Motherhood after Spinal Cord Injury: Breastfeeding, Autonomic Dysreflexia, and Psychosocial Health: Clinical Practice Guidelines

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The World Health Organization (WHO) recommends that children be breastfed exclusively for the first 6 months of age. This recommendation may prove challenging for women with spinal cord injury (SCI) who face unique challenges and barriers to breastfeeding due to the impact of SCI on mobility and physiology. Tailored provision of care from health care professionals (HCPs) is important in helping women navigate these potential barriers. Yet, HCPs often lack the confidence and SCI-specific knowledge to meet the needs of mothers with SCI. An international panel of clinicians, researchers, consultants, and women with lived experience was formed to create an accessible resource that can address this gap. A comprehensive survey on breastfeeding complications, challenges, resources, and quality of life of mothers with SCI was conducted, along with an environmental scan to evaluate existing postpartum guidelines and assess their relevance and usability as recommendations for breastfeeding after SCI. Building on this work, this article provides evidence-based recommendations for HCPs, including but not limited to general practitioners, obstetricians, pediatricians, physiatrists, lactation consultants, nurses, midwives, occupational therapists, and physiotherapists who work with prospective and current mothers with SCI.
Key words: *breastfeeding, motherhood, spinal cord injury*

Introduction

Background and clinical significance

Spinal cord injury (SCI) is a devastating event that impacts an individual's physiology, mental health, and various aspects of quality of life. SCI often results in increased reliance on health care services. Yet, a recent national survey on the needs of 1549 Canadians with SCI found that a lack of SCI-specific knowledge among health care professionals (HCPs)

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was a major hindrance to meeting their health care needs. In fact, only 59% of respondents reported the SCI knowledge of their service professionals to be satisfactory "to some degree," while 29% considered it "not at all satisfactory."[1]

Women living with SCI are still capable of giving birth to and breastfeeding their child. However, special considerations must be made by HCPs to help women navigate unique SCI-related challenges. It is unclear whether HCPs involved in the care of women with SCI are adequately equipped to meet these maternal health needs.

In 2003, the World Health Organization (WHO) recommended that children be breastfed exclusively for the first 6 months of age, with continued breastfeeding along with appropriate complementary foods for up to 2 years and beyond.[2] There is evidence to suggest that there are additional health benefits associated with breastfeeding for 2 years or more, including reduced risk of obesity and type II diabetes in children.[3] A Canadian national survey of women in the general population ($N = 6421$) who gave birth during 2005-2006 found that 51.7% of mothers were exclusively breastfeeding at 3 months after birth and 14.4% at 6 months after birth.[4] In comparison, a recent survey of mothers with SCI from Australia, Canada, Sweden, the United Kingdom, and the United States ($N = 102$) found that women with cervical SCI were 2.61 times less likely than women with SCI at or below T7 to meet the WHO's recommended minimum of 6 months of exclusive breastfeeding.[5] Furthermore, our recent review of the quality of guidelines for breastfeeding available worldwide reveals significant gaps in information tailored to mothers with SCI.[6] Given the immense physical and emotional benefits of breastfeeding for both the mother and child,[7] providing evidence-based guidelines for HCPs to support successful breastfeeding with SCI is imperative for improving health outcomes for mothers and children.[8]

Objectives and scope

The purpose of this article is to provide evidence-based recommendations for HCPs who work with prospective and current mothers with SCI, including but not limited to general practitioners, obstetricians, pediatricians, physiatrists, lactation consultants, nurses, midwives, occupational therapists, and physiotherapists. These clinical practice guidelines will be complemented by a separate consumer guide outlining recommendations for people with lived experience in lay language.

Specifically, the following questions on lactation and breastfeeding will be addressed:

- How can breastfeeding and health outcomes for mothers with SCI and their children be improved?
- How can clinicians, HCPs, and caretakers improve supports and services while respecting the diverse values and preferences of mothers with SCI?
- Does providing evidence-based research to HCPs assist them in making the most beneficial and nonjudgmental clinical decisions about breastfeeding facilitation and complications associated with SCI?
- How can HCPs aid mothers with SCI in optimizing the mother–child interaction? Does evaluating their breastfeeding experience allow them to make informed decisions about how to best integrate breastfeeding into day-to-day routines?
- How can improving awareness for all consumers (mothers with SCI, support networks, and HCPs) by providing information on breastfeeding with SCI be integrated into practice?
- How can the use of health care resources and community supports be promoted to facilitate optimal breastfeeding and independent living for mothers with SCI?
- How should future education and integration of evidence-based recommendations into lactation practice, breastfeeding support services, and community groups be approached to be most effective?
- How can evidence-based information help raise awareness and improve mental health screening, supports, and services to mothers with SCI, who are at heightened risk of postpartum distress, depression, and anxiety?

Methods and Development Process

In April 2015, an international pilot survey of 52 mothers with SCI was conducted to identify the most prevalent concerns and challenges in breastfeeding.[8] In October 2016, funding was obtained from the Craig H. Neilsen Foundation via a Quality of Life Project Grant, which allowed the research team to establish a larger-scale study with an expanded international sample of 102 mothers with SCI and breastfeeding experience. An expert panel of clinicians, researchers and consultants, and individuals with lived experience was recruited to develop two comprehensive questionnaires on breastfeeding complications, challenges, educational resources, and quality of life. Over the period of one year, the panel systematically interpreted findings and discussed applications to maternal care and lactation practice.

In addition, an environmental scan was performed to evaluate existing postpartum guidelines and assess the relevance and usability of their recommendations for breastfeeding after SCI. English-language guidelines published between 2000 and 2019 were selected, with a target audience of HCPs and caretakers/support networks for women with SCI. The following search terms were utilized on PubMed: breastfeeding, lactation, nursing, postpartum, guidelines, spinal cord injury, physical disability, disability. In addition, collaborators/reviewers were asked to share national/institutional guidelines (if applicable) for their country or health authority.

Our search yielded 19 documents (see **Appendix B**). The majority of the documents did not reference women with disabilities or SCI, and some did not mention breastfeeding. The strengths and limitations of each of these documents are noted in **Appendix B**. Of the 19 documents, seven were selected based on their focus on breastfeeding information. These seven documents were then evaluated by the panel using Agree II tool[9] to appraise the inclusion of both SCI and breastfeeding information.[6]

Based on findings from the pilot study, gaps in the scientific literature, consultants' input, and results of the environmental scan, the present guidelines were developed to expand upon the current body of clinical knowledge and update recommendations for best practice based on foundational evidence. Supported by the Craig H. Neilsen Foundation's Creating Opportunity and Independence Grant, this document was developed from 2019 to 2021 by an international group (with members from Canada, Denmark, Greece, India, Italy, South Africa, Sweden, the United Kingdom, and the United States) consisting of mothers with SCI with breastfeeding experience as well as clinicians and scientists with SCI experience (physicians, nurse, lactation consultants, occupational therapists, social workers, and independent living consultants). This document was then reviewed by three independent reviewers with SCI research and clinical expertise. Throughout this process, the benefits of breastfeeding were evaluated against the potential health risks specific to SCI.

These guidelines will be reevaluated every 5 years by updated systematic review and panel agreement. As more research and experience is gathered, advice and tools on how these guidelines can be put into practice will be recommended in various countries (see **Appendix C**).

Rating of recommendations

The recommendations provided here were based on evidence regarding breastfeeding following SCI from the literature and environmental scan (see **Appendix B**). The panel based its evidence ratings primarily on research evidence, guidelines, expert opinions, clinical experience, and lived experience of mothers with SCI. For individual consumers, decisions are best made by considering these recommendations in the context of clinical judgment, the latter informed by specifics regarding each woman's risk factors, potential for adverse effects, and resource availability. Ratings encompass the level of scientific evidence, the

Table 1. Nomenclature for rating of evidence and strength of panel agreement[9]

Level	Description
I	Evidence based on randomized controlled clinical trials (or meta-analysis of such trials) of adequate size to ensure a low risk of incorporating false-positive or false-negative results.
II	Evidence based on randomized controlled trials that are too small to provide Level I evidence. These may show either positive trends that are not statistically significant or no trends and are associated with a high risk of false-negative results.
III	Evidence based on nonrandomized, controlled, or cohort studies; case series; case-controlled studies; or cross-sectional studies.
IV	Evidence based on the opinion of respected authorities or expert committees as indicated in published consensus conferences or guidelines.
V	Evidence that expresses the opinion of those individuals who have written and reviewed this guideline, based on experience, knowledge of the relevant literature, and discussions with peers.

Table 2. Categories of the strength of evidence associated with recommendations[9]

Category	Description
A	The guideline recommendation is supported by one or more Level I studies.
B	The guideline recommendation is supported by one or more Level II studies.
C	The guideline recommendation is supported by only one or more Level III, IV, or V studies.

Table 3. Levels of panel agreement with the recommendations

Level	Mean agreement score
Low	1.0 to <2.33
Moderate	2.33 to <3.87
Strong	3.87 to 5.0

strength of the evidence, and the level of panel agreement with the recommendation (**Tables 1**-**3**). Ratings will be presented in parentheses after each recommendation.

Impact of SCI

Overview of normal lactation

Lactation, or milk production and ejection, is mainly controlled by both somatic and autonomic nervous systems, thus dependent on both hormonal and neural stimulation. As the child suckles the breast, afferent impulses are delivered from the mammary gland to the spinal cord via nerves throughout the T1-T5 region. The signal then travels to neurons in the hypothalamus to stimulate the release of oxytocin from the pituitary gland. Oxytocin binds to myoepithelial cells at the base of the mammary gland alveoli, causing them to contract. This is known as the "let-down reflex" or "milk ejection reflex," which allows milk to travel from the mammary gland to lactiferous ducts and be ejected from the breast. The sensory stimulation also affects sympathetic neurons, which control blood vessel tone and smooth muscle contraction of the breast to facilitate milk release.

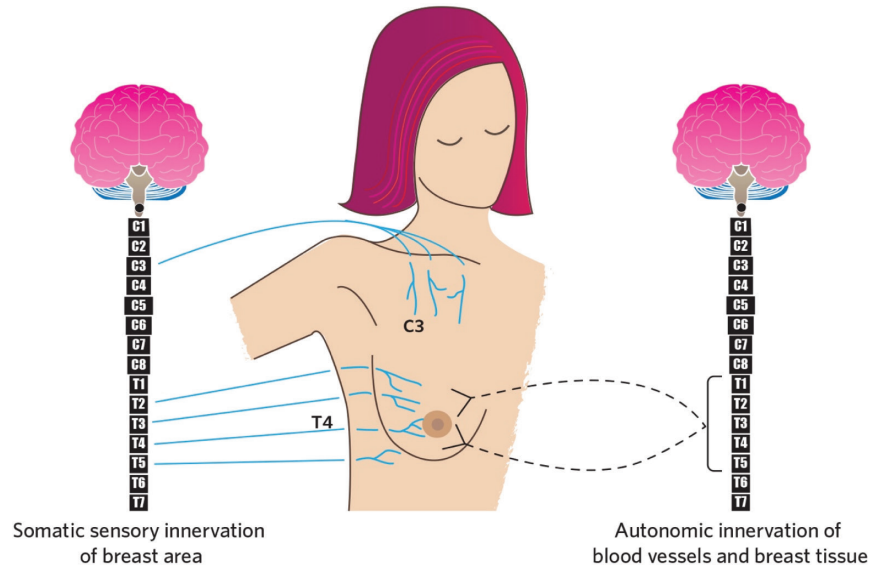

Figure 1. The somatic sensory (voluntary) and autonomic (involuntary) innervation (control) of the breast by the nervous systems. Black lines show the autonomic nerves (T1-T5 spinal cord levels) innervating breast tissues and blood vessels. Blue lines show the cervical (C) and thoracic (T) spinal nerves that convey sensory control of the breast and nipple areas. Milk production is a result of the coordinated functioning of the somatic and autonomic nervous systems.

Motor and sensory consequences of SCI

The breast is innervated by the fourth, fifth, and sixth intercostal nerves originating from T2-5 spinal cord segments (**Figure 1**). SCI at T5 level and above is particularly devastating, as impaired breast innervation may hinder impulses from the nipple area from reaching the pituitary gland. Less oxytocin is released, resulting in impaired lactation (milk production and ejection). Additionally, the let-down reflex may be disrupted by reduced afferent feedback upon a child's suckling. Lack of sympathetic nervous system feedback after SCI can also compromise myoepithelial cell contraction in the breast tissue, which is critical for milk ejection.

The outcomes and presentation of SCI differ not only by the level of the spinal cord lesion but also by sensorimotor completeness of the injury. Injury severity is described by the American Spinal Injury Association Impairment Scale (AIS) from a grade of A to E, where A is the most severe. This is ascertained by the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI), which determines sensory levels in response to stimuli such as light touch or pinprick and motor levels using muscle function grading.[10]

Neurological level of SCI generally corresponds with the lowest segment of the spinal cord with normal sensory and motor function on both sides of the body. However, the spinal level at which normal function is found often differs on each side of the body as well as in terms of preserved sensory and motor function. Thus, up to four different segments may be identified during determination of the motor and sensory level; each of these segments is recorded separately. It is important to note that the level of spinal column (bone) injury may not correlate with the neurological level of SCI.

Paraplegia refers to functional loss below the level of the upper extremities, which may involve loss of motor and/or sensory function within the trunk and/or lower extremities (legs). This implies damage to the spinal cord below the level of T1 and may include damage to the conus medullaris or cauda equina.

Tetraplegia (the preferred term to quadriplegia) refers to the loss of motor and/or sensory function in all four limbs due to spinal cord damage, with

impairment of the upper extremities as well as trunk, legs, and pelvic organs. This implies damage to the cervical spinal cord (at or above the T1 level).

Complete injury indicates an absence of sensory and motor function in the lowest sacral segment.

Incomplete injury indicates partial preservation of sensory and/or motor function is found below the neurological level and includes the lowest sacral segment.

- AIS A – Complete. No sensory or motor function is preserved in the sacral segments S4-S5.
- AIS B – Sensory incomplete. Sensory but not motor function is preserved below the neurological level, including the sacral segments S4-5 (light touch or pin prick at S4-S5 or deep anal pressure), and no motor function is preserved more than three levels below the motor level on either side of the body.
- AIS C – Motor incomplete. Motor function is preserved at the most caudal sacral segments for voluntary anal contraction, or the patient meets the criteria for sensory incomplete status (sensory function preserved at the most caudal sacral segments [S4-S5] by light touch, pin prick, or deep anal pressure) and has some sparing of motor function more than three levels below the ipsilateral motor level on either side of the body. (This includes key or non-key muscle functions to determine motor incomplete status.) For AIS C, less than half of key muscle functions below the single neurological level of injury have a muscle grade ≥3.
- AIS D – Motor incomplete. Motor incomplete status as defined for AIS C, with at least half (half or more) of key muscle functions below the single neurological level of injury having a muscle grade ≥3.
- AIS E – Normal. If sensation and motor function as tested with the ISNCSCI are graded as normal in all segments and the patient had prior deficits, then the AIS grade is E. A person without an initial SCI does not receive an AIS grade.

Autonomic consequences of SCI

In addition to motor/sensory deficits, individuals with SCI often also experience various autonomic dysfunctions including aberrant and labile blood pressure (BP) profiles.[11]

Known as autonomic dysreflexia (AD), a sudden increase in BP commonly occurs in individuals with SCI at or above T6, though its occurrence has been noted with SCI above T10. AD is characterized by transient hypertensive episodes with elevation of systolic BP up to 300 mm Hg. Individuals experiencing an episode of AD may also experience headache, sweating, flushing above the level of injury, and anxiety.[12] As AD is typically initiated by any painful or nonpainful stimulus below the injury level, it is plausible that a child's suckling, breast engorgement, or mastitis can trigger AD in women with upper thoracic and cervical SCI.

In addition to episodes of AD, individuals with SCI may have episodes of low BP (orthostatic hypotension) while seated, which may impact the length of time a mother can hold and breastfeed her child before experiencing fatigue or presyncope. Orthostatic hypotension (OH) is clinically defined as a decrease in systolic BP of 20 mm Hg or more, or a decrease in diastolic BP of 10 mm Hg or more upon moving from a supine position to upright posture.[12] Individuals with SCI are known to frequently experience OH, the incidence of which can be significantly increased in mothers with SCI who transfer from bed to an upright position to breastfeed their child at night.

Section 1: Lactation and Breastfeeding after SCI

Numerous guidelines have identified the key principles for effective breastfeeding both for individual mothers and for institutional practice (see **Appendix B**). Although most guidelines are not tailored for people with disabilities, they provide a foundation that may be modified to meet the specific needs of mothers with SCI.

General impact of SCI on lactation and breastfeeding

Mothers with SCI may experience breastfeeding challenges similar to mothers without SCI. For instance, their child may have difficulty latching/

feeding due to prematurity, tongue tie, or jaundice, or to maternal conditions such as inverted nipples, clogged ducts, mastitis, or an overabundance of milk. Management recommendations listed in other publications still apply to mothers with SCI,[13] but considerations specific to SCI may include the following.

Sensory changes: Decreased nipple sensation can impede the ability to identify a poor latch that would normally cause pain. Visual cues during latching, feeding, and immediately after feeding can help mothers identify a good latch.

Impaired milk production and lack of milk ejection reflex: Mothers with SCI often experience insufficient milk production and milk stasis, particularly if the injury is at or above T5 (which results in disrupted innervation of the breast). Since motor and sensory complete injuries (AIS A) are more likely to be autonomically complete injuries, it is likely that a mother with AIS A at or above T5 may produce little to no milk at all. Conventional management of milk stasis should be considered in mothers with SCI, such as therapeutic ultrasound and sunflower lecithin.[14,15]

Motor deficits: Holding the child in a position that facilitates effective feeding may be difficult due to SCI-related motor deficits. Fundamental for milk production is frequent and effective milk removal from the breast, ideally by the child. Limited mobility of the mother's arms/hands, spasms, or impaired trunk strength can affect how well the child is positioned to achieve and maintain an effective latch without damaging the mother's nipples. Poor hand function can also result in limited milk expression and impaired ability to perform self-lymphatic drainage and massage, further contributing to the development of clogged ducts and mastitis.[15] Hand expression and suckling, as well as clogged ducts and mastitis, can trigger episodes of AD (see Section 3 for guidelines regarding the management of AD). Ineffective or infrequent feeding can be a secondary cause of insufficient milk production (see Section 5 for specific guidelines regarding positioning during breastfeeding).

Autonomic dysreflexia: AD has been documented in several case studies of breastfeeding by mothers with SCI.[16,17] The potential for AD during breastfeeding is a major complication that should be addressed and managed in a timely manner, particularly in mothers with SCI at or above T6. Lidocaine jelly can be applied prior to manipulation to manage nipple blebs, which can cause significant ductal obstruction and elevate the risk of AD.[18]

Fatigue: Newborn care requirements are intense and often around the clock. For some mothers with SCI, their own requirements for care may limit their ability to feed their child. To facilitate the needs of both mother and child, there is immense benefit to having support from partner, family, care aide, or independent living consultant in establishing feeding plans.

Medications: Medications taken by the mother while breastfeeding could transfer via the milk to their child with adverse consequences. Mothers should be counseled about the need to either discontinue nursing or alter or avoid their prescribed medications.[19]

Recommendations

1. Counsel mothers with SCI at or above T5 about the possibility of impaired milk production and impaired let-down reflex because of impaired nipple sensation. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
2. Counsel mothers with SCI with impaired breast sensation and/or upper extremity impairment about the potential difficulties with breast manipulation/massage, child positioning, and areola latching. (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
3. Counsel mothers with SCI at or above T6 about the possibility of AD triggered by breastfeeding, clogged ducts/mastitis, or OH from prolonged sitting. (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
4. Counsel mothers with SCI that child requirements may be intense and exacerbate their fatigue secondary to SCI. (Scientific evidence - III/V; Grade of recommendation - C; Strength of panel opinion - Strong)

5. Management of milk stasis sequalae (clogged ducts, mastitis, etc.) in mothers with SCI should follow recommendations in general population.[6] (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
6. Counsel mothers with SCI regarding their medications and the possible impacts to breastfeeding on the child. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)

Early identification of difficulties that impact breastfeeding

Identifying possible SCI-related challenges in the early stages of breastfeeding can significantly reduce the distress that both mother and child might experience. The following methods have been shown to enhance the effectiveness of breastfeeding.

Skin-to-skin (STS) contact: As oxytocin release is enhanced by STS contact, families need support to provide STS contact in a safe and accessible manner. When pathways are intact, nipple stimulation by the child's suckling will facilitate the milk ejection reflex.

Appropriate latch: An appropriate latch can be determined in the rhythmic changes in the rate with which the child sucks and swallows during feeding. The child should also appear satiated after feeding. The nipple should not be distorted after feeding.

Hand expression: If the child is unable to latch and suck effectively, hand expression initiated by the mother or a support person should begin within the first hour of feeding. Additionally, a breast pump can be used.

Early colostrum: Early effective feeding is vital to the success of the breastfeeding journey. Lactation is initially dependent on the hormonal shift occurring with the delivery of the placenta (phase I postpartum). During this phase, colostrum, or first milk, is available for the child. Ongoing milk production (phase II postpartum) occurs with stimulation of the nipples, oxytocin (and other hormonal) release, and effective milk removal from the breast.

Breastfeeding assessment: Continued self-assessment can facilitate progress toward breastfeeding goals. It is recommended that mothers with SCI and their support system seek ongoing education and consultation with a lactation consultant or experienced community health nurse. With their support, mothers can create a care plan that accounts for specific markers of breastfeeding success, barriers, and potential supports or aids.

Recommendations

7. Utilize understanding of the neurological level of injury to determine potential difficulties in breastfeeding. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
8. Counsel mothers that latching and suckling need to be attempted and assessed early after delivery to be maximized. (Scientific evidence - V; Grade of recommendation - C; Strength of panel opinion - Strong)
9. Use visual cues such as child swallowing and satiation without nipple distortion after feeding to determine whether there has been an effective latch. (Scientific evidence - III/V; Grade of recommendation - C; Strength of panel opinion - Strong)

Aids for milk production

Should milk supply be insufficient, the use of nonpharmacological or pharmacological agents can be considered. Breast pumps and hand expression could be the first step to improve milk production.[20] Pharmacological agents should be considered as the next option. If all measures fail, the introduction of child formula should be considered.

Galactagogues have historically been used to increase milk production by increasing prolactin levels associated with milk production. Most of the evidence of effectiveness of medicinal galactagogues is with mothers of preterm and late preterm children. In Canada, the most commonly used galactagogue is domperidone; in the United States, metoclopramide is more commonly used. Caution is advised as the use domperidone as a galactagogue is considered "off-label" use. Oxytocin nasal spray is reported in the literature but there is great variability in study results.[21,22] All other nonpharmacological supports should be implemented before medicinal galactagogues. The effects of galactagogues on bowel, bladder, and respiratory function in women with SCI are not known. Women should consult with their primary care provider prior to initiation.

Clinicians should also be aware that peer support networks or other mothers with SCI may suggest the use of herbal teas (e.g., fenugreek), root extracts (e.g., shatavari or malunggay), and other naturopathic remedies (e.g., silymarin).[21,23,24] Although many of these over-the-counter supplements may not be regulated by governmental bodies, they are widely used and endorsed by practicing clinicians. Further high-quality research is needed to determine the efficacy and safety of these supplements.[24]

Recommendations

10. For improving milk production and ejection, first ensure nonpharmacological practices are in place (e.g., breast pumps, hand expression). (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
11. Utilize galactagogues (i.e., domperidone and metoclopramide) as a possible remedy for impaired milk production and impaired let-down reflex. (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
12. Ensure nonpharmacological practices are in place before suggesting galactagogues. Galactagogues will only be effective in combination with frequent and effective milk removal from the breasts. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
13. Discuss the clinical trial evidence (or lack thereof) of galactagogue safety and efficacy in milk production. (Scientific evidence – IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
14. Counsel mothers about introducing child formula with or without the use of a supplementary nursing system in the absence of milk production and let down reflex. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)

Individualized care

Regardless of the level of injury, care must be taken to evaluate and support each mother and child. It is not possible to predict during pregnancy the ability of individual mothers to lactate and breastfeed their child. Although the higher and more complete the injury, the more likely difficulties will occur, the physiological ability of the breasts will become evident only in the early postpartum stages. Mothers with SCI and their families may benefit from an approach that normalizes their experience and validates their difficulties as common and expected. Appropriate assessments need to be conducted to ensure progress and intervention as needed.

Clinicians should be aware of global breastfeeding guidelines[2] and provide information and support so that mothers can maximize their potential to breastfeed their child. Generally, mothers with SCI at or above T6 typically breastfeed for just 3.3 months on average compared to 6.5 months for mothers with SCI below T6.[5] It is important to note, however, that average numbers cannot be used to predict the breastfeeding duration for the individual woman. For some mothers with SCI, physiological limitations or health/injury may limit their ability to meet the global guidelines. For these mothers, clinicians can help them define their own success. For example, mothers with a history of breast reduction surgery, certain sensory deficits, or whose child is physically unable to breastfeed (e.g., due to a cleft palate) may still be considered as having "successfully breastfed" if they have provided as much human milk to their child as possible given their circumstances. In mothers with SCI, the definition of successful breastfeeding must take into consideration motor and sensory completeness and functional abilities.

Recommendations

15. As early as preconception, counsel mothers with SCI and their care partner(s) about anticipated needs for support for breastfeeding and child care according to the neurological level and severity (AIS grade) of injury and functional abilities. (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
16. An interdisciplinary personal care plan needs to be established with autonomy and collaboration.[25] (Scientific evidence - V; Grade

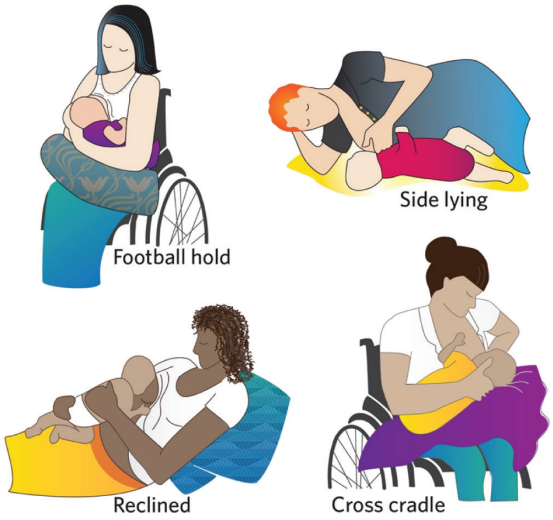

Figure 2. Alternative breastfeeding positions that may be adapted for mothers with SCI: football hold, side-lying position, reclined (skin-to-skin contact), cross cradle hold. All of these positions can be performed with skin-to-skin contact.

of recommendation - C; Strength of panel opinion - Strong)

Section 2: Mobility and Activities of Daily Living

Accessibility, positioning, and mobility concerns based on SCI level

An adequate latch is only possible with good positioning, which usually takes time and practice for mothers to establish. Limited mobility following SCI can complicate this process, with special attention required for the following aspects.

Access to the child may be impaired. Impaired motor recruitment of arm, shoulder, or upper and lower trunk abdominals may affect a mother's ability to lift or hold a child, retrieve a child from lower surfaces (such as a crib, change table, floor), move while holding the child, or use both hands to multitask.

Bed mobility may be challenging depending on the level of injury and its impact on hand function, arm strength, trunk control, and/or core strength. Bed mobility may become particularly more challenging in the later stages of pregnancy and the early postpartum period due to weight gain, child's position, increased spasms, and fatigue. This may significantly impact a mother's ability to roll, move from lying to sitting, and pick up, lift, position, and hold the child even when the child is lying in bed with them.

Furthermore, care and consideration should be given to exploring sleeping arrangements prior to the child's arrival to increase the mother's ease of access. Options include safe co-sleeping tools, such as use of a bassinet or a crib adjacent to the mother's bed, or modifying the height of the changing table. Practicing transfer and carrying routines is also important to the safety of mother and child.

Transfers may become increasingly difficult during pregnancy and postpartum due to pregnancy-related weight gain, increased spasms, decreased ability to shift weight forward during transfers, altered centre of gravity, and fatigue. After birth, transfers may be challenging due to healing post vaginal/Caesarean delivery. This is compounded by the higher frequency of transfers per day to meet increasing care demands.

Wheelchair modifications may be required to allow for additional trunk support and better stability while lifting and holding the child. Adjusting the seat slope or backrest angle can change the mother's center of gravity and improve stability. A backrest with deeper lateral trunk support will also add stability. Many mothers benefit from using a modified breastfeeding pillow or child carrier with a long waist strap that also wraps around the wheelchair backrest, which reduces their tendency to lean forward while holding the weight of the child in front.

Spasticity will likely impact the duration of breastfeeding or STS contact time. Mothers may need to explore alternative positions for holding their child for extended periods of time. This may include sitting up in bed with pillows, using an adjustable bed, or sitting in wheelchair with a breastfeeding pillow to provide support, enhance balance, and decrease child spit-up. The most preferred positions for mothers with SCI include reclined position, football hold, cradle hold, cross cradle hold, and side-lying position[5] (**Figure 2**).

Recommendations

17. Anticipate possible accessibility and mobility needs and how to address them in the overall care plan prior to delivery. (Scientific evidence - III/V; Grade of recommendation - C; Strength of panel opinion - Strong)
18. Consult physical therapists and occupational therapists regarding equipment and positioning, bed mobility, and access to and positioning of the child during breastfeeding. (Scientific evidence - III/ IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
19. Minimize the distance between mother and child during the night to reduce transfers for feeding and resultant fatigue. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
20. Encourage women to conduct their transfers safely using proper technique and equipment to avoid injury to themselves. (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
21. Avoid transferring mother and child simultaneously to prevent injury to either one. (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion -Strong)
22. Discuss with mothers the advice and equipment recommendations provided by other HCPs. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
23. Consult physical therapists and occupational therapists regarding equipment for wheelchair transfers and sitting with or without the child. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
24. Initiate a referral to a lactation consultant or occupational therapist experienced working with new mothers to explore breastfeeding positions and tools prior to the child's arrival. (Scientific evidence - III/V; Grade of recommendation - C; Strength of panel opinion -Strong)
25. Consult the appropriate HCPs for spasticity management. (Scientific evidence - III/V; Grade of recommendation - C; Strength of panel opinion - Strong)
26. Adapt accessibility and mobility options regularly in order to accommodate the changing needs of the mother and the child. (Scientific evidence - III/V; Grade of recommendation - C; Strength of panel opinion - Strong)

Additional aids

Mothers with SCI may also find the aids outlined below helpful in optimizing their breastfeeding experience.

Dolls that mimic the weight and muscle tone of a child can be used to practice different ways of lifting, positioning, and laying down the child in different settings (e.g., while in a wheelchair, while on a bed, in and out of crib, on and off a changing table, in and out of a bassinet or playpen). These dolls are available at many maternity speciality stores and are often used in prenatal/doula classes. This approach allows mothers to try different techniques to find what works best without fear of endangering a real child.

Wedges can provide support for sitting upright in a bed (providing support for the back, belly, or the child after birth) or be used as leg support to reduce spasms and improve BP. General and pregnancy wedges for therapeutic use are available at most sleep stores.

Carriers (harnesses, wraps, and ring slings) can be used during breastfeeding and for other purposes. They may also be useful in positioning the child when bottle-feeding and keeping the child upright after a feed to reduce spit-up/reflux. Placing the child in the carrier facing forward is not only beneficial for mothers who use wheelchairs with

higher arm rests but also ensures the child's legs are not caught by wheels.

Breastfeeding pillows are available at children stores and online in a variety of shapes, weight, and stiffness (firm versus lighter and more flexible). Some mothers find that their own regular pillows work well if the breastfeeding pillows do not provide enough support.

Self-Care

A mother's own lengthy self-care routine, especially while recovering from delivery, may impact available time and energy to breastfeed. Completing maternal tasks of daily living (e.g., toileting, showering, transferring, dressing, pumping, breast care, feeding, lifting the child, laundry) are tedious in of themselves. Given the mother's care routine and limited mobility due to their SCI, fatigue and burnout are even more likely.

Women may experience an increased risk of skin breakdown due to weight gain during pregnancy, perineum healing postdelivery, and extended periods of time sitting on or semi-reclined in bed while breastfeeding. Mothers with higher-level injuries are less likely to be able to weight shift while breastfeeding and holding their child. All of these factors contribute to heightened risks of sacral-coccyx pressure or shear injury.

Recommendations

27. Discuss the availability of personal care support from partner, friends, family, or hired caregivers and develop a plan in advance of the child's arrival. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
28. Adapt the mother's personal care routine, environment, and equipment to determine the best energy conservation strategies or alternative techniques. (Scientific evidence - III/V; Grade of recommendation - C; Strength of panel opinion - Strong)
29. Perform regular skin checks (ideally twice a day) to ensure skin health and integrity. (Scientific evidence - II/V; Grade of recommendation - C; Strength of panel opinion - Strong)
30. Ensure surfaces that the mother is sitting and lying on are appropriate to avoid pressure and shear complications. (Scientific evidence - V; Grade of recommendation - C; Strength of panel opinion - Strong)
31. Consider hiring a postpartum doula to assist with child care during the early postpartum period. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)

Accessibility in the community

Many new mothers seek out support groups in their community to obtain more information, reduce feelings of isolation, and connect with other new mothers to foster a sense of solidarity during the early months of motherhood.

Unfortunately, many support group locations and activities are not wheelchair accessible. As such, mothers may wish to speak with the group facilitator prior to their attendance to discuss the group structure and to see if inclusive modifications could be possible. For example, setting out a circle of chairs to allow all participants to be at the same height level can increase inclusion. Setting up a folding table in advance as an accessible changing table can also facilitate community participation. Virtual groups may also eliminate some of the barriers associated with in-person events.

Recommendations

32. Advise women to seek community peer support groups prior to the child's arrival. (Scientific evidence - V; Grade of recommendation - C; Strength of panel opinion - Strong)
33. Advise women to check accessibility (e.g., stairs, doorways, change tables, bathrooms) of the locations of support group meetings in the community. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)

Section 3: Autonomic Dysreflexia (AD)

Principles, prevalence, consequences, and occurrence in breastfeeding

AD is characterized by uncontrolled and potentially life-threatening spikes in BP, which may reach as high as 300 mm Hg systolic BP. Commonly

observed in individuals with SCI at or above the T6 spinal cord segment, this aberrant response in arterial BP is caused by noxious or nonnoxious stimuli below the injury level that initiates a sympathetic surge resulting in widespread vasoconstriction without normal compensatory mechanisms.[26]

The act of breastfeeding itself, as well as mastitis, nipple fissures, or other painful processes originating from the breast, can trigger AD. Although little is known about the episodes of AD as triggered by breastfeeding, available data indicate that AD during breastfeeding affects 39% of mothers with high-level SCI.[8] Frequent and uncontrolled episodes of AD could result in discomfort to an individual with SCI and are associated with significant immediate and long-term health consequences, including cardiovascular disease, stroke, seizures, and even death.[26,27] Therefore, it is vital to prevent and manage AD in a timely manner. Anecdotally, this is not often discussed in postpartum care.

Recommendations

34. Review the established clinical practice guidelines on the management of AD in the general SCI population.[12] (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
35. Educate mothers with SCI on the major triggers of AD related to breastfeeding and potential life-threatening consequences of AD. (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
36. Advise mothers with SCI to stop breastfeeding upon experiencing an episode of AD and to wait until symptoms subside and BP is stable (close to baseline) before resuming breastfeeding. (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)

Presently, there are well-established clinical practice guidelines for management of AD in individuals with SCI.[12] For instance, an educational seminar on AD management with a web-based application entitled "ABCs of AD" was recently developed as a means of increasing actual and perceived knowledge of AD knowledge among HCPs.[28] However, as data on breastfeeding and SCI remain scarce, little information is provided with respect to management of AD in women with SCI who are planning to nurse. This knowledge gap must be addressed in future guidelines and knowledge translation initiatives.[28] Updated clinical practice guidelines were published in 2020 by Paralyzed Veterans of America: Evaluation and Management of Autonomic Dysreflexia and Other Autonomic Dysfunctions: Preventing the Highs and Lows: Management of BP, Sweating and Temperature Dysfunction.[12] Briefly, the guidelines include the following.

Recognize that those with an SCI at or above T6 may present the signs and symptoms of AD, including:

- Elevated systolic BP greater than 20 mm Hg above their usual baseline in adults and greater than 15 mm Hg above their usual baseline in children.
- Sudden-onset headache.
- Possible bradycardia or tachycardia.
- Cardiac arrhythmias.
- Profuse sweating and/or flushing of the skin, typically (face, neck, and shoulders) or possibly below the level of the lesion.
- Piloerection (goose bumps) above or possibly below the level of the lesion.
- Blurred vision and/or spots in the individual's visual fields.
- Nasal congestion.
- Feelings of apprehension or anxiety.
- Few or no symptoms other than elevated BP.

Be aware that AD may appear with minimal or no symptoms (silent AD or those with cognitive/verbal communication issues) despite a significantly elevated BP.

If signs or symptoms of AD are present, but BP is not elevated and the cause has not been identified, refer the individual to an appropriate consultant, depending on signs and symptoms.

If AD is diagnosed,

- immediately sit the individual up and lower the legs if possible.
- loosen any clothing or constrictive devices.

- monitor BP and pulse every 1 to 2 minutes.
- quickly survey the individual for other triggers, beginning with the urinary system.
  - If an indwelling urinary catheter is not in place, catheterize the individual.
  - If the elevated BP is at or above 150 mm Hg systolic prior to catheterization, consider rapid-onset and short-duration pharmacological management to reduce the systolic BP without causing hypotension.
    - Determine whether the individual has recently taken a vasopressor or an antihypotensive agent.
    - If not, consider the use of an antihypertensive agent (such as nitro paste, nifedipine, hydralazine, or sublingual clonidine) with rapid onset and short duration.
- If acute symptoms of AD persist, fecal impaction might be a factor.
  - If the elevated BP persists at or above 150 mm Hg systolic, strongly consider pharmacological management prior to laying the individual down to check for fecal impaction.
  - Check the rectum for stool, and gently remove if possible.
  - If AD becomes worse, or stool cannot be removed, stop the manual evacuation and administer pharmacological or additional pharmacological intervention and additional topical anesthetic.
  - When BP is stable below 150 mm Hg, proceed with an aggressive bowel evacuation regimen.
- If there is no fecal impaction or BP elevation persists despite disimpaction, check for other less frequent causes of AD.
- If there are no obvious triggers or if the BP cannot be managed locally, the individual must be referred to the hospital emergency department for evaluation and management and possible hospital admission.
- While the individual is being evaluated in the emergency department, continue to closely monitor BP to guide pharmacological management of AD and investigate other causes. Consider hospital admission if
  - there is poor response to the treatment specified above, or
  - the cause has not been identified.
- After successful identification of the trigger and treatment of the elevated BP, monitor the individual for symptomatic hypotension every 2 to 5 minutes until the BP is stable.

Section 4: Interdisciplinary Level of Knowledge and Collaborative Expectations

When assisting a mother with SCI to prepare and engage in breastfeeding, an interdisciplinary team is ideal, as it allows for synergy between experts, resulting in the fruitful development of a collaborative care plan.[25] The team would ideally be composed of a lactation consultant or other breastfeeding specialist, physiatrist, primary care physician, counsellor/psychiatrist, occupational therapist, physiotherapist, and nurse (preferably with a specialty in maternal fetal medicine). The team should ensure that every effort is made to normalize the birth and postpartum experience for mother and the child. For example, efforts should be made to ensure families' presencein the hospital to provide support around the clock and facilitate constant contact between the mother and child.

Interdisciplinary Team

There interdisciplinary team should include the following persons.

- *Lactation consultants/breastfeeding specialists* to conduct prenatal discussions of the importance of breastfeeding and factors to enhance breastfeeding success, i.e., skin to skin contact, frequency of effective feeding.
- *Physiatrists/primary care physicians/ obstetricians* to initiate prenatal discussion with mothers on
  - mode of delivery and its effect on breastfeeding (e.g., caesarean section could delay or impede breastfeeding).[29]
  - impact on the let-down reflex given the woman's level of SCI.[30]
  - current medication regimen and possible side effects on breastfeeding.
  - other relevant health care team members that can help create a breastfeeding plan.

  - advising women with SCI intending to become pregnant of the possible challenges may allow them enough time for practical and mental preparations.
- *Nursing and breastfeeding specialists* to conduct postnatal discussions on how to successfully initiate feeding, feeding frequency, and physical supports for feeding/ expressing.
- *Occupational therapists and physiotherapists* to review the influence of mode of delivery on the initiation of breastfeeding, positioning options for feeding, adapting feeding devices, and information on support devices (e.g., pillows, slings).
- *Counsellors/socialworkers/psychologists/ psychiatrists* to provide mental health support and resource referral.

Family or others in the mother's support/ caregiving networks should be actively involved in the educational activities outlined above.

Educational resources and essential components

Educational resources on breastfeeding are available for the general population. However, only a few mention issues specific to physical disability and breastfeeding and even fewer address SCI specific considerations.

Many HCPs have limited or no experience caring for mothers with SCI in the postpartum period. Women with SCI often seek out relevant information themselves and provide this information to members of their health care team.

Information specific to breastfeeding and SCI must be targeted to both mothers with SCI and HCPs. In addition to this clinical practice guidelines, please reference the complimentary consumer guide.

Essential components of education will vary depending on the role the HCPs play in the care of the mother, their education and training background, and their experience level. However, all team members should be aware of the following basic knowledge:

- The importance of breastfeeding and human milk.
- The basic principles that lay the foundation for breastfeeding success (including uninterrupted STS contact within the first hour, support for frequent, effective breastfeeding, and support for rooming-in and nonseparation of mother and the child).
- Signs of lactogenesis (breast changes and fullness).
- Overcoming and remediating the aforementioned obstacles should they occur (e.g., if the child is unable to have STS contact immediately after birth for medical or physical reasons, ensure that contact is established at the earliest possible time).
- Knowledge of AD and SCI, in particular how breastfeeding can cause AD and why and how to manage it.
- Potential side effects and/or interaction of medications currently being taken (for SCI-related complications or other indications).
- Ways to include family and support system in the process.
- Knowledge of the potential signs of postpartum depression (PPD) and appropriate resources.
- Awareness of community supports, peer networks, and resources or professionals in the community that prospective mothers can access in order to have a proactive plan for breastfeeding care and options.
- Ability to empower women to make informed decisions and how best to support them if they are unable to meet their child feeding goals.

In addition, the HCPs providing direct support with breastfeeding should be aware of the following:

- Positioning techniques, e.g., how to assess and assist mothers to modify their position according to their needs.
- Breast/nipple inspection, which is necessary due to potential altered sensation of the breasts and should include checking nipple shape immediately aftrr feeding, the skin integrity of the nipples looking for any blisters or cracks, signs of yeast (women may not be able to feel if their nipples are itchy or sore).

- Effective feeding; in other words, is milk production and transfer sufficient for appropriate child growth?
- Effective intervention when either milk production or milk transfer is ineffective.
- Knowledge of appropriate use of galactagogues.
- Physical supports, e.g., breastfeeding pillows, slings, holding the child for feeding, supplementary feeding systems, adaptation of devices.
- When necessary, providing supplements in a manner as supportive as possible to the mother's child feeding goals.

Recommendations

37. Create an interdisciplinary care team of HCPs to optimally manage breastfeeding in mothers with SCI. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
38. Clearly define each team member's role and coordinate accordingly between team members. (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
39. Each team member is expected to have basic knowledge of breastfeeding following SCI. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
40. Each team member is expected to share their specialized knowledge with the team. (Scientific evidence - II/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
41. Educational consumer resources should be made available to the women with SCI.(Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)

Section 5: Community Support for Breastfeeding Women with SCI

Independent living in the community after discharge from acute rehabilitation is the fundamental goal of rehabilitation of individuals with SCI.

Community support is a key factor in the lives of people with SCI as they return to their homes and communities and plan for and make decisions about next phases in their lives. The attitudes and behaviors of family, friends, neighbors, HCPs, and others shape the forms and degrees of community support. Assistance and support provided via community networks and from peers are vital for individuals with SCI to live and thrive in their communities. Consumer and advocacy organizations for and of people with SCI are sources of important peer support, advocacy, and information. These organizations may have a single focus, such as sports and recreation, social activities, and accessibility or focus on all major areas of life—education, employment, transportation, and peer support (e.g., regional or national peer support organizations and independent living resource centers) (see **Appendix D** for a list of various national SCI organizations and networks).

Accessibility of physical environments plays a crucial role in the lives of people with SCI. Accessibility can facilitate their full participation or create significant obstacles to participation, including fully experiencing motherhood. Accessibility measures need to address the wide range of needs of mothers with SCI: making the home accessible; ensuring easy access to the child's room, crib, changing table, and so forth; using transportation; accessing health facilities (including examination equipment or medical devices); and accessing social and sport facilities and other public places (e.g., nurseries or children's playgrounds).

Recommendations

42. Support breastfeeding mothers with SCI to continue to live and access resources in their chosen community where they have already established accessible housing, transportation, and social networks. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
43. Seek consultation from a professional experienced in accessibility and universal design or an accessibility consultant to support breastfeeding mothers and child health. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)

Section 6: Psychosocial Health

Grief

With increasing awareness of the importance of breastfeeding, most mothers aim to follow the WHO guideline of breastfeeding exclusively for the first 6 months.[2] Mothers who are unable to meet their breastfeeding goals (for instance, having to supplement or completely switch to bottle-feeding) often experience grief, guilt, and shame.[31] These feelings may be more frequent or troubling for mothers with SCI who may be burdened with societal judgment regarding their perceived parenting capacities or their own feelings of inadequacy about their physical limitations and complications related to their SCI.

Recommendations

44. Mental health should be assessed within the interdisciplinary team prior to childbirth to identify signs and symptoms of mental health challenges (e.g., depression, anxiety) that may arise during the postpartum period. (Scientific evidence - II/III/IV/V; Grade of recommendation - B/C; Strength of panel opinion - Strong)
45. Consult with a lactation specialist regarding ongoing support in the postpartum period to provide education, support, and counsel when women should consider terminating breastfeeding due to physical or psychological limitations. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
46. Provide psychosocial support to women who are unable to exclusively breastfeed or prematurely wean their child to ameliorate feelings of isolation, overwhelm, shame, and exhaustion. (Scientific evidence - V; Grade of recommendation - C; Strength of panel opinion - Strong)
47. Share possible contributors of breastfeeding difficulties, as an understanding of the underlying causes can sometimes help lessen the feelings of self-blame. (Scientific evidence - IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
48. Discuss with the support network that, while encouragement to breastfeed is helpful, it is equally important to recognize and acknowledge the mother's own strengths and limitations. Strength-based framing can reduce feelings of shame and inadequacy for not meeting a breastfeeding goal. (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)

Bonding and attachment

Clinicians should make every effort to educate women and fellow care professionals about the importance of STS contact and positive bonding time (such as holding the child, eye-gazing, rocking the child, cuddling) in addition to feeding and caregiving needs. Evidence shows that child who receives STS contact interact more with their mothers and cry less.[32] STS contact is also associated with a higher probability of exclusive breastfeeding up to 6 months.[33] Exploring ways to facilitate opportunities for STS contact (not just immediately after birth but also in the weeks that follow) outside of breastfeeding is highly encouraged. Encourage partners and caregivers to allow mother time with the child to cuddle and bond. That said, giving the mother time to rest or do self-care is of equal importance.

Recommendations

49. Counsel women and their caregivers about the importance and benefits of STS contact and its role in newborn physiological stability and fostering attachment. (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)

Fatigue and adjustments to parenthood

Physical exhaustion is inevitable in adjusting to parent life. This may be intensified for women who experienced fatigue prior to pregnancy due to SCI, recovery after a period of decreased activity during pregnancy, and/or balancing increased time requirements for self-care and caring for the child. Remind new mothers that this is a normal part of parenthood. Encourage mothers to seek out supports when needed, for instance, scheduling visits from

family and friends or hiring a postpartum doula or caregiver. Allow mothers the space to acknowledge feelings of being overwhelmed and advise them to seek out help if symptoms of depression and anxiety become prominent and enduring.

All new mothers struggle to figure out what works and what does not work when caring for their newborn child. However, these struggles can be intensified for women with SCI due to risk of isolation exacerbated by mobility challenges, anxiety/fears, accessibility, and/or limited social network. While many new mothers seek out information online about breastfeeding, child care, and child equipment, mothers with SCI may find it challenging to find information specific to their unique needs/challenges.

Recommendations

50. Educate women and caregivers of the factors that contribute to feelings of being overwhelmed and exhausted and teach coping skills and strategies to manage these feelings. (Scientific evidence - V; Grade of recommendation - C; Strength of panel opinion - Strong)

Risk for postpartum depression

A recent study of a cohort of 102 women with SCI found that 10% of women were diagnosed with PPD.[34] In the general population, PPD affects 8% to 12% of women who give birth, and 10% to 16% of women who developed PPD begin to experience depressive symptoms during their pregnancy.[35] Several factors can put a woman at higher risk for development of PPD[35]:

- History of mood or anxiety problems
- Family history of major depression or mental illness
- Hormonal changes
- Sleep deprivation
- Recent stressful life events, such as death of a parent or moving
- Expectations of themselves or partner's expectations
- Lack of support from family or friends
- Experience of abuse or violence
- Social inequalities like poor housing or inadequate income
- Isolation
- Medical complications

Other stresses may increase these risks:

- Emotional stress: After giving birth, women may feel overwhelmed with responsibility, less attractive physically and sexually, anxious from changes in routine or lifestyle, and guilty because of social pressures to be a "perfect" mother.
- Physical stress: In addition to hormonal changes, common physical changes after labour include weight changes, exhaustion, and soreness.
- Lack of physical and emotional support.

Challenges associated with an injury and societal views of disability further predispose mothers with SCI to PPD. Population-based studies have observed higher incidence of depression among mothers with disabilities compared to mothers without disabilities. These differences were found before, during, and after pregnancy.[36] These symptoms may be further intensified if a woman with SCI feels judged or ashamed if breastfeeding is not successful and bottle-feeding or formula is required.

Recommendations

51. Ensure mothers and their families have supports in place to lessen the risk of depression. (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
52. Provide mothers with SCI, their partners, and caregivers with information about the risks, signs, and symptoms of PPD and the possibility of intervening, as some new mothers may not immediately recognize symptoms or feel too ashamed or fearful to seek support. (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)
53. Encourage women, partners, and family members to seek out professional or peer support if they are experiencing even what they consider minor symptoms of depression

or anxiety and provide contact information/ resources (see **Appendix D** for suggestions). (Scientific evidence - III/IV/V; Grade of recommendation - C; Strength of panel opinion - Strong)

Conclusion

Postpartum care to ensure optimal maternal and child health is a complex process. The unique challenges of SCI necessitate the involvement of mothers in their own care plan and comprehensive education on breastfeeding with SCI for both her support network and interdisciplinary health care team. As the level and completeness of SCI (motor, sensory, and autonomic) vary with each individual, these recommendations should be carefully reviewed by the mother and the HCPs. Ideally, these guidelines would be reviewed by prospective mothers prior to giving birth, thus allowing them to maintain autonomy and empowerment during the breastfeeding process that will carry on throughout motherhood.

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Conflicts of Interest

The authors have no conflicts of interest to disclose.

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Appendix A

Definitions and Abbreviations

Definitions

Breastfeeding and lactation are often used interchangeably. However, for the purposes of this document, the following definitions are used:

Breastfeeding: The act of removing milk from the breast and delivering to child for consumption (e.g., child directly feeding from the breast or the mechanical act of milk removal by hand or breast pump to then feed the child human milk).

Exclusive breastfeeding: Feeding a child with the only source of nutrition being human milk. Exclusive breastfeeding is defined by the World Health Organization as no other food or drink (not even water) except human milk (including expressed milk) for 6 months of life. This definition still allows the child to receive oral rehydration solutions, drops, and syrups (e.g., vitamins, minerals and medicines).

Galactagogues: Pharmaceutical or herbal substances taken by a mother to increase milk production and supply.

Global public health guidelines: Guidelines that direct HCPs and can act as a measure of success of public health initiatives.

Health care professionals (HCPs): Certified practitioners who actively deliver standardized, evidence-based health care, including diagnosis, medical treatment, and rehabilitative services. Examples include medical doctors, nurses, midwives, pharmacists, lactation specialists occupational therapists, and physiotherapists.

Lactation: Physiological aspects of breast function, comprised of both milk production and ejection.

Lactogenesis: In the first few days, milk production is under endocrine control (Lactogenesis I). Autocrine control begins soon after (Lactogenesis II).

Milk ejection: Contraction of myoepithelial cells at the base of the breast alveoli resulting in milk release, activated by oxytocin.

Milk ejection reflex (let-down reflex): The milk ejection reflex or let-down reflex is the release of milk from the alveoli to the nipple in response to sensory stimulation of the nipple triggered by the child and the release of oxytocin. Psychologic stimulation may also elicit the milk ejection reflex.

Milk production: Prolactin causes the breast alveoli to take nutrients (proteins and sugars) from the blood supply and turn them into breast milk.

Nipple bleb: Inflammatory lesions found on the nipple surface that can cause significant ductal obstruction despite their small size.

Nonexclusive breastfeeding: Supplementing breastfeeding with other nutrition such as formula.

Personal goals: Mothers may choose to meet global breastfeeding guidelines or may choose other parameters for success based on their individual situation. Personal goals may include duration of exclusive and nonexclusive breastfeeding.

Spinal cord injury: Damage to the spinal cord (traumatic or nontraumatic) at any level resulting in various sensory, motor, and autonomic consequences.

Spinal cord injury–related complications: Various complications related to the injury of the spinal cord include autonomic dysfunctions (autonomic dysreflexia, orthostatic hypotension), pressure sores, and others.

Successful breastfeeding: Breastfeeding success can be measured against personal goals and global or national recommendations/guidelines, such as from the World Health Organization (WHO), Health Canada, and the Canadian Paediatric Society (CPS). For mothers with SCI, successful breastfeeding is often measured by personal goals developed with global guidelines in mind.

Abbreviations

AIS	American Spinal Injury Association Impairment Scale
ASIA	American Spinal Injury Association
AD	autonomic dysreflexia
BP	blood pressure
HCPs	health care professionals
ISNCSCI	International Standards for Neurological Classification of Spinal Cord Injury
OH	orthostatic hypotension
SCI	spinal cord injury
STS	skin to skin
PPD	postpartum depression
WHO	World Health Organization

APPENDIX B

Environmental Scan

The following table outlines the guidelines related to pregnancy and breastfeeding/lactation reviewed by the research panel with comments regarding applicability to populations with SCI. Target groups for these resources included women with SCI, their caretakers, and service professionals. The search criteria included the following key words: breastfeeding, lactation, nursing, postpartum, guidelines, spinal cord injury, physical disability, disability.

Author/Year/Title	Country	Source	Short description	Strengths and limitations and relevance to breastfeeding after SCI
1. The Queensland Spinal Cord Injuries Service Spinal Outreach Team. 2017. *The Impact of a Spinal Cord Injury on Pregnancy, Labour and Delivery: What You Need to Know.*	Australia	https://www.health.qld.gov.au/__data/assets/pdf_file/0027/425772/pregnancy-sci.pdf	Information booklet for consumers about how an SCI may impact pregnancy and labor.	One paragraph on autonomic dysreflexia (AD), spasticity, and milk reduction above T6.
2. Perinatal Services BC. 2015. *Health Promotion Guideline: Breastfeeding Healthy Term Infants.*	British Columbia, Canada	http://www.perinatalservicesbc.ca/Documents/Guidelines-Standards/HealthPromotion/BreastfeedingHealthyTermInfantGuideline.pdf	Guidelines based on current evidence and best practices consistent with The Child-Friendly Initiative; the recommendations of the BC Ministry of Health; Perinatal Services BC (PSBC) education Breastfeeding: Making a Difference©; the BC The Child-Friendly Network Resource Binder; and the Canadian documents, *Nutrition for Healthy Term Child* and *Family-Centred Maternity and Newborn Care: National Guidelines*	No specifics for women with SCI or any other physical disability.

3. Winnipeg Regional Health Authority. 2013. *Breastfeeding Practice Guidelines for the Healthy Term Infant.*	Manitoba, Canada	https://wrha.mb.ca/files/womens-health-breastfeeding-practice-guidelines.pdf	Evidence-based practice guidelines developed in collaboration with primary care professionals, nursing partners, and family members to promote optimal initiation of breastfeeding in the postpartum period and continuation of exclusive breastfeeding for the first 6 months of life; based on standards implemented by the WHO and UNICEF.	No specifics for women with SCI or any other physical disability.
4. M. Walker. 2014. *Breastfeeding Management for the Clinician.*	USA		Compendium for practicing clinicians using research-based evidence	Some reference to women with SCI (ch. 9, p. 536).
5. Registered Nurses' Association of Ontario. 2003. *Breastfeeding Best Practice Guidelines for Nurses.*	Ontario, Canada	https://rnao.ca/sites/rnao-ca/files/Breastfeeding_Best_Practice_Guidelines_for_Nurses.pdf	Guidelines containing recommendations, discussion of literature, assessment tools. Aimed toward all nurses (community and institutional) for promotion and support of breastfeeding.	No mention of disability or SCI; not updated since 2003.
Registered Nurses' Association of Ontario. 2007. *Breastfeeding Best Practice Guidelines for Nurses – Supplement.*		https://rnao.ca/sites/rnao-ca/files/storage/related/2457_Breastfeeding_Supplement.pdf	Supplement to the guidelines, containing revisions with implementation strategies and level of evidence for recommendations.	No mention of disability or SCI; not updated since 2007.

6. A.B. Jackson, L. Lindsey. 1998. *Pregnancy and Women with SCI - Professional Level.*	USA	United Spinal Association. https://askus-resource-center.unitedspinal.org/index.php?pg=kb.page&id=1586	Online info sheet outlining major health concerns during pregnancy, postpartum.	One section on breastfeeding.
7. G. Aune. 2012. "Everyday challenges for mothers with spinal cord injury: A qualitative study."	Norway	*Scandinavian Journal of Disability Research* 15(2):185-198. https://sjdr.se/articles/10.1080/15017419.2012.692708	Semi-structured interview with analysis; details daily experiences and challenges with motherhood after SCI.	No specific section on breastfeeding: focus on child care, assistance services, etc.
8. La Leche League. 2015. *Breastfeeding Tips + Guide.*		https://www.lllc.ca/sites/default/files/456_Revised_2015_CMYK_0.pdf	Consumer guide for mothers structured as Q & A handbook.	No mention of SCI or disability.
9. D. Wiessinger, D. West, T. Pitman. 2010. *The Womanly Art of Breastfeeding*. 8th ed.		La Leche League	Guide for nursing and expecting mothers; contains nursing advice for many mothers (working, single, stay at home, etc.), with strategies stories, guidance, and info.	No mention of SCI.
10. Idaho Assistive Technology Project. 2003. *Assistive Technology for Parents with Disabilities.*	USA	http://idahoat.org/Portals/60/Documents/Services/Resources/AT_ParentsHandbook.pdf	Handbook for families and caregivers containing information about legislation, availability of assistive technology to assist with parenting, funding avenues, and resources for parents with disabilities.	One page on adapted devices for nursing (p. 15).

11. Vancouver Coastal Health's Sexual Health Rehabilitation Service, BC Women's Hospital and Health Centre's Maternal Fetal Medicine Service, Rick Hansen Institute, Spinal Cord Injury BC. 2015. *Pregnancy and Spinal Cord Injury.*	British Columbia, Canada	https://scisexualhealth.ca/wp-content/uploads/2015/05/Pregnancy-and-SCI-booklet-V7.pdf	Information booklet for women with SCI on fertility, pregnancy.	One page on breastfeeding.
12. J. Rogers. 2005. *The Disabled Woman's Guide to Pregnancy and Birth.*	USA	Demos Health	Book authored by a birthing instructor, with interviews of women with physical disabilities as well as SCI; aimed toward women and health professionals to encourage dialogue with patients.	No specifics regarding SCI or breastfeeding (general info to "help women decide whether to breast- or bottle-feed their child, and suggestions for breast care and breast-feeding"). Pages 366-371 contain some information on SCI-specific considerations.
13. Infant Feeding Joint Working Group. 2015. *Nutrition for Healthy Term Infants: Recommendations from Birth to Six Months.*	Canada	https://www.canada.ca/en/health-canada/services/canada-food-guide/resources/nutrition-healthy-term-infants/nutrition-healthy-term-infants-recommendations-birth-six-months.html	Principles, research-based information, and recommendations for HCPs working with parents.	No specifics regarding SCI.

14. Paralyzed Veterans of America. 2010. *Sexuality and Reproductive Health in Adults with Spinal Cord Injury: A Clinical Practice Guideline for Health-Care Professionals.*	USA	https://pva.org/research-resources/publications/Clinical-Practice-Guidelines/	Clinical practice guidelines for sexual health and reproduction in males and females with SCI.	No mention of lactation, breastfeeding, or postpartum; mainly on fertility and sexual health.
15. Promotion of Breastfeeding in Europe Project. 2004. *Protection, Promotion and Support of Breastfeeding in Europe: A Blueprint for Action.*	Europe	https://ec.europa.eu/health/ph_projects/2002/promotion/fp_promotion_2002_frep_18_en.pdf	Framework to develop plans with activities of proven effectiveness.	No mention of any disability, including SCI.
16. National Institute for Health and Care Excellence. 2013. *Postnatal Care. Quality Standard 37.*	Britain	https://www.nice.org.uk/guidance/qs37	Quality standard for postnatal care.	No mention of SCI. Quality statement 5 (p. 28) is on breastfeeding.
17. BC Women's Hospital + Health Centre. 2017. *Postpartum Care for Women With Spinal Cord Injury (SCI).*	British Columbia, Canada	http://shop.healthcarebc.ca/phsa/BCWH_2/BC%20Women's%20Hospital%20-%20Maternal%20Newborn/C-06-12-61817.pdf	Best practice guidelines/procedures for women with SCI who have given birth.	One section on breastfeeding.
18. Breastfeeding Committee for Canada. 2017. *The Breastfeeding Initiative 10 Steps and WHO Code Outcome Indicators for Hospitals and Community Health Services.*	Canada	https://breastfeedingcanada.ca/wp-content/uploads/2020/03/Indicators-we2019-En.pdf	Steps and resources (e.g., checklists) for HCPs with indicators from the WHO for breastfeeding outcomes.	No mention of any disability, including SCI.

19. Health Canada. 2000. *Family-Centered Maternity and Newborn Care - National Guidelines*	Canada	http://www.media.pentafolio.com/design/FCMC.pdf	Guidelines for providing maternity care that is family centered from preconception to postpartum. Updated publication is in press.	Recommends that postpartum clinics be easily accessible for women with disability; otherwise, no mention of breastfeeding with physical disability or SCI.

APPENDIX [C]

Next Steps

Validation and implementation

These clinical practice guidelines will be validated and tested in clinical practice.

Key stakeholders will be identified for involvement, and will primarily be HCPs who work with prospective or current mothers with SCI. These individuals include (but are not limited to): general practitioners, physiatrists, obstetricians, nurses, lactation consultants, occupational therapists, physiotherapists, and midwives. Stakeholders will be identified across multiple international sites and be responsible for reviewing and evaluating these recommendations with the ultimate objective of developing a validated, standardized set of guidelines for clinical practice and improving quality of life and breastfeeding success in women with SCI.

Information for health care practitioners should be:

- readily available,
- detailed,
- evidence-based,
- medically focused,
- comprehensive and include recommendations, current guidelines, and a link to the consumer guide.

Consumer Guidelines

A separate document containing consumer guidelines will be drafted based on the clinical practice guidelines, the target audience being prospective/current mothers with SCI, their families, caregivers, and other members of their support networks who do not provide health care services in a medical setting.

This document will likely be in the format of an information booklet that is readily available online or from HCPs. The proposed format will be parallel to the clinical practice guidelines in order to foster patient–-physician dialogue and allow for a collaborative discussion when creating a postpartum care plan.

These consumer guidelines will also be evaluated for impact on quality of life and validated with the involvement of key stakeholders (in this case, women with experience breastfeeding after SCI) and input from clinicians.

The consumer guide should be:

- easy to obtain,
- evidence-based,
- written in lay -terminology,
- inclusive of peer stories, tips, and advice, and
- directly linked to the health care professional guidelines so mothers and their care professionals can connect the two sets of guidelines.

APPENDIX D

SCI Organizations & Network

Australia

Independence Australia: https://www.independenceaustralia.com

Paraquad NSW: http://www.paraquad.org.au

Spinal Cord Injuries Australia : https://scia.org.au

Women with Disabilities Australia: www.wwda.org.au

Canada

Canadian Paraplegic Association Manitoba: www.cpamanitoba.ca

Canadian Paraplegic Association Nova Scotia: www.thespine.ca

ICORD (International Collaboration On Repair Discoveries): www.icord.org

Rick Hansen Institute: www.rickhanseninstitute.org

Spinal Cord Injury Alberta: www.sci-ab.ca

Spinal Cord Injury Canada: http://sci-can.ca

SCI British Columbia (SCI-BC): https://sci-bc.ca

SCI Newfoundland: www.sci-nl.ca

SCI Ontario: www.sciontario.org

SCI Saskatchewan: www.scisask.ca

Spinal Cord Injury Research Evidence (SCIRE) Community: https://community.scireproject.com/resources/educational-resources/

UK

National Disabilities Practitioners: https://nadp-uk.org/

Spinal Cord Injuries Association: https://www.spinal.co.uk/

Aspire Charity: https://www.aspire.org.uk/

Back Up Charity: https://www.backuptrust.org.uk/

The Drugs in Breastmilk information Service: https://www.breastfeedingnetwork.org.uk/

USA

Life After Spinal Cord Injuries: https://www.edgepark.com/LASCI

Miami Project to Cure Paralysis: www.themiamiproject.org

Paralyzed Veterans of America: www.pva.org

South Carolina Spinal Cord Injuries Association: https://scspinalcord.org

Spinal Cord Injuries of Washington (SCIAW): http://www.sciaw.org

Other

Spinalpedia: www.spinalpedia.com