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Social Media Content Creators Living with Alopecia on Instagram

Supervisor: Professor Helena Sandberg

Examiner: Mia-Marie Hammarlin

Student: Anna Milena Böbs
an7572bo-s@student.lu.se

Department of Media and Communication

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Abstract

This thesis investigates the experiences of social media content creators living with Alopecia, focusing on their self-advocacy practices within Instagram. Alopecia, a condition characterized by hair loss, presents itself as a physicality of stigma (Goffmann 1963) and impacts individuals, shaping their self-perception and interactions with society. Against the backdrop of increasing digitalization and the rise of social media platforms, individuals with Alopecia have leveraged online spaces to share their stories, advocate for awareness, and foster community support. However, despite the growing visibility of Alopecia, there is a gap in the previous research examining the lived experiences of content creators and, by extension, women with hair loss.

Using a phenomenological approach to qualitative research, this study explores multifaceted dimensions of the social media content creation process among individuals with Alopecia. The study examines participants' illness identity and narrative through expert interviews with social media content creators and thematic analysis to uncover the intricate intersection of identity, narrative construction, representation, and mobilization within digital environments. The study illuminates how social media content creators live with Alopecia and the transformative potential of digital platforms in fostering societal and attitude change.

The findings reveal the complex interplay between the social media content creator living with Alopecia's personal identity, personal narrative, societal perception, and how they negotiated in the digital space. Moreover, the study forms a typology of six different types of social media content creators living with Alopecia - Personal Journey Advocate, Educational Advocate, Activist Advocate, Beauty and Fashion Influencer, Artist and Storyteller, and Product Reviewer. By amplifying the voices and experiences of social media content creators with Alopecia, the research contributes to a deeper understanding of the intersection of digital media, Sociology of health and illness through health advocacy and activism, and visual culture.

Keywords: Alopecia, Social Media Content Creators on Instagram, Health advocacy and activism, Stigma, Mobilisation of Vulnerability and Resistance

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Introduction

“A community of bald women on Instagram”

The thesis idea is based on previous research conducted during my master´s degree in media and communication at Lund University. Within the course “Media Audiences,” I looked into bald women´s media engagement and representation. The research findings concluded that bald women find their representation in social media content creators living with Alopecia (referred to as Alopecia content creators) on Instagram. My investigation of Alopecia (see Appendix 1) within media through the lens of the audience engagement created the interest to explore the experiences and practices of Alopecia Content Creators from their point of view. Through their disclosure of their Alopecia status online, Alopecia content creators practice self-advocacy to generate awareness about Alopecia as a health condition, de-stigmatize Alopecia and hair loss, and fill the gap in the representation of bald women in media through their presence on Instagram.

The thesis covers and intertwines three main areas of research: digital media research, sociology of health and illness through health activism and advocacy, and visual culture. The visual culture element originates from the visual nature of Alopecia as a health condition which manifests through the bald head/spots and the social hierarchy of appearance surrounding hair. Connecting these fields aims to give insight into the de-stigmatization of health conditions through health advocacy and activism by exploring the experiences and practices of Alopecia content creators on Instagram. The investigation draws on existing scholarship from these interdisciplinary perspectives, including media and communication, sociology of health and illness through health advocacy and activism intertwine with concepts from feminist studies and visual culture.

Contributing to media and communication studies, Alopecia is a previously unexplored health condition within digital media research. Previous investigations into hair (Mbunyuza-Memani, 2019; Cruz-Gutierrez, 2020; Oliveira et al., 2023) focused on the exploration of tensions surrounding the “natural hair” of women of colour, outlining a marginalised understanding of beauty and social hierarchies of appearance. However, hair has not been investigated from the perspective of loss. Alopecia, as a chronic health condition, is characterized by hair loss, which can have significant physical, emotional, and social implications for those affected. By centring the experiences of Alopecia content creators, this study sheds light on the unique challenges and opportunities they face in advocating for their health needs and raising awareness about Alopecia-related issues. The focus on this specific health condition adds originality to the study and contributes to a more nuanced understanding of health advocacy within diverse communities.

The investigation centres on digital media research on participatory cultures, specifically on Instagram connected to health and illness. It gives insight into Instagram as a mobilising tool to process the de-stigmatization and normalisation of Alopecia as an aesthetic health condition. The thesis contributes to the media and health field by drawing on the conceptual tools from medical humanities to explore and unravel the practices of health advocacy and activism through Alopecia content creators on Instagram. Additionally, it gives insight into how the previous “private” patients share their experiential knowledge (Brockman, 1976) on an open social media platform to generate a “space” (Lupton, 2017) of support.

The study makes use of concepts and perspectives from feminism studies using “vulnerability and resistance” (Butler, 2016) and “media-ready feminism” (Press & Tripodi, 2021). Adding a feminist element to the investigation of health advocacy and activism. Alopecia content creators use “glossy” social media platforms focusing on popular feminist empowerment messaging. By sharing authentic content about their health conditions, Alopecia content creators add the “moment of reception” (Press & Tripodi, 2021), where “popular feminism” (Banet-Weiser, 2018) becomes more critically reflexive and understood with an analysis of problematic societal structures and the hegemonic struggle. The authentic representation of Alopecia content creators adds an element of vulnerability to the de-stigmatisation process of their “aesthetic” health condition.

By focusing on female Alopecia content creators, the study aims to amplify their voices within academic research and capture their unique lived experiences and practices within their self-advocacy efforts in the digital space. Taking a phenomenological approach to gain access to the firsthand experiences of Alopecia content creators through semi-structured interviews, the thesis aims to provide a deep insight into how these individuals use the platform to exercise their agency and construct their illness narrative to contribute to a more nuanced and balanced understanding of Alopecia as a health condition within the digital space. Supplying the semi-structured interviews with Alopecia content creators allows for a deep exploration of their lived experiences and perspectives with supportive visualizations of the content through mood boards with non-specific images showcasing the content from the different types of Alopecia content creators.

Therefore, the thesis is guided by the following three research questions:

1. How does stigma manifest and impact the experience of Alopecia content creators on Instagram?
2. How do Alopecia content creators on Instagram utilise narrative techniques, such as personal storytelling, visual imagery, and community engagement, to construct and communicate their illness identities and experiences?
3. How do Alopecia content creators on Instagram conceptualise vulnerability when sharing their illness narratives?

The thesis is organized into five main parts: Chapter 1 introduces the topic and research objectives, Chapter 2 reviews relevant literature on stigma, Instagram as a platform and affordances, health advocacy and activism, vulnerability, and mobilising feminist networks on social media platforms, Chapter 3 describes the methodology used in the study, Chapter 4 presents the findings in the form of a typology of six types of Alopecia content creators, and Chapter 5 offers conclusions and recommendations for future research.

Literature review

This chapter of the thesis is arranged in four parts. First, the historical background of hair contextualises the tensions surrounding hair and outlines previous investigations into hair. The exploration is linked to media studies, and the research gap of investigation into hair from the perspective of hair loss is outlined.

Alopecia is a health condition that becomes apparent through its visual physicality, with the bald head and patterned spots; the second section considers definitions and theories from stigma linking these with the social hierarchy around appearance. The context of experiences, practice and interaction of Alopecia content creators regarding their advocacy work takes place on Instagram. Thus, the third section explores concepts surrounding visuality and photography as well as the platform culture and affordances of Instagram.

Alopecia content creators take on self-advocating roles by sharing content on their health condition on Instagram and linking their activities with health advocacy and activism. Therefore, the fourth section draws on conceptual tools of health and illness to determine the interplay of their practices.

The thesis explores the power dynamics that shape individuals' experiences advocating for visibility and acceptance on Instagram or how intersecting identities influence Alopecia content creators' engagement on Instagram. To close these gaps, the fourth section explores concepts and theories from feminist studies relevant to investigating Alopecia content creators. Leveraging the concepts from feminist theory enriches the investigation into health advocacy and activism among Alopecia content creators on Instagram. By integrating feminist perspectives into the research, the aim is to address previously overlooked aspects of inequalities and advocacy efforts within this specific community.

Hairstory

Exploring the historical context of hair reveals that its significance transcends mere aesthetics, embodying a complex fabric of cultural, spiritual, and socio-political meanings. Understanding the evolving narratives around hair provides valuable insight into broader themes of identity, power and resistance throughout history. Hair can be investigated through a wide variety of medical and nonmedical approaches. I can be approached in various ways, considering historical, artistic, mythological, and legendary material. For the investigation of Alopecia content creators, the historical context of hair supplies a deeper understanding of the societal, cultural, and symbolic meanings associated with hair, which informs the experiences, identities and advocacy efforts of individuals living with hair loss.

The sociologist Synnott (1987) views hair as a "most powerful symbol of individual and group identity" (p. 381). Synnott (1987) touches upon the physical nature of hair, making it a deeply personal matter and contrasting that with the visibility of that physicality that makes it a public matter. According to Cash (2001), the psychological perspective supplies that it can serve as a social sign of "gender, age, status, values, and group membership" (p. 161). Hair is a key aspect of self-identity and body image, which can be readily altered to create a desired appearance (Cash, 2001). Nyamba (2012) investigates the historical evolution of hair and beauty cultures and how it underscores the importance of expressing individual and group identities, considering pre-colonial and contemporary hairstyles within the African context. Meanwhile, Bromberger (2008) situates an investigation within Mediterranean studies within which he views hair as a powerful display of the expression of status, kin relations, and group membership, and can be used to both conform to and challenge social, political, and religious norms.

Overall, the importance of hair spans disciplines. Hair is a powerful symbol that transcends individual preferences to encompass broader dimensions of identity, social dynamics, and cultural meaning. Its significance lies in its ability to communicate information about individuals and groups, shaping perceptions, interactions, and societal norms. Understanding the importance of hair or its absence in the investigation into Alopecia content creators lies in its potential to provide insights into their lived experiences, identity formation, and advocacy efforts.

Within the fine arts, hair has been celebrated as one of the most prominent subjects of mythology (Giacommetti, 1967). Art forms have delineated the fortunes and misfortunes of possessing fine heads of thick hair and those that suffer from its loss. According to Hanna (2012), hair acts as a marker of identity and has remained paramount throughout history in cultures across the world. Hanna (2012) describes hair as an “inescapable dialectic” (p. 17) and elaborates that it can be traced across history, specifically about females in its symbolism and portrayals of rituals and adornment. Here, the transcending nature of hair is touched upon, and aesthetics become a subject of mythology. It encompasses the rich fuel to narratives, symbolism and rituals that span civilisations and epochs. In essence, the celebration and mythology surrounding hair embody a timeless and universal dialogue that continues to shape human perceptions, behaviours and experiences across generations and societies.

In “The Politics of Hair”, Connie Koppelman (1996) discusses the “magical, symbolic power” (p. 87) defined by myth and tradition in which hair continually regenerates itself. Koppelman (1996) mentions the stories of Samson and Delilah Medusa and Rapunzel as three fairy tales in which hair plays a central role - assigning and associating deep significance, symbolism or importance to hair within cultural narratives, beliefs and traditions. It implies that hair is not merely seen as a physical attribute but something that goes beyond the physicality of it and is seen as a symbol that carries weighty spiritual or cultural significance. Koppelman (1996), like Bromberger (2008), touches on the social implications of hair. Koppelman (1996) says hair helps determine economic, intellectual, marital status and religious affiliations.

Furthermore, Koppelmann (1996) underlines that “hairstyles can signify conformity” (p.87); an example would be army regulations or any group-determined aesthetic. This illustrates how hair is a marker of various identity and social status aspects. Additionally, hairstyles can indicate conformity to specific social norms, regulations or group definitions. In other words, the symbolism of hairstyles intersects with various aspects of identity and societal expectations, profoundly shaping perceptions and experiences. For content creators, the absence of hair symbolises empowerment, resilience and authenticity, challenging conformity and redefining beauty on digital platforms. Through their advocacy efforts and representation, Alopecia content creators inspire others to embrace their unique identities and celebrate the beauty of diversity.

Colonialism and globalisation

Various studies have evidenced that the intersection of colonialism, globalisation, and hair is complex and multifaceted. Within African American studies, Mothersill (2018) and History Faria (2020) explore ways Black women´s hair is impacted by racialised gender and neocolonialism. Mothersil focuses on London and Faria and the African synthetic hair trade. Historian Rycroft (2018) and research by Le Roux et al. (2021) situated in South African Humanities further contribute to this discussion by examining the role of hair in the fashioning of English manhood and the lingering influence of colonial narratives on hair trends and identity among South African women. These studies collectively highlight the enduring impact of colonialism and globalisation on the politics of hair, particularly Black women. In other words, Black women´s hair is deeply entwined with racialised gender dynamics and neocolonialism. This intersectionality extends globally, including in English contexts where hair has played a significant role in the construction of masculinity. In South Africa, colonial narratives shape hair trends and identity among women. The racialised gender dynamics around the intersectional issues around hair can be transferred to the perspective of hair loss. Content creators can play a crucial role in challenging these norms. By sharing their experiences, the importance of dismantling harmful stereotypes and promoting inclusivity within beauty standards can be highlighted.

Hair in Contemporary Media

By delving into the portrayal of hair in various media contexts, valuable insights can be gained into the complex interplay between media culture and identity in the modern world. Within multicultural education, Jeffries (2014) and the cultural perspective provided by Svetlinchnaya (2018) explore the artistic and communicative significance of Black female hairstyles. Jeffries (2014) focuses on the influence of media curriculum on the natural hair movement, while Svetlichnaya delivers the semiotics of hairstyles and their role in contemporary everyday culture. Both studies highlight the complex interplay between media, culture, and personal identity in shaping perceptions and attitudes toward Black female hair. It is interesting to note that the subject group centred in these studies are Black women, implying that there is a tension around hair within that group. There is a complex interplay between media culture and identity formation. Hairstyles are powerful symbols within this framework, carrying rich semiotic meanings that shape contemporary everyday culture. The natural hair movement, in particular, has gained momentum as a response to Eurocentric beauty standards perpetuated by media representations. Alopecia content creators are integral to this movement. With the representation they create on Instagram, they contribute to broader discussion about beauty, representation, and inclusivity.

Previous Investigation into Hair and Social Media

There was a need to find previous research within media and communication studies connecting media, specifically social media and alopecia. An additional search was conducted using "Communication Source" from Lund University. Centring the keywords "alopecia" and "media", the results were zero hits. The search was extended to "baldness" and "media", gaining two results where one touched upon the aesthetic element of chemotherapy when having cancer, while the other was unusable. Changing the approach to the search, the following keywords were "hair" and "media", coming up with 58 hits, narrowed down to three helpful articles that explore and investigate the tensions surrounding "natural hair" and the surrounding stigma Black Women and Brazilian Women experience that are connected with social media representation.

Mbunyuza-Memani (2019) uses online blogs about natural black hair that affirm blackness and resist hierarchical ideologies of beautiful hair. Mbunyuza-Memani´s (2019) research finds that online spaces have become sites of resistance, learning, positive Black affirmation, and support for and by Black women, what she considers sisterhood nets. Mbunyuza-Memani (2019) focuses on how social hierarchies of appearance are contested online and the overflow of offline spaces to affirm the physical feature of race long-marginalized in social understandings of beauty. The connection between tensions around "natural hair" in Black women and online spaces as a site of resistance and renegotiation of social hierarchies around natural hair conclusively lays a foundation for the struggle around social hierarchies around hair. The study verifies a marginalisation within the social understanding of beauty.

Cruz-Gutierrez (2020) focuses on the entanglement of "natural hair" and politics, concentrating on hair as an essential element in Black women´s socialisation (Banks, 2000). The article touches upon the naturalisation of weaves and relaxers in natural hair as a symbol of revolution. Cruz-Gutiérrez (2020) links Bulter ((1990) 2007) theory of performative femininity to urban spaces. The material used is a representation of Michelle Obama´s hair and how she is representing Black womanhood. The research by Cruz-Gutierrez (2020) confirms that relaxed hair is read as a performative strategy for fulfilling social expectations and contributing to achieving political goals as the US First Lady. In other words, hair is used as a mobilising force of political action directed by Michelle Obama with political motivations in mind. It describes hair in the context of politics and explains how the meaning applied to hair can vary depending on context.

Oliveira et al. (2023) address the manipulation and modification of curly and coily hair textures to discuss the relationship between hair, identity, and stigma among Brazilian women while emphasising the specificity of Brazilian society. Oliveria et al. (2023) identify the Brazilian context as a zone of tension in which there is a manifestation of “good hair” and “bad hair”. The analysis Oliveria et al. (2023) conducted centres on 8,000 spontaneous comments posted on a Brazilian YouTube channel. Oliveira et al. (2023) conclude two main results from this analysis. The research suggests that coily-haird Brazilian women are exposed to the “pain” that characterises power situations because they bear a stigmatised body attribute and points out a social transformation by which other references are incorporated into the notion of beauty, thus creating an alternative for them to be accepted with their “natural” characteristics. The racial tension around coily-haired Brazilian women is linked heavily with stigma and the process of identity construction. It brings in the concrete digital element by centring a social media platform for the analysis. Further, it elaborates on the identity-shaping process mobilised by online experiences that are transferred into real-life action.

In conclusion, the three articles use different approaches to investigating “natural hair” and racial tension. Additionally, the articles cover different media contexts, digital online blogs, the political representation of an aspirational figure and YouTube comments, and differing geographical contexts in America and Brazil. This previous research shows social hierarchies around hair and a marginalised understanding of beauty. Hair is an essential element in women´s socialisation and an aspect of the human body that can be politicised. Social expectations of femininity tied to hair view hair as a means to perform femininity. Indicating that identity and stigma are tied to hair and play a role in the construction of the self. This research still uses her as a point of departure; it validates an interest in hair loss. This previous research investigates “hair” in the sense of body inspired by visual culture studies as a means to look at aesthetic and aesthetic hegemony and societal expectations, while this research is investigating “alopecia” as the loss of hair from a health and illness sociological approach regarding it as a health condition with an aesthetic bodily signifier.

Stigma

The previous section outlines the historical significance of hair. Societal perceptions and cultural narratives surrounding hair have deeply influenced attitudes towards hair loss. These historical narratives outline the social hierarchy around appearance, creating biases and perpetuated stigma towards a health condition like Alopecia. Thus, understanding the historical context of hair provides valuable insights into the origins of the stigma that individuals with Alopecia continue to face. Linking stigma with content creators, the framework can help grapes the underlying dynamic, process and factor involved in stigmatisation.

Erving Goffman (1963) laid the foundational element of stigma studies with “Stigma, Notes on the Management of Spoiled Identity”. Goffman (1963) explores aspects of stigma and social identity, information control and personal identity, group alignment and ego identity, the self and its others, deviations, and deviance. The inquiry is still widely treated as a classic in the field of stigma studies and used to ground the conceptualisation of following investigations into stigma.

According to Goffman (1963), previous investigations into stigma have yet to attempt to describe the structural preconditions of stigma or find a conceptualisation of the term. Goffman (1963) conceptualises the stigma as “bodily signs designed to expose something unusual and bad about the moral status of the signifier” (p. 10). Today, the term is still used in its original sense, but it is more applied to the disgrace of the bodily evidence rather than the bodily evidence itself. For Goffman (1963), there is a difference between social and personal identity. Identity is viewed as a subjective sense of the situation and the continuity and character an individual obtains from various social experiences. Goffman (1963) adapts the term “self-identity and extends it to “self-identification”, which is, namely, the individual establishing his identity through documentation or testament. In other words, Goffman (1963) explores the complex interplay between bodily appearance, societal perceptions, and individual self-conception with a physicality perceived to be outside of the social norm.

Linking stigma to content creators, stigma is essential to understand their experiences as a marginalised group with the social hierarchy of hair and how that motivates their advocating efforts for change and promoting empowerment and resilience within the community.

Coleman (1986) extends Goffman's (1963) conceptualisation of stigma through the recognition of the role of dominant groups in shaping societal norms and value judgments (p. 142). According to Coleman (1986), stigma reflects the “value judgments of a dominant group” (p. 142). By recognising the influence of dominant groups, a deeper understanding of how stigma operates within society and how it can be challenged and addressed. Addressing the value judgments of a dominant group in research on content creators is essential for understanding the broader socio-cultural context within which they operate. Exploring the impact of societal attitudes, biases, and stereotypes on individuals' experiences and identities can foster an understanding of the motivation that leads to establishing the individual creator's advocacy efforts to challenge stigma and foster empowerment within the Alopecia community.

Segerstad et al. (2020) find that when studying the stigma of individuals, it is essential to realise that the stigmatised person might not encounter actual stigmatisation and discrimination in their immediate surroundings but is often pitted by their community and may encounter stigmatisation views in indirect context through stigmatising media representation or cultural values, with the description of this fluidity in perception from inside into the outside world and shaping of identity through world experiences. With Alopecia content creators, the stigma of individuals becomes interesting through the digital and physical world. Alopecia content creators might experience stigmatisation or discrimination digitally due to their broader scope of exposure disclosing their health condition. Conversely, Alopecia content creators could face harsh treatment in real life and build their online presence as an escape for positive interaction with fellow sufferers. These can manifest in self-stigma through the fluidity of experience of the digital and physical world.

Instagram: Platform culture and affordances

Examining Instagram´s platform culture and affordances in a study about social media Alopecia content creators living with Alopecia provides valuable insights into the digital experiences, communication strategies, and social dynamics within the Alopecia community.

Jenkins (2006) says, “Audiences, empowered by these new technologies, occupying a space at the interaction between old and new media are demanding the right to participate within the cultures” (p. 24), suggesting a clear shift in paradigms regarding the production and circulation of media content. This transformation has led to a dynamic convergence of old and new media, where traditional modes of communication intersect with the digital possibilities offered by platforms like Instagram. Van Dijck (2009) focused on different levels of engagement with the “active participant” (p. 43), who is “well-versed in the skills of “new” media” (ibid). The concept reinforces the shift from users or producers to platforms and their politics (Gillespie, 2010; Niederer & Van Dijck, 2010; Van Dijck, 2013; Van Dijck & Poell, 2013). Equipped with the skills and literacy of “new” media, they are demanding the right to participate in cultural conversations and narratives, challenging the traditional roles of users or producers—this transition from passive consumers to active participants within digital ecosystems. This shift has profound implications for social media Alopecia content creators living with Alopecia, who leverage platforms like Instagram to assert their voices and challenge dominant narratives surrounding beauty and identity.

According to Gillespie (2010), the term “platform” for entities like Instagram highlights the strategic positioning as intermediaries aim to establish within the digital ecosystem and the challenges associated with it (p. 349). This strategic positioning presents challenges, including content moderation issues, algorithmic bias and platform politics. Navigating these complexities requires a nuanced understanding of the socio-technical dynamics and a critical examination of the power dynamics inherent within digital platforms. Instagram as a platform serves as the context in which the experiences and practices of Alopecia content creators occur.

Instagram is a visually-driven platform for users to share content, connect with others, and discover new interests, making it a powerful tool for communication, expression and community building. New media theorist Manovich (2017) argues, “Instagram is for aesthetic visual communication” (p. 41), indicating that aesthetic visual communication is part of Instagram's character. Leaver et al. (2020) point out Instagram as a platform that demonstrates one form of “aesthetic normalisation” (p. 51). This “aesthetic normalisation” (ibid) is problematised when it comes to the representations and circulation of content regarding body image on Instagram, as it does not present a “realistic norm of society and often results in negative attitudes and perceptions” (Aziz, 2017, p. 19). The visuality of Instagram is interesting when it comes to Alopecia content creators due to the visuality of Alopecia as a health condition. The bodily sign of a bald or bald-patterned head falls outside the norm. From that, it can be learned how Alopecia content creators outside of the norm navigate their experiences and practices on Instagram.

Recently, the platform shifted from its original focus on visually appealing and polished content to becoming a more politically engaged, activist-oriented, and educational space. This change occurred as various communities and hashtag public asserted their presence on the platform (Al-Rawi, 2021; Childs, 2020). Alopecia content creators form a community within social media through hashtags and visual representation of their health status online to foster a networked public.

Therefore, it is interesting to investigate Alopecia content creators as a health-related form of sociality within a specific visual and emotive media ecology, Instagram. According to Walker-Rettberg (2014), “digital self-presentation and self-reflection are cumulative rather than presented as a definitive whole” (p. 5). Expanding on this, Walker-Rettberg (2014) describes that a social media feed comprises an ever-growing assortment of posts, potentially expressing a micro-narrative, a personal reflection, or an image portraying a facet of the author´s identity (p. 35). With Alopecia content creators, their illness identity is in some way centred on the content they distribute on Instagram, creating a narrative of their illness through sharing their experiences on social media.

Andalibi et al. (2017) acknowledge that social network sites like Instagram offer unprecedented opportunities for image-based sharing (p. 1485). They investigate how image sharing on Instagram facilitates disclosing negative emotions, psychological vulnerabilities, or stigmatised experiences and the potential for such sharing to precipitate supportive interactions. The potential for the emergence of a networked public is based on the bonding over shared experiences. Through this, sharing experiences from Alopecia content creators can be explored.

According to Leaver et al. (2020), Instagram´s foundational visualities are underpinned by the "digital reimagining of photographic traditions" (p. 41) - while photography has served as a technology for collecting and saving memories. Van Dijck (2008) argues that it "always served as an instrument of communication and as a means of sharing experiences" (p. 59). Van Dijck (2008) also sees a paradox in sharing personal pictures because of the ease of sharing them, and makes them accessible for manipulation and unauthorised distribution. In contrast, Essayist Susan Sontag (2005) views this critically. Sonntag (2005) acknowledges that a photo requires context or a caption to become meaningful (p.5). With Alopecia content creators sharing their experiences on Instagram, the visuality and photography element is integral to investigating their expertise on the platform and how they channel photography to make their experiences with Alopecia accessible to their audience.

Health advocacy and activism

Health advocacy and activism are crucial in addressing stigma and the surrounding awareness associated with health conditions. Within this investigation, health advocacy and activism lend the frame within which illness identity, illness narrative and self-advocacy are used as conceptual tools to engage with the experiences and practices of Alopecia content creators.

Health advocacy and activism is a multifaceted approach that involves the strategic use of media (Chapman, 2004). Brown & Zavestoki (2004) introduce the concept of Health Social Movements (HSMs) and discuss their significance in challenging medical policy, public health policy, and broader social structures (p. 679). HSMs are defined by collective challenges to various aspects of health policy, belief systems, research and practice. These movements encompass a range of formal and informal organisations, supporters, networks, and media that advocate for health access, quality of care, and broader social change (ibid). Health advocacy and activism are indispensable for promoting awareness, empowerment, and social change within the Alopecia community. By actively engaging in advocacy efforts, Alopecia content creators can contribute to a more inclusive, supportive and equitable society for individuals affected by the condition. The study's understanding of health advocacy and activism enhances the research's rigour, relevance, and ethical integrity, ultimately contributing to a more comprehensive understanding of the experiences and needs of Alopecia content creators.

Conceptual tools within health and illness

Stephanie Vicari (2021) discusses three conceptual tools for studying participatory cultures in health and illness: illness identity, illness narrative, and self-advocacy - as central to the emergence of these participatory cultures. These conceptual tools are beneficial to understanding the experience of Alopecia content creators for several reasons: understanding the lived experience, exploring stigma and identity, addressing narrative construction around an illness/health condition, and understanding promotion and advocacy efforts.

Illness Identity

Illness identity serves as a crucial conceptual tool, providing a framework for understanding the self-perception of health conditions that individuals experience. It deepens the understanding of how Alopecia shapes individuals' identities and experiences online and offline and offers a foundational element from which the individual illness narrative is constructed. Illness identity plays a vital role in the experiences and advocacy efforts of Alopecia content creators. The illness identity is the foundational element from which individuals derive their motivation to practice self-advocacy by sharing their experiences and constructing their illness narrative, which derives from their experiences.

When discussing the examination of illness experiences, Conrad (2010) points to the work of Anselm Strauss and his colleagues (Glaser and Strauss, 1965; Strauss and Glaser, 1975) as the start of sociological research investigating the experience of illness by examining it from the patient´s point of view (p. 180) and implying a renegotiation of understanding the experience of being a patient. The “category of the patient” (Landzelius, 2006) undergoes a process of mutation where “health activism to chaperone patienthood into new forms and associations” (p. 535). It touches upon interpersonal bonding and solidarity-building among sufferers, with patienthood becoming a community. Vicari (2022) indicates that community relations originate in sharing standard definitions of self-based on illness experiences.

Charmaz´s (1991, 2002a, 2002b) work on “illness identities” laid the foundation of scholarly work on how individuals with chronic illness experience their condition as embedded in their everyday lives, linking it with the construction of self. The “construction of self” (Frosh, 1991) can lend supportive elements. Vicari (2021) highlights that Charmz (1991) provides a remarkable account of the relationship between illness, time and identity, showing how any change in the development of chronic health conditions marks a shift in the patient's experience. This change is relevant because it influences the construction of narrative and its framing, audience engagement and advocacy efforts, as well as social relationships and intersectional experiences within the online community. Understanding this shift enhances the comprehension of the complex dynamics of living with Alopecia and informs more effective strategies for advocacy.

Vicari (2021) touches upon sharing personal experience; individuals co-construct the meaning of their illness and confirm that illness communities emerge from these encounters. Individuals collectively make sense of their illness experiences. This process helps them understand their “construction of self” (Frosh, 1991) to build a solid internal structure. Frosh (1991) phrases this building process as “to the self as an internal structure supplying integrity and depth to each person´s encounter with the world”, meaning that it gives depth to how they interact with the world around them. Personal experiences, combined with social media influences, contribute to forming this internal structure of thinking.

Additionally, the “performance of self” (Goffman, 1959), the way individuals perform or present themselves, influenced by sociocultural norms, also plays a significant role in how they perceive their health condition and incorporate it into their identity. Vicari (2021) points out the lack of scholarship despite its importance on how illness contributes to identity construction. In the context of illness, understanding the identity construction process empowers Alopecia content creators to express themselves authentically, advocate for positive change, build supportive communities, promote mental health and well-being, and advocate for greater visibility and representation within broader society.

Illness narrative

Illness identity is the foundational element for the construction of the illness narrative; it delves into how individuals' internal constructions of self intersect regarding their illness and is woven into narratives that express the illness experience, shaping their narratives and the collective understanding of health and identity within society.

Illness narrative centres on the act of storytelling derived from the illness identity process of an individual. Brody (2002) points out that research should pay more attention to narrative and storytelling within the medical literature.

Brody (2002) describes the publication of the first edition of *Stories of Sickness* (1987) and Arthur Kleinman´s *Illness narratives* (1998) as an early signal of a turn toward interest in narrative in medicine and health care. The "narrative turn" (Brody, 2002, p. 12) is reflected by broad interest in narrative throughout different disciplines: religion, psychology, anthropology, political science, linguistics, education, philosophy, and literature.

Illness narrative puts the act of storytelling at its centre, delving into narrative construction whose point of departure is the illness identity process tied to the lived illness experience of an individual. It draws on the sociological interpretation of illness as a "biographical disruption" (Bury, 1982). Slightly moving beyond the actual connection with storytelling is the "illness narrative" (Hydén, 1997) that focuses on coping with the disruption brought by the disease. Illness narratives are intrinsically linked with time. They connect events and symptoms along a temporal continuum within a biographical context (Charmaz, 2002a, 2002b). Hydén (1997) conceptualises illness narratives as "giving a voice to suffering in a way that lies outside of the domain of the biomedical voice" (p. 49). Essentially, the interpretation as a biographical disruption refers to the turmoil illness causes in an individual´s life caused by the onset of illness, which disrupts their sense of identity and normalcy. Illness narrative, on the other hand, provides individuals with a platform to articulate their experiences of suffering in a way that transcends the biomedical perspective. Storytelling allows individuals to reclaim agency over their narratives, meaningfully giving voice to their struggles and emotions. The process will enable individuals to assert their humanity and complexity outside of the medical diagnosis, instead fostering connection and understanding within the individual and societal contexts.

According to Hydén (1997, p. 55), there are three main types of illness narratives based on different relationships between the illness narrative and the narrator. The three types are the self-story, someone else's story, and illness as the story itself. In the context of illness narratives, it is important to recognise that individuals don't just recount the physical symptoms or manifestations of their illness; their bodies play a central role in shaping the narrative trajectory and direction of their stories. Frank (2013) describes it as "people telling illness stories do not simply describe their sick bodies; their bodies give their stories their particular shape and direction." (p. 27). This gives a deeper exploration of how individuals engage with their embodied experiences through storytelling and the implication of this process for understanding illness identity, narrative, and meaning-making.

Frank (1995) discussed that the wounded storyteller concept has been a significant framework for understanding illness narratives. However, this approach has been critiqued for its reductionist view of narrative and voice (Giaxoglou, 2022). Giaxoglou (2022) explores the mobilisation of illness stories in a digital context by examining the practices of story design, curation and uptake of narrative voice and "mediatised visibility" (p. 3) by incorporating the potential of digital media for amplifying and diversifying narratives of illness, while also raising questions about the ethics, politics, and implications of sharing such personal stories in online environments. It underscores the need for a nuanced understanding of how illness narratives are constructed, circulated, and interpreted in the digital age and the implications of these processes for individual communities and society. Connecting this to Alopecia content creators, a similar dynamic is at play. The creators don't just describe their physical condition but also supply how their experiences with alopecia shape the very essence of their storytelling. The creator's illness narratives are influenced by their relationships and experiences navigating their condition within the digital landscape. Additionally, the mediatised visibility of Alopecia narratives on Instagram amplifies the voices of Alopecia content creators, providing them with a platform to share their stories and advocate for awareness and acceptance to a broader audience.

Ogad (2005) touches upon the "therapeutic value of storytelling" (p. 164). Research, particularly in the digital space, has shown this. Yu (2011) and Adelson (2012) both highlight the potential of online platforms for sharing health-related stories and narratives of healing. While Yu (2011) highlights the therapeutic benefits and helpful learning resources, Adelson

(2012) looks at the digital as a platform for identity negotiation and digital stories as part of contemporary healing. Here, therapeutic storytelling occurs within the clinical intervention, while healing storytelling extends beyond formal therapy to include self-expression, connection and personal growth. They differ in focus, context, and outcomes. Divinyi (1995) provides practical guidance and intervention techniques, and Turturean (2015) also touches upon facilitating interaction through therapeutic storytelling. These findings collectively underscore the potential of online storytelling as a powerful and accessible means of promoting healing and well-being. Alopecia content creators can harness storytelling's therapeutic and healing potential to process their experiences, challenge dominant narratives, build community support, and foster empowerment within the digital space.

Self-Advocacy

The illness narrative moves into self-advocacy and represents a journey of self-awareness, expression and empowerment for individuals with Alopecia. By embracing their illness identity, sharing their stories, and advocating for themselves, they assert agency and promote positive change within their communities and beyond.

Martin et al. (2011) define self-advocacy as the process “whereby individuals demonstrate an increased assertiveness or willingness to challenge providers or other medical authorities and to actively participate in decision-making to ensure they receive the care and treatment they feel best meets their needs” (p. 178). In other words, it highlights the importance of individuals becoming more assertive and actively involved in their healthcare decisions to ensure they receive personalised care that meets their needs. Connecting this to Alopecia content creators, there is a similar expression of empowerment and advocacy within the online community.

Klawiter (1999) mirrors how the reshaping of contemporary cultures of health and illness moves patients to the front line of health social movements. Klawiter (1999) notes, “Unlike earlier historical moments in which cancer as a broad category had occupied centre stage, this time it was breast cancer that moved to the centre, and it was breast cancer survivors and activists who moved it there” (p. 105). It outlined how the patient activists have moved to the front and taken a central role in creating awareness around their health condition. Transferring this idea to Alopecia content creators, it can be said that the content creators take on a central role in raising awareness and advocating for their position.

An Alopecia content creator in an advocacy position carries a lot of responsibility when generating awareness for the health condition and communicating medical and professional knowledge as an individual with a niche health condition. Martin et al. point to the effect of patient literacy skills on healthcare interactions. Health literacy refers to an individual's capability to obtain and understand health information. Literacy proficiency in health-related contexts is vital in empowering patients to advocate for themselves and actively participate in healthcare decision-making processes. Individuals with higher literacy skills will be more willing to take on self-advocate roles. When it comes to content creators with high levels of health literacy and literacy proficiency, they are better positioned as advocates for themselves and others, challenge stigma and misinformation, and foster supportive online communities where accurate information and experiences are shared openly and respectfully.

Overall, self-advocacy is an extension of the illness identity process by including the willingness to share an individual's illness experience and generate awareness about their health condition on a societal level to further societal or policy change within health and illness. Within this process, an illness narrative is constructed to communicate the illness experience to the public. They are making self-advocacy a vocal point to which illness identity and illness narrative lead.

Feminist Praxis in the Digital Age: Navigating Vulnerability, Resistance, and Networked Activism

In feminist studies, exploring concepts such as vulnerability and resistance, networked feminism, and reconfiguring vulnerability in media-ready feminism provides a nuanced understanding of contemporary feminist discourse. These concepts shed light on the multifaceted nature of gendered experiences and offer insights into the evolving strategies and dynamics of feminist activism in the digital age.

Vulnerability & Resistance

Alopecia content creators share their illness experiences online to allow for authentic and meaningful exploration of their experiences. Generally, with health and illness, there is a vital element of vulnerability involved, be it emotional, mental or physical. Sharing your illness experience online and moving from a private patient to a self-advocate to a public audience creates exposure on a societal level creating a mobilising tool for action.

Butler (2016) explores a model of activism that offers a countermodel to previous conceptions of activism - resulting in a reconceptualisation of the terms of vulnerability and resistance. Butler´s (2016) point of departure contrasts vulnerability and resistance as oppositional. Vulnerability requires the need for protection and the strengthening of paternalistic forms of power at the expense of collective forms of resistance and social transformation.

Butler (2016) reinforces the idea that vulnerability has its roots in social relations and can change depending on context. Butler (2016) highlights an example where men position themselves as the "vulnerable population." (p. 23) to legitimise anti-feminist politics. Connecting this to the jade of resistance to vulnerability signifies the transformative potential of embracing vulnerability as a form of resistance against oppression. It highlights the courage and agency of individuals who refuse to be defined by their vulnerabilities, instead choosing to assert their identities and advocate for change. Alopecia content creators embody the jade of resistance to vulnerability by leveraging digital platforms to challenge societal norms and redefine narratives surrounding beauty standards and self-image. The online presence of the creators demonstrates resilience and assertiveness in embracing their authentic selves despite facing vulnerabilities associated with the visible physicality of their health condition.

Butler (2016) concludes that vulnerability is not precisely overcome by resistance but becomes a potentially effective mobilising force in political mobilisation. It outlines an uneven, vulnerable political terrain and then overcomes vulnerability by resisting the oppressive consciousness that characterises our lives (p.12). In other words, the goal is to recontextualise the discussion of vulnerability, linking it with paternalism and even with discourses of victimisation. Butler (2016) affirmatively argues that vulnerability, understood as deliberate exposure to power, is part of the very meaning of political resistance and embodied enactment. However, the vulnerability is focused on political activism and does not give insight into the vulnerability of digital activism needed in investigating Alopecia content creators.

Vachhani (2023) extends the discussion around vulnerability to the current digital media landscape but questions how we can understand the productive tensions and complexities of digital feminist activism and its relation to transformative social change. The paper contributes to understanding the complexities and differential effects of online environments, the mediation of feminist politics through digital knowledge cultures, and the possibilities, challenges, and productive tensions in the ever-increasing use of digital environments. The research results show new forms of feminist consciousness built on affective embodied engagement.

A key contribution is highlighting the tensions and complexity of digital feminism in achieving its radical potential through vulnerability as an agency. Vachhani (2023) demonstrates ways digital media can foster spaces for learning and feminist consciousness transnationality in the pursuit of organising against oppression. In connection with the sociology of health and illness, this showcases that digital media can foster spaces for learning and feminist consciousness in resistance regarding the advocacy movements within health and illness as it opens up new geographical opportunities for connecting and exchanging experiences.

Media-ready feminism

Recently, feminist discourse has witnessed the emergence of various iterations that intersect with media and popular culture. The manifestation, "media-ready feminism” (Press & Tripodi, 2023), has gained attention due to its resonance with contemporary digital media. With “media-ready feminism” (2023), Press and Tripodi manifest their concept of media-ready feminism - which they argue occurs at the “moment of reception” - where media breaks through the structures of popular feminism and addresses structural sexism. Connecting this argument with health and illness, it focuses on the reproduction of sexist discourses around the physicality of hair loss and how authentic expression of Alopecia content creators challenge the discourses surrounding it. Instagram adds the context of a “popular” media platform as a “space” (Lupton, 2017) to drive a critical engagement with the societal structures supporting the attitudes and perceptions around hair loss.

The acknowledgement of recent discussions (Banet-Weiser, 2019) has highlighted feminist scholar ambivalence at their reception of popular feminism, given that such narratives contain elements of feminism we all resonate with. Press and Tripodi (2023) take this as a point of departure to delve further into these contradictions with many media representations and into contradictions between lived experience and media culture experience. This is an interesting element to consider when looking at self-advocacy on social media for a medical condition due to the possible discrepancy between media representation of the health condition and the lived experiences. Here, there might arise tensions connected to the stigma and the degree to which it is experienced; it might be that the stigmatised person self-advocating online is not exposed to discrimination due to their stigmatisation in their real-life context but due to the exposure online will find such a thing happening to her.

To sum up, the key themes and concepts relevant to the study of health advocacy among Alopecia content creators on Instagram cover the historical context of hair, tracing the cultural significance and perceptions of hair, Instagram culture and affordances including its visuality, which raises a unique opportunity for individuals with Alopecia to raise awareness, share experiences and mobilise support for health-related issues.

Building on this, the literature review delves into the theoretical frameworks and conceptual tools of health and illness. It examines the concepts of illness identity, illness narrative, and self-advocacy, which are central to understanding how individuals with Alopecia navigate their illness experience, construct their identities, and advocate for Alopecia.
Further, the literature review situates the study within the context of feminist studies, exploring concepts such as vulnerability, resistance, and media-ready feminism. These frameworks provide critical insights into the intersectional dynamics of health advocacy and activism.

Overall, the literature review synthesises existing scholarship on hair, stigma, digital media, health advocacy and feminist studies to provide a comprehensive foundation for the study of health advocacy among Alopecia content creators.

Methodology and methods

Situating the Research

This study follows the principles of Flyvbergs (2001) phronetic research to contribute “reflexive analysis and discussion of values and interests” (p. 3). Works within phronetic research make extensive use of case studies. According to Flyvberg (2001), Phronetic research emphasises understanding social phenomena. In the case of Alopecia content creators, their practice of self-advocacy on Instagram leads to an inquiry into the lived experience, self-advocacy efforts, and interaction with their community. The work is “dialogical” (p. 139), which involves a dynamic exchange of perspectives and voices. The researcher engages with the array of voices of the participants. The goal is to create a polyphony of voices where no single voice, including that of research, holds final authority. It ensures that all voices are valued and included, contributing to a richer and more comprehensive understanding of the research topic. In the case of social media content creators with Alopecia, a dialogue is created with a vulnerable and marginalised group. According to Flyvberg (2001), phronetic research is always “context-dependent” (p. 136), centring on the lived experience and practices of Alopecia content creators on the social media platform Instagram.

The study adopts a social constructivist perspective in shaping individuals' perceptions of reality (Harding, p. 25). Drawing on social constructivist principles, I recognise that the experiences and identities of Alopecia content creators are socially constructed within the social media context of Instagram. Couldry and Hepp (2017) aim to understand how communication, specifically mediated communication, contributes to the construction of the social world (p. 15). This type of meaning-making is essential for Alopecia content creators and their experiences and practices online. According to Rantanen (2009), media have played a role in shaping space and territory; the experiences of Alopecia content creators online take place on the site of social experience, Instagram, which creates the social space in which interactions and community take place—acknowledging the influence of digital media platforms in mediating this social construction by highlighting the significance of digital platforms such as Instagram in shaping individuals self-representation, community and interaction, and health advocacy practices.

Brooker-Gross (1983) points to the hidden inequalities within the free global flow of media representation and information signals of news production, which is shaped by its sources and, therefore, the content of those representations. Alopecia content creators take their self-advocacy work online and challenge the media representation of Alopecia and, by extension, hair loss within media and the attitudes towards it in society.

“Changes” take place when the social world is not just mediated but mediatised - that is, changed in its dynamics and structure by the role media continuously (indeed recursively) play in its construction (Couldry & Hepp, 2017, p. 15). This touches upon the fact that the experiences and interactions of Alopecia content creators change when they move their experiences and interactions from a physical space into a digital space.

Phenomenology

According to Smith (2018), phenomenology studies the structures of consciousness experienced from the first-person point of view. Since the study aims to understand the reality of female Alopecia content creators and their experiences, practices, and interactions within the digital landscape of Instagram, a phenomenological approach was highly suited. Teherani et al. (2015) propose that phenomenology aims to describe the meaning of experience based on what and how the individual experienced the phenomena.

In considering phenomenology within epistemology, Smith (2018) highlights the role of defining phenomena that contribute to understanding consciousness and offering a distinctive perspective by centring firsthand knowledge. With the investigation of Alopecia content creators and their experience, practices, and interactions within the digital landscape of Instagram, the experiential knowledge of the social media content creators is used to achieve first-person knowledge. The experiential knowledge covers their knowledge as a female living with Alopecia and as a social media content creator on Instagram. The combination of first-person expertise as a social media content creator with a health condition and their experience, practices, and interaction within digital media makes them a good subject of the study.

Sample and Recruitment

Semi-structured interviews were conducted with 11 female social media content creators living with the health condition Alopecia Arreata, Universalis, Totalis, or Androgenetic Alopecia. The minimum follower count to be valid for the recruitment is 1.500 followers and above. The participants' age range is between 26 and 45.

Purposive sampling was conducted where the participants were selected based on a “significant relation” (Seale, 2018, p. 520) to the research topic. The criteria of inclusion used to determine the sample are age, gender, open account on Instagram, disclosure of Alopecia status on Instagram, and the follower count.

Table 1: Sample Characteristics

	Synonym	Age	Nationality	Follower Count	Alopecia Type
1	Grace	40	American	Nano (1.000-10.000)	Universalis
2	Lucia	33	Czech	Nano	Universalis
3	Jana	33	German	Micro (10.000-100.000)	Universalis
4	Marie	28	German	Nano	Universalis
5	Lane	40	American	Nano	Universalis
6	Evelyn	45	American	Nano	Diffused Alopecia Arreata
7	Caroline	30	American	Micro	
8	Olivia	33	American	Nano	Androgenetic Alopecia
9	Amelia	28	British	Nano	Universalis
10	Louisa	28	German	Nano	Universalis
11	Allison	32	American	Mega (100.000 - up)	Universalis

The first step in the recruitment was going on Instagram to look for Alopecia content creators on Instagram to fit into the criteria of inclusion. I used hashtags such as #alopecia and #alopeciaawareness. Additionally, I used the recommendation option from Instagram, which shows you similar people to follow when you are on a profile. I used the personal message

option or contact details provided on their Instagram account to send them a message with an outline of the aims and objectives of the study, asking for participation. The recruitment started from February 2024 onwards and ended in March 2024, after 11 interviewees had been selected. Since many people have yet to respond, a difficulty might have been that they have activated protective measures available from Instagram to sort possibly damaging messages due to the sensitivity of content and open feedback possible on Instagram. I had a relatively smooth stop-and-go process of people agreeing to participate in the study and going through with the interview. However, some people changed their minds for personal reasons or simply a lack of time within the given timeframe for conducting the interviews.
The sample scope for this study was pre-determined to include one pilot participant and ten interviewees. Following the completion of the data collection and analysis, it became evident that "informational redundancy" (Seale, 2004, p. 375) was reached. The diversity observed among Alopecia content creators participating in the study, the data collected revealed significant repetition within certain sections. Additionally, the recounting of the illness experience and construction of such is always different slightly based on the individual.

Data Collection Method

Semi-structured interviews with social media content creators

The data collection method used was qualitative semi-structured interviews. The benefit of this approach is that it is helpful for “accessing individuals’ attitudes, values and experiences” (Byrne, 2012, p. 220). Brunn (2016) acknowledges the difference between the genres of qualitative interviewing. According to Bruun (2016), the difference between the genres becomes apparent in the conceptualisation of human agency embedded in the research question, the methodological design of the study, and the connection with the publication of the research findings.

The qualitative interviews fall into the categories of expert and “lay” expert due to the participant's status as content creators on Instagram in a media context and their “lay” expertise for Alopecia as a health condition. According to Littig (2009), experts are defined by their occupational or professional knowledge and decision-making competencies” (p. 109). Complimentary Bogner et al. view experts as “crystallisation points” (p.2) for practical insider knowledge and as surrogates for a wider circle of players. Social media content creators can be considered expert interviewees within their specific niche or area of expertise. Social media content creators have specialised knowledge and skills in creating, curating, and sharing content on social media platforms. Additionally, their status as an Alopecian and their experiential knowledge and content focused on Alopecia frame their niche of expertise within the social media landscape. As such, they can provide unique insights and perspectives as expert interviews within their respective niches on Instagram.

Alopecia is a niche health condition, and sufferers cannot access much information on their experience of a health condition online. The people sharing content have a considerable knowledge gap to fill and a high level of agency on what content to share and distribute to their audience. Social media content creators advocate and raise awareness for alopecia by closing that gap. Through the exposure of their health status online to a broad audience, there is a possibility of making themselves vulnerable to harassment and the possibility of anonymity on Instagram; social media content creators open themselves up to face a higher degree of discrimination due to the societal stigma surrounding alopecia as a health condition.

Before the interview, an interview guide (Appendix 4) was designed. I initially conducted the interview guide to cover general background, motivation, experience as a social media content creator, Instagram as a platform, and interaction with the Alopecia community on Instagram. I was closing the interview guide with a last question that allowed the participant to reflect on the interview process. The first interview was used as a pilot to test the interview question, leading to a 40-minute interview. Following the pilot interview, it became apparent that the questions were a helpful red thread throughout the interview, but the diversity within the social media content creators regarding content (ex—educational content vs fashion content) and condition (ex—arreata vs. universalis or androgenetic) or how the individual participant approach the physicality of Alopecia (ex. wig-wearing vs. bald) called for individual adjustments within the initial questionnaire.

The data was collected through Zoom due to the geographical location of the participants from the US and Europe. The interviews were conducted in English and German (for the two German participants). Doing the interviews through a communication platform with a video connection can be a limitation. The setting will affect the quality of the connection.

According to Byrne (2012), it will affect the interview due to a more difficult understanding of non-verbal cues and body language.
Additionally, the video format might be uncomfortable for interviewees. Sally Seitz (2016, p. 232) describes the video format as "presenting an emotional barrier" due to the technological hitches and the perception of distance that arises through the introduction of technology. During the interview, I did not perceive the format as a limitation, as it allowed the participants to open up about their health conditions in a comfortable and known environment, which might not have been the case with a face-to-face interview.

During the interview, the audio was collected with an external recording device. The audio was then saved for transcription and will be stored for the duration of the research project outside of cloud computing services. Personal sensitive data may only be stored for the duration of the degree process and deleted after completing the examination. After the interviews, the transcription into text was conducted manually for proper immersion into the data (see Appendix 5 for a sample of the full transcript). The interviews were 35- 50 minutes, and the transcription for the individual interviews spanned between 7 and 12 pages.

Furthermore, I draw from autobiographical observations from the social media accounts of Alopecia content creators to offer my personal observation of their content and reflections. To create mood boards and give insight into the content of the different Alopecia content creators types without overstepping ethical guidelines.

Data Analysis

Thematic Analysis

Thematic analysis (Guest et al., 2012) will be employed to analyse the interview results. According to Guest et al. (2012), thematic analysis requires more involvement and interpretation from the researcher. The thematic analysis focuses on "identifying and describing both implicit and explicit ideas within data" (p. 11); those ideas are themes. Guest et al. (2012) refers to codes typically developed to represent the identified themes and applied and linked to raw data as summary markers for later analysis (p. 11). An analysis may include "comparing code frequencies, identifying code co-occurrence, and graphically displaying relationships between codes within the data set" (Guest et al., 2012, p. 11).

Seale (2018) points out how reading and re-reading data several times before going into formal coding enhances a researcher´s sensitivity to meanings. I achieved immersion by listening and re-listening to the interviews during transcription, which allowed me to familiarise myself with the data.

The coding process started by identifying and labelling meaningful data segments related to the research question and area of interest. I code the data using descriptive labels or codes that capture the essence of each segment. With the continuous process of coding the data, there were emerging patterns, connections, or contraindications within and across codes. I have looked for recurring themes, ideas or concepts that cut across multiple data segments. From these patterns and themes identified, the data begins to generate hypotheses or tentative explanations for the observed phenomena. There was consideration of how these themes relate to the research question, existing literature, and theoretical frameworks.

Coding has become an iterative process of coding, analysis, and reflection, refining my understanding of the data and emerging themes. I continuously compare, contrast, and revise the codes and interpretations in light of new insights and observations. I have interpreted the underlying meaning of the identified themes for the research.

I used identified themes to refine the existing theoretical framework that helps explain the phenomena under investigation - considering how the themes relate to existing theories and concepts and exploring the implications for advancing knowledge in the field. Here, a choice was made to focus specifically on the themes of covering the experiences related to the conceptual tools of health and illness due to the limiting scope of the thesis that did not allow for an in-depth exploration of the community aspect and the role of the social media content creator as a facilitator of the boundary work within those as gatekeepers and leader of facilitation within an open support group.

I synthesised the identified themes into a coherent narrative that tells the story of the data. The themes were organised logically, highlighting their interrelationship and significance to the research objective. Here, the typology of the six different Alopecia content creators was developed.

Ethics

Informed Consent

Prior to the interview, informed consent was obtained verbally and in written form (Appendix 3) from the interviewees. Informed consent gives agency to the individual participating and "safeguards the rights of people participating knowingly and voluntarily" (Seale, 2018, p. 132) in research.

Participants were recruited based on their willingness to participate in the investigation throughout the process, and the opportunity to discontinue the interview should the participant feel uncomfortable was emphasised. In Seale (2018), the "informed" participant needs to be aware of "potential risks" (p. 132) that need to be explained in "appropriate detail" (p. 132).

The scope of the research involves sharing sensitive and personal data to analyse a health condition. This step was taken by giving the potential participants background information on the purpose of the investigation, the research aims and objectives, and how their data will be handled (e.g. research project timeline). Furthermore, it emphasised the anonymity with which the data will be handled in the analysis. Additionally, the possibility of taking a break should the questions be overwhelming was emphasised to make the participants feel comfortable. I thanked the participants for taking the time and effort to participate in the interview and offering insight into a sensitive topic since it focuses on a health condition.

Images and Visualisation

For the images that characterise the typology within the analysis, I used the AI image tools DALL-E and PeopleMaker, based on textual descriptions, to visualise the six types within the typology. Visualisation allows a representation of the typology while respecting the ethical considerations regarding privacy and consent. I used Canvas to compile visual collages or mood boards using non-specific images, symbols, or icons that evoke the original content's themes, moods, or aesthetics. The compilation/mood boards help convey the overall visual style or tone of the content without displaying the original social media content.

Positionality of the Researcher

According to Merriam et al. (2001), all researchers begin the data collection process with assumptions about the phenomenon being investigated, situations observed, and people interviewed (p. 406). With the group being investigated being Alopecia content creators, it is essential to consider that I, as the researcher, am a woman living with Alopecia Universalis and an “insider” of the group.

Being an “insider” is a strength as “homogeneity can create a sense of community which can enhance trust and openness throughout the research process” (Merriam et al., 2001, p. 407). It could also help one gain access to a group that is more difficult to access. Throughout the recruitment process, I felt it was easier to access the interviewees due to disclosing my own Alopecia within the recruitment outline.

It has to be noted that I have extensive previous knowledge of Alopecia as a health condition and its media portrayal. Two of my previous essays in the Master´s communication program at Lund University have covered the topic.

Analysis

The analysis section of this study delves into the data collected through interviews with Alopecia content creators. The analysis section of this study delves into the data collected through interviews with Alopecia content creators. It explores how Alopecia content creators leverage Instagram for self-advocacy, aiming to destigmatize the condition through storytelling. It analyses the intersection of illness identity, narrative, and advocacy, presenting a typology of content creators based on their advocacy efforts. Additionally, the section delves into the negotiation of vulnerability in sharing personal experiences. It looks into the balance between authenticity and self-protection. The content creators' self-advocacy efforts and how they challenge societal norms and promote acceptance and empowerment within the Alopecia community.

Reframing Beauty: the intersection of traditional beauty standards and perceived stigma around Alopecia

In examining Alopecia content creators, it is crucial to consider the context in which the dynamic of the interplay between traditional beauty norms, stigma, and the lived experience of individuals is negotiated. Here, Instagram offers the context where women residing with Alopecia have the opportunity for the agency to share their experiences with a global audience and to challenge traditional beauty norms. Caroline, an Alopecia content creator, shares how the situation around Alopecia was when she started posting her social media content on the health condition within the following quote:

> “Alopecia as a health condition is not that well known; even seven years ago, it was still very taboo, and nobody talked about it.”

Caroline highlights that talking about hair loss was still taboo, and not many people showcased their status of Alopecia. This goes with a lack of information on Alopecia as a health condition. The taboo around hair loss is linked with the notion from Koppelmann (1996) that “hairstyles can signify conformity” (p.87), which illustrates hair as a marker of social status and conformity toward a social group.

“Beauty as a norm” (Liebelt, 2019) has caused the effects of various forms of exclusion for those who fall short of, exceed, or violate the normative parameters. The stigma around Alopecia focuses on the bald head or bald spots as a “bodily sign” (Goffmann 1965) that women living with Alopecia encounter in the world.

Looking at the self-advocacy of Alopecia content creators, it is essential to look at the complex interplay of societal norms representation in media, digital influence, and advocacy efforts needed to challenge the normative beauty standard. The normative beauty standard and the aesthetic hierarchy regarding hair are upheld by the “public stigma” (Corrigan & Kleinlein, 2005, p. 16), where stigma is publicly endorsed through key power groups in functional roles. Since the stigma around Alopecia refers to its physicality with the bald head/spots, the fundamental power players would be those in positions that set beauty standards, meaning key power players within the fashion and beauty industry. Caroline, who has worked as a model and actress and has previous experience with brand cooperation, recognises that challenging the influence of marketing messages that perpetuate stigma and discrimination is needed for society to work towards creating a more inclusive and equitable environment for all individuals. She describes the role of marketing as follows:

> “Marketing plays a massive part in the world, knowing that just because you have the thing that makes you different doesn't mean you are not a person and are just as worthy as everybody else.”

Caroline suggests that marketing can be understood as a tool for empowerment to influence how individuals view themselves and others, shaping societal norms and standards of worthiness and belonging. Marketing can play a central role in the de-stigmatization and normalisation of Alopecia and hair loss because the marketing process frames the individuals appearing in ads as something attainable.

Mbunyuza-Memanis´s (2019) study on “natural hair” and its negotiation of its place within social hierarchies of beauty and beautiful hair - a finding that determined how social hierarchies of appearance are contested online. Here, hair is still a central part of women's physicality; how does this marginalised understanding of beauty change when it thematises hair loss? Allison, who is a make-up artist, uses her Alopecia as a canvas to facilitate her creative talent in art and creates make-up looks that involve that whole head; she describes the beauty standards specifically to Los Angeles as:

> "I always felt that the beauty standards, at least where I live in Los Angeles, are very one-dimensional and are centred around having hair."

This observation derives from Allison's experience living as a bald woman in Los Angeles. The emphasis on having hair as a central aspect of beauty reflects this standard's narrow and often exclusionary nature, which marginalises individuals who do not fit into the norm. This underscores the importance of challenging and broadening these standards to be more inclusive and representative of diverse beauty ideals. The German Austrian social media content creator living with Alopecia, Jana, describes her experience going out without a wig in the following way:

> "We are looked at as if we have cancer, and these pitying looks are just annoying when you are in the swimming pool with a small child, and then you feel the looks on the back of your neck that say, "Oh God, so young" or "Aww, a young mother with a small child and she has cancer, For God's sake."

Jana underscores the perception of individuals from the public towards Alopecia where there is a lack of knowledge about Alopecia, and the "bodily signifier" (Goffman, 1991) is recognised as a visible indicator of cancer. It establishes the need for advocacy work for Alopecia to generate awareness for the health condition and work towards better representation and community support for individuals with Alopecia that can reshape societal perceptions and foster greater acceptance and understanding of Alopecia as a health condition.

The "sociocultural model" (Cash et al., 2011) of body image provides a framework for understanding how societal ideals of beauty influence individuals' perceptions and attitudes toward their bodies. Grace, a social media content creator who shares her journey with Alopecia on Instagram, describes the negotiation of "fluidity in perception" (Yeshua-Katz & Segerstad, 2020) of outside and inside the world's attitudes and perception of societal beauty standards regarding hair and hair loss:

> "The idea of societal beauty that we constantly try to combat within ourselves and with our cultures."

Grace highlights the ongoing struggle women with Alopecia face in reconciling their sense of beauty within societal standards. Grace underscores the “internalisation by individuals” (Cash et al., 2011) of cultural norms and pressure to conform to narrowly defined beauty ideals. It challenges the “internal structure” (Frosh, 1991) within identity construction to challenge and resist these standards. When “encountering the world” (Frosh, 1991) and possibly receiving negative feedback, it is a more complex internal process to challenge and resist these standards, while they can persist and impact individual self-esteem and perception of self-worth, additionally, through the outlining of Synott (1987) of hair as a “powerful symbol” of both individual and group identity (p. 381). Grace emphasises that confronting these beauty norms is a self-reflexive process.

According to Coleman (1986), stigma “mirrors culture and society” and is in “constant flux” (p. 141). It suggests that the perception of Alopecia and, by extension, hair loss is not isolated but reflects broader cultural attitudes, beliefs, and values regarding appearance and beauty. In other words, societal norms and standards regarding hair and beauty shape how individuals perceive and experience hair loss. As previously stated currently beauty standards are centring hair. Individuals who experience hair loss may feel stigmatised or ashamed.

Additionally, these perceptions are not fixed but are subject to change over time. Societal attitudes toward hair loss may evolve due to various factors such as cultural shifts, advancements in medical understanding and treatments, representation in media and popular culture, and advocacy efforts by affected communities. Evelyn, who shares her medical journey and experiential knowledge on Instagram with her community, her hair loss sisters, describes the stigma around hair loss as follows:

> “For some reason, there is shame around hair loss, even though it didn't involve me or my character.”

Evelyn eloquently captures the emotional impact of societal perceptions surrounding hair loss, particularly the unjustified feelings of shame experienced by individuals affected by Alopecia. Evelyn reflects on the pervasive shame that surrounds the condition. This perception of shame around hair loss showcases the hierarchical underpinning of hair loss being marginalised within the hierarchy of appearance and beauty. Here, the “public stigma” (Corrigan & Kleinlein, 2005, p. 16) creates a sense of widespread public endorsement by upholding this power structure surrounding hair only experienced by those suffering from marginalisation.

The previous section illustrates how individuals affected by Alopecia view the “social imaginary” (Taylor, 2004) of hair. Coleman (1986) mentions the term “downward mobility” (p. 142), which suggests that stigma can lead to a loss of status or position within the social hierarchy, relegating stigmatised individuals within society. According to Coleman (1986), this can result in social exclusion, discrimination, and marginalisation, further perpetuating cycles of disadvantage and inequality” (ibid). This contextualises the need for de-stigmatization and normalisation of Alopecia as a health condition to facilitate change within the “social imaginary” (Taylor, 2004) of hair toward self-advocacy work Alopecia content creators with Alopecia are doing. Lane, who shares fashion content and uses her Instagram account as her creative outlet, talks about the intention behind their self-advocacy work regarding the social hierarchy:

> “I want to normalise bald women. I want to see more bald women in my feed. I want to see them doing things, living their lives, and being beautiful in their natural states.”

Lane expressed the desire to normalise and celebrate baldness in women, advocating for more excellent representation and visibility of bald women in media and everyday life. Further, Lane emphasises the importance of diversifying the representation of bald women within social media. Calling for more images of bald women “doing things and living full lives” implies the desire for authentic and inclusive portrayals that reflect the diversity of human experiences and identities.

Exploring Instagram Affordances: Visuality, Commercialization, and Self-Advocacy

Instagram offers a dynamic platform for self-advocacy, allowing individuals the agency to amplify their voices, share their stories, and advocate for causes close to their hearts. By harnessing Instagram´s “aesthetics and functionalities” (Leaver, 2020), offered by the visual and interactive nature of the platform, it lets its users effectively communicate their messages through visual means like photography.

The foundational visualities of Instagram offer a “digital reimagining of photographic traditions” (Leaver, 2020) that links with the physicality of Alopecia as a health condition expressed through a “bodily sign” (Goffman, 1963). This adds a visual element to the self-advocacy practices of Alopecia content creators when sharing their experiences. Van Dijck (2008) argues that photography has “always also served as an instrument of communication and as a means of sharing experience” (p.59). Lucia, a Czech social media content creator living with Alopecia, expands on the reason she chose Instagram as a platform to work on:

> “Instagram is the best platform to share that because, for Alopecia, it is the best way to see people without hair.”

Lucia highlights Instagram as the ideal platform for Alopecia content creators to share their experiences and connect with others. Lucia views Instagram´s visual nature, which makes it particularly well-suited for showcasing baldness and allowing individuals affected by Alopecia to see representations of beauty that align with their own experiences—engaging with representation links with the “embodied simulation” (Gallese, 2017). From the perspective of the aesthetic experience, Gallese (2017) suggests that our experience of art and cultural artefacts is intimately connected to our sensory and motor responses. Within engagement with art, there is a simulation of the actions and sensations associated with creating and experiencing it. They are enhancing our understanding and appreciation of the artwork. Here, the representation that Alopecia content creators offer offers a point of reference for the audience to make sense of their own bodies by seeing the visual representation of bald women.

According to Leaver (2020), Instagram can be used to visualise the lesser-seen struggles of minority groups (p.151). Instagram as a “platform” (Gillespie, 2010) offers the agency to create content that sheds light on the challenges and experiences faced by marginalised communities often overlooked and underrepresented in mainstream media. This entails sharing stories, experiences, and perspectives that highlight the unique struggles and resilience of minority groups. German social media content creator Jana elaborates on Instagram as a powerful tool to generate awareness:

> “Social media can be a great tool to spread positive vibes, especially if you don't conform to the norm like we (women living with Alopecia) do.”

Jana suggests that social media platforms offer a unique space where individuals can express themselves authentically and diverge from mainstream expectations and conventions. Posting social media content with a bald head by Alopecia content creators serves as an “aesthetic normalisation” (Leaver, 2020). Through the continuous sharing of social media content of bald women, an everyday treatment is supplied for baldness, instigating a normalisation process. According to Aziz (2017), there is a problem with the representation of body image on Instagram. Instagram does not “represent a realistic norm and often results in negative attitudes and perception” (p.19).

In contrast, Alopecia content creators authentically account for body image by sharing their “bodily sign” (Goffman, 1963) of stigma openly. This highlights the transformative potential of social media content in shaping cultural norms and promoting positive change. It underscores the importance of using these platforms to amplify voices, challenge stereotypes, and foster greater societal acceptance and understanding.

In exploring the dynamics of the action of Alopecia content creators that would be classified as digital labour and value creation within the context of Instagram´s commercialization by the individuals. The concept of “free labour” (Terranova, 2000) is clarified as the moment where “knowledge consumption of culture is translated into productive activities that are pleasurably embraced and at the same time often shamelessly exploited” (p. 37) When considering the commercialisation of Instagram, Terronovas framework provides a lens through which to analyse how users labour and contributions are harnessed for economic gain, while also acknowledging the non-monetary rewards that motivate participation in online communities.

Within the online communities of Alopecia content creators, it is essential to note that some content creators have monetary gains through their Instagram accounts. In contrast, others do a lot of advocacy work to raise awareness where there is no financial compensation. Grace, who shares her personal journey and emotional insights around Alopecia, elaborates on her perspective on the Alopecia community:

> “The account becomes their full-time job, but then it becomes more of an ad, and sometimes that is disheartening because it takes away from the messages and the community feel from the emotional support, which becomes the sales tactic.”

Grace outlines and reflects on transforming social media accounts into full-time jobs, expressing concern over the shift towards commercialisation and promotional content. Grace illustrates how the pursuit of monetisation on a platform like Instagram can compromise the authenticity and community atmosphere that initially characterised these accounts. Without intervention, it can lead to a “commodification of patienthood”. This highlights the tension between financial incentives and the original purpose of social media accounts as spaces of meaningful engagement and support. Here, it is to say that in the case of Alopecia, financial incentives and financial compensation for reviews of products might not necessarily lead to a lack of authenticity in the created content outside of compensated content.

Exploring the intersection of illness identity, narrative, and self-advocacy: social media content creators with Alopecia

Illness identity (Charmaz, 1995) refers to the degree to which a chronic illness integrates into one´s sense of self. Understanding and acknowledging the diversity in illness identity is important to recognise the range of experiences and perspectives within the Alopecia community. According to Vicari (2021), digital mechanisms have offered the potential for illness to become an increasing network experience. Similar to “illness subcultures” (Conrad et al., 2010), digital experiences provide the opportunity to engage in an exchange with fellow sufferers.

Focusing on the self-advocacy of Alopecia content creators, it aims to explore how contemporary health activism can both reflect and drive epistemic shifts in the concept of the patient, leading to what Landzelious (2006) terms “prescriptions of patienthood” (p. 533). This phrase suggests a reconfiguration or redefinition of the traditional role and identity of the patient within the healthcare systems and broader society. It acknowledges that health activism has the potential to challenge existing norms, beliefs, and practices surrounding patienthood, while offering new perspectives and possibilities for patient engagement and empowerment.

Figure 2: Examples of Alopecia - What Androgentic or Totalis/Universalis could look like.

From the observation during the interview process, it can be established that Alopecia as a health condition can exist and manifest itself in several different ways from the various sub-sections of Alopecia like arreata, universalis, and totalis or a distinct condition with Androgenetic Alopecia. Some have Alopecia from childhood onwards, and others have acquired it later in life. This affects the perception of the "trauma" and attitudes towards struggles with living with Alopecia as a health condition. Since there are different choices regarding how to deal with the condition, for example, wearing a wig, going out bald, or having an in-between, those choices also reflect the construction of the illness narrative and how the experiential knowledge is set up as knowledge transfer for the followers. This translates into different types of self-advocates as Alopecia content creators on Instagram.

The motivation to become a social media content creator living with Alopecia who practices self-advocacy on Instagram comes from the "construction of identity" (Frosh, 1995) and, by extension, the "illness identity" (Charmaz, 1991). Self-advocacy can be determined as "intense engagement" (Dahlgren & Hill, 2020) as it touches on the temporal element of long-term commitment to keep up the self-advocacy work - the process towards the place of practice for self-advocacy work takes time to build an audience and gain visibility.

Allison elaborates on finding her purposes within her self-advocacy work, sharing her dedication to sharing her experiences to uplift and support others, opening up an opportunity for exchange and interaction among those who may be facing similar struggles:

> “I made it my lifework to be so loud about (Alopecia) because if it takes me being courageous now, I can help anyone along that journey, going through the challenging part of Alopecia towards being comfortable in their skin.”

Allison reflects on the commitment to using her own experience with illness and adversity to appease and ease the experience of others. Allison's motivation refers to a sense of obligation or solidarity outlined as a reason for motivation within “media engagement” (Dahlgren & Hill, 2020).

Typology of self-advocates of social media content creators with Alopecia on Instagram

According to Vicari (2021), self-advocacy is exposing oneself and one's personal experiences to others. Individuals connect around common identity traits defined by the attributes of their illness (p. 46). Within Alopecia content creators, this can manifest in various ways, reflecting their unique experiences, challenges, and the goals of their advocacy.

Creating a typology of six different Alopecia content creators involves categorising them based on various factors such as their content focus, advocacy approach, and personal experiences with Alopecia.

It is important to acknowledge that these categories may overlap and that many Alopecia content creators may embody multiple roles simultaneously. These overlapping roles highlight the complexity and diversity of Alopecia content creators, demonstrating how their illness identity forms and shapes their advocacy efforts, community building, and representation within online spaces.

Personal Journey Advocates

Figure 3:AI visualization of characteristics supplied to a Personal Journey Advocate

The first type is called the personal journey advocate. These content creators primarily share their "self-story" (Hydén, 1997, p. 55) by going in-depth with sharing their personal experiences with Alopecia, documenting their journey of diagnosis, treatment, and acceptance. They use their platforms to support, encourage, and empower others facing similar challenges. Grace outlines:

> "Any thoughts I didn't know where to put, I put them on Instagram. It was therapy for me."

Here, Grace outlines how personal journey advocates draw on their firsthand experiences with Alopecia to offer authentic and relatable insight into the emotional, physical, and social aspects of living with the condition. Frank (2013) states that "their bodies give their stories their particular shape and direction" (p. 27), using their personal journey with Alopecia as a health condition as a driving force of their "illness narrative" (Hydén, 1997). These Alopecia content creators engage in-depth with the embodied experiences through storytelling and the implications of this process for understanding illness, identity, and narrative meaning-making. Their experiential knowledge is at the centre of their storytelling and enables them to connect more deeply with their audiences due to an "affective mode" (Dahlgreen & Hill, 2020) of engagement.

The emotional element within the content of personal journey advocates is strong due to their vulnerability when sharing their experiences. Olivia touches upon her motivation to share the content she is creating by comparing it to writing a diary in the following way:

> "It was mainly a journal for me to express how I was feeling and not keep it all bottled up."

Olivia touches upon the "therapeutic value of storytelling" (Ogad, 2005, p. 164) by sharing their illness narrative online and working through their illness experiences synchronously by documenting their diagnosis, treatment, and acceptance journey. This type of self-advocacy is the closest to an "autobiographical description of illness" (Hawkins, 1999) and is a deeply personal and reflective process. They use their platforms to support, encourage, and empower others facing similar challenges, weaving their illness narratives into their personal stories of living with Alopecia.

With the focus on their personal journey as an "illness narrative", the Alopecia content creators centre the "biographical disruption" (Bury, 1982) this is brought about by the health condition and creates "digital self-presentation and self-reflection that is cumulative" (Walker-Rettberg, 2012, p. 35) by creating a social media feed that is comprised of ever-growing assortments and addition of posts that are expressing the progress of the journey of the social media content creator sharing their journey and with that portraying growth within the "identity construction" (Goffmann, 1963) of the "authors identity" (Walker-Rettberg, 2012).

Olivia implies that their illness narrative delves from their illness identity as they navigate the emotional and social aspects of living with Alopecia while sharing personal stories online and supplying evidence to Charmaz's (2002a, 2002b) claim that illness narratives intrinsically link with time and connect events and symptoms along a temporal continuum within a biographical context. Frank's (2013) description of "giving a voice to suffering in a way that lies outside of the domain of the biomedical voice" (p.49) focuses on the interplay of dynamics between the virtual and real life because real-life events connected to the health condition can disrupt and change the content that is disrupted online. To stay authentic, the up-and-down needs to be shared with the audience, and not shying away from the perhaps “ugly” truth that while a lot of the struggle around Alopecia is focused on visuality, it is still a health condition to work through. The Alopecia content creators recount their progress in dealing with Alopecia as a health condition in real-time, sharing positive and negative aspects and working through events alongside their audience. Additionally, there is an interesting dynamic of how this can affect audiences as social media content creator and audiences might be in differing temporal spaces within their personal journey with Alopecia.

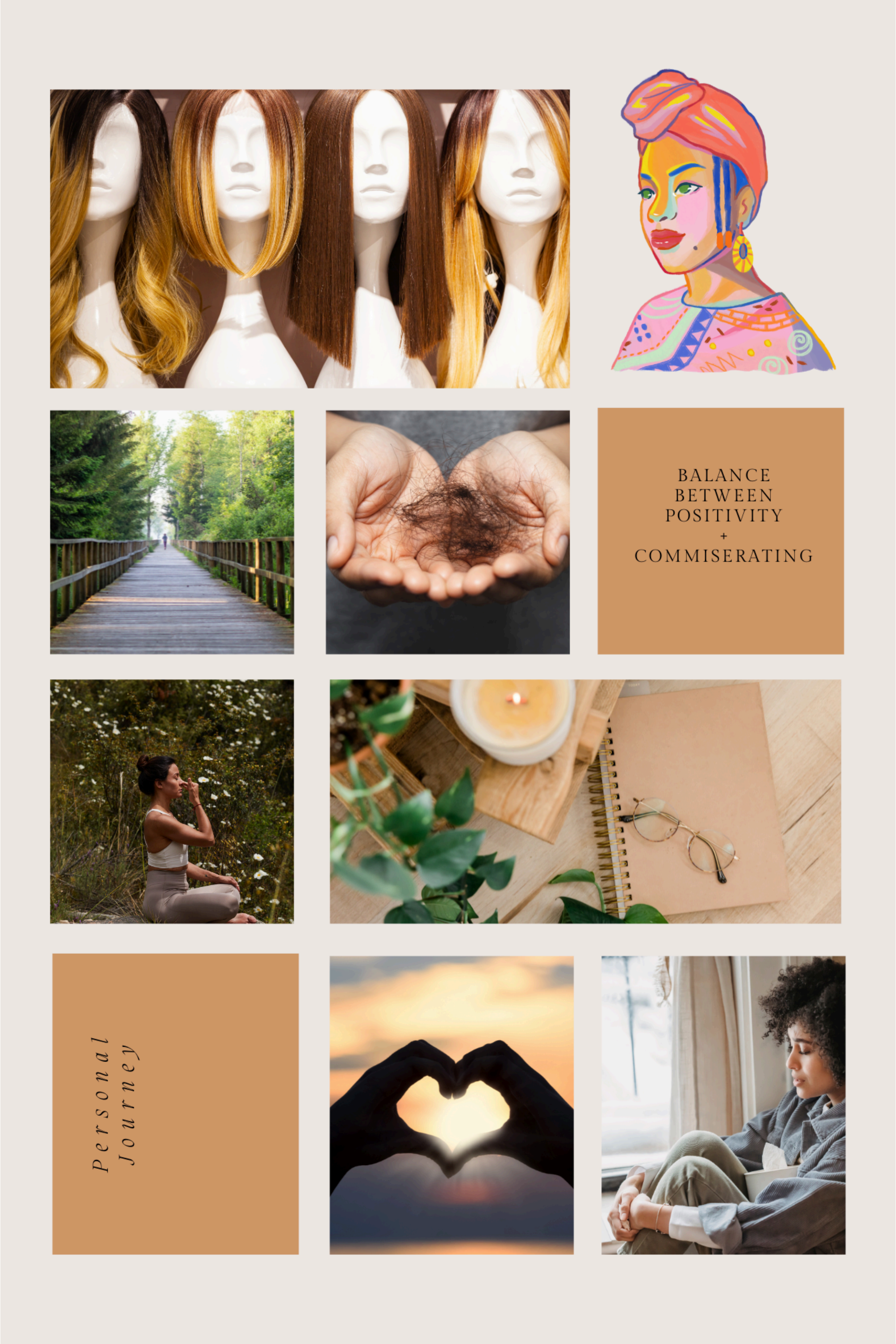

Figure 4: Visualization of social media content of the personal journey advocate through non-specific images

Educational Advocates

Figure 5:AI visualization of characteristics supplied to a Educational Advocate

The second type is called educational advocate. These creators provide information, resources, and awareness about Alopecia, including symptoms, treatments, and available support services. They may share medical insights, research updates, and practical tips for managing Alopecia. Evelyn also touches upon experiential knowledge and her professional knowledge of health conditions and infusion with her professional knowledge from working in a health profession, next to her social media content creation.

> *"I had learned so much from my hair-loss sisters that I thought I could communicate it in a way that would help other people, but it was hard for me to find information. Why couldn't I be brave enough to help a couple of people feel less alone?"*

These creators may also draw on research and professional expertise; they incorporate their own experiences with Alopecia into their educational content, providing practical tips, coping strategies, and insights based on their lived experiences; their experiential knowledge adds depth and authenticity to their educational materials. Jana has expanded her social media content creation and has transferred hair into other areas of her professional career by leading a second hair studio; there are some professional knowledge elements that she can pass on:

> "Simply do educational work to encourage others affected and show them that they are not alone. Some life hacks: If you do not have hair, how to do makeup or your eyelashes."

As Jana describes, this type of social media content is a strong educational element incorporated into the illness narrative that gears towards sharing insights and resources and creating awareness about the condition. It draws on a more "cognitive mode of engagement" (Dahlgreen & Hill, 2020) that invites more critical thinking or drawing on knowledge to work through the content (pp. 16-17).

In contrast, in the personal journey advocate, where the narrative around the "voice of suffering" (Frank, 2013) moves away from the "biomedical voice" with the content of the educational content creator, there is a more interwoven presence through the underlining of experiential knowledge with professional knowledge from the health sector when it focuses on content on Alopecia as a health condition. Additionally, this type of content invites more expert voices by featuring experts in medicine; hair enriches the educational material of the lived experiences.

Educational content creators need a higher degree of "health literacy" (Martin et al., 2011), which refers to the capability to obtain and understand health information - this is due to them not only obtaining the information for themselves as patients but also pass on the knowledge they receive to their audience entering a vital central role within the knowledge transfer from medical professionals and expert professional with the area of interests towards the audience of the social media content creator.

Figure 6:Visualization of social media content of the Educational Advocate with Alopecia, through non-specific images

Beauty and Fashion influencers

Figure 7: AI Visualization of beauty and fashion influencer type

The third type is called Beauty and Fashion influencers. These content creators use their platform to showcase their creativity and confidence in styling their hair and fashion choices despite living with Alopecia. They promote self-expression and diversity in beauty standards, challenging stereotypes and stigma surrounding hair loss. Jana, who owns a second hair studio and knows all about trends for wigs or new eyebrow alternatives, describes baldness in the context of hairstyling as:

> “My motto is: bald is just another hairstyle.”

Jana encapsulates a powerful message of acceptance, confidence, and self-expression. It challenges societal norms and stereotypes surrounding hair and hair loss, affirming that baldness is just as valid and beautiful as other hairstyles. Jana also encourages and fosters a sense of empowerment and self-assurance for individuals who may face stigma or discrimination due to baldness. Janas's motto inspires you to embrace your unique identity and redefine beauty on your terms. Here, the aesthetic representation from fashion and beauty influencers linked with “illness identities” (Charmaz, 1991, 2002a, 2002b) touches upon a possible re-working of self-perception of their health condition from the audience's perspective. It touches upon the “construction of self” (Frosh, 1991) and has a frame of reference for positive media representation. Instagram as a platform has been problematised when it comes to body image due to not representing a “realistic norm” (Aziz, 2017, p. 19), and often results in “negative attitudes and perceptions” (ibid). Regarding Alopecia content creators, this seems to be broken and leaves for a more positive sense of embodiment.

Beauty and Fashion influencer leverage their “experiential knowledge” (Brockman, 1976) to pass on styling techniques, beauty products, and practical advice and inspiration to others with Alopecia. Jana, who has professional experience within the hair care sector, outlines how new products influence her content:

> “Make-up stories: I do self-adhesive eyebrows and scratch tattoos where you put water on them and then peel them off, which are currently of great interest. I also do different wigs and new products”

Illness narrative plays a role in the storytelling of these creators as they showcase their creativity and confidence in styling their hair and fashion choices despite living with Alopecia. They share their journey of self-expression and acceptance using their illness narratives to challenge beauty standards and promote positivity within the Alopecia community. Lane, who has combined fashion and Alopecia, describes her content the following way:

> “It is a creative outlet and shows how I play with fashion. I wanted to serve as a normalisation of bald women. I would like to see women who are bald and accept that as a regular thing.”

Lane describes her intention to serve as a touchpoint of the normalisation of bald women. Through that, she aims to counteract stigma and encourage broader acceptance and representation of diverse beauty ideals. The content shows the embracement of baldness as a natural and normal part of their identity. This is important for the “story design” (Giaxoglou, 2022) about the narrative voice of the creator, in this case. Creating greater visibility and representation of bald women in fashion and media contributes to a more inclusive and diverse portrayal of beauty, fostering a culture of acceptance. Caroline describes her previous experience with brand cooperation:

> “I used to do a lot of brand partnerships. One brand partnership brings another partnership, and another brand sees that and continues to bring more opportunities.”

Caroline demonstrates the opportunity brand cooperation brings to a social media content creator and the power of visibility through which new networking opportunities are created. Positive representation and collaboration with the brand develop new opportunities and foster professional relationships through leveraging their platform visibility. Fashion and beauty influencers offer easy touch points for brands to collaborate. They break into new audiences through brand collaboration and featuring the content on the brand account or potentially other content creators. This can be linked to the concept of “mediatised visibility” (Giaxouglou, 2022), where brand cooperation offers opportunities to amplify their voices. Companies are looking to diversify their marketing, looking for interesting narratives, amplifying their brand, and striving to create a “more representative " visual culture” (Dimitrieska, 2019, p. 115). This push for diversity opens up new opportunities for Alopecia content creators, and they gain a more significant societal reach through the diversification of their audience. The visibility for the general public becomes higher, and their content is not only shared with their audience. This means the visibility of Alopecia as a health condition increases as well and offers more meaningful interaction to change attitudes and awareness. While it can seem superficial or “glossy”, - it allows for an easy engagement with fashion and beauty content. It will also increase interest in the baldness of the content creator, leaving room for a more critical engagement of the easily digestible content.

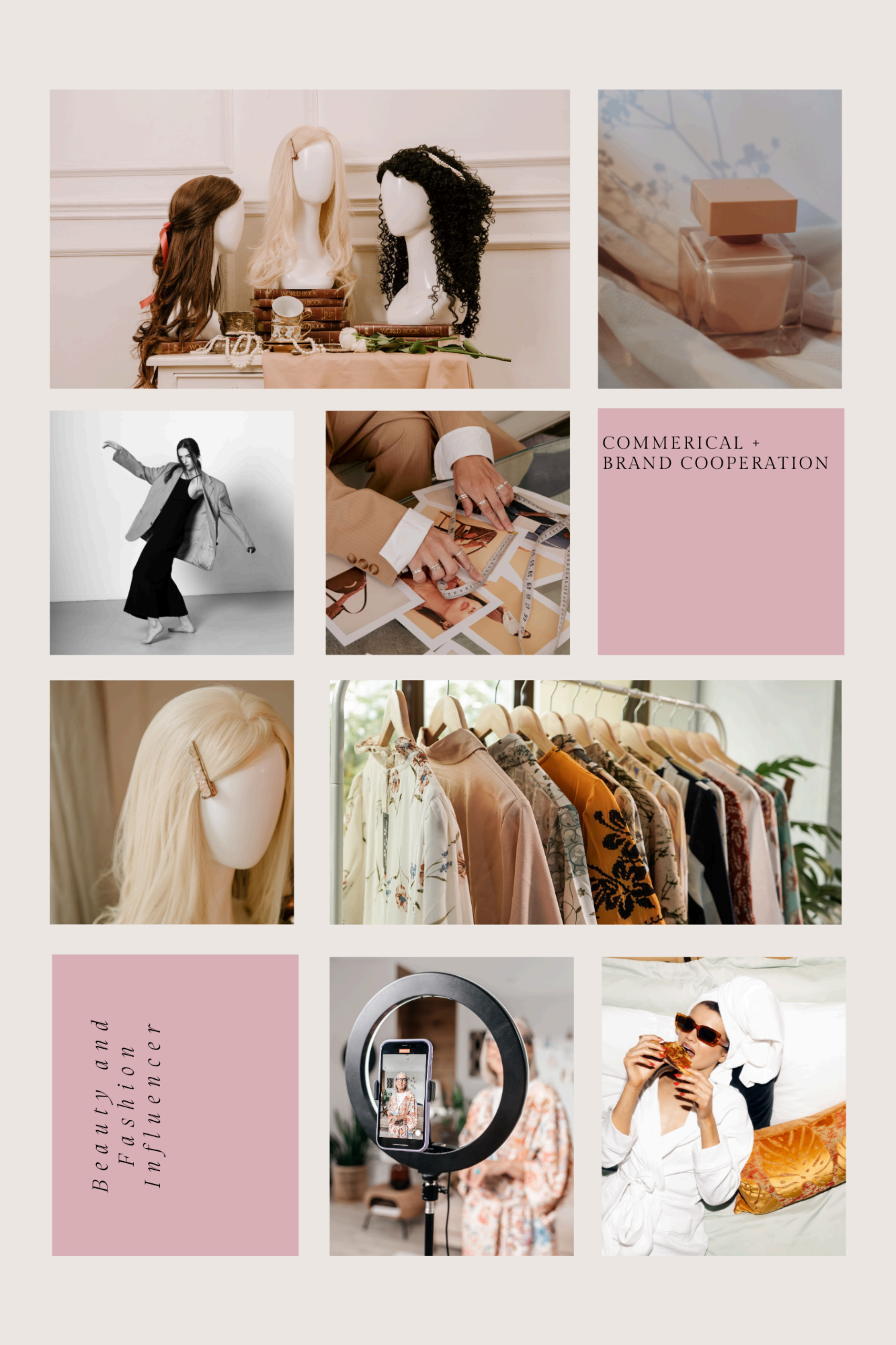

Figure 8:Visualization of the beauty and fashion influencer through non-specific images

Activists Advocate

Figure 9:AI visualization of characteristics supplied to Activist Advocate

The fourth type is called the activist advocate. These content creators are actively engaged in advocacy efforts to raise awareness, promote acceptance, and advocate for policy changes related to Alopecia. They may collaborate more intensely with organisations, participate in awareness campaigns, and lobby for greater support and resources for individuals with Alopecia. Louisa acknowledges how her advocacy work not only limits itself to Alopecia but has intermingled with other areas:

> “I would say it is more of a personal blog. It is often about personal concerns, ranging from feminism to climate issues or Alopecia—a personal concern and a personal narrative to share.”

Louisa uses sharing personal concerns and narrative as a powerful tool to connect with others. As the educational content creator type, the advocate and activist offer a more “cognitive engagement” (Dahlgreen & Hill, 2020). Their “experiential knowledge” (Brockman 1976) informs their advocacy efforts. A key point within Brockman's (1976) work is that the advocacy efforts delve from their experiential knowledge and expertise as the primary basis of decision-making. However, their firsthand experiences lend credibility to their advocacy messages and make them powerful advocates for change.

The content this type of Alopecia content creator evokes demands by touching more upon “cognitive engagement” (Dahlgreen & Hill, 2020) with a more critical reflection on the produced content. The content often touches upon “transmedia” (Jenkins, 2014), linked to content outside of Instagram. Lucia describes the content she is creating for her advocacy work and expands as the following:

> *“*I started by writing articles about my experiences with Alopecia—how it started and how it is going—and then I started interviewing other people. Example: women living with Alopecia, hairstylists, experts from the medical field*”*

During the interview, Lucia expands on distributing her articles through a personal blog, a platform outside of Instagram due to the limit of text posts on Instagram and using Instagram to drive traffic to her blog by creating supportive visual content and sharing it on Instagram, referring to the link in her bio. She expands on the motivation to create her account and the gap that she wants to breach with her content:

> *“*Nobody is sharing a lot of information. You can find some articles from hairstylists or medical articles, but not quite about people's experiences with it.”

Lucia is talking about the experiences of a new medicine that should cure Alopecia, which is quite popular in Czechia. Additionally, Grace, who is American, has implied that she also has opened up about regulations within the health insurance concerning Alopecia, saying:

> “I posted about how I got my eyebrows tattooed for the first time, and in America, it is not covered under health insurance. I was happy to get these eyebrows, but then I was so pissed that I had to do that on my own. I was just going through the struggles of not being supported by your country or your insurance.”

Grace describes the feeling of being lost and overlooked by the institutions that are supposed to provide assistance and care as disheartening. It reinforces the sense of isolation and marginalisation that many individuals living with Alopecia experience. Moreover, Grace underlines that the marginalisation of living with Alopecia does not just bring about physicality of it but is also supported by healthcare structures with health institutions. Here, the idea of the “activist-expert” (Epstein, 1995, pp. 414-415) takes on the role of challenging “professional” knowledge by Alopecia content creators through their content online.

These Alopecia content creators incorporate their illness narrative into their advocacy efforts to create credibility for their claims concerning healthcare thematising Alopecia. Sharing these illness narratives on social media serves as a powerful tool for humanising the condition and mobilising support for systematic change within society. The mobilisation of support is also further established by collaborating or promoting organisations that centre Alopecia in their work regarding medical research, opening for communal support. Lucia describes her engagement with organisations as follows:

> “I am promoting organisations for Alopecia that want to help and do better things for people with Alopecia.”

Their illness identity drives their passion for advocacy as they draw on their personal experiences to construct the illness narratives around their experience to humanise the condition and promote social change within society. Allison describes that passion as something ingrained when you have a platform that you should use to speak up, saying:

> “As someone with a platform, I think speaking up and sharing your experiences with the rest of the world is very important.”

Allison touches upon what Frank (2013) described as “giving a voice to the suffering” (p. 46) —allowing for a further extension of the “category of the patient” (Landzelius, 2006). The extension is characterised by the mobilising character archived through the digital media element. Within this discussion it touches upon the “notion of voice” (Giaxouglou, 2022) from the author sharing their illness experience. Evoking further debate about the negotiation around “telling rights” (p. 5). That negotiation adds context relating to the sufferers' meaning-making practices and world constructions (Hydén, 1997) that leads to the intention behind the mobilisation through sharing illness experience.

Figure 10:Visualization of the Activist and Advocacy content creator, through non-specific images

Artists and Storytellers

Figure 11:AI Visualization of Type Artists and Storytellers

The fifth type is called artist and storyteller. These creators use creative mediums such as art photography, writing, or performance to explore and express their experiences with Alopecia. They may use storytelling, visual imagination, or performance to challenge stereotypes, convey emotions, and foster understanding. Allison talks about her passion for make-up artistry that she shares on her account, making her Alopecia an integral part of her art by creating whole-head make-up looks and making herself into characters, and describes her evolution as a content creator:

> "I was originally posting makeup looks I was doing myself, even before I went to makeup school. I was playing around, just being creative with makeup, and then it just evolved. I felt so much more confident working in myself because I had all this control, and we have, you know, lovely, beautiful bald heads that offer room to play."

Allison describes how she incorporates the physicality of Alopecia with the real embodied experience, letting the physicality move into art and allowing for a deeper connection with the physicality of the "illness experience", becoming the canvas for her art. Frank (2013) recounts the physical symptoms or manifestation of their illness and how bodies take a central role in shaping the narrative trajectory and direction of the story. As the artist, Allison takes this trajectory and direction and moves beyond the physicality that is applied to her by her health condition. She acknowledged it by the incorporation but took charge of it by turning it into something else.

Experiential knowledge fuels the creative expression of these creators as they use art, storytelling, and other creative mediums to explore and convey the complexities of their experiences with Alopecia. Their artistry and storytelling abilities enable them to communicate the nuances of their lived experience in powerful and meaningful ways through a total embodiment of it. Amelia is a dancer and talks about how she incorporates her advocacy efforts by extending it into her real life by teaching dance classes; she clarifies:

> “I dance and teach dance classes. I teach with my bald head as part of my effort to raise awareness.”

Amelia embodies the construction of her “illness narrative” (Hydén, 1991) in real life, extending her advocacy work within her profession as a dance teacher and creating a fusion of the virtual and physical world. Amelia challenges the conventional notion of beauty and includes her students in her awareness work. The construction of their illness narrative serves as inspiration for their artistic creations, allowing them to communicate the emotional and psychological impact of Alopecia in a profound and evocative manner. Allison describes the benefits of her approach to turning her Alopecia into art,

> “I needed to use that art therapy on myself to work through what I had been through all these years.”

Their illness identity inspires their artistic creations as a heightened “performance of self” (Goffmann, 1959). Artistic content creators living with Alopecia benefit from the “therapeutic benefits” (Yu, 2011) by gaining a creative outlet and communicating the emotional and psychological impacts of Alopecia in a profound and evocative manner. This is then translated into the illness narratives infused with creative expression.

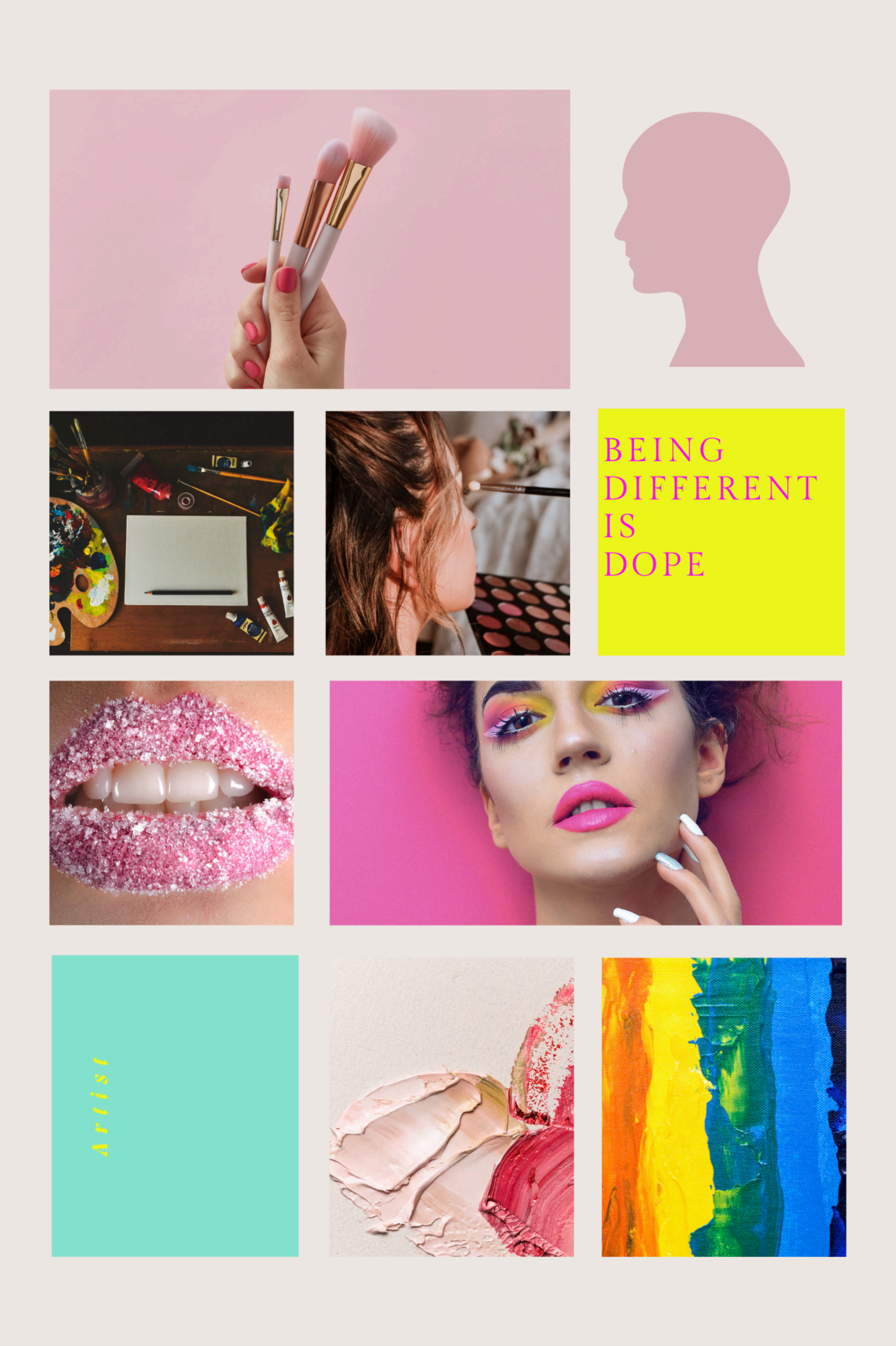

Figure 12:Visualization of the Artist and Storyteller, Make-Up Artist through non-specific images

Figure 13:Visualization of the Artist and Storyteller - Dancer, through non-specific images

Product Reviewers

Figure 14:Visualization of type product review through AI

The sixth type is called product reviewer. This type finds new brands and companies to review and test products specifically designed for individuals with Alopecia, such as wigs, hairpieces, and scalp treatments. They provide honest reviews, styling tips, and recommendations based on their personal experiences. Evelyn talks about her evolution from sharing her journey and lived experiences and turns it into a knowledge transfer with her audience:

> “I did some reviews; initially, I talked more about alopecia. Now, I talk more about wigs and so on.”

Evelyn underlines the fluidity of moving or evolving from one type of content creator to another. It showcases a reconfiguration of the “illness experience” (Conrad, 2010). It could point to a successful healing process where the “biographical disruption” (Bury, 1982) of the illness becomes normalised, opening opportunities to explore new areas of the experience. At the same time, the focus of the content on wigs would mean that it subscribes to a higher need for conformity within the normative beauty standard, but that is not necessarily the case.

Olivia, whose content is also centred on wig and wig care, says that there is a lot more to a wig than meets the eye and practical content and recommendations are important, describing the situation:

> “I would have started wearing a wig earlier in my hair loss journey if I was not hellbent on getting a human hair wig that looked and felt just like my bio hair. This kept me from getting into wigs for a very long time, and I was saving money wherever I could to get the human hair wig of my dreams, and that is not how wig-wearing worked for me.”

Olivia underpins the importance of “experiential knowledge” (Brockman 1976) regarding product reviews and recommendations for wig-wearing. The firsthand experiences with new companies are essential to provide someone with the knowledge to make the right choice when acquiring a wig. Furthermore, Olivia touches upon the “magical, symbolic power” (Koppelman, 1996) of hair, which is that a human hair wig can transcend the physicality of the truth of the health condition. The stress of the “human hair wig of my dreams” from Olivia indicates that the social hierarchy around the hair is also transferred to the wig-wearing community, indicating a difference in attitude toward “human” and “artificial” hair. Additionally, the “saving money” touches upon the financial aspect of hair, indicating that those who cannot afford a “human” hair unit try not to be genuinely authentic.

Evelyn further elaborates on the commercial aspect of wig-wearing. She describes that there is a sensitivity when it comes to wigs because not everyone can afford a human hair unit - there is a tension that she outlines as:

> “I want to be honest. I pay for most of my wigs, and for the ones that were gifted, I took down some of the reviews. Not that they were not honest; they were great, but I also didn't want it to be me selling to people. It just didn't feel authentic to who I am.”

The tension can be traced to the possibility that there might be an element of discomfort from the perspective of the audience if wig content is created by Alopecia content creators living with Alopecia or other hair loss conditions. Including this type of content within the illness narrative opens a possible discussion about the commodification of the “illness experience” (Conrad, 2010) should there be monetary compensation.

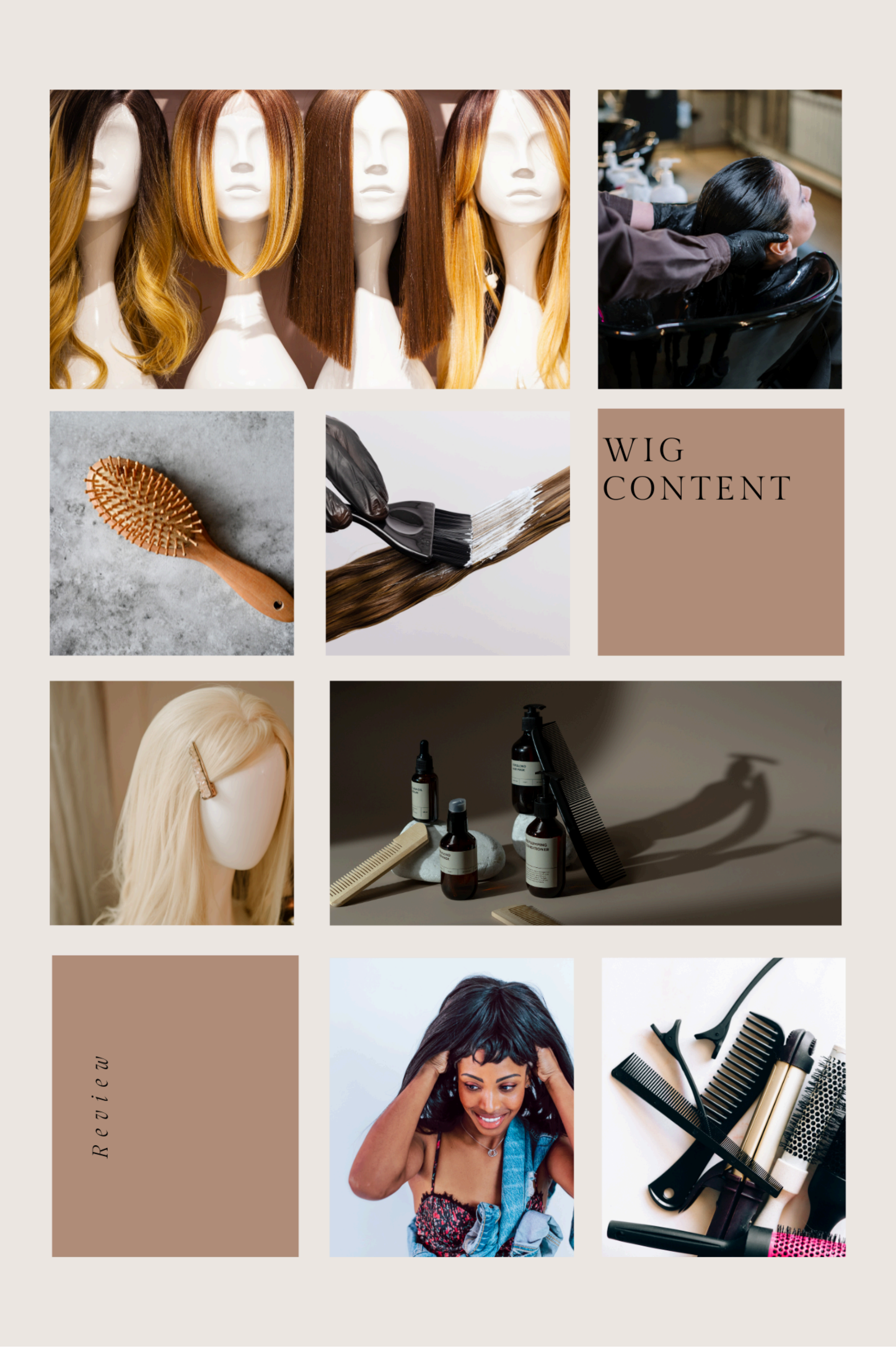

Figure 15:Visualization of social media content of Product Reviewer, through non-specific images

Mobilizing vulnerability and reconfiguring digital health activism

Mobilising vulnerability touches on the concept of networked feminism (Fotopoulou, 2016, p. 4) and combines it with the understanding of “vulnerability” (Butler, 2016) to reconfigure the traditional notions of health activism. Evelyn talks about vulnerability and how she manages personal boundaries when sharing content:

> “I opened myself up to feeling vulnerable. It was not like oversharing, not super personal stuff, just sharing what it feels like to have Alopecia and the different emotions that you experience. The more I am open and vulnerable about these things, the more feedback I get from my audience that my content is helpful.”

Evelyn illustrates the power of vulnerability in fostering connection, understanding, and support within communities affected by Alopecia. Butler (2016) reconsiders the significance of “embodiment and vulnerability” (p. 2) within political mobilisation. Mobilisation within the context of this study refers to the area of health and illness through a networked experience of advocacy efforts to challenge the stigma around Alopecia. Within the quote, Evelyn emphasises the focus on expressing the range of emotions and challenges associated with Alopecia, allowing others to relate to and empathise with their experience.

By opening up about their experiences with Alopecia, Evelyn emphasises the importance of sharing emotions and insights authentically, without oversharing or delving into overly personal details. The body becomes a “site of vulnerability and interdependence” (Butler, 2016), expressing a range of emotions and challenges associated with Alopecia. It allows the audience to relate to the Alopecia content creators, creating an “interconnectedness of human bodies” (Butler, 2016). Through this act of sharing their vulnerability, the individuals not only share their journey but also create a “space” (Lupton, 2017) for others to share their experiences and receive validation and support.

This power of vulnerability is important to note as vulnerability has been perceived as a weakness due to its connection to “passivity and victimisation” (Fotopoulou, 2016, p. 16). This is contradictory to the recounting of the Alopecia content creators about how they view sharing their vulnerabilities online and, instead, categorise it as a strength. Lane elaborates on this by touching upon encountering content from fellow Alopecia content creators:

Lane discusses how Alopecia content creators harness their vulnerability and incorporate it into their self-image and content creation. In some instances, it even extends to their everyday life decisions and careers. It seems to highlight that power can be a central component of one´s identity and influence the “performance of self” (Goffman, 1963). Within this context, bodies can move beyond “sites of vulnerability and precarity” (Butler, 2016) and become “agents of resistance” (ibid). The resistance enacted against societal norms arises from their vulnerability - a vulnerability that is not passive but instead actively challenges the oppressive power structures.

According to Vachhani (2021), the use of digital media for activist purposes can “amplify the affective intensity of public discourse surrounding the issue” (p.7), suggests the employing of digital media platforms for endeavours to enhance the emotional impact and intensity of public discussion, in this case, the stigma surrounding Alopecia. By utilising digital media, the activist can effectively amplify their message, reach a wider audience, and evoke strong emotional responses from the public. The typology of the different Alopecia content creators broadens the audience's touchpoints for raising awareness, mobilising support and provoking action on social and political issues.

Vachhani (2021) underscores the significant role digital media plays in contemporary activism by leveraging “emotional engagement” (Dahlgren & Hill, 2020) to garner and mobilise public attention and support social change initiatives. Allison, who is striving to share vulnerable content to facilitate the exchange with her audience, outlines an experience where a member of her audience told her that she would shave off the rest of her hair that was falling out due to her getting Alopecia:

> “I made changes to the content to be more vulnerable, and I heard positive feedback from the audience that the content was helpful and empowered them. They told me that they would shave their heads because they didn't care about it.”

This interaction between Allison and a community member underlines the opportunities that can arise from this affective intensity in the relationship between follower and creator. Recounting this event, Allison centres on the profound relatability within the relationship and the transcendence of that sharing of personnel from the virtual world into real-world effects and mobilisation of “agents of resistance” (Butler, 2016). Shaving one's head can be interpreted as a symbolic gesture of liberation, shedding societal norms or expectations and embracing authenticity and self-expression.

An interesting element to note is Allison's intent to push her content and become more vulnerable in her expression for her audience, creating this deep bond that leads to a liberating fallout and leaving behind societal norms or expectations. Here, a “moment of reception” (Press & Tripodi, 2021) becomes visible where Instagram is used as a context in which “glossy feminism” (Favaro & Gills, 2018) is subverted through critical engagement with the content created. From the intent, this gives us an example of “media-ready feminism” (Press & Tripodi, 2021) from the perspective of media production.

Conclusion

This thesis explored the experiences and practices of Alopecia content creators in their self-advocacy efforts on Instagram. Instagram's visual functionalities and the visual physicality of Alopecia as a health condition make it a good social media platform to explore Alopecia as a health condition. Instagram is for "visual communication" (Manovich, 2017), offering opportunities and possibilities to explore the self-advocacy efforts of Alopecia content creators.

In order to get that understanding, semi-structured interviews with Alopecia content creators were used as the primary data collection method. These were conducted with expert interviews of Alopecia content creators as experts of social media and Instagram and lay experts regarding the experiential knowledge that they have gained through living with Alopecia as a health condition. Interviews were conducted with 11 female Alopecia content creators of differing follower counts and creator classifications. Supported this method through observation to give a visualisation of the content created by the Alopecia content creators without implicating ethical consideration.

The following section addresses the research question posed at the beginning of this thesis. It provides suggestions for future research and justifies the thesis's contribution to knowledge.

The first research question asks: How does stigma manifest and impact the experience of Alopecia content creators on Instagram? The section set out to outline the evolution of reframing beauty from traditional beauty norms by unravelling the stigma around Alopecia and hair loss. Giving the context of the social hierarchies around appearance regarding hair and a marginalised understanding of beauty around Alopecia. It moves into the efforts of challenging these norms and stigma within the contemporary frame of self-advocacy work on social media by Alopecia content creators. The findings of the study situated hair loss as a "bodily sign" (Goffman, 1965) of stigma within the social hierarchies around appearance regarding the physicality manifestation of Alopecia as a bald head/spots. From the findings, it emerges that marketing can play a central role in the de-stigmatisation and normalisation process due to the attainable nature of advertisement. The unravelling of stigma around Alopecia underscores the need and frames the motivation of the self-advocacy practices of Alopecia content creators. The study has found that societal attitudes towards hair loss may evolve due to various factors, such as cultural shifts, advancement in medical understanding and treatments, and representation in media and popular cultures. Jana and Evelyn, two of the Alopecia content creators, make great points to showcase and underpin how society´s “social imaginaries” (Taylor, 2004) of hair uphold the societal and cultural stigma concerning hair and hair loss.

The second research question asked: How do Alopecia content creators on Instagram utilize narrative techniques, such as personal storytelling, visual imagery, and community engagement, to construct and communicate their illness identities and experiences? This study has identified the link between the visuality of Instagram and Alopecia creates a deeper engagement with the representation through sense-making of their own bodies, through seeing the visual representation of bald women. Furthermore, the transformative potential of social media content in shaping cultural norms and promoting positive change underscores the importance of using these platforms to amplify voices, challenge stereotypes, and foster greater acceptance and understanding in society. The commercial aspect is an important point of contestation when it comes to health and illness due to the potential for a “commodification of patienthood”. One of the more significant findings suggests a reconfiguration and redefinition of the traditional role and identity of the patient within the healthcare system and broader society through health activism. It acknowledges that digital media offers new ways to challenge existing norms, beliefs, and practices surrounding patienthood.

The most prominent find of the study is the typology of six different Alopecia content creators which involves the categorisation into types based on various factors such as their content focus, advocacy approach and personal experiences with Alopecia. It acknowledges the fluidity and overlapping within these types of creators. The personal journey advocate, educational advocate, beauty and fashion influencer, advocate and activist, artist and storyteller, and product reviewer. It can be noted that Alopecia content creators should not be generalised and there is an element of fluidity of roles.

Firstly, the personal journey advocate exemplifies the value of therapeutic storytelling and navigating the experiences of living with hair loss. Through self-stories, these creators demonstrate how their bodies give shape and direction to their narratives. By sharing their journey, these creators empower others within the community and use their narratives as tools to foster healing and connection and create an understanding among their audience. Here, an emotional mode of engagement is used to connect on a deeper level. Secondly, the educational journey advocates giving an output of information often combined with their experiential knowledge and supplying it with professional knowledge. Here, there is a high level if health literacy is employed to transfer medical knowledge. A cognitive mode of engagement is used. Thirdly, Beauty and Fashion Influencer's advocacy work focuses on the promotion of self-expression and diversity of beauty standards. They motivate their audience to redefine their definition of beauty and serve as aesthetic representation within the fashion and beauty industry. Often, they exemplify themselves as touchpoints of the normalisation of bald women by counteracting stigma and gaining acceptance and representation within media through brand collaborations.

Fourthly, the activist advocate is actively engaged in advocacy efforts, more intensely collaborating with organisations and participating in awareness campaigns. There is a potential policy element depending on the local health care system and its terms on Alopecia. Fifthly, artist and storyteller use their experiences with Alopecia and turn it into a creative outlet. Using storytelling, visual imagination or performance to advocate for Alopecia and challenge stereotypes. Here, an emotional mode of engagement is interwoven within the content. There is a lot of nuance in the way they communicate their experiences. Sixthly, the product reviewer - this type focuses on brands and companies to review and test products that are specifically designed for individuals with Alopecia, such as wigs, hairpieces and scalp treatments. Here, there is a lot of contestation around a possible commercialisation because it could influence the review. With wigs that cost a lot of money, the authenticity would be called into question.

The third research question asked: How do Alopecia content creators on Instagram conceptualize vulnerability in the context of sharing their illness narratives? This study has found that mobilising vulnerability and reconfiguring digital health activism opens the possibility for the audience to relate to the Alopecia content creators with Alopecia creating an “interconnectedness of human bodies” (Butler, 2016). Through the act of sharing vulnerability, it extends to digital space to exchange experiences and receive validation and support. Utilizing digital media to effectively amplify their message, reach a wider audience, and evoke strong emotional responses from the public. With the typology of the different Alopecia content creator types the diversity broadens the touchpoints for the audience to connect and engage with raising awareness, mobilize support and provoke action. The results within this section of the study indicate a productional perspective for media-ready feminism (Press & Tripodi, 2023) with the intention of the content creator using the "moment of reception" (Press & Tripodi, 2023) through vulnerability shared on social media that leads to the audience engaging critically with the media content that they are consuming.

In conclusion, the study of Alopecia content creators on Instagram reveals the impact of personal storytelling and self-advocacy efforts in challenging stigma and fostering empowerment. Alopecia content creators navigate the complexities of their illness experience with Alopecia through their narrative construction that drives their self-advocacy efforts. Alopecia content creators reclaim their agency over their illness identities and reshape societal perception regarding the physicality of hair loss. Through sharing their illness experiences and self-stories with vulnerability and authenticity, Alopecia content creators create spaces of support within the online community, promoting self-acceptance and understanding. Alopecia content creators fill a gap within the representation and inclusivity of bald women through their presence and self-advocacy efforts on Instagram. It is imperative to continue amplifying their voices to drive societal change to create a more inclusive and diverse understanding of Alopecia and hair loss.

Critical Reflection and Recommendation

This thesis is limited in scope in a number of ways. Firstly, 11 Alopecia content creators who produce and distribute content on Instagram have been interviewed. The 11 Alopecia content creators show the diverse and inclusive nature of the Alopecia community on Instagram and give and excellent coverage of the different Alopecia content creators practising advocacy and raising awareness for Alopecia as a health condition. However, the results of this study cannot be generalized to the Alopecia community overall. The typologies showcase the rich diversity in experience and expression within the Alopecia community on Instagram. The deeply personal element of the illness experience and building of the illness identity means that there is a lot of potential to be explored.

Additionally, the scope of the thesis meant that the focus of this study had to be narrowed down. It was decided on the phenomenological approach to gain insight into the lived experiences connected to the conceptual tools of health and illness with illness identity, illness narrative and self-advocacy that build the foundational element of the six types of

Alopecia content creators. For instance, an interesting element that could have been further explored would have been an affordance-based approach to the digital networked experience of the Alopecia community on Instagram. Here, the investigation would have explored the experience, practices and interaction within the Alopecia community as an open support group on an open platform - that brings about challenges like boundary work and the potential superficiality in interaction. A support group with an open character due to the affordances of the social media platform would be interesting to explore. Additionally, here it would be interesting to explore the "commodification of patienthood" with regard to the commercial character of Instagram as a platform. Another potential research, would be the topic of health advocacy when it comes to Reality TV. Looking into Reality TV persona that opens up about their health condition and takes place on Reality TV. An interesting element would be how the character arc becomes interwoven with the illness narrative and how that shapes audience opinions.

Additionally, it should be said that the findings of this study cannot be used to generalize the Instagram experience of women living with Alopecia, where the experience can be heavily influenced by the intersectionality of persona, type of Alopecia and characteristics and personality. However, the findings of this research can be transferred to open avenues for researching Alopecia further within the digital landscape and visual culture. Nevertheless, there can be an exploration of hair loss from a top-to-bottom approach to determine the stereotypes, attitudes, and perceptions of hair loss by women who have hair which allows for a more in-depth understanding of the stigma around hair loss.

The thesis findings are valid and have the potential to contribute to knowledge in various ways significantly. Firstly, the thesis addresses a research gap by exploring a topic and subject (Alopecia content creators) that had not been explored within the social media context before the conduct of this study. The absence of previous academic research in this area highlights the novelty and originality of this thesis. By examining the experiences and practices of Alopecia content creators, the thesis sheds light on a unique context and has provided insights into the lived experiences and practices they encounter within the Instagram landscape. This adds depth and nuance to the existing literature on content creators on Instagram. Furthermore, while there have been studies on the tensions around hair centring "natural hair" the social hierarchies and marginalized understanding of beauty have not been investigated previously from the point of view of hair loss.

Secondly, the thesis adds a new work in the process of bringing together media, specifically digital media and health, drawing on the field of sociology of health and illness. By bridging the gap between the disciplines through centring digital participatory cultures on Instagram and health advocacy and actvism. Creating an investigation across disciplines.

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Appendix

Appendix 1: Context: Alopecia as a health condition

The British Association of Dermatologists defines Alopecia as “the general term for hair loss” (BAD, 2023). It embraces alopecia arreata, universalis, and totalis, which describe the degree of progression of baldness in the body.

According to the British Association of Dermatologists, hair loss occurs when “it is affected by inflammation.” While the reason for inflammation is unknown, “it is thought that the immune system, the natural defense, which normally protects the body from infection and other diseases, may attack the growing hair” (BAD, 2023).

Alopecia UK (2018) outlines other versions of alopecia, which include:

- Androgenetic Alopecia, which relates to male and female pattern hair loss, where hair falls out in well-defined patterns, whereas with women, the hair is thinning
- Scarring Alopecia refers to conditions that destroy the hair follicle and replace it with scar tissue, causing permanent hair loss.
- Chemotherapy-induced Alopecia is hair loss following chemotherapy
- Traction Alopecia, which is when hair falls out because it has been pulled in the same way for a long time - this type of Alopecia is often caused by tight hairstyles, relaxers, or extension

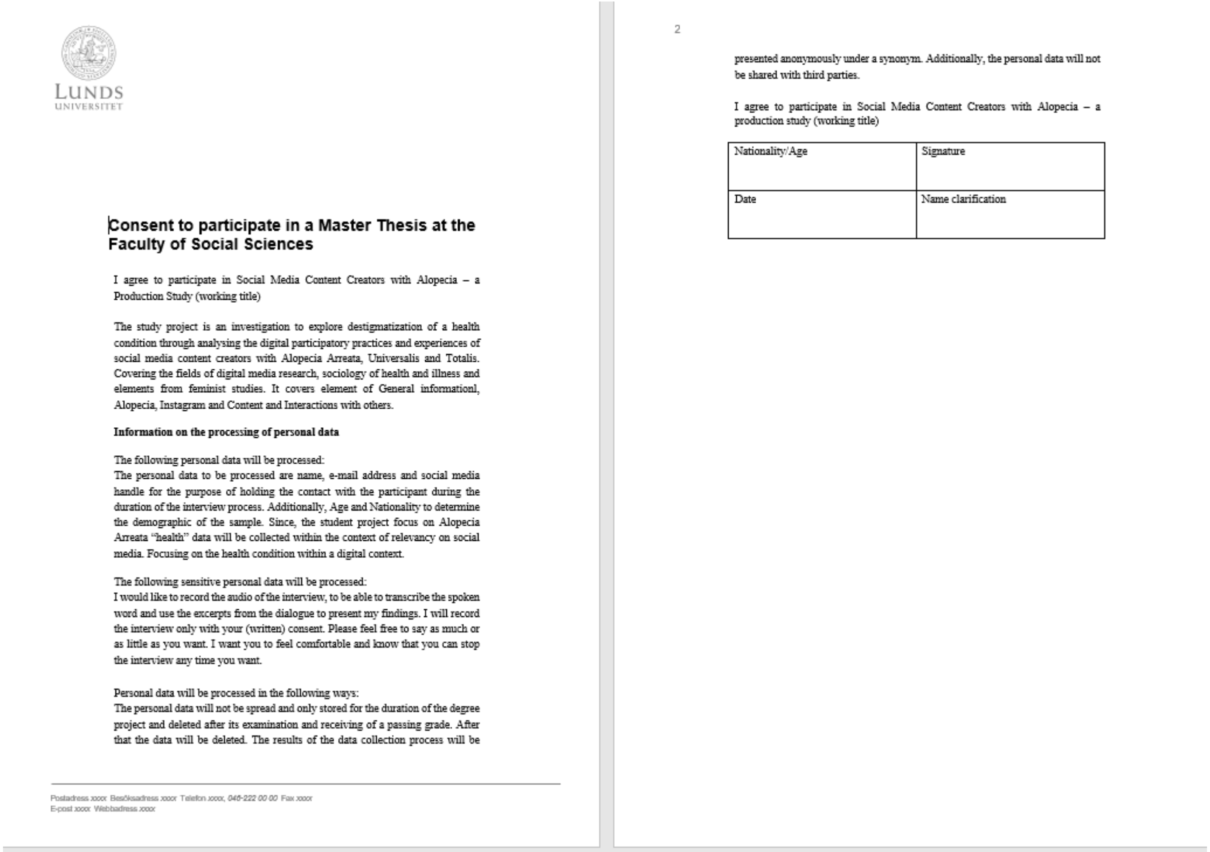
There is no cure for Alopecia, but there are different ways of treating the condition. Treatment for Alopecia will depend on the type of diagnosis. Available treatments include steroid creams, local injections, and steroid tablets (BAD, 2023). Additionally, wigs can disguise Alopecia, where a distinction is made between artificial and human hair.

Appendix 2: Ancient and Classical Societies to Medival and Renaissance Italy

The significance of hair in ancient and classical societies is a recurring theme in literature. Tassie (2009) gives a historical perspective, and Gkikaki (2014) provides an archaeological perspective, exploring the social ritual aspect of hair and hairstyles in ancient Egypt and Greek antiquity, respectively. They highlight the role of hairstyles in conveying social status and identity and the evolution of these styles over time. Hejzlarová (2021) extends the discussion to the Southern Altaians, emphasising the cultural and ritual significance of hair care and ornaments. Ashby (2014) provides a broader perspective by examining the role of hair grooming in early medieval Europe as a socially meaningful practice that contributed to constructing identities and maintaining social boundaries. These studies collectively underscore the importance of hair shaping and reflecting ancient and classical societies' cultural and social dynamics.

Art historian Welch (2009) and archaeologist Ashby (2014) emphasise hair's social and cultural importance in Renaissance Italy and early medieval Europe. They argue that hair accessories and grooming practices were a means of personal expression and played a crucial role in communicating social status and constructing identity. Lee (2007) extends this discussion through a fashion lens by tracing the evolution of women´s hairstyles from the Renaissance to the 20th century, highlighting the influence of historical, cultural and social factors on hair fashion. These studies underscore the complex dynamic role of hair in expressing individual and collective identities within the Renaissance period. In conclusion, in these historical contexts, hair served as a vehicle for expressing social identity, transmitting cultural values, and reinforcing social hierarchies. However, it is essential to note that these norms and practices varied widely across periods and regions, reflecting the past's diverse cultural landscape of hair. Connecting these historical observations with content creators, it can be seen how the absence of hair challenges traditional notions of beauty and social norms. In contrast to historical periods where specific hairstyles were symbolic of status and identity, individuals with Alopecia redefine beauty standards by embracing baldness openly.

Appendix 3: Consent Form



LUNDS UNIVERSITET

Consent to participate in a Master Thesis at the Faculty of Social Sciences

I agree to participate in Social Media Content Creators with Alopecia – a Production Study (working title)

The study project is an investigation to explore destigmatization of a health condition through analysing the digital participatory practices and experiences of social media content creators with Alopecia Arreata, Universalis and Totalis. Covering the fields of digital media research, sociology of health and illness and elements from feminist studies. It covers element of General informationl, Alopecia, Instagram and Content and Interactions with others.

Information on the processing of personal data

The following personal data will be processed:
The personal data to be processed are name, e-mail address and social media handle for the purpose of holding the contact with the participant during the duration of the interview process. Additionally, Age and Nationality to determine the demographic of the sample. Since, the student project focus on Alopecia Arreata "health" data will be collected within the context of relevancy on social media. Focusing on the health condition within a digital context.

The following sensitive personal data will be processed:
I would like to record the audio of the interview, to be able to transcribe the spoken word and use the excerpts from the dialogue to present my findings. I will record the interview only with your (written) consent. Please feel free to say as much or as little as you want. I want you to feel comfortable and know that you can stop the interview any time you want.

Personal data will be processed in the following ways:
The personal data will not be spread and only stored for the duration of the degree project and deleted after its examination and receiving of a passing grade. After that the data will be deleted. The results of the data collection process will be

Postadress xxxx Besöksadress xxxx Telefon xxxx, 046-222 00 00 Fax xxxx
E-post xxxx Webbadress xxxx

2

presented anonymously under a synonym. Additionally, the personal data will not be shared with third parties.

I agree to participate in Social Media Content Creators with Alopecia – a production study (working title)

Nationality/Age	Signature
Date	Name clarification

Appendix 4: Interview Guide

Interview Guide

Introduction
- Greetings, introducing myself, the topic of study
- Briefing on the informed consent of the participant and rights of the participant
- Acquiring informed consent - orally and written

General information
1. Please tell me a little about yourself.
    - Who are you and what do you like doing?

Alopecia and Instagram
1. Tell me about your Instagram account.
    - What was your motivation to care about your experiences with Alopecia?
    - Was there a moment when you moved from "private" to "open" to "professional"?
    - Does/ Why does it matter if you have a following viewing your content?

2. Are you aware of the demographic that is “following”/”consuming” your content?
   - Nationality, age, gender
3. As what kind of content creator would you describe yourself?
   - Advocate, influencer, or private person creating content that is important to them

Content Creation + Storytelling

1. How would you describe the content that you are creating?
   - How would you say you are presenting how everyday life with Alopecia is lived?
   - How would you say that is mirrored in your content?
2. What processes take place during the creation of the content you are sharing on Instagram centering Alopecia?
   - Are there certain topics you make an active choice highlighting?
   - Is there a difference in how you approach posts about Alopecia, about posts about other themes?
3. Some of the posts contain very personal and perhaps sensitive information. How do you feel about that?
4. How would you describe the atmosphere on Instagram regarding sharing “sensitive” and “personal” content?
   - Positive, negative, supportive, etc.
5. What expectations do you normally have when you upload new content on Instagram?
   - Getting more likes/followers, creating engagement in the comment section, DMs
6. Are there boundaries you have encountered when working with Instagram as a platform?
7. What are some of the challenges in maintaining your account?
8. What makes it worth it to maintain the account?

Interactions with Others

1. Did you follow other accounts on Instagram about Alopecia before you started sharing your content?
   - How do you feel, in general, when you scroll through the posts on Instagram focused on Alopecia?
   - excited, angry, curious, etc.
2. Do you have a feeling of community when sharing Alopecia content on Instagram?
3. In your own words, how would you describe the Alopecia community on Instagram?
   - Do you consider your “followers” and the people you interact with your content to be part of this community?
   - Have you built close relationships with other “creators” while sharing content regarding Alopecia on Instagram?
4. What is the most memorable interaction you have had on the platform?

Reflection

1. Are there any additional reflections that you would like to share?

Appendix 5

Q: **Could you tell me a little about yourself?**

- **Who are you, and what do you like doing?**

I am 44. I live in Charleston, Virginia. I am a wife and a mom, and yes, it has been an exciting journey. I developed Alopecia after giving birth, so after I had my daughter. A couple of months later, I started losing my hair, at first because, in postpartum, you do have some hair loss, but after months, it just kept going and going. Yeah, what else? I guess that is the

Q: Tell me about your Instagram account.

Sure, like I mentioned, this happened postpartum; I don't know if you are a mother, but during that time, it is a tough time for a woman because your identity is just kind of stripped all of a sudden you are a mother, You are so responsible for this little human being, and you kind of lose yourself. Ironically, Alopecia brought me out of that. It made me realise that I am not the same person I used to be like mentally, emotionally, and physically too; it broke the barrier that I should stop missing my life before children. I am a different person now. When you become a mother, your brain changes, and alopecia is the next step in physical change and difference. It helped me snap out of that postpartum depression. It allowed me to focus on myself, which is weird because many new mothers are so focused on being a mother, which is why they lose themselves. Still for me, because I was losing my hair and going through this traumatic experience, I had to do a lot of focus on myself, which is why I started that Alopecia account. Specifically, I have a personal account and an alopecia account, so I started following other women. That is how it began. There is obviously the idea of societal beauty that we constantly try to combat with ourselves and with our culture. So, I wanted to put these bald women mainly, I do follow some bald men too, but I follow primarily women. I want to reinforce the fact that they are beautiful, empowered, and kind of tell my own story, too. It started kind of like a journal, getting out my emotions about alopecia. Because nobody else will understand it except our community because talking to a therapist or friends is not the same. Then I realized it was such an important support for me and then I started actively being a support for other people. So … yeah, it was really instrumental in gaining my confidence and going through more of an acceptance, so it was pretty crucial for a couple of years.

That is a good question. I didn't want to be my personal account to just be all about Alopecia because I am much more than that. Having my personal account justasg my regular life, but then having my Alopecia account just for resonated with the Alopecia community. More focused messaging and posts about self-care, beauty, and confidence. They have different purposes.

Q: Are you aware of the demographic that is “following”/”consuming” your content?

Was I aware of the people following me? There was a lot of engagement. It is interesting that with Instagram, engagement is really about your engagement as well. So, in the beginning, I was very engaged with other people's posts and profiles and did a lot of private messaging. It was mostly women with Alopecia or balding women for other reasons. I did hear a lot from them, but privately. The demographic is mostly women.

Q: Tell me about how you navigate around being on Instagram. Would you consider yourself an influencer, advocate, private person, or content creator?
Oh Gosh, I didn't. I don't know any of the tricks or algorithms; it was really organic. I just followed the people whose messaging I liked and honestly engaged with the people who followed me. That was mostly what I did. I wish I were a little bit more savvy on Instagram.

Yes, it is my main social media. I think it is the one I am most comfortable with. I also think pictures are powerful, I think words are powerful too, but I think especially now I think attention spans are just smaller, shorter. Seeing a picture and taking a couple of seconds to see a picture then reading a post. I think the picture leads to the actual content, and it is kind of what invites you in. So, that is one of the reasons that I prefer Instagram I am a visual person, and when something catches your eye, you can engage with the actual content.

No, not really. Even when I was doing it actively, I was certainly an advocate, but I was not an influencer or a content creator. It was so much more personal than that.

Q: How would you say you are presenting how everyday life with Alopecia is lived?
I try to do a balance of staying positive but also commiserating, right, because that is just when you go through highs and lows. Having picture-perfect-like optimism that is nice and that is necessary sometimes but showing deep suffering too is just as impactful. I try to give a well-rounded picture of the struggles of Alopecia. I know one of my posts was about I got my eyebrows tattooed for the first time, and you know it was not covered under health insurance I was so happy to get these eyebrows, but then I was so pissed that I had to do that on my own. Just going through the struggles of not being supported by your country or your insurance. But also, just you know … I lost my train of thought there.

Q: Some of the posts contain very personal and perhaps sensitive information. How do you feel about that?
Yeah, so… I was … You know I was your age, right? I was a pretty private person. If you ask me, I will tell you, but I don't go out of my way to tell you my whole life story. Ahm … I think after, honestly, after having a child and going through Alopecia, it actually makes you become more vulnerable. You are physically exposed, even with a turban on, people know something is … you know. Automatically you become vulnerable, and I can't function like that, feeling exposed all the time. I had to spin that in my head, of being, you know, vulnerability is good, and then from then on, even in my professional career, I became vulnerable. It showed me that having the wall up all the time and not asking for help is not being strong at all and showing vulnerability and showing your struggles and learning from that outwardly is freeing.

Q: How would you describe the atmosphere on Instagram regarding sharing "sensitive" and "personal" content?

- **Positive, negative, supportive, etc.**

Ahm … I think for … I think it is double-sided, Right? I think the audience which I created it for, which is me and other people like me, I think it is highly valuable, right, because then you think you are not alone, you are not the only one thinking those thoughts and going through these struggles. But then there is the other part of me that is like, you know, that information is out there for anyone to see who does not know or is not part of this community, but I see that as spreading awareness and being an advocate, in that sense, like they may not understand completely, at least on top of seeing a picture, they understand the feeling behind it, too. I don't know. It is definitely a bit cringe to think so much information is out there, but in the end, it is all for the greater good. I am just a human with my own struggles and issues, and you are not alone. So …

I don't think I had a negative experience. I can't remember; it has been a couple of years, but I think I would remember. It genuinely was a very positive experience. At the time, I was very active. I felt like I had friends from all over the world, and that was a very comforting feeling. But there was no bad experience that I remember.

Q: How do you feel, in general, when you scroll through Instagram posts about Alopecia?

- **excited, angry, curious, etc.**

Yeah, for the last couple of years. It was a couple of months after the pandemic started. Life was so chaotic, and having the additional digital information in your face was just too much to handle. I started looking again … I am glad I did, too, because I think I have prioritised everything else in the past couple of years. After all, there has been so much going on in the world. Revisiting the alopecia account and all the people I follow, I think I need to see that, I need to see bald women in the feed because I need to remember that other women are going through it, and they are beautiful they are living life. I still follow, look to, and more than like to have a community to commiserate with. It is like tips on how they put on wigs or draw on their eyebrows; I was not a big makeup person. I draw my eyebrows every day, just learning about these things to make me feel more like myself. And wigs are so complex, and I know nothing about wigs. I have some, but I don't know how to wash them. Getting tips from other people is such a niche thing to learn about.

Q: What processes take place during the creation of the content you are sharing on Instagram, centring Alopecia?

Yeah, I kind of went through phases where I didn't really have a master plan written down. I went through phases of just talking about my feelings and some technical videos on how to do head wraps or something like that. The post that would take the longest was the intimate personal post; generally, with those, I would draft them out and work on the actual copy for a couple of days just to edit and refine. Other than that, I did not have a roadmap or ideas or I would get inspired by ideas.

Q: Are there certain topics you make an active choice highlighting?
Ähm … yeah, I think for me … what I try to convey in most of my posts is that you have to move forward. Alopecia is something that happens to you, but it doesn't have to run your life. Focus a lot on self-care, especially as women we are .. we give grace and patience to everyone else, and we give great advice, right, but then when it comes to ourselves, we don't give ourselves the same grace or listen to our own advice I have to remind myself of that often, and I think I use my post to remind myself and other people of that too because you really your number one for yourself is you. And I just think it is really important to have that sense of self-worth.

Q: Is there a difference in how you approach posts about Alopecia, about posts about other themes?
I mean, yeah, absolutely; my personal account is mostly my daughter's very mundane domestic things, right? I do share stories on feminism on my personal account, but with my Alopecia account, it was always a message of some kind of support or positivity or just support generally, right, whatever that means. There was definitely a different focus which is why I separated the two. My personal one is the lunch place that I went to that day, it is much more fluff. With the alopecia account, I took certainly more care in what I posted and curated that a little more with a specific focus.

Q: What expectations do you normally have when you upload new content on Instagram?

- **Getting more likes/followers, creating engagement in the comment section, DMs**

Yeah, that is a good question. I think, like … at the end, when I stopped being active or when I was active. When I got 100, I would consider that a successful post because that was a lot for me and the small audience that I had. Which is less than 10% of the people who actually followed me, but as far as expectations … like, I would know that there were certain people who would like the post regardless as far as expectations, it was hard to judge if people really liked the content. I don't know why it is such a guessing game sometimes. If I got a lot of comments, I would consider that a success too, but I did not have firm expectations when I posted.

Q: When creating content are you making a conscious effort in, for example, the language you use in your posts, to stay away from certain stereotypes or stigma in regards to Alopecia?
Yes, definitely, I am thinking of specific. I think I focus a lot on women but I focused a lot on not diminishing other people's experiences. Men and women who did not have alopecia but were balding. While my focus was on empowering women with alopecia mainly. I tried to make it more general that it would hit home to more than just that like a pool of people. I think hair loss affects just so many different types of people that it has to be broader.

Q: Are there boundaries you have encountered when working with Instagram as a platform?
That is a good question. I think the only one would probably be just obsessively checking how many likes a post got. It certainly is an adrenaline rush. You get the notification that people like it, and as time went on, it was too much. I ended up turning off my notification which is probably why I stopped doing it too. It can consume a lot of time and a lot of your mind. Otherwise, otherwise no boundaries, really, I messaged people and had conversations with them. I met a woman in real life. Boundaries are a double-edged sword I think not having boundaries can lead to opportunities like me meeting that woman in person, but it can also take and steal a lot of time and energy from you.

Q: What are some of the challenges/rewards in maintaining your account?
I think it is challenging; it is just the content. I knew that in order to stay relevant and maintain relationships, I had to post and engage. The time and energy required to stay relevant are a lot. I think that is the biggest challenge for me.
I mean, I think I have peppered that throughout these questions. I think I have made really genuine connections. Getting these private messages from people about how my story resonated with them felt really rewarding. Any thoughts I did not know where to put, I put them on Instagram. It was definitely a kind of therapy for me.

Q: Did you follow other accounts on Instagram about Alopecia before you started your own?
Ähm … I don't think I did. I think right away … I started a separate account that followed different people with Alopecia. I don't know if that was just my way of hyperfocusing and going head-in, but I did not follow any on my personal account if that was the question.

Q: Have you built any close relationships with other “creators” while sharing content regarding Alopecia on Instagram?
Yeah, it is funny. I did build relationships, but now that I am not active anymore, those relationships are gone. That is kind of sad. During my active time, sorry, what was the question? Yeah, well, most of the people that I really got close to were not necessarily creators; they were following me on their personal accounts; this was just about their everyday lives. I don't know if I made any big connection that is solely focused on Alopecia.

Q: What is the most memorable interaction you have had on the platform?
Ähm .. I think it was the same woman I met in person before we met in person there was this morning where she messaged me and asked for my number. I just have this situation that I need to tell someone about, and we had built this rapport before, so I felt safe giving her my number and we talked on the phone about the situation that she had. It was just kind of surreal to take it from Instagram. Looking at her post and then talking to her in person and then meeting her in person. We felt like we could trust each other and felt like we had a confidant, and that was super valuable.

Q: In your own words, how would you describe the Alopecia community on Instagram?

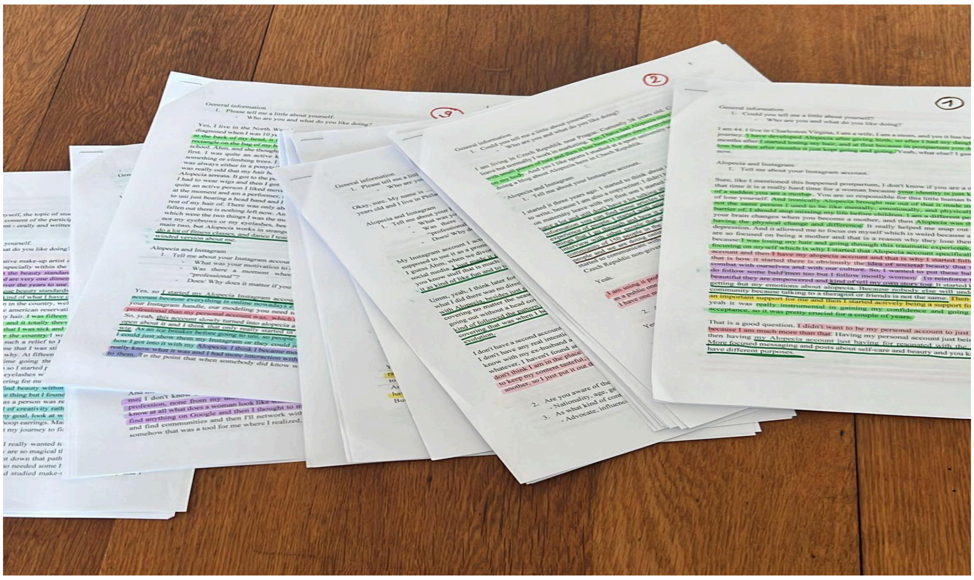
- **Do you consider your "followers" and the people you interact with your content to be part of this community?**

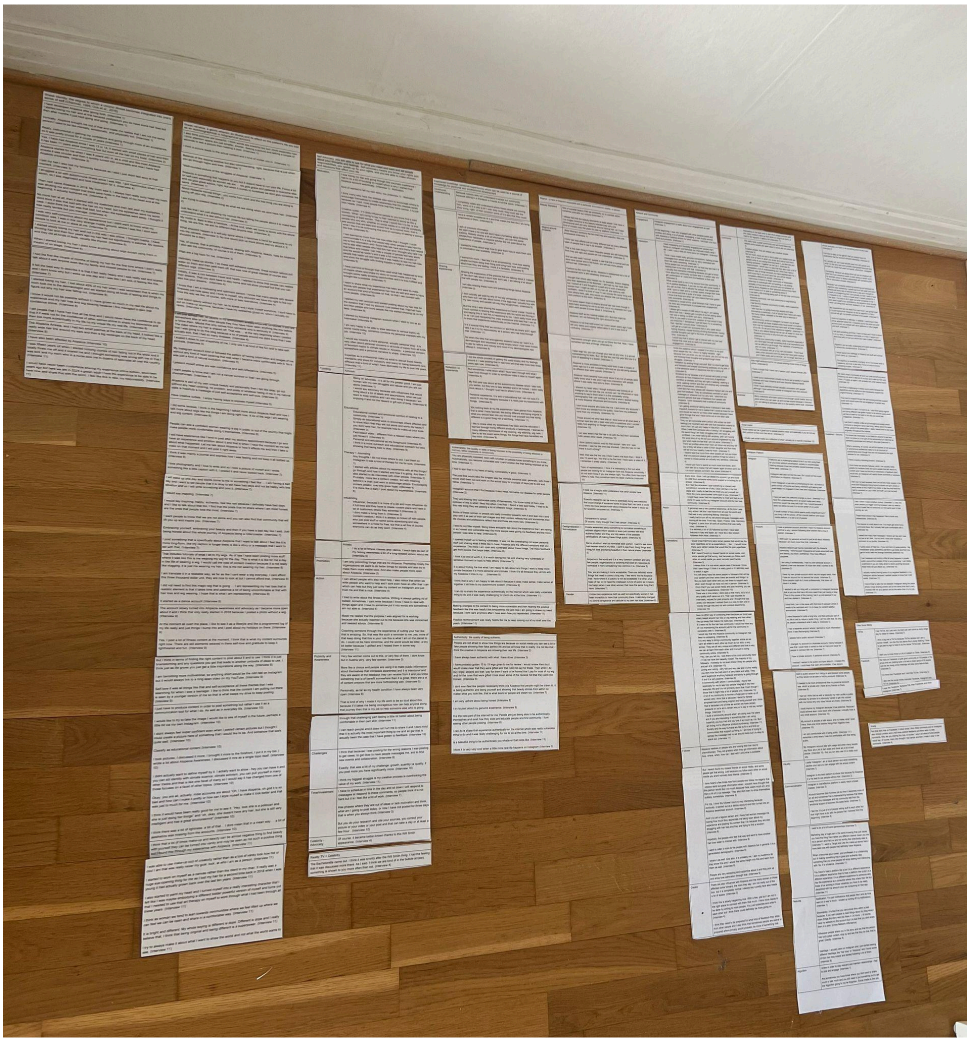
Oh .. Man … I would say, first of all, small, I wish it was bigger, but it is definitely small, but I did think it is very empowering, which is partly why I did it, I just wanted more content out there about Alopecia. I would say that, like the community, the people that I actually connected with is such a dichotomy of being strong and you kind of have to be but then also being a soft and squishy human, You can be a badass and tackle photos naked but there is also this realness to you. I don't think any alopecia creator goes through when they don't talk about the emotional suffering or emotional toll they have been through. With that community, it is all-encompassing; you get all kinds of angles; it is the emotional part and journey, it is the advocacy and the empowerment, it is also the educational when you lose all your hair, you don't know what to do anymore. I didn't even dress the same after that; so many things about my life changed, and adjusting to this new person took a village. In the alopecia Instagram community, there is always an account that will help you.

Q: Are there any additional reflections that you would like to share?

Ähm… No, I don't think so. I will say one disheartening thing about seeing Alopecia account is seeing when it turns; again, this is also a double-edged sword. One of the reasons I stopped my alopecia account is the time, the energy that it took, I have a full-time job, I am a mom, I am a wife, and sometimes having an account is a full-time job. I know some people's accounts where it is their full-time job, but then it becomes more of an ad, and sometimes that is disheartening because that takes away from the messages and the community feel from the emotional support it becomes the sales tactic which is just Instagram in general, but I think that is another reason I stepped away from the account for a while. I am all about you having to make money. You have to do what you have to do, but it becomes less personal and supportive than what I want. Things have changed like that, and that is why I want more out there. That's it, I think.

Appendix: Coding





Coding: Catgory

Category: Experiental knowledge: personal experiences which can be used as a source of knowledge for personal and professional development	
Sub-category: Communal Understanding: Shared comprehension among members of a community	Because nobody else will understand it except our community because talking to a therapist or friends is not the same. (Interview 1) I completely relate and understand where these people are coming from, some of it is also a bit I wish they could, they could see the silver lining, right, of their condition some of it is also that they could have a certain acceptance of it and that makes me feel like I am bring judgmental of them. (Interview 5) Lack of previous information We didn't have a lot and still don't have a lot talking about Alopecia publicly. Nobody shares a lot of information you can find some articles from hairstyles or medical articles but not quite about the experience of people. (Interview 2) I wanted to know about wigs how to glue them how to style them and no information was available. (Interview 2) I learned so much. I feel like it is so empowering. I love love seeing people out there doing their thing and living their lives and posting about how they are feeling. I think it is fantastic. (Interview 8)
Sub-category Sharing experiences: conveying personal insights, emotions, and observations to others, fostering connection within community/group	Sharing the experience of the parents that are talking about it, instead of like don't talk about it don't look don't ask. I am talking a lot about that with people too. (Interview 2) I am also sharing these mom and parenting things about Alopecia (Interview 2) I dont actually get paid by any of the wig companies or have contracts with them but I will talk about some of the wigs that I actually buy with my own money and people will say they bought them. (Interview 6) But this time I was sharing the experience on social media I found so much comfort in sharing that experience with the world and filming it and saying this is real this is happening to me. I dont really know what to do I am just navigating this crazy experience that best that I can do is share that experience authentically on the internet. (Interview 11)

	It is a special thing that we connect on and that we share and I again take it as it is my responsibility as a person who has lived through that. (Interview 11) So when the idea that androgenetic alopecia came up I went to a dermatologist and requested a scalp biopsy which I had never known to ask for before and nobody and none of my dermatologists had offered it. (Interview 8) I did the whole process of getting the scalp biopsy and my feelings around it. I was posting that in real time and that was more than three years ago now. (Interview 8)
Sub-category: Reflection on experience: consideration and analysis of one´s past action, thoughts and emotions leading to self-awareness and growth	But sometimes I write down what I have been through and what I have lived through in order to somehow make it clear to myself again. (Interview 4) My first post was about all the autoimmune disease which I also told you earlier, but this one is less detailed and to be honest. I didnt really think about it, I thought I just had to share it now. (Interview 4) Personal experience, it is sort of educational but I am not sure if it would fit into that category because it is really just my experience with things. (Interview 6) 30s looking back at my life experience I have gained from Alopecia that is what I have learned, like being different and being original is what you should lean into you should trust yourself into that being different is a good thing not a bad thing. (Interview 11) I like to share what my experience has been and the education I learned through trying different products or techniques. I learned so many different techniques of wig wearing, wig washing, wig care. I like to do the exact same things, the things that have benefited me the most. (Interview 8)