Beyond Morning Sickness

Exploring a Hyperemesis Gravidarum Support Group on Facebook

LUND UNIVERSITY

Thea Sjöstedt

Supervisor: Mia-Marie Hammarlin
Examiner: Fredrik Miegel
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Abstract

The experience of illness can often result in isolation, leaving individuals with a difficult decision to make—to disconnect from their everyday lives or to seek out alternative connections. In our modern society, people often strongly desire to connect with voices they can relate to. This study focuses on the role of Facebook in providing support to women suffering from Hyperemesis Gravidarum (HG), a severe form of morning sickness during pregnancy.

Using existential media and new materialism approaches, the study analyses the Hyperemesis Gravidarum Sverige (HGS) Facebook community in Sweden. It examines how members form a sense of community despite physical distance. With a multi-method approach, including digital ethnography, qualitative interviews and participative observation, this thesis highlights the challenges women with HG face and the role of social media in coping with the rare condition. The interviews were conducted with six participants selected based on the criteria of being members of the HGS Facebook group located in Skåne County and either diagnosed or self-diagnosed with HG. Transcripts and field notes served as the material for thematic inductive analysis. Concretely, this thesis explores how technology can constitute a caring media grounded in the members' engagement, shared identities, and purpose.

The findings demonstrate how social media can be a valuable resource for women suffering from HG, allowing them to connect with others, share their experiences and manage the condition with a greater sense of community and empathy. They also show how women derive meaning from the shared emotional connection of the group and that there is a sense of civic identity motivating members to continue to provide support. Furthermore, the findings indicate that Facebook contributes to providing the members with a safe space to explore existential questions and dilemmas, seek advice and support, and, in the process, reclaim a sense of agency. As such, this thesis argues that in vulnerable situations, media can help individuals maintain their sense of self and act as a literal lifeline.

Keywords: Hyperemesis Gravidarum, pregnancy, Facebook, health support group, social media, existential media studies, new materialist feminism, Sense of community, women's health

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List of Abbreviations and Medical Words

Abbreviations

HG–Hyperemesis Gravidarum
HGS–Hyperemesis Gravidarum Sverige (HGS)
SOC–Sense of Community
SOVC–Sense of Virtual Community
SODC–Sense of Digital Community

Medical Words

Cortisone–synthetic steroid medication to relieve pain and reduce inflammation.

IV (Intravenous Therapy)–helps administer fluids directly into an injected vein.

Ondansetron–medicine for treating nausea and vomiting caused by cytotoxic chemotherapy and radiotherapy and as prophylaxis and treatment of postoperative nausea and vomiting.

PICC line (Peripherally inserted central catheter)– a thin tube operated in a vein to lower the number of needles sticking in as it can stay in place longer.

Primperan–medications for reducing motility in the gastrointestinal tract and against nausea and vomiting.

Lergigan Comp–an antihistamine medicine that blocks allergic reactions. It has both a sedative effect and contains caffeine that can enhance the effect of motion sickness and pregnancy sickness.

TMP (Total Parenteral Nutrition)–nutrition feeding administered to the body similarly to IV therapy.

Title: A Physician Examining a Urine Specimen in Which a Faint Figure of a Baby Is Visible, a Female Patient Is Crying and Being Shouted at by Her Angry Mother, Indicating that She Is Pregnant (T.,I, 1826)

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1. INTRODUCTION

> Some breaking news out of Buckingham Palace: the Duchess of Cambridge Kate Middleton is pregnant after months of speculation and rumour. The royal family confirmed today that Kate is in the very early stages of pregnancy; she's being treated at a London hospital for severe morning sickness and is expected to stay for a few more days. The Queen, Kate's husband- Prince William, and the rest of the royal family are said to be delighted by the news[1]
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> - ABC News December 3, 2012

In December 2012, the world was caught up in a media frenzy when news broke that the, then Duchess of Cambridge, now Princess of Wales, was hospitalised at King Edward VII Hospital in central London due to severe morning sickness, a condition called Hyperemesis Gravidarum (HG) (Holden, 2012). The fact that her first child would become the heir to the throne, regardless of gender, due to recent changes in the rules of succession (The Royal Family, 2024) added to the excitement surrounding the pregnancy. The highly anticipated pregnancy announcement became even more dramatic with the addition of an illness very few knew about, triggering a public discussion about what this might mean. Hence, Middleton's condition catapulted a global spotlight on HG, showcasing a vulnerable representation of pregnancy that many royals rarely disclose.

This news story serves as an entry point for this thesis as it addresses a rare topic of HG and its impact on pregnant women that is often overlooked in our society due to the stigma surrounding illness and pregnancy (Douglas, 2002; Bost, 2010; Frank, 2013). Nausea and vomiting are common side effects of pregnancy, affecting up to 85% of all women. However, modern research has shown how HG, a much more severe condition, impacts only up to 3% of pregnancies and remains largely undiagnosed (Vinnars et al., 2024). HG is characterised by excessive vomiting that can persist for the entire duration of the pregnancy and can pose life-threatening risks to both the mother and the baby (Havnen, 2019; Fan & Yin 2024). The short-term consequences of HG include dehydration, malnutrition, anxiety, stress, and low birth weight (McCarty et al., 2011; Eagle, 2019). Moreover, the condition can also have profound long-term effects (Mitchell-Jones et al., 2020), such as depression and, in some cases, lead to bonding difficulties with the foetus (Tsalkitzi et al., 2021; Beirne et al., 2023) and even the termination of the pregnancy (Nana et al., 2021).

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[1] Prince William, Duchess of Cambridge announce pregnancy in royal statement.

In many Western societies, care is scarce and sometimes only available to those privileged enough to afford it, leading to marginalised individuals often feeling alone and desperate for support (Schwartz, 2019, p.83). This calls for a study highlighting the importance of exploring different forms of health support, including physical and online. Therefore, this thesis aims to shed light on the vulnerable situation that pregnant women with HG face and the challenges they encounter in seeking support and understanding.

Specifically, I examine the Swedish online community on Facebook called Hyperemesis gravidarum Sverige (HGS), which is dedicated to those affected by HG. Through this investigation, I explore the consequences of HG, how the HGS members use Facebook to cope with their condition, and how they form a sense of community in a digital space, following the model developed by MacMillan and Chavis (1986). I study this closed community through a digital multi-method approach (boyd:2015; Hine, 2015), drawing from theories of existential media philosophy and new materialism. Through the lens of existential media studies (Lagerkvist, 2017; 2019; 2022), the community members are seen as *existers*[2] who face a sudden life disruption brought on by sudden illness during an ongoing life transition into motherhood. Furthermore, through the same lens, these moments are seen as life-defining. The community members experience tremendous uncertainty and are conflicted by guilt, loss, suffering, and bewilderedness—all while attempting to navigate these experiences online (Lagerkvist, 2017, p.101).

According to previous studies, the primary motivations for joining Facebook support communities are the need for validation and identification (Morse & Brown, 2021), to escape loneliness (Gleeson et al., 2022), as well as access to useful information for decision-making (Wu & Hung, 2018; Potnis et al., 2023). These online communities play a crucial role in providing a support mechanism to eliminate external stigma surrounding their condition (Hendrix, 2023). While many studies have been written about health and parental support communities on Facebook, there appears to be a significant gap in research on this topic of severe morning sickness. I have only identified one previous study focusing on women facing severe morning sickness and how they coped with it via Instagram (Eagle, 2019).

Sharing coping strategies for HG on Facebook presents opportunities and challenges for women suffering from these conditions. Online interaction can provide a sense of community, allowing existers to connect with others sharing the same experience. This can help them manage their situations and find resources for self-maintenance, positively

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[2] Social media users.

reinforcing a sense of control in their social world (Couldry & Hepp, 2017, p.157). However, there are potential risks in online interactions. In particular, public vulnerability can thrust the user further into unknown territory (Balbie & Magaudda, 2018; Skeggs & Yuill, 2018; Lagerkvist, 2022; Zuboff, 2019). To exist online in this context can create insecurity and raise concerns about users being unable to control all the stored data, how it will be used, and by whom. Despite the challenges, Lagerkvist (2022) suggests that digital media can also constitute a caring medium and be a literal lifeline for those experiencing existential struggles.

1.1 Research Questions

The way we communicate with each other has a significant impact on how societies evolve. In our modern society, people often strongly desire to connect with voices they can relate to (Frank, 2013). This notion sets the stage for this paper's objectives: to investigate why individuals turn to an online space and how they navigate their existential meaning by holding on to the lifelines of digital media. Given the previous points about media users finding support online, this thesis will answer two research questions that have emerged in relation to the theoretical frameworks:

I. *How do existers in the HGS community find meaning and purpose in their engagement with the HGS community?*

II. *What existential challenges and struggles do members of the HGS community face, and how do these struggles influence their perception of the self and their engagement within the community?*

1.2 Purpose

The research questions guiding this thesis concern the existential and inner-emotional processes which I connect to the materiality of women's bodies inflicted with HG.
How we view our bodies and relate to vulnerability is not solely based on personal experience but is also influenced by society's larger power dynamics (Douglas, 2002; Butler, 2016; Schwartz, 2019). As taught by history, vulnerabilities *are* unequally distributed across different bodies. Women, in particular, have faced the effects of this societal influence in the

context of gynaecology, where they are often portrayed as weak and unstable due to natural biological events such as pregnancy, childbirth, and menopause (Cleghorn, 2021). When a pregnant woman is ill, it is often viewed as connected to her womb (Cleghorn, 2021, p.26), and the cultural beliefs surrounding her conditions are often met with both caution and suspicion (Douglas, 2002). She is either viewed as vulnerable and in need of care, or her body and unborn baby are seen as potential sources of social disruptions, leading to ambiguity about the potential risks involved (Douglas, 2002, p.118).

This is notably relevant in cases of severe morning sickness, where many women have often been misunderstood, misdiagnosed and denied appropriate treatment (Poursharif et al., 2008). As nausea and vomiting are seen and perceived by the overall society as a natural sign of healthy pregnancy (Hanson, 2004), many women with HG often find themselves confused by their condition. This often leads to an internalisation of guilt and shame for not being strong enough to handle the symptoms (Beirne et al., 2023). However, due to its rareness, many healthcare providers are often unaware of its severity and mistake it for regular morning sickness (Mitchell-Jones et al., 2020). The lack of knowledge about HG adds to the challenges of receiving the proper care (HER Foundation, 2024).

While much progress in healthcare has been made in the 21st century, power dynamics and misconceptions about women's bodies persist. As such, it is imperative to address the societal and cultural biases that have historically suppressed attention to this illness to mitigate unnecessary suffering. Therefore, this thesis pays attention to those who require our care and should not be dependent on monarchies to be affected before people become more aware or care about it.

1.3 Thesis Outline

In the introduction, I provide an overview of my research topic, the overall aims and objectives, as well as my two research questions. In Chapter 2, I review the existing literature, discuss research gaps, and address my own position in this field. Next, in Chapter 3, I construct my theoretical framework for studying women affected by HG and how they make sense of their condition through social media. My theoretical framework includes aspects of new materialism, existential media, and a sense of community. In Chapter 4, I elaborate on my chosen methodology, methods, ethical considerations, and limitations. Here, I illustrate how I selected my participants, conducted the interviews, and interpreted the materials. In Chapter 5, I analyse the collected materials, highlighting the key characteristics of HGS members and how they experienced their illness while navigating the digital network. Lastly, in Chapter 6, I discuss my findings, leading to conclusions addressing the thesis’s implications.

2. LITERATURE REVIEW

The literature review is divided into four sections and concludes with the intended contribution. It delves into how individuals experience life disruption in different forms and how it is connected to experiencing HG. In explaining HG, it also addresses why the approach has been limited and why we should pay attention to vulnerability. The review further provides a foundation for how women form intimacy and a sense of community in a digital context. The Chapter is tied together through a description of my intended contribution to the academic field of existential media, centring on those requiring our attention, thus contributing to a broader understanding of care, both online and offline.

2.1 Approaching Hyperemesis Gravidarum

In the history of Western medicine, nausea and vomiting have been observed as symptoms of ill health that can be both physiological and pathological (Hanson 2004). In 18th and 19th century Britain, morning sickness was viewed as a culturally influenced experience of illness (Russel, 2012, p.17). More specifically, it was seen as a confirmation of pregnancy and a natural protective response to physiological changes occurring within the woman's body (Russel, 2012, p.129).

However, medical professionals often provided biological justifications for societal gender differences, dictating social norms surrounding women's abilities and roles (Hanson, 2004; Cleghorn, 2021). Some even highlighted women's perceived essential nervousness, fragility, and tendencies toward hysteria as factors influencing the severity of morning sickness (Buckewalter & Simpson, 2002). For instance, Rudolf Kaltenbach (1842/1893) connected HG with hysteria, asserting that both were forms of neurosis. According to him, women who experienced the most severe vomiting and nausea during pregnancy expressed their aversion to pregnancy, as well as their distaste for their spouse and offspring (Buckewalter & Simpson, 2002). The historical context shows how women with HG have been pathologised, stigmatised, neglected treatment, and ultimately silenced by society.

Fast forward to the 21st century, Ranjana Das (2017) illustrates how this silencing persists. Her study investigates online parenting forums, revealing a discursive silencing of challenging birth stories and the emphasis on individualisation and self-management within women's childbirth tales (p.7). This connects to the digital mediation of pregnancy stories told in Ryan Eagles' (2019) study pinpointing the role of narrative agency and how women can craft societal perceptions around pregnancy and motherhood through Instagram. Eagle (2019) observed how the lack of societal knowledge about the severity of HG has often led to women not being believed or their conditions taken seriously. She specifically blames the domination of the current neo-liberal ideology that permeates pregnancy narratives in our society. This means that pregnancy, nowadays, can be commodified where women engage in both the reproduction of the foetus and as a consumer of mediated pregnancy or parenting lifestyle, including baby showers, gender reveal, clothing, etc. The many celebrated covers of popular magazines visualise this trend. Examples include actress Demi Moore, tennis player Serena Williams, and former US First Lady Melania Trump (see below), which, while challenging traditional portrayals of pregnancy, also navigate the fine line between empowerment and reinforcing "new momism" as described by Das (2017). Momism is defined as "a set of ideals, norms, and practices most frequently and powerfully represented in the media, that seem on the surface to celebrate motherhood, but which in reality promulgate standards of perfection that are beyond your reach" (cited in Das, 2017, p.3). In other words, new momism propagates an unachievable representation of pregnancy.

Both Das (2017) and Eagle (2019) conclude that to combat the discursive silencing and the perpetuation of market-driven childbearing narratives, there needs to be a space for meditating and validating more nuanced and diverse depictions, such as highlighting its health effects and the means of becoming a mother.

Demi Moore, on the cover of Vanity Fair August 1991, captured by Annie Liebowitz (Collins, 2018)

At seven months pregnant, Melania Trump can still knock 'em dead in her strapless party dresses—and in a teeny bikini, for that matter, writes Eve MacSweeney. Portraits by Annie Leibovitz.

FLY ME TO THE STARS
The mother-to-be in OMO Norma Kamali gold bikini and Carolina Herrera long gold silk coat with train. Shoes, Christian Louboutin. Necklace, Chopard. Shot on the steps of the Trump jet in West Palm Beach. Hair, Teddy Charles; makeup, Fulvia Farolfi. Details, see In This Issue.
IN THIS PORTFOLIO
Sittings Editor: Phyllis Posnick. Set design, Marguerite Wade for Mary Howard Studio.

Melania (and Donald) Trump, in Vogue Magazine April 2006, captured by Annie Liebowitz (MacSweeney, 2006).

Serena Williams, on the cover of Vanity Fair June 2017, captured by Annie Liebowitz (Bissinger et al., 2017)

Why study women's illness and vulnerability?

In social science, vulnerability has often been discussed as a weakness that requires fixing and overcoming (Harrison, 2008), even though it is a natural part of being human and an inherent, unavoidable aspect of our existence (Heidegger, 1962). Rather than viewing humans as inherently invulnerable and independent and that the “mind can think independently of the body” (Chamberlain, 2020, p.22), this thesis approaches it as a natural human state which everyone shares.

That said, vulnerability is not a concept to be used lightly as it is experienced and inflicted differently across bodies (Bost, 2010; Schwartz, 2019) due to social, political and economic inequalities (Butler, 2016). Judith Butler (2016) challenges two assumptions of vulnerability. Firstly, that vulnerable people cannot be part of (political) resistance, and secondly, being vulnerable often requires care and protection, which can lead to reliance on powerful patriarchal forces and social institutions instead of collective efforts towards structural change (Butler, 2016, p.12). Despite the preconceived notion that we become vulnerable when we resist, Butler flips this view, stating, "We are first vulnerable and then overcome that vulnerability" (ibid.). She argues that vulnerability is not simply about being passive or a victim lacking agency but a preconditioned situation to action. Hence, while believing vulnerability is a universal condition, Butler also claims it to be closely linked to precarity, where unfairly disadvantaged positions often are a starting point for fighting back or resisting (Butler, 2016, p.15).

Butler's (2016) conclusion is closely linked to Douglas's (2002) work, which explores why women are more prone to precarity. Douglas (2002) argues that the function of a body is similar to that of a society —both require a system of boundaries to organise and regulate their components. Social norms and taboos are constructed and maintained in a society by assigning meaning to things considered contaminated or "polluted" with deviancy (Douglas, 2002, pp.117-118). Thus, modern Western society can be viewed as a system with its own boundaries and rules, where the ideal body is that of a male. So, when something like menstrual blood crosses the bodily boundary, it symbolically reflects the potential for disorder within the social system, a deviance from the (male) ideal and a symbol of lack of control and excretion of something alien (Douglas, 2002, p.150). With such a premise of societal order, I interpret Douglas' argument as illustrating how the view of menstruation has shaped our historical and contemporary view of female bodies and physiologies. I further extend this premise to how the societal view of pregnancy has shaped how we view severe morning sickness.

Clare Hanson (2004) illustrates how the current view of pregnancy in Britain has been shaped over the last 250 years through the complex interrelation of medicine and culture. She characterises pregnancy as both an embodied and embedded experience; one, in the sense that the body goes through changes such as growing bigger and experiencing a range of physical and emotional health effects (Hanson, 2004, p.3). And two, how others perceive pregnancy externally depending on the existing cultural norms and beliefs (ibid.). While Hanson (2004) extensively outlines a deeply problematic past of cultural norms and beliefs concerning pregnancy, the most persuasive argument for why we need to study ill pregnant women is to combat the ideology of labelling women as "natural" and men as "cultural" (Hanson, 2004, p.11). What Hanson (2004) means is that pregnancy is difficult to conceptualise; either it is seen as a natural or an unnatural part of the bodily function where cultural context and belief define it. This division can have both positive and negative outcomes for them because if perceived as a natural state, women have a better chance of receiving practical help in managing their pregnancies. However, if perceived as unnatural, they are perceived as intellectually, physically, and emotionally inadequate (Hanson, 2004, p.12). Thus, viewing pregnant women as “natural” removes the perception of them as rational social beings, undermining their agency and intellectual capacity and silencing their expressed experiences, especially if those experiences deviate from the normative narrative.

2.2 Building a Sense of Community and Self

The interplay between precarity, communities and the broader societal context is central to this thesis. To understand this interplay, I provide a position on online communities and what motivates members to join. Furthermore, I review previous studies on Facebook support communities for women transitioning into motherhood and their motivations, and I outline various perspectives on building intimacy online.

boyd (2015) and Hine (2015) suggest that our experiences and actions on social media can be viewed as an extension of how we live and behave in the real world. Thereby, instead of developing separate definitions of online and offline communities, Kozinets (2010) proposes a unifying definition of community as “a group of people who share social interaction, social ties, and a common interactional format, location or space” (p.189). While acknowledging the need for different approaches when studying online and offline communities, the definition still holds whether the interactions or the “space” occur in the virtual or the real world.

Through my readings on different definitions of online and offline communities, I realised they all share the same affective aspects of people feeling part of one. What defines a community for this thesis's purpose is how community members feel like they are part of one, irrespective of location. Accordingly, I use McMillan and Chavis' (1986) Sense of Community (SOC) framework, which focuses on the affective aspects of community and the feeling of being part of one. Alongside other media scholars’ previous contributions, I develop their framework to make it more relevant to today’s environment.

Previous Studies on Facebook Support Communities

Continuing the discussion about motivations for joining health and parent-related communities, I provide an overview of previous studies on Facebook support communities for women during the transition towards motherhood. In their study, Wu & Hung (2018) showed how Facebook facilitates an understanding and supportive environment for pregnant and new mothers to navigate their journey. According to the Potnis et al. (2023) study, Facebook provides a supportive space for women seeking guidance on birth options, connecting with others in similar situations, and exchanging information, resulting in increased social capital. Additionally, Morse and Brown (2021) and Hendrix (2023) demonstrate how Facebook communities offer emotional support and advice on various issues, including breastfeeding or termination of pregnancies due to medical reasons. These groups foster a sense of understanding and care, which can help reduce feelings of loneliness among pregnant women and new mothers (Gleeson et al., 2022).

To better understand why the women across the studies share their experiences on Facebook communities, I draw inspiration from Nick Couldry and Andreas Hepp (2017). According to the two, digital media facilitates material resources for users to interact with each other, leading to three positive aspects of interacting with communicative media: *self-narration*, *self-representation,* and *self-maintenance* (2017, p.157). These aspects allow individuals to tell their own stories about themselves, present themselves in a different light and maintain their sense of self in the social and cultural world (ibid.). If these aspects are to be actualised, elements of self-disclosure among community members become key in forming personal connections, intimacy and sometimes even friendship (Carter, 2005).

Exploring Intimacy Online

In exploring people's use of social media platforms for support and discussion, I primarily draw from the insights of Sherry Turkle (1995;2011), Denise Carter (2005) and Deborah Chambers (2017). Their views on human-computer interactions are particularly relevant to my topic of forming intimate connections in online communities. In contrasting the perspectives of how intimacy is formed online, how to study it, and whether it can be separated from the offline environment, I clarify my own position on how to study the HGS online community.

Turkle (2011) discusses the limitations of forming deep emotions online, arguing that they cannot replace the depth of face-to-face interactions. She questions digital media's true nature in damaging the quality of human relationships. Instead of empowerment, it can create loneliness among people, leading them to prioritise the comfort of technology over the intimacy of physical human interaction (Turkle, 2011, p.209). By drawing on Anthony Giddens (1999), Carter (2005) contrasts Turkle's conclusion by arguing that intimacy, such as quality friendships, can, in fact, be formed online without ever meeting face-to-face. Instead, she describes intimacy as a deep personal connection built on trust that must be earned (2005, p.156). Like Giddens (1999), she views online friendships as “free-floating” because they are not anchored in any material factors such as social status, traditional roles, and obligations (Carter 2005, p.160). For Carter (2005), active trust-building, commitment, and self-disclosure matter to the quality of intimacy; if there is emotional investment and mutual engagement, external matters will be secondary (Carter 2005, p.164). Hence, sharing and disclosing vulnerability becomes a gateway to establishing trust and forming intimacy. Thus, the quality of friendship derives from the emotional and psychological bond between individuals rather than external possessions.

Chambers (2017) also explores intimacy and friendship online. For starters, Chambers (2017) addresses the role of social media platforms in shaping intimacy online, stating that “Facebook is not just a blank canvas on which sociality is allowed to thrive”, arguing that the network structures are not neutral. To understand the members’ agency, we must acknowledge the platforms’ influence on online relationship building (2017, p.29). Therefore, Chambers (2017) begs us to incorporate political and economic perspectives with cross-cultural studies to fully understand digital intimacy and emphasise the user agency's centrality.

The above perspectives call for more research with a broader perspective, incorporating social media platforms' technological frameworks and considering how individuals across cultures adapt, resist, and reshape these tools to engage in meaningful connection. In this thesis about the health support community on Facebook, I aim to answer this call by acknowledging the embeddedness of offline and online, the centrality of agency, and the importance of intimacy.

2.3 (Re)Locating Agency in the Digital Realm

Acknowledging human-computer entanglement and recognising its opportunities and challenges require us to thoroughly examine our interactions with social media, particularly as we have become “tethered” to them (Turkle, 2011, p.174). Thus, the theoretical questions of agency and influence become a critical aspect of this thesis: How are humans affected by (digital) technology? Furthermore, how do humans affect technology? Turkle (2011) keenly captures the necessity for reflection on these questions, noting:

> We have to love our technology enough to describe it accurately. And we have to love ourselves enough to confront technology’s true effects on us” (Turkle, 2011, p.243).

For Turkle (2011), loving ourselves also means not blindly accepting the benefits of technology at any cost but remaining critical and wary of its impacts on us and our surroundings.

Subsequently, Zuboff (2019) alleges that contemporary Western society has entered an epoch of a new economic logic where harvesting and selling information about personhood has become accepted and normalised. This condition “unilaterally claims human experience as free raw material for translation into behavioural data”(p.8). Hence, the ambiguity of the data collection perpetuated by Big tech companies is questionable, as people are unaware of what they are giving up in exchange for convenience online. This premise was also coined as a *participation paradox* (Balbie & Magaudda 2018, p.102), where individuals are led to believe that using the internet is cost-free when, in reality, it harvests their information to generate economic incentives. The data extracted leads to an individual’s behaviour being pre-determined by the tech moguls through affordances of nudging and directing individuals to the point of losing all agency and ultimately surrendering to technological determinism (Zuboff, 2019, p.225). In essence, Zuboff’s notion of *Surveillance Capitalism* aids in recognising the hidden costs of technology, which Turkle contends we owe ourselves to recognise.

To further understand the influence of technology, we need to understand how that power is configured, what power is, including its tangible materiality. As Hine (2015) suitably notes: “The intention [in studying digital technologies] is not simply to study and reflect on new developments but to use these to further our understanding of what we are and have always been” (p.45), implying that digital technologies can foster a deeper understanding of what it means to be human in the modern society. Moreover, reflecting on the complexities introduced by social networks’ affordances can help us explore an additional dimension to the power dynamics influencing our agency. To go beyond the dualistic perspective of agency versus technology, this thesis draws from the field of cyborg anthropology, particularly by new materialist scholars Donna Haraway (1988;1990), Karen

Barad (2003), Diana Coole and Samantha Frost (2010) and Rosi Braidotti (2019; 2022;2023). These scholars all emphasise agencies within non-human agents, arguing that technologies and other materiality have *always* influenced the human experience through engagement (Coole & Frost, 2010). They play an equal role in constantly co-shaping human existence and their perceived social reality (Braidotti, 2022). By reflecting on the human-tech interactions further forces the thinking of the means of existing in modern society, which is essential to Lagerkvist's (2017) existential inquiry; "what does it mean to be human in this digital age?" (p.97). In trying to understand this ambiguous question, this thesis will expand this by adding a more specific state of being: What does it mean to be a pregnant, ill human in this digital age?

2.4. Experiencing Limit Situation Online

Previous studies show how digital media platforms can play a crucial role in connecting individuals undergoing transformative life changes, particularly those who have felt vulnerable, lacked a sense of control, or have been silenced elsewhere (Christensen et al., 2017; Lagerkvist & Andersson, 2017; Stenström & Pargman, 2021; Lagerkvist, 2017;2019;2022). According to Lagerkvist (2017, p.101), such transformative life changes can be considered *existential limit situations*, referring to those defining moments of life such as death, loss, conflict, suffering, and guilt. When these instances occur, individuals face situations that test their limits, forcing them to make decisions about their lives (Lagerkvist & Andersson 2017, pp.554-555). As a consequence, they are faced with paradoxical needs; on the one hand, they want to disconnect from the usual existence of their everyday life; on the other hand, they want to seek out other alternative connections (Lagerkvist & Andersson 2017, p.560). While limit situations certainly provide a clear and useful characterisation of the HG experience, it is helpful to comprehend the existential philosophy underlying it. Here, I introduce two previous studies on how communities can be supportive during limit situations with topics intricately connected to mine, namely seeking support online for how to deal with the loss of a child (Christensen et al. 2017) and being unable to conceive one (Stenström & Pargman 2021).

In their study, Christensen et al. (2017) convincingly show that online forums could offer a place for bereaved parents to share their experiences of loss (Christensen et al. 2017). These forums aid the parents' journey of grief and help them break down taboos surrounding death by offering unconventional ways of displaying mourning for their loss (Christensen et al., 2017). As platforms enable a space of solace for parents to mourn, they are then termed by the authors as *grief ghettos*, whereby the parents can express their sorrow freely whilst simultaneously connecting with those who are doing the same (Christensen et al. 2017, p.59).

Kristina Stenström and Teresa Pargman (2021) conducted a similar study on people facing limit situations as they tried to find support on Instagram to make sense of their new reality. In the context of their research, the limit situation is about the struggle involving fertility issues. Here, Stenström and Pargman (2021) demonstrate how social media, with their own set of norms, can be a site for both a struggle and a safe space for coming to terms with infertility. Through participating in "trying-to-conceive communication", the women participate and share experiences in trying to conceive, how to better chances and, in some cases, coming to terms with not being able to conceive (Stenström & Pargman, 2021, p.168). By engaging with others undergoing the same process, individuals can understand, cope, and navigate their vulnerable conditions.

Like Christensen et al. (2017) and Stenström and Pargman (2021), my study about illness and pregnancy also represents a certain kind of loss: losing an old self and a healthy body while experiencing the precariousness of becoming a mother. Inspired by existential philosophy, psychotherapist Clair Arnold-Baker (2020) argues that motherhood can be considered an existential crisis, which evokes a range of feelings the woman faces. According to Arnold-Baker (2020), crises do not always involve traumatic events but also those life periods of profound disruption (Arnold-Baker, 2020, p.4). Thus, these transitions can be challenging for the new mother and affect her sense of identity, relationships, and daily routine – forcing her to re-evaluate, adapt and take responsibility for her life (ibid.).

It is often assumed that pregnancy is a time of joy and happiness (Arnold-Baker, 2020, p.4), but the experiences of illness related to pregnancy can contradict these assumptions. By incorporating Arnold-Baker's (2020) perspective on transitioning towards motherhood as a limit situation and connecting it with the uncommon illness of HG, I add another layer to this transition. Furthermore, this transition can also mark a significant phase of identity transformation in becoming a mother. In this thesis, I address the tension between our cultural imagination of pregnancy and the unspoken corporeal experiences of it. In doing so, I use the case of the Facebook community to illustrate how it can function further; it is a way for individuals to manifest and construct their sense of self through shared experience, vulnerability, and trust.

Addressing Research Gaps

My thesis contributes to three areas: the academic field of existential media studies, challenging the normative view of pregnancy, and the communal role in providing care. By applying existential media and new materialism theories to study pregnancy illness, I address the question of what it means to be a pregnant ill woman in the digital age.

For all the above reasons, the following Chapter will attempt to weave the theoretical threads together to provide a framework that helps to explain the digital community's feelings, the precarity of their situation, and the influences of technology and other material factors.

3. THEORETICAL FRAMEWORK

In this section, I will first situate the problem of the study before proposing a theoretical framework to instruct the analysis and address the theoretical gaps identified. I propose two lenses to situate the study: new materialist feminism and existential media studies. As part of the feminist and post-human theories movement, new materialism has a more integrated approach to subjectivity and ontology, meaning that it acknowledges the ongoing process of material-discursive phenomenon where the human and non-human agency is deeply interlinked. New materialist feminism provides a foundation for explaining how the materiality of the bodies and illness shape the precarity of the individuals' situation. The existential media perspective positions HG and pregnancy as a vulnerable limit situation, offering a logic for why women go online to find solace in how they might experience both existential security and insecurity posed by private third parties. With proposed revisions, the theory of Sense of Community acts as a theoretical framework to investigate the interplay of the members' identity, vulnerability, and engagement with social media.

3.1 New Materialist Feminism

The central argument for why I choose the new materialist feminism theory to situate the women in this study is its significant influence on what I perceive as shaping their vulnerable condition, particularly the unspoken aspects of materiality. Too much of our understanding of experiences comes either from language or cultural representation, missing the significance of materiality, as stated by Karen Barad (2003):

> Language matters. Discourse matters. Culture matters. There is an important sense in which the only thing that does not seem to matter anymore is matter (p.801).

Barad (2003) emphasises this point by offering the concept of *agential realism,* explaining it as a way of understanding material-discursive entanglement. She reasons that meaning is co-created and negotiated through what she calls intra-activity between the human and non-human, attributing agency to both (Barad, 2003, p.816). Here, agential realism can help to situate the vulnerable state of pregnant women by taking the perspective that the agency of the materials that surround them, such as medication, homoeopathy, or (COVID-19) pandemic precautionary procedures, acts upon and shapes their experiences. Thus, the scientific turn to new materialism replaces the rigid distinctions between nature and culture, or technology and matter, with the premise of a "nature-culture continuum" (Haraway, cited in Braidotti 2023, p.94).

Adding to Barad's agential realism, Margaret Schwartz (2019) assists in further situating the vulnerable state by including the perspective of the materiality of female bodies. From a new materialist lens, the human body is not just an empty shell. In a discourse where the aim is to understand the female experience that is connected to her bodily functions, we cannot simply rely on postmodern theories (in challenging universalism on truth) and essentialism theories (in believing in fixed truths); they all fail to unite theory with personal experiences of vulnerability and suffering (Schwartz, 2019 p.82). Schwartz (2019) argues:

> If we cannot introduce the embodied vulnerabilities that mark the reality of people's lives into our philosophical discourse, then the discourse is broken (Schwartz, 2019, p.83).

In her work, Schwartz (2019) specifically addresses biological sex differences, viewing them as an ontological and inherent characteristic— a basic part of existence that is natural and constant. This perspective contrasts with postmodern theories such as Butler's, which argue that gender is performative and continuously produced by our enactment of norms (Butler, 2016, p.22). However, gender theories fail to account for the role of matter in constructing our identities and its interplay with vulnerability (Jagger, 2015, p.322). It is not that Butler contends the existence of the role of materiality but rather places the focus of her discourse elsewhere.

While I acknowledge that emphasising the vulnerability of women may suggest that they are less powerful than men, particularly by directly addressing the biological factors of pregnancy, I argue that the misconception of women as weak can be challenged by utilising the new materialist perspective. This approach allows us to make adequate room for the role of materiality in the materialisation of female bodies. For instance, the body's materialisation of hormones acts with its own intention upon childbearing bodies, making the body grow and actively shaping the pregnancy experience, ultimately determining the alignment or misalignment with the preconceived notions of pregnancy. As such, to better understand their experiences, it is necessary to attend to this perspective of acknowledging the role of the materiality (Coole & Frost, 2010, p.1) of pregnant bodies, such as hormones, bleeding, and genetic makeup, and that they, too, have their own agency.

To further emphasise this matter, Suzanne Bost (2010) explores the topic of bodies and the power of their materiality. Here, the materiality is manifested in Chicana[3] feminist writings by Gloria Anzaldua, Cherrie Moraga and Ana Castillo, who have dealt with illness, loss and health struggles. For instance, Bost (2010) describes how female monthly bleeding often has been viewed as a *thing* that exists outside the scope of critical discourse, whereby this natural event is often reduced to a simplistic personal matter that should be hidden or dealt with alone. Bost (2010) express:

> Unlike other texts [discourse], bodies are never static. Once they fail to assume their familiar shapes, they become something else: a source of embarrassment, a medical problem, a theoretical provocation, or an emotional provocation. A body that bleeds elicits reactions that go beyond objective reason: fear, disgust, pain, pleasure. (p.1).

The bleeding represents not only an experience of not having any control over the body's biological functions but also a deviance that is not supposed to happen (Bost 2010; Douglas 2002). Similarly, when a body becomes pregnant, it loses control over its health effects, which is then viewed by society as a failure and in conflict with the normative views of a healthy body. Her matter should be hidden or dealt with alone rather than seeking care. These cultural beliefs about female bodies are further highlighted by Douglas' (2002) work, where she emphasises how a pregnant body has symbolic meanings attached to her conditions.

Expanding on this idea, Braidotti (2022) argues that how we perceive our bodies is further shaped by how they are represented through digital media. According to Braidotti (2022), “the [human] body is not merely a biological given or a social construction but rather an ontological becoming” (p.113). This means that bodies are more than biological entities and that cultural and social forces cannot solely define them; they are influenced, shaped and materialised by various factors, including genetics, nature and technology (ibid.). As such, the constructed understanding of the body does not always respond to the corporeal experiences of the individual. It can even be viewed as both fiction and fact—fiction in the sense that it is created (unnatural) and fact in that it has real, tangible effects on the world and on how we, women, perceive ourselves and are perceived by others (Haraway,1988, p.559). The co-existence and inseparability of fact and fiction and the vitality of the situation is aptly characterised by Haraway (1990) as “a struggle over life and death, but the boundary between science fiction and social reality is an optical illusion.” (p.149). Hence, connecting

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[3] Chicana feminism is discussed by Bost as a movement that points to the specific struggles Latina women are facing in the American context. Their stories highlights how corporeal experiences can deepened the understanding of identity, vulnerability and resistance.

Braidotti's (2022) arguments with Bost's (2010) arguments, I reason that the difficulty in finding sufficient labels is also rooted in the complexity of the fluidity of ontological becoming.

The interplay between the physical bodies and our identities reveals how the labels we attach to our experiences can sometimes hinder the ability to fully understand what our bodies are trying to articulate (Frank, 2013). This point of view is particularly relevant in the context of experiencing HG, where labels of pre-existing terms such as morning sickness fail to capture the severity of the symptoms accurately. The dissonance between corporeal experiences and what is being told externally can lead to questioning oneself and identity, as the affected person may wonder why they are experiencing such severe symptoms when others are not–or if it is all imagined (Frank, 2013). Thus, we must attend to the uncomfortable stories being told because otherwise, these voices will remain silenced and unheard of (Frank, 2013, p.58).

As it has become clear, vulnerability is an utmost subjective experience. Because it is experienced differently across different bodies, it is challenging to determine what bodily matters should be considered medical versus spiritual or existential concerns. New materialism offers a nuanced viewpoint on understanding agencies from various aspects, but it can sometimes be challenging to comprehend. Nonetheless, it emphasises the idea of "brute thereness", which suggests that the presence of other things around us undeniably and inevitably affects us (Coole & Frost, 2010, p.7). Further criticism of new materialism is that it characterises feminism as having ignored biological realities, which, according to Sarah Ahmed (2008), is a "false and reductive history of feminist engagement with biology" (p.24). However, this criticism was later countered by Noella Davis (2009), who argues that the point was that new materialism has a different stance on biological factors, viewing them as entangled and inseparable from society.

3.2 Existential Media Studies

To provide a more nuanced understanding of women's precarious situation, I introduce Amanda Lagerkvist's (2017; 2019; 2022) existential media theoretical framework. Lagerkvist's (2017, p.101) theory examines the role of digital media in individuals' lives when confronted by limit situations, particularly those involving death, illness, and loss. Applying this framework to my study can give a better understanding of how women navigate and use digital media to cope with the challenges of HG.

Inspired by Karl Jaspers (1883-1969), Lagerkvist (2017) reintroduces his concept of the limit situation. Jaspers posits that the human consciousness is acutely felt when faced with situations that break beyond their known world, forcing them to make critical decisions about their lives and existence (Lagerkvist 2017, p.96). Accordingly, being human means being situated in a world where our existence is a "rupture in being", meaning that we are not always in limit situations but inescapably situated as part of existing in this world (Fuch, 2013, p.302). However, these moments of despair also present opportunities to become a new and true version of ourselves that were previously unfathomable due to our limited knowledge of existence (Bornemark, 2006, p.63). In Lagerkvist's (2017) reintroduction, she retitles this concept as a *digital limit situation*, directing the discussion to what it means to experience existential limits and be human at the intersection of technology in a world where "people's lives and memories are increasingly shaped in, by, and through digital media forms" (p.98). At this intersection, we are exposed to new kinds of vulnerability that are both tangible and far-reaching at the same time. This means that people can become braver in expressing themselves online while simultaneously being unaware of the dangers rooted in online platforms' affordances, aggressive algorithms, and the forces of surveillance capitalism (Miller, 2019, p.172). As we need to be more aware of our vulnerabilities on social media platforms, we also need to understand how these platforms speak to our vulnerabilities, as asserted by Turkle (2011): "Technology is seductive when what it offers meets our human vulnerabilities" (p.1). Consequently, vulnerability can take on a whole new form and meaning in this context as our media usage and online presence become "momentous and life-defining" (Lagerkvist, 2017, p.99).

So, let us begin by diving deeper into how individuals enter a state of limit situation in this context. What occurs during these moments of profound disruption? Here, the concept of *thrownness* describes the transitory experience of entering a digital limit situation, as suggested by Lagerkvist (2022). She explains this concept as the feeling of:

> …being projected in a certain direction yet remaining in midair, of pending and waiting in uncertainty - in fear and trembling, in pain and suffering, in hope and anticipation- while being pushed to act responsibly (Lagerkvist, 2022, p.33).

This idea expands on the philosopher Martin Heidegger's (1962) notion of being displaced in an absolutely uncertain situation. Being *digitally thrown* refers to how our existence and identity are being displaced in the digital realm without us knowing how it will (trans)form our identity (Lagerkvist & Andersson, 2017, p.551). Schwartz (2019) makes an illustrative connection between being thrown and our vulnerability. She argues that losing control and predictability of the future inevitably places one in a vulnerable state (Schwartz, 2019, p.84). In this thesis, vulnerability is also referred to as being thrown into an illness and exposed to its physical and emotional consequences as much as being thrown into the unknown terrain of digital media.

Lagerkvist (2017) argues that the media users or the existers identities are inseparable between offline and online. She characterises existers as "a stumbling, hurting, and relational human being, who navigates within limits and among interruptions through the torrents of our digital existence, in search for meaning and existential security" (Lagerkvist, 2017 p.96). Subsequently, our engagement with technology has become symbiotic in merging real-life experiences with online realities (ibid.).

To further explore how the existers navigate digital spaces, one can take two lenses: a perspective that emphasises their individual experience or one that focuses on their relational and social experiences. Here, Lagerkvist (2017) draws inspiration from classical existential themes: *being-there* (Dasein) and *being-in-and-with* (Mitsein). Being-there refers to how our existence is defined by the digital tools in which we actively engage and how our digital footprints give rise to a separate existence that extends our vulnerability and insecurity beyond our control (ibid.). Consequently, it creates a feeling of ambivalence about how data is being stored and us not knowing how it will be used in the future (Lagerkvist, 2017, p.105). Being-in-and-with explores our presence in relation to our connections and interactions with others, as well as how new communities and social dynamics change how we relate to one another (ibid.).

In this context, digital media represents more than just material, portable devices; it can further offer positive reinforcements for existers to find resources, allowing them to organise themselves and maintain control in their social world (Couldry & Hepp, 2017, p.157). Lagerkvist (2022) suggests that digital media can constitute a caring medium that can be used as a literal lifeline for those who have experienced unimaginable disruptions such as loss, death, and illness. In effect, digital media can become *salvific*, offering a *humanitarian presence,* and sharing *mundane and material* aspects of life while shaping and sustaining an individual's *ontological being* (Lagerkvist, 2022, p.156). In combining these two perspectives, we can investigate the transformative impact of digital technologies and spaces on our personal and social lives. Here, digital social media is argued to change how we act, who we are, and how we relate to one another in an online community. Therefore, these perspectives on digital existence guide us in understanding the entangled connections between how we shape our individual and shared identities online and offline.

To summarise, Lagerkvist's (2017; 2019; 2022) existential media theory can be seen as a means of awakening our consciousness about our existence in the digitalised world by recognising our vulnerability and viewing it as an inherent and natural part of being human. Because her theory is grounded in existential philosophy, it is often difficult and sometimes overwhelming to grasp the heavy concepts, especially if unfamiliar with them (Grelz, 2023). This can hinder a full understanding of its applicability in new cases. Furthermore, her readings demand a significant comprehension of ethics and vulnerability, which is not as simple as it sounds.

In today's world, where online identities may lack authenticity, depending solely on empathetic insight à la Jasper's teachings might not always capture what is truly genuine. This could potentially compromise the theory's effectiveness in understanding limit situations in a social media context. To mitigate such compromise, I develop a sense of community framework that adds a relational perspective and a contextual awareness to explore further the frailty of forming intimacy online. However, it is to be noted that studying humans will *always* be a complex and challenging task as human experiences are often "messy and complicated", in which our identities are sometimes unstable and influenced by various factors such as surroundings and emotions (Bost, 2010, p.26). The combination of existential philosophy and new materialist feminism can contribute to a more inclusive worldview that moves beyond the current political tension surrounding identity, gender, and race. Instead, it focuses on the shared vulnerabilities of the hurting and suffering bodies that feel pain and strive to connect via lifelines online.

3.3 Expansion of Sense of Community

To explore how HGS members communicate and relate to one another, I was inspired by the Sense of Community (SOC) model developed by Macmillan and Chavis in 1986. They outlined four core features that conceptualise a Sense of Community (SOC):

- *Membership* refers to the feeling of belonging, sharing a sense of personal relatedness and being a part of a community (McMillan & Chavis,1986, p.9).
- The concept of *influence* relates to feeling that the group matters to each member and that each member matters to the group (McMillan & Chavis, 1986, p.11).

- *Integration and fulfilment of needs* is the feeling that one's needs will be met by being a member; conceptually, it is a reinforcing mechanism between the group and the individuals driven by that people do what serves their needs (McMillan & Chavis,1986, pp.12-13).
- *Shared emotional connection* represents the strength of the bond between the community members, grounded in members identifying with a joint history or experiences (McMillan and Chavis 1986, pp.13-14).

The concept of SOC is briefly defined as: “a feeling that members have of belonging, a feeling that members matter to one another and to the group, and a shared faith that members’ needs will be met through their commitment to being together” (p.9). These attributes were my starting point when trying to understand the dynamics of an online community. However, the SOC model was created over three decades ago and has certain limitations regarding societal, technological, and linguistic dimensions. Thus, I update it by drawing on previous contributions such as Sense of Virtual Community (SOVC) by Abfalter et al. (2011), weaving it with contemporary media theories from scholars such as Baym (2010), boyd (2011), Kozinets (2010), and Dahlgren & Hill (2020), among others. Through this lens, I offer a renewed vision of community that I call Sense of Digital Community (SODC) to resonate with the complexities of our contemporary media landscape (see Figure 1 and Figure 2).

Accessibility

The first addition I make to McMillan and Chavis’s (1986) and Abfalter et al. (2011) framework for SOC is a new element titled *accessibility,* which makes the model suitable for today’s context with social media. This update is necessary, as social media has made communities exponentially more accessible and, in turn, transformed how we find, select, and participate in communities (Kozinets, 2010, p.71), thus acting as a precursor to that of MacMillan & Chavis’ (1986) first element of *membership*. There are two primary arguments for how a sense of accessibility can impact SOC: Creating a stronger sense of shared identity (Baym, 2010, p.114) and a stronger sense of connection (Kozinets 2010, p.35). First, a stronger sense of shared identity can come from recognising the shared space (Baym, 2010; Porter, 2006). Here, everyone in the group had other options to join, but choosing this one can create a sense of belonging (Porter 2006). Second, accessibility can create a stronger sense of connection as the community can be perceived as omnipresent in their lives; one can carry this "shared space" in the pocket, and it is always available when needed (Turkle, 2011, pp.171-186).

The public nature and persistence of social media platforms (boyd 2011, p.46) enable them to peek into potential communities: see who is engaged now, how the historic engagement has been, and with minimum effort, request to join a community (boyd, 2011; boyd & Marwick, 2014). Moreover, the constant connectivity, both synchronous and asynchronous communication (Abfalter et al., 2011), coupled with the scalability and searchability (Bossetta 2018, p.479) allows members in vulnerable positions to build new friendships and develop or maintain social capital (Ellison et al., 2007; Potnis et al., 2023).

Membership

To expand and update McMillan and Chavis' (1986) membership concept, I have integrated additional theories and concepts into the authors' five community membership attributes[4]. Firstly, to have a membership, a community must have boundaries to separate people who belong from those who do not (McMillan & Chavis 1986, p.9). The boundaries set the structure for the group's security, and when members trust that security, a sense of emotional safety can be established, allowing for intimacy to develop (McMillan & Chavis, 1986, p.10). Here, emotional safety offers a sense of security. McMillan and Chavis (1986) describe the sense of belonging and identification as more intimate. I view identification as a form of engagement and draw upon Dahlgren and Hill's Parameters of Engagement (2020) to understand it as an affective experience of their engagement. They describe it as:

> An emotional experience that can embody, for example, moral, passion, resentment, pleasure, curiosity, fear, anxiety, anger, humour and not least identity processes - which in turn relate to the subjectivity of the self, both individual and collective" (Dahlgren & Hill, 2020, p.5).

Hence, I examine the self and its relation towards the collective and how it acts as a motivating force that ultimately impacts the members' sense of agency and control.

Influence

Influence is a bi-directional concept rooted in the members' need for consensual validation and the community's need for conformity (McMillan & Chavis 1986, p.11). The HGS

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[4] They are boundaries, emotional safety, sense of belonging and identification, personal investment, and common symbol system.

community is an excellent example of how this concept plays out in practice, as members receive helpful and empathetic responses when they post threads and express gratitude for the support they receive. Simultaneously, the community matters to the members, which, in numerous posts, showcases members expressing their gratitude for the support they have been provided with, thus motivating them to continue to be a part of the community even after their HG journeys to reciprocate the support they received. As such, community conformity creates a necessary cohesiveness in the group that is reinforced by community norms.

Integration and Fulfilment of Needs

McMillan and Chavis (1986) emphasise that reinforcements are instrumental to SOC; however, they need to provide more guidance on navigating the complexity of identifying these different reinforcements. One such guidance can be found by integrating the community attribute identified by Baym (2010) titled *shared resources and support*, where she provides the perspective that these unidentified needs could be found to be either resources or three distinct types of support, namely: *esteemed*, *informational* and *emotional* (Baym, 2010, p121-122). Thus, these different types of support aid a more straightforward analysis and deeper understanding of the needs being reinforced to create a sense of community, e.g., why do women go online to seek or give support to strangers?

Shared Emotional Connection

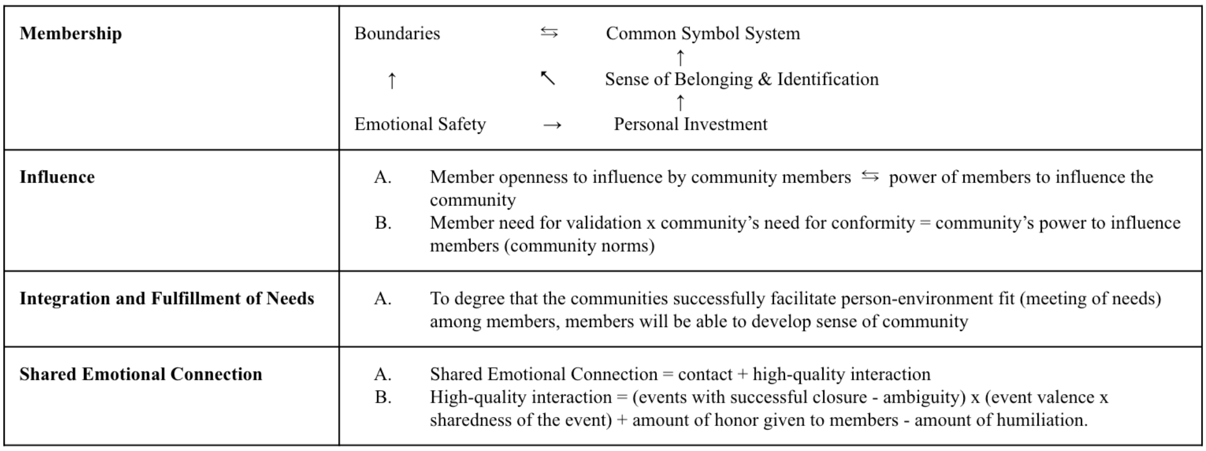
McMillan and Chavis (1986) argue that this attribute is grounded in the member's belief and commitment that they share the same history or similar experiences; however, they are not bound to have the same history, but they *must* identify with it (McMillan & Chavis, 1986, p.13). McMillan and Chavis (1986) list seven different hypotheses for what can enhance the strengthening of bonds or impact the shared emotional connection in communities (see Figure 1). I deem two hypotheses as central contributors to the emotional connection among members in the case of the HGS community: the *shared valent event hypothesis* and *the spiritual bond*. The shared valent event hypothesis reasons that sharing an emotionally significant event, such as suffering from HG, fosters stronger emotional connections. The spiritual bond hypothesis captures the deep and complex existential transformation that the HGS women undergo and how their own spiritual experience around carrying a life threatened by illness both influences in which is influenced by the other women in the community.

Privacy

I expand the framework by including privacy as a critical attribute, highlighting how feeling safe from external threats and internal leakage is essential to a person's sense of agency, especially for communities like HGS, where emotional safety hinges on privacy. Defining privacy is a complex task, and people's relationship with it has shifted with the emergence of social media platforms (boyd, 2011; boyd & Marwick, 2014). On this ground, it has compromised the private nature of our communication, and it is no longer private by default but public by default (boyd, 2011). Considering this, I find boyd and Marwick’s (2014) perspective viewing privacy as related to agency and the ability to control a social situation online (boyd & Maverick, 2011, p.1). Building on boyd (2011) and Zuboff (2019), I introduce two potential threats of invasion of privacy coming from context collapse and platform surveillance. They refer to an accidental breach of privacy (boyd, 2011, p.51) and surveillance by invisible third parties (Balbie & Magaudda, 2018; Skeggs & Yuill, 2018).

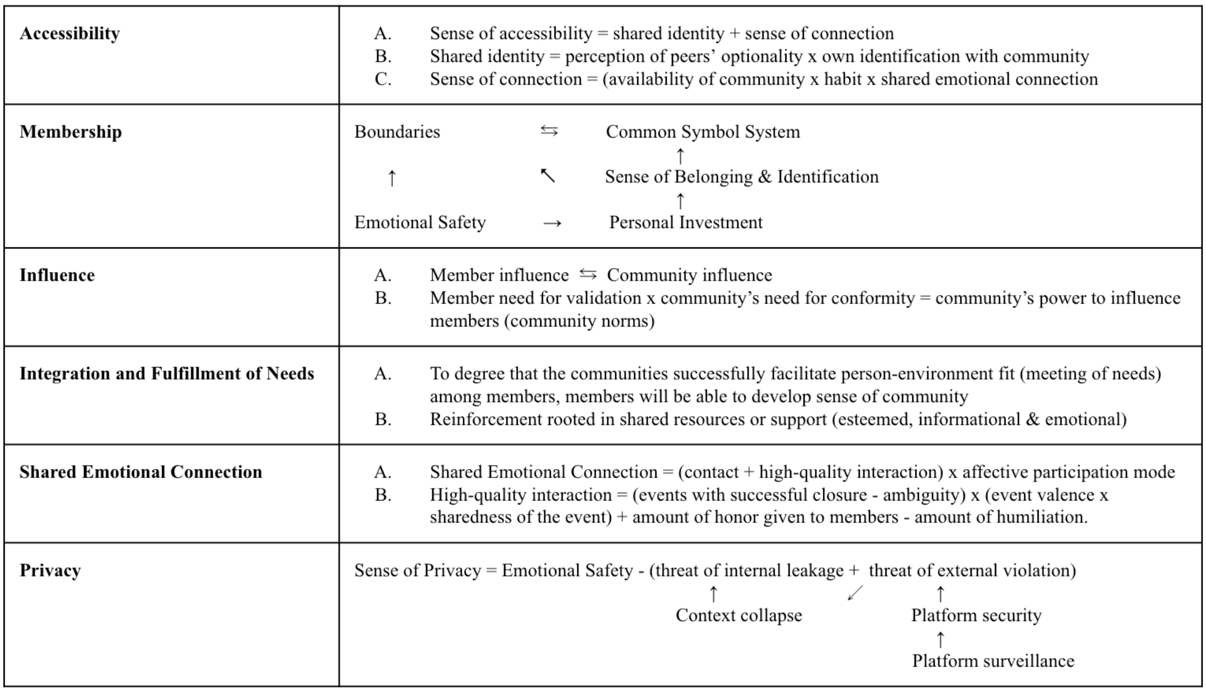
Sense of Digital Community

McMillan and Chavis (1986) summarise the elements of SOC and their relationships in Figure 1. I summarise my changes by proposing a new figure, which includes the two additional elements and adjustments to the pre-existing five.



Membership	Boundaries ⇆ Common Symbol System ↑ ↑ ↖ Sense of Belonging & Identification ↑ Emotional Safety → Personal Investment
Influence	A. Member openness to influence by community members ⇆ power of members to influence the community B. Member need for validation x community’s need for conformity = community’s power to influence members (community norms)
Integration and Fulfillment of Needs	A. To degree that the communities successfully facilitate person-environment fit (meeting of needs) among members, members will be able to develop sense of community
Shared Emotional Connection	A. Shared Emotional Connection = contact + high-quality interaction B. High-quality interaction = (events with successful closure - ambiguity) x (event valence x sharedness of the event) + amount of honor given to members - amount of humiliation.

Figure 1 - *Elements of Sense of Community and Their Hypothesised Relationships* by McMillan and Chavis (1986)



Accessibility	A. Sense of accessibility = shared identity + sense of connection B. Shared identity = perception of peers' optionality x own identification with community C. Sense of connection = (availability of community x habit x shared emotional connection
Membership	Boundaries ⇆ Common Symbol System ↑ ↑ ↖ Sense of Belonging & Identification ↑ Emotional Safety → Personal Investment
Influence	A. Member influence ⇆ Community influence B. Member need for validation x community's need for conformity = community's power to influence members (community norms)
Integration and Fulfillment of Needs	A. To degree that the communities successfully facilitate person-environment fit (meeting of needs) among members, members will be able to develop sense of community B. Reinforcement rooted in shared resources or support (esteemed, informational & emotional)
Shared Emotional Connection	A. Shared Emotional Connection = (contact + high-quality interaction) x affective participation mode B. High-quality interaction = (events with successful closure - ambiguity) x (event valence x sharedness of the event) + amount of honor given to members - amount of humiliation.
Privacy	Sense of Privacy = Emotional Safety - (threat of internal leakage + threat of external violation) ↑ ↙ ↑ Context collapse Platform security ↑ Platform surveillance

Figure 2 - *Sense of Digital Community Model* (SODC)

4. METHODOLOGY

This chapter explains the methodology and methods employed in this study. The multi-method-designed research consists of face-to-face interviews and digital ethnography on Facebook for the HGS community. Furthermore, the research design will be outlined, detailing autoethnographic reflexivity, the thesis' ethical considerations, and its limitations.

4.1 Setting: Hyperemesis Gravidarum Sverige

This thesis explores a closed online community on Facebook called Hyperemesis Gravidarum Sverige (HGS)[5]. Founded in 2014, this Swedish support group offers a space for women suffering from severe morning sickness in the form of HG. With almost 3000 members since the start of 2024, the group is private, and only members have access to all the content and an overview of other members based on their locations and common friends. To gain membership, Facebook users must answer a few application questions, evaluated by the administrators. Since HG is a transient condition, the group's most active members are those who are currently pregnant or planning to conceive once again. This highly interactive community regularly generates 60+ threads each month, demonstrating its ability to attract new members and grow in popularity. Moreover, the group leverages Facebook's affordance, including a point system incentivising engagement.

The HGS group was chosen partly because its domain, Facebook, is the world's biggest and most-used social media platform, with over three billion active users (Statista, 2023). In Sweden, Facebook is the most used social networking platform, with millions using it to stay connected with loved ones, friends, coursemates, and colleagues (Internetstiftelsen 2024). With its sophisticated algorithmic filtering, matching, targeting, and strategic geographical locations, Facebook's open network structure allows users to easily search and discuss topics of their interests (Bossetta, 2018, p.491).

The Approach

I have adopted Christine Hine's (2015) approach to understanding digital milieus as embedded, embodied, and everyday. This approach goes beyond providing practical instructions on studying online environments. It is exceptionally useful in encompassing a

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[5] Link to the Facebook Group: https://www.facebook.com/hgsverige/

broader context awareness, acknowledging the blending of online and offline, and recognising the influence of deeper ingrained cultural factors. This connects with my thesis as it illustrates this blending by arguing how people can form connections and feel a sense of community, regardless of whether these interactions happen in a physical or a digital space. While Hine's perspective explains this intermingling and how to study it ethnographically, existential media studies provide a deeper understanding of the means of living and engaging with digital media. For Lagerkvist (2022), being thrust into the digital limit situations also means we are 'becoming in and with' digital media as it shapes and reshapes our experiences and perceptions. Thus, new ethical and normative challenges are created, which prompts us to rethink our moral choices and how we interact with media (Lagerkvist, 2022, pp.31-33).

4.2 Methods

Considering the impossibility of fully capturing or representing anyone's experience through any form of representation (Lagerkvist, 2022, p.56), I have leaned onto the *phronesis* approach. In doing so, I address the interplays between knowledge, experiences, and points of view that shape our understanding of social reality (Flyvbjerg 2001, pp.60-61). This approach helped me to better observe and comprehend women's experiences with HG and their motivations for engaging with the HSG community. To achieve this, I have employed boyd's (2015) research method, which combines immersive online observations with in-depth face-to-face conversations. Using these methods, I better understood users' real-life situations and could be more nuanced in how I observed the material online.

To understand how ill pregnant women might relate to an online community or seek care, it is imperative to acknowledge the broad context of the precarity they might have undergone. Like many, they were affected by lockdown restrictions, resulting in isolation and limited care. Hence, the global pandemic caused by COVID-19 is a prime example of material factors outside of our control that caused a global ripple effect of ecological, social, and economic impact (Braidotti, 2023, p.94). As a result, the pandemic added another layer of complexity to vulnerable situations, further emphasising the role of technology and digital media for individuals in the modern world (ibid.).

In selecting interview participants strategically, I utilised features available on Facebook, which allowed me, as a fellow HGS member, to have an overview of all members, including their proximity to my location. Given HG is a highly individualised infliction (medically diagnosed or not), I specifically reached out to participants who were deemed likely to participate in an interview. Thus, the criteria for selection included physical proximity to Malmö and some visible activity within the group, such as posting, commenting, or reacting to any content on the platform. Following Hine's (2015) advice: "Any mode of interviewing needs to be chosen to be comfortable and convenient for the interviewee" (p.79), I told the participants that I preferred to conduct the interviews in person and offered to meet in central Malmö. However, most felt more secure being interviewed in the comfort of their homes, to which I readily complied.

Six semi-structured interviews were conducted in Swedish and one in English with women who have had or are suffering from HG. All the interviewees were women between 30 and 40 years old based in Skåne County, where one was pregnant, three had one child, and two had two children. Preceding each interview session, which lasted 1.5 to 2 hours, I engaged in an informal chat with them while setting up the recording device and while they read through and signed the physical consent form.

Analysing Materials

The research approach is that of an inductive qualitative method whereby the interview materials were transcribed manually, colour-coded, and grouped into themes. Using Braun and Clarke's (2006, p.87) method, the first coding phase started with familiarisation by reading through the data collected and forming opinions and ideas about potential themes. Recognising my position and relationship with the research topic, reading, and listening to the interviews multiple times was instrumental, thus gaining both immersive and more distanced vantage points for making interpretations. The systematic coding process was done with an inductive zig-zag approach, where I iteratively went back and forth between data gathering and analysis until I was confident that thematic saturation was reached (Seale, 2011, p.369).

The open coding conducted on the transcripts of the interviews can be seen in Appendix 9.1, where passages were marked with open codes that are descriptive by nature. Subsequently, I distilled the open codes into analytical codes, and eventually, potential themes were iteratively developed. The figure below illustrates an example of how I arrived at the potential theme of Corporeal dissonance. To create an overview, a codebook was created, mapping out the overarching thematic areas containing individual themes tied to broader categories (see Appendix 9.2). The overview provided by the code book enabled me to further refine the data analysis, with the final result including three overarching themes, eleven themes, and twenty-seven analytical codes.

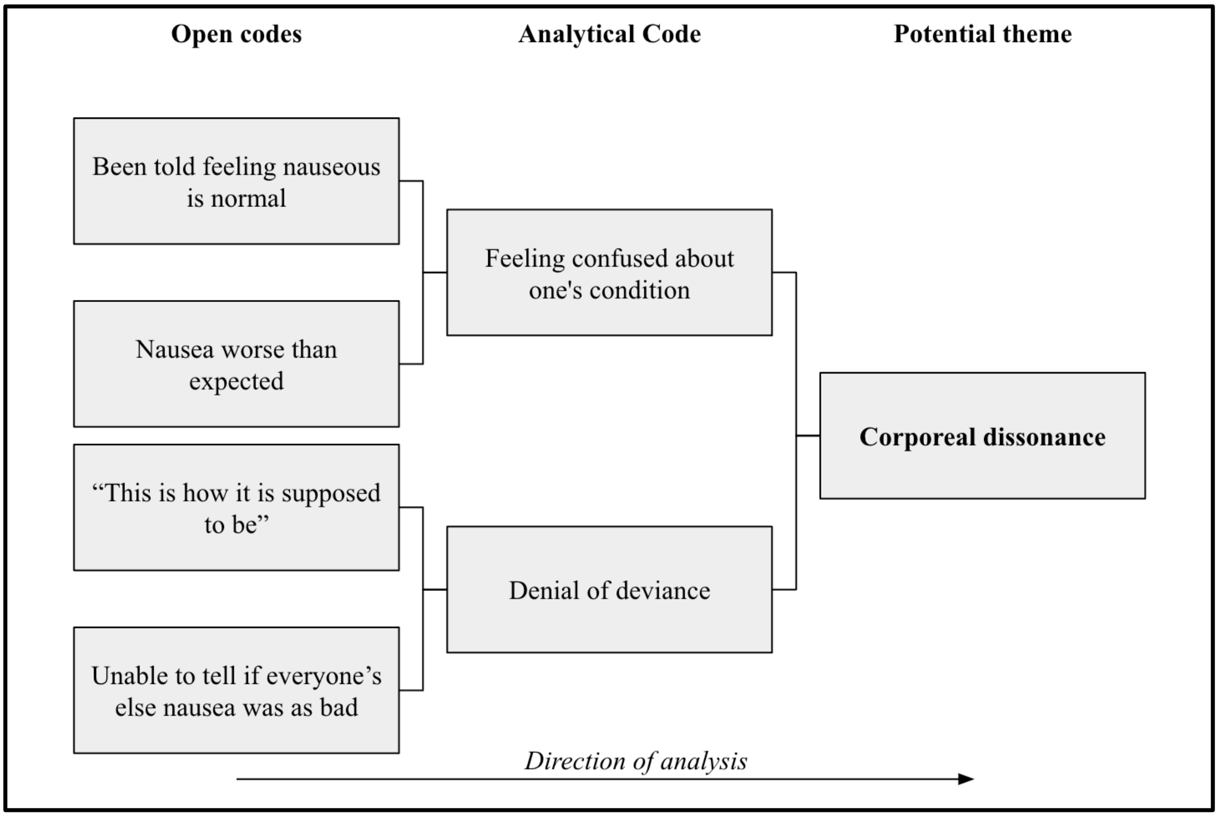

Figure 3. Example of Code, Category and Theme Development

4.3 Ethical Considerations

Due to the HGS community's strict rules and the fact that its administrators highly protect it, I concluded it would be intrusive to make a recruitment post. This could disrupt the sociality in the group, make the members feel exposed, or even risk the chance of getting blocked. For that reason, I informed the potential participants by sending them a private message, explaining who I was, describing my research project and asking them if they were interested in participating (see 9.3 Appendix: Informal Chat). Moreover, I revealed that I, too, have experienced HG and, therefore, see the importance of spreading knowledge about this rare and misunderstood condition. If they were interested in participating, I would send more information about the project's aims and objectives, followed by a consent form regarding confidentiality, including their rights to withdraw or end the interview session at any time (Appendix 9.4: Formal Invitation & Consent Form).

Because HG can be categorised as trauma, and those who experienced it as vulnerable, it is assessed with the utmost sensitivity, based on: “how private, sacred, or stressful an issue is, how much potential there is for stigmatisation, and how (politically) controversial the issues are” (Tiidenberg, 2018, p.5). As such, I have adopted strict guidelines to ensure the confidentiality and informed consent of the participants. Firstly, I make sure not to befriend any of the participants on Facebook, nor do I use direct quotes from the community that could risk being traced back to the user. If used, then their consent is given beforehand, and they are informed of potential implications. Secondly, informed consent means detailing how they can cancel their participation at any time during the process and ensure their identity is protected. Therefore, I have replaced their real names with pseudonyms, and any identifiable information is retracted.

To further emphasise the ethical considerations for this thesis, I lean on Benson and O'Reilly's (2020) conventions on reflexivity: positioning, navigating, and interpreting (p.178). I have had this mindset throughout my research, acknowledging that I have worn two hats throughout this fieldwork—that of a researcher and a participant. Hence, it is crucial to be open about my relationship with the research and how it might impact the procedure or influence the interpretation of the data. This transparency is especially apparent through my writing, where I actively use my own voice in an autoethnographic approach and acknowledge how my previous experiences affect this project. In doing so, I am following Richardson's (1994) advice on experimental writing, where she stresses, "How can we nurture our own individuality while still laying claim to knowledge?" (p.517). As such, I give an honest account of how my research was done and was always conscious that I discovered the thesis topic through my experiences, not *because* of my experiences.

In addition, I made sure to inform the women about my interview style before all the interview sessions. Inspired by MacInnis & Portelli (2002, p.41), I followed a dialogical interview mode and strived to establish an equal relationship between myself and the participant. As someone who also suffered from the health effects of HG, I actively engaged with them during the interviews. If the participants had questions about me, I would answer them and, when appropriate, ask sensitive follow-up questions. While I admit that I do not have extensive experience as an interviewer, I adhere to the advice of Frank and Solbraekke (2023). Frank and Solbraekke (2023) view autoethnography as “a hybrid genre, with any particular work positioned somewhere between memoir and social scientific report” (p.80). They propose merging one's experiences with one's expertise and argue that the researcher’s narration can offer an insider perspective that can help enrich their studies. In short, I approached the individual sessions with empathy, actively participating with the interviewees and respecting how they could hold their own when faced with a threat that affected their bodies and self-identifications (Frank & Solbraekke, 2023, pp.81-82).

4.4 Limitations

During the research process, I initially sought to conduct ten interviews. However, after my first interview, I realised that the materials I got from the participants were much richer than expected regarding information and insight. Despite requesting one hour of their time in the invitation form, the first interview session went much longer than expected. Upon scheduling the other sessions, I informed the other participants about this, and they agreed to the extended time. Unlike virtual interview sessions, face-to-face interactions in their homes require more time and effort than anticipated, often ending with two to three hours of interactions. They involved longer informal chats, both before and after each session, sharing my own background and history with the illness, and on one occasion, the interview was conducted with two toddlers present.

After recognising the breadth and the deepness of the materials and the time and effort they took, I was recommended by my supervisor to stick to six interviews. The adjustment serves the purpose of being able to go deeper into each interview, exploring the very specific condition of HG. Moreover, due to the richness of the interview materials, I did not systematically analyse the group's contents. Instead, I made extensive field notes describing each interview setting. Here, the main focus is on the interview materials. When analysing peoples' vulnerability and personal suffering, it needs to be sufficiently contextualised to be meaningful. I conclude that their experiences are complex and should not simply be treated as data to be collected or analysed–but also understood. This is why the analysis chapter will be extended generously, as it takes up a lot of space when reproducing their perspectives through quotations.

5. ANALYSIS

Inspired by Amanda Lagerkvist' (2017), the analysis is divided into three themes. They are based on the six interviews conducted with women in the HGS community concerning their experiences with HG and their engagement in the Facebook community. The first analytical theme, "Thrown into the Unknown", refers to the participants' feelings about HG, pregnancy, motherhood and how their identity has evolved before and during. Here, I argue that the participants have undergone a limit situation, forcing them to transition and re-evaluate their new reality. This section is followed by "A Sense of Digital Community–Negotiating Vulnerability," which discusses the elements of SODC, revealing insights into how the vulnerability is negotiated within the HGS community, including the potential limitations and implications for its members. It also argues that a strong sense of community can turn it into a uniting force of new connection. The third section, "Facebook as a Lifeline", explores how the HGS community functions as salvific, providing a humanitarian presence, being mundane and material, and entailing an ongoing project. This section illustrates why women seek out the HGS community and how its existential functions relate to their health, sociality, and identity transformation.

5.1 Thrown into the Unknown

This section focuses on understanding the challenges faced by Maja, Clara, Katarina, Linnea, Sophia and Fredrika, all of whom have been thrown into situations of utmost uncertainty, particularly concerning pregnancy and illness. To complement Lagerkvist's perspective, Arthur W. Frank's (2013) book, *The Wounded Storyteller*, is used to highlight the different narratives that emerge when facing illness. His perspective of experiencing illness aids my analysis in understanding how the participants in limit situations experience their challenges and navigate their way through them.

Life Before

Before pregnancy and facing its potential health effects, all the women interviewed were content with their situations and excited to start a new chapter in life. Through our conversations regarding their experiences with HG, I realised that to understand their journey and transformation, it was essential to know them and their lifestyle before pregnancy. During our discussions, two things became apparent: Firstly, they all began their pregnancy journey in good physical and mental health. Secondly, they were happy and content with having control over their bodies and daily routines. For instance, Clara proudly shared how she maintained her well-being through exercise and nutrition before pregnancy, which embodied her liveliness.

> You can see pictures (lifts her phone out and opens the photo app). I look completely different. I worked out six days a week and ran four days a week. I was very particular about what I ate and what entered the body. It was all organic, without sugar, and not a lot of fat; it couldn't be anything that could negatively affect my health. I still ate whenever I wanted without restrictions. I was happy and playful. I was like: let's do it tomorrow. We had our entire life ahead. Something along those lines, I lived for the moment. (Clara)

Sophia also pointed out that she was in a good place in life, with future plans that excited her and made her happy.

> I felt as if I was in a good spot in life. We had just bought our house, I was studying, and I was active. I had plans for the future. It was an excitement to get kids. Happy with life. (smile) (Sophia)

Posing the simple question of "How did you feel before the pregnancy?" revealed an array of emotions, hinting that there was much to be explored. Although initially intended as one of the warming-up questions, it instead spoke directly to an emotionally charged topic where the sense of loss was apparent, particularly a loss of the "old" self.

Expectations versus Reality

For many, pregnancy is a time of joy and anticipation, marking a significant transition in life (Arnold-Baker, 2020, p.3). However, what the women experienced was quite different. Struck with extreme nausea, their joy and expectations were abruptly shattered, and they were thrown into an unfamiliar world of illness. This sudden loss of control and predictability can be perceived as a limit situation (Fuch, 2013). The mother-to-be is confronted with the unpredictability of life and forced to make existential decisions about who they are and how they relate and respond to their new reality. In such situations of loss, guilt, and death, "the rug is so to speak yanked from under my feet; something is also broken,"[6] meaning that the familiar shelters of the world are no longer present. This is when the women became acutely aware that their reality had tremendously changed, whereby they could no longer control their lives, and the "everyday familiarity collapses" (Heidegger 1962, p.189).

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[6] A translation by Christian Fuch (2013) on Jaspers 'The Psychology of Worldviews (Psychologie der Weltanschauungen)' p.302.

In the interviews, all participants expressed feelings of disappointment and loss due to the stark contrast between their expectations and reality. They had built up a preconceived idea of what pregnancy would be like based on media portrayals and the experiences of friends and family. As Braidotti (2023) argues, our bodies are “relational and affective” (p.113), meaning that they can absorb external influences from our surroundings and show their own effects. When asked about her previous expectations of pregnancy, Linnea reflected on her past naive self and how that reality never materialised.

> No, I suppose it was about being able to see your belly grow, get to do what you want, and work out into the final stretch, as I’ve seen everyone else do. Sure, I expected you to be a bit nauseous the first weeks, but that should pass in week twelve- I can manage that. But then I expected to be able to live like normal, but it did not quite turn out that way (laugh). (Linnea)

Similarly to Linnea, Katarina also felt deprived of a “normal” pregnancy, almost brought to laughter by the stark contrast with her expectations.

> I'm losing out on a normal pregnancy experience, doing all of these things that society tells you should do and wearing cute pregnancy clothes and all of these things, right? I didn't have any of that, obviously. So that is also kind of a sadness for me that I didn't get to experience those things. Expectation versus reality, you know? (bittersweet laugh) (Katarina)

When Linnea and Katarina were faced with the debilitating effects of HG, they found themselves put in a vulnerable position, their expectations shattered, and in a state of instability. This was a sentiment expressed by all participants.

While HG is a severe condition that most women do not experience during pregnancy, the disappointment and feelings of loss expressed are not uncommon (Arnold-Baker, 2020). Societal expectations and the perpetuation of "new momism" can set unachievable expectations of perfection (Das, 2017, p.3). Hence, this leads to a collapse of expectations—where one realises oneself is no longer on that ideal path—denoting the initial moment of displacement. Frank (2013) would call the collapse of idealised expectations a failure of the mirroring body, marking one’s attempt to mirror the image of the ideal body that has been imposed through consumption (Frank, 2013, pp.43-44). Being involuntarily thrown into an ill body and away from a healthy pregnancy, positions them in a vulnerable condition, as further identified by Schwartz (2019): “Thrownness leads to vulnerability because it marks the limits of individual control: our situations shift without warning, and our footing is uncertain wherever we land” (p.84). Consequently, these unexpected events can force us to change how we view ourselves and others through our experiences.

Corporeal Dissonance

Furthermore, it proved challenging to capture the participants' lived experiences fully. Even though I knew exactly what they meant, it sometimes felt impossible to describe them to others who had not experienced them first-hand.

> If I were to explain it to someone who has never heard of it, I usually say it is like having stomach flu for nine months that never ends. Then, add a little bit of anxiety on top (laugh). It takes an extreme toll, both physically and mentally. It is not something one can imagine before you experience it yourself. (Sophia)

Beyond feeling isolated in her struggle, Sophia shared how she often found it difficult to make others understand the severity of HG, as the labels and terms used to describe it are often insufficient. HG is a rare condition frequently substituted with the term "morning sickness", which fails to capture its severity. According to Bost (2010), such situations can conflict with a person's self-identification, pushing them to the edge and forcing them to change their way of seeing themselves and the world through their experiences. The interplay between the physical bodies and their identities reveals how the labels we attach to our experiences can sometimes hinder our ability to understand what our bodies are trying to articulate fully. As Frank (2013) points out, it is not always easy to translate what the body communicates into words: "The ill body is certainly not mute" (p.13). Although we do not have the language for it, the body has its own way of telling us.

The disconnection between the physical experiences of those with HG and the labels they are given can lead to a sense of dissonance between their bodies and identities (Bost, 2010, p.4). It can lead to questioning one's sense of self and feelings of weakness when comparing their experiences to those of those who do not experience HG. Katarina reached a point where she could not even bear to see a close pregnant friend. The anger over her condition and the dissonance with how she should be feeling became far too much to handle.

> She was concerned about me, but it was so hard for me to see her having such a great pregnancy and going through that experience and doing all of that stuff while I was not able to do any of them. So, I felt jealous, and I was angry, which is like, of course, unfair because it's not her fault. I mean, it's great for her that she had a good experience, but I was angry about my situation. (Katarina)

In recounting Katarina's vulnerable position, signs of an identity struggle can be sensed, where the materiality of her body conflicts with her self-identification. She did not want to feel jealous or angry but became so due to the precarious situation of immobility and hospitalisation. The dissonance between whom they had become and whom they felt they ought to be brought all the participants' feelings of guilt and shame for having previously unthinkable dark thoughts.

> I had so many thoughts that I could not recognise myself. Even if I wanted a child, I had the overbearing feeling of wanting it [pregnancy] to end. I have been to therapy and advised to recognise that it was not my child that I wanted gone, but rather the nausea. So, I have been trying to think in such ways because it was not him [the child] I wanted gone; it was everything else surrounding me. But yes, I went through a personality change. That is what I felt, at least... (Sophia)

Listening to the participants telling their raw accounts of losing weight, countless vomiting without any sense of relief, and feeling their muscles deteriorate after months of immobility, I cannot help but empathise with them. There were many familiar incidents that I also experienced when I was hospitalised with the same condition. Hospitalisation changes your perspective of yourself and your body. Your body becomes someone else's object as a patient, and your identity gets entangled with medical labels. Moreover, it is also challenging to determine what bodily matters should be considered medical versus spiritual or existential concerns, as the utmost subjective experience is unclear (Bost, 2010). On top of the body being subjected to uncontrollable symptoms, there is added pressure from societal expectations to regain health as fast as possible, or at the very least conceal the illness (Frank, 2013, p.31). Thus, it can conflict with the personal identification of those unaffected and can lead to a tendency to look away from other people’s medical problems—either to protect their privacy or our own comfort (Bost, 2010, p.5). While it is impossible to describe HG fully, listening to the raw and uncomfortable corporeal experiences is a good start.

Existential Struggle

As illustrated, illness entails being forced to think about choices in how we perceive ourselves, our bodies, and their abilities. However, these decisions are not made instantly. While speaking with the participants, it became evident that they all underwent some transformation. I noticed a common thread running through their experiences where they described feeling trapped in nausea and disconnected from their identity as if they were no longer the same person they used to be. Yet, they have not fully transformed into someone new. Katarina's case was particularly severe as she had to spend most of her pregnancy hospitalised due to constant vomiting. She had hoped that her nausea would disappear after a certain week of pregnancy, as suggested by the medical practitioners, but unfortunately, it never did. Her condition worsened, and she ended up throwing up 35-40 times a day. She could not eat or drink anything without throwing up and had to undergo a PICC-line operation to make it easier to receive fluid and TMP (Total Parenteral nutrition) via an IV drip (Intravenous therapy). Due to the countless times of needle sticking, her arms have formed many scars.

Katarina describes this state as fragmented: “During my pregnancy, I saw the world in black and white; it was like I couldn’t see colours”. She was unable to do anything except lie in the hospital bed and fall into an in-between state. This colourless existence can be seen as a survival mechanism where one adopts a primal existence, singularly capable of surviving. As Jean Améry reflects, “I had grasped well that there are situations in life where our body is our entire self and our fate. I was in my body and nothing else” (cited in Frank's, 2013, opening page). In other words, the impairment of illness can prolong the transient period of a limit situation, leaving the women suspended in existential limbo over several months. In contrast, during "normal pregnancies", one is afforded the opportunity for internal reflection and transition towards motherhood.

Similarly, Linnea described feeling helpless when she sat and vomited for hours waiting to see a doctor, desperate for care, yet told there was nothing they could do as there were no rooms available. She recalled that her partner carried her to the hospital every morning for the first five months of pregnancy, but it was when denied IV treatment that she felt most vulnerable and hopeless. This left her distraught and unable to grasp “Why can’t somebody help me?”. Linnea's question is profound and captures an important aspect of the existential struggle for all interviewees—an internal negotiation of surrender and survival.

All the participants underscore the dimensions of becoming ill, where one not only surrenders one’s body but also one's voice to the medical narrative of the physician (Frank, 2013, p.5). Hence, the ill person is further exposed to the vulnerability of not having the vocabulary for their corporeal experiences, and at the same time, labels are being imposed on them by medical practitioners. This means that the women often had to surrender their bodies to the care of a doctor in the hope that they would get the help they needed to manage their ongoing existential struggle. In this way, the materiality of their bodies and medical treatments become intertwined with their ability to respond to existential questions—nausea and medical care become a pathway to rebuilding one's identity. To treat the body means to release one from the existential limbo.

5.2 A Sense of Digital Community: Negotiating Vulnerability

Against this backdrop, having described how women with HG are thrown into situations that test their limits, this analytical theme explores how a Facebook group became such a powerful source of support. In this section, I use a sense of digital community as an explanatory framework to interpret the participants' stories about how they perceive and engage with the HGS community. The results reveal vulnerability as a central determining factor in forming SODC. In that light, I illustrate how and why the community successfully exemplifies Butler's (2016) empowering perspective on vulnerability: "We are first vulnerable and then overcome that vulnerability" (p.12). I argue that while vulnerability can tear us apart and cause a withdrawal from social connection, a strong sense of community can become a uniting force of new connections (Lagerkvist, 2022, p.158). To support that claim, I will delve into the six elements of SODC, offering insights into how vulnerability is negotiated within the community, including the potential limitations and implications for its members.

Accessibility

I will begin by highlighting two aspects of Facebook accessibility for the HGS community. The first relates to how members discover and enter the community, while the second refers to how accessible they experience it. Both these aspects can amplify or deter the sense of community because accessibility makes a community more broadly available for anyone qualified to join and lowers the barriers to engagement.

For a community to effectively reach new members in a vulnerable and largely isolated state, it had to be easily findable where they already seek care: googling symptoms and talking to healthcare professionals. Clara, Linnea, and Katarina learned about the group from their doctors, nurses, and midwives. In contrast, Fredrika and Maja learned about the group by searching on Facebook and socialising on other Facebook groups. For Sophia, a broad search for information via Google about her condition led her to the group. However, it was the identification and sense of shared experience that made her engage:

> After I got the diagnosis from the doctor, I felt "I needed to google this!". Then I think it showed up under a keyword on Google or Facebook, and I felt, "OK, I'll have to check this out". Then I got a strong sense of recognition: "This is how I have felt; do other people feel this way as well?". (Sophia)

The participants also revealed that external material factors such as COVID-19 significantly enhanced the precariousness of their condition. The pandemic caused them to be more isolated and withdrawn from their daily social world, making social media more attractive when vulnerable (Turkle, 2011, p.1). Sophia expressed how it made her hesitant to meet anyone, and as a result, going online and searching for information became natural, an almost manic habit to both distract from nausea and find ways to cope with it.

Although the participants found the community in different ways, it is to be noted that they already used Facebook regularly and were active in other groups beforehand. Going online and engaging across different platforms and communities can be done without much deliberate effort or an articulated objective (Wohn et al. 2012). Moreover, Linnea and Maja shared how they joined multiple Facebook pregnancy and parent-related groups during their pregnancies.

The findings also showed that members use several other platforms to control their narratives and the extent of their intimacy. This speaks volumes about how poly-mediated communication can offer users choices that can lessen their vulnerability to being surveilled by an unintended audience (Chambers, 2017, p.34). Therefore, the accessibility of the HGS group caters to its members' vulnerable state by taking place on a platform that is already part of their daily routine, making engaging in a group less time-consuming or demanding. Consequently, it can lead to more frequent engagements, which in turn can strengthen the sense of community.

Membership

The HGS community is a closed Facebook community tightly managed by gatekeepers (administrators), separating those who belong and do not belong. To gain access to it, users must fill out applications that include clarifying questions to ensure they qualify for membership before they are allowed to join. I believe that the explicitness of the group's FAQs serves to account for the boundaries of HGS, whereby the closed nature of the group has been essential to its value for its members—for everyone's benefit; it is apparent who belongs to this group: women in Sweden suffering from HG.

The most crucial quality of this attribute is members' identification with the community. Here, the identification stems from the fact that the members and the collective identity are anchored in the shared transformation journey of simultaneously being thrown into illness and parenthood. It is the member's identification with the group that forms their engagement as suggested by Dahlgren & Hill (2020). All the participants' engagement with the group stems from seeing others who have had the same experience and understand their suffering, making them feel less alone. Thus, the experience of suffering alone can be viewed as a significant personal sacrifice that brings members together and strengthens their community. Katarina shared this view:

> I think it's so hard for people not going through it to understand it, and through a group like that, when everyone has gone through it, we can relate and understand each other. (Katarina)

To distinguish those who belong from those who do not, the community creates a shared understanding of the contextual meaning of certain symbols. I understand symbols or things as materials (Coole & Frost, 2010) the HGS members commonly upload, share, and discuss, such as hospital selfies and photos, ultrasound sonograms, IV Drips, pregnancy tests, growing belly pictures, newborn pictures, quotes, memes, or mentions of certain medications, such as Lergian, Pimperan, Ondansetron, Cortisone, etc. Although some posts were more serious than others, there were also posts aimed to be answered quickly, such as a mundane question posted by Clara:

> A question for all of you who take Ondansetron. How many mg do you have, and how many are you allowed to take per day?

A short post like this gathered 14 comments from women who were keen to share their dose of ondansetron intake, a medicine against nausea often used by cancer patients going through chemotherapy. This showed how comfortable many members were disclosing such personal information to help confirm others through mutual understanding of the means behind such posts. McMillan & Chavis (1986) make the critical point that “understanding common symbol systems is prerequisite to understanding community” (p.10), meaning that if one understands what a meaningful symbol for a community is, one could also better understand how that community perceives meaning. To be a community member, one needs to be or have been suffering from HG and behave in a way that conforms with the group's norms.

Influence

Influence is a two-way street rooted in the members’ need for consensual validation and the community’s need for conformity (McMillan & Chavis 1986, p.11). The HGS community is an excellent example of how the members receive helpful and empathetic responses and express gratitude for their support, motivating them to reciprocate and remain part of the community (GrafeFarfaglia et al., 2006, pp.94-95).

Hearing Fredrika's general experience and reflection on the motivations surrounding the HGS community was interesting. She said that it was an inherent part of human nature to seek out others who are in the same situation and form connections. For Fredrika, the group provided her validation and made her feel seen by answering her post empathetically. This, in turn, prompted her to reciprocate and do the same for others by answering posts she felt she could contribute. Furthermore, she noted that Facebook sometimes notified her about someone's post on the group, nudging her to react and engage with them.

> When someone else is in a [vulnerable] situation, and I feel like I can answer a question or be kind, I will do it…it takes me very little energy and time. (Fredrika)

Fredrika's reflection on the community norms and boundaries caught my attention because she understood the group's functions and the platform's capabilities well and even shared an anecdote about censorship faced by members during the pandemic. She said the word 'corona' was not allowed in group discussions for some time as it violated Facebook's sensitive topics policy. Hence, the way to know how to act and appropriately use practices within the group is based on community norms (Baym, 2010, p.113). This can only be learned by engaging in groups and observing acts of these norms being negotiated and reinforced (ibid.). In this case, evidence of community norms can be found in the six community guidelines stated in the Facebook group, including keeping a friendly tone, respecting each other's privacy, no hateful content or bullying, no spam or advertisement, studies & data collection require admin consent and a ban on sharing medicine.

The latter was a concern for all the participants, as they told me it was a sensitive topic. However, there have been instances where some members, out of solidarity, sent out their leftover prescription medications for others who had not gotten them prescribed themselves. As a result, the administrator added to the guidelines and prohibited it from happening again.

> I think they put it in [the guidelines] because I know more people did it, and they suggested sending medicine to others. "Are we trading drugs here?" (Clara)

Clara and the other participants felt discomfort when seeing similar posts about medication that went off-topic. For instance, Maja expressed concerns about how some of the posts can sometimes scare people and do more damage than good, especially for members who are first-time parents.

> It can be a bit dangerous if you write specific medical advice to someone you don't know well on Facebook, and then it comes up with all sorts of tips that may not be helpful or even harmful. (Maja)

Linnea pondered the same sentiment, telling me that she understood that people mean well and wanted to warn others about the side effects of some medications. However, she also felt conflicted as such a post can become problematic for those who need to get medicated to function.

> Of course, I think about it [side effects], but simultaneously, to survive, I need to take it! (Linnea)

The participants reflected on the complexity of online interactions that constantly involve negotiating restricting attitudes. (Christensen. et al., 2017). As such, the community can offer support while imposing new limitations, creating alternative ways of displaying empathy (Lövheim, 2013). Hence, community conformity creates a necessary cohesiveness (Macmillan & Chavis, 1986, p.11) in the group that is reinforced by community norms– imposed by the administrators, members, and the platform's policy.

Integration and Fulfilment of Needs

Community integration and fulfilment of needs require shared priorities, needs, and goals among members (McMillan & Chavis, 1986). The alignment of such, for the HGS members, comes from the shared experience of all having been thrown into this illness while pregnant and now going to Facebook for support. All participants spoke of the support they have received and their devotion to, in turn, supporting others. From the lens of Baym’s (2010) three types of support resources, the interviews revealed that all three –esteemed, informational, and emotional–function as reinforcement mechanisms within the group.

To illustrate an example of informational support, Sophia shared a post about understanding the practicalities around registering for sick leave and gave me explicit consent for citing it.

> I called my midwife today to discuss extending my sick leave with a doctor. Unfortunately, they have no time with the doctor connected to the maternity care centre until Monday. My sick leave expires the Friday before. What should I do? Do I go to work on Monday? Do I call in sick? What have you done? I have never been on sick leave before, so I really don’t know how this works. (Sophia’s post in HGS Group)

Sophia received much helpful guidance in the comments. Although her issue was resolved and she considered deleting her post, she left this post in the group as a resource, as an act of reciprocating the support, hoping it can help other readers facing similar difficulties. Like Sophia, Fredrika also told a story of the emotional support she received from the group, telling me how the group has been a great source of comfort during her pregnancies, particularly the second one, where she was more prepared for HG. One of her posts during her pregnancy was simply about self-maintenance and seeking out information on how to navigate her pregnancy this time around:

> …I feel inadequate for my child, who is too young to understand why I can't bear to play with her, even though I try to explain as best I can. Nine months is an eternity when you feel like this. I know that you know. (Fredrika)

Now, more than two years after her last pregnancy, Fredrika is still active, although not as active, in the group, helping others based on her own experiences. In conclusion, powerful reinforcement mechanisms of support within the HGS group make the community strong and cohesive. The fact that the members remain members, even years after giving birth, could be explained by a need to give back the support they received or a sense of civic responsibility towards those inflicted by HG.

Shared Emotional Connection

Shared emotional connection refers to a strong bond between members with similar histories or experiences, allowing them to identify with each other (McMillan & Chavis, 1986, p.13). Previous studies have shown how emotional connections can be built around a shared vulnerability (Christensen et al., 2017; Lagerkvist & Andersson, 2017; Stenström & Pargman, 2021). The findings elucidate two sources of identification shaping their emotional bond: the shared, indescribable experience of suffering from HG and a profound sense of female friendship.

When I inquired with Sophia about her group posts, she presented her latest one on her phone, beginning with the phrase, “I just have to vent a little bit to you all who understand.” This prompted me to ask further about who exactly understands, to which she responded that those enduring the same extreme emotional and physical burden of HG. All participants expressed similar explanations of bonding through uniquely understanding the indescribable experience. Clara expanded this slightly, recognising a shared vulnerability in which all are desperate to find help:

> To find someone who understands. And who has experienced the same thing, who understands one's feelings, one's despair...and understands how desperate one is in the situation to find something to help the moment. (Clara)

The indescribable experience refers to the previously discussed corporeal dissonance, whereby the community allows them to form the connection and bond that the absence of labels and accurate language hinders them from finding elsewhere. Sometimes, the nausea can dominate their life to the point where many have felt conflicted over continuing their pregnancies. Katarina said she had often seen posts about women considering abortion, but the responses were often supportive. This prompted me to ask further in detail about what makes it supportive. She answered:

> You're extremely vulnerable when you're going through that [HG]. I experience that people have written in a more supportive sense, like: "Either way, it's the right decision, even if you choose to have the kid, or if you do an abortion like it's up to you, it's right decision either way, whatever you choose". (Katarina)

These reflections showcase the bond between the group members, distinctively among women and can be characterised as a form of sisterhood or female friendship.

The women in the interviews highlighted the positive and supportive sisterhood in the community, contrasting it with other female-only groups that often have an element of competition. Sophia pointed this out, explaining how the community is warm and has the spirit of caring for one another. Finding a sisterhood during such a vulnerable time is something they were all grateful for, and as Clara states, the norms of the group became that of support and love:

> There is so much love, and I am so grateful for that because my experience of being close to other women or socialising with women is that women stab each other in the back. We are not nice, but there was none of that in this group. It was only pure love. (Clara)

Another perspective on female friendship is that it is a spiritual bond formed around an exclusively embodied female experience. Like how they can feel inarticulate in expressing their illness, there is an indescribable element to the experience of pregnancy and carrying a life (Bost, 2010). With HG, it becomes even more complex and difficult to describe, as life is now also being threatened by illness, a precarity that the members can all identify with. Therefore, friendship can be explained as the quality that comes from individuals' emotional and psychological bonds rather than external material possessions (Carter, 2005, p.164). It is solely based on the feeling of connection through vulnerability and trust.

Privacy

The attribute above illustrates how socialising online is part of the members' daily lives. They are prompted by easy accessibility to a space provided by social media platforms to connect with like-minded others and build new relationships while simultaneously negotiating norms and boundaries (Lövheim, 2013). All of this is happening at a distance. The online threats and dangers the members face are intensified by their partial awareness of them, fostering a sense of invulnerability as they expose themselves from behind their keyboards, seemingly removed from immediate physical harm (Miller, 2019; Zuboff, 2019). To exist online and with others means an ongoing internal negotiation of privacy and vulnerability (Miller, 2019, p.172). Accurately, the interviews revealed that when one is as vulnerable as when suffering from HG, privacy concerns take a back seat to the need for help. In that sense, the members decidedly view the community as a relatively safe space, and while their internal negotiations around privacy may inform their engagement, they remain largely uninhibited by it. Their choice to not be too restricted by seemingly abstract threats is connected to their determination to remain autonomous.

When asked about their awareness of privacy concerns and their impact on their engagement, participants all agreed that they were aware of potential threats yet were not concerned that they were overly exposed to them. While they may feel confident in their choices, concepts such as surveillance capitalism, dynamic ambiguity, and the participation paradox highlight the core issue: the lack of awareness about the extent of their vulnerability online means that their decisions are often uninformed (Zuboff, 2019; Lagerkvist 2017; Balbie & Magaudda, 2018). Regardless of whether it is built on an illusion of control, the sense of privacy is a crucial element in building SODC, especially in this case, where emotional safety heavily relies on the feeling of privacy when seeking existential security. Without the sense of privacy, it becomes difficult to express vulnerability, pursue intimacy, and seek support online.

5.3 Facebook as a Lifeline

Building on the previous analytical themes' depiction of women facing a limit situation due to HG and their engagement in the HGS community, this section explores their decision to seek online support. It focuses on the members' shared vulnerability and examines the motivations behind this choice in greater detail. What does Facebook offer that they could not find offline? While the preceding section explains how the community operates in fostering a sense of community, this section delves into the impact of this sense of community on its members. Concerning the discussion of the motivations, I will pay particular attention to Lagerkvist's (2022) depiction of how social media can be salvific, providing a humanitarian presence, mundane and material, and entailing an ongoing project (p.156). This is to illustrate how Facebook can function as an existential lifeline in relation to the members' health, sociality, and identity transformation.

Salvific

All the interview materials showed that seeking advice for relieving nausea was central to how the HGS community functions as salvific. The participants agreed that conversations about different medications were the group's most common posts. For them, the community functioned as a salvific tool to gather information from others about the medications that have helped them and how to ask healthcare practitioners for them. The findings showed that not only can medication help the members break the physical pattern of nausea and constant vomiting, but it also plays a pivotal role in providing a glimmer of hope that their condition might improve.

At times, the urgency can be overwhelming due to the desperation felt when engulfed in the fog of nausea. Clara specified this urgency and told me why she thinks women engage with the community.

> In the midst of HG, you're so desperate to get rid of it that you're like a junkie looking for a high. What's next? What's the next fix? What is the next thing I can do to get 10 minutes without this nausea? (Clara)

Clara explained how the group has helped her process her traumatic HG journey, where she was hospitalised from week 13 to week 28. Unlike Katarina, who received empathetic hospital care, Clara's experience was quite the opposite. During her stay at the hospital, Clara shared she was given all sorts of medication and was fed liquid form of food through tube feeding. While already at most vulnerable, her experience became more challenging, enduring both emotional and physical abuse by the healthcare provider: "They didn't believe me and said that I was exaggerating because I was given medicine…so I should not feel sick anymore.". Clara continued about how the constant vomiting conflicted with her type one diabetes and how this caused her sugar levels to deteriorate. Her experience with pregnancy and hospitalisation became even worse when cared for by a staffing nurse who had not treated women with HG before and was blatantly ignorant. Clara remembers many occasions where she was treated badly and mentioned one specific time when she had vomited to the extent that the tube feeding had jumped off a few times, which irritated the nurse who took care of her.

> She got so angry that she didn't numb my throat or put lube on it; otherwise, it might be hard to come down. No lube, no anaesthetic. She pushed it down, so I bled something so terrible. My partner was there, and he saw everything that happened. (Clara)

Despite all this ordeal, Clara's eyes always light up when talking about the community's role in her healing process. She described the community as "a warm hug and like a big pregnancy family" that gives support that no one who has not experienced HG can. She even went on to praise the group as having more knowledge than the whole of Lund's University Hospital and that the members know more about the consequences of HG. She concluded that her experience with the community was, in many ways, unforgettable.

Clara's sentiments about the group's value and role as a place to vent and receive affirmation emerged as common themes among the participants. As such, the Facebook community's role can be salvific because it operates as a lifeline when the healthcare system or any other source of support fails. Therefore, in this context of framing the HGS community as a lifeline, it illustrates the role of digital media in addressing deeply personal and life-changing events, which can justify why digital media has deep existential implications.

Humanitarian Presence

While going through this ordeal, knowing that there are people who truly understand what one is going through is one of the lifelines of the Internet (Lagerkvist & Andersson, 2017, p.556). Sometimes, no amount of medical advice or prescribed medication can replace the meaningful presence, the act of kindness, and the non-judgemental atmosphere in a supportive online community. In the community, women share their experiences, vent their frustrations, and seek emotional support from those going through the same thing. However, during moments of physical and mental distress, finding the right words can be challenging. According to Stage and Hougaard (2018, p.3), emojis can be a powerful tool for these individuals to convey their feelings more "relational, affective". With the help of Facebook's affordances in the form of emoticons, the members were given tools to display a sense of shared emotions. For Fredrika, it felt freeing being able to vent one's frustration, and there would be a caring response from other members, "Sometimes you just write that you have a shitty day and people would respond…or they could just send hugs, and that would be enough", she said. Fredrika said she believed that all humans are social creatures, but our current society is not structured that way. She elaborates:

> It is so individualised, and most people consciously or unconsciously search for their village to meet like-minded people who can give a group or village feeling. (Fredrika)

All the participants agree with Fredrika's premise about their search for belonging. Sophia, for example, also talked about the community feeling similarly, telling me that she thinks everyone in the group is there because they need confirmation that they are not alone. Just knowing that others are going through it, too, was comforting enough. There were many times when Sophia felt a yearning for social interactions during her pregnancy, and thinking back, she told me that she should have sought help and talked to someone about her conflicted feelings about keeping the baby. On top of having difficulties bonding with the foetus in her belly, Sophia also feared her friends and husband would think negatively about her and get a different opinion about her character if they knew her inner thoughts. Although she did not share or disclose these feelings in the community like many others, she found it comforting to read other people's posts and realise that she was not the only one feeling conflicted and miserable.

There was a "sense of security to get validated that people were going through the same ordeal", she said. Like Sophia, Maja also talked about the important function of the HGS community and how her fear of being misunderstood led her to engage with this group. She described how she sought help from the maternity care centre many times but was often rejected due to strict ketone measurement[7]. My interview with her was the only one conducted outside the home, at a meeting room in Malmö's library. It was emotionally charged, and there were moments when Maja struggled to hold back tears. As she spoke, I could see the frustration in her eyes while telling me her conflicted thoughts:

> I was always afraid to whine too much to friends or family, and I held a lot inside of me about how tough it had been. It was mostly my partner who had to put up with it, and I often felt that I had nowhere to release these feelings. (Maja)

Although not every participant related to everything said in this group, they found solace in the group because there were no other options for talking to people with HG. Katarina explained that even though she did not share anything on Facebook except for sometimes liking posts, solely reading other people's posts gave her a sense of not feeling alone. Katarina explained:

> I didn't ventilate my thoughts as we've talked about, but it was still a sense of not feeling alone, reading other people's stories, and supporting each other going through that because it's so hard. (Katarina)

The participants' voices showcase how emotional connection and recognition of vulnerability were the most important functions of the community. It is not about being active producers. Sometimes, it is not about words but about displaying empathy towards other members

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[7]. Urine measurement can be used to analyse dehydration. However, it is not always reliable on pregnant bodies (Howden, 2024).

through platform affordances, using affective clicks such as a thumbs up, a heart (or a broken one), a hug, or a crying emoji.

The act of observing and not sharing anything is what many media scholars call *lurkers*. This term generally refers to those who participate in all the information but do not post anything themselves, remaining largely invisible and "passive" (Boyd, 2011; Preece et al., 2004; Baym, 2010). Lurkers often passively observe, protecting their privacy, and then, once comfortable, they reveal themselves to the group and allow the emotional connection to be reciprocated (Kozinets, 2010, p.34). However, the collected materials have shown that lurkers are primarily misunderstood in this context, as it underestimates the shared emotional connection in a community. Simply because they are not posting does not mean they are passive or cannot contribute to a shared emotional connection (Preece et al., 2004). It was evident that all participants were active members, but not through posting but through emotional relatability. They felt engaged through the readings and identifications of the storytelling, which led to an emotional attachment to other group members (Tonteri et al., 2011, p.2221). As such, the most silent group members can still form solid emotional bonds by recognising a shared identity and spiritual connection.

The Mundane & Materials

When one falls ill, their entire world changes. The sick person finds themselves in a unique situation where their body feels both personal and shared pain as an illness serves as an opening to "becoming a diadic body" (Frank, 2013, p.36). While the person experiences her own pain completely, she also empathises with others who have suffered or are suffering the same way (ibid.). However, seeking support is not always easy, as individuals may feel forced to enter an unfamiliar world and struggle to make sense of their new reality. In this context, the mobile devices become *haptic*, in the literal sense that they can hold on to them while isolated in the hospital bed waiting for what is to come (Lagerkvist, 2022, p.161), just like what Turkle (20211) is saying about us being "tethered" to our machines. Moreover, the HGS community can become a lifeline in managing the members' conditions simply by using Facebook to stay connected during times of uncertainty.

When asked what kinds of sociality and materials are shared in the community, all the participants agreed that most posts involved shared text, informational links, and photos. One of the most recent topics that all the participants recalled was a news report about the newly discovered gene GDF15, which causes severe nausea (Fejzo, 2024). For many, this news was well received by the members, with the causes finally being scientifically labelled, confirming they were not weak or failed. Linnea talked about this news with great enthusiasm and told me that she used to sit next to a woman while receiving IV therapy who said, “I will never do it [pregnancy] again unless they find a cure.” Linnea shrugged her shoulders and guessed that this news might change that person’s mind.

Beyond the written materials, many pictures were also shared. Fredrika told me that she had seen many of them, many of which were taken when someone was hospitalised or receiving IV therapy. However, the most memorable materials the participants remembered were pictures of newborn babies. These pictures were a powerful source of motivation for managing the participants' mental conditions. Clara told me that the baby pictures represent the ultimate reward of this ordeal:

> Some names you recognise and who have made many posts, so when you see them posting about their baby's arrival, including pictures, you are just happy for them. It's something I think cheers up those who are still pregnant. (Clara)

This feeling of reward prompted Sophia to share a picture of her newborn with the group. Although initially reluctant about how it would be received or if it is ethical to post pictures of children online, she did so anyway because she felt happy seeing others sharing them. From seeing them, she also got the reassurance that their birth went well, it could go well, and nausea would disappear. Sophia explained:

> You look at the pictures and get happy; you know exactly this feeling. “Yes, it's over, and yes, everything went well, and I have a child!”...that kind of feeling. (Sophia)

Maja, who has yet to give birth, agrees with Clara’s and Sophia’s viewpoints and even describes how she would not have been able to keep her mood up if it were not for imagining a baby coming out of this misery. That will be her biggest reward, she said. Thus, these pictures act as a way to connect with physically distant people; even though they are not close, they can help the members feel validated through “embodied connectivity” (Lagerkvist, p.161). As such, this connects to the previous sub-section about the importance of knowing somebody is always there for you.

An ongoing project

The final lifeline is the ongoing project that gives meaning and purpose, involving engaging in certain activities that keep one focused and motivated. According to Lagerkvist (2022, p.161), individualised activities can become a continuous project sustained by social media platforms like Facebook. Even after giving birth, the participants of such projects continue to be group members. Hence, their continuous membership can provide a sense of stability and normalcy, which can be comforting during uncertain times.

When the transitory condition of HG ends, the women land and find a new footing in this new reality, looking around to evaluate where they landed and who they have become through the journey. Arnold-Baker (2020) argues that limit situations often offer a chance to break away from outdated aspects of oneself. In these moments, individuals can choose to take responsibility for crafting the life they desire for the life they created.

There were three commonalities in what the participants expressed about who they have become after HG that I wish to highlight. Firstly, many shared a newfound appreciation for life, exemplified by Sophia saying, "We celebrate what we can celebrate; you never know if you'll die tomorrow!". Secondly, the participants expressed that alongside their new perspective on life, they have also lost and become strangers to who they used to be, as recounted by Clara who has had a change of perspective on motherhood:

> The person I was before my pregnancy is no longer there. At the same time, I can see that I appreciate things on a whole other level now that I have a child. I cannot really place my finger on what makes me not the same person I was before. The only thing I think about now is that: instead of being a 'baker-mum', I want to do everything I can to be there for her, here and now." (Clara)

Thirdly, and perhaps most profoundly, all expressed sadness and feelings of guilt in struggling to negotiate whether they can have another child or not. As Katarina regrettably expressed, "I don't think I ever want to go through it again, which I'm really sad about because I would like to have a sibling for Louie, but I don't think it's worth it". What Katarina said represents another layer of loss on top of losing the imagined pregnancy experience.

This was further highlighted in my interview with Fredrika, a mother of two with whom I shared an emotional afternoon in her kitchen. While we spoke, her five-year-old sat and coloured beside me, and on the opposite side of me sat Fredrika, breastfeeding her youngest. Witnessing this raw motherhood scene that I could relate to helped me to contextualise her situation and her longing for what could have been if it had not been for HG. Like the others, Fredrika explained how she was so happy when finding out she was pregnant after trying to conceive for over two years. During those two years, while trying, she prepared her body with supplements, ate organic food, and envisioned herself keeping up with a healthy lifestyle by practising yoga and other health practices. This soon would become an illusion when HG caught up to her. She explained that her vision of pregnancy became interrupted in the ways that she could only plan her day after day. When asked about her challenges and memories with HG, Fredrika became emotional. Tears were falling down her cheeks, and she switched to English (so that her kids would not understand), telling me how she envisioned herself with more children, and now it was not even a possible thought. The burden of guilt of having a body that fails to meet society's healthy standards adds to the struggle. Being unable to give their children another sibling was a recurring theme throughout all interview sessions, as all members talked about their insecurities about going through the same ordeal again. Moreover, they felt tremendous guilt towards their partner and towards their first child, both for the implications of having more children in the future and for not being present and requiring care throughout the pregnancy.

From these conversations, I realise that HG may be a transient physical challenge, but its impact persists. As Frank (2013) aptly puts it, "The voices that speak to us at particular moments in our lives, especially during transitions or crises, imprint themselves with a force that later voices never quite displace." (p.xii). To this day, HG still evokes a lingering trauma, easily triggered by nausea to bring them mentally back to their darkest period, and acts as a guilt-ridden burden on future dreams of having more children. Knowing this made me wonder how this could have been prevented or better cared for.

6. CONCLUDING DISCUSSION

Beyond morning sickness, there is a precarious life. In my preceding analytical themes, I have shown that life can be unpredictable and, at times, even throw us into situations we have not chosen or aimed for, leaving us vulnerable. We have seen how the participants have experienced vulnerability during pregnancy while grappling with the challenges of a widely misunderstood illness. The lack of awareness about HG made it difficult for them to make sense of their condition and explain it to others, as there are no fitting labels to describe it.

Although the participants in this study had an idea of how their pregnancy could look—based on impressions of others and mediated experiences—their bodies' responses to pregnancy conflicted with the reality of their materiality. This puts them in a position where they feel a loss of control, are exposed to tremendous guilt, and experience an existential awareness inhabited by the uncertainty of what is to come. Due to the global COVID-19 pandemic, which caused an unprecedented time of uncertainty, the precarity of most participants in this study was further heightened. As such, it illustrates how outside material factors beyond the scope of a human-centric point of view can shape our experiences.

Adopting a new materialist lens revealed how materials such as nature, culture, and biological have their own agency—co-shaping the human experience—and, in this case, making the participants more vulnerable, isolated, and withdrawn from their daily social world (Braidotti, 2023, p.94). Already here, we could understand why the participants felt the need to seek out and connect with others to cope with their limit situation. This is where the HGS community became relevant for all the participants. They all found it comforting to know that others are going through the same ordeal, and by coming together, they can safely process their vulnerability.

Common Purpose

By utilising the SODC framework to analyse the community, we gained a more granular perspective of the underlying forces, providing a basis for answering the first research question: *How do Existers in the HGS community find meaning and purpose in their engagement with the HGS community?* Standing out is how a shared emotional connection and female friendship provide meaning across their engagement and how their drive to help others pointed towards a seemingly uniting purpose of civic responsibility to better care for anyone inflicted by HG.

To clarify, there was a sense of understanding that beyond reciprocating the support received, the purpose derived from feelings of injustice towards the insufficient care, resources and support provided in the physical world for women with HG. As the existers had never heard about HG before, nor have many health care providers, the members are fighting a battle on two fronts. The first battle is to provide immediate care to the women suffering from HG, while the second is the long-term battle in spreading knowledge about the illness so that others can be met with appropriate empathy by society and medical caregivers in the future. I relate this to the existers having developed a *civic identity*, a sense of agency that is ethically and politically motivated through their engagement with the HGS community (Dahlgren & Hill, 2020, p.8).

The interviews also revealed that what lay beneath the shared emotional connection and female friendship was the identification with the vulnerable existential and physical limbo they had all been thrown into (McMillan & Chavis, 1986; Christensen et al., 2017; Lagerkvist & Andersson, 2017; Stenström & Pargman, 2021). The vulnerable limbo is difficult to untangle, as it is both an embodied experience triggered by the body's materiality as well as an embedded experience where HG conflicts with the culturally imagined pregnancy (Hanson, 2004). The complexity creates an indescribable experience with a deep spiritual bond among those who can uniquely understand it—only through being in it.

Furthermore, their vulnerability takes on a new form as the existers navigate it online; as suggested by Turkle (2010, p.1); it is in these cases where technology is especially seductive. Interestingly, participants in the community continued to engage actively despite being aware of privacy risks on Facebook. Thus, the potential risks are perceived as secondary, whereby they feel safe enough to form intimacy in the closed forum and feel in control of their exposure. Unlike privacy, intimacy is about sharing, not hiding. It is seen as a rewarding part of relationships that requires effort and commitment from both sides, whereby they continuously work on and adjust their connection based on mutual understanding and trust (Carter, 2005). However, this perceived sense of control can arguably be illusory, potentially giving way to a false sense of security that further exposes them to surveillance capitalism's subtle yet potent forces (Zuboff, 2019). Nonetheless, as the participants felt safe enough to engage, they could gain a meaningful and fulfilling experience and form a sense of community.

Navigating the Self

Despite the challenges of being vulnerable online, social media can also open up new opportunities to manage one's life and illness (Lagerkvist, 2022). This brings us to conclude the last analytical theme: the HGS community can also serve as a caring medium that helps “limit and mitigate our fall” (Lagerkvist, 2022, p.150). With mobile devices in hand, the existers can manage their condition even while disconnected from the outside world and suffering from severe nausea and vomiting. Facebook is always accessible and can offer comfort and care around the clock, serving as a literal lifeline (Lagerkvist, 2022, pp.151-152). Here, we look at how that lifeline reflects how the existers navigate the self through this digital limit situation.

The analysis's findings showed three thematic motivations from the interviews: self-maintenance, ventilation, and seeking advice and information. These motivations were positioned following Lagerkvist’s (2022) characterisation of lifelines on the Internet to fathom why the participants decided to engage in the HGS community. The participants’ responses traced back to the existential challenges and struggles they were confronted with.

Understanding how Facebook can function as a lifeline clarified how their engagement in the community could be viewed as representative of their evolving perception of self, and as such, addressing the second research question: *What existential challenges and struggles do members of the HGS community face, and how do these struggles influence their perception of the self and their engagement within the community?* Based on the responses of the participants, it was evident that they struggled physically and mentally with nausea, which they found imperative to relieve. However, through the community, they could express their conflicted feelings about their illness and receive practical guidance on how to cope with it. One key aspect that emerged was the importance of advice and information about medication, which assisted in navigating their bodies' materiality and provided hope and relief, enabling them to manage HG and continue their pregnancies. Subsequently, the HGS community offer a safe space for the participants to narrate their own stories without feeling judged. Knowing that others were there and sharing a similar experience was enough to provide meaningful comfort, and something as simple as sending cheering emojis could motivate and help them feel better.

Throughout the analysis, the participants' perceptions of themselves were influenced, so they are now more humbled towards life. Although nausea and vomiting disappear after pregnancy, the emotional burden is still lingering. Their lives continue, but the person they were before pregnancy is not who they are today. The fact that five of the six participants I interviewed were no longer pregnant yet still active (sometimes nudged by Facebook) in the group shows how powerful the reinforcement mechanism of support is within the HGS community. The continued engagement is interpreted as motivated by reciprocating support or a civic and ethical responsibility regarding the treatment of HG, yet I suspect that there is also an ongoing therapeutic element in being able to create something positive from their suffering, thus healing the old scars by trying to heal and care for others (Frank & Solbraekke, 2023, p.81).

In summary, the existers may initially turn to the HGS community as a lifeline to relieve their immediate physical burden. However, once there, they come to feel safe enough to explore existential questions and dilemmas by sharing their thoughts with others and reclaiming their sense of agency. When their HG journey eventually ends, they reflect on how it has been, how it is now, and who they have become. Finally, on the other side of the journey, they are empowered with civic identity and can process their lingering pain by helping others. Hence, engagement in the community enables the existers to overcome their vulnerability and feel safe enough to navigate their limit situation.

Final Reflections

To relate my findings to a wider discussion about media usage during times of vulnerability, arguing whether digital media is good or should be resisted perpetuates a narrative that oversimplifies our agencies and our purposes—assuming that one or the other cannot grasp the whole picture of how the vulnerability is experienced, lived and practised. As danah boyd (2015) notes: “Social media certainly make it much easier to peek into people’s lives, but it is also quite easy to misinterpret online traces.” (p.18). Hence, to fully grasp participative motivations, boyd suggests (2015, p.18) we should incorporate qualitative research involving more detailed open-ended questions about people’s lives and social media habits.

Hearing the existers talking about their experiences, it became apparent that the journey towards motherhood is often attended by difficulties and precarity that arise at any stage. What was eye-opening about this revelation was the diverse set of stories that move beyond morning sickness, some of which involved loss, miscarriages, diabetes and giving birth prematurely. Such situations can already be considered limit situations, as Stenströms and Pargman's study (2021) highlights. This revelation made me realise there is more to explore as the path towards parenthood is rarely straightforward. Hence, there is an inherent limitation as I oversimplify the limit situation to that of HG during pregnancy, while there could be unrelated yet equally transformative events influencing the participants' vulnerability. Succinctly, further research about vulnerability, precarity, and its challenges, both on the individual and structural levels, is needed. Being open to vulnerability and addressing its challenges can be one way to understand our responsibility and accountability in our digitalised world.

Against this backdrop, I wish to mention three opportunities for future research. First, while this thesis aims to address a scarcity of studies on the condition of HG, much more is needed from a media perspective to understand its implications. Second, we could all benefit from understanding what a health support group means for the people involved, and studying them can help healthcare institutions, family, and friends provide better care in real life. While I discuss various explanatory logics for why the participants continue to care for others in the HGS community, including reciprocation of care received, motivation by a civic identity, or even a therapeutic process for processing one's trauma - the question remains open and deserves further attention. Thus, the third suggestion involves a better understanding of creating digital spaces where caring for others simultaneously fulfils one's needs and creates a reinforcement mechanism of community care.

Illustrating how a digital community can offer care and support those in a vulnerable state is a central tenant of this thesis—the HGS community is argued to represent a caring media. While I acknowledge the entanglement and often inseparability of the online and offline, I do not adopt Couldry and Hepp's (2017) argument that all aspects of human lives are now "fully mediated" by technology (p.7). More specifically, I want to underline the indispensable nature of human interaction and care, especially during illness when we depend on the human touch. I instead assert Lagerkvist's (2019) position that some elements exist outside the technological reach and remain non-digitalised, such as a "hug, a meal, or the wind" (p.8). More than that, what happens to those with vulnerable bodies that require the care of "a gentle touch, soothing, bathing, or holding?" (Schwartz, 2019, p.85). If these activities do not count, then Lagerkvist's (2017, p.97) question about what it means to be a human being in the digital age needs to be rephrased, whereby the term 'human being' ought to be changed to technical beings (Lagerkvist, 2019, p.8). On this account, the emphasis on the participants' engagement online is not meant to overlook their offline experiences. Rather, it is a way of taking a broader perspective on care: digital support together with—not instead—of human support.

7. ENDNOTES

This thesis was conceived through my own personal account of HG, a limit situation that has deeply impacted me and changed how I think, act, and see the world. Writing this thesis has been a journey of self-discovery and a way to positively contribute to society by shedding light on the rare topic of HG. If my research can alleviate some suffering for others, it would be a great privilege.

8. REFERENCES

ABC News. (2012). *Kate MIDDLETON PREGNANT: Prince William, Duchess of Cambridge announce pregnancy in royal statement* [Video]. YouTube. https://www.youtube.com/watch?v=GzvHdQt5fBU

Abfalter, D., Zaglia, M. E. & Mueller, J. (2012). Sense of Virtual Community: A Follow up on Its Measurement, *Computers in Human Behavior*, vol. 28, no. 2, pp.400–404

Ahmed, S. (2008). Open Forum Imaginary Prohibitions: Some Preliminary Remarks on the Founding Gestures of the `New Materialism', *European Journal of Women's Studies*, vol. 15, no. 1, pp.23–39

Arnold-Baker, C. (2020). Introduction: The Existential Crisis of Motherhood, in C. Arnold-Baker (ed.), *The Existential Crisis of Motherhood*, [e-book] Cham: Springer International Publishing, pp.3–16, Available Online: https://link.springer.com/10.1007/978-3-030-56499-5_1 [Accessed 6 May 2024]

Balbi, G. & Magaudda, P. (2018). A History of Digital Media: An Intermedia and Global Perspective, New York London: Routledge, Taylor & Francis Group

Barad, K. (2003). Posthumanist Performativity: Toward an Understanding of How Matter Comes to Matter, *Signs: Journal of Women in Culture and Society*, vol. 28, no. 3, pp.801–831

Baym, N. K. (2010). Personal Connections in the Digital Age, Cambridge, UK ; Malden, MA: Polity

Beirne, E. R., Andrews, L. B., Murtagh, L. P., Browne, S., Curran, S. B. & O'Brien, E. C. (2023). The Far-Reaching Burden of Hyperemesis Gravidarum – an Exploration of Women's Experiences and Perceptions of Healthcare Support, *Women & Health*, vol. 63, no. 7, pp.485–494

Benson, M. & O'Reilly, K. (2022). Reflexive Practice in Live Sociology: Lessons from Researching Brexit in the Lives of British Citizens Living in the EU-27, *Qualitative Research*, vol. 22, no. 2, pp.177–193

Bissinger, B., Leibovitz, A. and Diehl, J. (2017) 'Serena Williams on her pregnancy, finding love, and more,' *Vanity Fair*, 27 June. https://www.vanityfair.com/style/2017/06/serena-williams-cover-story.

Bornemark, J. (2006). Limit-Situation. Antinomies and Transcendence in Karl Jaspers' Philosophy, *SATS*, [e-journal] vol. 7, no. 2, Available Online: https://www.degruyter.com/document/doi/10.1515/SATS.2006.63/html [Accessed 6 May 2024]

Bossetta, M. (2018). The Digital Architectures of Social Media: Comparing Political Campaigning on Facebook, Twitter, Instagram, and Snapchat in the 2016 U.S. Election, *Journalism & Mass Communication Quarterly*, vol. 95, no. 2, pp.471–496

Bost, S. (2010). Encarnación: Illness and Body Politics in Chicana Feminist Literature, 1st ed., New York: Fordham University Press

boyd, d. (2011). Affordances, dynamics, and implications. In Papacharissi, Z. (Ed.), *A networked self: Identity, community, and culture network sites* New York, NY: Routledge, pp.39–58

Boyd, d & Marwick, A. E.. (2014). Networked Privacy: How Teenagers Negotiate Context in Social Media, *New Media & Society*, vol. 16, no. 7, pp.1051–1067

Boyd, d. (2015). Making Sense of Teen Life: Strategies for Capturing Ethnographic Data in a Networked Era.In Hargittai, E. & Sandvig, C. (eds). Digital Research Confidential: The Secrets of Studying Behavior Online, [e-book] The MIT Press, Available Online: https://direct.mit.edu/books/book/2285/Digital-Research-ConfidentialThe-Secrets-of [Accessed 8 May 2024]

Braidotti, R. (2019). A Theoretical Framework for the Critical Posthumanities, *Theory, Culture & Society*, vol. 36, no. 6, pp.31–61

Braidotti, R. (2022) *Posthuman feminism*. Polity Press.

Braidotti, R. (2023). Affirmative Ethics, New Materialism and the Posthuman Convergence, in G. Di Capua & L. Oosterbeek (eds), *Bridges to Global Ethics*, [e-book] Cham: Springer International Publishing, pp.93–108, Available Online: https://link.springer.com/10.1007/978-3-031-22223-8_7

Braun, V. & Clarke, V. (2006). Using Thematic Analysis in Psychology, *Qualitative Research in Psychology*, vol. 3, no. 2, pp.77–101

Buckwalter, J. G. & Simpson, S. W. (2002). Psychological Factors in the Etiology and Treatment of Severe Nausea and Vomiting in Pregnancy, *American Journal of Obstetrics and Gynecology*, vol. 186, no. 5, pp.S210–S214

Butler, J (2016) *Vulnerability in resistance*. Duke University Press

Carter, D. (2005). Living in Virtual Communities: An Ethnography of Human Relationships in Cyberspace, *Information, Communication & Society*, vol. 8, no. 2, pp.148–167

Chamberlain, C. (2020). What Am I? Descartes's Various Ways of Considering the Self, [e-journal], Available Online: https://jmphil.org/article/id/2147/

Chambers, D. (2017). Networked Intimacy: Algorithmic Friendship and Scalable Sociality, *European Journal of Communication*, vol. 32, no. 1, pp.26–36

Christensen, D. R., Hård Af Segerstad, Y., Kasperowski, D. & Sandvik, K. (2017). Bereaved Parents' Online Grief Communities: De-Tabooing Practices or Relation-Building Grief-Ghettos?, *Journal of Broadcasting & Electronic Media*, vol. 61, no. 1, pp.58–72

Cleghorn, E. (2022). Unwell Women: A Journey through Medicine and Myth in a Man-Made World, Paperback edition., London: Weidenfeld & Nicolson

Collins, N. (2018) 'Demi's big moment,' *Vanity Fair*, 16 April. https://www.vanityfair.com/style/2018/04/demi-moore-cover-story-august-1991.

Coole, D. & Frost, S. (2010). Introducing the new materialisms. In Diana H. Coole & Samantha Frost (eds.), *New Materialisms: Ontology, Agency*, and Politics. Duke University Press. pp. 1--43.

Couldry, N. (2017) *The mediated construction of reality*. Edited by A. Hepp. Polity Press.

Dahlgren, P. & Hill, A. (2020). *Media Engagement*, London: Routledge

Das, R. (2017). Speaking About Birth: Visible and Silenced Narratives in Online Discussions of Childbirth, *Social Media + Society*, vol. 3, no. 4, p.205630511773575

Davis, N. (2009). New Materialism and Feminism's Anti-Biologism: A Response to Sara Ahmed, *European Journal of Women's Studies*, vol. 16, no. 1, pp.67–80

Douglas, M. (2005). Purity and Danger: An Analysis of Concept of Pollution and Taboo, London ; New York: Routledge

Eagle, R. B. (2019). "Have You Tried Ginger?": Severe Pregnancy Sickness and Intensive Mothering on Instagram, *Feminist Media Studies*, vol. 19, no. 5, pp.767–769

Ellison, N. B., Steinfield, C. & Lampe, C. (2007). The Benefits of Facebook "Friends:" Social Capital and College Students' Use of Online Social Network Sites, *Journal of Computer-Mediated Communication*, vol. 12, no. 4, pp.1143–1168

Fan, J. & Yin, M. (2024). Offspring of Women with Hyperemesis Gravidarum Are More Likely to Have Cardiovascular Abnormalities, *BMC Pregnancy and Childbirth*, vol. 24, no. 1, p.119

Fejzo, M., Rocha, N., Cimino, I., Lockhart, S. M., Petry, C. J., Kay, R. G., Burling, K., Barker, P., George, A. L., Yasara, N., Premawardhena, A., Gong, S., Cook, E., Rimmington, D., Rainbow, K., Withers, D. J., Cortessis, V., Mullin, P. M., MacGibbon, K. W., Jin, E., Kam, A., Campbell, A., Polasek, O., Tzoneva, G., Gribble, F. M., Yeo, G. S. H., Lam, B. Y. H., Saudek, V., Hughes, I. A., Ong, K. K., Perry, J. R. B., Sutton Cole, A., Baumgarten, M., Welsh, P., Sattar, N., Smith, G. C. S., Charnock-Jones, D. S., Coll, A. P., Meek, C. L., Mettananda, S., Hayward, C., Mancuso, N. & O'Rahilly, S. (2024). GDF15 Linked to Maternal Risk of Nausea and Vomiting during Pregnancy, *Nature*, vol. 625, no. 7996, pp.760–767

Flyvbjerg, B. & Sampson, S. (2011). Making Social Science Matter: Why Social Inquiry Fails and How It Can Succeed Again, 13. printing., Cambridge: Cambridge Univ. Press

Frank, A. W. (2013). The Wounded Storyteller: Body, Illness, and Ethics, Second edition., Chicago: The University of Chicago Press

Frank, A. W. & Solbraekke, K. N. (2023). Becoming a Cancer Survivor: An Experiment in Dialogical Health Research, *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, vol. 27, no. 1, pp.78–93

Fuchs, T. (2013). Existential Vulnerability: Toward a Psychopathology of Limit Situations, *Psychopathology*, vol. 46, no. 5, pp.301–308

Gleeson, D. M., Craswell, A. & Jones, C. M. (2022). It Takes a Virtual Village: Childbearing Women’s Experience of a Closed Facebook Support Group for Mothers, *Women and Birth*, vol. 35, no. 2, pp.e172–e180

Grace-Farfaglia, P., Dekkers, A., Sundararajan, B., Peters, L. & Park, S.-H. (2006). Multinational Web Uses and Gratifications: Measuring the Social Impact of Online Community Participation across National Boundaries, *Electronic Commerce Research*, vol. 6, no. 1, pp.75–101

Grelz, A. (2023). Amanda Lagerkvist, Existential Media: A Media Theory of the Limit Situation, *Svensk Teologisk Kvartalskrift*, [e-journal] vol. 98, no. 4, Available Online: https://journals.lub.lu.se/STK/article/view/24953

Hanson, C. (2004). A Cultural History of Pregnancy, [e-book] London: Palgrave Macmillan UK, Available Online: http://link.springer.com/10.1057/9780230510548

Harrison, P. (2008) 'Corporeal Remains: Vulnerability, Proximity, and Living on after the End of the World,' *Environment & Planning. A*, 40(2), pp. 423–445.

Haraway, D. (1988). Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective, *Feminist Studies*, vol. 14, no. 3, p.575

Haraway, D. (1991) *Simians, cyborgs, and women : the reinvention of nature*. Routledge.

Havnen, G. C., Truong, M. B.-T., Do, M.-L. H., Heitmann, K., Holst, L. & Nordeng, H. (2019). Women’s Perspectives on the Management and Consequences of Hyperemesis Gravidarum – a Descriptive Interview Study, *Scandinavian Journal of Primary Health Care*, vol. 37, no. 1, pp.30–40

Heidegger, M. (1962). Being and time. In J. Macquarrie, & E. Robinson, (Trans.), New York, NY: Harper & Row

HER Foundation (2024) *About Hyperemesis Gravidarum (HG) - HER Foundation*. Available Online: https://www.hyperemesis.org/about-hyperemesis-gravidarum/.

Holden, M. (2012). Hospital divulges Kate’s condition in radio hoax. *Reuters*. Available Online: https://www.reuters.com/article/idUSBRE8B40HJ/

Hine, C. (2020). Ethnography for the Internet: Embedded, Embodied and Everyday, 1st edn, [e-book] Routledge, Available Online: https://www.taylorfrancis.com/books/9781000183030

Internetstiftelsen (2024). *Facebook*. Available Online: https://internetstiftelsen.se/guide/anvandarvillkoren/facebook/ [Accessed 8 May 2024]

Jagger, G. (2015). The New Materialism and Sexual Difference, Signs: Journal of Women in Culture and Society, vol. 40, no. 2, pp.321–342

Johannisson, K. (2015). Den Sårade Divan: Om Psykets Estetik Och Om Agnes von K, Sigrid H Och Nelly S, Stockholm: Albert Bonniers Förlag

Howden, C. (2014). Ketones – Why They Are Not an Indicator of Dehydration | Pregnancy Sickness Support. Available Online: https://pregnancysicknesssupport.org.uk/2024/01/18/ketones-why-they-are-not-an-indicator-of-dehydration/

Kozinets, R. V. (2010). Netnography: Ethnographic Research in the Age of the Internet, 1st ed., Thousand Oaks, CA: Sage Publications Ltd

Lagerkvist, A. (2017). Existential Media: Toward a Theorization of Digital Thrownness, *New Media & Society*, vol. 19, no. 1, pp.96–110

Lagerkvist, A. & Andersson, Y. (2017). The Grand Interruption: Death Online and Mediated Lifelines of Shared Vulnerability, *Feminist Media Studies*, vol. 17, no. 4, pp.550–564

Lagerkvist, A. (ed.). (2019). Digital Existence: Ontology, Ethics, and Transcendence in Digital Culture, London; New York: Routledge, Taylor & Francis Group

Lagerkvist, A. (2022). Existential Media: A Media Theory of the Limit Situation, New York: Oxford University Press

Lövheim, M. (2013) 'Negotiating empathic communication,' *Feminist Media Studies*, 13(4), pp. 613–628.

MacInnis, C., & Portelli, J. P. (2002). Dialogue as Research. *Journal of Thought*, *37*(2), 33–44
.
Marwick, A. E. & Boyd, D. (2014). Networked Privacy: How Teenagers Negotiate Context in Social Media, *New Media & Society*, vol. 16, no. 7, pp.1051–1067

McCarthy, F. P., Khashan, A. S., North, R. A., Moss-Morris, R., Baker, P. N., Dekker, G., Poston, L., Kenny, L. C., & on behalf of the SCOPE consortium. (2011). A Prospective Cohort Study Investigating Associations between Hyperemesis Gravidarum and Cognitive, Behavioural and Emotional Well-Being in Pregnancy, *PLoS ONE*, vol. 6, no. 11, p.e27678

McMillan, D. W. & Chavis, D. M. (1986). Sense of Community: A Definition and Theory, *Journal of Community Psychology*, vol. 14, no. 1, pp.6–23

Miller, V. (2019). The Ethics of Digital Being: Vulnerability, Invulnerability, and 'Dangerous Surprises', In: Lagerkvist A (ed.) *Digital Existence: Ontology, Ethics and Transcendence in Digital Culture*. London: Routledge, pp. 171–186

Morse, H. & Brown, A. (2021). Accessing Local Support Online: Mothers' Experiences of Local Breastfeeding Support Facebook Groups, *Maternal & Child Nutrition*, vol. 17, no. 4, p.e13227

Schwartz. M. (2019) Thrownness, vulnerability, care: A feminist ontology for the digital age. In: Lagerkvist A (ed.) *Digital Existence: Ontology, Ethics and Transcendence in Digital Culture*. London: Routledge, pp. 81–99

Mitchell-Jones, N., Lawson, K., Bobdiwala, S., Farren, J. A., Tobias, A., Bourne, T. & Bottomley, C. (2020). Association between Hyperemesis Gravidarum and Psychological Symptoms, Psychosocial Outcomes and Infant Bonding: A Two-Point Prospective Case–Control Multicentre Survey Study in an Inner City Setting, *BMJ Open*, vol. 10, no. 10, p.e039715

Nana, M., Tydeman, F., Bevan, G., Boulding, H., Kavanagh, K., Dean, C. & Williamson, C. (2021). Hyperemesis Gravidarum Is Associated with Increased Rates of Termination of Pregnancy and Suicidal Ideation: Results from a Survey Completed by >5000 Participants, *American Journal of Obstetrics and Gynecology*, vol. 224, no. 6, pp.629–631

Porter, C. E. (2006). A Typology of Virtual Communities: A Multi-Disciplinary Foundation for Future Research, *Journal of Computer-Mediated Communication*, vol. 10, no. 1, pp.00–00

Potnis, D., Halladay, M. & Jones, S. (2023). Consequences of Information Exchanges of Vulnerable Women on Facebook: An "Information Grounds" Study Informing Value Co-creation and ICT4D Research, *Journal of the Association for Information Science and Technology*, vol. 74, no. 12, pp.1365–1383

Poursharif, B., Korst, L. M., Fejzo, M. S., MacGibbon, K. W., Romero, R. & Goodwin, T. M. (2008). The Psychosocial Burden of Hyperemesis Gravidarum, *Journal of Perinatology*, vol. 28, no. 3, pp.176–181

Preece, J., Nonnecke, B. & Andrews, D. (2004). The Top Five Reasons for Lurking: Improving Community Experiences for Everyone, Computers in Human Behavior, vol. 20, no. 2, pp.201–223

Richardson, L. (1994). Writing: A Method of Inquiry. In Denzin, N. K., & Lincoln, Y. S. (Eds.), *Handbook of qualitative research* (pp. 516–529). Thousand Oaks, Calif: Sage.

Russell, R. & Sciences, U. of M. F. of L. (2012). Nausea and Vomiting: A History of Signs, Symptoms and Sickness in Nineteenth-Century Britain, [e-book] University of Manchester, Available Online: https://books.google.se/books?id=ALh_0AEACAAJ

Schwartz. M. (2019) *Thrownness, vulnerability, care: A feminist ontology for the digital age*. In: Lagerkvist A (ed.) *Digital Existence: Ontology, Ethics and Transcendence in Digital Culture*. London: Routledge, pp. 81–99.

Seale, C. (2011). *Researching society and culture* (3. ed). Sage.

Skeggs, B. & Yuill, S. (2019). Subjects of Value and Digital Personas: Reshaping the Bourgeois Subject, Unhinging Property from Personhood, *Subjectivity*, vol. 12, no. 1, pp.82–99

Stage, C., & Hougaard, T. (2018). *The language of illness and death on social media: An affective approach*. Emerald Publishing Limited.

Statista (2024) *Facebook: quarterly number of MAU (monthly active users) worldwide 2008-2023*. Available Online: https://www.statista.com/statistics/264810/number-of-monthly-active-facebook-users-worldwide/.

Stenström, K. & Pargman, T. C. (2021). Existential Vulnerability and Transition: Struggling with Involuntary Childlessness on Instagram, *Nordicom Review*, vol. 42, no. s4, pp.168–184

The Royal Family (2024). *Succession*. Available at: https://www.royal.uk/encyclopedia/succession

MacSweeney, E. (2006). Golden girl. *Vogue*, *196*(4), 334–337.

T., I. (1826). A Physician Examining a Urine Specimen in Which a Faint Figure of a Baby Is Visible, a Female Patient Is Crying and Being Shouted at by Her Angry Mother, Indicating That She Is Pregnant. Watercolour by I.T., 1826., [e-journal], Available Online: https://jstor.org/stable/community.24840812

Tiidenberg, K. (2018). Ethics in Digital Research, in *The SAGE Handbook of Qualitative Data Collection*, [e-book] 1 Oliver's Yard, 55 City Road London EC1Y 1SP: SAGE Publications Ltd, pp.466–479, Available Online: https://sk.sagepub.com/reference/the-sage-handbook-of-qualitative-data-collection/i3094.xml

Tonteri, L., Kosonen, M., Ellonen, H.-K. & Tarkiainen, A. (2011). Antecedents of an Experienced Sense of Virtual Community, *Computers in Human Behavior*, vol. 27, no. 6, pp.2215–2223

Turkle, S. (1995). Life on the Screen: Identity in the Age of the Internet, New York: Simon and Schuster

Turkle, S. (2011). Alone Together: Why We Expect More from Technology and Less from Each Other, New York: Basic books

Tsalkitzi, E., Nikolakopoulos, P. & Karanikas, E. (2021). "Which Baby?": A Qualitative Study Exploring the Fantasies about the Unborn Baby among Women with Hyperemesis Gravidarum, *Journal of Psychosomatic Obstetrics & Gynecology*, vol. 42, no. 4, pp.320–327

Vinnars, M., Forslund, M., Claesson, I., Hedman, A., Peira, N., Olofsson, H., Wernersson, E. & Ulfsdottir, H. (2024). Treatments for Hyperemesis Gravidarum: A Systematic Review, *Acta Obstetricia et Gynecologica Scandinavica*, vol. 103, no. 1, pp.13–29

Wohn, D., Velasquez, A., Bjornrud, T. & Lampe, C. (2012). Habit as an Explanation of Participation in an Online Peer-Production Community, in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '12: CHI Conference on Human Factors in Computing Systems, Austin Texas USA, 5 May 2012, Austin Texas USA: ACM, pp.2905–2914, Available Online: https://dl.acm.org/doi/10.1145/2207676.2208697

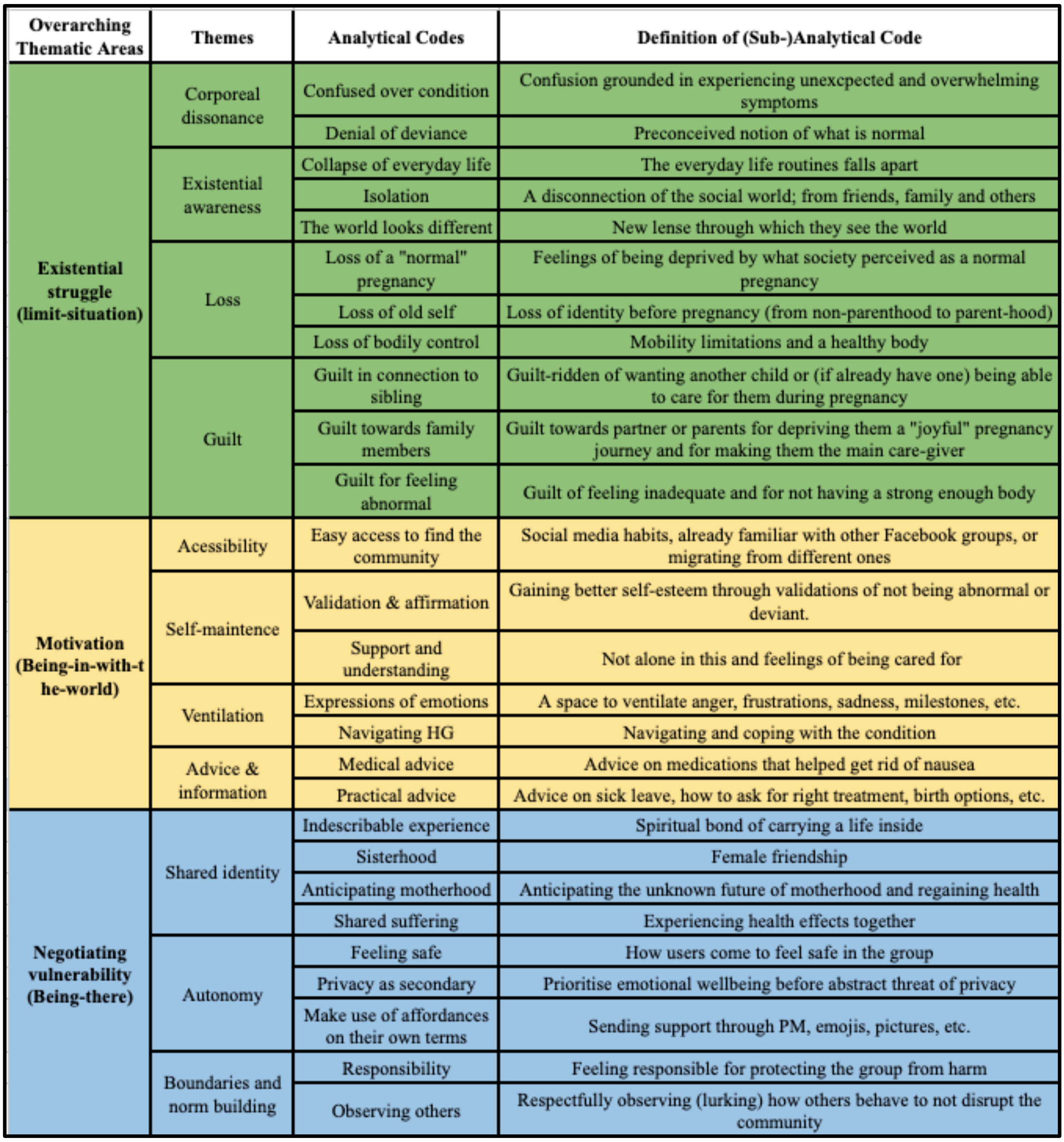
Zuboff, S. (2019). *The Age of Surveillance Capitalism: The fight for a human future at the new frontier of power*. London: Profile Books.

9. APPENDICES

9.1 Appendix: Example of Open Coding

First of all, I've never heard of HG before. I didn't know that was the thing. So, in the beginning, we tried to have kids for like, half a year or to get pregnant… for half a year. And I knew immediately when I was pregnant. You know, kept track of it. And it wasn't long until I started to feel nauseous. But you know, you have heard about it before and that is very normal. You know, (people would say): "oh you're pregnant in the beginning, you're gonna feel nauseous, right?", "You're going to experience nausea, yada, yada" So, the kind of nausea I experienced, I thought that was normal. I was like: "oh, this is how it's supposed to be. This is how all women feel when pregnant, this is how bad it is for all of them" Wow, I didn't know it was this bad, you know? So, I didn't know that it was not normal. But basically, the nausea started like right away, but it was my first appointment at BVC (Children's Healthcare Centre). Uh, where she (midwife) was like: "Oh, this is not normal, you need to get help"... because then I have already lost so much weight and I haven't been able to keep any water down or no food, nothing like that for about 3 days before I got there. So it got severe quite quickly. (Katarina)	Unheard illness
	Been told to expect nausea
	Been told feeling nauseous is normal
	Nausea worse than expected
	Unable to tell if everyone else's nausea was as bad
	Been told it is not normal

9.2 Appendix: Final Code Book

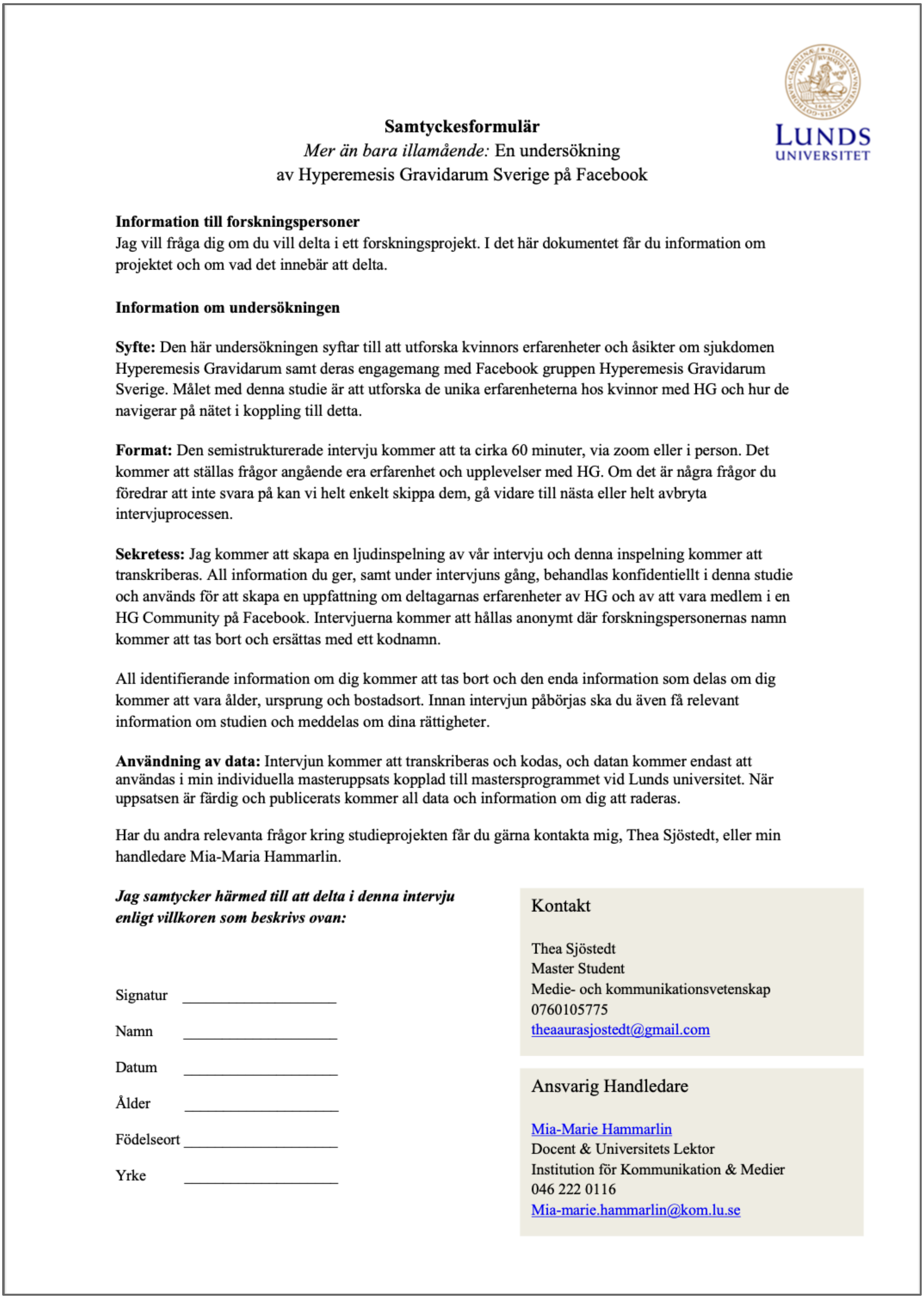


Overarching Thematic Areas	Themes	Analytical Codes	Definition of (Sub-)Analytical Code
Existential struggle (limit-situation)	Corporeal dissonance	Confused over condition	Confusion grounded in experiencing unexcpected and overwhelming symptoms
		Denial of deviance	Preconceived notion of what is normal
	Existential awareness	Collapse of everyday life	The everyday life routines falls apart
		Isolation	A disconnection of the social world; from friends, family and others
		The world looks different	New lense through which they see the world
	Loss	Loss of a "normal" pregnancy	Feelings of being deprived by what society perceived as a normal pregnancy
		Loss of old self	Loss of identity before pregnancy (from non-parenthood to parent-hood)
		Loss of bodily control	Mobility limitations and a healthy body
	Guilt	Guilt in connection to sibling	Guilt-ridden of wanting another child or (if already have one) being able to care for them during pregnancy
		Guilt towards family members	Guilt towards partner or parents for depriving them a "joyful" pregnancy journey and for making them the main care-giver
		Guilt for feeling abnormal	Guilt of feeling inadequate and for not having a strong enough body
Motivation (Being-in-with-the-world)	Acessibility	Easy access to find the community	Social media habits, already familiar with other Facebook groups, or migrating from different ones
	Self-maintence	Validation & affirmation	Gaining better self-esteem through validations of not being abnormal or deviant.
		Support and understanding	Not alone in this and feelings of being cared for
	Ventilation	Expressions of emotions	A space to ventilate anger, frustrations, sadness, milestones, etc.
		Navigating HG	Navigating and coping with the condition
	Advice & information	Medical advice	Advice on medications that helped get rid of nausea
		Practical advice	Advice on sick leave, how to ask for right treatment, birth options, etc.
Negotiating vulnerability (Being-there)	Shared identity	Indescribable experience	Spiritual bond of carrying a life inside
		Sisterhood	Female friendship
		Anticipating motherhood	Anticipating the unknown future of motherhood and regaining health
		Shared suffering	Experiencing health effects together
	Autonomy	Feeling safe	How users come to feel safe in the group
		Privacy as secondary	Prioritise emotional wellbeing before abstract threat of privacy
		Make use of affordances on their own terms	Sending support through PM, emojis, pictures, etc.
	Boundaries and norm building	Responsibility	Feeling responsible for protecting the group from harm
		Observing others	Respectfully observing (lurking) how others behave to not disrupt the community

9.3 Appendix: Informal Chat

Hej, mitt namn är Thea och är student på Lunds universitet. Just nu håller jag på att skriva en masteruppsats om kvinnors erfarenheter av Hyperemesis Gravidarum och undrar ifall du skulle vilja ställa upp på en intervju? Jag har själv upplevt HG med mina två graviditeter och tycker det är viktigt att fler vet om ämnet!

9.4 Appendix: Formal Invitation & Consent Form



LUNDS
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Samtyckesformulär
Mer än bara illamående: En undersökning
av Hyperemesis Gravidarum Sverige på Facebook

Information till forskningspersoner
Jag vill fråga dig om du vill delta i ett forskningsprojekt. I det här dokumentet får du information om projektet och om vad det innebär att delta.

Information om undersökningen

Syfte: Den här undersökningen syftar till att utforska kvinnors erfarenheter och åsikter om sjukdomen Hyperemesis Gravidarum samt deras engagemang med Facebook gruppen Hyperemesis Gravidarum Sverige. Målet med denna studie är att utforska de unika erfarenheterna hos kvinnor med HG och hur de navigerar på nätet i koppling till detta.

Format: Den semistrukturerade intervju kommer att ta cirka 60 minuter, via zoom eller i person. Det kommer att ställas frågor angående era erfarenhet och upplevelser med HG. Om det är några frågor du föredrar att inte svara på kan vi helt enkelt skippa dem, gå vidare till nästa eller helt avbryta intervjuprocessen.

Sekretess: Jag kommer att skapa en ljudinspelning av vår intervju och denna inspelning kommer att transkriberas. All information du ger, samt under intervjuns gång, behandlas konfidentiellt i denna studie och används för att skapa en uppfattning om deltagarnas erfarenheter av HG och av att vara medlem i en HG Community på Facebook. Intervjuerna kommer att hållas anonymt där forskningspersonernas namn kommer att tas bort och ersättas med ett kodnamn.

All identifierande information om dig kommer att tas bort och den enda information som delas om dig kommer att vara ålder, ursprung och bostadsort. Innan intervjun påbörjas ska du även få relevant information om studien och meddelas om dina rättigheter.

Användning av data: Intervjun kommer att transkriberas och kodas, och datan kommer endast att användas i min individuella masteruppsats kopplad till mastersprogrammet vid Lunds universitet. När uppsatsen är färdig och publicerats kommer all data och information om dig att raderas.

Har du andra relevanta frågor kring studieprojekten får du gärna kontakta mig, Thea Sjöstedt, eller min handledare Mia-Maria Hammarlin.

Jag samtycker härmed till att delta i denna intervju enligt villkoren som beskrivs ovan:

Signatur ____________________

Namn ____________________

Datum ____________________

Ålder ____________________

Födelseort ____________________

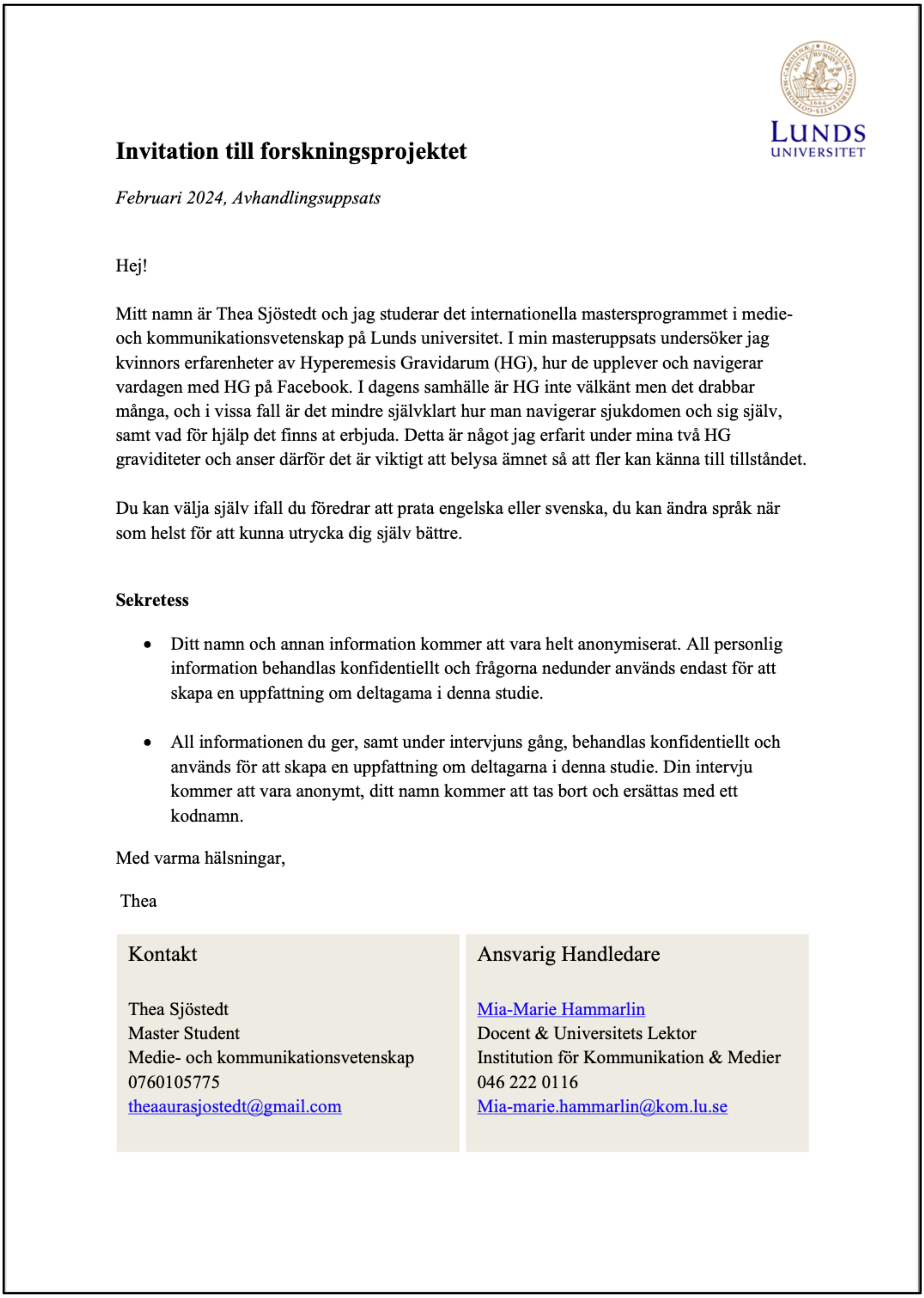
Yrke ____________________

Kontakt

Thea Sjöstedt
Master Student
Medie- och kommunikationsvetenskap
0760105775
theaaurasjostedt@gmail.com

Ansvarig Handledare

Mia-Marie Hammarlin
Docent & Universitets Lektor
Institution för Kommunikation & Medier
046 222 0116
Mia-marie.hammarlin@kom.lu.se



LUNDS UNIVERSITET

Invitation till forskningsprojektet

Februari 2024, Avhandlingsuppsats

Hej!

Mitt namn är Thea Sjöstedt och jag studerar det internationella mastersprogrammet i medie- och kommunikationsvetenskap på Lunds universitet. I min masteruppsats undersöker jag kvinnors erfarenheter av Hyperemesis Gravidarum (HG), hur de upplever och navigerar vardagen med HG på Facebook. I dagens samhälle är HG inte välkänt men det drabbar många, och i vissa fall är det mindre självklart hur man navigerar sjukdomen och sig själv, samt vad för hjälp det finns at erbjuda. Detta är något jag erfarit under mina två HG graviditeter och anser därför det är viktigt att belysa ämnet så att fler kan känna till tillståndet.

Du kan välja själv ifall du föredrar att prata engelska eller svenska, du kan ändra språk när som helst för att kunna utrycka dig själv bättre.

Sekretess

- Ditt namn och annan information kommer att vara helt anonymiserat. All personlig information behandlas konfidentiellt och frågorna nedunder används endast för att skapa en uppfattning om deltagama i denna studie.

- All informationen du ger, samt under intervjuns gång, behandlas konfidentiellt och används för att skapa en uppfattning om deltagarna i denna studie. Din intervju kommer att vara anonymt, ditt namn kommer att tas bort och ersättas med ett kodnamn.

Med varma hälsningar,

Thea

Kontakt

Thea Sjöstedt
Master Student
Medie- och kommunikationsvetenskap
0760105775
theaaurasjostedt@gmail.com

Ansvarig Handledare

Mia-Marie Hammarlin
Docent & Universitets Lektor
Institution för Kommunikation & Medier
046 222 0116
Mia-marie.hammarlin@kom.lu.se

9.5 Appendix: Interview Guide

Intro

Jag börjar med att berätta om vem jag är, vad jag gör och vad forskningsprojektet handlar om. Sedan frågar jag kvinnorna om de läst på samtyckes kraven och ifall de är medvetna om sina rättigheter. Jag kommer att berätta att intervjun hålls anonymt och att de får avstå att svara eller avbryta intervjuprocessen när som hel**st.**

Tema I: Utmaningar med HG

- Kan du beskriva hur det kändes när du fick reda på att du var gravid?
    - När började illamåendet komma?
- Kände du till tillståndet HG innan du blev gravid?
- Har du blivit diagnostiserad med HG av sjukvården?
- Är/var du medicinerad?
    - Vilka mediciner?
- Med dina egna ord, hur skulle du beskriva HG?
- Finns det något som du tror folk inte känner till med HG?
    - Vad är den största utmaningen med HG?
    - Fick du något stöd under graviditeten?

Tema II: Identitets Transformation

- Vad var dina tidigare föreställningar om graviditet och moderskap?
    - Hur ser du på dessa föreställningar nu?
    - Vad stämde/vad stämde inte?
- Vad med HG utmärker sig för dig?
    - När var HG som värst?
- Kan du beskriva ditt mentala och fysiska mående innan HG?
- Vad tror du är de vanligaste konsekvenserna med HG?
    - Vad för inverkan har HG haft på dig?
    - Vad för inverkan har HG haft på ditt liv?
    - Vad tror du HG har/haft för inverkan i din familjs liv?
- Har du någonsin känt dig sårbar under graviditeten?
    - Kan du beskriva ett tillfälle där du kände dig som mest sårbar?
- Vill du ha fler barn i framtiden?

Tema III: Socialisera i HGS Community

- Hur fick du reda på gruppen Hyperemesis Gravidarum Sverige?
- Hur länge har du varit aktiv i gruppen?
- Hur ser ett typiskt besök ut för dig?

Tema IV: Engagera sig med HGS Community

- Med dina egna ord, hur skulle du beskriva HGS gruppen?
- Vad tycker du om gruppen?
- Vad stack ut för dig med HGS?
- Vad gillar du med gruppen?
    - Vad gillar du inte med gruppen?
- Anser du att gruppen är tillförlitlig?
    - Anser du att Facebook är tillförlitligt?
- Har du reflekterat över att dina meddelande/ inlägg är arkiverade på hemsidan?

- Är du medlem i andra Communitys på Facebook?
- Varför tror du kvinnor söker sig till gruppen?

Tema V: Kommunicera med andra Existers

- Hur skulle du beskriva stämningen i gruppen?
- Har du lagt upp något i gruppen?
    - Vad fick dig att göra det?
- Skulle du vilja berätta/visa ditt första och senaste inlägg i gruppen?
    - Vad fick du för svar?
- Vilka är de vanligaste inläggen du stöter på?
    - Vad är det för material som läggs upp?
- Kommer du ihåg något minnesvärt inlägg?
    - Vad gjorde den minnesvärd för dig?
- Känner du någon i gruppen?
    - Har du träffat någon från gruppen?
- Hur har ditt medlemskap i gruppen påverkat (om alls) din upplevelse med HG?
- Är att vara medlem något du rekommenderar?
- Är det något annat du vill tillägga?

Avrunda och summera intervjun. Tackar forskningspersoner för deras samarbete och ber dem höra av sig ifall de har fler frågor kring projektet.