bodywork in which women must labour (literally) in order to maintain a body that is in line with normative feminine ideals (Dworkin and Wachs, 2004, p. 114; Nash, 2011, 2012c).

Participant-produced photographs invite us into a world of experiences and emotions in post-pregnancy that is normally concealed from view. The photographs that my participants took of themselves are valuable because they stand in contrast to popular representations of post-pregnancy. It was often the mundane images of track pants, barren wardrobes, and self-portraits in a bathroom mirror that provided the most unexpected insights into women’s transitions to motherhood.

Acknowledgements

Thanks to Eliza Burke and anonymous reviewers for feedback on this chapter.

Notes

1. The headless photographs may be attributed to the public nature of the website and the need for anonymity.
2. The questions that spell the acronym SHoWeD include: ‘What do you See here? What is really Happening here? How does this relate to Our lives? Why does this situation, concern, or strength exist? What can we Do about it?’ (Wang, 1999, p. 189)
3. ‘First-time mother’ or ‘new mother’ refers to participants who gave birth for the first time during the course of the study.
4. ‘Experienced mother’ refers to participants who already had children.
5. Australian colloquial term for tracksuit pants.
6. AU size 16 is equivalent to UK size 14 or US size 12.
7. AU size 14 is equivalent to UK size 12 or US size 10.

8

‘My Doctor Told Me I Can Still Have Children But ... ’: Contradictions in Women’s Reproductive Health Experiences after Spinal Cord Injury

Heather Dillaway and Catherine Lysack

Introduction

Women who have sustained a traumatic spinal cord injury (SCI) are sexually active, menstruate, become pregnant, carry healthy babies to term, have a range of childbirth experiences, use birth control, experience menopause, and have the same risks for reproductive diseases, illnesses, and conditions as able-bodied women. In other words, disabled women can have full reproductive lives. Yet we know relatively little about how women with SCI think about and experience ‘normal’ reproductive processes within the context of a permanently impaired body. Using data from 20 in-depth interviews with US women with SCI, this chapter describes the impairment-related contexts and social barriers that women with SCI confront in relation to their reproductive capacities. As the data show, knowing only that disabled women are diagnosed as ‘capable of getting pregnant’ or that they have unique health conditions after SCI tells us little of their lived experiences of reproduction. Our data reveal that the everyday experience of reproduction for a woman with an SCI is much more complex and uncertain than her ‘normal’ reproductive capacity might suggest.

Women and SCI

The focus on women’s reproductive issues after SCI is relatively new, in part, because SCI primarily happens to men. Approximately 270,000 individuals in the US currently have a SCI and an estimated 12,000 new injuries occur each year; however, 81 per cent of all injuries occur to males (National Spinal Cord Injury Statistics Center [NSCISC], 2013).
Approximately 70 per cent of SCIs occur to males worldwide, so women have a greater percentage of SCIs outside of the US (Rutberg et al., 2008). SCI is a devastating injury (Dijkers, 2005); some persons lose the ability to use their legs and lower body (paraplegia) while others lose this ability from the neck down (tetraplegia). Complete or partial motor paralysis necessitates lifelong wheelchair use and coping with a range of serious medical complications (Jensen et al., 2007). In effect, they must deal with the impairment and the physical effects of the impairment at the same time as the social barriers created by an ableist society that defines their bodies as ‘abnormal’ (Hughes and Patterson, 1997; Morris, 2001; Shildrick, 2002; Thomas, 1999).

Furthermore, women with SCI must confront their ‘double disadvantage’ of being women and disabled (Deegan and Brooks, 1985; Lloyd, 2001; Shildrick, 2002; Thomas, 1999; Wendell, 1996), facing prejudice and discrimination because of both social locations. For instance, disabled women are often stereotyped as ‘asexual', 'celibate', 'non-reproductive', or 'infertile', and not mothers (Becker et al., 1997; Nosek, 2000; Welner, 1999; Wendell, 1996). Sexual beings and mothers are assumed to be able-bodied while disabled bodies are assumed to be broken, childlike, and incapable of 'normal' activities (Wendell, 1996; see also Shildrick, 2002). This has serious consequences for disabled women's health. McCoil (2002) describes the health challenges facing women with SCI as a precarious ‘house of cards’. The most serious problems include a lack of primary and preventative health care in basic areas of reproductive health (e.g. pelvic exams, Pap smears, mammograms). The reasons for this include physicians' lack of knowledge about the impact of impairments on reproductive health (Reitiz et al., 2004), and a lack of sensitivity to women's health needs (Becker et al., 1997; Brandeis, 2003). Kaplan (2006) details how even a simple gynaecologic exam may be difficult to obtain because many physicians will never have (or, rather, assume they will never have) patients with disabilities in their practice and lack the appropriate office equipment or staff.

Unique reproductive health experiences?

Many questions remain about how disabled women make decisions about reproductive health within a context of limited medical knowledge and public stereotypes. There is some evidence that women with SCI face higher risks in pregnancy and delivery because of their higher risk of diabetes and high blood pressure (Nosek et al., 2001); thus some impairment-related contexts may shape reproductive experiences. The rates of forceps use, vacuum extraction, and caesarean section are also higher for disabled women, but data are largely anecdotal (Jackson and Wadley, 1999). It is unclear why these interventions are used more often with disabled women, but the reasons may be related to doctors' lack of knowledge about how to deal with disabled birthing bodies. In addition, a temporary period of amenorrhea is probable immediately after SCI, but we do not know how this amenorrhea affects disabled women's fertility (DeForge et al., 2005; Dillaway et al., 2013). DeForge et al. (2005) published the largest systematic search of the literature on fertility to date. They found that no study between 1996 and 2003 focused on the fertility of women with SCI – all focused on men. Furthermore, there is a dearth of research on disabled women's everyday experiences of fertility, and women's actual contact with doctors, doctor's offices, and lay individuals about their reproductive capacities and reproductive health care. We also rarely hear the voices of disabled women as they experience fertility/infertility.

Existing research on women's reproductive health after SCI is often written in response to myths about the 'non-reproductive' and 'asexual' nature of disabled women. For instance, much of the existing research has simply argued that women can still become pregnant after SCI (see American Association of Clinical Endocrinologists [AACE], 2006; Welner, 1999). Other research seems to be generated purposely to inform health care providers about special screening and treatment issues that arise from the effects of physical impairment (e.g. bladder management, labour management, osteoporosis, cardiac problems, or lack of sexual feeling) or the risks of particular birth control methods (DeForge et al., 2005; Estores & Sipski, 2004; Nosek, 2000; Welner, 1999). This research reinforces the definition of women with SCI as different and 'abnormal', and stands in contrast to research that documents the 'normality' of women with SCI (Shildrick, 2002). Thus, a tension exists in this small body of literature: Do women with SCI have 'normal' or 'abnormal' reproductive health experiences? Overall, we know little about the embodied experiences of reproduction among disabled women (Turner, 2001). We also know little about how a 'normal'/ 'abnormal' dichotomy might limit disabled women's reproductive options and experiences (Shildrick, 2002). By focusing on their 'difference' alone, we forget that disabled women are living full reproductive lives that are affected but not completely determined by their physical impairments (Shildrick, 2002). The purpose of this chapter is to address these gaps in knowledge, drawing on in-depth interviews with US women with SCI.
Conceptual framework

The literature on the sociology of the body and within disability studies can be useful in expanding how we conceptualise disabled women's reproductive experiences. Merleau-Ponty (1962, p. 206) has observed that the 'lived body' is a location of meaning and identity as well as a material entity: 'We are in the world through our body, and ... we perceive that world within our body.' While the objective, physical body can be an object of intellectual inquiry, so can the 'subjective body of personal experience' and also body image as individuals negotiate 'identities, experiences and social relationships' while living in with particular bodies (ibid.). Turner (2001, p. 253) has also argued that it is necessary to examine the production of bodies within society - i.e. the social rules, constraints, and barriers that structure embodied experiences. In looking at the latter, Turner suggests that this is where we find that bodies are 'vulnerable', 'contingent', and socially created (not 'natural') (ibid.).

The disability studies literature expands on sociological approaches to embodiment by 'separating out' "impairment" (that is, the functional limitations of our bodies and minds) from "disability" (that is, the disabling barriers of unequal access and negative attitudes) (Morris, 2001, p. 2). Hughes and Patterson (1997) and Thomas (1999) further remind us that we need to pay attention to embodied experience of impairment while also paying attention to the social barriers (inequalities) associated with impairment. As Thomas (1999) explains, impairment is not a fixed property of a person but, rather, a 'social relational' entity, which means that how one lives with a physical impairment is more telling about what an impairment truly is for a person than any material reality of the body. Societal definitions of impairment matter in shaping disabled women's embodied experiences (Shildrick, 2002).

Shildrick (2002, p. 81) has proposed that physically impaired bodies represent an openness and vulnerability that western discourse insists on covering over - a 'monster' that 'haunts' us but can never be completely 'expelled'. Disabled women's bodies, she argues, are liminal and exist at the nexus of 'normal' and 'abnormal' (ibid.). Women's reproductive bodies have been similarly theorised through a framework of monstrosity and liminality in their blurring of corporeal boundaries. Bodies that lack dexterity control, that use physical space differently than socially expected, that leak, or that grow and produce life are all suspicious in their ability to cross over socially constructed boundaries of what the self or subject is.

Method

This chapter is underpinned by a feminist disability perspective. A feminist disability perspective emerges from the premise that disabled women are both women and disabled persons and, therefore, both gender and disability shape their thoughts and experiences (Deegan and Brooks, 1985; Lloyd, 2001; Wendell, 1996). Disability can shape the way in which women might experience gender, and vice versa, in that gendered meanings and experiences are filtered through the context of having a disability as much as the meanings of and experiences of disability are filtered through their gendered social context. In line with Shildrick (2002), we steer away from a definition of the disabled gendered body as 'abnormal' or 'monstrous' (when compared to male, 'able', or non-reproductive bodies) and instead allow disabled women to define their own lived experiences of reproduction. Nonetheless, we acknowledge the importance of the 'normal'/ 'abnormal' dichotomy in defining women's embodied experiences of disability and reproduction, and seek to understand how and when disabled women's reproductive experiences both accommodate and disrupt this dichotomy.

Second, we align ourselves with feminist scholarship that has expanded conceptualisations of reproduction (Ginsburg and Rapp, 1991; Rich, 1977). In postmodernity, women's 'reproductive' experiences include more than just conception, contraception, pregnancy, and birth. Reproductive experiences also include: menstruation and menopause, contemplation of fertility, use of and problems with contraceptives, negotiating body image (e.g. asexual and non-reproductive images in the case of disabled women), and making informed choices and seeking health care in any of these instances. We are also of the view that reproductive experiences must be viewed as embodied (Shildrick, 2002; Turner, 2001) and social (Ginsburg and Rapp, 1991). In this chapter, we discuss disabled women's interactions with doctors, their feelings about being able to get pregnant, and their contact with asexual, non-reproductive, and non-mother images associated with disability, to continue broadening definitions of 'reproductive' experiences.

Participants

The sample was recruited from an earlier study on independent living after SCI in Detroit, Michigan, USA ('Community living after spinal cord injury: Models and outcomes'; R01#1HD43378, funded by the National Institutes of Health; PI: Lysack). All participants granted permission to be contacted for future research and, therefore, the list of participants
from the earlier study became the sampling frame for the current study. After multiple attempts, we contacted 27 of the 44 women (61 per cent) who participated in the original study by telephone. Twenty-four (88 per cent) agreed to participate in our study on ‘reproductive health and SCI’, and we completed in-depth interviews with 20 women (83 per cent). Ethics approval was secured for the follow-up study before any data were collected and informed consent procedures were followed according to university regulations. Participants received USD$35 at the completion of the interview.

Sample characteristics
Participants’ average age was 46 years (range: 27 to 66 years), and they had been injured for 19.5 years on average (range: 3 to 41 years). Eight of the women (40 per cent) never married, seven (35 per cent) were married, with the remainder divorced or separated (5 or 25 per cent). All women described themselves as heterosexual. Eleven women (55 per cent) had paraplegia, and nine women (45 per cent) had tetraplegia. Automobile accidents were the cause of injury for half of the sample (n = 10), followed by violence (n = 4), pedestrian-automobile crashes (n = 2), falls (n = 2), a sporting accident (n = 1), and an acute spinal tumour (n = 1).

The women in this study had a broad range of reproductive health experiences. Overall, 17 of the 20 women (85 per cent) reported having menstrual experiences at some point after their injuries, although only seven were still menstruating at the time of the interview (because of the ages of women in the sample). Fifteen of the women (75 per cent) reported a pregnancy at some point in their lives, and six women had healthy babies after their injury. Three women lost pregnancies at the time of injury. Six women reported using some form of birth control post-injury. Most women (65 per cent) were in their late reproductive years because they were aged 35–45 at the time of interview, or at the age when the endocrine, biological, and clinical features of perimenopause commence (Freeman et al., 2001). Thus most of the women were looking back over decades of reproductive health experiences pre- and post-injury (see Dillaway et al., 2013).

Data collection
Each woman participated in one face-to-face interview, lasting two to three hours on average. All interviews took place in the women’s homes. We employed a feminist phenomenological interviewing style (Brown et al., 2006; Creswell, 1998; Reinharz, 1992; Rubin and Rubin, 1995), meaning that we kept our interviews conversational and ‘loose’. A feature of feminist phenomenological interviewing is that the interviews are guided by the participant. However, probing questions arose from interviewees’ narratives after general questions were asked (e.g. ‘Tell me about X’) (Reinharz, 1992, p. 21; see also Creswell, 1998). All interviews included questions about overall health and physical functioning (to explore the effects of impairment), reproductive health attitudes and experiences, contact with health care providers, and reproductive health-seeking behaviours post-injury.

Two research staff conducted the interviews (Lysack and a research assistant). Together, they had seven years of experience conducting interviews with women with disabilities and they received additional training about women’s health interviewing from the first author. Training ensured that key topics were recognised, probed, and handled sensitively. Sometimes the best data came at the end of the interviews, when women felt comfortable enough to speak unprompted about reproductive health issues that were important to them (e.g. desires for children, sexual relationships, childbirth experiences, patient-doctor interactions, etc.).

Data analysis
A computerised database was used to track data collection, transcription, coding, and analysis. The interviews were transcribed verbatim and qualitative software (QSR NUD*IST) facilitated coding and data analysis. The two interviewers randomly checked 5 of the 20 transcriptions each against the tape-recordings for accuracy and found a nearly perfect correspondence. To analyse the data, we followed the constant-comparison method (Glaser, 1978). Analysis began with a close reading of all 20 transcripts by both authors. In a first round of coding the authors reached 100 per cent agreement in defining which interview conversations were about ‘reproductive’ experience. In the second stage of coding, we organised the data into three general categories: (a) ‘the ability to get pregnant’; (b) ‘feelings about reproductive capacity’; and (c) ‘unique reproductive contexts’. We also reached 100 per cent agreement in this second stage. Data within these three categories were compared and contrasted to identify similarities and differences among interviewees, and to find nuances within the grouped data. Early findings were shared with one woman in the study; discussions with her helped us to finalise our analysis. While our systematic coding and analysis procedures help to support our interpretations of the data, the ultimate validity and trustworthiness of the data must be judged within the wider context of the rich descriptions offered (Creswell, 1998; Glaser, 1978).
The results reported below are the interpretation of the women’s experiences by the research team, although every effort has been made to provide first-hand accounts and verbatim descriptions of women’s lived experiences. Throughout this chapter, we use pseudonyms to protect participant anonymity and confidentiality. Furthermore, we focus only on a selection of participants in our findings in order to provide continuity in the stories that we share.

Results

In this section we illustrate how women had to respond to varying assessments of how ‘reproductive’ they were and whether they, in turn, deserved a full range of reproductive health care opportunities in light of their impairments. Sometimes they also faced the effects of impairment but, for the most part, reproductive opportunities were shaped by social and not impairment-related barriers. Ultimately these women found themselves in a contradictory space as they led (or even contemplated) their reproductive lives.

‘You can still get pregnant’

Women in our sample were not stereotyped as non-reproductive by their physicians; in fact most were told by doctors that ‘they could still get pregnant’. Terry (two children before injury) discussed what she learned from doctors post-injury:

That’s what I learned in the hospital: “(a) You can get pregnant again; (b) If you take birth control you will die; [and] (c) You’ll never walk again.” They told me that 3 times a day, all day long, and they wondered why I was crying.

Damita (one child after injury) reported a similar conversation with a doctor.

I know one of my greatest concerns right after my injury wasn’t so much about walking but whether I could be a mother or not ... I remember asking the doctor, “Could I still have children?” To me that was far more important than being able to get back on my legs .... The doctor told me that I could still have children but ... I was still in denial about that for 14 years ... Yeah, he said, “If you’re going to engage in something like that (sex) you need to protect yourself” ... even with that, I figured [that] because I couldn’t feel the part, it just didn’t work ... [When] I found out I was pregnant, that’s when it really sunk in ... he was right!

Prompted or unprompted, doctors shared information about reproductive capacity very quickly after injury and characterised women as having the ‘choice’ to get pregnant. In general, impairment was not defined as limiting reproductive capacity; as material entities, their bodies were defined as ‘normal’. There were exceptions to this, of course. Candace (two children after injury) talked about how her doctor never mentioned the possibility of pregnancy after injury. She attributed this to the fact that her injury happened 40 years prior to the interview (in 1968): ‘It wasn’t really talked about by the doctors at that time ... [Now women can say] “You know what? I want to have a child, so I’m going to do this”.’ On the whole, women reported that doctors were supportive of their desires to have children (or not) after Injury.

Am I ‘normal’?

As indicated by the extracts above, women sometimes thought that doctors were wrong about their reproductive capacity, or that they were not ready to hear information about reproductive health in the aftermath of their injury. Thus living a reproductive life was not always as easy as merely deciding to get pregnant and having a child. The embodiment of impairment involved thinking about oneself as ‘abnormal’ and questioning ‘normal’ reproductive capacity at least at the start; starting to think about oneself reproducitively after injury (within the context of a new and permanent disability) took time.

Terry also discussed how health care providers defined the return of menstruation after her injury positively, but it was hard for her to see it positively because in the moment she did not see why others were so ‘happy’ about a ‘normal woman’s function’.

When they [her periods] came back, [small laugh], the nurses at the rehab hospital cheered. ... They were so excited, [they said,] ‘That’s a normal woman function and that’s fabulous!’ I went, ‘Okay, this was the only part about this whole accident that was actually seeming good. Will you stop cheering ‘cause I’m crying!’ They cheered up and down the hallway of this hospital.... I’m like, ‘You guys need to get a life, because I’m not seen’ what is happy about this’.

Despite reactions from medical providers, Terry felt that she was embarking on a different ‘normal’ than the ‘normal’ that able-bodied women
experience, and she did not want to be compared to ‘able-bodied’
women. The ‘normal’ versus ‘abnormal’ dichotomy activated by the reac-
tions of hospital staff to Terry’s menstruation led to mixed emotions –
she did not know how to think about menstruating as a disabled woman.

Kendra (one child before injury and pregnancy loss at time of injury) also
found it difficult to think of herself as both reproductive and physi-

cally impaired, and decided she would rather have a hysterectomy than
deal with the logistics of both.

I’d love [a hysterectomy]. I said, ‘Will you pull out my uterus?’ They

said: ‘No’. [Interviewer: Were they concerned that if they took your ovaries

you’d get osteoporosis?] Yep ... I’m taking Posamax. I don’t like my

periods, they’re messy ... I don’t like it, I want nothing to do with it,

okay? But they won’t let me have my uterus pulled out.

Kendra wanted to end the hassle associated with menstruation but she
also wanted to limit her risk of pregnancy. Within the context of her

disability she did not want to manage ‘normal’ reproductive processes

anymore. Thus doctors were sometimes more positive about ‘normal’

reproductive function than the women themselves. Unprompted, nine

women in our sample (45 per cent) specifically mentioned that they

thought of themselves as ‘normal’ and ‘healthy’ in relation to their

reproductive health, and others (n = 6) also acknowledged their ability
to reproduce (even when they did not refer to themselves as ‘normal’).

Yet it still took time for women to contemplate how their experience of

living with an impairment might shape their reproductive lives. While

acknowledging themselves to be reproductive like any other woman

(and activating the ‘normal’ versus ‘abnormal’ dichotomy as they talked

about themselves), embodying reproduction in the face of impairment

was complicated and confusing at times (see Dillaway et al., 2013).

Having a body that was capable of ‘normal’ reproductive functions was

less important than what it meant to live with disability every day and

simultaneously engage in reproduction.

Unique reproductive contexts

Warnings often came with doctors’ discussions of participants’ abili-
ties to get pregnant as well. For example, doctors wanted to make sure

that Terry knew that she could not use hormone-based birth control

(e.g. the pill) because of the risk of blood clots. Similarly, Damita’s doc-
tors wanted to make sure that she understood that a lack of feeling in

her pelvic region did not preclude pregnancy. Kendra’s doctors would

not contemplate hysterectomy post-injury because of her higher risk

of osteoporosis; instead they offered her Depo-Provera (and eventually

a tubal ligation) to meet her desires for non-reproductive status.

Even though many women in our sample led full reproductive lives

post-injury, their reproductive options and ‘choices’ were often con-

strained by impairment-related contexts.

Further, despite being told by doctors that they were ‘normal’ and

capable of having children, our interviewees faced considerable obstacles when

attempting to access reproductive health care. While some barriers were

structural (e.g. exam tables that could not accommodate disabled bodies), a

large proportion of barriers were attitudinal (e.g. doctors and office staff

sometimes chose to not make the effort to examine disabled women’s

bodies). These social barriers left women struggling to make sense of their

own identities and reproductive health care options: in theory they were

‘normal’ women in need of reproductive health care but they experienced

significant problems of access. Kendra brought her daughters to her gynaec-

ological appointments (to lift her out of her wheelchair and to hold her

legs while she was on the exam table). She understood that doctors would

not accommodate her impairment-related needs. Unfortunately, some

women in the study opted out of regular gynaecological care because of

these types of obstacles and others acquiesced to incomplete or substan-

tial health care. In these cases, structural and attitudinal barriers interacted

with the effects of impairment to simultaneously shape disabled women’s

reproductive ‘choices’ and challenges.

Questionable mothers?

Unprompted, four women in our study reported interactions that reaf-

firmed negative attitudes towards disabled mothers. Terry contemplated

having a third child (what would have been her first child post-injury)

but she was worried about the physical risks of pregnancy after her

injury and therefore thought about adoption. Eventually, Terry de-

cided to forgo additional childrearing altogether because disabled women are

often seen as questionable (and unfit) mothers.

[People said, ‘There is no way that you would ever get a [child]

because you would not qualify’. Because I’m in a wheelchair they

would not deem me as an appropriate parent. And so I’m not a
decent parent for the two kids (born pre-injury) that I have? ... It
didn’t matter that financially we could have had [a third child]. We

have the room ... [W]ho would ... help me be able to convince these

idiots that I would be a good parent? ... I would have been desperate}
if I would have thought that I no longer, you know, that somebody would say I couldn't be a mother.

Damita also talked about lay attitudes towards disabled motherhood.

[My doctors have been pretty thorough in explaining to me, you know, about having children and that you can still do that even in spite of your injury. But it's not so much that, it's about how people have responded to the fact ... that I have a child ... That I gave birth ... I think the hardest thing (her emphasis) that I've had to come to grips with is that people look at me as an asexual being ... And I just think it's a common response to women with disabilities ... For example, you and I could be walking down the street and my kid is with me and they'll probably think that my kid is your kid. You know, 'cause they think, 'How could she have sex?' [Interviewer: Do people ever say that to you?] It's implied ... I think sometimes we're viewed as half-people, not whole individuals. Or, as children. You know, as if we're not capable of doing things.

In this extract, Damita described her surprise and anger in response to individuals who view disabled women as asexual or unfit mothers. Like Damita, participants found themselves trying to negotiate contradictory attitudes towards their impairments in the context of reproduction. From one perspective, it was acknowledged by doctors that participants were sexual beings who were able to conceive like other 'normal' women. From another perspective, women were confronted with negative public attitudes in relation to their reproductive capacities. Finally, participants also faced impairment-related situations that made for frustrating interactions with doctors and hospital staff. For example, staff had to adapt their medical interventions to accommodate the physical impairments of women with SCI and the women themselves had to learn how to 'be' women with irrevocably altered bodies. While we do not have data on the reasons why the non-mothers in our sample chose not to have children post-injury, or why some women in our sample did not have more children after injury, we suspect that the simultaneous weight of impairment-related contexts and social barriers may have limited their reproductive options.

Discussion and conclusions

The majority of women with SCI in our study were told by doctors that 'they could still get pregnant'. Yet while doctors reminded women of their 'normal' reproductive status, they also warned them about the effects of their impairment on reproductive 'choices'. Further, when women in our study tried to seek reproductive health care, structural barriers in medical office settings and doctors' unwillingness to deal with their disabled bodies meant that accessing high quality reproductive health care was difficult. Thus medical providers left women in a contradictory space, effectively defining them as both 'normal' and 'abnormal' in their reproductive and disabled statuses. Women struggled with having a body capable of reproducing and living with a disability (that either limited reproductive options or created structural and attitudinal barriers to this reproduction). Women had to actively work through their own thoughts about their impairment and reproductive capacity, their embodied experiences of reproductive activities, others' attitudes towards their bodies and their potential motherhood, and the effects of impairment on their reproductive 'choices' and health care. While the impairment consequent to SCI might not limit reproductive opportunities and options, our data reveal that the everyday experience of being a woman with an SCI was much more complex and uncertain than their 'normal' reproductive capacity might suggest.

Additionally, some interviewees were exposed to asexual and non-reproductive images of themselves in other non-medical, public interactions. Women were aware of their physical impairment and what it meant to live with SCI but they were not always prepared to justify their existence to a (non-disabled) public that continues to view disability as not only 'difference', but also 'deficit' (Finkelstein, 1996; Hughes and Patterson, 1997; Shildrick, 2002; Thomas, 1999). Participants reported that their most significant struggles were in 'public' spaces, either around unsupportive medical staff or around lay individuals who repeatedly challenged their legitimacy as reproductive beings. Thus the barriers participants faced in leading reproductive lives were overwhelmingly attitudinal or social-relational in nature. Even their individual experiences of physical disability were socially created in part (and not completely determined by the physical impairment itself), because of medical providers' lack of understanding of disabled women's needs.

It is important to note that almost a third of our sample bore children post-injury and many women made 'choices' post-injury about menstruation, birth control, sexual relationships, hysterectomies, and other reproductive procedures. Thus limitations on their reproductive 'choices' did not prevent them from living out reproductive lives. Nonetheless, some interviewees never had children, and this may be because they were discouraged from realising new reproductive experiences after
injury. Others were apparently finished having children before injury and may have felt the impact of disability on reproductive experiences less directly.

Reproductive experiences were not uniform across our sample and not all women experienced disability in the same way. Of the five women we quoted in this chapter, only Candace was tetraplegic. Terry, Damita, and Kendra were paraplegic. Paraplegic women may find it easier than tetraplegic women to navigate reproduction post-injury, because impairment effects are different; however, we cannot judge this from our current data. Moreover, it is beyond the scope of the chapter to discuss differences among interviewees in birth control use, respiratory problems, urinary tract problems, sexual function, motor control, etc. In this way, varying impairment-related conditions that women with SCI faced make it difficult to generalise our disability-related findings about reproductive experience. Some women in our sample were also more willing than others to battle with health care providers to access high quality reproductive health care and make possible the reproductive experiences they desired. Understanding why some interviewees felt a greater sense of ‘empowerment’ as they engaged in reproductive lives is extremely important if we aim to understand disabled women’s reproductive lives in full. On this front, there is still much to explore.

Disabled women in our study are not just the sum total of their impairments. However, these women experienced unique reproductive conditions and accessibility issues that were related to both physical impairment and the inability of non-disabled individuals and social institutions to effectively deal with disabled bodies. Shildrick (2002) has argued that all bodies (especially when they enter the ‘space of discourse’) do not fit with the norm, and this idea applies well to women’s reproductive bodies and disabled bodies. As the data show, a ‘normal’/‘abnormal’ dichotomy cannot sufficiently explain embodied experiences of disabled women’s reproduction (Shildrick, 2002). Knowing only that disabled women are diagnosed as ‘capable of getting pregnant’ or that they have unique health conditions after injury tells us nothing of their lived experiences of reproduction or the barriers they face.

On one hand, this study cannot be used to generalise about the reproductive experiences of disabled women (in that SCI is a very specific kind of injury and we interviewed a very small sample of women) or women in general. On the other hand, the lens we use in this chapter can help reframe how we think about all contemporary women’s reproductive lives. We explored how we might separate out women’s reproductive capacities and their related meanings from women’s embodied experiences of reproduction. We also highlighted the social barriers that particular groups of women might face in their reproductive lives. Our findings allow us to see how women think and feel and experience their reproductive bodies, as they navigate complicated social-relational landscapes related to both reproduction and disability. As reproductive ‘choices’ and challenges change across time and place, and bodily experiences expand for some and contract for others, scholars of reproduction should continue to complicate notions of both reproductive capacity and lived reproductive experiences. As this chapter shows, the ‘normal’ reproductive body is an empty concept in postmodernity.

Notes

1. We do not know whether the women who were successfully contacted differed from those who did not respond. We acknowledge that this is a possible sampling bias.
2. This is an ethnographic technique and we found it useful in our study since many of the themes in the data were unexpected; we undertook cross-interview comparisons to understand the nuances in our coded data.
3. ‘Member checking’ is a common method of establishing validity in qualitative research (see Creswell, 1998).
4. A prescribed drug used to treat and/or prevent osteoporosis.
5. A prescribed hormonal contraceptive that women receive as an injection every three months.
Reframing Reproduction
Conceiving Gendered Experiences

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