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"Beyond pure health": Exploring diagnostic pathways, quasi-medicalization, and patient expertise in dermatology

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Abstract

Patients are increasingly assuming the role of lay 'experts,' driven by evolving desires towards autonomy, the omnipresence of the Internet, and other factors, leading to an influx of self-diagnosis and self-treatment. While patient expertise has been of ongoing study, dermatology has received less attention, despite the high grounds for patient involvement, given the visually-bound nature of many dermatological conditions and the reliance on heuristics and patient-reported data in its clinical practice.

By drawing on theoretical and empirical literature on *diagnosis*, *doctor-patient relationships*, and *'expert' patients*, this thesis explores how patients construct dermatological concerns with respect to various diagnostic pathways, dermatological conditions, and the types of knowledge sources mobilized in this process. Twelve semi-structured interviews were conducted with individuals diagnosed with a dermatological condition either by doctors or themselves. A combined thematic analysis and grounded theory methodological framework was used to analyze the data, producing themes and a paradigm model.

Findings suggest that dermatological concerns, along with the medical practice, industry, and dermatologists, were often understood in an aesthetic orientation that extend "beyond" mere health towards bodily enhancements and consumerism. Despite this, participants addressed their dermatological concerns by combining biomedical and alternative approaches and were found to be the primary agents of diagnosis. The discussion discusses various explanations, including the quasi-medicalization and simultaneous aestheticization of dermatology.

Keywords

dermatological concerns, diagnosis, expert patient, lay understanding of health, illness experience, digital health, quasi-medicalization, aestheticization, biomedicine, alternative medicine

Abstrakt

Pacienti stále více přebírají roli laických "odborníků", jejichž iniciativy jsou motivované vyvíjejícími se touhami po autonomii, všudypřítomností internetu a dalšími faktory, což vede k nárůstu sebediagnostiky a samoléčby. Zatímco tato expertizace pacientů byla předmětem stávajících studií, dermatologii se dostalo menší pozornosti, a to i navzdory vysokého zapojení pacientů, vizuální povaze dermatologických potíží a spoléhání se na heuristiku a údaje hlášené pacienty při jejich léčbě.

Tato práce prostřednictvím teoretické a empirické literatury o diagnostice, vztazích mezi lékařem a pacientem a skrze důraz na koncept tzv. 'expertních' pacientů zkoumá, jak pacienti konstruují dermatologické obavy vzhledem k různým způsobům diagnózy, dermatologickým stavům a zdrojům expertízy, která je mobilizovaná v tomto procesu. Výzkum je založen na dvanácti polostrukturovaných rozhovorech s jednotlivci s dermatologickou diagnózou, stanovenou ať už jimi samotnými, nebo lékaři. K analýze dat byl použit kombinace tematického kódování a metodologický rámec zakotvené teorie, který inspiroval otevřené kódování a budování paradigmatického modelu.

Výsledky naznačují, že dermatologické obavy spolu s lékařskou praxí, farmaceutickým průmyslem a dermatology byly často chápány skrze estetickou perspektivu, která přesahuje výlučné chápání dermatologických problémů coby problémů zdravotních a orientuje se na tělesné zdokonalením a konzumerismus. Účastníci výzkumu představovali hlavní aktéry diagnostického procesu a zabývali se svými dermatologickými obavami tak, že kombinovali biomedicínské a alternativní přístupy. Závěrečná diskuze práce se zabývá tzv. kvazi-medikalizací a současnou estetizací dermatologie.

Klíčová slova

dermatologické obavy, diagnóza, odborný pacient, laické chápání zdraví, zkušenost s nemocí, digitální zdraví, kvazi-medikalizace, estetizace, biomedicína, alternativní léčba

Název práce

"Přes pouhé zdraví": Zkoumání diagnostických cest, kvazimedicíny, a odbornosti pacienta v dermatologii

Declaration of Authorship

1. The author hereby declares that he compiled this thesis independently, using only the listed resources and literature.

2. The author hereby declares that all the sources and literature used have been properly cited.

3. The author hereby declares that the thesis has not been used to obtain a different or the same degree.

In Prague on 30 April 2024

Dana Alsaialy

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1. Introduction

Diagnosis is the point at which medicine, culture, politics, and technology meet (Brown, 1990; Jutel, 2009; Jeske et al., 2024). By identifying what clusters of symptoms and forms of human behavior constitute '*disease*,' a diagnosis profoundly shapes perceptions of health and illness (Aronowitz, 2001). It further impacts one's sense of identity, determines access to resources and social support, and evokes various emotional responses, from relief to grief, for those on the end of the diagnostic label (Jutel & Nettleton, 2011). Simultaneously, evolving patient desires towards autonomy, the proliferation of online health information, and lack of access to healthcare, among other factors have led patients to assume the role of lay health 'experts' (Brown, 2001; Shaw & Baker, 2004; Lupton, 2013). In practical terms, this has led patients to employ self-assessment, self-monitoring, self-treatment, self-diagnosis, and other forms of self-reliance in connection to their health and illness (Fox et al., 2005; Lupton & Jutel, 2015).

Against this backdrop, dermatology is an area of rising curiosity due to its visually-bound nature and reliance on clinical data (clinimetrics) and patient-reported data (psychometrics) in diagnosing and treating patients (DeBord et al., 2018; Lowenstein et al., 2019; Glines et al., 2020). The dermatological medical practice often depends on cognitive shortcuts, such as an 'expert eye' and instinct, rather than logical analysis and (sometimes) evidence-based science altogether (Lowenstein, 2018, pp. 1238-1242). Considering these heuristics and dermatology's association with cosmetic industries (Klingman, 2000), there are potentially high grounds for patient engagement, self-diagnosis, and self-treatment of dermatological conditions. Despite this, there is a notable absence of studies investigating this area.

Thus, by drawing on literature on diagnosis, doctor-patient relationships (DPRs), and 'expert' patients, this thesis presents a novel study into how the construction, diagnostic interpretation, and therapeutic management of dermatological concerns is conducted by patients with various diagnostic pathways (i.e., doctor-diagnosed, self-diagnosed, and undiagnosed) and conditions (i.e., acne, alopecia, atopic dermatitis, eczema, herpes, shingles, and xerosis). In doing so, this thesis aims to highlight that a dermatological diagnosis often transcends a mere 'moment.' Rather, it involves multiple agencies, primarily the patient. Additionally, this thesis opens a debate on the aestheticization and quasi-medicalization of (some) dermatological conditions to consider framing forms of patienthood into clienthood, where 'expert' patients assume roles akin to skincare 'gurus.'

Employing qualitative methodology, twelve semi-structured interviews were conducted with individuals who received a dermatological diagnosis from physicians or had self-diagnosed/undiagnosed

dermatological conditions. In particular, the sample consisted of Bachelor-level university students and recent graduates (age range, 19-24) with various skin and hair conditions. The data was coded using *ATLAS.ti (Version 24)*, a computer-assisted qualitative data analysis software (CAQDAS), and analyzed via a combined thematic analysis (TA) and grounded theory (GT) methodological framework. Findings are presented in the form of five themes and a paradigm model (PM).

This thesis is structured in the following way: First, the key theoretical and empirical literature is reviewed; Next, the methods of data collection and analysis are outlined, showing the research process in detail; Then, the study's findings are presented in the form of themes alongside a complementary PM; After that, the findings are interpreted and situated in existing scholarship and the broader context; Finally, the conclusion includes a summary of the entire paper, discusses the study's limitations, and suggests potential directions for future research.

2. Literature Review

This chapter establishes a background for studying diagnostic pathways¹ and patients' constructions of dermatological concerns by reviewing existing theoretical and empirical literature. In Section 2.1, the lack of literature on the present study's topic is addressed and the theoretical framework is outlined. Then, Sections 2.2, 2.3, and 2.4 explore the contents of the theoretical framework, discussing past papers on diagnosis, doctor-patient relationships (DPRs), and the 'expert' patient phenomenon. Finally, Section 2.5 summarizes the entire chapter. See Figure 1 for a visual representation of this chapter leads to the development of the research question and its sub-questions.

Figure 1. Literature review flowchart



2.1. Theoretical Framework

Studying how patients construct dermatological concerns and approach them in terms of diagnosis and treatment has not been previously explored, making this work of novel design. Past papers in

¹ In medical sciences, "diagnosite pathway" (or sometimes broadly "clinical pathway") signifies the specific procedures and steps clinicians take in order to diagnose a patient (De Bleser, 2006). However, in sociological science, the term refers to the diagnostic journey taken by patients, such as being self-diagnosed then receiving a traditional diagnosis, or scanning various diagnostic labels until one resonates with their illness experience (Jeske et al., 2024).

dermatology predominantly lie in biomedicine and social-psychology, employing quantitative methodology; namely, they focus on aspects such as emotional distress caused by dermatological conditions (Rumsey, 2018), the importance of psychometric outcome measures in cosmetic dermatology and skin cancer surgery (Mori & Lee, 2019), the positive relationship between the presence of skin issues and negative body image (Hinkley et al., 2020), and how "pimpled skin becomes meaningful through dynamic interactions between science and culture" (Carey, 2017, p. 2). Thus, the following literature review presents the theoretical and empirical scholarship in core areas of the *sociology of health & illness*, *medicine*, and *diagnosis*. In particular, investigating the social construction of illness labels via diagnosis and the process of medicalization, the evolution of doctor-patient relationships from paternalistic to participatory models, and the emergence of patient expertise in evolving healthcare landscapes.

2.2. Navigating Diagnosis

Brown (1990, p. 388) was the first to push for a *sociology of diagnosis*, critiquing the diagnostic process by discerning it as a "central component of social control." In his Foucaudlian view, giving a name to a deviant state is to begin constructing its social label (Brown, 1990). Prior to these observations, Zola (1972, p. 487), in his account of medicalization, observed that medicine replaced religion and law as the "new repository of truth," where judgments made by "supposedly morally neutral and objective experts" are positioned "in the name of health." The canon of scholarship at this time discussed how the healthcare institution bestowed socially constructed labels to name deviance as a disease and make 'health' and 'illness' pertinent in every aspect of human existence (Zola, 1972; Brown, 1990; Conrad & Waggoner, 2017). Indeed, caring for the sick is—or at least should be—the ultimate goal of medicine. Yet, the fluctuating history of what constitutes a disease, the advent of misdiagnosis, and the lack of adherence to diagnostic criteria beg to differ (Jutel, 2014; Hofmann, 2016). Furthermore, the rise of self-diagnosis due to the advent of alternative knowledge sources adds complexity to the diagnosis phenomenon (Lupton & Jutel, 2015). Prior to delving into these matters, it is essential to discuss what is a diagnosis.

A diagnosis identifies the nature of an illness and is a tool for organizing and classifying medical conditions (Bowker & Star, 2000; Raker, 2024). This dualism of diagnosis, both as a category and a process, is deeply intertwined and mutually influential. By recognizing and categorizing ailments, a diagnosis bestows legitimacy upon them, thereby granting select individuals medical services, insurance coverage, and social support (Bowker & Star, 2000; Jutel, 2009; Campbell, 2021), while significantly shaping health realities by determining resource allocation, management jurisdiction, and one's sense of identity (Blaxter, 1978; Brown, 1995; Jutel & Nettleton, 2011). Once formalized within disease

classification systems, such as the ICD (International Classification of Disease), diagnostic labels and categories solidify views of illness, privileging certain perspectives while silencing and (sometimes) stigmatizing others (Mayes & Horwitz, 2005; Nettleton, 2006; Jutel, 2011). Despite being treated as objective truths by medical institutions, these classifications are not fixed but evolve over time; Aronowitz (2001, p. 803) notes that while biological and clinical factors "set boundaries" for "disease concepts," "social influences" additionally "determine which symptom clusters become recognized as diseases." Operating at the juncture between symptoms and disease, abstract complaints and tangible problems, diagnosis may additionally grant individuals permission to be exempted from duties of everyday life, ranging from sick leave acquisition to disability passes and even fulfilling lighter everyday duties (Parsons, 1975; Jutel, 2009). By virtue of diagnosis, the ill individual may, hence, find themselves being pampered rather than blamed (Freidson, 1972).

Diagnosis also represents medical knowledge while simultaneously crafting the presentation of disease and what should be treated as deviance (Jutel, 2009). For instance, the removal of homosexuality as a mental illness and the recognition of Alzheimer's as a debilitating disorder stemmed from political activism and media attention (Mendelson, 2003; Jutel, 2009). Similarly, the expansion of diagnostic categories, influenced by factors such as medicalization, can lead to unintended consequences, including iatrogenic effects and commercial exploitation (Illich, 1975; Scott, 2006). Medicalization involves affixing diagnostic labels to various behaviors and conditions, legitimizing them as medical concerns, and institutionalizing them through diagnosis (Zola, 1983). Scholars have applied this model to a range of social conditions, including alcoholism (Blaxter, 1978), compulsive gambling (Rosecrance, 1985), menstruation (Vertinsky, 1994), pregnancy (Barker, 1998), obesity (Jutel, 2012), and other parts of social life. Medicalization, as seen in ADHD, can lead to overdiagnosis due to broadening diagnostic criteria, resulting in excessive diagnosis rates and overprescription of medications such as stimulants, fueled by social, economic, and pharmaceutical factors (Conrad & Potter, 2000; Timimi & Timimi, 2015; Timimi & Leo, 2017). Hence, the modern landscape of clinical practice, impacted by neoliberalism, globalization, and commodification in framing disease and risk factors, reflects an evolving approach to diagnosis (Jutel & Nettleton, 2011).

However, diagnosis is emotionally contested as well, resulting in relief and grief for the patient on the receiving end. When a disease is named, it can lead to various psychological processes such as biographical disruption (Bury, 1982), loss of self (Charmaz, 1983), narrative reconstruction (Williams, 1984), or symbolic transformation (Fleischman, 1999). In the diagnostic process, an interpretative exchange occurs between lay individuals and professionals, reshaping lay stories of embodied experiences by medicine, which sometimes entails surrendering narrative control (Leder, 1990; Frank, 2013). Hence, diagnosis is ultimately understood as a foundational starting point for sense-making and crafting experiences within the illness domain (Frank, 2013). In response to these views, some works embrace new materialist ideas that humans come to understand their bodies through the involvement of non-human agencies (e.g., discourses, objects, and materials), while bodies, in turn, imbue significance and shape these non-human agencies (Haraway, 2013; Lupton, 2019). The "mutual constitution of entangled agencies" is often emphasized in these regards, explaining that "distinct agencies do not precede, but rather emerge through, their intra-action" (Barad, 2007, p. 33). Concepts inspired from new materialism have been adopted in healthcare research on disability, female reproduction, human embryos, and stem cells (Lupton, 2019). However, these only scratch the surface, leaving ample room for "innovative and creative [...] inquiries [...] into human health and embodiment (Lupton, 2016a; Lupton, 2019, p. 2007).

2.3. Transformation of Doctor-Patient Dynamics

Another aspect pertinent to understanding health and illness constructions is the evolving doctor-patient relationships (DPRs). Prior to the 1970s, compliance in sickness was at the locus of patienthood, mediated by a physician's social and professional authority, material sources, assumptions over unified expertise, and asymmetrical knowledge about healing² (Stone, 1979; Goodyear-Smith & Buestow, 2001). Patients assumed a passive and compliant role, reflecting the etymology of the term 'patient' rooted in the Latin 'patior,' meaning to suffer or bear, emphasizing the patient's reliance on the expert healer (Neuberger & Tallis, 1999). The nature of DPRs has since evolved to include the consumer model (where power resides with the patient), the partnership model (where power is equally distributed between doctor and patient), and the participatory³ model (where there is no power involved but solidarity), in addition to the original paternalistic model (where power resides with the doctor) (Shutzberg, 2021). In theory, this power transformation suggests a higher synergy between doctors and patients. However, empirical observations reveal that physicians frequently label patients who possess information about their condition and treatment preferences as "difficult" (Topol, 2014, p. 6). The question becomes, *why*?

DPRs are a novel addition to medical practice compared to the historically prevalent focus on concrete 'things,' such as anatomical structures and pathological entities (Szasz & Hollender, 1956). It implies that a doctor's clinical knowledge and technical skills are meaningful if they are effectively

² In this sense, medical information and influence in clinical settings is considered as power (Shutzberg, 2021).

³ Explained in Shutzberg's (2021) work as a "bureaucratic parsimony" and "solidarity between comrades."

communicated to the patient and rapport is formed (Morgan, 2018). The fundamental models of DPRs are summarized in Table 1 (Szasz & Hollender, 1956; Charles et al., 1999; Mead & Bower, 2000).

Model	Definition
(a) Activity-passivity (paternalistic)	Physician does things to the comatose patient, who is unable to respond or simply receives intervention without interference.
(b) Guidance-cooperation (informed)	Physician advises the patient, who has sought the physician's expertise and is actively willing to obey the physician's instructions.
(c) Mutual participation (shared or participatory)	Physician helps patient to help themselves; the patient is a participant in their own health, providing key information used as therapeutic clues.

Table 1. Three basic models of the doctor-patient relationship (adapted from Szasz & Hollender, 1956, p. 568)

These relationships are recognized as both situations and processes (Szasz & Hollender, 1956). For the former, imagine a patient being screened for breast cancer via mammography under the *activity-passivity* model. For the latter, imagine a patient with diabetes milieus who has transformed from being handicapped at the peak of their chronic condition to gaining insights on how to administer insulin shots, monitor their health, and update their physician with their glycogen levels. Here, the patient moved from one DPR model to the next as a process, ending at the *mutual participation* model. While Table 1 provides a helpful overview of overarching DPR models, it ought to be clarified that various DPR models co-exist, such as those proposed by Shutzberg (2021), yet their chronological sequence is telling of the paradigmatic shifts from paternalistic to participatory practice.

It has been contended that all three DPRs, regardless of model, share one common condition to function: Both the physician and the patient must forge a mutual agreement on what constitutes "health" and "illness," establishing consensus for normality, abnormality, symptoms, severity, treatment, and the alike (Szasz & Hollender, 1956; Jagosh et al., 2011). In other terms, definitions of well-being and disease are socially constructed and highly dependent on spatiotemporal contexts; for instance, medical professionals, and thereby populations, once believed that fevers were a negative symptom of the flu, which differs significantly from the modern (and widespread) recognition of high temperatures as a signal of the body's natural immune response in fighting the disease (Prior, 2003). While the flu example presents a transformation of consensus, the quantity of factors requiring agreement between the physician and the patient is expanding: Philosophies on the mind-body connection (Benson, 2019), vaccine hesitancy (Paterson et al., 2016), and ranging opinions on 'disruptive' prevention strategies for conditions like cancer (Kerr et al., 2018), among others, are topics of debate now. Moreover, they are progressively being discussed among patients and lay communities in what is dubbed 'citizen science' (Heyen et al.,

2022). In practical terms, this has led to the shrinkage of doctor-patient consensus—a mismatch that has continued over the past century, let alone decades.

In the wake of the 21st century, public and private medical settings began to react to the lay public's growing desire to 'democratize' or 'become liberated' from traditional healthcare in some geographical contexts (Prior, 2003; Topol, 2014). Awareness of diverse treatment tradeoffs challenged the notion of physician superiority, raising concerns about decision consistency and appropriateness (Roos, 1984; Chassin et al., 1986; Lomas et al., 1989; Eddy, 1990; Charles et al., 1990). Healthcare has even become seen as a commodity by those within the system in addition to the public, ignoring the non-proprietary necessity of helping the sick (Sulmasy, 1993). Ultimately, these forces led to the delegitimization of professionalism, as some have considered the concept of an expert to be anti-democratic (Habermas, 1985; Prior, 2003). In medical practice today, being receptive to lay assessment and attuned to patient perspectives is an expectation from physicians rather than an option (Topol, 2014).

Another aspect responsible for the shift towards 'liberation' is the decentralization of medical information from the doctor and the hospital to the Internet, and effectively into the hands of the lay population (Lupton, 2016a). The proliferation of online platforms and the emergence of sensor-enabled wearables and applications led to novel representations of the human body, the circulation and prosecution of personally generated data, and lay understandings of medicine (Lupton, 2016a). Hence, information about health and illness is no longer exclusive to professionals and institutions (Akerkar & Bichile, 2004). The Internet provides several beneficial functions; it is a bottom-up medium where one can consume and publish content, feedback channels provide these consumers and publishers with direct opinions from forums or comment sections to refine content, adapt mindsets, or gain information—and the entire thing happens quickly and flexibly (Anderson et al., 2003). Furthermore, the rise of wireless devices, particularly sensor-enabled technologies, and the use of mobile health applications (such as sleep, nutrition, or menstrual trackers) added a quantifiable nuance to lay online discourse on health and illness (Lupton, 2016b).

2.4. Emergence of Patient Expertise

Having picked up on changing patient desires, medical settings began reacting. Manifestations of these reactions include the National Health Service's (NHS) Expert Patient Training Program in the United Kingdom, which encourages primarily older individuals with chronic conditions to take active

roles in their health via the empowerment of digital technologies (Department of Health, 1999; Department of Health, 2001), the shared-decision making model in clinical consultations (Elwyn et al., 2000), professional participation in patient decision-making (Brown, 2001), and rise of patient-centered care (PCC) (Stewart, 2001; Oprea, 2009). Additionally, the institutional push towards prevention has been driving individuals to seek knowledge, with health promotion campaigns and patient education programs playing a significant role in increasing health awareness (Anderson et al., 2003). In this emerging participatory landscape, psychometrics, subjective health constructions, and preconceived notions on condition and treatment plans are pivotal forces, propelling physicians into the role of partners who refrain from interfering with a patient's progress towards self-reliance (Pinner & Miller, 1952). However, for the most part, physicians do not shift their attitudes and label patients as "non-compliant," and reciprocally, patients perceive physicians as "unsympathetic" (Topol, 2014).

Patient expertise is an outcome of shifting internal patient preferences towards individualized healing, along with structural changes in healthcare systems and technological advancements (Badcott, 2005). This so-called 'expert' patient identifies symptoms, actively monitors and manages his or her health, self-administers medications, adopts lifestyle changes, and/or seeks information to inform health decisions (Wilson, 2001; Shaw & Baker, 2004; Fox & Ward, 2006). These individuals transform the biomedical paradigm of their role, erasing notions of professional power structures and blurring the lines between expertise and experience. Ironically, they simultaneously comply and take control of their health management (Paterson & Thorne, 2000). However, in essence, expert patients take it upon themselves to perform do-it-yourself (DIY) medical practice outside of traditional medical settings with the additional embodiment of falling sick and becoming well—hence, it is often contested that experience (with disease) is confused with expertise (on disease) (Prior, 2003; Iedmena & Veljanova, 2013).

What makes a patient, a layman, an expert has been of continuous discourse. In the 1990s, concerns over lay beliefs transformed into lay knowledge, whereby lay individuals became portrayed as multi-skilled and well-informed, akin to epistemologists (Busby et al., 1997; Willians & Popay, 2013). This evolution culminated in the term 'lay expert patient,' although earlier works limited this so-called expert to self-care (Sarangi, 2001). Recently, it refers to individuals with skills in diagnosis, medication for minor illnesses, pharmaceuticals, and more (Hibbert et al., 2002). Nonetheless, the boundaries of what defines an expert patient remain complex. It is often argued that lay expertise stems from firsthand experiential knowledge and may emerge within social groups or family caregiver settings, who act as biographical and biological translators (Busby et al., 1997; Monaghan, 1999; Brown et al., 2001). Hence, lay experts are not only acknowledged by their peers but also gain recognition within both public and

private medical realms, positioning them on par with individuals possessing formal scientific training (Epstein, 1996; Arksey, 2021).

Within the expert patient phenomenon, online discussions, information dissemination, and user interactions within digital health spaces have been extensively studied (Lupton, 2016a). This body of work has predominantly focused on interpreting health, illness, and medicine discussions within online forums, as well as examining information-seeking behaviors and how individuals navigate the expanding landscape of online health-related information (Pitts, 2004; Ayers & Kronenfeld, 2007; Broom & Tovey, 2008). More recent lines of inquiry have explored the multiplicity of identities and embodiments expressed online and examined the dynamics of online communities and their implications for perpetuating or challenging dominant discourses and norms. For example, Fox & Ward (2006) utilized Deleuzian theory to examine how identities are represented and negotiated in online forums surrounding Viagra, weight loss drugs, and pro-anorexia; their analysis underscored the spectrum of viewpoints, from active pharmaceutical consumers to individuals expressing skepticism toward medicine on pro-anorexia platforms, asserting that online perceptions and encounters with health are shaped by the interaction of bodies, technologies, and emotions. Furthermore, Cimini (2010) investigated attempts by activists in online forums to redefine disability, while Giles (2014) explored the reactions of the Asperger's disorder community to changes in diagnostic criteria.

Nonetheless, the idea of lay expertise has faced criticism from various angles. Some argue that it introduces linguistic contradictions and mistakenly conflates experiential knowledge with genuine expertise (Prior, 2003; Badcott, 2005). Additionally, it is noted that this concept tends to overlook entrenched professional power dynamics and structural barriers related to resource access (Tang & Anderson, 1999). On the other hand, some scholars advocate for prioritizing the concept of 'illness experience,' emphasizing the unique realms of patient and caregiver knowledge as forms of 'collective knowledge' and stressing the importance of recognizing the differences between lay individuals and experts (Prior, 2003; Wilcox, 2010). Indeed, research suggests that a collaborative approach, integrating professional expertise with patient experience, fosters a harmonious environment, leading to satisfaction for both parties and, crucially, positive health outcomes for the patient (Oprea, 2009). Moreover, the notion of lay expertise is acknowledged as a response to challenging medical hegemony and may signal broader systemic or structural issues, such as healthcare inequality, where acquiring lay expertise becomes a necessity rather than a preference (Prior, 2003).

2.5. Chapter Summary

In light of the sections above, it is clear that perceptions of (ab)normality are contolled by healthcare systems via diagnosis, an institutionalization of ailments, human behavior, and social life. Through social control, diagnosis imbues a threshold over who is exempted from normal social life, gains access to vital resources, or even gets blamed and stigmatized. Additionally, the narrowing knowledge gap between doctors and patients is juxtaposed with a sense that their relationship may be drifting apart. Historical shifts and the emergence of online health information, in addition to other complex forces, has led patients to opt for DIY diagnostic and therapeutic alternatives over hospital visits, driven by factors such as the convenience and desires to avoid negative iatrogenic effects from "invasive" medical procedures. This is not to state that doctors are becoming replaceable, but rather supplementary sources of medical information and medical care in some disease contexts.

What foundational literature seldom points out is the inherent assumption that diagnosis *pre*cedes or *pro*ceeds illness experience explanations—how it is strictly positioned at the start or end of medical practice. In addition, current scholarship is focused on official diagnoses constructed by the physician, clinicians, and other healthcare professionals rather than by the patient (Jagosh et al., 2012; Jutel, 2015), leaving questions over whether self-diagnosis possesses similar functions. Moreover, the *sociology of diagnosis* has been primarily discussed in terms of psychiatric disorders, chronic physiological conditions, and aspects such as gambling, alcoholism, and pregnancy (Jutel & Nettleton, 2011; Jeske et al., 2024). Hence, there is room to explore the diagnostic phenomenon in dermatology.

3. Data and Methods

3.1. Research Questions

In line with the theoretical framework and identified gaps in the literature, this study addresses the following research question with sub-questions (a~c) listed below:

- 1. How does a diagnostic pathway shape the understanding of a dermatological concern?
 - a. What role do diagnostic pathways play in dermatology?
 - b. How are dermatological concerns socially constructed?
 - c. How are experiences and expert knowledge mobilized to address these dermatological concerns?

The following sections explore the methods of data collection and analysis, followed by ethical considerations, which serve as the foundation for the findings detailed in Chapter 4.

3.2. Data Collection

This study employed qualitative methodology via conducting semi-structured interviews. Semi-structured interviews are frequently used for health research, as they provide both guidance and flexibility, yielding an organized conversation that allows participants to discuss their perspectives and experiences in detailed accounts; in other words, the focus is on what participants make important rather than the researcher imposing importance to a topic (Gill et al., 2008; Kallio et al., 2016). The one-on-one, private nature of interviews tends to create a comfortable environment for participants to discuss sensitive matters, such as dermatological conditions, in greater breadth and depth (Strokes & Bergin, 2006). The interviews were conducted either in-person or virtually over ZOOM; this mixed-mode format was adopted to suit individual participants' personal preferences and to account for geographical or other restrictions. The sample purposively includes two groups of participants (Group U & Group T), all of which adhere to the following criteria:

- 1. All participants engage with their dermatological condition, such as self-checking, conducting online searches, health management, seeking medical care, etc.
 - Dermatological conditions concern the skin, hair, and nails, including but not limited to acne, alopecia, atopic dermatitis, eczema, herpes, hives, fungal infections, psoriasis, skin cancer, rosacea, shingles, vitiligo, and/or other conditions
- 2. All participants are diagnosed, were diagnosed, or in the process of diagnosis for a dermatological condition(s) belonging to either of these two diagnostic pathways:
 - a. Traditionally diagnosed by a physician, doctor, or other healthcare professional → Labeled as 'Group T'
 - b. Not traditionally diagnosed, therefore 'undiagnosed' (but interactive with their dermatological health) or self-diagnosed → Labeled collectively as 'Group U'
 - Diagnostic pathway labels (T/U) were assigned based on the individual's last updated diagnostic grouping according to their narration; for example, if a patient self-diagnosed then went to the physician to confirm and accept the physician's advice, they would end up in 'Group T.'⁴

⁴ At this stage, it is important to note that these diagnostic pathways were adopted to provide structure, in addition to reflecting the inherent assumption that there are indeed two distinct groups. However, the participants' assigned diagnostic pathway did not guide the analysis process; instead, an inductive, open approach was taken, detailed in Section 3.3.

In addition to said requirement, according to the initial research design (see Appendix A), a portion of the sample had to be users of digital spaces, including but not limited to websites, social media platforms, online forums, applications, and/or other digital spaces when engaging with their dermatological condition. In this sense, there is an inherent assumption that participants utilize digital spaces for dermatological health purposes.

Interview participants were recruited via non-random snowball sampling, a technique used often in qualitative studies (Parker et al., 2019). The researcher's personal contacts were asked, either via text or in daily-life interactions, whether they knew individuals who could be potential candidates for the study (see Appendix B). Once selected, participants had access to the researcher's WhatsApp, which was used for exchanging information on the general research purpose, organizing and explaining the interview, and submitting the signed consent forms (see Appendix C). Ultimately, a total of N=12 participants (N=6 from each diagnostic pathway) participated, as seen in Table 2. All participants were current university students or recent graduates at the Bachelor level.

Ν	Pseudonym	Condition (self-described)	Group	Age	Sex	Occupation (self-described)	Nationality
1	Aisha	Shingles & Acne	Т	22	Female	Student	Saudi
2	Soyeon	Acne	Т	22	Female	Student	Korean
3	Noor	Acne	Т	21	Female	Fresh Graduate	Saudi
4	Elena	Acne	Т	19	Female	Student (& Office Manager at Pharma Firm)	Ukrainian*
5	Carla	Atopic Skin & Acne	Т	24	Female	Adverting & Marketing	Spanish
6	Ivan	Herpes	Т	23	Male	Freelancer	Kyrgiz*
7	Zayn	Eczema	U	21	Male	Student	Emirati*
8	Martin	Xerosis	U	24	Male	Marketing Specialist	Czech
9	Omar	Acne	U	20	Male	Student	Saudi
10	Lucas	Atopic Dermatitis	U	21	Male	Student	Polish*
11	Jisoo	Acne	U	21	Female	Student	Korean
12	Gabi	Alopecia	U	23	Female	Int'l Development Intern	Mexican*

Table 2. Biographical details of interview participants (N=12)

**Participants* #4, #6, #7, and #12 currently live in Czechia, while participant #10 currently lives in the Netherlands; the rest of the participants' current residence matches their nationality.

Each interview lasted, on average, around an hour, with some as short as 40 minutes and others as long as an hour and a half. To ensure a semi-structured approach and steer the discussions, an interview guideline was employed (see Appendix D). These components underwent finalization following a trial, a pilot interview conducted a week before the commencement of the actual interviews, with only minor adjustments made to the original interview questions. This methodological approach to data collection

was modeled off of Fox, Ward, & O'Rourke (2005) work on expert patients in online weight-loss communities, who conducted twelve qualitative interviews, followed by virtual observations of said online communities. In this study, the number of interviews conducted was prompted by the model paper in addition to saturation criteria, which serve as a confidence tool for qualitative data (Saunders et al., 2018). Repetitive ideas were noted around the tenth to eleventh interviews, leading to the fulfillment of twelve interviews.

3.3. Data Analysis

Due to the exploratory nature of this study and its novel research area, an inductive approach was adopted. In particular, thematic analysis (TA) with elements of grounded theory (GT)⁵ was employed, as they allow for adaptability and are often used in health research (Braun & Clarke, 2006; Chapman et al., 2015; Campbell et al., 2021).

TA is an analytical method used to produce meaningful patterns (themes) by systematically color-coding and organizing qualitative data (Braun & Clarke, 2006). Meanwhile, GT, often dubbed a 'data-first approach,' is a methodological process of collecting and analyzing data concurrently with the aim of developing a theory or paradigm model (PM) that is 'grounded' in the data (Glaser & Strauss, 2017). This study combined elements of both methodologies to provide a comprehensive understanding of the interplay between diagnostic pathways and constructions of dermatological concerns to not only identify core themes in the data but also to understand the relationships between them. In practice, the five-stage methodological framework utilized in this study is shown in Figure 2, combining Braun & Clarke's (2006) six-phase TA and GT's three-step coding.







⁵ There are eleven elements of doing GT according to Corbin & Strauss (1990); however, this study took inspiration from select elements, including data collection and analysis as interrelated processes (element no. 1), constant comparison (element no. 5), and writing theoretical memos during the research process (element no. 8), along with the common coding steps.

Stage one is data familiarization, whereby the data is transcribed and read several times, and initial research memos are taken (Braun & Clarke, 2006). In this study, the semi-structured interviews were recorded in audio format and transcribed incrementally within the span of a little over a month. Two-stage transcription was used, whereby the *BEEY.IO* tool automatically converted the audio file into text, which was then manually cross-checked for errors and to go over the raw data. Due to the iterative data collection process and validation of automated transcriptions, it was possible to be fully immersed in the data and take each interview for what they are individually before looking at the broader picture. This "digesting and reflecting" of data prior to coding is also commonly used in GT (Saldana, 2013, p. 101). Memos taken during this process can be found in Appendix E.

Stage two is open coding⁶ and generating initial codes. This stage involves identifying and labeling data features across the entire dataset in the form of codes; in particular, line-by-line coding was used as it promotes trustworthiness (Braun & Clarke, 2006; Charmaz, 2006; Charmaz, 2008). In this study, the interview transcripts were color-coded using computer-assisted qualitative software (CAQDAS), *ATLAS.ti (Version 24)*. A total of 550 open codes were generated to capture the nuances of 16 hours of interview data. Table 3 displays examples of codes applied to interview transcript extracts.

Table 3. Generating initial (open) codes (sample excerpt from this study's data)

	Data extracts	Coded for
Ex. 1	"Well, it happened when I was starting puberty, like at 17 or 18, and like, all the acne started showing on my face. I was facing difficulties because I was going to my school, and some people don't like seeing people with a lot of acne."—Omar, Group U	 etiology concern; <i>linking</i> growing up/hormones & condition visual cues appearance; <i>bad assumption</i> effect on social life
Ex. 2	"Like I already knew that, well, if it's a skin condition, I Google the thing closest to my type of case and think it is that, and nothing more serious. I didn't die in a year; probably, I'm not going to die in the next ten years. I decided to just stick with that mindset because I don't want to be on hormonal therapy to mess up how my body works."—Ivan, Group T	 condition as a minor issue searching online; personal/relatable symptoms treatment hesitancy; invasive assumption

Stage three is axial coding, which builds upon open coding by organizing codes into coherent categories or 'axes' (Strauss & Corbin, 1998), as shown in Figure 3. This stage further involves determining the dominant and less important codes, removing redundancies by merging and deleting codes, and selecting the most representative codes to reorganize the dataset (Boeije, 2009). The initial 550 codes were collated into 150 codes and categories, with 75 of those being used in the final analysis; these codes were selected on the basis of frequency in the dataset and relevance to the research aims.

⁶ Sometimes referred to as "initial" coding (Saldana, 2013, p. 100).



Figure 3. Relationships between categories (circles) & codes (boxes) (sample excerpt from this study's data)

During this stage, initial themes were generated by collating relevant codes and categories into potential themes based on emergent patterns (Braun & Clarke, 2006), as shown in Figure 4. These themes were revised for coherence, validity, and distinctiveness. This involved reviewing coded data extracts to ensure coherence within themes, and then considering the validity of themes in relation to the entire dataset (Braun & Clarke, 2006). Consequently, the number of themes were narrowed down and selected, and subsequently organized into a PM.





Stage four is selective coding,⁷ whereby the core phenomenon that encapsulates the essence of the research is identified, and the result is presented in a PM (Strauss & Corbin, 1998). However, Glaser

⁷ Sometimes referred to as "theoretical" or "conceptual" coding (Saldana, 2013, p. 223).

(2005) mentions that not all studies require this stage, and it is better to omit a model than to develop one inaccurately; thus, the PM presented in this study is meant to scratch the surface of the phenomenon under study and was combined with five themes to provide rigor. Accordingly, this fourth stage was where themes are defined and named, described by Braun & Clarke (2006, p. 87) as a stage "to refine the specifics of each theme and the overall story the analysis tells."

Stage five involves writing up the final analysis in the form of a report (Braun & Clarke, 2006); in this case, it was a thesis project. The content of this study's findings can be found in the findings chapter.

3.4. Ethical Considerations

This thesis addressed standard ethical considerations of social science research. The interview participants' confidentiality was maintained by ensuring personal data was anonymized and no identifiable information was made available in the research process and output. In adherence to the standard of past papers in the field, a pseudonym with no association with the participants' original name was adopted, including solely standard biographical information (Table 2, Section 3.2). All participants were required to sign an informed consent form detailing the study's aims, use and presentation of data, and all following procedures (see Appendix C). Additionally, participants were notified of their right to withdraw from the study without facing any consequences or the need to clarify the reasoning and were verbally informed at the end of every interview that inquiring to edit or exclude any information provided throughout the interview process is possible in the weeks following the interview; to note, no such attempt was made. Furthermore, as this study surrounds discussions of personal health and illness, a topic potentially sensitive to some, special attention was paid to the quality of interview questions (relevancy, wording, etc.), reminding participants that there are no wrong opinions or experiences, and allowing them to skip a question if desired (see Appendix D). Overall, this thesis followed ethical guidelines set out by relevant professional bodies.

4. Findings

This study's primary aim is to explore how diagnostic pathways shape individuals' understanding of their dermatological concerns, specifically paying attention to the role of diagnosis, how concerns are constructed, and how experience and expert knowledge areare mobilized to address these concerns. Hence, 12 interviews were conducted, collecting data from traditionally diagnosed, self-diagnosed, and

undiagnosed individuals in the realm of dermatology. The transcripts were coded following a combined TA and GT methodological framework, yielding 75 selected codes and categories (see Appendix F).

In this chapter, the findings are presented in the form of a PM and five themes. Figure 5 shows the skeleton of this study's PM, which will be integrated with the contents of themes explored in Sections 4.1 to 4.5. At the end of this chapter, the filled-in PM is presented in Figure 7, illustrating the interconnections among said themes. It is important to note that the PM in this thesis was altered to fit the study's data by adding an arrow for "intervening conditions" (apply to the entire sample) and "contextual conditions" (apply to a portion of the sample) on the "core phenomenon," as well as showing a co-relationship between the "core phenomenon" and "strategies/actions/interactions." Additionally, the titles of boxes "causes," "core phenomenon," and "strategies/actions/interactions," "contextual conditions," and "consequences" were kept as they were suitable for the study's findings.



4.1. Appearance & Interpretation of Abnormality

As anticipated, the visually-bound nature of dermatology was important for participants in recognizing and responding to their dermatological concerns. These encompassed various sensory cues

(visual, tactile, and instinctual), severity, and lay understandings of disease and etiology.⁸ Ultimately, participants' experiences and interpretations of abnormality led to how they constructed their dermatological concerns.

4.1.1. Cues (Indicators) & Severity (Levels)

When asked, "*how did you come to realize you had this condition*?" participants unanimously answered that it was a matter of common sense—it was obvious that something about their dermatological health was "different" or "wrong," and in some cases, even the specific medical diagnosis was obvious to them. For example, Zayn (U) promptly booked a dermatologist's appointment, knowing he had eczema, with the purpose of accessing necessary treatment:

"It was obviously eczema. I had dry spots on my cheeks; like, what else is it going to be? [...] I don't know... Like I don't have any allergies. Usually, that's why. Although the dermatologist didn't tell me what the condition was or diagnose me; I just assumed."

Accordingly, some combination of visual cues, tactile cues, and an instinctual "gut" feeling indicated abnormality or a changing (health) status. Common manifestations of these cues included skin redness, dryness, itchiness, the emergence of pimples, blackheads, acne, and hair loss. Meanwhile, gut instincts typically consisted of a sense that the number of, color of, or feeling of those cues was not normal—a form of intuition. Aisha (T), in particular, mentioned intuition multiple times in her narration of contracting shingles, a temporary viral infection. Despite dismissal from her family members, who claimed she was exaggerating her symptoms, she sought a dermatologist to confirm or deny her suspicions:

"It was weird... I was trying to sleep, but I couldn't [sleep] because my skin was burning, and I felt like that wasn't normal. So I guess, trust your gut?"

Interestingly, in addition to serving as initial indicators of abnormality, cues were then organized by level of severity. This severity level, in turn, determined whether participants constructed their condition as problematic or a routine aspect of life. Beyond visual, tactile, and instinctual severity indicators, such as pain and condition prevalence, severity sometimes stemmed from socially-defined sensitivity, reinforced by cultural norms, values, and media portrayals. At times, these societal expectations prompted not only the severity but also the recognition of a dermatological concern. To

⁸ Etiology (or "aetiology") refers to the cause of a disease (Cambridge Dictionary, n.d.a.). In the context of this thesis, "disease etiology" represents the causes participants attributed their dermatological concern to.

illustrate this, consider Carla (T), a Spanish participant whose standard of "healthy skin" rose from illnesss-free to "glass-looking skin" that is "glowy" and "bright" post visiting Seoul, South Korea.⁹ As can be inferred, heightened subjective perceptions of condition severity resulted in more urgency and proactivity, and vice versa. In practical terms, severity level determined the difference between self-diagnosis or booking a medical consultation, managing the condition on the side or desiring to treat it effectively and quickly. For instance, Jisoo (U) compared her acne to others' and concluded that her case was too mild to deserve care:

"In comparison to people around me, the severity of acne I had wasn't serious enough for me to read up on extra materials or want to be clinically diagnosed and work with a dermatologists one-on-one."

Noticing cues and labeling severity level was not only imposed *by* participants but imposed *on* participants by others, albeit peers (family, friends, colleagues, etc.), physicians, or the aforementioned social expectations (cultural norms, values, media, influencers, etc.). However, the comments of peers and physicians did not appear to significantly influence dermatological concerns. Rather, peers refrained from commenting unless it was culturally appropriate, such as adhering to the norm in Korean culture to "point out obvious pimples" as a form of "teasing." Meanwhile, participants perceived physicians' comments on blemishes as a means to suggest further skincare products—a motive seen as economically driven. Additionally, while cues served as indicators of abnormality, they served the dual purpose of indicating normality or an improvement in health status. Gabi (U), who self-diagnosed herself with alopecia after losing large amounts of hair, mentioned:

"It's about severity. If I would start getting bald completely, then like maybe I would try a specialist, of course, but since my remedies started working, why I did not go to any physician for it?"

4.1.2. Lay Understandings of Disease & Etiology

Underlying lay understandings of abnormality additionally influenced dermatological health constructions. These preconceptions consisted of inherent ideas over the "right" time to experience a condition, whether or not they would resolve themselves, and habits related to the condition. For example, Carla (T) exemplified how her response to what she perceived as late-stage acne was influenced by a blend of expectations regarding the onset of acne in addition to social factors:

⁹ South Korea's capital, Seoul, has been dubbed the "cosmetic," "beauty," and "surgery" "capital of the world" due to its successful skincare and plastic surgery industry—globally, it is known as "k-beauty" (Kwon, 2020).

"I got acne when I was older, at 17. I was in the last years of high school and it really affected me because I was getting it when everyone was getting rid of it. If I had gotten it at around 13, when everyone else was, I wouldn't have gotten a treatment."

A similar experience was voiced by Jisoo (U), who mentioned she was ultimately prompted to see a dermatologist because she believed she was "too old" to have naturally-occuring acne:

"I thought I was old enough at 18-19; I expected that to be the cut-off for acne. Then I realized, *'maybe my hormones aren't the issue anymore*,' so that hope that it's going to go away with time and puberty diminished. Once I felt this isn't an age thing anymore, I was prompted to visit the doctor's office and treat it like a real condition."

Alongside cues, severity, and preconceptions, understanding disease etiology emerged as another pivotal factor in interpreting abnormality—the causes and catalysts exacerbating conditions. The most common factors participants attributed to their conditions were puberty or growing up, hormones and stress, dietary factors, environmental stimuli such as bacteria or dust, seasonal changes, and genetic predispositions. For instance, Aisha (T) speculated whether she contracted shingles from a virus during a hotel visit or at the gym, Omar (U) attributed his acne to puberty and excessive consumption of dairy products, and Ivan (T) argued that his herpes infection was activated by a combination of his naturally weak immune system and exposure to chemical sprays at work. It is worth noting concerns over disease etiology were not necessarily shared by healthcare professionals, who, according to participants' narration, were primarily focused on condition consequences and solving the problem. Accordingly, dermatologist visits were thus considered "underwhelming" because they often lasted "shorter than expected," and "little inspection" was conducted. Instead, there was a sense that physicians had go-to solutions they prescribe upon viewing the condition at a glance. With Jisoo (U), she mentioned:

"My father, a health professional, was talking about how he really wants us to stay away from Accutane, if possible; like that's kind of why I refrain from going to the doctor, because that's their immediate solution."

This manifested into a dynamic where some participants were keen on the solutions-oriented approach, while others believed it prevented treatment plans from being tailored, leading them to express that they "did not feel like a real patient receiving real care." An example of this sentiment being expressed was when Zayn (U) critiqued his medical consultation, stating "the dermatologist did not even mention the air conditioning, let alone other potential causes," leading him to believe, "it's more of a business than them [dermatologists] actually caring."

4.2. Diagnostic Pathways & the Centrality of the Patient Voice

In light of the experiences voiced in the section above, there was a curiosity over what role diagnosis actually played in dermatology. Initially, this study categorized participants based on whether they were traditionally diagnosed by a physician (Group T) or were self-diagnosed/undiagnosed (Group U); however, findings show that diagnostic pathways are more complex. This is because the *moment* of diagnosis pertinent to traditional medical practice was often absent in dermatological settings. Instead, prescription medication was unlocked upon visiting a dermatologist, void of receiving a diagnostic label or further explanation of the condition itself. To demonstrate, Soyeon (T), like many participants, does not recall being diagnosed by her physician:

"I mean, I knew I had hormonal acne—it was just a question of reaching an age where I could start Accutane. I'm not even sure if the dermatologist diagnosed me."

Only in chronic cases, which among this study's dataset included 3 participants (Elena, Carla, and Lucas), did dermatologists confirm the diagnosis; however, participants already had the label in mind prior to the medical consultation. For example, it took Lucas (U) 2-3 years to access topical steroids he knew he needed to cure his self-diagnosed atopic dermatitis due to a lengthy waiting list:

"The things I knew I needed access to were, and still are, locked behind prescriptions I can only get my hands on if I see a dermatologist. Looking back, I remember my mom being disappointed when they confirmed my diagnosis; it was almost underwhelming? So, to me, doctors are a bit of a necessary evil."

Since physicians were seldom the primary agents of diagnosis, participants often found themselves constructing their own diagnoses. This process was influenced by whether they understood their dermatological condition as a health-related or aesthetic-related concern (elaborated in Section 4.3). Consequently, official diagnoses primarily served as a formal means to access prescription medications, while self-diagnoses were mechanisms for rationalizing ailments and becoming knowledgeable about one's body (detailed in Section 4.3). For example, Omar (U) explained:

"I wondered '*what is proper way to address yourself*?' And I searched about it, then I found some research states that dairy products play with your hormones to produce these kind of acnes, the white-yellow acne."

By organizing their symptoms and experience into a coherent label, such as "white hormonal acne" or "mild chemical eczema," it was practically possible for participants to intervene by seeking further information or purchasing products that match their specific case. As Carla (T) put it, "no one

knows your body, or what you want, better than you." While these diagnostic labels were typically born out of observing and interpreting abnormality, other times, they came as a result of experimentation with one's personal dermatological status. In other words, some participants labeled themselves as an afterthought or were bestowed a label from peers, products, or media. To illustrate this, consider Martin (U), who became aware of his dermatological health after being introduced to skincare:

"There was no problem per-se. Sometimes I would have pimples and dead skin, which I wouldn't think of taking care of. But then, when my friend let me try some skincare, I noticed improvements to my natural skin! [...] The product literally said something about having 'glowy skin complexion,' which raised the standards for me."

4.3. The Social Constructions of Dermatological Concerns

Having discussed diagnostic pathways, this theme centers on showing how participants understood their dermatological issues. Dermatological concerns were constructed in two ways: In terms of health and aesthetics. These constructions were then subsequently tackled using biomedical approaches or those akin to complementary and alternative medicine (explained in Section 4.4).

4.3.1. The Health Construction

In the health construction, dermatological conditions were considered "illnesses" or "diseases" originating from internal bodily processes, with participants' goals being restoring health and relieving discomfort. This construction was embraced when either of two thresholds were reached—experiencing physical pain and/or when conditions dictated daily life, albeit physically or mentally. For example, Lucas (U) understood his dermatological condition to be health-related; having struggled with atopic dermatitis since childhood, he viewed his health as a status forced to maintain:

"Atopic dermatitis dictates a lot of my day-to-day decisions. Itching... itching doesn't really ever go away. Normal people itch sometimes, and then other times they're fine, whereas I'm itchy all the time. It comes down to a little bit of willpower to not act on those itches and internal struggles. That is the most pervasive symptom."

Additionally, the health construction was adopted as a way to avert responsibility from oneself over to the health system, sometimes considered retrospectively helpful for building healthy habits. Elena (T), who has been dealing with acne since adolescence, mentioned:

"I go from specialist to specialist, trying to find an answer. I cannot imagine dealing with it myself; it's too much responsibility. Acne is something that you literally face

every day. Especially because at my stage, it is starting to hurt."

Hence, participants constructed their dermatological concerns in terms of health when they viewed their symptoms as severe or their condition has intensified, prioritizing immediate concerns and solutions.

4.3.2. The Aesthetic Construction

The aesthetic construction accounted for the majority perspective (8/12), whereby dermatological conditions were seldom viewed as conditions to begin with, sometimes considered temporary or sudden "abnormalities," a natural "part of life," or a "nuisance." They were described as surface-level matters (literally and figuratively), with the primary objective being to restore normality, enhance facial or bodily aesthetics, and gain confidence. There was an inherent minimization, or lack of problematization, of the condition at hand. To illustrate this, Omar (U) persistently mentioned his self-diagnosed hormonal acne was due to puberty, avoiding a doctor's visit who, he believed, would overcomplicate the condition:

"My acne was and is a result of puberty, so it's not extreme enough to warrant a doctor's visit and become a patient first. I'm sure there are more advanced ways to get rid of it, but I just did the standard things: Taking care of myself, improving my overall hygiene, and not eating random foods."

Under the aesthetic construction, participants often regarded dermatological concerns as extending *"beyond* pure health." That is, enhancing skin rather than merely curing it or eliminating illness from it. This was true for Martin (U), who considered himself undiagnosed but interactive with his dark circles, uneven skin tone, and other concerns after he was introduced to skincare products:

"This goes beyond pure health into the hedonic experience you want to have with the [skincare] product; you don't just expect it to look good and have a good effect on your skin, but to feel good when you're applying it."

Dermatology was synonymized with skincare regimens and communities where relationships are forged through discussions and debates over care techniques and products. Martin (U) drew parallels between skincare and football when referring to its "obsessive cult following," Carla (T) highlighted the transformative impact of social media influencers and her visit to Seoul, South Korea, reshaping her view of dermatology as a "trend," and Noor (T) explained that acne is a cosmetic issue as opposed to a medical one, as resolving it is a matter of personal preference:

"Personally, I don't like how acne looks on me. So that's why I chose to get it treated. For some people, I don't mind it, but just on me, I hate it." As a result, the aesthetic model of dermatology expanded to include notions of fandom, beauty gurus, and a form of body positivity.¹⁰ Moreover, the health concerns emphasized in the health model were not replicated in the aesthetic model. Instead, individuals were primarily concerned with social factors, such as being perceived as "unclean" due to inadequate hygiene practices and general exclusion from society. Lucas (U) explained that "looking like a zombie," referring to his peeling skin, is "not ideal for work prospects or university." In another instance, Omar (U) explained how he is unable to engage in traditional Saudi greetings since others are "disgusted" by his facial acne:

"People don't like the appearance of disease; they get disgusted because they think you lack basic hygiene or are contagious or something. You can see it in the way people treat you. Especially in Arab countries, men kiss each other on the cheek to say 'hi,' but even this simple act becomes bothersome when you have facial acne.

4.4. Approaches to Address Dermatological Concerns

How individuals construct their dermatological concerns ultimately shaped their path towards diagnosis and treatment. In this section, the biomedical *and* alternative approaches used to address their concerns, along with their attitudes towards them, will be discussed.

4.4.1. The Biomedical Approach

The biomedical approach refers to seeking information via medical consultations, obtaining an official diagnosis from a dermatologist, undergoing medical procedures, and adhering to prescription medications. Surprisingly, while one might expect biomedical approaches to align with the health construction, this was not always the case. Instead, participants who embraced an aesthetic construction of dermatological concerns also employed both biomedical and alternative approaches. For example, Ivan (T) explained that although herpes was a minor worry, he was willing to address it biomedically:

"Even with the plasma treatment, I researched about it first, saw whether it worked or not before giving it a shot. I Googled what it is and what other people say about it. I know I'm making his [the dermatologist's] work harder, but I'm trying to not ruin my health, let's put this way, or at least I want to understand how it works."

Understanding why participants were open to combining approaches while frequently displaying distrust in '*pure*' biomedicine is crucial. The data indicates that participants exhibited apprehensive

¹⁰ "Body positivity," a social movement born in 2012, is a response to societal beauty standards that pressure, primarily women, to conform to unrealistic ("thin") body ideals, aiming to promote self-acceptance and normalization of diverse body types (Tylka & Wood-Barcalow, 2015). The critiques of this movement, along with its apparent spread from body sizes to skin appearances, will be explored in the discussion (section 5.2).

attitudes towards "invasive" treatments—a label that was attributed individually yet was consensual among all interviewed participants to characterize medication outside the scope of over-the-counter (OTC) drugs and natural remedies. Common examples were Accutane, topical steroids, hormonal therapies, and laser treatment. Treatments were labeled "invasive" when they were believed to affect internal bodily processes, necessitated prescription and meticulous administration, and were linked to "side effects" or "developing dependence." For example, Noor (T) mentioned she was scared to use a pill despite it being family-recommended because she was unsure of "how that would play" into her bodily system. Additionally, when Zayn (U) received his eczema-curing prescription medication, he ended up not sticking to the treatment plan:

"She [the dermatologist] specifically prescribed me two things: A foam that I should apply when I'm only having outbreaks and something else that has cortisol, but I don't want to use it because it has cortisol, so I'm kind of scared."

As can be seen, some participants even scrutinized treatment dosage, length of administration, and their chemical ingredients. Carla (T), for instance, negotiated her Accutane dosage with her dermatologist, opting for lower quantities over an extended period. In certain situations, participants extended their cautious approach to include common pharmaceuticals and medical consultations, preferring to allow their bodies to handle issues naturally before seeking medical intervention. For example, Omar (U) was an avid advocate of deferring visiting the hospital due to the probability of being on a prescription plan, while Jisoo (U) expressed:

"I'm wary of everything I'm putting into my body. Even if it's Advil I'll be like '*I'll try to stay healthy as much as possible*,' and it's more my last reserve, for painkillers too. Unless it's a life-threatening condition, which acne wasn't for me, [...] there's no tangible solution other than getting prescribed medication that I don't want to take."

Exceptions, however, did exist. Aisha (T) advocates seeking a professional's opinion and considers herself a "good patient," adopting the pure biomedical approach like suggesting blood tests to monitor Accutane dosage. Additionally, Elena (T) detailed her multi-stepped routine to treat her "papillose acne" administered by her dermatologist:

"My routine relies on my dermatologist's skincare line. I cleanse my face and dry it with a paper towel to avoid bacteria. During the day, I apply a hydrating cream, then ointment to affected areas, wait for 30 minutes, then add sunscreen for protection according to the weather index. At night, I use a chemical treatment [.....]"

These participants welcomed and preferred invasive treatments *for* their seemingly powerful properties. Nevertheless, these treatments were still regarded as "the last resort," whereby more "natural" remedies or waiting to see if the problem will "resolve itself" were already exhausted. Interestingly, acquaintance or familiarity with treatments aided in erasing the notion of invasiveness; that is, gauging others' experience with the "invasive" treatment, albeit from family, friends, or via Internet reviews, removed this mysticism barrier. In addition to biomedicine, a critical view was also reflected towards consumerism and the political economy of the dermatological industry, such as the promotion of skincare products online or in dermatology clinics. While Elena (T) depended on her dermatologist's skincare line, as detailed in the aforementioned quote, Carla (T) critiqued the business-like nature of physicians and the healthcare system:

"Like social media inluencers, health professionals also have partnerships with certain brands. So I felt when I went to the dermatologist, he would just say, '*take these creams*' and it would also always be like the same two brands. And I had tried every single product he recommended, but my skin wasn't getting better."

4.4.2. The Alternative Approach

Indeed, participants generally preferred taking a "natural," "simple," and "personalized" route. These so-called alternative approaches to medicine were characterized by altering prescribed treatment plans, using oils and creams instead of ointments and pills, in addition to purchasing skincare products. Much of this appeal came from control over what was being put into their bodies (*input*) and what the exact effect or desired outcome would be (*output*). Interestingly, participants did not shy away from dermatology-approved skincare—medical treatments seemingly packaged into product form. For example, Ivan (T) purchased soap to heal his herpes instead of continuing plasma transfusion treatment:

"I tried one thing that really helped. I was using normal soap from a conventional supermarket, but changed it to a soap I found inside an eco-friendly market that was dermatology-approved, no extra chemicals inside it; it was basically a baby soap."

As can be noticed from the excerpt, the boundaries of pure biomedical and pure alternative approaches are somewhat blurred, commonly overlapping. For example, Gabi (U) self-diagnosed herself with alopecia and believed that "everything involved with the body is a health issue." Despite this perspective, she opted for rosemary oil to "heal the scalp" after hearing about its effectiveness from her stylist friend, who previously experienced significant hair loss as a symptom of a severe illness. To

demonstrate further, Lucas (U) fully viewed dermatology as a medical matter, yet mentioned he had to experiment with treatments that mimic prescription drugs, as he received a late diagnosis:

"I am constantly designing daily habits and systems to deal with it. It was about taking note of what worked and what didn't. You know, '*here's a moisturizer from a particular company from, god knows where*... *Argentina?!*' And you use that for 2 weeks and then you don't use any other moisturizers to observe what happens during those 2 weeks and then evaluate."

Meanwhile, Zayn (U), who explained dermatology leans towards aesthetics, did not fulfill his dermatologist's plan:

"I just stopped taking her products. Instead, I apply tea tree oil if I get a pimple, and it just goes away because it's antibacterial. So I would rather do natural remedies that are more effective than putting sodium or sulfate and that stuff on my face."

These experiences indicate that distinguishing between biomedical and alternative approaches, particularly in the context of dermatological concerns, is challenging. Additionally, these results indicate that constructions of dermatological concerns (health/aesthetics) are not a salient predictor of approaches to diagnosis and treatment. Rather, "trial-and-error" was a cornerstone of the dermatological illness experience, with an emphasis on "what works for me" rather than "what is right." This concept was not confined to assigning diagnoses or trying various treatments, but even with "doctor-hoping"—searching for a healthcare professional that suited participants' individual needs and preferences.

As a result, participants felt they became knowledgeable about their personal health within and beyond dermatology, learning about their bodies and themselves. This manifested in several ways, such as discovering one's skin complexion (i.e., having "dry," "oily," "combination," "sensitive," or "acne-prone" skin), recognizing "how prone we are to diseases all the time," overcoming visual insecurities and forming a multi-step routine. For example, Soyeon (T), who generally relied on the biomedical approach, explained how alternative approaches she undertook during treatment as a by-product of her ill state led to better overall health:

"Dietary changes have been applied. I used to love sweets, but I found that healthier options help my skin become less irritated. In retrospect, these have improved my overall health, more than before."

Some participants went as far as to perceive themselves as "advocates," "gurus," or self-proclaimed experts in dermatology. A notable example is Carla (T), whose experience in treating acne and managing atopic dermatitis, combined with her visit to Seoul, ended up becoming a guru:

"In my circle, I am actually the friend that is most knowledgeable about skincare. And everyone comes to me for advice. So, I am the friend that impacts."

To conclude this analytical portion, Figure 6 encapsulates the combined, continuous, and contextual nature of dermatological concern constructions and the approaches taken to address them via a two-dimensional plane, whereby participants move between the empty spaces and along the axes. In general, this diagram could be adopted to illustrate how individuals or patients understand their health conditions in relation to how they choose to approach them while respecting the spatiotemporal and blurred nature of these aspects. Potentially, the diagram could be taken a step further, in which the titles under "construction" and "approach" are amended to suit other research phenomena.



Figure 6. Two-dimensional plane depicting constructions (horizontal axis) of dermatological concerns & the approaches used to address them (vertical axis)

4.5. (Dis) Trust in Sources of Information

Finally, it was found that participants were more concerned with the *source* of health information rather than the information itself. They utilized various digital platforms, including medical websites (WebMD, NHS), dermatology clinic blogs, research articles, and social media platforms (TikTok, Instagram, YouTube). Some found communities on Reddit and Telegram helpful, while a few mentioned using applications (iDoctor) or artificial intelligence (ChatGPT), albeit to a lesser extent. On these platforms, participants primarily engaged in symptom searching, diagnosis matching, treatment finding, and skincare routine curation. While some mentioned that they would specifically access the Internet for health purposes, others mentioned how it was a consequence of being online—it was up to the algorithm.

Additionally, digital platforms served a dual purpose of being a form of entertainment and relatability for participants, whereby it felt like a community of individuals in similar positions.

Within this process, participants were aware of the "dangers of misinformation." To combat misinformation, participants mobilized certain techniques to discern between reliable and unreliable sources. Initially, digital spaces were categorized based on their "inherent characteristics," such as being a dependable information repository, driven by consumerism, meant for entertainment, or serving other purposes. To note, there wasn't a unanimous agreement on whether a specific online platform was "good" or "bad," except for a few cases; instead, all participants unanimously acknowledged the risks of using the Internet for health-related purposes without a critical mindset and tended to utilize multiple platforms rather than relying solely on one. Moreover, cross-referencing multiple sources and viewpoints was deemed crucial, emphasizing repetition and positive feedback gleaned from online reviews and comments. For example, Ivan (T) had various techniques when navigating the Internet for health information:

"With TikTok videos, when someone says something, you—I mean it's critical thinking one-oh-one¹¹—check if they are affiliated with the product. Also, if they use general wording like '*research showed*,' '*the doctor said*,' that sounds weird. And if they say something that contradicts a statement in previous videos... these are all hints and a first line of defence to check whether the information is bullsh*t or not."

As can be seen, scrutinizing user credentials and content authenticity emerged as another critical approach. Furthermore, although these techniques were recognized as time-consuming, active engagement was generally viewed as advantageous. Nonetheless, some participants, particularly those adhering to the health model, refrained from participating in online activities for health purposes, considering them too generic and advertisement-driven.

Shifting towards information-seeking in the form of medical consultations, doctors were acknowledged for their value in providing certainty (the straightforward "truth") and access to effective treatment and tests (i.e., checking blood, allergies, etc.). Visiting a specialist was an "investment" when the quality of care was considered sufficient. Aisha (T), an advocate for seeking medical care, compared doctor visits to online sources:

"With a doctor, I'm 100 % sure about it, but with WebMD or social media, it's like I'm just looking into what could be the problem or what could be the solution. At the

¹¹ "One-oh-one" (101) is slang term that means "the most basic knowledge" of a subject or topic (Cambridge Dictionary, n.d.b.). In the context of the quote, "critical thinking one-oh-one" refers to having basics of critical thinking skills.

end of the day, a professional's opinion is more accurate than online sources."

However, others viewed doctors as a "necessary evil" means of accessing care, criticized their care as ill-advised (economically beneficial), and worried they would make their condition a bigger deal than warranted. In the context of dermatology, many regarded doctors as partners or supplements rather than an obligation. For instance, Ivan (T) explained his collaborative approach to medical visits:

"I don't blindly trust everything the doctor says. I respect their expertise and follow their prescriptions, but I also conduct my own research and use prior knowledge. It might be a little irritating, but I'm not viewing it as if I'm on the other side, arguing. It's about consensus; we are in a team solving a case."

As shown in Figure 7 below, the findings presented in the aforementioned themes are contextualized via the finalized PM.



Figure 7. Final paradigm model

5. Discussion

By relying on sensory cues, intuition, and severity perceptions—forms of illness experience and embodiment—participants identified and interpreted their dermatological condition(s). This led to the emergence of two distinct but interconnected constructions of dermatological concerns: Health and aesthetics. The health construction was embraced when one's condition was (or became) physically painful, mentally taxing, or otherwise pervasive in daily life. Under the aesthetic construction, dermatological concerns were considered temporary "phases," such as hormonal changes or "nuisances." In the former, dermatological issues were viewed as genuine diseases; in the latter, they were viewed as extending beyond pure health, encompassing cosmetic enhancements, confidence-building, and notions of body positivity. Therefore, dermatology, as a medical practice and an industry, was often discussed by participants in association with skincare products, beautification, consumerism, and the political economy. In addition, participants, rather than physicians, served as the primary agents of diagnosing and designing treatment plans. However, despite the prevalence of the aesthetic construction, participants frequently addressed their conditions by combining biomedicine with complementary and alternative medicine, mediated by general distrust in invasive treatments and mobilization of online platforms, among other factors. The following discussion is split into exploring the following: First, how multiple agencies are present in a dermatological 'social' diagnosis; Second, the quasi-medicalization and aestheticization of dermatology; Finally, a consideration to conceptualize 'expert' patients as 'influencers' or 'gurus' that engage in clienthood as opposed to purely patienthood.

5.1. A 'Social' Diagnosis by Multiple Agencies

Interpreting the results revealed gaps in how diagnosis is conceptualized in the context of dermatology. Contrary to previous literature (Brown, 1990; Jutel, 2014; Jeske at al., 2024), this thesis found that diagnosis does not solely dictate the construction of dermatological concerns; instead, they mutually influence each other, emerging simultaneously, akin to new materialist ideas posed by Haraway (2013) and Barad (2007). That is, diagnosis was not a prerequisite to begin constructing a dermatological concern. In the same vein, the presence of a dermatological concern or the belief that one is suffering from a dermatological condition was not a prerequisite to begin constructing a diagnosis. Moreover, the so-called 'diagnostic *moment*' or 'diagnostic process' stressed in the sociology of diagnosis literature (Blaxter, 1978; Jutel, 2009; Jeske et al., 2024) was often absent in participants' narrations of dermatology visits (if there was a visit at all). Among interviewed participants, participants such as Zayn (U) and Soyeon (T) did not "even remember being diagnosed."

There are several potential reasons for these findings. First, the absence of a diagnostic moment is likely due to the fact that various agencies contributed to diagnosing and constructing a dermatological issue, such as lay discourses of skin and hair conditions on social media, labels on skin treatments and care products, the experiences of others, and most importantly, the beliefs and knowledge possessed by the participants themselves. This is, of course, in contrast to the notion that diagnosis is primarily the job

of a healthcare professional.¹² For instance, Jisoo (U) only became distressed by her acne during her "post-pubescent" years, labeling it as abnormal after her prior assumptions were challenged. In another case, Carla (T) described how living in Seoul, South Korea, surrounded by a culture of people and products that emphasize and idealize glass-like skin, conditioned her to elevate her standards for what constitutes a healthy complexion. Thus, it is difficult to pinpoint where the dermatological construction and diagnosis start and end.

Second, the possibility of multiple agencies (and the centrality of the patient voice) in dermatological diagnosis seemingly manifested additionally due to the hands-on and externally-seeming aspect of skin and hair conditions. In other words, its *sensory* nature (e.g., a bald spot on one's temples, itching and flaking skin, a reddening and painful pimple). Recent research also highlights that patients and caregivers utilize various forms of 'sensing' (i.e., bodily intuition, sensory devices, and sense-making) to diagnose and treat ailments, and hence diagnosing and treating are not solely confined by scientific criteria and medical practice but influenced by cultural beliefs and practices (Maslen & Harris, 2021; Barth & Weinberg, 2024). Ultimately, due to the lack of data regarding the experiences of participants with various other types and stages of dermatological conditions, such as various skin cancers, psoriasis, or vitiligo, the findings over a non-prominent diagnostic moment cannot be generalized. In brief, the traditional impact of a diagnosis, as understood by a bulk of literature, is likely present in more severe and chronic conditions; in fact, this was hinted at in some instances among interviewed participants, such as Elena's (T) experience with her doctor-diagnosed "third-stage" and "papillose" acne.

Despite these limitations, it might be helpful to understand dermatological diagnosis as rather a 'social' diagnosis, in some contexts, whereby "it connects an illness or the act of diagnosing that illness to a set of political, economic, cultural and social conditions or factors [that is] conducted by different social actors" (Brown et al., 2011, p. 939; Richmond, 2017). According to this study's findings, lay participants seemed to hold more narrative power in their dermatological conditions, present in spaces such as Internet echo-chambers and within social networks (i.e., friends, family, etc.). Further in line with a 'social' diagnosis, the data showed that individuals perceived their dermatologically-imposed "disability" oftentimes as a social disability with social ambiguities, preventing them from engaging in normal social life in addition to (in some cases) existing medical disabilities and ambiguities (Brown, 2011; Gutin, 2022). As Jutel & Nettleton (2011, p. 798) put it, "[it is useful to] deploy diagnosis as an analytic tool" to "open some of the central problematics of the experience of illness and the practice of health care."

¹² In a paper by Jeske at al. (20240, doctor's diagnosis were found to produce "sudden" diagnoses common after surveillance and screening tests (e.g., in cancer or hypertension), "long, changing" diagnoses common in autoimmune disorders, and other outcomes, such when patients are "denied care."

5.2. The Quasi-Medicalization & Aestheticization of Dermatology

Understandings of dermatological concerns voiced by participants demonstrate that what constitutes *health*, *illness*, *symptoms*, *severity*, and *effective treatment* is socially constructed. For DPRs to function, agreement between physicians and patients must be established in the aforementioned fundamental aspects (Szasz & Hollender, 1956). This requirement was reflected in this study's findings, were participants tended to negotiate their preferences over treatment type, dosage, and duration with their dermatologists. However, most participants ultimately employed "do-it-yourself" (DIY) techniques to address their dermatological concerns, combining biomedical and alternative approaches. This shift towards DIY medicine and the integration of biomedical and alternative methods may be indicative of the growing distrust in 'pure' biomedicine, such as "blindly following" physicians' advice and opting instead for "non-invasive" natural remedies, leading to the generation of so-called *'protoscience'*¹³ (Prior, 2003; Iedema & Veljanova, 2013).

Surprisingly, participants' skepticism was additionally rooted in worries over healthcare as a commodity, whereby helping the sick is non-proprietary, as outlined by Sulmasy (1993) and Brown (1990). In dermatology, ideas on consumerism and the political economy extend beyond its conflation with cosmetic enhancement industries (e.g., beauty, plastic surgery, etc.). Instead, there was a unanimous view among participants that dermatologists primarily exist to sell or advertise skincare products rather than prescribe medicine and care for patients—notions that did not sit well with them. This led participants to conclude that dermatology is "more of a business than real medicine." Similar concerns over ill intentions in healthcare have been debated in existing literature, primarily in the pharmaceutical industry, mental health, and nutrition (Green & Lawson, 2011; Esposito & Perez, 2014; Menu, 2018).

Combining the aforementioned points with the primarily aesthetic construction of dermatology raises the question on the quasi-medicalization of dermatology and its implications. To reiterate the work of Zola (1983), who coined 'medicalization,' defined it as a process of social control whereby diagnostic labels are assigned to various behaviors and conditions, thereby legitimizing them as medical concerns and institutionalizing them through diagnosis. Similarly, quasi-medicalization can be viewed as a tool of social control, not in the sense of delegitimization or invalidation of medical conditions, as demonstrated by de-medicalization (Halfmann, 2012), but rather conceiving above-average forms of skin, hair, and nail appearance *in the name of health*. The prefix 'quasi' has been adopted to point out the following

¹³ According to Iedema & Veljanova (2013, p. 4), 'protoscience' represents patients' unique type of knowledge, influenced by the rise of alternative medicine, open-source technology, and DIY practices; it acknowledging different forms of expertise and experiences, rejecting the assumption that patients simply lack understanding biomedical science.

dichotomy: Inevitably severe and largely health-related dermatological issues are sometimes treated as non-medical issues (de-medicalization), while potentially cosmetic dermatological concerns are institutionalized by healthcare as medical problems (medicalization).

While dermatological concerns are quasi-medicalized, they are simultaneously subject to beautification or aestheticization. Edmonds (2013, p. 233) explains that through aestheticization or by using the terms employed in this thesis, quasi-medicalization, "medical needs are magnified" while the perceived "risks" of cosmetic "procedures are minimized." In the data, it was evident that participants, who primarily framed dermatological concerns as aesthetic matters, desired to enhance their complexions rather than merely alleviate ailments from them. These notions have been documented in plastic surgery (Elliot, 2011), fitness clubs (Frew & McGillivray, 2005), and prosthodontics (Khalid & Quiñonez, 2015), stressing that as "cosmetic" procedures "become linked to other medical procedures with perceived greater medical necessity, health and aesthetics become entangled" (Edmonds, 2013, p. 233). Dermatology is further quasi-medicalized as it depends on products vetted by various forms of expertise; conventional experts like dermatologists and healthcare providers, alternative sources of expertise like cosmetologists and skin specialists, in addition to lay populations and 'skincare gurus' online (explained further in Section 5.3 below).

Hence, this further raises the question of whether a form of body positivity, or rather 'skin positivity,' is emerging, whereby dermatological diseases are either accepted, aestheticized (quasi-medicalzied), or purely medicalized. On the one hand, pre-symptomatic or potential dermatology patients are being over-diagnosed, the scope of "healthy" skin is reduced, and the range of "ill" skin is enlarged and stigmatized (Zola, 1972; Iedema & Veljanova, 2013). On the other hand, harmful illnesses and dermatological procedures are disregarded by participants in their plight of focusing on aesthetics and confusing the externally-seeming nature of dermatology with being accepting of appearances. A similar criticism was pointed to the body positivity movemen in its occasional promotion of clinically obese bodies (Leboeuf, 2019).

5.3. From Patienthood to Clienthood, & Experts to Gurus

Designing self-care, diagnosis, and treatment, participants often perceived their interactions with dermatologists as "two experts tackling one case." Here, expertise stems not only from medical knowledge, caused by increased access to health information online (Lupton, 2016a), but also from a widening boundary of what constitutes an 'expert' to include personal embodiment and valuing others'

embodiment experiences. These findings reflect existing literature, which emphasizes the multi-skilled nature of lay patients, and the evolution from conceptualization of lay beliefs to lay knowledge, and thereafter, lay patient expertise (Willians & Popay, 2013; Lupton 2016a). Hence, the question becomes, *what about the term 'patient' in expert patient?* Interestingly, the data revealed that participants seldom identified themselves as "patients" or aligned with the notion of "patienthood."

It is thought that this stems from three primary reasons. First, the term conveys passivity, failing to acknowledge participants as primary agents in diagnosis and treatment experimentation. Second, dermatological concerns, as described previously, often transcended mere biomedical dimensions, rendering medical terminology, such as "patient," inadequate. Lastly, the term "patient" somewhat implies the reception of medical care, which contradicts the belief of many participants that dermatology entails matters extending beyond medical treatment, resembling a market exchange. In consideration of these points, the term "clienthood" may better capture the consumer-oriented relationship between participants and dermatologists while acknowledging the latter's agency. The tensions between self-reliance and compliance with medical management in dermatology, the desire to be an 'informed consumer' of skincare products, and the commercial initiatives present within participants' experiences additionally align with studies that position patients as 'clients' and 'consumers' (Fox & Ward, 2006).

Furthermore, it might be helpful to consider that there are various types of lay 'experts,' such as 'influencers' or 'gurus.'¹⁴ In certain dermatological contexts, the notion of gurus as an extension of skin, hair, and nail experts could be applicable, as several participants shared how their peers' multi-step skincare routines or online beauty influencers inspired them to take charge of their dermatological conditions—sometimes leading to a newfound concern. Even Carla (T), who dealt with both acne and atopic dermatitis and curated a routine using Korean products, considers herself (and is regarded as such by her social circle) an expert due to her experiences. In current scholarship, the concept outlined in this thesis as a 'guru' is similar to 'influencers or opinion leaders, who are positioned as "alternative authorities" to "mainstream experts" which embody "populist narratives, disinformation, and conspiracies" on online platforms, while simultaneously adhering to "discourse practices" of the respective platform in which they appear (Heřmanová, 2022, p. 188).

While sharing these characteristics, the term "guru" may be more fitting given some ritualistic features of lay dermatological care, such as the proliferation of protoscience, the passing down of

¹⁴ A guru is a "spiritual leader or teacher," originating primarily from the Indian region (Cambridge Dictionary, n.d.c.). However, in popular culture, this term also refers to someone that possesses skills or expertise in a particular area with the condition of bestowing this wisdom in the form of advice to others.

knowledge, emphasis on natural (i.e., herbal medicine, dietary supplements, etc.), and "cult following" and fandoms present online. According to Baker & Rojeck (2020, p. 10), "[lifestyle] gurus" "employ a mixture of selective scientific knowledge, folk tradition, and personal experience to offer alternative advice and guidance on medical, psychological, and social problems afflicting others." Studies over *myths and manners* have been conducted in medical practice, finding that doctors perform ritualistic behaviors, such as administering antibiotics (e.g., betadine and genatamicin), that go undocumented simply due to their inherently rationalized and commonsensical nature (Broom et al., 2017). Hence, by conceptualizing a type of expert as a guru, it is then important to further explore what ritualistic behaviors are evident, overlap with "normal" patient behavior, or are invisible. Indeed, Baker & Rojek (2020) state that since online platforms have reshaped how expertise is disseminated, individuals are enabled to present themselves as experts and foster para-social relationships where followers develop trust in *perceived authorities*. This trust amplifies the influence of skin gurus or skin influencers, who combine lay knowledge and personal experience to product discourses on skin types, skin diseases, self-care, and skincare products and matching these discourses to suit needs of those consuming this content.

6. Conclusion

Diagnosis serves as the most speculative and sensitive point in clinical practice. Traditionally a marker of expertise and a boundary between '*health*' and '*illness*,' it is evolving into a multifaceted tool influenced by factors like biology, technology, and social dynamics. This thesis, exploratory in nature, presents a novel study into how the construction, diagnostic interpretation, and therapeutic management of dermatological concerns is conducted by patients with various diagnostic pathways (i.e., doctor-diagnosed, self-diagnosed, and undiagnosed) and conditions (i.e., acne, alopecia, atopic dermatitis, eczema, herpes, shingles, and xerosis).

It found that dermatological concerns are influenced by a myriad of factors, including online discourses of dermatology, (in)direct illness embodiment, and labels on care products, among others. Notably, patients, rather than physicians, led the recognition, interpretation, diagnosis, and management of dermatological issues, positioning the lay 'expert' as the primary agency. Dermatological concerns were also often described in aesthetic (rather than health) terms, emerging from a combination of the externally-seeming nature of the dermatological condition in addition to the profound social ambiguities and influences on social life (rather than medical ambiguities that impact one's health). In line with these findings, this thesis argued that a dermatological diagnosis is, in some disease contexts, a 'social' diagnosis influenced by multiple agencies. In addition, patients often addressed their dermatological

concerns by integrating biomedical approaches and those akin to alternative and complementary medicine, mediated by the mobilization of alternative sources of health expertise and distrust in the perceived features of pure biomedicine. Hence, this thesis discussed the quasi-medicalization of dermatology, as inevitably severe and health-related dermatological issues are treated as non-medical issues (de-medicalization), while potentially cosmetic dermatological concerns are institutionalized as medical problems (medicalization). Finally, the study suggests that there are various types of 'expert' patients, such as clients who do not resonate with parenthood, or gurus who serve as alternative authorities that share knowledge and experiences within social networks in physical and digital realms.

Since this thesis studies a novel topic, its contribution primarily lies in exploring the untended area of dermatology from a sociological perspective, extending the ideas on diagnosis, DPRs, and patient expertise in this domain. Other strengths of this thesis include its attempt at presenting emerging themes and complementing these narrative explanations via a paradigm model (PM) to show the interconnected and cumulative conclusions of the phenomena. Additionally, a diagram (Figure 6) was presented at the end of the fourth theme to encompass the key finding that constructions of dermatological concerns and the ways in which they are approached (in terms of diagnosis and treatment) move between, along, and across aesthetics, health, biomedicine, and alternative and complementary medicine. It can be potentially utilized in different studies, as it is flexible and shows the continuous and contextual necessity in healthcare research.

While this study attempted to produce reliable results via sound methodological techniques, several limitations are inherent and inevitable given the scope of an undergraduate thesis. Firstly, using a single-method, in this case, semi-structured interviews, reduces triangulation and hence the reliability of results as compared to a multi-method approach (Pelzer & Teel, 2012; Chapman et al., 2015). Moreover, since this study conducted mixed-mode interviews, online modes pose a risk of losing human touch through difficulty in reading participants' visual cues and the potential for technical errors (Thunberg & Arnell, 2022). This study tried to mitigate these problems by selecting *ZOOM* as the virtual interview program; this platform was selected as Archibald et al. (2019) found that 66% of individuals in their study prefer being interviewed via *ZOOM* even compared to in-person interviews. In this thesis, the virtual option was appealing to participants due to geographical limitations and personal preferences. Regarding the sample, all participants are within the age range of 19–24 years old, mostly comprised of students, limiting this study's scope to this demographic group. Another limitation was the lack of variety of other dermatological diagnoses that are more severe and inevitably medicalized, such as skin cancer, and the over-representation of acne among interviewed participants, potentially skewing results. Nonetheless, the

participants came from diverse backgrounds with no bias in gender split (seven females to five males). Other important factors, such as socioeconomic status, were beyond this study's scope; however, they would have provided a deeper nuance and should be considered in future studies. In addition, snowball sampling is often influenced by selection bias since it is reliant on the researcher's personal network, risking distortion early on as participants often stem from a limited sample pool (Parker et al., 2019). Finally, limitations of using TA include its open-ended and flexible "anything goes" nature, whereas GT criticism often addresses its improper adoption among researchers (Allan, 2003; Braun & Clarke, 2006, p. 95). Thus, the aforementioned limitations in research design will most likely hinder this study's contributions from being empirically significant, albeit contributing to the scientific community. Looking forward, these are the potential challenges that may arise in future research.

Dermatology offers a unique lens into the various problematics described in the sociology of health & illness, medicine, diagnosis, and a plethora of other areas. Over the course of this research, several directions for future research were uncovered: First, a specific topic will be proposed, followed by suggestions on improving methodological rigor and general recommendations for future study. In this thesis, an area that was of particular interest to explore further was the sources of (dis)trust in biomedicine, echoing Illich's (1975) and Scott's (2006) 'iatrogenesis,' a process where social and medical issues arise as a result of medical interventions at three levels: Clinical, social, and structural. In particular, hesitance over engaging in pure biomedical approaches stemmed from concerns over "side effects" that problematize dermatological conditions (a *clinical effect*); how some participants are dependent on medical prescriptions while others state that since dermatology is not confined to medical institutions, neither is its authority over treating and aestheticizing skin, hair, and nails (compliance and rejection of the *social effect*); and finally, how dermatology potentially medicalizes "aging" (a natural part of human life), and other unexplored areas, leaves societies to deem themselves incapable of dealing with it on their own (a structural effect). Looking forward, it would be interesting to question what aspects of dermatology participants deem natural or normal; hence, future works could focus on hormonal cycles, puberty, stress, and reactions to environmental changes with respect to iatrogenic effects.

Regarding methodology, adopting a multi-step approach to data collection, such as supplementing interviews with (virtual) observations, would improve data triangulation and reliability. Moreover, it is recommended not to shy away from employing focus groups for a unique approach to healthcare research, especially as it could glean new insights into fandom-hood and the intersection between health and aesthetics in dermatology. In terms of the dataset, studies should focus on specific dermatological conditions (e.g., a study on types of acne, another on various skin cancers, etc.) and digital spaces for

depth. Other potential topics of interest include comparing dermatologists, cosmetologists, and other "skin specialists" to provide nuance into the dermatology field, practice, and industry; simultaneously, these studies may provide further evidence into the types of experts, such as skin gurus and online influencers. Finally, other identities and circumstances of interest in dermatology include older individuals, individuals with other skin, hair, and nail conditions, and individuals with varying educational, socioeconomic, or geographical contexts.

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Appendices

Appendix A: Initial research proposal

1. RESEARCH PROBLEM

Contemporary medicine and public health spheres are experiencing paradigmatic shifts; from curative to preventive care, paternalistic to patient-oriented/personalized treatment, and biomedical to bio-psycho-social models. In dawn of the digital era, characterized by the proliferation of wireless devices and the Internet, healthcare technologies are moving from the sidelines to the center of health and illness procedures and conceptualizations. Simultaneously, individuals, patients, or for that matter, users, are meeting these machines in the middle, whereby the relation between the organism and the machine becomes the unit of analysis. By this notion, humans understand their bodies and health via technologies and their bodies and health return meaning and configure technologies via enactments of life in a dynamic interplay between what is human and non-human in a cyborg assemblage. Consequently, the contemporary blurring of notions of medical authority, expertise, and understanding ought to be explored via the lens of diagnoses cases. Thus, this thesis will compare how traditionally diagnosed versus undiagnosed (including self-diagnosed) individuals understand their health position and integrate their self-construction into action in the context of dermatology. Further, inquiring where cyborg theory fits into conceiving related problems and solutions.

2. MERIT OF STUDYING THE PROBLEM

Within the digitalization of healthcare, dermatology is emerging as a prominent area due to the nature of the practice; overall, dermatology is visually-bound, dealing with skin, hair, and nail conditions diagnosed and treated through measurements collected by a combination of clinimetrics (clinical data) and psychometrics (patient-reported data). The increasing accessibility of digital technology tools and social media platforms, including AI chatbots, mobile applications, and online health forums, therefore, places psychometrics as an area of rising curiosity. That is, patients gaining exposure to digitalized and mediated dermatological information may potentially bring rise to digital- ly-embodied health identities, whereby digital health technologies and patients, excluded from a tra- ditional medical authority, are constituted through intra-acts, shaping patients' healthcare choices and constructions. In practical terms, this may lead to self-diagnosis, self-assessment, self-management, and other "self" related processes in connection to one's personal health and identity. More- over, studying the correlation between health, diagnosis, and technology may advance the under- standing of the role of cyborg theory in medicine.

3. LITERATURE REVIEW

1. Barad, K. (2007). Meeting the universe halfway: Quantum physics and the entanglement of matter and meaning. Duke University Press.

2. DeBord, L. C., Patel, V., Braun, T. L., & Dao Jr, H. (2018). Social media in dermatology: clinical relevance, academic value, and trends across platforms. Journal of Dermatological Treatment.

3. Hayles, N. K. (2006). Unfinished work: From cyborg to cognisphere. Theory, Culture & Society, 23(7-8), 159-166.

4. Jutel,A.(2009).Sociologyofdiagnosis:apreliminaryreview.Sociologyofhealth& illness, 31(2), 278-299. / Jutel, A., & Nettleton, S. (2011). Towards a sociology of diagnosis: re- flections and opportunities. Social science & medicine, 73(6), 793-800.

5. Lupton, D. (2013). The digital cyborg assemblage: Haraway's cyborg theory and the new digital health technologies. The Handbook of Social Theory for the Sociology of Health and Medicine, F. Collyer, Ed., Palgrave Macmillan, Forthcoming.

6. Lupton, D. (2016). The quantified self. John Wiley & Sons.

4. RESEARCH QUESTIONS

I. How do the intra-actions between digital technologies and individuals in the context of dermatology shape constructions of their bodies and healthcare choices? Are there mechanisms at play? II. Does diagnosis change the understanding of dermatological issues? If so, how and to what extent?

5. METHODS OF DATA PRODUCTION

As this thesis aims to gain an in-depth understanding of patients' health choices and con- structions concerning

their intra-action with various digital technologies, qualitative methodology will be used as it is well-suited for narrative and experiential respondents' accounts. To collect prima- ry data, online focus groups (OFGSs) via ZOOM will be conducted after digitally scouting poten- tial participants using non-random, convenience sampling. In particular, the sample will be through scavenging social media platforms and websites via personal and professional contact lists (i.e., ac- quaintances of individuals known personally or with the aid of the university/supervisor), as they must fit the criteria of using digital technologies for dermatological purposes. After the participants are collected, chat groups will be organized to further orient participants with the research aim, OFG instructions, and access to a blank consent form to be signed. In constructing the questions, attention will be paid to answering the research question and obtaining theoretically-sound and rele- vant data; this will be achieved via a secondary data review of sociological and medical literature supplemented with conversations with experts in both fields.

6. METHODS OF DATA ANALYSIS

The OFGs will be semi-structured and recorded in audio and video formats for two-stage transcription; in the first stage, the BEEY.IO tool will automatically convert the audio file into text, which will then be manually cross-checked and corrected by the researcher in case of errors. After that, the OFG data will be color-coded on the reQual software and followed by thematic analysis to identify patterns in the data and explore any relationships and associations among variables. Follow- ing these steps, the data will be visually represented by mind maps, tables, and other diagrams in ad- dition to the reported findings and discussion sections. Since primarily inductive coding methods will be employed, inferences from theoretical literature will be drawn to further interpret results and base them on the current discourse.

7. ETHICAL CONSIDERATIONS

This research carefully addresses ethical considerations. Firstly, the participants' confidentiali- ty will be maintained by ensuring that all personal data will be anonymized and no identifying infor- mation will be made available in any research output. Secondly, all participants will be required to sign an informed consent form detailing the study's aims and the procedures to be followed. Addi- tionally, they will be notified of their right to withdraw from the study without facing any conse- quences. Thirdly, the study will consider ethical considerations associated with digital technology to ensure that participants are not exposed to potential risks or harm. Further, as health is a personal topic and may be sensitive to some, attention will be paid to ensuring questions are relevant, remind- ing participants that there are no wrong opinions or experiences, and allowing them to skip answer- ing if desired; after the OFG, participants will be allowed to withdraw any information stated if they felt it does not represent their thoughts well or they wish to keep it private. Lastly, the research will follow the ethical guidelines set out by the university and relevant professional bodies.

Appendix B: Recruitment message

Hello!

I am a Bachelor's student seeking interview participants for my research on personal health in dermatology. Whether you're officially diagnosed, self-diagnosed, or undiagnosed, I would love to hear your experience and perspective. Participation involves a 45-60 min conversational interview that is completely anonymous and for academic purposes only.

If you are interested in contributing to this study or know someone who may be, please suggest a date, time, and mode (online or offline), and I will try to accommodate! If you have any questions, do not hesitate to ask. Thanks!

Dana

[Insertion of contacts: Personal email, WhatsApp number, & KakaoTalk ID]

Appendix C: Consent form

Informed Consent Form for the Interview

Prepared by: Dana Alsaialy

I understand that my participation in the research project will involve an interview about my views and experiences on my **dermatological health and illness** and will take approximately **40–60 minutes**.

I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason and without penalty.

I have received enough information about the research, the use and storage of data, and my participation both orally and in written format.

I understand that I am free to ask any questions at any time and am free to withdraw or discuss my concerns with Dana Alsaialy.

I understand that the information I provide will be held completely anonymous, so it is impossible to trace this information back to me individually.

I understand that this information may be retained indefinitely.

To enable the processing of all provided information, consent in the form of a signature is required.

I confirm by my signature that I have been informed of the research aims and processing of the provided data. I have also had the opportunity to ask questions about anything I was interested in regarding the upcoming interview.

Date (MM/DD/YYYY): ___

Name of respondent:

Name of researcher: Dana Alsaialy

Signature of researcher:

Signature of respondent:

Appendix D: Interview guide

Interview Guide

- Document Contents: · Required Recruitment Question
 - · Interview Questions [divided into categories highlighted in pink]
 - Interview Structure [for both online & offline scenarios]
- Scouting Material [administered to potential participants]

Recruitment Question (Affirmative Answer Required)

Have you ever been diagnosed by a doctor for a skin, hair, or nail condition? If not, have you ever self-diagnosed, or would you consider yourself undiagnosed in the realm of dermatology?

Interview Questions

<u>RQ #1</u>

Diagnosis

- 1. Could you walk me through the dermatological condition(s) you had in mind when we initially spoke? Describe the condition, how long it has been, etc.
- 2. What led you to recognize this condition (s)? How did it happen?
- How did you arrive at a dermatological diagnosis?
 How did you feel throughout the diagnosis process?
- 5. Did you take the diagnosis promptly?
- 6. Did you study extra material prior to or after the diagnosis?
 7. T → Did you negotiate or suggest a pre-conceived diagnosis?

Treatment

- 8. Are you currently being treated for the dermatological condition(s)?
- 9. Who administered this plan?
- 10. Why did you want to get treated & deal with this condition?
- 11. $T \rightarrow \text{Did you intervene or engage? If so, how?}$
- 12. U \rightarrow How do you decide about the treatment? What sources do you consult?

Reflection

13. ${\rm T} \rightarrow {\rm Can}$ you imagine what you would have done had you not had a diagnosis? How did it happen that you went to a doctor?

- 14. $U \rightarrow$ Can you imagine a situation where you got this condition checked by a physician? How did it happen that you did not go to a physician?
- 15. How often do you engage with your dermatological condition(s), maybe in comparison to other physical or psychological conditions? What role does dermatology play in your life? What about health?
- 16. How did you regard your health prior to the diagnosis?
- How did you regard your health now?
 (optional, if applicable) You speak of yourself as a (patient/diagnosed/undiagnosed/etc.), what does it mean to you?

<u>RQ#2</u>

Digital Space Use & Purpose

- 19. In terms of dermatological health, what digital spaces do you use?
- 20. How do you use them?
- 21. How did it happen that you ended up in this space?22. Did you consider using other spaces?
- 23. What is the purpose behind your use of (insert digital space participant uses)?24. What are the most important benefits you gain from using these platforms?

Information Seeking & Interpreting

- 25. Could you walk me through a typical way you would search for & access health information? Could you compare them with medical visits?
- 26. Are online interactions translated into face-to-face interactions? 27. How do you interpret the information on digital spaces? Could you compare it with what you
- hear from doctors or medical professionals?

Influences & Preferences

- 28. Do your friends or relatives play a role in your dermatological health?
- 29. Did these spaces impact your dermatological knowledge, perhaps generally or in relation to your condition(s)? What about treatment? 30. Do you prefer engaging with your dermatological health offline or online? What are some pros
- & cons?
- 31. (optional) Do you engage in post-production of your body, skin, hair, etc., before putting images online?

Appendix E: Memos

timeline Martin 0 Aisha 0 other cond. *ask friend Opw Gaune Rezzit #1: seem to be concerned w/ acticleyy. if cosmetic then self. s what are diff. and this time? * when did he got the info from? I did you want acutane? [pseudo.] # Lid you think about Doing to the Eactor? patient [2-stage] #11: mental nealth is important. [fundom; common gwunz] guvu WebMD & do you use social media, forums, AI? ¥hypothetical → if no wait not reject diagnosis [2-level] Google Swiki ALC: NO 1 Omar 4 seem to be away of calify, etc. Yumat if acre is a sign of stre else? iHerb YT + TIKTOK "Products" Soyeon A visual! smedicik? 19 - BA ---* normality is avail [Social media] * medicine in puckaging -> product -> "good" "agency " # autrame / reason / purinto MATTERS. Noor Lucas Agenetic # info - what did mom use? & pain vs aestletics -> importance Awhat did the doctor do? Facebook *what caused it? NHS metical or cometic? 저음 # experiences Elena Jisoo * cosmotologist *ache = pimple YouTube, friends, ache-prove sking * why did it go wrong ? # "this Kind" \$no concersation Instagram scias Isciere &personality. "face if" carefy about nemer T & friend is internet * cuttural Mental Health incomise is show Flace-up melanona thing fatigur Know + do. I to praint, asian, intritue principles 1970 se

Appendix F: High-frequency codes & categories (extracted from ATLAS.ti)

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○ ♦ product
> \diamond platform/entity 83
> \diamond presumed links between condition & other \sim 83 \circ
> \diamond using other's experience 79
> \diamondsuit feelings 73
>
> \diamondsuit invasive vs natural 60
>
> \diamond using online platforms (why + how) 56
○ ♦ diagnosis = 51
> \diamondsuit skincare routine 51
> \diamond doing research 44
>
> \diamond appearance of derma condition $=$ 39
> \diamond beliefs about doctors/medical visits = 38
> \diamond hesitation & skepticism = 38
○ ♦ knowledge 38
> \diamond concern over cause/etiology = 35
ି 🔷 desire for informed-decision making/reass 💻 ଓ ଓ 👘