



## Social support received by women with intellectual and developmental disabilities during pregnancy and childbirth: An exploratory qualitative study



Lynne A. Potvin, H.B.A (Specialization in Psychology and Birth Doula)<sup>a</sup>,  
Hilary K. Brown, PhD (Postdoctoral Fellow)<sup>b</sup>, Virginie Cobigo, PhD (Associate Professor)<sup>c,\*</sup>

<sup>a</sup> University of Ottawa, School of Psychology, 136 Jean Jacques Lussier (5078), Ottawa, Canada ON K1N 6N5

<sup>b</sup> Women's College Research Institute, University of Toronto, Department of Psychiatry, 76 Grenville Street, Toronto, Canada ON M5S 1B2

<sup>c</sup> University of Ottawa, School of Psychology, 136 Jean Jacques Lussier (5083), Ottawa, Canada ON K1N 6N5

### ARTICLE INFO

#### Article history:

Received 18 November 2015

Received in revised form

25 March 2016

Accepted 10 April 2016

#### Keywords:

Intellectual disability

Developmental disability

Pregnancy

Childbirth

Social support

Grounded theory

### ABSTRACT

**Objective:** this study aims to contribute to the development of a conceptual framework that will inform maternity care improvements for expectant mothers with intellectual and developmental disabilities (IDD) by exploring the structure, functions, and perceived quality of social support received by women with IDD during pregnancy and childbirth.

**Design/setting:** using a grounded theory approach, we conducted an exploratory study set in Ontario, Canada in 2015.

**Participants:** the sample included four adult women with IDD who had given birth in the last five years.

**Measurements:** data were collected using semi-structured interviews.

**Findings:** the structure of social support received by women with IDD consisted of both formal and informal sources, but few or no friendships. Women with IDD reported high levels of informational and instrumental support and low levels of emotional support and social companionship. However, a high level of available support was not always perceived as beneficial. Emergent core categories suggest that social support is perceived as most effective when three conditions are met: (1) support is accessible, (2) support is provided by individuals expressing positive attitudes towards the pregnancy, and (3) autonomy is valued.

**Key conclusions and implications for practice:** our study confirms and identifies important gaps in the social support received by expectant mothers with IDD. Women with IDD currently lack accessible informational support, emotional support, and social companionship during pregnancy and childbirth. Additional findings regarding the structure and functions of social support are presented, and a preliminary conceptual framework of effective social support during pregnancy and childbirth, as perceived by women with IDD is also proposed. Findings suggest that increasing support accessibility should be a social and clinical priority; however, maternity care providers should be aware of stigmatizing attitudes and respect the autonomy of pregnant women with IDD as they prepare for motherhood.

© 2016 Elsevier Ltd. All rights reserved.

### Introduction

Intellectual and developmental disabilities (IDD) are neurodevelopmental disorders characterised by limitations in cognitive and adaptive functioning (American Psychiatric Association, 2013). According to health administrative data from Ontario, Canada, the prevalence rate of IDD per 100 is 0.80 (Lin et al., 2013). Historically,

many women with IDD were involuntary sterilised and institutionalized (Kempton and Kahn, 1991). Today, legislation protects the reproductive rights of women with IDD in most developed nations, including Canada (Blackford, 1993), and the United Nations Convention on the Rights of Persons with Disabilities (2006) reaffirms the right of persons with IDD to “marriage, family, parenthood and relationships, on an equal basis with others” (article 23.1). This changing context has significant implications for childbearing in this population.

Many women with IDD have sexual relationships and desire children (Aunos and Feldman, 2002). Moreover, an increasing

\* Corresponding author.

E-mail addresses: [lpotv101@uottawa.ca](mailto:lpotv101@uottawa.ca) (L.A. Potvin),  
[hilary.brown@wchospital.ca](mailto:hilary.brown@wchospital.ca) (H.K. Brown), [virginie.cobigo@uottawa.ca](mailto:virginie.cobigo@uottawa.ca) (V. Cobigo).

number of women with IDD are using maternity services (Royal College of Midwives, 2000). The general fertility rate in women with IDD is 20.3 live births per 1000 women with IDD (Brown et al., 2016); pregnancy is therefore not uncommon in this population. Women with IDD have high rates of adverse perinatal outcomes, including preeclampsia, caesarean section, preterm birth, and perinatal mortality (McConnell et al., 2008a; Höglund, 2012; Mitra et al., 2015), suggesting that they are a high-risk maternity population whose individual needs should be supported.

Social support can be conceptualised in terms of structure and function. Structure refers to the number of relationships one has and the degree of interconnectedness between these relationships (Sherbourne and Stewart, 1991). Relationships may be formal (e.g., paid sources such as healthcare professionals) or informal (e.g., unpaid sources such as family members and friends) (Lyons and Zarit, 1999). Function refers to the nature of social support provided and the degree to which the relationship serves a purpose (Sherbourne and Stewart, 1991). Commonly cited functions of social support are informational support, instrumental support, emotional support, and social companionship (Sherbourne and Stewart, 1991; Willis and Shinar, 2000). Informational support includes the provision of knowledge, advice, and guidance. Instrumental support includes practical support such as transportation, financial aid, and help with household chores. Emotional support is defined by demonstrations of caring and acceptance like sympathetic listening. Social companionship refers to relationships that engage in social activities (Willis and Shinar, 2000). Perceived quality of social support refers to the subjective evaluation of support received by an individual, which may be positive or negative (Cohen and Syme, 1985; Bramston et al., 1999; Lunskey and Benson, 2001).

Research has identified pregnancy as a potentially stressful life event requiring social readjustment (Holmes and Rahe, 1967); however, it is especially stressful if it is unplanned (Geller, 2004) or high risk (Heaman, 1998). Women with IDD appear to be vulnerable to unwanted pregnancy (Wingfield et al., 1994; Servais et al., 2002) and represent a high-risk maternity population (McConnell et al., 2008a; Höglund, 2012; Mitra et al., 2015). Conversely, social support serves a protective function against the negative effects of stress (Cohen and Syme, 1985; Cohen and Wills, 1985) and contributes to the health and well-being of expectant mothers (Oakley, 1988). Effective and continuous social support, in general, has been associated with a reduced risk of emotional distress during pregnancy (Glazier et al., 2004), shorter labour, fewer obstetrical interventions (Lantz et al., 2005), and a lower risk for post partum depression (Morikawa et al., 2015). Moreover, research specific to women with IDD has demonstrated that adapted informational support increases self-efficacy in preparation for motherhood and confidence in making informed choices during pregnancy (McGarry et al., 2015).

Most adults with IDD experience low to moderate levels of social support (Lunskey and Benson, 1999). However, only a handful of studies, from the United Kingdom, Ireland, Sweden, and Australia, have described social support received by women with IDD during pregnancy and childbirth. Themes that have emerged from these studies include inadequately addressed needs for informational and practical support (Höglund and Larsson, 2013; Mayes et al., 2006; Redshaw et al., 2013; Walsh-Gallagher et al., 2012), feelings of loneliness (Walsh-Gallagher et al., 2012; Walsh-Gallagher et al., 2013) and social isolation (Llewellyn and McConnell, 2002), and distress over prejudicial beliefs held by family members and health care professionals towards the pregnancy (McConnell and Llewellyn, 2002; Mayes et al., 2006; McConnell et al., 2008b; Walsh-Gallagher et al., 2012; Höglund and Larsson, 2013; Walsh-Gallagher et al., 2013).

As such, this study aims to contribute to the development of a conceptual framework that will inform maternity care improvements for expectant mothers with IDD by exploring the structure, functions, and perceived quality of social support received by women with IDD during pregnancy and childbirth.

## Method

Ethics approval was obtained from the Office of Research Ethics and Integrity at the University of "X".

### Design/setting

We conducted a qualitative study using a grounded theory approach. Using pre-existing knowledge to understand the data, grounded theory uses constant comparison to identify and compare emerging conceptual elements, ask questions of the data, and code data into categories based on their theoretical properties (Robson, 2002; Holton, 2007). On the basis of this in-depth analysis, it is possible to generate explanatory models that are grounded in the data (Robson, 2002). The study was conducted in Ontario, Canada, in 2015.

### Participants

Participants were recruited using convenience sampling from local French and English service agencies for adults with IDD that agreed to forward information packages to potential participants. The sample included women who had a diagnosis of IDD (as confirmed by the service agency) and who: (1) were 18 years of age or older, (2) had a pregnancy that resulted in a live birth in the last five years, and (3) possessed sufficient verbal capacity to answer questions in an interview setting (e.g., able to recall experiences and verbally relay them to the interviewer).

### Procedures

#### Consent and confidentiality

Consent was evaluated through a series of five questions designed to assess: (a) capacity to consent (i.e., understanding of research purpose, risks, and benefits), (b) voluntariness, (c) understanding of the right to withdraw consent at any time without consequence, and (d) understanding of the right to refuse to answer questions (Arscott et al., 1998). Third parties present during the interview (i.e., case workers) had to be invited by the women and were required to sign a confidentiality agreement prior to the interview.

#### Avoiding distress

There is a potential for eliciting psychological discomfort when discussing sensitive topics and sharing personal information; therefore, we developed the following procedure: (a) adopted strong interviewing skills such as sensitivity and empathy; (b) took breaks where needed; (c) terminated the interview if it became too distressing; (d) assured participants that they could decline to answer any questions and withdraw from the study at any time without consequence; (e) remained with the participant and shifted the interview to pleasant exchanges before terminating the interaction if distress was suspected (Corbin and Morse, 2003).

### Measurement

#### Instrument

Data were collected in recorded one-on-one semi-structured

Download English Version:

<https://daneshyari.com/en/article/1084454>

Download Persian Version:

<https://daneshyari.com/article/1084454>

[Daneshyari.com](https://daneshyari.com)