From passive passenger to participating co-pilot – Pregnant women's expectations of being able to access their online journal from antenatal care

Charlotte Bergevi[a,*], Lena Lendahls[a,c], Elizabeth Crang-Svalenius[a,b], Marie G. Oscarsson[a]

[a] School of Health and Caring Sciences, Linnaeus University, Sweden
[b] Department for Health Sciences, Lunds University, Sweden
[c] Department of Research and Development, Region Kronoberg, Växjö, Sweden

ABSTRACT

Objective: The aim of the study was to describe pregnant women's expectations of being able to access their electronic health records from antenatal care.
Methods: Nine pregnant women passing 25 full gestational weeks were interviewed individually. Collected data were analysed with an inductive approach using content analysis. The study was performed in antenatal care units in southern Sweden.
Results: The following five categories emerged from the analysis: Being able to achieve increased participation, being able to have more control, being more knowledgeable about the pregnancy, identification of possible risks, and perceptions of one's own well-being can predict usage. The five categories led to one main category: 'Shift in power – from passive passenger to participating co-pilot'.
Conclusion: The pregnant women expected that having access to electronic health records would give them more control, make them more knowledgeable and increase their participation. Access to electronic health records may empower pregnant women and contribute to a more person-centred approach. This could provide greater knowledge for the woman and her partner about her health, thus, allowing them to make evidence-based choices in relation to the newborn baby and the woman's health.

Introduction

The overall goal of Swedish antenatal care, ANC, is to promote good reproductive and sexual health for the entire population. ANCs more specific objectives are to promote physical, mental and social health and prevent illness in pregnant woman, as well as the expected and the newborn baby [1]. Traditionally, midwives have worked using an approach where the woman is in the centre, by meeting her experiences, needs and preferences [2]. Allowing access to electronic health records, EHR, may be one of several measures to strengthen patients' position in healthcare, to achieve a more person-centred approach [3].

According to the Patient Data Act [4] in Sweden, all care and treatment carried out in the Swedish healthcare should be documented in a patient-bound record. The purpose of the patient record is mainly to ensure safe healthcare. Licensed healthcare professionals, such as midwives and physicians have responsibility to write and maintain records. Patients have right to read their journal; thus, it is the caregiver's responsibility to make sure the text is clear and simply written in order for the patient to be able to understand.

The European Commission has set a target for all European citizens to have access to their EHR by 2020 [5]. Since 2012, more and more counties in Sweden offer online access to records kept in healthcare. In Sweden, electronic records can be accessed through "1177 Vårdguiden e-services", and login authentication is required by e-identification. Individuals have the opportunity to block access to their EHR [6]. Sweden's county councils, regions and municipalities have the goal that all Swedish citizens should have access to all their EHR by 2017 [7]. Thus far, access to electronic ANC records is not at all widespread in Sweden; none of the counties offer this opportunity [8].

Few studies have investigated pregnant women's experiences of access to EHR from ANC. Three studies from countries where women have access to their records have been found. An ethnographic study conducted in Denmark by Winthereik [9] showed that women with access to their EHR felt greater responsibility for their own health. A Canadian randomised controlled trial by Shaw et al. [10] demonstrated that there was greater interest in access to personal information in the form of electronic records than general information. Women claimed to have better understanding of their pregnancy and were more involved in decisions regarding their care. An Australian retrospective study demonstrated that women felt that having access to their records was
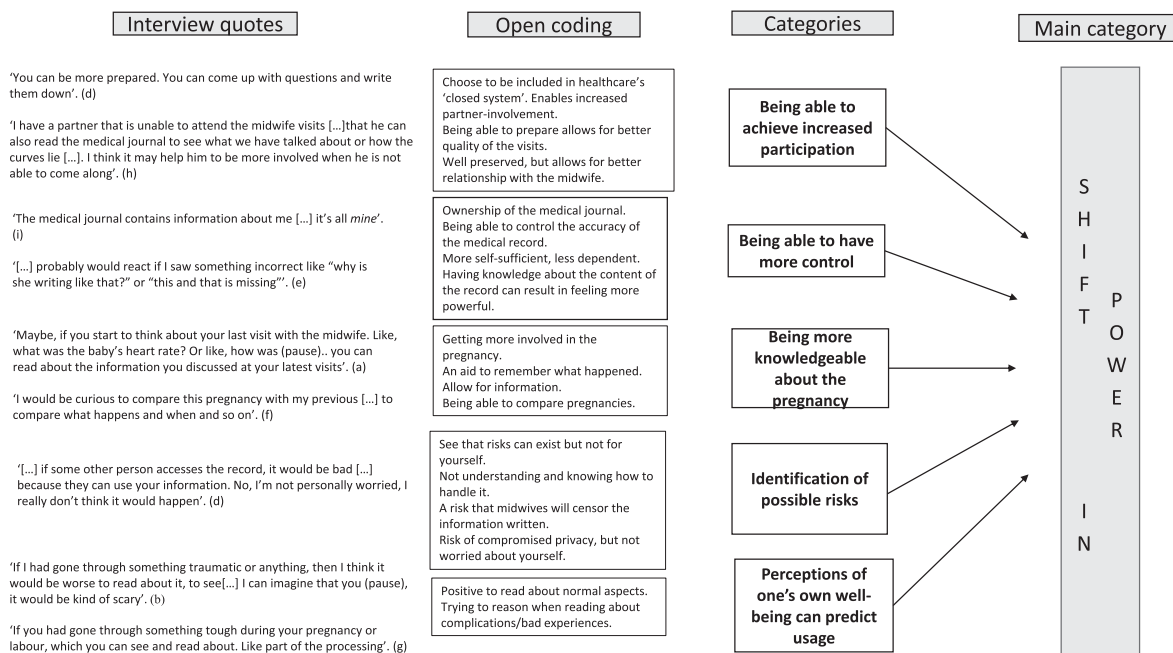

Fig. 1. Example of the procedure in the content analysis.

beneficial as it allowed them to remember what was said during their doctor visits and helped them to be more prepared for further visits [11].

The goal behind implementation of access to EHR has been to allow patients to be more informed and involved. EHR are part of the new healthcare, given the rapidly evolving information technology that is here to stay. Giving online access to records challenges and changes well-established structures and power relations in healthcare. For midwives at ANC, knowledge of women's expectations of access to their EHR will be valuable as they can prepare to meet women's expectations and questions. The aim of this study was to describe pregnant women's expectations of being able to access their EHR from antenatal care.

Methods

Data collection was performed through individual interviews with pregnant women and were analysed using content analysis with inductive approach according to Burnard [12,13].

Setting

In Sweden, midwives at ANC handle the care of women with normal pregnancies. The midwife plans for the medical monitoring, including individually by the parity, taking into account the woman's needs, lifestyle factors and possible risk factors such as chronic illness or complicated obstetrical history. In normal pregnancies, women are usually offered 8–10 visits to the midwife. In case of risks or complications to the mother and child, an obstetrician is consulted [1].

Participants and data collection

The sampling was purposive [14]. Inclusion criteria were women ≥ 25 weeks of gestation, who visited the ANC and mastered the Swedish language. Recruitment was done with help of midwives, in southern Sweden. In conjunction with a regular visit, the woman received oral and written information about the study. Twenty-one women were asked to participate, and 13 women were interested and provided their telephone number. The researchers contacted the women by telephone up to a week after the visit and gave further details. Of the 13 women, four did not participate: two due to the birth of the baby and two did

not respond when they were called.

Data collection took place during ten weeks in the fall of 2016 through individual interviews. The researchers constructed an interview guide after inspiration from previous studies [15,16]. At first, the women were asked background questions such as their age and occupation. Four open-ended questions followed: Tell me what you know about electronic health records? What do you think would be pros/cons of having access to your electronic health records from ANC? How do you think having access to the electronic health records would affect the experience of your pregnancy? Do you think that having access to your electronic health records would affect the relationship with your midwife? If so, how? The focus during the interviews was to encourage the pregnant women to openly share their thoughts as much as possible. The interviewer's task was primarily to guide the conversation to maintain the focus of the subject [14]. A pilot interview was conducted to evaluate the interview guide and resulted in minor changes. The pilot interview was included in the analysis. All interviews took place on location at ANC and were conducted by the first author. Before the interview started, the pregnant women were given an opportunity to ask questions about the study. They were also given time to read the written information and provide written consent. The interviews, which were recorded digitally, lasted between 13 and 23 min. The data were transcribed verbatim and coded.

Analysis

The data were analysed by content analysis with an inductive approach according to Burnard [12,13].

The analysis was performed by the first and second author. The third and fourth authors were also involved as co-readers to validate the analysis and check the categories against the original interview contents. The researchers listened to the recorded interviews to get an overall idea of the content. The transcribed data were read through carefully and repeatedly to get an idea of the whole, and notes were made on codes within the manuscript, i.e. phrases and quotes in the text answering the research question, so called open coding. The list of codes were reviewed and grouped according to their meaning. Categories from the open codes were generated freely with caution that none of the codes should fit in more than just one category and that the categories are clearly distinguished from each other. The list of