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# Experiences of maternity care: A qualitative study of women with chronic disease

## **Master's Thesis**

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## Forord

Dette kandidatspeciale afslutter mit studie på den sundhedsfaglige kandidatuddannelse på Københavns Universitet. Kandidatspecialet er udarbejdet på engelsk som en videnskabelig artikel og er for læsevenlighedens skyld opsat i spalter med figurer og tabeller placeret i teksten. Efter specialeforsvar og endelig godkendelse fra artiklens medforfattere er det hensigten, at artikelmanuskriptet indsendes til det videnskabelige tidsskrift *Women and Birth* med håb om publicering. *Women and Birth* udgives af forlaget Elsevier og er det officielle tidsskrift fra *The Australian College of Midwives*. Tidsskriftet publicerer videnskabelige artikler omhandlende alle aspekter inden for feltet kvinder og fødsler, fra prækonceptionel rådgivning, over graviditet, fødsel og barselsperiode, neonatal sundhed, familiedannelse, amning m.v. Tidsskriftets *Impact Factor* er angivet til 2,079 (2018).

Tilgængeligt som bilag er en kort beskrivelse af den indledende litteratursøgning, som blev udført, inden arbejdet med studiet påbegyndtes. Videre *Author Information Pack* fra *Women and Birth*, som giver indblik i de formelle retningslinjer artikelmanuskriptet er udarbejdet efter, samt *Standards for Reporting Qualitative Research (SRQR)*, som kræves indsendt med artikelmanuskriptet. Endelig medforfattererklæringer fra hver af artiklens øvrige forfattere.

Kandidatspecialet er udarbejdet på Københavns Universitetshospital Rigshospitalet i Forskningsenheden Kvinder og Børns Sundhed under Juliane Marie Centret.

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# Abstract

## Background

Women living with chronic disease face several possible health risks during and following pregnancy. Previous qualitative studies have implied that these women experience difficulties when interacting with healthcare professionals during pregnancy. However, there is a lack of understanding of women's experiences of maternity care.

## Aim

To explore how women living with chronic disease experience maternity care.

## Methods

A qualitative interview study with thematic analysis. Fourteen women with different chronic diseases who were referred to specialist care during pregnancy were interviewed face-to-face or by telephone during pregnancy or in the months following childbirth.

## Findings

Three overarching themes emerged from the analysis: *Chronic disease as determining pregnancy care*, *Childbearing woman as messenger and interpreter* and *Feelings of abandonment after the birth*. Women experienced maternity care as a monitoring process, while not being guided. Maternity care was characterized by risks and fragmentation, and a feeling of unpreparedness for significant events related to the chronic disease after the birth.

## Discussion and conclusion

Women living with chronic disease do appreciate the attention they receive from midwives and doctors during pregnancy. However, a primary focus on the potential health risks at the expense of uncomplicated aspects of pregnancy can result in feelings of confusion, insecurity and concern. Professionals ought to acknowledge that women living with chronic disease experience maternity care as confusing and should help them navigate the healthcare system and interpret complex information. Women express a need for continuity in care during pregnancy and after the birth, which could be prioritized in maternity care.

## Keywords

Pregnancy, chronic disease, prenatal care, experience, midwifery, qualitative research.

# Resumé

## Baggrund

For kvinder der lever med en kronisk sygdom, er der risiko for adskillige helbreds- og graviditetskomplikationer i løbet af og efter en graviditet. Tidligere studier har antydnet, at disse kvinder oplever vanskeligheder i mødet med sundhedsprofessionelle i løbet af graviditeten. Der eksisterer dog ingen sikker forståelse af kvinders oplevelser med svangreomsorgen.

## Formål

At undersøge hvorledes kvinder, der lever med kronisk sygdom, oplever svangreomsorgen.

## Metode

Et kvalitativt interviewstudie med tematisk analyse. Fjorten kvinder med forskellige kroniske sygdomme, som var henvist til svangrekontroller hos obstetrisk speciallæge, medvirkede i et interview, ansigt til ansigt eller på telefon i løbet af graviditeten eller i månederne efter fødslen.

## Resultater

Gennem analysen identificeres tre overordnede temaer; *Den kroniske sygdom determinerer svangreomsorgen, den gravide kvinde som budbringer og fortolker, samt følelser af forladthed efter fødslen*. Kvinderne oplevede svangreomsorgen som et forløb hvor de blev monitoreret, men ikke vejledt. Svangreomsorgen var videre karakteriseret af en opdeling i flere forløb, og kvinderne savnede hjælp til at fortolke lægefaglige informationer, ligesom de oplevede at være uforberedt på forløbet af den kroniske sygdom efter fødslen.

## Diskussion og konklusion

Kvinder der lever med kronisk sygdom, er taknemmelige for ekstra graviditetskontroller. Dog kan et primært fokus på potentielle risici på bekostning af ukomplicerede aspekter af graviditeten føre til, at kvinder oplever forvirring, usikkerhed og bekymringer. Sundhedsprofessionelle bør anerkende, at kvinder der lever med kronisk sygdom, oplever svangreomsorgen som forvirrende, og bør hjælpe kvinderne med at navigere i sundhedssystemet og fortolke komplekse informationer. Kvinder udtrykker et behov for kontinuitet under graviditeten og efter fødslen, hvilket med fordel kunne prioriteres i svangreomsorgen til kvinder, der lever med kronisk sygdom.

## Nøgleord

Graviditet, kronisk sygdom, svangreomsorg, oplevelse, jordemoderkundskab, kvalitativ forskning

# Experiences of maternity care: A qualitative study of women with chronic disease

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## Statement of significance

### Problem or issue

Knowledge about the experience of maternity care from the perspectives of women living with different chronic diseases is limited.

### What is already known

Women living with chronic disease have an increased risk of complications during pregnancy and childbirth. Previous qualitative studies have implied that women living with chronic disease experience unmet care needs during pregnancy.

### What this paper adds

In-depth understanding of how women living with chronic disease experience maternity care. Despite different chronic diseases, women share similar experiences of maternity care where professionals focus primarily on risks, resulting in feelings of confusion, insecurity and concern.

## 1. Introduction

The number of people living with a chronic disease is increasing worldwide <sup>(1)</sup>. Chronic diseases are diseases of long duration and often require ongoing management and treatment. In Denmark, approximately 30% of all adults are living with one or more chronic diseases <sup>(2,3)</sup>. Due to primarily improved diagnosis, treatment and management of chronic disease, the proportion of women in their childbearing years living with a chronic disease is increasing as well <sup>(3-5)</sup>. In Denmark, the number of childbearing women living with a chronic disease has increased from four to 16% over the past three decades <sup>(3)</sup>.

Women living with chronic disease have an increased risk of obstetric complications in pregnancy, e.g. spontaneous abortion, preeclampsia, gestational diabetes, and preterm labor, as well as complications during childbirth, e.g. caesarian section, when compared to women without a chronic disease <sup>(6-8)</sup>. Several chronic diseases can be affected negatively during pregnancy, while other conditions more often will be in remission in the pregnancy period. Equally, for some diseases there is an increased risk of flare-ups in the postpartum period, while not for other diseases <sup>(6,9)</sup>. Children of women with specific chronic diseases are more often born with low birthweight <sup>(5,7-10)</sup>. Furthermore, it is known that women living with epilepsy or other chronic diseases are more likely to experience depression and/or anxiety during pregnancy and in the postpartum period <sup>(11)</sup>.

Qualitative research regarding pregnancy and chronic disease have focused primarily on the experiences of

childbearing women or new mothers with specific diagnoses, e.g. epilepsy <sup>(12)</sup>, multiple sclerosis <sup>(13,14)</sup> or diabetes <sup>(15)</sup>. Only few studies have explored the lived experience of pregnancy or the postpartum period of women with various chronic diseases <sup>(16-18)</sup>. Despite these studies having explored different experiences of e.g. pregnancy or management of the chronic disease, the findings suggest that women although not suffering from the same chronic disease experience several identical concerns regarding the interaction between pregnancy, the chronic disease, the woman's own health, and the unborn child <sup>(16-18)</sup>. Furthermore, previous qualitative studies indicate that women experience difficulty with obtaining reliable information regarding their specific condition in relation to pregnancy, and childbirth and that the interaction with healthcare professionals is often a complex process which doesn't always meet the needs of the women <sup>(12-20)</sup>. However, none of the above studies have focused specifically on the experience of maternity care from the perspective of women living with chronic disease, and although the findings briefly concern women's experiences of interaction with healthcare professionals, they do not offer understanding of the reasoning behind the described experience.

In 2018 a large randomized controlled trial was initiated at Copenhagen University Hospital, Rigshospitalet (CUH), aiming to improve maternity care provided to women living with chronic disease <sup>(21)</sup>. While developing the intervention for this study, a search of the qualitative literature concerning pregnancy and chronic disease was performed in the scientific databases PubMed, CINAHL



and PsycINFO. This revealed a gap in knowledge regarding how pregnant women living with chronic disease experience maternity care. In order to refine the planned intervention <sup>(22)</sup>, and especially to gain a deeper knowledge of how women living with chronic disease experience the care they receive from healthcare professionals during pregnancy and after the birth we chose to conduct a qualitative study. Therefore, the aim of this study was to explore how childbearing women living with chronic disease experience maternity care.

## 2. Methods

### 2.1 Study design

We performed a qualitative study, with researcher triangulation and thematic analysis <sup>(23)</sup> of individual, semi-structured interviews to elucidate how women living with different chronic diseases experience maternity care. Individual interviews were preferred in order to make sure that participants could speak freely about their individual experiences, including potentially sensitive topics <sup>(24)</sup>. Furthermore, the practical circumstances of making appointments with mothers and their newborn babies made individual interviews the most pragmatic choice.

### 2.2 Description of current maternity care in Denmark

In Denmark, maternity care is free and universal. Maternity care is performed by both midwives and general practitioners at different stages throughout the pregnancy and almost all pregnant women receive midwifery care at a hospital. If the pregnancy is complicated, e.g. if the woman has a pre-existing chronic disease, the woman will be offered referral to an obstetrician at the hospital who will evaluate the need for further examinations. For a number of less frequent medical conditions, the care for pregnant women is centralized in larger, more specialized tertiary hospitals. Most women with pre-existing chronic diseases will also be in contact with a medical specialist within that specific field at a hospital <sup>(25)</sup>.

### 2.3 Setting and participants

The current study was carried out at CUH which serves as a tertiary referral center for women with serious heart, kidney, immune or bowel disease, other chronic diseases, and women with diabetes who require insulin treatment. CUH was selected to ensure that we were able to invite women with various chronic diseases to participate. Three clinics were involved; the midwifery outpatient clinic, the obstetric outpatient clinic and the antenatal inpatient clinic. This allowed us to identify women with experiences from different elements of maternity care. The different clinics also made us able to identify women who were

affected in various ways by the chronic disease during pregnancy, e.g. admitted due to complications or primarily receiving midwifery outpatient care.

To ensure rich descriptions of the experience of maternity care across chronic diseases, we employed a criterion based, purposeful sampling strategy guided by the principle of maximum variation <sup>(26)</sup>. Eligible participants were English or Danish speaking women diagnosed with a chronic disease at least six months prior to pregnancy who had been referred to specialist care during pregnancy. Prespecified criteria were imposed to achieve variation in chronic disease type, duration and severity, as well as parity.

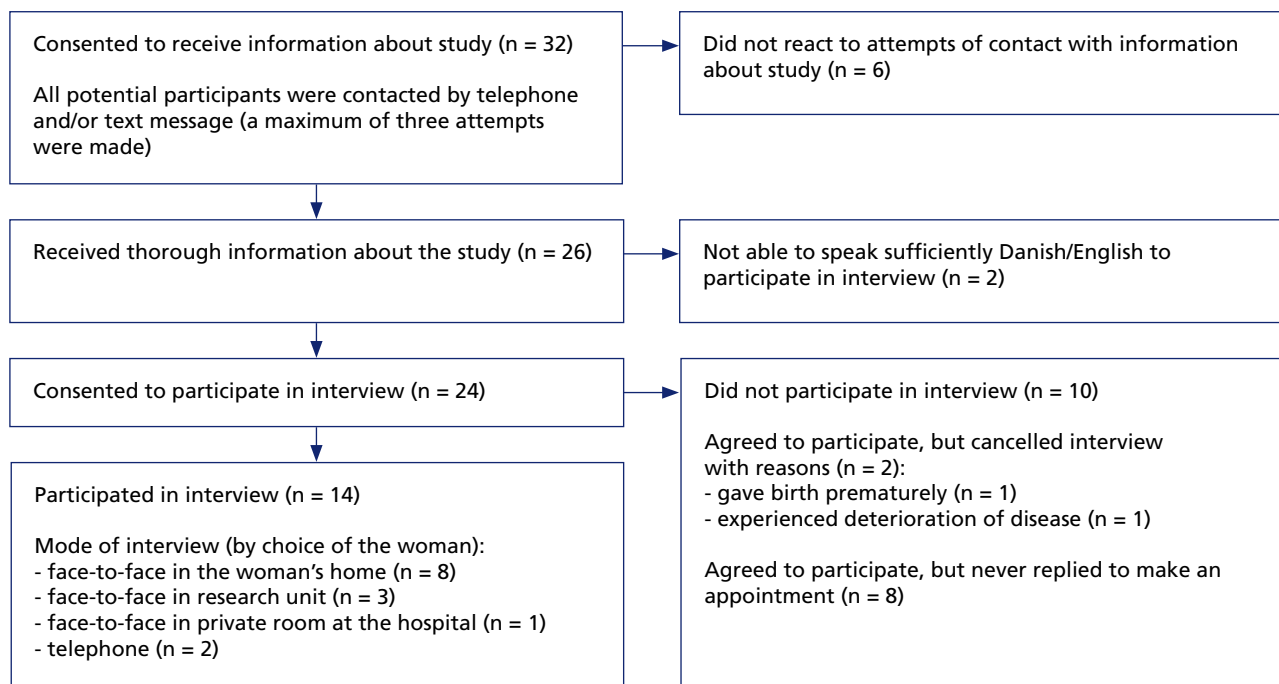
Women who fulfilled the eligibility criteria were initially identified and informed briefly about the study by midwives and obstetricians. Women who consented to further information about the study were contacted by telephone by MKH and received thorough information and the possibility of asking questions before consenting to participate in an interview (Figure 1). In total, fourteen women were included in the study, and recruitment of participants continued until we achieved satisfactory variation and information-richness according to the predefined sampling criteria <sup>(26)</sup>.

### 2.4 Data collection and analysis

Data was collected through individual, semi-structured interviews <sup>(24)</sup>. An interview-guide was developed before the initiation of the study, based on existing literature. It consisted of open-ended questions and was adjusted when new topics emerged. Information about the aim of the study was repeated prior to beginning the interview. The opening question encouraged the woman to recall if she had any special considerations when or before she decided to get pregnant. Subsequent questions concerned the experience of interaction with the healthcare providers she met during pregnancy (Table 1). All interviews (n = 14) were conducted by MKH or MdW between January 2018 and June 2019 and lasted between 28 and 75 minutes (mean: 43 minutes). Every woman was able to choose whether the interview took place face-to-face (n = 12) or over the phone (n = 2) (Figure 1). The women were interviewed during pregnancy in the late third trimester (n=2, > 35 weeks of pregnancy) or after the birth (n=12, 2-10 months after birth) to secure equally rich descriptions of both pregnancy and the post-partum period.

The interviewers MKH and MdW are both midwives with extensive clinical experience in supporting women in pregnancy and during childbirth. Both have experience with antenatal inpatient care for women with complicated pregnancies but had no professional relationship with any of the participating women other

**Figure 1**  
Flowchart of inclusion



than that of researcher. After each interview immediate reflections were noted down, and an open dialogue was sought between MKH and MdW in order to investigate initial assumptions regarding the interviews. This process allowed each interview to be evaluated and challenged any preunderstandings on the part of the researchers <sup>(27)</sup>.

Interviews were digitally audio recorded with the consent of the participants and subsequently transcribed verbatim by MKH and a study secretary. Data was organized and coded using NVivo version 12. Transcripts were analyzed using thematic analyses as described by Braun & Clarke (2006), since this method of analysis has been found to be particularly useful when searching for patterns across qualitative data <sup>(23)</sup>. Initially the transcribed interviews were read, reread and checked against audio-recordings for

accuracy. In this phase, preliminary codes were identified at an inductive data-driven level and was then used in the first process of coding, were meaningful units were identified and organized. The next phase consisted of searching for potential themes by sorting and organizing codes before the final themes were reviewed and refined <sup>(23)</sup>. Throughout the analysis, there was an ongoing iterative process of decontextualizing and recontextualizing, going back and forth between the interview data and the emerging themes to ensure that codes and themes were derived from the original transcripts in order to secure trustworthiness <sup>(27)</sup>. After analysis of the first 10 interviews both the sample and the emerging themes were reviewed. This process revealed which specific characteristics we should prioritize in the final inclusion of participants and the analysis and inclusion continued until the analysis showed sufficient

**Table 1**  
Sample questions from interview-guide

Topic	Question
Questions regarding time before pregnancy	Did your chronic disease affect your planning of pregnancy? If yes; how?
Questions regarding pregnancy	How was your experience of meeting with healthcare professionals (midwives, doctors, others) at consultations during pregnancy? Did you receive consistent information from different healthcare professionals? Did you have any specific concerns during your pregnancy?
Questions regarding postpartum period	How were the first days/weeks at home as a new family? Did you have any challenges with your chronic disease in the time following birth?

information-richness of the identified themes. Throughout the process of analysis an 'audit trail' with documentation of the researchers reflections was kept in NVivo to enhance confirmability, as well as frequent discussions with supervisors helped to avoid researcher induced bias (27,28).

## 2.5 Ethics

According to Danish law no ethical approval is required to perform qualitative research (29). Participants gave written informed consent and were carefully informed that participation was voluntary, and that consent could be withdrawn at any point during the study. All names are pseudonyms to ensure the anonymity of the participants. The study was approved by the Danish Data Protection Agency (JN RH-2017-346, I-Suite 06055) as part of a larger research project at CUH (21).

## 3. Findings

Fourteen women with a total of 18 different chronic diseases were included. The women were 26-40 years of age, and the median time since diagnosis was 10.6 years (range: 1-29 years). For ten of the women it was their first pregnancy, whereas four women had given birth before. Six women had more than one chronic disease and all participating women were referred to specialist care during pregnancy due to their primary chronic disease. The majority of women received care from more than one hospital and from multiple caregivers, including medical doctors, midwives, obstetricians, ultrasound specialists and nurses. Self-reported characteristics of the participating women are presented in Table 2.

### 3.1 Themes

Three overarching themes were identified from the analysis: *Chronic disease as determining pregnancy care*, *Childbearing woman as messenger and interpreter* and *Feelings of abandonment after the birth*. These themes and associated subthemes synthesized the women's experiences with maternity care (Table 3).

#### Chronic disease as determining pregnancy care

Women described how the chronic disease had a decisive role regarding pregnancy and childbirth. Most women had been informed since their early teenage years that it was essential to plan a future pregnancy in collaboration with the medical specialist due to the risk of pregnancy complications and the possible deterioration of the chronic disease. Several women had considered the potential health risks of pregnancy in relation to chronic disease before they decided to attempt getting pregnant. The women explained how especially the beginning of the pregnancy

**Table 2**  
Characteristics of participants

Self-reported characteristics	n (%)
Age (years, mean/range)	29.5 (26-40)
<b>Chronic disease<sup>a</sup></b>	<b>18</b>
Endocrinological or hematologic disease ( <i>graves' disease, diabetes mellitus, hypothyroidism, antiphospholipid syndrome</i> )	5
Circulatory or respiratory disease ( <i>pacemaker, hypertension, asthma</i> )	5
Neurological disease ( <i>multiple sclerosis, epilepsy, myasthenia gravis</i> )	4
Congenital malformation ( <i>congenital heart malformation, marfan syndrome</i> )	2
Disease affecting skin or connective tissue ( <i>systemic lupus erythematosus, psoriasis, psoriatic arthritis</i> )	2
Bowel or urogenital disease ( <i>ulcerative colitis, glomerulonephritis, kidney transplant</i> )	2
Multimorbidity	6 (43)
<b>Time since diagnosis (years, mean/range)</b>	<b>10.6 (1-29)</b>
<b>Ethnicity</b>	
Danish ethnic origin	13 (93)
Other ethnic origin	1 (7)
<b>Educational level</b>	
Low	0 (0)
Medium	1 (7)
High	13 (93)
<b>Parity</b>	
1st child	10 (71)
2nd child	3 (21)
3rd child	1 (7)
<b>Marital status</b>	
Married/living with partner	13 (93)
Single	1 (7)
<b>Employment status</b>	
Employed	10 (71)
Unemployed	3 (21)
Student	1 (7)
<b>Time of interview</b>	
Third trimester	2 (14)
Postpartum	12 (86)

<sup>a</sup> Several women had more than one diagnosis

was characterized by feelings of reservation; it was difficult to believe that complications would not occur. Without exception, the women described that pregnancy was characterized by a continuous one-sided focus on risk from healthcare professionals which often influenced the women's experiences and contributed to concerns and anxiousness.

*'(...) I thought a lot about the risk of having an attack during the pregnancy and after the pregnancy, because I have talked to quite a lot of doctors at the sclerosis clinic (...)' (Alma, multiple sclerosis/asthma).*

Table 3 Overview of subthemes and overarching themes	
Subthemes	Overarching themes
Continuous awareness of risk Worrying and insecurity is not relieved by frequent visits Diminished choices regarding pregnancy	<i>Chronic disease as determining pregnancy care</i>
Fragmentation of care Receiving abundant unfiltered information Feeling obliged to assume responsibility Only of importance as carrier of the child Normality, recognition and continuity	<i>Childbearing woman as messenger and interpreter</i>
Unprepared of chronic disease events postpartum Discontinued observation No recognition of reproductive stories Support from family and friends	<i>Feelings of abandonment after the birth</i>

The women described a profound awareness of the complexity regarding chronic disease and pregnancy, and many described experiencing, in consultation with doctors and midwives, that the chronic disease was of superior significance to the pregnancy. The women felt that their autonomy was restricted because of the chronic disease and that they did not have the options that pregnant women without a chronic disease would have.

*'And then I'm asking, you know, I'm just asking, well, what consequences does this have, could I, I hadn't had time to consider it yet, but would I, could I have the option of considering a homebirth? And they tell me then, that I don't have that [possibility]'* (Nora, congenital heart malformation).

When asked about the experiences of maternity care in early pregnancy, several women spontaneously mentioned the referral to specialist care. Women experienced this referral as a requirement, not a suggestion or choice, and for some of the women this came as an unpleasant surprise since the chronic disease was of little significance in their everyday life. The women explained how they were told that the many prenatal visits and the additional visits with the medical specialists were necessary in order to ensure that the pregnancy progressed as it should. As such, most women were grateful for the extra attention and visits, but they also described feelings of great ambivalence because the frequent visits often resulted in new worries and insecurity.

*'And those check-ups, they are a mixed blessing. Because it is fantastic that you are being followed so closely. We were really looked after, you could say that the obstetricians cared for her and the nephrologists cared for me, for my kidney, and that is good. But you are also in some kind of constant state of alert regarding what might come up the next time.'* (Sofia, glomerulonephritis/ kidney transplant).

A minority of women expressed being especially grateful for the additional specialist care. These women were in general mildly affected by their chronic disease but were aware of the potential worsening of the disease during pregnancy and had initially feared that they would not have been offered specialist care which would have left them feeling unsafe.

#### Childbearing woman as messenger and interpreter

Women explained that the maternity care and the ongoing chronic disease management was an experience characterized by a profound fragmentation and that the received care was experienced as several distinct processes which could cause confusion.

*'I still hold the opinion that within the healthcare system, we take care of our respective areas. So, neurology is one thing, obstetrics is one thing, and the midwife is one thing. And that can be difficult. That the neurologist says: That's not my area. The obstetrician says: Yes, well that's the medicine, the neurologists will take care of that.'* (Ellie, epilepsy).

The experience of fragmentation also existed in relation to distinct areas of maternity care, e.g. midwifery care, in that some women described repeatedly meeting a new midwife at consultations. Women who had given birth before expressed how they had anticipated this fragmentation since it was experienced in their previous pregnancy, but also described how it was still difficult to understand and navigate the healthcare system.

The women described how they were presented with small pieces of specialized knowledge regarding defined aspects of pregnancy, chronic disease or the health of their unborn child from different healthcare professionals. Often, the women experienced doctors or midwives who did not explain these fragments of information. This made some women come to their own interpretation of the clinical

information, leaving them feeling worried and insecure. Furthermore, some women described how the lack of assistance in the interpretation of clinical information resulted in misunderstandings of the actual information regarding recommendations or treatment.

*'That was what we were told, that some of the bacteria could make [the baby] really ill. That was why they considered whether or not I could give birth naturally. And then, it was after I told them to call each other, we learned that no, nothing would happen to [the baby] if I got a tear' (Isabella, pacemaker/ulcerative colitis).*

Although the women talked about how they had received thorough information about possible risks regarding pregnancy, they described feeling unprepared when actual complications occurred, and some women explained how they had received conflicting information before and during pregnancy regarding the same topic adding to this feeling.

*'I sat there, with the cardiologist and I started crying, because it was so overwhelming, that everything I have taken for granted and talked about with my specialist for many years, that it all of a sudden wasn't true anyway. It was like having the carpet pulled out from under me, completely, and my husband was also very confused because, because it was really radically overwhelming' (Agnes, Marfan syndrome).*

Especially in cases where several hospitals and professionals were involved in care, women experienced receiving conflicting information from multiple specialists. Some women experienced that departments or professionals recommended different treatment options, however without explaining these properly, leaving the women feeling responsible of making choices alone, basing it on insufficient information. The women experienced insecurity and confusion regarding who was responsible for their care and several women explained that they felt obliged to act as messenger, being responsible for transfer of information from one hospital, doctor, or midwife to another.

*'It's more because, everything that went on at [local hospital] didn't reach Rigshospitalet and all that communication had to go through me. And I even had to call everyone ... It was just a mess' (Isabella, pacemaker/ulcerative colitis).*

Furthermore, women experienced that even though specific care plans were arranged during pregnancy, they felt that it was their and/or their partner's responsibility to remind the staff of these decisions.

*'By the way it was my, and I don't know if it's because they're always so busy they don't read the files before they see you at the delivery ward, but it was my impression, that many of these things, I had to tell them myself or remind them' (Laura, hypertension).*

A minority of women experienced that healthcare professionals were only interested in the chronic disease (e.g. blood samples or test results) and not in the woman and her feelings and concerns. If observation of the unborn child due to complications was necessary, e.g. because of hearth malformations, women explained how it was their impression that they were only of importance as the carrier of the child. Others described how sensitive procedures, e.g. a placental biopsy, were being performed without addressing the concern and anxiousness of the woman.

*'And on the day of the procedure [placental biopsy], we just came into a room and then, up on the screen, 'is there a heartbeat, yes, then we insert the needle', and it was just out of the door again' (Agnes, Marfan syndrome).*

Several women had expected to receive excellent care at the highly specialized hospital, but their expectations were not always fulfilled.

*'Yes, but she is a specialist in multiple sclerosis, but that is also why she has all the expert knowledge in pregnancy and she is the one, if an article is written on multiple sclerosis and pregnancy, then she is the one you refer to, and she is the one doing research projects about it and things, so how in the world could I get an appointment with another doctor? Don't ask me. It was a specialist in multiple sclerosis, but it wasn't someone who knew anything about pregnancy, and what about medication? And what about breastfeeding? And what affects the fetus? And you have a lot of questions, and she couldn't answer any of them' (Ella, multiple sclerosis/ hypothyroidism).*

Women were equally disappointed with the midwifery visits during pregnancy, not fulfilling their expectations about a special, intimate relationship. Several women viewed midwifery appointments as being insufficient or superficial.

*'(...) I think it's nice to be at the midwife appointment, but my concerns just exceeded the standard like: feeling how the baby is positioned and listening to the heartbeat. So, it was more like a symbolic visit, I think' (Clara, antiphospholipid syndrome).*

However, some women also described positive experiences with maternity care and explained how recognition of individual needs was essential to these experiences. Several

women described how healthcare professionals who showed genuine interest in their life situation could relieve some of the continuous worry that characterized pregnancy. The women spontaneously emphasized the strong importance of repeatedly meeting the same doctor or midwife as fundamental to facilitate trust and allowing the women to speak about their worries and challenges during pregnancy.

*'It really was a good thing that they took care of me through the whole process, because it made me extra committed regarding [regulating the diabetes], they were really good, they weren't judging me in any way, but was like, they just helped me a lot and supported me, and instead of reproaching me, they gave me a bunch of different strategies to solve the thing with my blood sugar which fluctuated a lot' (Olivia, diabetes mellitus).*

The women further described how it could be challenging to maintain focus on the aspects of pregnancy which developed uncomplicatedly and how especially midwives had the capability of emphasizing this. Women who experienced that professionals paid attention to these aspects of pregnancy, e.g. fetal movements and thoughts about becoming a mother, expressed that this focus could help them stay confident about the pregnancy.

#### Feelings of abandonment after the birth

The women described how they felt unprepared and uninformed about what to expect in the postpartum period regarding the chronic disease, explaining how information about the postpartum period was not prioritized by healthcare professionals. For women who experienced chronic disease remission during pregnancy, it was overwhelming to experience unexpected exacerbation in symptoms from their chronic disease in the postpartum period.

*'Well, as I was there already then... they could perhaps have... also prepared me a little to how I would feel afterwards [concerning the chronic illness], like I said, they could have done that earlier as well...' (Victoria, myasthenia gravis).*

For a minority of women, the unexpected recurrence of symptoms and progression in the chronic disease after the birth compelled them to stop breastfeeding earlier than planned, which resulted in feelings of sadness and frustration.

*'No, because it [the medicine] goes through the breast, so they don't do that [recommend breastfeeding]. Otherwise they have to find another medicine for me, but they couldn't do that either because I have arthritis as well and I need strong medicine that relieves both. And that was*

*really tough, because my entire pregnancy I have thought that I wanted to breastfeed, that was it, and I prepared and everything. So, when I suddenly discovered that I couldn't breastfeed I was very upset about that' (Anna, psoriasis/psoriatic arthritis/diabetes mellitus).*

The women further described how they had anticipated that nurses and midwives would help them with breastfeeding, but that this was not fulfilled.

In the first days following the birth, several women described how they felt unwanted in the postnatal ward, feeling that they were just taking up a bed, which was a stark contrast to the frequent check-ups during pregnancy.

*'(...) I actually felt, because we had to stay there for three days, I felt in the end, because we were feeling so well, I felt as if we were taking up space in there. Like "you are so healthy, why are you even here"' (Victoria, myasthenia gravis).*

After discharge from the hospital, women described having difficulties with the transition of chronic disease management over to the general practitioner or the medical specialist at the hospital. Women who met with their medical specialist in the months after the birth were surprised that there was no interest in their experiences with pregnancy and childbirth, but only in the chronic disease, which left the women feeling insignificant. Some women were offered postpartum consultations with an obstetrician or midwife with the purpose of summing up their experiences with pregnancy and childbirth. These women described that during this consultation there was no room for their experiences, that conversations were dominated by the knowledge and opinions of healthcare professionals. They described feeling misunderstood and betrayed after the meetings.

*'Then he asked if I intended to have more children, because even if I breastfed, I could become pregnant. And then I said, well I'm not planning for that [a new pregnancy] and there's not really, there's not a great probability I'm going to get pregnant unintended while being admitted to the neonatal intensive care unit, it's not like you have that much privacy here. And then he said, 'well, you are probably going home soon' and that was it' (Emma, asthma/graves' disease).*

One woman had a contrasting experience and described how the postpartum consultation with a midwife was of significant value to both her and her partner since they were allowed to tell their stories about a complicated pregnancy and birth and how their stories were acknowledged.

Interaction with other women and the possibility to exchange experiences and narratives were also important to the women and some mentioned that participation in mother's groups after the birth had relieved them of the feelings of loneliness.

*'Well, when I started in the mother's group, the others hadn't had complicated pregnancies, but just to have someone to talk to, that had been in the same situation was just such a giant relief' (Clara, antiphospholipid syndrome).*

Also, a supportive partner could help women resist the challenges they faced during pregnancy and after the birth. However, several women explained that they wished for access to peer-support so they would be able to have their own experiences reflected.

#### 4. Discussion

The aim of this study was to describe how women living with chronic disease experience maternity care. To our knowledge, this is the first paper that has specifically explored the maternity care experiences of women living with different chronic diseases. The findings from this study suggest that women living with chronic disease experience maternity care as primarily focused on the chronic disease and the medical aspects of pregnancy at the expense of the uncomplicated aspects of pregnancy. Within this medicalized focus, the women experienced intensive attention from healthcare professionals which was appreciated, but the concomitant lack of guidance and help to understand and interpret complex medical information left the women feeling insecure, confused and worried. Interestingly, we did not identify any differences in the experiences of maternity care specifically connected to the different chronic diseases.

The women described how the chronic disease came to determine pregnancy care which was characterized by an ongoing awareness of risk and frequent visits with doctors and midwives. This is in accordance with findings from other qualitative studies investigating women's lived experience of pregnancy with chronic disease <sup>(16,18,20)</sup>. Thomas (2003) identified, that women living with chronic disease had been aware of the possible risks of pregnancy for years before actually getting pregnant and that the chronic disease was of superior significance to professionals during pregnancy <sup>(20)</sup>. Furthermore, the experience that the frequent visits with midwives and doctors added to the worrying and the feeling of pregnancy being high-risk

has been identified in previous studies <sup>(16,18,20)</sup>. Tyer-Viola & Lopez (2014) found that women living with chronic disease receive an overflow of information about possible risks and describe how women were constantly aware of the reality of the chronic disease and the complications that could occur during pregnancy <sup>(16)</sup>. As in this study, these possible risks were, according to the women, often stated by staff, and the women had the experience that it was unlikely that the pregnancy would develop without complications <sup>(16)</sup>. Corbin (1987) identified in a qualitative exploration of women's definition and subsequent management of risk levels in pregnancy affected by chronic disease, that frequent prenatal visits and the ongoing information from professionals about possible risks resulted in the perception that the pregnancy was high-risk <sup>(18)</sup>. Women in the present study described that they were grateful for the extra care but also experienced great ambivalence, since it emphasized that the pregnancy was not entirely a joyful event. Weckesser & Denny (2017) have explored how pregnancy an early motherhood could 'rework' the biographies of women living with epilepsy, by employing the concept of *biographical disruption* to the analysis of the women's narratives <sup>(19)</sup>. Biographical disruption, in the authors' interpretation, concerns the process by which chronic disease interferes with everyday life. For some women *'pregnancy and early motherhood were points in their lives at which epilepsy, which may have previously been taken for granted and normalized, came to be problematized'* <sup>(19)</sup>. The women in our study described similar feelings of the chronic disease being of particular importance during pregnancy, overshadowing the importance of the pregnancy and the transition to motherhood.

Another significant finding from the present study was the women's perception of it being their responsibility to act as messenger and interpreter of the complex information they received from multiple caregivers, experiences that has not been identified previously. A review of the experiences of pregnancy and reproductive health among women living with epilepsy showed that women experienced conflicting information regarding pregnancy from their medical specialist and the general practitioner, and that communication between these healthcare professionals was often quite poor <sup>(12)</sup>. Furthermore, women living with multiple sclerosis have described how they received conflicting advice from professionals and insufficient information regarding multiple sclerosis and childbearing <sup>(13)</sup>. The experiences of being presented with conflicting information from several healthcare professionals was recognized by the women in our study. However, the women further described how they perceived it their obligation to act as messenger, i.e. transfer information

between professionals, and that lack of explanation and help to integrate the complex information in the women's individual situations often resulted in insecurity, confusion and worry. These findings offer insight into the potential consequences of the experience of fragmented care. During the past decades, a patient-centered approach has been recognized as central for high quality healthcare<sup>(30,31)</sup>. In a recent review of the literature regarding patient-centeredness, Langberg et al. (2019) suggests that patient-centeredness could be described by three core elements; *the patient, the doctor-patient relationship* and *the coherence of treatment in the healthcare system*<sup>(30)</sup>. Women in our study expressed that the recognition of their individual stories and perspectives and a trusting relationship with a known healthcare professional were key in sharing their numerous concerns with professionals. These aspects relate to the first two elements of patient-centeredness, where it is recommended that the patient's experiences of the disease and how it influences the patient's life situation are considered in care, and that the healthcare professional is responsible for developing a trusting relationship between patient and professional<sup>(30)</sup>. The third element concerns the coordination of care, which women in our study described as inadequate and sometimes entirely lacking. Langberg et al. emphasizes that in order to apply patient-centeredness in healthcare, the patient's treatment in the extended healthcare system must be coherent and accessible<sup>(30)</sup>, conditions which were not necessarily fulfilled according to the women in our study.

In the postpartum period, the women described how they felt abandoned by health care professionals. Thomas (2004) similarly found, in an exploration of women's postnatal experiences following a medically complicated pregnancy, that women felt abandoned by professionals and described, as in our study, that they did not receive help or recognition of their disease in the postnatal ward<sup>(17)</sup>. A recent review of research regarding low risk childbearing women's experiences of maternity care has shown that, among a variety of themes, insufficient emotional support and help with breastfeeding as well as busy staff was a common experience on the postnatal ward<sup>(32)</sup>. This indicates that the feelings of being abandoned after the birth are not restricted to women living with chronic disease, but these women experience the additional aspect of managing their disease as well as their role as a new mother. Some of the women in our study experienced that it became necessary to cease breastfeeding earlier than they had wished due to progression in the chronic disease and a following need for medication. Even though this was not a challenge to all of the participating women, the need for medication is often referred to as a barrier when it comes to breastfeeding, despite the fact that treatment

for most conditions is possible with medications that are considered safe for both the woman and the infant<sup>(33,34)</sup>. Furthermore, a previous study has shown that women sometimes, instead of discontinuing breastfeeding, will discontinue medication, which underlines the importance that women receive sufficient and qualified information regarding breastfeeding and medication, and that the wishes and perceptions of the individual woman is taken into consideration<sup>(35)</sup>.

The women in our study spontaneously mentioned the strong importance of meeting the same midwife or doctor at consultations who could facilitate a trusting relationship between the woman and the professional and help her to open up and speak about concerns and worries. Such circumstances of care have been described in the literature as *continuity of care*<sup>(36)</sup>. In an extensive review of the empirical literature regarding continuity of care, Haggerty et al. (2003) identified three types of continuity; *informational continuity*; the utilization of past events and personal circumstances to secure that current care is appropriate to the individual, *management continuity*; the delivering of healthcare services accommodated to the needs of the individual patient, and *relational continuity*; the ongoing therapeutic relationship between the patient and one or more health care providers<sup>(36)</sup>. In our study, all three types of continuity were, implicit or explicit, requested by the participating women, but in particular the women expressed a need for *relational continuity*, which they described was particularly important for the experience of being recognized as an individual. Results from a recent Australian survey of women's experiences of pregnancy care following a randomized controlled trial of caseload midwifery compared to standard care showed that women allocated to caseload midwifery perceived a higher level of quality of care compared to women allocated to standard care<sup>(37)</sup>. Of specific interest to this study, women with identified risk factors (including chronic medical conditions) reported significantly higher levels of emotional support<sup>(37)</sup>, which again implies that continuity can be an important component in improving maternity care for women living with chronic disease.

This qualitative study has provided insight into the experiences of maternity care from the perspective of women living with chronic disease, but the important question of how we can best organize maternity care to accommodate the special needs of women with chronic diseases remains unanswered. At CUH a randomized controlled trial of the efficacy of a midwife-coordinated, individualized and specialized maternity care intervention is currently undertaken, in which continuity of care and continuation of midwifery care in the postpartum period



are essential components in the intervention <sup>(21)</sup>. The results from this trial will hopefully assist clinicians and researcher with the complex task of improving the quality of care for women with chronic diseases while they are experiencing pregnancy, childbirth and early motherhood.

#### 4.1 Strengths and limitations

The primary strength of this study is the achieved variation regarding the predefined sample criteria. The participating women represented a wide range of chronic diseases, with differentiation regarding chronic disease duration and severity. To some extent, variation was further achieved regarding parity. The sample size of 14 women is considered appropriate since it provided detailed and extensive descriptions of the experience of maternity care <sup>(38)</sup>. To secure reflexivity and trustworthiness in the process of analysis we employed researcher triangulation and the research group comprised of both midwives and a psychologist which helped elucidate any preunderstandings of the field of maternity care <sup>(27)</sup>. Further validation could have been obtained by inviting doctors and childbearing women to participate in conducting the study <sup>(27)</sup>. All members of the research group were involved in the process of analysis and after coding and analyzing 11-12 interviews, no new main themes was identified. Throughout the process of coding and analyses an 'audit trail' documented any progress, thoughts and reflections which increased the confirmability of the findings <sup>(27)</sup>. The extended period of time used for collection of data (almost 18 months) should be mentioned, since it could be considered a limitation due to the possibility of changes over time, e.g. within the healthcare system. However, we have not identified such changes in the period in question and it could be argued that the long period of collecting data allowed for repeated reflections. There were no major variations in the women's experience regarding our predefined sampling criteria. Minor variations were identified regarding the self-rated severity of the chronic disease prior to pregnancy, with women who were not affected by the chronic disease before pregnancy described being surprised with the sudden intense attention during pregnancy and regarding parity, with multiparous women being prepared for the experienced fragmentation of care. However, these circumstances did not influence the overall experience of maternity care, which was uniform to all the participating women. The findings from this study must be interpreted in the light of the Danish health care system and since healthcare including maternity care are free and universal in Denmark, the transferability is limited to settings with socialized medicine.

The sample consisted of primarily well-educated, employed women of Danish ethnic origin, despite great effort to identify and recruit women with social disadvantages,

which is an obvious limitation of the study. The challenges of navigating maternity care with multiple disadvantages, social as well as medical, has earlier been shown to be characterized by confusion, fear and insecurity, themes that were identified in our study as well <sup>(39)</sup>. However, the severity of the described challenges in a study by McLeish & Redshaw (2018) indicate that there exists an additional layer of powerlessness and low self-esteem <sup>(39)</sup>, topics that were not identified in our study. Future research could address the maternity care needs of women living with chronic disease and with non-Danish ethnic origin, low socioeconomic status or other disadvantages to further elucidate the experiences of these women.

#### 4.2 Implications for practice

The findings from this study suggest that midwives and doctors should recognize the importance of pregnancy as a family event and emphasize the aspects of pregnancy that develop uncomplicatedly, even though the childbearing woman is living with a chronic disease. Furthermore, information about the anticipated development of the chronic disease after the birth and concerns regarding breastfeeding could preferably be addressed during pregnancy. Healthcare professionals should notice that the women stated a significant need for continuous support in managing the chronic disease in the postpartum period, and recognition of their childbearing experiences in chronic disease management. Continuity of care was of particular importance to the women and the organization of maternity care could advantageously implement this concept to maternity care delivered to women living with chronic disease, as part of a patient-centered approach.

### 5. Conclusion

Women's experiences of maternity care while living with chronic disease were characterized by feelings of being monitored but not guided by healthcare professionals. While the intensive attention from specialist during pregnancy was generally appreciated, the women described that it resulted in feelings of insecurity, confusion and worry. Midwives and doctors should be aware that women living with chronic disease experience maternity care as challenging and confusing and should help them navigate the healthcare system and interpret the complex information they are obliged to communicate to the women. Furthermore, women express a need for continuous support from healthcare professionals after the birth.

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