

Abstract

Background

Although more disabled women are pursuing motherhood over time, little is known about their needs and experiences in achieving this goal.

Methods

A three-phase study was designed with the aim of identifying ways for services to be more responsive for women living with physical or sensory impairment during and after pregnancy. This paper draws on the qualitative phases of a three-part mixed method study, which involved individual and focus group interviews with the women and maternity and child health practitioners

Results

Sixty-two mothers with either a physical or a sensory impairment, and 28 health practitioners participated in the study. Three themes were identified in relation to the current approaches to service provision: that the women were often responsible for educating the practitioners about their impairment; they often encountered disabling environments and; it was not uncommon for them to also encounter disabling attitudes from others. Strategies suggested by our participants to improve the provision of maternity services were for women's impairments to be taken into account in the structure and process of service provision, and for practitioners to problem solve and think ahead of how to meet the needs of disabled mothers.

Conclusion

The need to take the woman's impairment into account was an overarching issue and strategy identified by both women and practitioners. This consideration has relevance not just at the practitioner/women interaction level but also for educational, structural service provision and policy levels.

Keywords: physical impairment, sensory impairment, pregnancy, birth, postpartum, qualitative descriptive, health professional.

Background

Becoming a mother is highly valued in Western societies; it gives a woman status (McKeever, Angus, Lee-Miller & Reid., 2003; Walsh Gallagher, Sinclair, Conkey, (2012). Blackford, Richardson and Grieve argue that achieving this status is one of the contributing factors to the growing number of women who are disabled choosing to become mothers (Blackford, Richardson & Grieve, 2000). However, international studies have shown that disabled women are subject to negative stereotypes when seeking reproductive health care (Blackford, Richardson & Grieve, 2000; Gill, 1996; Kallianes & Rubenfeld, 1997; Nosek, Howland, Rintala, Young & Chanpong,2001; Prilliltensky, 2003; Sands, 2005). For example, a common stereotype they may confront is the belief that they are asexual and concomitantly lack the ability to attract sexual partners of either gender (Gill, 1996; Nosek, Howland, Rintala, Young & Chanpong , 2001; Prilliltensky, 2003). Compounding this is a common belief that their impairments limit their ability to carry out the tasks associated with mothering (Prilleltensky, 2003). Evidence exists of some disabled women being encouraged to terminate pregnancies and to be sterilised; or feeling that their children may be taken from them because they had been judged as 'unfit mothers'; and of their being denied access to reproductive technology (Kallianes, & Rubenfeld, (1997; Kirshbaum & Olkin, 2002; Sands, 2005; Walsh GallagherD, Sinclair, Conkey, 2012).

With a history of such negative stereotypical beliefs about 'mothering and disability' embedded within society, it is likely that some health professionals involved in maternity care may hold such beliefs. Such beliefs may also influence health education and thus maternity practitioners may lack the expertise to care and advocate for disabled women. For example, Kirshbaum and Olkin (2002) found in their survey of disabled women's

experiences within the healthcare system, that 62% indicated the health professionals they connected with lacked the necessary knowledge and expertise to care for them. In addition, women who are pregnant and live with impairments such as epilepsy, multiple sclerosis and rheumatoid arthritis, need health practitioners who are knowledgeable about the effects of disease modifying agents because of the risk of the drugs causing foetal abnormality (Carty, 1998; Geisser, 2003; Lorenzi & Ford, 2002; Thomas, 1999).

There is also a belief that women with impairments are at risk for having 'defective babies' because of their condition that is widely believed within society to be inherited, even by the mothers themselves and their health practitioners (Carty, 1998; Prilleltensky, 2003). The assumption that for a woman to have a 'perfect baby' requires a lack of maternal 'imperfection' appears to put subtle and not so subtle pressure on disabled women to terminate their pregnancies. Disabled women offered prenatal testing and abortions by health practitioners have reported they are not asked about their view on being pregnant, and if they decided against having such interventions, some have been treated with disapproval (Carty, 1998; Prilliltensky, 2003; Walsh Gallagher, Sinclair & Conkey, 2012).

The New Zealand maternity system is unique internationally. Midwives can "provide all primary maternity services without medical supervision; they have prescribing rights, the same access to hospital and specialist services and the same funding for maternity care provision as doctors" (Grigg & Tracy, 2013, p. 60). Two key principles that underpin New Zealand's maternity care are midwifery's concept of being in 'partnership' with women and continuity of care. The former recognises the woman as an active partner in her relationship with her midwife throughout her passage to motherhood. The latter is where the New Zealand structure of Lead Maternity Carer (LMC) offers women continuity of carer(s). The

LMC can be a midwife, general practitioner with a diploma in obstetrics and gynaecology or an obstetrician. The LMC assumes overall responsibility for the care of a woman from pregnancy through to six weeks postpartum.

Whilst the physiological aspects of pregnancy have been explored in relation to some physical impairments (Birk, Ford, Smeltzer, Ryan, Miller, Rudick, 1990; Confavreux, Hutchinson, Hours, Cortinovic-Tourniaire & Moreau, 1998; Ostensen, Fuhrer, Mathieu, Seitz & Villiger, 2004), there has been a relative paucity of research into the experiences of disabled women in relation to pregnancy, birth and motherhood. Except for Savage's (1989) study, there is little such research in our own country of Aotearoa New Zealand despite its respected stance on disability rights and equity (Ministry of Health, 2001). One recent exception is the inclusion of disabled women in a Maternity Service Survey. The 2011 Maternity Service Survey found that disabled women were comparatively less satisfied with all aspects of maternity care, i.e. 26% of the disabled women reported being dissatisfied with all aspects of maternity care in comparison to 15% of the non-disabled women. The authors concluded "The overall care from the Lead Maternity Carer is close to being considered a relative strength of maternity care amongst these women. However, care received during their hospital stay after birth, care received at home (following birth) and the quality of information that was readily available are all identified as priority areas for improvement" (Ministry of Health, 2012, p. 79).

To our knowledge, there has been scant research exploring the experiences of maternity health practitioners regarding their experiences of caring for disabled mothers particularly during pregnancy, birth and the early postnatal period. Because of this lack of knowledge, the aim of the overall study was therefore threefold:

1. to investigate the experiences of women with either physical or sensory impairments, and those of health professionals who may be involved such women's care, and
2. to identify the strategies that facilitated the women's physical, social and emotional experiences of motherhood.
3. to identify a consensus on priority actions and strategies (this will be the subject of a future publication).

The current paper addresses the first two aims with our focus on the key issues experienced by the women, the useful caring strategies they identified, and the views of health professional perspectives on issues and strategies.

Throughout the paper we have used the phrase disabled women/mothers in preference to that of women/mothers *with* disabilities. Our rationale is that firstly, it was frequently used by the women in our study. Secondly, the phrase references the social model of disability (Oliver, 1990) which recognises that disability is for many created by external factors such as societal attitudes or lack of wheelchair access rather than impairment alone.

Method

Study design and sample

As noted above, the current paper draws on the findings of the first two phases of the study which involved a postpositivist qualitative descriptive methodology. Borland (1990) identifies postpositivism as having the following associated axioms, that: reality is constructed; there are multiple realities; the researcher is not detached from the research

process in that a relationship exists between the researcher and the researched; and thus truth is partial and limited. Postpositivist research often interprets data at the level of identifying and describing the themes within the data. Thematic analysis is the layering of understanding that happens through the interview process and ongoing re-interpretation of the text (Greenfield, Greene & Johansen, 2007, p. 48). Thus while descriptive qualitative research analyses and interprets the data, its interpretation stays close to the data not applying a philosophical layer (Sandelowski, 2010).

The study involved individual and focus group interviews with the women (see tables 3 and 4) and maternity and child health practitioners (see table 4). The objective of the two qualitative phases was to explore the perspectives of women and practitioners. (The third phase of the study undertook a Delphi survey to identify and prioritise specific recommendations and publication of that will follow).

Purposeful sampling (Patton, 1990) was used to recruit participants from throughout Aotearoa, New Zealand. Key national disability organisations and maternity health providers were involved in the recruitment process; identifying and contacting potential participants through their networks. Women aged 18 – 50 years were eligible to participate if they lived with a physical or sensory impairment and had given birth in the preceding ten years. Our rationale for the time span was to ensure we could recruit at least 6 – 8 women from each region and to allow for variability of impairment type. Health practitioners were eligible to participate if they provided care for women during pregnancy and/or early childhood. We aimed to recruit a sizeable sample in regards to qualitative research (anticipating more than 60 disabled women) to allow for variability to determine whether there were specific

demographic variations in relation to their type of physical or sensory impairment or geographical location (i.e. urban or rural) (Kitzinger, 2006).

Seven disabled women who had decided not to pursue pregnancy and motherhood also took part in the main study and this data will be reported elsewhere. Ethics approval was gained from the New Zealand Multicentre Health and Disability Ethics Committee.

Data collection

In Phase One individual, face to face semi-structured interviews were held with mothers living with physical or sensory impairment who resided in the Auckland area (a city with a population of 1.5 million people). Using open questioning each woman was asked to give a history of her impairment and then describe her experiences of becoming a mother, for example: what factors shaped her decision to become a mother; which health professionals were involved in her care during pregnancy, birth and the postnatal period; what were the issues she had confronted and what helped or might have helped her to manage or overcome these issues. These interviews were used to identify the key issues experienced by these women and to form the basis of the Phase Two focus group topics.

Phase Two consisted of two components:

1. Focus groups with women were used to confirm and extend our analysis of Phase One's findings through group interaction (Kitzinger, 2006). Seven focus groups were held in a range of main urban and rural locations in New Zealand outside of Auckland (again with disabled women). We also wanted to identify if there were similarities and differences with women located in regions other than Auckland. Focus group prompts included: How did your impairment impact on your decision to become a mother? What support did you have from health professionals in relation to

becoming pregnant, through pregnancy, birth and postnatally? What were your experiences of government supports and services? What worked well for you? Each group had two of the research team present (most frequently DP and BG), one to convene, and one to take contemporaneous notes.

2. Individual interviews were held with a variety of health professionals from throughout New Zealand who provided services to disabled mothers. Interview prompts included: what experiences have you had of caring for disabled mothers; which other health professionals do you refer to when caring for disabled mothers; what have been the issues for you when caring for such women? Again two researchers were present (most frequently DP and BG). Telephone interviews were held with women and practitioners wishing to take part but unable to be interviewed face to face due to their distance from the interview location.

All interviews were recorded and transcribed verbatim and throughout. Sign language interpreters were used in our interviews with women who had hearing impairments.

Data analysis

An inductive thematic analysis was used to analyse the individual and focus group interviews (Braun & Clark, 2006; Pope, Ziebland & Mays, 2006). Firstly, DP and BM individually read and reread the first five of the transcripts to become familiar with the data and identify the key issues articulated by the participants and the strategies that they had found helpful. Then on subsequent re-reading broad codes were identified and noted on each of the transcripts. Secondly, the two researchers met together and worked through the five transcripts. Any disagreements regarding the initial codes were discussed with KM (and other members of the team in steering group meetings as required) and the transcript

section reread and recoded. Then the categories that best fit that coding were selected. Lastly, where categories appeared linked, themes were developed. These themes were presented to the full team and the key disability advisor to confirm our initial analyses. This process continued with by DP, BM and DR coding the remainder of the transcripts, and refining the coding framework as new findings emerged. All participants were given a copy of our key findings and the opportunity to feedback. Some language in findings was amended accordingly but no substantive changes made. Rather than both population groups being presented separately, data was synthesised across both to facilitate shared understanding and because a number of issues were similarly considered problematic (or positive) for both disabled women and the health professionals who cared for them. Findings presented here address the key issues women and practitioners confronted, and the strategies they employed to address some of these concerns.

Results

Description of the sample

In total 90 people were interviewed for the study. In Phase One 22 mothers were interviewed in Auckland. In Phase Two seven focus group interviews with a range of 4 to 8 women (n=26 women) were undertaken. Also in Phase Two an additional 14 individual interviews were undertaken (3 via phone) due to the difficulties some women had attending a focus group in their area (See Tables 1 and 2). Thus, in total 62 disabled women were involved in these phases.

A total of 28 health professionals from throughout New Zealand (e.g. Midwives, various specialists including Obstetricians and Gynaecologists, Occupational Therapists, General Practitioners and Plunket Nurses (child health nurses)) were interviewed (see Table 3) . 20

health professionals were interviewed individually (n= 17 face to face; n=3 via phone). Two worksite focus groups were held to capture the perspectives of several health professionals and promote discussion around shared and different experiences of delivering care (n=8).

Key issues and strategies

Our findings (see Table 4) highlighted that services did not fully meet the needs of the disabled women with the women encountering issues that made their maternity experiences problematic. A key issue was the nature of the services that the women required in that, due to the lack of information available, the women became the educators. The women also often encountered a disabling environment and disabling attitudes. The key strategy identified by the participants that helped or would have helped, was for the service providers to take the woman's impairment into account when planning and providing care. Taking women's impairments into account needed to occur not just at the level of maternity practitioner/women interaction but also at a wider structural level with regard to the organisation of services, and required strategies of problem solving and thinking ahead.

Service provision issues

Becoming the educator

The most significant issue identified by women and practitioners in the study was the paucity of, and difficulty in, obtaining information about pregnancy, birth and mothering in relation to the different kinds of impairment. This often resulted in the women becoming the educators.

The midwives only knew what I told them, ... I had to tell them. ...They didn't know anything about MS. They didn't know any of the side effects of it. They didn't know any of the complications and things like that that could have happened, would happen. They knew nothing. (Mother with multiple sclerosis)

Another mother with epilepsy when asked about her midwife's knowledge of epilepsy replied:

My midwife didn't really know anything about epilepsy.

Int: She didn't know anything? [No] How did that make you feel?

Mother: It made me feel fine in that it made me contact my neurologist about the TENs machine instead of just questioning her. I think it was probably me letting her know about me, you know, teaching her. (Mother with epilepsy)

Only one of the practitioners had had more than one experience of caring for disabled women. As such, it would seem disabled women may well be a relatively unknown group to maternity and other service providers. Women described struggling to find maternity practitioners who had any experience of caring for women with similar impairments and an in-depth knowledge of their impairment. Being unable to be cared for by practitioners who knew about their impairments created a situation whereby the women became the experts in how their pregnancy might impact on their impairment or vice versa. Some mothers were able to access other health practitioners to answer their queries or they drew on their own knowledge. This information they then passed on to their maternity practitioner/midwife.

Encountering a disabling environments

All women spoke about the difficulties accessing facilities and resources which would have that facilitated their ability to care for themselves and their infant.

I searched and searched and searched for a pram with a handbrake rather than a foot brake because I can get the foot brake down but I don't have enough power in my foot to be able to get it back up again. You have to bend right down to almost ground level to flick that up. (Mother with cerebral palsy)

During their pregnancies the women appeared to be the key 'actors' involved in finding home equipment and devices that would facilitate them to care for their infant. For example, women with physical impairments searched for prams, cots and pushchairs that they could manage and manoeuvre; women with hearing impairments sourced devices that would alert them to the cries of their babies. For women able to find other mothers with the same impairment the search to find out what equipment was best and where it might be obtained from was made easier. For those unable to access such advice, searches ranged from local stores through to international internet searching, often proving to be time consuming and expensive. For the women, obtaining appropriate equipment appeared to be a positive strategy enabling them to be actively engaged in the care, wellbeing and safety of their infant. As shown above, having accessible equipment, such as a pram, allowed mothers to care for their infants with fewer difficulties.

Since 2001 building requirements in New Zealand have stipulated that all new and renovated public buildings should have reasonable and adequate facilities for disabled people to visit, work and carry out normal activities there. This would include any maternity service buildings. However, modifications may be blocked by decision-makers using the rationale of cost effectiveness. For example:

We opened a new antenatal practice, and we didn't have any wheelchair stipulation put on us when we changed the purpose of the building. We were prepared to do it and we certainly made the bathroom that way. But the bathroom door itself wasn't wide and it hasn't been widened. [...] After 11 years of never having anybody through the doors in a wheelchair, it was seen as a lot of expense. (Midwife)

The midwives did lobby for the renovations to be fully accessible for disabled women (and their partners) but their requests were not heeded. Even though legally required, the renovation of the antenatal clinic to be made accessible was not considered feasible or

warranted. Such decisions seem to reflect a marginal status for disabled women and a lack of awareness regarding the rights of disabled people. While midwives may be able to visit disabled women in their homes, this may not always be desirable either for the midwife or the woman.

Having accessible birthing and maternity units that accommodated their needs was identified by the women as important:

Once I got up into the ward there were a few obstacles that I faced with a new child, like the bassinet was too high, to lift the baby in and out by myself. I was reliant on buzzing a nurse each time I needed to pick my baby up, or feed him, that sort of thing. And then the bathing they taught the way that you should hold him. But I didn't stay in the hospital very long with my son, and the quicker I could get home into my own environment that was set up for me, the better it was. (Mother with spinal cord injury [SCI])

For women with physical impairments, having maternity units that provided wheelchair accessible facilities and equipment such as bassinets that could be accessed from the side - or for women with muscular dystrophy high seated chairs- allowed women to be more autonomous in performing the tasks required to care for their baby. Encountering facilities that did not provide for their impairment created an unnecessary difficulty and exacerbated their experience of dependency on staff.

Disabling attitudes

Whilst only two women in our study reported being overtly challenged in their decision to become mothers, these experiences had a marked effect. One woman recalled:

I was in the café with a few of my other friends who had come to visit and a random lady in the line had heard that I'd obviously had a baby. She turned around and she was horrified, she was disgusted and outright said that to us, to all of us, to myself (Mother with SCI)

It was not uncommon for women/and or their family members to be aware of people's concern around about their decision to pursue motherhood and their abilities.

I won't say they (my family) were doubtful. Like they never said anything to me like, 'I think you should get rid of it', or 'What did you do a stupid thing like that for', or anything like that, but they were concerned about how I would cope (Mother with spina bifida)

This concern placed the women and/or their family members in the position of having to justify why they wanted to become mothers and to explain how they were going to manage caring for and raising their child.

Several women were made aware either directly or indirectly of health professional's concerns about their ability to provide care for their infant. For example, one woman said:

In the later stages of my pregnancy [...] a big meeting was called. For the first half of an hour of the meeting my husband and I weren't allowed in. and it turned out that my midwife was the one with the concerns and she basically didn't have the balls to talk to me about it so she felt the need to involve Child Youth and Family Services. The concerns were things like I didn't have all the equipment that I was going to need and my husband didn't appear very supportive, he was very work driven and doing shift work, and how was I going to cope at home on my own at night and would happen if there was an emergency with my baby. (Mother with spina bifida)

While a direct challenge to the mother was not a common experience, several women perceived that they were monitored by their maternity and health service providers more

closely than might non-disabled women. The women felt that they were more scrutinized in their ability to care for their infant and that there was more potential for governmental agencies to be alerted and to become involved in the welfare of their child. These references to concerns or worry passed on to the women, while sometimes with the best intentions, nevertheless emphasized the mother's disability rather than ability.

Taking it into account

Becoming informed

All the women wanted their impairment to be taken into account by their maternity practitioners and were clear on what this would require. They wanted practitioners to become informed about how the impairment impacted on each stage of pregnancy, birth and postpartum, and in turn, how the physical and physiological processes of pregnancy and birth might impact on the impairment. For example, the women with hearing impairments required practitioners who accommodated for their unique communication needs, particularly during birth.

When you're in labour, everything just narrows right down. I was so focussed on my midwife watching what she was telling me because I've got to know when to stop pushing, you know? So it was like thinking, right how many centimetres.... tell me when to stop. But she was good because she had said 'When I pat your knee like that, stop'. She had worked out some cute little physical instructions. (Mother with hearing impairment)

For others it was the very specific monitoring or actions required to ensure their and their baby's wellbeing.

Autonomic dysreflexia occurs sometimes if you feel the pain differently and your blood pressure can go sky high. But the midwife was reassuring and was monitoring my blood pressure all along to make sure that that didn't happen. [...] So it was about her learning how to deal with somebody if she ever comes across autonomic dysreflexia it again. She did put things in place like a spray if I needed it, how to cope with it if I did get it. (Mother with SCI)

For some mothers the process of taking their impairment into account provided the reassurance that they did not require routine medical oversight or intervention during pregnancy and/or birth because of their impairment. For some women, particularly one rural woman, this kept open the choice of giving birth in their local maternity hospital. For others, it was determining how their impairment created the need for finding different ways of communicating or performing various activities. For all the mothers taking their impairment into account gave them assurance of their baby's; and their own wellbeing and safety.

Problem solving

The mothers spoke most positively about those practitioners who identified some of the problems their impairment posed in meeting their baby's needs, and then thought of ways to solve such problems. What was important to the mothers was that the practitioners thought beyond the 'normal and accepted' ways of caring for the infant and created alternative ways, which enabled the mothers to care their infant themselves.

It took a while to get the hang of breast feeding. I was still having trouble getting her to latch on [...] somebody would have to come and help, because I couldn't see the child's head [...] She said, "I've thought about it. If you put your fingers over your nipples and put your nipple out and then get this hand to find his mouth." She

realised that hand-to-hand coordination is really important for me, because I can't do hand-to-eye coordination. (Mother with visual impairment)

As exemplified in this excerpt the midwife had recognised how reliant the mother was in others assisting her to initiate breastfeeding. Rather than accepting this as the only way of ensuring that the baby was latched on properly, the midwife developed a strategy that allowed the mother to achieve this herself. She used her creativity and insight to solve the problem – to find other ways that considered the mother's unique situation and capabilities. Thus the mother was encouraged in her own ability to care for her baby.

Thinking ahead

Several women and practitioners, particularly midwives, identified how caring for women throughout the whole maternity period provided maternity practitioners with a unique and significant opportunity.

I think they [practitioners] should talk to each woman about what she wants. And maybe looking into the impairment a bit themselves, and then making up suggestions of things that they might think the woman might need. But I mean it is quite good because midwives have got that whole nine months in order to do that, so they have the time. It's not like they're going in all of a sudden with some sort of, you know, health problems. They've got the pregnancy. They've got the time to get to know somebody. (Mother with SCI)

New Zealand's maternity system attempts to provide women with one lead maternity carer who is responsible for the woman's care from pregnancy through to six weeks after birth. Thus during the antenatal appointments the LMC has the opportunity to systematically gather and build knowledge about the mother and her impairment. The antenatal period therefore provides the opportunity for the LMC to think ahead about the resources that the

women requires and to begin accessing these and setting them in place for birth and the postnatal period.

Some of the midwives used the antenatal period to ensure that the home was prepared for the postnatal period. They worked to steer the process of providing the necessary information but without taking over from the mother's own learning opportunities, or reducing their autonomy. They identified the mother's existing networks, and facilitated the mother to extend these. However, they did not leave the mother solely responsible for accessing resources she may require. Rather they stepped in when the mother was unable to access information or resources.

I find out what kind of supports the women have in place, what their home environment is like and how it's set up for the baby, depending on what their concern is or whatever their disability is. Then I give them the information so that they can access it. Unless obviously there's a major problem and they can't source something, then I would. The idea is to empower women, not to remove the autonomy from them. (Midwife)

Guided by the practitioner in this way mothers may be enabled to build on and extend their existing supports and knowledge base. The mothers may also be enabled before the birth of their baby to anticipate and determine their own needs and to be prepared.

Discussion

While the rights of people with disabilities have received recognition internationally through the United Nations' Convention of the Rights of Persons with Disabilities (2006), our study suggests that disabled mothers remain, and are considered to be, a relatively small group of mothers, and this in turn may contribute to their needs being marginalized. Our findings add

support to those of the recent New Zealand Maternity Consumer Survey 2011 (2012) which identified that disabled women were comparatively less satisfied with aspects of maternity care. Our key findings were that services did not fully meet the needs of the disabled women and that the practices of taking the woman's impairment into account and thinking ahead adopted by some of their midwives worked to address the issues faced by the disabled women and the practitioners.

Lack of accessible information created difficulties for both the women and their health providers. This deficit has been identified by other authors (such as Begley et al., 2009; Kaiser, Reid & Boschen, 2012; Mitton, Treharne, Hale, Williams & Kitas, 2007; Thomas & Curtis, 1997) and may hamper the opportunity for disabled women to be given appropriate care. It is clear that midwives cannot be specialists in all the kinds of impairment that may affect pregnancy, and so it is important that in such situations they liaise and work with other health professionals to ensure that the woman receives care tailored to her needs.

Our finding that often the women reported themselves as the main sources of information for their health providers has the potential to position disabled women as the more powerful knowledge provider in the client/practitioner relationship. Indeed, Signore, Sprong, Kotoski, Shinowara & Blackwell (2011) recommend that practitioners include physically impaired women in decision-making and planning as they "often have insight into their own capabilities and what they expect from their bodies during labour" (p. 941). While women may know about their impairment and their capabilities, they may not necessarily know about pregnancy, birth and managing motherhood and how these may affect one another and intersect with her impairment. To that end, an assumption that the woman is the expert may therefore place her in an uncomfortable and unrealistic position, especially

if she is not able to access appropriate information. Furthermore, having to take up this responsibility entails speaking out, this at times may take courage. For first time mothers particularly, lack of experience and knowledge may limit their ability to anticipate, plan and prepare for what is ahead. Therefore the relationship between the mother and her maternity service provider and other health providers needs to be carefully negotiated and discussed, with the providers recognising that disabled women want to receive care that is centred on their needs and allows them to have control, supported by the expertise of the 'practitioner partner/s' (Clarke, 2009; Curtis, 1997; Kaiser A, Reid D, Boschen, 2012, Mitton, Treharne, Hale, Williams & Kitas, 2007; Thomas &). This can contribute to mothers having better quality of care and a positive birth experience (Kayes, McPherson, 2012; McPherson, Headrick & Moss, 2001; Smeltzer, 2007; Walsh Gallagher, Sinclair, Conkey, 2012).

The routine inclusion of information about pregnancy, birth and motherhood in materials provided by disability organisations (such as those dealing with specific impairments e.g. multiple sclerosis, arthritis, spinal cord injury) and disability in maternity and parenting educational and information materials has potential to increase both the mother's and practitioners' confidence. Having confident carers has been shown to help, for example, other work describes that it helps "the women to feel calm and confident in their abilities to manage the event" (Tebbet & Kennedy, 2012, p. 766). In addition, awareness of the social model of disability, in which the social context is examined for the physical, economic, social, attitudinal and other types of barriers that may exist for disabled women and their families when accessing maternity services is key for all health professionals and maternity service providers (Clarke, 2009).

Our participants experienced great difficulty in accessing resources such as childcare aids. The absence of appropriate resources meant some of the women had to become unnecessarily dependent on staff, family and other support persons. The resultant dependency (due to the disabling environment) may reinforce some maternity practitioners' and others' beliefs that women with impairments are not capable of being mothers. There is evidence that the provision of these resources improves confidence and independence and allows disabled women to better care for their children (Begley et al., 2009). One strategy for providing equipment for disabled mothers could be that maternity units and/or disability organisations develop local or regional resource and equipment pools that could be lent or hired out to disabled women and their families. This would facilitate maternity practitioners' ability to source such aids and equipment in advance of the birth.

Some women and midwives in our study reported experiencing a range of institutional structural barriers. Lawler, Lalor and Begley (2013) suggest that the existence of such physical barriers may be perceived by physically disabled women as unwelcoming, discouraging them so that they delay making appointments. The 'cost effectiveness' rationale used by some providers to justify not making buildings completely accessible or investing in resources, we believe, needs to be challenged.

Many of our participants were aware of societal attitudes reflecting negativity about disabled women becoming mothers, though only two faced overt confrontation from members of the public. Several women considered that they were 'under surveillance' because of their impairment from maternity practitioners with the threat of being reported to the government agency, Child Youth and Family Services, whose focus is the welfare and

safety of children. Walsh-Gallagher, Sinclair and McConkey (2013) also found that their participants believed they were the 'subjects of discriminatory practices' and were being watched closely in their ability to care for their baby. It has been suggested that health professionals (and indeed the general population) may be fearful of disability (Patston, 2007), and as a result conversations regarding the level of support the mother may require may be difficult to initiate. As with most patient-professional relationships, it is likely that discussion of concerns or issues (on the part of the mother or the practitioner) would result in a more shared understanding of the level of support or supervision is required. However, we suggest that in such discussions maternity practitioners need to be aware of the disabling effects of negative attitudes and beliefs on women with impairments and to negotiate the level of support in ways that enable rather than disable these women.

Being informed, assessing and planning ahead is important for every maternity practitioner and each mother whom they care for. Caring for disabled mothers brings another element of into play (Signore, Sprong, Kotoski, Shinowara & Blackwell, 2011). The way, and the extent to which, the impairment will influence women's journey through pregnancy to motherhood will vary from woman to woman. For the woman to travel safely through each stage and to take on the role of mother, she needs a practitioner who can take her impairment into account.

Midwifery-led continuity of care has been found to be "safe, cost effective and associated with lower intervention rates, higher normal birth rates and increased satisfaction ... the effects may be a result of care mediated by human relationship and the potential to innovate and to work within a consistent philosophy" (Page, 2013, p. 690). But as Page also

points out only a minority of women have access to midwifery-led continuity of care. While some countries such as Australia, United Kingdom and Ireland provide combinations of midwifery-led, medical-led and shared models of continuity care, (Sandall, Soltani, Gates, Shennan & Devane, 2013), only in the Netherlands and New Zealand is continuity of care the dominant model of care. Continuity of care is a principle of the New Zealand maternity care with a Lead Maternity Carer providing a woman's antenatal, intrapartum and postnatal care. This is reflected in the New Zealand Report on Maternity 2010 (Ministry of Health, 2012) that 85.7% of women registered with an LMC during pregnancy and 91.6% had care from a LMC midwife.

As shown in our findings, continuity of care enhances the opportunity for maternity practitioners and the women to build a relationship over the period. For disabled women this may be particularly significant as their needs can be identified and worked towards meeting in a timely and effective manner from the antenatal period onwards (Rotherham & McKay-Moffat, 2007). Regardless of the maternity service structure if it is to fully consider the woman's needs the assessment process must be ongoing, problem solving, forward thinking and holistic. As shown above, the woman's impairment and the ways it uniquely impacts on her pregnancy, birth, postpartum and mothering needs to be taken into account. This calls for the practitioner to be flexible, which is critical if disabled women are to feel that they have control and have choice.

Limitations

The main limitations of this study were that participants self-selected and it was retrospective. However, these are necessary limitations given the lack of a national database. Our findings are specific to the women who took part in the study and cannot be

generalised to all women who have a physical or sensory impairment or all health professionals who work with them during their maternity care. Whilst we attempted to recruit women from all the main cultures in New Zealand, we were unsuccessful in recruiting women who identify as Pasifika or Asian and specific investigation into these populations is therefore warranted.

Conclusion

Becoming a mother can affirm disabled women's status of womanhood (McKeever et al., 2003; Walsh Gallagher et al., 2012). Health service providers have the potential to either perpetuate or remove the barriers that disabled pregnant or birthing women may encounter: they can be part of the problem or part of the solution. Two aims of our study were to investigate the experiences of women with either physical or sensory impairments, and those of health professionals who may be involved such women's care, and to identify the strategies that facilitated the women's physical, social and emotional experiences of motherhood. Our study identified the provision of appropriate resources as the key concern and the important need for health practitioners to be proactive advocates in taking women's physical or sensory impairment into account.

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Table One. Women's age groups

Age group	Number of women
20 – 25 years	2
26 – 30 years	8
31 – 35 years	17
36 – 40 years	21
41 – 45 years	13
46 – 49 years	1

Table Two. The women's types of impairment.

Type of impairment	Number
Rheumatoid arthritis	6
Multiple sclerosis	16
Muscular dystrophy	4
Hearing	7
Visual impairment	5
Spinal injury	4
Neurological : TBI, stroke, brain tumours, brain stem injury	6
Epilepsy	3
Cerebral palsy	3
Spina bifida	3
Other	5

Table Three. The health practitioners participating in the study.

Health Profession	Number
Plunket Nurses	2
Midwives	7
General Practitioners	2
Occupational Therapists	6
Speech & Language Therapists	1
Obstetrician	4
Rheumatologists	2
Spinal Cord Injury Sexual Health Nurse	1
Rehabilitation Consultants	3

Table Four. Themes/sub-themes

Theme: Service provision issues	Theme: Taking it into account
<ol style="list-style-type: none">1. Becoming an educator2. Encountering a disabling environment3. Disabling attitudes	<ol style="list-style-type: none">1. Problem solving2. Thinking ahead