Essay

How can we as Midwives, implement collaborative woman-centred care to childbearing Women who have a significant physical impairment?

INTRODUCTION AND BACKGROUND:
As the number of physically disabled women electing to have baby’s increases, midwives and other healthcare professionals are more frequently faced with providing care and support in areas where they may have little experience (Carty, 1998). It is estimated that there are currently over 2 million women with disabilities living in Australia, with approximately 20% of these women being of childbearing age (Australian Institute of Health and Welfare, 2010; Women With Disabilities Australia, 2014). However, current birth records in Australia do not denote maternal disability status, resulting in a statistical deficit in regards to the number of women with physical disabilities currently accessing maternity care services (Stella McKay-Moffat & Cunningham, 2006).

Women with disabilities continue to be one of the most marginalised and isolated groups in Australia’s society, with the majority experiencing disproportionate levels of inadequate access to health care, increased discrimination, social exclusion, socioeconomic disadvantage, and are at increased risk of sexual and physical abuse (Women With Disabilities Australia, 2014). Despite a paucity of research exploring pregnancy outcomes for women with physical disabilities, limited findings suggest that these women experience higher rates of pregnancy complications such as low birthweight infants and premature birth (Morton et al., 2013). Additionally, women with disabilities reportedly experience the symptoms of pregnancy more severe than women without disabilities, with their pregnancy often altering the course of their disability temporarily or even permanently (Tarasoff, 2015).

It is evident from the literature that there is an overall lack of awareness amongst maternity care providers in how to best provide care and support for this inimitable group of women (Rotheram & McKay-Moffat, 2007). Of note is the increasing reported criticism that maternity care providers are poorly educated in disability awareness, and receive minimal relevant training which leaves
them ill-equipped to meet the unique maternity needs and expectations of this population group (Tarasoff, 2015; Walsh-Gallagher, Mc Conkey, Sinclair, & Clarke, 2013).

In order for Midwives to adequately provide care and support for women with physical disabilities, we must first explore the lived views and experiences of these women, to ensure that our midwifery care is not only evidence based and safe, but also woman centred and appropriately suited to the unique and diverse needs of these women (Nursing and Midwifery Board of Australia, 2006).

**DISABLED WOMEN’S EXPERIENCES OF MATERNITY SERVICES:**

As a group, women with physical disabilities have historically been viewed through pervasive discriminatory and prejudicial attitudes that assume that disabled women neither want, nor are able to have children, or indeed able to look after them (Rotheram & McKay-Moffat, 2007; Tarasoff, 2015). From reading the literature, the majority of challenges and barriers currently encountered by women with physical disabilities appear to stem from enduring prejudicial attitudes and the exclusionary practices of health care providers and institutions (Begley et al., 2009). In fact, a recent literature review by Tarasoff (2015) reported that a high percentage of women with physical disabilities were either refused care by obstetric physicians because of their disability, counselled not to become pregnant, or encouraged to terminate their current pregnancy. This is despite previous research which has shown that pregnancy for women with physical disabilities can be relatively straightforward, depending on the severity of their disability (Becker, Stuifbergen, & Tinkle, 1997; Cross, Meythaler, Tuel, & Cross, 1992; Greenspoon & Paul, 1986).

These attitudes are further emboldened by recent research by Moreten et al. (2013) which contends that women with physical disabilities experience higher rates of premature birth, lower birthweight babies, and increased incidences of antenatal and intrapartum maternal infections (Morton et al., 2013). Additional research has shown that women with disabilities are more likely to require epidural anaesthesia, more likely to give birth by caesarean section, less likely to successfully breastfeed, and experience longer hospital stays (Redshaw, Malouf, Gao, & Gray, 2013).

These recent findings have negatively reinforced ingrained attitudes amongst maternity care providers who view disability in pregnancy as problematic and ‘high risk’. (Walsh-Gallagher et al., 2013). This assumed high risk classification held by many healthcare care providers exposes these women to increased and unnecessary medical intervention, particularly known risks associated
with caesarean and instrumental deliveries (Berthelot-Ricou et al., 2013; Gurol-Urganci, Cromwell, Mahmood, van der Meulen, & Templeton, 2014; Raees, Yasmeen, Jabeen, Utman, & Karim, 2013). Moreover, this classification instantly limits disabled women’s options for different provisions of perinatal care, and diminishes their right for maternal choice and autonomy (Begley et al., 2009).

In order to fully understand the implications of current research related to maternal outcomes for women with physical disabilities, we must additionally explore current maternity care provision by seeking the views and experiences of this population group. Recent qualitative research exploring the perinatal care experiences of women with physical disabilities has revealed that the majority of these women report that there is a significant absence of information regarding the interaction between pregnancy, childbirth and their disability, with many healthcare providers completely lacking in awareness, knowledge and expertise (Tarasoff, 2015). This is despite directives by the Australian Human Rights Commission through the Disability Discrimination Act (1992), which draws attention to the duty of care for service providers to improve care access, disability awareness, information exchange, expertise training, and equality in care (Stella McKay-Moffat & Cunningham, 2006). Indeed, an American based national survey recently conducted amongst parents with disabilities revealed that a lack of disability awareness and experience amongst maternity care providers was shown to be the major cause of antenatal and intrapartum complications for these women (Barker & Maralani, 1997).

Furthermore, lack of collaboration and fragmentation of care between disability carers and maternity care providers was also reported as a significant barrier preventing women from receiving competent and effective perinatal care (Redshaw et al., 2013). Research showed that the majority of care providers were not co-located resulting in fragmentation of care, which created an overall unwillingness amongst care providers to treat both the disability and pregnancy related issues collaboratively. This resulted in increased transport and access difficulties for these women, and a general sense of dissatisfaction in their care experiences (Andrews, 2011). Additionally, communication between service providers was found to be deficient, as was consultation with the women, with the majority of women reporting having little to no involvement and choice in regards to their care options (Redshaw et al., 2013).

Another significant barrier encountered by women with disabilities when accessing maternity care, was physical access barriers. Throughout the literature many women reported an absence of ramps, inadequate doorway openings, confined small spaces preventing access to maternity facilities, and inaccessible ultrasound and examination tables (Tarasoff, 2015). Furthermore, unsuitable equipment such as non-adjustable cribs and beds additionally prevented them from
adequately and opportunistically caring for their babies (Tarasoff, 2015). This lack of suitable equipment and poorly designed facilities further results in significant financial burden for these women as they are forced to source specialised equipment such as wheelchairs, cribs, personal attendant services and accessible transport (Tarasoff, 2015).

**MIDWIFERY CARE TO ADDRESS THESE WOMEN’S NEEDS:**

As Midwives, we are required under both professional and government guidelines to protect and advocate for the rights and well-being of all childbearing women (Australian Human Rights Commission, 1992; Nursing and Midwifery Board of Australia, 2008). It is important therefore, that as Midwives we recognise and acknowledge the significant barriers and challenges faced by women with disabilities, and allow their experiences and views to inform and guide our practice. Additionally, we must reflect on and recognise our own inadequacies, and the inadequacies of current services, that prevent us from providing equitable and optimal care for this population group (Nursing and Midwifery Board of Australia, 2006).

It is not acceptable for midwives to remain unaware and uneducated in how to best provide care for women with disabilities, as this deficit in knowledge and experience can lead to unsafe practice, poor maternal satisfaction, and adverse maternal and neonatal outcomes for this group of women (Stella McKay-Moffat & Cunningham, 2006). In accordance with Midwifery Competency Standards, we as midwives must be commitment to seeking appropriate training and experience to address these skill and knowledge gaps (Nursing and Midwifery Board of Australia, 2006). However it is important that such education and training enlists the participation of women with disabilities, recognising them as the experts in their own bodies and care requirements (Walsh-Gallagher et al., 2013). This collaborative learning ensures midwives and women work in true partnership to ensure optimal and safe outcomes for both women and infants (S Mckay-Moffat & Rotheram, 2007).

While continuity of care is now well recognised for its benefits to women and their offspring, it should be offered equitably to all women regardless of ability or disability status (Jenkins et al., 2015; McLachlan et al., 2012; Sandall, Soltani, Gates, Shennan, & Devane, 2013). Midwives are well positioned to provide continuity of care, and can effectively coordinate collaboration amongst the different care providers involved in supporting disabled women in pregnancy (S Mckay-Moffat & Rotheram, 2007). For care to be truly woman centred, care needs to move beyond the focus on the disability to more holistic and multidimensional care that incorporates the involvement of a diverse yet specialised range of service providers such as midwives, obstetricians, physical therapists, occupational therapists, general practitioners, social workers,
and disability carers (Malouf, Redshaw, Kurinczuk, & Gray, 2014). With a continuity midwife as the lead care provider, this ongoing and trusting relationship can facilitate the coordination of personalised and effective care strategies and collaboration that is well suited to addressing the unique and diverse needs of women with physical disabilities (Jenkins et al., 2015).

In recognition of transport and access barriers identified by women with disabilities, midwives can actively seek to facilitate timely and convenient consultations to occur at a central and suitable facility to decrease the number of trips women need to make (Tarasoff, 2015). In this way transport, access and financial barriers can be reduced, and improved awareness and collaboration amongst healthcare providers is encouraged (Tarasoff, 2015). In addition Midwives can assist in sourcing appropriate equipment and facilities for these women, that are uniquely suited to their individual needs (Tarasoff, 2015).

However, the most significant contribution midwives can make towards providing woman-centred collaborative care to women with disabilities is to raise awareness within our own profession and the wider community, through continued research and education (Malouf et al., 2014). In order to achieve this we must advocate for the involvement of this population group in practice and policy reviews, and demonstrate the provision of personalised care that is innovative and flexible in consultation with this unique group of women. By doing this midwives can positively improve awareness and ensure that care provided to disabled women remains safe, evidence based, and woman centred (Malouf et al., 2014).

**CONCLUSION:**

While the literature on disability in pregnancy is deficient and currently ineffective in informing policy and instigating attitudinal changes, Midwives still have a duty of care under government and professional governing bodies to provide care that is informed, equitable, woman centred and collaborative, to improve the experiences and outcomes for women with disabilities (Australian Human Rights Commision, 1992; Nursing and Midwifery Board of Australia, 2008).

The current attitudinal, physical and financial barriers encountered by women with disabilities prevents this population group from having a positive pregnancy, birthing and motherhood experience, potentially impacting further on maternal and neonatal outcomes (Tarasoff, 2015). Eliminating these barriers for women with physical disabilities is of paramount importance if midwives are to improve perinatal care experiences and outcomes for this population group.
REFERENCES:


