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Perinatal care needs and expectations of women with low vision or total blindness in Warsaw, Poland

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ABSTRACT

Background: As estimated from the number of published studies, in Poland the research into the perinatal care experiences of women with low vision or total blindness remains limited.

Objectives: The purpose of the study was to fill this gap by investigating satisfaction with perinatal care received by women with visual impairment in four city hospitals in Warsaw, Poland, and to recommend, if required, modifications in midwives' education and care standards based on the women's perceptions and expectations.

Methods: Hour-long interviews were conducted between 30 August 2014 and 2 September 2015 with 16 blind or low vision women in perinatal care, audio-recorded and transcribed verbatim. The accounts were subsequently evaluated using the Interpretative Phenomenological Analysis (IPA) approach. Five major themes were pre-selected: perceived stigma and lack of affirmation for the interviewee's motherhood, accessibility of childbirth preparation, accessibility of perinatal care and hospital facilities, midwives' attitudes and the interviewees' expectations for care improvements.

Results: Overall, the accounts demonstrated the lack of satisfaction with the quality of perinatal care, including the childbirth preparation classes, hospital facilities and hospital staff approach as not actually meeting specific functional needs. They also suggested how the quality of care could be improved.

Conclusions: Specific standards and procedures for perinatal care for women who are blind or have low vision should be developed and introduced in clinical practice in Poland based on research into the experiences of these women. Also, the training of health care professionals should be modified and their attitudes changed to meet maternal needs.

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Introduction

The quality of perinatal care provided in Polish hospitals benefited greatly by the introduction of the Perinatal Care Standards in 2012.¹ The Standards did not, however, address the specific needs of women with disabilities, a group in need of individualized perinatal care. This partially results from insufficient research into the needs of Polish patients, including pregnant women, with disabilities and the quality of care they receive. What scarce research there is tends to focus on the largest subset of subjects with motor disabilities.^{2–4} There have been no studies in Poland on

perinatal care of women with sensory disabilities, including low vision or total blindness, resulting in the absence of the legal standard of perinatal care tailored to the specific needs of these women.

The existing research into the specific needs of pregnant women with disabilities demonstrates their specific pregnancy and birth care requirements which should be met by identifying the areas for improvement and introducing novel evidence-based policies. The issues include, but are not limited to, the lack of knowledge and awareness of the needs and expectations of this group of women among health-care professionals (HCPs), shortage of adequately trained HCPs, including midwives, hospital facilities that at present are not designed to meet these specific needs, lack of proper care standards and procedures and, last but not least, stigmatization and social exclusion of women who are blind or have low vision, sadly extending to the behavior of HCPs.^{2,5,6} The purpose of this study was to fill the gap in relevant research with very few published studies in Poland by investigating whether at least some of these

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putative problems identified by researchers would be manifested in the actual clinical setting of obstetric wards of city hospitals in Warsaw.

The qualitative research we performed was aimed at identifying the perception and assessment by the women of individual components of the perinatal care received, their experiences before, during and after childbirth and their perceived significance. Such information could be used for developing an evidence-based set of perinatal care standards for women who are blind or have low vision as well as have some impact on midwifery education, i.e. academic and clinical course content.

Methods

The study group consisted of 16 puerperal women, who were blind or had low vision, in the obstetric wards of four city hospitals in Warsaw, Poland. Permission for performing the study was obtained from the hospital management. The head midwives informed all blind and low vision women in the wards about the study. And all gave verbal informed consent to the interview, documented by recording it with the interview, and to the use of the content for research purposes. Confidentiality and non-disclosure of personal data were guaranteed to all participants. The personal data were anonymized using initials other than the original ones.

The study was approved by the Bioethics Committee at the Medical University of Warsaw.

The qualitative research was conducted in the period from 30 August 2014 till 2 September 2015 (52 weeks), with the entire span of work on the paper, from early conceptualization to the completion of the draft in the years 2013–2016. The approach used was the Interpretative Phenomenological Analysis (IPA), consisting of recording the interviewee's freely expressed account of her experiences, problems and grievances and a subsequent exploration of the collected accounts.⁷ The focus was on gaining insight into the accounts the participants gave of the experiences of perinatal care they considered to be of personal significance and how they made sense of these experiences.

Semi-structured interviews were conducted with the participants three days after the childbirth. After recording the interviewees' demographic data [Table 1], the researchers asked them to freely voice their opinions on each of the five major aspects of their perinatal care (the themes were preselected by the researchers and the list presented to the interviewees) [Fig. 1].

The women spoke as long as they wished on each of the five themes. They were not interrupted nor asked any additional questions by the interviewers to avoid any bias and ensure effective independence from undue influence. The average length of an interview was 60 min. The interviews were all recorded and detailed verbatim transcripts were produced.

Study group characteristics

The study group consisted of 16 women with different levels of visual impairment, including six women unable to see since birth and diagnosed, according to the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM), with complete blindness, i.e. total inability to sense light; four women who lost sight in childhood, most probably due to the genetic cause manifesting after age 4 years; five women with severe and progressive visual impairment since adolescence; and one woman with severe visual impairment caused by a mechanical injury. The women who were blind from birth had no visual impressions or experiences, and their cognitive structure had tactile-auditory character only. The women who experienced sudden or gradual

Table 1
Participant characteristics (n = 16).

	N	
Age (years)	≤30	5
	31–35	6
	≥36	5
Marital status	Unmarried	2
	Married	10
	Divorced	1
	In a civil union	3
Gravidity	First pregnancy	8
	Second pregnancy	2
	≥Third pregnancy	6
Parity	First childbirth	10
	Second childbirth	5
	≥Third childbirth	1
Type of delivery	Vaginal	6
	Vacuum extraction-assisted vaginal	7
	Cesarean	3
Gestational age at delivery (hbd)	≤37	4
	38–40	9
	≥41	3
Education	Below high school diploma	2
	High school diploma	6
	College degree or higher	8

vision loss after age 4 years had preserved memories of visual impressions and structures of visual imagination, which significantly aided their daily functioning. These women possessed richer memory content than those blind since birth. Detailed characteristics of the study participants are given in Table 1.

All the women included in the study were occupationally active before pregnancy as most were either skilled workers or professionals. Among eight women with a university degree there was a lawyer, a psychologist, a physiotherapist, a sociologist, a history teacher and an employee of the Polish Association of the People with Visual Impairments. Of the 13 participants who were either married or in a civil union, eight had partners without disability or visual impairment. Two of the partners had visual impairment since birth and three had a moderate visual impairment. In addition, three of the 13 partners had motor disability.

Results

Below are presented quotes from the interviewees' accounts of their experiences defined by each of the five preselected themes.

Theme 1. Perceived stigma and lack of affirmation for the subject's motherhood

The participants reported their joy at the prospect of motherhood being unaffected by their awareness of the limitations resulting from their disability and dependence on others. Many considered motherhood the most important experience in their lives. *"The pregnancy had not been planned, but when my husband and I found that I was pregnant, we were overjoyed. - WW; "The news brought me much joy, it was like dreams coming true. I always wanted to have more children. My children are my entire life, thanks to them I feel needed. Although bringing up children is an enormous challenge, I am very happy that I am their mom. - KR"*

Still, some of the women considered motherhood a challenge, and they expressed doubts or worries about their future performance as mothers: *"I have never cared for a small child, I do not know*

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