Breastfeeding and Safe Sleep: Promoting a Collaborative, Informed Shared Decision Making Model

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Abstract

Members of the British Columbia Lactation Consultant Association (BCLCA) work closely with families in the real life world of infant care to help achieve breastfeeding goals. Our membership are concerned that there is a paucity of resources to support families in making the best decisions to support the intense nighttime care work of infants in a safe manner. We recommend a collaborative working group be established to review the evidence and consider the perspective of the healthcare consumer in the development of resources.

1.0 Background

BCLCA is a non-profit organization whose members are dedicated to the promotion, support and protection of breastfeeding in our province. We are affiliated with the Canadian Lactation Consultant Association. Most (87%) but not all members hold the qualification of International Board Certified Lactation Consultants (IBCLC).

Many of our members hold a second healthcare professional designation in addition to IBCLC, such as Registered Nurse, Registered Dietician, Medical Doctor or other professional qualification. We have members employed by each of the Health Authorities in British Columbia, although very few are directly employed as IBCLC's. In most cases, IBCLC's are employed primarily through their other professional designation and they have the additional responsibility of lactation support.

In the spring of 2013 the BCLCA Board polled members to form our strategic plan. Sleep and breastfeeding was identified as a priority issue for BCLCA members. Specifically, members were concerned about conflicting messages regarding infant sleep in our province and the fact that much of this advice does not support the realities of families wishing to breastfeed.

Most alarming was the experience shared by many members that the families they work with are adopting less safe sleep strategies in order to follow public health safe sleep advice. This is especially concerning given that many BCLCA members feel that their employer has limited them from having a proactive conversation about the interrelatedness of sleep and breastfeeding and the realities of nighttime infant care.

2.0 Breastfeeding in B.C.

Current recommendations are that "breastfeeding - exclusively for the first six months, and sustained for up to two years or longer with appropriate complementary feeding - is important for the nutrition, immunologic protection, growth, and development of infants and toddlers" (Health Canada, 2014). Many other professional and health organizations have similar recommendations (Canadian Pediatric Society & World Health Organization).

The Ministry of Health has identified Maternal Child and Family Health as a core program in BC's Guiding Framework for Public Health (Ministry of Health, 2013). Breastfeeding has well-documented positive effects on the health of infants and mothers that fits under this goal. Breastfeeding promotion is a public health strategy that contributes to better health outcomes and has potential to reduce health inequities – an important mandate set by the Ministry of Health.

Most women want to breastfeed their babies. In 2005, the rate for breastfeeding initiation was 97% (Public Health Agency of Canada, 2009), while the rate of exclusive breastfeeding upon discharge from hospital was only 69.5% for the same year (Perinatal Services BC, 2006). The decrease in rates from initiation to discharge suggests that the system that supports mothers and infants is not operating optimally. The literature supports the idea that the majority of mothers are not able to meet their own personal goals to breastfeed as long as they intend (Odom et al., 2013; Public Health Agency of Canada, 2009).

Collectively, we all have responsibility to ensure that the healthcare system does not inadvertently block families in achieving their goals and indeed works to create a context that facilitates healthy behavior. Families and stakeholders value breastfeeding for a variety of important reasons, including health promotion of mother and babe in both the short and long-term (Horta et al., 2013; Hoddinott et al., 2008; Ip et al., 2009; Owen et al., 2002; Talayero et al., 2006; Zheng et al., 2000).

3.0 Sleep and Bedsharing

Nighttime parenting is a considerable issue for all new mothers. Around the world and throughout history, the best solution to the challenges of attending to a young, vulnerable baby has been to sleep close to mother (Russell et al., 2013). It was not until quite recently, with the availability of formula and cribs, that prolonged separation at night was a viable option.

Current Canadian recommendations regarding nighttime infant sleep state that is safest to have the infant in a crib in the parental room for the first 6 months of life (Canadian Pediatric Society, 2014). However, the Canadian Pediatric Society (CPS) also "acknowledges that some parents will, nonetheless, choose to share a bed with their child" (CPS, 2014).

The CPS have summarized "what we know" from the best available evidence:

- Sleeping on the back carries the lowest risk of SIDS
- Room-sharing lowers the risk of SIDS
- The risk of SIDS is increased when infants bedshare with mothers who smoke cigarettes

- Bedsharing with an adult who is extremely fatigued or impaired by alcohol or drugs (legal or illegal) that reduce arousal can be hazardous to the infant
- The use of soft bedding, pillows and covers that can cover the head increase the risk of death in all sleeping environments
- Sleeping with an infant on a sofa is associated with a particularly high risk of sudden unexpected death in infancy
- An infant is more at risk of sudden unexpected death if he/she bedshares with people other than his/her parents or usual caregiver

(Level II-2, Grade B evidence – see appendix for more information on grading of evidence)

The National Institute of Health & Care Excellence (NICE) in the UK has been updating its recommendations, which are currently on-line with the final guideline to be released December 2014. They have been looking at the relationship between bedsharing, what they call co-sleeping, and Sudden Infant Death Syndrome (SIDS). This is important, as the NICE draft review includes the results of a recent meta-analysis by Carpenter and colleagues (2013), which was an attempt to "resolve uncertainty as to the risk of SIDS associated with sleeping in bed with your baby if neither parent smokes and the baby is breastfed" wherein they suggested there is risk. This analysis has been met with significant controversy by other researchers, who have expressed concern over methodological, statistical and interpretational issues (Ockwell-Smith et al., 2013; Renz-Polster et al., 2013). Indeed, the results of an even more recent case control analysis come to a different conclusion, stating "there is no significantly increased risk for SIDS associated with bed-sharing in the absence of sofa-sharing, alcohol consumption and smoking" (Blair, Sidebotham, Pease & Fleming, 2014).

The draft NICE guideline summarizes the issue as follows:

> "The cause of sudden infant death syndrome (SIDS) is not known. It may be that there are many factors contributing to SIDS . . . However, the evidence does not allow us to say that co-sleeping causes SIDS. Therefore the term 'association' has been used in the recommendations in this update to describe the relationship between co-sleeping and SIDS."

What adds to the confusion is that CPS and NICE documents use "bedsharing" and "co-sleeping" to describe the same thing: sleeping on the same sleep surface with an adult caregiver (CPS, 2014; NICE, 2014). This could be a North American style mattress and box spring, a futon on the floor, or a couch. Confusion persists in the sleep research, as there are different terms and definitions used to describe a variety of sleep situations. However our preliminary knowledge informs us there are very different risks associated with each of the described sleep environments. For example, CPS clearly states that "**sleeping with an infant on a sofa is associated with a particularly high risk of sudden unexpected death in infancy**".

In our experience working directly with families, parents continue to sleep with their infants for a variety of reasons, both intentionally and unintentionally. Although we have no accurate measure of the rate of bedsharing in BC, data collected from 1, 867 Oregon mothers in 1998/1999 looked at sleep arrangements and found that 76% of mothers reported bedsharing at least some of the time (Lahr et al., 2007). This is consistent with the results of a survey of 1,122 mothers in Manitoba, where researchers found that 72% of mothers reported bedsharing on a regular or occasional basis (Ateah et al., 2008).

Most alarming is that many of our members report that families say they are sofa sleeping due to fears regarding falling asleep with the infant in the parental bed. We have no direct BC data, but this is consistent with a 2008 survey of 4,789 American mothers where researchers found that **25% of mothers admit to having fallen asleep while breastfeeding their infants on chairs, sofas or recliners** (Kendall-Tackett et al., 2010). These findings align with SIDS research collected over a 20 year period in the UK. Blair and colleagues did a case control study of 300 SIDS deaths from 1984 to 2003 and it was noted there was an **increase in the number of deaths of infants sleeping with a parent on a sofa** (Blair et al., 2006).

Therefore, despite what has historically been a well-intended predominantly anti-bedsharing message to parents, mothers continue to sleep with their babies at night. In some situations this occurs out of desperation to settle the infant, in others it is a cultural or value driven approach to nighttime care. Still, in other situations it is that real choice is constrained by socioeconomic realities, e.g. not having a crib that meets safety guidelines. For many others, bedsharing occurs to facilitate breastfeeding, an important health behavior.

4.0 The Connection Between Sleep and Breastfeeding

Research shows a strong relationship between breastfeeding and bedsharing (Academy of Breastfeeding Medicine, 2008). In sleep lab studies, infants who share a bed with their mother breastfeed more often, double the frequency of feeds, and for longer duration, with an almost 40% increase in length of each feed, compared to solitary sleeping breastfed infants (McKenna et al., 1997). Additionally, many studies describe how breastfeeding mothers are more likely to bedshare (Blair et al., 2004; Buswell et al., 2006; Clements et al., 1997; McCoy et al., 2004; Santos et al., 2009).

Generally, breastfed babies are feeding as frequently throughout the night at 3 months of age as they were at 1 month (Ball 2003; Elias et al., 1986), thus the normative nighttime care of breastfed babies is intense work. Bedsharing facilitates the ease of nighttime care and breastfeeding through proximity. Waking through the night is biologically normal for young infants regardless of feeding method (Weinraub et al., 2012). The evidence suggests that mothers who exclusively breastfeed get more sleep in terms of both objective (Doan et al., 2014) and

subjective (Kendall-Tackett et al., 2010; Quillin et al., 2004) measures, despite more night awakenings.

5.0 The Role of the Healthcare Provider in the Family's Decision Making Process

There are a variety of healthcare providers who engage in discussions with families about safe sleep and breastfeeding, including Family Physicians, Pediatricians, Registered Nurses, Midwives and IBCLC's. Each profession has a code of conduct that guides them in their work with families. For example, the Code of Professional Conduct for International Board Certified Lactations Consultants (2011) dictates that every IBCLC shall:

1. Fulfill professional commitments by working with mothers to meet their breastfeeding goals.
2. Provide care to meet clients' individual needs that is culturally appropriate and informed by the best available evidence.
3. Supply sufficient and accurate information to enable clients to make informed decisions.

Other professional organizations have a similar ethical directive which support partnership in healthcare planning and informed shared decision making (e.g. CMA, 2004; CNA, 2008). In meeting our professional obligations it would be useful for all healthcare providers to consider the following ethical principles and paradigms as we face potential dilemmas in supporting families in their lived experience of nighttime infant care.

In the past, strong attention was given to compliance with "expert" healthcare provider advice. This has been replaced with an adherence paradigm, supported by reference to the value of autonomy and shared decision-making (Sandman et al., 2011). In the adherence view, there is more consideration given to the ability and motivation of the individual to carry out the plan of care and whether the plan is congruent with personal values.

Increasingly, there is an expectation that decisions about plan of care be shared, particularly when healthcare consumers are faced with more than one option. The term "shared decision making" can be defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options to achieve informed preferences (Elwyn et al., 2012). Shared decision making assumes the professional is almost always superior in power to the patient and will to a large extent set the agenda for the decision-making process—thereby influencing the extent to which the patient can exercise his or her autonomy (Sandman et al., 2011).

The expanded term **informed** shared decision making underscores the ethical principle of veracity. In applying veracity, one must be honest about knowledge of the issue and the limits of that knowledge. This is important in the case of infant

sleep and breastfeeding as we have strong evidence that some variables and conditions pose a safety risk, e.g. prone position, sofa sleeping, exposure to smoke. Other variables, such as "bedsharing" and "co-sleeping" are not yet defined specifically and consistently in the research as to their inherent risk.

A recent trend has been to use decision support tools (DSTs) to aid health care consumers facing complex situations, such as infant sleep safety. DSTs are not meant to replace dialogue with a knowledgeable health care provider, but rather support that interaction and promote informed shared decision making (International Decision Aids Standards Collaboration, 2008).

The principle of veracity also applies to parents, expecting that they be honest with their real experience of nighttime parenting. In order to have a dialogue regarding the reduction of potential harm to the infant, there needs to be open discussion about what is really happening with families, something that could be shut down when parents perceive that they will be criticized or judged for not following prescribed advice.

Another important principle concerns beneficence. Beneficence requires that the healthcare provider help families minimize harm and risk, and promote good outcomes. What constitutes a good outcome will vary depending upon the specifics of the situation and the beliefs and values of the individual. Increasingly it is considered that "good outcomes" be defined by those who are using healthcare services. "Nothing about me without me" has become the motto of many health groups in Canada and around the world, as healthcare consumers assert a more active role in determining healthcare planning and priorities (Change Foundation, 2014).

6.0 Current Provincial Sleep Resources

In 2011 the Ministry of Health published a one-page handout for parents called "Every Sleep Counts". In it parents are advised that "babies who share a bed or sleep surface with adults, children or pets are at risk for SIDS and accidental death" and "always place your baby on his/her back, in a crib for **every** sleep" (emphasis in original). Twice it is stated that it is "best not to sleep with your baby". In this handout there is a photo of a solitary sleeping baby in supine position in an empty crib. Anyone familiar with baby care would have a difficult time meeting all of babe's sleep needs in this environment and in this position.

In contrast to the "Every Sleep Counts" handout, Perinatal Services BC has developed "Health Promotion Guideline 1 – Safe Sleep Environment Guideline for Infants 0-12 months of Age", also in 2011, which gives a more nuanced message. The executive summary of this document bravely states that "the section on bedsharing is a contentious portion of this document" and goes on to discuss the dialogue between committee members regarding whether or not to promote bedsharing (Perinatal Services BC, 2011).

In the end, it is notable that this guideline, while not recommending bedsharing, does not make a statement against bedsharing when no risk factors are present. What is recommended in this document is that healthcare professionals are intentional in discussing sleep with families and the document makes recommendations on how to reduce risk if families choose to bedshare. This pragmatic and tailored approach would be more consistent with the ethical responsibilities of all healthcare providers in counselling families.

7.0 BCLCA Recommendations

7.1 "Bedsharing" and its relationship to unexplained infant death is only beginning to be broken down into the possible and specific variables that are thought to increase risk, such as bedding, temperature and type of sleep surface. This is a complex issue that warrants ongoing attention to the best available evidence. We know that many families sleep with their babies for a variety of reasons – one of which can be to facilitate breastfeeding, which is a valuable health strategy with short and long term consequences for mother and babe. While the BCLCA is primarily concerned about the issue of safe infant sleep in the context of breastfeeding, we understand that the importance of supporting an informed shared decision making process applies to all families no matter their method of feeding. Therefore it is our recommendation that the Ministry of Health immediately establish a working group to look at the issue of nighttime parenting and how to reduce risk and promote safety.

7.2 At BCLCA we envision that relevant academic and professional experts in the area of sleep, feeding and family health be invited to take part in this collaborative process. It is crucial that parents themselves be invited to participate, to ensure that the most relevant and accurate knowledge is translated to real life practice by allowing for the unique circumstances and values of individual families.

7.3 Further, we recommend that a priority issue be the development of a sleep resource for parents that supports informed shared decision making around this complex and contextual issue. It is imperative that this resource acknowledges the cultural and personal values of each family, as well as the very real socioeconomic limitations of some families in their experience of nighttime caregiving. It is important for parents to understand the known risks and what areas of research relating to nighttime care of the infant are still uncertain. It is important to take a pragmatic approach to the realities of families and share what we know about how to reduce risk when they choose to bedshare. Below is an example of a recently developed decision support tool for parents on nighttime care from Dr's Russell and Whitmore at the University of Durham:

https://www.dur.ac.uk/resources/sleep.lab/sim/RussellWhitmoreDurhaSIM2012.pdf

7.4 Finally, it is suggested that, in the meantime, the resource for healthcare providers in BC to use in their work with families is the Perinatal Services BC Safe Sleep Environment Guideline (2011). Currently this document is the best resource available to guide healthcare providers in our province, in order to facilitate a discussion regarding each family's unique circumstance and personal goals, in order to uphold their professional ethical responsibilities.

The BCLCA would like to thank the many reviewers of this document who gave willingly of their wisdom and their time.

"Cooperation is the thorough conviction that nobody can get there unless everybody gets there". ~ Virginia Burden

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Appendix

TABLE 1 New grades for recommendations

from the Canadian Task Force on Preventive Health Care for specific clinical preventive actions

The task force recognizes that in many cases, patient-specific factors must be considered and discussed, such as the value the patient places on the clinical preventive action, its possible positive and negative outcomes, and the context or personal circumstances of the patient (medical and other). In certain circumstances where the evidence is complex, conflicting or insufficient, a more detailed discussion may be required.

Level of evidence	**Description**
I	Evidence obtained from at least one properly randomized trial.
II-1	Evidence obtained from well-designed controlled trial without randomization.
II-2	Evidence obtained from well-designed cohort or case-controlled analytical studies, preferably from more than one centre or research group.
II-3	Evidence obtained from comparisons between times and places, with or without the intervention. Dramatic results in uncontrolled experiments could also be included in this category.
III	Opinions of respected authorities, based on clinical experience, descriptive studies or reports of expert committees.
Grade	**Description**
A	There is good evidence to recommend the clinical preventive action.
B	There is fair evidence to recommend the clinical preventive action.
C	The existing evidence is conflicting and does not allow a recommendation to be made for or against use of the clinical preventive action; however, other factors may influence decision-making.
D	There is fair evidence to recommend against the clinical preventive action.
E	There is good evidence to recommend against the clinical preventive action.
F	There is insufficient evidence to make a recommendation; however, other factors may influence decision-making.