Care of infants with neonatal withdrawal in Canadian hospital settings: Has practice advanced in ten years? Revision and pilot testing of a national survey instrument

by

Tara Loutit
BSN, University of British Columbia, 1997

A Thesis Submitted in Partial Fulfillment
of the Requirements for the Degree of

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Supervisory Committee

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Abstract

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Substance use during pregnancy can adversely affect both health and social outcomes for the infant and the mother. Many practices related to the care of infants with prenatal substance exposure are not consistent from one facility to another and have been developed on an anecdotal basis rather than based on empirical research. A replication study of a 2002 national practice survey is being planned that will describe some of the practices related to daily care, discharge planning, and community support for this group of infants and their caregivers. In this thesis, I present the findings of a pilot study that was conducted as a prelude to this larger national study. A summary of a literature review of recent survey research is presented along with a description of the process of revising a previously developed instrument to survey the practices used when caring for infants with prenatal drug and alcohol exposure and their mothers in the hospital setting. Content validity of this revised instrument was established with the support of a content expert group and the revised instrument was pilot tested with a small sample of nurses who practice in hospitals that will not be eligible for the national study. The findings from this pilot study will guide the research team in developing and conducting the national survey.

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Acknowledgments

Many individuals supported me with their encouragement and valuable contributions. The content experts who provided much needed input to the development of the survey and the individuals who completed the pilot survey provided valued feedback. Their open and honest feedback was central to the revision of this instrument. To my fellow graduate students who provided encouragement from near and far—in particular, Colleen Backlin who provided scholarly advice, personal counsel and encouragement and hours of humorous dialogue. I can't imagine going through this process without her constant support. And finally, I acknowledge my supervisor Dr. Lenora Marcellus who engaged in endless discussions, provided guidance throughout each step of the process, and who shared in all of my personal and scholarly milestones along the way. I am in awe of her personal and professional accomplishments and her commitment to the safe care of infants with neonatal withdrawal. Thank you.

Dedication

This thesis is dedicated to my friends and family. To my close friends who were there to provide much needed coffee breaks and for their reassurance that I could achieve balance between family life, work life and school life. To my parents, their partners, and my in laws who were always available to care for our young family while I studied and who supported me in every way. I especially dedicate this to my husband David, and our children, William, Andrew and Kathryn—whose generous love, understanding, support and silliness encouraged and sustained me throughout this program. Life has been busy and their support has never wavered—thank you. By example, my parents instilled in me their values of education, dedication and faith. I hope that my children will also cherish these values.

Finally, to the families struggling with addiction and withdrawal—may we learn together how to provide the best care possible in a supportive and understanding partnership.

Chapter 1

Background

Neonatal nurses recognize that the care of women with problematic substance use and their infants with prenatal substance exposure continues to be a significant issue in Canada and other countries around the world. Substance use during pregnancy can adversely affect health and the social outcomes for both infants and their mothers (Lall, 2008; O'Donnell et al., 2009; Walton-Moss, McIntosh, Conrad, & Kiefer, 2009). These families require multifaceted and personalized care involving the coordinated and collaborative teamwork of a number of healthcare professionals, both in the hospital setting and in the community. Many practices related to the care of infants with prenatal substance exposure and their mothers are not consistent from one facility to another and have been based on anecdotal rather than empirical research (Marcellus, 2002; Oei & Lui, 2007; O'Grady, Hopewell, & White, 2009; Sarkar & Donn, 2006; Velez & Jansson, 2008; Zellman, Fair, Hoube, & Wong, 2002).

In this thesis, I present the findings from a pilot study that I conducted as a prelude to a national study that will be conducted in Canada to describe practices used when caring for infants with prenatal drug and alcohol exposure and their mothers in the hospital setting, in particular the Neonatal Intensive Care Unit (NICU) setting.

In this paper I will present the following: (a) summary of a literature review of recent survey research focused on the care of infants with prenatal drug and alcohol exposure in neonatal intensive care units, (b) a description of the process of revising and piloting a survey instrument developed for a similar study conducted in 2002, and (c) presentation of the key findings of the pilot testing of this revised instrument.

This thesis is organized in five chapters. The background and research problem is described in the first chapter. The second chapter is a summary of the review of the literature that sets a foundation and justification for this pilot research project and the national study. The methodological approach is explained in chapter three. In chapter four I present the research findings and a discussion of these findings. Finally, in chapter five I reflect on the implications of my findings on development of the national study, and for future nursing practice, education, and research.

Background to the Problem

While it is generally acknowledged that substance use during pregnancy is a significant issue in the Canadian population, only limited prevalence estimates are available for tobacco, alcohol, and drug use during this time (Hutson, 2006; Kelly et al.,2012). Researchers analyzed the Canadian Maternity Experience Survey (Al-Sahab, Saqib, Hauser & Tamim, 2006) and reported a national prevalence of smoking of 10.5%, ranging from a low of 8.5% in British Columbia to a high of 39.4% in the Northern Territories. In national surveys of Canadian women, 10% reported smoking during pregnancy and less than 15% reported using alcohol during their last pregnancy (Health Canada, 2007; Public Health Agency of Canada, 2006). Walker, Al-Sahab, Islam, and Tamim (2011) report similar findings; despite widespread knowledge regarding the adverse effects of alcohol consumption during pregnancy, over 10% of Canadian women continue to use alcohol during pregnancy.[1] Further, it has also been recognized that cigarette smoking is a significant concomitant factor in women who struggle with drug use (Wright & Walker, 2007).

[1] This analysis mainly focused on low to moderate levels of alcohol use (≤1 drink per day) as this constituted the majority of the sample of mothers who consumed alcohol during pregnancy.

A U.S. national survey revealed that approximately 5% of pregnant women reported illicit drug[2] use during the preceding month (Substance Abuse and Mental Health Services Administration, 2008). The prevalence of illicit drug use is estimated to be less among Canadian women of childbearing age compared to those in the United States. Data collected in 2006 for the Canadian Maternity Experiences Survey[3] (2009) note that 6.7% of women used street drugs in the three months prior to becoming pregnant or realizing they were pregnant. However, this percentage dropped substantially to 1.0% once the pregnancy was recognized (Public Health Agency of Canada [PHAC]). Notably, studies rely heavily on maternal self-reporting, and therefore substance use may be underreported. Underreporting of substance use has been documented among individuals seeking substance use treatment and among pregnant women (Chermack et al., 2000; Lester et al., 2001). Some key reasons for underreporting include social stigma and fear of legal consequences, particularly removal of the infant from the mother and family (Hutson, 2006; Velez & Jansson, 2008). Further, it is recognized that licit drug abuse while pregnant can pose harm (Wendell, 2013) and it is impossible to deal with legal and illegal drugs in a totally separate manner as the diversion of licit drugs into illicit markets plays a key role in drug-related harms (Riley, 1998).

Maternal substance use during pregnancy is an important risk factor for poor pregnancy and neonatal outcomes (Lall, 2008; O'Donnell et al., 2009; Walton-Moss, McIntosh, Conrad, & Kiefer, 2009). Infants who are born to women who use drugs or alcohol are at greater risk of morbidity and mortality not only because of the substance exposure but also as a result of other

[2] Any psychoactive substance that is illegal for purchase or use in Canada such as stimulants, hallucinogens, opiates (and their synthetic substitutes), solvents, sedatives, and barbiturates (Knowledge Mobilization [Know Mo], 2010).

[3] This study excluded women living on reserves or in institutions and only included women who were residing with their infants at the time of the survey therefore excluding a population of women who are more likely to struggle with substance use.

maternal prenatal and postnatal factors such as poor health, irregular or no prenatal care, inadequate nutrition, poverty, mental health challenges, violence, and trauma (Beauman, 2005; Fraser, Barnes, Biggs, & Kain, 2007; Marcellus, 2000; Marcellus, 2008; Niccols, Dell, & Clarke, 2010; Walton-Moss, McIntosh, Conrad, & Kiefer, 2009). Persistent inequities in health and social indicators evident among women who use illicit drugs are "manifestations of the complex interplay of social, political and economic determinants that influence health status and access to healthcare" (VANDU Women CARE Team, 2009, p. 3).

Social determinants of health have been identified by the World Health Organization (2012) as "the conditions in which people are born, grow, live, work and age, including the health system…these circumstances are shaped by the distribution of money, power and resources at global, national and local levels" (para. 1). Factors that are generally understood to influence population health are income and social status, social support networks, education, employment/working conditions, social environments, physical environments, personal health practices and coping skills, healthy child development, biology and genetic endowment, health services, gender, and culture (Public Health Agency of Canada, 2004). There is increasing understanding of the relationship between these social determinants and how they shape the context of women's substance use during pregnancy and impact the infant's development (Lester, Andreozzi, & Appiah, 2004; Wong, Ordean, & Kahan, 2011). Pauly, MacKinnon, and Varcoe (2009) note that "inequities in access to healthcare interact with inequities in access to social resources (such as housing, education, and social assistance) and with institutionalized oppression to produce inequities in health outcomes" (p. 126). Therefore, from a social determinants of health perspective, women who use substances during pregnancy may experience health inequities due to the lack of resources and multiple barriers to accessing

services and healthcare, placing themselves and their newborns at an increased risk for poor health and social outcomes.

Because of these increased risks, the exposed infant is often admitted to the neonatal intensive care unit (NICU) or special care nursery (SCN) for specialized care. Perinatal Services BC (PSBC) (2011) reported that approximately 45% of infants experiencing withdrawal symptoms are cared for in a Level 2 or Level 3 NICU (a discussion on Levels of Care is included in "Sample and Setting" of this thesis). The remaining infants experiencing withdrawal symptoms are discharged before a diagnosis is made, or efforts are made to preserve the parent-baby relationship and the family and community connections by keeping the baby in their Level 1 or normal newborn nursery.

The practice of caring for mother and newborn together in the same room immediately from birth is preferred for the general postpartum population but is not yet standard practice of care for newborns of substance-using women. Abrahams et al. (2010) report that "rooming-in may facilitate a smooth transition to extrauterine life for substance-exposed newborns by decreasing NICU admissions and NICU length of stay for term infants, encouraging breastfeeding, and increasing maternal custody of infants at discharge" (p. 866). Rooming-in is not only a cost saving measure, but supports this vulnerable dyad, as separating the mother from her infant in this early postpartum period can have lasting effects on their bonding and attachment (Abrahams et al., 2010; Bystrova et al., 2009; Saiki et al., 2010). Separating women and their babies "is predictive of infant abandonment, abuse, and neglect in the non-addicted population, and is even more likely to be so for high-risk populations" (Abrahams et al., 2010, p. 867). Caring for mothers whose lives have been affected by drugs and/or alcohol use and their exposed infants requires the healthcare team to not only have the knowledge and skills necessary

to care for the affected newborn, but also to authentically engage in building a trusting relationship with the mother (Morton & Konrad, 2009).

Purpose and Objectives

In an article published over a decade ago, Marcellus (2002) described the practices of NICU health care teams when caring for substance-exposed infants in the hospital setting and surrounding discharge to the community. In Canada, a replication study is being developed to re-examine these practices from a ten-year interval perspective and to explore if there are any differences in practice and innovations in practice that have emerged over this time. The purpose of the national survey research study (of which I am a co-investigator) will be to describe the practices used when caring for women who have substance use issues and their infants in the hospital setting. Specific objectives of the national study are to:

- Describe current clinical practices (pharmacological and non-pharmacological) related to daily care, discharge planning, and community support for infants with prenatal substance exposure and their parents/caregivers in NICUs across the country;
- Identify any significant shifts and innovations in practice since 2002;
- Explore how clinical and caregiving practices integrate consideration of the mother baby dyad;
- Provide benchmarking data for neonatal organizations and health service teams to reflect on and improve their own practices; and
- Develop recommendations for nursing practice, research, and education.

The purpose of this pilot study was to test the instrument and procedures proposed for the national study. In other words, the intent of this pilot study is to assess the practicability of conducting the larger study—to explore how the system works and to allow modifications to be

made to the research design or procedures prior to conducting the larger scale investigation. Specifically, the objectives included:

- Revision of the original survey instrument based on content expert group recommendations;
- Administration of the revised survey instrument to a pilot group;
- Final revision of the survey instrument and development of sampling and administration recommendations in preparation for the national study

Research Question

The primary research question for both this pilot study and the national study is: What are the current practices in Canadian neonatal intensive care units related to daily care, discharge planning, and community support for infants with prenatal substance exposure and their parents/caregivers?

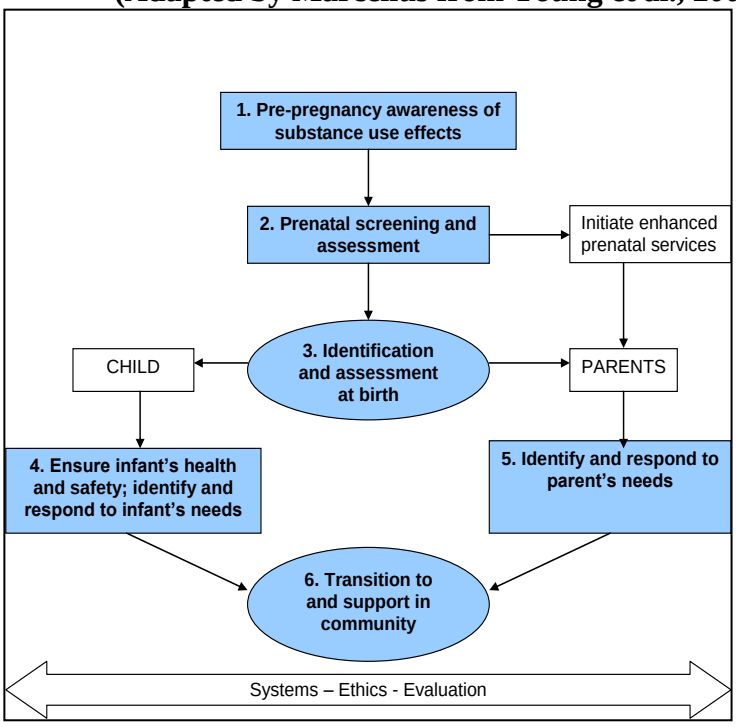
Conceptual Framework

I used the Policy and Practice Intervention Points for Children and Families framework (Young et al., 2009) as the conceptual framework for this pilot investigation. This comprehensive services framework was developed within the context of child welfare to address the continued fragmentation of health and social services when supporting families impacted by substance use. Although it takes a primarily child-centered perspective, the traditional focus on birth and the immediate post-partum period is expanded in this framework to be more inclusive of opportunities to support women before and during pregnancy, and on transition to the community after birth. In this framework, the authors assert that "a more comprehensive view is needed that takes multiple intervention opportunities into account, beginning with pre-pregnancy and continuing throughout a child's developmental milestones" (Young et al., 2009, p. 2).

Adapted slightly for this study, this framework outlines six points of intervention and defines points where policy and practice interventions can benefit infants with prenatal substance exposure and their families. This study focused on the resources and practices that support points three to six of this framework (see Figure 1).

The framework begins pre-pregnancy (*Point 1*) where the intervention is "to increase awareness of the effects of prenatal substance use" (Young et al., 2009, p.18). The authors then proceed through the prenatal period and birth (*Points 2 to 5*), which provides opportunities for prenatal screening; assessment; and collaborative, specialized, and individualized care. Finally, this framework outlines the importance of the transition to and support in the community (*Point 6*). When considering these interventions, the framework indicates continual consideration and reflection of the system linkages that would allow coordination of these needed interventions, ethical considerations when providing this care, and continual evaluation of these interventions and services provided by multiple agencies.

Figure 1: The Six Points of Intervention
(Adapted by Marcellus from Young et al., 2009)



Definition of Terms

Neonatal withdrawal. Neonatal withdrawal is a condition that develops in the infant as a result of abrupt removal of exposure to addictive substances. It is most commonly observed after maternal use of opioids such as heroin, morphine, or methadone, but may also be present after continuous fetal exposure to barbiturates, alcohol, tobacco or other psychoactive drugs (Murphy-Oikonen, Montelpare, Southon, Bertoldo, & Persichino, 2010; Oei & Lui, 2007). Often referred to as neonatal abstinence syndrome (NAS), this classification system refers to neonates experiencing withdrawal symptoms from the maternal use of drugs. Although the term NAS originally referred to withdrawal from opioids, it is now commonly applied to a physical dependence upon many other substances. Infant outcomes from substance exposure varies with the substance, the timing of the exposure, and the kind of exposure, but in general ranges from no obvious effects to significant effects, including intrauterine growth restriction, prematurity, neurobehavioral and neurophysical dysfunction, birth defects, and Fetal Alcohol Spectrum Disorder (Abdel-Latif, Bajuk, Lui, & Oui, 2007; Bio, Siu, & Poon, 2011; Crocetti, Amin, & Jansson, 2007; Lall, 2008). Infants with prenatal substance exposure may go unrecognized and may be discharged from the hospital with their families with limited or no community follow-up or support. They are at risk for a complex of medical and social issues, including abuse and neglect, and are often involved with child protection agencies (Dunn et al., 2002; O'Donnell et al., 2009). Most studies about interventions to support infants with NAS focus on pharmacological management, and there is less research available on other elements of care and service delivery (Velez & Jansson, 2008).

It is estimated that the number of infants with prenatal substance exposure is increasing, with 60-90% of substance-exposed infants developing signs and symptoms of NAS and of these

50-75% will requiring treatment (D'Apolito & Hepworth, 2001; Hudak & Tan, 2012). Increases in prevalence and the challenges associated with managing infants experiencing NAS are being reported throughout the U.S. (Hudak & Tan, 2012; O'Donnell, et al., 2009; Patrick, Schumacher, Benneyworth, Krans, McAllister, & Davis, 2012) and Canada (Canadian Institute for Health Information [CIHI], 2012; Provincial Council for Maternal and Child Health [PCMCH], 2010). In 2003-2004, 171 newborns were diagnosed with NAS in Canada, with an increase to 654 reported cases in 2010-2011 (CIHI). Dow et al. (2012) note that "a growing incidence of NAS across Canada is directly impacting scarce resources (in NICUs) due to prolonged length of hospital stay for specialized care and support of both the baby with NAS and the mother" (p. e488). These authors further note that fear of stigmatization "may prevent honest reporting resulting in an underestimation of the prevalence of substance use and addiction" (Dow et al., p. e490). Researchers have found that newborns who room in with their mothers were less likely to require treatment for neonatal withdrawal and more likely to be discharged home with their mothers (Abrahams et al., 2010; Bystrova et al., 2009; Saiki et al., 2010).

Infants with prenatal substance exposure. There are a number of terms used in the research and lay literature to describe this population. Some of the terms that are used (such as "crack babies," "drug babies,' and "oxy tots") are derogatory and stigmatizing for both infant and mother, and leading researchers are promoting the use of more respectful infant-centered terms (Marcellus, 2007; Newman, 2013). For the purposes of this study, the term "infants with prenatal substance exposure" will be used to describe the population.

Neonatal intensive care unit teams. Infants who need intensive medical attention are cared for in a specialized area of the hospital called the Neonatal Intensive Care Unit (NICU). The NICU combines advanced technology with trained healthcare professionals to provide care

for infants who are considered vulnerable for reasons such as prematurity and the presence of congenital anomalies or life threatening illnesses. This multidisciplinary team consists of registered nurses, neonatologists, social workers, dieticians, pharmacists, occupational therapists, physiotherapists, and registered respiratory therapists. The members of the NICU team work together with families to develop a plan of care for their high-risk newborns. Some units refer to their NICU as a Special Care Nursery (SCN)–although much of the professional literature now uses the term NICU.

Chapter 2

Summary of Literature Review

In this chapter, I provide an overview of the literature that researchers have published surveying current practices of caring for infants experiencing neonatal withdrawal. I also identify themes and gaps in this research.

I conducted a CINAHL Plus with Full Text database search for post-2002 journal articles regarding the care of infants with prenatal substance exposure. Sixty-eight articles were located. Many of the articles (17/68) focused on neonatal assessment and/or pharmacologic management (14/68) (See Figure 2). Others focused on protocols and/or scoring systems used to manage infants experiencing withdrawal. Several other themes were found throughout this literature review; however, the focus often remained on the infant. With the shift to mother-baby models of care, it is important to consider the mother as well. Three articles in this search focused solely on non-pharmacological management of the infant such as infant massage and rooming-in compared with standard care for newborns of mothers struggling with substance use. A complete list of this search can be found in Appendix A.

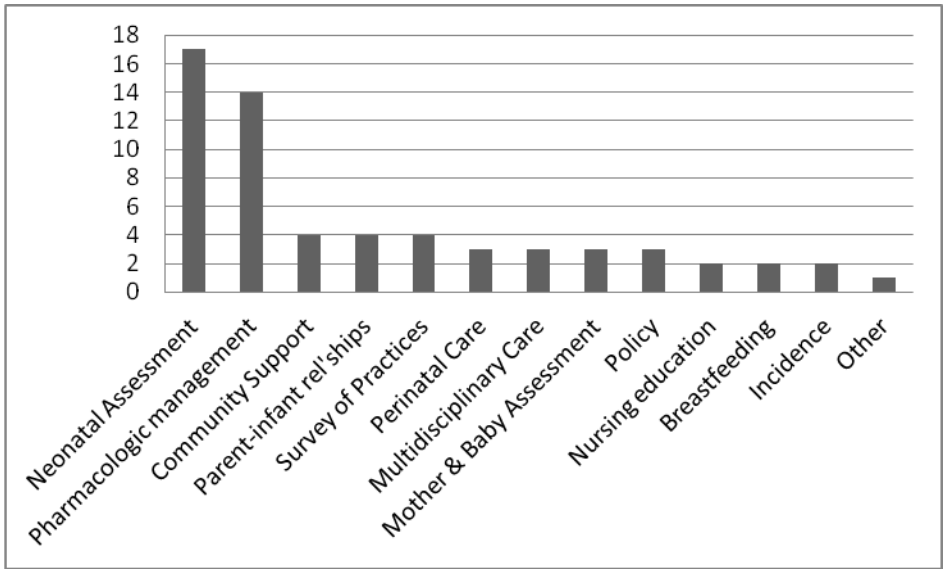


Figure 2: CINAHL Plus with Full Text database search for post-2002 journal articles

Since publication of the Canadian national study that Dr. Marcellus conducted in 2002, there have been a number of surveys published in other countries, including the United Kingdom and Ireland (O'Grady, Hopewell, & White, 2009), the U.S. (Crocetti et al., 2007; Sarkar & Donn, 2006), and Europe (Micard & Brion, 2003) on standards of practice with this population. For ease of reading and comparison, the survey results are summarized in Appendix B.

A postal questionnaire was conducted by O'Grady, Hopewell, and White (2009) and administered to a consultant paediatrician or neonatologist in the UK and Republic of Ireland. They sought data including the number of infants treated for NAS, abstinence scoring system used, policy on toxicology testing, and pharmacological management of opiate and polysubstance abuse. Their research further explored policies regarding discharge of infants on medication, breastfeeding, and the use of cranial ultrasound. The response rate for this survey was 90%.

Sarkar and Donn (2006) sought to determine monitoring and treatment practices for NAS following opiate or polydrug exposure *in utero*. This national online survey was distributed to the chiefs of the neonatology divisions of accredited Fellowship programs in Neonatal-Perinatal Medicine in the United States. This brief questionnaire collected data to determine the percentage of respondents using an abstinence scoring system, following a formal written policy or education program for management of NAS, and the use of pharmacologic management of opiate or polysubstance abuse. The researchers used a categorical scale in their instrument (yes or no) and had a 73.5% response rate.

A cross-sectional telephone survey was done by Crocetti et al. (2007) to explore the evaluation and management of opiate exposed infants among Maryland hospitals. This state survey was administered to each hospital to a provider with "the best knowledge regarding that facility's policy on the care of opiate-exposed newborns… (and) included directors of maternal and child health, nurse clinicians, case managers, and neonatologists located on the neonatal intensive care unit (NICU)" (p. 633). Questions about newborn delivery volume, number of opiate-exposed infants born per year, and existing policies and procedures for the care and management of NAS were sought. The questions were mainly open ended and there was an 82% response rate.

Finally, Micard and Brion (2003) surveyed French and European hospital pharmacists regarding the management of neonatal withdrawal. This online questionnaire explored the availability (or unavailability) of a written protocol for management and explored each hospital's first line pharmacological treatment used when treating withdrawal. The response rate was 60%.

The majority of surveys discussed were conducted by physicians seeking physicians' input with response rates varying from 60 to 90%. This review revealed that clinical practices

continue to vary among geographic areas, hospitals, and even practitioners. Further, many practices continue to be based on anecdotal evidence and there continues to be little research validating current strategies available on other elements of care and service delivery other than pharmacological management. There is limited focus on nonpharmacological treatment and scant mention of care elements related to the mother of the substance-exposed infant. In this review I also found wide variations reported in the scoring systems used when assessing neonatal withdrawal, variations in dosing regiments, and variations in the timing to initiate or discontinue pharmacological treatment. Many of the authors note that there are inconsistent applications of existing policies regarding diagnosis and treatment of neonatal withdrawal and few authors mention the care of the mother.

Through this literature review I have provided a basis for an exploration of current practices when caring for infants withdrawing from substances. In the next chapter I will discuss the methodology for this pilot study.

Chapter 3

Methodology

I employed a descriptive survey pilot study methodology for this study. This methodology will also be used for the national survey study. The methodological approach is organized in three sections. In the first section I review the approaches taken to this study, including a review of descriptive research, pilot study research, and replication studies as well as a thorough discussion on survey design. In the second section, I outline the method, the instrument, content validation and validating the instrument. In the final sections, I describe the setting and sample, data analysis, maintaining rigour and ethical considerations.

Approach

Descriptive Research. Descriptive research is a type of enquiry that aims to gather information about certain phenomena (Kelley, Clark, Brown, & Sitzia, 2003). Descriptive research does not fit neatly into the definition of either quantitative or qualitative research methodologies, but instead utilizes elements of both, often within the same study. Such is the case with this survey research instrument which consisted mostly of questions designed to measure quantitative variables but containing qualitative elements as well. Kelley et al. (2003) suggest that the aim of descriptive research is to "examine a situation by describing important factors associated with that situation, such as demographic, socio-economic, and health characteristics, events, behaviours, attitudes, experiences, and knowledge" (p. 261). Teddlie and Tashakkori (2009) explain descriptive analysis as the "analysis of numeric data for the purpose of obtaining summary indicators that can efficiently describe a group and the relationship among the variables within that group" (p.24). In summary, descriptive research describes a situation

and is not meant to identify causes. In this pilot study I collected data to make needed changes to the data collection instrument to ensure that it was valid and reliable.

Pilot Studies. A pilot study is a small sample study conducted prior to a larger scale study or clinical trial (Connelly, 2008, p. 411). Pilot studies fulfill a range of important functions and can provide valuable insights for other researchers (Van Teijlingen, Rennie, Hundley, & Graham, 2001). Many of these functions stress the importance of testing the logistics and gathering information prior to a larger study in order to improve the latter's quality and efficiency. Typically, a pilot study has similar methods and procedures to the larger full-scale study and produces data to help justify the larger study (Jairath, Hogerney, & Parsons, 2000). Dillman, Smyth, and Christian (2009) note that emulating procedures proposed for the main study allows the pilot to estimate rates, item nonresponse, and variable distributions. Further, conducting a pilot study is important because it can reveal deficiencies in the design of a proposed experiment or procedure, and these can then be addressed before time and resources are expended on a larger scale. Mason and Zuercher (1995) note that pilot studies can be "time consuming, frustrating, and fraught with unanticipated problems, but it is better to … deal with them before investing a great deal of time, money, and effort in the full study" (p. 11).

Conducting this pilot study pre-tested the reliability, adequacy, and relevance of the revised questionnaire and provided an opportunity to establish and test the sampling and recruitment strategies prior to the national study. Dillman et al. (2009) propose that the goal of such a study is to "determine whether the proposed questionnaire and procedures are adequate for the larger study… [and will] give a good sense of how the study procedures will work in practice" (p. 228). They warn that to neglect a pilot survey can be especially disastrous for web surveys.

I conducted the pilot test of this survey with participants not eligible to participate in the national study. These units' birth rates were too low to be eligible for the larger study and were distributed to participants who were working in hospitals with birthrates between 100 and 500 per year. This was done so that: (a) potential participants would not be burdened with completing the survey twice and (b) health professionals from smaller hospitals not eligible for the larger study could share their experiences of caring for this population with me and provide feedback on the process.

Replication Studies. Replication research is a way of establishing the credibility of findings from a previous study and, if findings are corroborated, supporting and strengthening these earlier results (Klein, Brown, & Lysyk, 2000). Strengthening these findings refers to having the scope of the previous conclusions extended and "leads to generalizable results, rather than merely to isolated and uncertain findings" (Lindsay & Ehrenberg, 1993, p. 217). Thus replication can demonstrate similarity of findings and strengthen confidence in the results obtained from the original study, extend the generalizability when the survey is repeated and further developed, and reduce the risk of spurious findings (Blomquist, 1986).

Survey Design

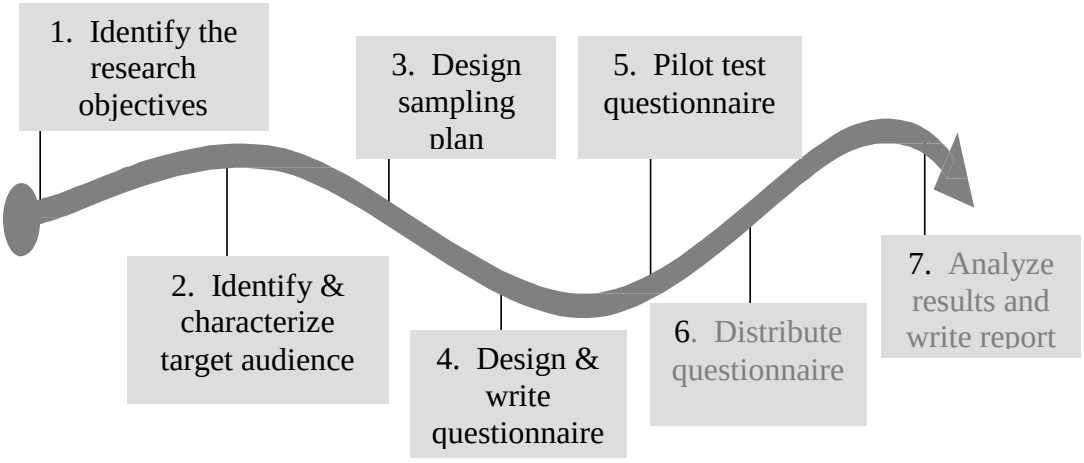
The survey is a widely used research method in many areas such as marketing, business, and social science (Morris, Fenton & Mercer, 2004; Zhang, 1999). The introduction and rapid expansion of Internet users has given Web-based surveys the potential to become a powerful tool in survey research (Millar & Dillman, 2011). With this systematic method, researchers can gather information from a large number of respondents and make planned comparisons at a relatively low cost. For select populations the cost, ease, speed of delivery and response, and

analysis all weigh in favor of the Internet as a delivery method for survey research (Morris, Fenton & Mercer, 2004).

Many factors are considered when selecting the type of survey most suited to the respondents. Further, the design and type of survey needs to suit the research question. Morris et al. (2004) note that online surveys can be embedded in e-mails, sent as an attachment to an e-mail, or in the form of a Web-based survey. These varying approaches allow Web-based surveys to be visibly pleasing and straightforward for participants (as the respondent can go directly to the survey on a Web address), and data can be automatically collected and recorded (Morris et al.).

A survey, when designed and conducted properly, allows you to "generalize about the beliefs and opinions of many people by studying a subset of them" (Kasunic, 2005, p. 3). Kasunic proposes a seven-stage process (Figure 3) when designing an effective survey and warns that careful attention to procedures must be followed throughout the process of designing, developing, and distributing the survey questionnaire in order to protect the validity of conclusions drawn from a survey. This study involved steps 1-5 of this process.

Figure 3: The 7 stage survey research process (Kasunic, 2005)



Step 1: Identify the research objectives.

Many researchers agree that the most important step in designing a survey is to start by clearly defining the question(s) the survey aims to answer (Jones, Story, Clavisi, Jones, & Peyton, 2006; Lancaster, Dodd, & Williamson, 2004; Wyatt, 2000). Furthermore, a survey can only be used for generalization when the survey process begins with clear objectives and continues to follow strict procedures. The objectives for this study (and the larger study) have been clearly outlined in the "Purpose and Objectives" section of this thesis.

Step 2: Identify and characterize target audience.

Kasunic (2005) next proposes identifying and characterizing the sample group. The author suggests a two-step process involving first identifying who will be most interested in the study's findings (target audience) and then selecting a subsample of this population for the sample (Kasunic). Identifying and characterizing the target audience and selecting a subset of this population to sample is important as these are likely the same individuals who will use the survey information to support decision making. Although it is noted that others involved in decision making such as policy developers and educators are also involved in this process, these individuals were not included in this sample group. This step will be discussed further in "Sample and Setting" of this paper.

Step 3: Design sampling plan.

During this stage, the researcher determines how the questionnaire will be distributed to the population of potential respondents (Kasunic, 2005). The researcher will need to consider whether the sample is representative of the whole population (probability sample) or unique to those participating in the survey (non-probability sample). This survey will use a non-probability sample, which is appropriate as the survey seeks information from a group of

individuals considered to be experts in a particular area of interest. However, Kasunic notes that "the reader of the report should understand that if the questionnaire were distributed to a different set of like-individuals, then a different set of results, perhaps in conflict with the original sample results, could be obtained" (p. 22). This will be discussed further in "Sample and Setting" of this paper.

Step 4: Design and write questionnaire.

This phase is divided into sub stages including the following: determine the questions to be asked, select the question type/format for each question and specify wording, design the question sequence and overall questionnaire layout and develop ancillary documents (Kasunic, 2005). In terms of layout of a web survey, Couper, Traugott, and Lamias (2001) report that respondents seek information from the instrument itself as well as using both the verbal and visual elements of the interface. For example, the visual design features and the interactive nature of Web surveys can facilitate or distract from the task of completing the survey.

Step 5: Pilot test the questionnaire.

Kasunic (2005) suggests that "the questionnaire instrument must be 'tested' with members of the target audience to remove bugs and improve the instrument" (p. 7). Kasunic further stresses the importance of pre-testing the questionnaire to expose problems or weaknesses in the questions, the questionnaire layout, the process, and the technology used when conducting a Web-based survey. This research study administered the pilot test of the instrument and survey process (see Chapter 4 for presentation and discussion).

Step 6: Distribute the questionnaire.

The questionnaire is now ready to be distributed to the sample as defined in the sampling plan (Kasunic, 2005). To maximize the response rate, Kasunic suggests providing a reasonable amount of time for individuals to respond.

Step 7: Analyze results and write report.

This final stage involves the task of "pulling the information together to make observations, conduct analyses, make interpretations, and draw conclusions (Kasunic, 2005, p. 83). This also involves interpreting these results so that they are understood by others (write the report, publish the findings, etc.). Although it is recognized that the predominant purpose of conducting a pilot study is to test the procedures prior to conducting a larger study, it has been acknowledged that despite the small sample size of pilot studies, "the preliminary data may prove to be significant both statistically and clinically" (Connelly, 2008). A brief discussion of these preliminary results of this pilot study is provided in Chapter Four of this document.

Methods

In this section, I will first describe the re-creation and revision of the survey instrument including literature to support these revisions and administration of the survey. Secondly, the setting and sample for both the larger investigation and this pilot study will follow. Finally, an analysis of the data from this pilot research process including ethical considerations will conclude this chapter.

Re-creation of the survey instrument. The instrument from the original survey was not available as the study was conducted twelve years ago. The survey instrument was re-created based on the published article from the original study (Marcellus, 2002). This survey consisted of eight key areas of practice:

- Facility information and statistics
- Policy development and committees
- Physical facilities
- NICU/SCN care
- Discharge planning
- Staff education and support
- Link to family and social services
- Additional comments

There were 31 closed-ended questions and 13 open-ended questions in the original survey instrument, with an option to provide additional comments to identify other practice issues that were not addressed in the survey. The intent of recreating the original study survey instrument was to facilitate examining changes over time in practice. As the literature review revealed, practices have evolved over the last decade and, new questions were added based on these changes. Therefore, the original survey was updated based on feedback from the content expert group, current evidence in the literature, and from pilot testing the questionnaire. This will be discussed further in "The Instrument" section of this project.

Revision of the survey instrument. A content expert group was convened to review the draft survey instrument and review the questions from the re-created survey. These experts consisted of experienced professionals in B.C. working with infants experiencing neonatal withdrawal. A questionnaire was sent to members of the content expert group for review and for feedback regarding the relevance and clarity of the questions. Additional comments were also encouraged on the instrument. These data were collected and revisions were made based on this valuable feedback. Revisions were also made using best practice literature on survey development. For example, Dillman, Smyth, and Christian (2009) advise that "one of the fundamental writing tools that exists for creating survey questions is to shift questions from one format to another" (p.73). This keeps the reader interested and attentive throughout the survey

process. Therefore, I ensured that questions alternated between open-ended questions and closed-ended questions throughout the survey.

The revised survey consisted of 50 questions. There were 43 closed-ended questions and 7 open-ended questions, again with an option to provide additional comments. A more thorough discussion on the revision of the survey is included in "Content Validation" of this thesis.

Incorporating "Better Practices" in Survey Design and Administration

Reducing Survey Error

Conducting surveys that produce accurate information reflecting the views and experiences of those caring for substance-exposed infants requires developing procedures that minimize all four types of survey error: coverage, sampling, nonresponse, and measurement (Groves, 1989).

Coverage. Dillman et al. (2009) explain that coverage error may occur when the choice of survey mode may not provide adequate coverage of the population of interest. To reduce this type of error, web surveys were delivered to those with active email accounts and each email account was confirmed before the survey was sent. Coverage error can also occur because the choice of mode may not provide adequate coverage of the population. The previous survey was pencil and paper based and was mailed to recipients. This pilot survey has reduced coverage error as it was a web survey targeted at specific professionals with computer access and capability. Commonly cited advantages of web based surveys include easy access, instant distribution, and reduced costs (Wyatt, 2000).

Sampling. When considering the sample size for pilot studies, Hertzog (2008) notes that the literature provides limited guidance. Some make no specific recommendations and others recommend obtaining approximately 10 participants or 10% of the final study size (Hertzog).

Nonresponse. Another source of error cited by Dillman et al. (2009) is nonresponse error. This occurs when the people selected for the survey do not respond or do not respond in a way that is important for the study. To reduce this type of error, this pilot study contacted those not eligible for the larger study yet the topic was still relevant to their practice. Further, a professional and personalized cover letter was sent along with clear instructions on how to access the survey. Also, my correspondence was delivered in the morning to reduce nonresponse as Dillman et al. report that "there is some indication that e-mail invitations are most successful if they are delivered to recipients' inboxes early in the morning" (p. 280).

Measurement. Lastly, measurement error occurs when "a respondent's answer is inaccurate or imprecise" (Dillman et al., 2009, p.18). For instance, perhaps the respondent may not have understood the question. By administering this pilot survey and having a content expert group review the questionnaire, this type of error has been reduced. Also, I provided clear instructions on how to complete the questionnaire in both the cover letter and each subsequent email/reminder—further reducing measurement error. Finally, while I worked to minimize measurement error in this pilot survey, I was also testing the survey for measurement error to ensure this type of error was reduced for the national investigation.

Content Validation

Content validation is important because it "concerns the degree in which an instrument has an appropriate sample of items for the construct being measured and adequately covers the construct domain" (Polit & Beck, 2010, p. 378). Dillman (2007) stresses the importance of getting feedback from experts with diverse expertise. Content experts for this study included five care providers and/or administrators with professional knowledge and understanding of

infants in neonatal withdrawal and their caregivers (Appendix C). Content experts represented disciplinary group such as physicians, nurses, and clinical guideline developers.

The content experts were emailed an introductory letter explaining more about the project, including information about the aims of the instrument/study with the evaluation tool attached (Appendix D and E). This evaluation tool was in a pdf fillable form for the professional to fill out and email back. Two of the five experts felt they were not suitable to give feedback and forwarded my request to colleagues they felt would be more appropriate. Two follow up emails were sent one week apart as reminders, and I received feedback from four professionals. The experts were asked to score every question on a four-point Likert scale from one to four on each of the following evaluation qualities: relevance and clarity. The experts were also given space to provide comments and/or suggest changes. Dillman (2007) also notes that providing content experts with another draft of the questionnaire is warranted for secondary feedback. Therefore, the instrument was sent out once, revised according to expert feedback, and sent out a second time for further feedback and revision (refer to Appendix F for more details on content expert feedback).

The most widely reported measure of content validity among nurse researchers is the content validity index (Polit & Beck, 2006). Using the content validity index at the item level (I-CVI) involves "having a team of experts indicate whether each item on a scale is congruent with (or relevant to) the construct, computing the percentage of items deemed to be relevant for each expert, and then taking an average of the percentages across experts" (Polit & Beck, p. 490). The ordinal scale used for this project had four points along the item-rating continuum. The most widely advocated scale was introduced by Davis (1992) and includes the following:

1 = not relevant

2 = somewhat relevant

3 = quite relevant

4 = highly relevant

Similarly, when assessing the clarity of the tool, the term "relevant" was replaced with "easily understood." Davis (1992) further suggests that for each item, "the I-CVI is then computed as the number of experts giving a rating of either three or four (thus dichotomizing the ordinal scale into *relevant* and *not relevant*), divided by the total number of experts" (Polit & Beck, 2006, p. 491).

Lynn (1986) recommends that no CVI lower than .78 be used when assessing content validity. When computing the CVI for this tool, I averaged the results and used .80 as my standard of acceptability. It has been recommended that for a scale to be judged as having excellent content validity, it requires strong conceptualizations of constructs, good items, carefully selected experts, and clear instructions to the experts regarding the underlying constructs and rating task (Lynn, 1986).

Setting and Sample

Setting for the national study. Canada has a highly regionalized system of perinatal and neonatal care. In each region, hospitals are divided into three levels of care, and patients are referred to the facility with the appropriate level of care, depending on their condition. The Canadian Paediatric Society (2011) refers to these levels as the following: Level 1 (normal newborn care), Level 2 (high-dependency care), and Level 3 (intensive care). Level 1 units provide basic newborn and maternal care but must have the personnel and equipment to respond and stabilize the more acute infant until transferred to an appropriate higher level facility. Level 2 units can provide care to "moderately ill infants with problems that are expected to resolve

rapidly or who are convalescing after intensive care treatment" (Canadian Paediatric Society Fetus and Newborn Committee [CPS], 2011, p. 303). Level 3 units can provide complete care for all critically ill newborn infants, including those who require surgical intervention. Level 3 care facilities serve distinct geographic regions and coordinate care with Level 1 and 2 care facilities. Provision of care at the appropriate level through regionalization of care continues to be important. Many studies have shown that centers designated at a higher level generally have lower mortality and morbidity rates for infants with comparable degrees of illness (Chien et al., 2001; Cifuentes et al., 2002; Phibbs et al., 2007).

Sample for the national study. Sampling this population for the national study will include contacting facilities with active maternal-child services with birth rates over 500 annually and distributing an on-line, self-administered questionnaire to directors of nursing responsible for maternal-infant nursing at each hospital across Canada. The directors will be requested to indicate if there is a NICU or SCN and then to have the survey completed by the person with the most appropriate knowledge and expertise related to the topic (step 2). In Dr. Marcellus' previous survey, she found that this was usually clinical leaders, clinical nurse specialists, or unit supervisors.

A cover letter was attached providing background information on the larger scale study, the motivation for development of this project, the purpose of both the larger scale project and the pilot study, the importance of response, assurance of confidentiality, and designated return date.

When determining how the national survey will be distributed, feedback from the pilot audience will be taken into account. This valuable feedback will guide the distribution of the larger investigation.

Dillman et al. (2009) describe sampling error as resulting from "surveying only some rather than all members of the population and exists as part of all sample surveys" (p. 17). Researchers for the larger study will attempt to gather information from health care providers and leaders working in NICUs and SCNs at each hospital across Canada with active maternal-infant services. The initial list of hospitals will be generated from the 2011 Guide to Canadian Health Care Facilities and includes approximately 100-150 potential participants.

This pilot survey was distributed to 10 participants who were working in hospitals with birthrates between 100 and 500 per year. This list was also generated from the Guide to Canadian Health Care Facilities database. However, electing to sample from these smaller hospitals not eligible for the larger study (possibly without a NICU or dedicated nursery staff) has the potential for the survey questions to be irrelevant.

The national study will recruit participants from hospitals with active maternal-infant clinical units with 500 deliveries or more annually *and* who have a separate designated nursery staff (i.e., Level 2 and 3 units). These units are also described as NICUs and Special Care Nurseries (SCNs) in the literature. The nursing professionals in these units will be identified through directors of patient care responsible for maternal-infant services at hospitals across Canada. Although all levels of care are included in this criterion, this national survey explicitly explores the NICU practices of those experienced in the care of infant with prenatal substance use and their mothers.

There are approximately 120 institutions in Canada with maternal-infant care units. The 2002 survey, based on a one-time paper-based mail out, had a return rate of 51% and represented 54% of the births in Canada. A higher participation rate is anticipated with the larger survey as the survey will be translated into French, which was not done with the first survey. Further, this

is a web-based survey with previously confirmed email addresses which will also likely contribute to an improvement in participation rates. However, the desired participation rate may not be achieved due to the following: complex organizations, regionalization, and emails not reaching the intended respondent.

Setting for the pilot study. In this pilot study I sought input from hospital facilities with active maternal-infant clinical units with 500 deliveries or less in British Columbia. The survey was sent to those ineligible for the larger study for several reasons. For example, many of the units that were contacted for this pilot study were Level I and did not have a separate nursery staff. Nevertheless, participants were experienced in the hospital care of substance-exposed neonates and their mothers. As noted, PSBC (2011) reported that 45% of infants experiencing withdrawal are currently cared for in a Level 2 or 3 units. The remaining infants are possibly discharged home or cared for in these smaller Level 1 facilities.

Sample for the pilot study. Primarily, I was interested in ensuring that the target audience (professionals experienced in the care of infants with prenatal substance use and their mothers in the hospital setting with less than 500 births annually) would see the survey as clinically relevant. Research has demonstrated that a higher response rate is more likely if the topic of the questionnaire is salient to the potential respondent (Groves et al., 2006; Groves & Peytcheva, 2008). Secondly, I wanted to reduce the chance of "survey fatigue" or "survey saturation" (Baruch & Holtom, 2008; Porter, Whitcomb & Weitzer, 2004). Over-surveying in a growing number of areas means that health care workers are flooded with questionnaires and administering multiple surveys can reduce response rates (Porter et al., 2004). Therefore, I did not want to burden respondents twice to complete the same survey (once for this pilot survey and again for the national study). For example, if the participant did complete the survey twice, they

may not put as much effort into the open ended questions a second time, which is essential for the national survey. Finally, I aimed to provide smaller facilities not eligible for the larger study an opportunity to share their practices and concerns regarding caring for infants experiencing withdrawal and their mothers. This approach has the potential to help us assess if there is a need to conduct a similar survey with smaller facilities, as recent shifts to mother-baby models of care have led to women staying closer to home in their own communities, with care being provided in community hospitals and rural facilities.

I utilized a convenience approach to sampling and contacted 10 health care professionals in maternal-infant clinical unit leadership roles in British Columbia. These professionals were identified through directors of patient care responsible for maternal-infant services at hospitals. The directors were requested to have the survey completed by the person with the most appropriate knowledge and expertise related to the topic. As anticipated, these participants reflected those of the previous survey with responses from clinical leaders, clinical nurse specialists, or unit supervisors. Overall, this pilot study sample included the following:

- Questionnaires distributed: n=10
- Number of respondents: n = 6
- Number who declined to complete the survey: n = 4

A number of challenges were encountered with recruitment. This included attempting to survey units who cared for infants on their unit yet were not eligible for the larger study. For instance, one respondent declined to complete the survey as her facility had no nursery or NICU (they are a mother-babe unit). Other participants responded that they did not usually care for infants on their unit and usually transferred these infants to a unit which provided a higher level of care. Therefore, it was challenging to find a balance between surveying smaller units who

take care of these infants yet not large enough to be eligible for the national study. It was also difficult to send the survey to those most familiar with the care of infants in withdrawal. This resulted in one respondent forwarding the survey to two of her colleagues to complete. Finding a balance between sending email reminders regarding survey completion without appearing bothersome, or simply accepting negative returns, (or non-responses) proved challenging.

Data Analysis

Whereas statistical analysis will be conducted with data from the national study, it is recommended that the analysis of data from a pilot study should be mainly descriptive (Lancaster, Dodd, & Williamson, 2004). Again, the intent of this pilot study, also called a "feasibility study," is to assess the practicability of conducting the larger study—to explore how the system works and to allow modifications to be made to the research design or procedures prior to conducting the larger scale investigation. Thabane et al. (2010) confirm that quite often when analyzing a pilot study the emphasis is wrongly placed on statistical significance, not on feasibility—which is the main focus of the pilot study. Therefore, the analysis of data from this pilot study is descriptive.

A one-year membership to Fluid Surveys© was purchased to conduct the larger investigation and this pilot study. This technology has the capacity to perform descriptive statistical analysis. However, because of the limited sample size and the overall purpose of this pilot investigation, attention is given to the research process rather than the data themself. In other words, the purpose of analyzing the data from the pilot is to assess whether or not additional changes to the survey itself or to its distribution and administration are needed prior to conducting the larger study.

Maintaining Rigour

The rigour of survey research is important. As mentioned, adherence to the original study was maintained as much as possible to ensure integrity of an exact replication. This helps to ensure the reliability of the findings in terms of the 2002 findings. . Litwin (1995) notes that reliability is the degree of stability exhibited when a measurement is repeated under identical conditions. A content expert group was convened to review the draft survey instrument and update the questions to reflect current practice issues, also ensuring that the current survey is valid and reflects current practices. Litwin defines validity as how well a survey measures what it sets out to measure. Establishing the reliability and validity of the survey instrument contributes to this study's trustworthiness. Further, Lancaster, Dodd, and Williamson (2004) add that pilot studies should have a "well defined set of aims and objectives to ensure methodological rigour and scientific validity" (p. 311). Careful attention was made to help us establish a sense of the survey's reliability and validity as well as its feasibility.

Ethical Considerations

Informed consent for the pilot study. A cover letter was sent providing background information on the motivation for development of the project, the purpose of the project, the importance of response, assurance of confidentiality, and designated return date. Attached to this cover letter was a letter of information for implied consent (Appendix G). One reminder was sent electronically two weeks after the first one. Returned completed surveys indicated voluntary participation and informed consent. All participants were provided with the emails and phone numbers of the research team in case they wanted to ask further questions prior to participating. Completion of the on-line survey indicated informed consent.

Potential benefit. This pilot study provided vital information that will inform revisions to and operationalization of the national investigation. Together, these studies will provide a platform for development of a research program focused on developing and testing interventions and processes used to care for infants experiencing withdrawal from drugs and alcohol after birth.

Potential harm. No potential harm was foreseen. However, it was recognized that the current state of practice in our Canadian healthcare system is demanding. Therefore, the time devoted to filling out the survey may be seen as inconvenient to some participants; however, an online survey hopefully alleviated some of this strain.

Confidentiality. All data were collected using Fluid Survey Technology© (online survey). Electronic files for the study were password protected and available only to the research team and me. Participants were reminded in the survey instructions to refrain from using identifying information in their responses. Using the Fluid Survey Technology (enabling the Anonymous Survey feature), I ensured all responses were anonymous and confidential including email addresses, referring URLs, and IP addresses. Any comments that were provided by participants in open text boxes that were considered identifiable were aggregated or edited (i.e., change identifying features) to ensure anonymity.

In consultation with the University of Victoria (UVic) ethics office, it was determined that approval through a Research Ethics Board (REB) process was not required as this project lies outside of the Human Research Ethics Board's mandate according to Article 2.1 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, 2010 (TCPS 2). As this study was limited to collecting information about organizations, policies, procedures, professional practices or statistical reports from anonymous personnel, these individuals were

authorized to release such information in the ordinary course of their employment. Therefore, this project did not require or qualify for UVic Human Research Ethics Board review (Appendix H).

Chapter Four

Results

In this chapter, I first present the results on the revision of the original tool from five clinical experts using the content validity index (Polit & Beck, 2006). Next, I present a discussion of the research process that was piloted with six participants who completed the revised survey. Although results were obtained from a small number of participants, it is again reiterated that the purpose of a pilot survey is to test the instrument and procedures prior to the larger investigation. The preliminary results are descriptive and focus on the survey development and administration process; the information gathered from this pilot study will guide the administration of the national survey.

Establishment of content validity

Lynn (1986) recommends that the I-CVI should be 1.00 when there are five or fewer judges. Polit and Beck (2006) recommend that to be judged as having excellent content validity, a scale would be composed of items with I-CVI that meet Lynn's (1986) criteria (I-CVI=1.00) with three to five experts. Therefore, revisions to the survey were made according to these guidelines. Three of the four content experts rated their responses on the Likert scale provided. One expert provided comments but did not rate his/her responses. Therefore, when calculating the I-CVI for this tool, I used a panel of three experts and used the information from the I-CVI to guide me in revising, deleting, and/or substituting questions/items when revising the survey.

Relevance. Appendix I shows the relevance ratings of three experts for a 49-item survey. Further discussion on specific revisions done to the tool is included in the next section of this thesis. All three experts rated 41 out of 49 items as relevant. However, the questions judged not

relevant differed for the three experts. The I-CVI was .93. An example of a question revised according to this feedback related to relevance is as follows:

- Original question: "Is your facility classified as a teaching hospital?"
- Revised question: "Is your facility affiliated with a university medical program?"

Clarity. Clarity ratings of the three experts are presented in Appendix J. All three experts rated 41 out of 49 items as easily understood. Again, the questions judged not easily understood often differed for the three experts. The I-CVI was .95.

An example of a question revised according to this feedback related to clarity is as follows:

- Original question: "What level of impact do you feel perinatal substance use has on your community?"
- Revised question: "What level of impact do you feel this issue is having in your community?" A list of responses was also added for clarity (no impact, slight impact, moderate impact, and significant impact).

Revisions Based on Content Expert Feedback

A number of changes to the original survey were made based on the valuable feedback provided by the content experts. First, many questions were clarified. For instance, some of the questions were felt to be vague, so these questions were re-worded for clarity. Second, many questions were changed to provide the respondent with the opportunity to reply using a multiple choice format. One open-ended question asked about the perceived impact substance use is having in their community. This question was changed from solely being an open-ended question to also giving the participant a choice of minimal, moderate or high impact from which to choose. Finally, many of the experts suggested that the revised survey should incorporate questions exploring not only care of the infant experiencing withdrawal, but also consider care

and support of the infant's caregiver(s) as well, in particular birth mothers. Therefore, questions were added based on this feedback. For instance, questions were included that explored parental involvement with routine assessment of neonatal withdrawal symptoms and described the support that birth mothers receive (or not) within the hospital setting and the community context. Overall, many of the questions from the original survey were maintained due to the high relevant I-CVI score and revised only to provide more clarity and/or to include the mothers' experience.

Once the revisions were made, the survey questions were again sent back to the content experts for further review. Positive feedback was provided at that point, and as no further revisions or additions were deemed necessary, the survey instrument was determined to be ready for pilot testing with a small sample of participants (see Appendix K for revised tool).

Discussion of the Pilot Study Research Process

Recruitment. An invitation to participate was sent to ten email contacts. This included an introductory letter with a hyperlink to the Web based survey. This cover letter invited respondents to participate in a pilot study (see Appendix L).

All technology (except for two email addresses that were undeliverable) relied on for this project was successful. This single mode survey effectively administered and collected data using Fluid Survey © technology. I will now discuss specific successes and challenges related to the process of conducting this pilot study and what may have influenced recruitment.

Response rate. When conducting a survey, maintaining a high response rate is desirable. For this pilot project, six out of ten participants responded. When I questioned why a higher response rate was not achieved, a review of recent research exploring nonresponse rates among health care professionals was conducted.

Sinkowitz-Cochran (2013) report that amongst health professionals, "response rate varies by target audience and is influenced by a number of factors including but not limited to incentives, survey length, and perceived burden" (p.1160). VanGeest, Johnson and Welch (2007) report similar findings in their systematic review of studies exploring surveying nurses confirming that, "the most important barrier to nurse participation is time" (p. 489). Finally, to improve response rates, Schaefer and Dillman (1998) suggest using a mixed method approach (e.g., those who do not respond to the web-based version then receive a mail-based version).

In their review of available studies, VanGeest and Johnson (2011) found that strategies for enhancing nurse cooperation, such as providing token monetary incentives, improved the nurses' response rates. Although no monetary incentives were given in this research project, an incentive that may entice potential individuals to respond is their opportunity to contribute to best practices when caring for infants with prenatal substance exposure. This was clearly outlined in the cover letter to each participant. Sinkowitz-Cohrane (2013) note that "respondents may be more likely to participate if they perceive some altruistic benefit to self and/or society and if they are generally interested in the survey topic" (p.1160). Further, research has confirmed that response rate is more likely if the topic of the questionnaire is salient to the potential respondent (Groves et al., 2006; Groves & Peytcheva, 2008).

This pilot project was sent to professionals with knowledge and expertise related to the topic who are likely motivated to respond. However, although the topic is relevant to the participants, VanGeest and Johnson (2011) note that nurses attitudes and understanding of research may influence whether or not they respond. Furthermore, these authors reveal that nurses' understanding "and/or the perceived value of a particular study influence whether or not they will participate" (p.489). Further, nurses are less likely to respond "if the value or relevance

of a study is unclear or perceived to be low or if research broadly is not valued" (p.489). In other words, although knowledgeable on the care of infants with prenatal substance exposure, potential participants may not have the time or the invested interest in survey research or the survey may not be relevant to their particular situation.

Umbach (2004) advises keeping the survey short (no longer than 20 minutes). The average time taken to complete this pilot survey was 22 minutes. Even so, it is recognized that our current health care system is demanding and participants may not have these minutes to spare. Few studies have examined the effect of questionnaire length on health care participants' response. In their review of available research on physician response, VanGeest, Johnson and Welch (2007) present an association between shorter questionnaire length and physician response. When exploring why the response rate to nurse surveys are typically below 60%, VanGeest and Johnson (2011) note that "time spent completing surveys competes directly with more arguable more important tasks" (p.489). Overall, a response rate of six out of ten appears to be a satisfactory response based on the literature.

Response time. In the initial phase of distribution of the survey, only one participant responded. A second reminder email was sent 9 days after with an improved response rate of six. On this final request, a deadline to respond (end of January) was included in the cover letter. A visual depiction of this process is included in Figure 4. Overall, two requests were sent for participants to respond.

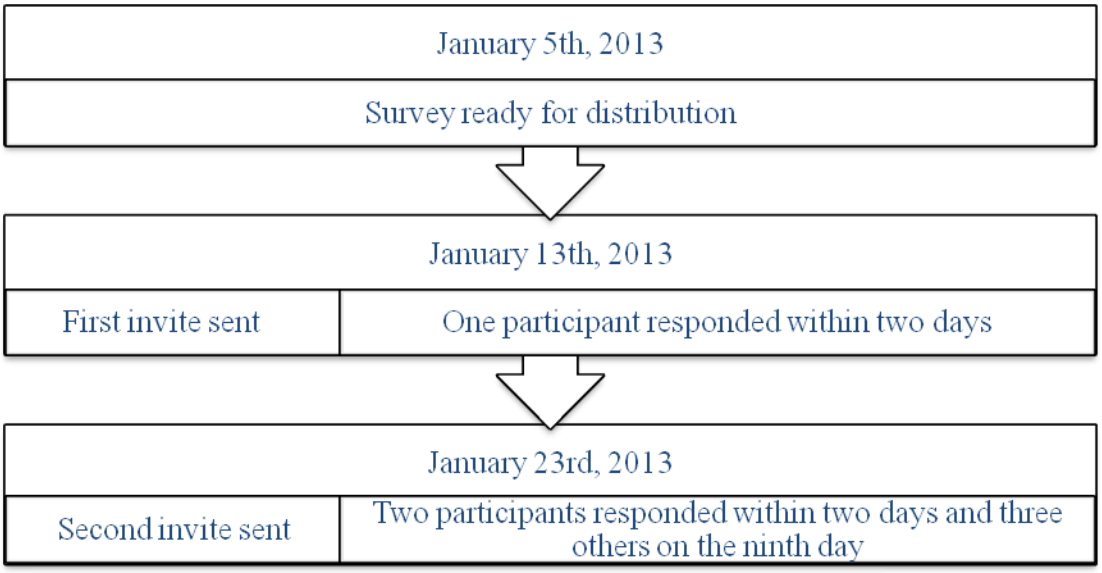


Figure 4: Timeline for survey distribution and response

Schaefer and Dillman (1998) recommend successively contacting and reminding potential respondents. This can reduce the loss of respondents who may tend to postpone and then forget to complete the questionnaire to improve response rate to email surveys. When considering how many times to contact individuals to respond, some researchers suggest that if people are going to complete a Web survey, they will do so in the first few hours or days (Crawford, Couper, & Lamias, 2001). These researchers also propose that a single reminder email will double the number of respondents and greater returns are observed when the reminder is sent 2 days after the initial request. One study suggests four contacts yield the highest response rate (Schaefer & Dillman, 1998). When surveying physicians, Matteson et al. (2011) sent an e-mail reminder approximately one week after the initial e-mail invite then successively sent three more e-mail reminders in 5-day increments. Umbach (2004) further recommends including a deadline to complete the survey and to personalize the email letters.

Pilot sample responses. My purpose in analyzing the data from the pilot was to assess whether or not additional changes were needed to the survey tool (reliability and validity) or to the research process (feasibility). Again, researchers advise that when analyzing a pilot study the emphasis is wrongly placed on statistical significance, not on feasibility—which is the main focus of the pilot study (Thabane et al., 2010). Therefore, advanced statistical analyses of the survey results have not been included. However, there were many strong informative and interesting qualitative comments noted, therefore it is anticipated that the structure of the survey will facilitate the gathering of this rich data in the national study (Appendix M). In the following section, I further explore these implications.

Limitations of the pilot study

This investigation tested the procedures proposed for the national study in regards to survey design, sampling strategies, content validation, and conducting revisions to a survey based on pilot study data and administration experiences. One limitation to this study is the small number of respondents. It is recognized that this sample does not represent the diversity of neonatal units included in the national study as the findings are only reflective of a limited number of smaller facilities (birthrates less than 500 annually) where a formal neonatal unit space to care for infants may not be available.

Chapter Five

Implications

This final chapter is divided into three sections. I begin with a discussion of the personal and methodological lessons I learned during this pilot study research process. I then summarise the research process and reflect in particular on (a) the processes of revising an existing survey instrument based on content expert feedback and (b) administering a pilot survey. Throughout this dialogue I weave recommendations to improve the survey and data collection procedures for the national study. Figure 5 summarizes these recommendations. Finally, I discuss implications for current and future nursing scholarship, education, and research.

The Research Process: Lessons Learned

The objective of conducting this pilot study was to familiarize myself with the process of survey research through revising a survey, assessing content validity, and conducting a small pilot study. I conducted the first five steps of a sequenced pilot study process: (1) identifying the research objectives, (2) identifying and characterizing the target audience, (3) designing the sampling plan, (4) designing and writing the questionnaire, and (5) pilot testing the questionnaire.

Revision of the original survey instrument. When I examined the original survey tool, it was clear that revisions were necessary. Clinical practices in this field have evolved over the last decade and as the literature review revealed, available surveys on the care of infants in neonatal withdrawal often explored only pharmacological treatment. This narrower perspective overlooks the experience of the mother and does not take into account the significant benefits of nonpharmacological treatment. One example is that there are clinical and social benefits to keeping the mother and baby together immediately following birth. Despite current research

suggesting this vulnerable dyad be cared for together (Abrahams et al., 2010), few studies explored this holistic perspective. The neonatal period is critical, and the health and emotional benefits of keeping mother and baby together from birth are lifelong (Kennell & Klaus, 1998). Consequently, as a result of conducting this literature review, I initially included questions to capture the mother's experience and further explore nonpharmacological treatments before I sent the survey instrument to the content experts. These experts then added further questions confirming the need to be more inclusive of the mother's experience and additional treatment options.

I believe that consulting a content expert group to review the questions for relevance and clarity will improve the rigour of the national study. These experts provided necessary feedback that guided revisions of the original survey instrument to capture the current context of NICU practice. As a result, questions were added, deleted, and revised based on their feedback. The process of consulting this group also introduced me to the research process of gathering contact information, drafting a cover letter, and answering questions from these experts, and iteratively refining a survey instrument.

Administration of the pilot study. One of the main functions of conducting a pilot study is to test the logistics and gather information prior to a larger study in order to improve the latter's quality and efficiency. Pretesting the survey can minimize deficiencies in the design that can be addressed in advance and improve the quality and efficiency of the larger study. Strengths and weaknesses were identified during this process that will certainly improve the quality and proficiency of the national study.

Strengths. One of the primary strengths identified while conducting this pilot study was use of web-based survey software (Fluid Survey ©). This do-it-yourself online software allowed

me to easily upload the survey instrument onto the site, collect data from a geographically diverse number of respondents, and analyze the data. This software made the process easier for me as a beginner and novice researcher and would be of use to clinical teams who may be working with limited resources. Conducting this pilot study provided me with greater familiarity with the details and mechanics of the process, which has given me confidence in not only the quality and efficiency of the process but also confidence in myself in developing and conducting survey research. I was also able to analyze the completed surveys to consider if the findings will reflect the purpose and objectives of the national study. Finally, using a web-based survey technology allowed the respondents to quickly respond to my request and reply with their responses, all at a relatively low cost.

There are many advantages cited in the literature to conducting online survey research. Evans and Mathur (2005) note that, "online surveys can be administered in a time-efficient manner; minimizing the period it takes to get a survey into the field and for data collection" (p.198). These authors identify many advantages to online survey methods including, but not limited to, convenience, ease of data entry and analysis, low administration cost, and the ease of obtaining large samples. Wright (2005) also suggests that benefits of conducting online survey research using Web survey products and services (such as Fluid Survey©) including "access to individuals in distant locations, the ability to reach difficult to contact participants, and the convenience of having automated data collection, which reduces researcher time and effort" (para 2).

Limitations. Primary limitations that emerged were related to coverage error and survey completion. Although a great deal of effort was made to reduce coverage error, two email accounts returned unsent emails. A consideration for the national study will be the need for

continued careful attention and scrutiny when collecting and inputting email addresses to ensure that they are accurate and current. We aim to minimize coverage error in the national study by having an experienced research assistant input the addresses for the larger study.

Two of the six respondents did not complete the entire survey as it was presented online. There are a number of considerations for this non-completion: (a) the survey questions may not have represented their individual clinical context, (b) respondents may have felt that they could not answer the question(s) and therefore left them blank, (c) the questionnaire took too much time to complete or was not as clear or as relevant as intended, and (d) they do not have an NICU/SCN or the resources to provide this kind of care in their small community (they do not have experience with infants in neonatal withdrawal). Challenges with recruitment and response rate were discussed in the previous chapter which captures these dilemmas.

Finally, some of the questions asked the respondents to share a clinical guideline or to share the scoring tool used in their facility. In the questionnaire I asked if they would mind sharing a copy, yet there is no way for me to know who would consider sharing as this was anonymous. Although I clearly gave my email to all those that responded, this limitation will be considered by the research team when we plan logistics for the national study. One recommendation may be to include the online opportunity to attach a clinical guideline document during the survey process.

Summary of recommendations for the national survey

1. Provide responding units with a copy of the research findings of the national study once data has been analyzed and written up
2. Provide an online opportunity for participants to share a clinical guideline document during the survey process
3. Provide a paper based option after online administration of the survey to further enhance response rate

Figure 5: Recommendations for the national survey as a result of conducting this pilot investigation

Just as there are many advantages to conducting online research found in the literature, disadvantages include but are not limited to the following: respondents being inexperienced with the Internet, the impersonal nature of online research, and unclear answering instructions (Evans & Mathur, 2005). Dewsbury (2011) warn that nurses need to engage fully with modern technology rather than having a passive relationship with technology. When reflecting on generational diversity in today's nursing workforce, Hendrix and Cope (2013) note that the use of technology to communicate is second nature to many nurses making up the majority of today's workforce. Therefore it is expected that respondents are familiar with e-mail and the World Wide Web. However, providing a paper-based hard copy mail-out is recommended for the national survey to further enhance response rate.

Feasibility

Assessing the feasibility of this pilot study will guide the planning of the national investigation. I found the revised instrument and research procedures worked well for this pilot study and suggest that they will likely work well for the national study for several reasons.

There appeared to be a willingness to share local context of care when it comes to caring for infants with neonatal withdrawal. Having a response rate of six out of ten reflects this willingness. However, pilot studies frequently do not have a reliable statistical foundation, because they are nearly always based on small numbers (Van Teijlingen, Rennie, Hundley, & Graham, 2001). Thus, this pilot study finding may (or may not) offer some indication of the response rate for the national study. There were no incentives given to participants to fill out this pilot survey. To improve the response rate for the national investigation, I recommend offering to provide a copy of the findings so that responding units might be more interested in participating.

Next, the quality of the data obtained was rich in that respondents completed most of the quantitative questions and provided thoughtful comprehensive feedback to many of the open-ended questions. In other words, the goal of obtaining quantity and quality in the responses from this small sample was achieved. Also, many of the participants seemed to be able to answer the questions without difficulty. This is important to note for the national investigation as further changes to the survey instrument are likely not warranted, reflecting that the revisions that were made based on feedback from the content expert group were justified.

Finally, using the Fluid Survey© technology was straightforward and practical for the purpose of collecting these data. Having a high response rate from this small sample demonstrates that the respondents were able to navigate the technology. The average time to complete this pilot survey was 22 minutes—which again will guide the national study as we will

be able to inform potential respondents that completing this survey does not require a large time commitment. Finally, the online software made the results of the pilot study convenient to interpret and review. This will be beneficial for the national study when interpretation of a much larger number of results will be needed.

The Research Process: Personal Reflections

Conducting a pilot study. The information obtained from my small sample size provided me with the opportunity to analyze data from the pilot and assess whether or not additional changes were needed to the instrument or the research procedures. I was able to survey a number of units in a short amount of time and at a low cost. Further, the results were convenient to review and interpret and the participants did not seem to find the questionnaire arduous to complete.

After reflecting upon this process, I was satisfied with the revised questionnaire and pleased with the most of the research processes, with the exception of my cover letter. Although I included the purpose of the larger study, I was not clear enough in outlining the purpose of this pilot study, which was to assess the feasibility of the national study. Thabane et al. (2010) suggest that "given the special nature of feasibility or pilot studies, the disclosure of the purpose to study participants requires special wording—that informs them of the definition of a pilot study, the feasibility objectives of the study, and also clearly defines the criteria for success of feasibility" (p.7). Heeding this advice, my cover letter and consent form would then read as follows: "The overall purpose of this pilot study is to assess the feasibility of conducting a large scale study to explore the practices related to the care of infants exposed to drugs and alcohol during the prenatal period."

Concerning the process of conducting a pilot study, I was surprised at the amount of work required to re-create and revise a previous survey and to administer a small pilot survey. There was much more to this process than I had ever imagined. This process included maintaining rigour and assessing content validity and reliability. I had not been familiar with or anticipated these essential steps when I started this project. I now have a solid understanding of the importance of pilot studies as I reviewed many articles on conducting pilot studies themselves to get a sense of what this process was like. I learned how important it is to the quality of research to conduct pilot studies prior to a full investigation, although I imagine this is highly dependent on the time and resources that are available to research teams. However, it is for this very reason that a pilot is essential, as without this preliminary data, there could be inherent flaws in methodology and operationalization processes that compromise the quality and ultimately the findings of the study.

Finally, I was surprised at the amount of work involved with encouraging ongoing responses of both groups of participants (content experts and those that participated in the pilot survey). Calculating the best time of day and day of the week to send my request, sending out reminder emails, and accepting that some people just were not going to respond was all part of my learning during this process.

Implications for Nursing Education and Research

First of all, it is important for nurses to increase their knowledge about the process of developing and administering a survey. Nurses often rely on surveys to assess care and patient experiences and so a more thorough understanding of this methodology is needed.

Finally, it appears that research exploring the experiences of health care providers practicing in community and rural hospitals without NICU resources is necessary. Such was the

case with this pilot sample that was ineligible for the national investigation yet provided rich qualitative data on the care of infants in neonatal withdrawal. Although this pilot study surveyed smaller units, it is recognized that these smaller facilities are also going to be increasingly caring for this group of mothers and babies, often without the formalized support and funding to do so, therefore more research on this aspect of clinical care is warranted.

Using a rigorous research process to gather and report information related to clinical practice is important. Nurses can have a significant impact on improving pregnancy and neonatal outcomes by connecting with women and their families in a non-judgemental, supportive way to address substance use issues and challenges related to social determinants of health (Small, Taft, & Brown, 2011). A woman's personal and family context and the socio-environmental and political conditions in which she lives strongly influence her health and the health of her baby. Research shows that the foundations of adult health are laid before birth and in early childhood (WHO, 2003). Further, challenging circumstances during a woman's pregnancy "can lead to less than optimal fetal development via a chain that may include deficiencies in nutrition during pregnancy, maternal stress, a greater likelihood of maternal smoking and misuse of drugs and alcohol, insufficient exercise and inadequate prenatal care" (WHO, 2003, p. 14). Ongoing nursing education in this area and development of comprehensive care models are essential for the optimal care of infants with prenatal substance exposure and their mothers in these challenging circumstances.

Personal reflections

As a neonatal nurse and neonatal nurse educator, I had some knowledge of my phenomenon of interest. However, I embarked on a scholarly expedition that consumed the next

year of my life. I conclude this thesis with an overview of the successive research decisions I made that brought this study from proposal to completion.

Although my background is in the care of neonates, I had to update myself on the current state of evidence related to the care of babies experiencing neonatal withdrawal. I was well versed on the social determinants of health and how these influence the vulnerable woman and her newborn. However, my knowledge of specific gaps and inconsistencies in the literature and current practices in NICUs related to daily care, discharge planning, and community support for infants with prenatal substance exposure and their parents/caregivers was somewhat vague at the onset of this project.

I began writing the research proposal for this thesis with little to no knowledge of survey design, sampling strategies, content validation and making revisions to a survey based on pilot data. Through examining the literature and reading examples of countless studies, I began to familiarize myself with this process. Initially, I underestimated the complexities of survey research and I now have a greater understanding of the importance of this process to ensure the content validity of the survey instrument.

Regarding identifying the methodology for this thesis, I began this process believing that this investigation utilized a mixed method approach as it used both quantitative and qualitative elements. Many hours were spent reading books on mixed method design. Tashakkori and Teddlie (2003) define mixed methods as "a type of research design in which (qualitative) and (quantitative) approaches are used in types of questions, research methods, data collection and analysis procedures, and/or inferences" (p. 711). However, as noted, descriptive research does not fit neatly into the definition of either quantitative or qualitative research methodologies, but instead it can utilize elements of both. Such is the case with this research project. I now have a

greater appreciation of the importance of carefully identifying a methodology that can most effectively answer the research question that is being posed.

Once I had familiarized myself with my phenomenon of interest and the process of survey research, a great deal of learning came from finding a conceptual framework for this investigation. I ended up choosing "The Policy and Practice Intervention Points for Children and Families framework" (Young et al., 2009), as I believed it was the most suitable. My advisor provided much needed guidance when considering a suitable framework and although adapted slightly, this framework guided the entire investigation.

Summary

The objective of conducting a pilot study is to assess intended instruments and the feasibility of the study so as to guide the planning of a large scale investigation. This was achieved through administering a pilot survey to 6 participants in British Columbia and describing these findings. Through this process, I acquainted myself with the process of survey research design, sampling strategies, content validation, and made changes to a survey based on this pilot data. I modified the original survey based on content expert feedback and then administered this revised instrument to a pilot audience. The high response rate amongst this small group that provided information on a wide range of topics suggests that a national survey would be an effective method of capturing important trends in practice.

I believe through conducting this pilot study, I have contributed to likelihood of success of the national study. The applications of these research findings have the opportunity to improve the validity of the national survey and ultimately contribute to improving our understanding of how we currently care for infants with prenatal substance exposure and their families during this critical time of transition.

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Appendix A: CINAHL Plus with Full Text database search for post-2002 journal articles

	Article	Focus
1.	Marcellus, L. (2008). (Ad)ministering love: Providing family foster care to infants with prenatal substance exposure	Family foster caregiving
2.	Porter, L.S. & Porter, B.O. (2004). A blended infant massage-parenting enhancement program for recovering substance-abusing mothers	Parent-infant relationships
3.	Wunsch, M.J. (2006). A chart review comparing paregoric to methadone in the treatment of neonatal opioid withdrawal	Pharmacological treatment
4.	Vasquez, E.P., Pitts, K., & Mejia, N.E. (2008). A model program: Neonatal nurse practitioners providing community health care for high-risk infants	Community Support
5.	Jackson, L., Ting, A., McKay, S., Galea, P., & Skeoch, C. (2004). A randomized controlled trial of morphine versus phenobarbitone for neonatal abstinence syndrome	Pharmacological treatment
6.	Lainwala, S., Brown, E.R., Weinschenk, N.P., Blackwell, M.T. & Hagadorn, J.I. (2005). A retrospective study of length of hospital stay in infants treated for neonatal abstinence syndrome with methadone versus oral morphine preparation	Pharmacological treatment
7.	Zellman, G.L., Fair, C.C., Hoube, J. & Wong, M. (2002). A search for guidance: Examining prenatal substance exposure protocols	Health policy
8.	Abstracts presented at the 5th National Advanced Practice Neonatal Nurses Conference, 2008	Various topics
9.	Hiles, M. (2011). An evidence-based intervention for promoting sleep in infants experiencing NAS due to maternal methadone use	Parent-infant relationships
10.	Buprenorphine produces less withdrawal in babies than methadone	Pharmacological treatment
11.	Butz, A.M., Pulsifer, M., O'Brien, E., Belcher, H.M.E., Lears, M.K., Miller, D., Kaugmann, W. & Royall, R. (2002). Caregiver characteristics associated with infant cognitive status in in-utero drug exposed infants	Parent-infant relationships
12.	Fraser, J.A., Barnes, M., Biggs, H.C., & Kain, V.J. (2007). Caring, chaos and the vulnerable family: Experiences in caring for newborns of drug-dependent parents	Parent-infant relationships
13.	Salladay, S., & Bell, K.S. (2009). Christian ethics. Facing ethical dilemmas	Ethical decision making
14.	Boukydis, C.F.Z., Bigsby, R., & Lester, B.M. (2004). Clinical use of the Neonatal Intensive care Unit Network Neurobehavioral Scale	Neonatal assessment
15.	Katz, L., Ceballos, S.G., Scott, K. & Wurm, G. (2007). Collaborative practice. The critical role of a pediatric nurse practitioner in an early intervention program for children with prenatal drug exposure	Community support
16.	Zimmermann-Baer, U., Notzli, U., Rentsch., K. & Bucher, H.U. (2010). Finnegan neonatal abstinence scoring system:	Neonatal assessment

	normal values for first 3 days and weeks 5-6 in non-addicted infants	
17.	Marcellus, L. (2004). Foster families who care for infants with prenatal drug exposure: Support during the transition from NICU to home	Community support
18.	Jackson, L. (2006). Handling drug misuse in the neonatal unit	Multidisciplinary approach and pharmacological treatment
19.	Bertsch, C.M., Mullins, S.M. & Chaffin, M. (2006). Health services use and growth patterns among older siblings of infant with prenatal drug exposure	Sibling support
20.	McCarthy, J.J., Leamon, M.H., Parr, M.S. & Anania, B. (2005). High-dose methadone maintenance in pregnancy: Maternal and neonatal outcomes	Pharmacological treatment
21.	Lester, B.M. & Tronick, E.Z. (2004). History and description of the NICU Network Neurobehavioral Scale	Neonatal assessment
22.	Beauman, S.S. (2005). Identification and management of neonatal abstinence syndrome	Neonatal assessment
23.	Murphy-Oikonen, J., Montelpare, W.J., Southon, S., Bertoldo, L. & Persichino, N. (2010). Identifying infants at risk for neonatal abstinence syndrome: A retrospective cohort comparison study of 3 screening approaches	Neonatal assessment
24.	Wallman, C.M., Smith, P.B. & Moore, K. (2011). Implementing a perinatal substance abuse screening tool	Identifying neonates at risk for NAS using a multidisciplinary advisory committee
25.	Jansson, L.M. Dipeitro, J.A., Elko, A. & Velez, M. (2010). Infant autonomic functioning and neonatal abstinence syndrome	Neonatal assessment and autonomic regulatory functioning
26.	Dodge, P., Brady, M. & Maguire, B. (2006). Initiation of a nurse-developed interdisciplinary plan of care for opiate addiction in pregnancy women and their infants	Multidisciplinary approach to care
27.	Marcellus, L. (2011). Letters… Murphy-Oikonen, Brownlee, Montelpare, and Gerlach. The experiences of NICU nurses caring for infants with neonatal abstinence syndrome	Nursing education
28.	Sarkar, S & Donn, S.M. (2006). Management of neonatal abstinence syndrome in neonatal intensive care units: A national survey	Survey of NAS management in NICUs
29.	O'Grady, M.J., Hopewell, J. & White, M.J. (2009). Management of neonatal abstinence syndrome: A national survey	Survey of NAS management in NICUs
30.	Johnson, K., Greenough, A. & Gerada, C. (2003). Maternal drug use and length of neonatal unit stay	Neonatal assessment
31.	Dryden, C., Young, D., Hepburn, M. & Mactier, H. (2009). Maternal methadone use in pregnancy: Factors associated with the development of neonatal abstinence syndrome and implications for healthcare resources	Neonatal assessment with some focus on breastfeeding
32.	Miles, J., Sugumar, K., Macrory, F., Sims, D.G.& D'Souza,	Neonatal assessment with

	S.W.D. (2007). Methadone-exposed newborn infants: Outcome after alterations to a service for mothers and infants	some focus on mother-infant bonding
33.	Kelly, L., Dooley, J., Cromarty, H., Minty, B., Morgan, A., Madden, S. & Hopman, W. (2011). Narcotic-exposed neonates in a First Nations population in northwestern Ontario: Incidence and implications	Neonatal assessment and incidence
34.	Marcellus, L. (2007). Neonatal abstinence syndrome: Reconstructing the evidence	NAS and social attitudes
35.	Oral, R. & Strang, T. Neonatal illicit drug screening practices in Iowa: The impact of utilization of a structured screening tool	Health policy
36.	Leonidas, L. (2011). Neonatal opiate withdrawal	Overview of evaluation and management of neonatal opiate withdrawal
37.	D'Apolito, K. (2009). Neonatal opiate withdrawal: Pharmacologic management	Pharmacologic management
38.	Gentile, S. (2011). Neonatal withdrawal reactions following late in utero exposure to antidepressant medications	Neonatal assessment
39.	Wang, S., Chang, J., Dao, H., Hsu, C., Hung, H., Peng, C. & Jim, W. (2006). Neonates of drug-abusing mothers: Experiences in a medical center in northern Taiwan	Neonatal assessment
40.	Osborn, D., A., Jeffery, H.E. & Cole, M.J. (2010). Opiate treatment for opiate withdrawal in newborn infants	Systematic review focusing on pharmacologic management
41.	Zalice, K.K., Perozzi, K.J. & Locasto, L.W. (2006). Opiate/opioid addiction in pregnancy: A comprehensive overview	Neonatal assessment and pharmacologic management
42.	Winklbaur, B., Jung, E. & Fischer, G. (2008). Opioid dependence and pregnancy	Neonatal assessment and perinatal management
43.	Bakstad, B., Sarfi, M., Welle-Strand, G.K. & Ravndal, E. (2009). Opioid maintenance treatment during pregnancy: Occurrence and severity of NAS. A national prospective study	Pharmacologic management
44.	Goff, M. & O'Connor, M. (2007). Perinatal care of women maintained on methadone	Perinatal care
45.	Ebrahim, S.H. & Gfroerer, J. (2003). Pregnancy-related substance use in the US during 1996-1998	Incidence of perinatal substance use
46.	Noonan, K., Reichman, N.E., Corman, H. & Dave, D. (2007). Prenatal drug use and the production of infant health	Neonatal assessment
47.	Merewood, A. & Philipp, B.L. (2003). Promoting breastfeeding in an inner-city hospital: How to address the concerns of the maternity staff regarding illicit drug use	Breastfeeding
48.	Unger, A., Jagsch, R., Jones, J., Arria, A., Leitich, H., Rohrmeister, K., Aschauer, C., Winklbaur, B., Bawert, A. & Fischer, G. (2011). Randomized controlled trials in pregnancy: Scientific and ethical aspects…	Pharmacologic management
49.	Petty, J. (2010). Research digest	NAS prevention and control

50.	Petty, J. (2011). Research digest	Neonatal assessment
51.	Abrahams, R.R., Kelly, S.A., Payne, S., Thiessen, P.N., Mackintosh, J. & Janssen, P.A. (2007). Rooming-in compared with standard care for newborns of mothers using methadone or heroin	Enhancing parent-infant relationships
52.	Oei, J., Abdel-Latif, M.E., Clark, R., Craig, F. & Lui, K. (2010). Short-term outcomes of mothers and infants exposed to antenatal amphetamines	Neonatal assessment and perinatal management
53.	Oei, J., Abdel-Latif, M., Craig, F., Kee, A., Austin, M. & Lui, K. (2009). Short-term outcomes of mothers and newborn infants with comorbid psychiatric disorders and drug dependency	Neonatal assessment and perinatal management
54.	O'Brien, C. & Jeffrey, H. (2002). Sleep deprivation, disorganization and fragmentation during opiate withdrawal in newborns	Neonatal assessment
55.	Belcher, J., Butz, A., Wallace, P., Hoon, A., Reinhardt, E., Reeves, S. & Pulsifer, M. (2005). Spectrum of early intervention services for children with intrauterine drug exposure	Community Support
56.	Lester, B., Tronick, E., LaGasse, L., Seifer, R., Bauer, C., Shankaran, S….Lu., J. (2004). Summary statistics of NICU network neurobehavioral scale scores from the maternal lifestyle study: A quasinormative sample	Neonatal assessment
57.	Mendez, D., Jacobson, P., Hassmiller, K. & Zellman, G. (2003). The effect of legal and hospital policies on physician response to prenatal substance exposure	Health policy
58.	Murphy-Oikonen, J., Brownlee, K., Montelpare, W. & Gerlach, K. (2010). The experiences of NICU nurses in caring for infants with neonatal abstinence syndrome	Nursing education
59.	McQueen, K., Murphy-Oikonen, J., Gerlach, K. & Montelpare, W. (2011). The impact of infant feeding method on neonatal abstinence scores of methadone-exposed infants	Breastfeeding
60.	Lester, B., Tronick, E. & Brazelton, T. (2004). The NICU Network neurobehavioral scale procedures	Neonatal assessment
61.	Langenfeld, S., Birkenfeld, L., Herkenrath, P., Muller, C., Hellmich, M. & Theisohn, M. (2005). Therapy of the neonatal abstinence syndrome with tincture of opium or morphine drops	Pharmacologic treatment
62.	Tiedje, T. (2006). Toward evidence-based practice. [Commentary on] Relapse of major depression during pregnancy in women who maintain or discontinue antidepressant treatment	Perinatal care
63.	Winklbaur, B., Kopf, N., Ebner, N., Jung, E., Thau, K. & Fischer, G. (2008). Treating pregnant women dependent on opioids is not the same as treating pregnancy and opioid dependence: A knowledge synthesis for better treatement for women and neonates	Perinatal care
64.	Bio, L, Siu, A. & Poon, C. (2011). Update on the	Pharmacologic treatment

	pharmacologic management of neonatal abstinence syndrome	
65.	Crocetti, M., Amin, D. & Jansson, J. (2007). Variability in the evaluation and management of opiate-exposed newborns in Maryland	Survey of NAS practices
66.	Nandakumar, N. & Sankar, V. (2006). What is the best evidence based management of neonatal abstinence syndrome	Survey of NAS practices
67.	Brier, M. & Bellet, J. (2009). Stat consult. Neonatal opiate withdrawal	Neonatal assessment
68.	Liu, A., Bjorkman, T., Stewart, C. & Nanan, R. (2011). Pharmacological treatment of neonatal opiate withdrawal: Between the devil and the deep blue sea	Pharmacologic treatment

Appendix B: Surveys Exploring Management of Neonatal Withdrawal

Study	Purpose & Process	Results	Pharmacological treatment	Nonpharmacological treatment	Community Support	Recommendations
Management of neonatal abstinence syndrome: a national survey and review of practice. **O'Grady, Hopewell, & White, 2009**	A postal questionnaire. Data sought: -number of infants treated for NAS, -abstinence scoring system used -policy on toxicology testing -pharmacological management - policies regarding discharge of infants on medication -breastfeeding and - use of cranial ultrasound	Most units use the Finnegan tool (52%) - the Lipsitz tool (7%) -12% had developed their own scoring system and -10% were uncertain of which system was being used	92% used Morphine sulphate. Phenobarbitone used as a second line agent in combination with Morphine sulphate Chlorpromazine was used as an adjunctive treatment in 11.6% of units in their survey.	No explored. However, many units encourage mothers on methadone to breastfeed (81%) and fifty five per cent of units had a drug liaison midwife (which may or may not have encouraged nonpharmacological strategies).	Not explored.	Telephone follow-up and home visits with weekly outpatient clinic attendances. Evaluating unit practices and exploring the demographics of drug misuse, length of stay, treatment in the community and long-term neurological outcomes for future studies.
Management of neonatal abstinence syndrome in neonatal intensive care units: a national survey. **Sarkar & Donn, 2006**	Online survey. Data sought: -the percentage of respondents using an abstinence scoring system, -following a formal written policy or education program the use of pharmacologic management	65% use the Finnegan tool. Few respondents use the Lipsitz tool, while some don't use any abstinence scoring system or were unsure of the origin of the system being used.	Tincture of opium or morphine sulfate solution were most commonly used followed by phenobarbital for polydrug withdrawal and methadone for opioid withdrawal	There is no discussion or exploration of nonpharmacological treatment of neonatal withdrawal.	Not explored	The authors there are marked and inconsistent policies to determine diagnosis and treatment. Recommend developing evidence-based practice guidelines.

Variability in the evaluation and management of opiate-exposed newborns in Maryland. **Crocetti, Amin & Jansson, 2007**	Telephone survey. Data sought: -newborn delivery volume, number of opiate-exposed infants born per year, and existing policies and procedures for the care and management of NAS	52% of respondents have a standardized evaluation and treatment protocol. Most used a scoring tool however; there was variability in the type of tool used and inconsistency as to when to initiate pharmacologic treatment.	Marked variability was found in pharmacologic treatment in this survey. Morphine and diluted tincture of opium were the most commonly reported agents used as well as paregoric and phenobarbital.	Specific results were not sought regarding nonpharmacologic treatment of neonatal withdrawal in this survey.	Not explored.	Authors advocate for current evidence-based, standardized guidelines for the evaluation and management of neonatal withdrawal.
Management of the opioid withdrawal in the neonates: French and European survey. **Micard & Brion, 2003**	Pharmacists were surveyed. Data sought: availability of a written protocol for treatment and first line treatment. This included criteria for establishment of treatment, pharmacological treatment and route of	74% had a written protocol. In each of these units, the protocol indicated pharmacological treatment and dosage. Most centers use the	Oral Morphine Hydrochloride most commonly used in France and a sulphate solution in other European countries. Tincture of opium was used and a commercial oral	Nonpharmacological treatment was not the focus of this survey.	Not explored.	They advise that a specific preparation of Morphine should be developed and licensed to the management and treatment of neonatal withdrawal.

administration.	Finnegan scale with few using the Lipsitz tool or a derivative of the Finnegan scale.	solution of methadone. Phenobarbital was used alone or in combination.

Appendix C: Content Expert Group

Role
MD at FIR Square, BC Women's Health Center, BC
Neonatologist, Victoria General Hospital, BC
NICU Clinical Resource Nurse, Nanaimo Regional General Hospital, BC
Senior Practice Leader for FIR Square, BC Women's Health Center, BC
Senior Project Manager, Ontario Provincial Council for Maternal and Child Health

Appendix D: Letter of Invitation to Participate as a Content Expert

Consider being a part of a content expert group.

To contribute to the quality of the survey tool that will be used in a replication study exploring the care of substance-exposed infants and their caregivers:

"Care of infants with neonatal withdrawal in Canadian hospital settings: Has practice advanced in ten years?"

This is an invitation to contribute to the development of a survey tool that will be used in a subsequent research study. The purpose of this study is to explore the practices related to the care of infants in SCN and NICU settings who have been exposed to drugs and alcohol during the prenatal period. As you are likely aware, many practices have been developed on an anecdotal basis and there are few available research studies to validate these interventions.

In this study we propose to replicate a national survey of care that Dr. Lenora Marcellus conducted in 2000 and identify current practices related to daily care, discharge planning, and community support for this group of infants and their caregivers. In addition to identifying current practices, we will be able to determine if there have been any significant shifts in practice and develop a framework for future research in this field, in particular nursing interventions for daily care, discharge planning and community supports.

Your contribution as experts in this field is invaluable as we want this survey to gather relevant and pertinent data. The following questionnaire was extracted from the original study. We are asking for honest and candid input.

If you are interested in contributing to the body of knowledge about the care of substance-exposed infants and their parents/caregivers, please review the following questionnaire and reply back with your comments.

Questions may be directed to Tara Loutit, RN, BSN at the University of Victoria. I can be reached at xxx to leave a confidential voice mail message, or email xxx. Revising this survey is part of the degree requirements for a Masters in Nursing.

Thank you.

First, read the question then indicate if the question is relevant today in this setting – meaning does this question reflect current practices? Secondly, please indicate if the question is asked in a clear and concise manner. If you do not believe the question is relevant or clear, please indicate in the text box below each question. We are asking your expert feedback on this instrument's relevance and clarity on a 4 point Likert scale.

Appendix E: Care of Substance-exposed Infant Questionnaire. Original

Facility Information and Statistics

1. What is the annual birthrate for your facility?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

2. What level of care (maternal/newborn) is your facility rated to provide?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

3. Do you have a maternity unit with a separate neonatal nursing staff (e.g. NICU or SCN)?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

4. Which organization is your facility accredited by?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

5. Is your facility classified as a teaching hospital?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

6. Is your facility affiliated with a university?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

7. How many NICU beds does your facility have?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

8. Is perinatal substance use an issue in your community?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

9. What level of impact do you feel perinatal substance use has on your community?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

10. How many infants in your facility are identified with perinatal substance exposure?

This question is relevant

Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

Policy Development and Committees

1. Is there a maternal-newborn committee in place to review perinatal policies?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

2. Is there a process or committee in place to identify or monitor the progress of high-risk pregnancies?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

3. Does your facility have protocols/guidelines available to guide nursing/medical care for substance-exposed infants?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

4. What guidelines does your facility utilize related to caring for substance-exposed infants?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

Comments:

Physical Facilities

1. Where are substance-exposed infants cared for during their hospital stay? Symptomatic & Nonsymptomatic?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

2. If your facility has an NICU or SCN, is there a designated space in the NICU/SCN to care for substance-exposed infants?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

3. If so, describe this space?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

4. What environmental modifications are implemented when caring for substance-exposed infants?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

NICU/SCN Care

1. Does your facility routinely screen for the presence of substances? [yes/no]

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

2. Does your facility routinely screen infants for substances when maternal substance use is documented or in the presence of withdrawal symptoms in infants?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

3. What method of screening does your facility utilize for substance exposure screening?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

4. Does your facility routinely screen for Hepatitis B. Hepatitis C, or HIV?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

5. Which withdrawal-screening tool does your facility utilize?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

6. Does your facility use pharmacological therapy for management of withdrawal symptoms? [yes/no]

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

7. How does your facility manage the symptoms of opioid withdrawal?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

8. What other drug therapies are used to treat withdrawal symptoms?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

9. Does your facility routinely implement cardiac monitoring on infants being treated for withdrawal symptoms?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

10. Are medications utilized to manage abdominal discomfort associated with withdrawal?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

11. Is breastfeeding encouraged with this patient population?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

12. What supportive feeding measures are implemented with this patient population in your facility?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

13. What calming positions or measures are utilized with this patient population?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

14. What other non-pharmacological nursing interventions does your facility practice with this patient population?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

Discharge Planning

1. What is the minimum length of stay for this patient population in your facility?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

2. Are discharge meetings held to plan for the discharge of substance-exposed infants into the community?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

3. If so, which professionals attend these discharge-planning sessions?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

4. Does your facility have a written discharge protocol in place?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

5. Describe your facility's community follow-up procedures?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

6. Does your facility recommend to parents/caregivers of infants who have tested positive for infectious diseases to utilize gloves during diaper changes?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

7. What does your facilities discharge-teaching plan focus on?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

8. Does your facility recommend to parents/caregivers of infants who have tested positive for infectious diseases to utilize gloves during diaper changes?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

9. What nursing interventions does your facility use to prepare parents/caregivers for caring for their newborns at home?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

Staff Education and Support

1. Is education of substance-exposed infants included in your facility's basic NICU/SCN orientation program? [yes/no]

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

2. How is this information presented to new employees?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

3. Is there a specialized support position available at your facility to offer services related to care of the substance-exposed infants? [yes/no] If yes, describe.

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

4. What other educational resources are available to support the nursing staff who provide care for this group of babies and their families?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

Link to Family and Social Services

1. What percentage of substance-exposed infants are discharged into foster care?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

2. Are you aware of any programs available in your community to train and support foster families caring for substance-exposed infants?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

3. Are foster families supported to visit infants in hospital prior to discharge?

   This question is relevant
   Strongly disagree Disagree Agree Strongly agree

   This question is clear
   Strongly disagree Disagree Agree Strongly agree

   Comments:

Additional Comments

Please share any additional comments or identify any other practice issues that have not been addressed in this survey.

- Interagency communication
- Interest in establishing community partnerships
- Difficulty in caring for infants where there was no NICU/SCN available
- Referral process
- Development of protocols
- Other nursing interventions?

This question is relevant
Strongly disagree Disagree Agree Strongly agree

This question is clear
Strongly disagree Disagree Agree Strongly agree

Comments:

Additional comments on this instrument:

Again, thank-you - your time and sharing of expertise is invaluable.
Tara Loutit

Appendix F: Content Expert Group Feedback

Feedback regarding survey tool – RELEVANCE			
1= Strongly disagree	**2= Disagree**	**3= Agree**	**4= Strongly agree**
Content Expert #1	**Content Expert #2**	**Content Expert #3**	**Content Expert #4**
Facility Information and Statistics			*See CLARITY response for Content Expert #4.
1. 4	1. 4	1. 4	
2. 4	2. 4	2. 2	
3. 4	3. 4	3. 3	
4. 3	4. 3	4. 3	
5. 3	5. Do you mean is there medical students or in a rural hospital	5. 2	
6. 3	6. 3	6. 2	
7. 4	7. 4	7. 3 The baby may be nursed with its mother in community hospital MBU	
8. 4	8. 4 I might ask it as Has perinatal SU been identified as an issue…?	8. 3	
9. 2 What do you mean by community? Of nurses? Social Community?	9. 4 Would like to see a "measure" such as minimal, moderate or high impact	9. 3	
10. 4	10. 4 How are they identified: mec testing; urine testing; self-disclosure etc.	10. 3	
Policy Development and Communities			
11. 3	1. 4	1. 3	
12. 3	2. 4	2. 3	
13. 4	3. 4	3. 3	
14. 4	4. 4 I wonder if we will need this once the perinatal redesign and prenatal	4. 3	

	stuff gets sorted out.		
Physical Facilities			
15. 4	1. 4	1. 3	
16. 4	2. 4	2. 3	
17. 4	3. 4	3. 3	
18. 4	4. 4	4. 3	
NICU/SCN Care			
19. 4	1. 4 Would want to know what screening and do they obtain parental consent	1. 3	
20. 4	2. 4	2. 3	
21. 3	3. ok-	3. 3	
22. 3	4. 4 This is usually done in prenatal screening of mom	4. 3	
23. 4	5. 4	5. 3	
24. 4	6. 4	6. 3	
25. 3	7. 4	7. 3	
26. 3	8. 4	8. 3	
27. 4	9. 4	9. 3	
28. 4	10. 4	10. 3	
29. 4	11. 4 If not, why not	11. 3	
30. 4	12. 4	12. 3	
31. 4	13. 4	13. 3	
32. 4	14. 4	14. 3	
Discharge Planning			
33. 4	1. 4 Is there a space available for mother's stay near baby in hospital	1. 3	
34. 4	2. 4	2. 3	
35. 4	3. 4 Which community professionals are included in these discharge plans?	3. 3	
36. 4	4. 4	4. 3	
37. 4	5. 4	5. 3	
38. 3	6. 4	6. 3	

39. 3	7. 4	7. n/a Too vague – plan should focus on many variables	
40. 3	8. -	8. n/a Too vague – plan should focus on many variables	
41. 4	9. 4	9. 3	
Staff and Educational Support			
42. 4	1. 4	1. 3	
43. 4	2. 4 How frequently does the training occur and how are staff kept updated	2. 3	
44. 4	3. 4	3. 3	
45. 3	4. 4	4. 3	
Link to Family Services			
46. 2	1. 4	1. 3	
47. 2	2. 4	2. 3	
48. 3	3. 4	3. 3	
Additional Comments			
49. 4	1. – I would like to see more questions focusing on substance using mothers…	Rooming in with mother?	

Feedback regarding survey tool – CLARITY			
1= Strongly disagree	**2= Disagree**	**3= Agree**	**4= Strongly agree**
Content Expert #1	**Content Expert #2**	**Content Expert #3**	**Content Expert #4**
Facility Information and Statistics			
1. 4	1. 4	1. 4	
2. 4	2. 4	2. 3	
3. 4	3. 4	3. 3	
4. 3	4. 3	4. 3	
5. 3	5. – do you mean is there medical students or in	5. 3	

	a rural hospital		
6. 3	6. 3	6. 3	6. Do you want to specify how many are which levels?
7. 4	7. 4	7. 2	
8. 4	8. 4 I might ask it as Has perinatal SU been identified as an issue…?	8. 3	8. May want to ask if there are specialized programs in the community for this population.
9. 2 What do you mean by community? Of nurses? Social Community?	9. 4 Would like to see a "measure" such as minimal, moderate or high impact	9. 3 Easier to answer if you give options	
10. 4	10. 4 How are they identified: mec testing; urine testing; self-disclosure etc.	10. 3	
Policy Development and Communities			
11. 3	1. 4	1. 4	
12. 3	2. 4	2. 3	2. Do you want to include how many pregnancies are impacted by substance use?
13. 4	3. 4	3. 3	3. Perhaps include guidelines for the woman with substance use issues?
14. 4	4. 4 I wonder if we will need this once the perinatal redesign and prenatal…	4. 3	4. May want to request a copy.
Physical Facilities			
15. 4	1. 4	1. 3	1. May want to ask more specific questions about caring for mom and baby together?
16. 2 The second question needs to connect with the first.	2. 4	2. 3	
17. 4	3. 4	3. 3	
18. 4	4. 4	4. 3	

NICU/SCN Care			
19. 4	1. 4 Would want to know what screening and do they obtain parental consent	1. 3	1. May want to reword – such as what kind of routine screening is done when indicated by clinical condition?
20. 4	2. 4	2. 3	
21. 4	3. ok-	3. 3	
22. 3	4. 4 This is usually done in prenatal screening of mom	4. 3	
23. 4	5. 4	5. 3	5. Include babies and mothers – differentiate. May add syphilis.
24. 4	6. 4	6. 3	
25. 2 The facility does not manage but the healthcare staff does.	7. 4	7. 3	
26. 3	8. 4	8. 3	8. What medications? You may want to list these and include buprenorphine.
27. 4	9. 4	9. 3	
28. 4	10. 4	10 3	
29. 4	11. 4 If not, why not	11. 3	11. If so, which ones? Any non-pharmacological interventions to manage this discomfort?
30. 4	12. 4	12. 3	
31. 4	13. 4	13. 3	
32. 4	14. 4	14. 4	
Discharge Planning			
33. 4	1. 4 Is there a space available for mother's stay near baby in hospital	1. 3	
34. 4	2. 4	2. 3	
35. 4	3. 4 Which community professionals are included in these	3. 3	3. Do families participate in these meetings?

	discharge plans?		
36. 4	4. 4	4. 3	4. May want to add, "if so, are you willing to share?"
37. 3	5. 4	5. 3	
38. 3	6. 4	6. 3	
39. 3	7. 4	7. 2	
40. 3	8. 4	8. n/a	
41. 4	9. 4	9. 3	9. May want to add a question about sending babies home on Morphine therapy.
Staff and Educational Support			
42. 4	1. 4	1. 3	1. May want to add something about education on mothers/women and addiction/mental health/trauma and violence.
43. 4	2. 4 How frequently does the training occur and how are staff kept updated	2. 3	
44. 3	3. 4	3. 3	May want to add, "If so, can you describe it?"
45. 3	4. 4	4. 3	
Link to Family Services			
46. 3	1. 4	1. 3	1. may want to inquire about how we support mothers/birth families in the community too. Are we somehow able to get at what the current experience is for mothers being able to keep their babies?
47. 3	2. 4	2. 3	
48. 3	3. 4	3. 3	
Additional Comments		4. 3	
49. 4	1. – I would like to see more questions	Rooming in with mother?	

	focusing on substance using mothers…		

Appendix G: Letter of Information for Implied Consent

University of Victoria

Letter of Information for Implied Consent

Care of infants with neonatal withdrawal in Canadian hospital settings: Has practice advanced in ten years? A pilot study

You are invited to participate in a pilot study entitled "Care of infants with neonatal withdrawal in Canadian hospital settings: Has practice advanced in ten years?" that is being conducted by Tara Loutit - a graduate student at the University of Victoria.

As a Graduate student, I am required to conduct research as part of the requirements for a degree in Advanced Practice Nursing – Advanced Practice Leadership Option. It is being conducted under the supervision of Dr. Marcellus. You may contact my supervisor at xxx.

This research is being partially funded by UVIC internal research grant.

Purpose and Objectives
Many practices related to the care of infants exposed to drugs and alcohol during the prenatal period have been developed on an anecdotal basis. There are few available research studies to validate these interventions. Despite many advances in technology and in neonatal intensive care in general, there have been few changes noted in the care of this particular sub-population in the last 30 years. In this study we propose to replicate a national survey of care that Dr. Marcellus conducted in 2000 and identify current practices related to daily care, discharge planning, and community support for this group of infants and their caregivers. In addition to identifying current practices, we will be able to determine if there have been any significant shifts in practice and develop a framework for future research in this field, in particular nursing interventions for daily care, discharge planning and community supports.

Importance of this Research
Neonatal withdrawal is a condition that develops in the newborn as a result of abrupt removal of exposure to addictive substances. It is most commonly observed after maternal use of opioids such as heroin, morphine, or methadone, but may also be present after continuous fetal exposure to barbiturates, alcohol or other psychoactive drugs. General outcomes from this exposure range from no obvious effects to severe effects, including intrauterine growth restriction, prematurity, neurobehavioral and neurophysical dysfunction, birth defects, and Fetal Alcohol Spectrum Disorder. Substance-exposed infants may go unrecognized and may be discharged from the newborn nursery at risk for a complex of medical and social problems, including abuse and neglect. It is estimated that one out of ten infants are exposed to one or more substances during pregnancy. The financial and social costs of caring for drug and alcohol exposed infants are high, whether measured by the day, the neonatal treatment episode, or the entire spectrum of interventions during infancy and childhood.

Participants Selection

You are being asked to participate in this study because your director has acknowledged that you have the most appropriate knowledge and expertise related to the topic.

What is involved
If you agree to voluntarily participate in this research, your participation will include completing an online survey. This survey will consist of both forced choice and open-ended questions.

Inconvenience
The researchers recognize that the current state of practice in our Canadian healthcare system is demanding. Therefore, the time devoted to filling out the survey may be inconvenient to you – however, being an online survey will hopefully alleviate some of this strain.

Risks
There are no known or anticipated risks to you by participating in this research.

Benefits
This survey will provide a platform for development of a research program focusing on nursing interventions to support infants experiencing withdrawal from drugs and alcohol after birth. This group of infants tends to require intensive care services for prolonged periods of time. Development of these interventions will contribute to more effective use of limited specialized resources and with an earlier transition of the infant to a more supportive home and community environment. As this is a replication study, the potential benefits of your participation in this research include contributing to the state of knowledge regarding best practice for substance-exposed infants and their caregivers.

Voluntary Participation
Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. However, because this is an anonymous study, your data will still be analyzed.

Anonymity
In terms of protecting your anonymity, The Fluid Survey technology completely protects your anonymity.

Confidentiality
Your confidentiality and the confidentiality of the data will be protected by the Fluid Survey technology.

Dissemination of Results
It is anticipated that the results of this study will be shared with others in the following ways: Thesis and a published article and possibly presented at scholarly meetings.

Disposal of Data
Data from this study will be downloaded into a spreadsheet and saved on a secured hard drive in a locked and secured office.

Contacts
Individuals that may be contacted regarding this study include:
Dr. Lenora Marcellus at xxx
Tara Loutit at xxx

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

By completing and submitting the questionnaire, **YOUR FREE AND INFORMED CONSENT IS IMPLIED** and indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

Please retain a copy of this letter for your reference.

Appendix H: Human Research Ethics Board Response

University of Victoria
Human Research Ethics Board
University of Victoria
Office of Research Services
Administrative Services Building- 2"d Floor
3800 Finnerty Road
Victoria, BC V8P 5C2
Tel: 250-472-4545 Fax: 250-721-8960
Email: ethics@uvic.ca

Notification of Outside of Human Research Ethics Board Mandate

To: Lenora Marcellus

Date: February 23, 2012

Study Title: **Care of infants with neonatal withdrawal in Canadian hospital settings: Has practice advanced in ten years?**

Principal Investigator: Lenora Marcellus

This memo is to confirm that proposed study entitled "Care of infants with neonatal withdrawal in Canadian hospital settings: Has practice advanced in ten years?" has been deemed to be outside of the Human Research Ethics Board mandate according to Article 2.1of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, 2010 (TCPS 2}.* The information you provided to us (February 1ih, 2012) indicates that your study is limited to *collecting information about organizations, policies, procedures, professional practices or statistical reports from anonymous personnel who are authorized to release such information in the ordinary course of their employment. Such individuals are not considered participants for the purposes of the TCPS 2.* Therefore your project does not require or qualify for UVic Human Research Ethics Board review.

The UVic Human Research Ethics Board encourages you to follow the protocol submitted for Ethics review and requires that you remove the statement regarding ethics approval from the Human Research Ethics Office from the consent form. Also, please modify the contact information for Research Assistant Shannon Cross to remove any affiliation with VIHA.

Should your project evolve to include participants as defined in Article 2.1of the TCPS 2, you are required to submit an ethics application for review.
Please contact the Human Research Ethics Office at (250) 472-4545 or ethics@uvic.ca if you have any questions.

Sincerely

c.c.: Shannon A. McDonald,
BSc, MA Human Research Ethics
Facilitator
hre@uvic.ca (250) 472-5555

Appendix I: Analysis of Relevance Ratings

Ratings on the Survey Tool by 3 Experts: Items Rated 3 or 4 on a 4-Point Relevance Scale

Item	Expert 1	Expert 2	Expert 3	# in agreement	Item CVI
1	X	X	X	3	1.00
2	X	X	- *	2	0.75
3	X	X	X	3	1.00
4	X	X	X	3	1.00
5	X	-	-	1	0.33
6	X	X	-	2	0.75
7	X	X	X	3	1.00
8	X	X	X	3	1.00
9	X	X	X	3	1.00
10	X	X	X	3	1.00
11	X	X	X	3	1.00
12	X	X	X	3	1.00
13	X	X	X	3	1.00
14	X	X	X	3	1.00
15	X	X	X	3	1.00
16	X	X	X	3	1.00
17	X	X	X	3	1.00
18	X	X	X	3	1.00
19	X	X	X	3	1.00
20	X	X	X	3	1.00
21	X	X	X	3	1.00
22	X	X	X	3	1.00
23	X	X	X	3	1.00
24	X	X	X	3	1.00
25	X	X	X	3	1.00
26	X	X	X	3	1.00
27	X	X	X	3	1.00
28	X	X	X	3	1.00
29	X	X	X	3	1.00
30	X	X	X	3	1.00
31	X	X	X	3	1.00
32	X	X	X	3	1.00
33	X	X	X	3	1.00
34	X	X	X	3	1.00
35	X	X	X	3	1.00
36	X	X	X	3	1.00
37	X	X	X	3	1.00
38	X	X	X	3	1.00
39	X	X	-	2	0.75
40	X	-	-	2	0.33
41	X	X	X	3	1.00
42	X	X	X	3	1.00
43	X	X	X	3	1.00
44	X	X	X	3	1.00

45	X	X	X	3	1.00
46	-	X	X	2	0.75
47	-	X	X	2	0.75
48	X	X	X	3	1.00
49	X	-	-	1	0.33
				Mean I-CVI	.93
Proportion Relevant	.96	.94	.88	Mean expert proportion	.93

I-CVI: Item-level content validity index
Scale adapted from Polit and Beck (2006).

* "-"denotes the respondent did not answer the question.

Appendix J: Analysis of Clarity Ratings

Ratings on the Survey Tool by 3 Experts: Items Rated 3 or 4 on a 4-Point Clarity Scale

Item	Expert 1	Expert 2	Expert 3	# in agreement	Item CVI
1	X	X	X	3	1.00
2	X	X	X	3	1.00
3	X	X	X	3	1.00
4	X	X	X	3	1.00
5	X	- *	X	2	0.75
6	X	X	X	3	1.00
7	X	X	-	2	0.75
8	X	X	X	3	1.00
9	-	X	X	2	0.75
10	X	X	X	3	1.00
11	X	X	X	3	1.00
12	X	X	X	3	1.00
13	X	X	X	3	1.00
14	X	X	X	3	1.00
15	X	X	X	3	1.00
16	-	X	X	2	0.75
17	X	X	X	3	1.00
18	X	X	X	3	1.00
19	X	X	X	3	1.00
20	X	X	X	3	1.00
21	X	X	X	3	1.00
22	X	X	X	3	1.00
23	X	X	X	3	1.00
24	X	X	X	3	1.00
25	-	X	X	2	0.75
26	X	X	X	3	1.00
27	X	X	X	3	1.00
28	X	X	X	3	1.00
29	X	X	X	3	1.00
30	X	X	X	3	1.00
31	X	X	X	3	1.00
32	X	X	X	3	1.00
33	X	X	X	3	1.00
34	X	X	X	3	1.00
35	X	X	X	3	1.00
36	X	X	X	3	1.00
37	X	X	X	3	1.00
38	X	X	X	3	1.00
39	X	X	-	2	0.75
40	X	X	-	2	0.75
41	X	X	X	3	1.00
42	X	X	X	3	1.00
43	X	X	X	3	1.00
44	X	X	X	3	1.00

45	X	X	X	3	1.00
46	X	X	X	3	1.00
47	X	X	X	3	1.00
48	X	X	X	3	1.00
49	X	-	-	1	0.33
				Mean I-CVI	.95
Proportion Relevant	.93	.96	.92	Mean expert proportion	.94

I-CVI: Item-level content validity index
Scale adapted from Polit and Beck (2006).

* "-"denotes the respondent did not answer the question.

Appendix K: Care of the Substance-exposed Infant Questionnaire. Revised

Facility Information and Statistics

1. What is the annual birthrate for your facility?
2. What level of care (maternal/newborn) is your facility rated to provide?
3. Do you have a maternity unit with a separate neonatal nursing staff (e.g. NICU or SCN)?
4. Which organization is your facility accredited by?
5. Is your facility classified as a teaching hospital?
6. Is your facility affiliated with a university?
7. How many NICU beds does your facility have?
8. Is perinatal substance use an issue in your community?
9. What level of impact do you feel perinatal substance use has on your community?
10. How many infants in your facility are identified with perinatal substance exposure?

Policy Development and Committees

11. Is there a maternal-newborn committee in place to review perinatal policies?
12. Is there a process or committee in place to identify or monitor the progress of high-risk pregnancies?
13. Does your facility have protocols/guidelines available to guide nursing/medical care for substance-exposed infants?
14. What guidelines does your facility utilize?

Physical Facilities

15. Where are substance-exposed infants cared for during their hospital stay? Symptomatic & Nonsymptomatic?
16. If your facility has an NICU or SCN, is there a designated space in the NICU/SCN to care for substance-exposed infants?
17. If so, describe this space?
18. What environmental modifications are implemented when caring for substance-exposed infants?

NICU/SCN Care

19. Does your facility routinely screen all newborns for the presence of substances?
20. Does your facility routinely screen infants for substances when maternal substance use is documented or in the presence of withdrawal symptoms in infants?
21. What method of screening does your facility utilize for substance exposure screening?
22. Does your facility routinely screen for Hepatitis B. Hepatitis C, or HIV?
23. Which withdrawal-screening tool does your facility utilize?

24. Does your facility use pharmacological therapy for management of withdrawal symptoms?
25. How does your facility manage the symptoms of opioid withdrawal?
26. What other drug therapies are used to treat withdrawal symptoms?
27. Does your facility routinely implement cardiac monitoring on infants being treated for withdrawal symptoms?
28. Are medications utilized to manage abdominal discomfort associated with withdrawal?
29. Is breastfeeding encouraged with this patient population?
30. What supportive feeding measures are implemented with this patient population in your facility?
31. What calming positions or measures are utilized with this patient population?
32. What other non-pharmacological nursing interventions does your facility practice with this patient population?

Discharge Planning

33. What is the minimum length of stay for this patient population in your facility?
34. Are discharge meetings held to plan for the discharge of substance-exposed infants into the community?
35. If so, which professionals attend these discharge-planning sessions?
36. Does your facility have a written discharge protocol in place?
37. Describe your facility's community follow-up procedures?
38. Does your facility have parent/caregiver teaching plans? Are these plans dispersed to the parent/caregiver prior to discharge?
39. What does your facilities discharge-teaching plan focus on?
40. Does your facility recommend to parents/caregivers of infants who have tested positive for infectious diseases to utilize gloves during diaper changes?
41. What nursing interventions does your facility use to prepare parents/caregivers for caring for their newborns at home?

Staff Education and Support

42. Is education of substance-exposed infants included in your facility's basic NICU/SCN orientation program? [yes/no]
43. How is this information presented to new employees?
44. Is there a specialized support position available at your facility to offer services related to care of the substance-exposed infants? [yes\no] If yes, describe.
45. What other educational resources are available to support the nursing staff provide care for this group of babies and their families?

Link to Family and Social Services

46. What percentage of substance-exposed infants are discharged into foster care?
47. Are you aware of any programs available in your community to train and support foster families caring for substance-exposed infants?

48. Are foster families supported to visit infants in hospital prior to discharge?

Additional Comments

Please share any additional comments or identify any other practice issues that have not been addressed in this survey.

- Interagency communication
- Interest in establishing community partnerships
- Difficulty in caring for infants where there was no NICU/SCN available
- Referral process
- Development of protocols
- Other nursing interventions?

Appendix L: Letter of Invitation to Participate in a Pilot-Replication Study

Invitation to participate

"Care of infants with neonatal withdrawal in Canadian hospital settings: Has practice advanced in ten years? A pilot study"

This is an invitation to participate in a research study. The purpose of this study is to explore the practices related to the care of infants exposed to drugs and alcohol during the prenatal period. Although you have received this invitation as a director of nursing for maternal- child services, we are hoping you will forward it to the person you feel would have the best knowledge of care practices in your NICU – i.e.: a nurse educator/leader/manager etc.

Many practices have been developed on an anecdotal basis and there are few available research studies to validate these interventions. Despite many advances in technology and in neonatal intensive care in general, there have been few changes noted in the care of this particular sub-population in the last 30 years. In this study we propose to replicate a national survey of care that Dr. Lenora Marcellus conducted in 2000 and identify current practices related to daily care, discharge planning, and community support for this group of infants and their caregivers. In addition to identifying current practices, we will be able to determine if there have been any significant shifts in practice and develop a framework for future research in this field, in particular nursing interventions for daily care, discharge planning and community supports.

Participation would include completing an online survey consisting of both closed choice and open-ended questions. Participation in this study is entirely voluntary, and if you agree to participate, you may change your mind and withdraw at any point without the need for explanation. You need not answer any questions that you are not comfortable answering nor do you need to address any topic you are not comfortable addressing. The survey will take approximately 30 minutes to complete. We are also interested in receiving copies of any guidelines related to the care of infants with prenatal substance exposure in your unit if you are comfortable in sharing. Following completion of this study we will be able to provide your team with an electronic copy of our final report.

The criterion for this research is that you are a director of nursing responsible for maternal-infant nursing in Canada with active maternal-infant services with less than 500 deliveries annually. If you are interested in contributing to the body of knowledge on substance-exposed infants and their caregivers, please forward the survey to the person with the most appropriate knowledge and expertise related to the topic.

Questions may be directed to Tara Loutit, RN, BSN at the University of Victoria. I can be reached at xxx to leave a confidential voice mail message, or email to xxx. Revising this survey is part of the degree requirements for a Masters in Nursing.
Thank you.

Appendix M: Summary Report of Findings

(Completion rate: 66.67%)

What is the annual birthrate for your facility?

Response		Count
<500		2
501-1000		3
1001-1500		1
>1500		0
	Total	**6**

What level of care (maternal/newborn) is your facility rated to provide?

Response		Count
Level 1B		1
Level 2A		1
Level 2B		2
Level 3A		0
Level 3B		0
Level 3C		0
	Total	**4**

Is your facility accredited by Accreditation Canada?

Response		Count
Yes		5
No		0
	Total	**5**

Is your facility affiliated with a university medical program?

Response		Count
Yes		3
No		2
	Total	**5**

How many beds are in your NICU?

Variable	Response
Level 1	The 5 response(s) to this question can be found in the appendix.
Level 2	The 5 response(s) to this question can be found in the appendix.
Level 3	The 5 response(s) to this question can be found in the appendix.
Total beds (if you are unsure of the levels)	The 2 response(s) to this question can be found in the appendix.

Has perinatal substance use been identified as a concern in your community? If so, please describe your community context.

Response		Count
Yes		5
No		1
	Total	**6**

If perinatal substance use has been identified as a concern in your community, please describe your community context (the 4 responses can be found in the appendix).

What impact do you feel this issue is having in your community?

Response		Count
No impact		0
Slight impact		3
Moderate impact		3
Significant impact		0
	Total	**6**

How many infants per year in your facility experience perinatal substance exposure?
(the 5 responses to this question can be found in the appendix).
Is a maternal-newborn/neonatal committee in place to review perinatal and neonatal policies?

Response		Count
Yes		4
No		1
	Total	**5**

Do you have a protocol/clinical guideline in place to identify and monitor the progress of high risk pregnancies, including perinatal substance use?

Response	Count

Yes		4
No		1
	Total	**5**

Do you have a protocol/clinical guideline in place to guide nursing and medical care of substance-exposed infants?

Response		Count
Yes		3
No		2
	Total	**5**

Do you have a protocol/clinical guideline in place to guide nursing and medical care of pregnant women with substance use issues?

Response		Count
Yes		2
No		3
	Total	**5**

If you answered yes to the previous questions regarding guidelines, would you mind sharing a copy?

Response		Count
Yes		1
No		3
	Total	**4**

Where are symptomatic substance-exposed infants cared for during their hospital stay?

Response		Count
NICU		1
Rooming in with the mother		1
Both		0
Other		2
	Total	**4**

Where are symptomatic substance-exposed infants cared for during their hospital stay? (Other, please specify...)

Response

1. transfer out
2. transferred out

Where are non-symptomatic substance-exposed infants cared for during their hospital stay?

Response		Count
NICU		0
With the mother		4
Both		1
Other, please specify...		0
	Total	**5**

The 5 response(s) to this question can be found in the appendix.

Do you have a designated area in your NICU for this group of babies?

Response		Count
Yes		1
No		3
	Total	**4**

If so, can you briefly describe this space?

The 2 response(s) to this question can be found in the appendix.

Which environmental modifications are used routinely in your unit for these babies?

Response		Count
None		1
Decreased overhead light		2
Decreased noise		0
Cot or incubator covers		1
Other, please specify...		0
	Total	**4**

Which environmental modifications are used routinely in your unit for these babies? (None specified)

When are infants screened for the presence of maternal substances?

Response		Count
Routinely		0

Based on maternal history		4
Never		1
Other, please specify...		0
	Total	**5**

How are infants screened at your facility for the presence of maternal substances?

Response	Count
Urine	3
Meconium	2
Hair	1
Other, please specify...	1
Total	**5**

How are infants screened at your facility for the presence of maternal substances? (Other, please specify...)

1. unsure

What tests are mothers routinely screened for in your facility?

Response		Count
Hep B		3
Hep C		3
HIV		4
Syphilis		3
Not routinely screened unless there is no prenatal information for mother		0
Other, please specify...		2
	Total	**5**

What tests are mothers routinely screened for in your facility? (Other, please specify...)

#	Response
1.	unsure
2.	GBS

Do you use a scoring tool to assess the severity of withdrawal symptoms?

Response		Count
No		0
Finnegan – original version		0
Finnegan – modified version		0
Lipsitz tool		0
Zahorodny withdrawal inventory		0
Rivers scoring system		0
Green's narcotic withdrawal index		0
BC Women's/FIR Square		2
We use one but I don't know the name of it		4
Other, please specify & consider sharing this tool...		0
	Total	**5**

Are parents involved at all when scoring the withdrawal symptoms?

Response		Count
yes		1
no		1
sometimes		3
	Total	**5**

Does your facility routinely use non-pharmacological strategies for management of withdrawal symptoms?

Response	Count
yes, environmental modifications as noted previously	3
no	2
Other, please	0

specify...		
	Total	**5**

Do you use a scoring algorithm or clinical guideline to decide when to start treatment?

Response		Count
Yes		4
No		1
	Total	**5**

Do you continue to use the scoring algorithm or clinical guideline to decide drug dosage alterations and /or discontinuation of treatment?

Response		Count
Yes		3
No		2
	Total	**5**

Are medications utilized to manage abdominal discomfort associated with withdrawal?

Response		Count
Yes		2
No		3
	Total	**5**

If medications are utilized to manage abdominal discomfort associated with withdrawal, which are used? (the 2 response(s) to this question can be found in the appendix.

How is breastfeeding approached for this population?

Response		Count
Not encouraged		0
On an individual basis		5
Other, please specify...		0
	Total	**5**

What supportive feeding measures are implemented with this patient population in your facility (check all that apply)?

Response		Count
Adding additional		2

calories		
Scheduled feeds		4
Demand feeds		2
Elevating head of bed for reflux		2
Other, please specify...		0
	Total	**5**

Do you use supportive strategies to help mom with her life conditions?

Response		Count
Yes		3
No		2
	Total	**5**

If so, what supportive strategies do you use? (the 2 responses to this question can be found in the appendix).

What caregiving approaches do you use to support women while in the hospital? (the 3 responses to this question can be found in the appendix).

How do you think your facility does supporting these moms in the unit/hospital?

Response		Count
not very well		2
fair		2
very well		0
Other, please specify...		1
	Total	**5**

How do you think your facility does supporting these moms in the unit/hospital? (Other, please specify...)

#	Response
1.	we do try but there are many obstacles and when a baby needs extra care we cannot provide it consistently.

How do you think you could improve the support these mothers receive in your unit/hospital? (the 4 responses to this question can be found in the appendix).

Do you routinely monitor substance-exposed infants?

Response	Count
Yes	2
No	2
Total	**4**

If you answered yes to the above question, how is this monitoring done?
(the 2 responses to this question can be found in the appendix).
Who usually does the ordering when caring for infants experiencing withdrawal?
(the 4 responses to this question can be found in the appendix).

Do you have a minimum length of stay for this population in your facility?

Response	Count
Yes	0
No	4
Total	**4**

If you answered "yes" to the above question, what is the minimum length of stay for this population at your facility?
There are no responses to this question.

Are discharge meetings routinely held to plan for the discharge of substance-exposed infants into the community?

Response	Count
Yes	3
No	1
Total	**4**

If so, which professionals attend these discharge planning sessions? Please check all that apply.

Response	Count
Parents	3
Parents support (who they identify as their own support, ie. family, friends)	3
NICU nurse	1
Hospital social worker	3
Pediatrician/neonatologist	1
Case coordinator or nurse	2

manager		
Public health nurse		2
Community social worker		2
Community/family physician		3
Other, please specify...		0
	Total	**3**

Are there any specialized programs for this population of mothers and babies in your community?

Response		Count
Yes		0
No		4
	Total	**4**

If you answered "yes" to the above question, please describe these programs.

There are no responses to this question.

Please describe your usual community follow-up for these babies and their families:

(the 3 response(s) to this question can be found in the appendix).

Do you have a routine pre-discharge teaching plan for caregivers?

Response		Count
Yes		3
No		1
	Total	**4**

If so, what items are included (check all that apply)?

Response	Count
Community resources	3
Feeding	2
Infant safety	3
Infant cues	3
Developing a relationship with your baby	3
Dealing with irritability and crying	3

Related health issues	3
Dealing with sleep challenges	2
Respite/relief care	1
Self-care	2
Universal precautions	2

Do you discharge babies home on medications given to treat their withdrawal?

Response	Count
Yes	0
No	4
Total	**4**

Is education on the care of substance-exposed infants and their families included in your facility's unit orientation?

Response	Count
Yes	1
No	3
Total	**4**

Is education about how to support women struggling with addiction/mental health/ trauma and violence provided to your staff?

Response	Count
Yes	0
No	4
Total	**4**

What form does this information take (check all that apply)?

Response	Count
Lecture	0
Learning module	0
Review of guidelines	0

Other, please specify...		1
	Total	**1**

What form does this information take (check all that apply)? (Other, please specify...)

#	Response
1.	we do give education but it is not formalized. We need to create a more formal learning plan. It is case by case.

Is there any specialized support or expertise in your facility or community organizations to help you care for this group of babies and their families?

Response		Count
Yes		1
No		3
	Total	**4**

If so, please describe: (the 1 response to this question can be found in the appendix.

Approximately how many of the babies who have experienced prenatal substance exposure are discharged into foster care per year? (the 3 responses to this question can be found in the appendix).

Are you aware of any programs in your community that are available to train and support foster families to care for infants with prenatal substance exposure? If so, please name:

Response		Count
Yes		0
No		4
	Total	**4**

If so, please name: There are no responses to this question.

Are you aware of any programs in your community that are available to support pregnant or postpartum families struggling with addiction? If so, please name:

Response		Count
Yes		2
No		2
	Total	**4**

If so, please name: (the 2 responses to this question can be found in the appendix).

When considering your unit experiences of discharging the substance-exposed infant, would you say that...

Response		Count
most are discharged home with their birth family		1
some are discharged home with their birth family		3
they are rarely discharged home with their birth family		0
Other, please specify...		0
	Total	**4**

Please share any additional comments or identify any other practice issues that have not been addressed in this survey. (the 1 response to this question can be found in the appendix).

If perinatal use has been identified as a concern in your community, please describe your community context. |

Common themes include respondents stressing the importance of community service providers having an open door policy and sharing that their community struggles with drug and alcohol issues.

How many infants per year in your facility experience perinatal substance exposure? |

1. not sure as this is not tracked
2. approx 6
3. unsure
4. 5-10
5. ?6

How do you decide where these infants are cared for during their hospital stay? |

1. history and assessment
2. they can only stay with us if able to be cared for by mother most of the time.
3. MD dependant
4. level of care required
5. policy

If so, can you briefly describe this space? |

1. usual care room, no special consideration
2. we do not have a NICU

If medications are utilized to manage abdominal discomfort associated with withdrawal, which are used? |

1. unsure
2. Tylenol

If so, what supportive strategies do you use? |

Common themes include social work supports and specialized teams knowledgeable on high risk infants.

What caregiving approaches do you use to support women while in the hospital? |

Social work involvement, MCFD if appropriate, extra teaching and support from nursing staff

How do you think you could improve the support these mothers receive in your unit/hospital? |

Themes include providing education and knowledge so that pregnant women struggling is treated respectfully and receives optimal care.

If you answered yes to the above question, how is this monitoring done? |

1. in the NICU
2. monitor

Who usually does the ordering when caring for infants experiencing withdrawal? |

Most indicate pediatrician or the family physician.

Please describe your usual community follow-up for these babies and their families: |

Public health or aboriginal health social work was cited as well as midwifery follow-up.

Approximately how many of the babies who have experienced prenatal substance exposure are discharged into foster care per year? |

Most replied a small number where others indicated this was impossible to know.

Please share any additional comments or identify any other practice issues that have not been addressed in this survey. |

Themes extracted from this rich data include the following: 1. Connected with the woman in a timely and authentic way 2. Be aware of our own assumptions and bias' when caring for this population