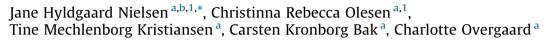
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#### **ORIGINAL RESEARCH – QUALITATIVE**

# Reasons for women's non-participation in follow-up screening after gestational diabetes



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#### ABSTRACT

*Background:* Due to the increased risk of type 2 diabetes, follow-up screening after birth is recommended to women with previous gestational diabetes. Low participation in such screening has been shown to delay detection of diabetes with potentially serious consequences for the women's future health. The women's experiences of treatment and care during their pregnancies may affect participation.

*Aim:* This study aimed at understanding the women's experiences with treatment and care during pregnancy and to understand how these experiences influence participation in follow-up screening.

*Methods*: A qualitative study was undertaken drawing on a phenomenological methodology. Seven women treated for gestational diabetes at a university hospital in the North Denmark Region participated in interviews.

*Findings:* The women experienced lack of continuity in care between hospital departments and health sectors. We identified the following causes for low participation in follow-up screening: poor coordination, little elaboration of information, a lack of clear coordination of responsibility for follow-up screening among health care professionals and absence of focus and inclusion of their individual needs and preferences.

*Conclusion:* The women wished to be reminded of screening to increase their sense of safety. The women's experiences seem to reflect a lack of patient-centeredness during the pregnancy, which may be remedied by increasing the focus on the women's need for improved continuity in treatment and care. Participation in follow-up screening after gestational diabetes may be increased by sending reminders to the women. Raised awareness of the women's individual needs and preferences for treatment and care offers potential for improvement.

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#### 1. Introduction

A comparison of women with gestational diabetes and women with normoglycaemic pregnancies shows that women with previous gestational diabetes have a seven times higher risk of type 2 diabetes.<sup>1,2</sup> Follow-up screening after a pregnancy

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complicated by gestational diabetes is therefore recommended by the National Institute of Clinical Excellence and the Danish Society of Obstetrics and Gynaecology among others due to the increased risk of diabetes.<sup>3,4</sup> Follow-up screening is recommended within three months after birth to be followed by annual or biannual screenings.<sup>3,4</sup> However, low participation rates risk delaying early detection of diabetes and may have serious implications for the women's health.<sup>1,2</sup> International studies show that the level of participation in the recommended follow-up screening after birth is highly different, with participation rates ranging from 61% to 14%.<sup>5–7</sup> In our recent register-based study, we followed a group of 2171 women with pregnancies complicated by first-time gestational diabetes for a period of approximately eight years. We found decreasing participation in follow-up screening

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over time, and that non-attenders were less likely to receive diagnosis and treatment.<sup>8</sup> Our results emphasise the unexploited potential for the prevention of late complications related to nonparticipation in follow-up screening. Women attending a minimum of one follow-up screening have a higher chance of early detection of diabetes (HR 2.7; 95% CI 1.1–5.9).<sup>8</sup> As the prevention or early detection of diabetes is likely to influence women's longterm health status, a better understanding of the causes of the low level of participation in follow-up screening is crucial. Lacking continuity and poor coordination of care among health providers have been suggested as key obstacles to effective communication concerning the importance of follow-up screening.<sup>6,9-11</sup> The patients' involvement in and eventual compliance with treatment is jeopardised by low levels of information in combination with errors and a lack of patient-centeredness,<sup>12,13</sup> which may adversely affect participation in follow-up screening and women's experiences of treatment and care. Despite the free access to public health services in Denmark participation in follow-up screening remains low.<sup>14</sup> The access, availability and affordability to healthcare services for gestational diabetes possibly constitute a bigger barrier in low- and middle-income countries. Even though the generalizability of findings between countries may be hindered by differences in the organisation of healthcare system a general tendency regarding low participation in follow-up screening occurs across countries.<sup>15</sup> In Denmark care of gestational diabetes during pregnancy is handled in the secondary health sector by obstetricians and after birth the care of the women is handed over to general practitioners who are responsible for follow-up screening.<sup>4</sup> In other contexts follow-up screening is handled by obstetricians.<sup>6</sup> This study was undertaken to improve our understanding of how women with gestational diabetes experience the treatment and care offered by a regional health service in Denmark, including obstetricians, midwives and nurses in the secondary health sector and general practitioners in the primary health sector. We also sought to understand how the women's experiences influenced their subsequent participation in follow-up screening.

#### 2. Method

This article is an independent study that reports on the results of our register-based study, which documented a low level of participation in follow-up screening after gestational diabetes in the northern region of Denmark. As our previous study did not allow a deeper understanding of the women's reasons for non-participation, the present study was undertaken to explore their experiences and perceptions of treatment and care during and after a pregnancy complicated by gestational diabetes. As the aim of this study was to understand, explore and describe the women's experiences of treatment and care. A qualitative study was undertaken drawing on a descriptive phenomenological methodology.<sup>16</sup> Seven women agreed to participate in a qualitative interview. The semi-structured interviews had the dual purpose of elucidating the women's experiences and uncovering reasons for their low participation. The phenomenological approach is reflected in the four-step analysis procedure, in which meaning units were identified and the content of these were abstracted and summarised.<sup>18</sup> The analysis of the women's experiences will be presented as descriptive results grounded in the women's statements.

#### 2.1. Settings

The setting was the Department of Gynaecology and Obstetrics, Aalborg University Hospital in the North Denmark Region, which admits women with gestational diabetes from the entire region. The interviews were conducted in April 2014.

#### 2.2. Participants

In cooperation with the management at the department at Aalborg University Hospital, women with previous gestational diabetes were contacted by surface mail. The letter, which was sent by the hospital, followed Danish legislation, <sup>19</sup> and gave information about the study. contact information on the research team and invited the women to participate. The invitation letter was sent to 40 women who were representative of the population in the register study with respect characteristics such as age (approximately 30 years old) and occurrence of first-time gestational diabetes. The strategy for recruitment of participants was based on "random selection"<sup>20,21</sup> since all women with the specific characteristics were considered relevant for the aim of the study regarding experiences. This resulted in an invitation of forty women who were identified through the hospital admission system from which we choose the first eligible. All of the women had been registered with gestational diabetes between 1 June 2012 and 1 June 2013 and had given birth between one and two years previous to those dates. At receipt of the letter, they were thus between their first and second recommended follow-up screening visit.

The invitation to participate in the study was accepted by seven women. Table 1 below summarises their personal data. The women's characteristics were representative of women with first time gestational diabetes in this region. All of the included women had participated in the first follow-up screening.

The women were free to choose the location for the interview session; three chose their own homes, two the clinic and two the interviewers' (JHN and CRO) workplace at Aalborg University. Interviews were conducted by one researcher at the time.

#### 2.3. Data collection

An interview guide was developed guided by an open, phenomenological approach seeking to explore the participants' own subjective experiences. At the same time it was drawing on existing literature on reasons for non-participation in follow-up screening. The phenomenological approach was supported by open-ended questions in the interviews and a thematic focus allowing the interviewer to explore the participants' experiences with treatment and care and reveal a common essence in the women's statements, which is the key element in a phenomenological approach.<sup>16,17</sup> While the thematic dimension supported the themes of the interview, the dynamic dimension aimed at promoting positive interaction and stimulate the interviewees' motivation to speak openly about their experiences.<sup>20</sup> A pilot interview aiming at testing the guide was undertaken with one woman. Her reflections on the interview questions gave way to spontaneous descriptions of further perspectives and experiences. The positive dynamics of the test interview gave no reason for changing the interview guide or further test interviews. As the test interview offered comprehensive insight in the woman's experiences of treatment and care, this interview was included in the study.

Table 1	
Participants	characteristics.

Women	Age	Civil status	Ethnicity	Education
1.	27 years	Cohabiting	Asian	Post-secondary education
2. 3.	32 years 31 years	Cohabiting Cohabiting	Caucasian Caucasian	Post-secondary education Post-secondary education
4.	29 years	Cohabiting	Caucasian	Post-secondary education
5.	34 years	Cohabiting	Caucasian	Post-secondary education
6.	36 years	Cohabiting	Caucasian	Post-secondary education
7.	29 years	Cohabiting	Caucasian	Post-secondary education

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