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BEYOND EXHAUSTION AND PAIN – THE INTERTWINEMENT OF HEALTH AND SUFFERING AMONG WOMEN AND MOTHERS

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Beyond exhaustion and pain – the intertwinement of health and suffering among women and mothers
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To the many mothers in my life and my two daughters

ABSTRACT

Aims: The overall goal of the thesis was to understand and to conceptualize health and suffering among women living with exhaustion and long-lasting pain, with a particular focus on motherhood.

Methods: The thesis' design was interpretative, descriptive, and observational and used both qualitative and quantitative approaches. In study I, unstructured qualitative interviews were conducted with 21 women living with long-lasting pain. These interviews were analyzed via application of Gadamer's philosophical hermeneutics. Study II was a psychometric evaluation and further development of the Health and Suffering Scale, and both classical test theory and Rasch analysis were applied. Study III is an exploratory investigation of health and suffering and perceived social support among women and mothers with exhaustion and long-lasting pain. Study II and study III are based on the same samples of women, one sample of women living with exhaustion and/or long-lasting pain (n = 166) and one reference sample of women studying and working within health care (n = 129). In study IV, 27 phenomenological interviews were conducted with 14 mothers with exhaustion and/or long-lasting pain. The interviews were analyzed applying both Gadamer's hermeneutics and Ricoeur's interpretation theory.

Findings: Women living with exhaustion and long-lasting pain appear to be vulnerable on a relational level (study I, III & IV). Feeling insufficiently supported by others risked turning difficult experiences and responsibilities in life into an overwhelming burden (study I & IV). This experience could turn into suffering and carried a risk of life being perceived as meaningless. Suffering and the perception of meaninglessness in life were found to be interwoven (study I & II). Motherhood could be part of an overwhelming life burden but could also offer women an essential source of strength and meaning in life (study IV). When women were embedded in reliable relational ties or reconsidered the relations in their lives, they were better equipped to bear difficult life experiences and caring responsibilities and could reconcile their selves and lives (study IV). Suffering became integrated into life, was more bearable and one's own health became more balanced (study II & IV). The synthesis of these findings suggest that women's health could be understood as an ongoing movement of how one relates to essential aspects of one's life and oneself. As a natural counterpoint to health, suffering then could be understood as an interruption of these meaningful and authentic relations in life.

Conclusion: Women and mothers suffering from exhaustion and long-lasting pain need to create and recreate essential relations in life, which would help alleviate their suffering. In this process of reconciling self and life, these women are dependent on supportive and caring relationships. Motherhood is a period in women's life in which women are particularly dependent on support and care from others. In the effort to improve health and alleviate suffering among women, society and health care, in particular, need to broaden its understanding of health as inseparable from suffering and vulnerability and interwoven with caring responsibilities.

LIST OF SCIENTIFIC PAPERS

I. Arman, M., **Gebhardt, A.**, Hök Nordberg, J., Andermo, S. (2020). Women's Lived Experiences of Chronic Pain – Faces of Gendered Suffering. *Qualitative Health Research, 30(5),* 772-782. Copyright © 2019 The Authors, Sage Publishing. DOI: 10.1177/1049732319888478.

II. **Gebhardt, A.**, Langius-Eklöf, A., Andermo, S., Arman, M. (2021). The health and suffering scale: Item reduction, reliability and validity among women undergoing rehabilitation for exhaustion and long-lasting pain. *Nursing Open, 00*, 1-12.

III. **Gebhardt, A.**, Langius-Eklöf, A., Andermo, S., Arman, M. (2021). Health and suffering are associated with social support: a cross-sectional study of women and mothers with exhaustion and pain. *BMC Women's Health, 259*, 1-11.

IV. **Gebhardt, A.**, Andermo, S., Arman, M. (2021). Relational vulnerability and health in motherhood – voices of women suffering from exhaustion and pain. *Manuscript.*

CONTENTS

LIST OF ABBREVIATIONS

HSS	Health and Suffering Scale
ICC	Intraclass Correlation Coefficient
ICD	International Classification of Diseases
KEDS	Karolinska Exhaustion Disorder Scale
MSPSS	Multidimensional Scale of Perceived Social Support
NBHW	National Board of Health and Welfare
SALAR	Swedish Association of Local Authorities and Regions
WEF	World Economic Forum
WHO	World Health Organization

1 PREFACE

One of the most fundamental phenomena in humankind is that humans care for each other. From an evolutionary perspective, caring for others and caring for offspring meant enhanced survival both for males and females. Nowadays, much of caring is performed by women and mothers. As a woman, daughter, sister, wife, friend, nurse, midwife, and mother, I started to wonder at some point in my life: What does it mean to care, what does it mean to be a woman and a mother, and what do women's situations in life mean for their health? What kind of care do women and mothers need for themselves?

Throughout my academic education I had several opportunities to focus on women's health from various perspectives, particularly in relation to motherhood. I am deeply grateful that the Swedish educational system gave me the opportunity to broaden and deepen my understanding of the complexity of women's and mothers' health and to contribute to improving the care they need. During the course of my studies, I was lucky to meet Associate Professor Maria Arman, who became my main supervisor for this thesis. She taught me that women's health and care can only be understood in the context of suffering. To be honest, studying the nature of suffering was not my first choice, but I could sense the meaning of it, and I opened my mind to studying the world of suffering. Today, after several years of studying women living with exhaustion and long-lasting pain, I am convinced that health care must include both suffering and vulnerability in its understanding of health. Like counterpoint in a musical composition, health, suffering, and vulnerability should be understood as interdependent but independent voices in human lives. With the understanding of health as an inherently dynamic phenomenon, which embraces existential aspects of life, we might be better equipped to care for women's and mothers' health and suffering. Doing so would mean caring for those who care at the core of humankind. In this thesis, I hope to thoroughly substantiate my reasoning for these claims.

Anja J. Gebhardt
Segersäng, October 2021

2 INTRODUCTION

Globally, women and men often display different health patterns in life and these disparities are influenced by gender norms (Hawkes & Buse, 2013). Although women generally have a higher life expectancy and a lower disease burden than men (Hawkes & Buse, 2013), the gender gap in sickness absence (Mastekaasa, 2014) and sex differences in health care consumption (Osika Friberg, Krantz, Maatta, & Jarbrink, 2016) indicate that throughout their lives, women face other significant obstacles to health. Despite the fact that large parts of the gender gap in sickness absence remain unexplained (Østby, Mykletun, & Nilsen, 2018), there are two aspects in women's health patterns that deserve attention. First, Swedish women were found to present more often with mental, behavioral, and musculoskeletal disorders in clinical encounters than men (Osika Friberg et al., 2016). Furthermore, they were shown to have a forty percent higher risk than men to go on sick leave due to stress-related ill-health, especially sick leave due to exhaustion (Swedish Insurance Agency, 2020). Second, Swedish women's sickness absence increases when entering parenthood and significantly exceeds men's sickness absence during at least 16 years of parenthood (Angelov, Johansson, & Lindahl, 2020). Women's ill-health implies not only suffering for the woman, but also her family. Furthermore, society is burdened with the substantial socioeconomic costs of ill-health that often afflict women like long-lasting pain or mental and behavioral disorders (Breivik, Eisenberg, & O'Brien, 2013; Gustavsson et al., 2012; Osika Friberg et al., 2016). Unfortunately, care offered for individuals suffering from long-lasting pain or exhaustion show only limited health improvements (Kamper et al., 2015; Perski, Grossi, Perski, & Niemi, 2017; Pietilä-Holmner, Enthoven, Gerdle, Molander, & Stålnacke, 2020; Wallensten, Asberg, Wiklander, & Nager, 2019). Hence, healthcare is confronted with the challenges of developing and improving the prevention, care, and rehabilitation of long-lasting ill-health like exhaustion and pain. This might be more feasible if we reconstruct 'health' as a construct and recognize suffering as an inherent part of human existence (Eriksson, 2006; Leonardi, 2018). The significance of understanding health as it is intertwined with suffering has been underscored by the medical humanities and the caring sciences (Andermo, Hök, Sundberg, Falkenberg, & Arman, 2018; Bueno-Gómez, 2017; Eriksson, 2006; Morse, 2001; Svenaeus, 2015). Against this background, the overall goal of this thesis is to understand and conceptualize health and suffering among women living with exhaustion and long-lasting pain with a particular focus on motherhood.

3 LITERATURE REVIEW

3.1 THE GENDER GAP IN SICKNESS ABSENCE

For decades, European women have had higher rates of sickness absence than men (Mastekaasa, 2014). Several studies have tried to identify factors involved in the gender gap in sickness absence (Angelov et al., 2020; Mastekaasa, 2014; Østby et al., 2018). In Sweden, the gender gap was observed to start when women and men become parents; during parenting years mothers take sick leave 0.5 days/month up to 0.85 days/month which is nearly twice as high as fathers' sickness absence (Angelov, Johansson, & Lindahl, 2013a). Similarly, Norwegian mothers were found to be twice as absent from work due to sickness than fathers (Østby et al., 2018). However, signs of severely impaired health among mothers that could explain the gap were not observed (Angelov et al., 2020; Østby et al., 2018). Stressors both at work and within family life have also been considered possible determinants of women's higher sickness absence, but the results remain inconclusive (Nilsen, Skipstein, Ostby, & Mykletun, 2017; Østby et al., 2018; Svedberg, Mather, Bergström, Lindfors, & Blom, 2018). Although the gender gap remains difficult to explain, research suggests that parenthood somehow entails an increased risk for sickness absence among women (Angelov et al., 2020; Floderus, Hagman, Aronsson, Marklund, & Wikman, 2012).

3.2 EXHAUSTION AND LONG-LASTING PAIN IN WOMEN

Long-lasting pain and stress-related ill-health like exhaustion are the most common reasons for sickness absence and are demanding public health problems both in Sweden (Gustavsson et al., 2012; Swedish Insurance Agency, 2018b, 2020) and in the European Union (Aumayr-Pintar, Cerf, & Parent-Thirion, 2018; Breivik et al., 2013; Cimmino, Ferrone, & Cutolo, 2011). The prevalence of both long-lasting pain and exhaustion is generally difficult to estimate due to inconsistent definitions and evaluation instruments (Breivik et al., 2013; Cimmino et al., 2011; Lastovkova et al., 2018). Despite these challenges, the prevalence of long-lasting pain in European countries was estimated to be 25–35% and is mostly related to the musculoskeletal system (Breivik et al., 2013). In Sweden, around 12% experience long-lasting pain that significantly interferes with their everyday life and 7% seek care (SALAR, 2016). Exhaustion prevalence rates range from 2–24% in different European countries (Aumayr-Pintar et al., 2018). The estimate for Sweden was 13% (Norlund et al., 2010). Behavioral and mental disorders and musculoskeletal disorders, alongside with cardiovascular diseases, require the largest amount of health care resources in Sweden measured by per capita costs (when controlling for sex-specific conditions) (Osika Friberg et al., 2016). It is important to note that women use more Swedish healthcare resources related to behavioral, mental, and musculoskeletal disorders than men (Osika Friberg et al., 2016). Generally, it is well known that conditions involving long-lasting pain are more common among women than men (Borchers & Gershwin, 2015; Casale et al., 2021; Fitzcharles et al., 2021). Compared to pain, exhaustion seems to be more evenly distributed between women and men according to the international literature (Marchand, Blanc, & Beauregard, 2018; Purvanova & Muros, 2010).

However, women seem to be more severely affected by exhaustion (Beauregard et al., 2018; Marchand et al., 2018; Roskam & Mikolajczak, 2020) and in Sweden, women were shown to have a forty percent increased risk (compared to men) for sick leave due to stress-related ill health, specifically related to exhaustion (Swedish Insurance Agency, 2020).

The relationship between mood disorders like anxiety and depression, and conditions involving long-lasting pain is well-investigated, and stress responses have been suggested to be involved in the development and maintenance of pain (Eller-Smith, Nicol, & Christianson, 2018; Fitzcharles et al., 2021; Yalcin & Barrot, 2014). Additionally, significant co-occurrences were found between long-lasting pain and exhaustion (Du, Baccaglini, Johnson, Puvvula, & Rautiainen, 2021; Langballe, Innstrand, Hagtvet, Falkum, & Gjerlow Aasland, 2009; Salvagioni et al., 2017). Generally, long-lasting pain increases with age, as the risk for ill-health increases with age. Nevertheless, long-lasting pain is common among both older and younger individuals (Mills, Nicolson, & Smith, 2019). The impact of age on exhaustion turned out to be more complex, as demonstrated in a Canadian study: whereas the degree of exhaustion was found to decrease with age among men, women were found to be more exhausted in younger ages and when older than 55 years (Marchand et al., 2018). Furthermore, the prevalence of long-lasting pain is higher in socio-economically disadvantaged groups (Mills et al., 2019). Levels of exhaustion were found to be higher among Swedish women who were in a low socio-economic situation, but this relationship could not be confirmed among men (Norlund et al., 2010). Regarding exhaustion related to parenthood, sociodemographic factors have been suggested to play only a marginal role in levels of exhaustion (Mikolajczak, Raes, Avalosse, & Roskam, 2018).

3.2.1 Long-lasting and chronic pain

In 2019, chronic pain was classified for the first time as a medical condition in and of itself in the International Classification of Diseases (ICD-11) and has been systematically structured by the International Association for the Study of Pain (Nicholas et al., 2019). The intention in classifying chronic pain as a medical condition was to move away from a dichotomized biomedical thinking of physiologically and psychologically induced pain as separate entities. Instead, the International Association for the Study of Pain wanted to bundle scientific insights that clearly showed a need for biopsychosocial perspectives on chronic pain and all conditions that involve chronic pain (la Cour, 2017; Nicholas et al., 2019). According to the ICD-11, chronic pain is now categorized into chronic primary pain and chronic secondary pain. Chronic primary pain involves conditions with unclear etiology: chronic widespread pain, complex regional pain syndrome, chronic primary headache or orofacial pain, chronic primary visceral pain, and/or chronic primary musculoskeletal pain. Chronic secondary pain, on the other hand, refers to pain that is secondary to another, primary, underlying cause, e.g., surgery or cancer (Nicholas et al., 2019). Chronic pain is defined as pain lasting or recurring for more than three months that cannot be explained by another diagnosis (Nicholas et al., 2019). Furthermore, chronic pain involves emotional distress and interferes with everyday life. In this thesis, the term ‘long-lasting pain’ is used (with exception of study I) as equivalent to chronic primary pain. The reasoning behind this is that the term *chronic* is considered to belong to the medical paradigm and signals that the pain has come to stay, giving the impression of something persistent and final. As the point of departure in this thesis are the caring sciences, the term *long-lasting* was thought to signal that something is under development and continuous change.

3.2.2 Exhaustion and burnout

In contrast to long-lasting pain, an international consensus on a detailed definition or accepted criteria for burnout or exhaustion is missing (Lastovkova et al., 2018). In the ICD-11, burnout is classified as an occupational phenomenon and not as a medical condition (WHO, 2019). Sweden, on the other hand, in 2005, was the first country in the world to introduce the diagnosis of ‘exhaustion disorder’. Exhaustion disorder includes all forms of stress causing long-term health problems and is not limited to work-related stress (NBHW, 2003). Exhaustion disorder was defined as “a condition that has developed as a consequence of one or more stressors that have been present for at least six months” (NBHW, 2003, p. 30). The condition involves physical and mental exhaustion during at least two weeks and the experience of reduced mental energy (Beser et al., 2014). Further, cognitive exhaustion, sensitivity to stress, sleep disturbances, and emotional irritability are usually involved. Similarly to long-lasting pain, exhaustion has a substantial impact on everyday life and cannot be explained by reasons other than exposure to stressors (Beser et al., 2014). Burnout has been conceptualized in various health measurement scales but there is no international consensus on a clear definition (Schaufeli, 2021). Exhaustion is considered to be the essential element in what is often described internationally as ‘burnout’ (Schaufeli, 2021). Therefore, the term exhaustion is used as a core concept, and also as a synonym to burnout throughout this thesis.

3.2.3 Living with long-lasting pain and exhaustion

Women with long-lasting pain often experience mistrust from health care providers and struggle to be taken seriously in their experiences of pain or exhaustion (Arman, Hammarqvist, & Rehnsfeldt, 2011; Samulowitz, Gremyr, Eriksson, & Hensing, 2018; Toye et al., 2013). In a review, Samulowitz et al. (2018) found treatment of long-lasting pain to be characterized by gendered norms and andro-normativity: Women were generally described in comparison to men and as not fitting to the male norm (Samulowitz et al., 2018). It was also found that healthcare providers were inclined to psychologize women’s pain and to prescribe less effective pain medication and more antidepressants, compared to prescriptions for men (Samulowitz et al., 2018). It is common that individuals living with pain seek care for many years without receiving a formal diagnosis and with either no or limited alleviation of their pain and related ailments (Fitzcharles et al., 2021). Without a clear medical diagnosis, individuals living with pain experience not being believed about the extent of their pain and have feelings of shame and guilt (Toye et al., 2013). In a similar way, individuals suffering from exhaustion were found to feel that they were questioned by healthcare providers and not offered treatment (Arman et al., 2011).

Against this background, it might not come as a surprise that the International Association for the Study of Pain presented three of five case vignettes of individuals identifying as female to illustrate fibromyalgia, complex regional pain syndrome, and low back pain. No physical abnormality could be found in any of the cases and various treatments during the years did not result in long-lasting improvement to the women's health (Nicholas et al., 2019). The vignettes reflect a long history of personal suffering and ineffective treatment that is the unfortunate reality for the majority of women living with long-lasting pain (Samulowitz et al., 2018; Toye et al., 2013). When pain remains medically unexplained, it creates challenges in encounters with fellow human beings and with healthcare (Borchers & Gershwin, 2015; Samulowitz et al., 2018; Toye et al., 2013). Living with a disabling condition like pain that is both unexplained and invisible to others has been described as a struggle, in part because planning everyday life is difficult due to pain's unpredictable nature (Toye et al., 2013). Living with long-lasting pain often involves other interrelated symptoms which can be experienced as even more burdensome than the pain itself: hypersensitivity, sleep disturbances, stiffness, fatigue, cognitive inhibition, depression, and anxiety (Borchers & Gershwin, 2015). All these ailments interplay with or risk spilling over into family life and challenge women in their identity as a wife and/or mother (Feddersen, Kristiansen, Andersen, Hørslev-Petersen, & Primdahl, 2017; Wilson & Fales, 2015). For example, it has been described that women living with rheumatoid arthritis experience feeling that they are a burden to their families when they are unable to take responsibility for family life according to social norms (Feddersen et al., 2017). However, women living with long-lasting pain were also found to continue to take up familial responsibilities and to live up to social expectations, even though it might imply crossing their own limits (Evans & de Souza, 2008; Samulowitz et al., 2018). In a phenomenological study on maternal exhaustion (Hubert & Aujoulat, 2018), women were found to have overinvested in motherhood. Social norms and their own expectations appeared to be driving forces behind the women's stressful parental commitment which had made them physically and mentally tired. In the end, the women had become emotionally distanced from their children and their own lives and some had developed thoughts of suicide and even infanticide. The women were found to feel shame, guilt, loneliness, self-hate, and fear (Hubert & Aujoulat, 2018). Not placing expectations on oneself and unconditional beingness were found to be key elements in well-being for women diagnosed with stress-related ill health, like exhaustion (Hörberg, Wagman, & Gunnarsson, 2020).

3.3 WOMEN'S LIFE SITUATION IN SWEDEN

Sweden and other Nordic countries are characterized by a strong gender equality discourse and rank highest in the yearly global gender gap report by the World Economic Forum (WEF, 2021). Nordic countries have the highest female employment rate among women in Europe, with Sweden and Iceland at the top (Eurostat, 2021). During their lifetime, most women in Sweden become mothers (86%) (Statistics Sweden, 2018a). Among women living in Sweden with children under the age of 12, the employment rate was 83% in 2018; 11% lower than for men. Among those women, 65% are working full-time (Statistics Sweden, 2019). This is a clear increase compared to 40 years ago (in 1980, 30% were working full-time) and applies specifically to mothers of children under the age of six (Angelov, 2011). Parental leave was implemented in Sweden 1974 to support the possibility of both parents taking part in the labor market despite building a family. In international comparison, the Swedish State offers generous regulated parental leave for both parents; a total of 480 paid days, and publicly-provided childcare and education (Swedish Insurance Agency, 2018a). Fathers increasingly take parental leave, but women still take 72% of parental leave days (Swedish Insurance Agency, 2018a). This has negative long-term consequences for their careers, income development and their pensions (Angelov, Johansson, & Lindahl, 2013b; Government Offices of Sweden, 2019; Swedish Insurance Agency, 2018a). Despite efforts to support and promote gender equality within families through paid parental leave, and publicly-funded, affordable and accessible childcare (Government Offices of Sweden, 2019), working mothers in Sweden still take significantly more responsibility for unpaid work within the household and the family than men (Hagqvist, Toivanen, & Vinberg, 2019; Statistics Sweden, 2018b).

Work–family conflict among working women is a well-known phenomenon that has been investigated in relation to aspects of women's health and sickness absences (Bucher-Koenen, Farbmacher, Guber, & Vikström, 2020; Hagqvist, Gadin, & Nordenmark, 2017; Nilsen et al., 2017). In various countries across Europe, both women and men were found to perceive less well-being with greater work–family conflict (Hagqvist et al., 2017). Counterintuitively, this negative association was more pronounced in more gender-equal countries compared to countries with more conservative norms (Hagqvist et al., 2017). Nevertheless, women and men generally reported less work–family conflict and more well-being in countries characterized by gender equality (Hagqvist et al., 2017). A systematic review and meta-analysis (Nilsen et al., 2017) showed that women are exposed to significantly more work–family conflict than men and that work–family conflict was found to be related to sickness absences later in life. Bucher-Koenen et al. (2020) underpinned the idea of the damaging effects of intense work–family conflicts on women's health with an investigation of working mothers who had given birth to twins. This investigation indicated that all-cause mortality and mortality causes associated with stress was higher among women (55 years and older) who had had an intense child-rearing period in their lives (represented by twin birth). This effect on women's health was shown to be specifically strong for highly educated and working women (Bucher-Koenen et al., 2020).

It is nevertheless important to keep in mind that combining parenthood with paid work was found to be beneficial for women's health and well-being (Feddersen et al., 2017; Grönlund & Öun, 2010; Lebert-Charron, Dorard, Boujut, & Wendland, 2018; Nilsen, Brannen, & Lewis, 2013). For example, it was found that women who were employed and working full-time were significantly less exhausted than women who were at home or were working part time (Lebert-Charron et al., 2018). Grönlund and Öun (2010) found that work–family conflict does not necessarily have a negative influence on well-being and life satisfaction. Rather, the researchers suggested that—depending on the countries' policies—work–family conflict might be counterbalanced by enhanced well-being and life satisfaction, however, women with similar demands at work as men seemed to experience higher levels of work–family conflict than men

(Grönlund & Öun, 2010). A perceived balance in the demands from family and paid work seems to be crucial for the health and well-being of both men and women (Hagqvist, 2016). According to the gender gap in sickness absence, some women and mothers nevertheless seem to struggle with the demands of their everyday lives. This suggests that some women might be vulnerable in their life situation as women and mothers (Lebert-Charron et al., 2018; Mikolajczak et al., 2018; Nilsen et al., 2013). For example, an unequal division of domestic responsibilities has been suggested to be related to higher levels of work–family conflict and impaired health among women (Eek & Axmon, 2015).

3.4 CARE AND REHABILITATION FOR LONG-LASTING PAIN AND EXHAUSTION

Multidisciplinary rehabilitation based on a biopsychosocial understanding of health is offered to individuals with long-lasting pain in Europe and other high-income countries around the world (Kamper et al., 2015). In Sweden, multidisciplinary (or multimodal) rehabilitation is offered both on a primary care level and specialist care level (SALAR, 2019) and is also based on a biopsychosocial perspective on long-lasting pain (Swedish Agency for Health Technology Assessment, 2010). The biopsychosocial perspective on health was suggested by George Engel in 1977 with the aim of encouraging healthcare to not just consider the biomedical aspects in health and disease but also the psychosocial aspects (Bolton & Gillett, 2019). Furthermore, this understanding of health suggests that all three aspects of health; the biological, psychological, and social, are inter-related and in causal relationships (Bolton & Gillett, 2019). This view is reflected in multidisciplinary rehabilitation in which medical, physical, psychological, and social interventions are offered; teams with members from various healthcare disciplines offer and coordinate these interventions (SALAR, 2019).

In 2016, a national Swedish report on health care for long-lasting pain pointed out that health care both on primary and specialist care levels was insufficient and unstructured considering care supply and knowledge (SALAR, 2016). Since then, economic investments have been made in healthcare and research, aimed specifically at improving the care of individuals with long-lasting pain and exhaustion (SALAR, 2019). Rehabilitation interventions for individuals with stress-related ill-health like exhaustion varies, but common components are psychological interventions, relaxation training, pacing or time management, and coping techniques (Perski et al., 2017). In Sweden, cognitive behavioral therapy and psychodynamic psychotherapy are offered, but supply was found to be insufficient and does not meet the high demand (SALAR, 2019). Some regions in Sweden offer multidisciplinary rehabilitation on the specialist care level—not only for individuals with long-lasting pain but also for individuals suffering from exhaustion. Care is also offered by physiotherapists and related health professionals independent of rehabilitation programs, but it is unclear whether the interventions offered are intended to alleviate acute pain symptoms or to prevent long-lasting pain (Swedish Agency for Health Technology Assessment, 2016). Furthermore, evidence supporting such possible preventive interventions for long-lasting pain was found to be insufficient (Swedish Agency for Health Technology Assessment, 2016).

Multidisciplinary rehabilitation was found to be more effective than usual care, when measured by a return to work (Kamper et al., 2015; Perski et al., 2017). Reviews and meta-analyses show that multidisciplinary rehabilitation is beneficial in returning individuals to work, and in other aspects of health among individuals suffering from exhaustion or long-lasting pain, however, effects are often inconclusive or small (Kamper et al., 2015; Perski et al., 2017; Wallensten et al., 2019). Women who had participated in multidisciplinary rehabilitation perceived the received care as beneficial as it offered them ways of breaking up their isolation and embracing their lives in a new way (Arman & Hok, 2016; Pietilä Holmner, Stålnacke, Enthoven, & Stenberg, 2018; Semedo, Stalnacke, & Stenberg, 2020). These lifechanging aspects of rehabilitation have been suggested by health care professionals to be important to consider when evaluating the effects of rehabilitation (Stenberg, Pietilä Holmner, Stålnacke, & Enthoven, 2016). Considering that long-lasting pain and exhaustion are difficult to treat, and considering the seemingly small effects of rehabilitation, and the lack of evidence as to means of prevention, more profound knowledge is needed for the improvement and development of healthcare and preventive interventions (Eller-Smith et al., 2018; Swedish Agency for Health Technology Assessment, 2016; Wallensten et al., 2019).

3.5 SUFFERING AS PART OF HEALTH

The underlying reasons for exhaustion and pain, as well as their explanatory models, have changed throughout the centuries and have thereby continuously influenced and altered the care of individuals suffering from exhaustion and pain (Meldrum, 2003; Schaffner, 2016). Women who currently suffer from exhaustion or long-lasting pain move within a health care tradition that seeks to diagnose, to explain, and to cure (Schaufeli, Leiter, & Maslach, 2009; Toye et al., 2013). This gives rise to a conflicting situation for afflicted individuals as long-lasting pain and exhaustion are invisible and immeasurable in nature and therefore barely explainable in biomedical terms (Toye et al., 2013). The prevailing biopsychosocial model has made valuable contributions in the care and treatment of long-lasting pain, but it has also been criticized as being limited in its ability to understand long-lasting pain (Racine et al., 2012; Toye et al., 2013). Even though the biopsychosocial understanding of health and disease makes efforts to incorporate personal experience, it remains explanatory and causal at its core as it seeks to explain health and disease through biopsychosocial relationships (Bolton & Gillett, 2019). In such reasoning, health is at risk of being reduced to a state that can be controlled and attained, leaving little space for fluid processes of human experience and human existence. Further, Bullington (2009) stressed that pain still tends to be objectified in both the medical field but also in therapeutic approaches that aim to enhance the acceptance of pain (Bullington, 2009). Therefore—instead of, or as a complement to explanation and objectification—the significance of existential questions and embodied experience has been emphasized in the care and rehabilitation of individuals with long-lasting pain (Bullington, 2009; Toye et al., 2013). Incorporating existential aspects of health in the prevailing healthcare tradition requires a greater understanding of the varieties of 'health' than currently exist. A greater variation of health constructs has been proposed to be particularly valuable in the area of long-lasting ill-health as these conditions involve huge challenges for health care (Leonardi, 2018). In formulating these definitions of health, it has been argued that health must be understood as a dynamic and existential process that also involves malaise or suffering (Leonardi, 2018; Sigurdson, 2016). In this thesis, the experience of health and suffering is understood as an existential and continuously ongoing process.

The experience of long-lasting pain and exhaustion means that life, as it is known and familiar, is ruptured and entails suffering (Arman et al., 2011; Bullington, 2009; Svenaeus, 2015; Toye et al., 2013). In caring science, suffering is an integral term that is understood in relation to health; when suffering is integrated into one's own life, experiences of health can emerge (Eriksson, 2006; Morse, 2001). Suffering is regarded as an existential experience that can be a source but also a hindrance of personal growth (Eriksson, 2006; Rodgers & Cowles, 1997). During some periods in life, suffering might become unbearable. It is then irreconcilable with health and becomes a hindrance to individual growth. Bearable suffering, on the other hand, is compatible with the experience of health when suffering is integrated into life (Eriksson, 2006).

In "Oneself as another", Ricoeur (1994, p. 190), defined suffering not "solely by physical pain, nor even by mental pain, but by the reduction, even the destruction, of the capacity for acting, of being-able-to-act, experienced as a violation of self-integrity." Eriksson also described suffering as a paralyzing state of being that involves a process of dying (Eriksson, 2006). In a similar manner, Rodgers and Cowles (1997) thought suffering to be a process involving a loss of humanness and dignity. Morse (2001) found suffering to be an emotional state connected to losses whereas enduring is understood to be protecting the integrity of the self when emotional suffering is perceived as too demanding or unbearable. Both Eriksson (2006) and Morse (2001) describe the different states or responses to a threat or loss—unbearable/bearable suffering and enduring/suffering—as interconnected and dynamic in nature. Suffering individuals are suggested to be able to move from unbearable suffering or enduring to bearable suffering or acceptance, reaching a deeper and richer understanding of life (Eriksson, 2006; Morse, 2001). This process is considered not to be straightforward but rather resembling a back and forward movement that follows its own pace (Eriksson, 2006; Morse, 2001). This movement also entails a recognition, acknowledgement and finally acceptance of a loss (Morse, 2001). When something is lost, the future necessarily becomes altered which can be accepted by a reformulated self (Morse, 2001). According to Eriksson (2006), accepting and reconciling the inevitable realities of life involves experiencing suffering which can be ascribed meaning. To find meaning in suffering, the suffering human needs time and space to suffer (Eriksson, 2006). Having time and space to reconcile with the inevitable realities of life means that suffering can become an invitation to reorient oneself and to understand life in a new way (Wiercinski, 2013).

The experience of pain has been described as relentlessly pervading life in which a person becomes alienated from her body as her actions in life become ruptured by the pain experience, thereby the person also becomes alienated from life (Svenaeus, 2015). Thus, the experience of pain seems to involve a loss of meaningfulness in life (Svenaeus, 2015). Similarly, exhaustion has been described as a threat of loss of meaning that did not seem connected to disturbed action but rather to non-authentic action in life (Arman et al., 2011). This reduction in being-able-to-act, as reflected in Ricoeur's definition of suffering, underlines the significance of understanding exhaustion and pain as an existential experience. According to Ricoeur (1994), humans are acting *and* suffering beings. Therefore, health care needs to embrace pain and exhaustion not as a fragment or part of a person but as an experience that pervades one's whole existence. Alleviating suffering would mean helping a suffering person to find meaning in a life that has been profoundly changed, to find meaning in suffering, thereby enabling a person to act again.

This existential understanding of health as a process of integrating suffering into life challenges the existing healthcare tradition and ways of evaluating health. In understanding health and suffering as essential parts of human existence, "We have to focus not only on what we 'lose' when we suffer, but also on the various cultural, personal, and social adaptations and resources to manage suffering." (Bueno-Gómez, 2017, p. 9). Caring science literature has highlighted how important it is that care and rehabilitation support suffering individuals in the process of coming to a new understanding of life and of reformulating the self (Bullington, 2009; Morse, 2001; Rehnsfeldt & Eriksson, 2004). Existential encounters have been described as valuable for the progression of suffering and the development of a new understanding of life (Rehnsfeldt & Eriksson, 2004). Articulating experiences was proposed to help in reformulating the self which is thought to be supported in various therapeutical approaches such as physiotherapy, dance, or music therapy (Bullington, 2009). Although it is anticipated that these therapies and related caring practices share common ground in an existential understanding of health, evaluating a change in how health is experienced by the person herself remains challenging.

Instruments commonly used to measure health-related quality of life mainly consider individuals' symptoms and function in everyday life (Brazier et al., 1992; Herdman et al., 2011; WHO, 2002). Existential aspects of health, like the perception of meaning in life, have been conceptualized (WHO, 2002). Nevertheless, existential aspects tend to mainly be encapsulated in relation to a suggested state such as well-being or challenging life situations but not as a *lived* health experience. Therefore, Andermo et al. (2018) conceptualized the back-and-forth movement between the experiences of suffering and health into a health measurement scale that aims to measure perceived suffering in relation to health and health as an integrated process. Individuals' iterative movement between unbearable suffering and health was suggested to be reflected in experiences of passion in life, personal freedom, presence in life, relationships, and perceived meaning in life (Andermo et al., 2018). This new instrument has been developed based on empirical studies and the theory of health and suffering as outlined above. The scale's psychometric evaluation is part of the thesis.

3.6 MOTHERHOOD AS A LIFE-LONG EXPERIENCE

Becoming and being a mother usually means a life-changing experience and involves a life-long engagement that contributes to but also challenges the health and well-being of women (Duarte-Guterman, Leuner, & Galea, 2019; Nomaguchi & Milkie, 2020; Rich, 1976/1995). In 1976, Adrienne Rich (1976/1995) identified motherhood to be both a social and cultural construct oppressing women—motherhood as institution—but also to be an empowering experience for women. The oppressive forces of socially-constructed motherhood, which Rich (1976/1995) refers to, are, for example, reflected in the events of the industrial revolution when women increasingly were excluded from productive work outside the home and made solely responsible for the welfare of men and children at home. "For mothers, the privatization of the home has meant not only an increase in powerlessness, but a desperate loneliness" (Rich, 1976/1995, p. 53). Although women subsequently and increasingly became part of the paid labor force, women as mainly responsible for the care of the family and the home has remained a deeply-rooted idea in the social construct of motherhood (Blair-Loy, 2003; Orgad, 2019; Rich, 1976/1995). Hence, women were given full caring responsibility for their children without having the power to decide on the conditions of care (O'Reilly, 2016; Rich, 1976/1995; Ruddick, 1980).

Motherhood as an experience, on the other hand, can also be empowering. According to Rich (1976/1995), motherhood can unfold as an empowered experience in the absence of institutionalized motherhood and in mother–child relationships, particularly in mother–daughter relationships in which feminine perspectives and values are both lived and taught. In this sense, motherhood is a feminine experience and inheritance that also can become a strength by which love, confirmation, self-worth, and pride in being female is passed on from one generation to another (Rich, 1976/1995). Being a mother has also been described as empowering through the experience of one's own reproductive power and of an individual's capability to protect and raise their own children (Ruddick, 1980). According to Ruddick (1980), responding to a child's demands fosters a scheme of thought among women—maternal thinking—through which women can achieve social change. In empowered mothering, women resist the forces of institutionalized motherhood and create social change through child rearing, women also attend to their own needs and involve others in childcare responsibilities (O'Reilly, 2016).

Against the background of motherhood being considered as both an institution and an experience, the terms 'mother', 'being a mother', and 'motherhood' used in this thesis comprise (inspired by the phrasing of O'Reilly (2016)) the feminine experience of and engagement in caring responsibilities for a child and caring relationship with a child as a central part of an individual's life. These terms are not thought to be restricted to caring relationships and responsibilities for biological children or children under the age of eighteen. Furthermore, these caring experiences must be understood in the social and cultural contexts in which they are embedded, because not all women experience motherhood similarly (Dow, 2016). African American women, for example, have been described as experiencing caring responsibilities for children as integrated into their communities (Dow, 2016). Although being a mother is thought to imply a central and often life-long experience in women's lives (Nomaguchi & Milkie, 2020; O'Reilly, 2016), it needs to be emphasized that being a mother "is *one* part of female process; it is not an identity for all time." (Rich, 1976/1995, p. 37).

4 RATIONALE

Long-lasting pain and exhaustion are public health challenges that more often or more severely manifest in women than in men. Living with long-lasting pain or exhaustion entails suffering in afflicted women and their families. Due to the invisible and immeasurable nature of exhaustion and long-lasting pain, women often feel they are misunderstood or not taken seriously by parts of the health care system. Furthermore, available care and multidisciplinary rehabilitation offer only limited beneficial effects for women's health. Considering the existential nature of exhaustion and pain and the challenges faced by health care to offer treatments for exhaustion and long-lasting pain that make a substantial difference for women's health, there is a need to further understand and conceptualize women's health and suffering. As principal understandings of health influence healthcare practice, decision-making in social policies and individual's personal reflections and experiences of their health, working out an existential view on health will make an important contribution to further development and improvement of care. Although many studies have investigated exhaustion and long-lasting pain using a wide spectrum of perspectives, little is known about how afflicted women experience their health and suffering in relation to their existence as women and as mothers. Considering women's and men's disparities in health patterns, understanding and conceptualizing health and suffering from the perspective of women and mothers would make a valuable contribution to the prevention, care, and rehabilitation of exhaustion and long-lasting pain among women.

5 RESEARCH AIMS

The overall goal of the thesis is to understand and to conceptualize health and suffering among women living with exhaustion and long-lasting pain with a particular focus on motherhood. Understanding women's health and suffering will contribute to the further development of women's health care, as well as inform social policies. Conceptualizing health and suffering will offer a theoretical basis for caring practice.

The following aims guided the work of this thesis:

Study I

The aim was to understand the lived experience of women with chronic pain from a caring science and gender perspective.

Study II

The aims were to investigate the necessity of an item reduction and to evaluate estimates of dimensionality, reliability, and validity of the Health and Suffering Scale among two groups of women, one undergoing rehabilitation for exhaustion and long-lasting pain and one reference group.

Study III

The aim was to describe health and suffering of women and mothers undergoing rehabilitation for long-lasting pain and exhaustion and its correlation with perceived social support.

Study IV

The aim was to understand health and suffering in motherhood among women living with exhaustion and long-lasting pain.

6 MATERIALS AND METHODS

6.1 DESIGN

The thesis design is interpretative, descriptive, and observational, encompassing qualitative and quantitative approaches. The two qualitative studies (study I & IV) are performed within a hermeneutical tradition. Study II is a psychometric evaluation and further development of a health measurement scale. Study III is an exploratory investigation of women's health and suffering and perceived social support. Study II and study III are based on the same dataset, comprising cross-sectional observations. Data were collected in three different settings, but all involved women undergoing rehabilitation for exhaustion and/or long-lasting pain at specialized clinics in the province of Stockholm. One of the three data collections also included women studying in health care programs at Karolinska Institutet. A summary of the four studies included in the thesis is presented in Table 1.

Table 1. Overview of included studies in the thesis.

Study	Participants	Data collection	Data analysis
I	21 women undergoing rehabilitation for long-lasting pain	Unstructured qualitative interviews	Gadamer's phenomenology of understanding
II	Women undergoing rehabilitation for long-lasting pain and/or exhaustion (n = 166); Reference group of healthy women (n = 129)	Sociodemographic data Type of rehabilitation HSS KEDS	Descriptive statistics Two sample t-test Paired sample t-test Cronbach's alpha Intraclass coefficient ($ICC_{2,1}$) Exploratory factor analysis Andrich Rating Scale model within Rasch analysis
III	Women undergoing rehabilitation for long-lasting pain and/or exhaustion (n = 166) Reference group of healthy women (n = 129) • Mothers with exhaustion and pain (n = 129) • Childless women with exhaustion and pain (n = 37) • Healthy mothers (n = 108) • Healthy women without children (n = 21)	Sociodemographic data Type of rehabilitation Caring responsibilities HSS KEDS MSPSS	Descriptive statistics Two sample t-test Linear regression
IV	14 mothers undergoing rehabilitation for long-lasting pain and/or exhaustion	Phenomenological interviews	Gadamer's phenomenology of understanding combined with Ricoeur's interpretation theory

HSS, Health and Suffering Scale; KEDS, Karolinska Exhaustion Disorder Scale; MSPSS, Multidimensional Scale of Perceived Social Support; $ICC_{2,1}$, Intraclass coefficient according to Shrout and Fleiss (1979).

6.2 PARTICIPANTS

This thesis is based on interviews and observations of four different samples of women: three samples of women undergoing rehabilitation for long-lasting pain and/or exhaustion and one reference sample of women studying and working within health care.

6.2.1.1 Participants study I

The sample for this study was taken from an ongoing research project on the lived experience of individuals with long-lasting pain in a variation of care contexts. Women were invited for interviews in the end of a rehabilitation program for long-lasting pain in both standard and integrative care contexts in the province of Stockholm, Sweden. The inclusion criterium was being in the end of or having recently completed a rehabilitation program for long-lasting pain. Standard rehabilitation lasted between six and twelve weeks, whereas the integrative rehabilitation was split up into two parts: three weeks of inpatient care with anthroposophical therapies followed by two ten-weeks periods of day care once a week that was rounded off after one year. The women were consecutively recruited for voluntary study participation from each care context. Researchers provided the women with both oral and written information about the study and scheduled the interviews. Out of 15 eligible patients, 6 women from Danderyd University Hospital, and 15 out of 18 eligible patients from the Vidar clinic took part in the interviews, yielding 21 participating women aged between 20 and 61 years. The women were between 20 and 61 years old. Most of the women were mothers of one to four children of any age. All women were, to varying degrees, employed. All women had recently participated in rehabilitation for long-lasting pain.

6.2.1.2 Participants studies II–III

Participating women were undergoing rehabilitation for exhaustion and/or long-lasting pain at Bragée clinics in Stockholm or were women studying in a healthcare program at Karolinska Institutet. The women living with exhaustion and/or pain were recruited during the second half of their 10-week long rehabilitation. The students were thought to provide a reference group of healthy women that had an established life situation in which they were both working and studying within health care.

Participating women were, in the first step, informed orally by the researcher about the study in connection to a lecture at the clinic (patients) or university (students). Those women who had voluntarily signed up to receive written information were sent an email that included further information about the study and a personal link to the web-survey. Two reminders were sent after two and four weeks. Two weeks after having sent in a completed survey, the reference group received a re-test survey, exclusively consisting of the below presented Health and Suffering Scale. The reference group was considered for re-test because their health was anticipated to be more consistent in comparison to the health of women undergoing rehabilitation. Similar to the main survey, two reminders were sent out for the re-test survey. There were 297 eligible patients and 209 eligible students. The response rates for the surveys were 56.2 % among women undergoing rehabilitation, yielding 167 women in the patient sample; and 61.7 % among reference women, yielding 129 women in the reference sample; and 83.7 % for the re-test, yielding 108 women in the re-test sample. One woman in the patient sample did not answer any of the items of the Health and Suffering Scale (presented below) and was therefore excluded from the sample, yielding a final sample of 166 women.

The women in the patient sample had a mean age of 47.7 (±11.1), more than half of the women (57.8 %) had higher education, and 50.6 percent were employed. Most women (77.7%) were mothers. The women were either currently participating, or had participated in rehabilitation primarily for long-lasting pain (56.6 %) or exhaustion (41.6%) during the last three months. The women in the reference sample had a mean age of 38.1 (±7.7), all had higher education, and 90.9% were employed. Again, most women were mothers (83.7%). The percentage of women born outside Sweden was similar in the two samples (14.5% of the patient sample and 13.2% of the reference sample). Some of the women (6.2%) were or had participated in rehabilitation for long-lasting pain during the last three months. For more detailed sample description see study III.

6.2.1.3 Participants study IV

In study IV, 14 women were recruited during the second half of their 10-week long rehabilitation at Bragée clinics in Stockholm, Sweden, for either exhaustion or long-lasting pain. To participate in the study, the women had to be a mother of at least one child. Women with children in any age group ranging from toddlers to adult children, living at home or not at home, were invited to participate in the study. After having been orally informed about the study, 32 women were interested in participating in the study and had voluntarily signed up to receive written information by email. Out of these, 20 women agreed to schedule an interview of which six were canceled due to the covid-19 pandemic. The plan was to recruit women with a variation in type of rehabilitation (for exhaustion or pain), number and age of the children, and the women's age and country of birth. This goal was achieved in all regards despite the women's country of birth, as all women were born in Sweden. The women were recruited in February and October 2020.

The women were between 34 and 63 years old. More than half of the women had higher education. All women were mothers who had one to six children in various ages from small children to adult children. The share of women who participated in rehabilitation for long-lasting pain, exhaustion or a combined program was evenly distributed. All women were born in Sweden.

6.3 DATA COLLECTION

6.3.1 Unstructured qualitative interviews (study I)

Interviews with 21 women with long-lasting pain had been conducted either at the clinic or in the women's homes, depending on the women's preferences. The interviews were unstructured in nature but framed by an interview guide that covered the following themes: the experience of illness and pain, ideas about their causes, interactions with the health care system, and perceptions of rehabilitation. Unstructured interviewing involves attentiveness and openness by the interviewer to those experiences that are brought up by the informant. At the same time the interviewer needs to guide the interview patiently and sensitively, according to themes decided on beforehand. Thus, the interviewer needs to navigate between a loose structure for the interview and the experiences shared by the informant.

Interviews were opened with the question "Can you tell me how your illness started and what it has meant to you?" During the interview women were asked to elaborate on experiences that came up and that were connected to the themes of the interview guide. The interviewers strived to conduct the interview with empathy and sensitivity and to build a respectful atmosphere. The interviews were conducted between 2014 and 2016 by my co-authors and two students and had a length of 45–90 minutes. All interviews were transcribed by a professional typist or by a student.

6.3.2 Survey (study II–III)

Study II and study III are based on data collected via a web-survey that consisted of three instruments: the Health and Suffering Scale (HSS), the Karolinska Exhaustion Disorder Scale (KEDS), the Multidimensional Scale of Perceived Social Support (MSPSS), and sociodemographic questions. The introductory first page informed participants about the aim and content of the study and study participation. On this page, the women were also informed that sending in the survey was considered informed consent to study participation. Two reminders were sent out by email after two weeks and after four weeks. Data were collected between October 2018 and August 2019.

Health and Suffering Scale

A first version of twenty items for further development of a measurement of health and suffering had been worked out by Andermo et al. (2018) in Swedish rehabilitation contexts. The twenty items included two general items explicitly reflecting on the interrelated phenomena of health and suffering: "unbearable suffering—bearable suffering" and "barriers to health—health". The remaining 18 items reflected more implicitly the concepts of health and suffering and were assigned to five subscales: life passion and energy, presence in life, relationships, personal freedom, and meaning. Items consisted of opposing words forming pairs that represented various attributes of health and suffering, e. g. "stuck in negative life patterns—in a process of development" or "resigned—faith/hope in future". Participants responded to the items on a visual analogue scale (VAS), that ranged between 0 and 100 and that was placed between word pairs, as exemplified above. A low score of the observations indicates suffering close to unbearable and a high score indicates perceived health or bearable suffering. In study III, the nine-item version of the Health and Suffering Scale (HSS) with five response categories (resulting from the psychometric evaluation in study II) was chosen for analysis. Internal consistency of this final version was α = 0.95 (CI 0.94–0.96) in the patient sample and α = 0.94 (CI 0.93–0.95) in the reference sample.

Karolinska Exhaustion Disorder Scale

The Karolinska Exhaustion Disorder Scale (KEDS) (Beser et al., 2014) consists of nine items measuring clinical exhaustion through self-reporting and was developed in a Swedish context. The items assess, on a seven-point Likert scale, a participant's ability to concentrate, memory, physical stamina, mental stamina, recovery, sleep, sensory impressions, experience of demands, and irritation and anger. A total sum score >19 indicates clinical exhaustion, with higher scores reflecting more pronounced exhaustion (Beser et al., 2014). Internal consistency of the KEDS was α = 0.84 (CI 0.81–0.87) in the patient sample and α = 0.88 (CI 0.85–0.9) in the reference sample.

Multidimensional Scale of Perceived Social Support

The Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, Dahlem, & Farley, 1988) is a self-report scale that captures perceived social support from family, friends, and significant others. The scale has been translated to and tested in two different Swedish contexts: among women with hirsutism and among health care students (Ekbäck, Benzein, Lindberg, & Årestedt, 2013). The scale consists of twelve items that are equally assigned to three subscales: Family, Friends, and Significant others. The response format is a seven-point Likert scale on which respondents rate a statement with between 1 = very strongly disagree and 7 = very strongly agree, e. g., "There is a special person who is around when I am in need". A high sum score indicates high perceived social support. Internal consistency of the MSPSS was α = 0.94 (CI 0.93–0.95) in both samples.

Sociodemographic questions

Items from the government agency Statistics Sweden were used to acquire sociodemographic data, and the response format is described in parentheses. These items covered age (year of birth); country of birth (Sweden, Scandinavia, Europe, other countries); information about partnership (single vs married/cohabiting); and three items about children: having children or not, number of children (including adult children), number of children living at home, and their age group (0–5 years, 6–12 years, 13–17years, 18 years or older). Data were also collected on income (five income categories ranging from 0 to >60 000 SEK); education (comprehensive school, secondary school, higher education/university); professional life (free comment field for own description of profession); and type of main activity/employment (multiple choice response). Finally, participation in and type of rehabilitation during the last three months was explored (rehabilitation for pain, rehabilitation for exhaustion, no rehabilitation). One item asked about caregiving responsibility for relatives other than children offering a dichotomous response format (yes/no). An affirmative response was followed up by a free comment field where the participants were asked to report the relationship to the relative they cared for and the underlying reason necessitating their care (for example a father with dementia).

6.3.3 Phenomenological interviews (study IV)

In study IV, 27 phenomenological interviews were conducted with 14 women living with exhaustion and/or long-lasting pain. Phenomenological interviews are time-consuming (Hoffding & Martiny, 2016) and therefore two interviews were planned with each woman. With the goal of acquiring rich insights into women's experiences of their own health and the meaning of motherhood, two interviews were considered necessary, regarding the time required to build mutual trust but also the time needed to cover both areas. The first interview was usually conducted during the end of the rehabilitation program, whereas the second interview was planned to take place after the women had finished their rehabilitation after approximately four weeks. Mainly due to the circumstances surrounding the covid-19 pandemic, this time span varied from 3 to 23 weeks (median 7 weeks). A further consequence of the pandemic was that women were offered the choice of either taking part in the interviews via video call or at the clinic, depending on their own preferences. Half of the interviews were conducted at the clinic and half were done so remotely. Thirteen women participated in both interviews, and one woman had to cancel the second interview due to health problems and a changed life situation, yielding 27 interviews. The interviews were both conducted and recorded by me between March and November 2020 and lasted between 50 and 90 minutes. All interviews were transcribed verbatim by a transcription service.

Phenomenological interviewing means to invite and encourage the informant to talk and reflect about personal experiences of the phenomenon in question and to follow up on concrete experiences in a sensitive way (Hoffding & Martiny, 2016). According to Hoffding and Martiny (2016), it is expected that questions that directly address the phenomenon will not result in rich descriptions, and it is at this point were the quality of phenomenological interviewing comes into play. In phenomenological interviews there is no predetermined interview guide, rather the interview is defined by an unpredictable dynamic of questions and answers (Hoffding & Martiny, 2016). The interviewer needs to adopt a phenomenological attitude that is rather contrary to an a-priori method of outlining and anticipation (Längle & Klaassen, 2019): this enables the researcher to look out for invariant phenomenological structures of meaning within the interview without being distorted and limited by the structures of a strict methodology (Hoffding & Martiny, 2016; Längle & Klaassen, 2019). The opening question of the first interview was *"What did, and still does, it mean to you to be a mother?"* and for the second *"How do you experience your health?"*. Following up on concrete and essential experiences that were exclusively brought up by the women and to ask for further elaboration requires attentiveness, presence, and receptiveness by the interviewer. This inner and outer openness by the interviewer resulted in rich and essential descriptions of the phenomena of health and suffering and motherhood, as the women could express, and were seen in, their uniqueness (Längle & Klaassen, 2019).

6.4 DATA ANALYSIS

6.4.1 Data analysis study I & IV

The analysis of interviews and their transcripts requires an awareness of how we understand and interpret texts. Both Gadamer's and Ricoeur's thinking provide essential methodological elements of the thesis. In the following paragraphs, the main characteristics of the philosophical work of Gadamer (Gadamer, 2004) and Ricoeur (Ricoeur, 1981/1998) are shortly presented to convey how their thinking was applied in the studies' analyses. Gadamer's major work *Truth and Method* (Gadamer, 2004) is on the phenomenology of understanding in which the fundamentals of hermeneutics are worked out. Parts of Ricoeur's philosophical work (Ricoeur, 1981/1998) are on the interpretation of texts and problems within hermeneutics. In study I, Gadamer's phenomenology of understanding was the methodological main emphasis, whereas in study IV Ricoeur's philosophy is reflected in the movement between explanation and understanding.

6.4.1.1 Data analysis study I

Gadamer (2004) emphasizes that, in hermeneutics, the interplay of *understanding* and *interpretation* always involves *application* because the reader of a text relates the text to the present and to her or his own situation. Considering the aim of this thesis, understanding the experiences of women living with pain and exhaustion means to interpret, and at the same time, to apply what is understood from a caring science perspective. According to Gadamer (2004), to understand always means to apply. In hermeneutics, understanding does not require a strict method as a guarantee yielding objective insight, rather on the contrary, understanding requires an openness towards what is foreign or strange, outside one's own horizon (Gadamer, 2004). Striving towards this openness, the analysis in study I was directed by the following question: *How do women experience living with long-lasting pain their lives and their suffering?* Two readers of the interview transcripts (a co-worker and myself) independently wrote out a naïve understanding of what brought together the experiences of all 21 women. A comparison of these two naïve understandings showed that they were touching on similar phenomena of women's health and suffering. These phenomena were worked out as themes and built the basis of the interpretation.

Gadamer (2004) termed the dialectical concept of reaching a shared understanding a "*fusion of horizons*". This fusion of horizons involves a tension between the text and the reader's present, between strangeness and familiarity, and thus touches on the aforementioned concept of application. Gadamer (2004) underlines that the hermeneutical task is not to conceal this tension but instead to unfold it by recognizing otherness and understanding oneself in relation to this otherness. Overcoming this tension entails an openness in which the interpreter both is distanced and belongs to what is understood. Hermeneutic takes place in this in-between of distance (or *strangeness*) and *belonging*. Thus, the understanding, interpretation, and application of texts requires openness (Gadamer, 2004). The interpretative work with the interview transcripts required openness to the women's experiences—both to those perceived as strange and those perceived as familiar. Thus, I as an interpreter, accompanied by my co-workers, entered a hermeneutical in-between space of strangeness and belonging in which we strived to reach a shared understanding. Moving between strangeness and belonging involved living with the texts for a while and critically reflecting and discussing any meanings that appeared.

Gadamer (2004) emphasizes that openness is not endless but is structured by a question and that openness and questions condition each other: The question directs the openness and questions should be open (and not be answered beforehand). The analytical work with the first study but also the thesis as a whole was guided by an interest (open question) in understanding the health and suffering of women with exhaustion and long-lasting pain from a caring science perspective. Importantly, the new and different understanding reached through working with the transcribed interviews from study I yielded new question horizons: *How are health and suffering associated with women's immediate social environment? How do women experience their motherhood and health?* These new questions became the points of departure for studies III and IV.

6.4.1.2 Data analysis study IV

Ricoeur's thoughts on interpretation were particularly valuable in the fourth study in which meaning unfolded on various structural levels of the transcribed interviews. Bringing together fragmented meanings into one shared world of meaning was accompanied by moving back and forth between fragmented meanings, their concrete context, and their final interpretation.

Ricoeur (1981/1998) elaborates on the meaning of distanciation within hermeneutics and puts Gadamer's view on openness (as an opposition to strict scientific method) into perspective. The text itself is considered a discourse through distance, as the text is a written distanciation of what has been said. This distanciation from the original context gives the text autonomous status available to everyone who can read. Therefore, Ricoeur (1981/1998) places great emphasis on linguistics in discourse, because through language, discourse and meaning are linked and articulated. Anchoring the meaning of discourse in linguistics—that which should be grasped through interpretation—involves a more structured and methodological approach to interpretation than Gadamer suggests.

As part of this study's structural analysis, a naïve interpretation close to the linguistic structure of the transcripts was written for each pair of interviews after having thoroughly read a woman's paired transcript. Through the reading, the world of a woman's experience was inhabited and emerging meanings within this unfolding world between me as a reader and the sense of the transcripts were grasped. When documenting these first impressions in naïve interpretations, a hermeneutical circle was entered, moving between interpretation and explicative parts of the transcript. These parts could be everything between words and metaphors used by the woman herself or coherent and concrete parts of her life story. This part of the analysis resulted in 14 separate naïve interpretations.

According to Ricoeur (1981/1998), structural analysis is a necessary part of interpretation because it prevents understanding from being based on mere intuition but instead to become validated through *explanation*. Explanation means considering the meaning and structure of words, phrases, sentences, and larger parts of a text or a work. Hence, the character of explanation offers an opportunity to validate the meaning of a text. However, Ricoeur (1981/1998) emphasizes that *explanation* and *understanding* are interdependent. Understanding is mediated by explanatory practices, and, at the same time, explanation will not make sense without understanding. This interplay of explanation and understanding when acquiring knowledge on human phenomena represents the hermeneutical circle. Thus, the above-described naïve interpretations of the women's experiences meant moving between explanation and understanding making explanation an integral part of interpretation.

During the interpretative and analytical work with the naïve interpretations new meanings emerged connecting the various experiences of the women. The structure of these new and connecting meanings were formulated in interpretative statements. At this point, these newly emergent meanings were understood, interpreted, and applied through the lens of health and suffering. Striving to understand these emerging meanings in relation to each other made a new coherent structure of meaning appear which turned out to be a woman's movement between suffering and health. The interpretative statements were weaved into one coherent interpretation reflecting the phenomenon of women's health and suffering as ongoing movement. Discussing and reflecting with my co-workers—the readers of the transcripts—these emerging structures of meaning was also a way to anchor and validate the interpretation of the transcripts. Finally, quotes substantiated the interpretation both to illustrate the interpretation but also to reflect the intertwinement between explanation and understanding throughout the hermeneutical process.

6.4.2 Data analysis studies II & III

When performing statistical analyses, it is important to be aware of the various assumptions that underly each analysis and to explore in what way they are fulfilled or violated. Classical test theory and the Rasch model were applied in the second study. Below, assumptions of relevance to the analyses applied in this thesis are described.

6.4.2.1 Data analysis study II

In classical test theory it is assumed that the derived test statistics of an instrument are only valid for the specific context (sample dependency) in which the test was evaluated, thus, it is assumed that the test characteristics will change in a different sample (Streiner, Norman, & Cairney, 2015). Rasch analysis, on the other hand, assumes that the probability of succeeding on any one item is the presence of one single construct or characteristic (assumption of *unidimensionality*). As a consequence of assuming unidimensionality, the probability of succeeding on any specific item will be unrelated to the probability of endorsing other items *when* the influence of the measured construct or characteristic is removed (assumption of *local independence*) (Streiner et al., 2015). This implies that item qualities are independent of the context in which they are used, and persons' abilities/constitutions are independent of the instrument measuring their abilities/constitution (Bond & Fox, 2015). An additional consequence of assuming unidimensionality is that the Rasch model is only meaningful for evaluating constructs where items are effect indicators and not causal indicators (Bond & Fox, 2015; Streiner et al., 2015). The existing twenty items in HSS were considered to be effect indicators of the underlying construct of health and suffering. Prior to applying the Rasch model, the existing twenty items were first explored for multidimensionality with an exploratory factor analysis. To evaluate how well the observations generated through the HSS fit the Rasch model, fit statistics were calculated.

Data analysis for further development and psychometric evaluation of the Health and Suffering Scale (HSS) (study II) was structured according to explorations of dimensionality, item reduction, reliability, and construct validity. From the perspective of face validity, the first version of the HSS, consisting of twenty items, was anticipated to have five dimensions: life passion and energy, presence in life, relationships, personal freedom, and meaning. Exploring the scales' dimensions with empirical data had not been done before and was therefore a necessary step before proceeding with other psychometric tests. Explorative factor analysis was applied to investigate dimensionality. Dysfunctional or redundant items were expected as a possible outcome and therefore a reduction of items was taken into consideration (Streiner et al., 2015). Items were excluded based on their psychometric qualities derived from both factor analysis and Rasch analysis. During the process of item reduction items' psychometric qualities were weighed up against their theoretical significance.

Reliability indicates how strong the observed scores and the true scores are linked—how consistent a test measures (estimation of the error)—and how well an instrument can differentiate between individuals (Streiner et al., 2015; Weir, 2005). This linkage and consistency were explored via factor analysis (regarding the items' uniqueness) and Rasch analysis (regarding the items' hierarchical order) and in a test–retest setting analyzed via both a paired sample t-test and the intraclass coefficient (ICC). The test–retest was only carried out in the reference group of healthy women because they were expected to have a stable health condition in contrast to the patient group undergoing rehabilitation. There exist many different ICC models that in the first instance were developed to evaluate rater reliability; hence, choosing an ICC model for a test–retest setting as was done in study II requires careful consideration (Weir, 2005). Regarding the fact that each person included in the test-retest was observed twice, a 2-way model was needed (Weir, 2005). According to Shrout and Fleiss (1979), estimating the agreement of two measurements of the same individuals (equivalent to the agreement of two judges) implies that a random effect (error due to special circumstances on the test day) must be considered, requiring the application of the ICC model (2,1).

Furthermore, systematic error was considered due to ‘learning’ effects; individuals might get sensitized to the concepts of suffering and meaning in life after having taken the first test. $ICC_{2,1}$ addresses both random and systematic error (Weir, 2005). Hence, the $ICC_{2,1}$ was chosen to estimate the agreement between the measurements of the test and the retest. Estimating agreement is a more conservative measure than estimating consistency and results in lower scores (McGraw & Wong, 1996; Streiner et al., 2015). An ICC estimate of 0 indicates no reliability and 1 indicates perfect reliability. Internal consistency was evaluated with the alpha coefficient as an estimate of the final Health and Suffering Scale’s homogeneity. Homogeneity only matters when the items are considered to be effect indicators of an underlying construct (Streiner et al., 2015) which turned out to be the case for the HSS.

Validity indicates how the observed scores and the characteristic or construct under investigation are linked, implying that the observed scores of the HSS should be linked to the construct of health and suffering. A strong linkage then in turn means that the HSS as an instrument should be independent of the context where it intends to measure health and suffering (Boone, Staver, & Yale, 2013). To meet these requirements of invariance in measurement, Georg Rasch developed a probability model for fundamental measurement in the human sciences (Bond & Fox, 2015). Rasch defined the probability of a person answering an item ‘correctly’ versus ‘incorrectly’ as the difference between the person’s ability (what is measured) and the item’s difficulty (Boone et al., 2013). Hence, the validity of the Health and Suffering Scale was evaluated (and further improved) by applying the Rasch model to explore item hierarchy from a theoretical point of view and by investigating what the scale’s measurement qualities looked like in two different groups of women: the patient group and the reference group. Within the family of various Rasch models, the Andrich Rating Scale Model (polytomous Rasch model) was applied because the HSS items generated ordinal data. Furthermore, a two-sample t-test was applied to investigate whether the scale can differentiate between women with pain and exhaustion and healthy women. As such an investigation only determines, at minimum, discrimination of limited usefulness (Streiner et al., 2015), the Rasch analysis was used to explore HSS’ levels of finer discrimination within the same sample. Convergent validation was performed by correlating the HSS with a clinical measure of exhaustion, the Karolinska Exhaustion Disorder Scale, with the expectation that the correlation would not be overly high.

Skew was −0.14 and kurtosis was 2.36 for the distribution of the patient sample whereas the skew of the reference sample distribution was (−0.69) with a kurtosis of 3.36. Thus, assumptions of normal distribution with a skew of 0 and a kurtosis of 3 (Norman & Streiner, 2014) was not severely violated.

6.4.2.2 Data analysis study III

The data analyses were mainly exploratory, using descriptive statistics and linear regression. The scores of HSS and MSPSS of mothers and women without children and of mothers in rehabilitation and healthy mothers were compared with two-sample t-tests to explore possible differences. To explore whether variation in HSS scores can be partially explained by MSPSS scores, various regression models with and without possible confounders were tested. In linear regression it is assumed that the residuals of the dependent variable are normally distributed (with a mean of zero) but there are no assumptions made about the distributions of the independent variables. The only recommendation that is made regarding independent variables is that they should not highly correlate with each other (Norman & Streiner, 2014). Additionally, residuals should have a constant variance which means that they are homoscedastic. None of these assumptions were severely violated by the applied regression models, as evaluated through plots of residuals and diagnostics of influence and multicollinearity. In the first linear regression model, HSS scores were the dependent variable and the total sum scores of MSPSS were the independent variable. In a second step, it was of interest to explore how various resources of social support—from family, friends, or significant others—were associated with health and suffering. Therefore, the three subscales of the MSPSS were included as three independent variables into the second regression model, with HSS scores as the dependent variable. In a third regression model, the relationship between HSS and MSPSS was adjusted for possible confounders: degree of exhaustion disorder (total sum score of KEDS), living in a relationship (yes/no), number of children living at home, and age.

Data were analyzed using two programs: MatLab version R2019b (MathWorks) and Winsteps version 4.5.3 (Winsteps & Facets Rasch Software).

6.5 ETHICAL CONSIDERATIONS

The included studies were approved by the Swedish Ethical Review Authority (ethical approval no. 2014/283-31/5 and complement no. 2015/201-32; ethical approval no. 2015/412-31/4 and complement no. 2016/993-32 and complement no. 2018/1681-32; ethical approval no. 2019-02584) and have been conducted according to the World Medical Association Declaration of Helsinki (WMA, 2013).

Knowledge and insights gained from the included studies were valuable in developing preventive measures as well as for the further development of the care of women living with exhaustion and long-lasting pain. Therefore, the research was expected to yield general long-term benefits for women suffering from exhaustion and pain. Nevertheless, the study design required that healthy women were also involved. This implied that women who were not afflicted by exhaustion or pain were exposed to some risks connected to study participation, without gaining some possible benefits from the knowledge achieved. Possible risks connected to study participation were as follows:

Participants might have felt they were in a dependent relationship with their healthcare center, or university, and they might have hoped or feared they would positively or negatively influence the care, treatment, or academic education they received through participation or non-participation in the study. Being in a dependent relationship might increase the risk of answering in a more socially acceptable way. For those reasons, voluntary participation was emphasized both in oral and in written information when recruiting participants (Swedish Research Council, 2017). Specific to the studies included in this thesis was that participants were confronted with existential questions both in the web-survey as well as in interviews. Moreover, most participants were patients undergoing rehabilitation and were therefore regarded as belonging to a vulnerable group of individuals experiencing ill-health. The confrontation with existential questions might have started a process of reflection within the women that could have either positively or negatively influenced the women's experiences of their own health and suffering. Therefore, it was necessary that the interviewers were adequately trained in interviewing, sensitive, and respectful when asking questions, but also to follow up on the informant's experience of the interview. All interviewers were either trained healthcare professionals and/or had received additional training in interviewing. Being interviewed can imply a benefit for health in terms of an opportunity to reflect on one's own health and life situation. All participating women were asked in the end how they had experienced the interview. The women generally expressed that the interview had been a positive and valuable experience despite some women also acknowledging that difficult experiences had been brought up which could be perceived as tiring but also as a necessary step in alleviating their own suffering. Regarding the web-survey that included items of existential character, cognitive interviews had been performed when the first version of the instrument was developed in which patients had perceived the items as meaningful (Andermo et al., 2018).

Participation in the study meant that both personal information (e.g. name) and sensitive personal information (e.g. information on health) were collected and stored. The collected data was administrated confidentially and stored safely in accordance with regulations regarding public authority archives: data is protected from unauthorized use and is only collected for the explicit purpose of research. Moreover, only research-relevant data was collected. To achieve secure and confidential data storage, technical measures were applied: encryption, secure authorization, and separate processing of personal identifying information from sensitive personal information (Karolinska Institutet, 2018). The participants received written information that sending in the web-survey was considered to be giving consent to study participation and data storage. The research process was documented in the electronic logbook ELN provided by Karolinska Institutet.

7 RESULTS

7.1 SHORT OVERVIEW

Study I

This study showed that women suffering from long-lasting pain experienced their lives, including family life, as overwhelming and felt lonely. The women perceived their physical and mental suffering as intertwined.

Study II

The psychometric evaluation of the Health and Suffering Scale among women living with exhaustion and long-lasting pain, and among healthy women found nine of twenty original items to be part of a reliable and unidimensional structure. The scale could discriminate between women suffering from exhaustion and long-lasting pain and healthy women. Women with exhaustion and pain reported significantly more suffering and poorer health (HSS sum score mean +/− SD; 26.4 +/ – 8.4) than healthy women (37.2 +/ – 6.8; $p < 0.001$, d = 1.4). For the final version of the HSS in English, see the publication and for the final version in Swedish see the appendix.

Study III

The results showed that mothers living with exhaustion and long-lasting pain perceived greater suffering and poorer health (HSS sum score mean +/− SD; 26.5 +/− 8.2) than healthy mothers (37.9 +/− 6.5; $p < 0.001$, d = 1.518). The health and suffering of women with exhaustion and pain was associated with perceived social support both among women without children ($F_{2,35} = 11.9$, $p < 0.05$; $R^2 = 0.253$) and among mothers ($F_{2,127} = 66.3$, $p < 0.05$; $R^2 = 0.343$); the more the women and mothers felt supported by their family, friends, and significant others, the better health and less suffering they reported (b = 0.275, $p < 0.01$; b = 0.31, $p < 0.001$).

Study IV

The findings of this study suggested that health and suffering of women living with exhaustion and long-lasting pain are intertwined with motherhood, relational vulnerability, and life burdens. Suffering could be alleviated when women related in a new way to their burdens in life, their vulnerability, themselves, and others.

In the following, more detailed findings of these four studies have been combined into a coherent whole.

7.2 SYNTHESIS OF THE FINDINGS

7.2.1 Introduction

Women living with exhaustion and long-lasting pain appeared to be vulnerable on a relational level (study I, III & IV) suggesting that a central part of their existential shelter—a place where they can be themselves and express themselves—might be insufficient or missing (study IV). Feeling insufficiently supported by others risked turning difficult experiences and responsibilities into an overwhelming burden which could turn into suffering (study I & IV). Suffering became difficult to meaningfully integrate into life (study I—IV) when women were insufficiently embedded in reliable and comforting relationships (study I, III & IV). Consequently, the relationship between women's selves and lives and how they had developed could become conflicting (study I & IV). This meant that life risked appearing meaningless. Suffering and the perception of meaninglessness in life were found to be interwoven (Study I & II). In the absence of meaning in life, women tended to experience suffering close to unbearable, or vice versa, deep suffering might make life appear meaningless (study I–IV). When women were embedded in reliable and comforting relational ties or reconsidered their relations in life and were actively building an existential shelter, it seemed that they were better equipped to bear difficult life experiences and caring responsibilities. Then women also appeared to be more prone to reconciling their self and life (study IV). Due to its reconciliation with life, suffering became integrated into life, was more bearable and the women's health became more balanced (study II & IV). The synthesis of the studies' findings suggests that women's health could be understood as an *ongoing movement of how one relates to burdens in life, the own vulnerability, fellow human beings, the self, and meaning in life*. As a natural counterpoint to health, suffering then could be understood as an *interruption of these meaningful and authentic relations in life*. Health and suffering become integrated when relations are re-created in a meaningful and authentic way (Figure 1).

7.2.2 Overwhelming life burdens (I & IV)

The women described their lives as overwhelming, filled with difficult life experiences, caring responsibilities and/or a challenging family life (study I & IV). Often, women had had a difficult or even traumatic childhood in which they had experienced abuse or emotional neglect by a parent or had had a parent that suffered from addiction (study IV). There were also experiences of violence and/or mental abuse in relationships. Losses due to separations, homelessness, or addiction could also be painful experiences. Both ordinary and severe concerns and responsibilities for the health, wellbeing, and development of children had to be faced and taken care of over the course of decades (study IV). These experiences and responsibilities risked becoming an overwhelming burden when accumulated over years and when carried mainly in loneliness (study I & IV). Carrying this burden could evolve into existential feelings of guilt, shame, worthlessness, rage, or anxiety. Thus, difficult life experiences could be overwhelming in and of themselves, but they could also give rise to feelings touching on one's own existence (study IV). These accumulated experiences and related feelings might have become exhausting, causing the women suffering they perceived as close to unbearable (study I & IV). Being a mother could be part of this burden. To be a mother was experienced as double-edged: besides a joyful and meaningful enrichment of life, motherhood meant a daily commitment that lasted for life that could be described by the women as arduous, tough, and tiring (study IV). Sometimes the women's children had special care needs (study I & III) that were experienced as an extra challenge in the daily care of the children

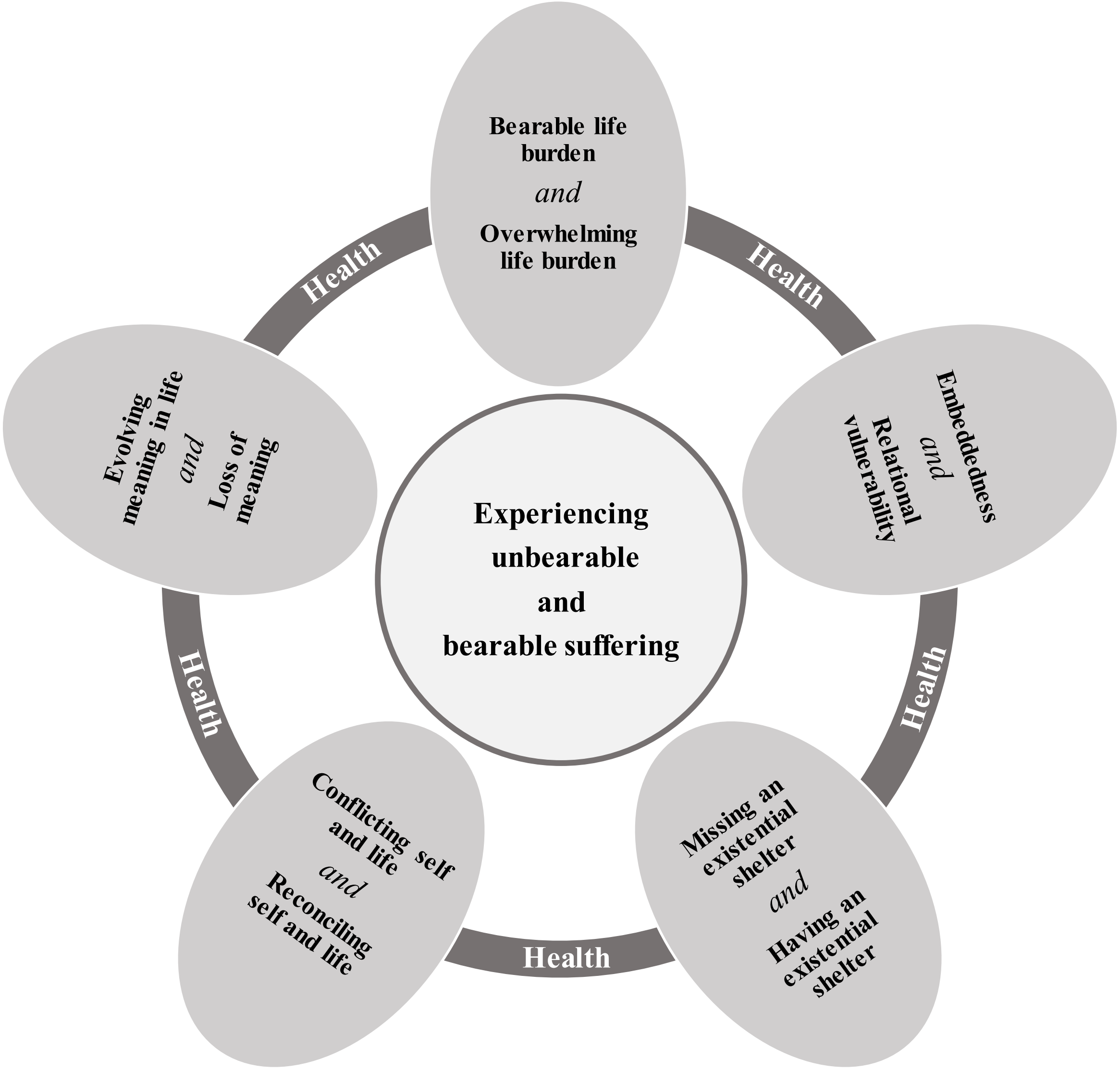

Figure 1. **Integrating health and suffering.** Suffering involves an interruption of meaningful and authentic relations in life. Health means moving within these changing relations to life burdens, one's own vulnerability, fellow human beings, the self, and meaning in life. Integrating suffering into life means to re-create these interrupted relations.

(study I & IV). The women could also feel confronted with difficult childhood experiences which could evoke strong and difficult feelings when caring for their own children. The development of strong mothering ideals seemed to be rooted in these early life experiences (study IV). Living up to these inner ideals of how to be a good mother further added to the burden.

7.2.3 Relational vulnerability (study I, III & IV)

The studies' results indicated that the women's social ties and support were perceived as insufficient (study I, III & IV) implying that they had little to fall back on when they faced difficult experiences in life or caring responsibilities. Over and above living with relations among whom the women could feel lonely or unsupported, women frequently shared that they had to care for fragile relatives other than their children, like older parents or mentally ill siblings (study I, III & IV). Relations harmful to their own health could be part of the women's life (study I & IV), in particular when being exposed to violence and abuse by a partner (study IV). In general, women with pain and exhaustion were more often living without a partner (34.9%) than healthy women (16.3 %) (study II). It was not unusual that the women had experienced a difficult childhood, making the women vulnerable in a relational sense from early on (study IV). Mothers living with long-lasting pain and exhaustion reported significantly less perceived social support from family, friends, and significant others, than the reference group of healthy mothers ($p < 0.001$, $d = 0.82$) (study III).

7.2.4 Missing or having an existential shelter (study I & IV)

The phenomenon of an existential shelter and its significance for women's health became apparent in the fourth study, but it was also implicitly present in the remaining studies. Existential shelter described a space in time or in relations with others or a spatial place where one could express oneself and where one might be cared for and listened to by others or oneself. The women seemed to miss being sheltered and cared for by others, but they also seemed to miss a time or a place where they could dwell in simply being (study IV). Instead, the women shared how they constantly cared for their children, family, or were at work without being cared for themselves (study I).

Mothers with long-lasting pain and exhaustion had higher caring responsibilities for relatives (13.2 %) than healthy mothers (2.8%) and perceived themselves to be significantly less supported by their immediate social environment, compared to healthy mothers (study III). The women described how they were longing for an existential shelter where they could recover from the strains of constantly caring for others, a calm and peaceful place (study I). Missing such a shelter could become a threat to their own existence as the women did not perceive enough space to listen to their own needs and alarming signals from their bodies like pain and signs of exhaustion (study I). It therefore appeared that the women—out of touch with themselves—could temporarily lose meaning in life causing them suffering on an existential level (study I & IV). Those women who had an existential shelter or had started building an existential shelter seemed to be better equipped to relate to their suffering and to successfully integrate it into life (study IV).

7.2.5 Conflicting versus reconciling self and life (study I & IV)

Striving to live up to norms, outside expectations, and ideals of how to be a good woman or mother and idealistic views of life could make the women perceive inner conflicts (study I & IV). Inner conflicts tended to arise in situations in which the women, according to their own ideals of being a 'normal', 'good' or 'perfect' mother failed or when they surpassed their available inner resources (study IV). Such inner conflicts could also stretch over several years, when women, for example, stayed in harmful relationships with their partners believing that they would offer their children a better childhood in a classical nuclear family than as a single mother. The women strived to be patient and attentive mothers engaging in their children's life as much as possible which meant that the women reached or even crossed their own limits of mental and physical resources (study IV). These inner conflicts might have been reinforced by the fact that the women's ideals and internalized norms and expectations were tied up with their own upbringing. The women were prone to offer their children aspects of a childhood they themselves had wished for but painfully missed. Then, the relation of the women's self and how life had developed risked becoming conflicting as the women were living non-authentic lives challenging their health (study I). The women could reflect that they had not been themselves when looking back. This had come at a high cost to their health as the women had not recognized their own needs. The women's suffering then risked becoming close to unbearable (study I).

Those women who had some supportive and reliable social ties seemed to have better preconditions to integrate their life burden into their lives, making it bearable. This process of integration was described as a painful process that also was a deeply personal matter—despite its dependence on authentic relations with others. It appeared to involve personal growth in which the women started to relate to their own self, their vulnerability, and idealistic views of life and fellow human beings in a new way. Relating in a new sense to their own existence meant letting go of idealistic views of life and previous life experiences and abilities. This could, for example, imply that the women had reconsidered relationships that were harmful to their health. To let go meant to let the bereavement sink in, and to mourn. Then women could meet their own needs, could listen to them, and could strive to adjust their lives accordingly. This ongoing process of letting go, listening inwards, and adjusting life seemed to reconcile the women's self and their life. The women had developed an awareness that this process of reconciling oneself and one's life was ever-evolving and life-long. Relating in a new sense to oneself and one's life was experienced as a necessary and enriching—although painful—development involving grief. Eventually, reconciling women could feel their pain and exhaustion alleviated and their suffering seemed to have become more bearable (study IV).

7.2.6 The experience of meaning in life (study I, II & IV)

Women suffering from exhaustion and long-lasting pain could describe a loss of meaning in life, and some had experienced a severe loss of meaning (study I & IV). The loss of meaning in life seemed to be intertwined with the experience of life as overwhelming and having too little energy left to live. Longing for calmness in life and a wish to withdraw from life were expressed with a few women having had considered suicide (study I). These women's suffering had become close to unbearable. Unbearable suffering was found to be closely related with loss of meaning in life (study II). Motherhood enriched women's life with a deep meaning in life and was a source of joy and happiness, but also involved an important sense of togetherness with the children. Children could be part of women's existential shelter, especially when they were grown up. Hence, being a mother could be perceived as giving strength during periods of suffering and offered the women an essential source of meaning in life (study IV).

7.2.7 Experiencing unbearable and bearable suffering (study I – IV)

Women living with exhaustion and long-lasting pain seemed to struggle to integrate suffering in a meaningful way into their own lives. In contrast, healthy women reported suffering that was to a higher extent perceived as bearable and compatible with the experience of health (study II & III). The integration of suffering might have been complicated by women's relational vulnerability and dependency on an existential shelter (study IV). The more women perceived themselves to be supported by their family, friends, and significant others, the more they experienced their suffering to be bearable, suggesting that suffering becomes bearable in meaningful encounters with others (b = 0.31, $p < 0.05$) (study III). This intertwinement of perceived health and suffering with relational vulnerability was also indicated in the two qualitative studies (study I & IV). The health and suffering of women who were mothers was more strongly correlated with perceived social support (b = 0.31, $p < 0.001$, $R^2 = 0.343$) than among women without children (b = 0.275, p < 0.01, $R^2 = 0.253$) suggesting that the health of mothers, specifically, might be dependent on their immediate social ties (study III).

7.2.8 Conceptualizing and measuring unbearable and bearable suffering according to an existential definition of health (study II)

The definition of health as a process of integrating suffering into one's own life was found to be a useful concept in discriminating between women living with exhaustion and/or pain and healthy women. The psychometric evaluation of the Health and Suffering Scale (HSS) suggested that this existential concept of health was unidimensional, indicating that various theoretical and empirical aspects of health were part of one single underlying process of integrating suffering into life. The following nine items out of an original twenty reflecting these theoretical and empirical aspects, were meaningful to include in the measurement of health and suffering from a statistical point of view: Without value–Valuable life; Life without meaning–Meaningful life; Unbearable suffering–Bearable suffering; Life is dark–Life is bright; Lost grip on life–Understanding about life; Resigned–Faith/hope in future; Stuck in negative life patterns–In a process of development; Life is a struggle–Life is a gift; Tired of struggling–Engagement in life. In a test–retest among healthy women, the HSS showed moderate reliability ($ICC_{2,1} = 0.63$, CI 0.5– 0.73). Further, the perception of health and suffering (HSS) was moderately related with clinical exhaustion (KEDS) in both women with exhaustion and pain ($rho_P = -0.58$; CI −0.82 – −0.51) and healthy women ($rho_P = -0.42$; CI −0.63 – −0.28), indicating that suffering is positively associated with exhaustion but dissimilar to the construct of exhaustion.

8 DISCUSSION

The four studies included in the thesis and their synthesis brought out two major insights about the health and suffering of women living with long-lasting pain and exhaustion: First, on a contextual level, the health and suffering of these women seem to be related to a relational vulnerability and to their life experiences as women and as mothers. Second, on a conceptual level, the women's health and suffering reflected an ongoing movement of relating to essential parts of life like vulnerability, life burdens, life meaning, the self and being sheltered.

Considering women's *relational vulnerability*, it is well-known that social support plays an important role in individual health (Thoits, 2011) and it is also known that women, from an evolutionary point of view, have always been dependent on support from others in childrearing (Hrdy, 2011). Nevertheless, a connection between women's life circumstances and their existence as women and mothers and women's ill-health like pain and exhaustion has been scarce in the scientific literature. This is problematic because an inherent part of female health and suffering is at risk of remaining unrecognized. This thesis' results indicate, on several levels, that women with exhaustion and pain are dependent on relational ties in which they can share and are supported in everyday responsibilities and burdens. Furthermore, it was shown that the women encountered an accumulation of ordinary and difficult life burdens and experiences which in the absence of reliable relationships could become an *existential burden*. This burden was suggested to be related to the women's personal history and motherhood. However, it seemed that the burden could be relieved when the women were embedded in reliable and caring relationships where they could relate to life and to themselves in a meaningful way. Then, the women's suffering could become alleviated. In the following, it will be first discussed how the health and suffering of women living with exhaustion and pain can be understood in the context of women's vulnerabilities and life burdens and how it seems to go hand in hand with contradictory social expectations placed on women and mothers. In a second part, how women's health and suffering can be understood as part of an existential view on health and why it is necessary to include vulnerability and human's interdependence in the understanding of health and suffering will be discussed on a theoretical level.

8.1 CONTEXTUAL DISCUSSION

8.1.1 Women's burdens in life and the role of emotional embeddedness

The findings suggest that women with exhaustion and long-lasting pain experience overwhelming life burdens, many of which are connected to their existence as women and mothers. While women are part of a wider social context through paid work and thereby less isolated to their homes, they may at the same time risk experiencing loneliness in managing the demands of everyday life as described in this thesis' studies (study I & IV). One central question that arises is how women's health and suffering related to exhaustion and long-lasting pain can be understood in the context of Sweden as one of the most gender equal countries in the world. In order to discuss and deepen the understanding of this overarching finding, some general aspects of women's life context need to be reconsidered. Taking a closer look at the life situation of women in Sweden shows that 80 percent of women are employed, which is the highest female employment rate in the European Union (Eurostat, 2021). Women who are committed to paid work were shown to be very satisfied with life and reported high levels of well-being, but experienced on the other hand, more work–family conflict than men (Grönlund & Öun, 2010). A meta-analysis of European studies found that women experience more work–family conflict than men and work–family conflict was related with subsequent sickness absence regardless of gender (Nilsen et al., 2017). Swedish women were shown to have a 41% higher risk than men of going on sick leave for stress-related disorders compared to men (Swedish Insurance Agency, 2020). Indeed, a significant gender gap in sickness absence among parents exists in all European countries with Sweden, Denmark and Norway in the top (Angelov et al., 2020). In Sweden, the gender gap within couples was found to exist for 16 years after the birth of the first child (Angelov et al., 2020). Besides self-reported health, work- and family-stressors were found to be determinants of the gender gap in sickness absence, nevertheless, major parts of the gender gap remained unexplained (Østby et al., 2018). Further, Angelov et al. (2020) did not find objective indications of deteriorated health (in-hospitalization) among women that could explain the gender gap after having become a parent but suggested economic incentives within a family as an alternative explanation. Information that might go unrecognized in such epidemiological investigations of health is the fact that stress-related ill-health like exhaustion and long-lasting pain mostly lack established measurement (Fitzcharles et al., 2021). These conditions are more common among women than men (Beauregard et al., 2018; Borchers & Gershwin, 2015; Cimmino et al., 2011; Wijnhoven, de Vet, & Picavet, 2006). Thus, the general picture of women's health remains complex as there are both studies that provide evidence for a double burden among women jeopardizing their health (Bucher-Koenen et al., 2020; Chandola, Booker, Kumari, & Benzeval, 2019) and studies that challenge that theory (Mastekaasa, 2013; Narusyte et al., 2015). This thesis contributes to this complexity with a perspective embracing women's own experience of their health and suffering related to their existence as women and mothers: The women shared experiences of an overwhelming life that seemed to be inherently interwoven with a personal history of rare support and care from others. Thus, a more nuanced picture emerges when women's experiences of their health and suffering are incorporated into these more general insights accomplished by sociology, epidemiology, and evolutionary psychology. This will be more profoundly elaborated on in the following.

Beyond scarce practical support from the closer social environment in daily demands, this thesis indicates that these women living with pain and exhaustion seemed to lack sufficient emotional support and care on their own (study I, III & IV). It has been emphasized that those who care for and nurture others need themselves to be nurtured and cared for in close relationships (Herring, 2016; Luthar & Ciciolla, 2015). From an evolutionary point of view, the women's experiences of loneliness in family responsibilities challenges human nature at its core and thereby women's health: raising children means an immense effort that throughout the evolution of humans has never been shouldered by mothers alone but by a whole community, simply because it is not manageable by one single person (Hrdy, 2011).

Furthermore, the dependency of practical support from others in childcare was interwoven with the development of human's capacity to empathize with others (Hrdy, 2011). "[T]his dependence produced selection pressures that favored individuals who were better at decoding the mental states of others, and figuring out who would help and who would hurt." (Hrdy, 2011, p. 66). Hence, it becomes comprehensible that these women who feel alone in caring responsibilities, with rare opportunities to ask for support, might suffer from feeling overwhelmed and exhausted (study I & IV). However, it must be acknowledged that compared to international convention, women and men in Sweden receive generous financial and practical support from the Swedish welfare system for child rearing (Government Offices of Sweden, 2017; Karimi, Lindahl, & Skogman Thoursie, 2012). But what might be missing is the emotional support that naturally occurs in interactions within smaller and more intimate social support contexts. It is not in question that the Swedish welfare system offers great opportunities and advantages for women and their families. However, there seems to be a need to reflect on some of the parts that might be insufficient or even missing in the general welfare system and, by extension, health care.

8.1.2 Living in a tension between mother ideals and gender equality

The women who were living with exhaustion and pain appeared to strive for good motherhood ideals (study IV) within a context where a working and independent mother is yet another ideal to live up to. Thus, tensions seem to arise between expectations and ideals that women are confronted with in everyday life and in the contexts in which they live: expectations to be a caring woman and mother that necessarily involve being dependent on support from others, but at the same time they live in a society in which the individual independence has become an emissary of gender equality (Heinö, 2009). Swedish women live in a gender equal context in which being a working woman or working mother is not just the norm involving huge advantages for the lives of women but also represents a hidden ideal of a good mother (Collins, 2019). The percentage of Swedish women working full-time has increased during the last decades from around 40% in the 1980s to 57% in 2018 (Statistics Sweden, 2018b). This trend coincides with the fact that women in Sweden still spend considerably more time on household and childcare per week (ca. 16 hours) than men (ca.10 hours) (Statistics Sweden, 2018b). Remarkably, this perceived work–family conflict was found to have stronger negative associations with the well-being of individuals living in more gender-equal countries like Sweden and other Nordic countries than in countries in which gender equality is less valued (Hagqvist et al., 2017). As an explanation, it has been suggested that ideals of a good mother still prevail, in parallel, to a highly-valued norm of gender equality; this in turn, creates demands that might have an impact on individuals' well-being (Hagqvist et al., 2017). Exhaustion and pain among women might therefore be interpreted as signs of suffering that occur when living in this field of tension between two paradox social expectations. Indeed, women who experience pressure to live up to the image of a perfect mother were found to perceive higher stress levels and higher levels of parental exhaustion (Henderson, Harmon, & Newman, 2016; Meeussen & Van Laar, 2018). It was also shown that the more women strived for perfect mothering the lower work–life balance they perceived (Meeussen & Van Laar, 2018).

Striving for gender equality in Sweden made Swedish society to one of the most individualistic in the world as the individual woman or man is recognized as the basic unit of society (instead of the family) (Heinö, 2009). "This direct link between the state and the individual has diminished the importance of smaller units in civil society such as the family or the local community" (Heinö, 2009, p. 308). The consequences of strong individualism may have the most damaging impact on those who are the most dependent on emotional and practical support from others, those who are vulnerable, and those who are involved in the care of the vulnerable, which often is provided by women and by mothers. In conclusion, this suggests that in an individualistic society like Sweden, women and mothers who live with a relational vulnerability but continue to intensely care for their families and others are at risk of being left in an empathy vacuum. Living without empathy and care from others is something that humans, according to evolutionary theory, are not equipped to live with. On the contrary, without empathy humans would not have evolved as they are (Hrdy, 2011). Interestingly, in an international comparison (Roskam et al., 2021), exhaustion related to parenthood was found to be influenced by how much a society was characterized by individualism: in more individualistic societies, parents were more often and more severely exhausted (Roskam et al., 2021). Against this background, the contradictory social expectations of a caring but independent woman might emerge as one of the many complex forces of health and suffering beyond the surface of exhaustion and long-lasting pain. Women with exhaustion and long-lasting pain were found to be vulnerable in a relational sense and, thus dependent on a welfare and health care system that acknowledges women's vulnerability and their need for emotional support and empathy. Unfortunately, the women in this study often felt neither that they were taken seriously or helped by the healthcare system (study I).

8.1.3 Exhaustion and pain as expressions of suffering

The women's health and suffering as rooted in an overwhelming life and a relational vulnerability has now been discussed within the wider scientific literature of the humanities and provides one possible way of understanding exhaustion and long-lasting pain among women. In the following an attempt is made to partly bridge the physiological gap between this interpretation of women's health and suffering and the clinical manifestation of exhaustion and long-lasting pain. This undertaking will not be entirely undisputed, foremost because each illness narrative is unique and leaves space for various interpretations (Kleinman, 2020). Even though the interaction of psychosocial processes, including stressful life events, and long-lasting pain is well documented (Edwards, Dworkin, Sullivan, Turk, & Wasan, 2016), many of the biological mechanisms involved in the complex relationship of stress, social disconnection and pain are not completely understood or even conflicting (Abdallah & Geha, 2017; Eisenberger, 2012; Lunde & Sieberg, 2020). However, it might be helpful to underpin the interpretative discussion of health and suffering among women with exhaustion and long-lasting pain, as outlined above, with some studies that have investigated similarities and associations between stress, socially stressful situations, pain, and exhaustion.

In study III no differences were found in levels of clinical exhaustion between mothers undergoing rehabilitation for exhaustion and mothers undergoing rehabilitation for pain. Furthermore, in studies I and IV it appeared that women were exhausted from an overwhelming life. Taken together, these findings suggest that women with long-lasting pain suffer from an underlying exhaustion. Although evidence supporting an association between pain and stress exists (Lunde & Sieberg, 2020), as well evidence for the comorbidity between pain and mood disorders (Heikkinen et al., 2019; Yalcin & Barrot, 2014), only a few studies have investigated the relationship between exhaustion and the experience of long-lasting pain (Du et al., 2021; Marchand & Blanc, 2020). For example, a large study among farmers in the U.S.A. found that musculoskeletal pain was more strongly associated with high levels of stress and exhaustion than with the physical demands of manual labor (Du et al., 2021). Lunde and Sieberg (2020) proposed a pain–stress model in which stress is suggested to have a protective impact on pain development. But stress also exhibited a potential to turn at some point into a damaging force enhancing pain development (Lunde & Sieberg, 2020). The model also emphasizes the mutual impact of stress and pain where pain negatively influences the experience of stress (Lunde & Sieberg, 2020). In connection to stress and work–family conflict, women with greater childcare responsibilities and full-time work were found to have higher allostatic loads compared to full-time working women without or with fewer childcare responsibilities (Chandola et al., 2019). Another investigation found intense periods of childcare in life as represented by twin births, combined with high labor market attachment, to be associated with all-cause mortality later in life (Bucher-Koenen et al., 2020). Moreover, sleep disturbances have been suggested to be an important factor in causing inflammatory responses that are interconnected with the onset and maintenance of long-lasting pain (Nijs et al., 2017). Interestingly, in that review many reasons for sleep disturbances are mentioned—but the authors fail to mention disrupted sleep due to child rearing that can stretch over several years or even decades, as experienced by the mothers in study IV. Supporting restful sleep has been emphasized as one important part in the prevention and rehabilitation of exhaustion (Wallensten et al., 2019).

Foremost, the findings suggested that women with exhaustion and pain were vulnerable regarding their relationships with others (study I, III, IV). One substantial source of strain among women in study IV appeared to be difficult or even traumatic life experiences often connected to childhood. Traumatic interpersonal experiences during childhood were found to have a strong association with pain development later in life (Edwards et al., 2016). But also perceived adverse parenting styles during childhood, like emotional neglect, were shown to be associated with long-lasting pain in adulthood (Shibata et al., 2020). In study III, women with exhaustion and pain were shown to perceive significant less social support from their social environment than healthy women; additionally, the less social support the women perceived, the more suffering they experienced. Perceptions of social disconnection as painful, also referred to as social pain, were shown to overlap with the experience of physical pain on a neurobiological level (Eisenberger, 2012). This overlap has been suggested to have evolutionary reasons; physical pain signals potentially life-threatening damage of the body and initiates an interruption of harmful behavior. Similarly, it has been hypothesized that humans' survival throughout evolution has been enhanced when behavior or events that threaten social connectedness with others are terminated through pain signals (Eisenberger, 2012). These substantial overlaps and associations between experienced strain, socially painful experiences, exhaustion, and pain provide insights into the complexity of exhaustion and long-lasting pain that have implications for clinical practice (Sturgeon & Zautra, 2016): it has been suggested that individuals living with pain should be supported in creating meaningful social ties, that relatives and partners might be included in treatment approaches, and that healthcare should offer compassionate and empathetic encounters (Sturgeon & Zautra, 2016). Overall, these insights support recommendations for a more pronounced focus on non-pharmacological treatments as well as prevention of long-lasting pain and exhaustion (Eller-Smith et al., 2018; Fitzcharles et al., 2021; Wallensten et al., 2019).

8.2 THEORETICAL DISCUSSION

8.2.1 Relating to suffering, vulnerability, and to oneself in a meaningful way

The major theoretical finding of the thesis is that health and suffering emerged as an ongoing movement of relating to essential parts of life like vulnerability, life burdens, life meaning, the self, and being sheltered. Health and suffering appeared as an ever-evolving relation between self and life: In a discordant relation between self and life suffering is more likely to be experienced as unbearable whereas in a harmonic relationship between self and life, suffering might be recognized as an inherent part of life and experienced as bearable. In a harmonic relationship, suffering becomes both reconcilable with health *and* an essential part of health (Eriksson, 2006; Rehnsfeldt & Eriksson, 2004). This process of relating to and integrating suffering into life in a meaningful way was successfully conceptualized in a new health measurement scale, the Health and Suffering Scale, of which the final version showed to have good-to-excellent psychometric properties (study II). Thus, the Health and Suffering Scale provides a way of capturing health and suffering as integrative processes and thereby makes an important contribution to a desirable variety of health definitions, something that will further be discussed at the end of this thesis.

The suffering women seemed to struggle in discordant relationships between their selves and their lives, whereas women who had started to strive for a harmonic relation between self and life were found to be in a process of reconciliation. Reconciling women in study IV were aware that they were in a continuous process of *becoming* that both was perceived as deeply personal and meaningful but also painful. In the ontological health model, Eriksson (2006) considered reconciliation with life circumstances as a part of health in which the individual finds meaning in his or her suffering. In study II, the perception of meaning in life was closely intertwined with the experience of less suffering and better health. Eriksson understands "health as doing, being and becoming *in relation* to suffering" [emphasis added] (Eriksson, 2007, p. 201). According to Eriksson (2006), *becoming* is the most valuable degree of health in which the individual has integrated suffering into life and found meaning in the own suffering. Hence, human *becoming* is interwoven with the experience of meaning in suffering and thereby personal growth (Eriksson, 2006). Further, Eriksson emphasizes that suffering involves a *dying* as something of oneself is lost or sacrificed. These aspects of dying or sacrifice were reflected in the thesis' findings when reconciling women embraced the own suffering by actively mourning losses in life connected to difficult experiences (study IV). The women were able to relate to difficult experiences or fellow human beings in a new way when they had let go of old relations to life. This reconciling process meant finding meaning in suffering and experiencing an altered and more authentic relation between oneself and life. Gustafsson, Wiklund-Gustin, and Lindström (2011) described reconciliation as a process by which an individual goes through a transition from suffering and grief towards feelings of wholeness and the experience of health.

This view on health as relational and iterative in nature and inevitably interwoven with suffering, uncovers human beings' vulnerability in relation to others but also the agency of the individual. Vulnerability is an inherent part of human existence (Gjengedal et al., 2013; Herring, 2016). Economic, socio-cultural, and political factors have been identified as general contributors to vulnerability but also relational factors through which powerlessness and dependency have been emphasized (Mergen & Akpınar, 2021). How vulnerability is experienced depends on the relationship one has with others; whether individuals in encounters with others are taken care of in their vulnerability or not (Gjengedal et al., 2013). Therefore, vulnerability has been suggested to be a relational phenomenon (Gjengedal et al., 2013; Stern, 2020). The women were vulnerable as suffering human beings and, in their suffering, dependent on others to be able to reconcile oneself with life. At the same time, it seemed that the women were suffering as they were living in a relational vulnerability, feeling that they were left alone with their burdens (study III & IV). Hence, there are two different kinds of vulnerability involved in the women's suffering: a vulnerability-through-need (as a suffering human being in need of care and protection) and vulnerability-through-trust (putting oneself in the hands of someone else). This distinction of vulnerability brought forth by Stern (2020) might be helpful in understanding how the women could progress from unbearable suffering towards bearable suffering and health. On the one hand, women's relational vulnerability was part of their suffering as the women had not been met in their needs of care and protection during significant parts of their lives (e.g., as a child or a mother), thus they were vulnerable-through-need. On the other hand, it seemed that the women's relational vulnerability was partly maintained through the women themselves when they for example, stayed in harmful relationships for several years, and their trust was abused by others (vulnerable-through-trust) (study I & IV). Importantly, the women could become aware of their agency and took responsibility to care for themselves within relationships or to break off from less beneficial or even harmful relationships in their lives. This could, however, involve a reinforcement of their vulnerability-through-need as they, for example, could end up as single mothers facing economic burdens and challenges in finding a secure homeplace for themselves and their children (study IV). Striving for and caring for reliable and warm relationships amidst vulnerability and suffering was both a prerequisite for, but also an emerging part, of reconciliation itself. “This dependent relation with others is part of our ‘existential vulnerability’ and that our identities are only complete through our commitment to others” (Purcell, 2013, p. 51).

The women were well-aware of their agency in embracing their own suffering (study IV); in this process, the women nevertheless were dependent on others as any other human being would be. To move on in life when facing vulnerability requires a new interpretation of life and that interpretational work is dependent on others and oneself (Synnes et al., 2020; Wiercinski, 2013). Research on the existential health of people who had survived a natural disaster showed how meaningful relationships with others helped to redefine life (Rehnsfeldt & Arman, 2012). Considering the women’s reconciliation, it becomes clear how the women found meaning in their suffering in reliable relationships with others, where a meaningful relation to oneself and the own vulnerability could unfold (IV). It has previously been suggested that vulnerability and interdependence with others should be recognized in the understanding of health (Herring, 2016). Recognizing vulnerability as an essential phenomenon in understanding the relation of health and suffering expands Eriksson’s ontological health model. Being sensitive to the women’s vulnerability may help to understand women’s health and suffering from the women’s own perspective and thereby enables a kind of care in which women feel understood and believed (see Gjengedal et al., 2013). Understanding women’s health and suffering as intertwined with relational vulnerability and human interdependence elucidates the necessity of an empathetic care for women living with exhaustion and long-lasting pain. In the remaining section it will be discussed how this existential view on health fits within prevailing healthcare frameworks.

8.2.2 A need for varied understandings of health

In Sweden, large parts of health care, and specifically multimodal rehabilitation for long-lasting pain and exhaustion, is based on the biopsychosocial model (Swedish Agency for Health Technology Assessment, 2010). The biopsychosocial model was developed with the intention of overcoming the limitations of a purely biomedical perspective on individual’s general health (Bolton & Gillett, 2019). In this manner, it has brought forth invaluable achievements in the understanding and treatment of long-lasting pain (Gatchel, Peng, Peters, Fuchs, & Turk, 2007). However, the biopsychosocial model is general, leaning on causal logic and an objective view of biopsychosocial mechanisms (Bolton & Gillett, 2019). This clear strength of the model might also come with drawbacks as it unintentionally risks leaving less tangible and less obvious unique personal experiences of health and existence behind. Even though the biopsychosocial model explicitly integrates psychosocial hindrances and resources in the understanding of health, it does this on a causal and, thus, generalizing level, without counterbalancing for unique personal experiences. Consequently, an important dimension of health risks remain hidden beyond the surface of symptoms and outward manifestations of biopsychosocial interactions. This might possibly explain why more than forty years after the development of the biopsychosocial model affected women were found to still feel disbelieved in their encounters with the healthcare system (study I). The experience of being disbelieved is a well-documented phenomenon among individuals living with long-lasting pain (Toye et al., 2013).

A core challenge for the biopsychosocial model in relation to women living with pain and exhaustion might be that its epistemological perspective is limited to an understanding of health as causal and thereby as static. Leonardi (2018) points out that “health is not simply present in nature, waiting to be discovered by scientists, but rather is continuously created by individuals and groups who interact among themselves in different social contexts” (Leonardi, 2018, p. 739). This characteristic of health as continuously created in interdependence with others was reflected among the women living with pain and exhaustion (study III & IV). The health and suffering experienced among the women was also deeply existential in nature as this experience embraces relations to essential aspects of life and oneself. Sigurdson (2016) emphasizes that existential health should not be considered as one further dimension of health. Rather it is the core of health encompassing how human beings relate to their health and suffering, and to respect that the experience of relating to one’s own health and suffering is subjective (Sigurdson, 2016). There is, however, a challenge in taking on the view of health as an existential phenomenon of relating to one’s own health and suffering and oneself. It risks placing all responsibility for good health on the person herself, suggesting that it is up to the person to become capable relating to their own suffering and to live in a ‘proper’ or ‘healthy’ way. Furthermore, an undesirable relativism might arise when suffering is considered to be a natural part of health and human life and when health is understood as how one relates to their own suffering. Underlying messages could then be to accept suffering, to not complain, and to move on with life as it is, and consequently, care intending to alleviate suffering might not be necessary (despite ethical reasons) as the experience of suffering is an internal matter and part of life. Because of these fallacies, it is essential to understand health and suffering as interwoven with human vulnerabilities and interdependence (see Herring, 2016; Purcell, 2013). Humans evolved through meaningful and mutual understanding and engagement with others (Hrdy, 2011), and we relate to ourselves through others (Herring, 2016). When abandoned in essential relationships, it might become more difficult to relate to oneself and to one’s suffering in a meaningful way, and health may become a reflection of a relational vulnerability. Hence, the suffering and vulnerable human being should be cared for in meaningful encounters that offer unselfish love and a sense of being sheltered (Arman & Rehnsfeldt, 2006). Such existential encounters invite reflections on existential aspects of life, thereby offering an opportunity to reconcile with life and to progress from unbearable suffering to bearable suffering (Arman & Rehnsfeldt, 2006; Rehnsfeldt & Eriksson, 2004). These kinds of encounters have an unsatisfactory basis in an understanding of health as a state caused through biopsychosocial mechanisms but make sense within an existential view on health. In conclusion, health remains a complex phenomenon that cannot be covered by one single definition, instead a spectrum of health definitions are required that offers a variation of definitions dependent on context (Leonardi, 2018). In this sense an understanding of health as intertwined with suffering and vulnerability and as a phenomenon of relating to oneself and essential aspects of life might be applicable in contexts of long-lasting ill-health. It might be in exactly those contexts in which there is the greatest need for a pluralistic view on health as these views influence health care and policies, but also individuals' own perspectives on health (Leonardi, 2018).

8.3 METHODOLOGICAL DISCUSSION

This thesis is based on both interpretative research and descriptive, observational research requiring different approaches to evaluating the research's validity. In the hermeneutic or interpretative tradition, the goal is to understand more deeply what it means to be human. As human life is not static but contextual and relational, and therefore ever-changing, the application of strict methods has been questioned as a guarantee claiming certainty about an achieved understanding (Angen, 2000; Gadamer, 2004). It has been argued that the term *validation* is more appropriate for the evaluation of how valid interpretations are as *validation* refers to something that is in process but not final (Angen, 2000). In quantitative research on the other hand, methods are central as they help to achieve a necessary distance for external measurement. An awareness and reasoning on the methods' limitations is nevertheless required which is reflected in the evaluation of an inquiry's *validity*. Hence, in the following a validation according to Angen (2000) suggestions of *ethical* and *substantive validation* on the interpretative parts of the thesis are presented, as well as reflections on aspects of validity regarding the quantitative parts.

8.3.1 Validation of the interpretative parts of the thesis

8.3.1.1 Ethical validation

As interpretations are embedded in cultural and temporal contexts, they are open to re-interpretation. Therefore, it has been suggested that interpretative research is not as much obsessed by epistemological questions of what and how we can reach knowledge but ethical questions of how the research moves us to new horizons of understanding and how it stimulates fruitful dialogues within the field (Angen, 2000). In the interpretative studies included in this thesis, an understanding emerged of what life means to women living with exhaustion and pain. This new understanding showed these women as vulnerable and living overwhelming lives. Thereby, the interpretation moved beyond an understanding about clinical manifestations of long-lasting pain and exhaustion to an understanding in which many-faceted meanings evolved. Moving beyond a present understanding towards a new or different understanding has been suggested as an ethical aspect of interpretative research (Angen, 2000).

The meanings generated in study I opened new questions about women's social support and women's experience of their motherhood, informing the design of studies III and IV. One central ethical aspect of research efforts is that these efforts should be useful and practical (Angen, 2000). Despite the usefulness of contributing to and inviting fruitful dialogue within the field, it adds an existential and female dimension to prevailing understandings of health and suffering among women living with exhaustion and pain. This contribution should not be underestimated as women often feel that they are not taken seriously in their encounters with the healthcare system or tend to be treated differently than men (Samulowitz et al., 2018; Toye et al., 2013). Hence, enhancing awareness of existential aspects in women's health and suffering may give rise to a change in the care of women with exhaustion and long-lasting pain. However, whether discourse continues and whether research will initiate change through understanding is nothing that can be evaluated now, only retrospectively.

The interpretations that emerged in study I and study IV, as well as in the synthesis have given rise to further theoretical developments as to how health and suffering are intertwined, thereby contributing further insights to and strengthening the ontological health model and the progression of suffering developed by Eriksson (2006) and Rehnsfeldt and Eriksson (2004). They also widen the general spectrum of existential views on health in the scientific literature (Herring, 2016; Sigurdson, 2016; Toye et al., 2013). The significance of pluralistic perspectives of health has been emphasized to meet various health care challenges in which definitions of health are of varying utility, depending on the context (Leonardi, 2018). Moreover, individuals' own understanding of their health and the decisions of policy-makers are influenced by prevailing views on health (Leonardi, 2018). Hence, the thesis and the included interpretations of health and suffering contribute to a diversity of health definitions and may stimulate further improvement of women's health care but also health care in general.

8.3.1.2 Substantive validation

"Having ruled out methodology as the basis for validity, the substance of the inquiry becomes an important focus for evaluating an interpretive piece of research" (Angen, 2000, p. 390). This substance evolves in an interplay with our pre-understanding, hence, it is essential to critically reflect on one's previous understanding, and one's own horizon, when engaging in interpretative research (Angen, 2000). When entering interpretative research on health and suffering among women with pain and exhaustion, my pre-understanding encompassed 15 years of professional and academic engagement within women's health, mostly reproductive health, from various angles. My understanding of long-lasting pain and exhaustion was restricted to experiences and narratives within my social environment, as well as personal experiences. To some degree, I had reservations in engaging in a research project striving to understand what life is for women who suffer from pain and exhaustion. Interestingly, when reading a preliminary, naïve interpretation of these women's experiences of their health and suffering, I felt invited into a dialogue, a conversation that I wanted to be part of. My reflection on this is that the interpretation touched something in me, the part of me who is a woman and a mother, obviously, but also questions that I had come to think of while engaging with others around me. To put it in Gadamer's words, this *question horizon* in me offered a creative ground for further exploration and interpretation of women's existence, health, and suffering. This explorative and interpretative work naturally involved a change in how I relate to myself as a woman and a mother. This was a work that was heavily dependent on mutual understanding and engagement with others on that topic, helping me to become aware of my own horizon. Personal commitment is significant in Ricoeur's interpretation theory (Ricoeur, 1981/1998) and Gadamer's philosophical hermeneutics (Gadamer, 2004). To be open in a conversation or to a text means to recognize otherness or strangeness and to accept that this otherness might have an impact on the self. When engaging in the interviews and in the reading of the transcripts, foreign experiences and meanings could unfold that both invited and challenged me to see life through the eyes of the women, thus altering my own sight. Gadamer (2004) emphasizes that to understand means to reach an agreement or shared belief which necessarily implies alteration. In a similar way Ricoeur (1981/1998) described how reading a text involves the reader's subjectivity and personal commitment as he or she strives to understand it and apply it to the present context; the reader's subjectivity responds to the sense of the text. In this in-between of me as a reader and the sense of the texts about the women's experiences, a world of meaning unfolded. To inhabit this world of meaning as a reader necessarily involves both losing and finding oneself in it and eventually understanding oneself (Ricoeur, 1981/1998).

The substance of interpretative research has been the result of a chain of interpretations that needs to be documented to strengthen the comprehensiveness of interpretation and to enable judgement on its thoroughness (Angen, 2000). A limitation within the documentation of the interpretative work included in this thesis is that I did not write a reflective diary as has been suggested in the literature on qualitative inquiry. However, the studies' methodological descriptions provided detailed information about how Gadamer's and Ricoeur's thinking have influenced the interpretative process, thereby offering insights into and allowing for judgement of the thoroughness and quality of the interpretation. Further, naïve understandings were written as a way of documenting preliminary understandings and meanings within the interpretative process. These understandings and emerging meanings were discussed with fellow researchers. Phenomenological interviewing is of a reciprocal and co-creating nature, hence this method heavily relies on an interviewer's concentration, empathy, and training (Hoffding & Martiny, 2016). Despite their challenges, unstructured and phenomenological interviews offered space for women's own interpretations of their health and suffering, enriching the chain of interpretations. Moreover, outside a clear interview structure or guide, these interviews provided the freedom to suggest interpretations that spontaneously came up during the interviews and thereby to create interpretations together with the women.

8.3.2 Validity and generalizability of the quantitative parts of the thesis

Both women with long-lasting pain and exhaustion and healthy women participated in the studies included in this thesis. Data on diagnoses that the women had received were not collected, nor was any data on the women's pain experiences. The reasoning behind these decisions were that the most important criterion for the research aim was that participating women were severely challenged through either exhaustion or pain, regardless of any potential causes. In this regard, it should be considered that receiving rehabilitation for exhaustion or long-lasting pain in Sweden is preceded by a thorough medical assessment. Consequently, women who undergo rehabilitation for exhaustion and/or pain can be expected to perceive significant health hindrances. However, as more detailed information on diagnoses and pain is missing, it cannot be said to which specific patient groups under the umbrella of long-lasting pain the knowledge generated in this thesis applies. On the other hand, by crossing the borders of specific diagnoses through the inclusion of both women with exhaustion and women with long-lasting pain, the contributions of this thesis can be considered to be more general in character. This knowledge on health and suffering, generated in a broad context, might therefore be generalizable to other patient groups with long-lasting ill-health or challenging life situations who must learn to live with their suffering. For example, has the theory of health and suffering been usefully applied in understanding of women's experiences of breast cancer (Arman & Rehnsfeldt, 2003). A major limitation regarding sampling is the choice of reference sample represented by female students studying in a health care program. As these women represented a highly-educated group of women with a secure employment situation and a more stable social situation there is an increased risk for bias regarding their experiences of health and suffering. Further, this group of healthy women was also significantly younger than the women in rehabilitation. For this reason, regression analyses were adjusted for this confounding factor. Nevertheless, such statistical adjustments can only account for parts of the differences between the groups and potential biases. This suggests that a sample recruited from the general population matching the life situation and age of women in rehabilitation would have been preferred. Considering that the resources of this research project initially had been very limited, and a reference sample had not been planned for, the existing reference sample is nevertheless considered to have contributed with valuable information. These studies, however, should be replicated in samples from the general population and other contexts of long-lasting ill-health.

Another important aspect of the studies' validity are the instruments used to generate the data. Included instruments were the Karolinska Exhaustion Disorder Scale (KEDS), developed and evaluated in the Swedish context (Beser et al., 2014) and the Multidimensional Scale of Perceived Social Support (MSPSS) that had been culturally adapted to and evaluated in the Swedish context (Ekbäck et al., 2013). Both instruments had sound psychometric properties in previous studies that had included nursing students and/or individuals (mainly women) with exhaustion disorder syndrome or women with hirsutism. Furthermore, in the studies included in the thesis, these instruments' alpha coefficients were in the range indicating a good level of reliability. The third instrument included, the Health and Suffering Scale (HSS), was under development: its psychometric evaluation and further development was part of the thesis. After an extensive item reduction, the HSS was found to have good-to-excellent psychometric properties. Thus, data collection was based on valid and reliable grounds, implying that accurate inferences could be made about the participating women. One limitation however is that the data collected to evaluate the psychometric properties of the HSS were also used in the exploration of correlations between HSS and MSPSS in study III. This implies a possible risk of confounded results as only parts of the items that the women had completed were used (Streiner & Kottner, 2014). Thus, it would be valuable to replicate the analysis of study III within a similar context. Another point of concern are the Wright maps of the HSS in both the patient and the reference samples. Even though the maps clearly demonstrate that the HSS can differentiate between the two samples, the maps indicate that items covering experiences of better health and less suffering are needed. This need is particularly reflected in the observed ceiling effects in the reference sample, which might have biased correlations between HSS scores and MSPSS scores among healthy women.

9 CONCLUSIONS

The thesis brought out the significance of understanding women's health as an ever-evolving phenomenon of meaningfully relating to life burdens, one's own vulnerability, fellow human beings, the self, and meaning in life. Suffering deepens and risks becoming unbearable when meaningful relations to life and the self become interrupted. Women and mothers suffering from long-lasting pain and exhaustion need to create and recreate essential relations in life, thereby alleviating their suffering. In this process of reconciling self and life, these women are dependent on supportive and caring relationships. Motherhood is a period in a woman's life in which women are particularly dependent on care, help, and support from others. Thus, those women who already are vulnerable in a relational sense might become overwhelmed during motherhood and risk experiencing suffering close to unbearable. This thesis showed that women living with exhaustion and pain care for society, their social environment, their wider family, and their children and that they often feel lonely and overwhelmed by these essential caring efforts and responsibilities. Being overwhelmed and lonely appears to rob these women of their abilities to iteratively revive their relation to themselves and to life. Caring and being cared for is human, caring for others means becoming vulnerable, but caring for others in a state of loneliness may imply suffering. Many women seem to be caring *and* suffering human beings who need to be seen in their vulnerability and who themselves need to be sheltered and cared for. Striving for improved health and alleviated suffering among women, society and health care needs to widen its understanding of health as interdependent with suffering and vulnerability, and interwoven with caring responsibilities.

10 POINTS OF PERSPECTIVE

10.1 IMPLICATIONS FOR HEALTH CARE

To alleviate women's suffering, health care needs to acknowledge relational and existential aspects of women's health. Sharing life burdens in therapeutic encounters will help women relate in new ways to difficult experiences and adjust to everyday life. Women with exhaustion and pain are vulnerable on a relational level and need reliable caring relations in which they feel that they are taken seriously and seen with their life burdens. Asking women about their situation and listening to their personal history will make a difference for women suffering from exhaustion and pain. This applies particularly to women who have children, as being a mother means to be dependent on support from others. Women care for, nurture and mother their children and/or fellow human beings, but they themselves scarcely receive care and nurturance and experience little space for own recovery. Therefore, these women need to be offered time and space and support to recreate their own womanhood and motherhood. Offering preventive or rehabilitating support groups at workplaces or in primary care might help women to reflect on and balance expectations with their personal resources and values. These support groups might also offer women a sense of togetherness and mutual understanding and care. Health care might temporarily offer women a shelter as part of rehabilitation where suffering women can exist and express themselves as well as recover from the strains of everyday life. Therapies that support and enhance ways of articulation might therefore be particularly beneficial to these women. Aside from individual caring approaches, it should be kept in mind that women with exhaustion and pain are often in vulnerable relational situations. Therefore, preventive and rehabilitating interventions should not focus exclusively on the woman but also include her wider social environment, for example encouraging partner- or family therapy. In the care of women with exhaustion and pain, it is also important to recognize that the women's caring responsibilities within the family continue whether they are on sick leave or not. These responsibilities will probably delay their recovery which should be taken into consideration when planning for a return to work.

10.2 FUTURE RESEARCH

The Health and Suffering Scale was found to be a promising measurement of health, as an existential process of integrating suffering into life, in the context of women living with exhaustion and long-lasting pain. Considering that the studies included in this thesis were the first that have investigated this integrational process with quantitative observations, it is recommended that these studies are replicated in similar settings. Further, the HSS was conceptualized to capture the movement between health and suffering to evaluate rehabilitation and care interventions that aim to alleviate suffering, and therefore it will be particularly important to test the HSS' sensitivity to change and observe how the integration of health and suffering fluctuates over time. As this integrational process has been observed in the experience of individuals living with other forms of long-lasting ill-health like cancer and in individuals who have gone through decisive life challenges, it would be valuable to test the psychometric properties of the HSS in such contexts.

Furthermore, it would be valuable to explore the possibilities of implementing an existential understanding of health and suffering, as brought forth in the thesis, in the care and rehabilitation of women with exhaustion and long-lasting pain. Although this thesis contributes with theoretical and contextual elements to the further development of caring interventions for women with exhaustion and pain; the ways in which such complementary interventions can be offered and implemented in existing rehabilitation programs and care merit further exploration. How preventive and rehabilitating interventions should be designed to support women in creating and recreating their life situation as women and mothers according to personal resources, values and the own vulnerability also merits study. The above implications for health care might provide a starting point for future intervention studies.

With this thesis the question arises as to whether it might provide some insights on men's health. Foremost, the intention was not to declare experienced health and suffering among men living with exhaustion and/or long-lasting pain to be irrelevant by exclusively focusing on women. On the contrary, it is equally important to understand men's health and suffering which should be part of future studies. Nevertheless, as this thesis showed, it can be valuable to understand exhaustion and long-lasting pain in light of gender-specific experiences that do not necessarily overlap with each other. In relation to the gender-specific differences in exhaustion, research has emphasized that an in-depth understanding of men's and women's specific life circumstances is needed (Beauregard et al., 2018). Similarly, the role of gender has been highlighted as a necessary aspect to include in pain research (Boerner et al., 2018). There were no intentions to discriminate against men's health or to consolidate a separation between women's and men's health, but to become aware of beneficial and potentially harmful structures in women's existence. Similarly, it would be important to deepen the knowledge of such existential structures related to men's and father's health and suffering in future research.

11 SVENSK SAMMANFATTNING (SUMMARY IN SWEDISH)

Syfte: Det övergripande målet med avhandlingen var att förstå och utveckla begreppen hälsa och lidande bland kvinnor som lever med utmattning och långvarig smärta med specifikt fokus på moderskap.

Metod: Avhandlingens design var både tolkande, beskrivande och observerande och inkluderade kvalitativa och kvantitativa ansatser. I studie I genomfördes ostrukturerade intervjuer med 21 kvinnor som lever med långvarig smärta. Intervjuerna analyserades med stöd av Gadamers filosofiska hermeneutik. Studie II bestod av en pyskometrisk utvärdering och vidareutveckling av Hälsa och Lidande Skalan med klassisk testteori och Rasch analys. Studie III var en explorativ undersökning av hälsa och lidande och upplevt socialt stöd bland kvinnor och mödrar med utmattning och långvarig smärta. Studie II och studie III är baserade på samma urval av kvinnor; en grupp med kvinnor som lever med utmattning och långvarig smärta (N = 166) och en jämförelsegrupp med kvinnor som studerar och arbetar inom hälso- och sjukvården (N = 129). I studie IV genomfördes 27 intervjuer med 14 mödrar med utmattning och/eller långvarig smärta. Intervjuerna analyserades med både Gadamers hermeneutik och Ricoeurs tolkningsteori.

Resultat: Kvinnor som lever med utmattning och långvarig smärta visade sig vara sårbara på en relationell nivå (studie I, III & IV). När kvinnorna upplevde otillräckligt stöd från omgivningen riskerade kvinnorna att uppleva allt ansvar och olika händelser i livet som oöverkomligt. Denna erfarenhet kunde förvandlas till ett lidande och livet riskerade verka meningslöst. Lidande och en uppfattning av meningslöshet i livet visade sig vara sammanvävda (studie I & II). Moderskap kunde utgöra en del av en oöverkomlig livsbörda men kunde också vara en livsnödvändig källa till styrka och mening i livet (studie IV). Om kvinnorna befann sig i tillförlitliga relationer eller omprövade relationer i livet var de bättre utrustade för att klara av svåra livshändelser och omsorgsansvar och kunde försona sig själv med livet (studie IV). Lidandet kunde integreras i livet, blev uthärdligare och den egna hälsan blev mer balanserad. Syntesen av studieresultaten tyder på att kvinnors hälsa kan förstås som en pågående rörelse av hur man relaterar till nödvändiga aspekter i livet och till sig själv. Som en naturlig kontrapunkt till hälsa kan lidande förstås som en störning av dessa meningsfulla och autentiska relationer i livet.

Konklusion: Kvinnor och mödrar som lider av utmattning och långvarig smärta behöver utveckla och omstrukturera essentiella relationer i livet vilket kan leda till ett lindrat lidande. I denna process av att försona sig själv med livet är kvinnorna beroende av att befinna sig i stödjande och omsorgsfulla relationer. Moderskap är en period i kvinnors liv där kvinnor är särskild beroende av omgivningens stöd och omsorg. För att kunna sträva mot bättre hälsa och lindrat lidande bland kvinnor måste samhället och hälso- och sjukvården bredda sin förståelse av hälsa som oundvikligt sammanhängande med lidande och sårbarhet sammanvävd med ett omsorgsansvar.

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14 APPENDIX

Hälsa och Lidande Skalan

Markera på linjen var du uppskattar att du befinner dig mellan nedanstående ordpar, till exempel:

Livet är mörkt ○ ○ ○ ⊗ ○ Livet är ljust

Så här upplever jag mig själv och mitt liv just nu:

Livet är en kamp	○	○	○	○	○	**Livet är en gåva**
Förlorat greppet om livet	○	○	○	○	○	**Förståelse för livet**
Trött på att kämpa	○	○	○	○	○	**Engagemang i livet**
Fastnat i livsmönster	○	○	○	○	○	**I egen utveckling**
Uppgiven	○	○	○	○	○	**Framtidstro**
Livet är mörkt	○	○	○	○	○	**Livet är ljust**
Utan värde	○	○	○	○	○	**Värdefullt liv**
Meningslöst liv	○	○	○	○	○	**Meningsfullt liv**
Outhärdligt lidande	○	○	○	○	○	**Uthärdligt lidande**