Midwifery 29 (2013) 592–598

Contents lists available at SciVerse ScienceDirect

Midwifery

journal homepage: www.elsevier.com/midw

The postnatal support needs of mothers with an intellectual disability

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ARTICLE INFO

Article history:
Received 21 March 2012
Received in revised form
10 May 2012
Accepted 12 May 2012

Keywords:
Intellectual disability
Mothers
Postnatal care

ABSTRACT

Objective: there is growing evidence that many parents with intellectual disabilities can parent successfully when given adequate support. This paper aims to explore the postnatal care experiences of mothers with an intellectual disability.
Design: a qualitative design was used and data were collected using a semi-structured interview format and analysed using Interpretative Phenomenological Analysis.
Setting: the study took place in community settings in Scotland.
Participants: six mothers with intellectual disabilities were interviewed about their experiences.
Measurements and findings: two super-ordinate themes are discussed with accompanying subthemes: challenges of providing support and how support was delivered.
Key conclusions: the mothers valued formal postnatal care, but this was secondary to informal support. How mothers perceived the support impacted on its effectiveness and building effective relationships with professionals presented challenges.
Implications for practice: the study suggests the structure and quality of the wider support networks of mothers with an intellectual disability are central and should be taken account of by professionals. Providing information and advice in ways that validates the mother's role is also important, particularly as the mother's perception of how help is given can impact on the degree to which mothers engage with professionals.

Introduction

Parents with an intellectual disability (ID) are more likely, than any other group of parents, to have their children permanently removed by child protection services and placed in care (Booth and Booth, 2005) and a UK survey found that 48% no longer had their children living with them (Emerson et al., 2005). Whilst there is no robust evidence to indicate why some parents with ID struggle and others succeed in providing 'good enough' parenting, it has been identified that having access to formal or informal social supports may be an advantage for parents (International Association for the Scientific Study of Intellectual Disabilities IASSID, 2008). Murphy and Feldman (2002) propose that, when given adequate support, parents with ID can effectively parent.

Research, however, suggests that mainstream parenting support services may be perceived as inaccessible or irrelevant to the needs of groups such as parents with ID (Tarleton et al., 2006). As a result there are limited social support networks for parents with ID, and those that are available typically involve family members (Guinea, 2001; Kroese et al., 2002). Mothers with ID were found to rely on informal support networks for help in areas such as shopping and transport to hospital in times of emergency. Mothers also considered support with childcare as one of the most helpful aspects of informal support (Kroese et al., 2002). Expectant mothers with ID have been found to recognise the need for practical assistance following the birth of their child and to proactively negotiate a support network around them prior to their infants' births. Furthermore, they were careful to ensure they included people who were likely to recognise the central importance of the mother's role in the infant's life. Despite this, many of these parents managed the responsibility of child-rearing with limited external support (Mayes et al., 2008).

Research consistently shows that the ways in which parents perceive the support offered to them is central to whether the support is experienced as being helpful or not (Tucker and Johnson, 1989; Aunos et al., 2004). Indeed, Llewellyn (1995) found that some parents were reluctant to seek professional support because they felt that the staff did not acknowledge the

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http://dx.doi.org/10.1016/j.midw.2012.05.002

comprehension difficulties that were associated with having an intellectual disability. Tucker and Johnson (1989) outline a distinction between support that is ‘competence-promoting’ and ‘competence-inhibiting’. The latter seeks to enhance the parent’s self-reliance and sense of competence in their role, while the former, in contrast, reflects a critical or domineering approach which disempowers parents.

This work has contributed to developments in the concept and definition of parenting, such that it goes beyond the responsibility of the individual parents and instead is viewed as a social responsibility or ‘distributed’ task (Booth and Booth, 1998) with support being available from a range of individuals, organisations and social structures (Booth and Booth, 2000). Midwives play a central role, as part of this ‘distributed’ care network, as formal providers of expert support and advice in the ante and postnatal periods (Magill-Cuerden, 2006; Hodnett et al., 2007).

Childbirth is a significant life event and support at both the antenatal and postnatal periods is important. Support during the former period helps lay the foundations for future parenting success (Nelson, 2003), while postnatal care is important in facilitating a positive transition to motherhood (Demott et al., 2006). This is also the time when parents first learn to nurture and care for their child. Support at this time is likely to be particularly important for parents with ID, as research suggests that many experience difficulties in childcare (Kroese et al., 2002; Tarleton and Ward, 2007). This difficulty may be exacerbated for mothers by the experience of undiagnosed mental health problems (Cotson et al., 2001; O’Keeffe and O’Hara, 2008), such as postnatal depression, particularly because screening tools may not be as reliable when used in this population (Gaskin and James, 2006).

Despite the recognition of the need for appropriate support for mothers with ID and the recent emphasis that parents with intellectual disabilities should be supported to access generic postnatal support services (e.g. Tarleton et al., 2006; Department of Health, 2007), there is only a limited evidence base which focuses on parental experiences of formal support. This highlights the importance of being listened to and receiving practical support with parenting skills (Tarleton and Ward, 2007), as well as receiving appropriate and accessible information in a non-judgemental context (Starke, 2010). Walsh-Gallagher et al. (2011) explored the parenting experiences of disabled women and the participants included some women with an intellectual disability. While the experience of formal support was not the sole focus of research, the participants reported a number of negative experiences during pregnancy and childbirth, in their interactions with a range of professionals, including GPs, social workers and health visitors, The women reported feeling scrutinised, judged and discriminated against. The limited research into the postnatal period (McKellar et al., 2009), however, means it remains unclear to what extent the support needs of mothers with ID are being met. The present study, therefore, aims to explore how mothers with an intellectual disability experience postnatal care.

Method

Design

As the study aimed to achieve an understanding of individual participant’s lived experiences, phenomenological methodology using Interpretative Phenomenological Analysis (IPA) (Smith, 1996) was chosen for the study. This methodology has been adopted by a number of studies of adults with ID (e.g. Baum and Burns, 2007; Mayes et al., 2008).

Participants

Six mothers with ID participated in the study. The mothers were aged between 20 and 55 years. All mothers were known to a community learning disability team (CLDT) comprising social care and health professional staff based within a rural population in Scotland. No formal measure of intellectual or adaptive functioning was completed as part of the study, however all of the mothers were considered to have a mild intellectual disability. Two mothers were single and four mothers, one of whom was married, currently lived with a partner. All of the mothers had experienced one or more of their children being removed by child protection agencies. For two of the participants, this was the only child they had. The other participants had between 2 and 8 children. The ages of the participants’ youngest children ranged from 10 weeks to 15 years. All potentially identifying information was removed or altered to protect the anonymity and confidentiality of the participants.

Procedure

Ethics and recruitment

Permission for the study was obtained from the authors’ educational institution and National Health Service ethical committees. Following approval, potential participants were recruited via CLDT members. All the mothers who were recruited had an intellectual disability and had previous or current contact with the CLDT. It is recognised that individuals with ID may be vulnerable to acquiescence (Finlay and Lyons, 2002) and in order to ensure that potential participants possessed the capacity to consent to the study a number of steps were taken. Firstly, potential participants were initially approached by a member of the CLDT, who was familiar to them and who described the study. If the mother was interested in participating, her consent was sought to provide her contact details to the first author, who then arranged an initial screening interview. During this, the mothers were provided with an accessible participant information sheet, which was read to them, where necessary, and subsequently discussed with them. This provided information about the study and the associated limits of confidentiality (for example if child neglect or abuse was disclosed). Following this discussion, the first author asked the potential participants about their understanding of what taking part in the study would involve, the potential benefits and burdens in taking part and that they understood that they could choose not to take part and could withdraw at any point. The mothers were given 24 hrs to decide whether they wished to participate. If so, a second interview was arranged, at the beginning of which the first author again checked that the participant understood what the study was about, the implications of taking part and that she still wished to be involved. Written consent was obtained before the interview began.

Data collection and analysis

Data were collected by the first author using a semi-structured interview schedule. The questions and prompts covered areas which were highlighted from previous research as being potentially important. An assessment of content validity was also provided by obtaining feedback from three professionals who worked in the field of intellectual disability. The researcher adopted a ‘self-developing’ technique (Booth and Booth, 1996), and adapted communication as required as the interview progressed in response to any comprehension difficulties that arose. This included employing prompts to probe participants’ responses and asking more questions. The interviews lasted for between 57 and 69 mins. Four of the interviews were conducted in the participants’ homes and two in a health centre.