MOTHERHOOD AFTER SPINAL CORD INJURY: LACTATION, BREASTFEEDING, AUTONOMIC DYSREFLEXIA AND POSTPARTUM CONSIDERATIONS

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Abstract

Lactation dysfunction following spinal cord injury has been previously documented. However, the extent of lactation dysfunction and influence of spinal cord injury on breastfeeding ability and behaviour is not well understood. The research aim was to identify major barriers to lactation and breastfeeding related to spinal cord injury, specifically comparing injuries above and below the T6 spinal cord segment.

A retrospective survey design was used to evaluate breastfeeding barriers in an international cohort of women who gave birth following their spinal cord injury. In the pilot study, 52 women participated in two online questionnaires. The follow-up study evaluated 102 participants with one questionnaire. An expert panel of clinicians and mothers with spinal cord injury systematically developed and reviewed all questionnaires.

Exclusive breastfeeding duration significantly differed between women with spinal cord injury above versus below T6. Women with cervical spinal cord injury were less likely to breastfeed for at least 6 months (as recommended by the World Health Organization). Breastfeeding difficulties rated most severe were insufficient milk production and impaired milk ejection. Breastfeeding barriers also included autonomic dysreflexia (particularly with cervical and upper thoracic injuries), impaired access to the infant and balancing breastfeeding with personal care and tasks of daily living. A considerable proportion of women did not receive education specific to breastfeeding with spinal cord injury. Postpartum depression and anxiety were self-reported by this population at a higher incidence than is reported in the general population. The prevalence of self-reported postpartum depression was greater than prevalence of clinical diagnosis, indicating a greater need for early screening and postpartum mental health support.

This research provides novel insight into the breastfeeding barriers presented by spinal cord injury, which differ based on level of injury. Multidisciplinary care is recommended to address these barriers, which range from physiological (i.e. impaired milk production and autonomic dysreflexia) to psychological (i.e. postpartum depression) to fundamental functioning (i.e. functional independence and personal care) in order to improve the chance of successful breastfeeding. These findings provide the impetus for further research into motherhood after spinal cord injury to improve breastfeeding outcomes and quality of life for this population.

Lay Summary

Although spinal cord injury (SCI) is a devastating event, many women who sustain SCI go on to pursue motherhood. As women's health after SCI is particularly under-studied, no comprehensive source of knowledge exists on breastfeeding after SCI. The objectives of this project were to: 1) ascertain the specific challenges to breastfeeding that are consequential to SCI; 2) evaluate breastfeeding behaviour and quality of life outcomes in mothers with SCI. The present project involves the largest cohort study to date providing key contributions on motherhood and breastfeeding after SCI, including data demonstrating the differing experiences and needs of mothers based on level of SCI. In addition to supplementing the sparse body of knowledge on this topic, this work provides a foundation for future research and evidence-based clinical practice to improve breastfeeding outcomes and quality of life for mothers with SCI and their families.

Preface

All of the work presented henceforth was conducted in two sites: 1) Autonomic Laboratory at the International Collaboration on Repair Discoveries (ICORD), University of British Columbia and 2) Karolinska Institutet, Stockholm, Sweden.

This project, entitled "Motherhood after spinal cord injury: lactation, breastfeeding and autonomic dysreflexia" was approved by the University of British Columbia's Behavioural Research Ethics Board (certificate # H16-02495) and the Karolinska Institutet Research Ethics Board (certificate #2017/1069-31/1) All participants provided written informed consent according to the Helsinki II Declaration using an online informed consent form on the first page of each questionnaire.

This thesis is divided into 6 chapters. Chapter 1 is a narrative literature review of the current body of scientific knowledge regarding lactation and breastfeeding after spinal cord injury.

Chapter 2 details the pernicious effects of autonomic dysreflexia in a case study of a woman with high-cervical spinal cord injury. It has been published as Lee AHX, Phillips AA, Squair JW, Barak OF, Coombs GB, Ainslie PN, Sarafis ZK, Mijacika T, Vucina D, Dujic Z, Krassioukov AV. Alarming blood pressure changes during routine bladder emptying in a woman with cervical spinal cord injury. *Spinal Cord Series and Cases.* 2017 Dec 28;3(1):17101. I was responsible for data collection, analysis and manuscript composition. Phillips AA, Squair JW and Vucina D contributed to data collection. Phillips AA, Dujic Z and Krassioukov AV were involved in early stages of concept formation. Krassioukov AV was the supervisory author on this project. All authors contributed to manuscript edits.

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List of Abbreviations

AD	autonomic dysreflexia
AIS	American Spinal Injury Association (ASIA) Impairment Scale
BF-SES	Breastfeeding Self-Efficacy Scale
MCS	Maternal Confidence Survey
MDD	major depressive disorder
OH	orthostatic hypotension
PAWB	Positive Affect & Wellbeing
PPA	postpartum anxiety
PPD	postpartum depression
PRAMS	Pregnancy Risk Assessment Monitoring System
PRL	prolactin
QOL	quality of life
SBP	systolic blood pressure
SCI	spinal cord injury
SNS	supplemental nursing system
WHO	World Health Organization

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To my parents, I extend special thanks for their unwavering support and belief in me.

Finally, thank you to all of the participants of these studies who provided their time and valuable insight. I truly hope that this research will improve the quality of life for women everywhere with spinal cord injury.

Dedication

To my family

1 LACTATION AND BREASTFEEDING AFTER SPINAL CORD INJURY: A REVIEW

1.1 Introduction

Spinal cord injury (SCI) afflicts 755 individuals per million North Americans, with male patients outnumbering female patients at a ratio of 3.8 to 1.[1] As the majority of patients sustain a traumatic SCI when they are of childbearing age, reproductive health after SCI is an important topic to address. However, female reproductive health after SCI is vastly understudied, despite the fact that an increasing proportion of patients are women.[1] Female fertility is not typically impacted after SCI, and rates of fertility and miscarriage are reported to be comparable between the general population and women with SCI.[2] Complications during and after pregnancy can occur, such as an increased risk of urinary tract infections or thromboembolism, but timely management can successfully result in healthy outcomes for mother and baby.[3–5] As acquired SCI has not been found to increase the risk of congenital malformations, mothers with SCI are capable of giving birth to and raising healthy infants with the appropriate clinical care and support.[6]

A major component of optimizing infant growth and health outcomes is breastfeeding, which provides significant health benefits to both mother and child. However, success in breastfeeding may be especially difficult to accomplish for mothers with SCI due to physiological factors. These challenges are compounded by the lack of research and evidence-based standard practice guidelines regarding breastfeeding after SCI. The paucity of research in this area directly affects clinical care, maternal outcomes and patient satisfaction: a qualitative study of 17 mothers with SCI in Switzerland reported difficulties with availability and accessibility of SCI-knowledgeable providers, accessible facilities and education programs.

Women furthermore stated a lack of satisfaction with the care process which stemmed from poor integrated care and the unmet need for detailed information about motherhood and SCI.[7]

To facilitate breastfeeding success, enhance clinical care, and improve health outcomes for women with SCI and their infants, it is critical to first examine the existing body of knowledge and identify gaps. The aims of this review are to discuss the prevalence of breastfeeding and lactation in women with SCI, to highlight SCI-related challenges, and to make recommendations for future research in this area based on the current body of knowledge.

1.2 Methods

1.2.1 Information sources and search strategy

In this stage of the research project, we undertook a comprehensive narrative literature review of the current scientific body of knowledge regarding lactation and breastfeeding with SCI. A target search was performed using any combination of the following search terms: "lactation, breastfeeding, spinal cord injury and physical disability". The databases searched were PubMed, Web of Science, Medline, Scopus/Embase, Cochrane Central Register for Controlled Trials, Cochrane Database of Systematic Reviews, Clinicaltrials.gov, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and the Informit Health Collection from inception through January 16, 2018. For all primary and review articles, references were screened to ensure that no relevant citations were missed in the original key word search. Returned records were exported to RefWorks, a reference management software, and duplicates were removed. A second search was performed with the keywords "galactorrhea" and "spinal cord injury" and five novel studies were added.

1.2.2 Study selection

Three reviewers independently screened record titles and abstracts, and then followed with full-text screening for eligibility (Figure 1.1). Exclusion criteria included articles that were not in English, not peer-reviewed, letters of correspondence and non-human studies. Relevant articles were those which discussed lactation and/or breastfeeding experiences and barriers among women with SCI. Study methodology could be quantitative, qualitative or mixed-method. Because of the paucity of published studies in this area, a wider eligibility was sought and included randomized controlled trials (although none were found), meta-analyses, narrative or systematic reviews, experimental trials, observational studies, cohort studies and case reports.

1.2.3 Data extraction and synthesis

Data were extracted by three reviewers and tables were used to record study outcomes, participant characteristics, breastfeeding rates, and information pertinent to SCI-related barriers to breastfeeding. The data were summarized, and themes were generated from the existing literature to categorize the findings.

1.3 Benefits of breastfeeding

Due to the well-documented benefits of breastfeeding for both mother and child, breastfeeding is touted as the optimal method of infant feeding by international standards. It is currently recommended by the World Health Organization (WHO) to exclusively breastfeed infants for the first 6 months of life followed by breastfeeding for up to 2 years of age or beyond as a complement to solid foods.[8]

Children who are breastfed exclusively for at least 6 months receive significant short-term and long-term benefits compared to infants who are either not breastfed or who are breastfed for a short length of time (i.e. 3-4 months, even if this period of exclusive breastfeeding

is followed by breastfeeding mixed with formula). For example, exclusive breastfeeding is associated with improved cognitive development, reduced early mortality and reduced risk of childhood infections including gastroenteritis and respiratory tract infections.[9,10] With respect to the WHO recommendations, infants exclusively breastfed for at least 6 months exhibited lower rates of morbidity due to gastrointestinal infection than infants who were breastfed non-exclusively for 3-4 months.[11] In addition to reduced risk of infection during infancy, increased breastfeeding duration is associated with improved motor skills, sociability, and adaptability in young children.[12]

The benefits of breastfeeding extend into adolescence and adulthood: those who were breastfed as children exhibit reduced adult risk for obesity and diabetes (type 1 and type 2).[13,14] This may be connected to the association found in those breastfed as infants with lower levels of total cholesterol and low-density lipoproteins in adulthood, suggesting long-term benefits for cardiovascular health.[15]

Multiple epidemiological studies have determined significant maternal benefits, including bonding in early infancy, enhanced maternal sensitivity (i.e. ability to perceive and interpret infant cues and needs) and higher quality relationships with their babies.[16,17] In fact, the incidence of postpartum depression in mothers has been associated with either not breastfeeding at all or early cessation of breastfeeding their infants.[14] Additionally, breastfeeding is associated with reduced relative risk of maternal breast and ovarian cancer, particularly as the duration of breastfeeding over the mother's lifetime increases.[18–20] It has previously been reported that mothers who breastfeed undergo greater postpartum weight loss and reduced risk of developing type 2 diabetes.[21]

1.4 Public health implications

For developed countries such as Canada, the United States of America (USA) and Australia, there is a considerable amount of evidence for breastfeeding-related risk reduction in a variety of pediatric diseases such as sudden infant death syndrome, necrotizing enterocolitis, and lower respiratory tract infections.[22,23] USA cost analysis for these diseases finds that 80% compliance with recommendations to breastfeed exclusively for 6 months would save the United States $10.5 billion and prevent 741 child deaths annually, or $13 billion and 911 deaths upon increasing to 90% compliance.[24] Similarly, current suboptimal breastfeeding rates in the United States are estimated to result in an additional $18.3 billion in maternal health care costs as well as excess cases of breast cancer (n=4981), hypertension (n=53,847) and myocardial infarction (n=13,946).[25] It therefore appears that suboptimal breastfeeding is not only a factor in increased child and maternal morbidity and mortality, but it is a public health concern that must be addressed given the potential economic burden.

1.5 Breastfeeding prevalence

In Canada, a high proportion of the general maternal population does plan to breastfeed. A Canadian national survey conducted by the Public Health Agency of Canada surveyed a representative sample of 6,421 women whose infants were 5-14 months old. Between 71.9-96.7% of participants intended to breastfeed their infant exclusively (with no other form of nutrition). These rates of intended exclusive breastfeeding differed based on the participants' home province/territory. Of all the participants, 90.3% of respondents initiated breastfeeding, and breastfeeding was maintained post-birth by 51.7% at 3 months and 14.4% at 6 months.[26,27]

There is less certainty on breastfeeding rates and experiences in the SCI population. To date, studies often have not investigated breastfeeding in relation to the level of SCI, nor have

separated women of all physical disability from those with SCI. It has been previously stated that 53% of mothers with disabilities breastfed compared to 77% of non-disabled mothers.[28] Furthermore, studies often utilize subjective, self-reported measures.

Although it is expected and shown that mothers with SCI or physical disability exhibit lower rates of breastfeeding, a few studies have also indicated successful experiences: Cross and colleagues' 1991 report of 16 women with SCI states that all women who chose to breastfeed were able to do so, although no indication was given on the number of women who attempted breastfeeding, relation to level of injury, duration or other parameters of breastfeeding success.[29] Another study in 1999 by Jackson and Wadley compared breastfeeding patterns in women who gave birth before and after SCI: of the women who gave birth prior to sustaining SCI (n=242), 28% breastfed for 4.1 months on average, compared to 11% of mothers who breastfed following SCI (n=68), for an average of 6.2 months.[30] The conflicting results presented in the current body of literature are compounded by the lack of an able-bodied control group in many studies, which instead utilize a convenience sample of women with SCI. These surveys report between 62-70% of their sample as being able to breastfeed, albeit without specification of how breastfeeding ability or success is defined. A compilation of all studies to date that examine breastfeeding prevalence in women with physical disability (with emphasis on SCI) is presented in Table 1.1.

Despite the lack of consensus as to how many women with SCI breastfeed and for how long, a multitude of complications to lactation and breastfeeding have been reported in this population. Certainly perceived and actual obstacles to breastfeeding exist for any mother, such as a reluctance to breastfeed in public, insufficient milk production, and physical factors like fatigue or sore/cracked nipples.[31] These complications may be exacerbated in a woman with SCI due to secondary issues of SCI. The common difficulties that arise repeatedly in case reports and

survey-based studies implicate a series of barriers that are specific to SCI, yet not comprehensively studied.

1.6 **Breastfeeding physiology**

Understanding breastfeeding challenges and complications that arise specifically from SCI requires a review of the physiology of breastfeeding. For the purposes of this review, lactation refers to the processes of milk production and ejection, whereas breastfeeding describes the act of feeding the infant. Successful breastfeeding thus comprises mechanical (e.g. holding and positioning the infant, latching onto the breast, nipple shape) and physiological (e.g. lactation, neurohormonal reflexes) elements.

Milk production requires the function of a complex of hormones produced by the anterior pituitary gland, including prolactin, adrenocorticotropic hormone, thyroid-stimulating hormone, and growth hormone.[32] Tonic inhibition of prolactin (PRL) production by dopamine from the hypothalamus suppresses milk production. Stimuli such as estrogen or suckling of the breast remove this tonic inhibition to allow milk production and ejection.[32] Though necessary for the onset and maintenance of milk production, PRL levels do not correlate well to the volume of milk produced once lactation has been established after several weeks.[33]

Milk ejection is also a neurohormonal process that is dependent on sensory afferent inputs from the breast (e.g. from suckling) and the stimulation of the hormone oxytocin, produced by the posterior pituitary gland. Oxytocin directly produces myoepithelial cell contraction, resulting in milk ejection from the mammary gland alveoli, and indirectly relaxes peripheral milk ducts to allow for the flow of milk.[34] This process is termed the “let-down” reflex (also called the “milk-ejection reflex” or the “oxytocin reflex”). Due to conditioning, the

let-down reflex may also be stimulated simply by touching, smelling, or even hearing the baby cry; conversely, stress can inhibit let-down.[33]

Milk production and ejection are modulated by somatic and autonomic control, with dependence on hormonal and neural stimulation. SCI can result in either partial or total loss of sensory information ascending from the nipples and breast to supraspinal structures. This impaired breast sensation can result in reduced afferent input to the pituitary gland. Lactation is then disrupted secondary to reduced PRL and oxytocin production. The breast is innervated by the fourth, fifth, and sixth intercostal nerves originating from T1-5 of the spinal cord (Figure 1.2). Therefore, injuries at or above T6 can result in reduced afferent input that disrupts the let-down reflex. After SCI above T6, lack of sympathetic nervous system feedback can also compromise myoepithelial cell contraction in the breast tissue which is critical for milk ejection.[35–37] Depending on sensorimotor or autonomic completeness of injury, mothers injured above T6 are also likely to have more significant mobility impairments, which add a mechanical obstacle to breastfeeding.

Maternal and infant benefits of breastfeeding have positive public health implications: exclusive breastfeeding is associated with lower health care costs, prevention of chronic disease and reduction of mortality caused by conditions negatively associated with breastfeeding. All mothers, including those with SCI, are therefore encouraged to utilize this method of infant feeding. To facilitate breastfeeding, it is imperative to outline the obstacles faced by women with SCI.

1.7 **Autonomic consequences of spinal cord injury**

It has been well-established that blood pressure profiles are often labile after SCI, with resting hypotension being quite common. For a mother with persistent low blood pressure,

fatigue may be exacerbated when holding her baby for an extended period to breastfeed. Orthostatic hypotension (OH) is also frequently experienced after SCI and is clinically defined as a decrease in systolic blood pressure of 20mmHg or more, or in diastolic blood pressure of 10mmHg or more, upon moving from a supine position to upright posture and is often accompanied by dizziness or light headedness.[38] OH is commonly experienced during 59-74% of orthostatic maneuvers in patients with SCI.[38,39] The incidence of OH presents a caveat: breastfeeding in the general population is associated with short- and long-term reductions in blood pressure and reduced rates of hypertension when compared to women who only used formula or non-exclusive breastfeeding (mix of formula and breast milk).[40–42] Women with SCI were previously encouraged to breastfeed with the intent of preventing the development of hypertension.[35] However, lowering systolic blood pressure may actually have deleterious consequences for individuals with SCI who typically exhibit lower baseline arterial blood pressure than able-bodied individuals and induce OH.[43]

Another major consequence of sympathetic dysfunction following SCI is Autonomic Dysreflexia (AD), a condition characterized by transient hypertensive episodes with elevation of systolic blood pressure up to 300mmHg and associations with increased cardiac event-related mortality.[44,45] AD commonly occurs in individuals with SCI at or above the T6 spinal segment, although it is known to occur with SCI above T10 as well. As AD is typically initiated by any painful or non-painful stimulus below the injury level, it is plausible that an infant's suckling, breast engorgement or mastitis would be sufficient triggers for AD in women with upper thoracic and cervical SCI. Currently no systematic reviews exist of AD incidence triggered by breastfeeding, and case reports on breastfeeding and SCI often do not delineate issues based on

level of SCI or ASIA Impairment Scale (AIS) scores, which provide a standardized method of neurological classification for SCI.[46]

Two case reports do document AD after breastfeeding in women with tetraplegia.[47,48] In the first case, a woman with tetraplegia (level and severity of SCI unknown) developed severe AD while breastfeeding her twins. This could only be resolved with a combination of breast pumping, bromocriptine to suppress lactation and diazoxide (a potassium channel activator used to treat acute hypertension in emergency situations).[47,49] The second case involved a woman with incomplete SCI at C6 (AIS C) who was able to breastfeed her daughter and enjoyed the experience; however she experienced AD at day 7 and day 10 postpartum, with the latter incident occurring during a breastfeeding session. Symptoms of AD were so profound that the episode resulted in loss of consciousness. Upon stopping breastfeeding, her symptoms and experiences of AD ceased, strongly implicating the act of breastfeeding as being the primary trigger, as no mastitis or nipple cracks were observed upon examination.[48]

1.8 **Abnormal lactation following spinal cord injury: complications and galactorrhea**

Lactation complications are often reported after high-level injury, most notably insufficient milk yield and abolishment of the let-down reflex (Table 1.2). Conversely, several case studies report that women with even high-level SCI experience let-down or are at least able to induce it psychologically using mental imaging or pharmacologically with galactagogues.[50,51] However, the use of medications that act as galactagogues is not evaluated in the vast majority of studies.

Interestingly, lactation unrelated to pregnancy status has also been exhibited. A small subset of individuals with SCI have experienced this nonpuerperal lactation (galactorrhea), which is defined as the spontaneous flow of milk from the nipple in the absence of parturition or

after six months postpartum in non-breastfeeding women.[52,53] No clinical trials or cross-sectional studies concerning galactorrhea exist to date, although several case series and a prospective study were found (Table 1.3).

In the acute phase of SCI, women may experience transient amenorrhea, in which menstruation temporarily ceases, potentially due to elevated PRL levels which inhibit production of follicle-stimulating hormone (FSH) and luteinizing hormone (LH).[54] Amenorrhea may be accompanied by galactorrhea: this is termed galactorrhea-amenorrhea syndrome and has also been observed following acute SCI.[55] The leading cause is hypothesized to be abnormal PRL overproduction (hyperprolactinemia), due to the observation that bromocriptine therapy for galactorrhea-amenorrhea syndrome normalizes (i.e. decreases) PRL levels which is then associated in those patients with resolution of galactorrhea and resumption of menses. Hyperprolactinemia may transpire if SCI occurs concurrently with trauma to the pituitary stalk, which may disrupt dopaminergic pathways that exert tonic inhibition on PRL production, or damage the posterior pituitary which is primarily responsible for PRL production.[56–58] The psychological stress of SCI and its secondary complications have also been proposed to augment cortisol, catecholamines and PRL as part of the biological stress response, and several studies attribute increased PRL to stress and trauma.[53,59,60]

Stress may play a smaller role in chronic SCI once the individual receives the supports needed to adapt to living with their injury. Instead, other factors such as stage of pregnancy are implicated. For instance, it has been suggested that women who are pregnant or in the early postpartum period are more susceptible to developing galactorrhea. During pregnancy, PRL levels are elevated due to increased estrogen production, PRL secretion and PRL receptor expression in the hypothalamic nuclei.[56,61–63] Women who have undergone menopause are also

purported to have less risk of hyperprolactinemia: in one study, hyperprolactinemia was found only in pre-menopausal women (n=9), compared to women in menopause (n=7). However, none of the 16 women in total experienced galactorrhea, even if PRL levels were high.[53]

Although lactation dysfunction in breastfeeding women is more severe with SCI at or above T6, it is unclear whether severity of galactorrhea is also SCI level-dependent. While Berezin et al. found that higher lesions (thoracic paraplegia: T4, T6) were associated with augmented PRL levels and longer, more severe galactorrhea, a more recent study found that hyperprolactinemia was not correlated with SCI level or galactorrhea. Instead, hyperprolactinemia was associated with younger (childbearing) age, compared to women in menopause.[53] Conflicting evidence is further presented in a case series comparing four women with thoracic tetraplegia. The two women with high-thoracic SCI (T3-AIS A and T6-AIS B) exhibited PRL elevation that did not immediately resolve for at least 15 months, despite discontinuing medications including metoclopramide (a dopamine antagonist). It is possible that the patients' refusal of further treatment may have led to a loss of follow-up before the galactorrhea ceased. The two women with lower-level SCI (T8 and T11, both AIS A) exhibited normal PRL levels and slightly elevated PRL, respectively.[57] Discontinuation of metoclopramide resolved galactorrhea in the woman with T8 SCI. However, resolution of galactorrhea may not have been attributed to the fact that her SCI was relatively lower than the other participants: possible confounders include the fact that she was the only nulliparous participant and that all women were on a different combination of medications prior to galactorrhea onset.

In the able-bodied literature, galactorrhea has been associated with certain medications, particularly dopamine antagonists. Discontinuation of these medications has been linked to normalized PRL levels and diminishment of galactorrhea.[52,64–67] However the SCI literature is

less clear and does not suggest that previous medication regimes induce lactation dysfunction. Several cases of galactorrhea persisted despite discontinuing drugs such as dopamine antagonists, tricyclic antidepressants and H_2 receptor blockers, and bromocriptine (a dopamine agonist) therapy was required.[57] Additionally, some participants with galactorrhea were noted to have never received medications that are known to elevate PRL levels.

With respect to the effect of pharmaceuticals on lactation, several cases of able-bodied women report successful induction of lactation to breastfeed their adopted infants. Milk production volumes ranged from 300-700 mL per day using a combination of pharmacologic treatment with galactagogues and manual stimulation using either hand expression or electric breast pumps.[68,69] Nonpuerpal lactation was also successfully induced in a transgender woman using a regimen of domperidone and a breast pump in addition to her regular androgen blockade medication. She breastfed exclusively for 6 weeks, and began supplementing breast milk with formula due to concerns about insufficient milk volume.[70] These interesting cases provide an impetus for examining pharmacological methods of facilitating lactation in mothers with SCI who experience insufficient milk volume.

More research should be conducted on the incidence of galactorrhea, whether increases in PRL levels compound the difficulties in lactation or breastfeeding and if pharmacological inducement is successful in improving milk volumes for mothers with SCI. Prospective longitudinal studies are needed to establish the prevalence of mothers with SCI who experience galactorrhea after childbirth, as well as the efficacy and side effects of using galactagogues.

1.9 **Mobility**

A major consequence for individuals with SCI is paralysis and mobility impediments which certainly present as challenges to positioning while breastfeeding. Although it is

recommended that health care professionals consider mobility issues and alternative breastfeeding positions, it is unknown how severe this barrier is perceived to be by mothers with SCI.[71] In high-level SCI, weakness in the upper extremities and poor hand function and grip may necessitate the use of a wrap, harness, support cushion or care aide to help with holding the baby. Although upper extremity motor function is preserved in individuals with lower level SCI, impaired trunk stability may contribute to difficulties with breastfeeding. To educate medical professionals on the appropriate support to facilitate positioning during breastfeeding, further research is required to identify specific mobility-related challenges and appropriate solutions.

1.10 **Postpartum depression**

The act of breastfeeding is also an important part of establishing the emotional bond between mother and child and has been described by many women as an incredible experience of intimacy.[72] As part of the transition into motherhood, breastfeeding becomes central to one's identity and self-esteem as a mother and a woman.[73,74] The emotional closeness facilitated by breastfeeding has important maternal mental health implications: mothers who continue to breastfeed for six months postpartum experienced reduced rates of postpartum depression (PPD): PPD itself is a risk factor for adverse child outcomes.[75] PPD is linked to impaired mother-child interaction patterns, which can result in deficient maternal attachment and sensitivity that is vital to fostering a child's healthy social and behavioural development.[76]

In the general maternal population, PPD is estimated to affect 13% of women[14] while nearly 35% of women with SCI have reported experiencing symptoms of PPD.[77] Additionally, a cross-sectional survey of 287 women found that in comparison to mothers without disabilities, mothers with disabilities reported being diagnosed more frequently with depression before (39% vs 16%), during (25% vs 7.6%), and after (30% vs. 10%) their pregnancy, and also reported

more PPD symptoms after controlling for pre-pregnancy depression diagnosis.[78] However, these rates were not examined specifically for women with SCI and it was not determined whether factors related to disability contributed to mothers' subjective experiences of depression or negative affect. Given that stress, anxiety and mood disorders increase the risk of developing PPD, being unable to meet breastfeeding goals may be a contributing factor to the incidence of PPD in new mothers with SCI.

1.11 **Future directions**

While impaired milk production, ejection, incidence of AD and mobility concerns have been reported in the literature, there is still a lack of comprehensive data on how prevalent these complications are and the severity/priority that mothers with SCI ascribe to them. No study to date has established the most important breastfeeding challenges, including main issues such as lactation dysfunction, autonomic conditions like AD, mobility, and psychosocial health. To evaluate these, further studies must be done that are longitudinal and cross-sectional in nature, with specific emphasis on SCI since impact on breastfeeding will vary based on the level of SCI and autonomic completeness of injury. There is also a profound need for knowledge translation and education to improve clinical practice and supports for mothers with SCI who choose to breastfeed. To navigate SCI-related challenges to breastfeeding, a multi-disciplinary approach is recommended which necessitates comprehensive research covering all facets of breastfeeding challenges presented by SCI.[79,80]

Table 1.1 Breastfeeding rates and behaviours after spinal cord injury.

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Findings
Holmgren et al., 2018 Sweden & Canada N=52 (In press).	The influence of spinal cord injury on breastfeeding behaviour.[81]	**Population:** Women who attempted to breastfeed after SCI (N=52). **Age:** Mean maternal age = 31 years **SCI:** 28 women with high-level SCI (at or above T6 level) and 24 with low-level SCI (below T6).	Questionnaire on lactation and breastfeeding experiences after SCI.	Duration of exclusive breastfeeding was significantly shorter ($p<0.05$) in the high-level injury group (3.3 months) compared to women with low-level SCI (6.5 months).
Gragg 2015. USA N=1	Breastfeeding experience of a mother with a spinal cord injury at C6/7.[82]	**Population:** One mother (n=1) **Age:** Not reported. **SCI:** C6/C7 (unknown AIS)	Case report decribing one mother's breastfeeding experiences, including challenges and supports	Although some difficulties with ineffective latch were experienced, infant latched successfully overall with assistance (while in hospital and early postpartum). A lactation consultant made informal home visits early in postpartum which may have helped. Mother did experience let-down. Infant was breastfed exclusively until milk supply decreased at 7-8 weeks. Night supplementation began until 10 weeks. Donated human milk was then used until 12 weeks.

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Findings
Mitra et al. 2015 United States N=13,361	Maternal characteristics, pregnancy complications and adverse birth outcomes among women with disabilities.[83]	**Population**: Women with disability (n=1,015) and women without disability (n=12,346). **Age:** Categorized as <20, 20-29, 30-39 and 40. **SCI:** Not reported.	Cross-sectional survey on maternal attitudes and experiences collected from the 2002–2011 Rhode Island Pregnancy Risk Assessment Monitoring System (PRAMS) survey.	70% of women with disabilities reported ever breastfeeding or pumping compared to 75% of women without disabilities ($p<0.01$). 45% of women with disabilities were currently breastfeeding versus 53% of women without disabilities ($p<0.01$). Type of disability is not specified: participants self-identified by answering "Are you limited in any way in any activities because of physical, mental, or emotional problems?"
Rasul & Biering-Sorenson. 2015 Denmark N=62	Parents with a spinal cord injury.[84]	**Population**: Parents with an SCI (n=26 female; n=36 male). **Age:** 29-72 (mean 48.1 years) at time of survey; age at first childbirth (if after SCI was 21-54, mean 32.5 years) **SCI:** 56% had paraplegia and 44% had tetraplegia (no other information collected on SCI).	Anonymous questionnaire of parents with SCI.	17 out of 26 women (65.4%) could breastfeed without aids and no difference between paraplegia and tetraplegia. Authors acknowledge that tetraplegia is expected to have impaired lactation due to absent sympathetic innervation and suggests their findings are due to the small sample.

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Findings
Morton et al. 2013 United States N=34	Pregnancy outcomes of women with physical disabilities: a matched cohort study.[28]	**Population:** 48 pregnancies delivered by 34 women with various physical disabilities out of which 17 pregnancies were carried out by women who had a SCI at or above T6 and 5 who had a SCI below T6. **Age:** Median maternal age of 27 years (range 21-40 years). **SCI**: levels and AIS not reported.	Matched-cohort chart teview on obstetric and disability-related complications in pregnancy and deliver. Evaluated breastfeeding at 6 weeks postpartum for women with physical disabilities and the comparison group.	Women with physical disabilities less likely to breastfeed (53%) their children than an able-bodied control group (77%; p=0.02) Medications used by chronic SCI patients may affect breastfeeding rates. SCI group was divided between T6 and above and below T6. This was done for frequency of pregnancies, deliveries, and AD experience (which occurred in 10 out of 17 women with SCI T6 and above).
Cowley 2007 Canada N=1	Equipment and modifications that enabled infant child-care by a mother with C8 tetraplegia: A case	**Population:** One mother (n=1). **Age:** Not reported. **SCI:** C8 tetraplegia (AIS unknown).	Case report decribing the modifications and equipment used to facilitate various physical aspects of caring for her	No description of the mother's particular breastfeeding/lactation experience or whether or not lactation dysfunction occurred. Aids described were generally for mobility rather than lactation/breastfeeding itself (i.e. placing a couch beside the crib allowed mother to transfer from her wheelchair to the couch and place infant

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Findings
	report.[85]		infants, such as bathing, dressing and breastfeeding.	in the crib immediately after feeding).
Jackson & Wadley 1999 United States N=472	A multicenter study of women's self-reported reproductive health after spinal cord injury.[30]	**Population:** Women who gave birth pre-injury (n=242) and postinjury (n=66). **Age:** Mean age at interview = 40 years. **SCI**: cervical, thoracic and lumbar with AIS A, B, C, D. Lesion levels and breakdown not provided for women who answered pregnancy questions.	Cross-sectional survey on self-reported reproductive health issues of women with SCI. One section (completed by 308 of 472 women) compared experiences of women who gave birth pre-injury and postinjury.	Fewer women practice breastfeeding after SCI. Of women who gave birth pre-SCI, 28% breastfed their children pre-injury, only 11% breastfed post-injury ($p< 0.05$) Breastfeeding duration was longer post-SCI than pre-SCI at 6.1 months vs 4.2 months. Study did not state whether breastfeeding was exclusive or specify SCI level in each group.

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Findings
Charliefue et al. 1992 United States N=47	Sexual issues of women with spinal cord injuries.[86]	**Population:** 231 women with SCI; 47 live births occurred. **Age:** Mean age 32.7 years **SCI:** Quadriplegia (n=112; neurologically complete) and paraplegia (n=119; 77% neurologically complete). Specific levels not reported or broken up for women who gave birth.	Cross-sectional survey via telephone-interviews with women with SCI regarding general aspects of sexuality after SCI.	29 out of 47 women (62%) chose to breastfeed. The most common reason not to breastfeed was inconvenience.
Cross et al. 1991 United States N=16	Pregnancy following spinal cord injury.[29]	**Population:** 16 women with SCI, with a total of 22 live births. **Age:** Average maternal age (at delivery: 25.6 years **SCI:** C1-T-12, AIS A, B, D. 9 injured at or above T6 (12 live births), 7 injured below T6 (10 live births).	Retrospective study using interviews about pregnancy outcomes and complications.	All women who chose to breastfeed were able to do so (number of women or SCI level is not stated for those women). One woman reported an increase in spasticity while breastfeeding her child.

NB: SCI = spinal cord injury; AIS = American Spinal Injury Association (ASIA) Impairment Scale

Table 1.2 Impaired lactation after spinal cord injury.

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Findings
Liu & Krassioukov 2013 Canada N=1	Breastfeeding in the woman with a compromised nervous system.[36]	**Population:** 1 woman with Brown-Séquard-plus Syndrome, impaired motor function on the right side. **Age:** 33 years **SCI:** C4, AIS D	Case report.	Significant lack of lactation from right breast during first month postpartum. After following pediatrician's advise to pump, breast milk from the right breast remained 83% less than the left breast and she eventually switched to formula feeding.

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Findings
Cowley 2005 Canada N=3	Psychogenic and pharmacologic induction of the let-down reflex can facilitate breastfeeding by tetraplegic women: a report of 3 cases.[51]	**Population:** 3 women with tetraplegia **Age:** Not reported. SCI was sustained 12 years before childbirth for participant 1 and 9 years prior for participant 2. **SCI:** C6-8 with AIS A, B	Case series report of 3 women.	The 3 women were able to elicit the let-down reflex, and breastfeed even with high-level SCI, using mental imaging or pharacological treatment. Participant 1 used mental imaging to induce the let-down reflex and breastfeed her twins for 52 weeks and third child for 54 weeks. Participant 2 required oxytocin nasal spray to induce let-down and breastfed for 6 months. Participant 3 breastfed her first child (born before sustaining SCI) for 9 months. She breastfed her second child (born after sustaining SCI) for 3 months.

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Findings
Halbert 1998 United States	Breastfeeding in the woman with a compromised nervous system.[35]	Not applicable.	Narrative review of selected publications (manuscripts, textbooks and nursing guides) on SCI and pregnancy.	Lactation is controlled largely by hormonal regulation as well as the sensory and autonomic innervation of the breast. Suggested that SCI would have a negative effect on the let-down reflex, particularly at injuries T6 or higher.
Baker & Cardenas 1996 United States	Pregnancy in spinal cord injured women.[4]	Not applicable.	Narrative review of selected publications on management of issues during SCI and pregnancy, including antepartum issues, delivery and postpartum complications.	Breastfeeding has been successful in SCI mothers without deficiency in the let-down reflex, even with high cervical lesions. It is suggested that impaired milk production demonstrated in Craig 1990 study may be related to frequency of suckling.

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Findings
Charliefue et al. 1992 United States N=47	Sexual issues of women with spinal cord injuries.[86]	**Population:** 231 women with SCI; 47 live births occurred. **Age:** Mean age 32.7 years **SCI:** Quadriplegia (n=112; neurologically complete) and paraplegia (n=119; 77% neurologically complete). Specific levels not reported or broken up for women who gave birth.	Cross-sectional survey via telephone-interviews with women with SCI regarding general aspects of sexuality after SCI.	29 out of 47 women (62%) chose to breastfeed, of whom 6 experienced problems: 4 reported insufficient milk, 1 had issues with clogged milk ducts and 1 woman's baby was allergic to her milk

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Findings
Craig 1990 United States N=9	The adaptation to pregnancy of spinal cord injured women.[37]	**Population:** A total of 13 pregnancies across 9 women with SCI (n=8) or paralysis due to polio (n=1). **Age:** At time of study, women were 27-48 years old (mean 34.66 years). **SCI:** C4-T12 (AIS unknown). SCI at or above T6 (n=4) or below T6 (n=4).	Case series interviewing women with SCI on their pregnancy, labor and postpartum experiences.	The 4 women with SCI at or above T6 noted a decrease in milk production 6 weeks post-partum The women with low SCI did not report any lactation difficulties, leading the author to conclude that lactation may be impaired in women with high-level SCI (above T6).

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Findings
Robertson et al. 1972 United Kingdom N=9	Pregnancy and labour in the paraplegic.[50]	**Population:** 26 women with paraplegia who delivered a total of 39 babies. Traumatic paraplegia (n=20). Other causes of paralysis were spinal cord disease (n=4) and poliomyelitis (n=2). **Age:** Not reported. **SCI:** C4-5 was highest level of traumatic paraplegia; T3 reported in the only woman who was injured during pregnancy. No other levels or AIS scores reported.	Case series reported over 20 years (1952-1972) by the women's physicians.	All women were able to breastfeed their infants and experienced the let-down reflex.

NB: SCI = spinal cord injury; AIS = American Spinal Injury Association (ASIA) Impairment Scale

Table 1.3 Galactorrhea and hyperprolactinemia after spinal cord injury.

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Confounds: pregnancy status, gynecological history, prescription medications	Findings
Rutberg 2008 Sweden N=16	Amenorrhoea in newly spinal cord injured women: an effect of hyperprolactinaemia? [53]	**Population**: 16 women with acute SCI (sustained 30 days before s-prolactine was sampled) **Age:** Mean age at injury 44.8 years (range 20-79) **SCI:** C1-L5, ASIA A-D	Prospective, single-centre study	7 in menopause, 6 had amenorrhea after SCI (but otherwise normal gynecological history), 3 normal gynecological history, 0 were pregnant or postpartum	No galactorrhea in subjects. Hyperprolactinaemia found in women of childbearing age (n=9) but not in menopause (n=7); hyperprolactinaemia strongly associated with amenorrhea in 6 women of childbearing age within 6 months of injury. No correlation between s-prolactine levels and SCI level or degree, so transient increase in prolactine attributed to stress response rather than pituitary trauma.

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Confounds: pregnancy status, gynecological history, prescription medications	Findings
Faubion & Nader 1997 United States N=1	Spinal cord surgery and galactorrhea: A case report.[87]	**Population**: Woman (n=1) who underwent surgery for syringomyelia several weeks before galactorrhea onset. **Age:** 39 years. **SCI:** Surgical field from C7-T4 (dural incision at T4), AIS unreported.	Case study	2 previous normal pregnancies, no current hormonal abnormalities or pregnancy. "Sporadically" taking fluoxetine (SSRI) before surgery.	High PRL values (52 ng/mL compared to the normal value of <25 ng/mL) and galactorrhea. Both normalized after bromocriptine treatment.

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Confounds: pregnancy status, gynecological history, prescription medications	Findings
Yarkony 1992 United States N=4	Galactorrhea: a complication of spinal cord injury.[57]	**Population**: 4 women with thoracic paraplegia **Age:** 19-30 years. **SCI:** T3-T11, AIS A and B	Case study	1 had never been pregnant 3 had given birth 2-7 years before SCI; 1 became pregnant 34 months after onset All were previously on medications (DA antagonists, H2-R blockers, TCAs or a combination).	Galactorrhea occurred one to five months after spinal cord injury and persisted for 22-34 months (exact duration unknown because some declined treatment and may have been lost to follow-up). Discontinuing metoclopramide (DA antagonist) resolved galactorrhea and slightly elevated PRL in a nulliparous woman with slightly elevated PRL. Discontinuing all other mediations (DA antagonists, H2-R blockers, TCAs) did not alleviate hyperprolactinemia or galactorrhea for two others who declined treatment. One woman had normal PRL and galactorrhea which ceased at 22 months without treatment (unknown if related to discontinuing H2-R blockers and TCAs which did not immediately have an effect).

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Confounds: pregnancy status, gynecological history, prescription medications	Findings
Berezin et al. 1989 Israel N=6	Hyperprolactinemia, galactorrhea and amenorrhea in women with a spinal cord injury.[56]	**Population:** 6 (out of 61) SCI patients with previously normal menstruation who developed transient galactorrhea-amenorrhea syndrome after traumatic dorsal/lumbar SCI. **Age:** 15-50 years. **SCI:** D4, D6, D12, L5. AIS not reported.	Case series	3 women technically do not meet the definition of galactorrhea: 1 was pregnant and 2 women were postpartum (1 month and 4 months, respectively).	All women had elevated PRL 3-4 weeks post-injury. 4 women received bromocriptine, which normalized PRL, galactorrhea, and menstruation. PRL in untreated patients gradually normalized over 12 months. Cessation of galactorrhea and restoration of menstruation occurred sooner. Higher lesions (D4, D6) associated with longer, more severe galactorrhea-amenorrhea and highest levels of PRL.

Authors; Year; Country; Total Sample Size	Title	Population (N, Mean Age or Range, SCI)	Study Type; Methods	Confounds: pregnancy status, gynecological history, prescription medications	Findings
Boyd et al. 1978 United States. N=2	Neurogenic galactorrhea - amenorrhea.[61]	**Population:** Woman (n=1) who at age 26 received a laminectomy from C2-T3 for thoracic ependymoma **Age:** 32 years **SCI:** C2-T4, no AIS reported (but describes sensory deficit and weakness of extremities in this range).	Case study of two women with galactorrhea-amenorhea. Second case triggered breast stimulation, not by SCI or spinal event.	No prior pregnancies.	Amenorrhea occurred from immediately post-operation to 6 months. At age 30, galactorrhea occurred during first pregnancy. Both amenorrhea and galactorrhea were resolved 6 weeks after bromergocryptine was given but recurred 1 month after medication stopped. PRL taken over five days ranged from normal to slightly elevated (12-42 ng/mL).

NB: SCI = spinal cord injury; AIS = American Spinal Injury Association (ASIA) Impairment Scale; PRL = prolactin; DA = dopamine; H2-R blockers = histamine H2 receptor antagonists; TCAs = tricyclic antidepressants; SSRIs = selective serotonin reuptake inhibitors.

Figure 1.1 PRISMA diagram for literature selection and review.

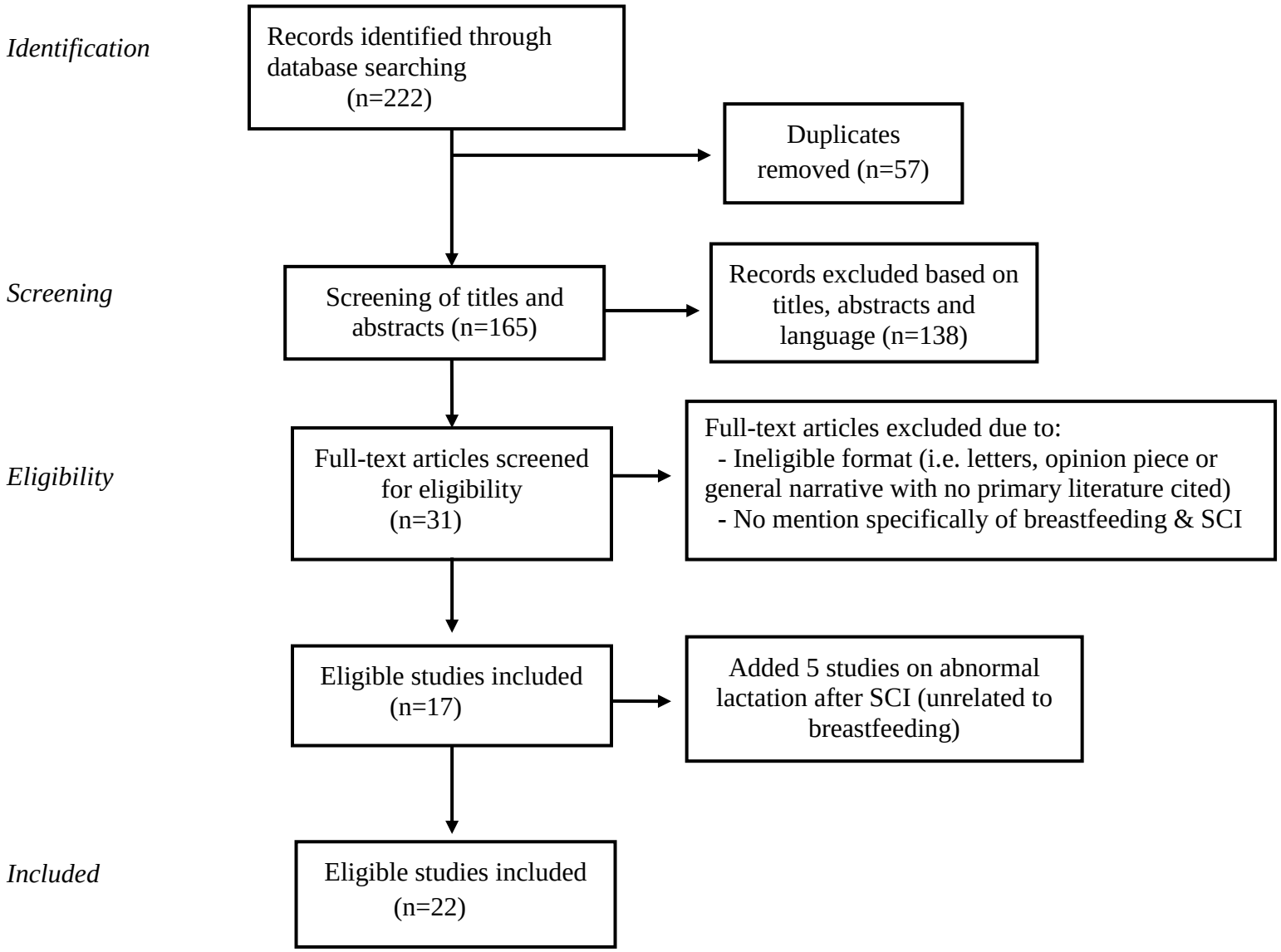
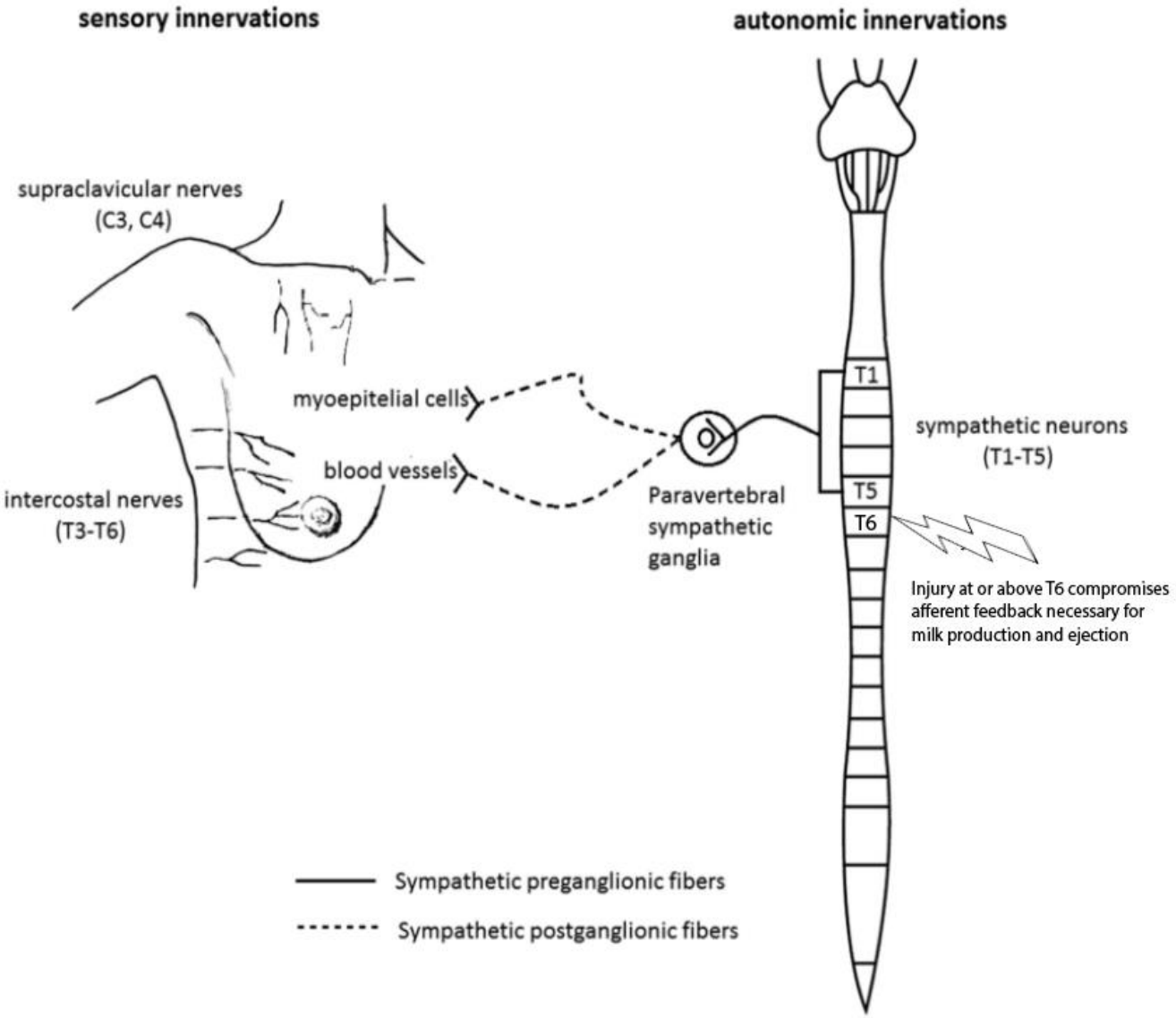


Figure 1.2 Perturbations in breast innervation after spinal cord injury.



Sensory and autonomic innervations of the breast. Injury at or above the T6 spinal segment is particularly devastating for lactation processes. Autonomic function is also disrupted, resulting in consequences such as autonomic dysreflexia and orthostatic hypotension. Adapted with permission from Liu & Krassioukov.[88]

2 ALARMING BLOOD PRESSURE CHANGES DURING ROUTINE BLADDER EMPTYING IN A WOMAN WITH CERVICAL SPINAL CORD INJURY[1]

2.1 Introduction

Autonomic dysreflexia (AD) is a life-threatening condition that occurs in individuals with high-level SCI, particularly in cervical SCI.[44] It is characterized by abrupt and transient episodes of hypertension: systolic blood pressure must be elevated by at least 20 mmHg to meet the definition of AD, and can reach up to 300 mmHg.[44,45] During AD episodes, individuals typically simultaneously experience flushing above the level of injury, sweating, anxiety and a pounding headache.[44,45] AD can occur in response to both noxious and non-noxious stimuli below the level of injury including pressure sores, spasms or even a tight shoelace.[45] However, the most common triggers are bladder and bowel distension.[44] Over time, untreated episodes of AD may lead to arrhythmias,[89] cerebral hemorrhage,[90] myocardial ischemia[91] and stroke.[44] Its relative frequency of occurrence (an average of 11 times per day in chronic SCI)[92] and grave consequences in the long-term (e.g. cerebral hemorrhage, cardiac arrhythmias, stroke) make it a priority and major concern for those living with SCI.[44,45,89,93] Here, we report the case of an individual with chronic SCI who experienced profound AD with arrhythmia triggered by use of the Credé maneuver, wherein manual pressure is applied to the lower abdomen to void the bladder.

[1] A version of Chapter 2 has been published. Lee AHX, Phillips AA, Squair JW, Barak OF, Coombs GB, Ainslie PN, Sarafis ZK, Mijacika T, Vucina D, Dujic Z, Krassioukov AV. Alarming blood pressure changes during routine bladder emptying in a woman with cervical spinal cord injury. *Spinal Cord Series and Cases.* 2017 Dec 28;3(1):17101.

2.2 **Case presentation**

Ms. X is a 58-year-old woman who was involved in a diving accident resulting in C3 motor complete sensory incomplete SCI (C3 AIS B) according to the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI).[46] Her injury was managed surgically and following 6 months of inpatient rehabilitation, she was discharged home. For the last 44 years since her injury, she has lived independently at home with support from a personal assistant. She does not currently use any medications. As a result of her SCI, she has developed numerous secondary conditions typical of individuals with cervical SCI which include the following: resting hypotension, episodes of AD, and neurogenic bladder and bowel. Her bladder management initially started with the use of Foley catheters. However, due to frequent urinary tract infections, this was discontinued and for the last 15 years, her bladder has been expressed manually using the Credé maneuver three to four times a day. She reported that for the last 10 years she has experienced symptomatic AD with headaches of varying severity whenever her bladder was full or during her bladder management routine performed by one of her caregivers.

Ms. X came in as a volunteer participant for a study conducted by an international team at the University of Split, Croatia which involved complex cardiovascular assessments of individuals with SCI. As a part of her baseline evaluation for the study she underwent neurological (ISNCSCI)[46] and autonomic screening (ISAFSCI)[94] assessments. While completing her ISAFSCI, we documented information regarding unstable blood pressure control and neurogenic bladder (only relevant parts of the assessment were completed: see Table 2.1). After baseline evaluations, participants underwent complex evaluations of various cardiovascular and respiratory parameters according to the approved protocol. Ms. X was fitted with a standard 3-lead electrocardiogram (ECG) (lead II; Powerlab Model ML132) and beat-by-beat blood

pressure monitoring device (Finometer, Finapres Medical Systems BV, Arnhem, The Netherlands). Her arterial blood pressure and ECG were recorded continuously for approximately three hours during various evaluations. She initially presented with low arterial blood pressure (100/64 mmHg) and a heart rate of 84 bpm with no evidence of arrhythmia while supine at rest (Figure 2.1a). When in a seated position, her lowest BP documented was 90/51 mmHg with a heart rate of 82.

Approximately two hours after initiation of her evaluation, a gradual increase in her BP to 130 mmHg was noted, and she complained of a slight headache. She indicated that this was a typical sign of a full bladder for her, and that she needed to conduct her bladder routine. Her caregiver assisted with bladder emptying by rhythmically applying pressure over the suprapubic area (Credé maneuver), which was done with significant impacting force. Our team continued with simultaneously monitoring her cardiovascular parameters (arterial blood pressure, heart rate, and numerous cardiac function measures) throughout this procedure. Her already elevated systolic pressure spiked rapidly up to 230 mmHg when pressure was applied to the abdominal wall to initiate voiding (Figure 2.1b). During this procedure, Ms. X complained of a pounding headache and excessive flushing of the face was observed. This episode of AD during the Credé maneuver was also associated with multiple premature ventricular contractions (PVCs) that were recorded on her ECG (Figure 2.1b). After the bladder was expressed, she was transferred to a semi-seated position until her blood pressure gradually decreased (125/89 mmHg). Her symptoms resolved with her arterial blood pressure returning to baseline approximately 7 minutes after the Credé maneuver was stopped.

2.3 **Discussion**

Presently, it is acknowledged that motor and sensory deficits should be evaluated when examining a person with SCI. Over the last decade, international efforts have contributed to developing standards for evaluating autonomic functions that are currently represented by the ISAFSCI table (2012).[94] In this clinical case, the ISAFSCI effectively collected crucial information related to the severity of Ms. X's AD. Although a novel tool, the ISAFSCI has demonstrated numerous clinical advantages and reliability for evaluating autonomic function after SCI, and is presently being considered for review by the International Autonomic Standards Committee as an evaluation tool with possible inclusion of information to document the severity of conditions exhibited after SCI, such as AD or orthostatic hypotension.[95,96] While assessing autonomic functions, clinicians and scientists also must consider existing international SCI datasets for assessment of autonomic dysfunction following SCI, including datasets for cardiovascular function,[97] bowel function,[98] skin/thermoregulation[99] and sexual/reproductive function.[100]

The Credé maneuver is a method of manually expressing urine from the bladder by applying suprapubic pressure.[101] The Valsalva maneuver is an alternative technique wherein abdominal muscles and the diaphragm are voluntarily activated by the individual to express the bladder.[101] Both of these maneuvers result in increased intraabdominal pressure and consequently bladder expression. Although both methods are described in the Paralyzed Veterans of America (PVA) Clinical Practice guidelines, they are only recommended for individuals with lower motor neuron injuries with low outlet and external sphincter resistance. Additionally, it is suggested to consider avoiding these methods as the primary method of bladder emptying due to potential complications such as incomplete emptying, abdominal

bruising, inguinal hernias and hydronephrosis.[101–103] As demonstrated by this case, AD is also a major complication that can result from manual pressure being applied on the abdominal wall for bladder expression in individuals with cervical SCI.

The primary underlying mechanisms of development of AD involve an excessive sympathetic discharge of spinal autonomic circuits that lack descending inhibition due to disruption of the spinal pathways.[104] Numerous studies have previously documented various cardiac arrhythmias associated with episodes of AD including atrial fibrillation,[89] premature atrial contractions,[105] and bradycardia.[106] In this case, multiple PVCs were observed throughout the bouts of AD, with bradycardia of 55 bpm. PVCs are associated with sudden cardiac death and total cardiac death, providing another potential link between AD and the augmented risk for cardiac mortality in those living with SCI.[107]

Given the fact that bladder irritation and distension are the most prevalent triggers of AD, optimizing bladder care for individuals living with SCI is critical to minimize incidence and manage AD episodes. This is particularly important for individuals with cervical or high-thoracic SCI who are prone to greater impairment of cardiovascular function and more severe episodes of AD.[43,44,108] Currently, clean intermittent catheterisation (CIC) is considered the gold standard for management of neurogenic bladder following SCI.[109,110] In individuals with impaired hand function or limited assistance from caregivers, other options which can be considered include urethral indwelling or suprapubic catheters.[111] These methods of bladder management provide continuous urine outflow and decrease the bladder distension and consequently episodes of AD.[101] However, regular surveillance and follow-up by a urologist is required with these catheters due to increased risk of bladder cancer.[101] Although no longer as common in North America, the Credé technique is still currently practiced for spinal cord injuries in a number of

countries around the world. Greater outreach is required to establish the benefits versus risks of this practice and mitigate its use.

This case provides additional evidence for the importance of selecting the optimal bladder management protocol for each individual with SCI to accomplish efficient and safe urine evacuation without triggering life-threatening episodes of AD. With respect to this thesis project, this case of AD in a woman with high-cervical SCI demonstrates the vulnerability of cardiovascular control in women with SCI that is affected by various peripheral stimuli. Given the fact that no study has assessed onset of AD during breastfeeding, this case is the first that assesses real-time AD occurrence in a woman in response to an external stimulus. Similar studies that observe blood pressure changes during breastfeeding are also necessary to advance understanding of how lactation and breastfeeding can cause blood pressure aberrations or even elicit AD. Therefore, this case is crucial to our knowledge of how AD can develop during events that are seemingly innocuous, whether it be a full bladder or suckling of the breast.

Table 2.1 Autonomic standards assessment.

Autonomic Standards Assessment Form

Anatomic Diagnosis: (Supraconal □, Conal □, Cauda Equina □)

Patient Name: Ms. X

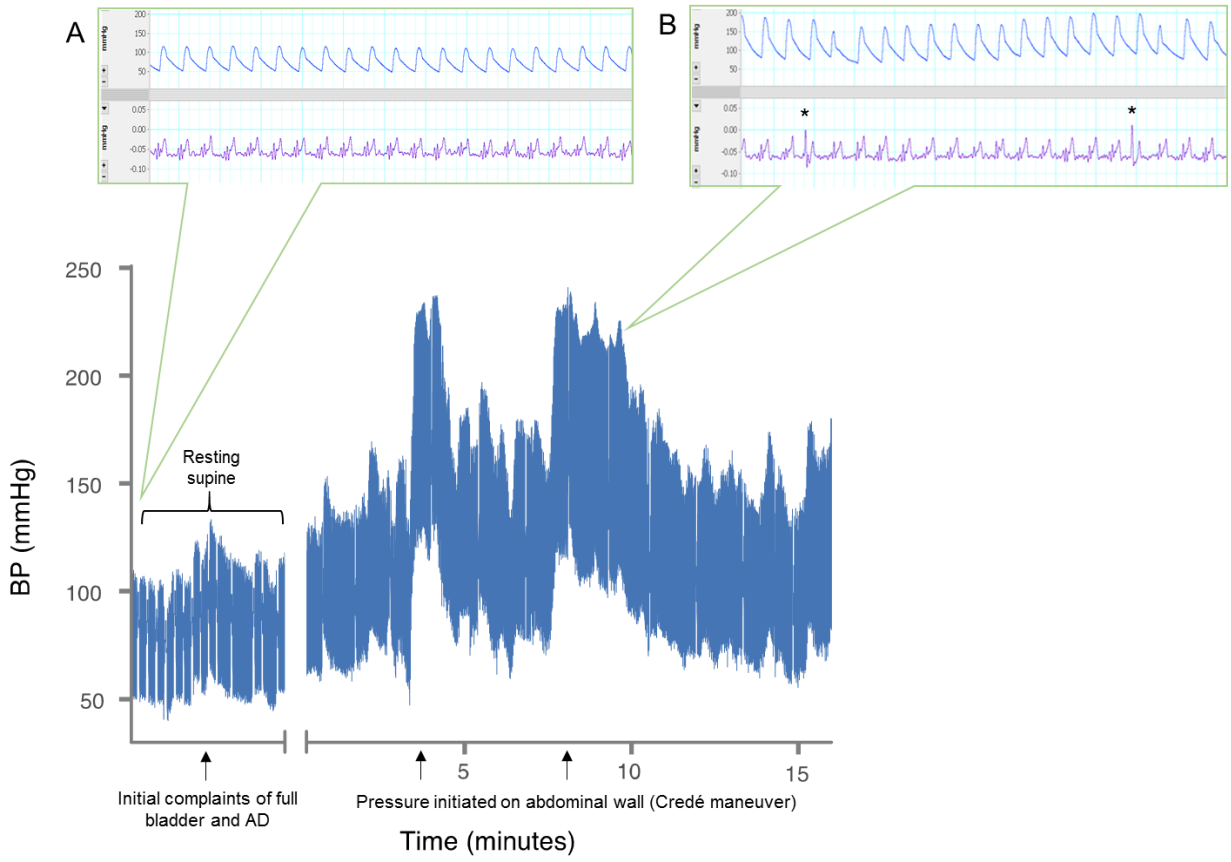
System/Organ	*Findings*	*Abnormal conditions*	*Check mark*
Autonomic control of the heart	**Normal**		
	Abnormal	Bradycardia	
		Tachycardia	
		Other dysrhythmias	X
	Unknown		
	Unable to assess		
Autonomic control of blood pressure	**Normal**		
	Abnormal	Resting systolic blood pressure below 90 mmHg	X
		Orthostatic hypotension	
		Autonomic dysreflexia	X
	Unknown		
	Unable to assess		
Autonomic control of sweating	**Normal**		
	Abnormal	Hyperhydrosis above lesion	
		Hyperhydrosis below lesion	
		Hypohydrosis below lesion	
	Unknown		
	Unable to assess		
Temperature regulation	**Normal**		
	Abnormal	Hyperthermia	
		Hypothermia	
	Unknown		
	Unable to assess		
Autonomic and Somatic Control of Broncho-pulmonary System	**Normal**		
	Abnormal	Unable to voluntarily breathe requiring full ventilatory support	
		Impaired voluntary breathing requiring partial vent support	
		Voluntary respiration impaired does not require vent support	
	Unknown		
	Unable to assess		

System/Organ	*Score*
Lower Urinary Tract	
Awareness of the need to empty the bladder	0
Ability to prevent leakage (continence)	0
Bladder emptying method (specify)	Credé Maneuver
Bowel	
Sensation of need for a bowel movement	
Ability to Prevent Stool Leakage (Continence)	
Voluntary sphincter contraction	
Sexual Function	
Genital arousal Psychogenic (erection or lubrication) Reflex	
Orgasm	
Ejaculation (male only)	
Sensation of Menses (female only)	

2=Normal function
1=Reduced or Altered Neurological Function
0=Complete loss of control, NT=Unable to assess due to preexisting or concomitant problems

Autonomic standards assessment form according to the International Standards to Document Remaining Autonomic Function after Spinal Cord Injury (ISAFSCI).[8] The form was completed following assessment and interview of this 58-year-old woman with C3 AIS B SCI. Based on her interview and evaluation we documented the following sections: low resting blood pressure, autonomic dysreflexia (AD), bradyarrhythmia, neurogenic bladder with no sensation of filling, and no ability to prevent leakage. Only parameters related to the issues described in the case were completed, as denoted by (x) in the corresponding areas. The Credé maneuver was used for bladder management.

Figure 2.1 Blood pressure elevation and electrocardiogram abnormalities upon bladder distension and emptying.



Differences were observed in beat-by-beat blood pressure (BP) and electrocardiogram (ECG) between baseline condition and during bladder filling and emptying via the Credé maneuver. Baseline supine systolic BP was 100 mmHg with normal ECG trace as shown in a 25-second excerpt (A). Elevation in systolic BP occurred due to bladder distension; initiation of rhythmic pressure to the abdomen caused an immediate rise in systolic BP above 200 mmHg consistent with the episode of autonomic dysreflexia (AD). Premature ventricular contractions (PVCs) occurred concurrently with bradycardia during the AD episode, as denoted by (*) and shown in a 25-second excerpt (B).

3 BREASTFEEDING BEFORE AND AFTER SPINAL CORD INJURY: A CASE REPORT OF A MOTHER WITH C6 TETRAPLEGIA[2]

3.1 Introduction

The majority of mothers with or without SCI wish to breastfeed if possible. Human milk production and ejection are heavily reliant upon intact neurohormonal signalling which involves sensory stimulation of the breasts (e.g. suckling). Breast afferent sensory innervation as well as autonomic efferent innervation of breast tissue and blood vessels occurs via the fourth through sixth intercostal nerves originating from the upper thoracic spinal cord. Lactation can be impaired after SCI by disruption of either/or both ascending and descending spinal pathways involved in sensory and autonomic control.[36] Furthermore, paralysis resulting from SCI (especially involvement of upper extremities) can hinder a mother's ability to pick up, position and hold her infant for breastfeeding. Dysfunctional lactation and reduced breastfeeding prevalence and duration after SCI have previously been reported, including in a small cohort of eight women, where lactation was impaired after SCI at T6 or above [28,30,81,86]. However, information regarding SCI-specific barriers to breastfeeding is lacking. As the proportion of female SCI patients is increasing, it is imperative for patients and clinicians to understand breastfeeding after SCI and methods to attain breastfeeding goals.[1]

We present the unique case of a Canadian mother who breastfed both before and after sustaining a cervical SCI in order to enable health professionals to better understand lactation and breastfeeding after SCI, and the types of clinical supports that are beneficial. This

[2] A version of Chapter 3 has been submitted for publication. Lee AHX, Wen B, Hocaloski S, Sandholt N, Hultling C, Elliott S, Krassioukov AV. Breastfeeding before and after spinal cord injury: a case report of a mother with C6 tetraplegia.

participant was initially a respondent to a multicentre retrospective online study examining motherhood after SCI, which was approved by the University of British Columbia Behavioural Research Ethics Board (see Chapter 5). The participant's informed consent for publication was obtained.

3.2 History and observational assessment

"Ms. Q" is a 39-year-old woman who was involved in a motor-vehicle accident at the age of 23, resulting in a C6 motor and sensory complete (AIS-A) SCI based on the neurological examination according to the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI).[46] At the time of SCI, Ms. Q had a 20-month old daughter and was approximately six months pregnant with her son. Following her injury, Ms. Q underwent spinal fusion surgery and remained in acute care for 4 weeks, after which she was transferred to a rehabilitation hospital. She completed basic rehabilitation for one month until the birth of her son, followed by intensive rehabilitation until her discharge at eight months postpartum. Discharge was delayed by one month due to a pressure ulcer. The timeframes of Ms. Q's injury, the birth of her children, and breastfeeding duration are shown in Figure 3.1.

3.3 Management

Ms. Q's healthcare team post-SCI included her physiatrist, obstetrician within the high-risk maternity clinic, registered nurses (RN) at the maternity ward, and personal care aides. Ms. Q reported that none of these individuals had significant clinical experience caring for mothers with SCI. She received no SCI-specific information about motherhood or breastfeeding, such as positioning her infant or managing spasticity and other conditions secondary to SCI. She reported that her care team was neutral regarding her abilities to breastfeed following SCI and

did not develop a breastfeeding plan such as targeted breastfeeding duration or timepoint of formula introduction.

After the birth of her son, RNs helped with latching and ensured she demonstrated competency in breastfeeding. The first feed occurred within one hour of birth. Ms. Q also reported that during her in-hospital stay, neither her spouse nor family members were involved in learning breastfeeding skills. Upon discharge, she was referred to a pediatrician and there were no follow-up home visits.

As Ms. Q had successfully breastfed her daughter, she was confident in her ability to breastfeed her son despite challenges resulting from SCI. Ms. Q believes, however, that if her first child had been born post-SCI or if she did not have supportive family (including her mother who had previously breastfed her own children), it would have been beneficial to receive breastfeeding education from individuals such as lactation consultants.

3.4 **Breastfeeding: mobility and physical aids**

When breastfeeding her daughter, Ms. Q had full function in her arms and could independently pick up and support her infant in a breastfeeding position. Following SCI, Ms. Q required assistance from others to pick up her son. A donut pillow was wrapped around her abdomen and used to prop her son up during feeds. Ms. Q usually breastfed her son while seated in a wheelchair but would also breastfeed in bed using wedges and pillows to support her back.

Ms. Q attempted to express milk with her daughter but stopped due to difficulties using a breast pump. Had she been able to express milk, she states it would have been immensely helpful by allowing others to bottle feed and share infant feeding duties. With her son, Ms. Q did not attempt to express milk and no household physical adaptations were made to facilitate breastfeeding. Both infants latched successfully and were breastfed in a cradled position.

3.5 **Breastfeeding cessation**

After nine months, Ms. Q stopped breastfeeding her daughter as it was no longer an enjoyable experience. She described feeling "like a cow" and was overwhelmed as she bore all the responsibility for feeding her child.

Similarly, with her son, feeling overwhelmed was Ms. Q's main reason for stopping breastfeeding after several months, albeit for different reasons. Because Ms. Q's son was born just two months after her injury, she had to simultaneously adjust to living with her SCI and caring for her infant. For example, she had to breastfeed her son in between exercises whilst in the rehabilitation gym. She also lacked time to complete her activities of daily living and personal care routine while breastfeeding regularly. Although Ms. Q had a sufficient number of supportive family members and care aides to assist her in the postpartum period, she was overwhelmed considering the recentness of her injury and the feeling that no individual could relieve her from infant feeding duties. As she could not stop rehabilitation therapy, Ms. Q stopped breastfeeding. Her spouse had difficulty coping with her SCI and subsequently was not present to assist with breastfeeding and childcare, which she states would have alleviated some stress.

Despite feeling overwhelmed at times, Ms. Q believes her breastfeeding experience was helpful for mother-infant bonding. She experienced no feelings of depression or anxiety throughout breastfeeding.

3.6 **Outcomes**

AD is a common and well-documented complication of SCI that manifests as spontaneous, hypertensive episodes. Ms. Q indicated that while she does not experience AD often, it does occur with typical triggers like bladder infection, full bladder or bowel movements.

Breastfeeding did trigger AD, but Ms. Q stated that she did not perceive it as a major complication due to her ability to identify and manage the stimulus: “I know what the noxious stimulus is [so] I don't panic… Even if I was pumping and I was getting autonomic [dysreflexia], I would just lay off and then go back in a bit later...but I didn’t get to the point where I got headaches.”

Regarding breastfeeding duration, Ms. Q breastfed her daughter for nine months and her son for under three months. Although Ms. Q did not recall the volume of milk produced per feeding session, she acknowledged that she had “tons” of milk pre-SCI with frequent leakage. Ms. Q recalls that leading up to birth, she visually observed her breasts to be engorged and took this as an indication of significant milk production. Less milk was produced postpartum and she felt “less engorged.” As Ms. Q has no breast sensation below the nipple, this may have affected her ability to detect breast fullness after SCI.

Ms. Q did not experience the subjective feeling of milk let-down. Her physiatrist suggested using domperidone to augment lactation but as Ms. Q assessed that her son always seemed satisfied after a feed, she did not use this medication.

3.7 **Discussion**

SCI is a devastating event with physiological and psychosocial consequences. For instance, AD has deleterious long-term consequences. An episode of AD can be triggered by noxious or non-noxious stimuli below the injury level, resulting in a sudden elevation in systolic blood pressure (SBP) by at least 20 mmHg. SBP can even exceed 300 mmHg, and AD symptoms include sweating, goosebumps or a headache.[45] Chronic AD is associated with life-threatening complications, particularly an increased risk of cardiovascular events. As AD can be triggered by breastfeeding, it is vital to manage in mothers with SCI who choose to breastfeed.[35,81]

The acute period after injury is particularly challenging as individuals who have sustained an SCI cope with their diagnosis, begin rehabilitation, and adapt to marked changes in their functioning. Even with acute SCI, there is expected variability in the types of barriers experienced. For example, spinal shock presents immediately after SCI and consists of loss of sensation, function and reflexes below the injury level. Neurogenic shock also occurs, and results in autonomic malfunction due to absent sympathetic activity and unopposed parasympathetic tone: this leads to hypotension and bradycardia.[112]

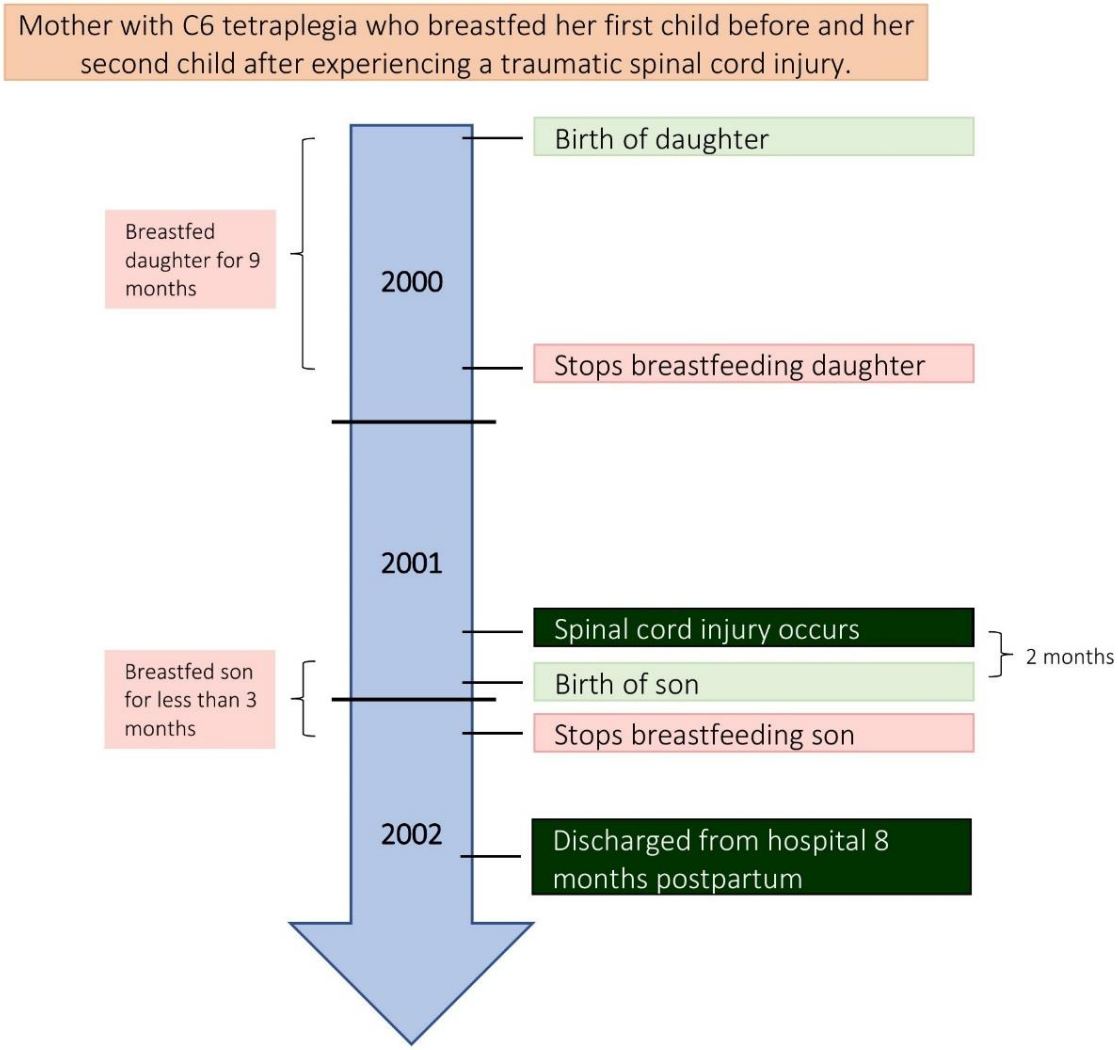
In this case description, spinal and neurogenic shock would be expected to have been resolved by the time Ms. Q began to breastfeed (two months post-SCI), as both conditions typically are present for a few days to a few weeks.[112] However, individuals in the acute phase of SCI are still in the process of active rehabilitation and adjusting to their new situation. Ms. Q stated that feeling overwhelmed was the main reason to stop breastfeeding both before and after SCI. However, the demands of simultaneously managing an acute SCI and breastfeeding contributed significantly to the shorter breastfeeding duration post-injury. Though a mother with SCI may be supported by family and care providers who assist with physical aspects of infant care and breastfeeding, difficulties will occur if no respite from breastfeeding is provided. Thus, respite measures, such as supplementing human milk with alternative nutrition, are recommended. Although expressing milk with a breast pump to allow bottle feeding by others is possible, this may trigger AD. Additional strategies and individualized breastfeeding plans should therefore be developed after assessing the mother's mobility and autonomic function.

Clinician knowledge regarding breastfeeding after SCI is lacking: mothers with SCI have reported dissatisfaction with their healthcare providers' SCI-specific knowledge.[7] Although Ms. Q was not dissatisfied with her healthcare team, she acknowledges that specific information on

breastfeeding and SCI would have been beneficial, especially if she had not had previous successful breastfeeding experience. There is great need for clinical guidelines regarding breastfeeding after SCI that will enable clinicians to better counsel their patients about breastfeeding expectations, barriers and aids. For example, beyond galactagogues to stimulate lactation, mental imaging techniques, nipple shields, or supplemental nursing systems can also support lactation and breastfeeding. This is particularly important for first-time mothers who do not have prior experience to guide them in breastfeeding after SCI. As described in a case study on a mother with C8 tetraplegia, specialized equipment and home modifications can also be utilized to facilitate breastfeeding and increase maternal independence.[85] It is necessary to educate a mother's support network about ways they can help in addition to physical assistance, such as bottle feeding or providing emotional support and encouragement. Inclusion of a lactation consultant, occupational therapist or physical therapist into the mother's care team may be highly beneficial.

Though lactation is thought to be particularly disrupted among mothers with high-level SCI, there have been reports of successful breastfeeding in this group.[4,51] Milk production may be reduced compared to before SCI but can still be sufficient for the infant as seen in the present case. Ms. Q's experience demonstrates that breastfeeding after acute SCI presents unique challenges, but successful lactation and breastfeeding are possible, particularly with targeted clinical and social supports using an interdisciplinary approach.

Figure 3.1 Timeline of breastfeeding and spinal cord injury.



This figure indicates the relative timing of the participant's two child deliveries, her spinal cord injury and breastfeeding cessation.

4 THE INFLUENCE OF SPINAL CORD INJURY ON BREASTFEEDING ABILITY AND BEHAVIOUR[3]

4.1 Background

Little is known about women's health after SCI as women represent a minority of affected individuals, as 80.7% of all spinal cord injuries are sustained by men.[113] Although fertility in women is typically not affected by SCI, little is known about the challenges faced by women with SCI during pregnancy and postpartum, including breastfeeding [114]. It is suggested from evidence from the literature that health care providers often lack specific knowledge of managing pregnancy in women with SCI, and obstetricians report insufficient confidence in caring for this population.[7] Despite this need for knowledge, most research on reproductive and sexual health after SCI is focused on men's health issues. While women are a minority of the SCI population, the average female who sustains a traumatic SCI is of child-bearing age, confirming that management of sexual and reproductive health is integral to SCI treatment and care.[115]

4.2 Benefits of breastfeeding

The WHO recommends at least 6 months of exclusive breastfeeding, with continued breastfeeding as a complement to solids for 2 years or beyond.[116] Numerous short- and long-

[3] A version of Chapter 4 has been accepted for publication. Holmgren T, Lee AHX, Hocaloski S, Hamilton LJ, Hellsing I, Elliott S, Hultling C, Krassioukov AV. The influence of spinal cord injury on breastfeeding ability and behaviour. *Journal of Human Lactation.* 2018 May 1:0890334418774014.

term benefits for both mother and child have been documented in longitudinal studies. In infants, exclusive breastfeeding is associated with benefits to cognitive development and to reduced risk of obesity, diabetes and cardiovascular disease later in life.[117] Maternal benefits include decreased rates of primary postpartum hemorrhage, reduced maternal risk of ovarian and breast cancer and reduced blood pressure.[9,118–122]

4.3 **Physiology of lactation and breastfeeding after SCI**

Breastfeeding success is dependent on both maternal and infant factors, as well as mechanical and physiological components. With respect to maternal factors, the mechanical component includes (but is not limited to) hand function, nipple shape,[123] and breastfeeding position.[124] The physiological component of breastfeeding includes lactation, sensory feedback, neuroendocrinology and breast tissue function.[124,125] Lactation is comprised of both production of milk in the breast tissue and ejection. Milk ejection occurs with initiation of the "let-down reflex" in which somatosensory and endocrine components are crucial.[126] This reflex can be triggered with or without breastfeeding (e.g., if it is conditioned in the mother by the sound of her baby crying).[124,127] Infant factors (e.g., latching and mouth shape) are also crucial to breastfeeding.[128,129] However this study specifically focused on maternal factors of lactation and breastfeeding (mechanical and physiological).

The breast is innervated by the fourth, fifth and sixth intercostal nerves, which originate from levels T1-5 of the spinal cord.[36] SCI at T6 or above is particularly devastating for breastfeeding success, as impaired breast innervation may hinder impulses from the nipple area from reaching the pituitary gland and allowing the hypothalamus to release its tonic inhibition of prolactin production. Less oxytocin is also released, resulting in impaired lactation (milk production and ejection). [35,36] After SCI, the let-down reflex may be disrupted by reduced

afferent feedback.[51] Impaired sympathetic nervous system feedback can also compromise myoepithelial cell contraction in the breast tissue which is critical for milk ejection.[35]

Breastfeeding rates have been reported as significantly lower in the SCI population compared to able-bodied women.[28,86] However, no study to date has examined low breastfeeding rates after SCI, difficulties or underlying pathophysiological impairment that interferes with lactation and breastfeeding. It is unknown how common these problems are after SCI, and to what extent they affect breastfeeding practices. The aims of this study were to 1) describe the population of women with SCI and their experiences with lactation and breastfeeding and 2) identify challenges to breastfeeding related to high and low-level SCI.

4.4 Methods

4.4.1 Design

A retrospective survey was conducted using two online questionnaires on the online survey platform FluidSurveys. Women who met eligibility criteria accessed the survey through a link, which brought them to an electronic informed consent form. Upon indicating their consent, they could proceed to the first page of the survey. Given the small population of women who chose to breastfeed after their SCI, this study used a retrospective, multi-centre design. This study was approved by the University of British Columbia (UBC) Behavioural Research Ethics Board and all methodology adhered to their standards of ethical human research.

4.4.2 Setting

The study population included mothers with SCI across the world who were primarily recruited through two well-established SCI research and treatment centres: International Collaboration on Repair Discoveries (ICORD) (Vancouver, Canada) and Spinalis, Karolinska Institutet (Stockholm, Sweden). ICORD is associated with outpatient clinics that reach over 500

individuals with SCI. Spinalis is affiliated with over 1000 individuals with SCI. The online questionnaires were not restricted to participants based in Canada or Sweden. Data were collected from April 2015 through December 2016.

4.4.3 Sample

The target population was mothers who breastfed after sustaining SCI. The sample population was a convenience sample recruited via institution websites, snowball sampling and social media through advocacy group partners. Eligible women were at least 18 years of age and chose to breastfeed at least one child after their SCI. Exclusion criteria included women who were not fluent in English and did not breastfeed after SCI. Figure 4.1 depicts the recruitment process. Online questionnaires were available internationally, but participants were primarily from Canada and Sweden, which were the two sites that actively promoted the study and were affiliated with a high number of individuals with SCI. To assess differences in breastfeeding experience and challenges, participants were categorized as having high-level SCI (injuries at or above T6) or low-level SCI (below T6). This level (T6) was selected based on the spinal cord segments associated with breast innervation, and it was important to assess SCI level to account for the impact it has on milk production, breast tissue and upper extremity function.[35]

Obtaining an adequate sample size is a well-known difficulty for SCI researchers. Additionally, women are a minority in the SCI population and recruiting mothers who also chose to breastfeed after SCI is a particular challenge. SCI research studies using surveys have been shown to range in average sample size from 35-100; our sample size of 52 participants is considered adequate for this unique population.[130]

4.4.4 Measurement

Two web-based questionnaires were developed by the research team, which included clinicians with expertise in SCI and women's health. A 37-item questionnaire (Questionnaire 1 available April through September 2015) and a 9-item follow-up questionnaire (Questionnaire 2 available October through December 2015) assessed breastfeeding behaviour and perceived difficulties of breastfeeding and lactation with SCI. Questionnaires 1 and 2 are included in Appendix A and Appendix B, respectively. Questions were in the form of multiple choice, yes/no, open text or Likert scales. Questionnaire 1 consisted of demographic characteristics (including neurologic injury classification), pregnancy, childbirth, and breastfeeding duration. Women were asked for total duration of breastfeeding. Participants were asked if they experienced the let-down reflex (yes/no), which was defined in the survey as milk flowing freely from the breast(s) while breastfeeding, potentially accompanied by a tingling sensation in the breast.[33]

Questionnaire 2 consisted of 9 questions asking participants to specify duration of exclusive breastfeeding. For two questions, participants ranked their top five reasons for introducing supplementary nutrition (e.g. formula or solids) and stopping breastfeeding completely. Breastfeeding difficulties were assessed: participants selected the challenges they experienced and ranked the perceived severity of each on a Likert scale from 1 to 5 (e.g., 1 indicated a very mild problem and 5 indicated a very severe problem). Specific breastfeeding difficulties included autonomic dysreflexia, insufficient milk production, difficulty latching, spasticity, fatigue and positioning challenges.

4.4.5 Data analysis

Descriptive analysis was done on participant characteristics. Three women were excluded from analysis of breastfeeding duration: one did not attempt breastfeeding and two were still breastfeeding at the time of the study. Shapiro-Wilks test in combination with Q-Q plots were used to determine normality of continuous variables. An independent t-test was used to determine significant variances of means of normally distributed variables. For non-normal variables, a Mann-Whitney U test was used. To test differences between proportions, a chi-squared test was employed, or Fischer's exact test where sample sizes were too small. Differences were significant at $p < 0.05$, where *p*-values shown are two-tailed. IBM SPSS Statistics v. 23 was used for all statistical analysis.

4.5 Results

4.5.1 Characteristics of the sample

Participants were primarily from North America and Scandinavia (Table 4.1). Countries of origin included Canada, the United States of America, Sweden, Norway, Denmark, Australia and Brazil. Questionnaire 1 was completed by an international sample of 52 women, of which 38 completed Questionnaire 2 (one participant did not complete the section on supplementary nutrition). All original participants were e-mailed an invitation to take Questionnaire 2, yielding a 73% response rate.

The number of years between SCI and pregnancy was recorded for high-level SCI (M = 10.94, SD = 5.28) and low-level SCI (M = 10.74, SD = 7.61). Mean maternal age was also calculated for high-level SCI (M = 31.94, SD = 4.24) and low-level SCI (M = 28.52, SD = 5.15). In total, 86 live births resulted from 101 pregnancies.

4.5.2 Study aim 1: Experiences with breastfeeding

The let-down reflex was experienced by 46.4% (n=13) of women with a high-level SCI compared to 79.2% (n=19) of women with low-level SCI. Of the 28 women with high-level SCI, 42.9% (n=12) had a complete injury. Of those 12 participants, 8 women had cervical motor-sensory complete injuries, none of whom experienced the let-down reflex. Four women had injuries from level T1-T6: 75% of these women (n=3) reported the let-down reflex.

With respect to breastfeeding duration and exclusivity, 18 women with high-level SCI and 19 women with low-level SCI who had already ceased breastfeeding answered this section of the questionnaire. Duration of total breastfeeding (i.e. exclusive and non-exclusive) did not differ between high-level SCI (M = 13.00, SD = 14.98) and low-level SCI (M = 13.08, SD = 9.49). Women with high-level SCI breastfed exclusively for a mean duration of 2.78 months (SD = 2.87) which was significantly shorter (p=0.007) than in low-level SCI (M = 6.45 months, SD = 4.81). Exclusive breastfeeding comprised 21.4% and 49.6% of total breastfeeding duration for women with high-level SCI and low-level SCI, respectively. Only 22.2% (n=4) of women with high-level SCI exclusively breastfed for at least 6 months (as per WHO recommendations) versus 47.4% (n=9) of women with low-level SCI.

4.5.3 Study aim 2: Breastfeeding difficulties in women with high- and low-level SCI

Breastfeeding difficulties experienced by the high-level SCI group were reported to be both more frequent and severe (Tables 4.2-4.3). On average, each woman with high-level SCI experienced 7.7 (SD = 4.4) difficulties compared to 5.0 (SD = 4.7) difficulties per woman with low-level SCI. AD was reported by 38.9% (n=7) of women with high-level SCI, and by 18.4% (n=7) of women with low-level SCI. Two of the women with high-level SCI who experienced

AD cited the severity of their AD symptoms as the reason for discontinuing breastfeeding completely.

Both groups indicate the most difficult problem as positioning and rated insufficient milk production as a severe difficulty. However, the frequency of women experiencing the latter was significantly greater for high-level SCI ($p<0.05$). This group more frequently cited insufficient milk production as their reason for ending exclusive breastfeeding and introducing supplementary nutrition. In contrast, women with low-level injuries most commonly cited maternal choice (Table 4.4).

4.6 **Discussion**

This study provides new insight into lactation dysfunction and difficulties with breastfeeding related to SCI. Our findings first reveal that SCI has deleterious effects on the physiological aspects of milk production and ejection function. Secondly, women with SCI reported significant breastfeeding difficulties directly related to SCI due to physical ability and/or breast and nerve tissue functions. Finally, we found that the level of SCI directly affects breastfeeding practices and breast function, likely due to disruptions in upper extremity motor function and breast innervation following SCI.

Until now, only two small studies have involved lactation and breastfeeding difficulties, reporting clogged milk ducts and insufficient milk production; however limited information was provided regarding breastfeeding difficulties and specific level of SCI.[37,86] Our data suggests that although both groups (high- and low-level SCI) experienced overlapping difficulties, numerous difficulties were group-specific. Insufficient milk production and AD were significantly more common in women with high-level SCI.

4.6.1 Breastfeeding duration

Only one previous study has investigated breastfeeding duration in women with SCI: 11% of women were found to breastfeed post-SCI compared to 28% of women who breastfed pre-SCI.[30] Although breastfeeding duration after SCI was reported as 6.2 months, there was no indication of breastfeeding exclusivity or separation by SCI level. While this study excluded women unable to breastfeed, our study included all women who chose to breastfeed (regardless of success). This may have contributed to the shorter duration we observed after SCI, as many participants experienced lactation difficulties that prompted them to turn to supplementary nutrition.

4.6.2 Difficulties with milk production

Previously, it was revealed in a cross-sectional survey of women with SCI (unspecified level) that 6 out of 29 women who breastfed experienced problems: four (14%) reported insufficient milk supply.[86] Craig (1990) interviewed eight women with SCI ranging from C4-T12. Of the four women with SCI above T6, all reported substantial decrease in milk production approximately 6 weeks postpartum.[37] In our study, insufficient milk production occurred more frequently with high-level SCI but was rated as a "severe difficulty" by both groups. Interestingly, 35% of women with low-level SCI (preserved sensory and autonomic breast innervation) reported insufficient milk production, at a similar rate reported in able-bodied mothers who cited perceived insufficient milk as the primary reason for early weaning.[131] Based on previous findings and our data, insufficient milk production after SCI may be underestimated if injury levels are not considered.

4.6.3 Difficulties with milk ejection

Our findings demonstrated that significantly more women with high-level SCI did not experience the let-down reflex compared to women with low-level SCI, for whom breast innervation would be preserved.

Varying results have been reported regarding let-down after SCI: a case series reported that all nine women (including one tetraplegic participant) experienced let-down but did not specify the level of SCI.[50] Breastfeeding was assumed to be successful in these women if lactation was possible but did not account for duration or the need for aids/supplements. Another study included 16 women with SCI ranging from C4-T12: all who chose to breastfeed were able to, although this number was unspecified. One woman (with unspecified SCI level) experienced increased spasticity attributed to breastfeeding.[29] In one case report, three tetraplegic women used mental imaging or oxytocin nasal spray to facilitate let-down.[51]

Despite these diverse findings and a lack of more recent research, these findings implicate oxytocin as central to the let-down reflex and breastfeeding success. More research is needed to examine the therapeutic potential of oxytocin and other galactagogues for lactation difficulties in SCI.[132]

4.6.4 Difficulties with positioning during breastfeeding

In this present study, the top difficulty described by women with both high- and low-level SCI was breastfeeding position: this has been highlighted in able-bodied women but not in SCI populations.[124] Positioning difficulties reported by women with high-level SCI is likely attributed to upper extremity weakness, poor hand function and difficulties with grip. Spasticity may also impede positioning. Although upper extremity motor function is preserved in individuals with low-level SCI, impaired trunk stability may also impede positioning. Clinicians should be

prepared to provide education and appropriate support (e.g. nursing pillows) to facilitate positioning during breastfeeding. Further research is needed to identify optimal solutions.

4.6.5 Reasons for ending exclusive breastfeeding

Potential reasons for why women with SCI do not breastfeed or stop exclusive breastfeeding have not been examined previously. In our study, women with low-level SCI ended exclusive breastfeeding and introduced supplementary nutrition primarily due to maternal choice. This included believing the time was right, that their infants were ready for formula/solids or returning to work. By contrast, the high-level SCI group most commonly reported insufficient milk production as their reason for introducing supplementary nutrition. This further emphasizes the prevalence of lactation difficulties and their considerable influence on breastfeeding practices.

4.6.6 Autonomic Dysreflexia

AD commonly occurs in individuals with SCI at or above the T6 spinal segment, and is characterized by transient hypertensive episodes with elevation of systolic blood pressure up to 200-300 mmHg.[45] As AD is typically initiated by any stimulus below the injury level, it is plausible that an infant's suckling, breast engorgement or mastitis are sufficient triggers. Previously, only two case reports documented women with tetraplegia (one with cervical SCI, the other with unspecified SCI level) who suffered from AD while breastfeeding.[47,48]

The high rates reported in our study (18.4-38.9%) suggest that breastfeeding-induced AD is more common than previous literature suggests, as only case studies have explicitly focused on AD onset during breastfeeding. Therefore, maternal AD should be managed, particularly with SCI at or above T6.

Interestingly, numerous studies show increased risk of developing hypertension among able-bodied women who do not breastfeed optimally.[25,133] Able-bodied women who breastfed exclusively at one month postpartum exhibit lower systolic blood pressure and heart rate than women who fed their infants using formula.[134] These cardiovascular effects have been documented to persist well after postpartum: women who underwent intervention to promote exclusive breastfeeding had lower rates of diagnosed hypertension 11.5 years after childbirth compared to the control group.[135]

Presently, there is no data available on the effect of breastfeeding in women with SCI. It was previously suggested that the therapeutic potential of breastfeeding in lowering blood pressure would extend to AD and should be encouraged after SCI.[35] However, it must be considered that baseline arterial blood pressure in individuals with SCI is actually lower than their able-bodied counterparts, particularly if the SCI is high thoracic or cervical.[45] In this population, the potential blood pressure reduction of breastfeeding may have deleterious effects on resting blood pressure and orthostatic hypotension (decline in blood pressure with obtaining an upright position).[44] Closely monitoring blood pressure for both hypotension and hypertension in breastfeeding women with high-level SCI is indicated. This may be done with regular clinic visits or 24-hour ambulatory blood pressure monitoring which is a well-validated method of tracking blood pressure aberrations in daily life for individuals with SCI.[92,136]

4.7 **Future directions**

Presently we have identified several SCI-related barriers that impede breastfeeding practice, including: disrupted lactation, impaired milk ejection, mobility challenges and AD. While there is a need for more in-depth research and longitudinal studies in these areas, clinicians should be aware of these difficulties and considerations for high- versus low-level SCI.

Blood pressure fluctuations and AD during breastfeeding should be studied to clarify whether benefits of breastfeeding outweigh the risks from a cardiovascular health perspective. Research should also be conducted on SCI-specific challenges that may present during breastfeeding, including OH, spasticity, fatigue and making time for personal care routines. To optimize breastfeeding support, it is also necessary to evaluate the efficacy of breastfeeding aids that specifically address the breastfeeding challenges identified in this study. These include therapeutic galactagogues (e.g. oxytocin for facilitating let-down) or positioning aids such as pillows.

4.8 **Limitations**

An inherent limitation of self-reported questionnaires is unreliable recall, particularly in this study due to the wide range of time elapsed between childbirth and survey completion. To minimize response bias, Likert scales were used when possible and survey questions were clearly defined to minimize ambiguity. Infant factors of breastfeeding (e.g., colic, inability to latch due to ankyloglossia) were not evaluated. Additionally, this sample was primarily from Canada and Sweden; future studies should strive for larger, heterogenous samples. The term "breastfeeding" was used throughout the survey with vague definitions (aside from the definitions of exclusive versus non-exclusive breastfeeding). Surveys were newly created, untested tools which should be validated in future studies.

4.9 **Conclusions**

In this study, insight has been provided into lactation dysfunction and breastfeeding practices in women with SCI. Breastfeeding challenges differ in type, prevalence and perceived severity between high-level SCI and low-level SCI. These differences indicate a need for postpartum care and lactation practices to accommodate women based on their level of injury

and personal breastfeeding goals. Further research should use a larger sample and include more domains such as accessibility to one's infant and the impact of breastfeeding difficulties on psychosocial health and quality of life in mothers with SCI. Our findings provide the impetus for further research into AD, lactation therapies, breastfeeding aids and support required to navigate SCI-related breastfeeding difficulties. Given the immense health benefits of breastfeeding for mother and child, it is imperative to provide health care professionals with evidence-based understanding to improve lactation practice and care for mothers with SCI.

Table 4.1 Demographic characteristics of the sample.

		High-level SCI: Injury at T6 or above (n=28)	Low-level SCI: Injury below T6 (n=24)	Total (N=52)
Characteristic		n (%)	n (%)	n (%)
Age groups	< 25 years	0 (0.0)	1 (4.2)	1 (1.9)
	25-34 years	4 (14.3)	6 (25.0)	10 (19.2)
	35-44 years	14 (50.0)	9 (37.5)	23 (44.2)
	45-54 years	9 (32.1)	5 (20.8)	14 (26.9)
	55-64 years	1 (3.6)	2 (8.3)	3 (5.8)
	> 64 years	0 (0.0)	1 (4.2)	1 (1.9)
Regions	North America	16 (57.1)	12 (50.0)	28 (53.8)
	Scandinavia	9 (32.1)	12 (50.0)	21 (40.4)
	Other	3 (10.7)	0 (0.0)	3 (5.8)
Level of injury	Cervical	22 (78.6)	0 (0.0)	22 (42.3)
	Upper thoracic	6 (21.4)	0 (0.0)	6 (11.5)
	Lower thoracic	0 (0.0)	15 (62.5)	15 (28.8)
	Lumbar	0 (0.0)	9 (37.5)	9 (17.3)
Class of injury	Tetraplegic	20 (71.4)	0 (0.0)	20 (38.5)
	Paraplegic	8 (28.6)	24 (100.0)	32 (61.5)
Severity of injury	Do not know	0 (0.0)	1 (4.2)	1 (1.9)
	Complete	12 (42.9)	13 (54.2)	25 (48.1)
	Incomplete	16 (57.1)	10 (41.7)	26 (50.0)

SCI = spinal cord injury.

Table 4.2 Prevalence of reported problems related to breastfeeding.

	High-level SCI: Injury at T6 or above (n=18)	Low-level SCI: Injury below T6 (n=20)	Total (N=38)		
Reported problem	n (%)	n (%)	n (%)	χ^2	*p*
Problems with positioning	15 (83.3)	13 (65.0)	28 (73.7)	6.56	0.26
Leaky breasts	12 (66.7)	12 (60.0)	24 (63.2)	1.68	0.89
Sleep deprivation	13 (72.2)	10 (50.0)	23 (60.5)	4.64	0.46
Engorged breasts	14 (77.8)	9 (45.0)	23 (60.5)	0.40	0.048
Sore nipples	10 (55.6)	12 (60.0)	22 (57.9)	7.21	0.13
Insufficient milk production or ejection	14 (77.8)	7 (35.0)	21 (55.3)	5.10	0.048
Latching difficulties	12 (66.7)	8 (40.0)	20 (52.6)	4.64	0.33
Clogged milk ducts	7 (38.9)	10 (50.0)	17 (44.7)	3.96	0.41
Sadness/depression	9 (50.0)	7 (35.0)	16 (42.1)	2.89	0.41
Baby unwilling to feed	9 (50.0)	6 (30.0)	15 (39.5)	2.32	0.68
Baby spitting up	6 (33.3)	3 (15.0)	9 (23.7)	0.95	0.62
Autonomic Dysreflexia	7 (38.9)	0 (0.0)	7 (18.4)	3.68	0.018
Mastitis	4 (22.2)	2 (10.0)	6 (15.8)	1.57	0.46
Breast abscess	3 (16.7)	0 (0.0)	3 (7.9)	0.77	0.58
Other	1 (5.6)	0 (0.0)	1 (2.6)	0.77	0.58

SCI = spinal cord injury. Frequency of breastfeeding difficulties reported in high- and low-level SCI. Percentages do not add up to 100, as responders could state more than one reason. Differences were significant at the $p < 0.05$ level.

Table 4.3 Comparison of severity scores for problems related to breastfeeding.

	High-level SCI: Injury at T6 or above (n=18)	Low-level SCI: Injury below T6 (n=20)	Total (N=38)		
Reported problem	Severity score M (SD)	Severity score M (SD)	Severity score M (SD)	*t*	*p*
Problems with positioning	2.60 (1.60)	2.85 (1.51)	2.71 (1.50)	6.70	0.00
Leaky breasts	2.92 (1.47)	2.83 (1.73)	2.88 (1.49)	5.71	0.00
Sleep deprivation	2.20 (1.28)	1.91 (1.30)	2.08 (1.33)	6.49	0.00
Engorged breasts	2.62 (1.31)	2.50 (1.55)	2.57 (1.36)	5.51	0.00
Sore nipples	2.20 (2.00)	2.50 (1.60)	2.36 (1.66)	4.35	0.001
Insufficient milk production or ejection	4.07 (1.16)	3.86 (1.53)	4.00 (1.29)	9.59	0.00
Latching difficulties	3.08 (1.87)	2.38 (1.64)	2.80 (1.71)	4.80	0.00
Clogged milk ducts	2.29 (1.73)	2.50 (1.89)	2.41 (1.77)	3.38	0.015
Sadness/depression	2.11 (1.55)	1.71 (0.00)	1.94 (1.39)	3.56	0.09
Baby unwilling to feed	2.89 (2.06)	2.50 (2.06)	2.73 (1.66)	5.43	0.001
Baby spitting up	1.50 (1.73)	2.33 (1.299)	1.78 (1.50)	2.33	0.102
Autonomic Dysreflexia	3.14 (1.16)	-	3.14 (1.16)	-	-
Mastitis	1.75 (1.89)	3.00 (2.83)	2.17 (2.31)	1.75	0.22
Breast abscess	1.00 (0.00)	-	1.00 (0.00)	-	-
Other	1.00 (0.00)	-	1.00 (0.00)	-	-

SCI = spinal cord injury. Severity scores were achieved by asking participants to grade the perceived severity of their experienced breastfeeding problems on a Likert scale from 1-5, where 1 indicated a very mild problem and 5 indicated a very severe problem. Problems that were not experienced do not have severity scores. Independent t-test, significant difference at the $p < 0.05$ level.

Table 4.4 Reasons stated for introducing supplementary nutrition.

	High-level SCI: Injury at T6 or above (n=18)	Low-level SCI: Injury below T6 (n=19)	Total (N=37)
	n (%)	n (%)	n (%)
I did so by my own choice - I thought the time was right.	7 (38.9)	10 (52.6)	17 (45.9)
I wasn't producing enough milk	10 (55.6)	6 (31.6)	16 (43.2)
I was advised by health care professionals to do so	5 (27.8)	6 (31.6)	11 (29.7)
I had various difficulties breastfeeding	6 (33.3)	3 (15.8)	9 (24.3)
I wasn't getting enough sleep	4 (22.2)	1 (5.3)	5 (13.5)
Baby wasn't growing according to growth plan	3 (16.7)	1 (5.3)	4 (10.8)
I couldn't find time for both breastfeeding and personal care	2 (11.1)	0 (0.0)	2 (5.4)
I had to go back to work	1 (5.6)	1 (5.3)	2 (5.4)
I was sad or depressed	1 (5.6)	1 (5.3)	2 (5.4)
I never intended to breastfeed exclusively	1 (5.6)	0 (0.0)	1 (2.7)

Percentages do not add up to 100, as responders were allowed to state more than one reason.

5 A MULTI-CENTRE RETROSPECTIVE STUDY ON MOTHERHOOD AFTER SPINAL CORD INJURY: LACTATION, BREASTFEEDING AND AUTONOMIC DYSREFLEXIA

5.1 Introduction

Despite the deleterious impact that SCI has on both the physiological and psychological outcomes of individuals, research on motherhood after SCI remains limited.[81,137] Our preliminary study (described in Chapter 4) was the largest cohort study of women who chose to breastfeed after SCI (n=52) at the time. It was also the first to identify the major barriers to lactation and breastfeeding presented by SCI. It is a well-established fact that in comparison with other neurological conditions such as stroke, Parkinson's and Alzheimer's disease, SCI affects a small number of individuals. Over four times as many men as women sustain a traumatic SCI in Canada and the United States, making women a relative minority of this group.[138,139] Furthermore, not every woman with SCI gives birth and chooses to breastfeed. Despite these challenges, the paucity of literature in this area necessitates the use of a larger representative sample and a more in-depth look into the specific barriers to lactation and breastfeeding that these women perceive as the highest priority. As such, it was necessary to conduct a wider-scale study using a more comprehensive set of questionnaires.

The T6 segment has been established to be critical, as SCI at this level or higher result in drastic lactation dysfunction and breastfeeding difficulties.[30,35,81] However, it must be acknowledged that individuals with upper thoracic lesions (T1-T6) may have partially disrupted innervation to the breast, compared to high cervical lesions (C1-C8) which would be associated with significantly greater disruption of breast innervation. Previously, our pilot study divided SCI level into two levels: SCI at or above T6 and SCI below T6. For a more in-depth

examination of differences in breastfeeding barriers, our follow-up study involved dividing SCI level into three categories: cervical (C1-C8) SCI whose breast innervation would be completely disrupted, upper thoracic (T1-T6) SCI with partially disrupted breast innervation and lower level SCI (T7 and below) with no disruption to breast innervation.

The purpose of this present study was to expand on our preliminary findings by describing a larger international sample of women with SCI and their experiences with lactation and breastfeeding with emphasis on the following research questions:

1) Do breastfeeding behaviour and duration differ based on SCI level?

2) What are the most severe barriers to breastfeeding for women with cervical, upper thoracic and lower level SCI?

5.2 Methods

5.2.1 Participants

Methodology largely followed the same methods as described in Chapter 4. In this retrospective, multi-centre study, participants (n=102) were mainly recruited by two leading SCI research centres: 1) the International Collaboration on Repair Discoveries (ICORD, Vancouver, Canada) and 2) the Karolinska Institutet (Stockholm, Sweden). Recruitment strategies included snowball sampling, social media and word-of-mouth from contacts at SCI centres, which were based in countries such as the United States, Australia and the United Kingdom. Inclusion criteria included women were at least 18 years of age, who breastfed after SCI and who had English comprehension.

This study was approved by the University of British Columbia (UBC) Behavioural Research Ethics Board and the Karolinska Institutet Research Board. All methodology adhered

to their standards of ethical human research and participants provided informed consent using an online form that preceded the survey.

5.2.2 Procedure

A retrospective survey was conducted using an online questionnaire that was based off the pilot study questionnaires and administered internationally using the online survey platform, FluidSurveys. An expert panel was recruited which consisted of experts in SCI and women's health: two women with lived experience (mothers with SCI) and eight clinicians (physiatrist, neurologist, sexual health physician, registered nurse, lactation consultant, occupational therapist, physiotherapist, independent living consultant). The panel identified major themes for SCI-related breastfeeding complications and developed the first 57-item questionnaire (Questionnaire 1: available December 2016 through February 2017. See Appendix C). After reviewing the interim data with the first participants (n=64), the panel then revised the survey. Revisions included: removing redundant questions, clarifying ambiguous wording, changing open-ended questions to multiple-choice to minimize the unreliable recall. The revised 61-item questionnaire was disseminated, and the original 64 participants also completed the revised questionnaire (Questionnaire 2: available February through June 2017. See Appendix D). Question formats included yes/no questions, multiple-choice, Likert scale to rank options and open-text response. Both questionnaires were systematically developed over three face-to-face meetings and regular correspondence. This involved using the Delphi method, which is based on the principle decisions made by a structured group of individuals are more accurate than those from unstructured groups.[140,141]

The questionnaire also included several standardized, validated measures of QOL and psychosocial health. This portion of the study is detailed in Chapter 6.

5.2.3 Data analysis

Descriptive analysis was done on participant characteristics. Chi-squared analysis was used for frequency comparisons. Differences were significant at $p < 0.05$, where *p*-values shown are two-tailed. These analyses were performed using IBM SPSS v. 20. A logistic regression model was then applied to determine the variables that significantly affected breastfeeding duration. Significance was compared at the 0.05 confidence level. Correction techniques included the Bonferroni correction and the False Discovery Rate – Benjamini Hochberg method (FDR). Bonferroni corrections were used to control for Type I error (false positives); family-wise error and the FDR was used to ensure true effects were detected (controlling for false discovery). Significance values for the FDR are expressed as *q*. For logistic regression analyses, R version 3.4.1 was used.

5.3 Results

5.3.1 Characteristics of the sample

Participants were primarily from North America and Scandinavia (Table 5.1). In total, 105 women were recruited. However, three women did not complete information on demographics and their SCI and were therefore excluded from analysis. The difference between maternal age at childbirth after SCI and at the time of survey completion was 12.1 years. The majority gave birth between 1 to 2 infants: 47.1% (n=48) of women gave birth to just one child, 41.2% (n=42) gave birth to two children, 8.8% (n=9) gave birth to three children and 2.9% (n=3) gave birth to four children. Further details on the number of infants delivered by mothers in each SCI group are given in Table 5.2. Miscarriages were experienced by 76.7% (n=23) of women with cervical SCI, 83.3% (n=10) of women with upper thoracic SCI and 57.4% (n=35) of women

with lower level SCI. However, it was not specified whether these were pre- or post-SCI, or whether participants also included abortions.

5.3.2 Research Question 1: Do breastfeeding duration and behaviour differ by SCI level?

To assess duration of exclusive breastfeeding, women were asked to select from a list of discrete categories time the option that best described the duration they breastfed their first infant (e.g. a few days, over one year, etc). Figure 5.1 displays the results for the entire cohort for each of these categories of breastfeeding duration. Duration of exclusive breastfeeding was significantly affected by SCI level. The lower level SCI group was 2.61 times more likely than the cervical SCI group to breastfeed for over 6 months, as per WHO recommendations (Figure 5.2). This difference was statistically significant ($q = 0.044$). Maternal age also was a major factor in breastfeeding duration: with every increase in maternal age by one year, the odds of breastfeeding exclusively for greater than 6 months was 1.11 times greater (i.e. older mothers breastfed longer) and this finding was statistically significant. The onset of skin to skin contact did not differ significantly between groups, although the proportion of women who reported having skin to skin contact within one hour after birth generally decreased with higher SCI (Figure 5.3). Between 75 to 93% of women attempted to breastfeed within the first 24 hours after birth, and there was no statistically significant difference between groups nor SCI level-dependent general trend (Figure 5.4).

5.3.3 Research Question 2: What are the most severe barriers to breastfeeding for women with cervical, upper thoracic and lower level SCI?

5.3.3.1 Most severe breastfeeding barriers

Participants rated their top five categories in terms of which barriers impeded breastfeeding the most, where a score of 1 indicated the most severe issue and a score of 5 was

the lowest severity within their top barriers. Overall, **absence of a let-down reflex** was perceived as most severe by women with cervical SCI, while the other two groups reported **insufficient milk production** as being the most severe barrier. These two difficulties were most commonly reported across all women as the most severe barrier and a χ^2 frequency comparison revealed that with increasing level of SCI, more participants reported insufficient milk production and lack of a let-down reflex (Table 5.3). Additionally, major barriers that were commonly reported included latching difficulty (by upper thoracic and lower level SCI) and sleep deprivation (by all groups) (Table 5.4).

5.3.3.2 Cessation of exclusive breastfeeding

Participants were also asked about motivations for ceasing exclusive breastfeeding in favour of formula and/or solids. The frequency of women who reported each reason as the most prominent factor for stopping breastfeeding was tabulated (Figure 5.5). Several mothers reported sleep deprivation and feeling embarrassed to breastfeed in public as being common deterrents to continuing to breastfeed (not unlike able-bodied mothers). However, the top reason for both cervical and upper thoracic SCI was not being able to find time to balance both breastfeeding and personal care. Personal care included, but was not limited to, activities of daily living such as showering, toileting and meal preparations.

5.3.3.3 Independent ability and accessibility

Regarding independent ability for facilitating breastfeeding, 50.0% (n=15) of women with cervical SCI were able to independently pick up their infant, compared to 91.7% for upper thoracic SCI (n=11) and 93.4% of lower level SCI (n=57). Despite only half of women with cervical SCI being able to independently pick up their baby, many women in this group reported being able to independently have the baby latch onto the nipple (73.3%; n=22) compared to

83.3% of the upper thoracic group (n=10) and 91.8% of the lower level SCI group (n=56). Although it is likely that upper extremity weakness did impair independent ability, environmental set-up (i.e. location and accessibility of the crib) may also have caused significant difficulty for independently picking up the infant. The importance of an environment that facilitates independent access to the baby has been noted in several case studies,[82,85] and is therefore important to assess in future research.

Where assistance was used to hold or support the baby while breastfeeding, nursing pillows were the most commonly used aids among all women (80.0% in cervical SCI; 83.3% in upper thoracic SCI; 70.5% in lower level SCI). The help of personnel was more heavily emphasized in cervical SCI, as 63.3% of this group used a spouse or caregiver's assistance to maintain the baby in a breastfeeding position compared to 23.0% and 41.7% of upper and lower level SCI levels respectively (Figure 5.6). A substantial proportion of women with upper thoracic (91.7%) and lower level (85.2%) SCI attempted pumping, although there was no statistically significant difference found between the three groups (Figure 5.7).

5.3.3.4 Autonomic Dysreflexia

As described in previous chapters, AD is prevalent in mothers with SCI at or above T6 and it can significantly impede breastfeeding success and outcomes. Out of the total cohort, 24.3% (n=25) reported AD as being a significant difficulty during breastfeeding. Mothers who did not experience AD while breastfeeding were also 3.17 times more likely to breastfeed for over 6 months (q = 0.0117). Consistent with the literature, prevalence of AD during breastfeeding was found to be SCI-level dependent: notably, nearly half (46.7%; n=14) of the women with cervical SCI considered AD as a barrier to breastfeeding, although it is likely that prevalence of AD experienced while breastfeeding was higher (Figure 5.8). The fitted logistic

regression revealed that the odds of breastfeeding for over 6 months was 6.18 times greater for the lower level SCI group compared to cervical SCI (q = 0.0006).

5.3.3.5 Education

Participants were asked to select all that applied from a list of sources from which they obtained information specific to breastfeeding with SCI. These sources were collapsed into four categories: 1) None (did not receive any information); 2) Self-research (Internet, other women with SCI, family/friends, pregnancy books); 3) Health care providers (general practitioner, obstetrician, pediatrician, physiatrist, lactation consultant, nurse, midwife); 4) Non-medical care aids (independent living consultant, prenatal course instructor, doula). Women who did receive information mainly did so via self-research, such as through community support groups or the Internet. Overall, the majority of participants obtained information on breastfeeding via self-research or not at all. These proportions were 66.6% for cervical SCI, 50.0% for upper thoracic SCI and 51.8% of lower level SCI (Figure 5.9). Breastfeeding knowledge obtained did not significantly affect duration of exclusive breastfeeding and the source of information did not differ based on participants' SCI level.

5.4 Discussion

To our knowledge, no new research has been conducted on breastfeeding after SCI in the time between our pilot study (Chapter 4: currently in publication), and this present study (Chapter 5). Hence, our research provides a more comprehensive description of the barriers and priorities for breastfeeding mothers with SCI, and furthermore is the first study to examine this population's psychosocial wellbeing.

First, duration of exclusive breastfeeding generally was shorter in groups with higher SCI levels. This discrepancy was significant between cervical and lower level SCI, reflecting our

previous findings, where women with SCI at or above T6 breastfed for a significantly shorter duration of time compared to women with SCI below T6 (see Chapter 4).[81] Both the pilot study and these findings support what has been previously demonstrated in the literature: that SCI impairs lactation, with the most dramatic outcomes present with high SCI.[30,35,36]

The SCI-level dependent discrepancy in exclusive breastfeeding duration may be due to a variety of factors, such as autonomic integrity of the breast. As previously described, disruption to afferent impulses can both diminish milk production and impair the milk ejection reflex. Indeed, these two factors were reported by our cohort as the most severe barriers that impeded breastfeeding. Participants from all three SCI groups attempted to mitigate insufficient milk production by pumping for breast milk, although participants were not asked how long they attempted to do so, nor the degree of success. The surprisingly high percentage of women with cervical SCI who pumped may be explained by the fact that only *attempts* to pump were reported. Pumping was more common in upper thoracic and lower level SCI than cervical SCI, although there was no statistically significant difference: pumping may not have been useful for women whose ability to produce and eject breast milk was significantly compromised by their SCI. With respect to impaired milk ejection, subjective absence of the let-down reflex was prominent in women with cervical SCI.

5.4.1 Autonomic Dysreflexia

AD was perceived as a significant barrier to breastfeeding by women in each SCI group, most notably with higher levels of injury. Overall, 23% of women in our cohort considered AD to significantly impede their breastfeeding success – this is a relatively high incidence compared to the numbers reported from national databases, which range from 10-22.7% in the United States.[142,143] However, it is important to note that these studies include both male and female

individuals with complete or incomplete SCI. Lindan et al. have also reported that AD occurred in 48% of 213 patients with SCI at or above T6 within 12 months of injury, although all patients had complete SCI.[144]

However, it is important to note that the *prevalence* of AD in general was not queried on the survey, and in fact may be much higher given the numerous stimuli that can trigger an episode. AD can be elicited by even benign, non-noxious events such as bladder filling or tight clothing, and may therefore occur several times each day.[92,142] Silent AD may also occur asymptomatically, where the individual is unaware of AD occurrence due to a lack of clinical symptoms.[145,146] It is likely that women who breastfed did experience increased frequency of AD episodes, but that they were not listed as a top complication for several reasons, including: 1) attribution of AD to another event; 2) undetectable (silent) AD; 3) adaptation to AD incidence such that experience AD was normalized; 4) novel difficulties that were more challenging to navigate for first-time mothers (e.g. lack of milk production).

Follow-up studies are required to evaluate the number of AD events that were actually triggered by breastfeeding, and to determine the extent to which AD impacted actual breastfeeding behaviour. For example, it is possible that women with higher SCI avoided pumping or nursed less frequently due to increased propensity for AD.

5.4.2 Personal care and breastfeeding routines

In addition to the physiological factors that impeded breastfeeding, several other major barriers related to SCI were very commonly reported. Numerous women in each SCI group reported difficulty with finding the time for both breastfeeding and a personal care routine (including toileting, showering, meal preparation and tasks of daily living). Implementing daily living routines that enable independent outcomes after SCI requires a great deal of time and

attention.[147,148] In our pilot study (Chapter 4), only two women (5.4%) indicated that needing time for personal care was one of the top reasons for switching from exclusive breastfeeding to supplementary nutrition. However, this may be due to our small sample (n=37), as well as the fact that many women had been injured several years prior: the rehabilitation process is more time-consuming and physically taxing in the acute phase of SCI. As reported by our sample, this life care planning process can be considerably more complex when faced with breastfeeding, especially if there are breastfeeding difficulties. For example, one participant with a T1 SCI experienced particular difficulty with accessing her infant for night feeds. She qualitatively described these night feeds, which necessitated her transferring out of bed, making her way to the crib and picking up her infant, and transferring back into bed and attempting to fall asleep again. Needing to pick up and support her infant (sometimes independently) and experiencing blood pressure aberrations made night feeds more arduous. It is likely that independent ability related to mobility and arm/hand function are main factors responsible for the difficulty mothers with high level SCI (i.e. cervical) had in accessing their infants for night feeds. Numerous women with higher SCI and less upper extremity function also indicated impaired access to the infant at night to be a major breastfeeding barrier.

5.4.3 Independent ability and accessibility

Generally, women who could pick up their baby could also facilitate the baby's latch onto the nipple. Independence in these two abilities tended to be concurrent for both the upper thoracic and lower level SCI groups. However, a discrepancy did exist for cervical SCI: in this group, only 50% (n=15) of women could independently pick up their baby (50%, n=15) compared to 73.3% (n=22) of women who could independently latch the baby. This discrepancy may be attributed to the fact that many women with cervical SCI (63.3%; n=19) were assisted by

personnel to pick up, hold or support the baby while breastfeeding, or that the infant was able to find and latch once close to the nipple. Personnel included but were not limited to: spouse, family member or personal care aide. With cervical SCI, it is likely that a main deterrent to breastfeeding is physical access to the baby, which can be rectified by assistance with bringing the baby to the mother in the correct position. We suspect that once personnel assisted with positioning and holding the baby, latching difficulty was remedied. This notion is supported by the finding that latching difficulty was ranked as one of the top five barriers for all groups but cervical SCI, but impaired access was a moderate to high priority with cervical SCI. Women in this group used nursing pillows as breastfeeding aids, but more highly emphasized the use of personnel to assist with physically accessing and supporting the baby. In contrast, women with upper thoracic and lower level SCI tended to use pillows, cushions and harnesses as their primary aid.

Understanding the primary source of assistance used by women with SCI has significant implications for clinical management for breastfeeding. An individualized care strategy tailored to each mother based on her level of SCI can be immensely beneficial. For example, women with higher SCI can benefit from a personal care aide in the postpartum period. In addition to facilitating breastfeeding positioning, having nighttime personnel can also address the challenges of accessing the baby for night feeds. Breastfeeding strategies have not been examined in research. However, one case report does describe adaptations that supported a mother with C8 tetraplegia to successfully breastfeed her infant.[85] This included furniture rearrangements, such as placing a couch at 90 degrees to the infant crib, where the mother could transfer from her wheelchair before and after feeding. The crib was also modified to include sliding door access to the baby through the side of the crib while the mother was seated in her wheelchair. In another

case report, a mother with C6/7 SCI utilized a custom-built crib which was raised to allow a wheelchair to fit underneath.[82] This modification allowed the mother to place her breast on the crib and scoop her baby closer to her, rather than lifting the baby out of the crib into a cradling position.

All members of the mother's postpartum health care team should collaborate to devise strategies (such as environmental modifications) to support her breastfeeding goals. As described in the aforementioned case study, it is recommended to have follow-up home visits by a lactation consultant after discharge from the hospital, as well as home evaluation by an occupational therapist. These would allow the family to develop strategic adaptations that help with breastfeeding positioning, as well as balancing breastfeeding with the mother's activities of daily living and personal care routine. The development of such plans necessitates comprehensive education of health care professionals, which is reportedly lacking.[5,7]

5.4.4 Education

The lack of research in the field of breastfeeding and SCI directly impacts the amount and quality of educational resources for women with SCI who seek information when pursuing motherhood. Our findings reveal that the majority of participants did not receive information specific to breastfeeding with SCI from a professional source, such as a health care provider. This speaks to the scarcity of standardized information that is available on the parenting after SCI, which has also been observed in several qualitative studies. Women with SCI have stated a clear desire for health care providers who have knowledge in both obstetrics and SCI, as educational programs such as prenatal classes were perceived as "useless" or "inadequate" if they did not address SCI.[7] In a qualitative study of 17 mothers with SCI, several factors contributed to dissatisfaction with the care process: in addition to lack of knowledge, poor

integrated care was reported. Participants reported the desire for more comprehensive, continuous care where services could be received from one site. These mothers noted a lack of communication between care providers and perceived the need to seek providers who had the desired level of knowledge – which led to inconvenience and disappointment.[84]

In light of the previous literature and the lack of knowledge provided to our cohort, there is a blatant need for standardized guidelines and comprehensive sources of information on motherhood after SCI that are accessible to both consumers and clinicians.

5.5 **Limitations**

As mentioned in Chapter 4, retrospective studies have the inherent limitation of recall bias, which we attempted to minimize by using multiple-choice questions in order to allow answer options to prompt more accurate recall, as opposed to open-text comments. Additionally, despite the fact that this was the largest cohort study to date on breastfeeding and SCI, the sample was small. Given the small sample and high number of comparisons made in the linear regression model, an underpowered study was one consequence of including the degree of SCI completeness (i.e. comparing between motor/sensory complete and incomplete SCI). These comparisons were performed but did not yield significant differences between complete and incomplete SCI in terms of breastfeeding outcomes: analysis of this data should be performed again with completeness of SCI as a factor. The retrospective nature of this study did not allow us to evaluate completeness or incompleteness of the autonomic nervous system (which furthermore requires specialized techniques, such as sympathetic skin response).[149]

Participants frequently reported insufficient milk production and difficulties with both milk ejection and latching. These are highly common difficulties that all mothers tend to experience while breastfeeding. The 2012 Canadian Community Health Survey evaluated

breastfeeding in the general Canadian population and obtained 130,000 responses over two years (2011-2012). Of the mothers who breastfed for less than six months, 44% ceased exclusive breastfeeding because they felt they had insufficient breast milk, while 18% cited difficulty with breastfeeding technique. Future studies should assess these breastfeeding barriers that frequently occur in all mothers and evaluate to which extent they are influenced by SCI. For instance, asking women whether they were trained in latching and asked to demonstrate competency in those skills by a professional may have elucidated whether latching difficulty was mobility-related or due to a poor understanding of proper latch.

5.6 **Conclusions**

The findings of this present study have first and foremost demonstrated that insufficient milk production and absence of a let-down reflex are the most severe barriers to breastfeeding. This is consistent with previous research. However, novel findings establish other major deterrents to breastfeeding success, which include a surprisingly high prevalence of AD, latching difficulty, impaired physical access to the infant and navigating the personal care routine of a person with SCI while breastfeeding. This study is also the first to evaluate the types of aids used to facilitate breastfeeding, and we noted that SCI level and degree of mobility do contribute to the types of aids that are most useful.

Ultimately, SCI level determines the type of breastfeeding care plan that must be set in place. A multidisciplinary approach, starting in the hospital and/or at delivery, that accounts for the mother's breastfeeding goals, wishes and expectations is highly recommended. This plan should be supplemented with comprehensive information for both mother and clinicians involved in her care via standardized guidelines and accessible resources.

Based on the present findings, future directions include development of such consumer and clinician guidelines in order to develop evidence-based standards for best practice. By augmenting the current state of knowledge on navigating the SCI-related barriers to breastfeeding, further management strategies can be created to facilitate breastfeeding success, thereby improving health outcomes and QOL for both mother and infant.

Table 5.1 Participant demographics.

Characteristic	Total participants (N=102)
Country	**n (%)**
Canada	34 (33.3)
USA	16 (15.7)
Sweden	40 (39.2)
Norway	2 (2.0)
Denmark	3 (2.9)
UK	2 (2.0)
Australia	5 (4.9)
Maternal characteristics (years)	**M ± SD**
Maternal age at survey	41.3 ± 9.8
Maternal age at childbirth	29.2 ± 6.5
Duration between SCI and childbirth	10.3 ± 8.2
Plegia	**n (%)**
Tetraplegia	31 (30.4)
Paraplegia	71 (69.6)
Completeness of injury (AIS)	**n (%)**
AIS A	34 (33.3)
AIS B	24 (24.5)
AIS C	24 (24.5)
AIS D	12 (11.8)
Lesion level	**n (%)**
Cervical, C1-C8	30 (29.4)
Upper thoracic, T1-T6	12 (11.8)
Lower thoracic & lumbar, T7 & below	60 (58.8)

Note. SCI = spinal cord injury; AIS = American Spinal Injury Association Impairment Scale. Age and times are presented as mean years ± SD. Participants' SCI levels ranged from C4-L5. Percentages may not add to 100% due to missing responses. One participant did not provide demographics information.

Table 5.2 Number of infants delivered by participants.

Number of infants	Cervical (C1-C8) n (%)	Upper thoracic (T1-T6) n (%)	Lower level (T7 & below) n (%)
1	15 (50.0)	6 (50.0)	27 (45.0)
2	11 (36.7)	5 (41.7)	27 (45.0)
3	4 (13.3)	1 (8.3)	4 (6.7)
4	0 (0)	0 (0)	2 (3.3)
Total	30	12	60

Note. SCI = spinal cord injury. Percentages are presented as the proportion of women in that particular SCI group who gave birth to a given number of infants. For example, 15 women (50% of women with cervical SCI) gave birth to only 1 infant.

Table 5.3 Frequency comparison of most severe barriers.

Factor	Cervical (C1-C8) n (%)	Upper thoracic (T1-T6) n (%)	Lower level (T7 & below) n (%)	χ^2	*p*
Insufficient milk production	23 (76.7)	7 (58.3)	22 (36.7)	13.60	0.001
Let-down reflex present	8 (26.7)	7 (58.3)	43 (71.2)	15.54	<0.001
Total	30	12	60		

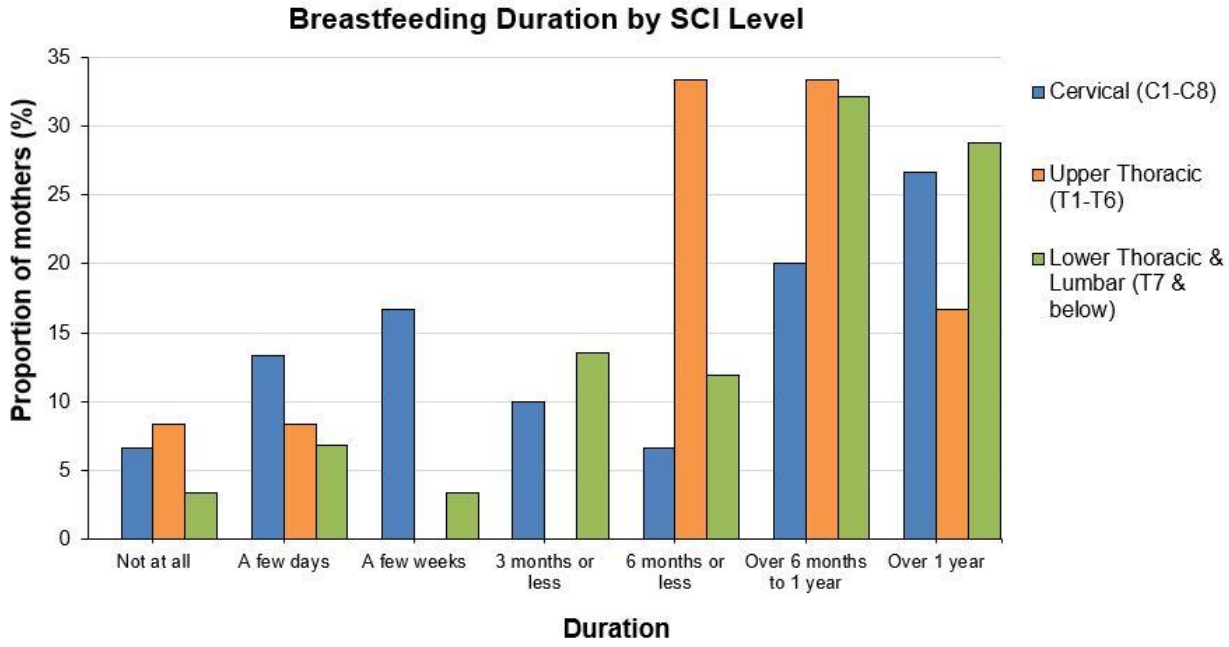
Note. Significance taken at the $p<0.05$ level.

Table 5.4 Top five most severe barriers to lactation and breastfeeding by SCI level.

Severity	Cervical (C1-C8)		Upper thoracic (T1-T6)		Lower level (T7 & below)	
	Barrier	n (%)	Barrier	n (%)	Barrier	n (%)
1	No let-down reflex	8 (26.7)	Insufficient milk	7 (58.3)	Insufficient milk	22 (36.7)
2	Insufficient milk	23 (76.7)	UTI	3 (25.0)	Latching difficulty	36 (60.0)
3	Impaired access to baby for night feeds	18 (60.0)	Latching difficulty	5 (41.7)	Sleep deprivation	48 (80.0)
4	Sleep deprivation	19 (63.3)	Baby unwilling to feed	6 (50.0)	Breast pain	35 (58.3)
5	Mobility challenges	21 (70.0)	Sleep deprivation	9 (75.0)	Sore nipples	41 (68.3)
Total	30		12		60	

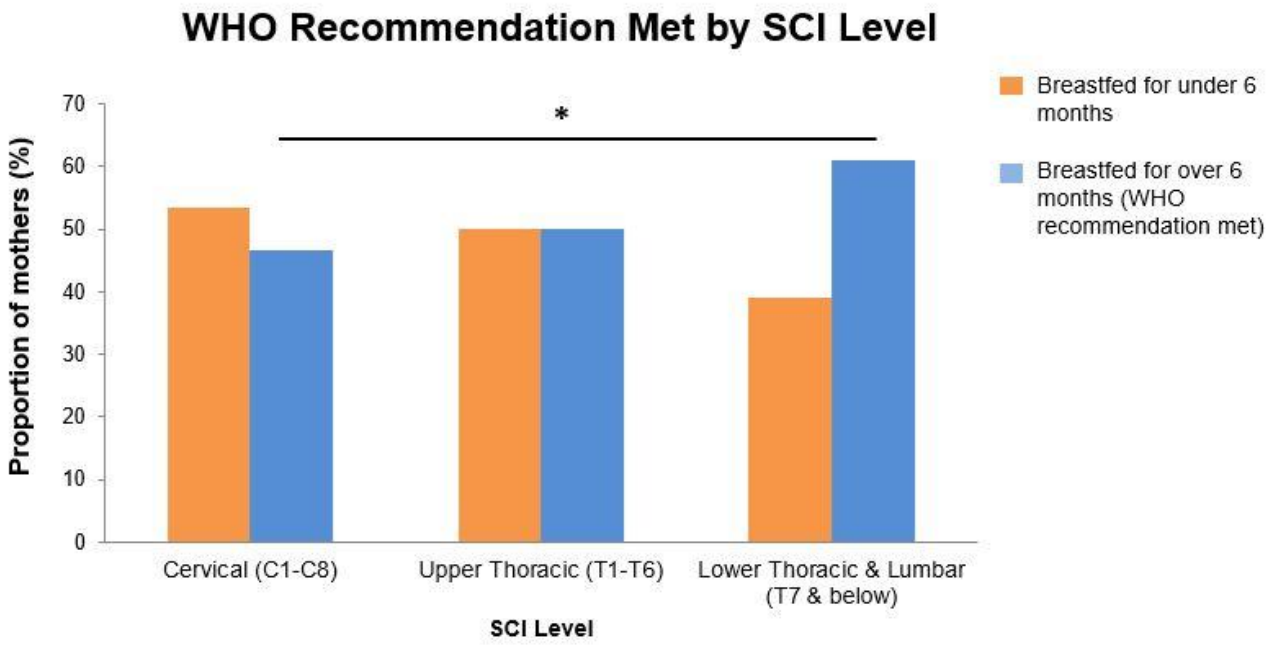
Severity indicates how highly the barrier was ranked in terms of severity, where 1 = most severe barrier indicated by each SCI group as a whole and 5 = least severe of the top five barriers reported.

Figure 5.1 Exclusive breastfeeding duration.



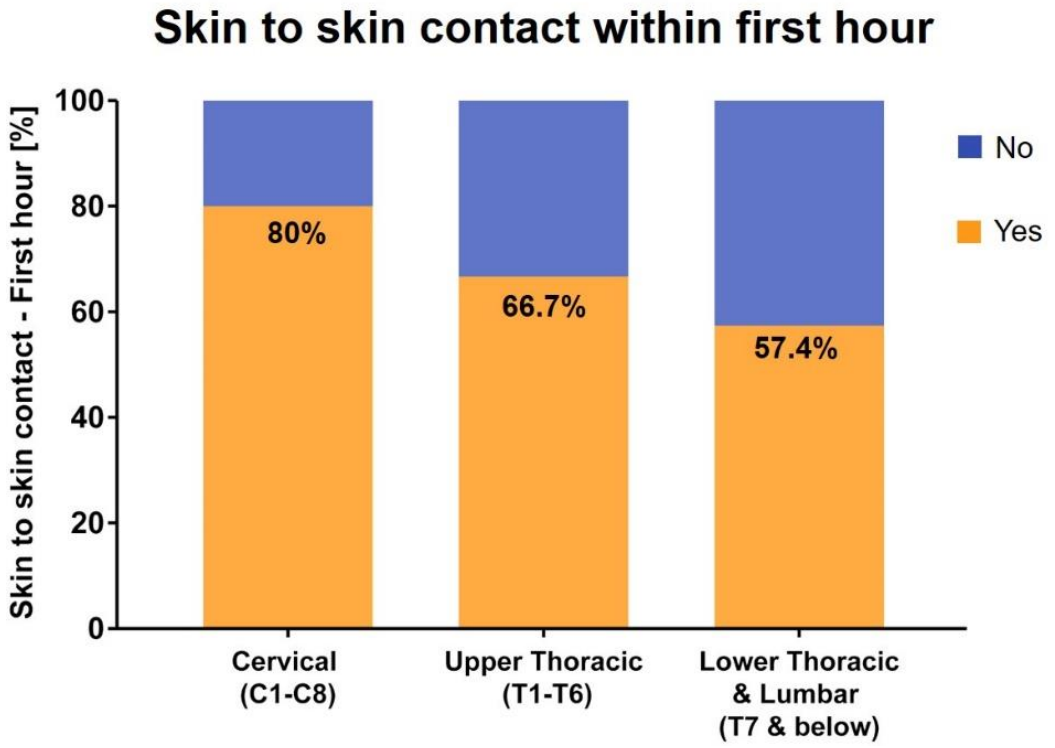
SCI = spinal cord injury. Distribution of exclusive breastfeeding duration across all participants according to SCI group.

Figure 5.2 Proportion of mothers who breastfed exclusively for over 6 months.



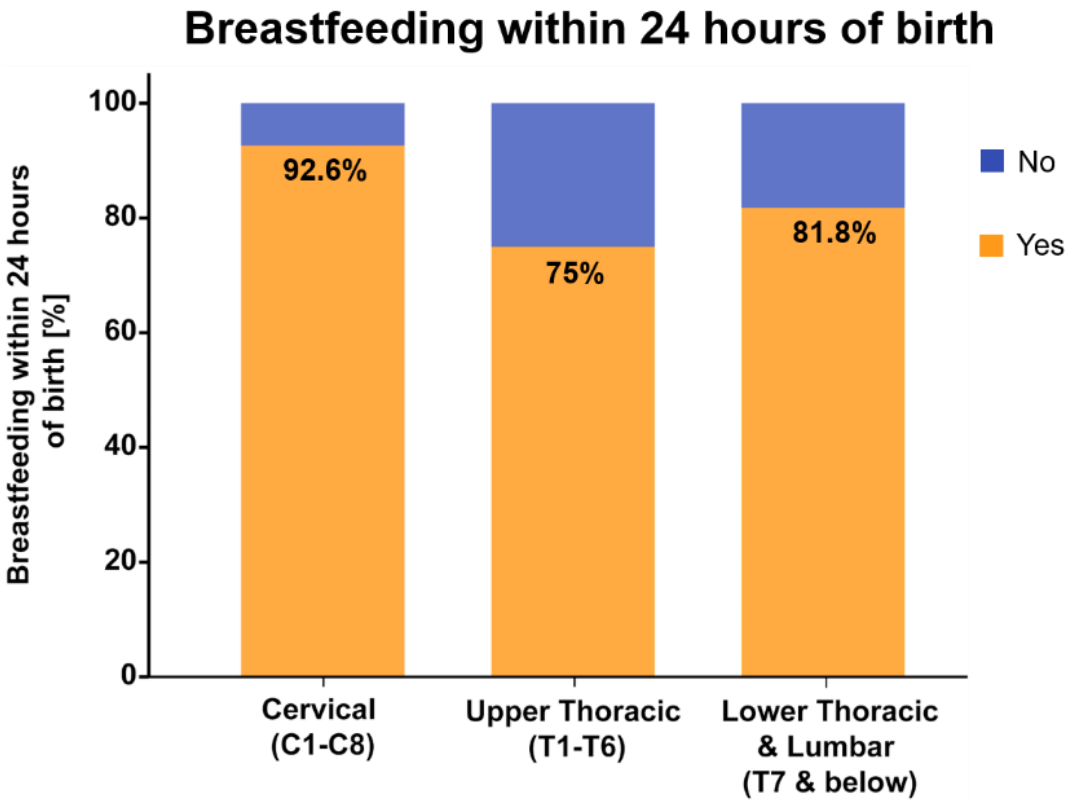
WHO = World Health Organization; SCI = spinal cord injury. The lower level SCI group was 2.61 times more likely than the cervical SCI group to breastfeed exclusively for over 6 months (which is the minimum duration as recommended by the WHO).

Figure 5.3 Skin to skin contact within first hour of birth.



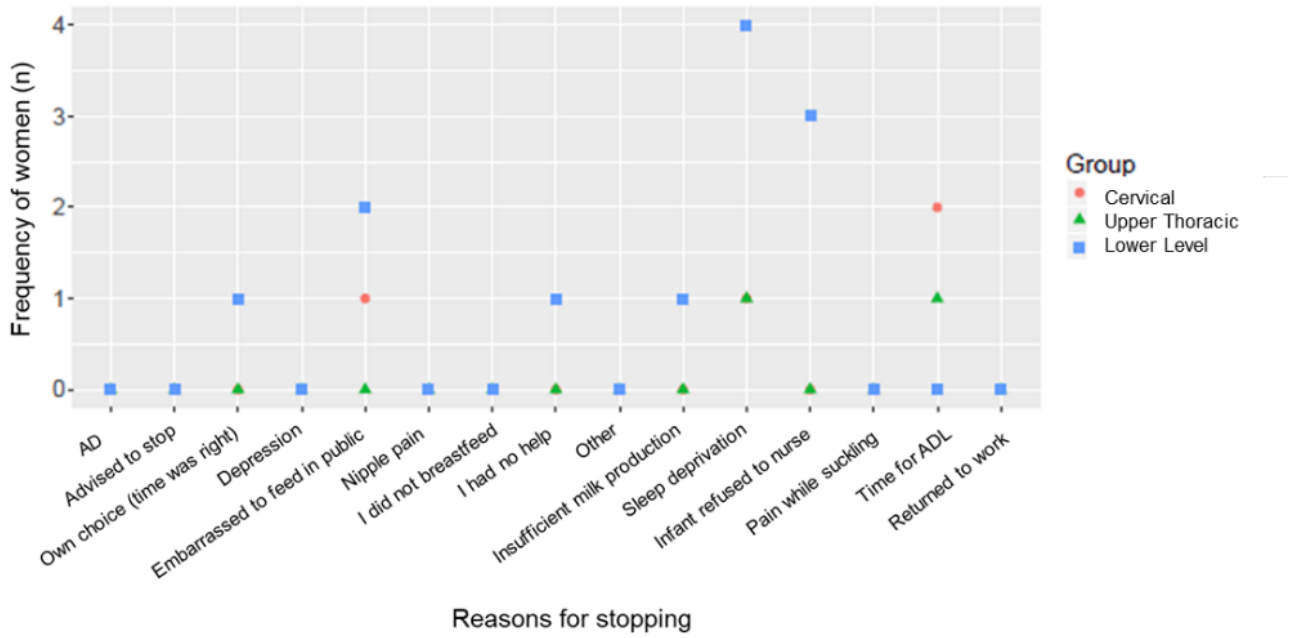
SCI = spinal cord injury. Prevalence of establishing skin to skin contact within one hour of birth was highest in the cervical SCI group, followed by upper thoracic and lower level SCI.

Figure 5.4 Breastfeeding within 24 hours of birth.



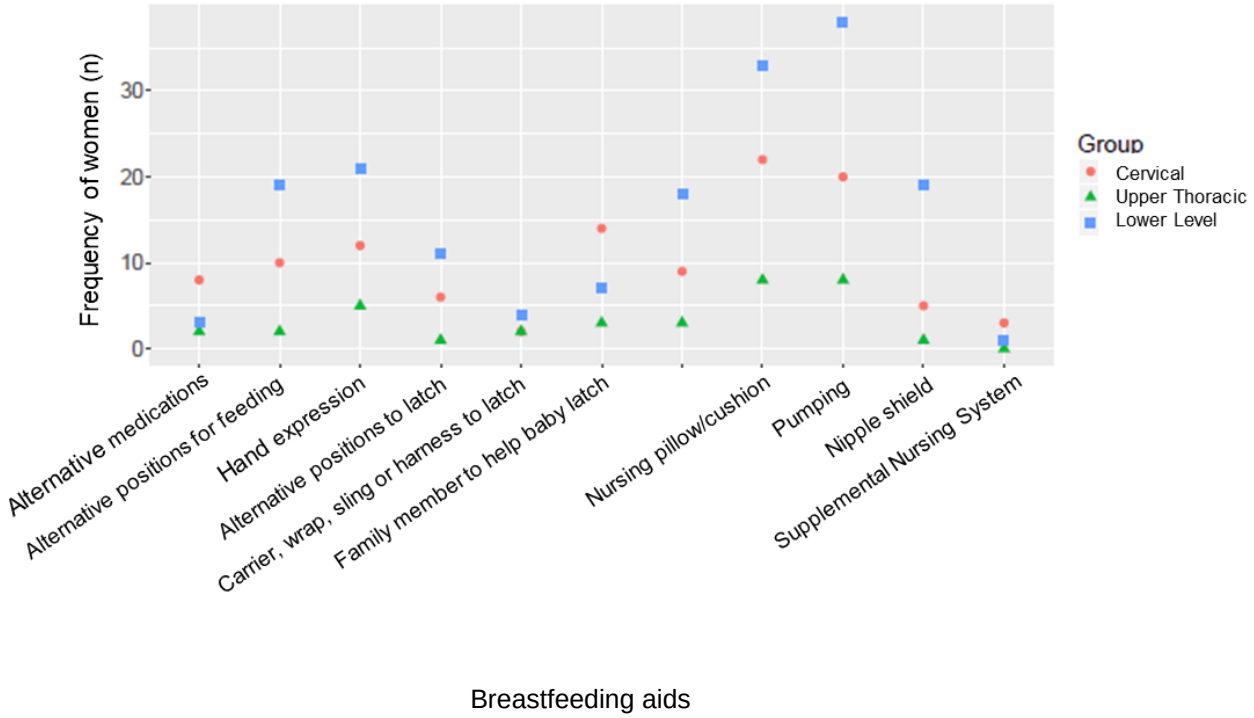
SCI = spinal cord injury. Prevalence of having the first breastfeeding session within 24 hours of birth was not dependent on level of injury. Prevalence was highest in the cervical SCI group, followed by lower level injury, followed by upper thoracic injury.

Figure 5.5 Reasons for cessation of exclusive breastfeeding.



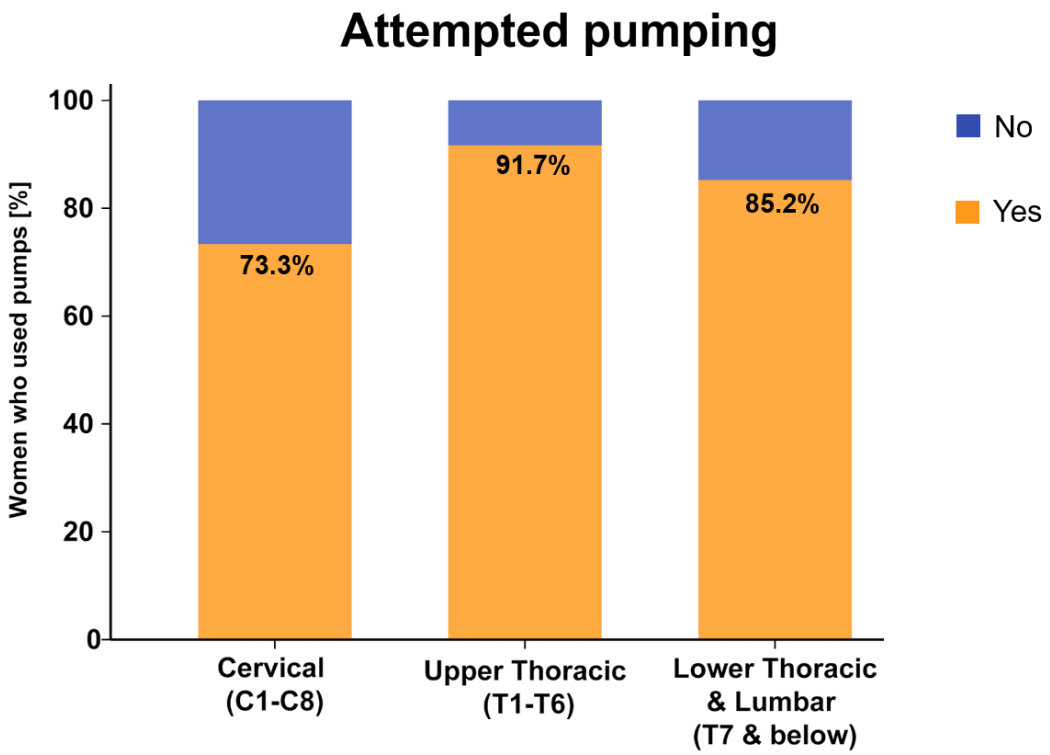
AD = autonomic dysreflexia; ADL = activities of daily living. Scatter plot displaying the frequency of reasons cited for stopping exclusive breastfeeding in favour of formula and/or solids (either supplementation or switching from breast milk completely).

Figure 5.6 Aids for breastfeeding positioning and support.



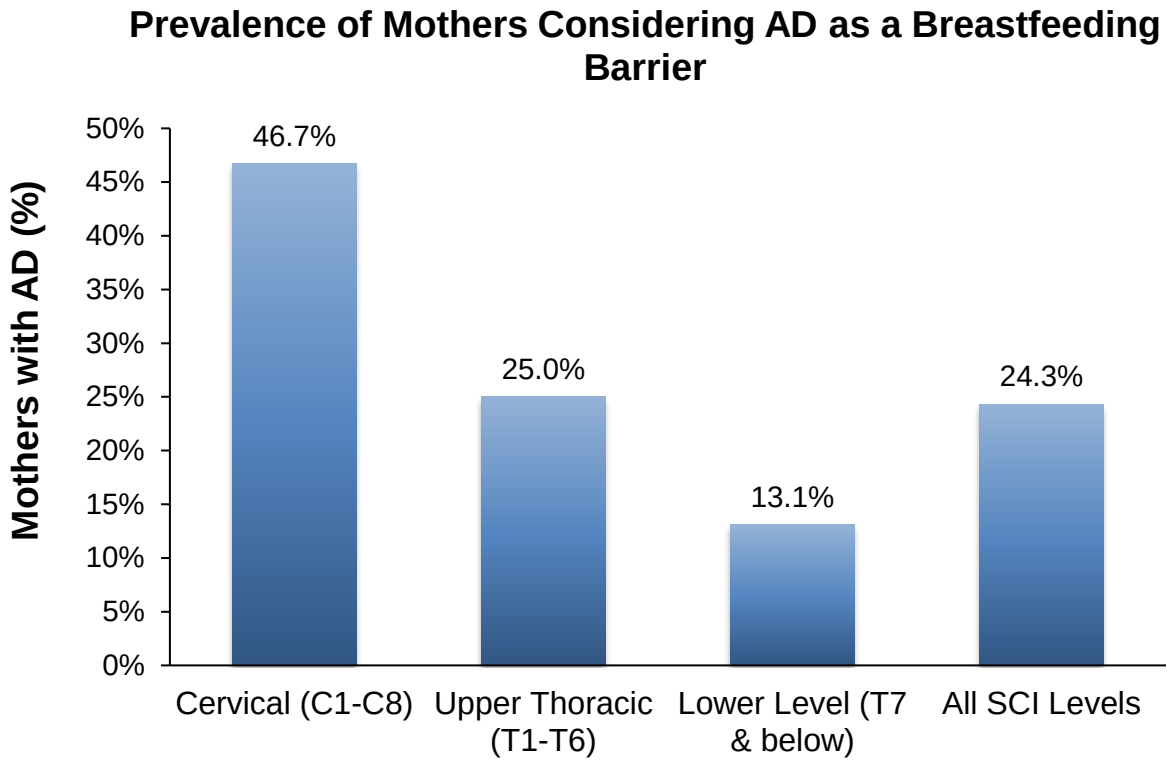
SCI = spinal cord injury. The most commonly used aids for cervical and upper thoracic SCI were nursing pillows/cushions. For lower level SCI, pumping was most frequently attempted.

Figure 5.7 Attempted pumping.



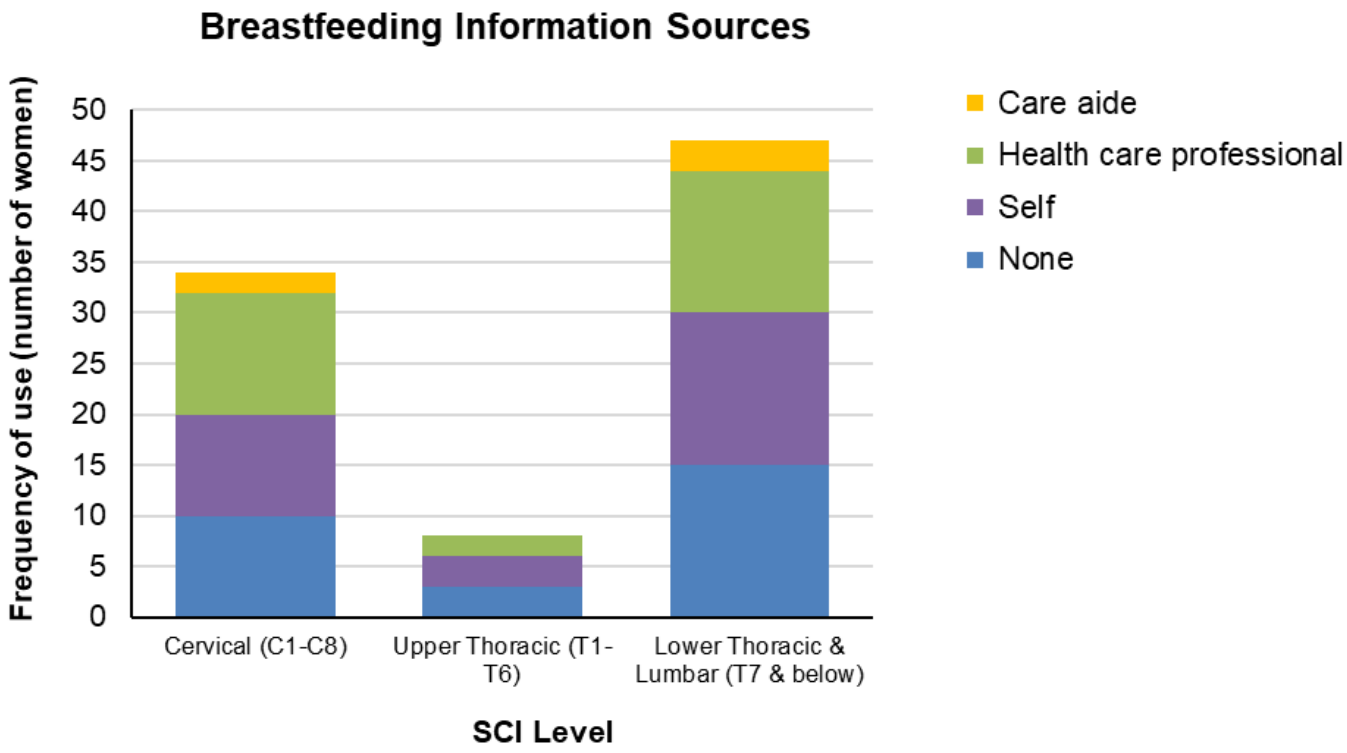
SCI = spinal cord injury. Prevalence of women who attempted to pump for breast milk. Prevalence was highest in the upper thoracic SCI group, followed by lower level SCI, followed by cervical SCI.

Figure 5.8 Autonomic Dysreflexia.



SCI = spinal cord injury; AD = autonomic dysreflexia. Nearly half of the participants with cervical SCI perceived AD to be a barrier during breastfeeding.

Figure 5.9 Education.



SCI = spinal cord injury. Participants indicated the sources they accessed to obtain information specific to breastfeeding with SCI. These sources were collapsed into four categories: 1) None (did not receive any information); 2) Self-research (Internet, other women with SCI, family/friends, pregnancy books); 3) Health care providers (general practitioner, obstetrician, pediatrician, physiatrist, lactation consultant, nurse, midwife); 4) Non-medical care aids (independent living consultant, prenatal course instructor, doula). The proportion of women who either did not receive education on breastfeeding and SCI or primarily searched for this information on their own (categories 1-2) ranged from 50.0% - 66.7% across all groups.

6 QUALITY OF LIFE AND PSYCHOSOCIAL HEALTH IN MOTHERS WITH SPINAL CORD INJURY[4]

6.1 Introduction

As previously described, mothers with SCI face a unique set of challenges not only regarding the physical aspects of breastfeeding (lactation dysfunction, mobility challenges and AD), but from balancing breastfeeding and a complex personal care routine due to the numerous secondary complications of SCI. Considering the increased prevalence of depression and mental health issues that are associated with SCI compared to the general medical population,[150] it is important to evaluate mental health in this population as well. However, there is a significant paucity of research regarding postpartum health in women with SCI, let alone the psychological consequences secondary to breastfeeding difficulties. Therefore, the final objective of this study was to evaluate the state of psychosocial wellbeing and QOL in our cohort of mothers with SCI, with emphasis on breastfeeding self-efficacy, postpartum depression (PPD) and postpartum anxiety (PPA).

6.1.1 Maternal confidence

Maternal confidence, or a mother's confidence in her perceived ability to care for her infant, mediates both breastfeeding outcomes and breastfeeding self-efficacy.[151,152] In a longitudinal study of 64 mothers in the general population, pregnant mothers who lacked confidence in being able to continue breastfeeding until the infant was two months old were twice as likely to discontinue breastfeeding by that timepoint.[153] Given the strong association

[4] A version of Chapter 6 has been submitted for publication. Lee AHX, Wen B, Walter M, Hocaloski S, Hodge K, Sandholt N, Hultling C, Elliott S, & Krassioukov AV. Increased prevalence of postpartum depression and anxiety among women with spinal cord injury.

between maternal confidence and breastfeeding behaviours, this factor is a major construct that should be examined in mothers with SCI (although to date no studies have evaluated the role of maternal confidence in breastfeeding behaviour in women with SCI).

6.1.2 Self-esteem and positive affect

Two major components of emotion-related QOL are self-esteem and positive affect, which both have major implications for psychological wellbeing and life satisfaction. After sustaining SCI, self-esteem is reported to be at least temporarily diminished as the individual adjusts to changes in their self-image and social perceptions.[154] Positive affect refers to subjective feelings of positive emotions including happiness and optimism about the future. A high degree of both self-esteem and positive affect are inversely related to depression and positively correlated with adaptation and improved outcomes after SCI.[155,156] In the general population, stronger social health (i.e. increased self-esteem, greater coping capacity, lower levels of depression and anxiety) is significantly associated with longer breastfeeding duration.[157] This has not been examined in the SCI population.

6.1.3 Breastfeeding self-efficacy

Self-efficacy is defined as the belief that an individual has the ability to succeed in a specific situation. First described in Bandura's 1977 seminal paper on social learning theory, self-efficacy has since been established as one of the most salient determinants of behaviour: expectations of one's own ability of succeeding at a task strongly predicts whether the individual 1) pursues or avoids an activity, and 2) copes with challenges to persist during the task.[158] Higher levels of perceived self-efficacy result in increased persistence and more active efforts towards the task.

Perceived self-efficacy has been shown to be highly predictive of many health behaviours in the general population, including breastfeeding.[159–161] Breastfeeding self-efficacy indicates the degree to which a mother perceives herself able to breastfeed her infant, and is also associated with greater maternal confidence. Using the theoretical framework of social learning and self-efficacy, studies have indicated that breastfeeding self-efficacy is a strong predictor of breastfeeding initiation, duration, efforts and emotional response to difficulties.[162,163] Although several existing instruments measure this construct, the Breastfeeding Self-Efficacy Scale Short-Form (BSES-SF) is the most frequently used and has been validated internationally in several languages.[162,164,165]

With respect to SCI, self-efficacy has been shown to be strongly associated with better mental health over time: a Dutch study interviewed 60 patients with recently acquired SCI within 4 weeks of injury, 3 months later and 6 months after the initial interview. Psychological factors (including self-efficacy) were stable up to 6 months post-discharge and did not change over time. Greater self-efficacy were positively associated with increased scores on the Mental Health Index (a reliable and valid measure of mental health in the SCI population), indicating high self-efficacy is associated with mental wellbeing.[166]

6.1.4 Postpartum depression and anxiety

PPD is an affective disorder characterized by persistent feelings of sadness, guilt or anhedonia that often specifically pertain to the baby. For instance, mothers may experience lack of enjoyment or feelings of inadequacy in caring for their newborn.[167] Left untreated, PPD has been linked to adverse childhood outcomes including developmental delay, lower IQ, and behavioural problems.[168] It is purported that PPD symptoms are more prevalent in women with disability, which may be due to the fact that a higher prevalence of major depressive disorder

(MDD) exists in the SCI population.[78] However, this highly relevant and crucial topic remains understudied in women with SCI. One study of 41 women whose pregnancies after SCI resulted in delivery showed that 13 (35%) women experienced PPD.[77] This a considerably higher rate than the reported prevalence of 13% in the general maternal population.[169]

While the majority of research on postpartum psychiatric disorders is focused on PPD, postpartum anxiety (PPA) is also a widespread condition that affects up to 18% of women in the general maternal population and is often described as being more common than PPD.[170] Like PPD, children of mothers with untreated PPA have been found to develop more behavioural, emotional, and conduct disorders.[168] Although it is suggested that women with SCI experience more anxiety (including fear related to childbirth and care), clinically diagnosed PPA has not been examined in this population.[5,77,115]

In light of the lack of knowledge surrounding maternal psychiatric health in the SCI population, it is imperative to understand the extent to which mothers with SCI experience PPD and PPA compared to the general population so as to guide management strategies. Furthermore, it is imperative to understand psychological QOL of mothers with SCI: this may be done by evaluating key factors that influence breastfeeding behaviour such as maternal self-confidence, self-esteem, positive affect and breastfeeding self-efficacy.

6.2 **Methods**

6.2.1 Participants

Participants (n=102) were recruited as part of a larger-scale retrospective study on motherhood and breastfeeding after SCI (detailed in Chapter 5). Inclusion criteria included women were at least 18 years of age, who breastfed after SCI and who had English comprehension. Data were collected from February through November 2017. Participants were

grouped into the following categories: cervical (C1-C8), upper thoracic (T1-T6) or lower level SCI (lower thoracic & lumbar: T7 & below). All participants provided informed consent using an online form that preceded the survey.

6.2.2 Materials

All questions referred to participants' first child after SCI to control for any adaptation to motherhood after SCI that may occur: challenges may be perceived as less severe after having experienced them previously. Only participants who completed all PPD scale items or all PPA scale items were included in the respective prevalence calculations. Ages are expressed as mean ± standard deviation. To evaluate differences in group mean scores of maternal confidence, self-esteem, positive affect and breastfeeding self-efficacy, a one-way analysis of variance (ANOVA) was performed. Significance was taken at the $p<0.05$ level and a Tukey's post-hoc test was performed. To assess internal consistency of each scale, Cronbach's alpha coefficient was used, where a value of at least 0.70 was deemed acceptable and the scale could be considered reliable.[171] Statistical analysis was completed using IBM SPSS Statistics (V25).

Standardized measures for self-esteem and positive affect were obtained from the Spinal Cord Injury – Quality of Life (SCI-QOL) measurement system, which was developed and validated to evaluate various domains of QOL in the SCI population. All domains have demonstrated internal consistency and test-retest reliability.[172,173] Postpartum depression and anxiety were evaluated using tools from the Pregnancy Risk Assessment Monitoring System (PRAMS), which is administered nationally by the Center for Disease Control in the United States to assess maternal health behaviours and outcomes. Scales from the PRAMS that pertain to postpartum depression and anxiety have been previously used in women with disability.[78,174]

Participants were asked whether they had received clinical diagnoses of MDD prior to childbirth as well as PPD. All instruments are detailed below and found in Appendix E.

6.2.2.1 Maternal Confidence Survey

The Maternal Confidence Survey (MCS) was used evaluate maternal confidence with respect to breastfeeding. Participants were asked to think back to when they were breastfeeding their first infant and to rate their level of confidence at the time in their ability to breastfeed in 10 different retrospective situations using a scale of 1 (very unsure) to 6 (very confident). As previously described, scores for only participants who answered at least 9 of the 10 questions were confidence scores were calculated. This was done by summing the numerical value of each response and dividing by the total number of responses.[175,176] Cronbach's alpha coefficient for this scale was 0.93.

6.2.2.2 Self-Esteem SCI-QOL

General self-esteem was evaluated using the short form of the SCI-QOL Self-Esteem bank, an 8-item scale which presented eight statements describing feelings of lack of self-worth or esteem during the postpartum period for which they were breastfeeding.[177] Participants indicated to what extent they agreed with each statement from a scale of 0 to 4 (0 = always; 4 = rarely) and items are reverse scored so that higher scores indicate a higher level of self-esteem. Cronbach's alpha coefficient was 0.922 in this study, indicating a high degree of reliability.

6.2.2.3 Positive Affect & Wellbeing (PAWB) SCI-QOL

The SCI-QOL PAWB scale was drawn from the SCI-QOL item bank (originally from the Neuro-QOL bank which assesses health-related QOL in adults with neurological conditions).[172,178] The short-form version has 8 items: participants indicate to what extent they

agree with statements that describe feelings of wellbeing, purpose and positive emotions (0 = never, 4 = always). The scale normally prompts participants to indicate their level of positive emotion in general living as a person with SCI: question stems were adapted to ask participants to recall the time they were breastfeeding and indicate their positive affect during that time. A higher score indicated more positive affect during the breastfeeding period. Cronbach's alpha coefficient was 0.93 in this study, indicating very strong reliability of this scale.

6.2.2.4 Breastfeeding Self-Efficacy Scale Short-Form (BSES-SF)

The BSES-SF is a 14-item scale that evaluates a woman's perceived ability to breastfeed her infant in several situations. It is adapted from the 33-item self-report instrument that measures breastfeeding confidence, with scores ranging from 14-70 where higher scores indicate higher levels of self-efficacy.[179] The short-form has demonstrated acceptable validity and reliability in both a Swedish population and Canadian population (Vancouver, British Columbia).[164,165] Internal consistency and reliability was extremely high in the present study (Cronbach's alpha coefficient = 0.97).

6.2.2.5 PPD - Pregnancy Risk Assessment Monitoring System (PRAMS-3D)

Self-reported PPD was evaluated using the PRAMS-3D, which is a 3-item depression subscale from the PRAMS that assesses the incidence of PPD based on frequency of depressive symptoms in the postpartum. Using a cut-off score of 9, the PRAMS-3D is 80% sensitive and has a positive predictive value of 70% for detecting PPD.[180] High reliability was demonstrated in this study (Cronbach's alpha coefficient = 0.86).

6.2.2.6 PPA – Pregnancy Risk Assessment Monitoring System (PRAMS-2A)

Self-reported PPA was evaluated using two anxiety items drawn from the PRAMS. A cut-off score of 6 is 75% sensitive and has a 37% positive predictive value for detecting PPA. This 2-item combination has demonstrated good sensitivity and specificity for detecting true prevalence of anxiety.[174] Good reliability was demonstrated in this study (Cronbach's alpha coefficient = 0.77).

6.3 Results

Participants had SCI ranging from C4-L5 and AIS ranging from A-D. Demographics are shown in Table 6.1. Of the 102 total participants, 101 completed the PRAMS-3D for PPD and 98 completed the PRAMS-2A for PPA.

Between SCI groups, there was no statistically significant difference in mean scores for MCS, PAWB, BSES-SF or the Self-Esteem SCI-QOL scale (Table 6.2). Several general trends (not statistically significant) were demonstrated: maternal confidence and self-esteem during the breastfeeding period were greater with lower levels of SCI (scores were highest for cervical SCI, followed by upper thoracic, and lower level SCI). Both positive affect and breastfeeding self-efficacy was highest in the upper thoracic SCI group, followed by lower level SCI and then cervical SCI.

There were large discrepancies between the prevalence of clinically diagnosed and self-reported PPD, with the latter being up to 4 times greater (Table 6.3). Prevalence of PPD and PPA was greatest in the cervical SCI group, followed by the upper thoracic (T1-T6) then lower SCI (T7-L5) groups. Within the cervical and lower SCI groups, at least 70% of women who had diagnoses of MDD prior to pregnancy met criteria for self-reported PPD. Additionally, 16% of all participants (n=16) had both self-reported PPD and PPA.

6.4 Discussion

6.4.1 Maternal confidence, self-esteem and positive affect

In our cohort, greater maternal confidence was exhibited in groups with lower levels of SCI. Qualitative assessment of maternal confidence was beyond the scope of this study: however, it must be acknowledged that factors related to physical disability have been shown to contribute to mothers' subjective experiences of depression or negative affect.[78] Able-bodied women often experience positive and congratulatory reactions from others regarding their new status as a mother. In comparison, women with physical disability may face disbelief from the public, intrusive questions or even condescension.[181] These factors may all contribute to mothers with SCI lacking confidence in their ability to breastfeed and care for their infants.

Decreased maternal confidence may also be mediated by general levels of self-esteem and confidence as an individual living with SCI. Women with higher levels of SCI exhibited lower self-esteem, although this was not statistically significant and positive affect did not seem to be SCI-level dependent. Further studies should be done to understand whether women with SCI are less confident in their maternal abilities or if this is a residual effect of decreased self-esteem due to their injury.

6.4.2 Breastfeeding self-efficacy

In the literature, a bidirectional effect between breastfeeding self-efficacy and behaviour has been suggested for the general population. Able-bodied mothers who breastfed for over 6 months have reported significantly higher breastfeeding confidence and self-efficacy compared to mothers who could not establish breastfeeding.[157] In our study, although breastfeeding self-efficacy scores were not SCI-level dependent, the mean scores of the BSES -SF ranged from 43.56 to 50.03 in each group. This was lower than the mean score of 57.4 ± 8.8 reported for

primiparous mothers in a study that validated the short-form scale in a Swedish population. These findings suggest that our cohort was less confident in their breastfeeding capability than the able-bodied cohort in the Swedish study.[164] Again, further work should be done to understand if this is due to lower self-esteem after SCI or underestimating one's competence as a mother living with SCI. Given the retrospective nature of this study, it was also not possible to determine whether a lack of breastfeeding self-efficacy existed prior to attempting breastfeeding, or if encountering breastfeeding barriers and difficulties diminished mothers' confidence. Future studies should acknowledge that if the inability to breastfeed does decrease breastfeeding self-efficacy, then maternal confidence and hence breastfeeding success may differ based on parity. For example, encountering breastfeeding difficulties may weaken a mothers' breastfeeding self-efficacy and cause barriers to achieving breastfeeding success for the next child.

6.4.3 Postpartum depression and anxiety

Several studies that previously examined gender differences in depression among individuals with SCI have revealed that women exhibit significantly higher rates of lifetime depression diagnosis than men.[182,183] This finding reflects the depression literature in general populations, as women are estimated to be twice as likely to suffer from depression in their lifetime compared to men.[183] This apparently increased susceptibility to depression in women may be due to a vast array of factors such as gonadal hormones, cultural norms and increased sensitivity to adverse experiences in childhood and adolescence.[184] Mental health care should therefore be emphasized in women with SCI, including prospective or current mothers.

Our findings point to a higher prevalence of PPD (25-37%, range across three SCI levels) and PPA (18-33%, range across three SCI levels) in women with SCI compared to the general maternal population, in which PPD and PPA are estimated to affect 13% and 18% of

women, respectively.[169,170] Women with disability are reported to have greater incidence of perinatal and PPD symptoms compared to able-bodied women. For example, a cross-sectional survey revealed that compared to women without disabilities (n=3,440), women who self-reported having a disability (n=287) were diagnosed more frequently with depression before (39% vs 16%) and after (30% vs. 10%) pregnancy. This discrepancy in diagnosed PPD occurrence persisted even after controlling for diagnosis of depression before and during pregnancy.[78] However, it must be acknowledged that the data on number of subjects compared to other disabilities was not reported, and this study was not SCI-specific.

Certain protective factors against PPD may also be impeded by the unique set of challenges faced by mothers with SCI. For example, breastfeeding is purported to alleviate risk of PPD in the general population.[185] It was recently demonstrated that able-bodied mothers (n=376) who exclusively breastfed their infants for at least three months experienced reduced rates of PPD compared to mothers (n=436) who did not initiate or maintain exclusive breastfeeding.[186] However, as discussed in previous chapters, mothers with SCI may not reach their goals for breastfeeding duration due to factors such as mobility limitations and lactation dysfunction.[81]

External stressors and a history of major depression are well-known risk factors for the onset of PPD, as demonstrated in the general population.[167,187] MDD is significantly more prevalent in individuals with SCI (estimated 9.8 – 38%) compared to the general population (4.7-7.1%).[150,188] Therefore, evaluating diagnosis of MDD (which is a substantial risk factor for PPD) therefore provided more insight into maternal psychiatric health after SCI.

Approximately 70% of participants in our study who met PRAMS-3D criteria for PPD had also been diagnosed with MDD prior to pregnancy. Although not examined specifically in

SCI patients, a prior history of depression has been established as a risk factor for PPD. One study ascertained that 65% of women with a history of MDD (n=26) developed PPD compared to 35% of women with no prior MDD (n=183).[189] A more recent Canadian study cited history of depression as a major variable that increased the risk of both sub-clinical PPD (OR = 2.27, CI = 1.42-3.63) and major PPD (OR = 2.78, CI = 1.56-4.97).[190]

Additionally, outcomes may present differently in acute and chronic SCI: neurological impairment as measured via the AIS scale has been found to be inversely correlated with scores on the Beck's Depression Inventory within the first three months of SCI occurrence.[191] Adapting to neurological-functional deficits and coming to terms with pain interference[192] may also contribute to differences in incidence of depression between acute and chronic SCI.

New mothers who have not yet adjusted to life after SCI may therefore be at greater risk of PPD, and it is difficult to ascertain the extent to which depressive symptoms are attributed to SCI, PPD or PPA. Future studies should consider pre-and post-injury depression history, time elapsed between SCI and childbirth and use validated scales to account for psychosocial wellbeing. Currently, there are existing scales for aspects of psychosocial health (i.e. depression, self-esteem, positive affect and well-being) that have been validated for use in SCI populations.[172]

Although a discrepancy between clinically diagnosed and self-reported PPD has been reported previously, this value is relatively small, in the range of 2%.[187] The larger discrepancy observed in this study, where self-reported PPD was up to 4 times more prevalent than clinically diagnosed PPD, may suggest that clinical PPD is especially under diagnosed in mothers with SCI. Along with health care professional normalization of transient "postpartum blues", clinical PPD may be also be under diagnosis in women with SCI may be due to SCI-specific factors. As

a result of mobility changes following SCI that necessitate the use of aids such as wheelchairs, clinician offices often become physically inaccessible to individuals with SCI. Mothers may require assistance from personnel or transportation services to get to a clinic, and they may also avoid seeking healthcare services due to concerns about stigmatization. SCI also results in a multitude of medical sequelae, including spasticity, bladder and bowel dysfunction, and life-threatening hypertensive episodes termed autonomic dysreflexia. Sexual dysfunction also occurs after SCI, and contraceptive challenges also exist, especially in less mobile women with SCI. Management of these conditions may take precedence over recognition of mental health problems, which are relatively less visible. There is a paucity of research on maternal health and SCI, leading to a lack of satisfactory SCI-specific knowledge among clinicians. As such, mothers with SCI may not feel confident approaching their healthcare providers.

6.4.4 Limitations

As with all retrospective studies, the chance of biased recall and subjectivity of self-reporting psychological wellbeing are limitations that must be acknowledged. In our sample, all the scales demonstrated validity and reliability and have been well validated for use in the general population. However, they have not undergone rigorous validation specifically for women with SCI. Future studies should utilize factor analysis to ascertain construct validity of these instruments.

6.5 Conclusion

We have demonstrated that postpartum psychological wellbeing is impacted by SCI, with implications for breastfeeding and more broadly, QOL. PPD and PPA may be underdiagnosed in women with SCI, even though individuals with SCI are typically at elevated risk of psychological conditions, such as depression and anxiety.

The present findings of this study have significant implications for clinical practice. It is necessary for clinicians and allied health professionals to be aware of the high prevalence of PPD and PPA among mothers with SCI, particularly cervical lesions. Early screening and initiation of evidence-based treatments are recommended to prevent adverse maternal and child health outcomes associated with PPD and PPA. Easily administered screening questionnaires such as the PRAMS subscales are available and validation of such tools in mothers with SCI should be considered.

In addition to vigilant screening for PPD and PPA, increasing general self-esteem, maternal confidence and perceived breastfeeding self-efficacy are major factors that can drastically improve maternal experience and behaviours in women with SCI. It is important to understand whether decreased maternal confidence is attributed to the injury that negatively impacts self-esteem or if women with SCI are less confident in their maternal abilities in a manner that is unrelated their general self-esteem. Clinical interventions that teach infant nursing skills and reduce maternal stress have been recommended for the general population.[152] Adapting these interventions and including postpartum support for the SCI population using a multi-disciplinary approach are recommended. Comprehensive education on postpartum health and the issues surrounding breastfeeding with SCI can empower women to initiate breastfeeding and cope with challenges that arise, thereby improving breastfeeding outcomes and QOL for mothers and their infants.

Table 6.1 Participant demographics.

Characteristic	**Total participants (n=102)**
Age at childbirth	30 ± 6
Time between SCI and childbirth	11 ± 8
Time since childbirth	12 ± 9
Plegia	n (%)
Tetraplegia	31 (30)
Paraplegia	71 (70)
Completeness of injury (AIS)	**n (%)**
AIS A	34 (33)
AIS B	24 (24)
AIS C	24 (24)
AIS D	12 (12)
SCI level	**n (%)**
Cervical, C1-C8	30 (29)
Upper thoracic, T1-T6	12 (12)
Lower level, T7 & below	60 (59)

Age and times are presented as mean years ± SD. Participants' SCI levels ranged from C4-L5. Percentages may not add to 100% due to missing responses. One participant did not provide demographics information.

Table 6.2 Quality of life and psychosocial scores.

Domain	Cervical (n=13)	Upper Thoracic (n=9)	Lower level (n=41)	*p*
	(M ± SD)	**(M ± SD)**	**(M ± SD)**	
MCS	3.00 ± 1.25	3.42 ± 1.24	3.36 ± 1.54	0.507
Self-Esteem	23.50 ± 6.60	24.25 ± 7.70	25.24 ± 7.08	0.536
PAWB	23.00 ± 6.41	25.17 ± 4.69	24.63 ± 5.52	0.372
BSES-SF	43.56 ± 16.70	50.83 ± 12.43	50.03 ± 18.17	0.241

MCS = Maternal Confidence Survey, PAWB = Positive Affect and Well-being, BSES-SF = Breastfeeding Self-Efficacy Scale (Short-Form). Significance was taken at the $p < 0.05$ level.

Table 6.3 Prevalence of postpartum depression and anxiety

	PPD		MDD			PPA	
SCI Level of PPD scale respondents	**Clinical diagnosis**	**Self-reported**	**Clinical diagnosis of MDD before pregnancy**	**Clinical diagnosis of PPD[a]**	**Self-reported PPD[a]**	**Self-reported**	**SCI Level of PPA scale respondents**
Cervical, C1-C8 (n=30)	3 (10)	11 (37)	4 (13)	3 (75)	3 (75)	9 (31)	Cervical, C1-C8 (n=29)
Upper thoracic, T1-T6 (n=12)	1 (8)	4 (33)	1 (8)	0 (0)	0 (0)	3 (25)	Upper thoracic, T1-T6 (n=12)
Lower level, T7 and below (n=59)	4 (7)	15 (25)	10 (17)	0 (0)	7 (70)	10 (18[b])	Lower level, T7 and below (n=57)

SCI = spinal cord injury, PPD = postpartum depression, MDD = major depressive disorder, PPA = postpartum anxiety. Data is presented as number of individuals and percentage, i.e. (%).

[a] Percentage given for mothers with a history of MDD in each SCI group who developed PPD.

[b] Percentage given for mothers with lower thoracic & lumbar injury who fully completed the 2-item PPA scale (n=57).

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APPENDIX A. Pilot Study Questionnaire 1

Demographics and SCI

1. What is your age group? (select one)
    - Under 17 years old
    - 18-24 years old
    - 25-34 years old
    - 35-44 years old
    - 45-54 years old
    - 55-64 years old
    - 65 years or older
    - Prefer not to answer
2. What country do you currently live in?
3. How many years since you had your spinal cord injury?
4. Which of the following best describes where your spinal cord injury occurred? (select one)
    - Injury in my neck (i.e. cervical spine)
    - Injury in my upper back (i.e. upper thoracic spine)
    - Injury in my mid back (i.e. lower thoracic spine)
    - Injury in my lower back (i.e. lumbar spine)
5. Which of the following best describes the classification of your spinal cord injury? (select one)
    - Quadriplegia (also referred to as Tetraplegia) – an injury that has affected your arms, hands, trunk and legs.
    - Paraplegia – an injury that has affected your trunk and legs (includes cauda equina).
6. Please indicate which of the following best describes the completeness of your spinal cord injury? (select one)
    - Complete
    - Incomplete
    - Don’t know
7. If known, please indicate your neurological injury level and American Spinal Injury Association Impairment Score (AIS)
8. Which of the following best describes the cause of your spinal cord injury?
    a. Traumatic spinal cord injury causes
    b. Non-traumatic spinal cord injury causes
9. Traumatic spinal cord injury causes (select one)
    - Transport – a transport injury event (e.g., crashes and other injurious events occurring in the course of transportation, and/or injury resulting from events involving a device being used primarily for conveying persons or goods from one place to another).
    - Fall – falling by stumbling, jumping, slipping (e.g., falling from a building or structure, falling while being carried [i.e., being dropped], falling to the ground).
    - Assault (blunt) – striking, crushing, abrading or rubbing (e.g., planned/intended injury arising from contact with a person, object or animal that is non-penetrating).

- Assault (penetrating) – cutting, tearing, severing, stabbing or piercing (e.g., planned/ intended injury arising from contact with a bullet, knife or other implement that punctures).
- Sports – professional and non-professional sports and exercise (e.g., sport competition, practising for competition, working out/ improving physical health, jogging, playing street hockey, wrestling, cliff-jumping).
- Other traumatic cause – injury, not related to an assault, caused by a blunt or penetrating external force of any magnitude (e.g., explosion, crushed by a crowd/stampede, struck by a falling object), please specify: _____

10. Non-traumatic spinal cord injury causes
    - Tumour
    - Infection
    - Stroke within the spinal cord (and not in the brain)
    - Degenerative spine
    - Congenital
    - Neurological syndrome (e.g. transverse myelitis)
    - Surgical complication
    - Other non-traumatic cause, please specify: _____
11. What is your primary mobility aid? (select one)
    - Power wheelchair
    - Manual wheelchair
    - Walker
    - Cane
    - None
    - Other, please specify: _____
12. Do you use any aids to support grip or dexterity in your hands (eg universal cuff)?
    - Yes
    - No

Pregnancy & Childbirth

13. How many pregnancies have you had since your SCI?
14. How many live births have you had since your SCI?
15. How many years after your injury did your pregnancy(ies) occur?
16. In which country and city did you give birth?

Breastfeeding

17. Did you receive information on breastfeeding prior to delivery?
    - Yes
    - No
18. If yes, from whom?
19. Did you access any of the following supports for breastfeeding (select all that apply):
    - Family Physician
    - Midwife
    - Doula

- Obstetrician
- Nurse Practitioner
- Physiatrist (Rehabilitation Medicine Doctor)
- Lactation Consultant
- Public Health Nurse
- Community breastfeeding support group
- Other_____

20. Did you access information on breastfeeding and SCI from any of the following sources (select all that apply):
    - Internet
    - Pregnancy books
    - Another woman with SCI
    - Physiatrist
    - Other_____
21. Did you try and breastfeed?
    - Yes
    - No
22. Were you able to breastfeed successfully?
    - Yes
    - No
23. How long did you breastfeed for?
24. How long did you try to breastfeed?
25. Did you try any medications to help with breastfeeding?
26. Did you try any of the following to help with breastfeeding? (select all that apply):
    - Hand expressing
    - Pumping
    - Complementary/ Alternative medicines
    - Alternative breastfeeding positions
    - Other: _____
27. Did any of the above help with breastfeeding?
28. Many women with SCI note that they have better success in breastfeeding using one breast rather than the other; did you experience this?
    - Yes
    - No
29. Did you have any mobility issues in terms of positioning for breast feeding?
    - Yes
    - No
30. Did your hand function impact how you breastfed your baby?
    - Yes
    - No
31. Do you have full sensation in both of your breasts?
    - Yes
    - No
32. Were you able to tell by sensation if your child was latched properly?
    - Yes

- No

33. Did you experience the sensation of “let down” (the involuntary flow of breast milk) while breastfeeding)
    - Yes
    - No
34. Did you ever experience Autonomic Dysreflexia (uncontrolled spikes in blood pressure in response to stimulus below the level of injury) while breastfeeding?
    - Yes
    - No
35. Did you ever experience changes with spasticity while breastfeeding?
    - Yes
    - No
36. Did you receive adequate information on alternatives to breastfeeding e.g. bottle feeding, Supplemental Nutrition System etc.?
    - Yes
    - No
37. What kind of information or support would have been useful to you when you were breastfeeding/ contemplating breastfeeding?

APPENDIX B. Pilot Study Questionnaire 2

1. How old were you when you had your baby(-ies)?
2. Did you smoke (tobacco and/or marijuana) during pregnancy or while breastfeeding?
    - Yes
    - No
3. Were any of your children born prematurely (i.e. 3 or more weeks early)?
    - Yes
    - No
4. How were each of your children delivered?
    - Planned vaginal
    - Planned caesarean
    - Emergency caesarean
    - Induced vaginal
    - Assisted vaginal (includes the use of forceps or vacuum)

5. If you were able to breastfeed, for how long did you breastfeed exclusively? (i.e. at what age did you introduce formula or any other supplementary nutrition, even water. Breast milk that was obtained through pumping and then fed to child is still considered to be breastfeeding) (Dropdown box for each baby to indicate years, months, weeks)

6. If you were able to breastfeed exclusively initially, why did you introduce formula or any other supplementary nutrition? *Please choose the (up to) five most important reasons and rank them by typing a number (1 being most important) in the box beside it.*
    a) ___ I did so by my own choice, I thought the time was right
    b) ___ I never intended to breastfeed exclusively
    c) ___ I was advised by health care professionals to do so
    d) ___ The baby wasn't growing according to growth plan
    e) ___ I wasn't producing enough milk
    f) ___ I couldn't find the time for both breastfeeding and personal care
    g) ___ I wasn't getting enough sleep
    h) ___ I had to go back to work
    i) ___ I had various difficulties breastfeeding (see question below)
    j) ___ I didn't breastfeed at all
    k) ___ I was sad or depressed
    l) ___ Other, please specify

7. If you breastfed your children, why did you choose to stop breastfeeding completely? *Please choose the (up to) five most important reasons and rank them by typing a number (1 being most important) in the box beside it.*
    a) ___ I did so by my own choice, I thought the time was right
    b) ___ I was advised by health care professionals to do so
    c) ___ I wasn't producing enough milk
    d) ___ I couldn't find time for both breastfeeding and personal care
    e) ___ I wasn't getting enough sleep

f) ___ I had to go back to work
g) ___ I had various difficulties breastfeeding (see question below)
h) ___ I didn't breastfeed
i) ___ I was sad or depressed
j) ___ Other, please specify

8. Please specify to what extent the reasons you gave in question 7 influenced your decision to introduce formula or any other supplementary nutrition. Use the below scale of 1-5, where 1= no influence and 5 = very strong influence.

i) Reason 1
No influence (1) - Weak influence (2) - Some influence (3) - Strong influence (4) - Very Strong influence (5)

ii) Reason 2
No influence (1) - Weak influence (2) - Some influence (3) - Strong influence (4) - Very Strong influence (5)

iii) Reason 3
No influence (1) - Weak influence (2) - Some influence (3) - Strong influence (4) - Very Strong influence (5)

iv) Reason 4
No influence (1) - Weak influence (2) - Some influence (3) - Strong influence (4) - Very Strong influence (5)

v) Reason 5
No influence (1) - Weak influence (2) - Some influence (3) - Strong influence (4) - Very Strong influence (5)

9. Did you experience any of the below complications while breastfeeding your child? Please specify how severe you perceived this problem by using the scale of 1-5, where 1 = very mild problem and 5 = very severe problem.
a) Autonomic Dysreflexia
b) Insufficient milk production or ejection
c) Problems with positioning
d) Latching difficulties
e) Baby unwilling to feed (i.e. sleepy, uninterested)
f) Baby spitting up
g) Increased spasticity
h) Sleep deprivation
i) Leaky breasts
j) Engorged breasts
k) Clogged milk ducts
l) Mastitis
m) Breast abscess
n) Sore nipples
o) Sadness/Depression
p) Other, specify_____

APPENDIX C. Lactation and Breastfeeding After SCI - Survey 1 (February 2017)

1) DEMOGRAPHICS AND SCI

1. What year were you born?

2. In what country do you currently live?

- ○ Canada
- ○ United States
- ○ Sweden
- ○ Italy
- ○ Other, please specify... _____

3. How would you rate your English language ability?

- ○ 1 – Poor (Difficulty reading/comprehending written English)
- ○ 2
- ○ 3 - Fair (Some difficulty reading/comprehending written English)
- ○ 4
- ○ 5 - Excellent (No difficulty reading/comprehending written English)

4. How many years has it been since you had your spinal cord injury?

5. Which of the following best describes where your spinal cord injury occurred? (select one)

- ○ Injury in my neck (i.e. cervical spine = C1-C8)
- ○ Injury in my upper back (i.e. upper thoracic spine = T1-T6)
- ○ Injury in my mid back (i.e. lower thoracic spine = T7-T12)
- ○ Injury in my lower back (i.e. lumbar spine = L1-L5)

6. Which of the following best describes the classification of your spinal cord injury? (select one)

- ○ Quadriplegia (also referred to as Tetraplegia) – an injury that has affected your arms, hands, trunk and legs.
- ○ Paraplegia – an injury that has affected your trunk and legs (includes cauda equina).

7. Which of the following best describes the completeness of your spinal cord injury? (select one)

- ○ Complete (no sensation or movement below the level of injury)
- ○ Incomplete (some sensation or movement below the level of injury)
- ○ Don't know

8. If known, please indicate your neurological injury level and American Spinal Injury Association Impairment Score (AIS)

- ○ ASIA A - Complete
- ○ ASIA B - Sensory Incomplete
- ○ ASIA C - Motor Incomplete
- ○ ASIA D - Motor Incomplete
- ○ ASIA E - Normal sensory and motor function
- ○ Don't know (describe your injury to the best of your ability) _____

9. Which of the following best describes the cause of your spinal cord injury?

- ○ Traumatic SCI
- ○ Non-traumatic SCI

10. If your injury was from a traumatic cause, please choose one of the following:

- ○ Transport – a transport injury event (e.g., crashes and other injurious events occurring in the course of transportation, and/or injury resulting from events involving a device being used primarily for conveying persons or goods from one place to another).
- ○ Fall – falling by stumbling, jumping, slipping (e.g., falling from a building or structure, falling while being carried [i.e., being dropped], falling to the ground).
- ○ Assault (blunt) – striking, crushing, abrading or rubbing (e.g., planned/intended injury arising from contact with a person, object or animal that is non-penetrating).
- ○ Assault (penetrating) – cutting, tearing, severing, stabbing or piercing (e.g., planned/ intended injury arising from contact with a bullet, knife or other implement that punctures).
- ○ Sports – professional and non-professional sports and exercise (e.g., sport competition, practicing for competition, working out/ improving physical health, jogging, playing street hockey, wrestling, cliff-jumping).
- ○ Other traumatic cause – injury, not related to an assault, caused by a blunt or penetrating external force of any magnitude (e.g., explosion, crushed by a crowd/stampede, struck by a falling object, spine surgery), please specify... _____

11. If your injury was from a non-traumatic cause, please choose one of the following:

- ○ Tumour or cancer
- ○ Infection
- ○ Stroke within the spinal cord (and not in the brain)
- ○ Degenerative spine
- ○ Congenital
- ○ Neurological syndrome (e.g. transverse myelitis or multiple sclerosis/MS)
- ○ Surgical complication
- ○ Other, please specify... _____

12. What is your primary mobility aid?
Please choose one of the following:
○ Power wheelchair
○ Manual wheelchair
○ Walker
○ Cane
○ None
○ Other, please specify... _____

13. I was able to independently:
Select all that apply:
☐ Pick up my baby
☐ Hold my baby
☐ Support my baby in a breastfeeding position
☐ Latch my baby (feed my baby)

14. In order to pick up, hold or support my baby while in the breastfeeding position, I used the help of:
☐ Spouse/partner/family/friends (eg. To place the baby in my arms)
☐ Lactation consultant or nurse (eg. To hold the baby in the correct position)
☐ Nursing pillow/cushion
☐ Baby carrier, wrap, sling or harness
☐ Alternative positions (list most effective position): _____
☐ Other, please specify... _____

2) PREGNANCY AND BIRTH

15. Please indicate the year of each of your live birth(s) (includes both vaginal and Caesarean births).
If you have twins, please list the elder twin before the younger twin. For example, if you had 1 single child followed by twins, list your eldest child as the 1st baby, your elder twin as the 2nd baby and your younger twin as the 3rd baby for this question and all questions afterward.

For each baby: [ ]

16. Were any of your children born prematurely (ie 3 or more weeks early)?

	Yes	No
For each baby:	○	○

17. Did you experience any miscarriages?
○ Yes ○ No
If so, what year(s) did you experience a miscarriage?
[ ]

18. How were your children delivered?

Please read each choice carefully. (Questions repeat for each child the participant has had)

- ○ planned caesarean
- ○ emergency caesarean
- ○ induced vaginal (medication was given to help induce labor)
- ○ assisted vaginal (ie includes the use of forceps or vacuum)
- ○ unplanned vaginal (eg. premature)
- ○ planned vaginal

19. Did your baby need to spend time in the Neonatal Intensive Care Unit (NICU) in the hospital after delivery?

○ Yes ○ No

If yes: how long did your baby have to spend in the NICU?

Open text for each baby: [ ]

20. If your baby spent time in the NICU, did you hand express or pump your breasts?

	No	Within the first hour of birth	After one hour	Within 6 hours of birth	6-24 hours after birth	More than 24 hours after birth
For each baby	○	○	○	○	○	○

21. When did your baby first go skin-to-skin with you?

	Within the first hour of birth	After one hour	Within 6 hours of birth	6-24 hours after birth	More than 24 hours after birth
For each baby	○	○	○	○	○

22. When did your baby first breastfeed?

	Within the first hour of birth	After one hour	Within 6 hours of birth	6-24 hours after birth	More than 24 hours after birth
For each baby	○	○	○	○	○

3) LACTATION AND BREASTFEEDING: DURATION, COMPLICATIONS, AIDS

23. Are you aware of any risk factors (other than your injury) that might affect your breastfeeding experience (e.g. breast reduction surgery, inverted nipples)?

[ ]

24. Are you aware of any risk factors that might affect your baby's ability to breastfeed (e.g. prematurity, tongue-tie)?

[ ]

25. Did you have full sensation in both of your breasts around the time your baby was born?

○ Yes ○ No

26. Did your breasts feel fuller 2-4 days after delivery?

○ Yes ○ No

27. Did you notice that your breasts felt fuller before a feed and softer after a feed?

○ Yes ○ No

28. Did your baby breastfeed from both breasts at each feeding?

○ Yes ○ No

29. Many women with SCI note that they have better success in breastfeeding using one breast rather than the other; did you experience this?

○ Yes ○ No

30. Did you experience the sensation of "let down"?

Some women may feel a tingling "pins-and-needles" feeling and the milk starts to flow involuntarily.

○ Yes ○ No

31. Were you able to tell by sensation if your child was latched properly?

○ Yes ○ No

32. In order for my baby to latch, I used the help of:

☐ Spouse/partner/family/friends (eg. To help baby grasp my breast)
☐ Lactation consultant or nurse (eg. To help baby grasp my breast)
☐ Nursing pillow/cushion
☐ Baby carrier, wrap, sling or harness
☐ Alternative positions (list most effective position): _____
☐ Other, please specify... _____

33. If you were able to breastfeed, how long did you breastfeed for?

For each baby

○ Not at all
○ A few days
○ A few weeks
○ 3 months or less
○ 6 months or less
○ More than 6 months to 1 year
○ More than 1 year

34. Did you breastfeed for as long as you wanted to?

○ Yes ○ No

35. Did you experience any of the below complications while breastfeeding your child? Please specify how severe you perceived this problem by using the scale of 1-5, where 1= No problem and 5 = very severe problem.

For choice A: Autonomic Dysreflexia is when your blood pressure rises rapidly due to a stimulus below your injury level. Symptoms may or may not include headaches, flushing of the face, sweating above the level of injury, cold skin below the level of injury, nausea, blurred vision and slowed heart-rate.

	1 = no problem	2	3	4	5 = very severe problem
Autonomic Dysreflexia	○	○	○	○	○
Urinary tract infection (UTI)	○	○	○	○	○
Worsening or increased spasticity (Spasticity is involuntary, sudden stiffening of muscles which can result in flexing or jerking around)	○	○	○	○	○
Improved spasticity or decrease in your overall spasticity level	○	○	○	○	○
Bladder spasms	○	○	○	○	○
Worsening of neuropathic or SCI-related pain at or below your level of injury	○	○	○	○	○
Insufficient milk production	○	○	○	○	○
No evidence of the milk “letting down”	○	○	○	○	○
It took too long for my milk to come in	○	○	○	○	○
Problems with positioning due to my mobility limitations	○	○	○	○	○
Problems with my hand function which disrupted breastfeeding	○	○	○	○	○
Problems with positioning due to seating set up of my wheelchair (i.e. armrests in the way, no armrests, lateral supports in back cushion got in the way, etc.)	○	○	○	○	○
Impaired access to baby for night feeds (eg. Took a great deal of energy to transfer, feed baby, return to bed and fall back asleep)	○	○	○	○	○
Latching difficulties	○	○	○	○	○
Baby unwilling to feed (ie sleepy, uninterested)	○	○	○	○	○
Baby nursed too often	○	○	○	○	○
Baby wouldn’t wake up to nurse regularly enough	○	○	○	○	○
Baby spitting up	○	○	○	○	○
Baby didn’t gain enough weight or lost too much weight	○	○	○	○	○
Sleep deprivation	○	○	○	○	○
Leaky breasts	○	○	○	○	○
Engorged breasts	○	○	○	○	○
Clogged milk ducts	○	○	○	○	○
Mastitis (infection of the breast), yeast infection of the breast or breast abscess	○	○	○	○	○
Breast pain	○	○	○	○	○

Sore, cracked or bleeding nipples	○	○	○	○	○
Sadness/Depression	○	○	○	○	○
I needed to take medications that were not compatible with breastfeeding (i.e. unsafe for my baby)	○	○	○	○	○
Other, please specify below:	○	○	○	○	○

If you experienced any other major complications while breastfeeding your child or have any comments, please comment below:_____

36. If you were able to breastfeed exclusively at first, why did you introduce formula or any other supplementary nutrition?

Please choose (up to) five most important reasons and rank them by priority (1 being most important).

	1 - most important	2	3 - moderately important	4	5 - least important
I didn't breastfeed at all	○	○	○	○	○
I did so by my own choice; I thought the time was right	○	○	○	○	○
I was advised by health care professionals to do so	○	○	○	○	○
I never intended to breastfeed exclusively	○	○	○	○	○
The baby wasn't growing according to growth norms	○	○	○	○	○
I wasn't producing enough milk	○	○	○	○	○
My baby was unhappy	○	○	○	○	○
I couldn't find the time for both breastfeeding and personal care (eg. complete tasks of daily living such as shower, meal prep, toileting, etc)	○	○	○	○	○
I wasn't getting enough sleep	○	○	○	○	○
I had to go back to work/school	○	○	○	○	○
I had various difficulties breastfeeding	○	○	○	○	○
I was sad or depressed	○	○	○	○	○
Problems with Autonomic Dysreflexia during breastfeeding that could not be resolved	○	○	○	○	○
Pain during breastfeeding due to nipple damage	○	○	○	○	○
Pain during breastfeeding due to sucking/letdown	○	○	○	○	○
Pressure to bottle feed from family/friends	○	○	○	○	○
I believe that formula is as good as breastfeeding or that formula is better	○	○	○	○	○
I wanted my body back to myself	○	○	○	○	○
My baby was about 6 months old and ready	○	○	○	○	○

to start solids						
My baby was old enough that the difference between breast milk and formula no longer mattered	○	○	○	○	○	
I was embarrassed to breastfeed in public	○	○	○	○	○	
I did not have the help I needed (from people I lived with or care aids)	○	○	○	○	○	
Other, please specify below:	○	○	○	○	○	
I didn't breastfeed at all	○	○	○	○	○	
I did so by my own choice; I thought the time was right	○	○	○	○	○	
I was advised by health care professionals to do so	○	○	○	○	○	
I never intended to breastfeed exclusively	○	○	○	○	○	
The baby wasn't growing according to growth norms	○	○	○	○	○	
I wasn't producing enough milk	○	○	○	○	○	
My baby was unhappy	○	○	○	○	○	
I couldn't find the time for both breastfeeding and personal care (eg. complete tasks of daily living such as shower, meal prep, toileting, etc)	○	○	○	○	○	
I wasn't getting enough sleep	○	○	○	○	○	
I had to go back to work/school	○	○	○	○	○	
I had various difficulties breastfeeding	○	○	○	○	○	
I was sad or depressed	○	○	○	○	○	
Problems with Autonomic Dysreflexia during breastfeeding that could not be resolved	○	○	○	○	○	
Pain during breastfeeding due to nipple damage	○	○	○	○	○	
Pain during breastfeeding due to sucking/letdown	○	○	○	○	○	
Pressure to bottle feed from family/friends	○	○	○	○	○	
I believe that formula is as good as breastfeeding or that formula is better	○	○	○	○	○	
I wanted my body back to myself	○	○	○	○	○	
My baby was about 6 months old and ready to start solids	○	○	○	○	○	
My baby was old enough that the difference between breast milk and formula no longer mattered	○	○	○	○	○	
I was embarrassed to breastfeed in public	○	○	○	○	○	
I did not have the help I needed (from people I lived with or care aids)	○	○	○	○	○	
Other, please specify below:	○	○	○	○	○	

If you had any other major reason for switching to formula/supplementary nutrition, please comment below:

37. If you were able to breastfeed, why did you choose to stop breastfeeding completely?
Please choose (up to) five most important reasons and rank them by priority (1 being most important).

	1 - most important	2	3 - moderately important	4	5 - least important
I didn't breastfeed at all	○	○	○	○	○
I did so by my own choice; I thought the time was right	○	○	○	○	○
I was advised by health care professionals to do so	○	○	○	○	○
I wasn't producing enough milk	○	○	○	○	○
I couldn't find the time for both breastfeeding and personal care (eg. complete tasks of daily living such as shower, meal prep, toileting, etc)	○	○	○	○	○
I wasn't getting enough sleep	○	○	○	○	○
I had to go back to work/school	○	○	○	○	○
I was sad or depressed	○	○	○	○	○
Problems with Autonomic Dysreflexia during breastfeeding that could not be resolved	○	○	○	○	○
Pain during breastfeeding due to nipple damage	○	○	○	○	○
Pain during breastfeeding due to sucking/letdown	○	○	○	○	○
I was embarrassed to breastfeed in public	○	○	○	○	○
I did not have the help I needed (from people I lived with or care aids)	○	○	○	○	○
My baby refused (nursing strike)	○	○	○	○	○
Other, please specify below:	○	○	○	○	○

If you had any other major reason to stop breastfeeding, please comment below:

38. If you pumped for breastmilk for any baby, why did you choose this method?

- ☐ I did not pump
- ☐ difficulty getting baby to latch
- ☐ inadequate milk supply from breastfeeding alone
- ☐ less painful than breastfeeding
- ☐ to manage Autonomic Dysreflexia symptoms
- ☐ ability to measure how much baby was drinking
- ☐ challenges in positioning baby when breastfeeding
- ☐ allowed caregivers to help with feeding

☐ I was embarrassed to breastfeed in public
☐ Other, please specify... _____

39. On average, how many mLs per pumping session were you able to produce?

For each baby:
- ○ None
- ○ 10 mL or under
- ○ 30 mL
- ○ 50 mL
- ○ 70 mL
- ○ 90 mL
- ○ 120 mL
- ○ Over 120 mL

40. Did you try any medications to help with breastfeeding?

For each baby: [ ]

41. Did you try any of the following to help with breastfeeding?

Select all that apply.

For each baby:
- ☐ Hand expressing
- ☐ Pumping
- ☐ Complementary/ Alternative medicines
- ☐ Alternative breastfeeding positions
- ☐ Supplemental Nursing System
- ☐ Nipple shield
- ☐ Other, please specify below...

41. Please specify what other methods you tried to help with breastfeeding.

For each baby: [ ]

42. Which of these methods selected actually did help?

For each baby: [ ]

4) INFORMATION AND EDUCATION ON BREASTFEEDING

43. Did you plan to breastfeed prior to delivery/birth of your baby?

	No, I did not plan to breastfeed	Yes, I planned to breastfeed for a few days	Yes, I planned to breastfeed for several weeks	Yes, I planned to breastfeed for several months or more	Yes, I planned to only pump and give breastmilk in bottles
For each baby:	○	○	○	○	○

44. Which sources were the most helpful in providing information on breastfeeding with SCI? Please select your top 5 sources and score them from 1-5 (1 being the most helpful and 5 being the least)

If you did not receive any info, please rank the first option as 1 ("I did not receive any breastfeeding information with SCI") and leave the rest blank.

	1 - most helpful	2	3	4	5 - least helpful
I did not receive any breastfeeding information with SCI	○	○	○	○	○
A licensed midwife	○	○	○	○	○
Doula (an assistant who provides physical/emotional support during childbirth, but in a non-medical capacity)	○	○	○	○	○
Obstetrician	○	○	○	○	○
Pediatrician	○	○	○	○	○
GP (Family doctor)	○	○	○	○	○
Nurse Practitioner (who was not a lactation consultant)	○	○	○	○	○
Lactation consultant	○	○	○	○	○
Public Health Nurse	○	○	○	○	○
Prenatal Course Instructor	○	○	○	○	○
Physiatrist (Rehabilitation Medicine Doctor)	○	○	○	○	○
Independent Living Resources Centre (programs providing breastfeeding assistance for hire and peer support. In British Columbia this includes Choice in Support for Independent Living)	○	○	○	○	○
Community breastfeeding support group	○	○	○	○	○
Pregnancy books	○	○	○	○	○
Internet	○	○	○	○	○
Another woman with SCI	○	○	○	○	○
Family/friends	○	○	○	○	○
Other (please specify below):	○	○	○	○	○

If you indicated another important source for information on breastfeeding with SCI, please specify:

45. Did you have any help from someone with breastfeeding once you were at home?

Select all that apply

- ☐ No
- ☐ Yes, from family and friends
- ☐ Yes, from a lactation consultant at home
- ☐ Yes, from a nurse or lactation consultant through an independent living resources centre
- ☐ Yes, from a lactation consultant at the hospital or community health department
- ☐ Yes, from a healthcare practitioner in my home
- ☐ Yes, from my midwife or doula

□ Yes, from a healthcare professional at the hospital or a clinic
□ Yes, from my paid caregiver (did they have experience or training in lactation?)
_____

6) EMOTIONAL HEALTH

46. Was breastfeeding an enjoyable experience for you?
○ Yes, I feel it enhanced my bond with my child
○ Yes, but it was challenging at times
○ No, but I continued to breastfeed due to the health benefits
○ No, I felt physically uncomfortable breastfeeding
○ No, I felt uncomfortable breastfeeding due to social/emotional reasons (i.e. uncomfortable feeding in public, felt judged, etc.)
○ No, I felt like a failure each time I attempted to breastfeed as I was not successful in providing adequate nutrition via breastfeeding for my child.

47. Below is a list of feelings and experiences some women experience after childbirth.
Please describe how often you felt or experienced this way after your baby was born by rating each choice from 1 to 5:

	1 = Never	2 = Rarely	3 = Sometimes	4 = Often	5 = Always
I felt down, depressed, hopeless or sad	○	○	○	○	○
I felt hopeless	○	○	○	○	○
I felt slowed down	○	○	○	○	○
I felt like I was experiencing the same adjustment to motherhood issues as other mothers	○	○	○	○	○
I felt panicky	○	○	○	○	○
I felt restless	○	○	○	○	○

48. Were you ever diagnosed with postpartum depression?
○ Yes ○ No

49. Prior to your pregnancy/ies, were you ever diagnosed with clinical depression?
○ Yes ○ No

50. While breastfeeding your child, did you take prescription medication for your depression?
○ Yes ○ No

51. Did you enroll in counselling for your depression at any point in time after having your baby?
○ Yes ○ No

52. Prior to your pregnancy/ies, did you ever experience high levels of anxiety?
○ Yes ○ No

53. After your baby was born, how often did you feel anxious?

○ Always ○ Often ○ Sometimes ○ Rarely ○ Never

54. Please respond to each statement by indicating to what extent you have felt this way while you were breastfeeding your baby

	Never	Rarely	Sometimes	Often	Always
Because of my injury, I was unhappy with who I am	○	○	○	○	○
I felt bad about myself	○	○	○	○	○
I felt I was no longer a "whole person"	○	○	○	○	○
I felt embarrassed about my physical limitations	○	○	○	○	○
I felt inferior to my friends or family	○	○	○	○	○
Because of my injury, I felt embarrassed in social situations	○	○	○	○	○
I was unhappy about how my injury affect my appearance	○	○	○	○	○
I felt invisible to other people	○	○	○	○	○

55. Please respond to each statement by indicating to what extent you have felt this way while you were breastfeeding your baby

	Never	Rarely	Sometimes	Often	Always
I thought positively about my future	○	○	○	○	○
My life had meaning	○	○	○	○	○
My life had purpose	○	○	○	○	○
I was thankful to be alive	○	○	○	○	○
I had a sense of well-being	○	○	○	○	○
I had a sense of balance in my life	○	○	○	○	○
I felt cheerful	○	○	○	○	○
I was living life to the fullest	○	○	○	○	○

56. Rate your confidence in your ability to breastfeed in the following circumstances

	1 = Very Unsure	2	3	4	5	6 = Very Confident
During the hospital stay	○	○	○	○	○	○
During the first week or two at home	○	○	○	○	○	○
For 6 weeks after that	○	○	○	○	○	○
If my baby was born by C-section	○	○	○	○	○	○
If my baby was premature and had to stay in the hospital	○	○	○	○	○	○
If my breasts hurt	○	○	○	○	○	○

If my baby had a hard time learning to suck	○	○	○	○	○	○
If I was in a public place	○	○	○	○	○	○
If I became sick	○	○	○	○	○	○
If my baby seemed hungry all the time	○	○	○	○	○	○

57. Please think back to how you felt when you were breastfeeding your infant, and your confidence to do each of the following tasks. When I was breastfeeding, I could always….

	1 = Not confident at all	2	3	4	5 = Completely confident
Determine that my baby was getting enough milk	○	○	○	○	○
Successfully cope with breastfeeding like I could with other challenging tasks	○	○	○	○	○
Breastfeed my baby without formula as a supplement	○	○	○	○	○
Ensure that my baby was properly latched on for the whole feed	○	○	○	○	○
Manage the breastfeeding situation to my satisfaction	○	○	○	○	○
Manage to breastfeed even if my baby was crying	○	○	○	○	○
Keep wanting to breastfeed	○	○	○	○	○
Comfortably breastfeed with my family members present	○	○	○	○	○
Be satisfied with my breastfeeding experience	○	○	○	○	○
Deal with the fact that breastfeeding could be time-consuming	○	○	○	○	○
Finish feeding my baby on 1 breast before switching to the other breast	○	○	○	○	○
Continue to breastfeed my baby for every feed	○	○	○	○	○
Manage to keep up with my baby's breastfeeding demands	○	○	○	○	○
Tell when my baby had finished breastfeeding	○	○	○	○	○

58. Any other comments?

APPENDIX D. Lactation and Breastfeeding After SCI - Survey 2 (June 2017)

1) DEMOGRAPHICS AND SCI

1. What is your date of birth? Enter in the format: DD/MM/YYYY

2. In what country do you currently live?

○ Canada ○ United States

○ Sweden ○ Italy ○ Other, please specify:_____

3. How would you rate your English language ability?

○ 1 – Poor (Difficulty reading/comprehending written English)
○ 2
○ 3 - Fair (Some difficulty reading/comprehending written English)
○ 4
○ 5 - Excellent (No difficulty reading/comprehending written English)

4. How many years has it been since you had your spinal cord injury?

5. Which of the following best describes where your spinal cord injury occurred? (Select one)

○ Injury in my neck (i.e. cervical spine = C1-C8)
○ Injury in my upper back (i.e. upper thoracic spine = T1-T6)
○ Injury in my mid back (i.e. lower thoracic spine = T7-T12)
○ Injury in my lower back (i.e. lumbar spine = L1-L5)

6. Please type in the specific level of your spinal cord injury (for example: C6).
If you do not know, please type "don't know".

7. Which of the following best describes the classification of your spinal cord injury? (select one)

○ Quadriplegia (also referred to as Tetraplegia): an injury that has affected your arms, hands, trunk and legs.
○ Paraplegia: an injury that has affected your trunk and legs (includes cauda equina).

8. Which of the following best describes the completeness of your spinal cord injury? (select one)

○ Complete (no sensation or movement below the level of injury) ○ Don't know

○ Incomplete (some sensation or movement below the level of injury)

9. If known, please indicate your neurological injury level and American Spinal Injury Association Impairment Score (AIS)

- ○ ASIA A - Complete
- ○ ASIA B - Sensory Incomplete
- ○ ASIA C - Motor Incomplete
- ○ ASIA D - Motor Incomplete
- ○ ASIA E - Normal sensory and motor function
- ○ Don't know (describe your injury to the best of your ability) _____

10. Which of the following best describes the cause of your spinal cord injury?

○ Traumatic SCI ○ Non-traumatic SCI

11. If your injury was from a traumatic cause, please choose one of the following:

- ○ Transport – a transport injury event (e.g., crashes and other injurious events occurring in the course of transportation, and/ or injury resulting from events involving a device being used primarily for conveying persons or goods from one place to another).
- ○ Fall – falling by stumbling, jumping, slipping (e.g., falling from a building or structure, falling while being carried [i.e., being dropped], falling to the ground).
- ○ Assault (blunt) – striking, crushing, abrading or rubbing (e.g., planned/intended injury arising from contact with a person, object or animal that is non-penetrating).
- ○ Assault (penetrating) – cutting, tearing, severing, stabbing or piercing (e.g., planned/ intended injury arising from contact with a bullet, knife or other implement that punctures).
- ○ Sports – professional and non-professional sports and exercise (e.g., sport competition, practising for competition, working out/ improving physical health, jogging, playing street hockey, wrestling, cliff-jumping).
- ○ Other traumatic cause – injury, not related to an assault, caused by a blunt or penetrating external force of any magnitude (e.g., explosion, crushed by a crowd/stampede, struck by a falling object, spine surgery), please specify... _____

12. If your injury was from a non-traumatic cause, please choose one of the following:

- ○ Tumour or cancer
- ○ Infection
- ○ Stroke within the spinal cord (and not in the brain)
- ○ Degenerative spine
- ○ Congenital
- ○ Neurological syndrome (e.g. transverse myelitis or multiple sclerosis/MS)
- ○ Surgical complication
- ○ Other, please specify... _____

13. What is your primary mobility aid?
Please choose one of the following:

○	Power wheelchair	○	Walker	○	None
○	Manual wheelchair	○	Cane	○	Other, please specify: _____

14. I was able to independently:
Select all that apply:

☐	Pick up my baby	☐	Support my baby in a breastfeeding position
☐	Hold my baby	☐	Latch my baby (feed my baby)

15. In order to pick up, hold or support my baby while in the breastfeeding position, I used the help of:

☐ Spouse/partner/family/friends (eg. To place the baby in my arms)
☐ Lactation consultant or nurse (eg. To hold the baby in the correct position)
☐ Nursing pillow/cushion
☐ Baby carrier, wrap, sling or harness
☐ Alternative positions (list most effective position): _____
☐ Other, please specify... _____

2) PREGNANCY AND BIRTH

16. Please indicate the year of each of your live birth(s) . This includes vaginal AND Caesarean births.
If you have twins, please list the elder twin before the younger twin. For example, if you had 1 single child followed by twins, list your eldest child as the 1st baby, your elder twin as the 2nd baby and your younger twin as the 3rd baby for this question and all questions afterward.
For each baby: [ ]

17. Were any of your children born prematurely (ie 3 or more weeks early)?

	Yes	No
For each baby:	○	○

18. Did you experience any miscarriages?
○ Yes ○ No
If so, what year(s) did you experience a miscarriage?
[ ]

19. How were your children delivered?
Please read each choice carefully.
For each baby:
○ planned caesarean
○ emergency caesarean
○ induced vaginal (medication was given to help induce labor)

○ assisted vaginal (ie includes the use of forceps or vacuum)
○ unplanned vaginal (eg. premature)
○ planned vaginal

20. Did your baby need to spend time in the Neonatal Intensive Care Unit (NICU) in the hospital after delivery?

	Yes	No
For each baby:	○	○

If yes: how long did your baby have to spend in the NICU?

For each baby: ☐

21. If your baby spent time in the NICU, did you hand express or pump your breasts?

	No	Within the first hour of birth	After one hour	Within 6 hours of birth	6-24 hours after birth	More than 24 hours after birth
For each baby:	○	○	○	○	○	○

22. When did your baby first go skin-to-skin with you?

	Within the first hour of birth	After one hour	Within 6 hours of birth	6-24 hours after birth	More than 24 hours after birth
For each baby:	○	○	○	○	○

23. When did your baby first breastfeed?

	Within the first hour of birth	After one hour	Within 6 hours of birth	6-24 hours after birth	More than 24 hours after birth
For each baby:	○	○	○	○	○

3) LACTATION AND BREASTFEEDING: DURATION, COMPLICATIONS, AIDS

24. Did your physician advise you against breastfeeding?

○ Yes, because they considered it too risky with my injury
○ Yes, because of other risk factors unrelated to my injury
○ My physician did not discuss breastfeeding with me
○ No, I was encouraged to breastfeed
○ Other, please specify... _____

25. Are you aware of any risk factors (other than your injury) that might affect your breastfeeding experience?

☐ Breast reduction surgery
☐ Inverted nipples
☐ Baby unable to latch
☐ Medication (please specify): _____
☐ Other, please specify... _____

26. Are you aware of any risk factors that might affect your baby's ability to breastfeed?

☐ Prematurity
☐ Tongue-tie or lip-tie
☐ Other, please specify... _____

27. Did you have full sensation in both of your breasts around the time your baby was born?

○ Yes ○ No

28. Did your breasts feel fuller 2-4 days after delivery?

○ Yes ○ No

29. Did you notice that your breasts felt fuller before a feed and softer after a feed?

○ Yes ○ No

30. Did your baby breastfeed from both breasts at each feeding?

○ Yes ○ No

31. Many women with SCI note that they have better success in breastfeeding using one breast rather than the other; did you experience this?

○ Yes ○ No

32. Did you experience the sensation of "let down"?

Some women may feel a tingling "pins-and-needles" feeling and the milk starts to flow involuntarily.

○ Yes ○ No

33. Were you able to tell by sensation if your child was latched properly?

○ Yes ○ No

34. In order for my baby to latch, I used the help of:

☐ Spouse/partner/family/friends (eg. To help baby grasp my breast)
☐ Lactation consultant or nurse (eg. To help baby grasp my breast)
☐ Nursing pillow/cushion
☐ Baby carrier, wrap, sling or harness
☐ Alternative positions (list most effective position): _____
☐ Other, please specify... _____

35. If you were able to breastfeed, how long did you breastfeed for?

For each baby:
- ○ Not at all
- ○ A few days
- ○ A few weeks
- ○ 3 months or less
- ○ 6 months or less
- ○ More than 6 months to 1 year
- ○ More than 1 year

36. Did you breastfeed for as long as you wanted to?

○ Yes ○ No

37. Did you experience any of the following complications while breastfeeding your child? Please specify how severe you perceived this problem by using a scale of 1-5 (1 = No problem, 5 = very severe problem).

Note for first choice: Autonomic Dysreflexia is when your blood pressure rises rapidly due to a stimulus below your injury level. Symptoms may or may not include headaches, flushing of the face, sweating above the level of injury, cold skin below the level of injury, nausea, blurred vision and slowed heart-rate.

	1 = no problem	2 = slight problem	3 = somewhat of a problem	4 = moderate problem	5 = severe problem
Autonomic Dysreflexia	○	○	○	○	○
Urinary tract infection (UTI)	○	○	○	○	○
Worsening or increased spasticity (Spasticity is involuntary, sudden stiffening of muscles which can result in flexing or jerking around)	○	○	○	○	○
Problems with my hand function or positioning due to mobility limitations which disrupted breastfeeding	○	○	○	○	○
Impaired access to baby for night feeds (eg. physical difficulty or not enough energy to transfer, feed baby, return to bed and fall back asleep)	○	○	○	○	○
Insufficient milk production	○	○	○	○	○
No evidence of the milk “letting down”	○	○	○	○	○
Latching difficulties	○	○	○	○	○
Baby unwilling to feed (ie sleepy, uninterested)	○	○	○	○	○
Baby nursed too often	○	○	○	○	○

Baby spitting up	○	○	○	○	○
Sleep deprivation	○	○	○	○	○
Mastitis (infection of the breast), yeast infection of the breast or breast abscess	○	○	○	○	○
Breast pain	○	○	○	○	○
Sore, cracked or bleeding nipples	○	○	○	○	○
Leaky breasts	○	○	○	○	○
Engorged breasts	○	○	○	○	○
I needed to take medications that were not compatible with breastfeeding (i.e. unsafe for my baby)	○	○	○	○	○
I did not have the assistance I needed to help physically facilitate breastfeeding (partner, care aide, someone in the household, etc.)	○	○	○	○	○
Other (please specify in text box below):	○	○	○	○	○

If you experienced any other major complications while breastfeeding your child or have any comments, please comment below:

38. If you were able to breastfeed exclusively at first, why did you introduce formula or any other supplementary nutrition?

Please choose (up to) five most important reasons and rank their priority by selecting a number (1 being most important, 5 being least important).

	1 - most important	2	3 - moderately important	4	5 - least important
I didn't breastfeed at all	○	○	○	○	○
I did so by my own choice; I thought the time was right	○	○	○	○	○
I was advised by health care professionals to do so	○	○	○	○	○
I never intended to breastfeed exclusively	○	○	○	○	○
The baby wasn't growing according to growth norms	○	○	○	○	○
I wasn't producing enough milk	○	○	○	○	○
My baby was unhappy	○	○	○	○	○
I couldn't find the time for both breastfeeding and personal care (eg. complete tasks of daily living such as shower, meal prep, toileting, etc)	○	○	○	○	○
I wasn't getting enough sleep	○	○	○	○	○
I had to go back to work/school	○	○	○	○	○
I had various difficulties breastfeeding	○	○	○	○	○

I was sad or depressed	○	○ ○	○ ○
Problems with Autonomic Dysreflexia during breastfeeding that could not be resolved	○	○ ○	○ ○
Pain during breastfeeding due to nipple damage	○	○ ○	○ ○
Pain during breastfeeding due to sucking/letdown	○	○ ○	○ ○
Pressure to bottle feed from family/friends	○	○ ○	○ ○
I believe that formula is as good as breastfeeding or that formula is better	○	○ ○	○ ○
I wanted my body back to myself	○	○ ○	○ ○
My baby was about 6 months old and ready to start solids	○	○ ○	○ ○
My baby was old enough that the difference between breast milk and formula no longer mattered	○	○ ○	○ ○
I was embarrassed to breastfeed in public	○	○ ○	○ ○
I did not have the help I needed (from people I lived with or care aids)	○	○ ○	○ ○
Other, please specify below:	○	○ ○	○ ○

If you had any other major reason for switching to formula/supplementary nutrition, please comment below:

39. If you were able to breastfeed, why did you choose to stop breastfeeding completely?
Please choose (up to) five most important reasons and rank their priority by selecting a number (1 being most important, 5 being least important).

	1 - most important	2	3 - moderately important	4	5 - least important
I didn’t breastfeed at all	○	○	○	○	○
I did so by my own choice; I thought the time was right	○	○	○	○	○
I was advised by health care professionals to do so	○	○	○	○	○
I wasn't producing enough milk	○	○	○	○	○
I couldn’t find the time for both breastfeeding and personal care (eg. complete tasks of daily living such as shower, meal prep, toileting, etc)	○	○	○	○	○
I wasn’t getting enough sleep	○	○	○	○	○
I had to go back to work/school	○	○	○	○	○
I was sad or depressed	○	○	○	○	○
Problems with Autonomic Dysreflexia during breastfeeding that could not be resolved	○	○	○	○	○

Pain during breastfeeding due to nipple damage	○	○ ○	○ ○
Pain during breastfeeding due to sucking/let-down	○	○ ○	○ ○
I was embarrassed to breastfeed in public	○	○ ○	○ ○
I did not have the help I needed (from people I lived with or care aids)	○	○ ○	○ ○
My baby refused (nursing strike)	○	○ ○	○ ○
Other, please specify below:	○	○ ○	○ ○

If you had any other major reason to stop breastfeeding, please comment below:

40. If you pumped for breastmilk for any baby, why did you choose this method?
Note: if you select "I did not pump", skip to question 43.

- □ I did not pump
- □ difficulty getting baby to latch
- □ inadequate milk supply from breastfeeding alone
- □ less painful than breastfeeding
- □ to manage Autonomic Dysreflexia symptoms
- □ ability to measure how much baby was drinking
- □ challenges in positioning baby when breastfeeding
- □ allowed caregivers to help with feeding
- □ I was embarrassed to breastfeed in public
- □ Other, please specify why you chose to pump: _____

41. On average, how many mLs per pumping session were you able to produce?
If you did not pump for a particular baby, leave the box beside that baby blank.
For each baby:
- ○ None (I tried but did not produce milk)
- ○ 10 mL or under
- ○ 30 mL
- ○ 50 mL
- ○ 70 mL
- ○ 90 mL
- ○ 120 mL
- ○ Over 120 mL

42. Was the amount you pumped enough to feed your baby? ()
For each baby ○ Yes ○ No

43. Did you try any medications to help with breastfeeding?
For each baby: [ ]

44. Did you try any of the following to help with breastfeeding?
Select all that apply.
For each baby: □ Hand expressing

☐ Pumping

☐ Complementary/ Alternative medicines

☐ Alternative breastfeeding positions

☐ Supplemental Nursing System

☐ Nipple shield

☐ Other, please specify below...

Please specify what other methods you tried to help with breastfeeding.
For each baby:

45. Which of these methods selected actually did help?
For each baby:

4) INFORMATION AND EDUCATION ON BREASTFEEDING
46. Did you plan to breastfeed prior to delivery/birth of your baby?

	No, I did not plan to breastfeed	Yes, I planned to breastfeed for a few days	Yes, I planned to breastfeed for several weeks	Yes, I planned to breastfeed for several months or more	Yes, I planned to only pump and give breastmilk in bottles
For each baby	○	○	○	○	○

47. For your each baby, which sources were the most helpful in providing information on breastfeeding with SCI? Please select your top 5 sources and score them from 1-5 (1 being the most helpful and 5 being the least). If you did not receive any info, please rank the first option as 1 ("I did not receive any breastfeeding information with SCI") and leave the rest blank.

	1 - most helpful	2	3	4	5 - least helpful
I did not receive any breastfeeding information with SCI	○	○	○	○	○
A licensed midwife	○	○	○	○	○
Doula (an assistant who provides physical/emotional support during childbirth, but in a non-medical capacity)	○	○	○	○	○
Obstetrician	○	○	○	○	○
Pediatrician	○	○	○	○	○
GP (Family doctor)	○	○	○	○	○

Nurse Practitioner (who was not a lactation consultant)	○	○	○	○	○
Lactation consultant	○	○	○	○	○
Public Health Nurse	○	○	○	○	○
Prenatal Course Instructor	○	○	○	○	○
Physiatrist (Rehabilitation Medicine Doctor)	○	○	○	○	○
Independent Living Resources Centre (programs providing breastfeeding assistance for hire and peer support. In British Columbia this includes Choice in Support for Independent Living)	○	○	○	○	○
Community breastfeeding support group	○	○	○	○	○
Pregnancy books	○	○	○	○	○
Internet	○	○	○	○	○
Another woman with SCI	○	○	○	○	○
Family/friends	○	○	○	○	○
Other (please specify below):	○	○	○	○	○

If you indicated another important source for information on breastfeeding with SCI for your baby, please specify:

48. Did you have any help from someone with breastfeeding once you were at home?
Select all that apply

☐ No
☐ Yes, from family and friends
☐ Yes, from a lactation consultant at home
☐ Yes, from a nurse or lactation consultant through an independent living resources centre
☐ Yes, from a lactation consultant at the hospital or community health department
☐ Yes, from a healthcare practitioner in my home
☐ Yes, from my midwife or doula
☐ Yes, from a healthcare professional at the hospital or a clinic
☐ Yes, from my paid caregiver

Did your paid caregiver have experience or training in lactation?

○ Yes ○ No ○ Don't know

6) EMOTIONAL HEALTH

49. Was breastfeeding an enjoyable experience for you?
Choose the option that best describes how you felt most of the time during the breastfeeding period.

○ Yes, I feel it enhanced my bond with my child
○ Yes, but it was challenging at times
○ No, but I continued to breastfeed due to the health benefits
○ No, I felt physically uncomfortable breastfeeding
○ No, I felt uncomfortable breastfeeding due to social/emotional reasons (i.e.

uncomfortable feeding in public, felt judged, etc.)

○ No, I felt like a failure each time I attempted to breastfeed as I was not successful in providing adequate nutrition via breastfeeding for my child.

50. Below is a list of feelings and experiences some women experience after childbirth. Please describe how often you felt or experienced this way after your baby was born by rating each choice from 1 to 5:

	1 = Never	2 = Rarely	3 = Sometimes	4 = Often	5 = Always
I felt down, depressed, hopeless or sad	○	○	○	○	○
I felt hopeless	○	○	○	○	○
I felt slowed down	○	○	○	○	○
I felt like I was experiencing the same adjustment to motherhood issues as other mothers	○	○	○	○	○
I felt panicky	○	○	○	○	○
I felt restless	○	○	○	○	○

51. Were you ever diagnosed with postpartum depression?

○ Yes ○ No

52. Prior to your pregnancy/ies, were you ever diagnosed with clinical depression?

○ Yes ○ No

53. While breastfeeding your child, did you take prescription medication for your depression?

○ Yes ○ No

54. Did you enroll in counselling for your depression at any point in time after having your baby?

○ Yes ○ No

55. Prior to your pregnancy/ies, did you ever experience high levels of anxiety?

○ Yes ○ No

56. After your baby was born, how often did you feel anxious?

○ Always
○ Often
○ Sometimes
○ Rarely
○ Never

57. Please respond to each statement by indicating to what extent you have felt this way while you were breastfeeding your baby

	Never	Rarely	Sometimes	Often	Always
Because of my injury, I was unhappy with who I am	○	○	○	○	○
I felt bad about myself	○	○	○	○	○
I felt I was no longer a "whole person"	○	○	○	○	○
I felt embarrassed about my physical limitations	○	○	○	○	○
I felt inferior to my friends or family	○	○	○	○	○
Because of my injury, I felt embarrassed in social situations	○	○	○	○	○
I was unhappy about how my injury affect my appearance	○	○	○	○	○
I felt invisible to other people	○	○	○	○	○

58. Please respond to each statement by indicating to what extent you have felt this way while you were breastfeeding your baby

	Never	Rarely	Sometimes	Often	Always
I thought positively about my future	○	○	○	○	○
My life had meaning	○	○	○	○	○
My life had purpose	○	○	○	○	○
I was thankful to be alive	○	○	○	○	○
I had a sense of well-being	○	○	○	○	○
I had a sense of balance in my life	○	○	○	○	○
I felt cheerful	○	○	○	○	○
I was living life to the fullest	○	○	○	○	○

59. Rate your confidence in your ability to breastfeed in the following circumstances

(1 = very unsure, 6 = very confident) If the situation did not apply to you, answer how confident you would have felt breastfeeding if you were in that situation, hypothetically.

	1 = Very Unsure	2	3	4	5	6 = Very Confident
During the hospital stay	○	○	○	○	○	○
During the first week or two at home	○	○	○	○	○	○
For 6 weeks after that	○	○	○	○	○	○
If my baby was born by C-section	○	○	○	○	○	○
If my baby was premature and had to stay in the	○	○	○	○	○	○

hospital						
If my breasts hurt	○	○	○	○	○	○
If my baby had a hard time learning to suck	○	○	○	○	○	○
If I was in a public place	○	○	○	○	○	○
If I became sick	○	○	○	○	○	○
If my baby seemed hungry all the time	○	○	○	○	○	○

60. Please think back to how you felt when you were breastfeeding your infant, and your confidence to do each of the following tasks.

When I was breastfeeding, I could always….

	1 = Not confident at all	2	3	4	5 = Completely confident
Determine that my baby was getting enough milk	○	○	○	○	○
Successfully cope with breastfeeding like I could with other challenging tasks	○	○	○	○	○
Breastfeed my baby without formula as a supplement	○	○	○	○	○
Ensure that my baby was properly latched on for the whole feed	○	○	○	○	○
Manage the breastfeeding situation to my satisfaction	○	○	○	○	○
Manage to breastfeed even if my baby was crying	○	○	○	○	○
Keep wanting to breastfeed	○	○	○	○	○
Comfortably breastfeed with my family members present	○	○	○	○	○
Be satisfied with my breastfeeding experience	○	○	○	○	○
Deal with the fact that breastfeeding could be time-consuming	○	○	○	○	○
Finish feeding my baby on 1 breast before switching to the other breast	○	○	○	○	○
Continue to breastfeed my baby for every feed	○	○	○	○	○
Manage to keep up with my baby's breastfeeding demands	○	○	○	○	○
Tell when my baby had finished breastfeeding	○	○	○	○	○

61. Any other comments?

APPENDIX E. Quality of Life & Psychosocial Measures

Self-Esteem SCI-QOL
Please respond to each statement by indicating to what extent you have felt this way while you were breastfeeding your baby (Never, Rarely, Sometimes, Often, Always).

- Because of my injury, I was unhappy with who I am
- I felt bad about myself
- I felt I was no longer a "whole person"
- I felt embarrassed about my physical limitations
- I felt inferior to my friends or family
- Because of my injury, I felt embarrassed in social situations
- I was unhappy about how my injury affected my appearance
- I felt invisible to other people

Positive Affect & Well-Being (PAWB) SCI-QOL
Please respond to each question or statement by indicating to what extent you have felt this way while you were breastfeeding your baby (Never, Rarely, Sometimes, Often, Always).

- I thought positively about my future
- My life had meaning
- My life had purpose
- I was thankful to be alive
- I had a sense of well-being
- I had a sense of balance in my life
- I felt cheerful
- I was living life to the fullest

Maternal Confidence Survey
Rate your confidence in your ability to breastfeed in the following circumstances (1 = very unsure, 6 = very confident).

- During the hospital stay
- During the first week or two at home
- For 6 weeks after that
- If my baby was born by C-section
- If my baby was premature and had to stay in the hospital
- If my breasts hurt
- If my baby had a hard time learning to suck
- If I was in a public place
- If I became sick
- If my baby seemed hungry all the time

Breastfeeding Self-Efficacy Scale

Please think back to how you felt when you were breastfeeding your infant, and your confidence to do each of the following tasks. Please rate your confidence on a scale from 1 to 5 where 1 = not confident at all to 5 = completely confident.

When I was breastfeeding, I could always….

- Determine that my baby was getting enough milk
- Successfully cope with breastfeeding like I could with other challenging tasks
- Breastfeed my baby without formula as a supplement
- Ensure that my baby was properly latched on for the whole feed
- Manage the breastfeeding situation to my satisfaction
- Manage to breastfeed even if my baby was crying
- Keep wanting to breastfeed
- Comfortably breastfeed with my family members present
- Be satisfied with my breastfeeding experience
- Deal with the fact that breastfeeding could be time-consuming
- Finish feeding my baby on 1 breast before switching to the other breast
- Continue to breastfeed my baby for every feed
- Manage to keep up with my baby's breastfeeding demands
- Tell when my baby had finished breastfeeding

Postpartum Depression: 3-item depression scale from Pregnancy Risk Assessment Monitoring System (PRAMS-3D)

Below is a list of feelings and experiences some women experience after childbirth. Please describe how often you felt or experienced this way after your baby was born by rating each choice from 1 to 5 (never = 1, rarely = 2, sometimes = 3, often = 4, always = 5):

- I felt down, depressed, hopeless or sad
- I felt hopeless
- I felt slowed down

Postpartum Anxiety: 2-item anxiety subscale from Pregnancy Risk Assessment Monitoring System (PRAMS-2A)

Below is a list of feelings and experiences some women experience after childbirth. Please describe how often you felt or experienced this way after your baby was born by rating each choice from 1 to 5 (never = 1, rarely = 2, sometimes = 3, often = 4, always = 5):

- I felt panicky
- I felt restless