining the relationships of HS patients, we believe it is important to specifically shed light on the sexual experiences of HS patients who are sexually active with their romantic partners.

As for the sexual life of the patients, since they experience pain during sexual intercourse, they feel embarrassed and their sexual functioning is inhibited (Thorlacius et al., 2019). Also, the presence of negative psychological factors (e.g., depression, anxiety, poor mental state) has been shown to increase the risk of sexual dysfunction in patients (Quinto et al., 2021). As shown in one study, up to 66.7% of patients reported difficulties in their sexual lives; this is three times higher than the average of those suffering from other dermatoses (Sampogna et al., 2017). In addition to sexual dysfunction, patients with HS mostly reported their lack of partner intimacy and in some cases, sexual assault (Janse et al., 2017; Sisic et al., 2017). After their flare-ups, their lesions turn into scars, leaving substantial psychological distress and pain on patients’ shoulders (Keary et al., 2019). According to the study by Keary et al., (2019) HS patients felt invalidated when their partners seemed not to understand their pain and its severity, and those patients employed two different coping mechanisms regarding this situation. The adaptive defense strategy was social support while the maladaptive one was social withdrawal. The reason for the social withdrawal included the thought of others disgusted by their wounds and the fear of being judged. Those patients were reluctant to show their body to their expected partners due to the reasons mentioned and additionally the fear of being rejected. In a study by Thompson and colleagues (2022) aimed at understanding disturbances in patients' romantic relationships, researchers used an electronic survey to delve into the depths of patients' sexual relationships. Among the 873 patients surveyed, 60.9% reported that their relationships were affected due to HS discomfort, with 49.1% of these patients specifically noting issues related to sexual intercourse with their partners. Researchers concluded that patients' sexual lives and their ability to find a partner were impacted by HS, primarily affecting their general relationships. Patients expressed several concerns: they were scared about their partners seeing their lesions and wounds, feared that their partners might think HS is contagious, experienced pain during sexual intercourse, and were particularly scared about the odor and bloody drainage. One of the study's key findings was that as patients' Hurley stage increased, their discomfort also rose. The highest levels of discomfort in terms of sexual intercourse and finding a partner were reported by patients at Hurley Stage III. Female patients experienced more discomfort compared to male patients. When analyzed by age, patients under 30 reported that HS affected their ability to find a partner more than those over 30, while patients over 30 noted that their sexual relationships were more affected compared to those under 30. Regarding discussing their disease with their partners, Hurley Stage III patients, female patients, and patients under 30 were more reluctant to discuss their disease compared to Hurley Stage I-II patients, male patients, and patients over 30, respectively (Thompson et al., 2022). Researchers concluded that the difficulty in sharing their HS with others, including partners, stems from the fear of stigmatization and a lack of knowledge about the disease. Previous studies have shown that, compared to healthy controls, HS patients feel less acceptable as sexual partners, have less enjoyable sexual lives, and experience lower levels of sexual health (Andersen et al., 2020; Janse et al., 2017). In a very recent study, Krajewski et al., (2024) found that Hurley stage III and female patients had more sexual dysfunction, and this dysfunction was related to number of active lesions, psychosocial aspects such as stigmatization and depression. 71.4% of participants indicated that HS negatively impacted their relationships. Single female patients experienced a heightened fear of rejection and were more hesitant to meet new people due to their condition.

Furthermore, 94.3% of female patients and 80.8% of male patients believed that HS adversely affected their chances of forming relationships or engaging in sexual activities (Cuenca-Barrales & Molina-Leyva, 2020). Considering the results found in the literature, we hypothesize that patients' sexual lives will be negatively affected after diagnosis.

H5: Patients will perceive their sexual lives to be negatively affected after diagnosis.

1.3.4. Contribution to the Literature

This current exploratory study aims to focus on the post-diagnosis experiences of individuals diagnosed with HS in Türkiye. In this context, we aimed to examine the psychosocial effects of HS on patients. Specifically, within the framework of the Biopsychosocial model, we examined the relationships among the biological (disease severity), psychological (well-being and illness cognition), and social (perceived stigmatization and relationships with close others, including mother, father, siblings, romantic partners, and female/male friends) components.

Since HS has not been previously examined within a Biopsychosocial framework, we used this model to explore patients' post-diagnosis experiences by considering biological, psychological, and sociological factors; our focus was on the relationships between these factors. Despite HS having been a recognized condition within the medical community for the last decades and the subject of ongoing research, the impact of disease on relationships has only been studied qualitatively. For instance, in a 2016 study by Kirby et al., researchers asked patients, "How does your HS get in the way of relationships with other people?" and then qualitatively interpreted the responses. In our study, we use a form we have developed to gather this information and subject it to quantitative analysis, thereby contributing to the literature. Additionally, we examine relationships with close others in a comprehensive manner, focusing on relationships with parents, partners, and friends separately; also exploring these relationships’ connections with other variables; which had not been done in previous studies. This study aims to deeply investigate and shed light on the experiences of patients going through these processes and provides data that enables discussion on how support/intervention programs can be developed to facilitate their disease journeys. Additionally, since there is a lack of studies examining HS in conjunction with psychosocial variables especially relationship vise in the literature, this study contributes to filling this gap in the literature. Gaining insights into the experiences of HS can highlight potential areas for future research and pinpoint aspects of clinical care that need enhancement in this regard. Also, qualitative and quantitative research can yield new insights that surpass the findings of individual studies. Taking these facts into consideration, we aimed to conduct a comprehensive descriptive and quantitative study that could guide future research. Our study can be considered the first quantitative-correlational study in Türkiye that focuses on the experiences of HS patients while integrating the fields of social psychology and health psychology. Through the data obtained from the study, we gained a more detailed understanding of bio-psycho-social aspects of the HS on patients; thus, our theoretical knowledge increased in terms of developing and offering more suitable psychological treatment methods to patients.

In addition to the main study variables, we examined the percentages of delayed and misdiagnosis, the age of diagnosis, the duration of the diagnosis, the distribution of patients across Hurley stages, the elementary and extended family history of the disease, the types and prevalence of comorbid conditions, and the treatment durations and options that patients are currently undergoing. Besides, we questioned the patients' initiation of a relationship in terms of romantic partners and friendships as well.

Furthermore, we investigate the differences in the main study variables based on gender and the presence or absence of a romantic partner. In Türkiye, the variables of gender and having a romantic partner in HS patients have not been previously examined in relation to the variables we are considering. Therefore, as part of our research questions, we explore gender differences and the association of having a romantic partner with the variables we are analyzing among HS patients in an exploratory manner.

All in all, considering the literature, the significance of current study lies in its consideration of psychological and social effects HS might have on patients. Although there have been individual studies conducted in this area within the literature, to our knowledge, there is no study that collectively examines patients' well-being, illness cognitions (helplessness, acceptance, perceived benefits), perceived stigmatization, and relationships with their close others (mother, father, siblings, romantic partner, fe/male friends) separately, while also investigating how these variables change according to the severity of their disease. The aim of this study is to collectively examine the aforementioned variables and assess how each individually associates with the patients' experiences. By doing so, we aim to shed light on future research focused on the processes of individuals with various chronic and visible skin conditions, with a particular emphasis on HS.

CHAPTER 2

METHOD

2.1. Participants

Participants consisted of male and female individuals over the age of 17 who were diagnosed with "Hidradenitis Suppurativa (L73.2)" according to the International Classification of Diseases-11 (ICD), the international coding and classification standard for diseases and health problems (World Health Organization, 2022), as followed by the Ministry of Health of the Republic of Türkiye. Individuals were required to meet specific criteria to participate in the study; including being a native speaker of Turkish and providing their diagnosis through E-Nabız, the personal health record system served to citizens by the Ministry of Health. A total of 70 HS patients (M_{age} =34.14, SD=9.67, the age ranges from 17 to 61) were recruited through snowball and convenience sampling methods. Some participants were reached through social media platforms, including Instagram, Facebook, WhatsApp, and LinkedIn; while others were reached in the dermatology clinic of Selcuk University Faculty of Medicine, Konya.

A total of 55 participants completed the questionnaire online, while the remaining 15 filled out the paper-and-pencil version of the same questionnaire. There were 50 male, 18 female, 1 non-binary patient, and 1 patient who did not prefer to report gender. Participants were provided with an informed consent form outlining the purpose and nature of the study and given the right to participate in a draw organized by the researcher following the study. The draw was designed to randomly distribute 4000 Turkish Liras (₺) among 10 participants. It was conducted after the study, and each winning participant received a 400 ₺ worth grocery voucher.

2.2. Measures

The scales used in the research are as follows: Demographic Information Form, Positive and Negative Affect Schedule, Illness Cognition Questionnaire, Perceived Stigmatization Scale, and Assessment Form for the Impact of Receiving a Diagnosis of Hidradenitis Suppurativa (HS) on the Relationship with Close Others.

2.2.1. The Demographic Information Form

The Demographic Information Form was created by the researcher to obtain participants' demographic and general disease process information; containing 16 questions. The questions included were regarding age, gender, socio-economic status (SES), marital status, education, the age at which patients were diagnosed, the duration of the disease, the severity of the condition, the patient’s family medical history, other chronic conditions (comorbidities), treatments received or undergone, the length of time under treatment, and whether a misdiagnosis occurred or not.

2.2.2. The Positive and Negative Affect Schedule

The Positive and Negative Affect Schedule measures the emotional component of well-being. In this scale, participants report the extent to which they have experienced the feelings listed in the scale over the past four weeks; the scale consists of 12 items. Participants evaluate each item on a 5-point Likert Scale, ranging from never/very rarely (1) to very often/always (5). The original scale was developed by Diener et al. (2009) and translated into Turkish by Korkmaz (2016).

The average of six items was computed for positive affect and another average of six items was computed for negative affect. Consequently, the internal consistency coefficient for the sample from Türkiye was found to be .87 for positive affect and .78 for negative affect.

2.2.3. The Illness Cognition Questionnaire

The Illness Cognition Questionnaire was developed by Evers et al. (2001) to assess three basic cognitions, which are acceptance, helplessness and perceived benefits, seen in different chronic diseases. The questionnaire has 3 sub-scales: helplessness, acceptance, and perceived benefits. Helplessness highlights the negative aspects and aversive meaning of the disease, acceptance reduces this aversive meaning, and perceived benefits add a positive perspective to the disease. It consists of a total of 18 questions, 6 questions for each subscale.

The internal consistency coefficients of helplessness, acceptance and perceived benefits subscales for the sample of Rheumatoid Arthritis (RA) patients are: .88, .90, .84; for the sample of and Multiple Sclerosis (MS) patients are: .88, .91 and .85 (Evers et al., 2001); for the sample of psoriasis patients are: .88, .88, and .80 and for the sample of atopic dermatitis patients are: .88, .93 and .85 (Evers et al., 2007). The participants evaluate each item on a 4-point Likert scale, ranging from “not at all (1) to totally (4). The original scale was translated into Turkish by Aykul (2018). For the Turkish version of the questionnaire, the internal consistency coefficients were found to be .92 for the helplessness subscale, .86 for the acceptance subscale, and .89 for the perceived benefits subscale (Aykul, 2018).

2.2.4. The Perceived Stigmatization Scale

The Perceived Stigma Scale is a subscale of the Multidimensional Health Status Inventory developed by Evers et al. (2007) for chronic skin conditions (Impact of Skin Disease on Daily Life, ISDL). ISDL evaluates the effects of chronic skin diseases on health across a wide range, including the general and skin-specific aspects of quality of life related to the disease. The Perceived Stigma Subscale, used in this study, was designed to measure to what extent the patient feels stigmatized by others due to their skin condition, consisting of 6 questions. Participants evaluate each item on a 4-point Likert-type scale ranging from “not at all (1)” to “totally (4)”. The total score of the scale ranges from 6 to 24 (Evers et al., 2007).

The internal consistency of the scale was found to be .88 for psoriasis patients and .84 for atopic dermatitis patients. The mentioned 6-item subscale has been translated and adapted into Turkish by Akoğlu et al. (2021). The original scale was developed for visible skin disorders (such as psoriasis, eczema, acne, etc.).

HS may not be visible to everyone and can easily be hidden by the patient; therefore, the item based on the assumption that the disease is visible has been removed in the current study from the sub-scale (‘I have the feeling that other people stare at my skin disease.)’, and due to the possibility that the disease can be relatively concealed by the patient and thus remain invisible to others, adjustments were made to other items in the subscale to ensure their relevance without altering their meaning. For example, the statement ‘People find me unattractive because of my skin condition’ has been revised to ‘*I think* people find me unattractive because of my skin condition.’ As for the Turkish version of the scale, implemented on HS patients, Cronbach's alpha was found to be .88, indicating a high internal consistency.

2.2.5. The Assessment Form for the Impact of Receiving a Diagnosis of Hidradenitis Suppurativa (HS) on the Relationship with Close Others

The Assessment Form for the Impact of Receiving a Diagnosis of Hidradenitis Suppurativa (HS) on the Relationship with Close Others was developed by the researcher and examines relationships of HS patients with close others by dividing them into 3 groups: family (mother, father, siblings), romantic partner, and friendships (female and male friends). The form starts with whether patients disclosed their disease with these groups, and if so, we ask three main questions to assess how the experience of was disclosing for them, how their relationships have been affected overall after receiving a diagnosis of the disease, and the extent to which they receive social support from these groups. These questions were as follows: ‘How was your experience disclosing your HS diagnosis with X (mother, father, partner, etc.) ?’, ‘How would you evaluate X's support after disclosing your HS diagnosis?’, and ‘Overall, how has receiving an HS diagnosis affected your relationship with X?’. There are two questions to evaluate the initiation of a relationship in terms of romantic partners and friendships; which were as ‘How has receiving an HS diagnosis affected your potential attempts to establish romantic relationships/friendships?’. Also, since the patients’ sexual lives are generally affected, one question is designed on how much their sexual life is affected. Since the questions inquire about how these experiences were generally for the patients, the questions assess patients' experiences using a 9-point Likert scale, ranging from "very negative (1)" to "very positive (9).

2.3. Procedure

Prior to the research commencement, required ethical approval was obtained from the Middle East Technical University Human Subjects Ethics Committee. In addition, further ethical approval was obtained from the Selcuk University Clinical Research Ethics Committee to administer the scales to patients attending the dermatology clinic at Selcuk University Faculty of Medicine. During the data collection process, the confidentiality and anonymity of the participants were assured by the researcher. Informed consent about the purpose and the nature of the study was given at the beginning of the questionnaire and the participants who accepted it completed the questionnaire. The questionnaire was both in online and paper-pencil form. The online version was created on Microsoft Forms and distributed through various social media platforms, including Instagram, Facebook, WhatsApp, and LinkedIn. Especially in Facebook and WhatsApp platforms, a significant number of responses were obtained from groups established by patients and referred to as the "HS Solidarity Platform." Apart from that, the paper-pencil version of the questionnaire was conducted on patients who came to the hospital for a check-up at the dermatology clinic at Selçuk University Faculty of Medicine.

The whole questionnaire was composed of 5 scales, which are Demographic Information Form, Perceived Stigma Scale, Positive and Negative Affect Schedule, Illness Cognition Questionnaire, and Assessment Form for the Impact of Receiving a Diagnosis of Hidradenitis Suppurativa (HS) on the Relationship with Close Others. The completion of the whole questionnaire took approximately 10 minutes. At the end of the survey, all participants were assured that they could reach the researcher via e-mail if they had any questions or if they were wondering about the results of the study.

CHAPTER 3

RESULTS

Firstly, we analyzed descriptive statistics for demographics and the main study variables. Then, we examined the clinical presentation of the HS including diagnosis, disease severity, family history, comorbidities and treatments. After that, we ran the reliability analyses of the scales we used in the current study. As an exploratory analysis, we explored how many patients disclosed their diagnosis with their close others. Later, we conducted the independent samples t-test in order to see if females and males differ on the main study variables and to see whether people with romantic partners differ from those who do not have romantic partners. Also, we shared the results of our exploratory analysis regarding future relationship initiation for romantic partners and friendships. Later, we shared the results of the questions we asked patients about whether they would disclose their diagnosis to a future romantic partner or friend. To see the group changes regarding disease severity (Hurley I-II-III; biological component) on study's psychological (well-being and illness cognition) and social (perceived stigmatization and relationship with close others) components, we first checked whether we could meet the assumptions of ANOVA and examined the normality and homogeneity assumptions. Since we were able to meet those criteria after checking desirable levels of skewness and kurtosis and homogeneity; we ran five ANOVA tests separately. After that, to explore how the sexual lives of patients in our study were affected, we conducted a one-sample t-test with those who reported having a sexual partner. Lastly, we conducted a correlation analysis among the study’s psychological and social variables to see their associations. The results of these analyses are detailed in the subsequent sections of this paper.

3.1. Descriptive Statistics for the Demographics and the Main Study Variables

Descriptive statistics for the demographics are presented in Table 1. Seventy participants indicated their age ranges between 17 and 61 (*M* = 34.14, *SD*= 9.67). The majority of the participants were male patients (*n* = 50), followed by females (*n* =18), one participant did not identify within a binary gender system. Additionally, one participant chose not to answer the question.

As for the income level, most participants stated that to be belonged to the middle class (*n* = 31), followed by upper-middle class (*n* = 17), lower-middle class (*n* = 10), lower class (*n* = 7) and upper class (*n* = 3). Two participants did not prefer to answer the question. Very few participants identified themselves as students.

Among the student participants, 4 were in high school, 2 were in associate degree programs, 4 were in bachelor's degree programs, and 1 was pursuing a master's degree. The remaining participants reported the highest level of education they had completed: primary school graduate (*n* = 3), middle school graduate (*n* = 2), high school graduate (*n* = 22), associate degree graduate (*n* = 14), university graduate (*n* = 15), master's degree graduate (*n* = 4).

Regarding marital status, 37 participants reported being married, 19 were single, 7 were in a relationship, 5 were divorced, and 2 were widowed. All presented information is provided in Table 1; for details, please refer to the table.

Table 1. *Descriptive Statistics for the Demographics*

Variables	*N*	*%*	*M*	*SD*	*Min-Max*
Age	70		34	9.67	17-61
Gender	70				
Female	18	25.7			
Male	50	71.4			
Non-binary	1	1.4			
Prefer not to answer	1	1.4			
Socio-economic Status (SES)	70				
Lower-class	7	10			
Lower-middle class	10	14.3			
Middle class	31	44.3			
Upper-middle class	17	24.3			
Upper class	3	4.3			
Prefer not to answer	2	2.9			
Studentship Status	11				
High school student	4	5.7			
Associate degree student	2	2.9			
Undergraduate student	4	5.7			
Master's student	1	1.4			
Graduation Status	59				
Primary school graduate	3	4.3			
Middle school graduate	2	2.9			
High school graduate	22	31.4			
Associate degree graduate	13	18.6			
University graduate	15	21.4			
Master's degree graduate	4	5.7			
Marital Status	70				
Single	19	27.1			
In a relationship	7	10			
Married	37	52.9			
Divorced	5	7.1			
Widowed	2	2.9			

Descriptive statistics were calculated for the primary study variables. The mean, standard deviation, and range of scores for these variables are provided as part of the descriptive overview. The range of scores were from 1 to 5 for affect variables, 6 to 24 for illness cognition, 5 to 20 for perceived stigmatization, and 1 to 9 for relationship with close others variables. (see Table 2).

Table 2. *Descriptive Statistics for the Main Study Variables*

Variables	*N*	*M*	*SD*	*Min-Max*
Positive Affect	70	2.37	1.03	1-5
Negative Affect	70	3.20	.97	1-5
Helplessness	70	17.60	4.74	6-24
Acceptance	70	13.53	3.73	6-24
Perceived Benefits	70	12.61	4.42	6-24
Perceived Stigmatization	70	12.54	4.84	5-20
Relationship with Mother	64	6.75	1.86	1-9
Relationship with Father	55	6.38	2.06	1-9
Relationship with Siblings	62	6.30	2.08	1-9
Relationship with Partner	40	6.08	1.90	1-9
Relationship with Female Friends	70	5.02	2.39	1-9
Relationship with Male Friends	70	5.32	2.19	1-9

3.2. Descriptive Statistics for the Clinical Presentation: Diagnosis, Disease Severity, Family History, Comorbidities, and Treatments

71 participants started to scale; however, 1 of them did not provide informed consent. Consequently, 70 participants completed the scales. Since all the questions were required to be answered to move forward, there were no missing values.

Firstly, the diagnosis age for the participants ranged from 12 to 42, showing an average of 23.9 years of age. The duration of time they have lived with the HS diagnosis ranges from 1 to 30 years, with a mean of 10 years. Furthermore, 68.6% of the participants (*n* = 48) reported experiencing prolonged processes due to misdiagnosis or delayed diagnosis. Regarding the severity of the disease among patients, it was found that 13 patients were diagnosed by their doctors with Hurley stage I, 26 patients with Hurley stage II, and 31 patients with Hurley stage III. Additionally, the majority of patients reported that HS was not present in their elementary family (*n* = 60). In terms of extended family, only 13 patients reported that their relatives also have HS.

When examining the chronic comorbidities of patients, 26 out of 70 patients reported having other chronic conditions in addition to HS.

Table 3. *Descriptive Statistics for the Clinical Presentation: Diagnosis, Disease Severity and Family History*

Variables	*N*	*%*	*M*	*SD*	*Min-Max*
Diagnosis Age	70		23	7.29	12-42
Diagnosis Year	70		10	6.41	1-30
Mis and/or Delayed Diagnosis					
Yes	48	68.6			
No	22	31.4			
Disease Severity	70				
Hurley I	13	18.6			
Hurley II	26	37.1			
Hurley III	31	44.3			
Elementary Family History					
Yes	10	14.3			
No	60	85.7			
Extended Family History					
Yes	13	18.6			
No	57	81.4			

Among the patients, 15 reported having diabetes, 5 had obesity, 5 had hypertension, 3 had Hepatitis B, 2 had Familial Mediterranean Fever (FMF), and 2 had cancer. In addition to these conditions, epilepsy, vitiligo, asthma, sleep apnea, migraine, gout, and high cholesterol were also reported, though less frequently (see Table 4).

When asked about their treatment histories, only half of the patients (*n*=35) indicated that they had received treatment.

The duration of treatment ranged from less than one year to up to 20 years. The majority of patients undergoing treatment had been in treatment for 1-5 years, followed by those who had been in treatment for 6-10 years.

Patients reported undergoing various treatments, with some receiving multiple treatment methods concurrently. The treatments were reported as follows: biologic agents, antibiotics, excisional surgery, cortisol injections, laser surgery, ozone therapy, wound cleansing, painkillers and stem cell therapy respectively (see Table 4).

Table 4. *Descriptive Statistics for the Clinical Presentation: Comorbidities and Treatments*

Variables	*N*	*%*
Comorbidities		
No	44	53.0
Diabetes	15	18.1
Obesity	5	6.0
Hypertension	5	6.0
Hepatitis B	3	3.6
Cancer	2	2.4
FMF	2	2.4
Epilepsy	1	1.2
Vitiligo	1	1.2
Asthma	1	1.2
Sleep Apnea	1	1.2
Migraine	1	1.2
Gout	1	1.2
Cholesterol	1	1.2
Years of Treatment	35	
Less than a year	3	4.3
1-5 years	17	24.3
6-10 years	10	14.3
11-15 years	2	2.9
16-20 years	3	4.3
20+ years	0	0
Missing	35	
Treatments		
Biologic Agents	23	32.9
Antibiotics	21	30.0
Excisional Surgery	8	11.4
Cortisol Injection	6	8.6
Laser Surgery	5	7.1
Ozone Therapy	3	4.3
Wound Cleansing	2	2.9
Painkiller	1	1.4
Stem Cell Therapy	1	1.4

3.3. Internal Consistency Reliability Analyses for the Variables of the Current Study

Reliability analyses were conducted to assess the internal consistency of the scales used in the current study. Since one item was removed from the Perceived Stigmatization Scale, a reliability analysis was performed on the remaining five items. The internal consistency coefficient yielded a Cronbach's Alpha of .91, which is considered a very good level of reliability (Tabachnick & Fidell, 2013). For the other scales, the internal consistency reliability was found to be .78 for the Positive and

Negative Affect Schedule and .73 for the Illness Cognition Questionnaire, both of which also correspond to very good levels of reliability (Tabachnick & Fidell, 2013). Lastly, in the form titled "The Assessment Form for the Impact of Receiving a Diagnosis of Hidradenitis Suppurativa (HS) on the Relationship with Close Others", there were three common questions addressed to romantic partners, mothers, fathers, siblings, female friends, and male friends of the patients. These questions examined individuals' experiences of disclosing/sharing their diagnosis with these people, the support they received from them post-disclosure, and the overall impact on their relationships. By consolidating these three questions under the heading "relationships with close others" we derived composite scores. Additionally, we evaluated the internal consistency of these three items and found .62 for mother, .77 for father, .81 for siblings, .86 for romantic partners, .90 for female friends and .96 for male friends.

3.4. Exploratory Analysis for Disclosure with Close Others

We conducted crosstab analysis to examine the numbers of patients who had disclosed their diagnosis with their close others.

Table 5. *Disclosure with Close Others*

	Disclosure	*N*	*Percent*	*Valid Percent*	*Cumulative Percent*
Mother	Yes	62	88.6	96.9	96.9
	No	2	2.9	3.1	100
	Missing	6			
Father	Yes	52	74.3	94.5	94.5
	No	3	4.3	5.5	100
	Missing	15			
Siblings	Yes	58	82.9	93.5	93.5
	No	4	5.7	6.5	100
	Missing	8			
Romantic Partner	Yes	39	55.7	97.5	97.5
	No	1	1.4	2.5	100
	Missing	30			
Female Friends	Yes	49	70	70	70
	No	21	30	30	100
Male Friends	Yes	50	71.4	71.4	71.4
	No	20	28.6	28.6	100

Thanks to the sufficient number of patients who disclosed their experiences, we were able to conduct relationship-specific analyses. We found that almost all of the patients disclosed it with family members (mother, father, and siblings) and romantic partners. Approximately 70% shared their diagnosis with female and male friends (see Table 5).

3.5. Exploratory Analyses for Gender Differences and Having a Romantic Partner

We conducted an independent samples t-test to examine gender differences in the variables we considered.

Table 6. *Independent Samples t-test for Gender Difference across Study Variables*

Gender		*N*	*M*	*SD*	*SE*	*t*	*Sig. (2-tailed)*
Positive Affect	Female	18	2.73	1.17	.28	1.627	.109
	Male	50	2.28	.96	.14	1.476	
Negative Affect	Female	18	3.38	.93	.22	.770	.444
	Male	50	3.18	.97	.14	.787	
Helplessness	Female	18	17.39	4.53	1.07	-.356	.723
	Male	50	17.84	4.62	.65	-.360	
Acceptance	Female	18	13.56	3.84	.90	-.143	.887
	Male	50	13.70	3.63	.51	-.139	
Perceived Benefits	Female	18	12.83	4.31	1.01	.061	.952
	Male	50	12.76	4.44	.63	.061	
Perceived Stigmatization	Female	18	13.44	5.41	1.28	.882	.381
	Male	50	12.28	4.57	.65	.814	
Relationship with Mother	Female	16	7.25	1.68	.42	1.221	.227
	Male	47	6.59	1.93	.28	1.308	
Relationship with Father	Female	13	6.43	2.19	.61	.117	.907
	Male	41	6.36	2.07	.32	.114	
Relationship with Siblings	Female	17	6.10	2.36	.57	-.467	.642
	Male	44	6.38	2.00	.30	-.434	
Relationship with Partner	Female	11	6.79	1.47	.44	1.190	.242
	Male	27	6.02	1.90	.37	1.327	
Relationship with Female Friends	Female	18	4.96	2.62	.62	-.248	.805
	Male	50	5.13	2.31	.33	-.234	
Relationship with Male Friends	Female	18	5.17	2.46	.58	-.576	.567
	Male	50	5.51	2.03	.29	-.526	

Note: Abbreviations standing for as follows: Number of participants = N; Mean = M; Standard Deviation = SD; Standard Error of Mean = SE; Student t = t; Sig. (2-tailed) = Significance level at 95%.

As can be seen in Table 6, there has been no statistically significant difference between female and male patients in any variables considered. Specifically, there is no significant difference between female and male patients in terms of perceived stigmatization levels *t*(66) = .882, *p* = .381; helplessness , *t*(66) = -.356, *p* = .723; acceptance, *t*(66) = -.143, *p* = .887; perceived benefits, *t*(66) = .061, *p* = .952; positive affect, *t*(66) = 1.627, *p* = .109; negative affect, *t*(66) = .770, *p* = .444; relationship with mother, *t*(61) = 1.221, *p* = .227; relationship with father, *t*(52) = .117, *p* = .907; relationship with siblings, *t*(59) = -.467, *p* = .642; relationship with romantic partner, *t*(36) = 1.190, *p* = .242; relationship with female friends, *t*(66) = -.248, *p* = .805; and lastly, relationship with male friends, *t*(66) = -.576, *p* = .567 (see Table 6).

We conducted an independent samples t-test to examine whether there were differences in the variables between those with a romantic partner and those without.

Table 7. *Independent Samples t-test for Romantic Partner Difference across Study Variables*

Romantic Partner		*N*	*M*	*SD*	*SE*	*Sig. (2-tailed)*
Positive Affect	Yes	40	2.60	1.03	.16	.034
	No	30	2.07	.96	.17	
Negative Affect	Yes	40	3.00	.99	.16	.044
	No	30	3.47	.92	.17	
Helplessness	Yes	40	17.00	4.96	.78	.224
	No	30	18.40	4.38	.80	
Acceptance	Yes	40	13.20	3.67	.58	.398
	No	30	13.97	3.81	.70	
Perceived Benefits	Yes	40	12.08	3.83	.60	.241
	No	30	13.33	5.09	.93	
Perceived Stigmatization	Yes	40	12.25	4.78	.76	.563
	No	30	12.93	4.98	.91	

Note: Abbreviations standing for as follows: Number of participants = N; Mean = M; Standard Deviation = SD; Standard Error of Mean = SE; Student t = t; Sig. (2-tailed) = Significance level at 95%.

As can be seen in Table 7, there has been no statistically significant difference between patients who have a romantic partner and patients without a romantic partner in all of the study variables, except for positive and negative affect.

Patients with romantic partners were found to have statistically significantly higher positive affect and lower negative affect compared to those without romantic partners. Specifically, there is no significant difference in terms of perceived stigmatization levels, *t*(68) = -.582, *p* = .563; helplessness, *t*(68) = -1.228, *p* = .224; acceptance, *t*(68) = -.850, *p* = .398; perceived benefits, *t*(68) = -1.182 (see Table 7).

3.6. Exploratory Analyses for Future Relationship Initiation

When we asked patients who currently do not have a romantic partner (*n* = 30) if they would initiate a future romantic relationship, the majority indicated they would (*n* = 25), while the remaining (*n* = 5) indicated they would not. Additionally, when asked if they would initiate a new friendship after they had already had their diagnosis, more than half of the patients (*n* = 42) responded that they would, while the rest (*n* = 27) said they would not, and one patient indicated s/he did not prefer to answer. It is important to consider that some of these patients have been diagnosed for a very long time when interpreting and understanding these results. Finally, since almost all patients (with 1 or 2 missing) disclosed their diagnosis with their close circles including their mothers, fathers, siblings, romantic partners and fe/male friends, we did not feel the need to conduct additional analysis on this matter because our group sizes were not suitable for such analysis.

3.7. The Main Analyses for the Study Variables

3.7.1. The Relationship between Biological and Psychological Components

In total, 4 one-way tests were conducted to compare the effect of disease severity (Hurley Stages) on well-being, illness cognition, perceived stigmatization and relationship with close others. To do so, we checked the normality and homogeneity of variance assumptions to conduct ANOVA tests. Since the variables' skewness and kurtosis values fell between -1.5 and +1.5, it was legitimate to assume that they were normally distributed (Tabachnick & Fidell, 2013) (see Table 8).

Table 8. *Normality Assumption Check*

	Skewness	*Kurtosis*
Positive Affect	.612	-.282
Negative Affect	-.057	-.463
Helplessness	-.453	-.481
Acceptance	.139	-.188
Perceived Benefits	.863	.242
Perceived Stigmatization	.146	-1.195
Relationship with Mother	-.462	.021
Relationship with Father	-.479	-.043
Relationship with Siblings	-.352	-.121
Relationship with Partner	-.476	-.040
Relationship with Female Friends	-.026	-.545
Relationship with Male Friends	-.023	-.099

Table 9. *Test of Homogeneity of Variances*

	Levene Statistic	*df1*	*df2*	*Sig.*
Positive Affect	1.097	2	67	.340
Negative Affect	.035	2	67	.966
Helplessness	.431	2	67	.651
Acceptance	.596	2	67	.554
Perceived Benefits	.089	2	67	.915
Perceived Stigmatization	1.449	2	67	.242
Relationship with Mother	2.010	2	61	.143
Relationship with Father	.004	2	52	.996
Relationship with Siblings	2.391	2	59	.100
Relationship with Partner	.546	2	37	.584
Relationship with Female Friends	.031	2	67	.970
Relationship with Male Friends	.657	2	67	.522

According to the homogeneity assumption, Levene's test was not significant for any of the variables, indicating that the assumption of homogeneity of variances was met for all variables meaning that the spread or variability of the data points should be similar across all groups or levels of an independent variable (see Table 9). Here are the results of the ANOVA tests:

3.7.1.1. Disease Severity and Well-Being

Firstly, a one-way ANOVA was conducted to determine the effect of disease severity (Hurley I-II-III) on well-being of the HS patients. The results indicated a non-significant effect for positive affect, *F*(2, 67) = .001, *p* = .999; and negative affect, *F*(2, 67) = .399, *p* = .672 (see Table 10). Consequently, HS patients experience similar levels of positive affect and negative affect, in lieu of overall well-being, regardless of the severity of their disease (see Table 10).

Table 10. *ANOVA for Well-Being Across Different Levels of Disease Severity*

		N	*M*	*SD*	*SE*	*F*	*Sig.*
Positive Affect	Hurley I	13	2.36	.78	.22	.001	.999
	Hurley II	26	2.38	1.01	.20		
	Hurley III	31	2.37	1.15	.21		
	Total	70	2.37	1.03	.12		
Negative Affect	Hurley I	13	3.36	.93	.26	.399	.672
	Hurley II	26	3.24	1.01	.20		
	Hurley III	31	3.09	1.00	.18		
	Total	70	3.20	.98	.11		

Note: Abbreviations standing for as follows: Number of participants = N; Mean = M; Standard Deviation = SD; Standard Error of Mean = SE; F = Fisher's F ratio; Sig.= Significance level at 95%.

3.7.1.2. Disease Severity and Illness Cognition

Secondly, a one-way ANOVA was conducted to determine the effect of disease severity (Hurley I-II-III) on illness cognition of the HS patients. The results indicated a non-significant effect for all three subscales of illness cognition in terms of disease severity levels; rather helplessness, *F*(2, 67) = .189, *p* = .829; acceptance, *F*(2, 67) = .249, *p* = .780, and perceived benefits, *F*(2, 67) = .999, *p* = .374 (see Table 11.). As a result, HS patients experience similar levels of helplessness, acceptance, and perceived benefits regardless of the severity of their disease.

Table 11. *ANOVA for Illness Cognition Across Different Levels of Disease Severity*

		N	*M*	*SD*	*SE*	*F*	*Sig.*
Helplessness	Hurley I	13	17.54	5.30	1.47	.189	.829
	Hurley II	26	18.04	4.77	.94		
	Hurley III	31	17.26	4.60	.83		
	Total	70	17.60	4.74	.57		
Acceptance	Hurley I	13	13.77	3.40	.94	.249	.780
	Hurley II	26	13.12	4.06	.80		
	Hurley III	31	13.77	3.65	.66		
	Total	70	13.53	3.73	.45		
Perceived Benefits	Hurley I	13	12.00	4.04	1.12	.999	.374
	Hurley II	26	11.92	4.55	.90		
	Hurley III	31	13.45	4.46	.80		
	Total	70	12.61	4.42	.53		

Note: Abbreviations standing for as follows: Number of participants = N; Mean = M; Standard Deviation = SD; Standard Error of Mean = SE; F = Fisher's F ratio; Sig.= Significance level at 95%.

3.7.2. The Relationship between Biological and Social Components

3.7.2.1. Disease Severity and Perceived Stigmatization

A one-way ANOVA was conducted to determine the effect of disease severity (Hurley I-II-III) on perceived stigmatization levels of the HS patients.

Table 12. *ANOVA for Perceived Stigmatization Across Different Levels of Disease Severity*

		N	*M*	*SD*	*SE*	*F*	*Sig.*
Perceived Stigmatization	Hurley I	13	12.54	5.71	1.58	.783	.461
	Hurley II	26	13.42	4.78	.94		
	Hurley III	31	11.81	4.54	.82		
	Total	70	12.54	4.84	.58		

Note: Abbreviations standing for as follows: Number of participants = N; Mean = M; Standard Deviation = SD; Standard Error of Mean = SE; F = Fisher's F ratio; Sig.= Significance level at 95%.

The results indicated a non-significant effect; $F(2, 67) = .783, p = .461$, between groups (Hurley I-II-III) in terms of perceived stigmatization (see Table 12). As a result, HS patients experience similar levels of perceived stigmatization regardless of the severity of their disease.

3.7.2.2. Disease Severity and Relationship with Close Others

A one-way ANOVA was conducted to determine the effect of disease severity (Hurley I-II-III) on the relationships of the HS patients with close others including (mother, father, and siblings), romantic partners, and female and male friends (see Table 13.).

Table 13. *ANOVA for Relationships with Close Others Across Different Levels of Disease Severity*

		N	*M*	*SD*	*SE*	*F*	*Sig.*
Relationship with Mother	Hurley I	12	7.00	1.85	.53	.301	.741
	Hurley II	25	6.53	1.52	.30		
	Hurley III	27	6.84	2.18	.42		
	Total	64	6.75	1.86	.23		
Relationship with Father	Hurley I	9	6.52	1.91	.64	.113	.893
	Hurley II	19	6.19	2.23	.51		
	Hurley III	27	6.46	2.05	.40		
	Total	55	6.38	2.06	.28		
Relationship with Siblings	Hurley I	13	7.20	1.83	.51	1.884	.161
	Hurley II	22	6.30	1.66	.35		
	Hurley III	27	5.86	2.39	.46		
	Total	62	6.30	2.08	.26		
Relationship with Partner	Hurley I	6	6.39	2.47	1.01	.108	.898
	Hurley II	17	6.10	1.81	.44		
	Hurley III	17	5.96	1.88	.46		
	Total	40	6.08	1.90	.30		
Relationship with Female Friends	Hurley I	13	4.95	2.49	.69	.007	.993
	Hurley II	26	5.03	2.38	.47		
	Hurley III	31	5.04	2.43	.44		
	Total	70	5.02	2.39	.29		
Relationship with Male Friends	Hurley I	13	5.74	2.05	.57	.418	.660
	Hurley II	26	5.06	2.07	.41		
	Hurley III	31	5.35	2.37	.43		
	Total	70	5.32	2.19	.26		

Note: As for the relationship with close others, high scores indicate a positive relationship. Abbreviations standing for as follows: Number of participants = N; Mean = M; Standard Deviation = SD; Standard Error of Mean = SE; F = Fisher's F ratio; Sig.= Significance level at 95%.

The results indicated a non-significant effect for all the relationships in terms of disease severity levels; specifically, relationship with mother, $F(2, 61) = .301$, $p =$

.741; father, *F*(2, 52) = .113, *p* = .893; siblings, *F*(2, 59) = 1.884, *p* = .161; romantic partner, *F*(2, 37) = .108, *p* = .898; female friends, *F*(2, 67) = .007, *p* = .993; and lastly male friends, *F*(2, 67) = .418, *p* = .660 (see Table 13).

Consequently, we have no evidence for a differential influence on the various types of relationships with close others.

3.7.3. The Relationship between Psychological and Social Components

A Pearson correlation coefficient was computed in order to assess the associations between psychological (well-being and illness cognition) and social (stigmatization and relationships) components as well as the association between psychological components. As can be seen in Table 14, the well-being variables (positive and negative affect) within the psychological components were significantly correlated with each other. Positive affect was positively correlated with acceptance and negatively correlated with helplessness from the illness cognition variables, and it was also positively correlated with only one social component, the relationship with partner. Negative affect, on the other hand, was positively correlated only with the helplessness component of illness cognition and was not found to be associated with any other variables. When examining the social component variables, stigmatization and relationship with close others, stigmatization was found to be positively correlated with helplessness from illness cognition and negatively correlated with relationships with the father and female friends. The other social component, relationships with parents, siblings, and partners, was positively correlated with other psychological variables, including positive affect, acceptance, and perceived benefits. Specifically, the relationship with a partner was strongly linked to psychological and social variables, including positive affect, acceptance, and perceived benefits. Furthermore, considering the correlations among relationships with close others, it was found that all variables were correlated with each other, except for the relationships with partner and siblings. The results indicated that higher positive affect, lower negative affect and higher acceptance were correlated with lower helplessness. Higher positive affect, lower negative affect and higher acceptance were also linked to high scores on good relationship with partner. High scores on good relationship with partner was associated with high perceived benefits, positive affect, and good relationships with both parents. In terms of illness cognition, high acceptance was connected to high perceived benefits and positive affect; while higher negative affect and lower positive affect were associated with increased helplessness. Regarding stigmatization, high level of perceived stigmatization was associated with greater helplessness, but a good relationship with father and good relationship with female friends were linked to lower perceived stigmatization and helplessness. In the realm of relationships, good relationship with mother was associated with good relationships with both the father and siblings, and strong parental relationships corresponded to better sibling relationships. Additionally, a good relationship with partner was related to higher acceptance, perceived benefits, and higher positive affect. Friendships play a significant role as well; good relationship with female friends was linked to higher acceptance, perceived benefits. Similarly, good relationships with male friends were associated with high perceived benefits. These results are discussed in the following section, and potentially influencing factors are shared.

Table 14. *Pearson Correlation Coefficients for the Psychological and Social Components*

	1	2	3	4	5	6	7	8	9	10	11	12
1. Positive Affect	1											
2. Negative Affect	-.441**	1										
3. Helplessness	-.396**	.357**	1									
4. Acceptance	.378**	-.180	-.244*	1								
5. Perceived Benefits	.225	-.083	.125	.630**	1							
6. Perceived Stigmatization	-.228	.205	.534**	-.125	-.117	1						
7. Relationship with Mother	.105	-.012	-.099	.225	.213	-.058	1					
8. Relationship with Father	.132	-.208	-.329*	.167	.095	-.269*	.644**	1				
9. Relationship with Siblings	.148	.022	-.073	.138	.250	.005	.717**	.450**	1			
10. Relationship with Partner	.465**	-.049	-.229	.489**	.398*	-.170	.512**	.417*	.306	1		
11. Relationship with Female Friends	.116	.143	-.299*	.285*	.299*	-.264*	.427**	.283*	.538**	.348*	1	
12. Relationship with Male Friends	.157	-.027	-.054	.179	.319**	-.103	.329**	.294*	.386**	.598**	.411**	1

**. Correlation is significant at the 0.1 level (2-tailed) and *. Correlation is significant at the 0.5 level (2-tailed).

3.7.3.1. Analysis for the Sexual Lives of the Patients

When examining the relationships of HS patients, specifically their romantic relationships, research showed that their sexual lives were negatively impacted. In this context, to assess participants' perceptions regarding how their sexual lives were affected, we conducted a one-sample t-test with those who indicated having a sexual partner.

Table 15. *Sexual Lives of the HS Patients*

	N	*M*	*SD*	*SE*	*t*	*Sig. (2-tailed)*
Sexual Life	40	1.23	.42	.07	18.320	.000*

Note: Abbreviations standing for as follows: N = Number of participants; M = Mean; SD = Standard Deviation; SE = Standard Error of the Mean; t: t value (Student's t); *Sig. (2-tailed): Significance level at %95.

Among the patients who had a sexual partner (*n* = 40), we conducted a one-sample t-test. The results demonstrated that patients perceived their sexual lives to be negatively affected, *t*(39) = 18.32, *p* = .000. The respondents evaluation for the question ranged between 1 to 9 on a Likert-scale, 5 being the mean point, as lower scores corresponding to worse affect, mean of 1.23 and standard deviation of .42 shows that patients perceived their sexual lives were negatively affected (see Table 15).

CHAPTER 4

DISCUSSION

Increasing chronic health issues are impacting individuals' lives in various ways, including levels of independence, daily routines, employment status, close relationships, friendships, and emotional well-being (Taylor, 2005). The lives of individuals with chronic diseases undergo significant changes due to their health conditions; additionally, they face challenges requiring adaptation in physical, social, and psychological dimensions. The challenges faced by patients can be exacerbated by the treatments they undergo, including medications and procedures. Additionally, the healthcare system tends to focus primarily on the physical manifestations of chronic diseases, often neglecting the psychosocial issues these conditions can cause (Taylor, 2005). Therefore, addressing the psychosocial aspects of diseases can aid in both adapting to the diseases and preventing the psychological problems that may arise during the disease process. With this understanding, our study with HS patients aimed to shed light on the psychosocial experiences of these individuals post-diagnosis.

In this context, we aimed to examine the psychosocial effects of HS have on patients. Specifically, within the framework of the Biopsychosocial model, we examined the relationships among the biological (disease severity), psychological (well-being and illness cognition), and social (perceived stigmatization and relationships with close others, including mother, father, siblings, romantic partners, and female/male friends) components. With exploration aim, we assessed how many patients disclosed their diagnosis to their mother, father, siblings, romantic partner, and female/male friends, and how many did not. We then examined gender differences and the effect of having a romantic partner on the study variables among HS patients. Finally, we investigated whether patients without a current romantic partner would initiate a future romantic relationship and asked all patients if they would initiate a friendship in the future. Before testing our hypotheses, we conducted reliability analyses for all scales used in the current study. With our hypotheses in mind, we conducted several t-tests, ANOVA tests and correlational analysis. Based on our findings, we outlined the analysis results, study strengths, practical implications, and limitations under separate headings.

4.1. Evaluating the Results of the Current Study

4.1.1. Evaluating the Clinical Presentation: Diagnosis, Disease Severity, Family History, Comorbidities, and Treatments

Firstly, 68.6% of the participants in the current study reported experiencing prolonged processes due to misdiagnosis or delayed diagnosis. Studies of delayed diagnosis in HS are well documented, it is also well acknowledged that misdiagnoses of HS frequently occur; the most common being abscess (50.3%), cyst (44.8%), acne (31.5%), cellulitis (14.7%), and MRSA (13.3%) (Kromenacker et al., 2019).

Among Turkish family physicians, only 23.7% believed they could diagnose HS, while 21% had not received any related medical training, and 63% thought HS was an infectious disease of the apocrine glands. As shown by the study, even dermatologists face difficulties in diagnosing HS (Shi et al., 2022; Tsentemeidou et al., 2024). Nearly 50% of the dermatologists surveyed had very little understanding of HS during the first visit, and only one had a very high level of understanding (Shi et al., 2022). The disease is likely easier to identify in its later stages, which may partially explain the diagnostic delay (Tsentemeidou et al., 2024).

Secondly, when asked our patients the age at which they were diagnosed, the youngest age reported was 12; this patient also indicated experiencing a prolonged process due to misdiagnosis. According to the literature, HS has an average onset of 23 years and has been reported rarely in the child population (Hallock et al., 2021). Additionally, it is estimated that less than 2% of cases occur before the age of 11. Although rare, our study with a small sample of 70 individuals demonstrated that HS can indeed appear in the pediatric population. It is crucial not to overlook the possibility of HS in pediatric patients and for specialists in that field to be competent in diagnosing or referring HS cases to dermatology.

Thirdly, almost half of our patients (44.3%) had the Hurley Stage III of HS. Most patients had Hurley I and II stages worldwide, including Argentinean (Zimman et al., 2019), Korean (Lee et al., 2018), Greek (Katoulis et al., 2017), Italian (Bettoli et al., 2019) and Turkish (Işık Mermutlu & Keskinkaya, 2023) populations. In our study, the higher prevalence of Hurley Stage III patients compared to previous studies may be attributed to the specific clinic where data was collected, the timing of data collection, or the involvement of individuals who assisted in data collection being those with higher disease stage. Another possibility is that misdiagnosis or delayed diagnosis may be common for Hurley Stage I and II patients in Türkiye, or individuals at these stages may not be seeking treatment. However, by the time they reach Hurley Stage III, they may be more likely to consult a doctor. It is also possible that patients with advanced stages of the disease are more motivated to participate in factors affecting their well-being and health processes (Murillo, 2019).

Fourthly, the most common comorbidities observed in our patients were diabetes, obesity, and hypertension. This result supports findings from previous studies in the literature (Bettoli et al., 2015; Kimball et al., 2018).

Fifthly, in the current study, 10 out of the 70 patients reported having a member with HS in their elementary family, while 13 reported having members with HS in their extended family. Even though current evidence supports a genetic predisposition for HS development (Seyed Jafari et al., 2020), the previous research also suggests that genetic factors contribute to only about 5% of the disease's cases (Zouboulis et al., 2015); consequently, the numbers we have reached in our study corresponds to the earlier findings.

Lastly, the treatments reported by the patients included, in order: biologic agents, antibiotics, excisional surgery, cortisol injections, laser surgery, ozone therapy, wound cleansing, painkillers, and stem cell therapy. As previously shown in a review study (Rambhatla et al., 2012), the medical treatments of HS include antibiotics, biological agents, laser and excisional surgery, cryotherapy, photodynamic treatment, and the use of various drugs as solo treatments. Our results indicated that the majority of patients are open to choosing both long-established, widely accepted treatments, as well as newer and developing therapies (Ballard, 2024).

4.1.2. Evaluating the Results of the Exploratory Research

When we asked patients whether they disclosed their diagnosis with their close others, we found that almost all of them disclosed it with family members (mother, father, and siblings) and romantic partners. Approximately 70% disclosed their diagnosis with female and male friends. The reason patients might not disclose their diagnosis with all their friends could be that family members and partners, who live with them or see them frequently, are more likely to notice changes in their condition even if patients try to conceal it. Additionally, in Türkiye, a collectivist culture (Çelik, 2008) where experiences are often shared primarily with close relatives, particularly those with a blood relationship, might contribute to this difference. On the other hand, patients may avoid interacting with friends due to the discomfort caused by their disease and fear of being judged or stigmatized. Lastly, participants who disclosed their diagnosis might have been more inclined to participate in data collection, as they may feel more comfortable discussing their condition.

Furthermore, male proportion was higher in our study (*n* = 50). As for gender differences, we could not find any statistically significant difference between female and male patients in any of the study variables including perceived stigmatization, illness cognition (helplessness, acceptance and perceived benefits respectively), positive and negative affect (well-being), relationship with close others (mother, father, siblings, romantic partner, fe/male friends). Previous studies in the literature have found certain differences between male and female patients (Hammud et al., 2023; Sabat et al. 2022). However, these differences generally pertain to clinical manifestations such as the age of disease onset, disease severity, or which areas of the body are affected. For example, when analyzing the clinical presentation of HS, lesions were found more frequently in the groin area in women and in the armpits in men.

Additionally, women exhibited more skin areas with inflammatory nodules, whereas men more commonly had fistulas (Sabat et al. 2022). Also, female patients were found to be less likely to exhibit severe disease but tended to experience disease onset slightly earlier than males (Hammud et al., 2023). On the other hand, studies examining the variables included in our study did not show significant differences. For instance, a study found no difference in the perceived stigmatization levels between male and female HS patients (Akoğlu et al., 2021). Studies investigating the relationship between well-being and HS have not examined differences between male and female patients (Senthilnathan et al., 2019). Regarding relationships and illness cognition, our study is the first to examine these variables in an HS population.

When we look at relationships, particularly in the context of romantic relationships, studies in literature have controversial results. Studies examining relationships with romantic partners often focus on individuals' sexual lives and have found different impacts on the sexual lives of males and females. Specifically, male patients reported having worse sexual lives compared to female patients, along with erectile dysfunction (Kurek et al., 2012); this condition had been reported to affect their relationships with their romantic partners.

On the other hand, a very recent study found that female patients had more sexual dysfunction, and this dysfunction was related to number of active lesions, psychosocial aspects such as stigmatization and depression (Krajewski et al., 2024). Additionally, female patients have been found to be more reluctant to disclose their disease to their partners (Thompson et al., 2022). Consequently, our results, while not supporting either of the controversies in the literature, have yielded expected outcomes. However, since we examined disclosure and support in general rather than delving into sexual and general relationship details specifically within romantic relationships, it is understandable that our results may have turned out this way. Similarly, as the impact on relationships with family members and friends has not been extensively explored in the literature, our results could serve as a basis for future studies. Nonetheless, considering the small size of our sample and the predominance of male patients, there is a high likelihood that future studies may yield different results. We also wanted to examine whether there were differences between patients who have a romantic partner and those who do not among our variables, including perceived stigmatization, illness cognition (helplessness, acceptance and perceived benefits respectively), and positive and negative affect (well-being).

According to our results, there were no statistically significant differences between patients who have a romantic partner and patients without a romantic partner in the study variables, except for positive and negative affect. In the literature, it has been shown that relatedness and interpersonal attachment are so important that some theorists have defined them as a fundamental human need, essential for well-being (Diener et al., 2018). Successfully forming and maintaining romantic relationships can lead to significant outcomes in later stages of life (Arnett et al., 2014) and have been shown to contribute to individuals' mental and physical health, thereby enhancing their well-being (DeWall et al., 2011).

HS patients’ positive and negative affect scores varied depending on whether they had a romantic partner; however, having a romantic partner was not associated with other variables. Perhaps the state of disease so severely impairs patients' overall mental states that having a romantic partner does not make such a difference in their lives.

Alternatively, the romantic relationships of these individuals may not be the healthy relationships described in the literature that contribute positively to mental health. As for other variables (perceived stigmatization and illness cognition), there has been no study to look at the differences we had explored in our study.

4.1.3. Evaluating the Results of the Relationship between Biological and Psychological Components

In several ANOVA tests we conducted, we aimed to examine if there are differences among the varying levels of disease severity (Hurley I-II-III stages) in the patients regarding psychological components of our model (well-being and illness cognition).

Firstly, there was not a statistically significant difference for positive and negative affect, irrespective of the severity of their disease in the current study. In a 2019 study by Senthilnathan et al., the findings indicated that HS patients experienced lower levels of positive affect and higher levels of negative affect compared to healthy controls. Their scores were similar across different disease severities (Hurley I-II-III), with no statistically significant differences observed between the groups. Consequently, our results were expected in this matter.

Secondly, we checked the illness cognitions of the patients, and our study stands as the first study to use this concept. Although the difference was not statistically significant, patients at Hurley stage II showed a tendency to feel more helpless and perceive less benefit. It could be because they are at a transitional point, progressing from Hurley I to Hurley III. The chronic nature of the disease and the limited treatment options (Rambhatla et al., 2012) might contribute to their sense of helplessness as they anticipate advancing to Hurley III.

4.1.4. Evaluating the Results of The Relationship between Biological and Social Components

In several ANOVA tests we conducted, we aimed to examine if there are differences among the varying levels of disease severity (Hurley I-II-III stages) in the patients regarding social components of our model (perceived stigmatization and relationship with close others).

Firstly, we had found that HS patients experienced similar levels of perceived stigmatization regardless of the severity of their disease.

Secondly, HS patients experienced similar levels of helplessness, acceptance, and perceived benefits irrespective of the severity of their disease. Previous studies found that perceived stigmatization to be lower in Hurley I stage patients compared to Hurley III stage patients (Akoğlu et al., 2021; Matusiak et al., 2010). They also added that patients with severe disease are likely to have more acceptance compared to patients with moderate severity. Hurley stage II disease (moderate severity) may represent a transitional phase in the perception of stigma throughout the course of HS. Our results did not support these previous findings regarding perceived stigmatization and acceptance. As for helplessness and perceived benefits, we could not find any relevant previous research that had an emphasis on HS patients.

Thirdly, we found that HS patients' different types of relationships (relationships with mother, father, siblings, romantic partner, fe/male friends) were similarly affected post diagnosis, regardless of the severity of their disease. Unfortunately, the data did not support our hypothesis that claimed, ‘patients' good relationships with their close others would be associated with lower levels of disease severity’. The reason for this result might lie in the fact that once individuals are diagnosed with a disease, their disease journey begins, and while the duration of this process is unpredictable, it leads to the development of a patient identity. 'Being a patient' may become more prominent than the severity of the disease itself.

Additionally, individuals might be receiving social support from their surroundings regardless of the severity of their disease, which could explain the lack of differentiation based on disease severity.

Lastly, since our study was conducted solely with patients from Türkiye, it is important to consider cultural characteristics. The findings may be influenced by cultural factors.

4.1.5. Evaluating the Results of The Relationship between Psychological and Social Components

We conducted a correlation analysis to examine the relationship between the psychological and social components in our model. We hypothesized that having a good (good corresponding to higher levels of relationship with close other) relationship with close others (mother, father, siblings, romantic partner, fe/male friends) will be associated with higher positive affect, increased perceived benefits, and acceptance as well as decreased negative affect, helplessness and perceived stigmatization. According to our results, positive affect was negatively correlated with negative affect and positively correlated with acceptance and good relationship with partner. Negative affect was positively correlated with helplessness. As for stigmatization, as perceived stigmatization increased, so did helplessness among patients. In terms of illness cognition, high perceived benefits was linked to high levels of acceptance, whereas helplessness was correlated positively with negative affect and negatively with positive affect.

When examining patients' relationships with their close others, except for relationships with siblings and romantic partners, all relationships with close others were found to be correlated with each other. A good relationship with a romantic partner was linked to high levels of acceptance, high perceived benefits, high positive affect, and good relationships with both the mother and father. When looking at patients' relationships with friends, a good relationship with female friends was associated with high levels of acceptance and high perceived benefits. A good relationship with male friends was linked to high perceived benefits. Research on social relationships and health suggests that positive social connections (e.g., social integration, support) positively influence well-being. Numerous studies show that social support and positive social relationships positively affect mental and physical health and subjective well-being (Nguyen et al., 2015). In our study, we examined how having a good relationship with close others would correlate with other variables. We observed the different associations of various types of relationships with close others on study variables. Since HS is chronic condition that requires management, concepts and findings from previous studies on chronic illnesses may also be applicable to HS. In this context, research in other fields focuses on how individuals cope with traumatic events, such as rape, or chronic illnesses, like cancer. This area is known as "meaning making" (Park, 2010). According to the theory, after experiencing challenging events and situations, individuals try to make meaning, which helps them develop beliefs that their identity has led to positive qualities. For instance, Pakenham (2007) worked with people diagnosed with multiple sclerosis (MS) and found that patients had found benefits from their MS identity, along with having a better sense of humor, more patience and better relationships with other people. Meaning-making is associated with much more positive psychological outcomes, which are acceptance and growth perception and/or positive life changes. Consequently, HS patients also might be finding perceived or real benefits from their condition along with acceptance, leading them to have better psychological outcomes and better relationships with their close others. Besides, acceptance and positive affect were correlated negatively with helplessness, which is an expected result due to the operational definitions of the concepts. A good relationship with the father and female friends was associated with low levels of perceived stigmatization and helplessness. Among the various relationships we examined in our study, the association of perceived stigmatization and helplessness with both the father and female friends was surprising. Perhaps due to the influence of Turkish culture and as shown in previous studies, it is already expected that mothers provide social support to their children no matter what (Oakley, 2022); however, when this support comes from the father, it may have a more significant impact. As for female friends, their comforting and verbalizing approach may help patients feel more at ease, potentially contributing to a sense of comfort and support.

4.1.6. Evaluating the Result of the Sexual Life of the Patients Analysis

According to the literature, HS patients' sexual lives are inhibited (Thorlacius et al., 2019), with more than half of the patients experiencing difficulties. As many as 66.7% of patients reported challenges in their sexual lives, which is three times higher than the average for individuals with other skin conditions (Sampogna et al., 2017). The results from our study showed that patients perceived their sexual lives to be negatively affected and this result is consistent with findings in the literature.

On the other hand, a study reported that as patients' Hurley stages increase, the discomfort experienced during sexual intercourse also increases, with female patients experiencing more discomfort compared to male patients (Krajewski et al., 2024; Thompson et al., 2022). Unfortunately, due to the small number of participants in our study and the limited number of patients who reported being sexually active (n = 35), we were unable to conduct analyses to confirm these previous findings.

4.2. Limitations of the Current Study

Before starting our study, we obtained ethical approval and applied to various university and state hospitals in Türkiye to collect data. However, due to numerous rejections, we were only able to collect data from patients visiting the Dermatology Clinic at Selçuk University and through social media platforms. Additionally, many patients either did not wish to participate or dropped out midway because they did not feel psychologically ready, leading to a small sample size. Secondly, although we wanted to examine many variables (e.g., financial situations, physical symptoms, quality of life of patients) within the same study, we had to keep our survey short due to the limited time available with patients during hospital visits. Moreover, although previous studies have been conducted qualitatively, we aimed to complete our research quantitatively. However, the small sample size may have resulted in outcomes that differ from the expected results. Furthermore, the high number of male patients in our study might limit the generalizability of the findings to female and non-binary patients.

4.3. Strengths and Contributions of The Current Study

Many health problems have lasting and irreversible physiological, psychological, social, and economic consequences (Lukkahatai et al., 2019). Disruptions to the normal flow of life, physical symptoms, feelings of pain/discomfort, the determination of the disease and treatment, damage to family relationships, limitations in previously held competencies, and changes in future and self-perception are among the challenges posed by chronic health issues (Mete, 2008). As physical losses (money, job, home), losses in interpersonal relationships (divorce, distancing from loved ones, deterioration of friendships), and personal losses (self-esteem, confidence, well-being, time, opportunities) increase, sources of stress also increase (Taylor, 2005). Factors such as the type and severity of the disease, the effects of treatment, individual characteristics, responses from the social environment (e.g., stigmatization), and economic resources have the potential to influence the challenges patients face, the difficulties they encounter, and their emotional responses to these situations (Power & Orto, 2004). With this understanding, we aimed to explore HS patients' experiences during the post-diagnosis period from a psychosocial perspective. In this context, we wanted to investigate whether patients disclose their condition to their close circles, including romantic partners, family members, and friends; how they perceived this disclosure experience, the level of support they receive from these individuals; their perception of stigmatization due to the disease; and how these factors, along with the severity of the disease, influence their overall emotional states (well-being) and illness cognition. Examining these variables together and conducting this analysis in a quantitative manner is the strongest aspect of our research.

With the help of our results, we observed that patients' various types of relationships (relationship with mother, father, siblings, romantic partner, fe/male friends) were associated with studies’ variables differently throughout the process, with relationships with fathers and female friends being closely related to perceived stigmatization and the aspect of helplessness in illness cognition. To put it differently, a good relationship with the father and female friends was associated with low levels of perceived stigmatization and helplessness in illness cognition. Additionally, regardless of the disease severity, patients experienced high levels of perceived stigmatization, helplessness, and positive affect, as well as low levels of perceived benefits and negative affect. We found that patients with romantic relationships had higher levels of acceptance, perceived benefits, well-being, and better relationships with both their mother and father compared to those without romantic relationships; showing the supportive and positive effect of romantic relationships. With these results, our study aimed to shed light on the psychosocial aspects of HS experienced by the patients.

4.4. Practical Implications

Geoffrey Rose, MD, the president of the Sanger Heart and Vascular Institute (SHVI) in North Carolina, states that the primary determinants of disease are economic and social factors, and therefore, the solutions to diseases should also lie in the economic and social domains (2023). Therefore, it should be provided a treatment process that considers patients' economic conditions, access to healthcare services, and social features and cultural backgrounds. As for HS patients, most importantly, since HS has a dramatic and often negative impact on patients' mental health, clinicians caring for patients with HS should exercise caution considering the prevalence of psychiatric comorbidities, psychosocial effects and suicidality in this population. Through our study, we aimed to demonstrate the extent and manner in which HS patients diagnosis is associated with their psychosocial processes. Their relationships, emotional states, and illness cognition can be negatively associated with their disease during this challenging post-diagnosis process. Given this reality, intervention programs and support groups or organizations that patients can benefit from could be developed. When examining the psychosocial processes of patients post-diagnosis within the framework of the BPS Model, we observed that regardless of the disease severity, patients experienced average level of positive affect, above-average level of negative affect, high helplessness, low acceptance, low perceived benefit, and above-average level of perceived stigmatization.

Additionally, the relationships of patients with their close others were found to be associated with psychosocial variables irrespective of disease severity. Findings indicated that HS patients experience negative outcomes following diagnosis, regardless of their disease severity, which may lead to psychological distress. Despite the severity of HS, the condition remains under-recognized, and support structures for patients are lacking. Kirby et al. (2023) highlighted the ongoing frustration patients face in managing HS due to these gaps. For a life-defining disease like HS and to mitigate or eliminate the negative impacts associated with it, self-management competency is of utmost importance (Mann et al., 2023).

Although basic educational programs and support groups are commonly implemented in countries like the USA, the importance of HS care may be underestimated. Unfortunately, this underestimation is also observed in Türkiye. This study emphasized the importance of helping HS patients become experts in managing their disease to improve their daily lives and outcomes. The researchers suggested that introducing supportive measures, such as a specialized HS application designed to assess individual patient needs and develop personalized care plans, could be one approach to enhance patients’ self-management skills to manage their disease process. In this context, programs aimed at developing the self-management competency of HS patients can be implemented to mitigate and eventually eliminate the psychosocial challenges caused by HS. Also, as our study demonstrated, regardless of gender, having a romantic partner, or the severity of the disease, HS patients experience perceived stigmatization. At this point, it is crucial to develop interventions and programs aimed at reducing the levels of perceived stigma among patients. When we look at the literature, we can see that awareness of stigma in dermatology is increasing, with stigmatization now recognized as a multifaceted issue. There is an urgent need for the development and assessment of interventions specifically designed to address the negative impact of stigma on health and well-being. However, evaluating the effectiveness of broad psychosocial and informational interventions has proven challenging (Topp et al., 2019). Therefore, it may be more effective to focus on particular groups that are prone to stigmatization, such as schoolchildren, students, or healthcare professionals, by tailoring interventions to meet their specific needs (Topp et al., 2019). Addressing healthcare professionals as a potentially stigmatizing group is crucial because managing patients with visible chronic skin conditions should extend beyond physical treatment. In this context, specialized intervention programs could be developed for both those who have someone close with HS and practicing healthcare professionals and those currently in medical training for HS, to help reduce stigma and its associated negative effects for patients. In other respects, there are no local organizations established for skin conditions, including HS, in our country, Türkiye. European-based organizations such as the Hidradenitis Suppurativa European Research Group (HISERG) and the European HS Foundation (EHSF) provide comprehensive assistance and support to HS patients. The primary organization encountered in this regard is the "HS Foundation" (2022). This organization strives to improve the lives of individuals affected by HS, disseminate the latest HS information for professionals and patients, direct research based on unmet needs of patients, provide financial support and encouragement for research, and advocate for better treatment options, easier access to care, improved insurance coverage, and patient-centered outcomes in research and drug development. Another organization, "Hope for HS," founded in 2013 by Angie Parks-Miller and Dr. Melissa Williams in the United States, is the first face-to-face support group for HS patients, their families, and caregivers. The activities of the organization initially began at Henry Ford Hospital in Detroit and continue to operate in many other cities and states today (HS Foundation, 2022). Also, HS Connect is an organization created to allow individuals with HS to share their stories, ensure their voices are heard, and prevent them from living alone or in silence. It is a patient-centered organization that provides resources, support, and solutions to HS patients to manage their physical, mental, emotional, and financial processes. Their objectives include correcting misconceptions about HS, eliminating the stigma surrounding HS, and educating as many people as possible, including non-specialist dermatologists, surgeons, caregivers, spouses, children, partners, parents, family, and friends. Essentially, it is created to allow those with HS to share their stories, ensure their voices are heard, and prevent them from living alone or in silence (HS Foundation, 2022). Lastly, the International Association of Hidradenitis Suppurativa Network, Inc. (iahsn.org) has been advocating for stakeholders for over nine years, providing education to patients, caregivers, and those unfamiliar with the disease, and promoting research aimed at finding support and treatment. Additionally, since its inception, it has provided a community for millions of people affected by HS. As suggested by the previous research, patients need social support networks (Howell et al., 2021), to help them overcome negative influences associated with stigmatization, disease severity and impaired relationships. Unfortunately, there is no governmental agency or a non-governmental organization serving HS patients in Türkiye. As a result, we believe that efforts should be made to establish anorganization in our country that can provide assistance and support to such patients. We hope that our study will lead the way in this regard, at least in understanding the multifaceted impacts of the disease. Lastly, The James Lind Alliance was established to raise awareness regarding diseases and offer benefits to patients, healthcare professionals, and caregivers. In this context, HS was identified as a top ten research priority in 2013 with the question: "What is the impact of HS and its treatments on patients in terms of physical, psychological, social, financial aspects, and quality of life?" (Ingram et al., 2014). Consequently, our research tried to answer half of these questions by examining psychosocial aspects and their effects on HS patients.

4.5. Suggestions for Future Research

Future quantitative studies could explore patients' experiences from different angles that we were unable to control, using a larger and more gender-balanced sample. For example, adding the health locus of control variable to the illness cognition framework could help understand how patients' cognitions are affected. The Health Locus of Control Theory (Wallston & Wallston, 1982) states that individuals refer internally and externally to whether their health status is controlled by themselves. To express it more clearly, an individual who believes that their health status is under their own control says, "I am the one directly responsible for my health," and this is referred to as the internal locus of control. On the other hand, an individual who believes that their health status is not under their control and is solely dependent on fate says, "Whether I am healthy or not is a matter of luck, and there is nothing I can do about it"; this is referred to as external locus of control. Examining the connection between individuals' beliefs and perceptions about their illnesses and psychological impairment (Pavon Blanco et al., 2018), individuals with an external locus of control may deeply experience a sense of helplessness because they believe they cannot control their illnesses. In the current study, we did not control for health locus of control, but in future research, this theory could be included to discuss how it affects illness cognition; because previous study found that patients' beliefs and perceptions about their illness were more closely related to psychosocial impairment than the clinical severity of the disease (Pavon Blanco et al., 2018). Consequently, physicians can target these negative perceptions and emotions to improve patients' psychosocial well-being in future studies.

Additionally, investigating the intensity and variety of physical symptoms could provide insights into their impact on patients' well-being. Through these examinations, intervention programs could be developed to make way for patients' outcomes; for instance, determining how different physical symptoms and health locus of control of the patients predict psychological well-being.

REFERENCES

Akoğlu, G., Yildiz, I., Karaismailoğlu, E., & Esme, P. (2021). Disease severity and poor mental health are the main predictors of stigmatization in patients with Hidradenitis Suppurativa. *Dermatologic Therapy, 34*(3). https://doi.org/10.1111/dth.14910

Alavi, A., Anooshirvani, N., Kim, W. B., Coutts, P., & Sibbald, R. G. (2015). Quality-of-life impairment in patients with hidradenitis suppurativa: a Canadian study. *American Journal of Clinical Dermatology, 16*(1), 61-65. https://doi.org/10.1007/s40257-014-0105-5

Alavi, A., Farzanfar, D., Lee, R. K., & Almutairi, D. (2017). The contribution of malodour in quality of life of patients with Hidradenitis Suppurativa. *Journal of Cutaneous Medicine and Surgery, 22*(2), 166–174. https://doi.org/10.1177/1203475417745826

Albery, I. P., & Munafò, M. (2014). Defining Health Psychology. In *Key Concepts in Health Psychology* (pp. 1–18). SAGE Publications.

Alonso, J., Buron, A., Bruffaerts, R., He, Y., Posada-Villa, J., Lepine, J., Angermeyer, M. C., Levinson, D., De Girolamo, G., Tachimori, H., Mneimneh, Z. N., Medina-Mora, M. E., Ormel, J., Scott, K. M., Gureje, O., Haro, J. M., Gluzman, S., Lee, S., Vilagut, G., … Von Korff, M. (2008). Association of perceived stigma and mood and anxiety disorders: Results from the World Mental Health Surveys. *Acta Psychiatrica Scandinavica, 118*(4), 305–314. https://doi.org/10.1111/j.1600-0447.2008.01241.x

Alotaibi, H. M. (2024). Incidence, risk factors, and prognosis of hidradenitis suppurativa across the globe: Insights from the literature. *Clinical, Cosmetic and Investigational Dermatology, 16*, 545–552. https://doi.org/10.2147/ccid.s402453

Andersen, P., Nielsen, R., Sigsgaard, V., Jemec, G., & Riis, P. (2020). Body image quality of life in patients with Hidradenitis Suppurativa compared with other dermatological disorders. *Acta Dermato Venereologica, 100*(8). https://doi.org/10.2340/00015555-3464

Andersen, R., Rostgaard, K., Pedersen, O., Jemec, G. B., & Hjalgrim, H. (2024). Increased cancer incidence among patients with hidradenitis suppurativa – A Danish nationwide register study 1977–2017. *Acta Oncologica, 63*, 220–228. https://doi.org/10.2340/1651-226x.2024.26182

Aparício Martins, I., Figueira Vilela, B., & Cabete, J. (2023). Diagnostic delay in Hidradenitis Suppurativa: Still an unsolved problem. *Skin Appendage Disorders, 10*(2), 129–132. https://doi.org/10.1159/000534845

Arnett, J. J., Žukauskienė, R., & Sugimura, K. (2014). The new life stage of emerging adulthood at ages 18–29 years: Implications for mental health. *The Lancet Psychiatry, 1*(7), 569–576. https://doi.org/10.1016/s2215-0366(14)00080-7

Aykul, A. (2018). Hastalık biliş anketi'nin geçerlik ve güvenilirliği. [Master's thesis, Başkent University]. https://tez.yok.gov.tr/UlusalTezMerkezi/tezDetay.jsp?id=S_A1S0QfGqGyodEQMpGhsw&no=DKd-hdZX2jZdHnkXero72A

Balieva, F., Abebe, D. S., Dalgard, F. J., & Lien, L. (2023). Risk of developing psychiatric disease among adult patients with skin disease: A 9-year National Register follow-up study in Norway. *Skin Health and Disease, 3*(6). https://doi.org/10.1002/ski2.294

Ballard, K. (2024, May 6). Hidradenitis Suppurativa. StatPearls [Internet]. https://www.ncbi.nlm.nih.gov/books/NBK534867/

Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin, 117*(3), 497–529. https://doi.org/10.1037//0033-2909.117.3.497

Beals, K. P., Peplau, L. A., & Gable, S. L. (2009). Stigma management and well-being:

The role of perceived social support, emotional processing, and suppression. *Personality and Social Psychology Bulletin, 35*(7), 867–879. https://doi.org/10.1177/0146167209334783

Bettoli, V., Cazzaniga, S., Scuderi, V., Zedde, P., Di Landro, A., & Naldi, L. (2019). Hidradenitis Suppurativa Epidemiology: From the first Italian registry in 2009 to the most recent epidemiology updates – Italian registry hidradenitis suppurativa project 2. *Journal of the European Academy of Dermatology and Venereology, 33*(6), 4–6. https://doi.org/10.1111/jdv.15826

Bettoli, V., Naldi, L., Cazzaniga, S., Zauli, S., Atzori, L., Borghi, A., Capezzera, R., Caproni, M., Cardinali, C., DeVita, V., Donini, M., Fabbrocini, G., Gimma, A., Pasquinucci, S., Patrizi, A., Pinna, A. L., Raone, B., Ricci, M., Virgili, A., & Balestri, R. (2015). Overweight, diabetes and disease duration influence clinical severity in hidradenitis suppurativa–acne inversa: Evidence from the national Italian registry. *British Journal of Dermatology, 174*(1), 195–197. https://doi.org/10.1111/bjd.13864

Borrell-Carrio, F. (2004). The biopsychosocial model 25 years later: Principles, practice, and scientific inquiry. *The Annals of Family Medicine, 2*(6), 576–582. https://doi.org/10.1370/afm.245

Bouazzi, D., McPhie, M. L., Kjærsgaard Andersen, R., Alavi, A., & Jemec, G. B. E. (2021). Hidradenitis suppurativa and perceived stigmatization in a diverse Canadian clinic population: A pilot study. *British Journal of Dermatology, 184*(3), 570–571. https://doi.org/10.1111/bjd.19626

Brannon, L. & Feist, J. (2010). Health Psychology. Wadsworth, USA.

Brownson, R. C. (1998). Chronic disease epidemiology and control. American Public Health Association. Washington, DC.

Butt, M., Rigby, A., Leslie, D. L., Foulke, G. T., Flamm, A., Kirby, J. S., & Chinchilli, V. M. (2022). Associations of internalized skin bias with age, adverse psychopathology, and health-related quality of life among patients with Hidradenitis Suppurativa. *JAMA Dermatology, 158*(4), 432. https://doi.org/10.1001/jamadermatol.2022.0248

Cacioppo, J. T., & Hawkley, L. C. (2003). Social isolation and health, with an emphasis on underlying mechanisms. *Perspectives in Biology and Medicine, 46*(3). https://doi.org/10.1353/pbm.2003.0063

Chaudoir, S. R., & Fisher, J. D. (2010). The Disclosure Processes Model: Understanding Disclosure Decision Making and postdisclosure outcomes among people living with a concealable stigmatized identity. *Psychological Bulletin, 136*(2), 236–256. https://doi.org/10.1037/a0018193

Chaudoir, S. R., & Quinn, D. M. (2010). Revealing concealable stigmatized identities: The impact of disclosure motivations and positive first-disclosure experiences on fear of disclosure and well-being. *Journal of Social Issues, 66*(3), 570–584. https://doi.org/10.1111/j.1540-4560.2010.01663.x

Chen, H.L., Song, Y.P., & Liu, K. (2019). Problematic strength of the association between atopic dermatitis and Suicidality. *JAMA Dermatology, 155*(5), 637. https://doi.org/10.1001/jamadermatol.2019.0195

Chen, W.T., & Chi, C.C. (2019). Association of hidradenitis suppurativa with inflammatory bowel disease. *JAMA Dermatology, 155*(9), 1022. https://doi.org/10.1001/jamadermatol.2019.0891

Clair, M. (2018). Stigma. Core Concepts in Sociology, 318–321.

Cohen, S., Underwood, L. G., & Gottlieb, B. H. (2000). Social relationships and health. In *Social Support Measurement and Intervention: A Guide for Health and Social Scientists* (pp. 3–25). Oxford University Press.

Cole-Kelly, K. & Seaburn, D. B. Five areas of questioning to promote a family-oriented approach in primary care. *Families, Systems, & Health, 17*(3), 341-348. https://doi.org/10.1037/h0089875

Colón, E. A., Popkin, M. K., Callies, A. L., Dessert, N. J., & Hordinsky, M. K. (1991). Lifetime prevalence of psychiatric disorders in patients with alopecia areata. *Comprehensive Psychiatry, 32*(3), 245–251. https://doi.org/10.1016/0010-440x(91)90045-e

Consoli, S. M., Rolhion, S., Martin, C., Ruel, K., Cambazard, F., Pellet, J., & Misery, L. (2006). Low levels of emotional awareness predict a better response to dermatological treatment in patients with psoriasis. *Dermatology, 212*(2), 128–136. https://doi.org/10.1159/000090653

Cosmatos, I., Matcho, A., Weinstein, R., Montgomery, M. O., & Stang, P. (2013). Analysis of patient claims data to determine the prevalence of hidradenitis suppurativa in the United States. *Journal of the American Academy of Dermatology, 69*(5), 819. https://doi.org/10.1016/j.jaad.2013.06.042

Cotterill, J. A., & Cunliffe, W. J. (1997). Suicide in dermatological patients. *British Journal of Dermatology, 137*(2), 246–250. https://doi.org/10.1046/j.1365-2133.1997.18131897.x

Cuenca-Barrales, C., & Molina-Leyva, A. (2020). Sexuality in patients with Hidradenitis Suppurativa: Beliefs, behaviors and needs. *International Journal of Environmental Research and Public Health, 17*(23), 8808. https://doi.org/10.3390/ijerph17238808

Cuenca-Barrales, C., Montero-Vílchez, T., Szepietowski, J. C., Matusiak, L., & Molina-Leyva, A. (2021). Sexual impairment in patients with hidradenitis suppurativa: A systematic review. *Journal of the European Academy of Dermatology and Venereology, 35*(2), 345–352. https://doi.org/10.1111/jdv.16726

Dalgard, F., Svensson, A., Sundby, J., & Dalgard, O. S. (2005). Self-reported skin morbidity and mental health. A population survey among adults in a Norwegian city. *British Journal of Dermatology, 153*(1), 145–149. https://doi.org/10.1111/j.1365-2133.2005.06414.x

Deckers, I. E., Janse, I. C., van der Zee, H. H., Nijsten, T., Boer, J., Horváth, B., & Prens, E. P. (2016). Hidradenitis suppurativa (HS) is associated with low socioeconomic status (SES): A cross-sectional reference study. *Journal of the American Academy of Dermatology, 75*(4). https://doi.org/10.1016/j.jaad.2016.04.067

DeWall, C. N., Maner, J. K., Deckman, T., & Rouby, D. A. (2011). Forbidden fruit:

Inattention to attractive alternatives provokes implicit relationship reactance. *Journal of Personality and Social Psychology, 100*(4), 621–629. https://doi.org/10.1037/a0021749

Diener, E. (2009). Assessing subjective well-being: Progress and opportunities. In *Assessing Well-Being*, 25–65. https://doi.org/10.1007/978-90-481-2354-4_3

Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of Personality Assessment, 49*, 71-75. https://doi.org/10.1207/s15327752jpa4901_13

Diener, E., Oishi, S., & Lucas, R. E. (2003). Personality, culture, and subjective well-being. *Annual Review of Psychology, 54*, 403-425. https://doi.org/10.1146/annurev.psych.54.101601.145056

Diener, E., Seligman, M. E., Choi, H., & Oishi, S. (2018). Happiest people revisited. *Perspectives on Psychological Science, 13*(2), 176–184. https://doi.org/10.1177/1745691617697077

Dimitrov, D., & Szepietowski, J. C. (2017). Stigmatization in dermatology with a special focus on psoriatic patients. *Postępy Higieny i Medycyny Doświadczalnej, 71*(0), 0–0. https://doi.org/10.5604/01.3001.0010.6879

Dündar, Z., & Demirli, C. (2018). Medeni durumları farklı olan çalışanların psikolojik iyi olma düzeylerinin incelenmesi. *The Journal of Educational Reflections, 2*(2), 1-10.

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196*(4286), 129–136. https://doi.org/10.1126/science.847460

Esmann, S., & Jemec, G. (2011). Psychosocial impact of Hidradenitis Suppurativa: A qualitative study. *Acta Dermato Venereologica, 91*(3), 328–332. https://doi.org/10.2340/00015555-1082

Esposito, M., Saraceno, R., Giunta, A., Maccarone, M., & Chimenti, S. (2006). An Italian study on psoriasis and Depression. *Dermatology, 212*(2), 123–127. https://doi.org/10.1159/000090652

Evers, A. W. M., Duller, P., van de Kerkhof, P. C. M., van der Valk, P. G. M., de Jong, E. M. G. J., Gerritsen, M. J. P., Otero, E., Verhoeven, E. W. M., Verhaak, C. M., & Kraaimaat, F. W. (2007). The impact of chronic skin disease on daily life (ISDL): A generic and dermatology-specific health instrument. *British Journal of Dermatology, 158*(1). https://doi.org/10.1111/j.1365-2133.2007.08296.x

Evers, A. W. M., Kraaimaat, F. W., van Lankveld, W., Jongen, P. J. H., Jacobs, J. W. G., & Bijlsma, J. W. J. (2001). Beyond unfavorable thinking: The illness cognition questionnaire for chronic diseases. *Journal of Consulting and Clinical Psychology, 69*(6), 1026–1036. https://doi.org/10.1037/0022-006X.69.6.1026

Evers, A. W. M., Lu, Y., Duller, P., van der Valk, P. G. M., Kraaimaat, F. W., & van de Kerkhof, P. C. M. (2005). Common burden of chronic skin diseases? contributors to psychological distress in adults with psoriasis and atopic dermatitis. *British Journal of Dermatology, 152*(6), 1275–1281. https://doi.org/10.1111/j.1365-2133.2005.06565.x

Evers, A. W., Kraaimaat, F. W., van Lankveld, W., Jongen, P. J., Jacobs, J. W., & Bijlsma, J. W. (2001). Beyond unfavorable thinking: The illness cognition questionnaire for chronic diseases. *Journal of Consulting and Clinical Psychology, 69*(6), 1026–1036. https://doi.org/10.1037/0022-006x.69.6.1026

Farre, A., & Rapley, T. (2017). The New Old (and old new) medical model: Four decades navigating the biomedical and psychosocial understandings of health and illness. *Healthcare, 5*(4), 88. https://doi.org/10.3390/healthcare5040088

Fauconier, M., Reguiai, Z., Barbe, C., Colosio, A., Eschard, J.-P., Salmon, J.-H., & Direz, G. (2018). Association between hidradenitis suppurativa and spondyloarthritis. *Joint Bone Spine, 85*(5), 593–597. https://doi.org/10.1016/j.jbspin.2017.09.005

Fimmel, S., & Zouboulis, C. C. (2010). Comorbidities of hidradenitis suppurativa (Acne Inversa). *Dermato-Endocrinology, 2*(1), 9–16. https://doi.org/10.4161/derm.2.1.12490

Fitzsimmons, J. S., & Guilbert, P. R. (1985). A family study of Hidradenitis Suppurativa. *Journal of Medical Genetics, 22*(5), 367–373. https://doi.org/10.1136/jmg.22.5.367

Garg, A., Malviya, N., Strunk, A., Wright, S., Alavi, A., Alhusayen, R., Alikhan, A., Daveluy, S. D., Delorme, I., Goldfarb, N., Gulliver, W., Hamzavi, I., Jaleel, T., Kimball, A. B., Kirby, J. S., Kirchhof, M. G., Lester, J., Lev-Tov, H., Lowes, M. A., … Naik, H. B. (2022). Comorbidity screening in Hidradenitis Suppurativa: Evidence-based recommendations from the US and Canadian Hidradenitis Suppurativa Foundations. *Journal of the American Academy of Dermatology, 86*(5), 1092–1101. https://doi.org/10.1016/j.jaad.2021.01.059

Garg, A., Pomerantz, H., Midura, M., Papgermanos, V., Strunk, A., Merson, J., & Alloo, A. (2017). 222 completed suicide in patients with Hidradenitis Suppurativa: A population analysis in the United States. *Journal of Investigative Dermatology, 137*(5). https://doi.org/10.1016/j.jid.2017.02.237

Germain, N., Augustin, M., François, C., Legau, K., Bogoeva, N., Desroches, M., Toumi, M., & Sommer, R. (2021). Stigma in visible skin diseases – a literature review and development of a conceptual model. *Journal of the European Academy of Dermatology and Venereology, 35*(7), 1493–1504. https://doi.org/10.1111/jdv.17110

Gill, N., & Gniadecki, R. (2019). Incidence and prevalence of hidradenitis suppurativa: A systematic review and meta-analysis. *JAMA Dermatology, 157*(8), 924-931. https://doi.org/10.1101/19012559

Goffman, E. (1963). Stigma: Notes on the management of spoiled identity. Simon & Schuster.

Gooderham, M., & Papp, K. (2015). The psychosocial impact of Hidradenitis Suppurativa. *Journal of the American Academy of Dermatology, 73*(5). https://doi.org/10.1016/j.jaad.2015.07.054

Gupta, M A, & Gupta, A. K. (1998). Depression and suicidal ideation in dermatology patients with acne, alopecia areata, atopic dermatitis and psoriasis. *British Journal of Dermatology*, *139*(5), 846–850. https://doi.org/10.1046/j.1365-2133.1998.02511.x

Gupta, M. A., & Gupta, A. K. (2003). Psychiatric and psychological co-morbidity in patients with Dermatologic Disorders. *American Journal of Clinical Dermatology*, *4*(12), 833–842. https://doi.org/10.2165/00128071-200304120-00003

Gupta, Madhulika A., Pur, D. R., Vujcic, B., & Gupta, A. K. (2017). Suicidal behaviors in dermatology patients. *Clinics in Dermatology*, *35*(3), 302–311. https://doi.org/10.1016/j.clindermatol.2017.01.006

Gurková, E., & Soósová, M. S. (2018). Illness cognitions and health-related quality of life of patients with inflammatory bowel disease. *Gastroenterology Nursing*, *41*(1), 29–37. https://doi.org/10.1097/sga.0000000000000309

Hallock, K. K., Mizerak, M. R., Dempsey, A., Maczuga, S., & Kirby, J. S. (2021). Differences between children and adults with Hidradenitis Suppurativa. *JAMA Dermatology*, *157*(9), 1095. https://doi.org/10.1001/jamadermatol.2021.2865

Hammud, A., Avitan-Hersh, E., & Khamaysi, Z. (2023). Clinical-epidemiological Characteristics of Hidradenitis Suppurativa: A Retrospective Cohort Study. *Journal of Clinical Medicine*, *12*(12), 3921. https://doi.org/10.20944/preprints202304.0630.v1

Harrison, B. J., Read, G. F., & Hughes, L. E. (1988). Endocrine basis for the clinical presentation of Hidradenitis Suppurativa. *British Journal of Surgery*, *75*(10), 972–975. https://doi.org/10.1002/bjs.1800751011

Hatala, A. R. (2012). The status of the “biopsychosocial” model in Health Psychology: Towards an Integrated Approach and a critique of cultural conceptions. *Open Journal of Medical Psychology*, *1*(4), 51–62. https://doi.org/10.4236/ojmp.2012.14009

Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health, 103*(5), 813–821. https://doi.org/10.2105/ajph.2012.301069

Hay, R. J., Johns, N. E., Williams, H. C., Bolliger, I. W., Dellavalle, R. P., Margolis, D. J., Marks, R., Naldi, L., Weinstock, M. A., Wulf, S. K., Michaud, C., J.L. Murray, C., & Naghavi, M. (2014). The global burden of skin disease in 2010: An analysis of the prevalence and impact of skin conditions. *Journal of Investigative Dermatology, 134*(6), 1527–1534. https://doi.org/10.1038/jid.2013.446

Heatherton, T. F., Kleck, R. E., Hebl, M. R., & Hull, J. G. (2003). The Social Psychology of Stigma. Guilford Press.

Hidradenitis Suppurativa Foundation, Inc. (2022). A Year of Unprecedented Progress: 2022 Annual Report. HS Found. https://www.hs-foundation.org/annual-reports

History of hidradenitis suppurativa. International Association of Hidradenitis Suppurativa Network. (n.d.). https://www.iahsn.org/hsdisease/about-hidradenitis-suppurativa.html

Howard-James, C., & Tobin, A. (2023). An analysis of direct and indirect costs in Hidradenitis Suppurativa. *Skin Health and Disease, 4*(1). https://doi.org/10.1002/ski2.306

Howells, L., Lancaster, N., McPhee, M., Bundy, C., Ingram, J. R., Leighton, P., Henaghan-Sykes, K., & Thomas, K. S. (2021). Thematic synthesis of the experiences of people with Hidradenitis Suppurativa: A systematic review. *British Journal of Dermatology, 185*(5), 921–934. https://doi.org/10.1111/bjd.20523

Hughes, J. E., Barraclough, B. M., Hamblin, L. G., & White, J. E. (1983). Psychiatric symptoms in dermatology patients. *British Journal of Psychiatry, 143*(1), 51–54. https://doi.org/10.1192/bjp.143.1.51

Humphreys, F., & Humphreys, M. S. (1998). Psychiatric morbidity and skin disease: What dermatologists think they see. *British Journal of Dermatology, 139*(4), 679–681. https://doi.org/10.1046/j.1365-2133.1998.02467.x

Ingram, J. R. (2020). The epidemiology of Hidradenitis Suppurativa. *British Journal of Dermatology, 183*(6), 990–998. https://doi.org/10.1111/bjd.19435

Ingram, J. R., Abbott, R., Ghazavi, M., Alexandroff, A. B., McPhee, M., Burton, T., & Clarke, T. (2014). The hidradenitis suppurativa priority setting partnership. *British Journal of Dermatology, 171*(6), 1422–1427. https://doi.org/10.1111/bjd.13163

Ingram, J.R., Jenkins-Jones, S., Knipe, D. W., Morgan, C. L. I., Cannings-John, R., & Piguet, V. (2018). Population-based clinical practice research datalink study using algorithm modelling to identify the true burden of Hidradenitis Suppurativa. *British Journal of Dermatology, 178*(4). https://doi.org/10.1111/bjd.16515

Işık Mermutlu, S., & Keskinkaya, Z. (2023). Epidemiological and clinical characteristics of Hidradenitis Suppurativa Patients: 10-year experience from a single tertiary center. *Journal of Istanbul Faculty of Medicine, 86*(3), 235–244. https://doi.org/10.26650/iuitfd.1216589

Janse, I. C., Deckers, I. E., van der Maten, A. D., Evers, A. W. M., Boer, J., van der Zee, H. H., Prens, E. P., & Horváth, B. (2017). Sexual health and quality of life are impaired in Hidradenitis Suppurativa: A multicentre cross-sectional study. *British Journal of Dermatology, 176*(4), 1042–1047. https://doi.org/10.1111/bjd.14975

Jemec G. B. (2012). Clinical practice. Hidradenitis suppurativa. The New England *Journal of Medicine, 366*(2), 158–164. https://doi.org/10.1056/NEJMcp1014163

Jemec, G. B. E. (2003). Hidradenitis Suppurativa. *Journal of Cutaneous Medicine and Surgery: Incorporating Medical and Surgical Dermatology, 7*(1), 47–56. https://doi.org/10.1007/s10227-002-2104-z

Jemec, G. B. E., Heidenheim, M., & Nielsen, N. H. (1996). The prevalence of hidradenitis suppurativa and its potential precursor lesions. *Journal of the American Academy of Dermatology, 35*(2), 191–194. https://doi.org/10.1016/s0190-9622(96)90321-7

Jemec, G. B. E., Revuz, J., & Leyden, J. J. (Eds.). (2006). Hidradenitis Suppurativa (Vol. 1). Springer.

Johnson, S. B. (2013). Increasing psychology's role in health research and health care. *American Psychologist, 68*(5), 311–321. https://doi.org/10.1037/a0033591

Jung, J. M., Lee, K. H., Kim, Y.-J., Chang, S. E., Lee, M. W., Choi, J. H., Won, C. H., & Lee, W. J. (2020). Assessment of overall and specific cancer risks in patients with Hidradenitis Suppurativa. *JAMA Dermatology, 156*(8), 844. https://doi.org/10.1001/jamadermatol.2020.1422

Katerndahl, D., & Oyiriaru, D. (2007). Assessing the Biopsychosociospiritual model in primary care: Development of the biopsychosociospiritual inventory (BIOPSSI). *The International Journal of Psychiatry in Medicine, 37*(4), 393–414. https://doi.org/10.2190/pm.37.4.d

Katoulis, A. C., Liakou, A. I., Rotsiamis, N., Bonovas, S., Bozi, E., Rallis, E., Christodoulou, C., & Rigopoulos, D. (2017). Descriptive epidemiology of Hidradenitis Suppurativa in Greece: A study of 152 cases. *Skin Appendage Disorders, 3*(4), 197–201. https://doi.org/10.1159/000475822

Keary, E., Hevey, D., & Tobin, A. M. (2019). A qualitative analysis of psychological distress in Hidradenitis Suppurativa. *British Journal of Dermatology, 182*(2), 342–347. https://doi.org/10.1111/bjd.18135

Kimball, A. B., Sundaram, M., Gauthier, G., Guérin, A., Pivneva, I., Singh, R., & Ganguli, A. (2018). The comorbidity burden of Hidradenitis Suppurativa in the United States: A claims data analysis. *Dermatology and Therapy, 8*(4), 557–569. https://doi.org/10.1007/s13555-018-0264-z

Kirby, J. S., Martorell, A., Sayed, C. J., Alarcon, I., Kasparek, T., Frade, S., McGrath, B. M., Villumsen, B., & Zouboulis, C. C. (2023). Understanding the real-world patient journey and unmet needs of people with Hidradenitis Suppurativa through Social Media Research. *British Journal of Dermatology, 189*(2), 228–230. https://doi.org/10.1093/bjd/ljad104

Kirby, J. S., Sisic, M., & Tan, J. (2016). Exploring coping strategies for patients with Hidradenitis Suppurativa. *JAMA Dermatology, 152*(10), 1166. https://doi.org/10.1001/jamadermatol.2016.1942

Kirsten, N., Zander, N., & Augustin, M. (2020). Prevalence and cutaneous comorbidities of hidradenitis suppurativa in the German working population. *Archives of Dermatological Research, 313*(2), 95–99. https://doi.org/10.1007/s00403-020-02065-2

Kleinman, A., Eisenberg, L., & Good, B. (2006). Culture, illness, and care: Clinical lessons from Anthropologic and Cross-Cultural Research. *Focus, 4*(1), 140–149. https://doi.org/10.1176/foc.4.1.140

Koerts, N. D. K., Bouwman, K., Prens, L. M., & Horváth, B. (2023). Assessment tools and phenotype classification for Hidradenitis Suppurativa. *Clinics in Dermatology, 41*(5), 601–610. https://doi.org/10.1016/j.clindermatol.2023.08.016

Kök, H., & Demir, S. (2017). Şizofreni ve bipolar bozukluğu olan hastalarda içselleştirilmiş damgalanma, benlik Saygısı ve algılanan sosyal destek. *Cukurova Medical Journal, 43*(1), 1–1. https://doi.org/10.17826/cumj.340622

Kokolakis, G., Wolk, K., Schneider-Burrus, S., Kalus, S., Barbus, S., Gomis-Kleindienst, S., & Sabat, R. (2020). Delayed diagnosis of Hidradenitis Suppurativa and its effect on patients and healthcare system. *Dermatology, 236*(5), 421–430. https://doi.org/10.1159/000508787

Korkmaz, L. (2016). Complex connections: How self-esteem and group identity relate to well-being and out-group negativity (Doctoral dissertation). https://d-nb.info/1116080370/34

Krajewski, P. K., Strobel, A., Schultheis, M., Staubach, P., Grabbe, S., Hennig, K., Matusiak, L., von Stebut, E., Garcovich, S., Bayer, H., Heise, M., Kirschner, U., Nikolakis, G., & Szepietowski, J. C. (2024). Hidradenitis suppurativa is associated with severe sexual impairment. *Dermatology, 240*(2), 205–215. https://doi.org/10.1159/000536128

Kromenacker, B., Maarouf, M., Hendricks, A., Hsiao, J., & Shi, V. (2019). 192 diagnostic delay in Hidradenitis Suppurativa. *Journal of Investigative Dermatology, 139*(5). https://doi.org/10.1016/j.jid.2019.03.268

Kurek, A., Peters, E. M. J., Chanwangpong, A., Sabat, R., Sterry, W., & Schneider-Burrus, S. (2012). Profound disturbances of sexual health in patients with Acne Inversa. *Journal of the American Academy of Dermatology, 67*(3). https://doi.org/10.1016/j.jaad.2011.10.024

Kusnanto, H., Agustian, D., & Hilmanto, D. (2018). Biopsychosocial model of illnesses in primary care: A hermeneutic literature review. *Journal of Family Medicine and Primary Care, 7*(3), 497. https://doi.org/10.4103/jfmpc.jfmpc_145_17

Lapins, J., Ye, W., Nyrén, O., & Emtestam, L. (2001). Incidence of cancer among patients with hidradenitis suppurativa. *Archives of Dermatology, 137*(6), 730–734. doi:10-1001/pubs.Arch Dermatol.-ISSN-0003-987x-137-6-dst 00132

Lee, J. H., Kwon, H. S., Jung, H. M., Kim, G. M., & Bae, J. M. (2018). Prevalence and comorbidities associated with Hidradenitis Suppurativa in Korea: A nationwide population-based study. *Journal of the European Academy of Dermatology and Venereology, 32*(10), 1784–1790. https://doi.org/10.1111/jdv.15071

Leventhal, H., Brisette, I., & Leventhal, E.A. (2003). The common-sense model of self-regulation of health and illness. In L.D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour*. London: Routledge.

Leventhal, H., Phillips, L. A., & Burns, E. (2016). The common-sense model of self-regulation (CSM): A Dynamic Framework for understanding illness self-management. *Journal of Behavioral Medicine, 39*(6), 935–946. https://doi.org/10.1007/s10865-016-9782-2

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*(1), 363–385. https://doi.org/10.1146/annurev.soc.27.1.363

Lockwood, K., Smith, K., Taylor, R., & Ahmed, A. (2023). Suicidal behaviour in psychodermatology patients: Identifying characteristics and a new model for referral. *Skin Health and Disease*, *3*(4). https://doi.org/10.1002/ski2.207

Lukkahatai, N. (2019). Integrative Review on Cognitive Behavioral therapy in chronic diseases: The responses predictors. *Iris Journal of Nursing & Care, 1*(5). https://doi.org/10.33552/ijnc.2019.01.000525

Mac Mahon, J., Kirthi, S., Byrne, N., O'Grady, C., & Tobin, A. (2020). An update on health-related quality of life and patient-reported outcomes in hidradenitis suppurativa. *Patient Related Outcome Measures, 11,* 21–26. https://doi.org/10.2147/prom.s174299

Machado, M. O., Stergiopoulos, V., Maes, M., Kurdyak, P. A., Lin, P.-Y., Wang, L.-J., Shyu, Y.-C., Firth, J., Koyanagi, A., Solmi, M., Alavi, A., Piguet, V., & Carvalho, A. F. (2019). Depression and anxiety in adults with Hidradenitis Suppurativa. *JAMA Dermatology, 155*(8), 939. https://doi.org/10.1001/jamadermatol.2019.0759

Maes, S., & Karoly, P. (2005). Self-regulation assessment and intervention in physical health and illness: A Review. *Applied Psychology, 54*(2), 267–299. https://doi.org/10.1111/j.1464-0597.2005.00210.x

Mann, C., Staubach, P., Grabbe, S., Wegner, J., Hennig, K., Nikolakis, G., Szepietowski, J. C., Matusiak, L., von Stebut, E., Kirschner, U., Podda, M., Garcovich, S., & Schultheis, M. (2023). Self-management-competency as a new target in Hidradenitis Suppurativa Care. *Journal of Dermatological Treatment, 34*(1). https://doi.org/10.1080/09546634.2023.2245082

Matusiak, Ł., Bieniek, A., & Szepietowski, J. (2010). Psychophysical aspects of Hidradenitis Suppurativa. *Acta Dermato Venereologica, 90*(3), 264–268. https://doi.org/10.2340/00015555-0866

Matusiak, Ł., Bieniek, A., & Szepietowski, J. C. (2010). Hidradenitis suppurativa markedly decreases quality of life and professional activity. *Journal of the American Academy of Dermatology, 62*(4). https://doi.org/10.1016/j.jaad.2009.09.021

Matusiak, Ł. (2018). Profound consequences of Hidradenitis Suppurativa: A Review. *British Journal of Dermatology, 183*(6). https://doi.org/10.1111/bjd.16603

Maung, H. H. (2018). Dualism and its place in a philosophical structure for psychiatry. *Medicine, Health Care and Philosophy, 22*(1), 59–69. https://doi.org/10.1007/s11019-018-9841-2

McMillan, K. (2014). Hidradenitis suppurativa: Number of diagnosed patients, demographic characteristics, and treatment patterns in the United States. *American Journal of Epidemiology, 179*(12), 1477–1483. https://doi.org/10.1093/aje/kwu078

Mendonça, C. O., & Griffiths, C. E. M. (2006). Clindamycin and rifampicin combination therapy for Hidradenitis Suppurativa. *British Journal of Dermatology, 154*(5), 977–978. https://doi.org/10.1111/j.1365-2133.2006.07155.x

Mete, H. E. (2008). Kronik hastalık ve depresyon. *Klinik Psikiyatri, 11*(3), 3-18.

Meyer, I. H. (2003). Prejudice, social stress, and Mental Health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin, 129*(5), 674–697. https://doi.org/10.1037/0033-2909.129.5.674

Michalek, I. M., Loring, B., & John, S. M. (2016). Global report on psoriasis. Geneva: World Health Organization. https://apps.who.int/iris/bitstream/handle/10665/204417/9789241565189_eng.pdf.psoriasis?sequence=1.

Micheletti, R. G. (2014). Hidradenitis suppurativa: Current views on epidemiology, pathogenesis, and pathophysiology. *Seminars in Cutaneous Medicine and Surgery, 33*(3), 48–50. https://doi.org/10.12788/j.sder.0091

Moini, J., LoGalbo, A., & Ahangari, R. (2024). Introduction. In *Foundations of the mind, Brain, and behavioral relationships: Understanding physiological psychology* (pp. 3–9). Academic Press, an imprint of Elsevier.

Mortimore, A. M., Bullen, A., & McMeniman, E. K. (2022). The impact of Hidradenitis Suppurativa on quality of life is worse than inflammatory bowel disease and myocardial infarction. *Australasian Journal of Dermatology, 63*(4), 505–508. https://doi.org/10.1111/ajd.13910

Murdock, G. P. (1980). Theories of illness: A world survey. George Peter Murdock. University of Pitsburgh Press. https://www.journals.uchicago.edu/doi/10.1086/412555

Murillo, A. Z. (2019). The contribution of active patient in chronic diseases, the present and the future of Health Assistance. *Endocrinología, Diabetes y Nutrición (English Ed.), 66*(9), 531–533. https://doi.org/10.1016/j.endien.2019.08.006

Myers, D.G., & Diener, E. (1995). Who is happy? *Psychological Science, 6,* 10-19. https://doi.org/10.1111/j.1467-9280.1995.tb00298.x

Nabi, R. L., Prestin, A., & So, J. (2013). Facebook friends with (health) benefits? exploring social network site use and perceptions of social support, stress, and well-being. *Cyberpsychology, Behavior, and Social Networking, 16*(10), 721–727. https://doi.org/10.1089/cyber.2012.0521

Nguyen, A. W., Chatters, L. M., Taylor, R. J., & Mouzon, D. M. (2015). Social support from family and friends and subjective well-being of older African Americans. *Journal of Happiness Studies, 17*(3), 959–979. https://doi.org/10.1007/s10902-015-9626-8

Nguyen, T. V., Damiani, G., Orenstein, L. A. V., Hamzavi, I., & Jemec, G. B. (2021). Hidradenitis suppurativa: An update on epidemiology, phenotypes, diagnosis, pathogenesis, comorbidities and quality of life. *Journal of the European Academy of Dermatology and Venereology, 35*(1), 50–61. https://doi.org/10.1111/jdv.16677

Nur'aeni, A., & Mirwanti, R. (2020). Acceptance, perceived benefits, and helplessness among coronary heart disease patients undergoing treatment in a different ward. *Padjadjaran Acute Care Nursing Journal, 1*(2). https://doi.org/10.24198/pacnj.v1i2.27999

Oakley, Ann. (2022). Social Support and motherhood. Policy Press.

Ogden, J. (1997). Health Psychology. Buckingham: Open University Press.

Ogden, J. (2012). Health Psychology: A Textbook. Open University Press.

Onderdijk, A. J., van der Zee, H. H., Esmann, S., Lophaven, S., Dufour, D. N., Jemec, G. B. E., & Boer, J. (2013). Depression in patients with Hidradenitis Suppurativa. *Journal of the European Academy of Dermatology and Venereology, 27*(4), 473–478. https://doi.org/10.1111/j.1468-3083.2012.04468.x

Ovadja, Z. N., Schuit, M. M., Horst, C. M. A. M., & Lapid, O. (2019). Inter- and intrarater reliability of Hurley staging for Hidradenitis Suppurativa. *British Journal of Dermatology, 181*(2), 344–349. https://doi.org/10.1111/bjd.17588

Pakenham, K. I. (2007). The nature of benefit finding in multiple sclerosis (MS). *Psychology, Health, & Medicine, 12,* 190-196. Doi: 10.1080/13548500500465878.

Park, C. L. (2010). Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events. *Psychological Bulletin, 136*(2), 257–301. https://doi.org/10.1037/a0018301

Patel, A., Sharma, P. V., Kumar, P., & Binu, V. (2018). Illness cognitions, anxiety, and depression in men and women undergoing fertility treatments: A dyadic approach. *Journal of Human Reproductive Sciences, 11*(2), 180. https://doi.org/10.4103/jhrs.jhrs_119_17

Patel, K. R., Rastogi, S., Singam, V., Lee, H. H., Amin, A. Z., & Silverberg, J. I. (2019). Association between hidradenitis suppurativa and hospitalization for psychiatric disorders: A cross-sectional analysis of the national inpatient sample. *British Journal of Dermatology, 181*(2), 275–281. https://doi.org/10.1111/bjd.17416

Patel, Z. S., Hoffman, L. K., Buse, D. C., Grinberg, A. S., Afifi, L., Cohen, S. R., Lowes, M. A., & Seng, E. K. (2017). Pain, psychological comorbidities, disability, and impaired qualify of life in Hidradenitis Suppurativa. *Current Pain and Headache Reports, 21*(12). https://doi.org/10.1007/s11916-017-0647-3

Patterson, A. (2024). Jaad game changer: “Psoriasis and Suicidality: A systematic review and meta-analysis.” *Journal of the American Academy of Dermatology, 90*(2), 348. https://doi.org/10.1016/j.jaad.2023.08.034

Pavon Blanco, A., Turner, M. A., Petrof, G., & Weinman, J. (2018). To what extent do disease severity and illness perceptions explain depression, anxiety and quality of life in Hidradenitis Suppurativa? *British Journal of Dermatology, 180*(2), 338–345. https://doi.org/10.1111/bjd.17123

Perche, P. O., Singh, R., Senthilnathan, A., Feldman, S. R., & Pichardo, R. O. (2022). Hidradenitis Suppurativa’s impact on social activities: An observational study. *Cureus, 14*(5). https://doi.org/10.7759/cureus.25292

Phan, K., Loya, A., Ramachandran, V., & Smith, S. D. (2019). Hidradenitis Suppurativa and risk of suicide – systematic review and meta-analysis. *Journal of Dermatological Treatment, 31*(6), 615–616. https://doi.org/10.1080/09546634.2019.1613483

Philpot, L. M., Ramar, P., Roellinger, D. L., Barry, B. A., Sharma, P., & Ebbert, J. O. (2021). Changes in social relationships during an initial “stay-at-home” phase of the COVID-19 pandemic: A longitudinal survey study in the U.S. *Social Science & Medicine, 274*, 113779. https://doi.org/10.1016/j.socscimed.2021.113779

Picardi, A., & Pasquini, P. (2007). Toward a biopsychosocial approach to skin diseases. *Advances in Psychosomatic Medicine, 28,* 109-126. doi: 10.1159/000106800.

Picardi, A., Abeni, D., Melchi, C. F., Puddu, P., & Pasquini, P. (2000). Psychiatric morbidity in dermatological outpatients: An issue to be recognized. *British Journal of Dermatology, 143*(5), 983–991. https://doi.org/10.1046/j.1365-2133.2000.03831.x

Picardi, Angelo, Lega, I., & Tarolla, E. (2013). Suicide risk in skin disorders. *Clinics in Dermatology, 31*(1), 47–56. https://doi.org/10.1016/j.clindermatol.2011.11.006

Picardi, Angelo, Pasquini, P., Abeni, D., Fassone, G., Mazzotti, E., & Fava, G. A. (2005). Psychosomatic assessment of skin diseases in clinical practice. *Psychotherapy and Psychosomatics, 74*(5), 315–322. https://doi.org/10.1159/000086323

Picardi, Damiano Abeni, Cristina Re, A. (2001). Increased psychiatric morbidity in female outpatients with skin lesions on visible parts of the body. *Acta Dermato-Venereologica, 81*(6), 410–414. https://doi.org/10.1080/000155501317208345

Pink, A. E., Simpson, M. A., Desai, N., Dafou, D., Hills, A., Mortimer, P., Smith, C. H., Trembath, R. C., & Barker, J. N. W. (2012). Mutations in the γ-secretase genes NCSTN , PSENEN , and PSEN1 underlie rare forms of hidradenitis suppurativa (acne inversa). *Journal of Investigative Dermatology, 132*(10), 2459–2461. https://doi.org/10.1038/jid.2012.162

Power, P. W., & Dell Orto, A. E. (2004). Impact of Illness and Disability on Adults. In Families living with chronic illness and disability: Interventions, Challenges, and Opportunities. Springer.

Quinn, D. M., & Chaudoir, S. R. (2009). Living with a concealable stigmatized identity: The impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health. *Journal of Personality and Social Psychology, 97*(4), 634–651. https://doi.org/10.1037/a0015815

Quinn, D. M., & Chaudoir, S. R. (2015). Living with a concealable stigmatized identity: The impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health. *Stigma and Health, 1*(S), 35–59. https://doi.org/10.1037/2376-6972.1.s.35

Quinn, D. M., & Earnshaw, V. A. (2013). Concealable stigmatized identities and psychological well-being. *Social and Personality Psychology Compass, 7*(1), 40–51. https://doi.org/10.1111/spc3.12005

Quinto, R. M., Mastroeni, S., Sampogna, F., Fania, L., Fusari, R., Iani, L., & Abeni, D. (2021). Sexuality in persons with Hidradenitis Suppurativa: Factors associated with sexual desire and functioning impairment. *Frontiers in Psychiatry, 12,* 1-7. https://doi.org/10.3389/fpsyt.2021.729104

Rambhatla, P. V., Lim, H. W., & Hamzani, I. (2012). A systematic review of treatments for hidradenitis suppurativa. *Archives of Dermatology, 148*(4), 439-446. Doi: 10.1001/archdermatol.2011.1950

Revuz, J. (2015). Hidradenitis Supurativa. *EMC - Dermatología, 49*(1), 1–16. https://doi.org/10.1016/s1761-2896(15)70045-2

Robinson, V. (2023). Pathfinders in medicine. Legare Street Press.

Rodriguez, M. S. and Cohen, S. (1998). Social support. Encyclopedia of Mental Health. Academic Press, New York.

Ros, S., Puig, L., & Carrascosa, J. M. (2014). Cumulative life course impairment: The imprint of psoriasis on the patient’s life. *Actas Dermo-Sifiliográficas (English Edition), 105*(2), 128–134. https://doi.org/10.1016/j.adengl.2013.02.018

Rose, G. (1992). The strategy of preventive medicine. Oxford: Oxford University Press.

Rose, G. (2023). The strategy of Preventive Medicine. Oxford University Press.

Sabat, R., Tsaousi, A., Ghoreschi, K., Wolk, K., & Schneider-Burrus, S. (2022). Sex-disaggregated population analysis in patients with Hidradenitis Suppurativa. *Frontiers in Medicine, 9*. https://doi.org/10.3389/fmed.2022.1028943

Sampogna, F., Abeni, D., Gieler, U., Tomas-Aragones, L., Lien, L., Titeca, G., Jemec, G., Misery, L., Szabó, C., Linder, M., Evers, A., Halvorsen, J., Balieva, F., Szepietowski, J., Romanov, D., Marron, S., Altunay, I., Finlay, A., Salek, S., … Dalgard, F. (2017). Impairment of sexual life in 3,485 dermatological outpatients from a multicentre study in 13 European countries. *Acta Dermato Venereologica*, *97*(4), 478–482. https://doi.org/10.2340/00015555-2561

Scheinfeld, N. (2014). An atlas of the morphological manifestations of Hidradenitis Suppurativa. *Dermatology Online Journal, 20*(4). https://doi.org/10.5070/d3204022373

Schneider-Burrus, S., Jost, A., Peters, E. M., Witte-Haendel, E., Sterry, W., & Sabat, R. (2018). Association of hidradenitis suppurativa with body image. *JAMA Dermatology, 154*(4), 447. https://doi.org/10.1001/jamadermatol.2017.6058

Schrader, A. M. R., Deckers, I. E., van der Zee, H. H., Boer, J., & Prens, E. P. (2014). Hidradenitis suppurativa: A retrospective study of 846 Dutch patients to identify factors associated with disease severity. *Journal of the American Academy of Dermatology, 71*(3), 460–467. https://doi.org/10.1016/j.jaad.2014.04.001

Schultheis, M., Grabbe, S., Staubach, P., Hennig, K., Mauch, M., Burckhardt, M., Langer, G., Heise, M., Zamsheva, M., Schollenberger, L., & Strobel, A. (2023). Drivers of disease severity and burden of Hidradenitis Suppurativa: A cross-sectional analysis on 553 German patients. *International Journal of Dermatology, 63*(2), 188–195. https://doi.org/10.1111/ijd.16889

Seligman, M. E. P., & Csikszentmilhalyi, M. (2000). Positive psychology: An introduction. *American Psychologist, 55*(1), 5-14. https://doi.org/10.1037/0003-066X.55.1.5

Senthilnathan, A., Kolli, S. S., Cardwell, L. A., Richardson, I. M., Feldman, S. R., & Pichardo, R. O. (2019). Emotional well-being is impaired in Hidradenitis Suppurativa patients. *Skin Appendage Disorders, 5*(6), 366–369. https://doi.org/10.1159/000502296

Seyed Jafari, S. M., Hunger, R. E., & Schlapbach, C. (2020). Hidradenitis suppurativa: Current understanding of pathogenic mechanisms and suggestion for treatment algorithm. *Frontiers in Medicine, 7*. https://doi.org/10.3389/fmed.2020.00068

Shavit, E., Dreiher, J., Freud, T., Halevy, S., Vinker, S., & Cohen, A. D. (2015). Psychiatric comorbidities in 3207 patients with Hidradenitis Suppurativa. *Journal of the European Academy of Dermatology and Venereology, 29*(2), 371–376. https://doi.org/10.1111/jdv.12567

Shi, V. Y., Hsiao, J. L., Muscianisi, E., Nguyen, E., Darcy, J., & Kirby, J. S. (2022). A survey of dermatologist perspectives on disease management of patients with Hidradenitis Suppurativa. *JAAD International, 9*, 94–96. https://doi.org/10.1016/j.jdin.2022.08.023

Short, K. A., Kalu, G., Mortimer, P. S., & Higgins, E. M. (2005). Vulval squamous cell carcinoma arising in chronic hidradenitis suppurativa. *Clinical and Experimental Dermatology, 30*(5), 481–483. https://doi.org/10.1111/j.1365-2230.2005.01875.x

Shukla, N., Paul, M., Halley, M., Lowes, M. A., Hester, V., Aguilar, C., Guilbault, S., Long, T. S., Taylor, A., Thompson, A. C., Yannuzzi, C. A., Linos, E., & Naik, H. B. (2020). Identifying barriers to care and research in Hidradenitis Suppurativa: Findings from a patient engagement event. *British Journal of Dermatology, 182*(6), 1490–1492. https://doi.org/10.1111/bjd.18818

Singh, R., Kelly, K. A., Paris, P. H., Senthilnathan, A., Feldman, S. R., & Pichardo, R. O. (2023). Social support is associated with reduced impact of Hidradenitis

Suppurativa on quality of life: An observational study. *Dermatology Online Journal, 29*(1). https://doi.org/10.5070/d329160222

Sisic, M., Tan, J., & Lafreniere, K. D. (2017). Hidradenitis Suppurativa, intimate partner violence, and sexual assault. *Journal of Cutaneous Medicine and Surgery, 21*(5), 383–387. https://doi.org/10.1177/1203475417708167

Slade, D. E. M., Powell, B. W., & Mortimer, P. S. (2003). Hidradenitis suppurativa: Pathogenesis and management. *British Journal of Plastic Surgery, 56*(5), 451–461. https://doi.org/10.1016/s0007-1226(03)00177-2

Smith, R. C., Fortin, A. H., Dwamena, F., & Frankel, R. M. (2013). An evidence-based patient-centered method makes the Biopsychosocial Model Scientific. *Patient Education and Counseling, 91*(3), 265–270. https://doi.org/10.1016/j.pec.2012.12.010

Stangl, A. L., Earnshaw, V. A., Logie, C. H., van Brakel, W., C. Simbayi, L., Barré, I., & Dovidio, J. F. (2019). The health stigma and discrimination framework: A global, crosscutting framework to inform research, Intervention Development, and policy on health-related stigmas. *BMC Medicine*, *17*(1). https://doi.org/10.1186/s12916-019-1271-3

Tabachnick, B. G., & Fidell, L. S. (2013). Using Multivariate Statistics (6th ed.). Boston, MA: Pearson.

Taylor, R. R. (2005). Cognitive Behavioral Therapy for Chronic Illness and Disability. Springer.

Taylor, S. E (1995). Health Psychology. (3rd ed.). Mc Graw-Hill. New York.

Taylor, S. E. (2012). Health Psychology. (8th ed.). Mc Graw-Hill. New York.

Tesfaw, G., Kibru, B., & Ayano, G. (2020). Prevalence and factors associated with higher levels of perceived stigma among people with schizophrenia Addis Ababa, Ethiopia. *International Journal of Mental Health Systems, 14*(1). https://doi.org/10.1186/s13033-020-00348-9

Theut Riis, P., Pedersen, O. B., Sigsgaard, V., Erikstrup, C., Paarup, H. M., Nielsen, K. R., Burgdorf, K. S., Hjalgrim, H., Rostgaard, K., Banasik, K., Ullum, H., & Jemec, G. B. (2018). Prevalence of patients with self-reported Hidradenitis Suppurativa in a cohort of Danish blood donors: A cross-sectional study. *British Journal of Dermatology, 180*(4), 774–781. https://doi.org/10.1111/bjd.16998

Thompson, A. M., Rick, J. W., De, D. R., Fernandez, J. M., Maarouf, M., Seivright, J. R., Hsiao, J. L., & Shi, V. Y. (2022). Relationship disturbances in hidradenitis suppurativa: A patient perspective. *Skin Appendage Disorders, 8*(6), 448–453. https://doi.org/10.1159/000525131

Thorlacius, L., Cohen, A. D., Gislason, G. H., Jemec, G. B. E., & Egeberg, A. (2018). Increased suicide risk in patients with Hidradenitis Suppurativa. *Journal of Investigative Dermatology, 138*(1), 52–57. https://doi.org/10.1016/j.jid.2017.09.008

Thorlacius, L., Esmann, S., Miller, I., Vinding, G., & Jemec, G. B. E. (2019). Development of HISQOL: A hidradenitis suppurativa-specific quality of life instrument. *Skin Appendage Disorders, 5*(4), 221–229. https://doi.org/10.1159/000496234

Tilles, G. (2006). Verneuil and Verneuil’s Disease: An Historical Overview. In *Hidradenitis Suppurativa* (pp. 4–9). Springer.

Topp, J., Andrees, V., Weinberger, N. A., Schäfer, I., Sommer, R., Mrowietz, U., Luck-Sikorski, C., & Augustin, M. (2019). Strategies to reduce stigma related to visible chronic skin diseases: A systematic review. *Journal of the European Academy of Dermatology and Venereology, 33*(11), 2029–2038. https://doi.org/10.1111/jdv.15734

Trialonis-Suthakharan, N., Pattinson, R., Tahmasebi Gandomkari, N., Austin, J., Janus, C., Courtier, N., Hewitt, R. M., Bundy, C., & Augustin, M. (2023).

Patient prioritization of impact items to develop the patient-reported impact of dermatological diseases (PRIDD) measure: European Delphi Data. *Journal of the European Academy of Dermatology and Venereology, 37*(7), 40–50. https://doi.org/10.1111/jdv.19266

Tsentemeidou, A., Vakirlis, E., Bakirtzi, K., Chatzi-Sotiriou, T., Lallas, A., Kiritsi, D., & Sotiriou, E. (2024). Diagnostic delay in Hidradenitis Suppurativa: A systematic review and novel data from a Greek cohort. *Australasian Journal of Dermatology, 65*(4)*,* 378–380. https://doi.org/10.1111/ajd.14247

Tzellos, T., Zouboulis, C. C., Gulliver, W., Cohen, A. D., Wolkenstein, P., & Jemec, G. B. E. (2015). Cardiovascular disease risk factors in patients with Hidradenitis Suppurativa: A systematic review and meta-analysis of observational studies. *British Journal of Dermatology, 173*(5)*,* 1142–1155. https://doi.org/10.1111/bjd.14024

Van Alboom, M., De Ruddere, L., Kindt, S., Loeys, T., Van Ryckeghem, D., Bracke, P., Mittinty, M. M., & Goubert, L. (2021). Well-being and perceived stigma in individuals with rheumatoid arthritis and fibromyalgia. *The Clinical Journal of Pain, 37*(5)*,* 349–358. https://doi.org/10.1097/ajp.0000000000000929

Van Beugen, S., Schut, C., Kupfer, J., Bewley, A. P., Finlay, A. Y., Gieler, U., Thompson, A. R., Grazia-Cazaña, T., Balieva, F., Ferreira, B. R., Jemec, G. B., Lien, L., Misery, L., Marron, S. E., Ständer, S., Zeidler, C., Szabó, C., Szepietowski, J. C., Reich, A., … Dalgard, F. J. (2023). Perceived stigmatization among dermatological outpatients compared with controls: An observational multicentre study in 17 European countries. *Acta Dermato-Venereologica, 103*. https://doi.org/10.2340/actadv.v103.6485

Van Beugen, S., van Middendorp, H., Ferwerda, M., Smit, J. V., Zeeuwen-Franssen, M. E. J., Kroft, E. B. M., de Jong, E. M. G. J., Donders, A. R. T., van de Kerkhof, P. C. M., & Evers, A. W. M. (2017). Predictors of perceived stigmatization in patients with psoriasis. *British Journal of Dermatology, 176*(3), 687–694. https://doi.org/10.1111/bjd.14875

Van Brakel, W. H. (2006). Measuring health-related stigma-a literature review. *Psychology, Health & Medicine, 11*(3), 307–334. https://doi.org/10.1080/13548500600595160

Vangipuram, R., Vaidya, T., Jandarov, R., & Alikhan, A. (2016). Factors contributing to depression and chronic pain in patients with Hidradenitis Suppurativa: Results from a single-center retrospective review. *Dermatology, 232*(6), 692–695. https://doi.org/10.1159/000453259

Vasey, F. B., Fenske, N. A., Clement, G. B., Bridgeford, P. H., Germain, B. F., & Espinoza, L. R. (1984). Immunological studies of the arthritis of acne conglobata and hidradenitis suppurativa. *Clinical and Experimental Rheumatology, 2*(4), 309–311.

Vazquez, B. G., Alikhan, A., Weaver, A. L., Wetter, D. A., & Davis, M. D. (2013). Incidence of hidradenitis suppurativa and associated factors: A population-based study of Olmsted County, Minnesota. *Journal of Investigative Dermatology, 133*(1), 97–103. https://doi.org/10.1038/jid.2012.255

Velpeau, A. L. A. (1833). Aisselle, phlegmons, abcès. In *Dictionnaire de Médecine ou répertoire général des sciences médicales* (2nd ed., Vol. 2, pp. 91–101). Nabu Press.

Vivar, K. L., & Kruse, L. (2018). The impact of pediatric skin disease on self-esteem. *International Journal of Women's Dermatology, 4*(1), 27–31. https://doi.org/10.1016/j.ijwd.2017.11.002

Von Bertalanffy, L. (1967). General theory of systems : Application to psychology. *Social Science Information, 6*(6), 125–136. https://doi.org/10.1177/053901846700600610

Von Stülpnagel, C. C., Augustin, M, Düpmann, L., da Silva, N., & Sommer, R. (2021). Mapping risk factors for cumulative life course impairment in patients with chronic skin diseases – a systematic review. *Journal of the European Academy of Dermatology and Venereology, 35*, 2166-2184. doi: 10.1111/jdv.17348.

Wade, D. (2015). Rehabilitation – a new approach. part Two: The underlying theories. *Clinical Rehabilitation, 29*(12), 1145–1154. https://doi.org/10.1177/0269215515601175

Wade, D. T., & Halligan, P. W. (2017). The biopsychosocial model of illness: A model whose time has come. *Clinical Rehabilitation, 31*(8), 995–1004. https://doi.org/10.1177/0269215517709890

Wallston, K. A., & Wallston, B. S. (1982). Health locus of Control Scales. *Research with the Locus of Control Construct*, 189–243. https://doi.org/10.1016/b978-0-12-443201-7.50010-5

Warren, R. B., Kleyn, C. E., & Gulliver, W. P. (2011). Cumulative life course impairment in psoriasis: Patient perception of disease-related impairment throughout the life course. *British Journal of Dermatology, 164*, 1–14. https://doi.org/10.1111/j.1365-2133.2011.10280.x

Weigelt, M. A., Milrad, S. F., Kirby, J. R., & Lev-Tov, H. (2021). Psychosocial impact of Hidradenitis Suppurativa: A practical guide for clinicians. *Journal of Dermatological Treatment, 33*(4), 1861–1868. https://doi.org/10.1080/09546634.2021.1937483

Weiner, S. J., Schwartz, A., Sharma, G., Binns-Calvey, A., Ashley, N., Kelly, B., Dayal, A., Patel, S., Weaver, F. M., & Harris, I. (2013). Patient-centered decision making and health care outcomes. *Annals of Internal Medicine, 158*(8), 573. https://doi.org/10.7326/0003-4819-158-8-201304160-00001

Wertenteil, S., Strunk, A., & Garg, A. (2018). Association of low socioeconomic status with Hidradenitis Suppurativa in the United States. *JAMA Dermatology, 154*(9), 1086. https://doi.org/10.1001/jamadermatol.2018.2117

Weston, W. W. (2005). Patient-centered medicine: A guide to the biopsychosocial model. *Families, Systems, & Health, 23*(4), 387–392. https://doi.org/10.1037/1091-7527.23.4.387

Wieczorek, M., & Walecka, I. (2018). Hidradenitis suppurativa – known and unknown disease. *Rheumatology, 56*(6), 337–339. https://doi.org/10.5114/reum.2018.80709

Wills, T. A. (1991). Social Support and Interpersonal Relationships. In Clark, M. S. ed., *Prosocial behavior*. Newbury Park, CA: Sage, 265 – 289.

Wittkowski, A., Richards, H. L., Griffiths, C. E. M., & Main, C. J. (2004). The impact of psychological and clinical factors on quality of life in individuals with atopic dermatitis. *Journal of Psychosomatic Research, 57*(2), 195–200. https://doi.org/10.1016/s0022-3999(03)00572-5

Wolkenstein, P., Loundou, A., Barrau, K., Auquier, P., & Revuz, J. (2007). Quality of life impairment in Hidradenitis Suppurativa: A study of 61 cases. *Journal of the American Academy of Dermatology, 56*(4), 621–623. https://doi.org/10.1016/j.jaad.2006.08.061

World Health Organization. (1958). The first ten years of the World Health Organization. Retrieved from https://www.who.int/publications/i/item/9789241560146

World Health Organization. (2022). International Statistical Classification of Diseases and Related Health Problems (ICD). Retrieved March 10, 2024, from https://www.who.int/classifications/classification-of-diseases

Wu, J. H., & Cohen, B. A. (2019). The stigma of skin disease. *Current Opinion in Pediatrics, 31*(4), 509–514. https://doi.org/10.1097/mop.0000000000000792

Yüksel, M., & Basım, P. (2020). Demographic and clinical features of Hidradenitis Suppurativa in Turkey. *Journal of Cutaneous Medicine and Surgery, 24*(1), 55–59. https://doi.org/10.1177/1203475419887732

Zachariae, R., Zachariae, C., Ibsen, H. H., Mortensen, J. T., & Wulf, H. C. (2004). Psychological symptoms and quality of life of dermatology outpatients and hospitalized dermatology patients. *Acta Dermato-Venereologica, 84*(3), 205–212. https://doi.org/10.1080/00015550410023284

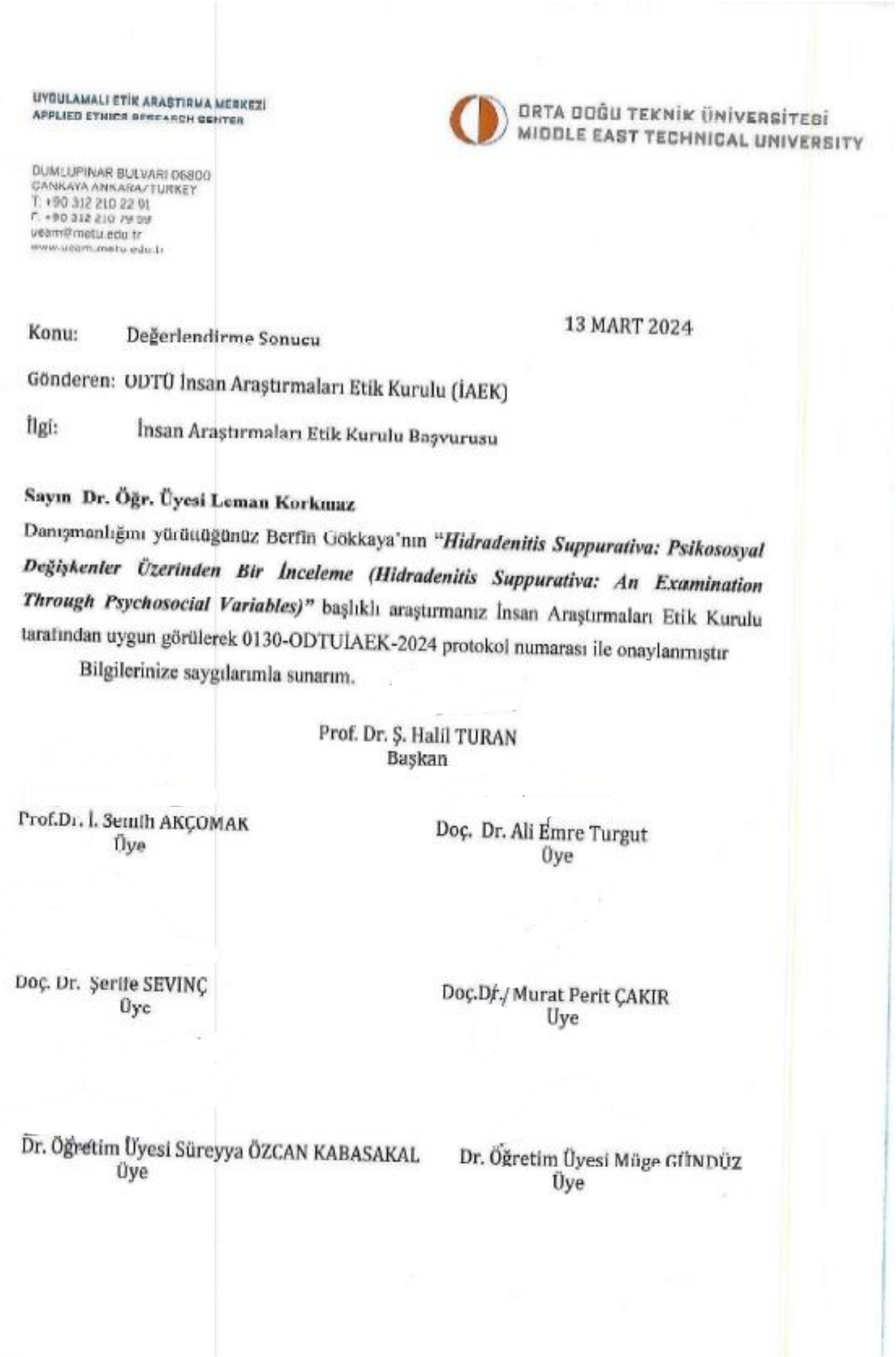
Zimman, S., Comparatore, M. V., Vulcano, A. F., Absi, M. L., & Mazzuoccolo, L. D. (2019). Hidradenitis Supurativa: Una aproximación a su prevalencia, Características Clínicas, Comorbilidades y Tiempo al diagnóstico, en un hospital Universitario de Buenos Aires, Argentina. *Actas Dermo-Sifiliográficas, 110*(4), 297–302. https://doi.org/10.1016/j.ad.2019.01.004

Zouboulis, C. C., del Marmol, V., Mrowietz, U., Prens, E. P., Tzellos, T., & Jemec, G. B. E. (2015). Hidradenitis Suppurativa/acne inversa: Criteria for diagnosis, severity assessment, classification and disease evaluation. *Dermatology, 231*(2), 184–190. https://doi.org/10.1159/000431175

Zouboulis, C. C., Desai, N., Emtestam, L., Hunger, R. E., Ioannides, D., Juhász, I., Lapins, J., Matusiak, L., Prens, E. P., Revuz, J., Schneider-Burrus, S., Szepietowski, J. C., van der Zee, H. H., & Jemec, G. B. (2015). European S1 guideline for the treatment of hidradenitis suppurativa/acne inversa. *Journal of the European Academy of Dermatology and Venereology, 29*(4), 619–644. https://doi.org/10.1111/jdv.12966

APPENDICES

A. APPROVAL OF THE METU HUMAN SUBJECTS ETHICS COMMITTEE



UYGULAMALI ETİK ARAŞTIRMA MERKEZİ
APPLIED ETHICS RESEARCH CENTER

ORTA DOĞU TEKNİK ÜNİVERSİTESİ
MIDDLE EAST TECHNICAL UNIVERSITY

DUMLUPINAR BULVARI 06800
ÇANKAYA ANKARA/TURKEY
T: +90 312 210 22 91
F: +90 312 210 79 59
ueam@metu.edu.tr
www.ueam.metu.edu.tr

13 MART 2024

Konu: Değerlendirme Sonucu

Gönderen: ODTÜ İnsan Araştırmaları Etik Kurulu (İAEK)

İlgi: İnsan Araştırmaları Etik Kurulu Başvurusu

Sayın Dr. Öğr. Üyesi Leman Korkmaz

Danışmanlığını yürüttüğünüz Berfin Gökkaya'nın ***"Hidradenitis Suppurativa: Psikososyal Değişkenler Üzerinden Bir İnceleme (Hidradenitis Suppurativa: An Examination Through Psychosocial Variables)"*** başlıklı araştırmanız İnsan Araştırmaları Etik Kurulu tarafından uygun görülerek 0130-ODTUİAEK-2024 protokol numarası ile onaylanmıştır

Bilgilerinize saygılarımla sunarım.

Prof. Dr. Ş. Halil TURAN
Başkan

Prof.Dr. İ. Semih AKÇOMAK
Üye

Doç. Dr. Ali Emre Turgut
Üye

Doç. Dr. Şerife SEVİNÇ
Üye

Doç.Dr. Murat Perit ÇAKIR
Üye

Dr. Öğretim Üyesi Süreyya ÖZCAN KABASAKAL
Üye

Dr. Öğretim Üyesi Müge GÜNDÜZ
Üye

B. INFORMED CONSENT FORM

Araştırmaya Gönüllü Katılım Formu

Bu araştırma, ODTÜ Psikoloji Bölümü Sosyal Psikoloji Yüksek lisans öğrencisi Arş. Gör. Berfin Gökkaya tarafından yüksek lisans tezi kapsamında Dr. Öğr. Üyesi Leman Korkmaz danışmanlığında yürütülmektedir. Bu form sizi araştırma koşulları hakkında bilgilendirmek adına hazırlanmıştır.

Çalışmanın Amacı Nedir?

Araştırmanın amacı, Hidradenitis Suppurativa tanısı almış bireylerin hastalık sürecindeki deneyimlerini incelemektir.

Bize Nasıl Yardımcı Olmanızı İsteyeceğiz?

Araştırmaya katılmayı kabul ederseniz, sizden beklenen, ankette yer alan bir dizi soruyu yanıtlamanızdır. Bu çalışmaya katılım ortalama olarak 25 dakika sürmektedir.

Sizden Topladığımız Bilgileri Nasıl Kullanacağız?

Araştırmaya katılımınız tamamen gönüllülük esasına dayanmaktadır. Ankette, sizden kimlik veya kurum belirleyici hiçbir bilgi istenmemektedir. Cevaplarınız tamamıyla gizli tutulacak, sadece araştırmacılar tarafından değerlendirilecektir. Katılımcılardan elde edilecek bilgiler toplu halde değerlendirilecek ve bilimsel amaçlı kullanılacaktır. Sağladığınız veriler gönüllü katılım formlarında toplanan kimlik bilgileri ile eşleştirilmeyecektir.

Katılımınızla ilgili bilmeniz gerekenler:

Anket, genel olarak kişisel rahatsızlık verecek sorular **içermemektedir**. Ancak, katılım sırasında sorulardan ya da herhangi başka bir nedenden ötürü kendinizi rahatsız hissederseniz çalışmayı yarıda bırakıp çıkmakta serbestsiniz. Böyle bir durumda anketi uygulayan kişiye, anketi **tamamlamadığınızı** söylemeniz yeterli olacaktır.

Araştırmayla ilgili daha fazla bilgi almak isterseniz:

Anket sonunda, bu çalışmayla ilgili sorularınız cevaplanacaktır. Bu çalışmaya katıldığınız için şimdiden teşekkür ederiz. Çalışma hakkında daha fazla bilgi almak için Psikoloji Bölümü öğretim üyelerinden Dr. Öğr. Üyesi Leman Korkmaz ya da Arş. Gör. Berfin Gökkaya ile iletişim kurabilirsiniz.

Yukarıdaki bilgileri okudum ve bu çalışmaya tamamen gönüllü olarak katılıyorum.

(Formu doldurup imzaladıktan sonra uygulayıcıya geri veriniz).

İsim-Soyisim	Tarih	İmza

C. DEMOGRAPHIC INFORMATION FORM

Demografik Bilgi Formu

❖ Aşağıdaki sorularda Hidradenitis Suppurativa hastalığı için “HS” kısaltması kullanılmıştır.

1. Adınız-Soyadınız: ______________________
2. Yaşınız: _______

3. Cinsiyetiniz:

☐ Kadın
☐ Erkek
☐ Diğer
☐ Sunulan seçenekler benim cinsiyet kimliğimi yansıtmıyor
☐ Kendimi ikili toplumsal cinsiyet sistemi üzerinden tanımlamıyorum
☐ Cevaplamak istemiyorum

4. Sosyo-ekonomik düzeyiniz:

☐ Alt sınıf
☐ Alt-orta sınıf
☐ Üst-orta sınıf
☐ Üst sınıf
☐ Çok yüksek sınıf

5. Medeni durumunuz:

☐ Bekar
☐ İlişkisi var
☐ Evli
☐ Boşanmış
☐ Eşini kaybetmiş

6. Öğrenci misiniz?

☐ Evet

☐ Hayır

(Evet ise) Şu anki Eğitim durumunuz:

☐ Lise öğrencisiyim.

☐ Yüksek okul (2 yıllık) öğrencisiyim.

☐ Üniversite (lisans) öğrencisiyim.

☐ Yüksek lisans öğrencisiyim.

☐ Doktora adayıyım.

☐ Cevaplamak istemiyorum.

(Hayır ise) Tamamladığınız en yüksek okul derecesi nedir?

☐ İlkokul

☐ Ortaokul

☐ Lise

☐ Yüksek okul (2 yıllık)

☐ Üniversite (lisans)

☐ Yüksek lisans

☐ Doktora

☐ Cevaplamak istemiyorum.

7. Kaç yaşında HS tanısı aldınız?

____

8. Kaç yıldır HS tanısına sahipsiniz?

____

9. Hastalığınız hangi seviye olarak belirlendi? (Başlangıç, orta, ileri | Hurley I-II-III)

____

10. Çekirdek ailenizde (anne, baba, kardeş) bildiğiniz bir HS geçmişi var mı? (Evet/hayır)

____

11. Geniş ailenizde (amca, dayı, hala, teyze, büyükanne, büyükbaba, kuzen, yeğen) bildiğiniz bir HS geçmişi var mı? (Evet/hayır)

____

12. Kronik hastalığınız var mı? (Kanser, tansiyon, diyabet, obezite, Crohn’s, vb.) Var ise, aşağıda hangi hastalık/lar olduğunu belirtiniz.

____

13. Hastalığınız için bir tedavi alıyor musunuz? (Evet/hayır) (Bu soruya yanıtınız evet ise, 14., 15. ve 16. Soruları yanıtlayınız. Hayır ise diğer ölçekleri çözerek çalışmaya devam edebilirsiniz.)

____

14. Kaç yıldır tedavi alıyorsunuz?

____

15. Hangi tedavileri aldınız ya da alıyorsunuz? (Antibiyotik, antiseptik, hormon tedavisi, ozon tedavisi, yara temizleme, kortizol iğnesi, ağrı kesici, ağrı kesici krem, skarlı (yaralı) bölge uzaklaştırması, deri nakli, ameliyat, vb.)

____

16. Yanlış tanı nedeniyle uzayan bir sürece maruz kaldınız mı? (Evet/hayır)

____

D. POSITIVE AND NEGATIVE AFFECT SCHEDULE (KORKMAZ, 2016)

Pozitif ve Negatif Duygu Durum Ölçeği

Lütfen son dört haftada yaşadıklarınızı düşününüz ve buna göre aşağıda belirtilen her bir duyguyu son dört haftada yaşama sıklığınızı 1 (Hiç/Çok Nadir) ve 5 (Çok Sık/Daima) arasında bir seçim yaparak işaretleyiniz.

	Hiç/Çok Nadir	Nadiren	Ara Sıra	Sık Sık	Çok Sık/Daima
1. Olumlu					
2. Olumsuz					
3. İyi					
4. Kötü					
5. Keyifli					
6. Keyifsiz					
7. Mutlu					
8. Üzgün					
9. Korkmuş					
10. Neşeli					
11. Kızgın					
12. Halinden memnun					

E. ILLNESS COGNITION QUESTIONNAIRE (AYKUL, 2018)

Hastalık Biliş Anketi

Aşağıda uzun süreli (kronik) hastalığı olan kişilerin açıklamaları yer almaktadır. Lütfen her bir ifadeyi dikkatlice okuduktan sonra 1 (Hiç değil) ve 4 (Tamamen) arasında bir rakam seçerek ifadelerin size ne kadar uyduğunu belirtiniz.

	Hiç Değil	Biraz	Büyük Ölçüde	Tamamen
1. Yapmayı en çok istediğim şeyleri hastalığım nedeniyle özlüyorum.				
2. Hastalığımla ilgili sorunları halledebilirim.				
3. Hastalığımla yaşamayı öğrendim.				
4. Hastalığımla uğraşmak beni çok güçlü bir insan yaptı.				
5. Hastalığım hayatımı kontrol ediyor.				
6. Hastalığımdan çok şey öğrendim.				
7. Hastalığım bazı zamanlar beni işe yaramaz hissettiriyor.				
8. Hastalığım hayatı benim için daha değerli yaptı.				
9. Hastalığım, gerçekten yapmaktan hoşlandığım şeyi yapmamı engelliyor.				
10. Hastalığım nedeniyle maruz kaldığım kısıtlamaları kabul etmeyi öğrendim.				
11. Geriye dönüp baktığımda, hastalığımın hayatıma aynı zamanda bazı olumlu değişiklikler de getirdiğini görebiliyorum.				
12. Hastalığım benim için önemli olan her şeyde beni kısıtlıyor.				
13. Hastalığımı tamamen kabul edebilirim.				
14. Hastalığım kötüye gitse bile sanırım hastalığımla ilgili problemleri halledebilirim.				
15. Hastalığım beni sık sık çaresiz hissettiriyor.				
16. Hastalığım hayatta neyin önemli olduğunun farkına varmamda bana yardımcı oldu.				
17. Hastalığımla etkili bir şekilde başa çıkabilirim.				
18. Hastalığım bana anın tadını çıkartmayı öğretti.				

F. PERCEIVED STIGMATIZATION SCALE (AKOĞLU ET AL., 2021)

Hidradenitis Suppurativa Hastaları için Algılanan Damgalanma Ölçeği

Aşağıdaki soruları dikkatlice okuyarak her bir ifadeye ne ölçüde katıldığınızı/katılmadığınızı işaretleyiniz.

		Hiçbir şekilde katılmıyorum	Kısmen katılıyorum	Çoğunlukla katılıyorum	Tamamen katılıyorum
1	Cilt hastalığım nedeniyle insanların beni çekici bulmadığını/bulmayacağını düşünüyorum.				
2	Cilt hastalığım nedeniyle insanların bana dokunmaktan rahatsız olduğunu/olacağını düşünüyorum.				
3	İnsanlar cilt hastalığımın bulaşıcı olduğunu/olacağını düşünür.				
4	İnsanların cilt hastalığım nedeniyle benden uzak durduğunu/duracağını düşünüyorum.				
5	İnsanlar bazen cilt hastalığımla ilgili canımı sıkan yorumlar yapıyor.				

G. ASSESSMENT FORM FOR THE IMPACT OF RECEIVING A DIAGNOSIS OF HIDRADENITIS SUPPURATIVA (HS) ON RELATIONSHIP WITH CLOSE OTHERS

Hidradenitis Suppurativa (HS) Tanısı Almanın Yakın İlişkiler Üzerindeki Etkisine Yönelik Değerlendirme Formu

- Aşağıdaki sorular genel yakın ilişkilerinizle (aile, sosyal ve romantik) ilgilidir. Bazı sorulara yanıt **"evet/hayır"** şeklindedir; bu soruların sonunda parantez içinde "(Evet/hayır)" ibaresi yer almaktadır.
- Diğer sorular için, cevaplarınızı size verilen ölçek üzerinde işaretleyiniz.
- **HS: Hidradenitis Suppurativa**

- Aşağıdaki soruları çözerken romantik ilişkilerinizi göz önünde bulundurunuz.

1. Romantik partneriniz var mı? (Evet/hayır.) (Bu soruya yanıtınız hayır ise, yalnızca 9. ve 10. soruları yanıtlayınız.)

____

2. HS tanısını ilişkinizin başlangıcından önce mi aldınız? (Evet/hayır.)

____

3. Hastalığınızı partnerinizle paylaştınız mı? (Evet/hayır.) (Bu soruya yanıtınız evet ise, 4., 5. ve 6. soruları yanıtlayınız. Hayır ise, 6. sorudan devam ediniz.)

____

4. HS tanınızı partnerinizle paylaşmak sizin için nasıl bir deneyimdi?

Çok Olumsuz — Nötr — Çok Olumlu

1	2	3	4	5	6	7	8	9

5. HS tanınızı paylaştıktan sonra, partnerinizin sürecinize desteğini nasıl değerlendirirsiniz?

Çok Olumsuz — Nötr — Çok Olumlu

1	2	3	4	5	6	7	8	9

6. HS tanısı almanız partnerinizle olan ilişkinizi genel olarak nasıl etkiledi?

Çok Olumsuz — Nötr — Çok Olumlu

1	2	3	4	5	6	7	8	9

7. Partnerinizle aktif bir cinsel yaşamınız var mı? (Evet/hayır.) (Bu soruya yanıtınız evet ise, yalnızca 8. soruyu yanıtlayınız. Hayır ise, diğer ölçeğe geçiniz.)

____

8. HS tanısı almanız partnerinizle olan cinsel yaşamınızı nasıl etkiledi?

Çok Olumsuz				Nötr				Çok Olumlu
1	2	3	4	5	6	7	8	9

9. HS tanısını almış olmanız, romantik ilişki kurmak adına olası girişimlerinizi nasıl etkiledi?

Çok Olumsuz				Nötr				Çok Olumlu
1	2	3	4	5	6	7	8	9

10. HS tanısı aldıktan sonra bir romantik ilişkiniz olursa, tanınızı partnerinizle paylaşır mısınız? (Evet/hayır.)

____

Ayrıca belirtmek istedikleriniz var ise aşağıdaki boşluğa yazabilirsiniz:

____

❖ Aşağıdaki soruları çözerken yakın aile bireylerinizi (anne, baba ve kardeş/ler) göz önünde bulundurunuz.

1. Anneniz hayatta mı? (Evet/hayır.) (Bu soruya yanıtınız hayır ise, 6. sorudan devam ediniz.)

____

2. HS tanınızı annenizle paylaştınız mı? (Evet/hayır.) (Bu soruya yanıtınız hayır ise, 6. sorudan devam ediniz.)

____

3. HS tanınızı annenizle paylaşmak sizin için nasıl bir deneyimdi?

Çok Olumsuz				Nötr				Çok Olumlu
1	2	3	4	5	6	7	8	9

4. HS tanınızı paylaştıktan sonra, annenizin sürecinize desteğini nasıl değerlendirirsiniz?

Çok Olumsuz				Nötr				Çok Olumlu
1	2	3	4	5	6	7	8	9

5. HS tanısı almanız annenizle olan ilişkinizi genel olarak nasıl etkiledi?

Çok Çok

Olumsuz Nötr Olumlu

1	2	3	4	5	6	7	8	9

6. Babanız hayatta mı? (Evet/hayır.) (Bu soruya yanıtınız hayır ise, 11. sorudan devam ediniz.)

____

7. HS tanınızı babanızla paylaştınız mı? (Evet/hayır.) (Bu soruya yanıtınız hayır ise, 10. sorudan devam ediniz.)

____

8. HS tanınızı babanızla paylaşmak sizin için nasıl bir deneyimdi?

Çok Olumsuz Nötr Çok Olumlu

1	2	3	4	5	6	7	8	9

9. HS tanınızı paylaştıktan sonra, babanızın sürecinize desteğini nasıl değerlendirirsiniz?

Çok Olumsuz Nötr Çok Olumlu

1	2	3	4	5	6	7	8	9

10. HS tanısı almanız babanızla olan ilişkinizi genel olarak nasıl etkiledi?

Çok Olumsuz Nötr Çok Olumlu

1	2	3	4	5	6	7	8	9

11. Kaç kardeşiniz var? (Kardeşiniz yok ise, kalan sorulara yanıt vermeyiniz. Birden fazla kardeşiniz varsa, gelecek sorulara kardeşlerinizin genel tepkilerini düşünerek ortalama bir cevap veriniz.)

12. HS tanınızı kardeş/lerinizle paylaştınız mı? (Evet/hayır.) (Bu soruya yanıtınız hayır ise, yalnızca 15. Soruyu yanıtlayıp diğer ölçeğe geçiniz.)

____

13. HS tanınızı kardeş/lerinizle paylaşmak sizin için nasıl bir deneyimdi?

Çok Olumsuz Nötr Çok Olumlu

1	2	3	4	5	6	7	8	9

14. HS tanınızı paylaştıktan sonra, kardeş/lerinizin sürecinize desteğini nasıl değerlendirirsiniz?

Çok Olumsuz Nötr Çok Olumlu

1	2	3	4	5	6	7	8	9

15. HS tanısı almanız kardeş/lerinizle olan ilişkinizi genel olarak nasıl etkiledi?

Çok Olumsuz — Nötr — Çok Olumlu

1	2	3	4	5	6	7	8	9

Ayrıca belirtmek istedikleriniz var ise aşağıdaki boşluğa yazabilirsiniz:

____

❖ Aşağıdaki soruları çözerken yakın arkadaş çevrenizi göz önünde bulundurunuz. “Yakın arkadaş” terimiyle her şey hakkında konuşabileceğiniz, sağlam güven bağına sahip olduğunuz, yargılanma korkusu olmadan kendinizi rahat hissetmenizi sağlayacak kişiler kastedilmiştir.

1. HS tanınızı yakın kadın arkadaş/larınızla paylaştınız mı? (Evet/hayır.) (Bu soruya yanıtınız hayır ise, 4. sorudan devam ediniz.)

____

2. HS tanınızı yakın kadın arkadaş/larınızla paylaşmak sizin için nasıl bir deneyimdi?

Çok Olumsuz — Nötr — Çok Olumlu

1	2	3	4	5	6	7	8	9

3. HS tanınızı paylaştıktan sonra, yakın kadın arkadaş/larınızın sürecinize desteğini nasıl değerlendirirsiniz?

Çok Olumsuz — Nötr — Çok Olumlu

1	2	3	4	5	6	7	8	9

4. HS tanısı almanız yakın kadın arkadaş/larınızla olan ilişkinizi genel olarak nasıl etkiledi?

Çok Olumsuz — Nötr — Çok Olumlu

1	2	3	4	5	6	7	8	9

5. HS tanınızı yakın erkek arkadaş/larınızla paylaştınız mı? (Evet/hayır.) (Bu soruya yanıtınız hayır ise, yalnızca 8., 9., ve 10. Soruları yanıtlayınız.)

____

6. HS tanınızı yakın erkek arkadaş/larınızla paylaşmak sizin için nasıl bir deneyimdi?

Çok Olumsuz				Nötr				Çok Olumlu
1	2	3	4	5	6	7	8	9

7. HS tanınızı paylaştıktan sonra, yakın erkek arkadaş/larınızın sürecinize desteğini nasıl değerlendirirsiniz?

Çok Olumsuz				Nötr				Çok Olumlu
1	2	3	4	5	6	7	8	9

8. HS tanısı almanız yakın erkek arkadaş/larınızla olan ilişkinizi genel olarak nasıl etkiledi?

Çok Olumsuz				Nötr				Çok Olumlu
1	2	3	4	5	6	7	8	9

9. HS tanısı almış olmanız, arkadaşlık kurmak adına olası girişimlerinizi nasıl etkiledi?

Çok Olumsuz				Nötr				Çok Olumlu
1	2	3	4	5	6	7	8	9

10. HS tanısı aldıktan sonra bir arkadaşlık kurarsanız, tanınızı arkadaşınızla paylaşır mısınız? (Evet/hayır.)

____

Ayrıca belirtmek istedikleriniz var ise aşağıdaki boşluğa yazabilirsiniz:

____

H. TURKISH SUMMARY / TÜRKÇE ÖZET

GİRİŞ

1.1. Genel Giriş

Hidradenitis Suppurativa (HS), ter bezleri içeren cilt bölgelerinde terminal foliküler epitelin bozulmasıyla karakterize, durmaksızın ilerleyen ve hareketsizliğe yol açan, gözle görülür, kronik, akıntılı bir cilt hastalığıdır (Zouboulis ve ark., 2015). Hastalığın genel prevalansına bakıldığında, genel nüfusun %1'inin HS'ye sahip olduğu, kadınlarda %4'e varan daha yüksek bir prevalans olduğu ve başlangıcının tipik olarak genç yetişkinlikte ortaya çıktığı tahmin edilmektedir (Jemec ve ark., 1996). Hurley klinik evreleme sistemi, HS hastalarını hastalık şiddetine göre üç gruba ayırır: Hurley I hafif şiddeti, Hurley II orta şiddeti ve Hurley III şiddetli hastalığı temsil eder (Wieczorek & Walecka, 2018). Görünür cilt hastalıkları hastalar için yalnızca fiziksel zorluklar yaratmakla kalmaz, aynı zamanda psikososyal refahları üzerinde de zararlı bir etkiye sahiptir (Germain ve ark., 2021). Özellikle HS, hastaların ruh sağlığı üzerinde derin bir etkiye sahiptir (Phan ve ark., 2020). Psikolojik sıkıntı, utanç duyguları (Mac Mahon ve ark., 2020), düşük yaşam kalitesi (Matusiak, 2018), daha yüksek depresyon oranları (Onderdijk ve ark., 2013), anksiyete, düşük benlik saygısı (Vivar ve Kruse, 2018), cinsel sıkıntı (Kurek ve ark., 2012) ve kişisel ve yakın ilişkilerdeki zorluklarla bağlantılıdır (Mac Mahon ve ark., 2020).

Bu çalışmada temel amacımız, araştırmamızı Biyopsikososyal Model (BPSM) etrafında şekillendirerek HS'li bireylerin tanı sonrası psikososyal açıdan nasıl etkilendiklerini araştırmaktır. HS'yi araştıran çalışmalar, hastalığın fiziksel etkilerinin yanı sıra bazı psikolojik ve sosyal yönlerine de değinmelerine rağmen, neden olduğu psikososyal sorunları genellikle tam olarak ele almamaktadır. Mevcut araştırmalar, hastalık duygusal durumu etkilerken, hastaların aynı zamanda damgalanma (Revuz, 2015) ve karşılaştıkları zorluklar nedeniyle yakın ilişkilerde bozulma (Mac Mahon ve ark., 2020) ile karşı karşıya kaldıklarını ve önemli fiziksel, psikolojik, sosyal ve duygusal sıkıntılar yaşadıklarını göstermektedir. Dahası, hastaların yaşadığı zorluklar hastalığın şiddetine göre değişmektedir.

Örneğin, yıllar içinde yapılan çalışmalar, HS hastalarının psikolojik iyilik halinin hastalık şiddetinden bağımsız olarak etkilendiğini kanıtlamıştır (Alavi vd., 2017; Senthilnathan vd., 2019), bu da hastalık şiddeti düşük olsa bile HS hastalarının genel duygusal durumunun hala etkilendiğini göstermektedir. Damgalama açısından, hastalık şiddeti ve HS'ye bağlı kötü ruh sağlığı, algılanan damgalamayı öngörmektedir; daha yüksek hastalık şiddeti, daha fazla algılanan damgalama ile bağlantılıdır. (Akoğlu ve ark., 2021). Literatür, yalnızca hastalık şiddeti ile psikolojik ve sosyal değişkenler arasındaki ilişkiye değil, aynı zamanda psikolojik ve sosyal değişkenlerin kendi aralarındaki ilişkilere dair bulgular da içermektedir. Literatürde vurgulandığı üzere, damgalama, sosyal etkileşimler, psikolojik iyi olma hali ve davranışsal tepkiler gibi çeşitli süreçleri kötüleştirerek veya engelleyerek hastaların sağlığını olumsuz yönde etkilemekte ve böylece sağlıklarını daha da kötüleştirmektedir (Hatzenbuehler ve ark., 2013). Algılanan damgalama, cilt rahatsızlıkları olan bireyler üzerinde önemli bir psikososyal yük oluşturmaktadır.

Yakın ilişkilere baktığımızda, katılımcıların %71,4'ü HS'nin ilişkilerini olumsuz etkilediğini bildirmiştir (Howells, 2021); ve önceki çalışmalar, hastaların kişisel ve yakın ilişkilerinde kötüleşmeden muzdarip olduğunu göstermiştir (Mac Mahon ve ark., 2020). Bu çalışmalar HS hastalarının sırasıyla iyi olma halini, damgalanmayı ve ilişkileri üzerindeki genel etkiyi incelemiş olsa da hastaların hastalık bilişlerini, hastalık bilişinin iyi olma hali ve damgalanma ile ilişkisini veya hastaların çeşitli ilişki türlerini incelememiştir. Ayrıca, hiçbir çalışma hastaların ilişkilerini ailevi, sosyal ve romantik kategorilere ayırarak analiz etmemiştir. Çalışmamızda, Biyopsikososyal model çerçevesinde, biyolojik (hastalık şiddeti), psikolojik (iyi oluş ve hastalık bilişi) ve sosyal (algılanan damgalanma ve anneler, babalar, kardeşler, romantik partnerler ve kadın/erkek arkadaşlar dahil olmak üzere yakın diğer kişilerle ilişkiler) bileşenler arasındaki ilişkileri araştırıyoruz.

1.1.1. Hidradenitis Suppurativa (HS) nedir?

HS, genellikle ergenlik döneminden sonra ortaya çıkan ve apokrin bez bölgelerini tutan kronik, tekrarlayan, zayıflatıcı ve görünür bir deri hastalığıdır (Howells ve ark., 2021). HS, kıl foliküllerinin tıkanması ile kendini gösterir (Alotaibi, 2024). Hastalığın prevalansı küresel popülasyonda %0,05 ile %4,1 arasında değişmektedir (Ingram, 2020). Değişen prevalans oranları, Türkiye'de hastalıktan etkilenen yaklaşık 400.000 kişi olduğu sonucuna varmamıza neden olmuştur.

Yüksel ve Basım (2020) tarafından Türkiye'de yapılan bir çalışmada, HS tanısı konan 208 hastanın kayıtları incelenmiştir. Bu vakaların %68,3'ü erkek, %31,7'si kadın olarak sonuçlanmıştır.

1.2. Teorik Çerçeve: Biyopsikososyal Model

Biyopsikososyal (BPS) model, klinik uygulamalarda bir rehber olarak kabul edilmekte ve sağlık ve hastalık kavramlarının biyolojik, psikolojik ve sosyal faktörlerin etkileşiminden ortaya çıktığını ileri sürmektedir. Çalışmamızı BPS Modeli etrafında şekillendirdik.

1.2.1. Mevcut Çalışmadaki BPS Modelinin Biyolojik Bileşeni

1.2.1.1.Hastalık Şiddeti

Hurley evreleme sistemi hastalığı 3 evreye ayırır. Hurley evre I medikal tedavi ile ilişkilidir, evre II lokal cerrahi ile uyumludur ve evre III geniş cerrahi eksizyon ile uyumludur (Ovadja et al., 2019).

1.2.3. Mevcut Çalışmada BPS Modelinin Psikolojik Bileşenleri

1.2.3.1. İyi Oluş

İyi oluş, bireyin fiziksel, ruhsal ve zihinsel olarak iyi olduğu bütüncül bir süreç olarak tanımlanmaktadır (Dündar ve Demirli, 2018). Öznel iyi oluş, bireyin kendi yaşamına ilişkin bilişsel ve duyuşsal değerlendirmelerini içeren çok boyutlu bir kavramdır. Çalışmamızda, Diener ve arkadaşlarının (2003) iyi oluş kavramının duyuşsal (olumlu ve olumsuz) boyutuna odaklandık.

1.2.3.2. Hastalık Bilişi

Evers ve diğerlerine göre (2001) üç temel hastalık bilişi vardır: kabullenme, çaresizlik ve algılanan faydalar. Yazarlara göre çaresizlik, hastalığın tiksindirici anlamını vurgular. Kabullenme, stresörün olumsuz sonuçlarını kabul ederek ve onunla yaşamaya uyum sağlayarak bu tiksindirici anlamı azaltır ve son olarak Algılanan faydalar, stresörün daha olumlu etkilerini vurgulayarak hastalığa olumlu bir anlam yükler.

1.2.3.3. Psikolojik Bileşenler Arasındaki İlişki: İyi Olma Hali ve Hastalık Bilişi

Hastaların hastalıklarına ilişkin bilişlerinin iyi olma hallerindeki farklılıkları açıklamada bir faktör olduğu gerçeğini (Maes ve Karoly, 2005) akılda tutarak şu hipotezi kurduk:

H1: Daha düşük çaresizlik, daha yüksek kabul ve algılanan fayda düzeyleri daha yüksek iyi olma hali ile ilişkili olacaktır.

1.2.4. Mevcut Çalışmada BPS Modelinin Sosyal Bileşenleri

1.2.4.1. Algılanan Damgalama

"Damgalama" oldukça itibarsızlaştırıcı ve aşağılayıcı bir niteliktir (Goffman, 1963). Algılanan damgalama, bireyin belirli bir durumla ilgili olumsuz tutum ve/veya uygulamaların farkında olması anlamına gelir; yani hasta kendisini çevresi tarafından damgalanmış olarak algılar ve bilişini bu yönde şekillendirir (Van Brakel, 2006). Ayrıca, gizlenebilir damgalanmış kimlikler (CSI), başkalarından gizlenebilen ancak yine de sosyal olarak değersizleştirilen ve olumsuz stereotiplere maruz kalan kimliklerdir (Quinn & Earnshaw, 2013). Diğer görünür cilt hastalıklarıyla karşılaştırıldığında, HS bir şekilde gizlenebilir görünmektedir ve bu da bir CSI olduğunu düşündürmektedir.

1.2.4.2. Yakın Diğerleri ile İlişkiler

HS hastaları, hastalığın yarattığı fiziksel zorluklar nedeniyle sosyal izolasyonu deneyimleyebilir; bu da ailevi, romantik ilişkilerini ve arkadaşlıklarını olumsuz yönde etkileyerek ruh sağlıklarına zarar verir (Perche ve ark., 2022). Çalışmalar, hastaların %71,4'ünün HS'nin ilişkilerini olumsuz etkilediğini (Howells, 2021), kişisel ve yakın ilişkilerde önemli ölçüde bozulma olduğunu bildirdiğini göstermiştir (Mac Mahon ve ark., 2020). Çalışmamızda, üç ana soru ile hastaların hastalıklarını yakınlarına (anne, baba, kardeşler, romantik partner ve erkek/kadın arkadaşlar) açıklayıp açıklamadıklarını inceledik. Bu kişilere tanılarını açıklamışlarsa, bu deneyimi nasıl algıladıklarını, sonuç olarak aldıkları sosyal desteği ve genel olarak ilişkilerinin nasıl etkilendiğini araştırdık. Bir hasta teşhisini annesine açıklarsa, bu deneyimi olumlu olarak algılarsa, destek alırsa ve genel ilişki iyileşirse, bu "anne ile iyi ilişki" için yüksek bir puan olarak yansıtılmıştır.

1.3.1. Biyolojik ve Psikolojik Bileşenler Arasındaki İlişki

1.3.1.1. Hastalık Şiddeti ve İyi Oluş

Araştırmalar, hastalığın hastaların fiziksel, sosyal ve iyi oluşu üzerinde önemli bir olumsuz etkisi olduğunu göstermiştir (Gooderham & Papp, 2015; Wolkenstein et al., 2007). Yapılan bir çalışmada, hastalığın ciddiyetine bakılmaksızın, olumlu ve olumsuz duygulanım puanları hastalar arasında çok benzerdi ve gruplar arasında istatistiksel olarak anlamlı bir fark bulunmadı (Hurley I-II-III). Araştırmacılar bu durumu, düşük düzeyde HS'nin bile iyi olma haline katkıda bulunduğu şeklinde yorumlamıştır (Senthilnathan vd., 2019). Sonuç olarak, hipotezimiz şudur:

H2: Hastalığın ciddiyetine bakılmaksızın, olumlu ve olumsuz duygulanım puanları gruplar arasında benzer olacaktır (Hurley I-II-III).

1.3.1.2. Hastalık Şiddeti ve Hastalık Bilişi

Bildiğimiz kadarıyla literatürde hastalık bilişi ve HS birlikte çalışılmamıştır; dolayısıyla çalışmamız bu ilişkiyi araştıran ilk çalışmadır. Bununla birlikte, hastalık bilişinin, hastaların birey olarak psikolojik ve fiziksel sağlık durumlarındaki farklılıkları hesaba katarak hastalıklarını algılama ve düşünme biçimlerini etkilediği gösterilmiştir (Evers ve ark., 2001). İyi olma hali ve hastalık bilişi arasındaki ilişkiyi göz önünde bulundurarak, hastalık şiddeti ve hastalık bilişi arasındaki ilişkiyi incelerken şöyle bir araştırma sorusu sorduk:

RQ1: Daha yüksek hastalık şiddeti, hastalık bilişinde daha yüksek çaresizlik ve daha düşük kabul ve algılanan fayda düzeyleri ile ilişkili olacak mıdır?

1.3.2. Biyolojik ve Sosyal Bileşenler Arasındaki İlişki

1.3.2.1. Hastalık Şiddeti ve Algılanan Damgalanma

Daha önce yürütülen bir çalışma, hastalık şiddetinin ve HS'ye bağlı kötü ruh sağlığının algılanan damgalanmanın yordayıcıları olduğunu bulmuştur. Hurley Evre III hastaları, Hurley Evre I hastalarına kıyasla dört kat, Hurley Evre II hastaları ise beş kat daha fazla damgalanma algısı bildirmiştir (Akoğlu vd., 2021). Bu önceki bulgunun aksine, başka bir çalışmada hastalık şiddeti ile algılanan damgalanma arasında anlamlı bir korelasyon bulunmamıştır (Bouazzi ve ark., 2021). Bu bulguları göz önünde bulundurarak araştırma sorusunu şu şekilde sorduk:

RQ2: Daha yüksek hastalık şiddeti daha yüksek algılanan damgalama ile ilişkili midir? (Hurley III > Hurley II > Hurley I).

1.3.2.2. Hastalık Şiddeti ve Yakın Diğerleri ile İlişkiler

HS hastalarının Hurley evreleri arttıkça, hastaların yaşadığı zorlukların da artma eğiliminde olduğunu gösteren kanıtlar vardır. Hastaların karşılaştığı zorluklardan kaynaklanan hastalık yükünün artması nedeniyle, yaşanan psikolojik sıkıntının hastalığın ilişkiler üzerindeki etkisini daha da kötüleştirebileceğini ve yakınlarla iyi ilişkiler konusunda düşük puanlara yol açabileceğini tahmin ediyoruz. Bu nedenle bir araştırma sorusu sorduk:

RQ3: Düşük hastalık şiddeti seviyeleri, hastaların yakınlarıyla iyi ilişkiler kurmasıyla (açıklama, deneyimi olumlu olarak algılama, sosyal destek alma ve genel ilişki kalitesi) ilişkili midir?

1.2.5. Psikolojik ve Sosyal Bileşenler Arasındaki İlişki

1.2.5.1. İyi Oluş ve Algılanan Damgalanma

Literatürde romatoid artrit, fibromiyalji, şizofreni, duygudurum ve anksiyete bozuklukları gibi çeşitli hastalıklarda algılanan damgalanma ile iyi oluş arasındaki ilişkiyi inceleyen çalışmalar bulunmaktadır (Alonso ve ark., 2008; Tesfaw ve ark., 2020; Van Alboom ve ark., 2021). Tüm bu çalışmalar, algılanan damgalanma ile iyi oluş arasında negatif korelasyonel bir ilişki bulmuştur. Ancak, bildiğimiz kadarıyla, hiçbir çalışma HS hastalarında bu ilişkiyi doğrudan araştırmamıştır. Literatürü göz önünde bulundurarak hipotezimiz şudur:

H3: Daha yüksek algılanan damgalanma, düşük pozitif duygulanım ve yüksek negatif duygulanım ile ilişkili olacaktır.

1.2.5.2. İyi Oluş, Hastalık Bilişi ve Yakın Diğerleri ile İlişkiler

Gizlenen damgalanmış kimlikler, bireylerin ruhsal ve fiziksel refahını olumsuz yönde etkileyebilir. Araştırmalara göre, açıklama yapmanın (disclosure) bireylerin uzun vadeli iyi oluşu üzerinde sonuçları olabileceği bulunmuştur (Chaudoir ve Quinn, 2010). Açıklama sonucunda ortaya çıkan olumlu ve destekleyici tepkilerin uzun vadede olumlu psikolojik faydaları olabilir. Bireyler, CSI'larını başkalarına açıklama gibi zorlu bir karar verdiklerinde desteklendiklerini ve kabul edildiklerini hissederler (Beals ve ark., 2009). Açıklama, uzun vadede iyi olma halini iyileştirebilir ve destek ve kabul duygularını teşvik edebilir (Beals vd., 2009; Chaudoir ve Quinn, 2010). Önceki çalışmalar, açıklamaya yönelik destekleyici tepkilerin daha iyi psikolojik iyi oluşla bağlantılı olduğunu göstermektedir (Quinn & Earnshaw, 2013). Literatürdeki bulguları göz önünde bulundurarak şu hipotezi öne sürdük:

H4: Yakın diğer kişilerle (anne, baba, kardeşler, romantik partnerler, kız/erkek arkadaşlar) iyi bir ilişkiye sahip olmak (daha yüksek puanlar yakın diğer kişilerle daha iyi bir ilişkiye karşılık gelecektir) daha yüksek iyi oluş, algılanan faydaların artması ve kabul görmenin yanı sıra çaresizlik ve algılanan damgalanmanın azalmasıyla ilişkili olacaktır.

Araştırmamızda, özellikle katılımcıların açıklama deneyimleri, kaçının teşhisini annesine, babasına, kardeşine, romantik partnerine ve arkadaşlarına açıkladığı ve kaçının açıklamadığı gibi çeşitli değişkenleri araştırdık. Ayrıca cinsiyet farklılıklarını, romantik bir partnere sahip olma ilişkisini ve mevcut bir partneri olmayan hastaların tanılarını gelecekteki bir partnere veya yeni bir arkadaşa açıklayıp açıklamayacaklarını da inceledik.

1.2.5.3. Romantik ve Cinsel İlişkiler

Önceki çalışmalar, sağlıklı kontrollerle karşılaştırıldığında, HS hastalarının cinsel partner olarak kendilerini daha az kabul edilebilir hissettiklerini, cinsel yaşamlarından daha az keyif aldıklarını ve daha düşük düzeyde cinsel sağlık yaşadıklarını göstermiştir (Andersen vd., 2020; Janse vd., 2017). Kadın hastaların %94,3'ü ve erkek hastaların %80,8'i HS'nin ilişki kurma veya cinsel faaliyetlerde bulunma şanslarını olumsuz etkilediğine inanmaktadır (Cuenca-Barrales & Molina-Leyva, 2020). Literatürde bulunan sonuçlar göz önüne alındığında, hastaların tanı sonrası cinsel yaşamlarının olumsuz etkileneceği hipotezini kurduk.

H5: Hastaların tanı sonrası cinsel yaşamları olumsuz etkilenecektir.

1.2.6. Çalışmanın Literatüre Katkısı

Mevcut çalışmanın önemi, HS'nin hastalar üzerindeki psikolojik ve sosyal etkilerini dikkate almasında yatmaktadır. Bildiğimiz kadarıyla, hastaların iyi olma halini, hastalık bilişlerini, algılanan damgalanmayı ve yakınlarıyla ilişkilerini ayrı ayrı inceleyen ve aynı zamanda bu değişkenlerin hastalıklarının şiddetine göre nasıl değiştiğini araştıran bir çalışma bulunmamaktadır. HS'ye özel bir vurgu yaparak, çeşitli kronik ve görünür cilt rahatsızlıkları olan bireylerin süreçlerine odaklanan gelecekteki araştırmalara ışık tutmayı amaçlıyoruz.

2. YÖNTEM

2.1. Katılımcılar

Katılımcılar, Hidradenitis Suppurativa tanısı almış 17 yaş üstü 70 erkek ve kadın bireyden oluşmaktadır. Katılımcılara sosyal medya platformları ve Selçuk Üniversitesi Dermatoloji Kliniği aracılığıyla ulaşılmıştır.

2.2. Ölçüm Araçları

Araştırmada kullanılan ölçekler aşağıdaki gibidir: Demografik Bilgi Formu, Pozitif ve Negatif Duygulanım Ölçeği (Diener vd., 2009; Korkmaz, 2016), Hastalık Bilişi Ölçeği (Aykul, 2018; Evers vd., 2001), Algılanan Damgalanma Ölçeği (Akoğlu vd., 2021; Evers vd., 2007) ve Hidradenitis Suppurativa (HS) Tanısı Almanın Yakın Çevreyle İlişkilere Etkisini Değerlendirme Formu.

3. SONUÇLAR

3.1. Demografik Özellikler ve Ana Çalışma Değişkenleri için Tanımlayıcı İstatistikler

Katılımcıların yaşları 17 ile 61 arasında değişmektedir. Katılımcıların çoğunluğu erkek hastalardan oluşmaktadır. Katılımcıların çoğu orta sınıfa mensup olduğunu belirtmiştir. Çok az katılımcı kendini öğrenci olarak tanımlamıştır. Medeni durum açısından katılımcıların 44'ü bir ilişki içinde, 26'sı ise bekârdır.

Birincil çalışma değişkenleri için tanımlayıcı istatistikler hesaplanmıştır. Bu değişkenler için ortalama, standart sapma ve puan aralığı, tanımlayıcı genel bakışın bir parçası olarak verilmiştir.

3.2. Klinik Sunum için Tanımlayıcı İstatistikler: Tanı, Hastalık Şiddeti, Aile Geçmişi, Komorbiditeler ve Tedaviler

Ortalama tanı yaşı 23,9'dur. Katılımcıların %68,6'sı yanlış tanı veya gecikmiş tanı nedeniyle uzamış süreçler yaşamıştır. 13 hastaya Hurley evre I, 26 hastaya Hurley evre II ve 31 hastaya Hurley evre III tanısı konulmuştur.

En sık görülen komorbidite diyabet olarak bulunmuştur. Hastaların sadece yarısı tedavi aldığını belirtmiştir. En yaygın tedavi biyolojik ajan olarak rapor edilmiştir.

3.3. Mevcut Çalışmanın Değişkenleri için İç Tutarlılık Güvenilirlik Analizleri

Mevcut çalışmada kullanılan ölçeklerin iç tutarlılığını değerlendirmek için güvenilirlik analizleri yapılmıştır.

3.4. Yakın Diğerleri ile Açıklama için Keşifsel Analiz

Hastaların neredeyse tamamı tanılarını aile üyeleri ve romantik partnerlerine açıklamıştır. 70'i tanılarını arkadaşlarına açıklamıştır.

3.5. Cinsiyet Farklılıkları ve Romantik Partnere Sahip Olmaya İlişkin Keşifsel Analizler

Kadın ve erkek hastalar arasında, ele alınan hiçbir değişkende istatistiksel olarak anlamlı bir fark bulunmamıştır. Romantik partneri olan hastalar ile romantik partneri olmayan hastalar arasında, pozitif ve negatif duygulanım hariç, çalışma değişkenlerinde istatistiksel olarak anlamlı bir fark bulunmamıştır.

3.6. Gelecekte İlişki Başlatma için Keşifsel Analizler

Şu anda romantik bir partneri olmayan hastaların çoğu gelecekte bir ilişki başlatabileceğini belirtmiştir. Hastaların yarısından fazlası gelecekte bir arkadaşlık başlatabileceğini söylemiştir.

3.7. Çalışma Değişkenleri için Ana Analizler

Varyans analizi sonuçları, HS hastalarının hastalıklarının şiddetinden bağımsız olarak benzer düzeyde olumlu ve olumsuz duygulanım, çaresizlik, kabullenme, algılanan fayda ve algılanan damgalanma yaşadıklarını göstermiştir. Sonuçlar, hastalık şiddeti düzeyleri açısından yakın diğer kişilerle olan tüm ilişkiler için anlamlı olmayan bir etki olduğunu göstermiştir. Sonuç olarak, yakın diğer kişilerle olan çeşitli ilişki türleri üzerinde farklı bir etkiye dair kanıtımız bulunmamaktadır.

Psikolojik ve sosyal bileşenler arasındaki ilişkileri ve psikolojik bileşenler arasındaki ilişkiyi değerlendirmek için bir korelasyon analizi yapılmıştır. Düşük iyi oluş ve yüksek algılanan damgalanma, daha yüksek çaresizlik ile ilişki bulunmuştur. Yüksek düzeyde iyi oluş ve kabul, daha düşük çaresizlik ve partnerle iyi ilişki ile ilişkili bulunmuştur. Yüksek kabul düzeyi, yüksek algılanan fayda ve iyi oluş ile ilişkili bulunmuştur. İlişkiler alanında, baba ve kadın arkadaşlarla iyi ilişkiler, daha düşük algılanan damgalanma ve çaresizlik ile ilişkilendirilmiştir. Romantik ilişkiler açısından, partnerle iyi ilişki, yüksek kabul, algılanan fayda, iyi oluş (pozitif duygulanım) ve ebeveynlerle iyi ilişkiler ile ilişkili bulunmuştur. Arkadaşlıklar da önemli bir rol oynamaktadır. Arkadaşlarla iyi ilişkinin, daha yüksek kabul, algılanan faydalar ve tüm alanlarda iyi ilişki ile ilişkili olduğu bulunmuştur.

3.7.1.1. Hastaların Cinsel Yaşamları Üzerine Analiz

Hastaların cinsel yaşamlarını incelerken, cinsel partneri olan hastalar arasında tek örneklem t-testi yapılmış ve hastaların cinsel yaşamlarının olumsuz etkilendiğini bulunmuştur.

4. TARTIŞMA

Kronik sağlık sorunlarının artması, bireylerin yaşamlarını bağımsızlık düzeyleri, günlük rutinleri, yakın ilişkileri ve duygusal iyi oluşları dahil olmak üzere çeşitli şekillerde etkilemektedir (Taylor, 2005).

Hastalıkların psikososyal yönlerinin ele alınması, hem hastalıklara uyum sağlamada hem de süreçte ortaya çıkabilecek psikolojik sorunların önlenmesinde yardımcı olabilir. Bu anlayışla, çalışmamız HS hastalarının tanı sonrası psikososyal deneyimlerine biyopsikososyal model çerçevesinde ışık tutmayı amaçladı. Hastalık şiddeti, iyi oluş, hastalık bilişi, algılanan damgalanma ve yakınlarla ilişkiler arasındaki ilişkileri, ayrıca açıklama deneyimi, cinsiyet ve romantik partner farklılıklarını inceledik.

4.1. Mevcut Çalışmanın Sonuçlarının Değerlendirilmesi

HS hastalarının %68,6'sı gecikmiş veya yanlış tanı deneyimlemiştir. Türkiye'deki aile hekimlerinin yalnızca %23,7'si HS tanısı koymada kendine güvenmektedir (Tsentemeidou ve ark., 2024). HS'nin en erken görüldüğü yaşın 12 olduğu bildirilmiştir; bu nedenle çocuk hastalarda HS olasılığını göz ardı etmemek önemlidir. Hastaların neredeyse yarısı Hurley Evre III'te olup, bu oran önceki raporlardan daha yüksektir (Bettoli ve ark., 2019; Katoulis ve ark., 2017; Işık Mermutlu & Keskinkaya, 2023). Bu durum muhtemelen erken evrelerde gecikmiş tanı veya yanlış tanı konulmasından ya da veri toplama dönemi ve çalışmanın yürütüldüğü spesifik klinik ile veri toplama sürecine katkı sağlayan bireylerin katılımından kaynaklanmaktadır.

Aynı zamanda, hastalığın ileri evrelerindeki hastalar, iyi oluş ve sağlık süreçlerini etkileyen faktörlere katılım konusunda daha motive olurlar (Murillo, 2019); belki de bu yüzden çalışmaya katılan bireylerin hastalık seviyeleri yüksekti. Hastalarda en sık görülen ek hastalık diyabet olup, bu bulgu literatürdeki önceki çalışmalarla uyumludur (Bettoli ve ark., 2015; Kimball ve ark., 2018). En yaygın tedavi biyolojik ajanlar olup, literatürü destekler niteliktedir (Ballard, 2024). Çalışmamızda erkek oranı daha yüksek olarak rapor edilmiştir.

Kadın ve erkek hastalar arasında istatistiksel olarak anlamlı bir fark bulunmamıştır. Literatürde, kadın ve erkek hastalar arasında belirli farklılıklar bulunmakta; ancak bu farklılıklar genellikle hastalığın başlangıç yaşı ve hastalık şiddeti gibi klinik belirtilere ilişkin olduğu görülmüştür.

Romantik partneri olan ve olmayan hastalar arasında, pozitif ve negatif duygulanım dışında çalışma değişkenlerinde istatistiksel olarak anlamlı bir fark bulunmamıştır. Literatüre göre, başarılı romantik ilişkiler kurmak ve sürdürmek, bireylerin mental ve fiziksel sağlığına katkı sağlamakta ve dolayısıyla iyi oluşlarını artırmaktadır (DeWall ve ark., 2011).

İyi oluş ve hastalık bilişi açısından gruplar (Hurley I-II-III evreleri) arasında istatistiksel olarak anlamlı farklılık gözlenmemiştir. Mevcut çalışmadaki HS hastaları, hastalıklarının şiddetinden bağımsız olarak benzer düzeyde algılanan damgalanma deneyimlemiştir. Önceki bir çalışmada, Hurley I evresindeki hastalarda algılanan damgalanmanın, Hurley III evresindeki hastalara göre daha düşük olduğu bulunmuştur (Akoğlu ve ark., 2021). HS, hareket kabiliyetini kısıtlayan, damgalanmaya yol açan ve yaşamın genel akışını bozan bir durumdur. Bu zorluklar, maalesef hastalığın her evresinde bireylere eşlik eder. Belki de hastaların hastalık seviyesi düşük olsa bile yaşadıkları olumsuzluklar nedeniyle, her seviyede damgalanma deneyimlemektedir.

HS hastalarının farklı ilişki türleri (anne, baba, kardeşler, romantik partner, kadın/erkek arkadaşlarla ilişkiler), hastalık şiddetinden bağımsız olarak tanı sonrası benzer şekilde etkilenmiştir. 'Hasta olmak,' hastalığın şiddetinden daha belirgin hale gelebilir.

Sonuçlarımıza göre, yüksek iyi oluş ve kabul, daha düşük çaresizlik ve özellikle partnerlerle iyi ilişkilerle ilişkilidir. Yüksek kabul, daha yüksek algılanan fayda ve iyi oluş ile bağlantılıyken, düşük iyi oluş ve yüksek algılanan damgalanma, artan çaresizlikle ilişkilidir. Partnerler, ebeveynler ve arkadaşlarla iyi ilişkiler, tutarlı bir şekilde düşük algılanan damgalanma, yüksek kabul ve algılanan fayda ile bağlantılıdır.

Sosyal ilişkiler ve sağlık üzerine yapılan araştırmalar, olumlu sosyal bağlantıların (örneğin, sosyal destek) iyi oluşu olumlu etkilediğini göstermektedir. Çok sayıda çalışma, sosyal desteğin ve olumlu sosyal ilişkilerin zihinsel, fiziksel sağlık ve öznel iyi oluş üzerinde olumlu etkileri olduğunu göstermektedir (Nguyen ve ark., 2015).

Anlam yaratma alanındaki farklı bir araştırma alanında; zorlu olaylar ve durumlar yaşandıktan sonra bireyler anlam yaratmaya çalışır ve bu süreç, kimliklerinin olumlu nitelikler geliştirdiğine dair inançlar oluşturmalarına yardımcı olur (Park, 2010. Bu süreç, kabul ve büyüme algısı ve/veya olumlu yaşam değişiklikleri gibi çok daha olumlu psikolojik sonuçlarla ilişkilidir. Sonuç olarak, HS hastaları da koşullarından algılanan veya gerçek faydalar bulup bunları kabul ederek, daha iyi psikolojik sonuçlar elde edebilir ve yakınlarıyla daha iyi ilişkiler kurabilir. Çalışmamızda incelediğimiz çeşitli ilişkiler arasında algılanan damgalanma ve çaresizlik ile baba ve kadın arkadaşlarla olan ilişkilerin ilişkisi şaşırtıcıydı. Belki de Türk kültürünün etkisiyle ve önceki çalışmalarda gösterildiği gibi, annelerin her durumda çocuklarına sosyal destek sağlamalarının beklenmesi olağandır (Oakley, 2022). Fakat bu destek babadan geldiğinde, daha yüksek ve pozitif bir etki yaratıyor olabilir. Kadın arkadaşlar açısından ise onların rahatlatıcı ve sözlü destek sağlayan yaklaşımlarının hastaların kendilerini daha rahat hissetmelerine katkıda bulunmuş olabilir, bu da bir destek hissine yol açmış olabilir.

4.2. Mevcut Çalışmanın Çalışmanın Sınırlılıkları

Veri toplama sosyal medya platformları ve Selçuk Üniversitesi Dermatoloji Kliniği ile sınırlı kaldı. Birçok hasta katılmadı veya çalışmadan çekildi ve bu da küçük bir örneklem boyutuna yol açtı. Hastalarla hastane ziyaretleri sırasında sınırlı zaman nedeniyle anket kısa tutuldu, bu da birçok değişkenin incelenmesini sınırladı. Erkek hastaların sayısının fazla olması, bulguların kadın ve kendini ikili cinsiyet kategorilerinin içinde tanımlamayan hastalara genellenebilirliğini sınırlayabilir.

4.3. Mevcut Çalışmanın Çalışmanın Güçlü Yönleri

Çalışmamızın güçlü yönü olarak, BPS modeli kullanarak HS hastalarının tanı sonrası dönemdeki deneyimlerini psikososyal bir perspektiften ele aldık. Araştırmamızı korelasyonel ve keşifsel bir şekilde yürüttük. Ayrıca hastaların ilişkilerine büyük önem verdik ve araştırmamızı literatürün aksine nicel olarak gerçekleştirdik.

4.4. Pratik Çıkarımlar

HS gibi yaşamı tanımlayan bir hastalık için ve bununla ilişkili olumsuz etkileri ortadan kaldırmak adına, öz yönetim becerisi büyük önem taşımaktadır. Hastaların hastalıklarını yönetme konusunda uzmanlaşarak günlük yaşamlarını ve sonuçlarını iyileştirmelerine yardımcı olacak eğitim ve müdahale programları geliştirilebilir. Damgalamanın sağlık ve iyi oluş üzerindeki olumsuz etkisini ele alacak müdahalelerin geliştirilmesi ve değerlendirilmesi gerekmektedir. Bu müdahalelerde, bakıcılar, sağlık profesyonelleri ve hasta aileleri gibi damgalanmaya eğilimli belirli gruplara odaklanmak daha etkili olabilir (Topp ve ark., 2019).

Son olarak, ülkemiz Türkiye'de HS dahil deri hastalıkları için kurulmuş yerel bir organizasyon bulunmamaktadır. Avrupa'da yalnızca HS hastalarına yönelik kurulan Avrupa HS Vakfı, Hope for HS ve HS Connect gibi birçok kuruluş bulunmasına rağmen, ülkemizde bu konuda bir eksiklik söz konusudur. Önceki araştırmaların da önerdiği gibi, hastaların damgalanma, hastalık şiddeti ve bozulmuş ilişkilerle ilişkili olumsuz etkilerin üstesinden gelmelerine yardımcı olacak sosyal destek ağlarına ihtiyaçları vardır (Howell ve ark., 2021).

Ülkemizde, bu tür hastalara yardım ve destek sağlayabilecek bir organizasyonun kurulması için çaba gösterilmesi gerektiğine inanıyoruz.

4.5. Gelecek Çalışmalar için Öneriler

Gelecek çalışmalar, daha büyük ve cinsiyet açısından dengeli bir örneklemle deneyimleri keşfederek ve sağlık kontrol odağı gibi ek değişkenleri içerebilir. Fiziksel semptomların yoğunluğu ve çeşitliliğinin araştırılması, bunların iyi oluş ve hastalık bilişi üzerindeki etkileri hakkında içgörüler sağlayabilir. Bulgular, hastaların sonuçlarını iyileştirmek için müdahale programlarının geliştirilmesine yardımcı olabilir; örneğin, farklı fiziksel semptomların ve hastaların sağlık kontrol odağının psikolojik iyi oluşu nasıl öngördüğü belirlenebilir.

J. THESIS PERMISSION FORM / TEZ İZİN FORMU

(Please fill out this form on computer. Double click on the boxes to fill them)

ENSTİTÜ / INSTITUTE

Fen Bilimleri Enstitüsü / Graduate School of Natural and Applied Sciences ☐

Sosyal Bilimler Enstitüsü / Graduate School of Social Sciences ☒

Uygulamalı Matematik Enstitüsü / Graduate School of Applied Mathematics ☐

Enformatik Enstitüsü / Graduate School of Informatics ☐

Deniz Bilimleri Enstitüsü / Graduate School of Marine Sciences ☐

YAZARIN / AUTHOR

Soyadı / Surname : Gökkaya
Adı / Name : Berfin
Bölümü / Department : Psikoloji / Psychology

TEZİN ADI / TITLE OF THE THESIS (**İngilizce** / English): HİDRADENİTİS SUPPURATIVA: PSİKOSOSYAL DEĞİŞKENLER ÜZERİNDEN BİR İNCELEME / HIDRADENITIS SUPPURATIVA: AN EXAMINATION THROUGH PSYCHOSOCIAL VARIABLES

TEZİN TÜRÜ / DEGREE: **Yüksek Lisans** / Master ☒ **Doktora** / PhD ☐

1. **Tezin tamamı dünya çapında erişime açılacaktır. /** Release the entire work immediately for access worldwide. ☒
2. **Tez iki yıl süreyle erişime kapalı olacaktır.** / Secure the entire work for patent and/or proprietary purposes for a period of **two years**. * ☐
3. **Tez altı ay süreyle erişime kapalı olacaktır.** / Secure the entire work for period of **six months**. * ☐

***** *Enstitü Yönetim Kurulu kararının basılı kopyası tezle birlikte kütüphaneye teslim edilecektir. / A copy of the decision of the Institute Administrative Committee will be delivered to the library together with the printed thesis.*

Yazarın imzası / Signature .... **Tarih** / Date ....
(Kütüphaneye teslim ettiğiniz tarih. Elle doldurulacaktır.)
(Library submission date. Please fill out by hand.)

Tezin son sayfasıdır. / This is the last page of the thesis/dissertation.