A Qualitative Study of Embodiment among Women with Physical Disabilities during the Perinatal Period and Early Motherhood

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
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Abstract

Although there are over 500,000 mothers with disabilities in Canada, little is known about how women with disabilities experience becoming and being mothers. This dissertation qualitatively explores how thirteen women with physical disabilities in Ontario experienced their embodiment during the perinatal period and early motherhood. Informed by feminist disability scholarship, embodiment here is understood as relational; that is, the intertwining of the body and the mind and the interplay between the material body and the social world.

Findings are presented according to three “stages”: pregnancy, breastfeeding, and mothering. I found that participants’ embodied experiences across these interrelated “stages” were shaped by dominant discourses of pregnancy, breastfeeding, and motherhood, as well as dominant discourses of disability, often enacted through social interaction. Participants desired to be perceived of as “good mothers,” seemingly to avoid being perceived of as “unfit” and in turn affirming stigmatizing discourses of disability. Meeting the expectations of the “good mother” proved to be challenging, however, as disability limited what participants could physically do. Consequently, some experienced ambivalent and negative feelings about disability. Importantly,
I also found that disability was experienced as valuable in the context of becoming and being a mother. The embodied experience of disability provided opportunity to subvert the sometimes-unrealistic expectations associated with pregnancy, breastfeeding, and mothering, as well as discourses of disability as defective and undesirable. Regarding pregnancy, the embodied experience of disability was appreciated, offering a reimagination of the “unruly” pregnant body. Disability in the context of breastfeeding and mothering called attention to the need for self-care and challenged understandings of accessibility and independence.

In sum, participants’ embodied experiences of the perinatal period and early motherhood both aligned with and subverted dominant discourses. In documenting how these discourses shaped embodied experience, I discuss their potential implications for health research and practice. Notably, I argue that the ways in which participants’ embodied experiences subvert dominant discourses evoke new ways to think about the body, disability, and parenting. These new ways of thinking add to feminist disability and perinatal embodiment scholarship, as well as present opportunities for more inclusive and equitable health research and practice.
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Dedication

To my one and only Mama, who made sure I could follow my dreams.
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Chapter 1
Introduction

Persons with disability continually confront erroneous and often stigmatizing assumptions about their life goals and desires, ability to live productively within communities, and participation in activities of daily life. Nowhere are such false societal views more entrenched than around the multitudinous issues raised by sexuality and reproductive health. The notion that a woman with disability, for example, would seek pregnancy and motherhood defies long-held social norms (Iezzoni & Mitra, 2017, p. 369).

1.1 Background and rationale

Based on interviews with women with physical disabilities who had recently become mothers, this dissertation explores how women with physical disabilities experience their embodiment during the perinatal period and early motherhood, in a context in which, as the above quotation suggests, women with physical disabilities are rarely imagined to be mothers. Informed by feminist disability (Wendell, 1996; Crow, 1996; Thomas, 1999; Kafer, 2013) and feminist scholars (Davis, 1997, 2007; Einstein & Shildrick, 2009), I understand embodiment as both the intertwining of the body and the mind (or self) and the physical body as interacting with the social world; embodiment is experienced as relational and dynamic processes in or of and through our bodies (see Chapter 2 for a more detailed discussion of embodiment). In this dissertation, I place embodiment at the forefront, as a lens to understand and analyze culture and society, and ultimately health and social inequities. Furthermore, as others (Wendell, 1996; Davis, 1997; Kafer, 2013; Inckle, 2014; Garland-Thomson, 2002) have theorized, it is my hope that focusing on embodiment evokes new understandings of self and in turn the body in a world where what is understood to be “normal” is often limited and maybe even detrimental.

In this dissertation, I primarily use the language of ‘women with physical disabilities’ because this is the language that most of my study participants used to identify themselves; however, I acknowledge that not all women with physical disabilities identify themselves in this way (for a lengthier discussion about language use, see Chapter 3).

1.1.1 Women with physical disabilities and health

According to the World Report on Disability, disability is more prevalent among women than among men globally (World Health Organization & The World Bank, 2011). Similarly, in
Canada disability is more prevalent among women compared to men (Bizier, Fawcett, & Gilbert, 2016; Burlock, 2017). Notably, analyses of data from the most recent Canadian Survey on Disability indicate that 11.4% of women aged 15-44 (i.e., women of reproductive age) in Canada report living with a disability, compared to 10.5% of men of the same age group (Statistics Canada, 2013a). In Ontario, the prevalence of disability among women aged 15-44 is slightly higher at 12.6% (though the prevalence of disability among men of this same age group is about equal at 12.7%) (Statistics Canada, 2013a). The most commonly reported types of disability among women are those related to pain, limits to flexibility (i.e., limited ability to bend down and pick up an object from the floor and/or with reaching in any direction, e.g., arthritis), and limits to mobility (Burlock, 2017; Statistics Canada, 2013b).

Despite policies and legislation protecting the health and human rights of people with disabilities, including the right to parenthood (e.g., the United Nations Convention on the Rights of Persons with Disabilities), many women with physical disabilities report experiencing barriers accessing health care, resulting in unmet health care needs and poor physical and mental health outcomes (Gibson & Mykitiuk, 2012; Casey, 2015; Cott, Gignac, & Badley, 1999; Wisdom et al., 2010; Krahn, Walker, & Correa-De-Araujo, 2015; Miles-Cohen & Signore, 2016). Sexual, reproductive, and perinatal health disparities among women with physical disabilities have been widely documented over the last two decades (e.g., see Kallianes, & Rubenfeld, 1997; Basson, 1998; Collins, 1999; Lipson & Rogers, 2000; Nosek, Howland, Rintala, Young, & Chanpong, 2001; Piotrowski & Snell, 2007; Tarasoff, 2015; Signore, 2016; Iezzoni & Mitra, 2017). In recent years major health authorities have begun to recognize the need to address reproductive health inequities and disparities experienced by women with disabilities. Notably, the World Health Organization (2009) has urged countries to include a disability component in their reproductive health care programs, the American College of Obstetricians and Gynecologists (2012) has developed online resources for clinicians working with women with disabilities, and the National Institutes of Health (2017) has funded several projects focused on the perinatal health of women with physical disabilities (e.g., Iezzoni, Yu, Wint, Smeltzer, & Ecker, 2013; Iezzoni, Wint, Smeltzer, & Ecker, 2015; Horner-Johnson, Darney, Kulkarni-Rajasekhara, Quigley, & Caughey, 2016; Mitra et al., 2017; Powell et al., 2017a).
Similar efforts in Canada to address the reproductive and perinatal health of women with disabilities are still in their infancy, though there are some important initiatives underway. For example, in 2017 Sunnybrook Health Sciences Centre in Toronto opened the Accessible Care Pregnancy Clinic—North America’s first clinic caring for pregnant women who have both invisible and visible physical disabilities (Sunnybrook Health Sciences Centre, 2017). Recently, the Vancouver-based Spinal Cord Injury Perinatal Interest Group developed an information booklet for women with spinal cord injuries who are considering pregnancy (Spinal Cord Injury BC, 2015), and this group is currently involved in research exploring the lactation and breastfeeding experiences of women with spinal cord injuries (Basso & Hodge, 2016; Hocaloski, Holmgren, Hamilton, Elliott, & Krassioukov, 2016; Hocaloski et al., 2017). As well, there is a project underway in Ontario focused on understanding midwives’ knowledge, attitudes, and practices related to care for clients with disabilities (Association of Ontario Midwives, 2018; Nicole Bennett, Ryerson University, personal communication). Finally, there is study underway to determine population-based estimates of fertility rates and perinatal outcomes among women with disabilities compared to non-disabled women in Ontario—the first study of its kind in Canada (ironically, funded by the National Institutes of Health; Hilary Brown, University of Toronto, personal communication). Despite these initiatives, in Canada, very little is known about how women with physical disabilities (or women with disabilities broadly) experience becoming and being mothers; many of these recently initiatives focus on outcomes or provide-level barriers to care with little attention to women with disabilities’ embodied experiences, experiences that may provide insight into addressing the poor outcomes and barriers to care experienced by women with disabilities during the perinatal period and early motherhood documented in the literature to-date.

1.1.2 Pregnant and mothering women with disabilities

While equivalent data are not readily available in Canada, population-based studies conducted in the United States indicate that women with physical disabilities are becoming pregnant at similar rates to non-disabled women (Iezzoni et al., 2013; Horner-Johnson et al., 2016). Despite the growing number of women with physical disabilities becoming pregnant, there is now a sizeable body of literature indicating that women with physical disabilities encounter attitudinal, informational, physical, and financial barriers to perinatal care and
experience perinatal health disparities (Iezzoni et al., 2013; Signore, Spong, Krotoski, Shinowara, & Blackwell, 2011; Tarasoff, 2015; Mitra, Clements, Zhang, & Smith, 2016; Horner-Johnson et al., 2016). For instance, Mitra and colleagues (2015) found that, compared to non-disabled women, women with disabilities are less likely to receive prenatal care in the first trimester. Numerous studies have found that women with physical disabilities are more likely to have caesarean deliveries and preterm and low-birth-weight babies (Kelly, Nelson, & Chakravarty, 2009; Signore et al., 2011; Redshaw, Malouf, Gao, & Gray, 2013; Morton et al., 2013; Mitra et al., 2015; Horner-Johnson, Biel, Darney, & Caughey, 2017). A systematic review and meta-analysis of perinatal outcomes among women with physical, sensory, and intellectual/developmental disabilities (Tarasoff, Ravindran, Malik, & Brown, in preparation) found that women with disabilities were at increased risk for gestational hypertension and hemorrhage, as well as at increased risk for caesarean delivery and postpartum hospital readmission.

Compared to non-disabled women, women with physical disabilities are more vulnerable to risk factors associated with adverse pregnancy outcomes, including poor mental health, obesity, emotional, physical, and sexual abuse, low socio-economic status, and lack of social support (Kim, Kim, Hong, & Fredriksen-Goldsen, 2013; Mitra, Manning, & Lu, 2012; Parish, Rose, & Andrews, 2009; Mitra, Clements, Zhang, & Smith, 2016; Steinmetz, 2006; Pharr & Bungum, 2012; Yoshida, Dumont, Odette, & Lysy, 2011; DisAbled Women’s Network Canada, 2014; Nosek et al., 2001; Nosek et al., 2008; Nosek, Hughes, & Robinson-Whelen, 2008). In other words, research has found that childrearing women with disabilities are at increased risk of poor physical and mental health outcomes. The high prevalence of poor health outcomes among women with disabilities has been linked to systemic issues such as lack of social and financial support, information, and resources (Miles-Cohen & Signore, 2016; Yoshida, Dumont, Odette, & Lysy, 2011).

From her analyses of Canadian Survey on Disability data, Furrie (2015) found that there are nearly 1 million (999,110) parents with disabilities with one or more child living in their home, and 580,825 of these parents with disabilities are women. In the United States there are more than 4 million parents with disabilities (i.e., six percent of American mothers and fathers are disabled) (Reeves, 2013; Kaye, 2012; National Council on Disability, 2012). Specifically, it
is estimated that 26% of adults with physical disabilities are parents (Preston, 2010). Further, analyses of recent Canadian Survey on Disability data indicate that women with disabilities are more likely to be lone parents (11%) than non-disabled women (7.8%) (Burlock, 2017).

There is a sizeable body of literature documenting how the mothering experiences of many women with disabilities are fraught with barriers, stigma, and surveillance (e.g., see Prilleltensky, 2003; Malacrida, 2007; DisAbled Women’s Network Canada, 2007; Begley et al., 2009; National Council on Disability, 2012; Kaiser, Reid, & Boschen, 2012; Wolowicz-Ruszkowska, 2016). For instance, there are many reports of mothers with disabilities having their parenting capabilities questioned and subsequent efforts to remove children from their custody (Kirshbaum & Olkin, 2002; CBC, 2012; Mulholland, 2012; National Council on Disability, 2012; Track, 2014). One study found that 13% of parents with physical disabilities in the United States reported discriminatory treatment in custody cases; parents with disabilities in general are more likely to lose custody of their children after divorce, and parents with disabilities face significant barriers to adopting children (National Council on Disability, 2012). In sum, while we know a lot about poor perinatal outcomes and opposition to mothering experienced by women with physical disabilities, there is limited research on how women with physical disabilities experience their embodiment during the perinatal period and early motherhood.

1.2 A brief review of the embodiment literature

In reviewing the childbirth embodiment literature, Walsh (2010) has argued that few studies focus on the embodied experience of becoming a mother itself; instead, he found that many studies focus on reproductive technologies, and by extension, pregnancy and childbirth as pathology. Similarly, referencing (Young, 2005a), Goldberg, Harbin, and Campbell (2011) have found that “the importance of women’s embodiment for gaining knowledge and understanding about their pregnancies and births is still neglected” (p. 175). Furthermore, Ryan, Todres, and Alexander (2011) contend that few studies on women’s experiences of breastfeeding focus on embodiment. I too found that the empirical research on how women experience their embodiment during the perinatal period and early motherhood is somewhat limited, particularly in comparison to the health and social sciences literature documenting women’s perinatal care experiences and outcomes more broadly. In particular, the empirical literature on how women with physical disabilities experience their embodiment during the perinatal period and early
motherhood is scarce. As well, I found that not all studies use the language of ‘embodiment,’ though I interpreted the findings of what I considered relevant studies through the lens of embodiment I used for this study as described in Chapter 2.

In short, I found that both (acquiring) disability and becoming and being a mother are embodied experiences that come with a heightened sense of awareness of the material body and in turn may evoke a reconceptualization of the self. Also, how women experience the perinatal period and early motherhood, as well as how they experience disability, is shaped by narrow ideals or discourses of femininity and the body, which may be both affirming and restricting. In the sections to follow I provide an overview of these common themes in the perinatal and disability embodiment literature.

1.2.1 Embodiment (and disembodiment) in the perinatal period

In has been argued that the body is central to a woman’s sense of self during pregnancy, labour, and birth (Young, 2005a), and as such, becoming a mother “offer[s] a fascinating opportunity to explore the relationship between the body and the self” (Bailey, 2001, p. 110; also see Warren & Brewis, 2004). Specifically, in research on the perinatal period and early motherhood, write Warren and Brewis (2004), “we typically see the dramatic appearance of the phenomenal [or material] body” (p. 229). For some women, this heightened sense of bodily awareness may represent “an epiphany” of the body and in turn the self as incongruent or unstable (Warren and Brewis, 2004, p. 220; also see Akrich & Pasveer, 2004). In other words, pregnancy, childbirth, and breastfeeding may be experienced as “boundary violations,” whereby the permeability of bodies and selves (or identities) become apparent (Bost, 2001, p. 164). The perinatal period may be experienced as a challenge to the notion that the body is under the control of the mind (or the Cartesian mind/body split).

For instance, from their interviews with new mothers, Warren and Brewis (2004) observed that pregnancy was experienced as “a period during which normal service is suspended, when the body apparently slips its moorings and refuses to ‘obey’ in the commonplace ways” (p. 221, emphasis in original). Rather than “merely a biological event” (Davis & Walker, 2010, p. 461), however, in the literature it has been reported that the embodied experience of pregnancy highlights the body as a “primary resource [or the source] for the
construction and consolidation of identity” (Warren & Brewis, 2004, pp. 220-221). Indeed, in writing about her embodied experience of pregnancy, Young (2005a) shares that a change in her body (pregnancy) is experienced as “becom[ing] different from what I have been” (p. 49).

For some of the women in Warren and Brewis’s (2004) study, pregnancy was an experience that made them feel particularly aware of their “female materiality” (p. 225). Likewise, many of the 30 first-time mothers in Bailey’s (2001) study experienced pregnancy as a “a confirmation of adult womanhood,” describing “themselves as feeling more womanly as their bodies changed” (p. 116). Despite some of the physical and psychological discomfort some women experience during perinatal period, the women in Bailey’s (2001) study too generally conceptualized their pregnant bodies as “a positive reflection on a feminine self” (p. 116).

Interestingly, pregnancy has not only been reported to be experienced as heightened awareness of one’s material body and an affirmation of femininity; some studies have found that during pregnancy some women feel “disembodied” or “alienated” from their bodies and in turn pre-pregnancy selves. For some women the embodied experience of pregnancy includes feeling as though they have lost bodily autonomy and agency and in some cases is experienced as a disconnect between a woman’s sense of self and how her perinatal body looks or is behaving (Young, 2005a; Akrich & Pasveer, 2004; Warren & Brewis, 2004; Nicolson, Fox, & Heffernan, 2010). Similar experiences have been documented regarding breastfeeding: “While some women perceive weaning their infants in terms of loss and exhibit reluctance to do so, others express relief that their bodies are once again their own” (Shaw, 2004, p. 104; also see Schmied & Lupton, 2001).

Related to feelings of disconnect, Nash (2012) and Nicolson and colleagues (2010) note that during the perinatal period, women’s relationships to their bodies are mediated by ideals of femininity related to body image and the pressure to “perform” femininity and mothering in particular ways (and by extension the surveillance of performance). The pressure to lose “baby weight” and to breastfeed (or to breastfeed only in particular spaces and for particular lengths of time) are two examples of the latter. Interestingly, however, it has also been reported that the loss of bodily control experienced during the perinatal period may be positive for women, as the perinatal period serves a unique period wherein women may feel freer from adhering to strict beauty and bodily norms. For instance, some participants in Nash’s (2002) study liked being
pregnant because their bodies appeared to be “more contained (‘good’ fat) and not ‘jiggly’ (‘bad’ fat)” (p. 73). Much of the literature however seems to focus on how women perform or feel pressured to perform (and are surveyed in their performance of) narrow ideals of the feminine body, rather than on how the perinatal period and early motherhood might be potentially subversive periods wherein women can embrace their “unruly” perinatal and mothering bodies.

In sum, the perinatal period represents a time in which many women experience a heightened awareness of their physical bodies, and for some, an alienation or disconnect from their bodies and in turn their pre-perinatal selves. Related to the latter is the equation of pregnancy, motherhood, and breastfeeding with a loss of autonomy, whereby some women feel as though their bodies have “taken over” (and/or their children have taken over their bodies) and in some cases have even conceptualized their perinatal bodies as “disabling” (Nash, 2012). Additionally, while becoming and being a mother is experienced by some women as an affirmation of womanhood, the literature also reveals that the embodied experiences of the perinatal period and early motherhood are shaped by narrow ideals of femininity.

1.2.2 Embodiment and women with physical disabilities

While some (e.g., Loja, Costa, Hughes, and Menezes, 2013) have argued that embodiment is underexplored in the disability studies literature, this is changing as medical and social models of disability are being questioned (see Chapter 3). There is a growing body of literature concerning the embodiment of people with physical disabilities, with a focus on 1) embodiment as it relates to acquiring a disability and 2) gender or femininity and masculinity (I do not take up the latter here; for e.g., see Shakespeare, 1999; Gerschick & Miller, 1995). However, like in the perinatal embodiment literature, the term embodiment is not always used in the disability literature; some disability scholars use ‘self-concept’ and ‘identity’ in their theorizing of embodiment.

Researchers have explored how people with disabilities experience their embodiment soon after they become injured, impaired, or otherwise become disabled, with an emphasis on how individuals with disabilities experience a change in embodiment between their pre-disabled and disabled selves. For example, from her study exploring the process of how people with disabilities come to form their identity as disabled, Galvin (2003) found that with changes in
appearance came a “a sense of dissonance between past and present identities” (p. 406). Similarly, in her study of how people with chronic illnesses adapt to their impairments, Charmaz (1995) reported that becoming impaired caused people to reconsider their sense of self, evoking taken-for-granted norms about the body. Her participants perceived their impaired bodies as distinct from their self-concepts. For many, it took time to “integrate new bodily facts into their lives and their self-concepts” (Charmaz, 1995, p. 663; also see Loja et al., 2013). Relatedly, as Yoshida (1993) concluded from her study of adults with traumatic spinal cord injury resulting in paralysis, it may be best to understand the embodiment of people with disabilities as a pendulum, whereby the reconstruction of identity specifically for those who have acquired a disability is a process that swings back and forth between aspects of the pre- or non-disabled and disabled self (also see Vick, 2013).

The reconstruction or reconceptualization of the disabled self and more broadly the embodied experience of disability, it has been found, is not always necessarily negative or burdensome. For instance, Loja et al. (2013) learned that some participants in their study experienced becoming disabled as an opportunity to challenge the status quo and see things differently; namely, bodily changes evoked new perspectives on “accessibility and on the penetrating nature of the non-disabled gaze” (p. 199).

Considering literature examining gendered aspects of embodiment, several researchers have found that some women with physical disabilities feel pressured to be perceived in traditional feminine ways (Barron, 1997; Zitzelsberger, 2005) and even perform hyper-femininity (Scott, 2015) due to their experiences of invisibility (Zitzelsberger, 2005). In other words, women with physical disabilities report that while their disabled bodies are often highly noticed, their capacities, lives, and desires often go unseen (Zitzelsberger, 2005). To make themselves visible in positive ways then, some women with physical disabilities feel the need to perform femininity in traditional ways. Some have reported that only when they presented themselves according to traditional expectations of femininity or in ways that might help them to “pass” as non-disabled do they feel included or acknowledged as women or “valued” by other people (Scott, 2015). In this way, the literature reveals how disability and gender are inter-related.
To avoid being perceived of as “abnormal” and in turn avoid hostility and rejection in social encounters, some women with physical disabilities have adopted strategies to minimize their disabilities, including concealing parts of their bodies, not disclosing their disability, and avoiding public spaces (Zitzelsberger, 2005). Moreover, it has been reported that having a disability contributes to some women questioning their capabilities of being active and productive individuals, wives, mothers, and caregivers (Reinikainen, 2008; Rice, Zitzelsberger, Porch, & Ignagni, 2005). This finding thus suggests that women with disabilities may internalize stigmatizing discourses of disability wherein women with disabilities are expected to only occupy limited and dependent roles (for more on the latter point, see Chapter 2).

Related to but also beyond gender, while Galvin (2003) found that becoming disabled can disrupt one’s sense of self, she also concluded that the embodied experience of disability provides an opportunity to subvert norms. Notably, from the stories of her 92 participants, Galvin (2003) contends that conventional views of sex and sexuality, as well as work and independence may be transformed and even challenged when one comes to form their disabled identity. Similar sentiments have been reported in some studies of women with physical disabilities; Zitzelsberger (2005) and Loja et al. (2013) found that some women with physical disabilities embrace their bodily differences as good and powerful, thereby rejecting dominant and stigmatizing discourses that include expectations of how disabled bodies and women’s bodies should look and behave.

In sum, I found that there are some parallels between the perinatal embodiment literature and disability embodiment literature. As Warren and Brewis (2004) note, “in accounts of the experience of illness [and disability], we typically see the dramatic appearance of the phenomenal [material] body, just as we do in the data on pregnancy and breastfeeding” (p. 229). This heightened awareness of the material body for some people pregnant women and people with disabilities evokes a reconceptualization of the self. As well, the literature regarding women with physical disabilities reveals that interactions with other people, as well as dominant discourses of femininity and disability, shape embodied experience (Reinikainen, 2008).
1.2.3 Embodiment and women with physical disabilities during the perinatal period and early motherhood

In her autoethnography, Heather Kuttai (2010), a Canadian Paralympian with a spinal cord injury, interlaces her two experiences of pregnancy, labour, and birth with critical disability and feminist theories (for a review see Tarasoff, 2011). One central theme of Kuttai’s autoethnography was how her embodied experience of becoming and being a mother shaped her sense of self, particularly herself as a someone who is sexual and gendered: “I needed to experience an embodied change as dramatic and altering as pregnancy and childbirth in order to finally see that I am a woman” (Kuttai, 2010, p. 31). Thus, for Kuttai (2010) the embodied experience of becoming a mother was experienced similarly to how non-disabled women experience becoming a mother, that is, as an affirmation of womanhood.

What is unique about the embodied experiences of women with physical disabilities, however, is that many grow up in a context where women with disabilities have long been denied the norms or “privileges” of femininity, such as motherhood; instead, women with disabilities have been typically perceived of as incompetent and dependent—characteristics that contrast what dominant discourses expect a “good mother” to be (Malacrida, 2009; see Chapter 2 for more on this). Indeed, for many women with disabilities, writes O’Toole (2002), “the training against motherhood begins when a woman is diagnosed as disabled and continues throughout her childbearing years.” In other words, “unlike most women, who experience social and emotional pressure to have children, disabled women are under pressure not to have children” (Rogers, 2006, p. 1, emphasis in original). Thus, while in some respects the embodied experiences of becoming and being a mother for women with physical disabilities echo those described by some non-disabled women, their embodied experiences cannot necessarily be estranged from the reality that becoming and being a mother is often not imagined as an experience they should or could have. As Kuttai (2010) experienced, the embodied experience of the perinatal period may be particularly significant for women with physical disabilities, because becoming a mother is experienced as providing the disabled body “a different value, status and worth” (p. 31).

The findings of Grue and Lærum’s (2002) study on mothers with physical disabilities in Norway echo what Kuttai describes in her autoethnography. Many of the 30 women with
physical disabilities interviewed by Grue and Lærum (2002) too reported that becoming a mother changed their perceptions of their body; some commented that as mothers their bodies were “made into something of great value” (p. 676). Specifically, becoming a mother was experienced by many women in their study as “capturing” a gender, or ‘recapturing’ a lost gender” and an “achieve[ment of] womanhood” (p. 676). Similarly, Walsh-Gallagher, Sinclair and McConkey (2012) report that for the women with physical disabilities in their study, pregnancy was experienced as an affirmation of feminine identity and in turn an affirmation of their worth as women and mothers. Finally, many of the mothers with physical and sensory disabilities in Lawler, Begley, and Lalor’s (2015) study reported experiencing motherhood as “a meaningful gain,” bestowing a status and a sense of value and purpose that they did not experience prior to becoming mothers (p. 1679).

Conversely, it has also been reported that mothers with physical disabilities’ embodied experiences of pregnancy and mothering include feeling “out-of-place” (particularly for those mothers who use mobility devices and as such have difficulty accessing physical and social spaces related to parenting, see McKeever, Angus, Lee-Miller, & Reid, 2003), as well as pressured to live up to the expectations of dominant discourses of pregnancy and motherhood. For instance, Kuttai (2010), in reflecting on why she had ultrasounds done, shared that she wanted to do or “perform” pregnancy like other (non-disabled) women do. Likewise, Grue and Lærum (2002) found that many of their study participants felt that “they had to go to great lengths to ‘present’ themselves and their children as managing ‘normally’ in order to be accepted as ‘ordinary’ mothers” (p. 671; also see Thomas, 1997; Malacrida, 2009).

Though limited, there is some evidence that the embodied experience of mothering for some women with physical disabilities does include subversion of dominant discourses of mothering and disability. From her interviews and focus groups with Canadian mothers and non-mothers with physical disabilities, Prilleltensky (2003) found that by advocating for help with childcare and directing that care (and other supports they were receiving), mothers with physical disabilities challenge the notion that independent physical care is equated with parental competence (also see Wolowicz-Ruszkowska, 2016). Similarly, while the mothers with disabilities that she interviewed experienced themselves as being dependent in many ways, Malacrida (2007) learned that these mothers also found ways to creatively embed themselves in
networks of dependence, whereby dependency came to be experienced not negatively but as a source of strength, connection, and identity.

In sum, the limited literature concerning how women with physical disabilities experience their embodiment during the perinatal period and early motherhood reveals the various ways in which expectations regarding gender or femininity and disability shape embodied experiences. Noticeably absent from this empirical embodiment literature, as well as the perinatal health literature concerning women with physical disabilities, is a focus on breastfeeding; much of the research on the perinatal and early motherhood experiences of women with physical disabilities focuses on pregnancy and mothering.

This dissertation study aims to build on the findings in the bodies of literature reviewed above, specifically by drawing upon feminist and feminist disability theorizing of embodiment—theorizing that has not been widely taken up in empirical studies of the perinatal period and early motherhood.

1.3 Research questions

This study addressed the following questions: 1) How do women with physical disabilities experience their embodiment during the perinatal period and early motherhood? 2) What factors, actors, discourses, and contexts shape their embodiment during the perinatal period and early motherhood?

1.4 Overview of chapters

In Chapter 2, I introduce the theoretical approaches that inform this empirical investigation. Specifically, I present my understanding of embodiment, as informed by the work of feminist disability scholars, and discuss dominant discourses which I believe to be informative to answer my second research question.

In Chapter 3, I describe the data collection methods and analytic strategies employed to address my research questions. In short, thirteen women with physical disabilities who had recently become mothers and who were living in Ontario participated in this study. They were interviewed using a semi-structured guide and completed a socio-demographic questionnaire. Ten of the thirteen participants were interviewed a second time (follow-up interview). Data
analysis was informed by a constructivist grounded theory approach (Charmaz, 2006), to identify common themes across participants’ experiences of embodiment during the perinatal period and early motherhood.

The substantive findings of this study are presented in Chapters 4, 5, and 6, each representing a different “stage” of the perinatal period and early motherhood. In Chapter 4 I discuss participants’ experiences of embodiment during pregnancy (including labour/delivery), organized according to four interrelated themes: (4.1) Achieving, feminine bodies, (4.2) Unrecognized and undesirable pregnant bodies, (4.3) Embodying ambivalence about disability, (4.4) Self-sacrificing, anxious bodies, and (4.5) Knowledgeable, unruly bodies.

In Chapter 5, I focus my analysis on the embodied experiences of breastfeeding. Notably, in this chapter I consider what some participants’ decisions not to breastfeed might mean in a context where it is expected that mothers breastfeed, yet women with physical disabilities are not expected to be mothers and subsequently rarely imagined to be breastfeeding. In this chapter, my analysis is organized under five interrelated themes: (5.1) Nurturing bodies, (5.2) Working maternal bodies, (5.3) Disabled and breastfeeding bodies, and (5.4) Ambivalent breastfeeding bodies, and (5.5) Subversive (non)breastfeeding bodies.

In Chapter 6, I explore the embodied experiences of mothering infants and young children, particularly considering how disability is experienced as both limiting and positive or valuable in the context of mothering. Echoing experiences reported in Chapter 4 regarding pregnancy, I begin Chapter 6 by discussing how participants experienced not being recognized by other people as mothers, as well as their experiences of heightened scrutiny and surveillance from other people when they were recognized as mothers, under the theme (6.1) “Is he yours?”: Unrecognized and over-monitored disabled maternal bodies. Under the next themes (6.2) Foregrounding disabled bodies, and (6.3) Making maternal bodies visible, I focus on how interactions with other people foregrounded different aspects of embodied experience for participants in the context of mothering. Building on analysis presented in Chapter 5, I then discuss embodied experiences of mothering as grounded in participants’ disabled bodies, under the theme (6.4) Challenging and painful bodies, and how participants wrestled with the expectations of dominant discourses of motherhood, under the theme (6.5) Wrestling with dependent bodies and the expectations of a “good mother.” I conclude this third and final
findings chapter by considering the various ways in which participants’ embodied experiences of mothering subvert dominant discourses of motherhood, under themes (6.6) Embodying interdependence, (6.7) Seeing disability differently, (6.8) The value of mothering with a disability, and (6.9) Confident bodies.

Finally, in Chapter 7, I provide an overview of the key findings of this study, specifically drawing out common themes that I identified across Chapters 4, 5, and 6. In doing so, discuss the theoretical and empirical contributions and implications of this study. I conclude with a discussion of future directions for research.
Chapter 2
Theoretical Underpinnings

Despite the growing number of women with physical disabilities who are becoming pregnant, there is little research on how they experience becoming and being mothers. One explanation for this gap in the literature may be the pervasiveness of discourses that imagine motherhood and disability as incongruent. In the first part of this chapter, I describe dominant discourses of pregnancy, motherhood, breastfeeding, and disability. In the latter part of this chapter, I discuss the theoretical approaches that informed my understanding of embodiment for this study, including the work of Kathy Davis (1997, 2007) and feminist disability scholars (e.g., Wendell, 1996; Thomas, 1999; Crow, 1996; Kafer, 2013). In short, I understand embodiment as both the intertwining of the body and the mind (i.e., a rejection of the Cartesian mind/body split) and the body as interacting with the social world; embodiment is simultaneously material or physical (i.e., in or of our bodies) and shaped by social interactions, discourses, and the environment around us (i.e., experienced through our bodies). In this way, embodiment is relational, dynamic, and fluid.

2.1 Discourse

Drawing on the work of Foucault (1972) and others, I understand discourse as “not a language or a text but a historically, socially, and institutionally specific structure of statements, terms, categories, and beliefs” (Scott, 1988, p. 35). Specifically, writes Foucault (1972), “discourse … is a practice that has its own forms of sequence and succession” (p. 169). Discursive practices thus work to establish norms and “truths.” In this way, “discourse is constitutive of [a particular] ‘reality’” (Sidhu, 2003, p. 34). By dominant then, I mean discourses that are pervasive (i.e., are public or popular discourses) in the Western world. Dominant discourses are generally taken for granted as “truth,” often shaping and constraining the imagination and social practices. Dominant discourses are often reproduced in social interaction, as well as produced and reinforced within institutions, such as the legal and health care systems and the mainstream media. Because dominant discourses are so prevalent, they often go unquestioned. In other words, argue Robinson and Robinson (1998), “because discourses are often so entrenched in a culture as to be invisible, one may grow up not realizing that a great deal of what one assumes is real is actually a culturally created myth” (p. 64). As such, we may come
to internalize dominant discourses as “normal” or right, particularly if they come to be touted as such by those in power or the dominant group. Discourses are enacted on and through bodies, shaping how individuals perceive themselves and others and how they behave in the world, ultimately shaping one’s sense of self.

2.2 Dominant or normative discourses of pregnancy, motherhood, and breastfeeding

In this section, I discuss some of the most pervasive or dominant discourses concerning pregnancy, motherhood, and breastfeeding in Western society, notably the discourses of self-sacrifice and individual responsibility. The idealization of women as the “natural” caregivers of children and in turn the idea that individual women are solely responsible for the fulfilling the duties and roles associated with pregnancy, mothering, and breastfeeding are common, often-unquestioned, discourses. These discourses align with the discourse or ideology of intensive mothering (Hays, 1996), which entails “self-sacrifice, social isolation, and conventional gender roles” (Fox & Neiterman, 2015, p. 673), as well as Rich’s (1976) theorizing of motherhood as an oppressive “institution.” The influence of these discourses is omnipresent; even women who are not mothers are expected to adhere to these discourses, or as Young (2005b) has argued, “whether they are mothers or not, women today are still too often cast in the nurturant role” (p. 90). This latter point speaks to a contradiction of these dominant discourses; that is, while pregnancy, mothering, and breastfeeding are experiences deemed “natural” for women (i.e., they are experiences that women are expected to desire and know how to perform), they are at the same time experiences that are expected to be performed in a particular way. Notably, these discourses are intertwined with discourses of risk management and medicalization (Conrad, 2007; Imperatore, 2014), whereby these “natural” experiences are conceptualized as medical or health conditions in need of management in order to avoid putting women and their infants “at risk” of poor outcomes.

2.2.1 Pregnancy

Dominant discourses of pregnancy come with the expectation that, as a “medical condition,” women are to behave in particular ways in order to avoid “fetal endangerment”; as such, pregnancy can be understood as “the first phase in a lifetime of intensive mothering”
Imperatore, 2014, p. 8). In other words, writes Jette (2006), “the pregnant body is disciplined by discourses and practices suggesting how a woman can have a ‘normal’ pregnancy by making the appropriate lifestyle choices (i.e., following proper nutrition and exercise guidelines, undergoing routine medical examinations)” (p. 334). In order to avoid risk to one’s child, to have a “proper” pregnancy and be a “good mother,” individual women are encouraged to look and behave in particular ways (e.g., not smoking, not drinking alcohol, eating “healthy”). A pregnant woman should be in optimal health; she must not be too skinny or too fat (Morrissey, 2012; Fox & Neiterman, 2015). Again, informed by discourses of self-sacrifice, individual responsibility, and risk management (or the fear of being “high risk”), pregnant women are tasked with practicing self-surveillance to deliver “healthy” babies (Harper & Rail, 2012).

Some feminist scholars have argued that dominant discourses of pregnancy place greater emphasis or value on the fetus or child than on the pregnant woman (Harper & Rail, 2012). These discourses may have translated to practice, as advances and integration of technology in reproductive and maternity care settings, such as amniocentesis, 3D ultrasounds, and fetal heart rate monitoring have been said to place a greater emphasis on the health and well-being of the fetus than the mother. In addition to reinforcing the expectations placed on mothers to ensure the health of the fetus, some have suggested that the increasing use of reproductive technologies implies which bodies are or are not valued or desired, and in turn, has increased discussions about disability (see Parens & Asch, 2003; Shildrick, 2004; Rapp & Ginsburg, 2007; Hubbard, 2006; Saxton, 2006; Shakespeare, 1998; Farrelly et al., 2012; Lord, 2013; McKinney, 2016). In other words, the advent of reproductive technologies reveal how disability, specifically the prevention or elimination of disability, is imbued within pregnancy discourse.

2.2.2 Motherhood

According to the dominant motherhood discourse, being a mother is considered to be the key aspect of a woman’s identity, “a crucial component of the life course and as making ‘real’ women of mothers” (Woollett, & Marshall, 2004, p. 172; also see Morgan, 1992). In other words, the “ultimate fulfillment as a woman is achieved by becoming a mother” (Hequembourg, 2007, p. 69). As such, motherhood, particularly biological motherhood, has been said to provide status or social value to women (Ulrich & Weatherall, 2000; Fox & Worts, 1999).
As the “natural” condition of women, writes Hequembourg (2007), “all women should be mothers and those who do not mother are deviant or deficient. Further, those who fall outside acceptable definitions of mothering are devalued” (p. 68). This latter point speaks to the good/bad or right/wrong discourse imbued within the dominant discourse of motherhood (i.e., the discourses of individual responsibility and self-sacrificial motherhood construct mothers as “good” or “bad” mothers). The dichotomous discourse of good/bad suggests not only how women are expected to experience pregnancy, breastfeeding, and mothering but also beliefs about who or which types of women should ultimately be mothers or which type women are imagined to be “good mothers.”

There has been much written about mother-blame (e.g., Ladd-Taylor & Umansky, 1998) and those who do not adhere to or seem to live up to the expectations of the “good mother,” including the substance-using pregnant woman/mother (e.g., Springer, 2010; Reid, Greaves, & Poole, 2008), the “welfare mother” (e.g., Croghan & Miell, 1998), the pregnant teen or teen mother (e.g., Wilson & Huntington, 2006), the adoptive mother (e.g., Wegar, 1997), the racialized or Black mother (Roberts, 1993; Akitunde, 2014), and the disabled mother (e.g., Thomas, 1997; Malacrida, 2009; Kuttai, 2010). Ladd-Taylor and Umansky (1998) suggest that it is predominantly white, middle-class women who are imagined as “good mothers.” Dominant discourses of motherhood imagine not only whiteness as desirable but also generally envision mothers to be cisgender (non-trans), heterosexual, “of legal age, married in a traditional nuclear family, fertile, pregnant by intercourse with her husband … able-bodied, or normal mental function” (Hequembourg, 2007, p. 69, emphasis added). In this vein, Rich (1976) and others have argued that the patriarchal institution of motherhood, and by extension the discourse of the “good mother,” functions to reinforce institutions and ideologies that govern Western culture and may be oppressive to women, including the nuclear family, genetic parenthood, patriarchy, and heterosexuality (Ulrich & Weatherall, 2000; Hequembourg, 2007; O’Reilly, 2004). Relatedly, it has been argued that “discourses outside of motherhood deem who will be a ‘good’ mother” (Powell, 2010, p. 38). Notably, the good mother/bad mother discourse, argues Powell (2010), is “fraught with hidden ideologies of class, race, and hidden rules” (p. 38). I would also argue that the good mother/bad mother discourse is fraught with ideas about disability. For example, a “good mother” is expected to be physically capable and focused on caring for others, not in need
of care herself (Malacrida, 2009). Moreover, though a “good mother” should not be too sexy or sexualized, a woman should be desirable as a sexual/reproductive partner, something women with disabilities are often not thought to be (Fine & Asch, 1985; Kallianes & Rubenfeld, 1997; Malacrida, 2007; Kuttai, 2010).

The undesirability of women with physical disabilities (and their “bad genes”) has been so pervasive that women with physical disabilities have been denied motherhood through involuntary sterilization and other means (O’Toole, 2002; Schur, 2004; Boyer, 2006; Iezzoni et al., 2013; Mutcherson, 2017). Indeed, findings from recent studies thus suggest that little has changed since the late 1980s when Asch (1989) found that over three-quarters of Americans viewed a woman’s disability as an acceptable reason for her to be prevented from having children. Women with disabilities continue to confront discrimination by child welfare agencies and local courts, despite legislation and policies that recognize the reproductive and parental rights of people with disabilities in Canada and the United States (e.g., the Convention on the Rights of Persons with Disabilities). The children of parents with disabilities are removed from their parents’ care at alarming rates compared to children of non-disabled (Blackford, 1993; Radbord, 2004; National Council on Disability, 2012; Track, 2014; Smith, 2013; Mutcherson, 2017; Powell, 2018). Furthermore, research indicates that women with physical disabilities’ ability to bear and care for children is often questioned by health care providers (Prilleltensky, 2003; Collins, 1999; Kirshbaum & Olkin, 2002; Kuttai, 2010; Walsh-Gallagher, Sinclair, & McConkey, 2012). For instance, women with physical disabilities have reported being met with surprise when they ask their health care providers about contraception or announce that they are pregnant (Kuttai, 2010). As well, women with physical disabilities reported having encountering health care providers who suggest that they terminate their pregnancies over “concerns that they will give birth to ‘defective’ babies and other prejudicial assumptions about their capacity to care for children” (Prilleltensky, 2003, p. 22). Likewise, while pregnant, some women with physical disabilities have reported a range of negative reactions from strangers, including intrusive curiosity, hostility, questioning of their competence to parent, and even not being recognized as visibility pregnant (Iezzoni et al., 2015). Some pregnant women with physical disabilities have even reported encountering similarly negative reactions from their own family members (Powell et al., 2017a).
While disabled and non-disabled women hold similar attitudes about motherhood and are equally likely to want to have a child, research has found that women with disabilities experience more ambivalence and uncertainty regarding motherhood and are less likely to follow through on their mothering intentions than non-disabled women (Shandra, Hogan, & Short, 2014; LaPierre, Zimmerman, & Hall, 2017). In addition to issues such as feasibility and cost, research has found that other peoples’ expectations and attitudes about disability cause women with disabilities to feel uncertain about having children (LaPierre et al., 2017).

Finally, the notion that motherhood is not meant for women with disabilities is reflected in popular culture and news media. While there seem to be more and more positive or celebratory stories—both real and fictitious—of other marginalized groups, such as lesbian and gay parents, in popular culture and news media, stories of real disabled parents are scarce. Of the stories that do exist for public consumption, these tend to focus primarily on the barriers that pregnant and parenting women with disabilities encounter (e.g., see Rush & Li, 2012; CBC, 2012; Mulholland, 2012; Picciuto, 2015; Joyce, 2017; Anderson, 2017). The continued discrimination and invisibility of mothers with disabilities reveals both the power and limits of dominant discourses; the image of the “good mother” has only expanded so far and this limited view of who should be or can be a mother may shape women with physical disabilities’ life choices and how they experience the perinatal period and early motherhood.

2.2.3 Breastfeeding

The good mother/bad mother dichotomy imbued within motherhood discourse is particularly evident with regard to breastfeeding. Lee (2008) notes that “even in societies where it is a commonplace practice, infant feeding with formula milk can compromise women’s identity as ‘good mothers’” (p. 467), or even, as Murphy (1999) found, call into question their identities as good partners and good women; mothers who do not breastfeeding or who formula-feed are “deviant” or “risky” (Murphy, 1999). Conversely, mothers who breastfeeding for too long may be considered deviant or demonized, as evidenced by a recent *Time* magazine cover story portraying a woman breastfeeding her three-year-old son that was met with choruses of people calling extended breastfeeding gross and even perverted, for example (Clough, 2012; Norwood & Turner, 2013).
Generally, breastfeeding is an experience or a process through which exclusive or intensive mothering (i.e., “good” motherhood, and in turn womanhood) is constituted (Shaw, 2004); “breastfeeding has become the measure of the mother” (Blum, 1999). Breastfeeding is imagined as a celebration of motherhood, fostering the embodied connection between mother and child (i.e., good for bonding and confirming a woman’s role as mother) and beneficial for the child’s health and well-being (Wall, 2001). In this way, breastfeeding discourse emphasizes maternal responsibility and children’s needs (Wall, 2001), and as such may be understood as an extension of discourses of self-sacrifice and individual responsibility that constitute dominant discourses of motherhood. In turn, as noted, not breastfeeding is often seen as a maternal failure.

The “breast is best” discourse is paramount in Western society (Knaak, 2006; Símonardóttir & Gíslason, 2018). Despite the reality that many women experience breastfeeding challenges, as well as inadequate breastfeeding-related supports, breastfeeding is touted as the best or sometimes the only option in the early months of a child’s life, powered by its footing in discourses of naturalness and purity (Wall, 2001) and emphasized by public health campaigns (Knaak, 2006; Avishai, 2011). At the same time as it has been promoted as “best” because it is natural, some have argued that, like pregnancy and childbirth, breastfeeding has become medicalized (Wall, 2001); that is, breastfeeding is something that women are expected to (medically) manage or do in a prescribed way (i.e., “through scientifically based professional intervention” (Wall, 2001, p. 594)). In other words, writes Avishai (2011), these discourses inform women to envision “the lactating body as a carefully managed site and breastfeeding as a mothering project – a task to be researched, planned, implemented and assessed, with reliance on expert knowledge, professional advice and consumption” (p. 24).

In sum, the dominant discourses of pregnancy, motherhood, and breastfeeding are somewhat contradictory, in that these experiences are conceptualized as “natural” yet simultaneously emphasize women’s individual responsibility to manage their bodies in (medically) prescribed ways. The dominant discourse of the “good mother” which extends from pregnancy (or even pre-conception) to breastfeeding and throughout mothering generally does not include women with physical disabilities or conceive of women with physical disabilities as capable of meeting the expectations of this discourse.
2.3 Disability as an individual problem

The most dominant discourse of disability is an individualizing one. That is, disability is largely understood to be “a personal problem afflicting individual people” (Kafer, 2013, p. 4). This individual model or discourse of disability is closely aligned with a medical model of disability, which “frames atypical bodies and minds as deviant, pathological, and defective, best understood and addressed in medical terms” (Kafer, 2013, p. 5). Together these discourses characterize disability as an individual problem, “inherent in particular bodies and minds. Solving the problem of disability, then, means correcting, normalizing, or eliminating the pathological individual, rendering a medical approach to disability the only appropriate approach” (Kafer, 2013, p. 5). As an inherent medical “problem” or “defect,” disability is thus imagined as something to avoid (prevent) or to be fixed (treat). Indeed, even in the field of public health, disability still is thought of primarily as a negative outcome (Lollar & Horner-Johnson, 2017).

While the individualizing/medical model of disability is pervasive in Western society, increasingly some individuals, scholars, and institutions have begun to understand disability in other ways. Notably, in the 1970s and 1980s, in tandem with growing activism among the disability community and the development of the Union of the Physically Impaired Against Segregation’s (UPIAS) definitions of disability and impairment (Thomas, 1999; Wasserman, Asch, Blistein, & Putnam, 2016) scholars in the United Kingdom developed a new framework to understand disability (Shakespeare, 2006). Rejecting the medical model, Michael Oliver (1983) and others conceptualized a social model of disability, reasoning that “disability is not fundamentally a question of medicine or health … rather, it is a question of politics and power(lessness), power over, and power to” (Devlin & Pothier, 2006, p. 2). In other words, they reasoned that “the ‘problem’ is not the person with disabilities; the problem is the way normalcy is constructed to create the ‘problem’ of the disabled person” (L. Davis, 1997a, p. 9). Social modellists differentiated impairment from disability to avoid the biological reductionism or essentialism of the eugenic and medical models of disability: “while impairment is the functional limitation(s) which affect a person’s body, disability is the loss or limitation of opportunities resulting from direct or indirect discrimination” (Crow, 1996, p. 208; also see Barnes & Mercer, 2003). In short, social modellists claim that “persons are manufactured as disabled” (Devlin &
Pothier, 2006, p. 5), or that disability is “a product of social relations” (Kafer, 2013, p. 6). Thus, for people with disabilities to fully participate in society, disabling barriers (including attitudes and physical structures) must be addressed; “social model thinking mandates barrier removal, anti-discrimination legislation, independent living and other responses to social oppression” (Shakespeare, 2006, p. 199).

The social model of disability has influenced disability rights legislation in many jurisdictions and remains a primary model in disability studies and activism around the world today (Thomas, 1999; Withers, 2012). Aspects of the social model of disability have even been incorporated into definitions of disability used by major health authorities such as the World Health Organization (2002). Nevertheless, I would argue that the individualizing/medical model of disability remains paramount in public discourse and continues to inform how people with disabilities are treated in all facets of life, including in their interactions with health care providers.

2.4 Feminist disability studies: Bringing the material body back

Feminist disability scholarship emerged in the mid-1980s in response to the lack of gender analysis in disability scholarship and activism (Gill, 2016). Feminist disability scholars criticized early disability scholarship and organizing for failing to address gender disparities, particularly calling attention to violence against women with disabilities and the “double oppression” women with disabilities experience (Fine & Asch, 1985). Relatedly, feminist disability scholars highlighted how non-normative bodies (i.e., sick or disabled bodies) are often gendered feminine, revealing how dominant discourses of the body construct both women and people with disabilities as defective and inferior (Garland-Thomson, 2002; Thomas, 1999; Shakespeare, 1999; Gershick & Miller, 1995; Ahlvik-Harju, 2016; Hirschmann, 2012; Shildrick, 1997, 2002). Moreover, feminist disability scholars challenged ideas of women with disabilities as only sexually vulnerable, victimized, or “at risk,” and incapable of caring for others. In doing so, they revealed that, for a long time, much of disability scholarship and advocacy work seemed to overlook the “private” or “intimate” and subsequently gendered concerns (e.g., sexuality, reproduction, caregiving) of people with disabilities. Specifically, with the social model of disability informing much of the theorizing and advocacy around disability, there seemed to be
much focus on enhancing people with disabilities’ participation in the “public” sphere (i.e., education, employment, independent living) and an absence of attention to other aspects of disabled people’s lives (e.g., sexuality and reproduction).

By emphasizing the intersection of gender and disability, feminist disability scholars brought the material body back to disability studies (Shakespeare, 2006). Feminist disability scholars (Crow, 1996; Wendell, 1996; Thomas, 1999; Morris, 1991, 1992, 1996; Fawcett, 2000) exposed some important limitations of the social model of disability, including a failure to consider gender-specific concerns, as mentioned, and that understanding the impaired body as separate from the socially disabling environment risks ignoring the embodied experiences of disability. Similarly, with regard to the latter, Hughes and Paterson (1997) have argued that the social model risks “cast[ing] physicality out into the discursive shadows” (pp. 326-327), thereby resulting in “a disembodied notion of disability” (p. 330). Echoing the sentiments of feminist disability scholars, Hughes and Paterson (1997) urged social modellists to consider an approach or understanding of disability that integrates disability and impairment. Specifically, they contend that

Disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning. … Most importantly, the (impaired) body is not just experienced: it is also the very basis of experience. … Disability is, therefore, experienced from the perspective of impairment. One’s body is one’s window on the world (Hughes & Paterson, 1997, pp. 334-335).

By ignoring impairment and focusing (only) on the ways in which disability is socially constructed, thereby placing responsibility for inclusion and a good quality of life on the social, political, and environmental aspects of society, feminist disability scholars revealed how the social model does not consider all aspects of the disability experience (Kuttai, 2010). Feminist disability scholars argued that social model reasoning overlooks the reality that, for many people with disabilities, “some bodily impairments are sources of suffering and frustration, disabling no matter what social context” (Hirschmann, 2012, p. 398; also see Wendell, 1996; Kafer, 2013). This sentiment is probably best articulated by feminist disability scholar Liz Crow (1996):

Most of us simply cannot pretend with any conviction that our impairments are irrelevant because they influence so much of our lives. External disabling barriers
may create social and economic disadvantage but our subjective experience of our bodies is also an integral part of our everyday reality (p. 210).

This is not to say that we should only focus on impairment to understand how people with disabilities experience their embodiment; “what we understand as impairing conditions—socially, physically, mentally, or otherwise—shifts across time and place, and presenting impairment in purely physical terms obscures the effects of such shifts” (Kafer, 2013, p. 7). Moreover, such an understanding reinforces the individualizing and medical discourses of disability, whereby disabled people/disabled bodies are perceived of as “naturally” and thus statically flawed, only made “normal” through medical intervention. In recognition of the subjective experiences of physical bodies in social context then, many feminist disability scholars have adopted a relational conception of disability (similar to the notion of embodied disability or the “sociology of impairment” proposed by Hughes & Paterson, 1997). Specifically, writes Thomas (1999), a relational understanding of disability is a “perspective on the body, on impairment, which does not collapse into fixed, categorical, universalistic and biologically deterministic ways of thinking. … [and] at the same time … [conceives of] material reality [a]s always and everywhere overlaid with socially constructed ideas about the body” (p. 143; also see Kafer, 2013). This understanding of how people with disabilities experience their embodiment proposed by feminist disability scholars, many of whom are women with physical disabilities themselves, informs my understanding of embodiment.

While feminist disability scholars were critical of early disability scholarship, they too took issue with the feminist movement and feminist theory for overlooking the experiences, voices, and bodies of women with disabilities (Morris, 1991, 1996; Wendell, 1996, 1997; Begum, 1992; Lloyd, 1992, 2001; Tilley, 1998; Sheldon, 1999). By adding a disability analysis to feminist issues, feminist disability scholars have pointed out many inconsistencies in feminist theorizing and organizing. For instance, feminist disability scholars have revealed how it is ironic that feminists have long ignored the experiences of women with disabilities given that disability is so prevalent in women’s lives; not only is disability more prevalent among women compared to men in almost all age groups (World Health Organization & The World Bank, 2011; Statistics Canada, 2013a), women are primarily the caregivers of the sick, the disabled, and the elderly (Hirschmann, 2012).
Feminist disability scholars have thus added disability perspectives to a variety of issues taken up by feminists, including caregiving (or the ethics of care; e.g., see Morris, 2001; Hughes, McKie, Hopkins, & Watson, 2005; Kittay, 2011), marriage, and motherhood. Regarding the latter, pioneer feminist disability scholars Asch and Fine (1997) have drawn attention to the fact that “women with disabilities have not been ‘trapped’ by many of the social expectations feminists have challenged” (p. 154). Other feminist disability scholars too have illuminated that while non-disabled women are expected, encouraged, even pressured, and, at times, compelled to get married and become mothers, women with disabilities are often not expected, sometimes actively discouraged, and even denied from having these “relative privileges of normative femininity” (Garland-Thomas, 2002; Kallianes & Rubenfeld, 1997; Collins, 1999; Mintz, 2007; Rogers, 2006).

Summing up the sentiments of many feminist disability scholars before her, Kuttai (2010) notes that, “feminist research has … undervalued and repeatedly excluded the female body with disabilities, and bodies that are not traditionally considered sexual, competent or physically strong” (p. 38). Relatedly, women with disabilities have been excluded from feminist organizing because women with disabilities are often seen as “reinforc[ing] traditional stereotypes of women being dependent, passive and needy” (Thomas, 1999, p. 66), thereby seemingly posing a threat to the gains feminist scholars and activists have made (Thorne, McCormick, & Carty, 1997). Unfortunately, as May and Ferri (2005) have pointed out,

In rejecting the characterization of womanhood as disabling … many feminists, then and now, paradoxically stigmatize disability as a means of asserting ‘women’s’ subjectivity. By definitively asserting that women are not disabled by their sex, many feminists have simply replaced one subject-object dualism (male vs. female) with another: woman vs. disability (p. 120).

In other words, attempts by non-disabled feminists to move away from women being defined solely by their biological/reproductive functions and considered to be inferior as a result (i.e., biological determinism or essentialism) risks erasing the very existence of women with disabilities (May & Ferri, 2005).

The exclusion of women with disabilities from feminist scholarship and organizing is particularly ironic given that feminists have long argued that narrow ideals of femininity, notably
those related to the body and appearance, can be oppressive to women (Garland-Thomson, 1997a, 2001, 2002; Wendell, 1996). Notably, writes Wendell (1996), while feminists have been critical of “the idealization and objectification of women’s bodies, recognizing them as sources of exploitation and alienation,” they have often expressed their own limited body ideals (p. 92; also see Hirschmann, 2012). Specifically, feminists often insist on women’s strength, “overlooking the fact that many women’s bodies are not strong” (Wendell, 1996, p. 92). Indeed, many contemporary iterations of feminism and women’s and girls’ empowerment emphasize “strong” non-disabled bodies; for example, the notion of “Girl Power” is not one that considers disabled girls and women (Erevelles & Mutau, 2005; Erevelles & Nguyen, 2016).

By exposing the limits and exclusionary nature of much of feminist theorizing, feminist disability scholarship makes “the body, bodily variety, and normalization central to analysis of all forms of oppression” (Hall, 2011, p. 6). Notably, feminist disability scholars such as Wendell (1996) have called on feminists to interrogate or re-evaluate their “own body ideals and confront the weak, suffering, and uncontrollable body in our [their] theorizing and practice” (p. 93); feminist disability scholars advocate for more inclusive understandings of bodily difference and an emphasis on embodiment, which includes highlighting, not disregarding, experiences of discomfort, pain, and dependence on medical interventions (Gill, 2016). In calling for a critical engagement with the “non-normative” body and embodiment, feminist disability scholarship works to disrupt the notion that the body and thus the self is always stable or static (Kafer, 2013).

2.5 Making sense of embodiment: The potential of a relational understanding of embodiment for collective reimagining

Post-structuralist theorizing aligns with my understanding of discourse, in that it focuses on how the constitutive force of discourses can shape understandings of self (i.e., post-structuralism is an analysis of power) (Barrett, 2005). Regarding embodiment, post-structural feminist scholarship thus deserves praise for “introduc[ing] gender/power relations to the analysis of the body” (Davis, 1997, p. 14), and in turn challenging biological essentialist or determinist theorizing that has limited women for so long (Walsh, 2010). However, some feminist scholars, including feminist disability scholars, have been critical of post-structural feminist scholarship, including the highly influential work of Butler (1990), because it tends to focus too much “on the cultural meanings attached to the body or the social consequences of
gender rather than on how individuals interacted with and through their bodies” (Davis, 1997, p. 8; also see Davis, 2007; Witz, 2000; Morrow, 2007; Einstein & Shildrick, 2009; Kuhlmann & Babitsch, 2002; Lennon, 2014). By focusing (only) on the discursive, that is, focusing upon the surface of the body and on how culture becomes imprinted upon it, post-structural feminist scholarship risks overlooking the material reality of women’s flesh-and-blood bodies and in turn lived, embodied experience (Clearly, 2016; Lennon, 2014; Kuhlmann & Babitsch, 2002). In response to these critiques, some feminist scholars have reimagined a new way to think about embodiment. Notably, Kathy Davis (1997) contends that embodied theory requires interaction between theories about the body and analyses of the particularities of embodied experiences and practices. It needs to explicitly tackle the relationship between the symbolic and the material, between representations of the body and embodiment as experience or social practice in concrete social, cultural and historical contexts (p. 15, emphasis added).

I understand Davis’ (1997) call for an integrated or relational notion of embodiment to be analogous with the understanding of disability and embodiment more broadly proposed by feminist disability scholars (Wendell, 1999; Thomas, 1999; Kafer, 2013) and others like Hughes and Paterson (1997), whereby embodiment is understood as relational and dynamic processes grounded in real bodies. Indeed, in her more recent writing Davis (2007) too sees a harmonization of her theorizing about embodiment with feminist disability scholarship; she specifically references feminist disability scholar Susan Wendell (1996) who has advocated for doing away with the mind-body dualism and the possibility to challenge notions of “normalcy” by focusing on bodily limitations rather than only capabilities.

In addition to feminist disability scholarship, Davis’ (1997, 2007) theorizing about embodiment echoes that of Einstein and Shildrick (2009) and other feminist scholars who have been critical of the often-abstract, post-structural feminist theorizing of the body, wherein the material body is lost. To echo Einstein and Shildrick (2009), I understand the embodiment as the intertwining of the body and the mind (a rejection of the Cartesian mind/body split), as well as the interplay between the body and the social world. Again, embodiment is relational; how we experience the world is rooted in our physical or material bodies (Shilling, 2003), bodies that engage in and with the world around us, in turn shaping how we experience the world and our sense of self (Grosz, 1987). As such, embodiment can be understood as an ever-evolving “event”
(Budgeon, 2003) or “process” (Turner, 2001; Shildrick, 2009), always “expanding over time and space, and including many layers of individual social existence in ever-specific shades” (Villa, 2012, p. 181); in this way, embodiment is not necessarily just about individual bodies (Turner, 2001; Pink, 2011; Kaul, 2014).

Davis (1997) takes her analysis further to argue that a feminist embodied theory should not only consider domination or how women are oppressed or suppressed through their bodies, but also how “women engage in subversion, in and through their bodies” (p. 15). This can be done, she argues, by “exploring, the tensions which the body evokes,” that is, “embracing rather than avoiding those aspects of embodiment which disturb and/or fascinate us” (Davis, 1997, p. 15). As aforementioned, Davis’ proposal to explore the tensions which the body evokes echo the sentiments of feminist disability scholars who champion exploring and confronting, rather than ignoring, the weak, suffering, uncontrollable, “unruly,” or otherwise “abnormal” body. In this dissertation, I take up Davis’ proposal of a feminist embodied theory, a theoretical approach that, like feminist disability scholarship, conceptualizes embodiment as relational and urges us to start our analysis at (or at least pay more attention to) points of possible contention, discomfort, or difference. An exploration of how women with physical disabilities experience their embodiment during the perinatal period and early motherhood may evoke new ways of understanding how pregnant, lactating/breastfeeding, and mothering bodies look, feel, and behave, and in turn challenge the idea that “normative” bodies are always stable or static.
Chapter 3
Methods

To understand how women with physical disabilities experience their embodiment during the perinatal period and early motherhood and what might shape their embodied experiences, I conducted a qualitative, constructivist grounded theory study, informed by Charmaz (2006, 2014). Data were collected using a socio-demographic questionnaire and one-on-one, semi-structured interviews. Thirteen women with a range of physical disabilities who had recently become mothers and who reside in Ontario participated in this study. Ten of the thirteen participants were interviewed twice.

3.1 Epistemology

I adhere to a constructivist paradigm; I approached this project with the understanding that scientific knowledge is socially constructed, and as such, there are multiple realities or ways of knowing (Charmaz, 2003). Relatedly, I believe that the questions that researchers ask as well as the ways in which we analyze/interpret data are influenced by several factors, including our own positionalities or social positions (Charmaz, 2006). As such, research findings are co-constructed by the researcher and the study participants; research findings are interpretive understandings of subjects’ meanings (Charmaz, 2003).

This epistemological position aligns with a post-structural feminist approach to research. As a branch of post-modernism, post-structural feminism focuses on issues of knowledge, power, difference, and discourse in relation to the lives and subjectivity of women (English, 2012), with the aim of “unravel[ing] the social processes and relations that have constructed the social world in hierarchical ways” (Hesse-Biber, Leavy, & Yaiser, 2004, p. 19). Specifically focusing on how women have been constructed as the lesser gender, post-structural feminism calls for an ongoing critique of taken-for-granted assumptions and continuous attention to gender-based inequalities, viewing all knowledge as socially constructed. Post-structural feminist researchers are “wary of privileging one truth over another” (Hesse-Biber, Leavy, & Yaiser, 2004, p. 19) and do not view researchers as separate from their data (Davies & Gannon, 2005). In calling the status quo into question, a post-structural feminist approach is focused on “moving beyond what is already known and understood” (Davies & Gannon, 2005, p. 313). Recognizing
the active role that women play in creating their subjectivity, post-structural feminism suggests that it is “possible for women to revise how they have been constructed and to grasp that they might inhabit multiple and possibly contradictory positions at the same time” (English, 2012, p. 711).

### 3.2 Constructivist grounded theory and reflexivity

Grounded theory is a recommended method of analysis for exploratory research into social processes (Glaser & Strauss, 1967); a grounded theory approach is often used to address “process questions,” such as “questions about experiences over time or changes that have stages and phases” (Creswell, Hanson, Plano Clark, & Morales, 2007, p. 239). For example, Charmaz (1995) used a grounded theory approach for her study of how people with chronic illnesses adapt to their impairments, and Zitzelsberger (2005) used a grounded theory approach for her study of the relationship between Western cultural representations of bodies and the experiences of women with physical disabilities and differences. What sets Charmaz’s (2014) constructivist grounded theory approach apart from a traditional or classic grounded theory approach is its explicit acknowledgement of “subjectivity and the researcher’s involvement in the construction and interpretation of the data” (p. 14). Thus, “any theoretical rendering offers an interpretative portrayal of the studied world” (Charmaz, 2014, p. 17). In sum, compared to a classic grounded theory approach, Charmaz’s constructivist grounded theory approach “places more emphasis on individuals’ views, values, beliefs, feelings, assumptions, and ideologies than on research methods” (Creswell et al., 2017, p. 251). In this way then, a constructivist grounded theory approach aligns with a post-structural feminist approach to research, in that both conceptualize knowledge as socially constructed.

In turn, reflexivity, that is, the “continual evaluation of subjective responses, intersubjective dynamics, and the research process itself” (Finlay, 2002, p. 532), is a key feature of a constructivist grounded theory approach (as well as many other qualitative and feminist approaches to research; Campbell & Wasco, 2000; Nagar, 2002; McCorkel & Meyers, 2003; Del Busso, 2007; Rice, 2009; Berger, 2015). With the understanding that findings are co-constructed then, researchers are “to be reflexive about what we bring to the scene, what we see, and how we see it” (Charmaz, 2006, p. 15).
Attending to my own social positions and what I bring to this study is thus an important exercise. Indeed, as Rice (2009) has argued, “because subjectivities are neither disembodied nor detached, researchers’ personal histories, physicalities and positionalities necessarily inform the theoretical stories they tell” (p. 245). I bring unique perspectives to this work based on my social position as a woman who is white, non-disabled, pursuing a PhD, from a rural, working-class background, bisexual, and not a mother. Being white and non-disabled, I have race and able-body privilege; regarding the latter, I found myself constantly re-evaluating how I experience my body and other people’s bodies as I worked on this project. In particular, my own experience of acquiring and receiving treatment for a sports-related injury, watching my sister-in-law and friends experience pregnancy, breastfeeding, and mothering, watching and caring for my maternal grandfather and my mother as they received treatment for cancer, and witnessing a now-deceased colleague document her chronic illness on social media have greatly shaped how I think about my own and other people’s embodiment. I have come to experience and perceive pain, fatigue, illness, and accessibility in many new and different ways as a result of these personal experiences, as well as from the experiences of women with disabilities I have read about and who I interviewed for this study.

Further, I have educational privilege, which comes with a particular set of tools, methods, and theories for understanding and navigating the social world. My background and the context in which I grew up also comes with a particular lens through which I view the world. As someone who is bisexual, I am constantly navigating a complex web of heterosexual privilege and bisexual erasure, invisibility, and stigma. While I am not a mother and have not experienced the physical bodily changes associated with becoming and being a biological mother, I am an aunt and have experienced myself in a maternal, nurturing role. In turn, I have watched others experience motherhood and fatherhood (and grandparenthood) around me and thought greatly about how bodies take on many functions and roles and how parenting tasks often fall along gendered lines.

While some have argued that qualitative researchers perhaps place too much emphasis on particular types of “comfortable” reflexivity practices (e.g., Pillow, 2003), such as disclosing their own social positionality as I have done, I agree with others (e.g., Creswell & Miller, 2000; Mays & Pope, 2000; Schutt, 2014), who contend that reflexivity can be a way to demonstrate or
ensure trustworthiness, and even rigour, in qualitative research. I feel it is important to
acknowledge what I bring to this work and to consider the potential weight or power that it
carries in all stages of the research process, including data collection and analysis.

As noted in Chapter 1, I use the language of ‘women with physical disabilities’
throughout this dissertation, as that was the language used by most of my study participants. However, I acknowledge that using this person-first language was not the preference of all my
participants or all women with disabilities more broadly. For instance, one participant in my
study did feel strongly about identifying as a “disabled woman,” noting that this identity was a
political “orientation,” “integral” to who she was: “[disability is] a big part of my make-up so I
don’t see it as I have an identity and then I’m a disabled person on top of that. But that disability
is integral. It’s who I am and there’s no way to separate that.” The language used by this
participant denotes her relationship to disability; the use of ‘disabled woman’ denotes a departure
from the medical model of disability (see Chapter 3) and is increasingly common in the
disability studies literature (which this participant happened to have some training in).

In the development of my data collection materials, I tended to use the language of
‘physically disabled women’ because this is the language used by many disability scholars (e.g.,
Titchkosky & Michalko, 2009; though there are also debates among disability scholars and
activists regarding language use—see Wilson & Lewiecki-Wilson, 2001; Harpur, 2012). For
instance, in the same year I started my doctoral studies, Filax and Taylor (2011) announced their
call for papers for the Demeter Press anthology, Disabled Mothers, with the following note to
explain their decision to use the language of ‘disabled mothers’:

Tanya Titchkosky argues that referring to ‘disabled people’ is preferable because it emphasizes disableness as a social process that prevents certain people from access to resources and goods available to others. ‘People with disabilities’ implies that disability is not part of what it is to be a person and leaves disability as a problem. We agree with Titchkosky and therefore our choice of the title for this collection is ‘Disabled Mothers.’ (see Tanya Titchkosky (2003) Disability, Self, and Society. Toronto: University of Toronto Press, chapter 2).

The term ‘disabled people’ stems from the social model of disability (Davis, 1996; Oliver, 1983,
2013); while those who adhere to the medical model of disability may use ‘people with
disabilities,’ social modelists may use ‘disabled people’ to highlight the political nature of
disability (as something imposed on them or socially created). However, as I began interviewing
my study participants, I soon realized that few of them used the language of ‘physically disabled
woman’ or ‘disabled woman’ to describe or identify themselves; instead, most used person-first language. In some instances, participants did not always identify as a person with a disability but instead as a person with a specific impairment or medical condition (e.g., “I’m a quad or quadriplegic,” “I have arthritis,” “I would say my spine’s not straight,” “I take medication every day”). Some also shared that they identified as a person with a disability only in specific circumstances, for example, to get access to government services—a finding resonating with the point made by Wilson and Lewiecki-Wilson (2001): “how disability is defined and who does the defining have important political and social consequences to stakeholders—in receiving services, seeking protection against discrimination… and the creation of a disability community” (p. 10).

In sum, as someone who does not live with a disability, to echo Ahlvik-Harju (2016), “while privileged on so many levels myself, I am deeply committed to the scholarly task of questioning, critically discussing, and challenging such discourses and practices that marginalize and oppress people with disabilities” (p. 230; also see DiBernard, 1996).

3.3 Inclusion criteria and sampling

To be included in this study, individuals had to: identify as a woman with a physical disability; reside in the province of Ontario, Canada; be aged 18 years or older; have given birth within the last five years; and be sufficiently fluent in English to understand the consent form and socio-demographic questionnaire and to participate in the interviews. For the purposes of this study, the criterion of physical disability includes those who have an acquired or congenital disability that limits their mobility, flexibility, or physical function in some way. These disabilities could be episodic or chronic.

In addition to addressing a gap in the literature, these disability inclusion criteria were largely established for feasibility reasons, including limited funds for travel and interpretation and connections with organizations to aid with recruitment. Notably, the Parenting with a Disability Network in Toronto indicated that the group of women who participate most in their activities are those with physical disabilities, such as cerebral palsy, multiple sclerosis, and spinal cord injuries (Carling Davis Barry, former Peer Program Assistant, Parenting with a Disability Network, personal communication).
The disability criterion was expanded partway through the recruitment phase of the study to include women who are blind, low vision, or vision impaired. It was decided, together with my supervisory committee, to include this population of women with sensory disabilities because not only is their scant research on the perinatal experiences of this population but because this population of women with disabilities may experience the perinatal period and early motherhood in similar ways to women with physical disabilities, particularly considering that (non-disabled) others, including perinatal care providers, might perceive them to be “unfit” for motherhood based on their disability (Frederick, 2014; Kent, 2002; Bieber-Schut, 1993). Conversely, it was decided not to include women with other sensory disabilities, such as women who are hearing impaired, deaf, or Deaf for feasibility reasons; participation for those who may require more resources for the study to be fully accessible to them (e.g., ASL interpretation, closed-captioning) were not available. Moreover, Deaf women may consider themselves to be part of a cultural group or community (i.e., “culturally deaf”), and, as such, may not identify as having a disability in the same way that those with vision or mobility impairments or limitations might (Lane, 2002).

3.4 Recruitment and screening

Participants were recruited between October 2014 and June 2015 through personal networks and the distribution of flyers (see Appendix A) via the electronic listservs and websites of over 60 organizations and groups that serve pregnant women, new parents, and/or people with disabilities across Ontario and Canada (e.g., Parenting with a Disability Network of the Centre for Independent Living Toronto, Ontario Federation for Cerebral Palsy, Spinal Cord Injury Ontario, Anne Johnston Health Station). Additionally, flyers were posted at several rehabilitation centres and high-risk birth units in the Greater Toronto Area.

Flyers were also shared on relevant social media sites (e.g., the Facebook group of a women’s centre that offers programming for women with disabilities). Finally, recruitment materials were posted on my personal website (https://latarasoff.com/doctoral-research/) and social media (e.g., Twitter), as well as shared by supervisory committee members through their networks.
In sum, my approach to recruitment was wide and aimed to reach a diverse group of participants, not only in terms of physical disability type but also socio-economic status, ethno-racial background, and sexual orientation (e.g., recruitment materials were shared with the Ethno-Racial People with Disabilities Coalition of Ontario and the LGBTQ Parenting Network). I aimed to reach “hard-to-reach” populations (i.e., not only those connected with disability-specific organizations or groups) by distributing flyers to various types of organizations and on social media.

Interested individuals contacted the study office by phone or email and were screened by phone to determine eligibility (see Appendix B). A total of 19 women contacted the study office. Of these, 13 were eligible to participate and were interviewed. The primary reasons for ineligibility were location (n=4; lived outside of Ontario) and age of children (n=1; youngest child was over five years old).

3.5 Ethics

All study procedures were reviewed and approved by the Health Sciences Research Ethics Board of the University of Toronto (see Appendix G) and the Research Ethics Board of the Centre for Addiction and Mental Health (see Appendix H). Participants received an honorarium of $30 for each interview and public transit fare if they travelled to my office for the interview. There were no pre-existing relationships between myself and any of the participants.

Prior to each baseline interview, participants provided written informed consent (see Appendix C). Each participant was given a copy of the signed information and consent form, which include a list of resources regarding parenting, disability, and other relevant services. All participants consented to be contacted for a follow-up interview. Those who participated in a follow-up interview gave verbal consent (to the same terms as shown in their original written consent form). All participants consented to have their interviews audio-recorded. Answering any or all interview questions was optional; prior to each interview participants were informed that they could skip any questions that they did not feel comfortable answering and were encouraged to take breaks if they felt tired or otherwise felt that they needed to take a break during the interview.
3.6 Data collection

Data were collected using a socio-demographic questionnaire and one-on-one, semi-structured interviews (baseline and follow-up interviews).

3.6.1 Pilot testing

Before officially launching the recruitment and data collection stages of this dissertation project, I conducted a pilot study to test the data collection instruments. Specifically, in late April 2014, I conducted a pilot study with one woman who met my study inclusion criteria, apart from geographic location (she lived in another province). From the pilot study, I was able to gauge how long an interview might take (the pilot interview lasted just under 80 minutes) and revised some of the questionnaire items and interview questions based on her feedback (e.g., I added the option of “tried/attempted to breastfeed” to the item regarding breastfeeding on the questionnaire). The pilot participant’s data were not included in the analysis presented in this dissertation.

3.6.2 Socio-demographic questionnaire

Before beginning the baseline interview, participants completed a socio-demographic questionnaire (see Appendix D). Participants were asked to report on their socio-demographic characteristics (e.g., age, sexual orientation, marital status, education level), their disability (e.g., type of physical disability, age in which they became injured or disabled, pain and activity limitations), and their most recent perinatal experience (e.g., prenatal class attendance, main perinatal care provider, type of birth). Many of the items included in the questionnaire were adapted from the following sources: the Canadian Survey on Disability (Statistics Canada, 2012), the Canadian Maternity Experiences Survey (Statistics Canada, 2007), and the Health and Well Being Issues Among Women with Physical Disability Survey (Feld, Colantonio, Yoshida, & Odette, 2003; Cooper, 2006; Yoshida, Dumont, Odette, & Lysy, 2011).

In a few cases, due to disability-related challenges (e.g., reduced dexterity), I read out each questionnaire item to the participant and physically filled in the answers based on their verbal responses.
3.6.3 Baseline interviews

Thirteen participants completed the first or baseline interview. These interviews followed a semi-structured guide which focused on several topics regarding the perinatal period and early motherhood. Notably, participants were asked about their decision to have children, their own and others’ reaction to their pregnancy/pregnant bodies, what they liked and disliked about being pregnant, what their perinatal care experiences were like, what challenges they encountered during pregnancy and as new parents (e.g., access to resources), how disability and other social identities or experiences shaped their embodied selves, and how they felt about their changing bodies during pregnancy and as mothers, among other things (see Appendix E). Some of the interview questions were informed by findings from other empirical studies of mothers with physical disabilities (e.g., see Kuttai, 2010; Grue & Lærum, 2002). Probe questions were used to encourage additional discussion and reflection, particularly to unearth participants’ experiences of embodiment.

The baseline interviews were conducted between November 2014 and November 2015 and lasted between 54 and 135 minutes (M=86 minutes). Ten of the thirteen participants were interviewed in-person, in locations of the participant’s choosing (study office (n=3), coffee shop (n=1), participant’s home (n=5), participant’s office (n=1)), and three participants who lived outside of the Toronto area were interviewed over the phone. Each participant was interviewed on a separate day, with two exceptions: two participants were interviewed on the same day, and in one instance, an in-person interview was not finished in one day and continued over the phone on a few days later. Regarding the latter, the participant and I decided to end the interview early (i.e., before all key questions were asked) to ensure that she could make her scheduled pick up time for accessible transportation (i.e., Wheel-Trans) and agreed to complete the interview over the phone a few days later at her convenience.

3.6.4 Follow-up interviews

This study was designed to include follow-up interviews, a practice common in constructivist grounded theory research (Charmaz, 2006). Follow-up interviews were conducted to gain a more in-depth understanding of some of the experiences that participants described in their baseline interviews, particularly those experiences related to how becoming a mother may
have shaped their embodiment and how they felt about their pregnant, lactating, and mothering bodies. In other words, I conducted follow up interviews to probe more deeply about participants’ experiences, as well as in an attempt to achieve saturation of emerging findings.

Like the baseline interviews, a semi-structured interview guide provided some structure to the follow-up interviews (see Appendix F) but was applied flexibly according to the issues most relevant to each participant (i.e., follow-up interviews were tailored to each individual participant, based on review of their baseline interview transcript). All participants however were asked a few additional questions in their follow-up interview, including the following two questions: 1) What words, language, terminology, label, or identifier do you use to describe yourself [in relation to your disability]? 2) If you breastfed/are breastfeeding, is breastfeeding important to you? (Or why is breastfeeding important to you?). Concerning the former question, after I had interviewed 3 or 4 participants I realized that, while I was using the language of ‘physically disabled women,’ this language was not necessarily the language that participants were using. For example, as noted, some participants shared that they identified themselves using person-first language (i.e., ‘person with a disability’) in some contexts or according to their specific medical diagnosis or impairment, rather than the more political language used by some critical disability scholars (i.e., ‘physically disabled women’”) that I assumed participants would be using. It was important for me to find out from participants what language they used so that I could use the same language in reference to their experiences. Further, I felt that an understanding of the language they use might provide some explanation as to why they experience their embodiment in particular ways; that is, I wondered if there might be a connection between their language use and the discourses that shape how they experience their embodiment during the perinatal period and early motherhood.

Regarding the breastfeeding question, I found myself feeling surprised upon learning that some participants had chosen not to breastfeed (one participant even shared that she “was disgusted by the whole thing”); I was curious why some participants made this decision. This curiosity caused me to reflect on my own views about the value and importance of breastfeeding; I realized that very few of the mothers I know had had a hard time breastfeeding (or at least did not share that if this was the case) or did not breastfeed their child. The “breast is best” discourse was paramount in my social circles and a discourse to which I adhered. In asking about the
importance of breastfeeding then, I was curious to know what discourses or other factors might shape participants’ embodied experiences of breastfeeding, including why breastfeeding was or was not important to them. In short, I believe my analysis of participants’ experiences of breastfeeding would not have been as careful and thoughtful had I not taken this time to reflect and ask further questions about the importance of breastfeeding.

It was important to me as a reflexive, feminist researcher to conduct follow-up interviews. I recognized my position as a non-disabled “outsider” conducting interviews with a population of women who are often marginalized (not only by society in general but who have experienced marginalization and exploitation from the research and medical communities as well) (L. Davis, 1997b; Kitchin, 2000; Iezzoni & Long-Bellil, 2012; McDonald et al., 2016; Barnes & Mercer, 1997; Oliver, 1992). Further, given the focus of this study, it was important for me to take time to build rapport with participants in order for them to feel comfortable to disclose details about their experiences of the perinatal period and early motherhood, experiences that some might consider to be quite intimate and personal. As well, building rapport with participants was important in recognition of research indicating that women with physical disabilities encounter barriers to perinatal care and because of this are at risk for poor outcomes (see Chapter 1), which could be experienced as upsetting or traumatic for them.

Follow-up interviews were conducted with ten of the thirteen participants. Those participants (n=3) who were recruited later into the study (between late May and November 2015) were not asked to do a follow-up interview. Their baseline interviews were slightly longer (135, 74, and 60 minutes) because these interviews included some of the follow-up questions regarding disability identity and breastfeeding described above.

Follow-up interviews were conducted between June and September 2015, three to eight months after baseline interviews. The range of time between baseline and follow-up interviews varied for several reasons. First, follow-up interviews were ultimately not scheduled until baseline interviews were transcribed and reviewed to ensure that appropriate follow-up questions were asked. Second, scheduling follow-up took two to three weeks and in one case, took five months (of phone and email tag) from initial contact to conducting the follow-up interview. Third, whereas weather-related issues were the primary reasons for rescheduling baseline interviews (most took place in the winter months of 2014-2015), vacations (i.e., being out of
town), having family in town, a sick child, and general busy family lives (and resulting phone and email tag) made scheduling follow-up interviews challenging in the summer months. Eight of ten follow-up interviews were conducted over the phone. Telephone interviews generally proved to be more accommodating for participants who had infants or who were at home caring for more than one child (i.e., some interviews were scheduled during naptime or when other childcare was available). Follow-up interviews lasted between 22 and 48 minutes ($M=37$ minutes).

### 3.7 Qualitative data analysis

I began data analysis by line-by-line, hand coding hard copies of four participants’ initial interview transcripts to identify words, phrases, or ideas that seemed potentially relevant to the research questions. This initial open coding process yielded a total of 157 codes and sub-codes, which were both descriptive in nature (largely focusing on what happened during participants’ pregnancies, labours/births, and early days and years of mothering) and conceptual or “in vivo” (Glaser & Strauss, 1967; i.e., terms used by participants, e.g., ‘spectacle,’ ‘internalized ableism’). As I completed line-by-line coding of the remaining interview transcripts, I narrowed the list of codes down to 59 codes (in some cases collapsing many codes into one or eliminating codes with little content relevant to embodiment, e.g., ‘unsupportive partner’). After I completed line-by-line coding of all transcripts, I imported the transcripts from Microsoft Word into QSR International’s NVivo 11 qualitative data analysis software to assist with organizing the coded data.

My selective or focused coding process was very iterative in tandem with writing each findings chapter. While I had a list of 59 codes, some of those codes included more descriptive data (e.g., ‘type of birth,’ ‘main perinatal care provider’), which were used to contextualize participants’ experiences, and/or were largely excluded from this dissertation. For instance, data describing participants’ perinatal care experiences and outcomes were analyzed for a separate paper (see Appendix I) and data initially coded as ‘microaggressions’ were excluded and/or reframed to be understood through the lens of embodiment. Likewise, some data that were originally coded descriptively, such as ‘reactions to pregnancy’ (with sub-codes: ‘positive,’ ‘negative,’ ‘mixed,’ and ‘own reaction’), were later re-coded through the lens of embodiment.
(i.e., how did reactions to participants’ pregnant bodies inform their embodied experiences of pregnancy?).

It is understood that a constructivist grounded theory approach allows for data analysis to be both inductive and informed by the researcher’s positionality and disciplinary background, as well as by concepts or findings in the literature (i.e., theory-informed)—what Charmaz (2006) and others (Blumer, 1954) refer to as “sensitizing concepts” or “points of departure.” Sensitizing concepts thus may serve as starting points for analysis. For this project, some of the data identified were coded according to concepts found in the theoretical and empirical literature on embodiment (e.g., “‘capturing’ a gender,” in Grue & Lærum, 2002).

I then conducted axial or relational coding, that is, the process of relating concepts and organizing them in relation to one another. In doing so, I often went back to review entire transcripts or sections of transcripts to compare participants’ experiences and to contextualize my interpretations of the data, to ultimately develop the themes for each findings chapter. In sum, as described by Gehrels (2013), “the whole process was iterative and on-going. It involved going back and forward between data … while my understanding and interpretation developed” (p. 22).

3.8 Rigour and trustworthiness

Rigour and trustworthiness in qualitative research are accomplished when researchers systematically monitor the research processes, maintain focus on the research question(s), and monitor the fit of the data and its interpretation with the conceptual framework (Morse, Barrett, Mayan, Olson, & Spiers, 2002). I also practiced reflexivity about my own positionality and how it may have shaped data collection and analysis to meet criteria of rigour and trustworthiness in qualitative research. Other techniques I employed to meet standards of qualitative rigour and trustworthiness included keeping field notes and memoing (i.e., monitoring my decisions of the research process, emerging ideas or directions of analysis, and assumptions (Sandelowki, 1986)) and peer debriefing.

After each interview, field notes were written to summarize key points and to capture informal interactions and observations about the participant within the context of the interview (e.g., participants’ emotional reactions). Field notes also served to document similarities and differences regarding participants’ experiences (the beginning stages of the constant comparative
analysis process central to a grounded theory approach) and in turn were used to inform the
direction of follow-up interviews; field notes and preliminary coding helped determine which
topics or categories needed to be refined through the collection of new data. Relatedly, follow-up
interviews served as a method of respondent validation, whereby participants’ accounts were
made richer and experiences shared in baseline interviews were built upon or confirmed by
participants.

Regarding peer debriefing, copies of two participants’ baseline interview transcripts were
shared and discussed with my supervisory committee (i.e., trustworthiness of the findings was
increased by several researchers accessing and discussing the data). Peer debriefing also proved
useful in the development of the follow-up interview guide, as my committee members identified
places where I could have asked probe questions in baseline interviews and pointed out things I
did not necessarily see or think about in my initial coding of transcripts or think to be related to
embodiment.

3.9 Participants

Pseudonyms were used throughout this dissertation to respect participant confidentiality.

3.9.1 Socio-demographic characteristics

Thirteen women with a range of physical disabilities participated in this study, including
four with cerebral palsy and three with spinal cord injuries (see Table 1 for a snapshot of
participant demographics). Many participants reported living with more than one disability or
health condition, as well as reported experiencing secondary or associated conditions, that is,
potentially “preventable physical, mental, and social disorders resulting directly or indirectly
from an initial disabling condition” (Kinne, Patrick, & Doyle, 2004, p. 443; Wilber et al., 2002;
Coyle, Santiago, Shank, Ma, & Boyd, 2000), such as fatigue and chronic pain. Specifically,
seven participants reported experiencing chronic pain (i.e., pain that is always present). Several
indicated that their experiences of pain were at times more limiting than their physical condition
(n=4, pain often limits daily activities; n=5, pain sometimes limits daily activities). Most
participants (n=11) reported that they use an assistive device on a regular or daily basis,
including a cane, power wheelchair, scooter, crutches, and other devices and tools for mobility.
and to assist with daily activities (e.g., tasks that require hand dexterity). Seven participants reported that they require assistance from other people to complete daily activities.

Participants ranged in age from 26 to 44 years old ($M=36.5$). Beyond disability type, participants were quite homogeneous in terms of sexual orientation, marital status, ethno-racial background, housing situation, and education level. All but one was married or in a common-law relationship with a non-disabled man, and only one identified non-heterosexual (queer). All were Canadian citizens and only one participant was identified as non-white (Asian background). All resided in large urban centres (populations greater than 130,000), mostly in the Greater Toronto Area (n=11), and only two reported living in subsidized housing at the time of data collection (though at least one other participant indicated that she had previously lived in subsidized housing). Eight participants reported a household income of $60,000 or greater (five reported having a household income of $100,000 or greater), and eleven participants had a university degree (6 reported having a graduate degree). At the time of data collection most (n=8) indicated that their main daily activity or responsibility was caring for their family, whereas 5 indicated that they were working for pay and caring for family (participants could select more than one option on the questionnaire; some participants reported that they were both working for pay and caring for family).

3.9.2 Children and childcare

Just over half of the participants (n=7) had one child. One participant had four children, though only two were her biological children. Three participants had a child under the age of three months. Nine participants (including one of those with a child younger than three months old) had a child or children ranging in age from ten months to three years at the time of baseline interview. All children live at home with the participants; no participants reported ever losing custody of their child or children. Two participants indicated that they had planned to have another child and three reported that they were undecided about having another child.

Several participants (n=5) indicated that they received help with childcare daily and three indicated that they received help with childcare once per week; however, because childcare was not defined in the questionnaire, qualitative data provide a more nuanced understanding of participants’ childcare support experiences. Some participants reported only needing help with
specific childcare tasks and only needing help for a certain period of time (i.e., in the first 6 or so months after their child was born/during the newborn stage). From their interview data, I found that participants reported a range of childcare arrangements including independently paid childcare (i.e., nannies), subsidized childcare, including via the Nurturing Assistance program, and help with childcare from their partners and mothers.

Visser and Lero (2015) provide an overview of what Nurturing Assistance is in their fact sheet on mothering and disability:

Nurturing assistants assist disabled parents with activities such as bathing, diapering, preparing meals, lifting, carrying, nursing, cuddling, and playing with children. Disabled parents who are able to arrange for this service are funded for a limited number of hours per week – up to six hours per day – through the Direct Funding Program administered by Independent Living Centres and funded through the Ontario Ministry of Health and Long-Term Care. … Currently, Nurturing Assistance is available only to parents who require attendant care themselves and meet the eligibility requirements for the Direct Funding Program. Parents without physical disabilities or those who can care for themselves unassisted but require help in order to care for their children are not eligible for the program (pp. 5-6; for more details about Ontario’s Nurturing Assistance program, see Centre for Independent Living in Toronto, 2017).

Access to funded or subsidized childcare is limited for parents with disabilities in Canada, and personal care assistants are generally prohibited from helping parents with disabilities with childcare tasks (Visser, & Lero, 2015). To my knowledge, Ontario is the only province that has a Nurturing Assistance program, which began in 1988, though it is not well-known (Visser, & Lero, 2015). Indeed, only some of my study participants knew about the program. The program is largely discovered through word-of-mouth and parents who are able to receive this support, including some of my study participants, have reported that information about the program is difficult to find and receiving support often only happens after much self-advocacy (Visser, & Lero, 2015; Prilleltensky, 2003).
Table 1. Description of participants

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Impairment/Disability</th>
<th>Uses an Assistive Device</th>
<th>Pain Limits Daily Activities</th>
<th>Marital Status</th>
<th>Number of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amy</td>
<td>Cerebral palsy</td>
<td>No</td>
<td>Often</td>
<td>Married</td>
<td>1</td>
</tr>
<tr>
<td>Angela</td>
<td>Cerebral palsy</td>
<td>Yes (forearm crutches, walker)</td>
<td>Often</td>
<td>Married</td>
<td>1</td>
</tr>
<tr>
<td>Dawn</td>
<td>Congenital bone growth disorder; arthritis; progressive sensory loss</td>
<td>Yes (cane)</td>
<td>Sometimes</td>
<td>Common-law</td>
<td>2</td>
</tr>
<tr>
<td>Heather</td>
<td>Congenital amputation</td>
<td>Yes (device to assist with driving)</td>
<td>Never</td>
<td>Married</td>
<td>1</td>
</tr>
<tr>
<td>Hillary</td>
<td>Lumbar spinal cord injury (partial paralysis); chronic pain</td>
<td>Yes (ankle foot orthotic, manual wheelchair)</td>
<td>Often</td>
<td>Married</td>
<td>1</td>
</tr>
<tr>
<td>Jennifer</td>
<td>Muscular dystrophy</td>
<td>Yes (motorized scooter, cane)</td>
<td>Rarely</td>
<td>Common-law</td>
<td>1</td>
</tr>
<tr>
<td>Julie</td>
<td>Cerebral palsy</td>
<td>Yes (motorized wheelchair, walker)</td>
<td>Never</td>
<td>Common-law</td>
<td>2</td>
</tr>
<tr>
<td>Kimberly</td>
<td>Cervical spinal cord injury (quadriplegia)</td>
<td>Yes (motorized wheelchair)</td>
<td>Sometimes</td>
<td>Single</td>
<td>1</td>
</tr>
<tr>
<td>Melissa</td>
<td>Congenital blindness</td>
<td>Yes (white cane, screen-reader, other computerized software)</td>
<td>Never</td>
<td>Married</td>
<td>2</td>
</tr>
<tr>
<td>Rachel</td>
<td>Cervical spinal cord injury (quadriplegia); osteoporosis; scoliosis</td>
<td>Yes (motorized wheelchair)</td>
<td>Sometimes</td>
<td>Married</td>
<td>4</td>
</tr>
<tr>
<td>Sarah</td>
<td>Juvenile idiopathic arthritis</td>
<td>Yes (tools to assist with dexterity)</td>
<td>Sometimes</td>
<td>Married</td>
<td>2</td>
</tr>
<tr>
<td>Simone</td>
<td>Fibromyalgia; scoliosis</td>
<td>No</td>
<td>Sometimes</td>
<td>Married</td>
<td>1</td>
</tr>
<tr>
<td>Whitney</td>
<td>Cerebral palsy; arthritic condition; degenerative disc disease</td>
<td>Yes (motorized scooter, manual wheelchair, walker, cane)</td>
<td>Often</td>
<td>Married</td>
<td>3</td>
</tr>
</tbody>
</table>
Chapter 4
Pregnancy

In this first findings chapter, I focus my analysis on the many ways in which participants experienced their embodiment during pregnancy/while pregnant, particularly drawing on data related to how participants felt while they were pregnant, other peoples’ reactions to their pregnant bodies, discussions about prenatal genetic counselling and testing, and participants’ interactions with health care providers in perinatal care settings. Specifically, I identified four interrelated themes to illuminate their experiences of embodiment during pregnancy: (4.1) Achieving, feminine bodies; (4.2) Unrecognized and undesirable pregnant bodies; (4.3) Embodying ambivalence about disability, (4.4) Self-sacrificing, anxious bodies, and (4.5) Knowledgeable, unruly bodies. While not all participants experienced embodiment in all of these ways, many did, revealing the complex ways in which women with physical disabilities experience pregnancy, that is, as both grounded in their physical bodies (including the challenges that their disabled bodies sometimes present) and relationally shaped by interactions with other people and discourses that position disability and pregnancy as incongruent.

4.1 Achieving, feminine bodies

When asked how they felt when they first learned they were pregnant, most participants reported that they were excited. Despite experiencing some discomfort, particularly in the third trimester, most participants generally enjoyed being pregnant. For example, Kimberly, who lives with quadriplegia, reported that “pregnancy was actually surprisingly easy. I didn’t really get morning sickness and I was kind of expecting that.” Being pregnant was an embodied experience that Kimberly enjoyed:

Yeah, I just—you feel good. Like, you feel healthy, happy.... My belly’s still the same size [laughs] as it when I was like 8 or 9 months pregnant because I don’t have the muscles. But then [when I was pregnant] it was like you look down and you have that like warm, happy you know feeling.

Several participants expressed pride in their ability to become pregnant; they felt good about themselves and what their disabled bodies could do. In this way, being pregnant was associated with feelings of strength and achievement. For instance, Melissa, who is blind, reflected that,
when she was pregnant with her first child, she felt useful as a woman with a disability in a way that she had not necessarily felt before:

*I loved doing something useful everyday just by walking around and eating well .... Something miraculous and amazing is [happening]. My body is used for something awesome. ... it has been more difficult being useful as a blind person. Like I’m more often hesitant to step in and help because I’m worried I won’t do it right.... But it was very different to use my body to help, to use my body to do something. That was pretty neat.*

Heather too commented that she “really liked” being pregnant and feeling as though her body was valuable. Heather, who was born without some fingers on each of her hands, reflected: “I liked feeling sort of vital and creating something new.”

In addition to experiencing their bodies as valuable, some participants experienced pregnancy as affirming or reaffirming their femininity and sexuality. For instance, Amy, who has cerebral palsy, shared that she often felt invisible and infantilized before she became pregnant with her son. When asked what she liked about being pregnant, she quickly responded: “I felt like I was a woman.” Similarly, Kimberly stated that, even though her belly was big, she felt “beautiful and sexy and stuff like that” when she was pregnant.

Participants’ experiences of their bodies as valuable and achieving while pregnant subvert discourses of disability that imagine people with disabilities as defective, dependent, and unproductive; instead, participants felt strong, relied upon, and productive in the creation of new life. In this way, pregnancy was a positive embodied experience. Similarly, participants’ experiences of their bodies as feminine and sexual subvert ideas of women with disabilities as asexual and undesirable.

### 4.2 Unrecognized and undesirable pregnant bodies

While pregnancy was experienced positively as an achievement, function, and affirmation of womanhood for some participants, many participants shared that this was not how other people seemed to perceive their pregnant bodies. Instead, other people did not view their pregnant bodies favourably. Many participants shared that their pregnant bodies were met with shock, suspicion, and/or disapproval. Moreover, many participants describe instances where they
were not recognized as pregnant by other people, as well as instances where it seemed that other people did not even recognize pregnancy as a possibility for them. Participants thus experienced themselves as unrecognized and undesirable pregnant or maternal bodies. For example, Hillary, who has a spinal cord injury that resulted in partial paralysis and chronic pain, reported: “I would get a lot of surprise like ‘oh, I didn’t think that was possible.’ [People seemed to be] surprised that someone in a wheelchair would be pregnant.” Reactions like this somewhat surprised Hillary, who assumed that people knew that spinal cord injuries do not necessarily impact women’s fertility. In this way, by experiencing themselves as unrecognized pregnant bodies, participants subverted dominant discourses of both pregnancy and disability.

Instead of being recognized as a mother-to-be in the same way that many non-disabled pregnant women typically are,¹ some participants reported that other people only saw them as being overweight. For example, Angela, who has cerebral palsy, shared: “people just thought that I was fat. They didn’t realize that I was pregnant…” Instead of having their pregnant bodies perceived of as physically growing and changing in a positive way, that is, temporarily, “not too much,” “properly,” with a baby bump (Fox & Neiterman, 2015; Nash, 2012), their “fatness” seemed to be interpreted by other people as characteristic of or an outcome of disability. By being perceived of as fat instead of pregnant, participants felt frustrated (see quote by Julie later), and worried that this perception would reinforce dominant discourses of disability, wherein the bodies of people with disabilities are understood primarily as excessive, defective, and incapable (also see Kuttai, 2010).

To resist dominant discourses that do not expect disabled bodies to also be pregnant bodies, a few participants shared that they engaged in explicit actions to prove to other people that they were indeed pregnant. For example, reported Angela:

[I went to] a women’s show or baby show. ...and I had my walker and the woman [at a booth] was just totally ignoring me and I finally went like this and pulled my shirt back to show my belly and she’s like “oh,” [be]cause she’s giving out

¹ Non-disabled women with larger bodies and other non-disabled women who for several reasons may not be deemed sexually undesirable too might experience feeling invisible while pregnant or unrecognized as pregnant, as well as met with disapproval when it is learned that they are pregnant.
something to do with pregnancy and she goes, “you’re pregnant too?” and I’m like, “yeah!”

In this way, for some, pregnancy was a bodily state that they felt had to be explicitly enacted or publicly performed for their disabled bodies to be recognized as such by other people.

Encountering negative comments, or even comments intended as positive, toward her disabled and pregnant body – “the positive were patronizing. Like oh you can get pregnant? You can have sex?” – was experienced as frustrating for Angela. Other participants also expressed feelings of frustration and hurt when recounting instances when other people did not recognize them as pregnant or viewed them as “inappropriately pregnant,” especially when comments from other people also presumed that participants being pregnant was a bad idea:

When I actually was pregnant, we get the question a lot of time, well is the baby going to be blind? That kind of thing. [Interviewer: And how did that make you feel when you got those kind of questions?] Umm, not the greatest. Like, I mean, you can kind of tell the person’s intention when they’re asking. Like so when sometimes people were asking, you could tell they’re like “you shouldn’t be having kids because you’re going to have a blind child, why would you do that to someone?” kind of thing. And that was really hurtful (Melissa).

As an example of other people not expecting disabled bodies to also be pregnant bodies, some participants reported encounters with other people who questioned how participants became pregnant in the first place. For instance, during her first pregnancy, Julie, who has cerebral palsy, reported having an encounter with a stranger who suggested that her pregnancy had been the result of non-consensual sex:

I was working in retail, and it was a customer that came in and asked me if I was raped. I was 7 months pregnant with my son. [Interviewer: So they just came up to you and flat out asked like that?] Well first they gave me the double-look and then I’m like, “yes, can I help you?” right, because I’m working so I have to be polite even though I know what they were looking at. Then she said, “were you raped?” and I was like “what?! I was shocked! ... Even if I was, what are you going to do about it? ... They wouldn’t walk up to someone else [who was non-disabled and] pregnant and ask that. Right, it is problematic. ... You know, there is an assumption there.

In addition to encountering explicitly negative reactions to their pregnant bodies, several participants shared that they did not encounter many of the commonplace reactions (e.g., positive curiosity, congratulations, questions of due date, sex of the baby, belly touching) that non-
disabled women often encounter\(^2\) from both strangers and family members when they were pregnant. These reactions suggested to participants that they should not be pregnant or that their pregnancies were not pregnancies to be celebrated. Julie felt as though she had been cheated from having these “typical” pregnancy experiences:

*I found that I was sort of ripped off in that way because everybody else, you know, people would walk up to them [and ask]: “oh, when are you due?!” and I didn’t really have any of that because people just assumed I was fat.*

Related to the previous theme of achievement and femininity, considering that women with physical disabilities are often deemed “unfit” for mothering, having a stranger ask when your baby is due, for example, may be an affirming experience for pregnant women with physical disabilities. Such an interaction signifies an acknowledgement of normalcy or acceptance of women with physical disabilities as mothers-to-be. Instead, unfortunately, experiences like the one Julie described above demonstrate that women with disabilities are often only imagined as victims, dependent, and asexual (Malacrida, 2009), and in turn that pregnancy is met with surprise or disapproval when disabled bodies experience it.

The sentiment of frustration expressed by participants when they were not recognized as pregnant or celebrated for being pregnant was especially apparent in participants’ descriptions of interactions in perinatal care settings. For example, following an appointment with her obstetrician, Whitney, who has cerebral palsy, reported: “I went up to the secretary to book my next appointment and she [the secretary] actually whispered to the doctor, ‘She’s not pregnant, is she?’ And the doctor said, “Well, yeah, that’s why she’s here.” Experiences like these suggested to participants that disabled bodies do not belong in or are not imagined to occupy perinatal care settings. Interactions like the one described by Whitney proved to be particularly ironic, as participants reflected that, of all people, health care providers should know that most women with physical disabilities have regular fertility (Signore et al., 2011) and that many perinatal care settings, at least in major urban centres where most participants accessed their care, are equipped to care for “high risk” patients. Notably, while Jennifer, who has muscular dystrophy,
commented that she knew she was not “their typical patient;” she “felt like disability wasn’t an expected part of this high risk clinic, even though high risk was usually associated with medical conditions.” In this way then, being disabled and pregnant seemed to put participants’ in an entirely different class of “high risk,” as many felt that disability was rarely considered or thoroughly understood by some of perinatal and allied health providers that they interacted with (for more on this, see Appendix I). To other people, pregnant women with physical disabilities were perceived of as unexpected and highly risky.

Despite both being married and having had prior conversations with their perinatal care providers about their desire to have children, including with their husbands present, two participants reported that their perinatal care providers questioned whether their pregnancies were wanted:

*During my first pregnancy, I had some bleeding at about five or six weeks pregnant. My husband and I went to the hospital because we were worried we might be having a miscarriage. I found it disconcerting that, while I was worrying about saving the life of my baby, every medical professional I encountered (person at the desk in emergency, nurses, doctors) asked me if this was a “pregnancy I wanted.” I’m not sure if this is just a question that gets asked to every woman early in pregnancy, or if my age (22) or my blindness were a factor (Melissa).*

*The first thing she [obstetrician] said is, is this a planned pregnancy? Are you looking to abort? And I was really taken aback; I’m like remember me, I was here less than a month ago wanting to know if I was pregnant, why would I be looking to abort? And I just think maybe she felt obligated to double-check because I have a disability, but I didn’t even want to broach the topic (Whitney).*

This type of questioning by care providers caused some participants to approach pregnancy with trepidation, feeling both uncertain of what was to come in terms of their care experiences and frustrated that they were asked these questions in the first place. In turn, this type of questioning caused participants to feel unwelcome and dismissed in perinatal care settings, thereby providing evidence that dominant discourses that do not expect disabled bodies to also be pregnant bodies inform practice. For instance, while Jennifer was promised that her disability-related needs would be attended to and that she would get an accessible room for her delivery, she shared that the week that her daughter was born “none of it came through.” In fact, Jennifer reported that she and her partner “ended up filing a complaint because we got treated terribly and I didn’t get any
accessible services … I felt really abandoned by the medical system and also like my voice didn’t matter at all.”

4.3 Embodying ambivalence about disability

While most participants spoke about the excitement they felt when they learned that they were pregnant, many also disclosed that they were “surprised,” “in shock,” and “worried.” For example, when asked how she felt when she first found out she was pregnant Angela answered: “Scared but ecstatic.” Similarly, Sarah, a mother of two who has lived with arthritis for much of her life, shared: “I was worried about how it would all work out and hoping that my baby would be born healthy, considering, you know, my disability.” Other participants expressed similar sentiments:

*I didn’t think I was able to do that [carry a child] with the disability [I have]. I thought I was too damaged. So it was nice to have that sense that I could at least provide that for a period of time for him and that he was ok (Hillary).

*I still kind of think it’s amazing that I was able I guess to carry my son, you know, [to] full pregnancy and that I was able to do that. And I’m very lucky in the sense (Angela).

Participants’ expressions of pride and joy were interspersed with feelings of disbelief, uncertainty, and self-doubt, as they reflected on being pregnant in the context of disability. In this way, some of the participants’ reactions to pregnancy paralleled those of other people, as described above. This finding suggests that participants may have internalized stigmatizing discourses of disability, including the belief that disabled women’s bodies are too defective or “damaged” to have children or carry a baby to term (though if they succeed in conceiving and carrying a “healthy” baby to term, they are “lucky”), and that disability produces disability, or that disability is contagious. While participants did not believe that disabled people are inferior, inherently defective, or undesirable, when reflecting on their experiences of pregnancy some did express ambivalence about disability and what it might mean to have a child with a disability. Participants’ expressions of ambivalence about disability were especially apparent when they discussed ultrasounds and genetic counselling and testing. For example, as she was sharing the experience of an ultrasound appointment, Heather revealed:
I didn’t know it was a he at the time, but like are the baby’s hands ok? ... they’re not really allowed to tell you much, the people who do the ultrasounds, so you’re in this situation where I’m like desperate to know and they’re not usually supposed to say anything but he said “yes, I’m going to show you: 1-2-3-4-5, 6-7-8-9-10” and I burst into tears, right, like, I didn’t realize it was that important to me. And I would have been fine anyway. I would have loved my child anyway but there was [a] part of me just didn’t want him to go through what I’ve been through.

The possibility that her son could be born with a disability caused Heather to reflect on her own feelings about disability. “As a person with a disability,” Heather found it “hard to reconcile all these things,” that is, feeling relieved upon learning that her son did have ten fingers while simultaneously contending she would be “fine” if her son did have a disability. In this instance, Heather came to recognize herself as experiencing internalized ableism: “it’s difficult to talk about because of internalized ableism too, you know, and you can start to recognize some things about your own viewpoints about having a disability.” It seemed that Hillary recognized how she may have internalized the social pressure to be “normal,” thereby placing more value on non-disabled bodies. In this way, by feeling relieved upon learning that her son had ten fingers, Heather may have felt as though she was betraying herself (i.e., what does that say about me and how I think of myself as a disabled person if having a non-disabled child is important to me?). Heather’s experience reveals that the embodied experience of pregnancy evoked ambivalent and conflicting feelings about disability that participants may not have had prior to pregnancy and becoming mothers.3

The relational nature of embodiment was apparent when participants spoke about their interactions with others. Participants reported instances during their pregnancies where family members and perinatal care providers made comments suggesting that disability is undesirable and thus should be avoided. For example, Whitney shared that her uncle did not want to hear about her ultrasound appointments: “[I don’t] want to hear anything until the baby’s born; let’s just make sure the baby’s healthy.” Similarly, Angela shared that after her son was born she found out that her aunts had a bet going as to “whether I was going to give birth to a healthy

3 I do however think that the final point made by Heather in the above quotation, that is, contextualizing her desire not to have a child with a disability based on what she’s “been through” as a person with a disability, is important to consider as part of this analysis in understanding how women with physical disabilities experience their embodiment during the perinatal period.
child or not…. They all assumed that because I had something wrong with me, my child was going to have something wrong [with them].” These types of reactions to their pregnancies both surprised and frustrated participants; they were upset that assumptions were made by those close to them, people who they thought were accepting of disability.

The topic of genetic counselling and testing evoked feelings of surprise for participants, particularly as other people in their lives urged them to engage in genetic counselling and testing.

We [husband and I] never thought about going for genetic counselling; we never cared … because we both saw that like I was pretty content with my life and had lived pretty well as a blind person, we weren’t too concerned if our child was blind. Umm, so we never—it was, it wasn’t really on our radar; it wasn’t a concern for us so then we go to the doctor and like every medical professional we end up seeing ends up saying: “have you been referred to genetic counselling?” That made me think, “oh, I guess this is an issue to people” but it wasn’t an issue to me. ... We don’t really mind if the child is blind but sure we’ll take the appointment because it’s free and it will be interesting information but, I guess even that though, I found it a little strange like then when we’re in genetic counselling they’re saying, “oh, it’s so exciting in 5 years we’ll be able to like screen children ahead of time for if they’re going to have a disability and then parents will be able to abort if they want to,” and you’re going “oh, that’s not good news” … one [of the genetic counsellors] was saying that genetic research, it’s so exciting; we’ll be able to screen for a lot of different disabilities and then parents will have the option, before having children, you know; they’ll know if their child is going to have such and such disability or not. Yeah, that didn’t make me feel very good. I was kind of going so you think my life isn’t worth living (Melissa).

While participants did not consider themselves to be defective or burdensome, the suggestion to engage in genetic counselling and testing emerged as a site of tension regarding disability, whereby participants could not escape the contention that disability is undesirable. Other peoples’ emphasis on participants’ need to engage in genetic counselling and testing suggested to participants that a disabled life is undesirable or not “worth living,” which did not make them “feel very good.” As Melissa’s quotation illustrates, genetic testing and worrying about having a disabled child was not her or her husband’s “radar.” Further, the push for genetic testing on the part of other people completely negated her lived experience as a person with a disability, a lived experience that she was “pretty content with.” Thus, the experience described by Melissa suggests that, to other people, not only are future disabled lives imagined as undesirable but living disabled people are dismissed as uniformed about the cost or burden of disability.
Jennifer, a mother of one who has muscular dystrophy, shared that she had an interaction with a family member who too suggested that disability is an undesirable future:

So my sister-in-law is pregnant for the 2nd time and she was pregnant for so long that she was very visibly pregnant and finally I had to say “are you pregnant?” ... She said, “yes I am, but I didn’t want to tell you because our genetic testing hasn’t been finalized yet and if the child has your condition, we’re not going to go ahead with the pregnancy.” And so, it’s one of these moments where you’re just like wow, for a lot of people this is such a serious life and death question, you know? At that point, you know, she was more than 3 months pregnant, so it would be a significant thing for her to terminate the pregnancy at that point. And yet for her, it was like such a big deal, and for me, it was such a slap in the face. So, it’s like, “Oh, so you don’t want a child with my condition?”

Other peoples’ insistence on genetic testing and the disposal of a “bad” test result reveal both how the embodied experience of disability is not understood as valuable and the interconnectedness of individualizing discourses of disability and “mother blame.” Regarding the latter is the understanding that disability is an inherent “fault” of individuals and that individual women are responsible for managing pregnancy to produce “normalcy” (i.e., a non-disabled child); if they fail (i.e., if a child is born with a disability), it is their fault. Jennifer’s sister-in-law arguably internalized these discourses; she seemed to understand aborting any departure from the “norm” as the “right” thing to do.

To Jennifer’s sister-in-law and Melissa’s genetic counsellor disability seemed to be perceive of as something that should not exist in the future. Further, their disabled lives were invalidated by others. It is significant, for instance, that Jennifer’s sister-in-law, someone who knows her and sees that she has a fulfilling life would still abort her child if they had the same disability as Jennifer. Relatedly, these interactions that some participants described suggest that other people negated participants’ embodied experiences of disability, as if participants themselves had not considered that living with a disability can be challenging at times:

[She said,] “If my child has a disability we would have to move because the house wasn’t accessible. Or it might have to get help with school.” You know, like just the laundry list of the cost of disability or like how hard it is to be a disabled person in Canadian society (Jennifer, sharing her sister-in-law’s thoughts about having a child with a disability).
While Jennifer did not perceive her experience of disability as burdensome, her sister-in-law seemed to only understand having a child with a disability as a burdensome, undesirable future—for both the child and for herself as a parent.

In sum, ultrasounds and genetic testing were experienced as sites where tensions about disability arose; in some instances, these experiences caused participants to re-evaluate their own feelings about disability. Some participants came to embody ambivalence about disability, whereas others came to feel defensive about disability, particularly as other people positioned the possibility of having a child with a disability as a burden or undesirable. In rejecting the undesirability of disability, during pregnancy, some participants affirmed their own disabled lives as valuable and fulfilling and the potential of having a disabled child as possibly challenging but not unwelcome.

### 4.4 Self-sacrificing, anxious bodies

Not only did other people that participants interacted with seem to internalize the individualizing and stigmatizing discourses of disability and “mother blame” (i.e., fear of disability transmission and blame for it), these sentiments were apparent in a few participants’ descriptions of what they did during pregnancy, notably descriptions of how they seemed to sacrifice their own health and well-being during pregnancy based on the belief that they were doing the right thing for their unborn child. These participants seemed to go above and beyond to be “healthy” and do all of the things that “good” pregnant women are “supposed to do” out of fear that if did not have a “healthy” child they would be to blame. For example, even though she experienced chronic pain that was exacerbated during pregnancy, Angela stated that she refused to take pain medication during pregnancy:

> My doctor kept saying that she could give me medication [and] that I’d be okay, that the baby would be ok but I couldn’t do it. ... I didn’t want to take anything during the pregnancy I felt because if something happens, if Jacob came out and something was wrong with him, I didn’t want people to turn around and say “well, see, it’s your fault.”

Angela’s experience suggests that because women with physical disabilities are already considered “defective” and “unfit,” they may feel increased pressure to be “good mothers.”
world where mothering is already imagined as inconceivable or inappropriate for women with physical disabilities, proving one’s self as a “good mother” (or mother-to-be) may be vital.

In Angela’s case, while she may have believed that she was doing all that she could to ensure that she had a “healthy” baby, she may have put her own health and well-being at risk. She shared that during pregnancy she “was in constant pain,” often “couldn’t make it to her walker, to the bathroom in time,” had “tears streaming down my face,” and “didn’t sleep, really, at night.” Pregnancy was physically and psychologically taxing for Angela: “I hate to say this, but I had some days where the pain was so bad that I just wanted to hurl myself down the stairs.” Angela got visibly emotional during our first interview together, sharing that during pregnancy she lacked support from her partner, felt isolated, and later confided that she felt “really guilty” about thinking about hurting herself to deal with the pain she experienced during pregnancy. She seemed to blame herself: “there’s nothing that I could have done differently to make the pain better. Like the only thing is like if I lost weight and was in better shape before I became pregnant.”

Changing health behaviours were not always feasible for participants, particularly given their mobility limitations and other issues related to their disabilities, as well as symptoms of pregnancy itself (e.g., nausea) and general life realities. Indeed, as noted in Chapter 3, many participants reported that they experienced chronic pain. Moreover, many shared that their experiences of pain were at times more limiting than their physical, mobility, or functional restrictions. Furthermore, many juggled paid work and other responsibilities in addition to managing their disability-related needs prior to and during pregnancy; several participants reported that they were working full- or part-time well into their pregnancies and six participants had more than one child.

Finally, pregnancy impacted participants’ bodies in ways that may not be experienced by non-disabled women. For instance, Sarah shared that, as someone who has arthritis, pregnancy-related weight gain proved to be particularly taxing on her body and in turn reinforced her “abnormal” embodiment as a disabled woman experiencing pregnancy:

*I could never just be the normal woman [laughs] because I would get all sort of extra complications happen to me so yeah, I didn’t like that. I guess that’s*
something I didn’t like about my pregnancy. … later in pregnancy, the more weight with arthritis. I think I’ve read that every 10 pounds of extra weight on you is like 40 pounds on your joints so I just found my knees and ankles in particular would get more sore as I got bigger.

Research indicates that “common symptoms of pregnancy may be more severe [for women with physical disabilities] than among women without disabilities; in addition, pregnancy may alter the course of the disability, temporarily or even permanently” (Smeltzer & Sharts-Hopko, 2005, p. 14; also see Signore et al., 2011). Most participants did express concern regarding the latter, worrying that pregnancy might result in greater loss of mobility or other function as well as increase pain. For some, these worries had become a reality. For example, Jennifer, who has muscular dystrophy, shared that when she was pregnant she was “still pretty mobile” but now she uses her scooter “all the time.” Several participants commented that these worries regarding pain, mobility, and other function were not adequately addressed by their care providers. For example, Hillary reported: “There were a lot of unknowns. I was told that the pain could be the same, could get worse, or could get better with pregnancy” (see Appendix I for more).

Understandably not knowing how pregnancy might impact disability or vice versa contributed to participants feeling anxious, on top of already worrying about how they might have to prove themselves as appropriate and capable mothers-to-be. Thus, participants’ sentiments of guilt, as well as expressions of ambivalence about disability could not be separated from their worries of the unknown. It is not surprising then that some participants felt both excited and apprehensive upon learning that they were pregnant because they had difficulties accessing information about pregnancy and disability and their perinatal care providers had a limited understanding of the impact of pregnancy on disability and vice versa (also see Appendix I).

Worries of the unknown coupled with the pervasiveness of discourses that suggest that disability is undesirable and women with disabilities are “unfit” for mothering as enacted by other people may have caused participants to feel ambivalent about disability and what their bodies might be capable of. Thus, Angela’s insistence not to take medication to manage her pain while pregnant, despite the potential detriment to her own health and well-being, suggests that women with physical disabilities may have so much more at stake in their pursuit of achieving “good mother” status. While some decided against genetic testing and rejected the notion that disabled lives are not valuable, others seemed to feel conflicted about the possibility of having a
child with a disability. According to dominant discourses, if a woman with a physical disability fails, that is, gives birth to a disabled child, she is not only a “bad mother” but confirmation that disability equals defect. In this way, by attempting to perform pregnancy according to dominant discourses, participants like Angela seemed to internalize the fear of disability transmission; it seemed that Angela wanted to avoid not only having a child with a disability but more so the belief that women with physical disabilities should not have children.

4.5 Knowledgeable, unruly bodies

In *Embodying the Monster: Encounters with the Vulnerable Self*, Shildrick (2002) writes that “it is not simply that the feminine [i.e., women’s bodies] is represented only as a lack … it is also the site of an unruly excess that must be repressed” (p. 105). While historically men’s bodies have been considered the norm, because of their reproductive functions (i.e., menstruation, pregnancy, labour/birth, breastfeeding), women’s bodies have been characterized as deficient, excessive, unruly, and unstable (Shildrick, 1997; Grosz, 1994). This “unruliness” has been used to justify women’s oppression or inferior status in society. Similarly, people with disabilities have been deemed defective and unruly and marginalized as a result. Shildrick (2002) and others have argued that female or feminine and disabled bodies are threatening to the well-being of the “normal” body or self because the “leakiness” of these “monstrous” bodies pose a challenge to the dichotomies or “distinctions between self and other, and between corpus and another” (p. 106). Or, as Couser (1997) puts it: “Part of what makes disability so threatening to the non-disabled, then, may be precisely the indistinctness and permeability of its boundaries” (p. 178).

The notion that pregnancy may threaten the boundaries of body and self or one’s sense of embodied selfhood is evident in the literature on non-disabled women’s experiences of pregnancy, as discussed in Chapter 1. To summarize, it has been found that some non-disabled women not only experience a sense of lost control over their pregnant bodies (Warren & Brewis, 2004; Upton & Han, 2003; Fox & Neiterman, 2015) but that their bodily unruliness poses a threat to their (pre-pregnancy) sense of self (Bondas & Eriksson, 2001).

Feminist disability theorizing regarding the unruliness of feminine and disabled bodies provide an interesting framework through which to understand some of my study participants’ experiences of embodiment during pregnancy. Notably, rather than experiencing pregnancy as a
loss of control or their pregnant bodies as a nuisance as some non-disabled women do, some participants in my study expressed feelings of appreciation of the unruliness that sometimes comes with a disabled body. Disability in the context of pregnancy was perceived of as a positive attribute to some participants. This sentiment is best articulated by Hillary, who in reflecting on her pregnancy experience in comparison to non-disabled women, remarked that in some ways she was better able to adapt to the bodily changes associated with pregnancy due to her bodily experiences as a woman with a disability:

I thought pregnancy was the hard part and it really wasn’t. It was easier than [I expected]. All the able-bodied women that I knew were complaining. ... I had it [morning sickness] but I wasn’t awful... I think in part because I’ve been dealing with physical limitations for so long, I was like, “this is it?” I think a lot of able-bodied women are like “ugh, I don’t have control over my body now and all the sudden I have to pee five times in the night.” I know what that’s like already, so it wasn’t really shocking to me to have the limitations, in terms of what I could do. You have to go with it and make adjustments. I think if you are able-bodied, you might have a harder time with that because you are just used being able to do whatever you want to do, whenever you want to do it.

Hillary’s experience suggests that women with physical disabilities may have a different or even advantageous embodied experience of pregnancy compared to non-disabled women; women with physical disabilities may be better able to adapt or even embrace the bodily changes associated with pregnancy given their experiential knowledge of living with a disabled body, a body that is not always controllable. Relatedly, participants’ embodied experiences of pregnancy suggest that dominant discourses of pregnancy are premised on a non-disabled body and in turn challenge the idea that a lack of bodily control is only experienced as negative or detrimental. Instead of experiencing a lack of bodily control during pregnancy as a shock or even a personal failure, the embodied experience of disability may provide women with physical disabilities with the ability to experience and therefore adapt to bodily changes during pregnancy as just another instance of bodily unruliness.

Moreover, participants’ embodied knowledge of disability seemed to serve as a source of resilience and confidence in a context where they faced numerous barriers to becoming parents, including interactions with other people who seemed to view disability as undesirable and perinatal care providers who had limited knowledge of disability. Participants’ embodied knowledge of disability, and their confidence in this knowledge, is evidenced in their narratives...
of self-advocacy in the context of perinatal care. Specifically, several participants reported that they were quite vocal in their encounters with perinatal care providers about how things could be done in the context of their labour and deliveries, including those who had had more than one child and therefore had not only a sense of how their disabled bodies might function generally but how their disabled bodies might behave in labour.

_I was pretty aware that it was pretty important that I know as much about myself before talking to a doctor and being able to suss out what they say to me without me saying that I know what’s going on in order to make decisions and push for certain things. ... I met with the anesthesiologist and we had like a 2-hour discussion about it [epidural]. And at the end of the discussion, he still came to the conclusion that it would be a good idea for me to have one. And it was a really hard conversation to have and I had to stick up for myself a lot and he just kept completely writing off my concerns and like, “it doesn’t matter if you are in bed for a couple of days, does it? You can get lots of rest.” Well, I was like, “I kind of want the choice to be able to move around or not” (Jennifer).\(^4\)

I figured that it would be known, that you kind of work with me, because I know my body, I’m very sensitive to my body. I went in and the first doctor it was like okay, we’ll hold your legs and you can push whenever; like we’ll help you bend and hold your legs in place. The second doctor that came along, okay, I want you to scoot down and your butt’s going to be in the air and you’re going to like push, and I’m like, no, that’s not going to happen. I’m trying to explain to her I cannot be half hanging off a table, because of the surgeries that I’ve had, and you know, trying to explain to her I have a disability, it’s real, it’s not just I have canes or I have a wheelchair or scooter because I’ve injured myself. ... After she [the second doctor] left I looked over at the nurses and said listen, I’m not an expert [a medical expert], but I’m going to scoot back up and we’re going to do it the other way, because if I keep pushing this way, I’ll be in traction (Whitney).

As Whitney and Jennifer’s experiences demonstrate, being able to advocate for oneself proved to be particularly vital given that most participants felt that their perinatal care providers had limited knowledge of (or seemed to overlook) their disabilities and disability-related needs (see Appendix I). Thus, not only might the embodied experience of disability prove advantageous for women with physical disabilities as they adjust to the “unruliness” of a pregnant and labouring

\(^4\) She did get her way; Jennifer was able to give birth without an epidural, despite the insistence of her perinatal care providers that she get one. While the labour/birth of her daughter was “a tough experience” for a variety of reasons, including having to deal with a “horrible” on-call obstetrician, Jennifer did share that, “the only funny thing that came out of it was when daughter finally emerged, I had a whole gush of amniotic fluid come out and it entirely covered his fancy black leather shoes [Interviewer: laughs] so I ruined his shoes and I was pretty happy about that.”
body but it may also provide them with the means, leverage, or authority to advocate in care settings that perhaps not all women have\(^5\) (though, as Whitney and Jennifer’s experiences suggest, advocacy may not necessarily lead to the outcome one desires if other people do not take their positions seriously). The embodied knowledge of what their disabled bodies were capable of, how their bodies might react, or what their bodies needed serves as a source of confidence for women with physical disabilities. In some ways, their embodiment of disability allowed participants to feel “more comfortable with your body” in pregnancy and labour/delivery, as Whitney imparted, and in turn be confident to advocate for the care experience that they desired. It was apparent from some participants’ labour and delivery stories that they seemed to know what would work best for their bodies, such as where their legs should be positioned or if they should get an epidural or not.\(^6\)

Finally, some participants’ descriptions of what they liked about pregnancy evoked a sincere appreciation of what women’s bodies can do.

[I] liked actually watching, seeing how the body changed. I thought that was so cool. Like I know a lot of women feel ugly when they are pregnant because you gain weight, and you get awkward and your balance [is] crap. But I thought it [was] just incredible to me that there was this person growing inside of me (Hillary).

Not only might the expectations of pregnancy as espoused by dominant discourses be unrealistic for many women to live up to, they also evoke feelings of shame or scrutiny of those who cannot

\(^5\) This embodied knowledge and subsequent advocacy for particular care experiences is not necessarily a surprising finding given that many participants in this study were born with a disability or acquired a disability at a young age and as a result have had frequent interaction with the health care system throughout their lives. However, this is not to suggest that all women with physical disabilities (or participants in this study) have/had the courage to or learned to speak up when they are treated unjustly or when their embodied knowledge is ignored or overlooked by care providers. I should also note that some participants’ experiential (e.g., those who had more than one child) and/or work/educational backgrounds may have assisted in their advocacy efforts. Yet, overall, I found that participants’ backgrounds were not a significant modifying factor or predictor (to use quantitative language) in determining the type of care experience they had (i.e., barriers to perinatal care were identified by most, if not all, participants). I did identify a few cases though where being partnered did seem to play a role in improving care experiences or at least access to more information and resources; some participants’ partners served as a source of advocacy or a means through which participants could direct the care they needed.

\(^6\) For example, it was important for Jennifer, who has muscular dystrophy, to be able to move around after she gave birth as opposed to being restricted to a bed as consequence of having an epidural. Jennifer shared that, “if you [someone with muscular dystrophy] get epidurals it can last a lot longer so there was a chance that instead of the epidural lasting 12 hours, it would last 48 hours and I’d be like completely immobilized and it just it didn’t seem like a risk worth taking unless I really felt overwhelmed by the pain.”
do pregnancy “right.” This overemphasis on doing pregnancy “right” arguably overshadows just how incredible the very physical act of pregnancy is. Women with physical disabilities’ embodied experiences of pregnancy, as shaped by the value of their embodied experience of disability, may serve as a reminder to spend more time appreciating what our bodies can do, and to embrace the unruliness or uncomfortableness that we might sometimes experience in our bodies. A greater awareness of the “unruliness” of disabled and pregnant bodies may shake up what many understand as “normal” for bodies and in turn how we may conceptualize bodies and self as (always) stable.
Chapter 5
Breastfeeding

In this second findings chapter, I describe how participants’ experiences of breastfeeding, including in some cases the decision not to breastfeed, shaped their embodiment as mothers with physical disabilities. Informing my analysis is an understanding of embodiment that is relational and encompasses participants’ disabilities, their interactions with health and social service providers and other people in their lives, and dominant discourses of mothering and subsequently breastfeeding that exclude women with physical disabilities. Participants’ embodied experiences of breastfeeding are considered within the context of the “breast is best” discourse, that is, the belief that breastfeeding is easy to do (i.e., “natural”), and in turn is the best option for mother and baby; according to this discourse, successfully breastfeeding is symbolic of being a “good mother.”

Participants’ experiences of breastfeeding came up in the natural progression of sharing their birth stories, which extended to their experiences of initiating breastfeeding. In this chapter, I start with an analysis of participants’ responses to questions about their breastfeeding experiences, including why breastfeeding was (or was not) important to them; this analysis is organized under the themes (5.1) Nurturing bodies, and (5.2) Working maternal bodies. I then consider the realities of participants’ breastfeeding experiences in relation to their disabled bodies and other facets of life, and how these lived realities shaped their embodied experiences of mothering and breastfeeding. These analyses are detailed under the themes (5.3) Disabled and breastfeeding bodies, and (5.4) Ambivalent breastfeeding bodies. Finally, I under the theme (5.5) Subversive (non)breastfeeding bodies, I consider how some participants’ decisions not to breastfeed or cease breastfeeding might be understood as subversive. Akin to the previous chapter, many of the themes discussed in this chapter overlap or are interrelated; not all participants’ embodied experiences of breastfeeding fall under each of these themes, though several participants simultaneously experienced breastfeeding in a myriad of ways.
5.1 Nurturing bodies

Some participants reported that breastfeeding was important to them because it facilitated a bond between themselves and their child. For example, Jennifer, who has muscular dystrophy, shared: “I think that it’s a great way to bond with your child.” Similarly, when asked about why breastfeeding is important to her, Simone, who has fibromyalgia and scoliosis, responded: “It’s important to me because there’s a connection there, too, right? That’s the cool connection that, you know, that, really – I wanted my daughter to benefit from the immunity thing.” Finally, Kimberly, who has a spinal cord injury that resulted in quadriplegia, shared:

*I think that you just need that bond with your baby. They need the nutrients that you provide in your breastmilk, which is not the same as any external source no matter how fortified in vitamins it is. I think that one-on-one, mom and baby time with nobody else around, is essential for the child’s emotional health ... Yeah, I think it’s an essential part of motherhood. ... I think that children when they’re born should basically be attached to their mother’s flesh, like one-on-one, side-by-side, for almost the first 6 months. They shouldn’t leave their mother’s side unless whatever because I think that part of the child’s emotional development is essential.*

In addition to considering breastfeeding to be important because of its potential to facilitate a bond between mother and child, breastfeeding was described by some participants as beneficial for the health and development of their infants—a finding echoed in several studies of non-disabled mothers (e.g., see Marshall, Godfrey, & Renfew, 2007; Schmied & Lupton, 2001; Burns, Schmied, Sheehan, & Fenwick, 2010; Losch, Dungy, Russell, & Dusdieker, 1995; Nelson, 2006). The pervasiveness of the “breast is best” medicalized expert discourse that is synonymous with or symbolic of being a “good mother” (Marshall et al., 2007; Stearns, 1999) was evident in some participants’ responses to why breastfeeding was important to them. For example, Whitney, who has cerebral palsy, shared: “It was important because you always hear about the health benefits.” Similarly, Angela, who also has cerebral palsy, responded that:

*It was important to me because it’s sort of like you hear from everybody that oh yeah, you know, you should breastfeed. You hear all these things about oh, it makes your child smarter or it does this or it does that. Like there’s so much attention put on it.*
Interestingly, when asked why breastfeeding was important to them, some participants, like Whitney and Angela, provided a response that focused on what other people think or have said about breastfeeding. The “breast is best” discourse, as espoused by other people, may have thus shaped some participants’ decisions regarding breastfeeding.

In sum, no participants explicitly challenged the “breast is best” discourse, particularly its promised health and developmental benefits. For several participants, to breastfeed was to perform or fulfill the nurturing role of the “good mother.” Indeed, Kimberly shared that she believed her limited breastfeeding duration resulted in not as much “closeness that I would really like” between her and her son:

There’s issues that are still carried on to this day that...because that wasn’t done properly, or the way that I wanted to. I mean not that there’s a proper way but the way that I would like to have done it. ... If I had the chance to do it again, I would do it differently.

By considering breastfeeding to be “an essential part of motherhood” and placing more value on breast milk than formula (see above) Kimberly’s narrative reveals how pervasive dominant discourses of motherhood and breastfeeding are. Some participants’ narratives suggest a desire to live up to the expectations reproduced in the discourses while at the same time recognizing that these expectations are not necessarily realistic or that there is only one way to bond with your child and in turn be a “good mother.”

5.2 Working maternal bodies

Several participants reported that breastfeeding was “a lot of work,” particularly in the context of having a disability (see themes below). In this section I specifically focus on Heather’s experience of breastfeeding as work, as it seemed that her embodied experience of breastfeeding was very much grounded an understanding of breastfeeding as the “work” that “good mothers” are “supposed to do.”

Heather, who was born without some fingers on each of her hands, experienced some breastfeeding difficulties initially, including getting her son to latch and positioning/holding challenges. Heather reported that soon after she brought her son home from the hospital, she hired a lactation consultant, whose step-by-step instructions she followed diligently.
That’s [breastfeeding] your main responsibility, right? It’s not working, and I’m failing and so now what’s gonna happen? She [lactation consultant] sat me down. She’s very militant. You’re gonna do this and you’re gonna hold the baby this way and you’re gonna do this and you’re gonna squeeze here and duh duh duh duh duh. Then it was the first time he slept, actually, so I had faith in her but she did say “I can’t believe they didn’t spend more time with you or pay more attention because you are at risk.” Of what? Being a failure, I guess? [laughs] I don’t know, not being able to figure out how to do this properly? But she provided me with very practical ideas on how to breastfeed.

While the lactation consultant was helpful to Heather, one could argue that she contributed to Heather experiencing herself as being “at risk” of failing to breastfeed because of her disability. As the above quotation indicates, to Heather, as a mother, breastfeeding was conceptualized as her main responsibility; thus, when breastfeeding was not working she perceived herself as a failure. While her supposed failure must be considered within a context of lack of specialized or tailored breastfeeding support for women with physical disabilities, she did seem to internalize the challenges of breastfeeding as a personal failure. This sentiment reveals the power of dominant discourses of breastfeeding, whereby breastfeeding-related challenges are equated with failure, or worse, being a “bad mother.”

Heather ultimately breastfed her son for 17 months, though the nature of her disability made it challenging for her to engage in numerous tasks that new mothers typically engage in, such as bathing her son, changing his diapers, lifting him in and out of his crib, and in the early months, even burping him after she had finished breastfeeding: “[Husband] did all of the burping, all of it, until his [son’s] head was stable, and all of the diapers almost.” For this reason, being able to successfully breastfeed was particularly important to Heather.

_It was the most important thing for me [to breastfeed] because and maybe it’s because—I don’t know if it was connected to my disability or not—but I was determined to do whatever was the best thing for him. So it was clearly the best thing for him, based on what I read. So he was gonna [sic] be breastfed for as long as I could do it and still manage it. That’s why. That’s why I wanted to make it work._

Once Heather figured out how to make breastfeeding work for her, she was determined to do whatever was the “best thing” for her son. In contrast to some other participants (see themes below), breastfeeding might be conceptualized as the experience essential to her embodiment as a mother with a physical disability, particularly in the first few months after her son was born.
How she thought about breastfeeding and ultimately her decision to make breastfeeding work, despite the challenges she encountered, did seem connected to her disability.

While like other participants Heather described breastfeeding as work, in her narrative of her breastfeeding experience she also reproduced discourses that position breastfeeding as what is “best” for children.

_It is work. It’s a lot of work so it felt like it was important work. ... But eventually, it becomes so convenient and so great for him and you love it because you got a little person and you’re all cuddled up. And everybody is feeling happy and warm. So it was good. It was...definitely for me and I was like that all the way through the pregnancy was whatever is the best for...I called him the bean when I was pregnant because he was a bean. Whatever is the best for the bean, that’s what I will do and then whatever was the best for [son], that’s what we will do. That’s why I stuck with it, but it’s to be admired, I think, [laughs] that women can do it._

While there is no denying that breastfeeding was ultimately a positive experience for Heather, with benefits such as convenience and bonding, her experience reveals how women with physical disabilities may feel even more intense pressure to succeed at breastfeeding compared to non-disabled women.

In sum, for some participants, it seemed important to prove that they could breastfeed and in turn they perceived their ability to breastfeed as an affirmation or confirmation of being a “good mother.” Dominant discourses of mothering and breastfeeding thus shaped these participants’ embodied experiences of breastfeeding, whereby breastfeeding is the self-sacrificing and nurturing work that “good mothers” are “supposed to do;” despite it being a lot of work, breastfeeding is what is “best” for their children. As well, their embodied experiences of breastfeeding seemed to represent an effort to subvert dominant discourses of disability as unproductive. In other words, because women with disabilities are not expected to be mothers and because breastfeeding may be challenging for them, breastfeeding may be something that they might feel they must succeed at to be recognized as “good mothers.”

### 5.3 Disabled and breastfeeding bodies

In this section, I discuss participants’ realities of breastfeeding through the lens of inadequate care or a lack of knowledge about how breastfeeding is uniquely experienced by
women with physical disabilities, both on the part of care providers and women with physical disabilities themselves. In this section I also explore how participants’ embodied experiences of breastfeeding were very much shaped by what their physical bodies could or could not do, and in turn, what they felt that they needed to do to 1) make breastfeeding work for them, and 2) manage their disability. For some, the need to manage disability-related symptoms (expectedly and unexpected) impacted their ability to breastfeed and/or their decision to cease breastfeeding. While discourses and social interactions played a role in shaping participants’ embodied experiences of breastfeeding, their very real material or physical bodies played a role too.

One of the central themes identified in qualitative studies of non-disabled women’s breastfeeding experiences (e.g., see Burns et al., 2010; Afoakwah, Smyth, & Lavender, 2013) is the discrepancy between women’s expectations of breastfeeding and what breastfeeding is really like. Breastfeeding challenges reported by participants in this study included several of those documented in studies of non-disabled women, such as difficulties latching, delayed milk production, and not producing enough milk. For some, it seemed that a lack of disability-specific breastfeeding support further exasperated these challenges. For example, Rachel, who has a spinal cord injury that resulted in quadriplegia and had twins, recounted:

*I was surprised that I didn’t have any special attention around breastfeeding. And I think that I actually should have had more of an intensive support. ... [Because of] the c-section and also my disability, right. I wasn’t sure what I was [doing].*

Furthermore, unique to women with physical disabilities, most, if not all, participants reported that functional limitations related to their disabilities and secondary conditions (e.g., chronic pain) made breastfeeding challenging—disability-related concerns, again, that participants felt were not adequately attended to by care providers:

*I just remember a lot more pain. And I remember when the nurses were trying to teach me how to nurse. They were encouraging me [to] go in all sorts of uncomfortable positions, which I think just aggravated my joints more than anything, you know? I don’t think the RA [rheumatoid arthritis] was considered at all; it was almost like they were just like figuring I would figure it out. There was no adaptation at all to my [disability].... My hands they were badly damaged by the rheumatoid arthritis, but they still didn’t seem to consider my comfort while [I was] holding my baby for long periods of time or even the fatigue (Sarah).*
Difficulties related to positioning or holding their infants were specifically noted by several participants. Further, some participants, like Kimberly, even commented that breastfeeding was more difficult than they had anticipated:

_I envisioned that I would be able to hold him properly .... Honestly, I didn’t know that it was going to be so difficult to breastfeed and if I didn’t have a disability, it would’ve just happened a lot easier. But because I did, I didn’t realize how hard it would be to hold my son. I thought I can put my arms together and that would kind of work, but a newborn infant needs complete [support], you know what I mean? You have to really support their head and I didn’t have the ability to do that._

For some participants breastfeeding thus evoked a new or heightened sense of self as disabled; as a relational act, breastfeeding evoked disability or reminded some participants of their functional limitations in a way that they may not have experienced or anticipated before becoming a mother. As Sarah’s quotations above suggests, interactions with care providers regarding breastfeeding too evoked a heightened sense of self as disabled. These interactions suggested to participants that other people seemed to perceive disability as an inherent flaw that they did not want to engage with and as such, in the context of breastfeeding, issues related to disability were perceived of as the individual responsibility of participants to manage or figure out. For instance, Whitney, who has cerebral palsy, shared that when she experienced breastfeeding difficulties with one of her three children she went to the hospital’s breastfeeding clinic. There she “felt like I was being at times talked down to or treated like a child,” and when she tried to bring up some of her breastfeeding concerns (in this case, her son was having trouble latching on), she reported that “some nurses didn’t even want to broach the topic”; she commented that “when you’re disabled …. Sometimes you can tell the person you’re working with is uncomfortable.” Thus, participants’ narratives suggest that some health care providers could not see past disability to common breastfeeding challenges that _any_ new mother might experience. In turn, some participants’ accounts of a lack of disability-specific breastfeeding support reveal how prevalent individualizing discourses of disability are, as well as how mothering and disability are not expected to be experienced by the same body.

In this way, while pregnancy and becoming a mother affirmed femininity and was a positive experience (see _Chapter 4_), breastfeeding challenges related to participants’ functional limitations and a lack of support or recognition by other people (further) exposed or reaffirmed
disability as burdensome and in turn their bodies defective and inferior compared to non-disabled bodies.

Managing disability-related symptoms or secondary conditions also had an impact on some participants’ abilities to initiate breastfeeding; some of the things that participants needed to do to manage their disability-related symptoms or secondary conditions (e.g., spasticity/spasms, pain), such as spending more time lying down or sleeping and taking medication, shaped their embodied experiences of breastfeeding. For instance, for Kimberly, her ability to initiate breastfeeding and ultimately to breastfeed her son for as long as she had hoped was dampened by unanticipated outcomes her son experienced related to the management of her disability-related symptoms.

For 2 days we were trying to feed. That first night he did a little bit but after that I was having a really hard time getting him to latch and there’d always be a couple nurses because I couldn’t hold his head up well enough and stuff like that and he was getting really mad, like raging mad, like screaming eternal red and it wasn’t until then that they realized and they did some tests ... I take methadone for pain and it’s not a large dosage and they [doctors] were worried about that. But the problem wasn’t with that; it was with the gabapentin, another medication which I take ... so he [son] was mad because he was going through withdrawals from my meds so he wouldn’t latch.

Kimberly’s experience speaks to several issues, including the very real and unique issues that women with physical disabilities must navigate when becoming mothers, as well as perhaps a lack of knowledge among some perinatal care providers about the impact of maternal medication on infants or the interaction of disability and perinatal and neonatal outcomes generally (see Appendix I for more). Despite having little control over what her son experienced, Kimberly felt terrible that something related to her disability had impacted her child:

I became completely devastated because they had to put him on morphine. ...They had to take my child away from me and they put him in the addictions unit or whatever, where I was not staying because it’s you know what I mean? It’s for the mothers that had alcohol or drug dependencies. He was put in the nursery area there and I was still staying in the other area and I felt like the worst mom in the world. I was mortified. I was crying day and night. How could I do this to my son? They said I can go see him as often as I want to but it’s just not the same thing, right? ... I can’t just get up out of bed and go see him, right? I couldn’t really breast[feed] ...the second they put him in there, they stuck a bottle in his mouth and that cancelled all hopes of breastfeeding, really, because once a bottle
with that size of a hole, a nipple for milk to come out of, they don’t want to do the work and latch and breastfeed like they’re supposed to. ...I remember feeling so bad, I was devastated. Because I had tried to go off my meds a little bit in my pregnancy and they [doctors] were like that will be more stress; it’s better to stay on your meds.

As noted earlier in this chapter, Kimberly felt quite strongly about breastfeeding as a means to facilitate a bond between mother and child and because of its health benefits. Her experience of being physically separated from her newborn son due to medication withdrawal for two weeks denied her the opportunity to bond with her son. She felt devastated that the management of her disability had caused harm to her son and frustrated that this outcome was not necessarily foreseen by her care providers. Conceptualized through the lens of dominant discourses of motherhood, this situation caused Kimberly to feel like a “bad mother,” as she had “failed” to mitigate risk to her child—something that “good mothers” are supposed to do to ensure the best outcomes for their children. Sadly, much of Kimberly’s early experience of mothering was shaped by the outcome her son experienced and subsequent breastfeeding challenges. Her embodied experience of mothering was grounded, at least in the first few months of her son’s life, in feelings of uncertainty and inadequacy. Such sentiments were evident throughout her interviews, as she readily commented on what she would do differently if she had another child (e.g., she would have tried harder to make breastfeeding work for a longer period of time). In sum, Kimberly’s embodied experience of breastfeeding was shaped by both her functional limitations and unanticipated outcomes related to the management of her disability, as well as a desire to experience the benefits of breastfeeding, which she may have equated with being a “good mother.”

Sarah, who has lived with arthritis for much of her life, shared that her need to take medication to manage her disability-related symptoms played a role in her decision to stop breastfeeding the first of her two children:

Yeah, I did [breastfeed] for a time, not very long, a couple of weeks because I had to go back on my medications. Because within the typical prognosis of what they say with people with inflammatory arthritis is that within 4 to 6 weeks your body will actually flare. I was starting to notice that within about a week so I tried to nurse her a little bit. Then I moved her over to formula.
I then asked Sarah how she felt about this decision—“Was that something that you were okay with or was that kind of frustrating?”—she responded that:

Yeah, it was [frustrating]. ...because I was probably in a place where I was producing lots of milk and there was no problem, right. Yeah, it was sad to let that go, especially when there’s so many expectations for mothers these days for breastfeeding. Everyone says, “breast is best” but then again, the whole system abandon[s] you when you try to do that [breastfeed].

Sarah expressed frustration, sadness, and perhaps even guilt about her decision to cease breastfeeding, yet at the same time she acknowledged the discrepancy between the “breast is best” expectation and the support required to uphold this expectation. Compared to some other participants, Sarah’s views on breastfeeding seemed to be more critical. For example, Kimberly used “I think” a lot when describing why breastfeeding was important to her (i.e., bonding and health benefits, as discussed in a previous section), suggesting that she may have internalized dominant discourses of mothering and breastfeeding. In contrast, Sarah seemed to recognize that the expectations associated with breastfeeding may be unrealistic, situating her experience within the context of both having a disabled body and a system that promotes yet does not always seem to adequately support those who may have challenges breastfeeding.7

In sum, the decision to cease (or not attempt) breastfeeding was rooted in participants’ very real disabled bodies, including, for some, like Sarah, the need to manage their bodies in ways that were considered vital for their overall health and well-being (i.e., the need to go back to taking medication to manage inflammation). Dawn, who has a congenital bone growth disorder that impacts her mobility and progressively her hearing and vision (and two children), optimistically shared that her family doctor was one of few providers that she encountered who understood this reality:

“I’m not going to lecture you about it [breastfeeding] because I know you have other issues that make it harder for you to do whatever to breastfeed” so that was

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7 Or as Schmied, Beake, Sheehan, McCourt, and Dykes (2011) found from their metasynthesis of the literature on women’s perceptions and experiences of breastfeeding support, “many women also described being given standardized information that was not appropriate to their situation (such as telling them what they already knew or missing information that they needed and did not know)” (p. 56, emphasis in original). They too found that much of the breastfeeding-related information that women did receive was presented in a very medicalized manner (i.e., “medical jargon,” “real[ly] technical”).
nice from my doctor but not the other one. But yeah, people don’t realize some things are much harder or different for people like us [women with physical disabilities].

5.4 Ambivalent breastfeeding bodies

In detailing the breastfeeding-related challenges that they experienced, several participants spoke of the often-unrealistic expectations put on women to breastfeed. Moreover, many acknowledged that breastfeeding was “a lot of work” and therefore contradicted dominant discourses that position breastfeeding as natural, simple, and easy.

I respect any woman’s choice on that [deciding not to breastfeed] because it is exhausting. Like, it’s exhausting already, but when it’s not working well, there’s so many things you have to do to try to make it work (Simone).

The assessment of breastfeeding as work seemed to shape some participants’ embodied experiences of breastfeeding. While most chose to breastfeed, some expressed ambivalence about what breastfeeding—in part, because it can be a lot of work—meant or what implication breastfeeding had on their embodied experience of mothering.

In the previous section I shared a quote from Dawn detailing her decision not to breastfeed her second child, a decision that she felt would make her life easier. Dawn went on to express some ambivalence about this decision, which perhaps suggests that in some ways she may have internalized the belief that breastfeeding is equated with being a “good mother.”

Breastfeeding I found was harder for me because—I think now I kind of regret, I should have like maybe tried again this time, maybe it would have been easier this time, I don’t know. ... [Interviewer: So your milk came in and you could breastfeed - it was more about the other things that were challenging?] Yes, I probably could have 100%, and that’s what, why I felt bad about it a little ... now I’m like I really regret not trying. I tried [with her first son]... and then it was like my arms hurt, it’s too painful, whatever. So this time I didn’t even try. But now I’m regretting that... maybe it would be different this time but whatever; I just wanted to try make it easier. Also I didn’t know my partner was going to be on this kind of shift where he’d be home most of the time. So I was all worried about breastfeeding and having to take my son to school and like being alone with my other son and having breastfeeding issues. I didn’t know how I would do it.... Yeah too late now and I’m trying not to dwell on it, whatever, you know.

[Interviewer: Yeah, you wanted to make other things easier—] Yeah, how to survive basically, yeah, exactly.
While Dawn did make the argument that breastfeeding can be “much harder for or different for people like us [women with physical disabilities],” her narrative above also seems to suggest that despite this, she hoped to fulfill the (breastfeeding) expectations of the “good mother.” Notably, she expressed some guilt and regret regarding her decision not to breastfeed her second child. Dawn’s experience is an example of how one’s experience of embodiment as a mother with a physical disability might change from child to child, and how a mother could experience internal conflict regarding breastfeeding, even once a decision was made. Dawn’s experience is unique in that she not only experiences mobility limitations and pain but in some respects functioned as a single mother because her partner worked long hours. For Dawn, breastfeeding a newborn, which she had previously experienced as challenging at times, seemed impossible when she also had a preschooler to look after. Dawn’s decision not to breastfeed her second child was very much shaped by her real disabled body and life circumstances (her need to “survive basically”), though as her above narrative suggests, this decision was one that she did not necessarily sit well with (“But now I’m regretting that”). In reflecting on her decision not to breastfeed her second child, Dawn seemingly put this decision into question based on a desire to live up the expectations of dominant discourses of motherhood.

Oftentimes, making the decision not to breastfeed or to cease breastfeeding led some participants to express conflicting feelings about their own values or perceptions of motherhood (or of themselves as mothers). Indeed, perhaps more so than in sharing their experiences of pregnancy (Chapter 4) and mothering (Chapter 6), participants’ embodied experiences of breastfeeding were not necessarily consistent or universal across interviews or even across time, context, and child. Several participants expressed mixed and at times seemingly conflicting feelings about breastfeeding and what breastfeeding meant to them within a single interview. For example, when asked whether breastfeeding was important to her role as a mother, Jennifer responded:

*I don’t know that I felt that way. [Pause] I guess because I don’t feel strongly about breastfeeding versus formula feeding. Breastfeeding, I just thought would be easier, and yeah, I think my reasoning was mostly economic and a desire to try it. Like I think it’s cool that bodies can feed another body so it was an experience I was interested in having but I’m not wedded to it. … I think if I wasn’t able to breastfeed, I [would] probably feel different about it. Like I might long for it a lot more or not feel as good of a mother because of it. But yeah, I mean, I just had a
bit of a mixed relationship with breastfeeding because it is a lot of work and I’m not one of those moms who basks in holding their beautiful child. I like my own space too so when breastfeeding ended, [daughter] was a year old and I was happy to give it up and I don’t miss it. So with the next kid—if it ever happens—I would want to breastfeed again for as long as I can, yeah.

Here Jennifer shares that she did not necessarily feel that breastfeeding as an important part or role of being a mother; breastfeeding was not an experience that she was “wedded to.” Consistent with the literature (see Chapter 1), Jennifer at times seemed to experience breastfeeding as a loss of autonomy or conceptualize breastfeeding as a potential threat to her autonomy: “I like my own space too.” For Jennifer, engaging in the physical act of breastfeeding may have been shaped by her desire to try something that women’s bodies can do, an act not necessarily defining of motherhood. Paradoxically, however, she expressed that if she was unable to breastfeed (she was one of few participants who reported that she did not experience major breastfeeding-related challenges) she might “long for it a lot more or not feel as good of a mother,” suggesting that in some ways she had internalized the expectation that “good mothers” breastfeed. When she had ceased breastfeeding her daughter she was “happy to give it up,” yet shared that if she had another child she “would want to breastfeed again for as long as” she could.

The contradictory feelings that many participants expressed regarding breastfeeding might be explained by the fact that women with physical disabilities who are now mothers live at the intersection of competing discourses. While dominant discourses of motherhood tend to exclude women with physical disabilities, when women with physical disabilities come to occupy the role of mother, some of the expectations associated with motherhood, including breastfeeding, may 1) be challenging for them to perform, given their disability-related limitations, and/or 2) not necessarily be expectations that they desire to fulfill or feel are worth the work to fulfill, for reasons related to their disabilities and other reasons (e.g., see the discussion above about Sarah and her need to go back to taking medication to manage inflammation and thus cease breastfeeding). By putting their own needs first, women with physical disabilities subvert dominant discourses of motherhood and breastfeeding.
5.5 Subversive (non)breastfeeding bodies

Participants responded to breastfeeding-related challenges in a variety of ways, including deciding not to breastfeed. While the decision not to breastfeed could be interpreted as a failure to fulfill the role of the “good mother,” some participants’ decisions not to breastfeed could also be interpreted as pragmatic and subversive. Some participants seemed to accept and even insist that, in order to experience good health and well-being themselves, to manage their disability-related symptoms and other things going on in their lives (e.g., acting often as a lone parent), it made more sense for them not to breastfeed. In other words, participants’ themselves and their children would be better served by having a “healthy mother” as opposed to a “good (breastfeeding) mother.” For example, when I asked Sarah, who had major complications during the labour/delivery of her second child which ultimately landed her in intensive care, if she had breastfed, she replied:

Well, I tried at first as I slowly regained a bit of the strength after that because then I had another surgery the day after he was born. ... [So] no, I didn’t [breastfeed him]. I thought, my baby would be better served by having a healthy, mother, complete. I just focused on myself at that point to get my strength up because I was so weak that I kind of abandoned the idea.

Sarah’s decision to stop breastfeeding her son was described by her as rational; improving her own health in the immediate postpartum period would be more beneficial to her children and ultimately to herself in the long run than putting in the work associated with breastfeeding. By describing (herself as) a healthy, non-breastfeeding mother as “complete,” Sarah subverts dominant discourses of motherhood and breastfeeding. Specifically, she subverts the notion that to fulfill the expectations of a “good mother” one must breastfeed (i.e., you are somehow insufficient or incomplete as a mother if you do not engage in the physical task of breastfeeding), as well as the self-sacrificial discourse of motherhood, whereby it is understood that mothers sacrifice their own health and well-being for the health and well-being of their children.

Importantly though, Sarah’s decision not to breastfeed her second child was also shaped by her (limited) experience of breastfeeding her first child. As described earlier, Sarah chose to cease breastfeeding her first child due to her need to return to taking medication to manage symptoms related to her arthritic condition. Sarah’s experience thus reveals how women with physical disabilities’ unique bodily needs shape their embodied experiences of breastfeeding.
(and that attending to these needs are important for their overall well-being). As well, her experience reveals how embodiment may be shaped by women’s shifting expectations or desires based on their previous breastfeeding experiences (i.e., embodiment is not necessarily static but an experiential process).

As discussed, for a few participants, the decision not to breastfeed their second child seemed to be related to the practicalities of being not only a mother with physical limitations but also now being a mother of two children. For these participants, it seemed that bottle- and/or formula-feeding was the more appropriate choice for them. For instance, Dawn, who has a congenital bone growth disorder, shared that while she was pregnant with her first child, her experience of pain dissipated. But when it came time to breastfeed, pain returned. Based on the struggles she experienced trying to breastfeed her first child then, she made the decision not to breastfeed her next child:

Well, so with [first son] I wanted to try [breastfeeding] so I tried doing it and so remember how I said it took the pain away. When, after I had him [second son], it was almost like all that came back at once, all the pain, so when I was trying to breastfeed him it was hurting my arms really bad…new positions and everything and he just wasn’t latching on and I was getting frustrated… Ack, I’m just going to bottle-feed. But I tried again a few times after we got home or whatever, I’m like this is not for me so then I decided the whole time, and even from the beginning with this one I’m not going to breastfeed only because I feel like having a 5-year-old, having a new baby, and with my physical limitations it’s just too much. Like I just I wanted to make my life easier not harder.

Similar to Sarah’s decision to not breastfeed, one could interpret Dawn’s contention not to breastfeed as an act of subversion, challenging the biological essentialist expectation of self-sacrificial motherhood discourse. Again, deciding not to engage in all the physical acts or tasks associated with biological motherhood, such as breastfeeding, might be understood as subverting dominant discourses that equate breastfeeding successfully with being a “good mother.”
Chapter 6
Mothering

In this third and final findings chapter, I consider how participants’ embodied experiences of mothering were very much shaped by their embodied experience of disability. Disability was experienced as both interfering with and adding value to participants’ embodied experiences of mothering, and in some ways, came to be experienced differently as a result of mothering.

To begin, I explore how participants experienced not being recognized as mothers, as well as their experiences of heightened scrutiny and surveillance from other people when they were recognized as mothers, under the theme (6.1) “Is he yours?”: Unrecognized and over-monitored disabled maternal bodies. These experiences brought disability to the fore in ways that participants had not necessarily experienced prior to becoming mothers, as discussed under the theme (6.2) Foregrounding disabled bodies. Together, these first three themes speak to how participants’ disabled bodies were made visible vis-à-vis mothering, and in turn reveal the relational and fluid nature of embodiment. Conversely, I then discuss how participants’ interactions with their children helped to make their maternal bodies visible, using the theme (6.3) Making disabled maternal bodies visible. Next, grounding their embodied experiences of mothering in their disabled bodies and the expectations of dominant discourses of motherhood, I discuss how mothering was experienced as challenging for participants, under the themes (6.4) Challenging and painful bodies, and (6.5) Wrestling with dependent bodies and the expectations of a “good mother.” In the remaining themes of the chapter, (6.6) Embodying interdependence, (6.7) Seeing disability differently, (6.8) The value of mothering with a disability, and (6.9) Confident bodies, I consider the various ways in which participants’ embodied experiences of mothering subvert dominant discourses of motherhood, discourses that are bound by expectations of physical independence and the privileging of non-disabled bodies.
6.1 “Is he yours?”: Unrecognized and over-monitored disabled maternal bodies

Several participants reported instances of not being recognized as mothers, even when they were out in public with their children. For example, Julie, a mother of two who has cerebral palsy, shared:

After my son in particular was born, the main question I got was “is he yours?” from everyone. [For example, one time when] I went to the mall with my husband and my son…. He [husband] was sitting on the bench and I took the stroller and pulled it alongside my [wheel]chair and this random stranger came running up behind me, “excuse me, excuse me, is he yours?” and I went, “what, yes, he’s mine, thanks.” … he [husband] came up and he’s like, “what’s the problem?” and I said, “tell her [that] this is my baby.” And she was blocking my movement, so I couldn’t go anywhere in case I was stealing the baby. It was so weird.

Like Julie, Whitney, a mother of three who also has cerebral palsy, reported an instance when a stranger did not realize that she was a mother and intervened:

I remember we were coming out of one store and she’s [daughter] walking in front of me... and I’m driving behind her very slowly and this woman comes up and goes, “oh, sweetie, the woman in the wheelchair is trying to get by,” and literally, physically lifts her up and plonks her down. And my daughter doesn’t have a chance to say [that I’m her mother].

These intrusive encounters with strangers frustrated and shocked participants. For instance, after sharing that she had “been asked a few times if my son’s adopted or they think that he’s not even my son,” Angela, a mother of one who also has cerebral palsy, expressed shock: “some of the questions that people have asked me, or some of the things that they’ve said to me, like right in front of my son, like I can’t believe it!” In these instances, strangers seemed to reject or were unaware that some women with disabilities can and do mother.

When recognized as mothers, many participants reported encountering heightened surveillance and scrutiny from both strangers and social service and health care providers. Notably, several participants, regardless of their martial or socio-economic status, reported having to meet with a social worker before leaving the hospital with their newborns (a practice that is not standard for non-disabled mothers leaving hospital). For instance, Melissa, who identifies as blind, reflected: “I feel like a non-disabled mom wouldn’t have had the social
worker … I feel like I got flagged as like ‘oh, you’re a special case; you need social work’ and that made me feel a little bit offended.” Similarly, Hillary, who sometimes uses a wheelchair, felt that the social worker she was required to meet with before leaving the hospital with her newborn son asked, “more questions [than an able-bodied mother would be asked] about whether I was capable of providing the care the baby needed.” Hillary felt that she was “put to a higher standard than an able-bodied parent would be.” Finally, Kimberly, a mother of one who has spinal cord injury that resulted in quadriplegia, shared:

*I remember being mad that a lot of people thought just because I have a disability that my son was going to be neglected or whatever.... If I was able-bodied, I would have gone home after like 2 days and that would have been the end of it. ... But like, no, because I had a disability I had all these people I had to meet with and see and prove things to.*

Participants expressed feeling frustrated, upset, and offended as they recounted instances where they seemed to be held to a different standard compared to non-disabled mothers. These experiences seemed to shape some participants’ early embodied experiences of mothering, whereby they entered motherhood feeling discouraged, as other people did not seem to perceive them as being capable of mothering. For example, in discussing her experience of having her parenting capability assessed by a social worker before leaving the hospital with her newborn, Hillary shared: “when you’re still figuring it [parenting] out yourself, it’s discouraging.”

Questions about their fitness to mother led a few participants to temporarily question their choice to become a mother. For example, before she had more consistent childcare support in place via the Nurturing Assistance program, Julie had privately hired a personal support worker to come to her home while she was recovering from the caesarean delivery of her first child. Instead of supporting her, Julie shared that the personal support worker judged her fitness for motherhood. This interaction caused Julie much distress. In describing the interaction below, it seemed that Julie internalized the personal support worker’s judgement, which in turn caused her to feel that she was undeserving and incapable of being a mother:

*I was recovering from c-section and I was in so much pain. It took me 20 minutes to move from my bed to my chair and I was postpartum and everything else and I was bawling and the woman who was supposed to be helping me said, “this is why people like you shouldn’t have kids.” So, I was horrified. I felt like the worst person in the world, and so I started telling my husband “I don’t want him [son],*
we should give him away” and whatever and so my husband is all upset, and he told her [the support worker] to like get out of our house and don’t come back.

The experiences described above (and in the previous section) reveal the relational nature of embodiment. Participants’ interactions with others who did not seem to recognize them as mothers and/or assume they would be “bad mothers” shaped their embodied experiences of mothering. Said interactions made disability stand out in a way that participants may not necessarily have experienced prior to becoming mothers. For a few participants, these negative interactions caused them to feel that they may not be able to meet the expectations of a “good mother,” and in turn to perhaps internalize stigmatizing discourses of disability as defective, in this case related to mothering.

6.2 Foregrounding disabled bodies

When recognized as mothers, participants’ disabled bodies seemed to become the primary focus of other people.

And I think yeah, my sense of self has definitely changed. [Interviewer: So it’s interesting, earlier you said when you were pregnant you felt like your disability was kind of hidden. But when once you had your daughter, it seems that your disability has come to the forefront]. Oh totally, absolutely. Yeah, definitely. And as like a parent and all of my interactions with people when I’m with daughter. Even at daycare (Jennifer).

Jennifer shared that once she became a mother her disability seemed to become front and centre in her interactions with other people. Becoming a mother in some ways changed not only how other people treated or interacted with participants but also how participants experienced themselves as disabled. Somewhat like the experiences described in Chapter 4 regarding pregnancy, being a mother evoked new feelings about disability for some participants. Notably, for some, being a mother evoked a new recognition or experience of themselves as a disabled person.

I’ve never really actually seen myself as a person with a disability really until I became a mom.... I mean I was aware that I had a disability. Like I’m not denying that, but I didn’t see myself as a person with a disability. ... But now I’m being a mom and I just find that when I go out with my son ... people come up and say things to me. I’ve never experienced this before, like to this extent. ... So I think I’ve become more aware that people see me as a person with a disability (Angela).
For Angela, other peoples’ perceptions of her as a person with a disability and a mother altered her perception of herself as person with a disability. Being judged or pegged as a potentially “unfit” mother evoked a heightened sense of self as a person with a disability for some participants. Thus, both Jennifer and Angela’s narratives reveal the very relational nature of embodiment, whereby interactions with other people who might perceive disability and motherhood as incongruent shaped how participants experienced their embodiment as mothers. These narratives in turn suggest that embodied experiences can change with context, as by way of mothering participants came to experience themselves as disabled in ways they may not necessarily have experienced prior to becoming mothers (more on this in later sections).

6.3 Making disabled maternal bodies visible

While several participants recalled strangers not recognizing them as mothers and having their fitness for motherhood questioned, some participants also shared that being out in public and being recognized as a mother made them feel proud and confident.

*They [strangers] most definitely looked at me funny or at least I felt like most of society did. But once my son was talking, started calling me mom, that made me more confident I guess, I responded differently to their reactions. People would look at me and weren’t sure whether I was the mother or not. I would smile because he called me mom, right (Julie).*

Julie’s narrative reveals the relational nature of embodiment, whereby the visible or public interaction participants had with their children or their child’s naming of their maternal identity shaped their embodied experience of motherhood; these interactions with their children brought motherhood to the forefront.

A few participants also shared how they strategically navigated public spaces to be recognized as mothers. For instance, though Angela’s son did not “always need” his stroller – “he’s a little bit big for it” – she often brought it when they were going out:

*I love being out with my son with the stroller ... I use it as a walker. ... If I’m out with him I always bring it because I can shove everything in it and he’ll hold on to the side but people see him and they see the stroller before they see my crutches because I tuck my crutches into it and it’s awesome. And I get comments like “Oh, your son’s so cute” but then I have people say “Oh, is that your son?” you know. But most of the time, they just see him and it’s good.*
Using a stroller was not only functional, allowing Angela to carry things and assist with her mobility but proved to be instrumental for her to be recognized or “pass” as a (non-disabled) mother and subsequently avoid judgement or intrusive questions from strangers. Indeed, it has been argued that when they are successful at “passing” as non-disabled, the initial stigma of disability becomes “neutralized,” allowing for relationships to develop and deepen and “other aspects of personhood emerge” (Garland-Thomson, 1997b, p. 13). In other words, “passing” as non-disabled aids people with disabilities to be recognized as more than just a disabled body or reduces their chances of only being perceived of according stigmatizing discourses of disability. For Angela, the site where embodiment was enacted included the stroller itself. In this account, (use of) physical objects associated with mothering played a role in shaping Angela’s embodied experience of mothering, pushing disability to the background to carve out space for her to be recognized as a mother.

Despite instances of being recognized as a mother without the weight of qualification or proof, however, mothering still proved challenging for many participants.

6.4 Challenging and painful bodies

While all participants stated that being a mother was a positive change in their lives, being a mother was also experienced as challenging. Many participants shared that the physical or functional limitations and secondary conditions that they experience, notably chronic pain, made engaging in some of the tasks expected of mothers challenging for them. As such, participants’ embodied experiences of motherhood could not necessarily be separated from their embodied experiences of disability. Indeed, as feminist disability scholars have argued, some bodily impairments may be disabling no matter the social context (Wendell, 1996; Crow, 1996; Hirschmann, 2012).

Even if they could visibly “pass” as non-disabled in some situations, some participants expressed that because of their disabilities it was often difficult and sometimes impossible for them to engage in activities that may be taken for granted as easy (or “natural” or “normal”) for non-disabled mothers (i.e., things mothers typically do without hesitation or much planning), such as changing diapers, lifting their baby out of their crib, and keeping up with other mothers.
while pushing a stroller (for a discussion of some of the limitations of “passing” more broadly, see Goffman (1968)).

For example, Hillary, who had a spinal cord injury that did not change her ability to walk, shared that her secondary condition of chronic pain limited her ability to keep up with other mothers:

I know I’m disabled but not necessarily the people around me [do] .... Being invisible some of the time, having the invisible disability can be difficult because you’re dealing with a problem that people aren’t aware of .... I have a hard time relating to other young mothers because there’s so many things I can’t do. I can’t keep up with the stroller walk; I just can’t walk as far as a lot of able-bodied women can so I don’t [do] that kind of social thing.... It’s hard to explain it [to] someone who hasn’t experienced pain in a significant way.

Because she was not able to keep up with other mothers who could walk while pushing a stroller, Hillary felt disconnected from this social experience of mothering. She felt as though other mothers would not to be able to understand her embodied experience. Thus, for some participants their disability prevented them from feeling as though they could relate to or connect with non-disabled mothers.

Not all participants were able to conveniently use or could afford equipment to disguise their disability and/or to confirm their status as mothers. For instance, Simone, who has scoliosis and fibromyalgia – disabilities that are not always visible – talked at length about how using a baby carrier is perceived as “a normal part of motherhood” but not something that was always practical for her: “it didn’t really work.” Instead, using a baby carrier and generally carrying her daughter caused a great deal of strain on her body.

What’s interesting is that no one really talks about the physicality about it after you have your baby, you know... everyone’s body is different. My hips are like the strongest part of my body. ...you know, they’re not perfectly straight, but they’re good hips [laughs] so carrying her for pregnancy, it was completely fine. ... She’s pretty big and we’re still breastfeeding and physically that’s a lot too. Like carrying ... physically that’s a lot for me. The pregnancy wasn’t the hardest part physically. It was the, it was this, afterwards, carrying. Even when she was an infant that was hard physically, and now [that she’s a toddler] physically it’s very hard.
Several participants explicitly shared that with motherhood came increased pain and decreased mobility.

Bodily changes and the limits posed by their secondary conditions, made some participants feel disconnected from other mothers, as well as feel and like they were failing at motherhood or letting their children down.

_The fatigue is another common complaint with the pain so that would probably the biggest thing ... if you’re always tired, it’s hard to be on your best, be the best parent_ (Sarah).

_People tell me to enjoy this period of my life because it goes [by] so quickly. They are not babies for very long. I wish I could enjoy it more because so much of his early months were really [exhausting]. I was dealing with a lot of pain just because of the amount of physical work I was doing to take care of him. It was hard to enjoy it because I was in a lot of pain a lot of time. So that definitely overshadowed that experience for me. ... Like the pain of my limitations, it does colour every aspect of how I look after him. I wish I could do more for him and I get really frustrated by how limited I feel. I wanted to do more. I like to take him on longer walks and do different activities and I just don’t have the energy. I wish I did. That’s where it has kind of overshadowed my sense of being a mother_ (Hillary).

The above narratives reveal that participants’ embodied experiences of mothering were very much shaped by their embodied experience of disability; Hillary, for instance, shared that her disability “colours” how she cares for her son.

In addition to reflecting on the immediate impact of disability on their mothering, some participants expressed worries about what impact the worsening progression of their disability may have on how they mother in the long-term. As Dawn points out, the long-term impact of disability on one’s body and consequently on one’s family is not an issue that most mothers have to worry about.

_With the second [child], I had developed a lot more pain in my body, and it makes me very limited in what I can do. ..... The more you carry a baby, the more pressure on your hips and things like that. It affects you. Yeah, since having the second one, for sure, it made a lot more pain in my joints and now I have to really focus on thinking about when am I gonna [sic] have that hip replacement and how I’m going to do it cause my husband works crazy hours. Who’s going to watch my kids while I have the surgery? So again, it’s something a normal, quotation “normal” mother would not have to worry about, where[as] it’s_
something that I have to look in the future and think about ok, how am I going to make myself better and not in so much pain so I can be a better mother for my children? Because I find and I’m sure other mothers understand, but when you’re in pain, it makes you so much more tired. When you’re tired, you have less patience. You’re irritable, and that’s just makes you not a good mother because I have no patience for my son. I’m like ok, mommy just needs to sit for a minute. And I’m lucky. Most of the time he’s quite understanding but it sucks. I want to be able to do lots and lots of things with him, you know? (Dawn)

Dawn’s narrative suggests that she was worried not only about how things might change for her physically over time but how the progression of her disability might impact the type of mother she was; she seemed to worry about not being able to live up the expectations of a “good mother.” Likewise, not being able to do some things for or with their children because of their disability caused some participants, like Dawn, to feel guilty: “not being able to do the things that I want to do because I’m in pain makes me feel like I’m a bad mom.” Julie, shared a similar sentiment when she described not being able to take her son outside to play in the winter:

... it was the middle of winter he’d been bugging me for days to go outside and play in the snow. He’s like “mommy I’ll be a good boy. Please I want to go. I’ll come in when you tell me...” so trying to get me to take him out but I knew that I would get stuck in the snow and it was just not safe for me to take a 2-year-old out in the snow. But I felt bad, he cried pretty much the whole day until my husband came home and took him outside. But I had to do what’s right; as bad as I feel, I knew that I just couldn’t do it, for his safety and mine.

In this instance, Julie demonstrates that she is indeed a good mother by ensuring the safety of her son and herself. Yet, like Dawn, Julie’s worries and feelings of guilt seemed to be shaped by a discourse of motherhood that posits that mothers be physically capable and independent in all aspects of childrearing, a discourse that in turn reinforces the notion that disabled bodies are not suited for mothering.

6.5 Wrestling with dependence and the expectations of the “good mother”

In this section, I highlight the relational nature of participants’ embodied experiences of mothering by focusing on their narratives of disability as limiting their ability to be independent in the context of mothering. Specifically, I discuss how not being able to do some physical childrearing tasks and thus having to rely on other people to care for their children caused some
participants to feel resentment about having a disability. For a few participants, not being able to
do some physical childrearing tasks also evoked feelings of resentment toward their non-disabled
partners and other people who were able to do said childrearing tasks. These experiences in turn
cause some participants to feel as though they were missing out on or not meeting the
expectations of a “good mother,” that is, being “all things at all times to their child: strong role
models, endlessly nurturant, child-focused and without limitations to their capacity to care”
(Malacrida, 2012, p. 393, emphasis added).

Amy, who has cerebral palsy, shared: “Whenever I cannot lift up my son, I see my
disability more than before. When my son wants to play with his dad, I see more limitation,
which, saddens or depresses me.” In this instance, Amy’s disability was experienced as
negatively impacting her embodied experience of mothering. For her, the inability to engage in
some physical parenting activities caused her to feel more disabled or experience disability in a
way that she may not have experienced before becoming a mother. Becoming a mother, yet not
being physically able to do all the things that mothers are “supposed to” do and in turn seeing
that other people could do them, caused some participants to feel less able or more dependent.

For some participants, a heightened sense of self as disabled and in turn resentment
towards disability and their non-disabled partners were particularly evident in the first weeks and
months of motherhood.

My husband changed most of the diapers at the start. So we were a team and
you’re up 24 hours a day anyway. He changed all of his diapers and did the
burping and I did all of the feeding and in the middle we would both share the
cuddling and trying to put him to sleep and stuff like that. But again [Husband’s
name] had a better chance at doing that because I had a lot of difficulty holding
him. So I felt really resentful at the start. That it’s my baby and you’re the one
who’s shushing him to sleep. I said to [Husband’s name] at the time that I have
never felt as disabled in my life as I did in that first period because I really felt
like it should have been me and it wasn’t …. I’m usually very proud to identify
with communities of people with disabilities and as a person with a disability.
Umm the only time really that I really resented since I’ve been a kid; I think being
a kid is hard right because people—because kids can be cruel and it can be hard
to fit in. But the only time I’ve really felt so negatively about having a disability
since then was that really early period of just having [son’s name] and trying to
figure out what to do and having to rely on my husband so much. Umm so at that
time period in time I think I felt more of the negative parts of being a person with
a disability and I really resented it. [Interviewer: And what about your identity as
a woman, being gendered? So that’s interesting that your husband really took on that traditional role that a woman might, was that maybe part of it too?] Yeah, definitely, you know, the gendered part of it. I’m supposed to be doing this because I’m his mom. These are things that moms do, not dads. And even though I don’t feel that way about anything else in my life, you know, we split everything; we split all of the stuff at home and I really felt like I should be doing that and I wasn’t doing that and I was kind of a failure for not being able to do it (Heather; bold indicates emphasis by the participant).

In the early weeks and months of mothering, Heather came to embody disability differently; Heather shared that she felt “the most disabled” she had ever felt: “I’ve never really had much that I couldn’t do. I’ve been able to negotiate schools and jobs and boyfriends. ... But that [ended] when he [son] came home and I couldn’t properly even hold him.” For Heather, becoming a mother had changed her perception of herself as a person with a disability. She found herself feeling negatively about having a disability—an experience she had not had since she was a child. She felt as though having a disability prevented her from doing what mothers are “supposed to be doing.” In her follow-up interview she again expressed feeling negatively about disability:

So I made him, I made him and he’s mine mostly is how I felt about it, right? I couldn’t decide when I could pick him up and I couldn’t—if he was crying and I knew he was hungry, I’d have to get his dad to come and help me pick him up. If his bum needed to be changed, I can’t hold him on the change table and change his diaper at the same time. So his dad has to do that. I felt completely disabled. I felt completely cut off from being able to do the things that I wanted to do, like really, really upset by it. I’m in my 40s. I’ve had a disability from when I was born. I don’t really remember ever feeling as resentful of having a disability as I did [in the early months of being a mom]. Because here was the most important thing, for me, that I couldn’t do it on my own. I couldn’t have any agency around it in the same way. So it was awful. It was an awful period. I remember I couldn’t just cry to my husband about it. Like “you don’t understand” and he didn’t really, but we’re doing it together. For me, it was my responsibility and I couldn’t do it. And the only way, for the first time, profoundly, that I couldn’t do it. So it makes me upset, just even talking about it.

Heather’s sentiment that certain childrearing tasks were her responsibility, by which she presumably meant her responsibility as a mother alone (i.e., “things that moms do”), suggests that dominant discourses of motherhood shaped her expectations of herself as a mother. Her inability to do some physical childrearing tasks seemed to bother her not only because they were things she wanted to do but because she seemed to feel a responsibility as a mother to do them.
Heather’s narrative suggests that her feelings of “failure” were shaped by the expectation that mothers are to be individually (or primarily) responsible for physically taking care of their children, and if for whatever reason they are incapable of doing so, they are “bad mothers” or “a failure.” Such a response by Heather was somewhat ironic though, as she too acknowledged that she does not feel like that (that is, bound by dominant discourses or traditional, binary gender roles) in other facets of her life. Heather’s narrative reveals just how pervasive dominant discourses of motherhood are for some women with physical disabilities, as their prior beliefs about what roles men and women should occupy seemed to become more sharply demarcated once they become mothers.

For example, Simone, when asked if she felt like other parts of her identity (beyond disability) had changed since she has become a mother, shared this:

*I’m really strong on gender stuff. I’m really quite a feminist* and so that does change with motherhood. I’ve always been the person that’s just like, I don’t have to be the one who goes on maternity leave. ... I’m the kind of person who’s like it could be either of us [her or her husband]. And I see people who do that, and it works and it’s, I think it’s great. Umm but at the same time now, I realize, like, ok, with breastfeeding, for example, do I really want to take a pump to work? right like ok, when I go to work I will have to because she’s still feeding. ... I just I feel like the burden is even greater than I originally anticipated on women.⁸

As Heather and Simone’s narratives suggest, participants have complicated feelings regarding dominant discourses of gender, mothering, and disability. While some participants did seem to recognize how dominant discourses of motherhood may be limiting (or burdensome) to women and perhaps even rejected gendered norms about parenting prior to becoming mothers, once they became mothers some participants seemed to feel a need or desire to live up to the expectations of the “good mother.” This need or desire was evident as participants reflected on and recognized the physical limitations of their bodies in relation to mothering and particularly amplified as

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⁸ In this case, bold indicates whispering. While Simone’s baby was the only other person present during our interview at her home, it was interesting to me that when she responded to my questions about how becoming a mother might change one’s identity, particularly as it pertained to gender or femininity, by whispering. Whispering to me suggested that she did not want others to know that she identified as a feminist and that perhaps she felt conflicted about what identifying as a feminist meant now that she was a mother who felt strongly about being the one who stayed home to care for her child.
participants shared their experiences of watching other people do things with and provide care for their children that they physically could not.

6.6 Embodying interdependence

While some participants seemed to fear experiencing themselves or being perceived of as dependent, most participants who needed some help with physical childrearing tasks did receive and ultimately welcome the necessity of this support. Several participants reported that they received help with childcare from their partners, particularly when their children were infants, as well as from their own mothers and other family members. Several participants also reported that they had formal (privately paid or subsidized) childcare in place, including childcare support through the Nurturing Assistance program (as discussed in Chapter 2).

I found that the need for childrearing or childcare assistance seemed to be accepted or welcomed by some participants more than others, notably those living with spinal cord injuries that resulted in quadriplegia and those who already had other people (e.g., personal support workers) helping them with some of their daily activities (e.g., bathing, dressing). For instance, Kimberly shared: “I want to do as much as I can by myself but not at the risk of harming my child.” For these participants, receiving help from other people was not particularly new, shocking, or threatening to them. In other words, some participants seemed to be accepting of and willing to reach out for support because they may have already conceptualized themselves as interdependent. In this way, participants subverted dominant discourses about what it means to be a “good mother,” whereby “good mothers” are expected to be the primary physical caregivers of their children (at all times).

With other people involved in physically caring for their children, participants’ embodied experience of mothering extended beyond their individual, physical bodies. Yet, some participants explicitly shared that, although they may not have been physically able to do all childrearing tasks on their own, they still played the dominant role in shaping their children’s lives as they instructed other people to provide the care that they physically could not:

*I’ve been very lucky now that I’ve had a regular [nurturant care] person since I was pregnant with my second child. It’s nice to be able to have somebody with you, because as I said, my husband was working and he was in school. So like*
pushing a baby stroller or something, I’m not going to do unless we rig something up and attach it to the scooter. There are safety issues with that... to have somebody that’s able to lift the child as the child gets bigger and put them in a baby stroller, and go with me. So basically, they’re an extension of you. ... It’s a balancing act. I think people perceive, well, you never do anything for your kid; there’s always somebody else doing something. That’s not true. Whether I’m the one doing the ironing or somebody else is doing the ironing, I’ve got to direct that. Or are they bonding more with your kid? No. .... I’ve never had an issue of my child bonding more with the other person. It’s just helping with the physical stuff (Whitney, who has cerebral palsy and three children).

As Whitney’s narrative suggests, mothering with a disability poses a challenge to the dominant discourse of motherhood. Instead of imagining mothering as a function restricted to the bodies of (individual) mothers, participants’ narratives suggest that the embodied experience of mothering is sometimes achieved through the assistance of other people (“they’re an extension of you”). Indeed, nurturing assistance, by its very definition, “is not a replacement for traditional childcare” or about having someone take your place as a parent but instead “enables a parent with a disability to direct a personal support worker, or attendant, in the physical care of their child” (Centre for Independent Living in Toronto, 2017, emphasis added). Nurturing assistance thus is another way to conceptualize independence, whereby independence may not be traditionally understood as self-sufficiency but instead decision-making and taking control of the parenting situation.

Several participants, including Whitney, shared that the use of nurturing assistance and other support persons to help with physical childrearing tasks, such as lifting children in and out of cribs and strollers, was advantageous for several reasons, including the preservation of their own energy, health, and comfort (which they felt was vital to be a good and healthy mother):

I’m sure that sometimes when I’m out in public, people might think I’m doing nothing, but I mean, I’ve packed everything, I’ve planned everything. I might be too tired, or I might be having a spasm, it might not be the greatest time for me to pick up the baby but thank God there’s somebody else there that can pick up the baby, you know (Whitney).

While people with disabilities are often regarded as dependent and as such it is generally perceived that supports/accommodation for people with disabilities are acceptable, the acceptance of support is contrary to what is expected of “good mothers.” As such, by accepting childcare support as a regular part of their embodied experience of mothering, women
with physical disabilities subvert dominant discourses of motherhood. As well, as noted, participants’ adoption of nurturing assistance may evoke a new perspective what it means to be independent.

Importantly, in the context of childcare, it should be stated that the availability of social support and financial means did vary among participants and arguably had an impact on their embodied experiences of mothering. While most participants were partnered, how much their partners contributed to childcare was variable, much like it is for non-disabled women. For instance, Angela shared that she wished she “demanded more support from [her] husband” while she was pregnant and noted that, even though her son is now three-years-old, her husband still seems to conceptualize caring for him as “babysitting” on the one evening a week she has negotiated to be free of childcare duties to go out of the house and do something for herself (our initial interview took place on one such occasion). In contrast, Heather, as discussed earlier, shared that her husband played a major role in caring for their son, especially in the early months when she was unable to do some tasks such changing diapers. Additionally, she acknowledged that they, her and her husband, “definitely enjoy a great degree of [financial] privilege.”

My husband was off work for 4 months. He’s a corporate lawyer so typically they take like 2 weeks off work but they just had a new change in their HR [human resources] policy that said if you think you know you should have more time in terms of parental leave make a case to us and you can have up to 16 weeks so that’s what he did. .... We do ok in terms of being able to afford things like ... an expensive stroller but if I didn’t have that money I don’t know what I would have done actually.

In addition to her husband’s well-paying job, Heather has a master’s degree and works full-time.

There was only one participant, Kimberly, who was a single parent. At the time of our interviews she had recently moved into a new subsidizing housing building, far away from family and friends, and found that few of the other tenants in her building were disabled and had children. While she had personal support workers to help her with her daily disability-related needs, it seemed that there were many things that made being a mother more challenging for her than other participants. For instance, Kimberly shared that now that her son was in school, she wanted to find a job but shared that she was having a difficult time finding work. Further, she was restricted to using public transit to get around. By comparison, Rachel, who like Kimberly
too had a spinal cord injury that resulted in quadriplegia, was married, had a master’s degree, and had worked for several years but decided to stay at home when her children were born (at least for now, as her children were not yet in school). Rachel shared that her husband had a good job, that they “built a house so it’s all accessible,” and that she had a van that was modified so that she could drive herself wherever she needed to go. Like Kimberly, Rachel has personal support workers to assist her with her daily disability-related needs but unlike Kimberly, Rachel reported that she has “a lot of friends who help out,” family members who live close by who also help out with childcare, as well as “a nanny that’s here [in their home] Monday to Friday” (privately paid for, not through the Nurturing Assistance program). In short, the contrasting backgrounds of participants suggest that the capacity to be dependent (in a good way) is very much classed; just like it may be for non-disabled women (e.g., see Byrne, 2006; Taylor, 2011), social and financial capital (or lack thereof) may shape the embodied experience of mothering for women with physical disabilities.

### 6.7 Seeing disability differently

While to varying degrees, participants experienced mothering as challenging, they too found ways to adapt to the challenges that they encountered and to perform the work of mothering in a manner they found satisfying. In doing so, some came to recognize that mothering was challenging for them for reasons beyond their disabled bodies or bodily differences. Notably, for some participants, with mothering came a recognition of structural barriers and challenges that they had not been aware of or experienced as disabling prior to becoming mothers, and in turn, they developed a new perspective on disability. Notably, participants shared that they were unable to access spaces and to participate in activities intended for mothers and their children, such as playgrounds and play groups.

*We did go to one of those moms and tots group things but I felt a lot of them, like, they were all sitting on the floor with their child in front of them and helping their child—like, this was when they were pretty small, right—clap and sing or do whatever and I couldn’t do any of that and didn’t really—I didn’t go very much because of that* (Kimberly, who uses a motorized wheelchair).

The playgroup’s normative requirement to sit on the floor with one’s child prevented Kimberly from fully participating in the group and her account suggests that she did not feel sufficiently included in the group to keep going. Other participants shared similar experiences of visiting
spaces and groups, like playgrounds and mommy-and-me play groups, that on the surface seemed inclusive of all mothers and parents but were ultimately not accessible to them.

_I was always aware that I would never be able to take my daughter to the park by myself. Or it’s like mommy and me classes were never an option. So there’s like all these things that are designed to help women on maternity leave not go crazy and none of them were accessible, like at least in [big city]. So, yeah. It’s just a complete lack of services and lack of imagination on who has kids and what they might need_ (Jennifer).

Through mothering, some participants came to view the world as inaccessible in new ways, and subsequently began to view disability differently. Specifically, as they engaged more and more with their children in public spaces, some participants began to experience or frame disability from more of a social model of disability lens. The social model, as discussed in Chapter 2, conceptualizes disability as a product of the barriers individuals face because of environmental and attitudinal factors rather than situating the “problem” of disability within the individual. Thus, participants’ understanding of access became deeper due to parenting; their understanding of disability as constituted or produced by inaccessible environments meant they were beginning to have a more politicized view of disability. In turn, as mothers, some participants came to identify parenting issues for them as disabled parents. For example, Jennifer identified playgrounds and un-shoveled sidewalks as barriers for her as a parent with a physical disability:

_It’s really, really, really hard for me to walk around a sanded playground. It’s one of those things where I didn’t really think about, what kind of material the playground was made out of but now I’m hyperaware, like, whether it’s bark mulch or sand…. [Also] everyone complains about how hard it is to get around in the snow but it’s like I’m supposed to take daughter to daycare every morning so if there’s a snowstorm and no one shovels their sidewalks, I can’t take daughter to daycare. It’s not part of people’s radars that this is an actual issue of parenting._

Interestingly, these barriers that Jennifer identified were not necessarily on her radar as possible parenting barriers prior to becoming a mother. The narrative below from Melissa reveals that not only did some participants come to recognize the world differently or as more inaccessible than they had experiences prior to becoming mothers, they too came to embody disability differently as a result:
I noticed things I can’t do the same. ...My son, for example asks, “can we go to the library?” And I feel a bit sad going to the library ... I want to take my son to the library. It’s great that he asks to go to the library. He can read but at the same time, what am I gonna [sic] do at the library? It’s just a whole bunch of inaccessible [non-Braille children’s] books. So it feels very isolating going in and being like well, all the other parents here are sitting here, reading to their children and I have to go like well, show me where a book is [that] you want to read and then tell me what pictures you see. That feels a bit—I guess being a parent suddenly makes you more emotional to everything, where it’s like oh I can’t read to my child, where it has never matter to me before that I can’t read print books.

In Melissa’s case, becoming a mother evoked an emotional response, including feelings of isolation and exclusion that she had not previously experienced. Melissa felt that she was excluded from being a mother as she could not read to her child because there were no accessible books. Her interaction with her son in an environment not set up with disabled people in mind caused her to feel differently about being a person with disability and to identify that environments can be inaccessible and thus disabling.

In sum, as a result of engaging in spaces that did not seem to be designed with parents with disabilities in mind, some participants came to understand disability as a social creation. In turn, these experiences suggest how limited understandings or expectations of who might (or could) be a parent are, and that these expectations dictate social practices and physical environments as they relate to parenting.

6.8 The value of mothering with a disability

When asked about what they liked about being a mother, some participants shared that their embodied experience of disability offered opportunities to educate their children about difference and disability, and in this context, disability was experienced as something they were thankful for.

One thing that I’m proud of though is fine, I’m different. But I’m very proud that I know I’m going to make my children not ignorant and they’ll be educated on people that are different and not care. And they’ll be very accepting. I just know they will be because I teach them that, you know? If he [older son] stares at anybody I say, “it’s not nice to stare at anyone; don’t do that.” And he’ll say “ok.” He asked me one time about something and I said, “well, why is that?” He’s like, “we’re all different and it doesn’t matter” so he knows. He’s learning.
That’s something that I love being a mom and being disabled about, because there are so many parents and children that are so sheltered and [who] in 2015, still make fun of people who are different, and it should not be that way. I’m proud that I will have a child or children that don’t do that (Dawn).

Participants were proud that their children had become attuned to difference and the ways in which the world can be inaccessible to people with disabilities.

I know my son has become very sensitive to accessibility. He likes everything to do with the public transit system. He wants to grow up and be an engineer and design the city – and redesign and make sure everything’s accessible. Or we go somewhere, and things are not accessible, and we heard him commenting, “oh, that’s not right, that shouldn’t be.” ... So, they’re becoming advocates, which I guess it’s good. I mean, I didn’t have kids to raise advocates, but they see it from another perspective (Whitney).

Additionally, some participants shared that not only did their children come to view the world as inaccessible and inequitable, but they also experienced their mothers’ disabled bodies as normal. For instance, Rachel, whose spinal cord injury resulted in quadriplegia, shared: “It’s an amazing experience being a mom… it’s interesting to see how my children react [to my disability] because they don’t know any differently.” Rachel went on to share that while her children did come to recognize that there were things that she could not do, they adapted quickly; for instance, once they were able to walk, they would climb up onto her lap while she was in her wheelchair. Similarly, Jennifer shared that her daughter seemed to recognize early on what Jennifer could and could not do:

I guess what really struck me was from a very young age—and I won’t be able to pinpoint how old—before she was a year old, she already had the sense that I couldn’t do the same things that my partner can do. And so she knew from a very young age not to pester me to pick her up, whereas if [my partner] came home she would spend 15 minutes whining for him to pick her up. Or if my mom came over, she’d immediately wanted to be picked up. But she like never bothered me to pick her up. And so things like that, I thought was pretty neat. She likes riding around on my scooter and we read a lot of books together. We play in some different ways than [what] she and her dad do or she does with other people. But I like that it’s relational in a sense that she has an understanding of me from very young and that’s just how things go.

Adapting to their mothers’ disabled bodies seemed intuitive for participants’ children, revealing that expectations or assumptions about mothering and disability are not inherent but learned. In
other words, if children are not exposed to discourses that suggest that disabled bodies could not or should not be maternal bodies, they may not see any incompatibility between disability and mothering; how their mothers do things may just seem usual to them.

In sum, the relational nature of embodiment is evident in how participants’ children both came to view the world regarding disability, that is, in similar ways that their mothers did, and how they interacted with their mothers; I learned that participants’ children often behaved in ways that were intuitively accommodating of their mothers’ bodily limitations. In turn, participants’ children’s internalization of dominant discourses of disability and motherhood (or lack thereof) informed their own experiences of embodiment as mothers.

6.9 Confident bodies

Generally, participants’ perceptions of their own bodies differed from other peoples’ perceptions of their bodies and their mothering capabilities as discussed under the previous themes. Notably, becoming a mother came with increased feelings of confidence and a sense of pride and achievement. Amy, a mother of one who has cerebral palsy, commented that although strangers often do not recognize her as a mother, “whenever I take him [son] outside I feel really proud of myself because now I became [a] mother, right…. I feel very proud of myself; I like to show the public [I’m a mother].” Similarly, shared Hillary:

*The process of pregnancy and childbirth and caring for a child really shows you what you’re capable of doing, even when you’re dealing with fatigue and frustration …. So, it is positive in that sense. …that I’ve been able to figure out a way to do it is, is an accomplishment.*

For many, with feelings of pride and accomplishment came a newfound sense of confidence, which manifested itself in many forms. For one, confidence was enacted by an increased likelihood of standing up for themselves, thereby countering ideas of women with disabilities as passive and weak. For instance, when asked if she feels differently about being a woman with a physical disability now that she is a mother, Kimberly responded:

*I became a stronger person through it all, like definitely. And I realize now that the mama bear is like totally true. … it’s that that made me a stronger person. When I had to stand up for myself or stand up for him … I sometimes have trouble*
voicing my feelings and ... I’m trying to change that. ... [becoming a mother has
given me] maybe more strength to stand up for myself.

Similarly, Jennifer shared, “I’m a lot more willing to ask for help and demand things from other
people in a way that I wasn’t before.” Likewise, Angela commented: “I think I’m more confident
and I think in the past I would just ignore people and not say anything [in response to their
negative comments], and now I speak up a bit more.” Dawn too expressed sentiments of
confidence, particularly as she reflected on how she thought about her own abilities prior to
becoming a mother and what other people thought about what she was capable of:

Before I think I was like, always have a huge, I can’t do it; I won’t be able do it
because of my legs or whatever but now I know I guess if you want to do
something you find a way to do it. I think I feel like I have more confidence now. I
don’t care as much what people think anymore.

For some participants, feeling confident manifested in both feeling more able to stand up for
themselves as well as not caring as much about what other people think about them.
Furthermore, confidence was realized by participants as they reflected on being more capable as
mothers than they thought they might be prior to becoming mothers.

I’ve realized I’m actually more capable than I thought. Even with my daughter,
when I think back to that and I wasn’t even as well then, that I could still do
things physically more than what people probably would think. I’ve changed for
the better (Sarah).

Mothering thus seemed to provide participants with an opportunity to realize, recognize, and
demonstrate their strength and capabilities, both to themselves and to others. This latter
sentiment, and thus the very relational nature of embodiment, is probably best exemplified by
Angela in her recounting of a story of going out with friends, whose reactions about what she
could do seemed to be patronizing or infantilizing. Her friends’ reactions frustrated her and in
turn resulted in her explicitly making referen
ces to the fact that she is a mother—an embodied
experience that she associated with strength and perseverance:

Somebody made a comment to me, “Oh, you’re doing so well,” you know, going
up these couple of steps. And I just kind of looked at her and I’m like, “Yeah, and
I have a 3-year-old son that I was pregnant with, too, you know?” And it wasn’t
anything to do really with what she said. It’s just like sometimes it annoys me that
people make comments like, “Oh yeah, look at you” kind of thing. They don’t
realize that we’re capable – I’m capable of much more than managing three steps.

In sum, with motherhood, participants came to define themselves on their own terms, proving to other people and to themselves that they could do more than is imagined of women with physical disabilities. By embodying strength and confidence, participants defy dominant discourses of disability.

In addition to heightened feelings of confidence and a sense of accomplishment, a few participants revealed that becoming a mother also came with a greater appreciation of their bodies, specifically viewing their bodies as valuable in a way that perhaps they may not have experienced before becoming a mother.

[Since I became a mother] I feel like my perspective on my body has changed, for sure. ... Like I do think that there’s value in my body and I think it was amazing that I was able to make a child and she exists in the world. So there’s a sense of accomplishment in being able to do that. Yeah I mean I’ve bad days, but there’s lots of times where I’m pretty proud of the way in which we were able to organize our lives and what we do. I don’t feel embarrassed to go out in public with daughter and I don’t know how she’s gonna feel when she gets older but right now, she loves riding on my scooter and stuff so it’s kind of a joyful time right now. Yeah, so I think I feel appreciative (Jennifer).

Again, despite the challenges that they experienced, several participants shared that being a mother evoked a greater appreciation of what their disabled bodies could do, and as discussed in the previous section, an appreciation of what disability brings to the experience of mothering. Disability was experienced as valuable in the context of mothering and participants were generally confident in their roles as mothers, perhaps even more confident and capable than they themselves even thought they would be and definitely more capable than other people expected them to be.
Chapter 7
Discussion

Based on interviews with thirteen mothers with physical disabilities in Ontario, I discussed in Chapters 4, 5, and 6 many of the ways in which they experienced their embodiment during pregnancy, as related to breastfeeding, and as mothers of infants and toddlers. With an understanding of embodiment as relational, I found that dominant discourses of pregnancy, motherhood, breastfeeding, and disability, often enacted through interactions with other people, including strangers, family members, and health care providers, shaped participants’ experiences of embodiment during the perinatal period and early motherhood. As well, participants’ embodied experience of disability shaped their embodiment during the perinatal period and early motherhood in a variety of ways. In turn, pregnancy, breastfeeding, and mothering shaped their embodied experiences of disability in both challenging and positive, value-added ways.

In this chapter I provide an overview of the different ways that participants experienced their embodiment during the perinatal period and early motherhood, specifically focusing on two overarching themes: 1) how dominant discourses of pregnancy, breastfeeding, mothering, and disability shaped participants’ embodiment during the perinatal period and early motherhood, and 2) how participants’ embodied experiences subverted these discourses in several ways, evoking new ways to think about disability and the body. In discussing these common themes, I consider how my findings fit within and extend the existing theoretical and empirical literature on women with disabilities during the perinatal period and early motherhood and embodiment, as well as contribute to feminist disability scholarship. I then discuss the implications of my findings for health research and practice. I conclude with a discussion of reflexivity, study limitations, and directions for future research.

7.1 The power of dominant discourses

I found that dominant discourses of pregnancy, breastfeeding, and mothering, notably those of risk management, individual responsibility, and self-sacrifice (see Chapter 2), shaped the embodiment of women with physical disabilities during the perinatal period and early motherhood. Some participants felt it was important to be recognized by others as “good
mothers” and to experience pregnancy, breastfeeding, and mothering according to the expectations of “good mother” discourse; they expressed a desire to meet these expectations, to be perceived of as, and to experience themselves as “good mothers.” For example, even though some experienced challenges related to breastfeeding, they felt that breastfeeding was an “essential part of motherhood” and were hard on themselves when breastfeeding was not experienced as expected. Likewise, some expressed feeling guilty, inadequate, and uncertain about their fitness for mothering when their disability inhibited their ability to engage in some physical childrearing tasks. These feelings were exasperated by encounters with others who perceived them to be “unfit” for mothering, as well as when participants compared themselves to non-disabled women and their non-disabled partners who were not limited in their ability to do childrearing tasks. In this way, the relational nature of embodiment was evident; dominant discourses, often enacted through interactions with others, as well as participants’ lived experience of disability, shaped their embodiment during the perinatal period and early motherhood.

In addition to finding that participants’ embodied experiences were shaped by dominant discourses of pregnancy, breastfeeding, and motherhood, I found that dominant discourses of disability also shaped their embodiment during the perinatal period and early motherhood. It seemed important for participants to experience themselves as mothers, and to be seen as feminine and maternal, rather than defective and undesirable. Participants did not wish to be perceived of as dependent or at fault for having a child with a disability. As such, some participants did work to perform pregnancy and mothering in ways expected of dominant discourses, seemingly even sacrificing their own well-being, and expressed relief upon learning that their children were not born with disabilities. Relatedly, the power of dominant discourses of disability were apparent in the narratives of those participants who expressed surprise that their “damaged” bodies could carry a child. In the context of mothering, some participants had embodied experiences that suggested that they had internalized ableism, whereby they felt negatively about having a disability. In these instances, the relational nature of embodiment was apparent, as participants’ physical bodies as well as views of their bodies shaped their embodied experiences of the perinatal period and early motherhood. Participants’ ambivalent and negative feelings about their disabled bodies were particularly evident as they described how they could
not engage in some physical childrearing tasks and instead had to observe other people, including their non-disabled partners, as aforementioned, do what mothers are “supposed to do.” Again, the relational nature of embodiment became evident in these instances, as social interaction with others, or rather observing others engage in childcare tasks, shaped participants’ embodied experiences of mothering. In sum, I found that some participants behaved to reproduce dominant discourses of motherhood and in turn in ways to distance themselves from dominant discourses of disability. As such, participants’ embodied experiences were constrained by intersecting discourses of disability, pregnancy, breastfeeding, and motherhood.

Others have also found that some mothers with physical disabilities go to great lengths to “pass” as non-disabled, to perform or represent themselves as “normal,” “good mothers” (Kuttai, 2010; Grue & Laerum, 2002; Malacrida, 2009; Thomas, 1997). Likewise, other researchers have documented how women with physical disabilities often encounter people who believe that they should not be mothers, how they experience not being recognized as visibility pregnant (or are perceived of as overweight), as well as how they do not feel recognized (or are celebrated) as pregnant in the same ways that the non-disabled women often are (Kuttai, 2010; Iezzoni, Wint, Smeltzer, & Ecker, 2015; Reinikainen, 2008; Prilleltensky 2003; Thomas, 1997). As well, experiences of heightened surveillance and scrutiny from other people, including health and social service providers, have been echoed by in other studies of mothers with physical disabilities. Further, women with physical disabilities in other studies too have reported encountering family members who viewed disability as undesirable (Powell et al., 2017a), as well as strangers who have asked them if their pregnancy was the result of rape (Iezzoni et al., 2015). This study adds to this literature by conceptualizing these experiences specifically through the lens of embodiment; that is, considering how these social interactions, seemingly informed by an understanding that disability and motherhood are incongruent, may shape the embodied experiences of women with physical disabilities during the perinatal period and early motherhood. Negative interactions with others may contribute to how women with physical disabilities perceive and experience themselves in the perinatal period and early motherhood, as well as may have implications for their perinatal and maternal health (see later).
7.2 Subverting dominant discourses: Evocative and valuable disabled bodies

Highlighting the major contributions of this study, in the section to follow I discuss how, through the lens of embodiment as it is theorized by feminist (Davis, 1997, 2007; Einstein & Shildrick, 2009) and feminist disability scholars (e.g., Wendell, 1999; Garland-Thomson, 2002, 2005; Hall, 2011; Kafer, 2013), participants’ embodied experiences during the perinatal period and early motherhood subvert dominant discourses of disability, pregnancy, breastfeeding, and motherhood. In turn, I consider how their embodied experiences of disability in the context of becoming and being mothers offer new or alternative ways to think about pregnancy, breastfeeding, mothering, disability, and the body.

7.2.1 Examples of subversion

While dominant discourses of pregnancy, breastfeeding, motherhood, and disability shaped participants’ embodied experiences in potentially limiting and detrimental ways, for instance, causing some to feel negatively about disability, many participants in this study also simultaneously experienced their embodiment in ways that subvert dominant discourses. For instance, some participants commented on how becoming pregnant was experienced as an important achievement and affirmation of femininity, thereby subverting notions of disabled women’s bodies as unproductive and defective. This finding that the experience of pregnancy confirmed that their bodies can function like those of “normal” women has been reported in other studies (e.g., Kuttai, 2010; Grue & Laerum, 2002; Prilleltensky, 2003; Rousso, 1988; Lawler, Begley, & Lolar, 2015). Like Lawler and colleagues (2015), I found that, for the women with physical disabilities in my study, “becoming a mother, being a mother and doing mothering were redefining life events, events that caused them (and others) to realize their abilities rather than disabilities” (p. 1680).

Not only do the findings of this study provide an example of subverting dominant discourses of disability, they too provide a counterpoint to (now-dated) feminist theorizing (e.g., Rich, 1976) that motherhood might be oppressive to women. Such theorizing evidently did not consider women with disabilities and others who have long been deemed “unfit” for motherhood and in some cases denied from becoming mothers. In other words, writes Begum (1992),
to many women, the absence of rigidly prescribed gender roles would be a great source of relief and a sense of liberation, but for those of us who have been constantly denied access to what could be construed as the “goals of womanhood,” the attainment of such goals can mean a real sense of achievement (p. 64).

The becoming and being a mother, simple as it may sound, may in fact be subversive and in turn empowering for women with physical disabilities.

By refusing genetic testing and not being gravely concerned about the possibility of having a child with a disability, some participants too subverted discourses of risk mitigation and of disability as undesirable and burdensome. In other words, drawing on the work of Kafer (2013), participants’ resistance to genetic testing and acceptance of the possibility of having a child with a disability subverts or “crips” “the expectations of reproductive futurity” whereby “cur[ing] and eliminat[ing] [disability is understood] as the ideal and preferred future for disabled people” (Hamraie, 2015, p. 308). By making their own recovery and well-being a priority, by wanting to take care of themselves and deciding not to breastfeed, some participants subverted discourses that expect women to sacrifice their well-being for others and deem “breast is best” for infant feeding. Further, some participants’ decisions not to breastfeed may be understood as subverting the increasing goal-oriented agenda of reproduction “in a neoliberal milieu that depends on economic and social competition and individual responsibility [and as such breastfeeding is equated with productive citizenship]” (Phipps, 2014). By embracing their need for support with childcare, participants subverted individual responsibility and self-sacrificial discourses of motherhood; by allowing others to take on a caregiving role for their children, participants subverted the narrow expectations of the “good mother.”

Participants’ embodied experiences during the perinatal period and early motherhood thus offer new or alternative ways to think about how mothering (or parenting more broadly) can be experienced. For instance, I would argue that participants’ experiences highlight a more expansive representation of parenting, whereby interdependence is becoming more of the norm as physical and social caregiving and educating of children is not necessarily always or always possible to be delegated or the responsibility of one only parent (mother), or even one set of parents (though of course this may vary by socio-economic status and culture; indeed, interdependence may be more common among non-Western cultural groups where multi-
generational households are prevalent). In other words, the experiences of mothers with physical disabilities challenge self-sacrificial motherhood discourse, and as Prilleltensky (2003) similarly found in her study, “stereotypical images of mothering where the provision of independent physical care has come to be equated with parental competence” (p. 42). Moreover, from my interviews with mothers with physical disabilities, I found that experiences of dependency or interdependence were not always negatively experienced by participants; instead, like Malacrida (2007), I too found that dependency or interdependency could be conceptualized as “a source of strength, connection, and identity” (p. 489). Importantly, I learned that participants’ capacity to provide nurturance was strong, at all stages of the perinatal period and early motherhood (also see Malacrida, 2007; Prilleltensky, 2003); despite their physical limitations, participants functioned as responsible and emotionally engaged parents who ensured the safety and well-being of their children. In sum, I want to echo the words of Fritsch (2017), to emphasize how women with physical disabilities’ embodied experiences of mothering, particularly as related to interdependent caregiving (i.e., nurturing assistance), are relational and challenge expectations of the “good mother” and in turn the devaluation of (inter)dependence:

nurturing assistance [is] a site of the relational emergence of disability that can contest the neoliberal individualizing of disability. This is to say that a relational approach to disability highlights the ways in which disability does not reside in an individual body that requires help to parent, but rather marks the ways in which disability is always within our social relations. … what should be taboo is not the desire for a nanny, but rather acquiring a nanny in order to achieve intensive mothering…. Displacing disability away from the individual body of the failed mother and emphasizing instead the macro and micro ways in which disability emerges within relations that have social, political, economic, and cultural consequences opens up room for reflection and concerted political action (p. 261, emphasis added).

By questioning dominant discourses, we may evoke a reimagination of what parenting could look like or broaden what (or who) raising children might include. Mothering in the context of physical disability may incite an expansion of “acceptable” or expected mothering practices. Though she does not write about mothering or parenting with a disability specifically, here we can draw on Kafer (2013) and her understanding of disability as relational to consider the value that disability brings to parenting; in the context of mothering or parenting, to create “accessible futures,” whereby parents (and children) with disabilities can thrive, we must understand disability as “grounded in the relational politics of interdependence” (Hamraie, 2015, p. 309). In
other words, an understanding of disability as relational may too evoke an understanding of interdependence as a “normal” or accepted part of the embodied experience of parenting. Further, one could argue that this study of how women with physical disabilities experience their embodiment during the perinatal period and early motherhood reveals how “inaccessible” dominant discourses of motherhood are for all mothers and parents.

In addition to recognizing how limiting the expectations of dominant discourses of motherhood can be, from some participants’ narratives I found that their embodied experiences of becoming and being mothers transformed how they perceived disability. Some participants came to embody disability differently as they took up a more critical perspective on disability. This was particularly evident when participants encountered barriers and challenges as mothers (e.g., inaccessible play groups, no braille books in the library), which meant that they could not be “good mothers.” From their experiences of encountering barriers and challenges as mothers, it seemed that some participants came to understand disability differently, as a social problem rather than an inherent individual issue or “problem” that they themselves should try to change or address to order to fit in or participate. They came to realize that existing social practices, institutions, and physical spaces for pregnant and parenting bodies need to be more inclusive of their difference. Furthermore, participants’ children too came to recognize the world as inaccessible as they interacted with and observed their mothers in the world. Participants’ embodied experience of disability thus served as a valuable teacher of disability justice and equity.

These examples of subversion and others evoke new ways to think about pregnancy, breastfeeding, mothering, disability, and the body more broadly. In the pages to follow, I further consider the key contributions of this study to the theoretical and empirical literature on embodiment.

7.2.2 Reimagined (disabled) bodies and futures

Feminist disability scholarship reimagines disability (Garland-Thomson, 2005) as well as gender (Hall, 2011); feminist disability theorizing reimagines new ways to think about both disabled and gendered bodies. Feminist disability studies reveals that commonplace ideas about constitutes a “normal” woman’s body may be limited and detrimental and work to reinforce the
marginalization of both women and people with disabilities. Feminist disability scholars such as Wendell (1996) suggest that ideas about the body as separate from and a burden to the mind contribute to anxieties about bodies “out of control” in general and disabled bodies in particular (Hall, 2011). Similarly, Shildrick (2009) has argued that because autonomy is a highly valued aspect of subjectivity, losses of bodily control can precipitate anxiety among non-disabled people. These anxieties are evident in some of the literature on women’s experiences of embodiment in the perinatal period as discussed in Chapter 1. In sum, research indicates that some non-disabled women do not particularly enjoy being pregnant because they experience pregnancy as a loss of control of their bodies (or as “disabling” (Nash, 2012)), and in some cases, report a disconnect between how they perceive themselves and how their bodies look and behave (or an uncomfortable disconnect from their pre-pregnancy sense of self when pregnant, breastfeeding, and mothering). Findings from this study thus offer a divergence from and perhaps a remedy for these anxieties. For some participants, the “unruliness” of a pregnant body was experienced as usual given their experiential knowledge of living with a disability body, wherein not always being in control of the body is experienced as a fact of everyday life; it seemed that some participants’ embodied experience of pregnancy did not include feeling disconnected from their pre-pregnancy selves or out of control or necessarily discomfort with a pregnant body. Instead, pregnancy was generally experienced positively, as participants’ embodied experience of disability offered something of value; the disabled body in the context of pregnancy was appreciated. In this way then, disability evokes tensions of the body and the mind-body dualism; pregnancy might be just an instance of bodily fluidity, rather than a potentially threatening embodied experience that might evoke discomfort and dissonance in the body and in turn one’s sense of self.

In this way, I would argue, as Scully (2003) has, that the embodied experiences of people with disabilities “are, by definition, different, but they are not always a problem” (p. 280, emphasis in original). Instead, in the context of pregnancy, I found that the embodied experience of disability was often of value; the knowledge of embodied states or the experiential knowledge of living with a disabled body proved to be advantageous for some participants as they experienced pregnancy and becoming a mother. While many participants did share how disability was experienced as challenging in a variety of ways, this study reveals that in the
context of the perinatal period and early motherhood disability was not experienced as purely burdensome or negative; in other words, writes Scully (2003), “however much an anomalous embodiment may be associated with daily difficulty and frustration, the subjective experience of disabled people is that anomaly itself is not a straightforward negative” (p. 279, emphasis added). Similarly, Overboe (1999) has proposed that we if come to understand ‘difference as ‘diagonal’ rather than ‘hierarchical’” then (“unruly”) disabled embodiment just simply exists, as difference in and of itself, rather being “devalued” (p. 25). Thus, instead of immediately seeking the erasure or avoidance of “non-canonical ways of being in the world,” the embodied experience of disability could serve as resource or an opportunity for others to draw on should they experience a significant bodily change (Scully, 2003, p. 280). This finding may incite us to embrace rather than avoid aspects of embodiment that may make us uncomfortable or look different from what is often expected, as feminist disability scholars have encouraged, and in turn illustrates that instability or fluidity in the way our bodies look, feel, and behave in the world should be seen as usual.

This finding concerning the value of disability in the perinatal period may contribute to the theorization of women’s relationships with their bodies more broadly; this study highlights what the embodied experience of disability may add to how women in general might experience bodily events, thereby providing promise for a feminist disability perspective on embodiment beyond the experiences of women with physical disabilities discussed here. Relational notions of disability and embodiment offer a useful analysis that may be relevant to other contexts in which people both with and without disabilities might experience significant bodily changes, both within and beyond their control, such as the aging body.

While this dissertation focuses on how women with physical disabilities experience their embodiment during the perinatal period and early motherhood, it may be considered part of a larger project that contributes to disrupting how “non-normative” bodies are understood and in turn expose how artificial or fleeting the dichotomies of self/other and non-disabled/disabled might be. Titchkosky and Michalko (2009) argue that “disability is a cogent and valuable aspect of an array of differences represented in any human and in any human collective” (p. 6), and thus evokes an imagination of what might be. This analysis aligns with Kafer’s (2013) proposal of “a politics of crip futurity,” wherein “disability is understood … as political, as valuable, as
integral” (p. 3). For Kafer (2013), there is a need to disrupt or “crip” how disability is understood in the present to reimagine disability in the future. Such a reimagination requires understanding disability as relational (as some other feminist disability scholars have), wherein the notion of disability as socially constructed and the subjective (sometimes-unruly) experience of disabled bodies cannot be separated; considering the latter is vital to the project of disability politics and reimagining a future wherein disability is valued (Kafer, 2013). As discussed, in the context of the perinatal period and early motherhood, we see examples of “cripping,” that is disrupting or “jolt[ing] people out of their everyday understandings of bodies and minds, of normalcy and deviance” (Kafer, 2013, p. 15); the embodied experiences of some participants during pregnancy, wherein disability provided an advantage to adjusting to the “unruly” bodily changes associated with pregnancy (as well as perhaps some participants’ refusal of genetic testing), for example, resists compliance with supposedly normal embodiment, behaviour, and desired futures. These instances are examples of Kafer’s (2013) call to disrupt the binary between disabled and non-disabled. To do this, she argues, we must devote “more attention to how different bodies/minds are treated differently, not less” (Kafer 2013, p. 13), and to echo the words of other feminist disability scholars (e.g., Wendell, 1996; Crow, 1996) as well as Davis (1997), doing this may mean starting with an exploration of the sometimes-uncomfortable or “unruly” experiences of our bodies. The embodied experience of becoming and being a mother may be one such “unruly” experience, as documented herein. My study may serve as an example for future research on the embodied experiences of women or people more broadly across the life course to consider how their embodied experiences challenge or subvert dominant discourses (we might, for instance, use the framework of embodiment discussed herein to consider the embodied experience of aging as offering valuable embodied knowledge for younger people, both disabled and non-disabled, to reimagine their own embodied experiences beyond fears of dominant discourses of aging, wherein aging and aging-related conditions (e.g., Alzheimer’s disease) are often understood negatively as the deterioration of health, bodies, and selfhood (for a discussion of the latter, see Kontos, 2004)). Indeed, as Kafer (2013) contends, “rethinking our cultural assumptions about disability, imagining our disability futures differently, will benefit all of us, regardless of our identities” (p. 14). To further hammer home this point, Kafer (2013) argues that much like “feminist activism benefits people who want no part of feminism, disability studies
and activism [and I would argue in particular the relational notion of disability and subsequently embodiment] ideally benefits people who are not interested or invested in it either” (p. 14).

The analysis above too aligns with Scully’s (2003) contention that there is much to learn from the embodied experiences of disabled, ill, and aging bodies. Again, build on arguments made by feminist disability scholars such as Wendell (1996) and Crow (1996), Scully (2003) notes that we

must not turn away from the ageing body, or the body immobilized, breathless, convulsing or demented. The “good” body and the “bad” body coexist, they are one flesh—and … our understanding of good and bad may be modified by circumstances. …. To understand embodiment fully requires allowing the body itself to take us into its limitations, to see how some of them turn out to be illusory, some may be transcended, and some remain to be confronted with rage or disappointment, or just lived with. … true justice for disabled people demands that those of us who are temporarily able-bodied be willing to cross, or at least peer, over into a lived experience that seems from the outside irredeemably negative, to explore it as far as we can while accepting the limits to our exploration, and to be open to what other corporeal modes have to teach us (pp. 279-280, emphasis added).

Findings from this study evoke a consideration of the value that disabled lives bring to our thinking about the future, wherein disability is understood as a resource and more broadly bodily difference is understood as a spectrum of possibilities and opportunities. As such, a focus on disability through the lens of embodiment works to challenge or “crip” discourses regarding the “normal” body; disability, writes Titchkosky (2007), “serves as an occasion when we might critically examine the cultural provision of dominant ways of keeping ourselves together” (p. 13). This study may help us to recognize our own and other peoples’ negative reactions to bodily changes or “abnormal bodies” as problematic, rooted in narrow discourses that could prove detrimental for those both with and without disabilities.

7.2.3 Advancing the body of knowledge

I have found that much of feminist disability theorizing focuses on women with disabilities’ everyday experiences of disability and the progression of disability with age. There has been little focus on specific periods of the life course and how the embodied experience of disability might change as it intersects with other bodily “events” such as pregnancy,
breastfeeding, and mothering. My study thus adds an understanding of the perinatal period and early motherhood to the feminist disability literature.

To both the perinatal health literature and the embodiment literature, this study in particular adds an understanding of how women with physical disabilities experience breastfeeding, including what breastfeeding means to them and decisions some had to make concerning breastfeeding. I found that women with physical disabilities may feel increased pressure to fulfill the expectations of the “breast is best” discourse of breastfeeding in a context where they often lack the supports to do so and have to make decisions regarding breastfeeding that most non-disabled women do not, such as having to take medication to managing disability-related needs or secondary conditions and in turn ceasing breastfeeding earlier than a non-disabled woman might, or deciding not to breastfeed at all. These findings regarding breastfeeding demonstrate the power of dominant discourses. In other words, if women with physical disabilities are rarely imagined to be mothers, it is unlikely that they are imagined to be breastfeeding (mothers) and subsequently that their unique breastfeeding needs to be considered. In this context then it may not be surprising that some participants’ embodied experiences of breastfeeding were so fraught with ambivalence and difficulty. As well, beyond some case studies (e.g., see Dunne, & Fuerst, 1995; Cowley, 2014), given the power of dominant discourses, it is not necessarily surprising that there is limited research on the breastfeeding experiences of women with physical disabilities (e.g., see Hocaloski, Holmgren, Hamilton, Elliot, & Krassioukov, 2016; Powell et al., 2017b). In sum, my findings regarding breastfeeding not only address a gap in the literature but may also have implications for service provision and shed light on why women with disabilities may be less likely to breastfeed compared to non-disabled women (Mitra et al., 2015).

7.3 Implications and offerings for health research and practice

Given the findings of this study and the literature on the perinatal care experiences and outcomes of women with physical disabilities (see Chapter 1), it is plausible that dominant discourses of disability, pregnancy, breastfeeding, and motherhood contribute to inequities in access to services for women with physical disabilities. As well, these discourses may explain why there is limited information and resources for women with physical disabilities in the
context of becoming and being a mother. For instance, from their evaluation of prenatal health information on Canadian federal, federal, provincial/territorial, municipal and public health region-hosted websites, and affiliated prenatal e-classes, Chedid, Terrell, and Phillips (2017) found almost a complete absence of targeted information, resources, and visual representation of women with disabilities. This absence of information for women with disabilities, as well as participants’ reports of negative encounters in perinatal care settings and experiences of invisibility during pregnancy, is evidence of informational and institutional erasure (for more see Appendix I).

Theorized by Bauer and colleagues (2009) to describe the health research and practice inclusion (or lack thereof) of trans populations, informational erasure includes both a lack of knowledge of marginalized groups and their needs and the assumption that such knowledge does not exist even when it may. Relatedly, institutional erasure occurs through a lack of policies that accommodate marginalized identities or “bodies, including the lack of knowledge that such policies are even necessary” (Bauer et al., 2009, p. 354). In other words, dominant discourses may contribute to the assumption that knowledge about how to provide perinatal care and parenting support for women with physical disabilities is not needed. Relatedly, if disability and mothering are not imagined to co-exist within the same bodies, the unique (care) needs of women with physical disabilities may be misunderstood or, worse, overlooked and possibly result in poor outcomes.

It is my hope that this dissertation encourages health researchers and practitioners to examine their attitudes or views about disability, as well as ideas regarding the “right way” to perform pregnancy, breastfeeding, and mothering, and to consider what discourses inform how and who they study, whose health they promote (or neglect), and which populations they believe are most deserving of health interventions (i.e., how they tailor interventions and to what aim—is there a particular body or population that one imagines when imagining the optimal “healthy population”? Can disability be healthy?). Specifically, there is a need for health researchers and practitioners to move beyond the medical model and broaden how they think about disability (i.e., to not only to think about disability as an outcome to prevent (Lollar & Horner-Johnson, 2017; Wisdom et al., 2010; Wilber et al, 2002)); indeed, it has been argued that only recently have people with disabilities been recognized as a health disparities population, that is, a
population who experience physical and mental health disparities that are the result of (avoidable) social, economic, and environmental disadvantages (Krahn, Walker, & Correa-De-Araujo, 2015; Goode, Carter-Pokras, Horner-Johnson, & Yee, 2014; relatedly, then, there is a need to do more work to explore the heterogeneity of the disability population, as not all people or women with physical disabilities may have the same resources and thus health and health care experiences – see below later for on this point). By primarily focusing on how to “manage” or prevent disability, argue Titchkosky and Michalko (2009), there is “no space for disability to be understood as a space for critical reflection on how the voice of normalcy seeks to dominate by speaking on behalf of disability experience” (p. 9). In other words, there is a need for health researchers and care providers to critically engage with disability in a way that questions how disability has come to be produced or primarily conceptualized as a deficit or negative outcome in the first place. As a starting point, public health and health services researchers may look to other health-related disciplines, such as psychology (e.g., see Olkin, 2002; Olkin & Pledger, 2003) and physical therapy (e.g., Yoshida, Self, & Willis, 2016), for examples of how to critically engage with disability studies and thus expand how they conceptualize disability.

The application of a relational understanding of embodiment as theorized by feminist and feminist disability scholars has much to offer beyond the study of how women with physical disabilities experience their embodiment during the perinatal period and early motherhood. Indeed, concerning health care provision, I agree with Einstein and Shildrick (2009) who advocate that, “recognizing the inseparability and contextualization of bodies can lead to a different approach to care, not necessarily to a more difficult one” (p. 297, emphasis in original). A greater understanding of patients’ embodied experiences may evoke more holistic and comprehensive care provision and in turn may help eliminate barriers to care and poor outcomes. In addition to its relevance to health care provision, the framework of embodiment used in this dissertation offers health researchers the opportunity to take on the challenge posed by Kuhlmann and Babitsch (2002) and Einstein and Shildrick (2009) to bring embodiment (back) to the study of women’s health (as conceptualized as part of public health or health services research more broadly). Notably, it has been argued that, for some time, there has been a tendency for feminist theorists and women’s health researchers to work in silos, whereby
“representatives of each field have tended to ignore the concepts and empirical results of the other” (Kuhlmann & Babitsch, 2002, p. 433).

Beyond the study of women’s health, more broadly this study points to the need for health researchers to consider more diverse and more current theoretical frameworks for understanding health inequities and disparities, particularly those that are born out of the lived experiences of marginalized groups, such as women with disabilities. There is much to learn from those who may be experiencing health inequities and disparities. Theoretical frameworks used to explore the experiences of marginalized groups may also evoke new ways of thinking about dominant groups or norms and in turn reveal factors that may be contributing to health inequities and disparities (i.e., as discussed, dominant discourses may have real health implications). If we are truly invested in improving the health of women and other marginalized populations, we must start to question discourses of “normal” bodies, as well as “actively identify and explore our own areas of ignorance” (Einstein & Shildrick, 2009, p. 297); we must acknowledge that there are embodied experiences that we know little or nothing about and be open to the possibility that these embodied experiences have things to offer.

7.4 Reflexivity, limitations, and (more) future directions

7.4.1 A return to reflexivity

In conducting this study focused on the embodied experiences of women with physical disabilities I have thought a lot about what doing this work might mean or how it might be interpreted due to the fact that I am a non-disabled researcher. I am aware of debates regarding the ethics of doing disability research and emancipatory research and feel strongly that I have presented the findings of this study in a way that sheds light on the unique – and sometimes challenging – experiences of becoming and being a mother with a disability in a context where they are not imagined to be mothers, and did so using methodological/epistemological and theoretical approaches that are not oppressive to people with disabilities. For instance, using a constructivist grounded theory approach that considers the co-construction of data and emphasizes reflexivity, and drawing on a relational understanding of embodiment, that is, an understanding that considers social model of disability theorizing as well as real bodily struggles as intertwined and vital to the experience of disability, I believe, are ways that I have met the
“emancipatory principles” of doing disability research as a non-disabled researcher (Stone & Priestley, 1996). It was important to me, as feminist disability scholars have advocated, to share both participants’ challenges related to disability in the context of the perinatal period and early motherhood but also celebrate what is unique about disability and what the embodied experience of disability adds or brings to pregnancy, breastfeeding, and mothering. By drawing on feminist disability scholarship, I hope I have shared their experiences through a critical lens, wherein their challenges and struggles are represented as just that, real, and potentially valuable experiences for others to gain insight from, rather than as further-marginalizing or re-stigmatizing (i.e., in ways that suggest that women with physical disabilities should not be mothers).

As discussed in Chapter 3, I believe my positionality as a non-disabled woman who is not a mother may have shaped my interactions with participants and my analysis and interpretation of the data. Though no participants asked me if I was a mother, had a disability, or if I had someone close to me who had a disability, for example, at times I felt that I made a conscious effort to share with participants that I had many children in my life and had recently become an aunt, as well as had been doing work in this area for several years and had connected with some women with physical disabilities (e.g., pilot interviewee, staff at organizations who serve women with disabilities and are disabled themselves) prior to interviewing them—this was perhaps my way of “proving” to participants that I was a trustworthy and ethical non-disabled researcher (even though, as mentioned, no participants asked me to “prove” any of this).  

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9 Another way that I “proved” my commitment to participants and to this work was by producing a community report of the study findings. Specifically, I produced a 17-page report that included (primarily descriptive) highlights of study findings and recommendations to better support pregnant and parenting women with physical disabilities (available here: https://latarasoff.files.wordpress.com/2014/10/report-draft-5.pdf). In fall 2017, I shared this report with participants (who responded with positive feedback) and community organizations and other relevant stakeholders (including those who helped me with participant recruitment). I have also shared and will continue to share study findings in academic publications (e.g., see Appendix I) and at conferences (so far, I have shared findings with midwives, nurses, obstetricians, and other perinatal care providers, as well as researchers in the public health and other disciplines). The inclusion of non-disabled researchers is important, as some participants in Kitchin’s (2000) study of disabled people and disability research argue, because “disability issues extend beyond disabled people to include carers, family members and service providers. As such, the disability movement consists of a variety of individuals and groups who work separately and collectively to fight ableist discrimination” (pp. 36-37). Indeed, I agree that “keeping non-disabled people involved allows the field to develop whilst the base of disabled academics grows” (p. 37). I hope I can continue to prove myself as an ally to the disability community/communities, including the community of disability researchers, and work together to challenge negative representations of people with disabilities.
My interactions with participants during interviews caused me to greatly reflect on the range of physical function that comes with different bodies and to consider disability beyond what I could see, notably, as I observed participants interact with me in ways I did not always recognize as “disabling” or different in a limiting way. Participants’ descriptions of chronic pain and fatigue, more so than their functional limitations that I could see, stuck with me the most as I began analyzing interview data. Further, as discussed in Chapter 3, participants’ experiences of breastfeeding and decisions not to breastfeed caused me to reflect on my own views regarding breastfeeding and the value of breastfeeding. As such, perhaps my focus on ambivalence in Chapter 5 reflects some of my own ambivalence regarding breastfeeding. Indeed, as a non-disabled researcher doing this work, an ongoing struggle or site of critical ambivalence for me has been making definite conclusions about what might be considered oppressive or empowering (or good or bad) for women with disabilities. Beyond the intersectionality-informed answer that women can experience oppression and empowerment or privilege simultaneously, I am still not sure I know how to answer this question or rather define what is oppressive or empowering for others though I do hope I have done justice to representing and interpreting participants’ experiences of embodiment in a way that at least achieves the feminist goal of consciousness-raising, that is, highlighting the ways in which women’s individual experiences may be linked to public, systematic issues, in an effort to bring about social change.

If I could go back, during the data collection, I would have delved deeper into participants’ breastfeeding experiences; my initial conceptualization of this project or rather the organization of the chapters of this dissertation did not originally include a specific chapter on breastfeeding, though, clearly, this is an area and experience that warranted attention and I hope will get more attention by researchers moving forward as the body of literature concerning the perinatal and maternal health of women with disabilities continues to grow. Future research on the breastfeeding experiences of women with physical disabilities perhaps could be situated within a broader framework of neoliberalism and the militancy around breastfeeding, including an analysis of the World Health Organization’s influence on breastfeeding discourses and practices.

In Chapter 3, I also discuss disability language use. I do believe the language that I initially used in my data collection materials may have been different and in turn my analysis of
participants’ disability-related identifiers or language greater and more critical if this had been a community-based study. Though I did not conduct a community-based research study for several reasons, including feasibility, in the future I hope to do community-based research with women with disabilities. As for the present study, I suspect that my discussion of language use and other areas of focus in this dissertation would have been different had I involved women with physical disabilities in all stages of the research process, including conceptualizing the research questions (i.e., what other discourses might they have identified as being informative to their embodied experiences? Would they have considered the discourses I focused on at all or in different ways? How might they define embodiment?), developing the data collection materials, and recruiting participants. Perhaps if I had a different group of participants, the more political language of ‘disabled women’ would have been used by more participants, though, I think, I assumed too that more participants in the current study would have used this more political language, given that many were well-educated, and some had connections to disability community and done volunteer and paid work related to disability (i.e., I assumed that more of my study participants would have been more political or use more political language in their discussions with me—in one instance, I asked a participant about feeling “radical” about being a mother and she was not comfortable with that categorization, though did consider herself as someone who others might see as challenging negative myths or beliefs about people with disabilities). Further, perhaps some of the study limitations I discuss below would have been addressed if this dissertation study was conducted as a community-based study. Notably, with an advisory committee of women with physical disabilities it is possible that I would have been more effective in my recruitment efforts; perhaps they could have advised me in creating recruitment materials that more strongly resonated with their peers than the materials that I, a non-disabled, non-mother, had created.

7.4.2 Study limitations

While this study has many strengths and contributes to new or alternative ways of thinking about pregnancy, breastfeeding, mothering, disability, and the body, there are some limitations that warrant attention and future study. While the women who participated in this study were diverse in terms of the types of disability that they report, despite my efforts, the participants as a group were homogenous in terms of their other demographic characteristics.
Like other qualitative studies (e.g., Iezzoni et al., 2015; Prilleltensky, 2003), most of my study participants were white, heterosexual, married or in common-law relationships, well-educated (e.g., six participants reported that they had graduate degrees), and resided in large urban centres—a sample not necessarily representative of women with physical disabilities at a population-level. Notably, compared to non-disabled women, women with physical disabilities in both Canada and the United States are more likely to have lower levels of educational attainment, workforce participation, and annual personal income (Horner-Johnson, Darney, Kulkarni-Rajasekhara, Quigley, & Caughey, 2016; Steinmetz, 2006; Savage & McConnell, 2016; Bizier, Fawcett, & Gilbert, 2016; Burlock, 2017). Furthermore, women with physical disabilities are less likely to be married or partnered or to marry later (making biological motherhood challenging) (Savage & McConnell, 2016; Burdock, 2017) and to live alone (Burdock, 2017). The findings presented here therefore may be transferable to women with physical disabilities who share similar demographic characteristics to my study participants but not necessarily transferable to or representative of all women with physical disabilities in Ontario or North America. The experiences of low-income women with physical disabilities, sexual minority women with physical disabilities, women with physical disabilities residing in rural and remote settings, and racialized women with physical disabilities are not reflected in this dissertation. Future research exploring how these subgroups of women with physical disabilities may uniquely experience their embodiment during the perinatal period and early motherhood is needed.

Moreover, for feasibility reasons, this study only included women who could speak and understand English; thus, the experiences of non-English speakers are not reflected here and warrant future study. Also, women with physical disabilities who may have had significant complications or issues with pregnancy, breastfeeding, and mothering, as well as those who may have felt that that participating in this study would make them vulnerable to be judged as “bad mothers” (e.g., those who may have fears regarding child custody) may have been reluctant to participate in my study. Indeed, although no participants reported ever having lost custody of their children, several expressed fears about having their children taken away should they be deemed “unfit” mothers. This fear of losing custody was especially top-of-mind as participants reflected on the local case of parents with cerebral palsy who almost had their son apprehended
by child welfare services (CBC News, 2012; Mulholland, 2012) and other related stories (e.g., see Picciuto, 2015; Tomasi, 2015) that were in the media at the time of data collection.

The inclusion of one woman who is blind may be considered another sample-related limitation of my study. Other researchers have included women with both mobility and sensory disabilities in their qualitative studies (e.g., Schildberger, Zenzmaier, & König-Bachmann, 2017; Malacrida, 2009), and found that those with sensory disabilities described experiences similar to those reported by women with mobility disabilities. Generally, I also found this to be true. However, in retrospect, when I did decide to include women with sensory disabilities in this project I did not greatly consider how embodiment may be uniquely experienced for this group, and in my analysis of the data of the one blind woman who did ultimately participate in this study, I fear that that I did not greatly consider how her experience might differ from those participants with mobility-limiting physical disabilities. Future research could use the lens of embodiment to explore how women with sensory disabilities, as well as intellectual and developmental disabilities, experience the perinatal period and early motherhood. Research on these subgroups of women with disabilities may too need to explore how particular discourses of disability and motherhood might shape their embodied experience (e.g., in that women with intellectual and developmental disabilities are paradoxically assumed to be both asexual and hypersexual).

7.4.3 Future research directions

Who ultimately participated in my study are important data to consider for future research and may address what I have termed “reproductive privilege.” While women with physical disabilities as a population encounter many barriers to becoming mothers and it has been documented that childbearing women with disabilities are at increased risk of poor physical and mental health outcomes (Kim et al., 2013), I have found that some women with physical disabilities may have more opportunities for childbearing than others. This notion of “reproductive privilege” can also be considered in light of findings from Cooper’s (2006) quantitative study of the pregnancy and parenting experiences of Canadian women living with physical disabilities. Though her study included a convenience sample (N=1095), she found that the women with physical disabilities in her study who had experienced pregnancy (n=69, or 6.3% of the entire study sample) reported higher rates of university completion, employment,
and annual income compared to the sample as a whole (Cooper, 2006). Though I did include some discussion of the potential impact of social support and socio-economic status on the embodied experience of mothering in **Chapter 6**, given the homogeneity of my study sample, in this dissertation I did not explore fully issues of diversity or the possible impact that different social determinants of health and identities may have had on participants’ embodied experiences of the perinatal period and early motherhood. From my preliminary analysis of data regarding social support and socio-economic status, however, I do believe there is evidence that a lack of social support and limited socio-economic resources exasperated some of the challenges that participants reported experiencing and in turn shaped their embodied experiences. Like Malacrida (2007), I found that some participants had to navigate being dependent in a variety of ways, and consequently encountered scrutiny and disapproval as a result, at the same time as they were expected to be nurturant, “good mothers.” Moreover, I believe some participants’ educational backgrounds, including some who had training in disability studies and the health sciences, as well as some participants’ work and advocacy experiences related to disability, may have shaped their embodied experiences in particular ways, as well as have helped them to better navigate systems of care and support.

Regarding the former, the language that participants used to describe or identify themselves with regard to disability may have been informed by more than or other discourses beyond the dominant discourses of disability; how some participants identified themselves may have been shaped by their own disability studies training and disability-related advocacy work, for example. As noted, when asked, most participants did use person-first language to describe themselves. For those who did use person-first language, perhaps after reviewing my interpretations of their narratives of how they came to perceive themselves and think differently about disability in the context of mothering, they might adopt different, more political language to describe themselves. As most used person-first language, denoting an individualizing, medicalized discourse on disability, whereby disability is understood as a negative limitation, it may not be surprising that some expressed ambivalence and sometimes negativity about disability in the context of becoming and being a mother. However, as discussed, through mothering, some did begin to see and embody disability differently, that is, in ways that align with a social model of disability (i.e., understanding disability as not a personal deficit but as
something socially and environmentally constructed). Interestingly, however, those participants who did use more political (or social modellist) language and who had training in disability studies too shared experiences that indicated that meeting expectations of the “good mother” was important to them. While I believe that attempts to be perceived of as disabled and experience oneself as disabled in a non-stigmatizing way were significant to some participants, the fear of not meeting the expectations of the “good mother” might be understood as the chief force that shaped all participants’ embodied experiences in one way or another. More research is needed on understanding language use or identity labeling in relation to the embodied experiences of women with physical disabilities during the perinatal period and early motherhood (i.e., a greater analysis of what it might mean to identify as a ‘disabled mother’ versus a ‘mother with a disability’ could be done).

Related to my aforementioned point regarding “reproductive privilege,” to better understand how women with physical disabilities experience embodiment during the perinatal period and early motherhood, and in turn to better understand their perinatal care experiences and outcomes, more research is needed on women with physical disabilities who may be marginalized in other ways beyond sex/gender and disability status (i.e., do all women with physical disabilities have the same opportunities for childbearing? To what extent do social determinants of health, such as socio-economic status, race, social orientation, and marital status, contribute to or mediate barriers to perinatal care and perinatal health disparities? In addition to dominant discourses of pregnancy, motherhood, breastfeeding, and disability, what other discourses or factors may play a role in shaping their embodied experiences of the perinatal period and early motherhood?). Intersectionality (Bowleg, 2012; Hankivsky et al., 2010) might be a useful framework to explore these questions.

Researchers, including some in Canada, have conducted qualitative research on perinatal care provider-level barriers to care for women with physical disabilities (Walsh-Gallagher, McConkey, Sinclair, & Clarke, 2013; Mitra et al., 2017; Smeltzer, Mitra, Long-Bellil, Iezzoni, & Smith, 2018; Joseph, Saravanabavan, & Nisker, 2018) and found that some of the barriers that providers identified are similar to those identified by women with physical disabilities themselves, such as lack of accessible care settings and equipment and disability-related training. However, I would argue that these studies shed little light on perinatal care providers’ attitudes
and knowledge about women with physical disabilities in relation to pregnancy, breastfeeding, and mothering, or rather what underlies some of their negative attitudes and lack of knowledge. Future research could explore the perspectives of perinatal care providers and other health and social service providers (e.g., social workers) who may “enforce” dominant discourses in ways that have tangible implications for women with physical disabilities during the perinatal period and early motherhood. Indeed, the challenges and barriers identified by my study participants in the perinatal period and early motherhood, such as being questioned by social workers before leaving the hospital with their infants (see Chapter 4) and a lack of information and resources about pregnancy and disability (also see Appendix I) suggest that addressing these barriers needs to remain a priority for health and social service providers; views held by health and social service providers seemingly have implications for how women with physical disabilities experience their embodiment during the perinatal period and early motherhood and in turn may impact perceptions of care, care experiences, and outcomes. Arguably, discourses that may be shaping how perinatal care and other health and social service providers’ (e.g., family physicians, public health nurses, social workers, sexual education teachers) view girls and women with physical disabilities may play a role in these girls’ and women’s sexual and reproductive health decisions, including their decisions regarding motherhood. In short, there is a need to consider how dominant discourses shape health and social service providers’ understandings and in turn practices of care for women with physical disabilities and to thus consider what interventions might be needed to mitigate the impact of these discourses in shaping perinatal care experiences and outcomes, and in turn embodied experience.

As this study revealed, there are many actors beyond health care providers who may adopt stigmatizing and narrow views of disability and mothering who, through social interactions, may shape the embodied experiences of women with physical disabilities during the perinatal period and early motherhood. Thus, broadly, through the lens of embodiment, future research could explore the attitudes and experiences of all the various actors who may contribute to women with physical disabilities’ embodied experiences of the perinatal period and early motherhood. Notably, beyond health and social service providers, future research could explore the experiences of both the children and partners of women with physical disabilities during the perinatal period and motherhood (i.e., one might ask partners and children how they perceive
their parents or partners during pregnancy and as mothers? Do children’s and partners’ perceptions of their mothers or partners’ bodies/embodiment change overtime?). Such an exploration might yield a greater understanding of the relational nature of embodiment, as well as lend support to the finding that disability adds value to parenting (see Chapter 6) and perhaps even child development or outcomes. For instance, in their study of teenagers’ perceptions of their parents’ mobility disability and its impact on their life, Iezzoni and colleagues (2018) found that while teenagers did express some fears and frustrations related to their parent’s disability (a finding echoed in other studies, e.g., see O’Dell, Crafter, de Abreu, & Cline, 2010; Jonzon & Goodwin, 2012), several reported finding meaning in their parent’s disability, having a sense of self within a larger community, and a greater sense of self-care and social justice, as well as experienced their parent’s disability as “completely normal” to them (also see Visser & Lero, 2015, for a summary of other uniquely positive and beneficial experiences reported by children of people with disabilities). These teenagers, write Iezzoni et al. (2018), “were not passively experiencing their parents’ disability” (p. 17).

Furthermore, conducting prospective, longitudinal research on women with physical disabilities’ experiences of the perinatal period and early motherhood would be fruitful. To my knowledge, this has yet to be done. Finally, future research could explore girls and young women with physical disabilities’ feelings about becoming mothers, to understand what discourses or other factors might influence how they think about their bodies and their intentions of mothering. Indeed, this direction of research would address a gap in the literature that I identified in my nearly eight-year search for population-based data on the number of parents with disabilities in Canada. Specifically, as I searched Statistics Canada publications about disability for the term “parent,” the vast majority of “hits” for “parent” were references to being a parent of a child with a disability. Though things are changing, what others have argued about the lack of research on parents with disabilities rings true today and thus gives reason for and significance to a study like the one presented here and the future directions of research I have outlined; as Prilleltensky (2003) wrote fifteen years ago in the introduction of her qualitative study on the experiences of mothers with physical disabilities,

Compared with the myriad of studies on children with disabilities and policies regarding their educational integration and accommodation, parents with disabilities continue to be primarily ignored by research and social policy. Olkin
(1999) contends that—*it is as if families have children with disabilities and then these children disappear from the face of the earth* (p. 126) (pp. 41-42, emphasis added).

We must not forget that many children with disabilities become adults and some of them may want to become parents.

### 7.5 Concluding thoughts

Despite the limitations described above, this dissertation has several strengths and provides a foundation for future research. Notably, this study included women with physical disabilities who had for the most part given birth within the last three years. Thus, participants’ recollections of interactions and events that shaped their embodied experiences were quite fresh, and as I found, the questions I asked them caused some to reflect deeply on what it meant to become and be a mother with a physical disability in a world where doing so is not typically imagined as a possibility for them. As well, in documenting recent experiences this study reflects contemporary contexts and social forces. Unfortunately, however, as aforementioned, some of my findings echo those of earlier studies, suggesting that little has changed regarding attitudes toward women with physical disabilities in the context of the perinatal period and early motherhood in recent years, including those of society broadly and perinatal care providers specifically (see Appendix I for more on the latter point).

This study adds to the limited research on how women with physical disabilities experience their embodiment during the perinatal period and early motherhood, specifically adding the experiences of women with physical disabilities in Ontario. Further, to the perinatal health literature and the embodiment literature, this study adds an understanding of how women with physical disabilities experience breastfeeding.

This study reveals how pervasive dominant discourses of disability, pregnancy, breastfeeding, and motherhood can be in shaping how women with physical disabilities experience their embodiment, including in ways that might be detrimental to their health and well-being, as well as evoke negative feelings about disability. I am not suggesting however that all participants in this study necessarily experienced the expectations of being a “good mother” detrimental or burdensome (also see Malacrida, 2009), or that they completely subverted
dominant discourses. Their experiences thus must be considered within a context wherein mothering is not imagined as a possibility for women with physical disabilities and as such provides understanding to why some of their embodied experiences may be fraught with ambivalence. Interestingly, as a disabled mother herself, Fritsch (2017) does not promote praising the good feelings and celebratory remarks mothers with disabilities experience and encounter when it is deemed that they are being “good mothers,” as doing so, she believes, “does not necessarily challenge or change the inequitable neoliberal social relations in which intensive mothering is normalized and in which disabled parents parent” (p. 258). In other words, becoming and being a mother may be experienced as affirming and even empowering for women with disabilities, but we must consider under what or whose terms this is possible or conceptualized as such.

This study sheds light on what disability can add to the embodied experience of the perinatal period and early motherhood. Some participants’ narratives specifically reveal that disability may be valuable in the context of pregnancy, offering ease to the bodily changes that some non-disabled women might have a difficult time adjusting to. In other words, some participants’ embodied experiences of disability worked to subvert or “crip” dominant understandings of how women’s bodies should function or how it is presumed women should feel about their bodies during pregnancy. Disability adds value to parenting and in turn challenges the ways in which we might understand what it means to be a parent. In addition, through the process of mothering, some participants began to embody disability differently, recognizing how the world did not accommodate for their differences. The embodied experiences of pregnancy, breastfeeding, and mothering added value or positive feelings about disability for participants as well, including feelings of achievement and increased confidence. In sum, in a context where women with physical disabilities are not often imagined to be mothers, I found that participants’ embodied experiences were not completely or always subversive; yet, how women with physical disabilities experience their embodiment during the perinatal period and early motherhood in some ways do subvert dominant discourses and in turn evoke new ways of thinking about bodies that do not always look, feel, or function in ways that make us comfortable. Participants’ embodied experiences of the perinatal period and early motherhood evoke the need to reconceptualize bodily difference as not necessarily negative but maybe just
different in and of itself and a consideration of what bodily difference and “unruliness” might offer those who are not used to having a body that looks, feels, or behaves differently than they might typically expect or are used to. Likewise, the “cripping” potential of disability in the context of becoming and being a mother urges a reimagining of a future where disabled bodies are valued.
References


**I was interviewed for this article**


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Tarasoff, L. A. (2017). “We don’t know. We’ve never had anybody like you before”: Barriers to perinatal care for women with physical disabilities. *Disability and Health Journal, 10*(3), 426-433. **See Appendix I for a copy**


Appendix A: Recruitment Flyer – Final Version

We’d like to hear about the pregnancy, labour, birth and mothering experiences of physically disabled women for a study at the University of Toronto.

We are interested to hear your recommendations to improve care experiences.

We want to speak with women 18 years of age or older who live in the province of Ontario and identify as a woman with a physical or mobility-limiting disability, and who have given birth in the last 5 years.

As a study participant, you would complete a short demographic survey and a 60 to 90 minute interview.

Interviews will be audio-recorded and take place at a time and accessible location of your choosing.

In appreciation of your time and sharing your experience, you will receive $30. TTC tokens, attendant care, and childcare will be provided, if needed.

Interested in participating? Want more information?
Please contact Lesley Torsos at

All correspondence will be kept confidential.

Lesley Torsos is a PhD Candidate at the University of Toronto supervised by Ers. Lelli Ross, Carol Strike, and Karen Yoshida.

This study has been reviewed and approved by the University of Toronto Health Sciences Research Ethics Board and the Centre for Addiction and Mental Health Research Ethics Board.

The flyer was designed by Ryan White (http://ryanwhite.ca), with funds provided by Carol Strike (thanks Carol!)
Appendix B: Recruitment and Screening Form

Appendix B – Telephone Screening Form

Thank you for contacting me about my PhD research examining physically disabled women’s experiences of pregnancy, labour, birth and early motherhood. First, I’d like to tell you a bit about the study and if you are interested to participate, I will need to ask you some questions about yourself to confirm your eligibility. This process will take about 10 minutes and I will record your answers.

The purpose of my PhD research is to learn about how physically disabled women experience pregnancy, labour, delivery/birth, and early parenting – with a particular focus on one’s body and sense of self during that period. The study will use interviews to investigate these issues. I am supervised by Drs. Lori Ross, Carol Strike, and Karen Yoshida at the University of Toronto.

I would like a diverse group of physically disabled women to participate. If you are invited and agree to participate in the study, I will travel to your home, or you may come to my office in downtown Toronto to do the interviews. Or we can meet at a community organization or other space of your choosing. You will participate in a 60 to 90 minute audio-recorded interview, as well as fill out a demographic survey. You will be compensated $30 for your participation, and provided with TTC tokens and/or childcare, if needed.

Do you wish for me to continue and do you agree to allow me to record the answers you give me while I assess your eligibility?

If yes - The information that I collect from you will only be used for screening purposes and will not be shared with anyone. The screening data will be destroyed should you not consent to participate in the study or withdraw from the study or if you are not chosen for the study.

If no - Thank you for your interest. I will not keep a record of your name and telephone number. [End call].

How did you hear about this study? [Q.1]

To be eligible to participate, you must identify as a woman with a physical or mobility-limiting disability (e.g., spinal cord injury, MS, muscular dystrophy, amputation, rheumatoid arthritis). Do you identify as a woman with a physical or mobility-limiting disability?

If yes - Are you willing to specify the nature of your disability or health condition? (Q.2a-2b)

If no - Explain reason for ineligibility.

To be eligible to participate, in the past five years you must have given birth. Does this describe you? [Clarify that this must be a live birth if asked] If yes - Q.3. If no - Explain reason for ineligibility.

To be eligible to participate in this study, you must live in the Toronto area. Does this describe you? If yes - Q.4. If no - Explain reason for ineligibility.

This screening form is modelled after the screening form for the “Creating Our Families” study (http://lgbtqhealth.ca/projects/creatingourfamilies.php)
Finally, to be eligible to participate in this study, you must be 18 years of age or older. Are you 18 or older? **If yes - Q.5. If no - Explain reason for ineligibility.**

**Meets eligibility criteria (Q.6):** You are eligible to participate in the study.

Do you think you might be interested in participating? **(Q.7a)**

If not interested: Thank you for your time. Do you mind if I ask what it is about the study that made you decide not to participate? **(Q.7b)**

If interested: As mentioned, I hope to interview a diverse group of participants to reflect a diverse group of physically disabled women and their experiences. As such, I have a few more questions for you. As with the earlier questions, all of your answers will be kept strictly confidential and will only be used for the purpose of determining eligibility and determining who I will ultimately interview. **Ask questions 8-11.**

Now I would like to get your contact information so that I can contact you to determine the best time and location for your participation. What is the best method of contacting you? If it is by phone, when is the best time of the day to reach you?

Do you have any questions for me? Thank you so much. I will be starting to do interviews within the next 4 weeks. If I select you to participate, I will contact you then.

---

**Screening form**

**DATE AND TIME OF SCREENING:**

**NAME OF PARTICIPANT:**

**PART A: INCLUSION/EXCLUSION CRITERIA**

1. Recruitment source:

2a. Disability: **YES NO**

2b. Type/nature of disability:

3. Given birth in the last 5 years: **YES NO**

4. Live in Toronto: **YES NO**

5. Age (**Must be 18 +**):
6. Does the participant meet the inclusion criteria (2-5)?

   YES   NO

6a. If not, why? __________________________________________

7a. Do you think you might be interested in participating in this study? YES NO

7b. If no, do you mind if I ask why not? _______________________________

PART B: MORE SCREENING QUESTIONS

8. Can you tell me a bit about your FAMILY?
   (Probes: Do you have a partner? How many children do you have?)

   ____________________________________________________________

   ____________________________________________________________

9. How do you identify your RACIAL, ETHNIC or CULTURAL IDENTITY/IDENTITIES?
   ____________________________________________________________

10. I need to ask you about your SEXUAL ORIENTATION. Can you tell me how you identify?
    (If necessary, use probe terms lesbian, gay, bisexual, two-spirit, queer, etc.)

    ____________________________________________________________

11. Is it ok with you if I leave messages on your voicemail saying that I am calling about this study?
    YES   NO
    (If no, let them know that I won’t leave messages but will call them back another time.)

PART C: PARTICIPANT INFORMATION

12. HOME PHONE NUMBER: ________________________ Best time to call: ____________

13. EMAIL ADDRESS: __________________________________________

14. MAILING ADDRESS: _________________________________________
A QUALITATIVE STUDY OF EMBODIMENT AMONG PHYSICALLY DISABLED WOMEN DURING THE PERINATAL PERIOD

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Contact – Email: l.ross@utoronto.ca; Tel: (416) 978-7514

Purpose
You are invited to participate in a research study that will explore how physically disabled women (PDW) experience the perinatal period (pregnancy, labour, birth, and early motherhood). In particular, from this study I hope to learn how PDW experience their bodies during the perinatal period and how bodily changes of the perinatal period and other social factors may affect one’s sense of self. It is my hope that this research will be used to help perinatal care providers to better understand PDW’s experiences in order to improve care experiences and outcomes.

This research study forms the basis of my doctoral research. The following information is provided in order to help you make an informed decision about whether or not you would like to participate. If you have any questions please do not hesitate to ask.
Procedures
You will be asked to complete a demographic survey and participate in a face-to-face interview. The interview will last 60 to 90 minutes, and take place in an accessible location of your choosing (e.g., your home, my research office, community organization).

During this interview you will be asked a series of questions about your experience of the perinatal period, as well as questions about your body and sense of self or identity/identities. You are free to refuse to answer any question that is asked, and you can end the interview at any time.
You may also be asked to participate in a follow-up interview, 2-3 months after your initial interview. The follow-up interview will last 30 to 60 minutes, and can take place in-person or over the phone.

Eligibility
To participate in this study you must:
1. Be 18 years of age or older;
2. Reside in the province of Ontario;
3. Identify as a woman with a physical or mobility-limiting disability;
4. Have given birth in the last 5 years;
5. Understand English well enough to understand this consent form, the interview questions, and the survey; and,
6. Agree to have the interview audio-recorded.

Risks and Benefits
I know of no significant risks or discomforts associated with this research. I do not anticipate that the interview will lead you to become emotionally uncomfortable; however, if you do become uncomfortable or want to take a break for any other reason, we can stop the interview and restart when you like. I have provided a list of resources at the end of this document that you can contact should you need further support.

Your participation will contribute to gathering knowledge about physically disabled women’s experiences of the perinatal period. You may benefit from the opportunity to reflect on your own experience of the perinatal period. You will be given the option of being contacted with the findings of the study, and notified of future research in this area.

Compensation
You will be compensated $30 for participating in this study at the time of the interview. TTC tokens, attendant services, and childcare will also be provided, if needed. You will receive full compensation even if you do not complete the entire interview. You will be compensated another $30 should you participate in a follow-up interview. I have a limited budget so please let me know in advance if you anticipate significant expenses related to your participation.
Follow-up Interview
You may be asked to participate in a follow-up interview. You may be selected for a follow-up interview so that the researcher can learn more about your experience, based on her analysis of your initial interview responses as well as the responses of other participants. In short, you may be asked to participate in a follow-up interview so that the researcher can further explore commonalities and differences in participants’ experiences. If you are selected to participate in a follow-up interview, you will be contacted via phone and/or email using the contact information that you provided during the screening process and asked to complete another consent form. Follow-up interviews may be done in person or over the phone 2 to 3 months after the initial interview, and last approximately 30 to 60 minutes. All of the protocols detailed in this information and consent form will be applicable to the follow-up interview, including compensation (i.e., you will be compensated an additional $30 for the follow-up interview).

Privacy, Confidentiality, and Security
The information collected will be used for research purposes only. Your responses to the interview questions will be kept confidential and private, and your name will not be associated in any way with your responses. No information that discloses your identity will be released or published without your consent, unless required by law. This means, for example, that the principal investigator is required to report to the authorities if it is clear that you or someone else is at risk of immediate danger, or if I have reasonable suspicion of neglect and/or physical or sexual abuse of a person less than 18 years of age.

Should you require attendant services, the attendant will be informed of the purpose of the study and asked to sign a confidentiality agreement.

The digital audio-recording of your interview will only be used to transcribe the interview and will be deleted once transcription is complete. Interview transcripts will be identified by code number, and any identifying information (e.g., your name, the names of health care providers and specific health care settings) will be removed during the transcription process, within four weeks of the interview’s completion. Only the principal investigator and possibly a research volunteer (transcriptionist) will have access to the audio files. The principal investigator will supervise the research volunteer, who must sign the Centre for Addiction and Mental Health (CAMH) confidentiality agreement and complete the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2) tutorial prior to commencing transcription.

You will not be asked to write your name on the demographic survey. Once all surveys are entered in an electronic database, they will also be stored in a locked filing cabinet at CAMH, together with hardcopies of the interview transcripts. Only the principal investigator, her supervisors, and an officer of the Office of Research Ethics at the University of Toronto will have access to study documents.

(Hard copy) transcripts of the interviews and surveys (data) and consent forms will be stored in two separate locked filing cabinets at CAMH. Electronic interview transcripts (MS Word) and survey data (MS Excel and SPSS) will be stored in secure, password-protected files on the CAMH
network/server. Again, only the principal investigator, her supervisors, and an officer of the Office of Research Ethics at the University of Toronto will have access to study documents. Identifying and contact information will be destroyed within six months of community dissemination of the findings.

Results of this study may be published in scientific journals, presented at scientific meetings, and/or community forums and may include quotations from your interview. A pseudonym will be used instead of your name and efforts will be made not to disclose your identity. However, it may be helpful for readers to know which quotations came from particular participants/to distinguish types of people (e.g., participants will particular types of physical or mobility-limiting disabilities). Because there are a small number of physically disabled mothers in Toronto, this amount of detail means that your anonymity cannot be guaranteed.

**Freedom to Withdraw**
Your participation in this study is entirely voluntary. You may choose to withdraw from the study at any time and do not have to provide a reason for doing so. Withdrawing from the study will in no way adversely affect your relationship with the principal investigator or the University of Toronto. If you withdraw from the study before your interview is transcribed, your responses to the interview will not be transcribed, and none of your responses will be quoted in any publication or report that might arise from this study; I will destroy the audio-recording. However, if you withdraw after your interview has been transcribed and the transcript has been de-identified and verified (i.e., approximately four weeks after your interview), the data will still be used as part of the study. It is difficult to withdraw data once the analysis process has begun and “it is difficult, if not impossible, to withdraw results once they have been published or otherwise disseminated” (2nd edition of Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, p. 30).

**Opportunity to Ask Questions**
You may ask any questions about this research and have those questions answered before agreeing to participate or during the study. In addition, if you have questions in the future you may contact the principal investigator at the telephone number or email address given on the first page. If you have any questions about your rights as a participant, you may contact University of Toronto Research Ethics Board, at ethics.review@utoronto.ca or (416) 946-3273.

Note: As part of the Research Services Quality Assurance Program, this study may be monitored and/or audited by a member of the Quality Assurance Team. Your research records and CAMH records may be reviewed during which confidentiality will be maintained as per CAMH policies and extend permitted by law. For more information, please contact Dr. Padraig Darby, Chair of the CAMH REB, at padraig.darby@camh.ca or (416) 535-8501 ext. 36876.
Consent
1. Having read and understood the information presented, my signature confirms that I consent to participate and have my interview audio-recorded.

_______________________________  ______________________________
Signature of Participant          Date

2. I agree to be re-contacted for a follow-up interview.

_______________________________  ______________________________
Initials of Participant           Date

3. I would like to be contacted about the study results.

_______________________________  ______________________________
Initials of Participant           Date

4. Signature of Principal Investigator  ______________________________
                                          Date

This letter is yours to keep for future reference.
Resources

The principal investigator does not endorse any of these specific resources but provides them as information only.

Parenting
Parenting with a Disability Network (PDN), Centre for Independent Living Toronto
The PDN is a peer support and information-sharing network for parents and prospective parents with a disability. The aim of PDN is to develop consumer friendly approaches to parenting with a disability by providing opportunities for networking, peer support, information-sharing and education.

Contact Information:
365 Bloor Street East, Suite 902
Toronto, ON M4W 3L4
Tel: (416) 599-2458
Email: melanie.moore@cilt.ca
Website: http://www.cilt.ca/parenting.aspx

LGBTQ Parenting Network, Sherbourne Health Centre
The LGBTQ Parenting Network promotes the rights and well-being of lesbian, gay, bisexual, trans, and queer parents, prospective parents, and their families and children through education, research, outreach, and community organizing.

Contact Information:
333 Sherbourne Street
Toronto, ON M5A 2S5
Tel: (416) 324-4100 ext. 5219
Email: lgbtqpn@sherbourne.on.ca
Website: http://lgbtqparentingconnection.ca

Violence
Assaulted Women's Helpline (24 hrs/7 days)
A free and confidential service that offers telephone crisis counselling, information and emotional support, referrals to emergency shelters, legal information and services and community services as well as culturally appropriate resources for abused women. Service is provided in over 151 languages.
Tel: (416) 863-0511 or Toll-free: 1-866-863-0511
TTY: (416) 364-8762
E-mail: info@awhl.org
Website: www.awhl.org

Toronto Rape Crisis Centre: Multicultural Women Against Rape
The Toronto Rape Crisis Centre provides crisis intervention and culturally sensitive counselling, support and referrals for survivors of rape/sexual assault/incest. Support for families and
friends of survivors. Crisis line is open 24 hours a day, 7 days a week.

**Contact Information:**
Tel: (416) 597-8808
TTY: (416) 597-1214

**Barbra Schlifer Commemorative Clinic**
The Barbra Schlifer Commemorative Clinic offers legal help, counselling and language interpretation to women who have experienced violence. The clinic offers: legal help in family, immigration and criminal law; compassionate support from diverse, skilled counsellors; and, interpretation and translation in more than 90 languages. We advocate for law reform and social changes that benefit women. We also provide professional development opportunities for service providers.

**Contact Information:**
489 College Street, Suite 503
Toronto, ON M6G 1A5
Tel: (416) 323-9149 - press 0 for reception assistance
TTY: (416) 323-1361
Open Monday to Friday, 9 AM to 5 PM
Website: [http://schliferclinic.com/](http://schliferclinic.com/)

**Springtide Resources Inc.**
The Women with Disabilities and Deaf Women’s Program at Springtide responds to community-identified needs to address barriers to service for abused women with disabilities and Deaf, deafened and hard of hearing women.

**Contact Information:**
Lynda Roy, Manager
215 Spadina Avenue, Suite 220
Toronto, ON M5T 2C7
Tel: (416) 968-3422 ext. 24
Email: lroy@womanabuseprevention.com
Website: [http://www.springtideresources.org/women-disabilities-and-deaf-women-program](http://www.springtideresources.org/women-disabilities-and-deaf-women-program)

**Disability**

**Anne Johnston Health Centre**
The Women’s Disability Action Awareness Group in Training (WDAAG IT) is an interactive peer-led group for women with disabilities guided by the principles of advocacy, mentorship and peer support within an independent living environment.

**Contact Information:**
Lucy Costa-Nyman, Peer Support Coordinator
Tel: (416) 486-8666 ext. 226
Expanding the Reach: Women with Disabilities Project, Scarborough Women's Centre
Conducted in partnership with Scarborough Women's Centre, Birchmount Bluffs
Neighbourhood Centre and Springtide Resources (formerly Education Wife Assault). The
Expanding the Reach: Women with Disabilities Project is a collaborative project of the Centre,
which is designed to provide an opportunity for women with disabilities to come together and
address issues related to freedom from abuse. This project aims to empower women with
disabilities by exploring a range of diverse topics.

Contact Information:
2100 Ellesmere Road, Suite 245
Scarborough, ON M1H 3B7
Tel: (416) 439-7111 ext. 3
TTY: 1-866-620-3849
Email: program@scarboroughwomenscentre.ca
Website: www.scarboroughwomenscentre.ca

ARCH Disability Law Centre
Legal clinic devoted to advancing the rights of people with disabilities in Ontario.

Contact Information:
Tel: (416) 482-8255
Email: archlib@lao.on.ca

Mental Health
Centre for Addiction and Mental Health (CAMH)
CAMH is Canada's largest mental health and addiction teaching hospital, as well as one of the
world's leading research centres in its field. CAMH provides high quality, client-centred care to
meet the diverse needs of people facing addiction and mental health challenges at different
stages of their lives and illnesses— from children to adults to seniors. Clinical services include
assessment, brief interventions, inpatient/ residential programs, day hospital services,
continuing care, outpatient/ambulatory services, and family support.

Contact Information:
CAMH main switchboard: Tel: (416) 535-8501
Website: http://www.camh.ca/en/hospital/visiting_camh/contact_us/Pages/default.aspx

Women's Mental Health Program (CAMH)
CAMH's Women's Mental Health Program primarily serves women who have a history of
trauma in combination with a diagnosis of mental illness.

Contact Information:
250 College Street, 9th floor
Tel: (416) 535-8501 ext. 34702

Across Boundaries: An Ethnoracial Mental Health Centre
Across Boundaries is a mental health centre which provides a range of supports and services to
people from ethnoracial communities in Toronto who are experiencing severe mental health
problems or serious mental illness. Model of service is a holistic approach to mental health care within an anti-racism framework.

**Contact Information:**
51 Clarkson Avenue
North York, ON M6E 2T5
Tel: (416) 787-3007

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**Community Support Services, Community Resource Connections of Toronto**
Community Support Services assists adults (16 and over) who are having a lot of difficulty in day-to-day living as a result of severe and persistent mental health issues. Community Support Services assists you to meet your basic needs such as food, housing, clothing, health care, manage crises, learn the skills you need to meet your goals, and connect to resources and services you need and want. The model of service is psychosocial rehabilitation.

**Contact Information:**
230 – 366 Adelaide Street East
Toronto, ON M5A 3X9
Tel: (416) 482-4103
Email: coster@crct.org

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**Mental Health Court Support Services, Community Resource Connections of Toronto**
The purpose of the Mental Health Court Support Program is to assist people charged with low-risk criminal offences to access and utilize mental health services and other supports.

**Contact Information:**
444 Yonge Street
Toronto, ON M5B 2H4
Tel: (416) 598-8103

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**Let's Discuss It/Multicultural Women's Wellness Program, Canadian Mental Health Association**
Women's support groups in partnership with settlement and community agencies in the Afghan, Greek, Hindi, Jamaican, Polish, Punjabi, Russian, Somali, Tamil and Italian communities. The goal of the women's groups, through a supportive group environment, is to promote the mental health of women who are: Socially isolated and experiencing cultural and linguistic barriers, and/or are at risk of mental health problems due to difficult life circumstances. Most of the groups are language-specific and women discuss, in their own languages, topics they feel are important to their wellness. The groups cover wellness topics and community resources, and support women to develop leadership skills. Supervised childcare is provided in some groups.

**Contact Information:**
1200 Markham Road, Suite 500
Toronto, ON M1H 3C3
Tel: (416) 289-6285
For Afghan, Greek, Hindi, Jamaican, Polish, Punjabi, Russian and Tamil groups in Toronto contact

For Somali and Tamil groups in Scarborough, Italian group in North York, and English-speaking groups at West Hill and Malvern contact

**Emergency or Distress**
Visit your local emergency department or call 911
Contact a nurse at Telehealth Ontario by dialing 1-866-797-0000

**Toronto Distress Centres:** Tel: (416) 408-4357 or 408-HELP (24 hrs/7 days)
**Warm Line, Progress Place:** Tel: (416) 960-9276 or (416) 960-WARM (Monday to Sunday, 8 pm to 12 midnight)

**Distress Centres in Ontario**
Website: [http://www.dcontario.org/help.html](http://www.dcontario.org/help.html)

**Ontario Mental Health Hotline**
Tel: 1-866-531-2600 (Free Health Services Information)
Website: [http://www.mentalhealthhelpline.ca/](http://www.mentalhealthhelpline.ca/)
Appendix D: Socio-Demographic Questionnaire

Demographic Survey

Below are a number of questions about you that will help me to get a better idea of who is participating in the study and to learn a bit about your perinatal experience.
All information provided by you will remain confidential.

Age
1. In what year were you born? ______________

Disability
2. Check ✓ all of the following disabilities or health conditions that you have:
   □ Amputee – please specify: ________________________________
   □ Cerebral Palsy
   □ Epilepsy
   □ Joint and connective tissue diseases such as, rheumatoid arthritis, fibromyalgia, lupus, chronic fatigue syndrome, osteoarthritis
   □ Multiple Sclerosis
   □ Muscular Dystrophy
   □ Osteoporosis
   □ Scoliosis
   □ Spina Bifida
   □ Spinal cord injury – Please specify: ________________________________
   □ Other – Please specify: ________________________________

3. At what age did you develop or acquire a disability or health condition? (I understand that some people may have more than one disability or health condition. When answering this question please refer to your earliest or what you would consider to be your most significant disability or health condition)
   □ Prior to birth
   □ At birth
   Acquired disability:
   □ 0-5 years of age
   □ 5-10 years of age
   □ 11-17 years of age
   □ 18-24 years of age
   □ 25-34 years of age
   □ 35-44 years of age
   □ 45+ years of age

4. If acquired, please specify cause (e.g., injury, accident, disease), if known: ________________________________

Activity Limitations
5. Because of a physical disability or health condition, are you limited in the kind or amount of activity you can do? Check ✓ all that apply.
   □ I am limited at home
□ I am limited at school
□ I am limited at work
□ Transportation to or from work or leisure time activities
□ Other – I am limited in other activities, such as: ___________________________________

Assistance
6. Do you use any kind of assistive device(s), for example, a wheelchair or cane?
□ Yes – Please specify: ________________________________________________________________
□ No

7. Do you need the help of another person for any or all of your daily activities? (e.g., bathing, housekeeping, positioning and transferring)
□ Yes – Please specify: ________________________________________________________________
□ No

8. I would like you to think about all of the help you receive with everyday activities because of a disability or health condition. How often do you usually receive help? Is it...?
□ Daily
□ At least once a week
□ At least once a month
□ Less than once a month
□ Never
□ Not applicable

9. Because of your disability, do you receive help with childcare?
□ Daily
□ At least once a week
□ At least once a month
□ Less than once a month
□ Never
□ Not applicable

Pain
10. Do you have pain that ...
□ Is always present
□ Comes and goes
□ I don’t have pain
11. How often does this pain limit your daily activities?
□ Never
□ Rarely
□ Sometimes
□ Often
□ Always

Sexual Orientation
12. Do you think of yourself as? Check ✓ all that apply.
□ Heterosexual (straight)
□ Lesbian
☐ Bisexual
☐ Queer
☐ Two-spirited
☐ You don’t have an option that applies to me – I identify as: __________________________

**Relationship Status**
13. *Are you?*
☐ Single and not dating
☐ Single and dating
☐ In a monogamous relationship
☐ In a non-monogamous (open) relationship
☐ In a polyamorous (multiple partners) relationship

**Marital Status**
14. *Are you?*
☐ In a common-law relationship
☐ Married
☐ Separated
☐ Divorced
☐ Widowed
☐ Single, ever married
☐ You don’t have an option that applies to me – I am: ______________________________

**Children**
15a. *How many biological children do you have?* _________________________________

15b. *Do you have any other children (e.g., step-children, adopted children, etc.)?*
☐ Yes – Please indicate number of other children: _________________________________
☐ No

15c. *Age of (all) child/children:*
____/____/____/____/____/____/____/____/____/____/

16. *Does your child/children live with you?*
☐ Yes
☐ No

17. *Have you ever lost custody of your child/children?*
☐ Yes
☐ No

18. *How many people live in your household, including yourself?* ____________________

**Housing**
19. *What is your current housing situation?*
☐ Living with family (i.e., in parent’s home)
☐ Supported/Subsidized Housing – live alone
☐ Supported/Subsidized Housing – live with roommates
☐ Supported/Subsidized Housing – live with partner/s and/or child/children
□ Independent Housing – live alone
□ Independent Housing – live with roommates
□ Independent Housing – live with partner/s and/or child/children
□ You don’t have an option that applies to me – Please specify: ________________________

Employment Status
20. What is your current primary employment status? Check ✓ all that apply.
□ Not in labour force (not working, not looking)
□ Unemployed (not working, but looking for work)
□ Employed full-time
□ Employed part-time or casually
□ Work program
□ On maternity leave
□ You don’t have an option that applies to me – Please specify: ________________________

21. Are you a student?
□ Yes – Please indicate full-time or part-time: ________________________
□ No

22. Which of the following best describes your current main daily activity and/or responsibility over the last 6 months? Check ✓ only one.
□ Working for pay
□ Working for pay and caring for family
□ Caring for family (keeping house and/or raising children full-time)
□ Looking for work
□ Going to school
□ Volunteering
□ Recovering from illness/disability or on disability benefits
□ You don’t have an option that applies to me – Please specify: ________________________

Household Sources of Income
23. What is/are your household source(s) of income (i.e., include spousal or other income)? Check ✓ all that apply.
□ Paid work
□ Retirement benefits – other than, or in addition, to CPP
□ Self-employed
□ Employment insurance
□ Disability benefits (e.g., ODSP, CPP-D, WSIB, Employment Insurance, private insurance)
□ Social assistance (e.g., Ontario Works)
□ Student loans/assistance
□ Maternity benefits
□ Family
□ Friends
□ You don’t have an option that applies to me – My source(s) of income is/are:
_________________________________________________________________________
Household Income
24. What was your combined household income before taxes last year (including all sources of income such as student loans, social assistance, etc.)?
□ Less than $10,000
□ $10,000 - $19,999
□ $20,000 - $29,999
□ $30,000 - $39,999
□ $40,000 - $59,999
□ $60,000 - $79,999
□ $80,000 - $100,000
□ Greater than $100,000

Education Level
25. What is your highest level of education?
□ Elementary school
□ Some high school
□ High school diploma
□ Some trade, technical or vocational school, or business college
□ Some community college, CEGEP or nursing school
□ Some university
□ Diploma or certificate from trade, technical or vocational school, or business college
□ Diploma or certificate from community college, CEGEP or nursing school
□ Bachelor’s or undergraduate university degree or teacher’s college (e.g., BA, BSc, LLB, BEd)
□ Graduate in progress (e.g., MA, MSc, MEd, MPH, MSW, PhD)
□ Graduate degree
□ Medical degree in progress (e.g., MD, OD, DVM)
□ Medical degree
□ Other degree

Racial, Ethnic, or Cultural Identity/Identities
26. How do you define your racial, ethnic, or cultural identity/identities based on the following categories developed by Statistics Canada? Check ✓ all that apply.
□ Aboriginal (North American Indian, First Nations, Métis, or Inuit)
□ Arab
□ Black – African
□ Black – Caribbean
□ Chinese
□ Filipino
□ Japanese
□ Korean
□ Latin American
□ Southeast Asian (e.g., Cambodian, Laotian, Vietnamese)
□ South Asian (e.g., East Indian, Pakistani, Sri Lankan)
□ West Asian/Middle Eastern (e.g., Afghan, Iranian)
□ White (e.g., European background)
□ You don’t have an option that applies to me – I identify as: __________________________
27. Are you perceived as a person of colour and/or as a racialized person?
   □ Yes
   □ No
   □ Sometimes
   □ I don’t know

Citizenship
28. What is your citizenship or immigration status?
   □ Canadian citizen
   □ Permanent resident
   □ Visitor
   □ Refugee
   □ Other – Please specify: __________________________

29. If you were born outside of Canada, in what country were you born? _____________

30. If you were born outside of Canada, in what year did you immigrate to Canada? ________

Perinatal Experience (most recent live birth only)
31. From which type of healthcare provider did you receive most of your perinatal care?
   □ Obstetrician
   □ Perinatologist
   □ Family doctor
   □ General practitioner (GP)
   □ Midwife
   □ Nurse or nurse practitioner
   □ Other – Please specify: __________________________

32. Did you attend prenatal classes?
   □ Yes
   □ No – Please specify reason (e.g., inaccessible, did not want to):

33. Did you have a vaginal or caesarean birth?
   □ Vaginal – Skip to #35
   □ Caesarean – Go to #34

34. Was the caesarean planned, that is, the decision was made before you went into labour, or was it unplanned?
   □ Planned
   □ Unplanned

35. Are you breastfeeding/did you breastfeed your youngest child?
   □ Yes – If currently breastfeeding, please specify for how many weeks or months you plan to breastfeed:

   □ Yes – Please specify for how many weeks or months: __________________________
   □ Tried/attempted to breastfeed
   □ No – Please specify reason: __________________________
36. Are you planning to have any more children?
□ Yes
□ No
□ Not sure

Community Involvement and Peer Support

37. Are you part of any organizations or groups that specifically serve people or women with disabilities? This can include participation in various capacities, such as work/employment, formal membership, volunteer, participated in a group or event, etc.
□ Yes – Please specify: _________________________________________________________
□ No

38. Have you connected with peers and/or organizations or groups specifically for parents with disabilities? Check ✓ all that apply.
□ Yes – Peers, in person
□ Yes – Peers, online
□ Yes – Peers via organizations or groups
Please specify organizations or groups: ____________________________________________
□ No, but I am planning to
□ No, because I do not know of any other parents and/or organizations or groups
□ No desire to

Thank you for completing this survey!
Appendix E – Draft Interview Guide

Thank you for agreeing to participate in my PhD research. Before we begin, let me remind you of the purpose of the study and what your participation entails [state study goals and provide overview of the consent form].

If there are any questions that make you feel uncomfortable or that you don’t want to answer, that is ok. You can just say pass. Likewise, if at any time you feel upset or tired or just want to take a break, please let me know. We can take a break and continue when you are ready.

Questions about you
I would like to start by getting to know more about you. What does your family look like?
Probes:
  – Are you single, partnered...? How many children do you have?

Can you tell me about the type and nature of your disability?
Probes:
  – At what age did you become disabled?
  – What was the cause of disability (injury, accident, etc.)?

[For those with congenital disabilities or who acquired a disability at a young age] Did your parents ever talk to you about becoming pregnant / having a family of your own?
Probes:
  – How did these conversations go?

Do you remember a time when you first felt feminine/gendered? When did you first experience feeling sexual (or think of yourself as sexual)?

Questions about your most recent perinatal experience
Tell me about how you [or you and your partner, or your co-parent] came to the decision to have kids.
Probes:
  – Was your (most recent) pregnancy planned?
  – Did you spend a lot of time deciding to have kids?
  – Even as a child, did you imagine having kids of your own?
  – Did you speak with other parents about having children – who?

Tell me what it was like when you first found out you were pregnant.
Probes:
  – How did you feel?
  – [If has partner] How did your partner react?
  – How did your family react?
  – How did your doctor or other care provider react?
    – What type of providers were involved in your care? Specialists?
- What types of things did providers say to you (when they found out you were pregnant, during your pregnancy, during labour, after delivery)?
- Did you ever feel unwelcome, uncomfortable, etc.?
- Did they have disability-specific resources?
- Did you ever feel like your pregnant body and your disabled body were talked about and/or treated separately?
- Did you receive any negative reactions? Did you receive any positive reactions?
- Was it ever recommended that you abort your pregnancy? [Preface this with saying I may ask some sensitive questions]
  - Did anyone’s reaction surprise you (good or bad)?
  - Can you remember a particularly good or bad experience with your provider or place of care that you would like to share?
  - How did these experiences make you feel about yourself?

What did you like most about being pregnant?
What did you like least about being pregnant?

During pregnancy and labour did you experience any medical interventions? [including drugs? Stay in hospital during pregnancy?]

Probes:
  - How did you feel about that? Did you feel like you were given a choice whether or not to have these interventions?
  - Did you feel as though you had all of the information you needed to make a decision?

Did you have a C-section?

Probes:
  - How did you feel about that? Did you feel like you were given a choice whether or not to have a caesarean delivery?
  - Did you feel as though you had all of the information you needed to make this decision?

Generally, during the perinatal period, did you feel like you were in control of your care?

Thinking back on your experience, would you say you faced any particular challenges or difficulties in accessing perinatal care services?

Probes:
  - Were these barriers related to your disability status (e.g., negative attitudes on the part of providers, lack of information, inaccessible spaces)? Or another aspect of your identity?

During pregnancy, did you connect with any other PDW?

Probes:
Now as a [new] parent, do you feel like you have peers you can rely on for support, if needed?

**Questions about your body and sense of self or identity/identities**
Are there any things that you learned during the perinatal period that you did not know or expect before becoming pregnant? Did you learn anything new about yourself during pregnancy, or during your first months/years as a mother?

Did you learn anything about your body or feel differently about your body during pregnancy compared to before you were pregnant? Do you feel differently about yourself and/or your body now that you have become a mother?

After pregnancy, did others perceive you/your body differently?

What do you think influenced how you and others felt about you/your body during pregnancy? Labour? Birth? Early motherhood?

Probes:
- Do you feel like others (partner, family, care provider) treated you differently during pregnancy as a disabled woman, as opposed to how they might treat someone who is non-disabled?
- Has your disability affected the ways in which you see yourself? If so, how? Do you think it has affected how others treat you?

Thinking back on your perinatal experience, do you feel as though you had/have any unique experiences or needs related to your identity as someone who is disabled?

Probes:
- What about your other identities or social locations (e.g., race, sexual orientation, social class, marital status)? What about combinations of these identities? [e.g., being a woman of colour with a disability—or whichever intersection seems most relevant to the participant]

Do you feel like your identity as someone with a disability overshadows your other identities?

Probes:
- Only in certain circumstances? When does it? When does it not/when does it foreground/background?
- Have you ever identified yourself as someone who is disabled to have your needs met, even if you don’t identify yourself that way normally? Have you ever felt like you had to act or present yourself in a certain way to get care?

**Closing**
Is there anything we haven’t covered that you feel is important for me to know about?
Appendix F: Follow-up Interview Guide

Follow-up interview guide

The purpose of the follow-up interview is to get a better understanding of particular situations participants described in their first interview and ways in which they felt in those situations, particularly how they felt about themselves and their bodies. As such, I will reiterate particular situations or events described in the first interview by the participant and ask the participant to provide more context about that situation. I will ask things like “can you provide me with some more context about [XYZ]? What was going on for you at that time? How did [XYZ] make you feel? About yourself? About your body?”

Based on my review on the initial interviews, some participants will be asked some of the following questions (after I review the initial consent form and let participants know that they will also receive an honorarium for the follow-up interview):

[To some participants] What words, language, terminology, label, or identifier do you use to describe yourself? How do you refer to yourself? How do you describe yourself? How do you see yourself? Is there any particular reason why you described/see yourself in that way or not?
   [Probes: Woman with a disability, disabled women, woman with a physical disability, physically disabled woman, woman with/living with [specific disability or chronic illness], woman with impairment]

[To some participants] How you see yourself has that changed over time or not? If yes, how has it changed?
   [Probe: If so, elaborate, for example, was there a specific situation(s) that caused you to change how you feel about or see yourself? Has motherhood changed how you see yourself? If yes, how? If no, why not?]

If you have a partner/co-parent, do they also have a disability?
   [Probe: If yes, what is the nature or type of their disability?-Why is this important to you?]

I want to make sure I have a clear idea of your journey to motherhood. Were you trying to get pregnant at the time you conceived?
   [Probes: Were you and your partner trying to get pregnant? If so, do you remember for how long/how many months you were trying? If no (unplanned), how did you feel about now being pregnant?]

Did you have any medical assistance in getting pregnant?
   [Probe: Did you take any fertility drugs, IUI?]

During your pregnancy did you see a genetic counsellor and/or have any particular genetic tests done? How did you feel about that? Was this something that you initiated on your own or did your doctor suggest that you do this?
   [Probes: (if doctor suggested it) how did that make you feel? Did you feel any assumptions were being made in relation to the genetic tests? What did seeing a genetic counsellor and/or have genetic testing mean for your growing body (body with growing baby inside)? Did you and your partner talk about the possibility of having a disabled child? How did these conversations go?]
[For those who acquired their disability at (their own) birth] Did your own birth experience/your mother’s have any impact on the type of labour/birth (vaginal v. c-section) you chose?

Was there a time(s) during your pregnancy or labour/birth that care providers were making you feel like you were putting them out because you needed extra accommodations or supports? If so, when did this occur? How did you react to this? How did this make you feel?

Because of lack of knowledge among providers, some participants noted that they felt like their pregnancy and labour/birth seemed like an “experiment.” Does this resonate with you? Did you ever get the sense that you/your pregnancy was treated like spectacle or differently from other women? For instance, were there more people/providers in the delivery room than you thought were necessary or you were told about? How did this make you feel?

Some participants commented that they felt like their perinatal care providers had a narrow view of disability, for instance, focusing on how their limited mobility may impact their pregnancy and their ability to parent (e.g., worrying about falls) and little attention to pain (management) and how pregnancy and labour/birth changed their body or particular parts of their body (e.g., spine). Is this at all reflective of your experience or not? Can you recall a particular instance when you might have encountered something like this?

[To all participants] How do you think your providers understood your disability?

[Probe: If yes, can you provide an example of something your provider said or did to indicate that they understood your disability? If no, what did your provider do or say that indicated to you that they did not understand your disability? Do you feel like your provider/s had a clear understanding of all of your disability-related concerns, or how your disability affects your everyday life?]

Did you hold particular ideas or assumptions about your body (and what it can or cannot do) prior to becoming a mother? Have these changed? Has the physical act of becoming a mother changed your relationship with your body? Do you feel like your perception of your body has changed since you’ve become a mother?

[Probe: Instead of focusing on the appearance of your body (as an object, evaluated by yourself and others), has pregnancy and becoming a mother altered the way you think about your body or what your body can or cannot do? Are there things that surprised you about your body during the transition to motherhood?]

Particularly in the media, there is increased focus on women’s bodies during pregnancy, that is, a focus on the ideal pregnant body (i.e., an unchanged body besides the “bump”). Did you ever feel pressured to look a certain way while you were pregnant?

Some women have commented that during pregnancy, they experienced a newfound respect or admiration for their bodies. Is this something that resonates with you? Did you experience your body as valuable or useful in a way that you hadn’t before becoming a mother? Yes or no?

[Probes: Did you feel more confident about your body since you’ve become a mother? Has becoming a mother made you feel more or less disabled? Does this resonate with you? Can you provide a specific example of when you might have felt like this (more or less disabled as a mother)?]
Has the nature of your disability changed since you’ve become a mother? If yes, how so?
   [Probes: more or less mobility, more or less pain? How do you feel about these changes? Were any of
   these changes a surprise to you? Did your provider talk to you about potential changes?]

A participant mentioned how she had little interest in breastfeeding; it wasn’t something that
appealed to her. Was there anything about becoming a mother that felt “unnatural” to you?
Are there any aspects of motherhood that you don’t particularly like or identity with? Or, are
there aspects of motherhood that you strongly identify with or particularly enjoy?

If you breastfed/are breastfeeding, is breastfeeding important to you?

[To all participants] Is there anything that we haven’t talked about that you feel is important for
me to know about?

[To all participants] Thank you again for participating in my dissertation research. Do you have
any questions for me?
Appendix G: University of Toronto Ethics Approval Letter

PROTOCOL REFERENCE # 30505

August 7, 2014

Dr. Carol Strike
DALLA LANA SCHOOL OF PUBLIC HEALTH

Ms. Lesley Ann Tarasoff
DALLA LANA SCHOOL OF PUBLIC HEALTH

Dear Dr. Strike and Ms. Lesley Ann Tarasoff,

Re: Your research protocol entitled, “A qualitative study of embodiment among physically disabled women during the perinatal period”

ETHICS APPROVAL

Original Approval Date: August 7, 2014
Expiry Date: August 6, 2015
Continuing Review Level: 1

We are writing to advise you that the Health Sciences Research Ethics Board (REB) has granted approval to the above-named research protocol under the REB’s delegated review process. Your protocol has been approved for a period of one year and ongoing research under this protocol must be renewed prior to the expiry date.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events in the research should be reported to the Office of Research Ethics as soon as possible.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your current ethics approval. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry.

If your research is funded by a third party, please contact the assigned Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your research.

Yours sincerely,

Elizabeth Peter, Ph.D.
REB Chair

Daniel Gyuwu
REB Manager
Appendix H: Centre for Addiction and Mental Health Ethics Approval Letter

PROTOCOL REFERENCE # 092/2014

October 20, 2014

Dr. Karen Urbanowski
Independent Scientist
Centre for Addiction and Mental Health
Health Service and Health Equity

Dear Dr. Urbanowski:

Re: Expedited Research protocol # 092/2014 entitled “A qualitative study of embodiment among physically disabled women during the perinatal period” by Urbanowski K, Strike C

We are writing to advise you that the Centre for Addiction and Mental Health Research Ethics Board (CAMH REB) has granted expedited approval to the above-named research study for a period of one year from the date of this letter. If the study is expected to continue beyond the expiry date, you are responsible for ensuring the study receives re-approval by submitting the CAMH REB “ANNUAL RENEWAL OF ETHICS APPROVAL” form on or before September 1, 2015. Should the study be completed prior to the annual renewal date, please submit a final report. The level of continuing review for this study is Level 2.

Your “consent form” (Appendix C) received September 10, 2014 has been approved and a copy is attached. Subjects should receive a copy of their consent form.

During the course of the research, any significant deviations from the approved protocol (that is, any deviation which would lead to an increase in risk or a decrease in benefit to human subjects) and/or any unanticipated developments within the research should be brought to the attention of the Research Ethics Office. Best wishes for the successful completion of your project.

Yours sincerely,

[Signature]

Sama Pion, MHSc
Manager, Research Ethics Office, CAMH

CC: Lesley Tarnoff

1 CAMH Investigators are reminded that should they leave CAMH, they are required to inform the Research Ethics Board of the status of any ongoing research. If a study is to be closed or transferred to another facility, the REB must be informed and any advertisements must be discontinued.

2 Level 2: Review of routine annual reports, changes and amendments to the approved protocol, adverse events, filing of a final report and audit of study documentation. Please retain a printed copy of this letter and all documents for your records.
Appendix I: Paper published in *Disability and Health Journal* focused on barriers to perinatal care based on dissertation study data
"We don’t know. We’ve never had anybody like you before": Barriers to perinatal care for women with physical disabilities

Lesley A. Tarasoff

Dalla Lana School of Public Health, University of Toronto, 6th Floor – 155 College Street, Toronto, Ontario M5T 3M7, Canada

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ABSTRACT

Background: While more women with physical disabilities are becoming mothers, many encounter barriers to perinatal care and experience poor outcomes. Little is known about the perinatal care experiences and outcomes of women with physical disabilities in Canada.

Objective: This qualitative study sought to understand the perinatal care experiences and outcomes of women with physical disabilities in one Canadian province, with an emphasis on identifying barriers to care.

Methods: In-depth interviews were conducted with 13 women with physical disabilities who had given birth in the last 5 years. Follow-up interviews were conducted with 10 of the 13 participants. All interviews were audio-recorded and transcribed verbatim. Data analysis was informed by a constructivist grounded theory approach.

Results: Based on analysis of participants’ interviews, five themes regarding barriers to care were identified: (1) Inaccessible care settings, (2) Negative attitudes, (3) Lack of knowledge and experience, (4) Lack of communication and collaboration among providers, and (5) Misunderstandings of disability and disability-related needs.

Conclusions: Study findings reveal that the perinatal care system is not set up with women with physical disabilities in mind and that barriers to perinatal care may contribute to poor outcomes. More research and training are needed to address barriers to perinatal care for women with physical disabilities.

Collaboration among perinatal and disability-related providers and meaningful inclusion of women with physical disabilities in educational initiatives and care plans are vital to improve care experiences and outcomes.

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With medical advances, growing community participation, and recognition of the reproductive rights of persons with disabilities, women with physical disabilities increasingly have opportunities for childbearing. Researchers in the United States have in fact found that women with physical disabilities are giving birth at similar rates to non-disabled women.

Women with physical disabilities, however, experience significant perinatal health disparities when compared to non-disabled women. Notably, they experience increased rates of cesarean delivery and preterm birth. Women with physical disabilities are also more vulnerable to risk factors associated with adverse pregnancy outcomes, such as poverty, poor mental health, obesity, abuse, and lack of emotional or social support. Moreover, women with physical disabilities report encountering barriers to perinatal care, including attitudinal barriers, informational barriers, and inaccessible care settings. These barriers may contribute to poor maternal and infant outcomes.

The objective of this study was to better understand the perinatal care experiences and outcomes of women with physical disabilities in Ontario, Canada, and to identify barriers to perinatal care.

Methods

In-depth, qualitative interviews were conducted to capture the perinatal care experiences and outcomes of women with physical disabilities who had recently given birth in the province of Ontario.

Recruitment and screening

To be included in the study, individuals had to: identify as a woman with a physical or mobility-limiting disability; reside in Ontario; be aged 18 years or older; have given birth within the last 5 years; and have given birth in the last 5 years.
years; and, be able to converse in English.

Interview participants were recruited through personal networks and the distribution of flyers via the electronic listservs and websites of over 60 organizations and groups that serve pregnant women, new parents, and/or people living with disabilities across Ontario. Flyers were also posted at a number of high risk birth units and rehabilitation centers in major urban centers and shared on social media.

Interested individuals contacted the author and were screened by telephone to determine eligibility. A total of 20 women contacted the study office. Of these, 13 were eligible to participate. The primary reasons for ineligibility were location (lived outside of Ontario) and age of children (over 5 years old).

Data collection and ethics

Using a semi-structured guide, qualitative interviews were conducted with 13 mothers with physical disabilities between November 2014 and November 2015. Baseline interviews lasted between 54 and 135 min (mean = 86 min). Ten of the 13 participants were interviewed in person, in locations of the participant’s preference, and three were interviewed over the phone. Shorter, follow-up interviews were conducted with 10 of the 13 participants between June and September 2015, primarily over the phone.

Those participants who were recruited later in the study were not asked to complete a follow-up interview. These three participants’ interviews tended to be longer however, as they were asked some of the questions created for the follow-up interview, which were based on preliminary analysis of earlier participants’ baseline interview data. Further, saturation was achieved on a number of themes (including all themes presented in this manuscript, with at least 3 participants with different disability types reporting similar experiences). All interviews were audio-recorded, with the participants’ consent.

After each interview, field notes were written to summarize key points and capture interactions and observations about the participant within the context of the interview (e.g., participants’ emotional reactions). Field notes were used to highlight similarities and differences in participants’ experiences and informed the direction of follow-up interviews. Follow-up interviews served as a method of confirmability, whereby participants’ accounts were made richer and experiences discussed in baseline interviews were built upon or confirmed. Follow-up interviews in turn helped to establish credibility (other techniques used to meet standards of qualitative rigor and trustworthiness included memoing and peer debriefing).

This study received ethics approval from the Research Ethics Board at the Centre for Addiction and Mental Health and the Health Sciences Research Ethics Board at the University of Toronto. Participants received a honorarium of $30 for each interview and public transit fare if they travelled to the author’s office. Names used in this paper are pseudonyms.

Prior to each interview, participants provided written informed consent and completed a demographic questionnaire (before the baseline interview only), including items querying disability type, age, marital status, and education level, as well as items related to disability (e.g., pain and activity limitations) and their most recent perinatal experience (e.g., prenatal class attendance, main provider, type of birth).

Data analysis was informed by a constructivist grounded theory approach, whereby themes were actively co-constructed through the author’s interaction with the data. The data presented here are part of a larger (dissertation) project exploring the transition to motherhood among women with physical disabilities, wherein the initial line-by-line coding process yielded 157 codes. This list of codes was then narrowed down to 59 codes which were shared and discussed with the author’s supervisory committee (i.e., peer review and debriefing). Transcripts were then uploaded to NVivo to assist with data management. Data from about half of those 59 codes were used for this present analysis. Coded segments within and between interviews were continuously compared and categorized into 5 themes concerning barriers to perinatal care presented below.

Results

Participant characteristics and outcomes

Participants reported having a range of disabling conditions, including cerebral palsy (CP) and spinal cord injury (SCI; see Table 1). Many participants reported experiencing chronic pain, and shared that their experiences of pain were at times more limiting than their physical condition. Most participants use an assistive device daily, including a cane, power wheelchair, scooter, crutches, and other devices and tools to assist with daily activities (e.g., tasks that require hand dexterity).

The average age of participants was 36.5 years (range 26–44). All but one were married or in a common-law relationship, and only one identified as non-white (Asian background). Most were well-educated and resided in large urban centers. Three had a child under the age of three months at the time of the first interview. Nine participants (including one of those with a child younger than three months old) had a child or children ranging in age from 10 months to 3 years at the time of first interview.

Most had an obstetrician as their primary perinatal care provider. Three participants also reported that they had a doula during pregnancy and/or present with them during labor and delivery, and four indicated that they had a postpartum doula and/or lactation consultant.

Though not formally assessed in the questionnaire, participants reported a range of postpartum outcomes, including what they considered to be postpartum depression and/or anxiety (n = 5), and preterm birth (n = 3). Five participants reported that their newborns spent time in the neonatal intensive care unit (NICU), including two due to medication withdrawal (2–4 week stays), and one due to maternal complications. Some reported that motherhood has resulted in increased pain and decreased mobility.

Qualitative themes

Five interrelated themes regarding barriers to perinatal care were identified: (1) Inaccessible care settings, (2) Negative attitudes, (3) Lack of knowledge and experience, (4) Lack of communication and collaboration among providers, and (5) Misunderstandings of disability and disability-related needs. The latter theme was arguably the most prominent, linking and underlying all others.

Inaccessible care settings

Several participants encountered inaccessible perinatal care settings, including inaccessible washrooms and inaccessible equipment such as examination tables.
Table 1
Select characteristics of study participants.

<table>
<thead>
<tr>
<th>Disabilitya</th>
<th>Age</th>
<th>Type of Birthd</th>
<th>Highest Level of Education</th>
<th>Housing Situation</th>
<th>Marital Status</th>
<th>Pain</th>
<th>Pain Limits Daily Activities</th>
<th>Pain Assistive Device Use</th>
<th>Number of Children</th>
<th>Main Perinatal Care Providerc</th>
<th>Type of Birthd</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arthritic condition</td>
<td>25–29 years</td>
<td>Vaginal</td>
<td>Graduate degree (e.g., MA, MSc, MSW, PhD)</td>
<td>Independent housing (house, condo, apartment)</td>
<td>Married</td>
<td>No</td>
<td>Never</td>
<td>4</td>
<td>11</td>
<td>Obstetrician</td>
<td>Vaginal</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>30–34 years</td>
<td>Midwife</td>
<td>Bachelor’s or undergraduate university degree</td>
<td>Subsidized housing (apartment)</td>
<td>Common-law</td>
<td>Yes</td>
<td>Rarely</td>
<td>3</td>
<td>2</td>
<td>Family doctor</td>
<td>Cesarean</td>
</tr>
<tr>
<td>Congenital amputation</td>
<td>35–39 years</td>
<td>Family doctor</td>
<td>Diploma or certificate from community college</td>
<td>Independent housing (house, condo, apartment)</td>
<td>Single/Never married</td>
<td>Often</td>
<td>Sometimes</td>
<td>5</td>
<td>31</td>
<td>General practitioner</td>
<td>Planned</td>
</tr>
<tr>
<td>Congenital blindness</td>
<td>40–44 years</td>
<td>General practitioner</td>
<td>Bachelor’s or undergraduate university degree</td>
<td>Subsidized housing (apartment)</td>
<td>Married</td>
<td>Always</td>
<td>Often</td>
<td>4</td>
<td>24</td>
<td>Other (e.g., family health team)</td>
<td>Unplanned/Emergency</td>
</tr>
</tbody>
</table>

Notes.  
a Some participants reported more than one disability or disabling condition.  
b Includes twins and two step-children.  
c Some participants reported having more than one perinatal care provider (e.g., a team of rotating obstetricians and nurses) or changing their main provider part way through pregnancy.  
d Most recent birth.

There were no accessible beds and so my partner always had to lift me up onto the bed. And it just seemed really ridiculous to me because out of any place, this should be where there should some specialized equipment. Every time you go in, you have to provide a pee sample and the washroom wasn’t accessible. It didn’t make sense to me. I felt like disability wasn’t an expected part of this high risk clinic, even though high risk was usually associated with medical conditions (Jennifer, who lives with muscular dystrophy and is a mother of one, accessed a “brand new maternity ward”).

At one point [during the postpartum hospital stay] I’m saying to my husband I want to go take a shower. So I said to them [nurses], “do you guys have a walker I could borrow, or is there anywhere in this hospital, is there a bench?” “No.” … they had a floor for people that had suffered strokes, so they said, “the best we can do is you can go up there, they have a walker that’s broken, and so it doesn’t lock” (Whitney, who lives with CP and is a mother of three).

Beyond inaccessible perinatal care settings and challenging accessing assistive devices, one participant also reflected on how the NICU was inaccessible to her as a parent with a physical disability.

They didn’t know how to deal with the disability [I have]. They really didn’t …. The fact that I was bringing my [wheel]chair into the NICU freaked a lot of people out because I’m bringing in outside germs into a place where there’s a lot of sick babies. But I was like, “I’m sorry. I cannot not [have my chair]. Provide me with a chair that’s sterile then. What do you want me to do? You all walk in in your street shoes; it’s the same kind of thing.” … There was no real [accommodation] (Hillary, who lives with a lumbar SCI and is a mother of one).

Negative attitudes

Many participants reported encountering negative attitudes about disability and comments about their fitness for motherhood. In one instance, Whitney reported that her obstetrician’s receptionist did not recognize her to be pregnant:

I went in for my appointment [to my OB and after] I went up to the secretary to book the next appointment. She actually whispered to the doctor, “She’s not pregnant, is she?” And the doctor’s said, “Well, yeah, that’s why she’s here.”

While she was recovering from the birth of the first of her three children, Whitney also recalled that nurses made comments about her fitness for motherhood when she asked for assistance to get out of bed in order to go use the washroom: “I asked for help twice and got a lecture by the head nurse about how the heck are you going to take care of a baby?”

Julie, who lives with CP and is a mother of two, had a somewhat similar experience, reporting that some of the nurses “treated me like I shouldn’t be having kids.” Shortly after the birth of her first child, she recalled:

I said to the one nurse, I buzzed her—I’m my husband’s asleep on the chair, poor guy—it was like 4 in the morning … “I really have topee, can you help me up?” and she [nurse] said, “well what’s your husband here for, isn’t that what he’s good at? … he knows how to lift you and everything.” I go, “he doesn’t lift me, I can move if you help me. I’ve just had surgery [cesarean].”

During her first pregnancy, Julie also recalled encountering an ultrasound technician who was “very rude”: “She expected that I
should be able to jump on this high bed by myself being 8 months pregnant, swollen feet, and disabled. And I couldn’t get on the bed and she was screaming at me.”

Finally, Whitney shared two experiences of interactions with nurses who seemed to have negative attitudes about disability. These nurses seemed to be uncomfortable to support her disability-related needs.

The other thing that I could not wrap my head around is disability phobia. I told them specifically I need somebody to grab my legs on each end [during labor] … But every time I have to push, the nurse drops my leg and the only thing I’m thinking of is, okay, I’m not an expert here, but like I’ve watched a birthing story or whatever on TVO. And able-bodied women get assistance with people holding their leg. They don’t get their legs dropped every time they push. So that’s why I said to her, “look, I realise that it might be heavy, it might not be the most comfortable – get another person to help you.” They were just freaking [out].

I was walking to the elevator; one of the younger nurses says, “oh, have a nice time showering,” but really mocking, to the other nurses, as if to say oh, you’ve got this chore to do. Not that she was showering me … it was just a matter of I needed a shower with a bench or a chair put in that I can maneuver.

Lack of knowledge and experience

Most participants reported difficulties accessing information about pregnancy and disability, both from providers and community resources.

I had a hard time finding information…. Even online. I dug around the internet and there just wasn’t a lot of information. What studies I did find were vague and said stuff I already knew. I found the high risk [pregnancy] unit affiliated with hospital X when I started saying I would like to try having a kid. We had a consult with them and they basically said come back when you were pregnant so that was the extent of the information I was able to find. That was very frustrating. There were a lot of unknowns. I was told that the pain could be the same, could get worse, or could get better with pregnancy (Hillary).

Going through the medical establishment was complicated because they didn’t have more information than I did … if you ask them questions about resources that I could tap into to help me parent, they had no idea and no resources and they weren’t hooked up to community groups … I felt like when there were people who were encouraging, who were like, “Oh it’s so encouraging to see disabled people having kids.” When you are like, “Yeah! So how can you help me?” They’re like, “Oh, I have no idea.” (Jennifer).

While several participants reported that their perinatal care providers were eager and willing to learn, most reported that their providers’ lacked knowledge regarding the interaction of pregnancy and disability and/or experience caring for women with physical disabilities.

They were pretty excited because they never had anyone with a disability at the hospital …. It was all like a big experiment (Kimberly, who lives with a cervical SCI and is a mother of one).

“We don’t know. We’ve never had anybody like you before” … I find it extremely hard to believe I’m the first person, the first mom with a disability, that you’ve ever come across …. But this is what they told me (Heather, who lives with a congenital amputation and is a mother of one).

I kept asking her, “so you’ve had experience with mothers with CP?” and she’s like “oh yeah, yeah” … No. [Another woman with CP] came into play and they were asking me questions to tell her because she had a different doctor but it was in the same group of doctors, [in] the same hospital. They had experiences with persons with disabilities but not specifically with persons with cerebral palsy (Angela, who lives with CP and is a mother of one).

The lack of knowledge and experience on the part of providers both surprised and frustrated participants, and in turn exacerbated their feelings of anxiety during pregnancy. Beyond worrying about how disability might impact pregnancy and vice versa, some participants were particularly concerned about how their medications might impact their infants and found that their perinatal care providers offered little clarity on this matter.

I had a fairly serious complication from my RA during pregnancy because I [had] come off my medications…. I don’t think they were confident on the safety and the information (Sarah, who has lived with rheumatoid arthritis for much of her life and is a mother of two).

They didn’t know how my meds would interact with [my son] … there were a lot of unknowns definitely (Kimberly, whose son had a two-week NICU stay due to medication withdrawal).

Hillary’s son, who was born “vital signs absent,” also spent time in the NICU due to medication withdrawal:

I heard after the fact, the obstetrician saying, “Well, you know, they shouldn’t have given her that medication when she was already on something else.” … Well, now you’re saying that?!! Why wasn’t this talked about before? I kept asking before I went into active labour, “what kind of effect will this have on the baby?” And the anesthesiologist said, “Oh, it’s fine, it’s fine.” Obviously they didn’t take into account or underestimated the impact it would have in conjunction with the medication I was already on. That was really frustrating and frightening because it definitely had a detrimental effect on my son.

Lack of communication and collaboration among providers

Related to perinatal care providers’ lack of knowledge and experience, several participants described a lack of communication and collaboration among perinatal and disability-related providers. For instance, commented Hillary:

There’s a lot of siloing that goes on in the medical community, especially if you have a complex disability like mine when you have issues dealing with chronic pain and a physical disability that the two don’t communicate. You get excellent care in those two separate areas but they don’t communicate with each other.

Some participants, such as Sarah, tried to initiate interprofessional communication:
I was watched by internal medicine and I kept telling them to get in contact with my rheumatologist. I don’t know how many times I asked and I don’t think they ever did at all.

Together with a lack of knowledge and experience, some participants felt as though the lack of communication and collaboration among providers may have contributed to some of the poor outcomes that they and their infants had experienced. Sarah in particular felt this way, as she experienced major complications during labor and delivery and as a result spent 8 days in the ICU after her son was born:

I asked so many times for them to touch base because I know my rheumatologist has had many pregnant women [as patients]. … He has a lot of experience but they never contacted him and I still remember, he was so angry after this whole [situation] because he came to visit me in ICU. So then they finally call me [he said]. But it was already too little, too late. I was in intensive care. I was critically ill. I think I came close to death, including my son. His Apgar score, when he was born, was 0. Luckily it went up. He wasn’t breathing because I wasn’t breathing.

Similarly, Hillary recalled that, moments after her son was born, “nobody was really talking to each other; not a lot of collaboration and then just sort of a flurry of activity to do damage control after the fact.”

Misunderstandings of disability and disability-related needs

Many of the barriers encountered by participants might be best explained by a lack of understanding of disability and disability-related needs among perinatal care providers. Some participants shared that their providers seemed to fixate on one aspect of their disability over others (e.g., mobility over pain management or vice versa) and/or seemingly overlooked their disability or disability-related concerns to focus only on their pregnancy and delivery.

I don’t really feel like I was cared for my arthritis very well by the obstetrical staff (Sarah).

There was a risk that I would lose mobility and he wasn’t interested in helping me with any of that aspect. He was just focused on the delivery. … I requested a prescription to go get afterwards and on the prescription pad for physio, they had put down the wrong diagnosis — MS [multiple sclerosis] — it’s like oh, you really are clueless with what’s going on (Jennifer, who has muscular dystrophy).

Relatedly, some felt as though their disability and disability-related concerns were dismissed as individual concerns and told that they would just “figure it out.”

I kept trying to say to people I have a disability and I need some help and I need someone to pay attention to that. And I really wasn’t getting a lot of uptake so in one way, it was kind of the opposite. People would say to me “oh well, you know, like look at you, you’ll do fine. You get along fine. You’re great. You’ll just figure it out, I’m sure.” Well, I don’t think I can figure this out on my own; I would like some help (Heather).

Some participants reported feeling dehumanized, as though their providers equated them with disability, and similarly, some reported feeling like a spectacle. For example, Heather contended that, “people talk about you and about your disability without actually talking to you about it.” In her follow-up interview, Heather shared a particularly inappropriate encounter that she had with her obstetrician during pregnancy:

They don’t see me as a person anymore. I’m a disability. … We were talking about something to do with my concerns, and she reached over and pulled my sleeve up. I tend to keep my sleeve down because I find it cuts down on my daily awkward exchanges and interactions. But she pulled my sleeve up and held my arms out to this resident. Like, “well you can see, she’s got this disability and this disability.” And it made me feel like ok, so I’m not a person in this exchange. … People didn’t seem to pay much attention [to my disability]. When it did flip, it was the wrong kind of attention.

Finally, participants’ reported instances of providers who seemed uninterested in consulting or acknowledging participants’ embodied knowledge of disability.

I figured that it would be known, that you work with me, because I know my body, I’m very sensitive to my body. … The second doctor that came along, “okay, I want you to scoot down and your butt’s going to be in the air and you’re going to like push,” and I’m like, “no, that’s not going to happen.” I’m trying to explain to her I cannot be half hanging off a table, because of the surgeries that I’ve had, and trying to explain to her I have a disability, it’s real, it’s not just I have canes or I have a wheelchair or scooter because I’ve injured myself. … I’m the doctor, I know what’s best … She just ignored me (Whitney).

The doctor was really, really unhelpful … they had me on my back and I needed to have my knees in the air but they had no equipment to help me keep my knees in the air … I was like you’re not listening to me at all, you have no interest in listening to me and you just want to get out of here (Jennifer).

I said “it will be difficult to get the baby out if you don’t hold my hip outwards” So the first time the OB did not listen and I was in labour and I was hyper … so that was sort of missed (Julie, who had a much better second birth experience when her OB “listened to what I told her”).

Discussion

Participants reported several issues that made their experiences accessing perinatal care challenging, including negative attitudes and a lack of knowledge among providers. Moreover, some participants felt as though the barriers that they encountered in perinatal care settings, including a lack of communication and collaboration among providers, may have contributed to poor outcomes for themselves and their infants.

Although it is not my intention to give the impression that the perinatal care experiences of all participants were entirely negative, borrowing words from Thomas, this paper emphasized the “bad” or “poor” rather than “good” perinatal care experiences with the hope that, once understood, steps can be taken to address these barriers. The fact that many of the barriers to perinatal care reported by participants in this study echo those of the participants in Thomas’ study and more recent studies further supports the contention that more needs to be done to address barriers to perinatal care for women with physical disabilities. It is appalling that little seems to have changed in nearly 20 years regarding the perinatal care experiences of women with physical disabilities. Indeed, many of the recommendations made below are consistent with those made 15–20 years ago.
What this study and others like it illuminate is that the pregnant body is assumed to be a non-disabled body and the practices and physical space of perinatal care settings are set up according to this assumption. In other words, the narratives of participants in this study reveal that the perinatal care system is not set up with women with physical disabilities in mind, or that many of the barriers reported by participants are manifestations of informational and institutional erasure. These two mutually reinforcing types of erasure theorized by Bauer et al. to describe the health care experiences of trans populations can be applied to women with physical disabilities in the context of perinatal care. Informational erasure includes both a lack of knowledge of marginalized groups and their needs and the assumption that such knowledge does not exist even when it may. Relatedly, institutional erasure occurs through a lack of policies that accommodate marginalized identities or “bodies, including the lack of knowledge that such policies are even necessary.”

Examples of institutional erasure include administrative forms that do not include marginalized identities and actual practices that exclude or ignore the possibility of providing service to marginalized populations, or in the context of this study, the possibility that women with physical disabilities can be pregnant in the first place, as evidenced by the interaction that Whitney had with her obstetrician’s receptionist.

To address erasure, a greater understanding of why many women with physical disabilities continue to report poor care experiences and outcomes is needed. Notably, there is a need to examine what factors might exacerbate or explain risks for poor care experiences and outcomes for women with physical disabilities, such as social support, socio-economic status, pre-pregnancy mental illness, and provider-level barriers. With regard to the provider-level barriers, a number of researchers have recently asked obstetricians and related health professionals to identify what they consider to be challenges or barriers to providing care to women with physical disabilities. The results from these studies in many ways echo barriers to care identified by women with physical disabilities themselves. For instance, Mitra and colleagues, who interviewed 14 obstetrician-gynecologists and certified nurse midwives who had experience providing perinatal care to women with physical disabilities in the U.S., found that providers also identified lack of inaccessible care settings and equipment and disability-specific training as barriers. Similarly, providers in Ireland acknowledged that they lacked knowledge regarding disability and subsequently did not always feel competent caring for women with physical disabilities.

Increasing disability content in medical school curriculum and continuing education is vital to improve care experiences and outcomes for women with physical disabilities. To ensure that this content is relevant, actively involving women with physical disabilities in the planning (design) and evaluation of training programs is recommended. While it may not be feasible for all general obstetricians to have or receive experiential training for women with physical disabilities, it seems reasonable that at least maternal-fetal medicine specialists receive this training—though this may not address issues of access, as some women with physical disabilities may not be able to afford specialist care or live in areas where they can easily access a specialist. Because women with physical disabilities may already have established relationships with their disability-related provider(s) (e.g., physiatrist, rheumatologist, pain management specialist, physical therapist), improving communication and collaboration among perinatal and disability-related providers may be a crucial strategy to address this gap. Finally, it should be noted that greater disability-related training is not only needed for obstetricians but for other health professionals, paraprofessionals, and staff in perinatal care settings (e.g., nurses, ultrasound technicians, receptionists), as evidenced by participants’ negative interactions with these individuals.

To identify what factors might exacerbate or explain risks for poor care experiences and outcomes, Mitra and colleagues have developed a perinatal health framework for women with physical disabilities that utilizes a life course approach. This framework is a valuable tool for researchers, providers, and decision-makers in that it outlines multiple factors, including individual factors (e.g., marital status, primary disabling conditions and secondary conditions, body structure and function, activity limitations), mediating factors (e.g., prenatal education, financial support, provider knowledge, maternal mental health, social support), and infant outcomes, and environmental context (e.g. physical accessibility of home and care setting, legislation and policy), that may impact the perinatal health of women with physical disabilities throughout the life course. This framework then highlights the need for greater collaboration among perinatal and disability-related providers, as well as “the need to include the disabled women themselves in their ‘plan of care’ for pregnancy, childbirth and postnatal care.” In short, this framework goes beyond the medical model of care to consider the whole person, in context, throughout the life course.

This study contributes to the limited research on the perinatal care experiences and outcomes of women with physical disabilities in Canada. This study is unique because it draws on the recent perinatal experiences of women with physical disabilities. In fact, most of the study participants had given birth within the last 3 years (including three who had given birth within 3 months of their baseline interview). Yet, the findings of this study and other recent studies with women with physical disabilities with older children suggest that little has changed over time regarding the perinatal care experiences of women with physical disabilities.

This study adds to the knowledge on the relationship between medication use among women with physical disabilities and infant outcomes. Though this relationship was not assessed quantitatively in this study, participants’ interview responses suggest that providers know little about this relationship or interaction. Because many women with physical disabilities use medication regularly, ideally before conception, it is advised that women with physical disabilities and their providers discuss the potential risks of medication on the fetus as well as on the woman’s health and quality of life.

One participant’s comments regarding the inaccessibility of the NICU are also noteworthy, as no other study to my knowledge considers women with physical disabilities’ experiences of the NICU. Hillary’s experience suggests that the NICU is designed only as a place for “sick” babies, not “sick” or disabled parents. Thus, not only is there a need to re-think the physical set up of perinatal care settings (e.g., labor/delivery rooms) and equipment in those settings to accommodate women with physical disabilities, there is a need to make NICUs more accessible and accommodating of physical disability, particularly given that some women with physical disabilities are at increased risk of preterm birth and in turn low birthweight infants. Using data from the 2002–2011 Rhode Island Pregnancy Risk Assessment Monitoring System, Mitra and colleagues, for instance, found that 13.8% of women with disabilities had an infant in the ICU at birth compared to 9.6% of non-disabled women.

Finally, there is a need for broader understandings of disability and disability-related needs. Participants’ narratives reveal that sometimes movement or mobility limitations related to disability are not always of primary concern. Instead, in some instances, participants’ experiences of chronic pain warranted further attention than did their mobility limitations in the context of perinatal care. This finding further emphasizes the need for discussion on medication use at preconception and throughout the perinatal
period.

The findings of this study are somewhat limited as they may not reflect the experiences of all women with physical disabilities in Ontario or Canada. Like other qualitative studies, 20,23 the findings presented here are based on interviews with a convenience sample of women with physical disabilities, most of whom were married, white, heterosexual, well-educated, and reside in large urban centers. As such, their experiences may not be representative of all women with physical disabilities, particularly women with disabilities who reside in rural and remote areas and who are lower-income and/or racialized. More research is needed on the perinatal care experiences of women with physical disabilities who may be marginalized in other ways beyond sex/gender and disability status (i.e., do all women with physical disabilities have the same opportunities for childbirth?).

Conclusion

Carty’s assertion that “physicians and other health care providers rarely have training in the accessibility and sociopolitical aspects of disability and chronic illness” 24, 25 seems to ring true nearly 20 years later. Women with physical disabilities continue to encounter barriers to perinatal care, including inaccessible care settings and providers who lack knowledge about disability. Moving forward, more research and training are needed to address these barriers. More urgently, perhaps, in order to improve care and outcomes, providers need to do a better job of listening to and working with women with physical disabilities. 26, 27

If you want me to talk about my disability or to explain something, then you should ask me. Don’t just decide for me (Heather).

Disclosures

The author has no conflicts of interest to declare.

Prior presentations

Some of the findings in this paper were presented at the Association of Ontario Midwives’ 32nd AGM and Conference (May 2016), the Society of Obstetricians and Gynecologists of Canada 72th Annual Clinical and Scientific Conference (June 2016), and the American Public Health Association 144th Annual Meeting and Exposition (October 2016).

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