From Department of Clinical Science, Intervention and Technology Division of Obstetrics and Gynaecology Karolinska Institutet, Stockholm, Sweden

CHRONIC PAIN RELATED TO CHILDBIRTH

PREVALENCE, CHARACTERISTICS, WOMEN'S EXPERIENCES ABOUT ITS IMPACT AND SUPPORT FROM HEALTHCARE

Beata Molin



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Prevalence, characteristics, women's experiences about its impact and support from healthcare

THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

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POPULAR SCIENCE SUMMARY OF THE THESIS

"I have no life as I see it because I cannot do anything I used to do; I do nothing I want to do; I am not happy as I used to be and the whole me has changed. The pain is destroying my life."

From an interview with a 28-year-old woman about her pain related to childbirth.

After childbirth, women are at risk of developing chronic pain from pain or injuries that they experience during pregnancy and/or labour. Chronic pain, defined as pain that persists after three months, often leads to suffering, reduced quality of life and an increased need for healthcare. Persons with chronic pain are at risk of developing complications, including physical, psychological, and cognitive dysfunctions, such as depression, anxiety, sleeping problems and fatigue. Over time, pain may become more complex and thus potentially more challenging to treat.

Knowledge about pain persisting after childbirth is limited, thus, the aim of this thesis was to evaluate how many women develop chronic pain related to pregnancy or labour and describe the characteristics of pain. Further aims were to describe the impact of pain on women's daily lives as well as their experiences of information and support from healthcare. Data were obtained through two questionnaires from 1,171 women as well as 20 interviews with women who had chronic pain related to pregnancy or labour.

The results show that one in six women report chronic pain and one in five experience pain during intercourse eight months after childbirth. The pain and its consequences have a negative impact on several aspects of women's lives, including their role as mothers. The women constantly struggle as the pain severely reduces their previous ability to perform physical and social activities, negatively impacts their psychological well-being and alters their self-image. Although pain and its consequences have a profound negative impact on women's lives, they do not receive adequate information from healthcare about pain, which may hinder them from seeking help for pain-related problems. Furthermore, when they do, their pain is often ignored or dismissed by healthcare professionals. In consequence, the pain is not identified, managed, or resolved. The women feel abandoned by maternal care after childbirth and forced to manage their condition on their own. The lack of adequate information and support contributes to women's suffering and may also lead to the development and persistence of chronic pain.

This thesis indicates the need to review the content and quality of current maternal care in terms of support for women with pain persisting after childbirth. The results also suggest a need for developing standards and guidelines for prevention and treatment of chronic pain related to pregnancy or labour as well as knowledge support and education for healthcare professionals. This can be an important step toward better recovery after childbirth, reducing

suffering, as well as preventing potential long-term health problems in a relatively young					
population.					

POPULÄRVETENSKAPLIG SAMMANFATTNING (SUMMARY IN SWEDISH)

"Jag har inget liv som jag ser det för jag gör ingenting jag brukade göra, jag gör inte saker som jag vill göra, jag är inte glad, som jag brukade vara och hela jag har förändrats. Smärtan har förstört mitt liv."

Från en intervju med en 28-årig kvinna med långvarig smärta relaterad till förlossning

Kvinnor riskerar att utveckla långvarig smärta efter att ha fött barn. Långvarig smärta, definierad som smärta som varar längre än tre månader, leder ofta till lidande, minskad livskvalitet samt ett ökat behov av hälso- och sjukvård. Personer med långvarig smärta riskerar att utveckla komplikationer, inklusive fysiska, psykologiska och kognitiva störningar, som depression, ångest, sömnproblem och trötthet. Med tiden kan långvarig smärta dessutom bli mer komplex och därmed svårare att behandla.

Kunskapen om långvarig smärta efter förlossning är begränsad. Syftet med denna avhandling var att kartlägga hur många kvinnor som utvecklar långvarig smärta efter förlossning samt att beskriva smärtans karakteristiska egenskaper. Ytterligare syften var att undersöka smärtans inverkan på kvinnors dagliga liv samt deras upplevelser av information och stöd från hälsooch sjukvården. Data samlades in genom två frågeformulär från 1171 kvinnor, samt genom 20 intervjuer med kvinnor som har utvecklat långvarig smärta i samband med graviditet och/eller förlossning.

Resultaten visar att en av sex kvinnor rapporterar långvarig smärta och att en av fem kvinnor upplever samlagssmärta åtta månader efter förlossningen. Smärta och dess konsekvenser påverkar flera aspekter av kvinnornas liv negativt, inklusive deras mammaroll. Kvinnorna kämpar ständigt med smärtan och dess konsekvenser som avsevärt minskar deras tidigare förmåga att utföra fysiska och sociala aktiviteter. Smärta påverkar även kvinnornas psykologiska välbefinnande negativt och förändrar deras självbild. Trots dessa allvarliga konsekvenser får kvinnorna inte tillräckligt med information om smärta från sjukvården. Bristande information kan bidra till att de inte söker hjälp för sina smärtrelaterade problem. När kvinnorna vänder sig till sjukvården, upplever de ofta att deras smärta ignoreras eller förminskas av vårdpersonalen. Följden blir att smärtan inte bekräftas eller behandlas. Kvinnorna känner sig övergivna av mödravården efter förlossningen och tvungna att hantera sitt tillstånd helt på egen hand. Bristen på adekvat information och stöd från sjukvården bidrar till kvinnornas lidande, men kan också leda till att långvarig smärta utvecklas och blir bestående.

Denna avhandling visar att det finns ett behov av att se över innehållet och kvaliteten när det gäller vård för kvinnor med smärta som kvarstår efter förlossningen. Resultatet indikerar ett behov av rekommendationer och riktlinjer för prevention och behandling av smärta relaterad till graviditet och förlossning samt kunskapsstöd och utbildning för hälso- och

sjukvårdspersonal. Dessa kan vara ett viktigt steg mot bättre återhämtning för kvinnorna, minskad lidande samt förebyggande av långvariga hälsoproblem.

STRESZCZENIE (SUMMARY IN POLISH)

"Nie mam w ogóle życia – tak to widzę. Nie robię nic, co kiedyś robiłam; nie robię nic, co chciałabym robić; nie jestem szczęśliwa jak kiedyś i zupełnie się zmieniłam. Ból zniszczył moje życie".

Z wywiadu z 28-letnią kobietą, która odczuwa przewlekły ból związany z porodem.

Po porodzie kobiety są narażone na rozwój bólu przewlekłego zwiazanego z ciążą lub porodem. Ból przewlekły, definiowany jako ból trwający co najmniej trzy miesiące, często prowadzi do cierpienia, obniżenia jakości życia oraz zwiększonego zapotrzebowania na opiekę zdrowotną. Osoby cierpiące na ból przewlekły narażone są na rozwój powikłań, w tym dysfunkcji fizycznych, psychologicznych i poznawczych, takich jak depresja i zaburzenia lękowe, problemy ze snem i zmęczenie. Z upływem czasem ból może stać się bardziej złożony, a przez to potencjalnie trudniejszy do leczenia.

Wiedza na temat przewlekłego bólu zwiazanego z ciążą i porodem jest ograniczona. Celem niniejszej pracy doktorskiej było zbadanie, u ilu kobiet rozwija się przewlekły ból i jaka jest jego charakterystyka. Kolejnym celem pracy było opisanie wpływu bólu na codzienne życie kobiet, jak również ich doświadczeń, jeśli chodzi o informację i opiekę ze strony służby zdrowia. Niniejsza praca zawiera badania empiryczne o charakterze jakościowym oraz ilościowym. Badania ilościowe zostały oparte na dwóch kwestionariuszach, na które odpowiedziało 1171 kobiet, natomiast dane do badania jakościowych pochodzą z 20 wywiadów z kobietami, odczuwającymi ból przewlekły, zwiazany z ciążą lub porodem.

Wyniki pokazują, że jedna na sześć kobiet zgłasza przewlekły ból, i jedna na pięć kobiet doświadcza bólu podczas stosunku seksualnego osiem miesięcy po porodzie. Ból i jego konsekwencje mają negatywny wpływ na wiele aspektów życia kobiet, w tym na ich rolę jako matek. Kobiety zmagają się z bólem, który poważnie ogranicza ich wcześniejszą zdolność do wykonywania czynności fizycznych i społecznych, negatywnie wpływa na ich samopoczucie psychiczne i zmienia obraz własnej osoby. Mimo, że ból i jego konsekwencje mają negatywny wpływ na życie kobiet, nie otrzymują one od służby zdrowia odpowiednich informacji na temat bólu, co może prowadzić do tego, że nie szukają pomocy w zwiazku ze swoimi problemami. Ponadto, jeśli już to robią, ich ból jest ignorowany lub bagatelizowany przez pracowników służby zdrowia. W konsekwencji ból nie jest diagnozowany ani leczony. Kobiety czują się porzucone przez opiekę poporodową i zmuszone do radzenia sobie we własnym zakresie. Brak odpowiedniej informacji i wsparcia przyczynia się w ten sposób do cierpienia kobiet, ale może również prowadzić do rozwoju i utrzymywania się bólu przewlekłego.

Niniejsza rozprawa sugeruje potrzebę przeglądu rodzaju i jakości obecnych usług opieki zdrowotnej dla kobiet odczuwajacych przewlekły ból po porodzie. Jej wyniki wskazują również na potrzebę opracowania standardów i wytycznych, dotyczących profilaktyki, oceny i leczenia bólu przewlekłego, zwiazanego z ciążą i porodem oraz poszerzania wiedzy na temat bólu wśród pracowników służby zdrowia. Podsumowujac, wyniki niniejszej rozprawy

mogą być ważnym krokiem w kierunku zmniejszenia cierpienia kobiet oraz zapobiegania długotrwałym powikłaniom zdrowotnym po porodzie.

ABSTRACT

Background: Pregnancy and labour often entail pain and tissue damage, which may lead to the development of chronic pain. Globally, chronic pain, defined as pain that persists after three months, is a leading cause of lasting suffering and disability. If pain is not timely diagnosed and adequately treated it can become a chronic condition. However, among healthcare professionals, there seems to be a lack of strategies for its prevention and treatment.

Aim: The aim of this thesis was to describe the prevalence and characteristics of chronic pain related to childbirth. Further aims were to explore women's experiences of pain and its consequences as well as information and support from healthcare professionals.

Methods: Study I was conducted as a prospective cohort study, Studies II and IV had a qualitative approach, and Study III was a mixed methods study with a sequential explanatory design. In Study I, as well as in the first, quantitative part of Study III, data were obtained through two self-administered questionnaires and the patient record system, Obstetrix. The first questionnaire was distributed on the maternity ward, 24–36 h after labour between April and December 2015. The second questionnaire was sent by post eight months after childbirth. Data from 1,171 women, who answered the second questionnaire, were analysed using descriptive statistics. Studies II and IV as well as the second, qualitative part of Study III, had a qualitative approach and included 20 individual semistructured interviews. Participants in these studies consisted of the same sample, recruited among women who had reported chronic pain related to pregnancy and/or labour in Study I. The interviews were conducted between June and November 2016, recorded and transcribed verbatim. The data were processed and analysed using inductive content analysis.

Results: The results of Study I showed that 17% of the women reported chronic pain related to childbirth. Approximately 80% rated their worst pain as moderate or severe and more than 40% of the women experienced pain constantly or daily. Dyspareunia related to childbirth was reported by 19% of the women, with approximately 60% experiencing their worst pain during intercourse as moderate or severe. Study II revealed that women constantly struggled with the pain and its consequences. Chronic pain had a negative impact on several aspects of women's lives, including physical and social activities, psychological well-being, self-image, as well as their roles as partners and mothers. The results of Study III revealed that the majority of the women did not receive information about risks of developing chronic pain related to childbirth. They did not have knowledge about when and where to seek help, and half of them did not consult healthcare professionals. The lack of information also led to women feeling unprepared for the pain causing emotional distress. In addition, as Study IV revealed, when women turned to healthcare, they did not receive the attention, recognition, and support they needed. They

reported not being listened to, not taken seriously, or believed by healthcare professionals and their pain was not assessed, diagnosed, or treated. The women felt abandoned after childbirth and forced to manage the condition on their own. There was an overall desire for more support and continuity regarding care as well as better knowledge among healthcare professionals.

Conclusions: Chronic pain eight months after childbirth was reported by one in six women and one in five experienced dyspareunia. Approximately 80% of the women rated their worst pain as moderate or severe, and more than 40% experienced pain constantly or daily. The pain and its consequences had a negative impact on several aspects of women's lives. In addition, women did not receive adequate information or support from healthcare. In consequence, they did not seek help or when they did, their pain was not recognised, treated, or resolved. Living with pain as well as the lack of adequate information and support from healthcare may also lead to emotional distress. Together this may contribute to women's suffering as well as an increased risk of development and maintenance of chronic pain. This thesis indicates a need to review the content and quality of current postpartum maternal care concerning pain assessment and management, as well as to develop standards and guidelines for prevention and treatment of pain persisting after pregnancy or labour.

LIST OF SCIENTIFIC PAPERS

- I. Molin B, Sand A, Berger AK, Georgsson S. Raising awareness about chronic pain and dyspareunia among women a Swedish survey 8 months after childbirth. Scandinavian Journal of Pain. 2020;20(3):565–74.
- II. Molin B, Zwedberg S, Berger AK, Sand A, Georgsson S. Grieving over the past and struggling forward a qualitative study of women's experiences of chronic pain one year after childbirth. Midwifery. 2021;103:103098–103098.
- III. Molin B, Zwedberg S, Berger AK, Sand A, Georgsson S. Disempowering women—a mixed methods study exploring informational support about pain persisting after childbirth and its consequences. BMC pregnancy and childbirth. 2022;22(1):1–510.
- IV. Molin B, Zwedberg S, Berger AK, Sand A, Georgsson S. Chronic pain related to childbirth - a qualitative study of women's experiences of healthcare professionals' support. *Manuscript*

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LIST OF ABBREVIATIONS

ACT Acceptance and Commitment Therapy

CBT Cognitive—Behavioural Therapy

CNS Central Nervous System

CI Confidence Interval

GDPR The General Data Protection Regulation

ICN International Council of Nurses

IASP The International Association of the Study of Pain

IMMPACT The Initiative on Methods, Measurement, and Pain

Assessment in Clinical Trials

MMR Multimodal rehabilitation

NRS Numerical Rating Scale

OR Odds Ratio

PROs Patient-Reported Outcomes

TENS Transcutaneous Electrical Nerve Stimulation

WHO The World Health Organisation

1 BACKGROUND

1.1 PAIN AS A MULTIDIMENSIONAL EXPERIENCE

Pain is defined as, "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (1). The experience of pain is unique for each individual and a result of extensive and complex processes in the nervous system. It involves three components: sensory-discriminative, motivational-affective, and cognitive-evaluative. The sensory-discriminative component is the experience of pain intensity, localization, character, and duration. The motivational-affective component includes emotional reactions to the pain, for example, fear, anxiety, frustration, or anger. The cognitive-evaluative component describes the effect of pain on thoughts, interpretations, and actions (2).

Several factors, such as genetic, biological, cognitive, psychological, social, and cultural context, play a significant role in how people perceive, experience, and react to pain. Emotions have a great impact on the experience of pain. In general, pain is enhanced by negative affect while decreased by positive affect. Feelings, such as anger, fear, and anxiety can enhance pain perception (3,4). Negative coping strategies may also make the pain worse, for example, persons indicating a high degree of helplessness, estimate the intensity of pain as higher, describe more extensive negative consequences of pain in their daily lives, and are more often depressed (3,5). Furthermore, evidence suggests that not only cognitive and emotional but also social factors modulate the experience of pain (3). For instance, studies of experimental and clinical pain revealed a positive role of social support. Patients with acute pain, such as postoperative pain, who have received higher hospital support needed less pain medication than their low-support counterparts (6). In addition, social support during childbirth was associated with decreased intensity of pain and reduced analgesic use (7). Factors, such as attention, expectations, and understanding, may also affect the experience of pain (3). No causal finding or confirmed diagnosis, providing an explanation for pain, can contribute to pain experience and emotional suffering (8). Also, cultural, ethnic, and religious factors seem to influence how pain is experienced, interpreted, and communicated to others. For example, in some cultures, patience and endurance are encouraged as a way of coping with pain, whereas complaining or crying are a sign of weakness (9). Studies have shown that believers/spiritual people with pain have a better psychological well-being and more often use positive coping strategies comparing to non-believers (10).

1.2 CHRONIC PAIN

1.2.1 From acute to chronic pain

Based on the time aspect, pain is divided into acute and chronic. Acute pain is defined as pain with a duration of less than three months (11). This type of pain is a useful survival mechanism that serves a protective and healing function. It is a symptom of an underlying disease or tissue damage with following inflammation, for example, after surgery (12). Chronic pain extends beyond the expected time of healing and is defined as pain that persists after three months (11). It should not be considered as acute pain prolonged in time as it has lost its functional significance and is no longer a symptom, but rather a syndrome or disease (13).

It has been estimated that approximately 20% of the adult population, both worldwide and in Sweden, experience chronic pain of moderate to severe intensity (14,15), and some reports indicate a prevalence up to 55% in the Swedish population (16,17). The most reported body locations for chronic pain are back (unspecified), lower back, neck, knee, head, or shoulder. Osteoarthritis and rheumatoid arthritis are the most common causes of pain followed by pain caused by deteriorated or herniated discs, degeneration or fractures of the spine and pain after trauma or surgery (14).

Transition from acute to chronic pain can be caused and influenced by biological factors, such as tissue injury, pain intensity and duration as well as psychosocial factors, for instance, emotional distress, anxiety, and depression as well as social network and support. In addition, these factors may contribute to long-term consequences and sequelae of chronic pain, such as physical and work disability, healthcare costs, and mortality (3).

Biological factors

Acute pain, for example, caused by trauma or surgery, is the most essential biological risk factor for the development of chronic pain (18). Noxious stimuli during tissue damage activate sensory nerve endings, the nociceptors. Signals from primary afferent nociceptors are transmitted into the spinal cord where the second-order nociceptive neurons are activated. These neurons project the information via the brainstem and thalamus to several regions of the cerebral cortex, such as the somatosensory and prefrontal cortex as well as to subcortical areas such as the limbic system. When the information is registered in the somatosensory cortex, pain intensity and localization are experienced, and when the nociceptive information reaches the limbic system, the affective or unpleasantness aspect of pain will be encoded (19,20). The activity of the ascending nociceptive system can be modulated at various levels

in the body. One of the modulatory systems originates from the brainstem. This descending inhibitory pathway projects to the dorsal horn of the spinal cord where it facilitates or inhibits spinal nociceptive processing and the final perception of pain (Figure 1) (19,20).

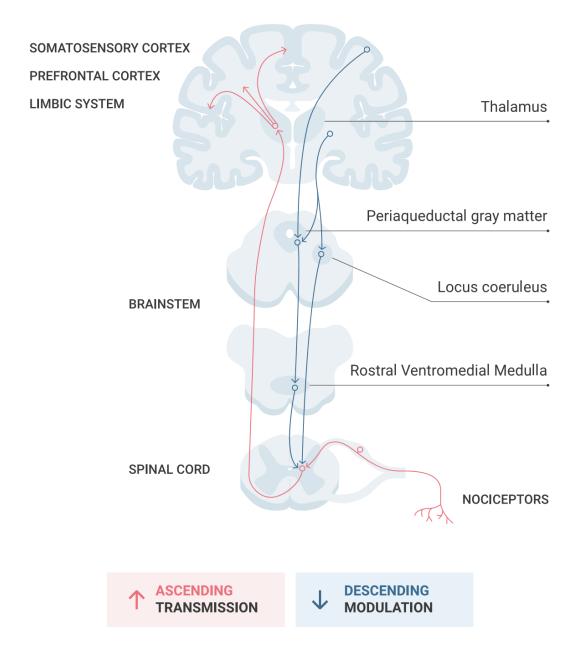


Figure 1. The pathways of nociceptive transmission and modulation.

Illustration: Natalia Antoszewska, 2022

The continuous or repetitive ongoing activity in nociceptive systems, initiated by acute injury, may lead to pathophysiological changes in pain processing from the periphery to the brain, resulting in chronic pain in susceptible patients. These changes lead to peripheral and/or central sensitization and include several mechanisms, such as increased communication between afferent neurons in the spinal cord, dysfunction in the descending

inhibitory system as well as anatomical and functional reorganization in the brain (21,22). In chronic pain, increased activity is seen in various areas of the brain, for example, in the somatosensory and prefrontal cortex as well as in the limbic system (22,23). Except for the development and maintenance of chronic pain, this increased activity can also lead to other consequences such as sleep disorders, fatigue, impaired memory, and concentration as well as depression (21). Although initially reversible, the pathophysiological changes in the nervous system may become more complex and difficult to reverse. As a result, the pain may be ultimately resistant to treatment. Therefore, according to existing knowledge, early and effective treatment is crucial to minimize the risk of developing chronic pain from acute pain, reduce the maintenance of chronic pain as well as decrease its long-term consequences (13,21,23).

Psychosocial factors

Psychosocial factors, for instance, emotional distress, depression, and anxiety are among the most robust predictors of the development, maintenance as well as outcomes of chronic pain (Figure 2). Other associated factors, such as pain-related catastrophizing and low self-efficacy, have in addition been linked to reduced effects of treatment (5). Fear of pain and catastrophizing, conceived as, "the tendency to magnify the threat value of pain stimulus and to feel helpless in the context of pain, and by a relative inability to inhibit pain-related thoughts" (5) are also associated with higher degree of pain intensity and physical disability (3,24). Self-efficacy is defined as an, "individual's belief to achieve a desired outcome" and has been recognized as a protective factor associated with lower intensity and unpleasantness of pain as well as increased physical disability (3).

Furthermore, coping, described as "the use of behavioural, emotional, and cognitive techniques to manage symptoms of distress" (25), also has an important impact on pain-related outcomes. Coping strategies can be classified as passive or active. A person using active coping strategies initiates actions to control pain, such as distracting one's attention from it or exercising. Passive coping strategies involve relinquishing control to others and withdrawal, such as resting and avoidance of activities which generate pain. Active coping has been associated with decreased pain sensitivity, better functioning, positive affect, and decreased depression (3,25). Research has shown that improving active coping strategies can enhance effects of many nonpharmacological treatments (3).

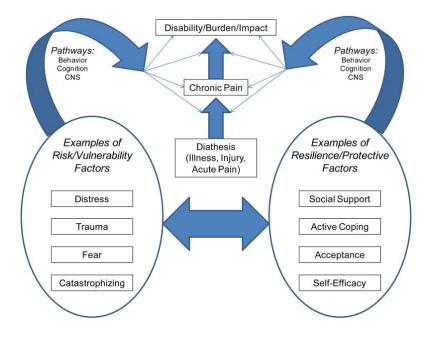


Figure 2. Illustration of the effect of psychosocial constructs and processes on pain-related outcomes.

Abbreviation: CNS, Central Nervous System.

Reprinted from The Role of Psychosocial Processes in the Development and Maintenance of Chronic Pain, by Edwards RR, Dworkin RH, Sullivan MD, Turk DC, Wasan AD., 2016, The Journal of Pain Sep;17(9):T70–92. Copyright 2016 by Elsevier (3). Reprinted with permission.

Acceptance of pain is also an important protective factor. It may be defined as, "a process of giving up the struggle with pain, and instead remaining active and learning to live a meaningful life despite pain" (26). When individuals do not accept their pain, they strive to avoid it and put all their energy and effort into seeking available interventions to reduce or eliminate it even when they do not result in the reduction in pain and may lead to missed opportunities for satisfying and productive functioning. However, it should be emphasized, that acceptance is not the same as resignation and cannot be interpreted in terms of there being no hope of making progress or that the condition will never improve (27). It should instead focus on, "participation in valued activities and the pursuit of personally relevant goals" (28). Acceptance of chronic pain has been linked to reduced pain severity, disability, and psychological distress (28).

Furthermore, positive social support has been associated with lower risk of developing chronic pain, such as phantom limb pain after amputation (29). Interactions between persons with chronic pain and their significant others may also impact adjustment to chronic pain and pain-related functioning. Social support at work and interactions with the social disability

compensation system have been linked to increased work disability, depressive symptoms, and decreased return-to-work rates (3,25).

The biopsychosocial model of chronic pain

A biopsychosocial model (Figure 3) is a widely accepted and holistic model which describes a complex interplay between pain and disability as a, "multidimensional, dynamic interaction among physiological, psychological, and social factors that reciprocally influence each other, resulting in chronic and complex pain syndromes" (3). Although pain can be affected by a single factor, the biopsychosocial model considers that its intensity and complexity can increase when the factors interact (2). In addition, all these factors should be considered in pain management in order to increase the probability of its effective outcome. Thus, the biopsychosocial model also forms the basis of the treatment strategy for multimodal chronic pain management (30), when different professions in healthcare cooperate to improve the patient's situation (multidisciplinary), preferable at the same care facility (interdisciplinary) (30–32).

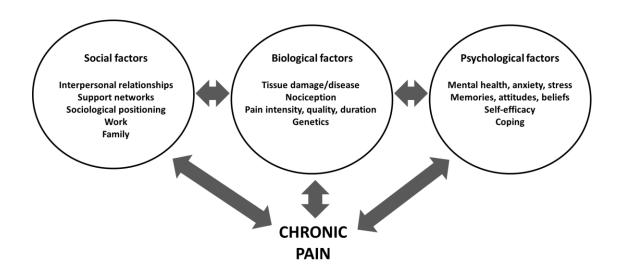


Figure 3. Illustration of the biopsychosocial model of chronic pain.

1.2.2 Consequences of chronic pain

According to WHO, chronic pain is a leading cause of lasting suffering and disability (33). It may lead to significant consequences for individuals, their families, and the community (21,22). Chronic pain can affect sleep (21) and lead to increased fatigue as well as impaired cognitive functions, such as memory, learning, and ability to concentrate (21,34). Persons with chronic pain report that it severely interferes with their daily activities, social and

working life, family relationships and sexual relations (14). Furthermore, pain can have a negative impact on mood and lead to depression, anxiety (21,35), and suicidal ideation (36). Chronic pain can negatively affect the individual's self-perception and contribute to social withdrawal and isolation (37). Studies have shown that quality of life was clearly affected in chronic pain sufferers (14,21). Pain may dominate the person's life and lead to feelings of being locked into the situation and loss of human dignity (38). If the pain persists for months or years, further changes can occur in the central nervous system, which can lead to the pain being generalized (the pain spread outside its origin) and transitions from being intermittent to constant (21). In addition, studies have shown that chronic musculoskeletal pain conditions were associated with a higher incidence of serious medical conditions, such as ischemic heart disease and cerebrovascular disease (39) as well as a higher mortality rate (40). Furthermore, pain is a common cause of why adults turn to health care (41). About 80% of patients in Swedish emergency departments report pain as a symptom (42) and 30% who seek primary care have pain-related problems (43). Together with mental illness, pain is the most common reason for long-term sick leave in Sweden and causes high socio-economic costs, both direct healthcare costs as well as indirect costs, mainly due to sick leave and reduced levels of productivity (44).

1.2.3 Management of chronic pain

As mentioned before, early, and effective therapy is crucial for preventing the development of chronic pain, but it can also offer the potential to reduce its long-term consequences. In addition, early initiation of treatment is important to minimize the risk of manifesting symptoms and generalizing the pain (21,22). A primary goal in managing chronic pain is to reduce pain and pain-related complications as well as to increase the quality of life. All people have the right to have their pain controlled to a level acceptable to them and must therefore be offered an individually adapted pain treatment (45,46). Management of chronic pain should, as far as possible, be chosen based on the underlying mechanisms of pain and initiated primarily to eliminate the cause of the pain and secondarily, to alleviate the symptoms. In many individuals with chronic pain, biomedical interventions, such as pharmacological treatment may lack long-term benefits, and there is a risk of unwanted side effects or addiction (31,47). Non-pharmacological treatment methods are therefore important, such as physical activity, TENS (Transcutaneous Electrical Nerve Stimulation), acupuncture, massage, and relaxation as well as Cognitive-Behavioral Therapy (CBT) such as Acceptance and Commitment Therapy (ACT) (47,48). According to research, the most effective form of treatment of complex chronic pain is multimodal rehabilitation (MMR). This method is based

on the biopsychosocial model of pain and implies comprehensive and individually adapted pain management (30,31). The healthcare staff work in teams consisting of doctors, nurses, physiotherapists, counsellors, occupational therapists, and psychologists where the patient is part of the team. The goal of multimodal rehabilitation is to relieve the pain experience, support the patient in coping with pain and disability, increase the patient's general functioning and ability to work, and help the patient to find a good quality of life despite pain, if pain relief cannot be achieved (2,31). In Sweden, MMR is well established when it comes to rehabilitation of patients with chronic pain, such as low back pain and fibromyalgia (31).

Pain management still remains a challenge. Studies have shown that 80% of the world population is affected by inadequate pain management (49). Several healthcare systems and healthcare professionals' barriers that hinder patients from achieving optimal pain treatment have been identified globally, and in Sweden. An example of system-related barriers is lack of national care standards and protocols. Patients with chronic pain are treated mainly in primary healthcare which often lacks competence and structure regarding chronic pain management. Healthcare professionals' barriers also include lack of availability, knowledge, interest and holistic perspective (49,50).

1.3 CHRONIC PAIN AMONG WOMEN AND RELATED TO CHILDBIRTH

1.3.1 Pain among women

The incidence of pain is generally higher in women regardless of cause and type of pain (44,51,52). Epidemiological studies of chronic musculoskeletal pain consistently show a higher incidence in women compared to men, although the difference between the genders varies between studies (51). For example, the proportion of women who reported chronic musculoskeletal pain in a Swedish population-based study was 38% and the proportion of men was 31% (53), while the corresponding figures in another Swedish study were 59% for women and 48% for men (54). Studies have indicated that women showed a higher prevalence of both localized chronic pain (56% vs. 44%) and widespread chronic pain (60% vs. 40%) compared to men (55). Conditions that affect women to a greater extent include fibromyalgia, irritable bowel syndrome, rheumatoid arthritis, low back and pelvic pain as well as temporomandibular pain (56,57). Furthermore, women report more intense pain regarding disorders of the musculoskeletal, circulatory and digestive systems, infectious diseases as well as acute inflammatory conditions, including postoperative pain (52,56). In experimental tests, using a variety of stimulus modalities, such as mechanical, electrical,

thermal, and chemical stimuli, the pain threshold is often estimated lower by women. Women seem to exhibit increased pain facilitation and reduced pain inhibition compared to men (51,56). It has been suggested that endogenous pain inhibition systems are less efficient in women than in men. Inability to activate the endogenous inhibition systems in an optimal way could be an important predictor for the development of chronic pain and explain why it is perceived as constantly present and widespread, for example by women with fibromyalgia (58).

Various mechanisms for these gender differences have been discussed, including hormones, endogenous pain inhibition, genetics, pain coping, and gender roles. Female sex hormones seem to have a considerable role in activating the pain system, where oestrogen in some contexts is considered to have a pro-nociceptive function, while testosterone generally has an anti-nociceptive effect (59). It has also been reported that women have greater emotional sensitivity with a lasting memory of negative emotional experiences compared to men (60). In addition, research has shown that women are engaged in maladaptive coping strategies, such as catastrophizing, more often than men (52).

1.3.2 Pain and injuries during pregnancy or labour

Although considered natural processes, both pregnancy and labour may entail pain and tissue damage. According to studies, up to 76% of women experience pain during pregnancy, and the most common pain conditions are low back and pelvic girdle pain (61). The pelvic girdle pain refers to pain in the symphysis pubis, sacroiliac joints and/or pain in the gluteal region. Studies have shown that, of the women reporting pain during pregnancy, 25% experienced severe pain and 8% had a severe disability. The aetiology and mechanisms of pregnancy-related pain are uncertain and include interactions between biomechanical, neuromuscular and hormonal factors (61).

Labour is a painful experience for the majority of women. Although often described as severe or extremely severe (62), the pain is a part of a normal physiological process, situation specific and with limited duration. During the first stage of labour, the pain is a consequence of ischemia in the myometrium, stretching and distension of visceral structures as well as dilatation of the cervix (visceral pain). During the second stage, pain occurs mainly as a result of stretching and distension of the pelvic floor, perineum, and vagina (somatic pain) (63). The severity of labour pain depends on biological factors such as frequency of uterine contractions, cervical dilatation, and foetal weight. Primiparas often experience pain during the opening stage as more intensive compared to multiparas, probably due to less flexibility

in the cervix and ligaments. In addition, psychosocial factors, such as anxiety, self-confidence, self-efficacy, coping strategies, previous experiences with pain as well as antenatal education may also influence the labour pain experience (63).

Furthermore, women suffer from trauma during vaginal birth as well as tissue damage from caesarean sections. Different parts of the pelvic floor and perineum, e.g., muscles, nerves and connective tissue may be injured during vaginal delivery as a result of stretching, compression, and rupture (64,65). Studies have shown that approximately 85% of vaginal deliveries are accompanied by perineal trauma (66). In Sweden, the incidence of the most severe perineal laceration, third, and fourth degree tears (damage to the anal sphincter complex), was reported as 4.5% for primiparas and 1% for multiparas (67). There are no official statistics on the incidence of less severe perineal trauma (first and second degree) in Sweden because these injuries have not been systematically reported to the Medical Birth Register. However, during the recent years, diagnostics, classification and registration of the less severe tears have been improved (68). The reported incidence of second degree tears in a Swedish study was 78% (69). There is still a lack of knowledge about the incidence of levator ani muscle lesions in Sweden (68), but international studies have shown that it ranges between 13 and 26% (64). Nearly 18% of deliveries are performed by caesarean section in Sweden (67). Like other surgical procedures, caesarean sections may lead to anatomic distortion of pelvic structures or adhesions, as well as nerve injuries leading to development of neuromas at the area of incision (70).

1.3.3 Chronic pain related to pregnancy or labour

There is still considerable uncertainty about the prevalence of chronic pain after childbirth. The reported prevalence of pain persisting after childbirth varies widely in the literature, with up to 43% regarding the pain related to pregnancy (71–77) and 0.3% to 55 % concerning pain persisting after labour (33,77–82). This large variation in prevalence rates may be attributed to several reasons, including heterogeneity with respect to definitions, study samples, and follow-up period. In addition, in many previous studies, the authors did not critically separate new pain after the childbirth from pre-existing pain (77). In addition to chronic pain, women can also suffer from dyspareunia as a consequence of changes and trauma during pregnancy and labour. Dyspareunia is defined as, "pain during sexual activities involving vaginal penetration" (83). According to previous studies, between 8% and 62% of women experience dyspareunia after childbirth (83–86).

Pain persisting after pregnancy or labour may have a negative impact on women's quality of life and lead to a higher rates of anxiety and depression compared to women without pain (74,83,87). Furthermore, pain can also negatively affect infant attachment and mothers' ability to care for their children (88,89). In addition, the experience of dyspareunia may lead to lower sexual desire, lower arousal, and less satisfaction which may have a negative impact on intimate relationships between the woman and her partner (83,86). The existing qualitative studies, which investigated women's experiences of postpartum pain have focused on pelvic girdle pain (90–92) or symptoms related to obstetric injuries (93–96). The results of these studies showed that chronic pain related to pregnancy had a profound negative effect on women's health and quality of life many years after the pregnancy (74,90–92). Pain could lead to serious functional limitations that affected the ability to perform meaningful daily activities (91,92). Pain and other childbirth-related morbidities, such as urinary and faecal incontinence, prolapses of vaginal walls, and sexual dysfunction, may also lead to psychological limitations and shattered expectations of family life (93). In addition, social and intimate relationships, could be negatively affected and many women felt frightened, isolated, and alone (90,97).

1.4 POSTPARTUM CARE IN SWEDEN

Care for pregnant women in Sweden is mostly provided by midwives at antenatal clinics within the primary healthcare sector and involves on average nine visits (98). Intrapartum care is in most cases hospital-based with midwives as primary caregivers during uncomplicated deliveries. In case of complications during labour, such as the need for an instrumental vaginal birth or caesarean section, the midwife works in collaboration with an obstetrician (99). The average length of postpartum care at the hospital is two to three days but some hospitals have a shorter care period of 6-12 hours if there are no complications for the mother or the child (100). During the first week after discharge, postpartum departments in the hospitals are responsible for the mother and her child. However, only one in three hospitals always monitors women's health after returning home from the hospital, and over half do so only in certain cases (100). Until recently, maternal healthcare did not follow up on women's health until 6–12 weeks after labour. According to new guidelines, midwives contact women by telephone during the first two weeks after birth to explore the need for further contact. Postnatal visits are preferably offered on several occasions, as needed, between 1–16 weeks after delivery (98). These check-up visits are voluntary, and include

discussion about childbirth experience, assessment of general, mental, and sexual health, gynaecological examination, including evaluation of pelvic floor muscle strength as well as contraception counselling (98). After the postpartum follow-up visits, the woman becomes an ordinary patient within primary healthcare (100).

1.5 THE IMPORTANCE OF HEALTH LITERACY AND PATIENT EMPOWERMENT

Research have shown that in general, persons with chronic pain are often not aware of where to find healthcare professionals to help them manage their pain, and have limited knowledge about the treatment of pain (101). Furthermore, during the postpartum period, women often do not know what symptoms are considered normal and experience the childbirth related morbidities as unexpected (90,92,95,96,102). According to studies, information provided to women regarding physiological changes after childbirth is often inadequate, incorrect, or inconsistent (103–105). Access to this kind of information is included in the concept of health literacy. Health literacy is defined as, "the ability to obtain, read, understand, and use healthcare information to make appropriate health decisions and follow instructions for treatment" (106). Insufficient health literacy is associated with poor health outcomes, increased hospitalization, and worsened mortality rates (107). Low health literacy in persons with chronic health conditions, such as asthma and diabetes is also associated with limited self-management skills (108). Among patients with chronic pain, health literacy had the potential to play a crucial role in self-management, what course of action they have taken and what healthcare treatment they decide to seek (109). The concept of health literacy includes health literacy responsiveness or organizational health literacy, which can be explained by how health services make health information and resources available and accessible (110,111). Providing the right information is essential to a person's active decision-making (112). According to the Swedish Patient Act, the patient has the right to receive information about the condition, available methods for examination and treatment, significant risks of complications and side effects, as well as methods for prevention of injury or illness. In addition, health professionals should individually adapt the provided information to the recipients, concerning age, maturity, experience, and cultural as well as linguistic background (113).

Research has shown that information is essential to the process of patient empowerment (114,115). According to WHO, empowerment is, "a process through which people gain

greater control over decisions and actions affecting their health, and as such individuals and communities need to develop skills, have access to information and resources, and the opportunity to participate in and influence the factors that affect their health and well-being" (115). Empowerment is an important factor for improving health outcomes and user satisfaction with healthcare as well as enabling good communication between patients and health professionals (116). According to Cerezo et al. (116), the outcome of empowerment is, "a patient with greater ability to exercise control, manage his/her own condition and to make an informed decision". Empowerment may also result in facilitation of well-being, hopefulness, identification of one's own strengths as well as enhancing self-efficacy and coping abilities. On the other hand, the absence of empowerment may lead to significant negative consequences, such as loss of autonomy and lower quality of life (117–119).

2 RATIONALE

Although considered as natural processes, pregnancy and labour can lead to the development of chronic pain. Pain may have many negative consequences for women's physical and social activities, psychological well-being, intimate relationships, and ability to care for their children. Furthermore, individuals with chronic pain are often at risk of developing complications, including physical, psychological, and cognitive dysfunctions. Over time, pain may become more complex in its pathophysiology and thus potentially more challenging to reverse and treat.

Knowledge regarding prevalence, characteristics, or experiences of chronic pain following childbirth in Sweden is scarce. Existing studies have focused mainly on low back and pelvic girdle pain persisting after pregnancy or on obstetric anal sphincter muscle injury. To our knowledge, there are no studies that focused on informational support from caregivers and women's experiences of healthcare.

Because chronic pain related to childbirth occurs relatively early in life, the physical, psychological, social, and financial consequences, for individuals, their families, and community, may be extensive. Women who have developed chronic pain need help and support from health professionals who should acknowledge the condition as a serious health issue. There is a need to raise awareness among healthcare providers of this clinical problem, as well as to revise and upgrade education and guidelines regarding information, prevention, and management of pain persisting after childbirth.

3 AIM

The overall aim of this thesis was to describe the prevalence and characteristics of chronic pain related to childbirth. Further aims were to explore women's experiences of pain and its consequences as well as information and support from healthcare professionals.

The specific aims of the thesis:

- I. To explore the prevalence of chronic pain 8 months after childbirth in a cohort of Swedish women. The characteristics of chronic pain, such as pain intensity, localization, and frequency as well as pain interference with daily activities were examined. An additional aim was to describe the prevalence and intensity of dyspareunia.
- II. To describe women's experiences of chronic pain related to childbirth approximately one year after labour.
- III. (1) To describe to what extent and which format women reported that they have received information regarding the risk of developing chronic pain related to childbirth from healthcare providers; (2) to investigate women's experiences of the received, or lack of, information and its consequences; (3) to describe to what extent and which format women would like to receive information.
- IV. To explore how women with chronic pain related to pregnancy or labour experienced support from healthcare professionals.

4 MATERIALS AND METHODS

This thesis consists of four studies and used quantitative methods (**Study I**), qualitative methods (Studies II and IV) as well as mixed methods (Study III). An overview of the methods is presented in Table 1.

Table 1. Overview of the studies and methods.

	Study I	Study II	Study III	Study IV
Design	Quantitative, prospective cohort study	Qualitative descriptive study	Mixed methods study with sequential explanatory design	Qualitative descriptive study
Participants/ Settings	1,171 women who gave birth at 7 hospitals and completed the second questionnaire	20 women interviewed one year after childbirth	1,171 women who completed the second questionnaire and 20 women interviewed one year after childbirth	20 women interviewed one year after childbirth
Data collection	Two structured questionnaires	Semi-structured individual in-depth interviews	Structured questionnaires and semi-structured indepth individual interviews	Semi-structured individual in-depth interviews
Data analysis	Descriptive statistics Pearson Chi-square test	Inductive qualitative content analysis	Descriptive statistics and inductive qualitative content analysis	Inductive qualitative content analysis

4.1 **DESIGN**

Study I was designed as a quantitative, prospective cohort study. Quantitative research aims to answer a specific research question based on numeric data and can, for instance, be used to measure a phenomenon or to test a hypothesis (120). In observational (descriptive) studies, a researcher describes the characteristics of a phenomenon in a specific population without answering the question "why" a particular phenomenon occurs. In a prospective study, a sample is selected from the population and then the variables of interest are measured (120). Studies II and IV had a qualitative approach. Qualitative research focuses on a person's

experiences or perceptions and its purpose is to gain an in-depth understanding of, for example, a phenomenon studied (121). Narrative data were collected through individual interviews and analysed using inductive qualitative content analysis. **Study III** adopted a mixed methods design, which is considered suitable when data from one source can be enhanced from a second, and provides a more comprehensive understanding of the research phenomenon (122). In **Study III**, a sequential explanatory design was applied which entails collecting and analysing quantitative, and then qualitative data, in two consecutive phases within one study (123). This design was used to confirm as well as further explore the results from a quantitative phase (data from questionnaires) with insights gained from qualitative interview findings. The quantitative and qualitative phases were connected while selecting the participants for qualitative interviews as well as during the discussion of the results (122,123).

4.2 SETTING, SAMPLING, AND INCLUSION CRITERIA

Data in this thesis are based on a convenience sampling and included women who had given birth at six hospitals in region of the capital of Sweden, Stockholm (2,239,407 inhabitants), and at Västerås Central Hospital in the medium-sized region Västmanland County (with approximately 260,000 inhabitants) (124). Recruitment took place on maternity wards 24-36 h after birth. All women, eligible for participation and who gave written informed consent, were invited to participate. The inclusion criteria were women who speak and read Swedish. Women, whose pregnancy ended in stillbirth, were excluded for ethical reasons.

In **Study I** and the quantitative phase of **Study III**, data were collected using two self-administrated questionnaires, the first, during 24-36 hours after labour (n=1,507), and the second, eight months after childbirth. In the analysis of **Study I** and the quantitative phase of **Study III**, a sample of 1,171 women who completed the second questionnaire was included.

Studies II and **IV** as well as the qualitative phase of **Study III** included a purposive sampling of 20 participants chosen among women who had reported chronic pain after childbirth in the second questionnaire (n= 195) and who gave written consent to be interviewed. The women who met the inclusion criteria were divided into three groups depending on pain onset to obtain as much variety as possible in the material and to deepen the understanding of women's experiences; 1) Pain with onset during pregnancy (n=106), 2) Pain with onset in relation to labour (n=53) and 3) Both pain with onset during pregnancy and in relation to labour (n=36). A random sample was selected in each group, and the women were contacted

by telephone, provided with verbal information about the study, and asked again if they wanted to participate. The selection procedure continued until a total of 20 women had given their second consent to be interviewed. After the interviews had been conducted, further three women were selected according to the selection procedure, as three of the interviews were not considered relevant to the study (one of the women no longer had pain, one had pain that started before pregnancy and one experienced pain with onset during previous labour). Of the included 20 interviews, five were with women who had pain with onset during the last pregnancy, eight women had pain that started in relation to labour, and seven had both pain with onset during pregnancy and in relation to labour. An overview of the selection procedure is presented in Figure 4.

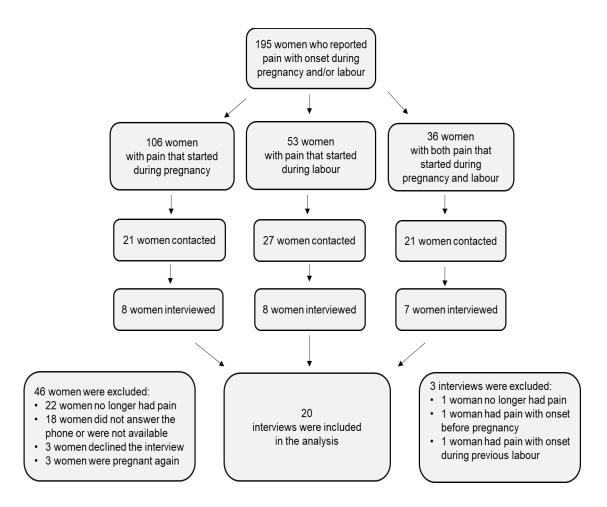


Figure 4. An overview of the selection procedure for **Studies II** and **IV** as well as the qualitative phase of **Study III**.

Reprinted from Grieving over the past and struggling forward – a qualitative study of women's experiences of chronic pain one year after childbirth by Molin B, Zwedberg S, Berger AK, Sand A, Georgsson S., 2021, Midwifery. 2021;103:103098–103098. Copyright 2021 by Elsevier. Reprinted with permission.

Power calculation

As we initially planned that the research project would include investigating risk factors for the development of chronic pain related to childbirth, we conducted a sample size calculation before the data collection. According to the calculation, with assumptions based on previous studies of the prevalence of chronic pain following vaginal birth and caesarean section respectively (79,80), the target sample size was 1,000 women to detect differences regarding risk factors, with a statistical power of 80%, and based on a significance level of 5%. The dropout was predicted to be approximately 30%, hence, 1,500 women should be recruited to reach the target sample size of 1000 women.

4.3 DATA SOURCES AND COLLECTION

4.3.1 The time point for the data collection

The time point for the data collection was chosen based on the definition of chronic pain as well as recommendations regarding duration of chronic pain for research purposes. According to the International Association for the Study of Pain (IASP), chronic pain is defined as pain that persists after three months (11). In addition, The Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT) recommends pain duration as at least six months to reduce the rate of spontaneous resolution of pain (125). Hence, we have chosen eight months for the collection of quantitative data and the interviews were performed 9-14 months after childbirth.

4.3.2 Questionnaires

The self-administrated questionnaires used for data collection in **Study I**, as well as in the quantitative phase of **Study III**, were developed by the research team with pain researchers, midwives, and an obstetrician. Both questionnaires were based on a systematic literature review and after an in-depth examination of available patient-reported outcomes (PROs). They were then validated face-to-face with 15 women, well perceived and understood, with the exception of two issues that had to be modified (one question about socio-economic data and one about localisation of pain). The first questionnaire was distributed by midwives on maternity wards, between April and December 2015. The questionnaire included questions about socio-demographic factors as well as baseline measures of common morbidities, including pain before and during pregnancy. In total, the questionnaire consisted of 59 items. A registry of women, who completed the first questionnaire and were therefore enrolled in

the study, was created. The second questionnaire with a pre-stamped return envelope was sent by post, eight months after the childbirth. Two reminders were posted to the women who did not respond. The second questionnaire consisted of 23 items. The women were asked if they experienced constant or recurring pain during the past week, including pain during intercourse, as well as if the pain had onset during pregnancy, in relation to labour, or weeks to months after childbirth. The second questionnaire also included questions about pain characteristics, such as severity, frequency, and bodily localization as well as the impact of pain on the woman's daily life. To estimate the worst and average pain intensity, a numerical rating scale, (NRS), ranging from 0 to 10, was used, with 0 being "no pain" and 10 being the "worst pain imaginable" (126). The evaluation of interference of pain with the woman's daily life, activities, and affect, included seven items: "walking," "work," "sleep," and "childcare" as well as "mood," "enjoyment of life" and "relations with others" (127). The items were rated by women on a numerical rating scale between 0 ("no impact") and 10 ("very high impact"). Pain intensity as well as its impact on daily life was translated into severity stages of "mild," (NRS 1-3) "moderate," (NRS 4-6), and "severe" (NRS 7-10) (128). For a description of the localization of pain, women were given alternatives: in/around vulva, in/around anus, between vulva and anus, surgical site after caesarean section, os coccyx, lower back, upper back, pelvis, abdomen, legs, breasts, head, and others. To assess the frequency of pain, the women were given the following options: constant, daily, a few times a week, a few times a month. If more than one onset of pain was reported, women were given an opportunity to describe pain characteristics for every specified pain. In addition, the second questionnaire included questions about information from healthcare professionals. Women were asked if they had received any information about the risk of developing chronic pain after childbirth, if so, by whom (a midwife, an obstetrician, both or other), how (verbally, in writing or both), and when this information was provided (at a maternity care unit during pregnancy checks, on a maternity ward during the immediate postnatal period or at a maternity care unit after childbirth). The second questionnaire also included an openended question, "If you would like to receive information about the risk for development of chronic pain related to childbirth, how would you like to receive it?" Furthermore, women were also asked if they sought healthcare due to persisting pain (yes/no).

4.3.3 Individual interviews

To address the aims of **Studies II** and **IV**, as well as the qualitative phase of **Study III**, data were collected through individual interviews. Participants were purposely chosen among women who had reported chronic pain related to pregnancy or labour in **Study I** and who

gave written and oral informed consent to be interviewed. A semi-structured interview guide for data collection was developed based on a literature review and discussed within the research group. The interview guide consisted of questions about womens' experiences of pain and its consequences, including perceptions of information and support from healthcare professionals. Before the interviews, a pilot interview was conducted to validate the questions. However, no questions required modifications. The pilot interview was not included in the analysis.

The interviews were guided by the following key questions:

- 1. "Could you tell me about your experience with pain?"
- 2. "Does the pain affect your life and, if so, how?"
- 3. "Can you tell me about your experience and thoughts regarding information about chronic pain?"
- 4. "How would you describe your healthcare experience?"

Support questions were used during the interviews to ensure the depth and details of women's experiences. All interviews were conducted by the doctoral student, between June and November 2016, in a location that was most convenient for the women, either at the woman's home, her workplace, or at the researcher's workplace. The interviews were audio recorded and lasted between 15 and 56 minutes (mean=32, median=28).

4.3.4 Patient record system

Obstetric data such as delivery route, parity, perineal tear (degrees 3 and 4), or episiotomy were obtained from the medical record system Obstetrix. This system was introduced in 2008 and is an electronic standard documentation tool that allows access to information about each pregnancy and birth. Extraction of data for the women who gave birth at six hospitals in the region of Stockholm was ordered from Region Stockholm in August 2016. The obstetric data for deliveries at the county hospital of Västmanland County were retrieved manually by the doctoral student in September 2016. Data regarding perineal trauma degrees 1 and 2 were not available at the time of the study, in the register or elsewhere.

4.3.5 The Swedish Medical Birth Register: Pregnancies, Deliveries and Newborn Infants

Data regarding the general population were obtained from The National Board of Health and Welfare, The National Medical Birth Register: Pregnancies, Deliveries and Newborn Infants. This register was founded in 1973 and has since then been used in many scientific projects. It

consists of information from all pregnancies that have led to the delivery of a child in Sweden (67). Data from the records were used to assess the representativeness of the sample, as the social and reproductive characteristics of participants were compared with routinely collected data for all women giving birth during the recruitment period in **Study I**.

4.4 DATA ANALYSIS

4.4.1 Descriptive statistics in Studies I and III

In **Studies I** and **III**, descriptive statistics were used to present the quantitative data and background characteristics. The data were presented as numbers (frequencies) and percentages. Missing data were left out of the analyses and no imputation was performed. Because of this, the numbers of responders included in the analyses vary. Comparative statistical analysis using the Pearson Chi-square test was performed for the analysis of proportions of categorical variables. Odds Ratios (OR) with 95% confidence interval (CI) were calculated and p-values equal to, or lower than, 0.05 were considered statistically significant. Data were processed and analysed using the statistical program SPSS IBM (Statistical Package for the Social Sciences) version 25.

4.4.2 Qualitative content analysis in Studies II, III, and IV

The 20 interviews were analysed using inductive qualitative content analysis. Qualitative content analysis is a method for the interpretation of textual data through a systematic process of coding and identifying patterns within the data (129). In the inductive approach, no existing theory or theoretical framework is tested in the analytical process (129). Content analysis can be performed at manifest or latent level, depending on the level of abstraction and interpretation. A manifest approach describes the obvious content that is directly seen in the text while latent approach refers to the underlying meaning of the content (129). In **Studies II, III,** and **IV**, the categories describe the content on a manifest level while the themes were constructed in a more interpretative manner. The analysis was performed in a stepwise manner inspired by that outlined by Graneheim and Lundman (130). Figure 5 illustrates the different steps in the analysis process.

In **Studies II-IV** Microsoft Word was used for verbatim transcription of the recorded interviews. The transcription was then read several times to get an overall understanding of the material. For the analysis of data for **Study II**, the calculation program, Excel was used to

support further data management, while for **Studies III** and **IV**, analyses were performed using the freeware Open Code 4.03 (131). The first step of the analysis was the identification of meaning units and their condensation, meaning shortening the text while preserving the core. Further, the condensed meaning units were labelled with codes consisting of one or a few words directly related to the context.

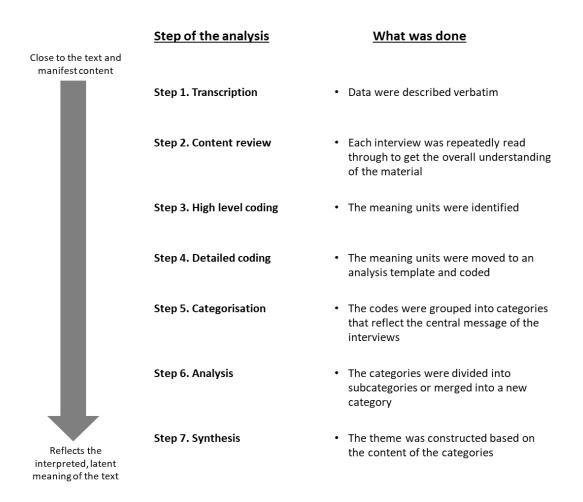


Figure 5. The steps of the qualitative content analysis adopted in **Studies II**, **IV**, and the qualitative phase of **Study III**.

After coding and re-coding, the codes were sorted in clusters creating categories and subcategories. During the process, the categories were compared for similarities and differences and either divided into subcategories or merged into a new category. Finally, a theme expressing the underlying meaning was formed from the categories. The process of analysis was carried out back and forth by the doctoral student and two supervisors.

Furthermore, the results were discussed by the whole research group until a consensus on the understanding of the data was reached.

4.4.3 Quantifying of open-ended question

To answer one of the aims in **Study III**, an open-ended question from the second questionnaire was quantified. The question was: "If you would like to receive information about the risk for development of chronic pain related to childbirth, how would you like to receive it?" The free text answers (qualitative data) were transformed into an additional variable (quantitative data): "Do the women wish to receive information about the risk for developing chronic pain related to childbirth?".

The main steps of the process were analysis of the messages in the free text answers, using content analysis, and independent coding (classification) of the data into five categories:

- 1. Yes, I would like to receive information. This category included all answers where women described when or how they would like to receive the information (verbally, in writing, from the midwife, the doctor, during pregnancy, during postpartum check-up),
- 2. No, I would not like to receive any information,
- 3. I don't know,
- 4. I am happy with the information I have received,
- 5. Answer is missing/no opinion.

Data were further quantified using descriptive statistics.

5 ETHICAL CONSIDERATIONS

The study protocol has been reviewed and approved by the Regional Ethical Board in Stockholm, Sweden, in March 2015 (Dnr 2015/236-31). All studies have followed the Declaration of Helsinki (132) and the ICN Code of Ethics (133). In human research, there are four basic ethics requirements, which are, the information requirement, the consent requirement, the confidentiality requirement, and the utilization requirement. All have been considered throughout the entire research project, from design to publications. Based on the information requirement, prior to quantitative data collection, the participants were provided with detailed written information about the purpose of the study, stating that participation was voluntary and that they could withdraw from the study at any time without having to state any reason. All participants were also informed that collected data would be treated confidentially and only used only for research purposes and that no person besides the research team would have access to the data. Furthermore, the consent requirement was fulfilled. The research group have obtained written consent to the quantitative and qualitative data collections. In connection with the distribution of the first questionnaire, the participants were asked to enter their personal data such as name, address, telephone number, and personal identification number as well as to sign the consent form. Written consent to participate in the qualitative data collection was obtained in connection to the second questionnaire where the participants gave their consent to be contacted for the follow-up interviews. In addition, the written consent was followed by verbal information and consent prior to the interviews. To meet the confidentiality requirement, personal data were stored and archived in accordance with The General Data Protection Regulation (GDPR) (Regulation 2016/679) (134). Data were protected by password and stored in a locked, fireproof space to which only the doctoral student and the main supervisor had access. Both questionnaires and interviews were deidentified and coded. The results from the studies with a quantitative approach have been reported at statistical group level and no individual has been able to be distinguished. The results from studies with a qualitative approach have been reported in a way that no individual can be identified. Based on the utilization requirement, the information collected had been used only for the research that had received ethics approval. Ethical reflections and the predominant current risk-benefit perspective have been considered. No questions of a nature that could be perceived as sensitive have been asked in connection with the interviews. There is always a risk that an interview can arouse emotions, which has been discussed within the research group prior to data collection. The participants were informed that if they

expressed psychological distress or needed help, they should contact healthcare. Within the framework of the research project, there were no invasive methods regarding data collection.

6 RESULTS

This section provides a brief summary of the findings for each study. For a more comprehensive description of the results please refer to the original articles listed at the end of the thesis.

Approximately 17% of the women in **Study I** reported chronic pain related to childbirth eight months after giving birth. Of these, 9% reported chronic pain that had begun during pregnancy, 5% experienced chronic pain related to labour and 3% had both chronic pain with onset during pregnancy and in relation to labour (each woman could only appear in one of the groups). Approximately 80% of the women rated their worst pain, and 50% (with pain related to labour) respectively 70% (with pain following pregnancy) rated their average pain as moderate or severe (NRS 4-10). More than 40% of the women experienced chronic pain constantly or daily. Over 35% reported pain interference with daily activities as ≥4 on a 0–10 NRS and approximately 60% a moderate to severe impact on mood. The most common localizations for pain related to pregnancy were the lower back and the pelvic area. After vaginal delivery, women experienced chronic pain most often in/around the vulva/anus, and the surgical site was the most prevalent localization for pain after caesarean section. Dyspareunia related to childbirth was reported by 19% of the women with approximately 60% experiencing their worst pain during intercourse as moderate or severe. The characteristics of the 1,171 included women are presented in Table 2.

In addition, data collection for **Study I** showed (unpublished data) that a further 19% (220/1,171) of women reported pain that began weeks or months after birth.

The results from **Study II** comprise one overarching theme "Grieving over the past and struggling forward," and three categories "Mourning the losses," "Struggling with the present" and "Managing the future." The themes, categories and subcategories are presented in Table 3.

The category, "Mourning the losses" describes how chronic postpartum pain and its consequences significantly restrained women's previous ability to perform physical activities. In addition, the experience of pain could severely limit maintaining social relationships, which in turn led to women isolating themselves from social interactions. Living with pain also had a negative impact on women's relation with their life partner. Furthermore, some women experienced that the pain and its consequences had changed them as persons to the degree that they could no longer recognize themselves.

Table 2. Characteristics of the participants in **Studies I** and **III** (n=1,171).

	n	%
Age mean (years) (n=1,171)	32.4	
Age groups (years)		
19-24	57	4.9
25-35	794	67.8
36-50	320	27.3
Country of birth (n=1,163)		
Sweden	1013	87.1
Another European country	72	6.2
Country outside Europe	78	6.7
Relationship status (n=1,162)		
Married or cohabiting	1147	98.7
Single	15	1.3
Education In 17, 4455		
Education level (n=1,160)	40	4.6
Elementary school	18	1.6
Upper secondary school	250	21.6
College Other	882	76.0
Other	10	0.9
Occupational status (n=1,168)		
Employed	1048	89.7
Student	46	3.9
Jobseeker	18	1.5
Other	56	4.8
84ada af himb (n. 4.474)		
Mode of birth (n=1,171)	916	78.2
Vaginal Instrumental	75	6.4
Spontaneous	841	71.8
Spontaneous	041	71.0
Caesarean section	255	21.8
Emergency	119	10.2
Planned	136	11.6
Pority (n=1 171)		
Parity (n=1,171) Primipara	685	58.5
Primipara Multipara	486	58.5 41.5
	400	41.3
Perineal trauma ^a		
Degree 1 and 2	738	80.6
Degree 3 and 4	50	5.4
Episiotomy	7	0.8

^a Of those women that had a vaginal delivery (n=916).

The category, "Struggling with the present" reveals that the women had to make many adjustments and compromises in their lives to avoid the pain or its aggravation. In addition, the women struggled with negative feelings such as failure, inadequacy, and disappointment about having pain and its profound impact on their lives but also because they could not meet their child's needs and live up to the role model of a mother.

The category, "Managing the future" describes how the majority of the participants had a positive attitude and hoped that their pain would improve over time. However, some women were worried that pain would endure and continue to limit their lives. They were also concerned about becoming pregnant and giving birth again, to such a degree in some women that they had decided to give up their dreams of having more children.

Table 3. Overview of theme, categories, and subcategories in **Study II**.

Theme	Categories	Subcategories
	Mourning the losses	Limited daily activities Affected relationships Altered self-image
Grieving over the past and struggling forward	Struggling with the present	Feeling like a failure Adjusting life Enduring the pain
	Managing the future	Hovering between hope and despair Ambivalence about having another baby

The results of **Study III** show that the majority of the participants did not receive any information, or the information was inadequate or insufficient. This led to women experiencing the pain as unexpected, which could cause emotional distress and suffering. The women were often told that pain is a natural consequence of pregnancy or labour and would resolve spontaneously over time. In consequence, they did not see their pain as a condition that required medical attention. In addition, the women did not know where to seek help and half of the women did not turn to healthcare with their pain-related problems, which may have delayed appropriate treatment and recovery. However, all women expressed the need to be informed, irrespective of the individual risk of developing chronic pain. A summary of the quantitative and qualitative results is presented in Table 4.

Table 4. Summary overview over quantitative and qualitative results in **Study III**.

Category	Questionnaire survey	In-depth interviews
Inadequate information	83% (954/1,155) of the women reported that they did not receive information about the risk of developing pain persisting after childbirth	Insufficient and inadequate information: The women experienced that they received no, insufficient, or inadequate information from healthcare providers about pain persisting after childbirth
		Seeking other sources: The women tried to find information and support through other sources, for example, social media
Negative consequences	Of those women who experienced chronic pain related to childbirth, 52% (100/192) did not seek healthcare for their problems	Emotional distress: Chronic pain related to childbirth was experienced by the women as unexpected, which led to emotional distress and unnecessary suffering
		Postponed seeking care: The women did not consult healthcare professionals about the pain, which could delay appropriate treatment and recovery because they did not see their pain as a condition that required medical attention but as a natural consequence of childbirth that would diminish spontaneously with time
		The women did not know when or where to seek help and felt confused about which healthcare settings were available and appropriate
		Some of the women felt too ashamed to talk about their problems with healthcare providers
Information needs and requirements	82% of the women (957/1,117) would like to receive information about risk of developing chronic pain	The women expressed the need to be informed in advance and irrespective of the potential risk of developing chronic pain

The overarching theme in **Study IV**, "The ignored pain" and four categories: "Pain experience," "Pain management," "Lost in the healthcare," and "Insufficient maternal care" emerged from the women's narratives (Table 5).

The category, "Pain experience" comprises three subcategories: "Feeling ignored and trivialized," "Being disbelieved," and "Relief upon confirmation". The first two subcategories describe that when the women turn to healthcare with their problems, the pain was not recognized and confirmed. They were not asked about, or examined for, pain during the postpartum check-up, and if the pain was mentioned it was often ignored or trivialized. During encounters with healthcare professionals, the women were not taken seriously, listened to, or believed, which may lead to feelings of being insulted and humiliated. The third subcategory refers to feelings of relief and gratefulness when sometimes healthcare professionals confirmed women's experience and their need for treatment.

The category, "Pain management," with subcategories "Lack of or ineffective treatment" and "Effective treatment at last," describes that the women often did not receive any treatment, alternatively, the treatment was ineffective or only effective to some extent. Only some women, who did not give up and continued seeking help, eventually received adequate and effective treatment.

The category, "Lost in the healthcare," which contains two subcategories: "Feeling abandoned after childbirth" and "Forced to manage on their own," relates to the women feeling overwhelmed by the fact that the focus of the healthcare professionals after childbirth shifts entirely to the baby, with little concern regarding the well-being of the mother. The women described experiences of being out of the healthcare system and being forced to find help on their own.

In the category "Insufficient maternal care," and the two subcategories "Absence of continuity" and "Poor knowledge", the women described shortcomings within maternal care in terms of a lack of a well-defined and well-functioning chain of care, accessibility, and scope. They also emphasized a need for better knowledge and competence of healthcare professionals regarding assessment, management, and professional treatment of chronic pain related to childbirth.

Table 5. Overview of theme, categories, and subcategories in **Study IV**.

Theme	Categories	Subcategories
	Pain experience	Feeling ignored and trivialized Being disbelieved Relief upon confirmation
The ignored pain	Pain management	Lack of or ineffective treatment Effective treatment at last
	Lost in the healthcare	Feeling abandoned after childbirth Forced to manage on their own
	Insufficient maternal care	Absence of continuity Poor knowledge

7 DISCUSSION

In this section, the main results are discussed in relation to previous research, followed by a description of the strengths and limitations of the included methods.

7.1 REFLECTIONS ON MAIN FINDINGS

7.1.1 Prevalence of chronic pain related to childbirth

The results of **Study I** show that pain persisting after pregnancy and/or labour is reported by one in six women and one in five experienced dyspareunia. Of the women that reported chronic pain related to childbirth, 9% experienced pain that had begun during pregnancy, 5% had pain related to labour, and 3% had both pain with onset during pregnancy and labour. In addition, a further 19% of women reported pain that began weeks or months after delivery. Due to the pain-free period, it is not possible to determine if this pain was related to childbirth, as these women could have developed it due to reasons not directly related to pregnancy or labour. However, some localizations indicate that pain could be caused by trauma or tissue damage during labour, as the pain was experienced by women in the surgical site after cesarean section, in/around the vulva or anus, or in the perineum. According to existing knowledge, chronic pain may develop after an asymptomatic (pain-free) period, for instance, neuropathic pain related to surgical interventions may have a delayed onset of weeks/months to years (135). Therefore, it is conceivable that pain with onset during weeks to months after labour, experienced by some of the women, emerged as a consequence of childbirth. Considering approximately 110,000 - 120,000 deliveries per year in Sweden (136), the results indicate that at least 19,000 women are at risk of developing chronic painful childbirth-related conditions every year.

7.1.2 Consequences of living with chronic pain

Chronic pain has considerable negative consequences for women's lives. According to findings in **Study I**, approximately 80% of women with chronic pain related to childbirth scored their worst pain as moderate or severe, and over 40% of the women had pain constantly or daily. As both **Studies I** and **II** show, pain interfered with and limited daily activities, forcing the women to compromise and adjust their lives to it. Furthermore, pain had a negative impact on sleep, enjoyment of life, self-esteem, and relations with others. Approximately 60% of the women in **Study I** reported a moderate to severe impact on mood and, as the descriptions of women's experiences in **Study II** reveal, pain had a profound negative impact on their psychological well-being. Women experienced various negative

emotions because of their condition, as well as due to the inability to fulfil the expectations and roles as a wife/partner or mother. The results concur with previous findings, showing that pain may disturb several aspects of women's lives and lead to a reduced quality of life (74,90–92). In addition, these consequences can increase the severity of pain experience, as, according to existing knowledge, pain has a multidimensional nature, and includes the affective and cognitive components that have a major impact on how individuals experience it (3,137). Furthermore, based on the biopsychosocial model of pain, psychosocial factors may increase the risk of the development and maintenance of chronic pain. They can also contribute to long-term consequences such as physical and work disability, healthcare costs, and extended mortality. Emotional distress may also negatively impact the ability to cope with pain (2,3).

7.1.3 Lack of adequate information and support

As Studies III and IV show, women do not receive information about the risk for development of chronic pain as well as when or where to seek help. In addition, when women turn to healthcare, they experience that their pain is not assessed or diagnosed but instead ignored and trivialized. Women are often told that pain is a natural consequence of childbirth and would resolve spontaneously. There seems to be a widespread belief among healthcare professionals that pain related to pregnancy or labour is a normal and acceptable consequence of childbirth, thus, nothing is done about it. However, the prevalence of pain persisting after pregnancy or labour is significant and as previous research has shown, pain can persist years after childbirth (72). These findings indicate that at least some pain conditions related to pregnancy or labour will not resolve with time. In addition, in medical assessment pain should always be recognized as a symptom that indicates something deviating. Therefore, efforts should be made to identify and treat pain following childbirth. However, as the results of this thesis indicate, current healthcare seems to fail in this regard. As **Study III** shows, the lack of adequate information may lead to women not seeking help for their childbirth-related morbidities. These results are in accordance with previous research, which reveals that barriers to women seeking support include not knowing which healthcare settings are available and appropriate, not recognizing their problem as morbidity or feeling ashamed (94,102,138,139). Furthermore, as shown in **Study IV**, women, who turn to healthcare with their pain problems, are often sent home without diagnosis or treatment. Thus, the lack of information and support may lead to delayed care and in consequence, increased risk of development and maintenance of chronic pain. Untreated or undertreated pain generates maladaptive changes in the central nervous system, which can lead to the development of

chronic pain. These pathophysiological changes may become more complex over time, and ultimately irreversible, and refractory to treatment (13). Therefore, according to consensus among pain researchers and clinicians, early and effective treatment should be provided, in order to prevent the development of chronic pain and reduce its associated long-term sequelae (13,21,140).

The women in **Study IV** also described experiences of negative encounters with healthcare professionals, as when they sought help for their pain-related problems, they were not listened to, taken seriously, or believed. These dismissive attitudes violated the women's sense of dignity and credibility as they felt insulted and humiliated. This is in accordance with previous research, showing that not believing, or rendering an individual's symptoms as trivial or psychological, can have a negative impact on psychological well-being and lead to loss of identity, social isolation, and stigma (141–143). However, because pain is a subjective and individual experience, it should always be accepted as "whatever the experiencing person says it is, existing whenever s/he says it does" (144). When patients with chronic pain experience not being believed, they focus on struggling for recognition and credibility and are not able to move forward in the process of adaptation to live with chronic pain. Confirmation of the experience and need for treatment are also important for successful pain management (145).

Furthermore, there are also ethical and legal aspects regarding lack of information and inadequate pain management. Access to information and pain management is considered a fundamental human right (45). All people should have their pain acknowledged and as the Declaration of Montreal states, have access to, "appropriate assessment and treatment of the pain by adequately trained healthcare professionals" (46). Furthermore, as the World Health Assembly resolved, "It is an ethical duty of healthcare professionals to alleviate pain and suffering" (45). According to the Swedish Patient Act (113), patients have the right to receive individually tailored information about their condition, available treatment including risks and side effects as well as methods to prevent disease and injury. Access to the information is fundamental for a person's active decision-making and achieving patients' empowerment. Low health literacy may reduce women's ability to understand, manage and control their own condition as well as lead to difficulties in navigating the health system and in consequence, reduce their chances for achieving empowerment and positive health outcomes (118).

7.1.4 Need for improved care including pain assessment and management

The results of **Studies III** and **IV** show that women experience a break in the thread between maternal care during pregnancy and the care that follows postpartum. As previously discussed, they are often confused about which healthcare settings are available and appropriate to turn to with their pain-related problems. Previous research has shown that 12% of women seek care at a hospital emergency department in the few weeks after giving birth, due to bleeding, infection, pain, and breastfeeding-related problems (146). According to a report about care after labour in Sweden, this may be an indication that it is unclear where women can get help if they have problems related to childbirth once the delivery hospital is no longer the primary care provider. Furthermore, it can be a sign that follow-up of the women's health after childbirth is deficient, and that there are no routines to identify women who need support and care (133). This is in accordance with the results of both **Studies III** and IV, revealing an overall desire among the women for well-defined and well-functioning chain of care, with better accessibility and scope. In addition, as **Study IV** indicates, the current check-up visits after childbirth fail to identify pain-related problems as pain is often not assessed or examined during these visits. According to new recommendations for postpartum maternal care in Sweden, the assessment of pain does not appear to be covered by the content of follow-up visits (98). However, poor assessment of pain is the biggest barrier to effective pain management. If not assessed, pain goes unrecognised or unrecorded, and the chances for good treatment decrease (140). We suggest that assessment of, and counselling on, pain should be included as standard during postpartum check-up visits in order to monitor the potential development of chronic pain and to ensure that the women receive the care they need. In addition, as emerged from results in **Study IV**, women wish for an easily accessible healthcare facility or clinic, to which they can turn with their postpartum morbidities, including pain. At these facilities, women could be provided with multimodal and interdisciplinary support from various healthcare specialists, such as midwives, obstetricians, physiotherapists, and psychologists, based on the biopsychosocial model of pain. In addition, both women and healthcare professionals would benefit, if visits at these facilities could be made without the requirement of a doctor's referral. This may make the healthcare more accessible for the women, shorten the chain of care as well as be economically beneficial.

Furthermore, there seems to be a concerning lack of knowledge about chronic pain among healthcare professionals. Such knowledge is necessary for providing adequate assessment and treatment as well as individually adapted information and follow-up. Lack of knowledge and training regarding diagnostics and management of perineal tears and their consequences,

including pain, incontinence, defecation problems, and psychological distress, is also highlighted in reports from The National Board of Health and Welfare (147). This report, and the results of **Study IV** suggest a need for education as well as knowledge support, in the form of guidelines and recommendations at national level to identify, treat, monitor, and support women with pain persisting after pregnancy or labour.

7.2 METHODOLOGICAL CONSIDERATIONS

Both quantitative (for **Study I**) and qualitative research methods (for **Studies II** and **IV**), as well as mixed methods (for **Study III**), were used to fulfil the aims of the thesis. Combining different research methods offers different perspectives on the research topic, however, methodological limits of the applied methods must be addressed.

7.2.1 Study I and the quantitative phase of Study III

Observational studies can be evaluated in terms of **validity**. Validity can be defined as a measure of "the degree to which an observation or instrument measures what it is supposed to measure" (120). It may be sensitive to bias, which can occur at any phase of research.

Selection bias is a common bias in observational studies and occurs when the study population is not representative of the target population. This kind of bias can limit the generalizability of findings and is a threat to external validity. The common treat to external validity is when small samples are chosen from a single geographic location or facility (148). To increase external validity, the first questionnaire, used to collect data in **Study I** and the quantitative phase in **Study III**, was distributed at six hospitals in the region of the capital of Sweden, Stockholm as well as at Västerås Central Hospital located in one of the middle-sized cities, Västerås. Västerås Central Hospital in Västerås is the county hospital of Västmanland County with approximately 260,000 inhabitants, in the year 2015. The county is subdivided into 11 municipalities and the biggest is Västerås municipality with about 145,000 inhabitants. In 2015, the region of Stockholm included 26 municipalities with a population of more than 2.2 million. The Stockholm municipality was the biggest with an estimated population of 920,000 and the rest of the inhabitants lived in the suburban areas, such as Huddinge (105,311 inhabitants), Nacka (97,986 inhabitants), and Södertalje (93,202 inhabitants) (124).

By using questionnaires as a method of data collection, the researcher is able to obtain data from a large sample. However, despite the large sample in **Study I** and the quantitative part

of **Study III**, the number of women recruited at the hospitals during the data collection period who completed the first questionnaire (n=1,507) represented a small share of the total number of deliveries (17,000). A possible explanation of the low response rate to the first questionnaire may be that midwives did not ask women if they would like to participate in the study due to time constraints, excessive workloads, and insufficient staffing. Furthermore, the convenience sampling we used to collect data led to the under-representation of some groups, such as women with a lower educational level as well as younger women. In addition, foreign-born women with a non-Swedish speaking background are also underrepresented in our sample (13%) as the share of foreign-born mothers in Sweden at the time of the project was approximately 28% (136). This may, to some extent, be attributed to the inclusion criteria we applied (women who speak and read Swedish). According to previous studies, lower socioeconomic status and educational level can be associated with a higher prevalence of chronic pain and worse pain outcome, for instance regarding pain intensity, and painrelated disability (81,149). Therefore, the prevalence of chronic pain related to childbirth may be higher in the general population. Furthermore, the under-representation of women with a lower educational level, and foreign-born women with a non-Swedish speaking background may also have influenced the results of **Study III**, as low educational level, language obstacles and low health literacy may be a barrier to seeking help for morbidities related to childbirth (150). Therefore, including more women from ethnic minorities and socially vulnerable groups of women in **Study III** might have provided a different perspective and should be investigated in the future. However, when compared with the overall population, the study participants seemed to be representative in relation to obstetric characteristics, such as mode of delivery, acute vs. elective caesarean sections, and instrumental/non-instrumental vaginal deliveries. In addition, loss to follow-up in data used in **Study I** and the quantitative part of Study III, was relatively low as the response rate to the second questionnaire, completed by the women eight months after childbirth, was 77.7%. Strategies used to increase the response rate were using a pre-stamped return envelope and two reminders send by post after two weeks and one month.

Validity can also be threatened by errors in measurement. In this respect, one important strength of our research was that we made efforts to prevent **information bias** by using a clear definition of the onset of chronic pain and by excluding pre-existing pain, as the first questionnaire consisted of questions about common maternal morbidities, including pain before pregnancy. Furthermore, in the second questionnaire, the women were asked about pain presence during the past week (yes/ no) as well as the onset of pain ("before pregnancy",

"during pregnancy", "in relation to labour" or "weeks to months after labour"). In addition to dichotomized yes-or-no questions, we used a valid and reliable instrument to estimate the intensity of pain, the Numeric Rating Scale (NRS). In chronic pain studies, the NRS is a recommended instrument for core outcome measures (127). The questionnaires that were used in **Study I** and the quantitative phase of **Study III** were self-developed but have demonstrated good face-validity for their intended use. They were developed by an interprofessional team with broad competence, consisting of pain researchers, midwives, and an obstetrician. The authors developed the questionnaires based on a systematic literature review and an in-depth examination of available patient-reported outcomes (PROs). An advantage of using researcher-designed questionnaires in a survey is being able to ask exactly what the researcher wants to know, but there is also a risk that the questions will be misinterpreted or misunderstood. However, all 82 single items in both questionnaires were tested for relevance, clarity, and understandability. They were validated through face-to-face interviews with 15 women, and well perceived and understood. Only two questions (one question about socio-economic data and one regarding localisation of pain) had to be modified. Recall bias may also have influenced the results; however, previous studies have shown that women's recollection of pregnancy or birth does not change much over time (151,152).

7.2.2 Studies II, IV, and the qualitative phase of Study III

Qualitative and quantitative research have similar requirements for good evidence, but the conception and operationalization of these criteria differ. In qualitative research, the terms of reliability and validity are replaced with the concept of **trustworthiness**. Trustworthiness addresses methods that can ensure that the research process has been carried out correctly. There are four aspects for assessing the trustworthiness of qualitative research: credibility, dependability, confirmability, and transferability (130,153).

Credibility refers to the extent to which the research addresses the aim. During data collection, credibility can be ensured by using unstructured or semi-structured data, depending on the purpose (154). Considering the aim of the data collection, we used a semi-structured interview guide, which was discussed and developed within the research group, based on a literature review. Prior to the interviews, a pilot interview was conducted to validate the interview questions and ensure whether they were suitable for obtaining rich data that addressed the aim. The fact that the same researcher conducted all interviews may also increase credibility. As a midwife and a pain educator, the doctoral student had a

preconceived knowledge of the phenomenon studied which is necessary to capture important nuances in the data that otherwise may be lost. On the other hand, preconceived knowledge may be a threat to both **credibility** and **confirmability** (153). Conformability refers to that the data accurately represent the information that the interviewed persons provided. During the entire process of data collection and analysis, the doctoral student made efforts to be self-aware and used reflexivity to avoid influencing the informants and the results with her own opinions. In addition, the involvement of other research group members with different professional and research perspectives, (investigator triangulation) counterbalanced this preconceived knowledge. The analysis was performed by the doctoral student and two of the supervisors (SZ and SG) carefully followed up in the whole analysis process and categorisation. In addition, the whole research team discussed the results until the interpretation, which best represented the meaning of the data, was found.

The sampling strategy can both have an impact on **credibility** and **dependability**, which concerns the stability of the data. A purposeful sampling technique was used to recruit participants who could provide in-depth and detailed information about the phenomenon studied. In addition, by dividing the participants into three groups depending on pain onset, efforts were made to obtain as much variety as possible in the material. The number of 20 interviews was chosen as it was considered optimal to yield a rich material and make it possible to attain saturation (155). We did not perform a preliminary analysis of the collected data, however, by the seventeenth interview, patterns in the women's experiences were recognized, and the last interviews verified that saturation had been obtained, which was also confirmed during the analysis.

The recruitment of participants in **Studies II**, **IV**, and the qualitative part of **Study III** resulted in the under-representation of single women and women with a lower educational level as well as foreign-born mothers with a non-Swedish speaking background. Furthermore, it is also conceivable that the women who decided to be interviewed experienced the most significant impact of pain on their lives. These factors may limit the degree to which these results may be **transferred** to other populations or settings. However, our findings in **Studies II**, **IV** and **III**, to some extent confirmed the findings of previous studies regarding pain impact on women's lives as well as their experiences of information and support from healthcare professionals even though the knowledge is limited.

7.2.3 Study III

This study had a mixed methods design, which may provide better understanding of a research problem, yield more complete evidence as well as strengthen the findings. In **Study III**, the results from the qualitative part agreed (convergence) with the findings in the quantitative phase. Furthermore, the qualitative results enriched and complemented the quantitative findings by providing information about the consequences of lacking and incorrect information (156). However, although we describe the consequences of missing or inadequate information as the reason for delayed care-seeking, no causal relationships could be established, due to the risk of bias.

8 CONCLUSIONS

This thesis provides new knowledge about prevalence and characteristics of chronic pain related to childbirth in Sweden. It also helps to understand women's experiences of living with chronic pain as well as of support from healthcare professionals and its consequences.

Eight months after giving birth, one in six women report chronic pain related to pregnancy or labour and one in five experience dyspareunia. Approximately 80% of the women rate their worst pain as moderate or severe and more than 40% experience pain constantly or daily. The pain severely reduces women's ability to perform physical and social activities, negatively impacts psychological well-being and self-image, as well as their roles as partners and mothers. Although pain and its consequences have a profound negative impact on several aspects of women's lives, they do not receive adequate information or support from healthcare. In consequence, women do not know when and where to seek help and half of them do not consult healthcare professionals. When women turn to healthcare, their pain is often not identified, assessed, or treated but instead ignored or trivialized. The lack of adequate information and support contributes to women's suffering but may also lead to development and maintenance of chronic pain. There is an overall desire among women for information as well as for a well-defined and well-functioning chain of care with better accessibility and scope. Furthermore, they express a need for greater knowledge and competence among healthcare professionals about pain and its management.

The results of this thesis show that, despite the relatively high prevalence of chronic pain related to childbirth and its profound consequences, the women are not informed about risks of developing chronic pain and the pain is not recognized, assessed, or treated. Thus, the results suggest a review of the content and quality of current healthcare services for women after childbirth concerning pain assessment and management. There is a need for developing standards and guidelines for prevention and treatment of pain persisting after pregnancy or labour. These can be important steps towards better recovery after childbirth, reduced suffering, and risk for potential long-term health problems as well as decreased need of healthcare and economic burden for the society.

9 CLINICAL IMPLICATIONS

The following key points offer suggestions for how the results of this thesis may lead to improvement of the content and quality of current healthcare services for women after childbirth:

• Recognition, prevention and management of pain should be considered a priority in postpartum maternal care.

To prevent development of chronic pain and its long-term sequelae, as well as to decrease women's suffering, assessment and treatment of pain should be considered a priority. Instead of assuming that pain is a normal and acceptable consequence of childbirth, healthcare professionals should provide women with recognition and acknowledgement regarding their experience and need for treatment.

Assessment of, and counselling on, pain should be included as standard in maternal postpartum care.

There is a need to review the content and quality of current postpartum maternal care concerning pain management. Assessment of, and counselling on, pain should be included as standard during postpartum check-up visits in order to monitor the potential development of chronic pain and to ensure that the women receive the care they need.

• Pain management needs to follow multimodal approaches.

Because of the complexity of chronic pain and its management, it is crucial to have a multidisciplinary approach, with midwives, obstetricians, physiotherapists, and psychologists working in teams that provide comprehensive physiological and psychological support for the women. Ideally, providing care at the same facility (interdisciplinary approach) would be preferable as it facilitates greater coordination of services and enables frequent communication among health care professionals.

• Providing comprehensible information is highly encouraged.

As there are indications that women do not seek healthcare because of insufficient information, availability of information is highly encouraged. Relevant information about the risk of developing chronic pain, symptoms, and treatment, along with advice about available healthcare resources where women can turn to, should be available. As the women express that they prefer written information, we propose that a booklet should be available and sent home with the woman, for instance, at the postpartum check-up visits as a part of antenatal or postnatal care. Another possibility could be a centralised website with relevant information in different languages.

Knowledge gaps among healthcare professionals about chronic pain need to be identified.

There are indications of lack of knowledge among healthcare professionals regarding pain in general as well as pain persisting after childbirth. Therefore, there is a need to investigate possible knowledge gaps regarding educational programs, continuing education as well as knowledge support, in the form of guidelines and recommendations at national level.

10 FUTURE RESEARCH

This thesis has provided new knowledge about chronic pain related to pregnancy or labour. However, several areas of chronic pain persisting after childbirth have to be further explored in the future:

- Risk factors for development of chronic pain related to pregnancy and labour in order to define and follow-up vulnerable groups of women.
- Etiology, mechanisms and progression of pain persisting after childbirth.
- Evaluation of current helthcare services for women who experience pain persisting after childbirth.
- Further evaluation of women's preferences regarding design and scope of information about pain persisting after childbirth.
- Implementation and evaluation of preventive strategies such as examination and assessment of pain as well as informational support at postpartum check-up visits.
- Investigation of therapeutic interventions for management of chronic pain related to childbirth.
- Experience of living with chronic pain as well as of health-seeking behaviour among women from different social and cultural backgrounds.
- Knowledge gaps about chronic pain related to childbirth among healthcare professionals.

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