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Midwifery

journal homepage: www.elsevier.com/midw

Normalising birth for women with a disability: The challenges facing practitioners

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ARTICLE INFO

Article history:

Received 11 March 2011

Received in revised form

5 October 2011

Accepted 16 October 2011

Keywords:

Maternity care

Pregnant with a disability

Normalising birth

Birthing experience

ABSTRACT

Previous research on pregnant women with a disability and their experience of maternity care demonstrated that these mothers perceived themselves to be the 'perennial outsiders' with midwives automatically categorising them as 'high risk' because of their disability. They also felt that their ability to make choices, stay in control and have continuity of care was not considered to be part of the mainstream maternity care for them because they did not fit the 'normal' category.

Objective: this research was undertaken to explore the perceptions of two multiprofessional teams in Irish hospitals as to how maternity services to these mothers can be improved.

Participants: nineteen health-care professionals from midwifery, social work and public health nursing were recruited.

Setting: two from two major maternity hospitals, one in the North and one in the South of Ireland. were featured.

Design: the method chosen was a qualitative approach, using focus group interviews in which case studies depicting a range and breadth of women's birthing experiences were presented and discussed. **Newell and Burnard's (2006)** six stage approach to thematic content analysis was used.

Findings: the professionals found the disabled women's stories believable, upsetting and challenging.

Key conclusions: Staff acknowledged their 'lack of competence, knowledge and skill' regarding disability and felt that, on reflection, their failure to consult and collaborate with disabled women contributed to their failing to provide individualised woman centred care to women with a disability.

Implications of practice: A series of recommendations for improved practice was agreed.

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Introduction

Disability has been defined as a consequence of impairments, physical, sensory and intellectual, which affect a person's ability to perform normal day to day activities (World Health Organisation, 2001). By contrast the social model of disability views it as a consequence of organisational, attitudinal and environmental barriers, which severely limit an impaired person's participation in society (Thomas and Curtis, 1997). The International Classification of Functioning (World Health Organisation, 2001) embraces both perspectives and provides a framework for optimising as well as assessing a persons participation in ordinary activities. For disabled women this includes child birth.

However, there is strong evidence to suggest that the non-disabled population, inclusive of health-care professionals and across the generation gap, have reservations about disabled women becoming mothers (Ash and Fine, 1998; Neville-Jan, 2004). As a group, these women have traditionally been discouraged or even denied the opportunity to bear and rear children (Nosek et al., 2001). Moreover the assumption that disability is a medical condition requiring specialised intervention has profoundly affected the healthcare provided to disabled women, especially in relation to pregnancy and child birth. This minority group is often deemed 'abnormal' and consequently, they are likely to be regarded as problematic and in some cases, 'incompetent' with regard to having a normal birth and becoming a good mother. Health-care providers who are poorly educated in disability awareness and with minimal relevant training, are ill-equipped to serve the needs and expectations of women with disabilities (Campion, 1990; Kallianes and

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Rubinfeld, 1997). Consequently, these mothers are perceived as 'high risk' and are not offered the same opportunities as their able bodied peers to achieve their optimum birthing experience.

Reports continue to be published of disabled women being 'marginalised' whilst accessing maternity services and not having their 'specific and individual' requirements met, regardless of their level of functioning and aspirations (Aunos and Feldman, 2002; Prilleltensky, 2003; Mac Kay-Moffat, 2007; Walsh et al., this issue). In particular, mothers report that they are subject to constant surveillance (Shackleton and Godard, 1997; Tymchuk, 1999; Walsh et al., this issue) and the custodial rights of mothers with disabilities are frequently questioned before and after birth. Indeed, professional bodies have recognised that modern maternity services are failing to provide the specialist services required by these mothers to enable them to have the much desired 'woman-centred-care' (RCM, 2000).

Royal College of Midwives (2000), published guidelines advising all midwives with regard to supporting mothers with disabilities. Midwives are advised to know their responsibilities under the Disability Discrimination Act (2005) and to provide flexible, creative and innovative midwifery care to meet individual needs, including choice, control and continuity of care for all women. In its document 'Maternity Matters', Department of Health (2007) the UK Government outlines its policy commitment to providing all pregnant women with appropriate and specialist services. However, there is little literature to identify the impact these initiatives have had on midwifery practice. It was against this background that the current research was undertaken and it provides one of the first significant publications in this area.

The aim of this study was to gain an insight into the professional barriers to the provision of a normal birth for women with disabilities and how these barriers might be reduced. A particular focus was on the professionals' views of disabled women making choices, of their being in control and the provision of continuity of care during and after their childbirth experiences.

The study drew on the experiences of front line staff, primarily midwives, working in a large maternity hospital in Northern Ireland, which comes under the British National Health Service and another comparable hospital in the Republic of Ireland, which has more devolved service policies and practices.

The 19 participants in the study were provided with the main themes arising from the interviews with disabled mothers and illustrated, using anonymous case studies of disabled women's experiences of 'high risk' birth in their respective maternity services (Walsh-Gallagher et al., 2011). They were eager for their stories to be heard and to serve as a catalyst for service reform. The women in the study had congenital and acquired impairments. They included: mild intellectual disability ($n=5$); status epilepsy ($n=4$); total visual impairment ($n=2$); mild intellectual disability and visual impairment ($n=1$); multiple sclerosis ($n=1$); spinabifida and hydrocephalus ($n=1$); brain tumour ($n=1$); cerebral palsy ($n=1$) and motor neurone disease ($n=1$). Their ages ranged from 17–40 years.

Extracts from the case studies were used with participants to stimulate discussion and reflection on current practices and, more importantly, to explore how the maternity services in both countries could be developed to improve the future experiences of disabled women entering their respective systems.

Methods

Ethical issues and recruitment of sample

Ethical permission was requested and obtained from University of Ulster Research Committee. Access to participants was gained to two major maternity hospitals, one in Northern Ireland, facilitated

through contact with the clinical expert adviser to the Department of Health and one in the Republic of Ireland. Following telephone negotiations with the head of maternity services for each hospital, 19 health-care professionals, were recruited for this study; 11 and eight in each of the two respective hospitals.

Focus group One comprised: 1 ward manager, 1 discharge co-ordinator (attached to hospital/community); 1 ward Sister (maternity outpatients department); 1 ward Sister; 3 midwives, 2 social workers, 1 trainee social worker (hospital); 1 practice educator (neonatal intensive care unit). Excluding the trainee, their years of practice ranged from 5–30 years.

Focus group Two comprised: 1 clinical midwife specialist (attached to fetal assessment unit); 2 midwives (maternity ward); 1 manager, 1 midwife (delivery unit); 1 social worker (hospital); 2 public health nurses/health visitors (community). Their years of practice ranged from 2–27 years.

GPs doctors, gynaecologists and obstetricians were invited to participate in the study, but all declined to do so.

Procedure

Focus group interviews were conducted in each of the participating hospitals, with one author as facilitator (DWG) and another as note-taker (MS). Participants on duty were released for the interview; those off duty got time off in lieu. Participation was entirely voluntary. After introductions, the first author summarised the main findings from 17 disabled women's experiences of accessing maternity services within the respective units, collected as part of a doctoral thesis (Walsh-Gallagher, 2009). Extensive use was made of direct quotations to illustrate the main themes. These were presented visually and read aloud. The women were each given a coded identity and their individual care was not discussed. Fig. 1 summarises the findings presented to the groups.

Open ended questions were used in the second part of the sessions to explore participants' perspectives around the women's experiences of their ante, intra and postnatal care and how they, as carers, felt the women's experiences could have been improved.

In addition, a comment sheet was given to all the participants so that they could communicate in confidence any further insights or reflections to the research team. This served to counterbalance possible monopolisation of the discussion by dominant personalities and to counteract possible pressure for conformity among participants in the group. These sheets were anonymous and left in a pigeon hole within the hospital for the

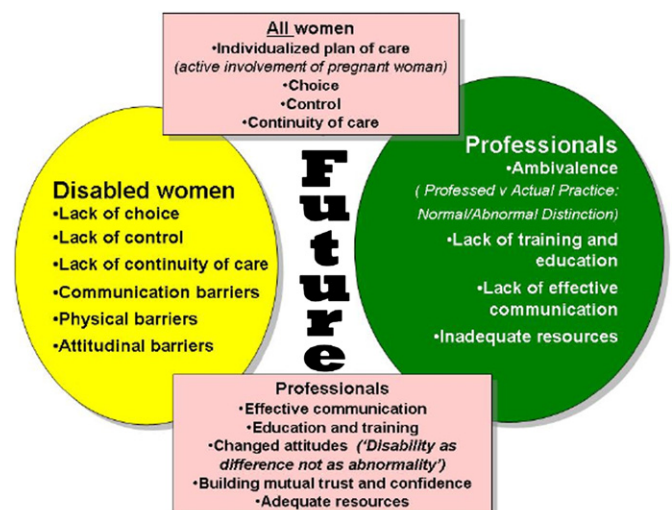


Fig. 1. Diagrammatic representation of the findings, suggesting improvements to service provision.

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