"INSIDE OF EACH STORY WAS A PIECE OF MY STORY": APPLIED FOLKLORE

ADDRESSING STIGMA AROUND PERINATAL MOOD AND ANXIETY DISORDERS

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Jodine Perkins

"INSIDE OF EACH STORY WAS A PIECE OF MY STORY":

APPLIED FOLKLORE ADDRESSING STIGMA AROUND PERINATAL MOOD AND

ANXIETY DISORDERS

Situated within scholarship on applied folklore, this dissertation discusses and evaluates the
2013–2015 Pacific Post Partum Support Society's (PPPSS) "Strengthening Community-based
Resources for Families Experiencing Perinatal Depression and Anxiety and Their Health Care
Providers" project. In this project, working with PPPSS staff, contractors, and volunteers, I used
mixed methods to create educational resources and new services for clients and professional
helpers. The overall project was designed to reduce the stigma of perinatal mood and anxiety
disorders (PMADs) and to encourage struggling new parents to reach out for help sooner, when
treatment is likely to be less expensive and more effective. Making use of post-project follow-up
interviews with project participants and staff, this dissertation documents, reflects on, and
evaluates this project in order to serve as a case study to guide the development and
implementation of similar applied folklore projects.

By analyzing the narratives of project participants, this dissertation also examines the
multifaceted, pervasive, and profound impact of stigma on new parents' perinatal experiences,
especially those experiencing a PMAD. This dissertation also discusses the process of sharing
personal experience narratives in a supportive environment that formed the key inspiration for
this applied project, as well some of the potential impacts on parents who share these narratives,
including providing a way to understand their own

experiences.

This dissertation encourages additional applied folklore work to support struggling new parents and offers suggestions for how health care providers, community support workers, and friends and family members can better support new parents in the hopes of promoting positive outcomes for families.

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Chapter 1: Introduction

I definitely think that the beginning of the healing was the Pacific Post Partum Support Society. You know, I'd had a day when I was just crying, and I just, nothing was working, I couldn't. I was not functioning.

I couldn't even get myself up and I, so I just picked up the phone and I made a phone call and—talking about how I was feeling for the first time—things changed in that moment, you know.

Just because I hadn't talked about it at all, at all, none of it. I hadn't talked about being afraid of, you know, things might happen to my children. I hadn't talked about even how isolated I'd felt. I never spoken of the struggles that I was having. So the minute that I started talking about that, I feel like that was the beginning of it.

And then, with the support group, having time to myself with two hands, sitting with a cup of tea, was like a moment of self-care that I hadn't had in, in months and months. And being able to listen and hear other women tell their stories and, each story was different. But inside of each woman's story was a piece of my story. And so, hearing those stories being told, I didn't even have to talk. . . . I started feeling better in those moments.

And it, in that space also was a safe place to cry, which I hadn't done either. And that was, that was huge, just being able to just cry and cry. And sometimes I would come to group and I would sit and I, and that's all I would do would be listen and to cry. Because I couldn't actually talk because it had been a whole week of just pressure and stress. But that's all that I needed.

And I would leave feeling a hundred percent better because I just needed a safe space to do that. Hands free, with a cup of tea, crying my face out (she laughs). And it was awesome, you know, being able to walk away that way. So that was a big piece.

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. . . it wasn't that anybody specifically said, you know: you need to do this to get better. But it was: you can do things to get better. . . . Within the group it was just the idea that I was responsible for me and my own healing and that I, that I, that I, had the power within myself to do that; to take the steps that I needed to do.

So having suggestions but . . . [knowing] that I was, I was, that I was strong enough, that I could do that myself. And that I was the only one that could do, fix it.
—**Robin**[1]

Every week participants in Pacific Post Partum Support Society's (PPPSS) parent support groups share their personal experience narratives to make meaning of and heal from their perinatal mood and/or anxiety disorder, an event that is firmly situated in Dan Ben-Amos' classic definition of folklore as "artistic communication in small groups" (2000/1972). The 2013–2015 Pacific Post Partum Support Society's "Strengthening Community-Based Resources for Families Experiencing Perinatal Depression and Anxiety and Their Health Care Providers" project was designed to find ways to expand this model of support beyond the small group and one-on-one encounter in order to serve more struggling new parents. In this project, working with PPPSS staff, contractors, and volunteers, I used mixed research methods to create research-based educational resources and new services for clients and professional helpers. The overall project was designed to understand and to reduce the stigma of perinatal mood and anxiety disorders

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[1] View Robin's excerpt at: http://postpartum.org/videos/video/robin-helped-recovery-2/, accessed November 23, 2016.

(PMADs) and encourage struggling new parents to reach out for help earlier, when treatment is less expensive and more effective.

By analyzing the narratives of project participants, this dissertation also examines the multifaceted, pervasive, and profound impact of stigma on new parents' perinatal experience, especially those experiencing a PMAD. In addition, this dissertation documents how sharing narrative in a supportive environment can reduce isolation and promote healing, and how parents with PMADs can use personal narrative to make meaning of difficult perinatal experiences. This dissertation encourages additional applied folklore work to support struggling new parents and offers suggestions for how health care providers, community support workers, and friends and family members can better support new parents in the hope of promoting better outcomes for families.

My research was undertaken in metro Vancouver, British Columbia, and the surrounding area, including sites such as interviewees' homes, community centers, PPPSS's offices, and other worksites. This project was designed within Dorothy Noyes' conception of folkloristic practice as being composed of the trinity of ethnography, theory, and engagement in the world:

> The field cannot theorize without strongly grounded, in-depth ethnography of particulars. The field has no purpose without engagement in the world, trying to understand and amend the social processes that created the F-word [folklore] and other, far worse stigmas. Practice in the world has not lasting efficacy without theory to clarify its means and ends and make its efforts cumulative. (2008, 39–40)

This dissertation also attends to the call of many folklorists, including Henry Glassie, to give back to the communities that they work with in the way that serves such communities best. Therefore, my collaborators and I used folkloristic theory and methods to scale-up the

educational and support methods that PPPSS uses in individual and small group settings to support and educate much larger numbers of people through technological mediation.

In this dissertation I take advantage of the rich range of literature in public health, medical anthropology, and related disciplines on PMADs, with particular attention to those works which focus on social and cultural factors that impact the development of, impact of, and recovery from PMADs (e.g., Abrams and Curran 2009; Dubus 2014; Foulkes 2011). I will also make use of scholarship that explores the role of creating and sharing personal narrative in making sense of illness, promoting health and healing, and understanding and mitigating the effects of stigma in many disciplines, including folklore studies (e.g., Blank and Kitta 2015; Bock 2012; Briggs 2012; Hufford 1985, 1998; Goldstein 2015), sociology (e.g., Berggren-Clive 1998; Taylor 1996), and public health (e.g., Brown et. al. 2010; Corrigan et. al. 2007; Montgomery et. al. 2012; Morrow et. al. 2008). In this dissertation, I hope to augment and extend the work in these other domains and disciplines by considering similar issues, with a folkloristic lens, in the context of PMADs.

Methodology

My methodological choices were informed by the work of scholars such as Charles Briggs (1986), Edward (Sandy) Ives (1995), Joseph Maxwell (1996), and Valarie Yow (1995). Analysis of data from video- and audio-recorded interviews, audio-recorded focus group PPPSS's sessions, and online surveys that were conducted from 2013–2015 as part of PPPSS's "Strengthening Community-Based Resources for Families Experiencing Perinatal Depression and Anxiety and Their Health Care Providers" project. The core of the project data consists of fourteen video-recorded interviews with individuals and couples, two individual audio-recorded

interviews, and ten audio-recorded focus groups. The audio recordings have been logged,

partially transcribed, and coded as part of the project. Email messages and documents related to

the planning and implementation of the project are also used in this study, as well as data from

PPPSS's own internal evaluation methods.[2] The rights to these materials are held by PPPSS

(who obtained releases from the participants), and permission for my research use of this

material has been granted by PPPSS. The results of my dissertation will be shared with the

Society and is intended to help them in their work.

I also conducted semi-structured follow-up interviews with interviewees, staff, and

contractors who participated in the project. Interview topics discussed included, but were not

limited to: the participants' reflections on their participation in the project, their assessment of

the impact of the project, and accounting for what has occurred in the participant's life since

their participation. Interviews were conducted in person, either at the interviewee's home or at

PPPSS's offices, and were logged and transcribed as needed. Because of the peer-support nature

of this nonprofit, almost everyone involved as a staff member or contractor on the project also

had personal experiences of a PMAD (which sometimes only was revealed after they had been

involved in the project for a while) either by themselves or with someone very close to them.

This study does not include the experiences of people who did not receive treatment for

PMAD, or those who participated in PPPSS's programs but did not choose to share their

experiences in the project. In this way, the subjects are self-selecting and this necessarily limits

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[2] Any personally identifying information in the data from internal evaluation methods has been removed and no individual experiences have been cited from that data that was generated prior to the start of this project.

the conclusions not to all people experiencing PMAD, but to the people who chose to be involved in the type of treatment program that encourages sharing their stories one-on-one or in a small group, and then, of those, people who chose to make their story known to others in a variety of levels of publicness: from filling out an anonymous survey to being video interviewed and having edited segments posted publicly on the web. Therefore, throughout this dissertation I will to be mindful of the particular nature of this study population and be careful when drawing conclusions that may apply beyond this particular group. The limitation is further contextualized by the recognition, especially in folklore studies, that talk about the self is a highly variable matter when seen in cross-cultural perspective. Individuals who live in North America and are part of the Euro-American/Canadian culture (who may or may not also be part of other cultural worlds) tend to find it helpful and satisfying to talk about themselves and their own experiences in a variety of contexts. Therefore, the possible broader conclusions of this research are also limited to the context of the Euro-American/Canadian cultural norms. In addition, many components of the applied folklore project discussed in this dissertation are built upon the power that telling and listening to personal narratives may have to increase understanding of, reduce stigma around, and promote healing for those with PMADs. My hope is that this dissertation will inspire future applied folklore projects, but it is important to note that the approach to personal narrative that was so critical to the success of this particular project are specific to the time and place of early twenty-first century Euro American/Canadian culture and may or may not be useful in other times, places, and communities.

History of Perinatal Mood and Anxiety Disorders

As Nancy Theriot (1990, 1993) discusses, mental illness, including mania and depression, has been connected in the Western world to the time of pregnancy and childbirth since at least the nineteenth century. At the time, Western physicians believed that insanity of pregnancy, insanity of lactation, and puerperal insanity, a set of psychiatric disorders associated with the perinatal period, accounted for about ten percent of asylum admissions.

Insanity of pregnancy was thought to be the least common of the three and most commonly involved symptoms of depression, ranging from low spirits to suicidal thoughts, and most often occurred with first pregnancies. Symptoms were thought to resolve within a few weeks, or at least with childbirth, and the disorder was rarely fatal. Insanity of lactation had similar symptoms to insanity of pregnancy, but was thought to be more common in women who had several children; it could end with life-long mental illness but was most often resolved within six months (Theriot 1990).

Puerperal insanity was the most common diagnosis and was associated with mania, which manifested with symptoms such as a general state of excitement, aversion to her spouse and child(ren), constant talking, sleeplessness, refusal of food, meanness, and obscenity. It usually began within fourteen days of childbirth, but sometimes manifested later. In most cases symptoms resolved within a few months, and treatment by the second half of the nineteenth century was rest, feeding, restraints or sedation if needed, close monitoring, and separation from her family and friends.[3] For all of these illnesses, the cause was thought to be a medical disorder

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[3] Although I am not a medical doctor, it seems that in severe cases, puerperal insanity was likely postpartum psychosis or severe postpartum anxiety. In milder cases it was probably postpartum anxiety.

of the body or reproductive organs, or as a result of the process of pregnancy or giving birth. Social or cultural factors were not considered relevant as a cause or component of effective treatment (Theriot 1990).

By the 1950s, psychiatric theories of mental illness were dominant and mental illness specifically connected to childbirth was no longer a distinctive diagnostic category in the American Psychiatric Association's *Diagnostic and Statistical Manual* (DSM). At least officially, childbirth and postpartum were not seen to be a particularly dangerous time for women's mental health. However, by the 1980s, mental illness connected to the perinatal period began to be discussed again, and several early studies showed that 50–80 percent of new mothers experienced a brief episode of baby blues, moderate depression occurred in 10–20 percent of women, and severe mental illness (including psychosis) in 1–2 percent (Taylor 1996). Postpartum depression was added to the DSM-V in 1994 as a modifier to major depression (rather than as its own disorder).[4]

I find it interesting that it was the most commonly diagnosed form in the nineteenth century (Theriot 1990), as currently this level of symptoms is thought to be fairly rare in the continuum of perinatal mental illnesses (Fairbrother, Janssen, Antony, Tucker, and Young 2016). Perhaps, just as today, in the nineteenth century milder symptoms of anxiety were thought to be signs of a properly vigilant and caring mother.

[4] Postpartum depression remains as a modifier to major depression, rather than its own disorder, in the DSM-V, despite efforts to change it by patient advocacy organizations such as Postpartum Support International (PSI) (American Psychiatric Association 2013, Serge and Davis 2013). The current diagnostic definition requires that onset be within four weeks postpartum, a situation that does not fit with many parents' experiences (especially non-birthing women and men). Also, currently major

Starting in the mid-1980s, postpartum depression began to be talked about in the popular media. In May of 1986, Glen Comitz, the husband of Sharon Comitz, who was in prison for infanticide, appeared on the *Phil Donahue Show* to spread awareness about postpartum depression and the need for treatment.[5] By the mid-1990s awareness of postpartum depression began to increase, especially fueled by celebrities' public disclosure of their own experience with the illness, including Princess Diana (in a widely seen 1995 television interview), Marie Osmond (in her 2001 book), and Brooke Shields (through her 2005 book and associated media activities, including an appearance on the popular *Oprah Winfrey Show*).

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depression, with postpartum onset, and psychosis, with postpartum onset, are the only mental health conditions officials recognized as related to pregnancy and postpartum in the DSM-V. However, the description of postpartum depression acknowledges that it often occurs in pregnancy and is co-morbid with anxiety. PSI and other individuals and organizations are also working to include the postpartum onset specifier for anxiety disorders, obsessive disorders, and hypomania, which will provide crucial diagnostic and treatment guidance, as well as to formally acknowledge that these condition can manifest during pregnancy (Serge and Davis 2013).

[5] Although her crime was preceded by a severe depression that was not properly treated, it seems Sharon Comity committed her crime during a psychosis, a state in which she was disconnected from reality, and not just a depression. However, a brief scan of articles about the case reveals headlines about the case such as "Women who kill their babies a bad case of 'baby blues'?" from the May 10, 1988, edition of the *Washington Post*. These headlines reveal that lack of understanding of the difference at the time. Although there has been some improvement in how the media and medical establishment present these stories, the problematic lack of distinction between psychosis and depression persists.

In recent years, the number of prominent women (such as actresses Drew Barrymore, Hayden Panettiere, and Gwyneth Paltrow) who have disclosed their own experiences of PMADs continues to grow. Such individuals have often expressed their motivation as hope to reduce stigma and encourage others to reach out for help. In addition, there is a thriving community of mommy bloggers, such as Bunmi Laditan (who entered the public online world tweeting anonymously as the "Honest Toddler") and Janelle Hanchette (at Renegade Mothering), who have disclosed their own struggles with perinatal mental illness, have actively campaigned for those suffering to reach out and access help and support, and have made their status as someone who has had a PMAD a key part of their online personas.[6]

Perinatal Mental Health Conditions

Perinatal includes the time surrounding the birth, including pregnancy, the birth, and after the birth. Difficult feelings after birth exist on a continuum, just as many other personal experiences and cultural phenomena do. Some of these conditions, such as baby blues and a difficult/stressful adjustment to parenthood, are not mental illnesses but can develop into one if the person who is experiencing them has other risk factors or is not well supported. The most common mental health conditions that appear during the perinatal period are depression and anxiety. They are

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[6] In 2016 blogger and Honest Toddler creator Bunmi Laditan began posting as herself about her mental health and parenting challenges on Facebook (Hatfield 2016). One of blogger Janelle Hachette's posts on PMADs can be found at www.renegademothering.com/2014/09/27/hey-new-moms-ive-thought-terrible-things/, accessed September 1, 2016.

separate conditions but often appear together (Fairbrother, Janssen, Antony, Tucker, and Young 2016).

Table 1. Continuum of Difficult Feelings for Women in the Perinatal Period[7]

Condition	Symptoms	When it appears	Prevalence
Baby blues	May have feelings of sadness, anger, anxiety, and fatigue.	Within the first two weeks after birth or adoption.	60–80 percent.
Difficult adjustment	Similar feelings to baby blues, but persists beyond a week.	During pregnancy or up to a year or more after birth or adoption.	Unknown.
Postpartum depression	May have feelings of failure, guilt, despair, anger, lack of interest in life, numbness, fatigue, suicidal thoughts, and many others. Sleep and appetite may be disturbed.	Can appear during pregnancy, or up to a year or more after birth or adoption.	4 percent in pregnancy. 4.8 percent postpartum.
Postpartum anxiety	May have feelings of persistent worry, intrusive thoughts, anger, irritability, panic, muscle tension,	Can appear during pregnancy, or up to a year or more after birth or	15.8 percent in pregnancy. 17.1 percent

[7] Table adapted from PPPSS's *Postpartum Depression and Anxiety: A Self-Help Guide* (2014). For a more extensive description of the signs and symptoms of postpartum depression and anxiety in plain language see Katherine Stone 2009, among others.

fatigue, and many others. Sleep and appetite may be disturbed. May be overly attentive to baby.	adoption.	postpartum.

The prevalence rates of postpartum depression and postpartum anxiety were taken from Nichole Fairbrother and colleagues' 2007–2010 study of mothers in Vancouver, British Columbia, which was the first study of prevalence to attempt to clearly differentiate between the two conditions (Fairbrother, Janssen, Antony, Tucker, and Young 2016). Depression and anxiety can also occur together, with 5 percent of study participants experiencing the two conditions at the same time, or can alternate with episodes following each other.[8] Although the American Psychiatric Association's DSM-V of "depression with peripartum onset" indicates that the depressive episode must occur during pregnancy or within four weeks after the birth, "clinical experience in British Columbia has shown symptoms can appear anytime up to one year postpartum" (British

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[8] Earlier studies estimated an incident rate of major depression from 5–16 percent in pregnancy and 9–31 percent in the first year postpartum. Earlier studies found a 1.3–8.5 percent rate of generalized anxiety disorder during pregnancy and 4.4 percent–8.2 percent rate in the first year postpartum (BC Reproductive Mental Health Program, Perinatal Services BC, BC Ministry of Health. 2014b). However, Fairbrother and colleagues' robust methodology seems to bear out the anecdotal evidence from PPPSS counselors and area clinicians: that earlier studies may have been misdiagnosing individuals who really had anxiety with depression, and missing other individuals with anxiety. In the clinical world this situation also has implications in that PPPSS clients informally report that it was more difficult to receive a diagnosis of perinatal anxiety than perinatal depression.

Columbia [BC] Reproductive Mental Health Program, Perinatal Services BC, Provincial Health Services Authority, BC Ministry of Health 2014a, 18).

There is much less research about prevalence of perinatal depression and anxiety in men, and none that clearly separates depression and anxiety. James F. Paulson and Sharnail D. Bazemore's meta-analysis of available data indicated that approximately 10 percent of new fathers experience depression and/or anxiety after the birth of a child, with approximately 25 percent of those occurring three to six months after birth, and that the prevalence is moderately correlated with a partner with maternal depression (2010). It's also beginning to be recognized that transmen, transwomen, and non-gender binary individuals can experience PMADs. There has been much less research about common symptoms, prevalence, and best treatment practices for these populations.[9]

Although the prevalence rate is unknown, the number of individuals who experience a difficult adjustment to parenthood, without reaching the clinical standards for depression and/or anxiety, seems to be significant. For example, PPPSS receives many calls from parents who are having a hard time coping with the stress and exhaustion of caring for an infant. Sometimes the individual has a mental health condition that requires professional treatment, but sometimes they just need to speak with someone who understands what it is like to be exhausted, be reassured that they are not the only one who finds this time really difficult, and perhaps come up with a plan for support from family, friends, and professional helpers. Often this is the only time that they talk to a PPPSS counselor, because simply knowing they are not alone in their feelings and

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[9] Perhaps because there is not a strong hormonal component, men and non-birthing parents tend to develop PMADs later during postpartum.

learning a bit about what might help is enough. Chi, who immigrated to Canada from China,

described her experience with what might have either been a difficult postpartum adjustment or

mild depression:

> So me I have two daughters. My first one, of course [I had] not much information how I can conquer my feeling and I'm not sure [if it] was postpartum or what.
>
> And a couple of months later, I encourage myself just get out of house, this moving around. And then I went to the library and then found out too there is like a kids story time. So I tried to go in there, tried to you know, [get] out of my mind. Fresh, freshness. And then I get the information about Family Centre. And then going to the Family Centre, lots of mum there, and [we ask] some questions. We exchange information and then [the mums] help one another figure [things] out: oh, that really helped.
>
> So second pregnancy, [I] just like figured out: just to go to the family places, something [like that], almost every day. I know the spot where you can go, so everyday go out, and I conquer this feeling.

In Chi's case, when she was able to get out of the house, spend time with other people, and

access some support from other mothers, she started to feel better. However, moderate-to-severe

depression and anxiety does not tend to get better by just getting out of the house. Instead,

professional treatment and intensive support is likely required. Some individuals have a dramatic

and obvious onset of the symptoms of a PMAD. Video interviewee Linda was being treated for

intense anxiety during her high-risk pregnancy and experienced a difficult labor and delivery.

She felt taken care of by the doctors and nurses while in the hospital after giving birth, but:

> I knew once we went home it would be just me and the baby alone and that scared me, that just frightened me. I've never taken care of a baby before. This is my first one. . . .
>
> So I remember I thought I was fine until I woke up the next morning and all I wanted to do was just cry. And I did. I just cried and cried and cried and cried. And I was being loud about it too, like I wanted everyone to know in the house that I wasn't okay. And it was like, you know, the next day back. And I remember family coming in, they just didn't know how to respond and they didn't know what to say to me, you know. Even though I had prepared everybody that the

likelihood was high that I might experience this. So I didn't think it was the baby blues, I remember reading about it, but it wasn't the baby blues because I had a lot of panic in me.

So I think what I was almost experiencing was a huge panic attack. But I didn't understand what was going on with me physically. Mentally all I knew was that I was really sad and feeling desperate and scared. So I had family stay with me for the first couple of days but then they left and (long pause) and then it was just me.

Others have a much quieter beginning of symptoms, and thus might be less likely to seek or be offered help. Before their daughter was born, Mariko and Kasimir were unaware of the possibility of PMADs. After the birth of their daughter, Kasimir thought that his wife, Mariko, would just start to feel better and that he just needed to wait it out:

Yeah, it's all clear now [that Mariko had a severe depression]. But at the time, it was far from clear. And it was just: what's going on here? From day to day [I would think] Mariko was not having a good day today: maybe tomorrow will be better. But then days led to weeks to months, and that didn't happen. So, it was, it was quite a thing. It's easy to talk about now. But at the time it seemed like this would just take care of itself and it doesn't require any outside intervention kind of thing.

I remember from some of the statistics of new mums that go through this it's quite a large number. And I was kind of shocked by that. I guess that comes back to the perception or what we know about postpartum depression. Before we hear about it, it just seems like something that happens to someone else, and it's just something in the minority. But it turns out that it's quite prevalent. So don't feel like you're unique in this. So try to talk to other people and, and try to support your partner and help them get the support they need.

Untreated PMADs may have poor outcomes for parents and their children, but with treatment most families have good outcomes. And the earlier that treatment is begun, the better the chances of a good outcome (BC Reproductive Mental Health Program, Perinatal Services BC, Provincial Health Services Authority, BC Ministry of Health 2014a).

Postpartum Psychosis

Postpartum psychosis is a loss of contact with reality for periods of time and it is a medical emergency. It is limited to women who have given birth (because it is triggered by hormonal changes after the birth) and often gets confused with postpartum depression and anxiety. Postpartum psychosis begins very quickly, usually within the first few weeks after birth, but sometimes later. However, unlike perinatal depression or anxiety, postpartum psychosis is extremely rare, only affecting about 0.1 to 0.2 percent of new mothers. Because hormonal changes are part of the trigger for the onset of postpartum psychosis, it does not affect men or non-birthing women. While a mother with perinatal depression and/or anxiety may have scary intrusive thoughts of harm coming to her child, she understands that they are not rational and is distressed by having them. She is no more likely to harm her child than any other mother.

However, a mother with postpartum psychosis will often leave reality. She will do things that do not make sense to others, but she will insist that they do. The majority of time, these are harmless things like believing that the radio is sending her personal messages. However, because a person experiencing psychosis is experiencing hallucinations and delusions, these can manifest in dangerous ways. For example, she may develop strong feelings that it is a good idea to harm herself or her children. That is why it is important to always seek immediate medical attention if a woman is showing signs of postpartum psychosis. Risk factors for postpartum psychosis include a personal or family history of bipolar, or a previous psychotic incident.[10]

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[10] For more information on postpartum psychosis, see PSI's web resource at http://www.postpartum.net/learn-more/postpartum-psychosis/, accessed August 1, 2016, among others.

When mothers harm themselves or their children in the immediate postpartum period,

horrific events that are reported in the media because they are dramatic and rare, the person

involved was often experiencing a psychosis. It is also important to note that only 4 percent of

women with *untreated* postpartum psychosis will commit infanticide, so although this is a

serious risk, infanticide is a still rare event even when mothers have postpartum psychosis

(Altshuler, Hendrick and Cohen 1998).

Related Perinatal Mental Health Conditions

The universe of perinatal mental health conditions has grown as the field's understanding has

grown. PPPSS focuses on the treatment of perinatal depression and anxiety, as these are the most

common perinatal mood and anxiety disorders and those in which they have expertise. However,

many of their clients are also experiencing another mental health condition that may be pre-

existing (and, especially if it is un- or under-treated, may lead to the individual also experiencing

depression and/or anxiety) or have a perinatal onset. The most common of these are obsessive-

compulsive disorder (OCD, which about 10 percent of new mothers will experience as a

perinatal onset), posttraumatic stress disorder (PTSD, which about 7–16 percent of new mothers

experience as a perinatal onset condition), and bipolar disorder (which about 2.9 percent of new

mothers experience as a perinatal onset condition).[11]

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[11] There has been less research about the prevalence of these types of conditions among new fathers, but

there is a growing body of literature in particular about the risk of developing PTSD from observing a

traumatic birth as a birthing or a non-birthing partner and having a baby with a severe health problem for

either parent (Harvey and Pattison 2012; Lefkowitz, Baxt, and Evans 2010).

Intrusive Thoughts

One of the most distressing and misunderstood symptoms of perinatal mood and/or anxiety disorders are intrusive thoughts. Because mothers who kill their infants are often portrayed as having postpartum depression in the media (although it is much more likely that they have postpartum psychosis), parents may be afraid that if they reveal they are feeling depressed they will be perceived as a potential child abuser, be reported to social services, and risk having their children taken into foster care.

Intrusive thoughts are very vivid thoughts, often described as a picture coming in a flash, of something that is often deeply distressing and unpleasant to the person experiencing them. Everyone has thoughts that just seem to come into one's head, but when the thoughts are disturbing because they do not fit with an individual's value system they may seem to linger and may be given a lot of importance by the person experiencing them.

For example, a person might think, while driving down the highway: What would happen if I just drove into that median? If the person just lets the thought pass by and does not give any meaning to it, then they might not ever really notice it. But, if the person who had this thought is worried that they will actually act on the thought and drive into the median, or is worried about what it says about their personal character and mental health if they are having a thought like this, then the thoughts can be extremely distressing. Having unpleasant intrusive thoughts alone does not cause someone to act on them. In fact, most people find them very distressing and

unpleasant, know what is happening in the thought is "wrong", and thus would be very unlikely to act on them. [12]

In their 2008 study, Nichole Fairbrother and Sheila R. Woody found that by four weeks postpartum, every new mother in their study reported experiencing unwanted thoughts of accidental harm coming to their infant and nearly half reported unwanted thoughts of intentionally harming their infant. By twelve weeks postpartum, 95 percent of participants reported they had experienced such thoughts in the previous week, and 19 percent reported unwanted thoughts of intentionally harming their infant. Therefore, experiencing at least some intrusive thoughts about harm coming to your child is a nearly universal experience for new mothers.

For new parents, intrusive thoughts often revolve around harm coming to their baby, such as the baby falling down a staircase. These types of thoughts can be very upsetting and the person may be reluctant to speak about them publicly for this reason alone—that is, they just can't go back there. These thoughts also can cause a lot of guilt: "I must be a terrible parent if I am thinking about my baby getting hurt." In addition, parents may have intrusive thoughts that focus on them accidentally causing harm to the baby, that is, they drop the baby down the stairs. These

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[12] In almost all cases when a new parent acts on strange thoughts and does harm to themselves and/or their children, they are experiencing a psychosis and thus are disconnected from reality. Therefore, they themselves may not realize that the thoughts are strange and may not be distressed by them. This is one reason why psychosis is a medical emergency. However, new parents and their families and care providers who do not understand this important distinction can mistake intrusive thoughts for indications of psychosis.

are often even more difficult to talk about, because in the thought the parent failed their baby in possibly the most fundamental way possible: keeping them safe. Finally, perhaps the most difficult type of thought to talk about are the ones that focus on the parent deliberately harming the child, such as the parent throwing the baby down the stairs. Participants in Fairbrother and Woody's study rated intrusive thoughts of intentionally causing harm to be more upsetting and to cause greater feelings of guilt than other types of intrusive thoughts. Parents who experienced these types of thoughts at twelve weeks postpartum reported higher levels of parenting stress and lower levels of social support. The study authors note it is not possible to know causation with this study design.

For interviewee Linda, when she experienced intrusive thoughts, she was afraid that they indicated that she had postpartum psychosis:

> Because my perception of postpartum depression was what I knew from the media, and I think that's generally speaking most people's perception. [We hear about] the extreme cases of the mother doing harm to the child or the baby. And so, I understood that that was psychosis, that's the extreme end and it's very rare, right? But I was having these crazy thoughts, was what I called them. I didn't understand intrusive thoughts until later on, what they were. I called them my scary, crazy thoughts. Scary thoughts, right? . . .

> And I just remember my scary thoughts were flashes of images in my mind while I was awake, that I had no control over. . . . like I'd see him rolling out of my hands and I'd see like, you know, the blood and everything, they were just awful images. And as a mum you're scared that you're having these images, right? Because you're thinking: Ok am I going through psychosis? That's what I kept thinking: is this psychosis? Right? Am I going through that rare part of postpartum that's psychosis?

Because she didn't understand what these thoughts were, Linda was afraid to tell anyone that she was having them:

> I was scared, I didn't even tell my husband about it because I didn't want him to judge me and I didn't want him to think that there was something wrong and then him tell somebody.

> And these scary thoughts were probably the worst part of the postpartum because I was always worried. I didn't even want to tell my doctors about them because I was worried that if I said something that they would feel an obligation to have to protect my son. So that they would have to report it to the Ministry. So I remember keeping these thoughts to myself. And trying to work through them and say: Ok, you know what, I have control, I have control. You know, these are just thoughts. I'm not actually going to act on them. I'm not going to do anything. They're just scary thoughts that go through into my mind.

Like Linda, many project participants found that one of the most difficult and disturbing symptoms of postpartum was intrusive thoughts. For many, an important part of recovery was learning about intrusive thoughts. As focus group participant Valerie stated:

> Even to be able to define what an intrusive thought is. (Agreement from other group members.) Like. I had no idea. I just thought I was crazy. (Yeah.) And then when we started talking about it I was like: Oh. there's a language around this. Oh, and all these other women. Oh. Like: I'm not a mental case. It was very helpful.

Many PPPSS project participants reported that one of the things that helped them most to cope with their intrusive thoughts was to just know that what they were and what they meant.

Pregnancy, Birth, and Postpartum in Metro Vancouver, British Columbia

This project was conducted in the metro Vancouver area of British Columbia (BC), an area that is composed of the city of Vancouver, as well as its suburbs and some outlying areas.[13] In order to provide important context for this dissertation, I will briefly touch on the landscape of pregnancy, birth, and postpartum in this geographic context. In many ways, metro Vancouver is

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[13] The area considered metro Vancouver is defined by geographic and political boundaries: the Salish Sea in the west, mountains in the north and east, and the US-Canada border in the south.

a resource-rich and service-rich place to give birth. It is part of a first-world country, Canada, that has a robust medical system, a system of single-payer provincially funded health insurance that pays for almost all medical costs related to pregnancy and birth (in BC this is the Medical Services Plan, commonly known as MSP). Parents may choose to be cared for by a family doctor who delivers babies, an obstetrician (OB), or a midwife.[14] They can chose to give birth in a hospital, supported by any of those clinicians, or (if they are low-risk) to have a home birth with a midwife. There are also significant resources and facilities available in the metro area to care for those with special medical needs or who have a high-risk pregnancy, as well as to care for infants with health conditions. At the six-week mark, care is transferred back to the woman's own general practitioner (GP).[15] The province also has a robust public health program for providing care in the community to pregnant and postpartum women, as well as to infants and young children, delivered through five regional health authorities and two provincial health authorities (Perinatal Services BC, 2016). [16]

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[14] In order to be covered by provincial insurance, midwives must be a registered member of the College of Midwives of British Columbia (http://cmbc.bc.ca/routes-to-registration/career-as-a-midwife/, accessed November 24, 2016).

[15] General practitioners (GPs) are in short supply, so for many women their GP is the head doctor of a walk-in clinic (who they have probably never met) who supervises a large group of doctors who serve the clinic, rather than a particular doctor or even group of doctors.

[16] The two province-wide health authorities in British Columbia are First Nations Health Authority (which provides culturally appropriate health services to First Nations, Metis, and Inuit individuals) and Provincial Health Services Authority (which provides specialized services, such as high-risk maternity care). For a description of Vancouver Coastal Health's services for pregnant women and families with

The province provides many information sources that are made available to help guide new parents, including dedicated publications like *Baby's Best Chance: Parent's Handbook of Pregnancy and Baby Care* (BC Ministry of Health, Healthy Families BC 2005) and funds such efforts undertaken by community organizations. For decades in BC, public health nurses made home visits to new parents in the first few weeks after they had given birth in order to check on the health of the family and to provide information and support. However, in 2012 funding for the program was cut and all new parents now receive a phone call to assess their health and risk level (CBC News 2011). Based on the results of this phone call, those deemed at risk are given a home visit. Public health nurses also conduct weekly drop-in parent–baby groups in a variety of locations, immunizations clinics, as well as programs targeted to particular groups who are seen as more at risk for health and social difficulties (Perinatal Services BC, 2016).

Becoming pregnant and delivering a child, or adopting a child, is one the most significant life changes for most people who experience it. Many project participants felt that health care practitioners as well as family and friends gave a lot of attention to the process of pregnancy and delivery. After the birth, they felt that a lot of attention was paid to the health, growth, and development of the newborn child, but that very little concern was shown for the emotional, physical, and spiritual process of becoming a parent to this newborn child. The collective focus tends to be on caring for the newborn, with often very little attention paid to caring for the parents (or to encouraging them to take care of themselves). In addition, participants felt the burden of high expectations about parenting, both from themselves and from those around them.

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children aged five and under, see http://www.vch.ca/your-health/health-topics/public-health-nurse--prenatal-to-5-years-/ (accessed November 24, 2016)

The impact of these expectations will be discussed extensively later in this dissertation, but in just one example, focus group participant Penny, who was an immigrant from China, stated:

> And the expectations I already have being a mum. I thought: yeah I will be happy, content and that, you know, [I have] two beautiful healthy girls. I should be able to get my cleaning done, change their diapers, do their bath, feed my husband, get his lunch packed, you know laundry done, the house should be kept in shape, you know the ideal home (others in group murmur agreement).
>
> But, it really can't be done and I had to really learn that I can't do that. I could barely get myself showered by the end of the day (light laugh). So like if I can have a five-minute shower I'm good.
>
> So, it's the expectations of other people, the expectations of myself, and what the society is as a whole. I couldn't see where I can actually meet those. And I have to really lower [those], dial back, and just not think.
>
> Okay, you know what? They have some food in their stomach. That's good enough. I've got them to enjoy at least a piece of toast (light laugh). Things like that, I have to really dial it down

For Penny, it was important to learn to lower the expectations that she and others had around daily life and parenting in order for her to feel happy and successful.

Many people living in metro Vancouver were not born in the area. At the time of the 2011 census, 15.8 percent of residents were born in Canada, but outside of British Columbia, and 42.3 percent were born in another country.[17] Therefore, a total of 58 percent of metro Vancouver

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[17] Data is taken from the 2011 census (Statistics Canada. 2011). For the purposes of this discussion, in my category of immigrants I have included individuals that the census designates as immigrants, which are individuals who have, or have ever had, permanent resident or landed immigrant status. These individuals may or may not currently have Canadian citizenship. A few of these individuals were born in Canada, but most were not. I have also included individuals that the census labels as non-permanent residents under my label of immigrants. This census category includes individuals who are legally in

residents were born outside of British Columbia. Although some moved there as children, 75.2 percent of permanent residents living in British Columbia in 2011 immigrated to Canada at age fifteen or older.[18] In addition, 9 percent of immigrants living in metro Vancouver came to Canada within the past five years.[19] Furthermore, anecdotal evidence from PPPSS clients indicate that it is not uncommon for new parents to move during pregnancy or in the early days of postpartum, for reasons such as moving into a larger home.

For example, video interviewee and Mexican immigrant Maria has just moved to Richmond from another part of metro Vancouver during her pregnancy. In her interview, she spoke about the difficulty of adjusting to life in a new part of the metro, as well as feeling unsettled because her new home was still being renovated when her son was born. In addition, she thought she had adjusted to living in Canada, but once she had her first child, everything changed:

> Even though I had been living in Canada for five years, back then, for me it was like feeling new in the country. Like a newcomer again because all my friends: they didn't have any babies. So I was new in Richmond. I was new as a mum.

Canada but only have temporary resident status. They may, or may not, intend to apply for permanent resident status when they are eligible.

[18] 8.2 percent of permanent residents arrived before age five, 16.6 percent arrived between the ages of five and fourteen, and 75.2 percent arrived when fifteen or older. I was unable to find the age of arrival for non-permanent residents in available census data.

[19] The number of metro Vancouver residents who came to Canada in the past five years is my estimate. I have included landed immigrants who arrived in the past five years plus non-permanent residents. Although the residency rules are complex, because non-permanent residence is intended to be a temporary status the majority of temporary residents have either left Canada or received permanent residency within five years of arriving.

And I didn't have any friends with babies. So for me is like: okay, where do I go? Where do you go with a six-month-old baby? Who do I talk to, what do I talk about? All these questions, right?

Finding a place to call home and receive support is important. Maria continued to describe how she found a new community:

And you're, you're afraid of your new experience as a mum. You want your baby to be fine at all times and you also want, you need to socialize, you need to go outside, right? So I forced myself to go out and I heard about the Richmond Family Place. And I have to say it's been so, so extremely helpful, that place for me. I could say I found the family that I didn't have at the Richmond Family Place.

Focus group participant Kenia, an immigrant to Canada from Cuba, did not experience a PMAD. She talked about all the sources of support she had during the postpartum period.

I have a lot of support [from my husband]. Even he was working most of the time, he was calling me all the time during the day. . . . My husband supports me a lot. So I have my time to do my manicure, my hair, my exercise, he take care of my son. And I have a day to go to my friend for the tea or for some conversation. Just give my time for one hour, this is my time. I no worry about the food, the baby, nothing. That's very important.

And I have a good friend here and she has a baby too, around three years older than my son and we have a great communication. Sometimes we talk about feelings. So I also have friendly support from here [at South Vancouver Family Place] and also the [Healthiest Babies and Strong Start] groups are very helpful. Yeah and [sharing] the experience with all these other mums is very helpful.

Kenia attributed her successful adjustment to parenthood in part to the extensive physical and emotional support she received from those around her.

Reproductive Mental Health Care in British Columbia

Compared to many other areas in and out of Canada, metro Vancouver is resource-rich in reproductive mental health care, at least for mothers who speak English.[20] As detailed in the Ministry of Health's 2006 report, "Addressing Perinatal Depression: A Framework for BC's Health Authorities," and recently reaffirmed in a 2014 position statement, the current guidelines in British Columbia are that all women should be screened with the Edinburgh Postnatal Depression Screening Scale (EPDS) between twenty-eight and thirty-two weeks of pregnancy and again at six to eight weeks postnatal, with the caveat that if such screening is done, there must also be systems in place for referring women to appropriate diagnosis and treatment.[21] In British Columbia, both primary care providers and public health nurses conduct these screenings. It is important to understand that the EPDS is just a screening tool, which means that it assesses the likelihood that a person would be diagnosed with depression (which should be done through

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[20] Non-English speakers are certainly underserved in metro Vancouver by reproductive mental health care programs, as well as by the services available through non-profits such as PPPSS (Morrow, Smith, Yuan, and Jaswal 2008). In British Columbia, men are not eligible for public reproductive mental health care, which is limited to women. Instead they must rely on their GP and the general public mental health system (which has even longer wait lists than reproductive mental health for access to mental health specialists), or pay for private care.

[21] In informal conversation with health care providers and support workers, as well as from feedback from project participants, it also seems that an additional screening later in the postpartum period would be helpful in diagnosing cases that might be currently missed. In addition, as the work of Nichole Fairbrother and her colleagues has shown (2016), the EPDS is a less effective tool for screening for perinatal anxiety than perinatal depression.

a diagnostic interview by a qualified mental health professional). However, because of the long wait lists, many individuals who screen as very likely to have depression are instead immediately offered antidepressant medication by their primary care provider and then wait for further help.[22]

In 2005 the BC Ministry of Health launched a strategic initiative to strengthen maternal and perinatal care, including care for perinatal depression (BC Reproductive Mental Health Program, BC Ministry of Health, 2006). Since this time, there have been many initiatives that have improved understanding of, and resources for, PMADs in BC. However, wait lists for treatment are still several months long for most services, and not everyone has a positive experience with the care that they are offered. In addition, perinatal mental health services in rural areas are still limited, and many populations, such as immigrant mothers, remain underserved (BC Ministry of Health 2015; Morrow, Smith, Yuan, and Jaswal 2008).

In metro Vancouver, psychiatric care for PMADs is available through specialized programs in reproductive mental health. British Columbia has a province-wide program for Reproductive Mental Health (BCRMH).[23] Primarily housed at BC Women's Hospital in Vancouver, the

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[22] In BC, medications are not covered by MSP. Low-income individuals qualify for some coverage of medications under the PharmaCare program and many working individuals and their families have some coverage through workplace extended health insurance programs (http://www2.gov.bc.ca/gov/content/health/health-drug-coverage/pharmacare-for-bc-residents, accessed November 24, 2016).

[23] Since 2008, BC Reproductive Mental Health has been part of the larger BC Mental Health and Substance Use Services, an agency of the Provincial Health Services Authority (PHSA). Along with five geographically based health authorities, PHSA was created in 2001 by the Ministry of Health to house specialized province-wide health services (http://www.bcmhsus.ca/history). Prior to that time, the

program provides outpatient and inpatient care, provides educational resources for patients and clinicians, and supports an active research program. They also have affiliated reproductive mental health programs at the following hospitals in metro Vancouver: St. Paul's (Vancouver), Richmond, Royal Columbian (New Westminster), and Surrey Memorial. The rest of the province is only served by a site at Victoria General Hospital (on Vancouver Island) and at Kamloops Perinatal Support Services (in the southern interior region). In the rest of the province, individuals with PMADs must rely on available general mental health resources or their GP, OB, or midwife.

Treatment may consist of medication, but in the context of PMAD, addressing the life factors that led to the onset of condition is almost always required. Common options include, but are not limited to: individual or group talk therapy, individual or peer group support, and increasing exercise. Talk therapy, either in a group or individual setting, is only covered by the provincial health insurance program (MSP) if it is accessed by referral through a provincial mental health clinic (in which demand far exceeds supply). Other women, who have the private financial means or some coverage through a workplace extended health program, can access private psychiatric or psychological care and talk therapy without long wait lists. Most individuals find that such treatment is only part of the answer to recovery from a PMAD. They also find they must address other factors in their life that contributed to developing a PMAD. The development

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program was known as Women's Reproductive Mental Health and was a service of BC Women's Hospital (https://reporductivementalhealth.ca/, accessed October 15, 2016). As Province-wide resources, BC Women's Hospital and Perinatal Services BC are also agencies under PHSA (http://www.phsa.ca/our-services, accessed October 15, 2016).

of PPPSS as an organization came out of this holistic orientation towards care of individuals

experiencing a PMAD.

PPSSS's Organizational History and Model of Care

The organization that conducted this project was PPPSS, which has been supporting families

experiencing perinatal distress and PMADs since 1971. The organization's mission is to end the

isolation, distress, and stigma experienced by many women with the profound life change that

accompanies the birth or adoption of a child. As a nonprofit, charitable organization, PPPSS

provides a variety of free or low-cost programs to clients, including:

- Toll-free telephone support five days a week for parents, as well as their supporters

- Seven weekly support groups for mothers in the metro Vancouver area

- Educational programs for partners and other family members

- Information resources in English and seven other languages

PPPSS's focus is on helping new parents engineer their own recoveries by emphasizing self-care,

coping and anger management skills, and healthy life choices. The organization conducts

hundreds of talks about adjusting to parenthood at parent–baby groups, conducts online and in-

person training workshops for volunteers and professionals, and has an array of English-

language self-help and professional publications.

Organizations like PPPSS fill a gap in the medical system. As David Hufford argued, one of

the reasons patients turn to unconventional treatments is that:

> Medicine does not and cannot provide everything that sick people and their
> families need. The point is not, as conventional wisdom usually assumes, to find
> out which things work and incorporated them into medical care and then stamp
> out the remainder. The point is to recognize the cultural position of medicine as

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> one of the many resources for dealing with sickness and to find ways to help
> medical personnel work gracefully with other resources instead of trying to
> capture sickness and death as the official domain of officially sanctioned
> professional experts. These alternatives are not all quackery and their use is not
> irrational. (Hufford 1998, 305)

In addition, individuals often face a wait of several months to receive reproductive mental health care in metro Vancouver (which is actually less of a wait than most individuals experience for non-reproductive publicly funded mental health care), while individuals in other parts of British Columbia may have very little access to this care. Therefore, PPPSS also provides support, along with public health nurses, GPs, OBs, and midwives, to fill this gap. In addition, PPPSS criteria for providing care is more open than many reproductive mental health programs. PPPSS serves any parent (or person supporting a parent) who is struggling with a mental health condition that is related to or impacted by the birth or adoption of a child. To join a support group, an individual's youngest child must be under nineteen-months old and, to receive telephone support the individual's youngest child must be under three years. In contrast, most regional and local reproductive mental health programs only provide care until the individual's youngest child turns one (although there are exceptions to these guidelines, for both PPPSS and reproductive mental health programs).

In Verta Taylor's discussion of the links between the feminist movement, self-help groups, and postpartum depression, the sociologist argues that postpartum support groups developed within the context of the overall feminist movements of the 1970s. Taylor explored whether women who joined postpartum support groups, which were "self-help movements that based their claims chiefly on women's traditional reproductive and nurturing roles," were then made aware of their societal disadvantages in general (1996, 21–22). Taylor links the development of postpartum support groups to feminist critiques of the medical establishment, as well as the

general movement for women's rights. As an organization, PPPSS's orientation that women could be empowered to be in charge of their own healing certainly developed within this landscape. The organization started in 1971 when a group of Vancouver Crisis Line volunteers noticed that there were many calls from distressed new mothers. In response, a small group of women began meeting to support each other in the Vancouver Crisis Line office, and over time Pacific Post Partum Support Society was born. From the start, the organization emphasized providing an alternative to the purely medical model for treating depression and anxiety. Instead, PPPSS emphasized the social, cultural, and individual factors that contribute to an individual being at risk (or not) to experiencing a PMAD, and that mitigating these factors was necessary for women to recover. In addition, in 1971 PMADs were much less known, so much early work revolved around increasing awareness.

In one example of how this orientation manifested, the medications prescribed for depression prior to the 1980s had significant side effects and low effectiveness. Therefore, earlier editions of the society's self-help guide spent extensive time discussing how women with perinatal depression and anxiety could refuse to take these ineffective medications that often caused more problems than they solved and instead pursue other avenues of healing, such as talk therapy and peer support. In the late 1980s, a new and more effective class of antidepressants called selective serotonin reuptake inhibitors, more commonly known as SSRIs and sold under now-familiar brand names like Prozac and Zoloft, began to be commonly prescribed for depression and anxiety. As medications and medical treatments for mental illness evolved, PPPSS's approach changed to focus more on collaboration with medical professionals, but it still continues to emphasize that individuals have the right and ability to be part of the process to make informed decisions about their own treatment and care. In addition, PPPSS operates with the fundamental

orientation that the causes and cures for PMADs are rarely completely medical, but rather must also include looking at the entire situation of social and emotional needs and supports.

For some individuals, there may be one very important factor, such as sleep deprivation. Once that situation improves, and the person receives appropriate treatment and support, the person recovers. For others, their situation can be more complex with many contributing factors. PPPSS finds the postpartum wheel (fig. 1), developed in partnership with counselor Sandra Knight, to be a useful tool for clients and professionals to think about possible contributing factors and gain a more holistic understanding of the experience of an individual parent.

Folkloristic Approaches to Planning and Implementing Community-Based Projects

This dissertation situates itself within scholarship on applied and public folklore, especially that which explores folkloristic approaches to planning and implementing community-based projects (e.g., Hufford 1985, 1998; Jones 1994; and Kirshenblatt-Gimblett 1992). Applied folklore has been given many different definitions, but the one offered by Michael Owen Jones provides a useful orientation for this dissertation:

> The field of applied folkloristic ethically utilizes concepts, methods and theories from the discipline of folklore studies as well as its own specialization to provide information, the formulation of policy, or the initiation of direct action in order to produce change or stability in behavior, culture, or the circumstances of people's lives including environment and technology. (1994, 13)

Applied folklore has a long history as part of the larger field of folkloristics. Some folklore scholars, most notably Richard Dorson, argued that the best way to make folklore a respected discipline was to emphasize its academic aspects and discourage applied folklore, which he saw as an attempt to use folklore as an instrument of social reform (Jones 1994, 12). Other scholars have recognized that applied folklore work can offer value to the wider world and does not

diminish the more purely academic work taking place in the discipline. Indeed, as folklorist

David Hufford has found:

> I know things now about folk tradition that I would not have known without
> pursuing questions raised by clinical necessity. I also have a set of direct
> empirical checks on my own theories beyond what peer review in scholarly
> journals can provide. Our own practical applications must flow from our theories,
> and if they don't work, then we know our theories are deficient. And perhaps
> most importantly, the bottom line of folklore applied to health is that as we
> expand our own knowledge and understanding, we are simultaneously serving our
> natural constituency, ordinary people from all backgrounds, as they struggle to
> find consolation and meaning in disability, suffering and death. (Hufford 1998,
> 310)

Not surprisingly, my own orientation towards applied work is aligned with that of David

Hufford. The situations that arose in the project, and the input provided by project collaborators

and participants provided essential feedback on the theories that project team members had about

topics such as what parents with PMADs needed to be able to heal. I could have simply

conducted a research project to explore these kinds of topics without any kind of practical output.

However, by putting the outputs into the world, allowing individuals to interact with them, and

asking them about their experience, we gained understanding about PMADs and postpartum that

would not have happened if we'd just published our results in an academic journal. In addition,

as Hufford points out, the practical outputs created during applied projects provide a natural way

to give back to all of those who made the project possible, such as parent interviewees and focus

group participants, public health nurses and community support workers, and PPPSS staff

members. I hope that these practical outputs will allow them to be more efficient and effective in

the work that they are all already doing in the world to help parents with PMADs.
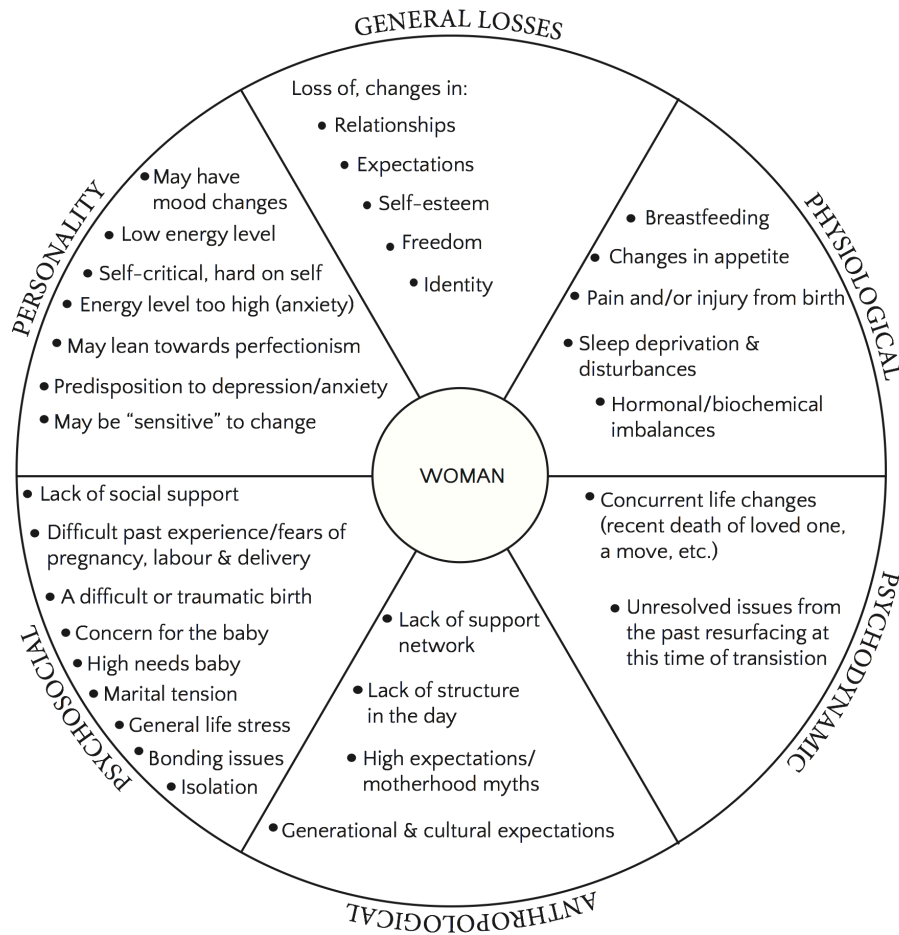
Figure 1. The Many Dimensions of Postpartum Depression. Reprinted with the permission of Sandra Knight and Pacific Post Partum Support Society.

The project team mindfully designed the project in order to facilitate shared authority for the construction of the project outputs that were informed by and created from participants' narratives (Frisch 1990). First, the project worked to acknowledge the expertise of all of those who were a part of the project. The narrators and focus group participants were all experts in being a new parent (with a particular set of additional expertise, such as a new parent who was also a new immigrant to Canada). The PPPSS staff were experts in providing a peer support to new parents. The contractors were experts in their particular skill. Community collaborators were experts about supporting families in their own communities. Almost everyone involved also

shared their own lived experience of living with, or being a close family member of someone living with, a PMAD or other mental illness. Second, with everyone's expertise in mind, we designed the project workflows and processes to facilitate meaningful collaboration in the creation of final outputs. For example, although we had a general idea of what kind of outputs we wanted to create (such as a more interactive and inclusive website), we did not do much to design the structure or the content until we had conducted the focus groups and interviews. We then could let what we learned guide the process of creation, instead of just cherry picking what we learned from new parents to support what we had already decided to do. We certainly could have gone further with this approach, and what we learned during this project will allow us to do so in the future.

This dissertation will make the following contributions to applied folklore theory and practice. First, this dissertation is a case study exploring how a theoretically informed and community-based process was used to design, implement, and evaluate a social service nonprofit's applied folklore project in order to create innovative outputs that meet the needs of the nonprofit's clients and reduce stigma both among clients and in the wider community. This dissertation also evaluates the effectiveness of this particular applied folklore project and is intended to inform the development and implementation of similar projects. In chapter two of this dissertation, I will discuss how the 2013–2015 PPPSS's "Strengthening Community-Based Resources for Families Experiencing Perinatal Depression and Anxiety and Their Health Care Providers" was planned, funded, and launched. In chapter three, I will document the implementation of the project and evaluate its impacts and outputs. In chapter four, I will examine the multifaceted, pervasive, and profound impact of stigma on the perinatal experience for new parents through the stigmatization of vernacular parenting practices, negative feelings

about parenting, and having a perinatal mood and/or anxiety disorder, as well as an analysis of ways new parents work to manage that stigma. In chapter five, I will explore the process of how reducing isolation and promoting healing occurs through sharing narrative in a supportive environment, and how parents with PMADs can use narrative to make meaning of difficult perinatal experiences. In chapter six, I conclude by encouraging additional applied folklore work to support struggling new parents and offer suggestions for how health care providers, community support workers, and friends and family members can better support new parents in the hope of promoting better outcomes for families.

Chapter 2: Planning the Project

Introduction to the Project

In chapters two and three of this dissertation, I will discuss and evaluate the 2013–2015 Pacific Post Partum Support Society's (PPPSS) "Strengthening Community-Based Resources for Families Experiencing Perinatal Depression and Anxiety and Their Health Care Providers" project from a theoretical and professional perspective. This is a case study exploring how a theoretically informed and community-based process was used to design, implement, and evaluate a social service nonprofit's project in order to create innovative outputs that meet the needs of the nonprofit's clients and reduce stigma both among clients and in the wider community. I will also evaluate the effectiveness of this particular project in order to inform the development and implementation of similar folkloristically informed projects.

In this project, working with PPPSS staff, contractors, and volunteers, I used mixed methods to create educational resources and new services for clients and professional helpers. The overall project was designed to reduce the stigma of perinatal mood and/or anxiety disorders and encourage struggling new parents to reach out for help earlier, when treatment is less expensive and more effective.

Conducted primarily in the metro Vancouver area of British Columbia (BC), with a focus on the Vancouver Coastal Health Service (VCH) area, and funded by an Integrated Primary and Community Care grant from VCH, the overall goals of this two-phase project were:

Phase One (January 2013–June 2014)

Goal: Enhance client resources to make them more engaging, culturally appropriate, and accessible.

Goal: Increase the relevance, cultural appropriateness, and accessibility of community health professional training materials.

Goal: Reduce stigma associated with perinatal mood and anxiety disorders (PMADs).

Phase Two (July 2014–October 2015)

Goal: Increase access to, use of, and effectiveness of client support services.

Goal: Increase access to and use of community health professional training materials.

Goal: Reduce stigma associated with perinatal PMADs.

Role of Narrative in PPPSS's Support Groups

In order to understand the genesis of the project, I will share my own experience observing narrative in a particular PPPSS support group, which I attended from September 2010 to June 2012 in Vancouver. This experience was the foundation of the design and implementation of the project discussed in this dissertation. However, it is important to understand that although I have checked these insights and conclusions with group facilitators and participants (some who were part of the same group and others who were part of other PPPSS groups) who have confirmed my thoughts, these conclusions are not the result of any formal study but rather just of my own lived experience.

In the summer of 2010 I gave birth to my daughter. For many reasons, I experienced severe postpartum depression and anxiety and was in active treatment for the condition for two years. I also discovered that I have an ongoing anxiety disorder that was undiagnosed but existed prior to my becoming pregnant. In my case medication, individual therapy, and a weekly facilitated peer

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support group for women with postpartum depression and/or anxiety, hosted by PPPSS, were all integral components of my treatment.

PPPSS's support group structure is designed to facilitate nonjudgmental peer support.[24] When new parents share their struggles with others, they are often told what to do and how to do it, or how they should be feeling. In the PPPSS groups everyone is there because they have complex and difficult feelings about new parenthood. Group members agree to a standard of conduct, which includes offering advice only if it was specifically solicited. The role of the facilitator includes helping everyone practice providing this nonjudgmental support and ensuring each group member's safety.[25]

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[24] All mothers in the support group have postpartum depression and/or anxiety. However, they may have another mental health condition (perinatal or not) such as post traumatic stress disorder (PTSD), bipolar, or a history of psychosis. Currently PPPSS support groups are only available to women whose youngest child is under the age of nineteen months. PPPSS telephone support is available to anyone, male or female, who needs support for themselves or a loved one. Some individuals who use telephone support have a PMAD while others are just experiencing a difficult adjustment to parenthood.

[25] In Canada, most new mothers who have been working prior to giving birth or adopting a child qualify for up to a year of paid maternity leave (part of this leave can also be shared with a non-birthing partner) (Service Canada 2016). Because of this leave, the in-person support group model for new mothers works well as most mothers are off work and free to meet during the day. It also means that, for many women, their life changes radically as they go from full-time working to full-time parenting. For many reasons, including the availability of maternity leave, child care for any child, but especially for infants, is difficult to obtain in metro Vancouver. Even if a woman wants to return to work earlier,

In my support group, the most important component was time for each member to share whatever she wanted that week. Sometimes members spoke about the challenges they had experienced that week: walking a colicky baby for hours, struggling to get out of pajamas and leave the house, or forgetting to eat all day. Other times, members might talk about difficulties in relationships with their partners or parents, or with past life events that were impacting their ability to parent in the way that they wanted.

In these sharing times, many narratives were told, with many purposes, but the stories that interested me the most were those told during special times of transition in the group. The groups were ongoing, with members entering and leaving as they felt was helpful for them. In order to help ease this transition, the society had developed a ritual. Every time a new member entered, the group would take an entire session to do introductions, in which each member told a narrative about who they were and what brought them to the group. Every time a member graduated from the group, the member who was moving on was given the opportunity to tell their narrative again, with the additional goal of talking about what had helped her heal and be ready to leave the group, as well as plans to work towards future wellness. In these times, people told what was often referred to within the group as their "postpartum journey."

The group leader always began with her own postpartum experience in order to set the stage. The narratives often began with the decision (or surprise) of pregnancy, what the pregnancy was like, when the person began experiencing difficulties, factors the person felt had contributed to her developing a mental health issue (such as a recent move or a difficult birth), their most

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she must either be able to afford a more expensive nanny, or wait until her child is more than twelve months old and able to attend toddler care (Lovgreen 2016).

troubling symptoms and experiences, and what was helpful (if anything at that point). There were often tears, from both the teller and the listeners. Many new group members had never told their story before, or at least not to others who shared some of their experiences and did not judge.

Many members of the group quickly recovered from perinatal depression and anxiety, with the help of treatment and increased support, and graduated after a few months. Others stayed in the group for much longer. When I first entered the group having time to myself, with someone else caring for my infant so that I could talk or even just sit with my own thoughts for two hours, was a lifesaving resource. I was part of my support group for almost two years, so as other members came and went, I heard members introduce themselves and tell their postpartum narratives over and over.

As I began to heal and emerge from my postpartum fog, as a folklorist I began to notice how narratives were changing as individuals moved through their healing process. During the fall of 2010, I had a discussion with my group facilitators about my observations and how they might lead to some kind of research project. I noticed that some group members had a fairly simple story with just a few components that did not change much over time. These members were the ones who tended to leave the group more quickly, as they were able to focus on those factors and do the healing work they needed to do. For example, a member might have experienced a significant health scare with her baby and needed to work through her feelings about that situation, but was not having difficulty with other aspects of her life. And once she was able to process and heal from that situation, she was often feeling better and ready to leave the support group.

But other members had complex situations that led to complex narratives. In these cases, all the basic components in a member's story might be there in almost every telling. Or the member might choose to focus on what the most salient aspects were for her at that time. My own bare outline near the beginning of my postpartum was probably something like: I had significant anxiety in pregnancy (but did not realize it); labor and delivery was a mostly positive experience; breastfeeding was horrible at first; my baby was re-hospitalized with a significant medical condition when she was five days old; I developed postpartum depression and anxiety very quickly; I moved to a new country at eight weeks postpartum; my baby is very difficult to soothe; I am experiencing significant difficulties in my relationships; I am completely exhausted; and here I am in the group. We each had perhaps ten to fifteen minutes to share during these introduction sessions, depending on the size of the group, so most members would not be able to tell their entire narrative each time. And so, at each telling different parts of the story were emphasized. Which parts might depend on what else was happening in the member's life that week, what things were troubling her the most, or what healing work she was currently most focused on. But I also noticed an overall pattern of change as members moved through the healing process.

I observed that at the beginning of their time in the group, members tended to focus on the difficulties of their immediate situation and their most distressing symptoms:

The baby won't sleep so I can't sleep.

No one is helping me with child care and housework.

I have frequent intrusive thoughts about harm coming to my child that terrify me.

But as members were part of the group longer and had a chance to explore all the factors that were contributing to their feelings, they often started to emphasize other parts of their story that were causes rather than symptoms:

I've realized I experienced significant anxiety for most of my life, but my ways of coping with it no longer worked after I had a baby.
I was in foster care as a child and I never had a good role model about how to be a mother.
Society expects that moms and dads can do it all on their own, but humans did not evolve to parent in a vacuum—I need to find my village.

As group members recovered from perinatal depression and anxiety and became ready to leave the group, their narratives also often began to emphasize the tools that they had gained that helped them to cope with their feelings and their hopes and dreams for their family's future. Through narrative, tellers were able to sort their feelings out, create a plan for moving forward, get feedback (if desired) and support from the other group members, and begin to implement that plan. The listeners were able to learn from the experience of others and feel that there was hope for their own recovery and growth.

My own situation was not simple, so I was in my support group for nearly two years. And during those two years I listened to many postpartum journey narratives. And I began to see how, in telling those narratives, group members were working to heal themselves, as well as make meaning out of what they had experienced. In this work, they discovered how they wanted to heal and move forward in their life, a process that would ultimately mean leaving the group. Furthermore, as group members sat listening to others' narratives, the listeners were also working to heal themselves as well as to provide support to the teller. Finding out that you are

not the only one who has felt that you wanted to leave your child and run away, or that you are

not the only one who has had disturbing and violent thoughts about harm that might come to

your child, or that you are not the only one who has felt she made a terrible mistake in having a

child, is an immensely powerful moment. As Robin stated in the quotation at the beginning of

this dissertation:

> And then, with the support group, having time to myself with two hands, sitting
> with a cup of tea was like a moment of self-care that I hadn't had in, in months and
> months. And being able to listen and hear other women tell their stories and each
> story was different. But inside of each woman's story was a piece of my story. And
> so, hearing those stories being told, I didn't even have to talk. I started feeling
> better in those moments.

This project was designed to take the magic of what was happening in the PPPSS support group,

a place where meaning-rich, expressive narration was happening at every meeting, and share that

with more people. In part this sharing would be with those who were not able to attend in-person

support groups because of geography, time constraints, or wait lists. Additionally, our goal was

to also share it with the friends and family of those who were suffering, as well as with health

care practitioners, community support workers, and others who work with families, who would

benefit from a better understanding of what those who were going through or recovering from

PMADs are experiencing.

Start of the Project

At the end of September 2012, several months after I left my own support group, I met with

PPPSS's volunteer coordinator, Georgie Hutchinson, in order to discuss the possibility of

volunteering for the organization. Like many who had used their services, now that I was feeling

better I wanted to help other struggling new parents. We discussed that perhaps I could get some

training and begin to do some outreach activities for the society. I also pitched a research project that I had been thinking about since my days as a group member, one that would explore how group members used narrative to affect their own healing. Georgie also shared some of her ideas, which included doing video interviews to capture former clients' postpartum narratives in order to share them on the web and in trainings. We agreed that this kind of project would require some substantial funding, funding that the organization did not currently have, and made plans for me to attend an upcoming training for new volunteers at the beginning of October 2012.

The next day, Georgie attended a meeting at Vancouver Coastal Health (VCH), one of the local health authorities, and sat next to two of PPPSS's long-time allies at VCH. At this meeting, one of them happened to receive email during the meeting that VCH had some funding left over in a grant program for community organizations to create innovative programming and patient resources designed to help support the work of primary care physicians. The British Columbia's Ministry of Health's Integrated Primary and Community Care (IPCC) program funded the grant. The catch was that the funding could not be used to simply fund existing services and the money had to be allocated soon (or VCH would have to return it to the province). Since she happened to be sitting right next to a staff member of a community organization, she asked Georgie if she knew of any projects that PPPSS would like to implement. Remembering our conversation of the previous week, Georgie pitched a version of our thoughts, and the VCH staff member was intrigued. She offered to make inquiries on her end and encouraged Georgie to start developing a proposal.

Soon after, Georgie called me and offered to come to my home to discuss this opportunity. We brainstormed many potential ideas, which she started to take to community partners both in VCH and in other social service agencies that supported new parents. Georgie and I also met

with PPPSS staff, especially Director Sheila Duffy and Administrator Stace Dayment, to discuss our ideas and incorporate their suggestions.

This project was carefully designed to fit within PPPSS's fundamental orientation to providing struggling new parents with the support and resources that they need to engineer their own healing. A top-down approach, in which an outsider, or even PPPSS's staff, decided what was needed and then worked to implement it, would not have been in keeping with the organization's own history and culture, and therefore would not have been successful. From the beginning this project was designed to go to new parents and to those who worked with them and to ask them what they needed to feel supported and be well, and then to use what we learned to design, create, and share the project outputs. Therefore, unlike some public health projects, we did not come in with set ideas of the messages that we needed to present (although there were certain broad areas that we wanted to be sure to address because our research and experience already told us that they were important). Instead, we encouraged our participants to tell the narrative that they wanted to tell, and then to let the educational materials emerge directly out of the research materials. We were fortunate that our funding allowed us to take this approach and did not require that we develop scripts or other prescriptive documents (as many funding sources do).

PPPSS also brought its own strong history of using face-to-face sharing of narrative to facilitate recovery and healing, as well as to reduce the stigma of PMADs and to encourage people to reach out for help. The society found this approach to be extremely powerful and effective, but also resource heavy because the experience was provided in a way that required a lot of staff time: 1:1 in a telephone support call, 1:8 in the support groups, or educational talks to

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relatively small groups, such as parent–baby drop-ins or sessions held for family members of those living with PMADs.

PPPSS made use of personal experience narratives in its print publications and had posted a few written narratives at times on its website, but overall the web was an underused resource by the organization. Although some people responded well to written narratives, for others they lacked the impact of a face-to-face encounter. These factors led us to emphasize video and audio resources, primarily delivered via the website, instead of written materials. One of the major questions in this project was: How to transfer that time-tested and powerful approach of providing face-to-face encounters with someone with a mental health condition to a mediated encounter that could be accessed from anywhere and reach a lot more people without more staff time? The answer seemed to be video interviews with parents who had experienced PMADs.

Stigma Reduction

Many components of this project were specifically designed to reduce stigma, a goal shared by both PPPSS and the funding agency. One of the main goals for PPPSS outreach and educational activities, which were conducted for new parents and their families as well as professionals, was to reduce the stigma of PMADs by putting a personal face to the experience. The way that this was accomplished was usually by the presenter sharing her own personal experience with PMADs. However, this limited the audience's example to the person standing in front of them, and it also required that everyone meet in the same space at the same time. This is, of course, an immensely powerful approach but also one severely limited by time, resources, and geography.

Therefore, the society wanted to be able to find effective ways to reduce stigma for people they could not meet in person. In the past, they published narratives in their print publications

and on their website. However, this was a more mediated experience and did not have the same power as hearing it from a particular individual, face-to-face. In the past, the society had experimented a bit with making video recordings with past clients, but they were not professionally filmed or edited, which made them a bit difficult to understand. In addition, they were only made to be used at internal trainings, so they were not appropriate to make publicly available online.

While planning the project, Georgie, Sheila, and I discovered that existing research in the field of mental health had found that providing personal encounters with individuals with mental illness, even when mediated by video, did diminish stigma (Brown et al. 2010, Corrigan et al. 2007). This approach fit well within the society's existing orientation to use personal narratives to reduce stigma, and the grant would provide the funding needed to professionally film and edit such videos, thus making them useful for a wider variety of purposes.

We believed that sharing the interviewees' stories through the edited video segments would help struggling new parents know that help is available and assist them in determining when they may need it. We also believed that providing video-mediated personal contact with individuals who have recovered from the condition will help to reduce the effect of stigma, thus enabling those who need treatment to feel free to reach out as well as helping the person's partner, friends, and family to be more compassionate and supportive as that individual moves through the recovery process.

Another important goal of the project was to create resources that would serve members of immigrant communities in metro Vancouver that had been previously underserved by PPPSS's support services and by other available treatment programs for perinatal depression and anxiety (see Morrow, Smith, Yuan, and Jaswal 2008 for a discussion of these underserved populations in

metro Vancouver). Unfortunately, the IPCC funding could not be used to provide ongoing service in one of the needed languages, so PPPSS instead looked to developing resources in languages other than English that were common in VCH's service area. One of our initial ideas for the project was to translate PPPSS's main client publication, *Postpartum Depression and Anxiety: A Self-Help Guide for Mothers*, into Chinese. For mothers who speak languages other than English, and do not speak or read English well, Chinese speakers are the most numerous in metro Vancouver. However, when Georgie took this plan to a community support worker from the Chinese immigrant community, with whom Georgie had worked with on previous projects, the community partner pointed out that the information contained in the self-help guide was not culturally appropriate for new immigrants who primarily spoke Chinese. Rather, she felt that if the woman was accustomed to Canadian society enough to find the information useful, then she almost certainly would read English well enough to be able to use the English-language version. From this extremely valuable advice, we decided that it would be much more useful to create brief publications in the most common languages other than English. Therefore, the available funding would be used to talk with new parents and community support workers from that community about their needs and concerns and then use what we learned to develop the content. In the end, the translation services were a small portion of the overall budget required to create these resources, but they are of far more use to community members than if we had simply translated PPPSS's North American-centric self-help publication into Chinese.

What started to shape up was a multifaceted project, now named "Strengthening Community Resources for Families Experiencing Perinatal Depression and Anxiety and Their Health Care Providers" that had the following goals, to be achieved with the following outputs (as described in the grant's executive summary):

The goal of the project is to utilize innovative ways of sharing personal stories of perinatal depression and anxiety to:

1. Enhance client educational resources to make them more engaging, culturally appropriate, and accessible.

2. Increase the relevance, cultural appropriateness, and accessibility of community health professional training materials.

3. Reduce the stigma associated with perinatal depression and anxiety.

The goals of the project will be achieved through the following steps:

1. We will gather information from patients about what helps in recovery and create recordings of individuals' experiences with perinatal mental health issues.

   a. Analyze feedback forms from individuals who have used our services with a focus on personal experience with perinatal depression/anxiety, the role of stigma, and what helped with recovery.

   b. Conduct population-specific focus groups with parents to share personal stories about perinatal depression/anxiety, the role of stigma, what helped with recovery, and ways to make PPPSS client resources more effective.

   c. Record video interviews of families about their experiences with perinatal depression/anxiety, the effects of stigma, and what helped with recovery.

2. We will gather information from health care professionals and community support workers about their training needs and patient/client needs.

   a. Analyze feedback forms from training workshop participants.

b. Conduct interviews with primary care physicians and hold language-specific focus groups with patients, health care professionals, and community support workers. Questions will focus on how to make PPPSS public education resources and health care provider training materials more informative, culturally appropriate, and effective at reducing stigma.

3. We will then use the information and recordings to:

a. Streamline existing distribution mechanisms for PPPSS resource materials.

b. Create new culturally appropriate content for the Chinese, Farsi, Punjabi, and Spanish language informational brochures.

c. Update training materials for community-based health care professionals, including the use of video interview segments designed to reduce stigma.

d. Make website more engaging, interactive, and culturally appropriate, including the use of video interview segments designed to reduce stigma.

PPPSS greatly benefited from the feedback of individuals within and outside of VCH on every aspect of the planning and grant writing process. The success of this project, beginning with writing the first grant, was greatly dependent on PPPSS's existing place in the community and relationships with a wide variety of people: former clients who were eager to give back, community support workers who wanted to help to create better resources to serve their own constituencies, and health care professionals who wanted to improve the vital support PPPSS gave their patients.

The grant-writing team also benefited from several collaborators who had experience working for VCH who helped to rewrite the grant with the goal of presenting our ideas in a way

that would meet the grant's requirements. For example, in our first draft we just listed the main project staff's salaries under a staff section. However, the grant required that no more than 10 percent of the funds be spent on administrative costs, and without a specific associated output this is what the salaries would be classed as. Therefore, we were advised to instead put the funds required to generate each project output under that section of the grant. Without these helpful collaborations, starting from the very beginning of the project, we never would have been able to create a successful plan nor to implement it once we received the grant.[26]

In addition, in order to create a fundable proposal, project planning decisions were made with VCH's particular demographics in mind. For example, the languages that we chose to focus on creating culturally appropriate materials were selected because census data indicated that, in VCH's service area, these languages were the most common languages spoken by people who were not also able to read or understand English.[27] VCH's current broad goals (both official and unofficial) were also taken into account. These included areas such as increasing support for

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[26] To highlight a few of the most essential community partners that helped with preparing the grant application in the fall of 2012, Barb Stackhouse and Janet Williams, who were VCH employees at the time of the first grant application, provided valuable feedback on how to ensure that what we proposed to do in the grant would meet the health authority's priorities and requirements. Folklorist Amber Ridington provided guidance on video production and web design that was essential for developing a realistic plan and budget. In addition, members of a PPPSS multicultural training workshop conducted by Georgie Hutchinson in the fall of 2012 gave PPPSS the valuable advice that simply translating our English-language self-help materials into other languages would not be helpful for new immigrants.

[27] For example, German is a common second language in British Columbia, but census data indicates most German speakers also speak and understand English well.

patients with mental illness and support for new immigrants. Clearly the ability to do this depended on the society's knowledge of VCH and its strong relationships with VCH staff members.

The project team was composed of PPPSS staff members and outside contractors, including the project manager, videographer, web designer, writer/editor and project assistant. Parent participants, who generously shared their experiences and insights in many ways, were vital to the success of this project. We completed the project plan, created the budget, recruited a set of needed professionals and community partners, and submitted the grant application in the first half of November 2012. The budget was returned to us for a round of revisions to meet VCH's requirements. It was approved at the end of the month, and work began in January 2013. Therefore, the IPCC funded project came together extremely quickly.

Throughout this multi-year project, the project team was a large group of PPPSS permanent staff, contracted project staff, and volunteers. Throughout this dissertation, I often refer to we as a way to not get too bogged down in particulars. However, it is important to understand that the individuals the "we" represent does change in regards to the part of the project that is being worked on. In the next chapter, I name the individuals that took key roles in certain project components. However, many members of the team were formally and informally consulted throughout the project about many aspects, so this is not meant to imply that no other members contributed to this part of the project.

Table 2: Project Staff and Volunteers

PPPSS Staff		
Title and Name	**Dates**	**Primary Project Roles**
Sheila Duffy, Director	2012–16	Supervised Project Manager. As Director, ultimately responsible for meeting terms of project grant. Assisted in grant writing and review of all project outputs. Participated in video interviewed and follow-up interview.
Georgie Hutchinson, Volunteer Coordinator	2012–16	Collaborated on grant writing. Liaised with existing community contacts and PPPSS alumni to recruit participants for focus groups and interviews. Co-facilitator of online-only support group pilot project. Text-message support counselor. Participated in follow-up interview.
Stace Dayment, Administrator	2012–16	Working with Project Manager and bookkeeper, paid and tracked all project expenses. Consulted on website redesign project. Liaised with existing PPPSS vendors to produce project outputs.
Counselors and Group Facilitators		
Emma Lee	2012–13	Planned, recruited for, and implemented focus groups. Wrote and edited Chinese-language culturally appropriate materials. Participated in follow-up interview.
Shealagh Davis	2014	Participated as a facilitator in the mock support group session for training video production. Helped to review and revise training materials.

Title and Name	Dates	Primary Project Roles
Hollie Hall	2014	Participated as a facilitator in the mock support group session for training video production.
Linda King	2014–15	Co-facilitator of online-only support group pilot project.
Kerry O'Donohue	2014–15	Text-message support counselor during pilot project.
Rita Shergill	2014–15	Editor and reviewer of Punjabi-language materials. Assisted with planning and implementing South Asian focus groups and interviews.
Bookkeepers		
Erick Cardona	2012–13	Tracked project financials and provided financial reports.
Christina Debruyn	2014–16	Tracked project financials and provided financial reports.
Childminders	2012–15	Provided child care during focus groups.

Contracted Project Staff		
Jodine Perkins, Project Manager	2012–16	Hired and supervised project staff. Designed and implemented project research. Collaborated with staff to supervise all outputs and meet grant requirements. Responsible for budgeting, evaluation, and reporting.
Emilie Irelan, Project Assistant	2013–14	Took lead on paper edits of video segments. Checked all edited video segments. Researched and reported on existing online support group models. Participated in follow-up interview.

Title and Name	Dates	Primary Project Roles
Linda Tobias, Writer/Editor	2013–15	Wrote and edited research-based educational materials for a variety of targeted audiences. Consulted on social media policy and design. Participated in follow-up interview.
Amanda Growe, Editor	2015	Edited long-form print materials.
Karen Boley, Education Consultant	2014–15	Created online training curriculum.
Chad Galloway, Videographer and Video Editor	2012–16	Designed and executed production of video-recorded interviews and training videos, created all video segments from paper edits. Participated in follow-up interview.
Popgun Media (Kyle), Web Designer	2012–16	Migrated and redesigned existing website and populated with provided new content.
Red Panda (Cathy), Transcriptionist	2012–13	Transcribed all recorded focus groups and interviews.
Focus Group Partners	2012–13	Assisted with planning, recruiting for, and implementing focus groups for targeted cultural communities. Attended and participated in focus group sessions to provide language and cultural translation.
MOSAIC, Translators	2012–15	Translated and typeset materials into target language.
Cultural Materials Reviewers	2012–15	Reviewed and edited English and non-English versions of culturally appropriate materials.

Name and Title	Dates	Primary Project Roles
Volunteers		
Board Members	2012–15	Supervised fulfillment of grant terms.
Focus Group Members	2012–15	Discussed their experiences as new parents.
Video Interviewees		
Allen	2012–15	Discussed his experiences as a new parent with a PMAD and as the partner of a parent with a PMAD in filmed interview. Collaborated on segment content. Reviewed, edited, and approved all segments.
Brianna	2012–16	Participated in focus group. Discussed her experience with a PMAD in filmed interview. Collaborated on segment content. Reviewed, edited, and approved all segments. Participated in follow-up interview.
Brianna's partner	2012–16	Discussed his experiences as a partner of a parent with a PMAD in filmed interview. Collaborated on segment content. Reviewed, edited, and approved all segments. Participated in follow-up interview.
Kasimir	2012–15	Discussed his experiences as a partner of a parent with a PMAD in filmed interview. Collaborated on segment content. Reviewed, edited, and approved all segments.
Linda	2012–15	Discussed her experiences with a PMAD in filmed interview. Collaborated on segment content. Reviewed, edited, and approved all segments.

Title and Name	Dates	Primary Project Roles
Maria	2012–15	Participated in focus group. Discussed her experiences a PMAD in filmed interview. Collaborated on segment content. Reviewed, edited, and approved all segments.
Mariko	2012–15	Discussed her experiences with a PMAD in filmed interview. Collaborated on segment content. Reviewed, edited, and approved all segments.
Noella	2012–16	Participated in focus group. Discussed her experiences with a PMAD in filmed interview. Collaborated on segment content. Reviewed, edited, and approved all segments. Participated in follow-up interview.
Pablo	2012–15	Discussed his experiences as a partner of a parent with a PMAD in filmed interview. Collaborated on segment content. Reviewed, edited, and approved all segments.
Robin	2012–16	Discussed her experiences with a PMAD in filmed interview. Collaborated on segment content. Reviewed, edited, and approved all segments. Participated in follow-up interview
Punjabi-speaking Mom, Interviewee	2013	Discussed her experience with a PMAD in an audio-recorded interview.
Family Doctor, Interviewee	2013	Discussed working with new parents in the Iranian and Arab communities in an audio-recorded interview.

Name and Title	Dates	Primary Project Roles
Book and Website Reviewers	2014–15	Reviewed English-language materials.
Text Message Training Participants	2015	Participated in training sessions with PPPSS staff to prepare for text-message support pilot project.
Mock Support Group Participants	2014	Participated in filmed mock support group sessions, which were edited into training videos.
Rae Kokotailo, Practicum Student	2014–15	Reviewed existing text-message support programs and developed training materials to prepare for pilot project.

In the next chapter, I will detail the implementation of this project and detail some of the project outcomes.

Chapter 3: Implementing the Project

Research Phase

With an iterative design and implementation process, the project team used what we learned in each stage to guide our next steps. Research activities over the course of the two-and-a-half year project included coding and analyzing data from client surveys, focus groups, individual interviews, and tracking service and educational resource use to guide design and implementation of new programs, resources, and training materials. Many project team members helped to collect the data. I performed the coding and analysis and discussed and finalized the conclusions with other project team members, especially Pacific Post Partum Support Society (PPPSS) staff members Stace Dayment, Sheila Duffy, Georgie Hutchinson, and Emma Lee, and project contractors Linda Tobias and Emilie Irelan.

As has been noted by many scholars and community workers, there is always a power differential between individual participants and even the most collaborative-minded scholars and community organizations. During the project, the team was mindful of this power differential and worked to mitigate it in the project design and implementation, and to provide meaningful opportunities for participants to help shape project outputs, provide feedback, and hold the final veto for any output that involved their voice or image. The project team also hoped that the fact that the majority of the project workers were individuals who themselves had experienced perinatal mood and anxiety disorders (PMADs) would make us more mindful of the concerns and needs of individual participants. But I must acknowledge the reality of this power differential in this project and any other such collaboration.

Because of the nature of the research method, the project team was able to collaborate in a much more meaningful way with video interview participants than most focus group participants (who merely participated in one focus group and then were not contacted again). However, some focus group participants later became video interview participants and others were involved in reviewing the culturally appropriate materials that were created for members of their cultural group.

Analysis of Existing Data

The first step, which Emma Lee and I completed in the winter of 2013, was to analyze existing data that the society had already collected from clients. The primary source of this data was feedback forms that clients who were leaving PPPSS's in-person support groups were asked to complete. A limitation of this data was that it was only from clients who had used the support groups. It thus excluded the much larger group of clients who had only used telephone support. In addition, not all former group members chose to complete the feedback forms. The forms contained information about topics such as what helped in recovery, what did not help, and what clients wished health care professionals knew. The results of this analysis stage were used to develop the lists of questions that were used in the focus groups and in-person interviews, and they were also used to guide the planning of the website content and other publications.

Focus Groups and Interviews

Given the project's overall orientation to begin with learning, directly from parents, what they needed to feel supported, the project team began by conducting a series of focus group sessions with targeted groups chosen to inform specific outputs as well as the entire project (Steward and

Shamdasani 2015).[28] By May 2013 the project team had planned, conducted, logged, and transcribed recordings from seven focus groups with the following groups: 1) mothers who were South Asian immigrants, 2) mothers who were Chinese immigrants, 3) mothers who were Spanish-speaking immigrants from a variety of Latin American countries, 4) mothers (including some who were immigrants) who had had a PMAD and had used PPPSS's services, 5) fathers (including some who were immigrants) who had either had a PMAD or had a partner with a PMAD, 6) a multicultural group of immigrants, and 7) mothers who were Farsi-speaking immigrants from Iran. We also conducted one-on-one interviews with a wide range of parents and one physician. Some of these interviews were professionally video-recorded while others were audio recorded. What the project team learned in the focus groups and one-on-one interviews was used in two vital ways: 1) to inform the design of nearly every project output and 2) to provide a source of content and direct quotations for those outputs.

It was relatively simple to organize focus groups to talk with former clients and partners of former clients. These individuals were highly motivated, and in fact we had to turn former clients away who wanted to participate. For each of the other groups (that were not primarily composed of PPPSS alumni or their partners), we sought a community partner who was familiar with the community and who could help us with recruitment and translation as needed. We found that it took a lot of effort to recruit for these focus groups and we had to rely on our community

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[28] For conducting the focus groups, the project team consisted primarily of myself and Emma Lee, with Georgie Hutchinson and Sheila Duffy providing their expertise in areas such as connecting with community contacts and reviewing questions lists. PPPSS child-minders and Red Panda Transcription also provided key services.

contacts—some existing and some new—in order to find participants. As former PPPSS staff member Emma Lee reflects, doing these focus groups benefited PPPSS and the communities because it:

> Was a form of engagement and outreach that we perhaps wouldn't have been forced to do before. Because it's easy to just do sort of the comfort-zone type thing. And our budget didn't allow us go beyond sort of the [normal] rotation [of groups PPPSS was invited to]. So I remember those groups where, I don't know if it made an impact, I'd like to think it did. That we reached out to people that we couldn't have before. To demographics we couldn't reach out to before and [we] had face time with [them].

These community contacts, created during this phase of the project, proved to be invaluable throughout the project as we created, reviewed, and edited the patient education materials and physician training materials. In addition, some of the individuals to be interviewed in the video interviews were recruited from the alumni, multicultural, and Spanish-speaking focus group participants.

We also found that we needed to change our approach for each focus group. The project team found that some groups (the mixed multicultural, Spanish speakers, Farsi speakers, and PPPSS alumni) were very informative, while others (Chinese speakers, fathers, and Punjabi speakers) were less so. In the less informative cases, we followed up with either individual interviews or speaking with other groups. Other than the fathers, we found the less informative groups tended to be composed of members who were newer immigrants and less likely to speak English. Therefore, we had to rely more on our community partners for translation. In addition, the questions that we were asking might have been less relevant to their own concerns and experiences and they may have been less familiar with the process of what is a very North American type of experience of participating in a directed group discussion.

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In order to make use of the data from these less-informative groups, the project team had to get creative. For example, after realizing there were many silences surrounding what the Punjabi-speaking mothers were willing to speak about in the recorded focus group, we attended a mommy–baby talk where PPPSS staff were already scheduled to speak about the importance of self-care for mothers to mothers from South Asia. After getting the mothers' verbal consent to allow us to use what we learned in the discussion in the project, we took some written notes during the session, which focused on areas such as: what types of self-care helped mothers cope better, what barriers prevented the mothers from taking care of themselves, and what health care professionals and family members could do to facilitate self-care. Therefore, we were able to conduct our planned session for the mothers, and at the same time gather information that guided the creation of new materials for mothers from South Asia. We found the mothers to be much more willing to share their candid insights and concerns in this more relaxed and familiar environment in which they were not being recorded.

In addition, careful consideration of what the mothers were not willing to talk about and what that unwillingness might mean, and then checking our assessments with our community contacts, was ultimately as valuable in guiding the creating of culturally appropriate materials as what the mothers did say in the focus group. For example, in the recorded focus group the mothers were very unwilling to say that their partners or in-laws were anything less than completely helpful, supportive, and considerate. But the stressful situations they described (which they themselves identified as difficult) would have clearly been less stressful if they had received more help from the multi-generational family members living in their household. However, in the non-recorded existing group, one in which the members trusted each other and the facilitators, mothers were willing to say that they wished they had more hands-on help and emotional support for the work of parenting from

other members of their household. The one disadvantage of this approach was that, because the group was not recorded, we did not have many direct quotations that we could later use in our content for South Asian parents. Therefore, I later conducted a one-on-one recorded interview with a South Asian mom who had experienced a PMAD (with the help of her niece to translate).[29]

At the beginning the project we had some preconceived notions about what were the most important challenges facing new immigrant parents in metro Vancouver. However, our focus groups revealed that although some of these challenges were fairly universal (such as unfamiliarity with Canadian health care systems and institutions), others were culturally specific. In many cases what we thought might be true for all immigrants was only true for Chinese-speaking immigrants, as they are the most numerous group. For example, we had an extremely illuminating interview with a Farsi-speaking physician who primarily works with members of the Farsi-speaking community and the Arabic-speaking community in North Vancouver. In our discussion, we discovered that many of our assumptions about what it was like to be a new immigrant parent in Vancouver were not true for the Farsi-speaking community. For example, we assumed that there were a lot of generational differences for Farsi-speakers (such as between parents and grandparents) about how children should be raised, how household work should be shared, and what the proper roles of mothers and fathers are.

However, the physician felt that there were not a lot of differences between the generations in regards to these issues. Instead, the main source of stress for new parents in regards to their own parents was that it was often very difficult for their own parents to get a visa to travel from Iran to Canada in order to help the new parents after the birth of a baby. Through this conversation,

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[29] See Briggs 1986 for an excellent analysis of cultural competency in social science interviewing.

much of which was later confirmed in the Farsi-speaking focus group, we realized that some of

our implicit assumptions about what it is like to be a new immigrant who is also a new parent in

metro Vancouver were primarily based on what it is like to be a new immigrant from East Asia.

We found that immigrants from South Asia tended to share many of these concerns, but the other

immigrant groups we spoke with had quite different experiences. Therefore, as we developed our

culturally appropriate materials, we had to continue to be mindful of these potentially false

assumptions and continue to check with members of each community as to what their particular

needs and concerns were.

The project team's experience developing these materials has been experienced by other

organizations. As Diane Goldstein notes in her discussion of developing culturally sensitive

health educational materials for AIDS prevention, another highly stigmatized condition, even

when these programs and materials are developed with the "best of intentions, [they have] not

been unproblematic" because, as critiques have noted, "they are often based on stereotypes of the

communities in question or are dependent on overgeneralized or badly contextualized cultural

information" (Goldstein 2004, 56 [discussing Goldstein 2001]). However, as Goldstein notes,

this is no reason to not attempt to create such culturally informed materials and programs, but

instead to work to make them as useful as possible by seeking collaborative partnerships with

community members and organizations (Goldstein 2004, 57).

In order to have comparative data, in a variety of ways the project team tried to recruit

mothers who had experienced PMADs but had not used PPSSS's services, but we were

unsuccessful. We twice scheduled, recruited for, and then cancelled this group due to lack of

participation. This might be in part because PPPSS has been successful advertising their services

in the metro Vancouver community, and individuals who are English speaking and struggling

with a PMAD who chose not to use PPPSS's services or did not find out about PPPSS's services also might choose not to join a focus group about their experience with PMADs or be unaware the focus group exists. We pursued a variety of options to try to contact this demographic, such as talking with contacts at BC Women's Reproductive Mental Health, but were ultimately unsuccessful due to a lack of time and confidentiality concerns with recruiting patients through a mental illness treatment program.

The focus groups were vital to the success of the entire project. The project team recruited several of our video interview participants from the focus groups. The data informed the design and implementation of the video interviews, website content in English and other languages, and revised training materials for health care professionals. What we learned in the focus groups also inspired creation of several outputs. For example, several mothers and fathers let us know that it is often very difficult to communicate to their family and friends what it is like to have a PMAD—particularly when there are cultural and generational differences. Stigma about mental health seems to present a particularly high barrier for communication with the patient's own parents. Parents with a PMAD suggested that it would be very helpful to have information that explained PMADs in a simple way and described how the grandparent might be able to help. The parent could then share this simple information sheet with their family to help explain what they are going through at a time when they often do not have the physical or emotional energy to explain their condition to loved ones themselves. We implemented this excellent idea on the

PPPSS's website.[30] For example, focus group participant Penny, who immigrated to Canada with

her parents as a young child, shared how this kind of resource would help her to communicate

with her own parents:

> Penny: I think there's a stigma. . . . I mean I've seen [materials directed at grandparents]
> before, but I think it has been different languages for different families, different
> backgrounds [existing materials are not in Chinese]. . . .
>
> Like I said my parents are stressors. I think if there was something in Chinese
> directed to them to let them know that this might happen, this is the norm, [here's]
> where you can find information to help; that'd be great. . . .
>
> I'm advocate—I'm an advocate for myself already, I've gone to my doctor, sort
> of gone to a counselor, I have searched online for everything. I can give
> myself . . . the energy to go on every day. But I think if I could communicate to
> my parents what I really want to say, it would be great.
>
> But I, I just can't at this moment, not now. If there was a pamphlet, I could just
> [say]: Here. Read this.
>
> Facilitator Emma: Hmm, material that's language-specific and geared towards
> more than just to mothers, but to dads, grandparents, [and] others as well.
>
> Penny: I think that's just, anybody who has any sort of education will be able to
> handle the situation better.

Holding the focus group sessions was more complicated than the project team had anticipated

and took more time. However, in the end it proved to be time well spent. As stated above,

through the recruitment of focus group participants, the project staff also built relationships with

many professionals who have been generous with their time and expertise, including community

support workers at Family Places, public health nurses, Healthiest Babies Possible facilitators,

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[30] For an example of culturally appropriate materials that were in part intended to be an educational

resource for friends and family of patients, see postpartum.org/translations/chinese-traditional/, accessed

December 5, 2016.

and others.[31] In addition, several focus group participants continued to be involved in the project through roles such as participating in video interviews or serving as resource reviewers. These contacts were invaluable throughout the project as continued sources of information and guidance.

Video Interviews

A year or so prior to the start of this project, PPPSS staff, volunteers, and former clients had been interviewed for another video project on postpartum depression conducted by Kids Care Canada Society. Kids Care is a nonprofit based in British Columbia that began in 1987 with the mission to use video to share evidence-based information on child development and effective parenting

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[31] Family Places are local nonprofit organizations that serve children aged 0–5 and their caregivers. They are intended to provide a place for young children and their caregivers to gather, chat, and play, and often offer programs such as drop-in playtimes, parenting support programs and classes, and parent and tot enrichment classes. The first family place in Canada, West Side Family Place, was founded in Vancouver in 1973, and now there are similar organizations in many Canadian communities (see http://www.westsidefamilyplace.com/about-us/history/, accessed November 26, 2016). The Healthiest Babies Possible program is jointly funded by the federal public health program and local partner organizations, such as local health authorities. Targeted at vulnerable women, such as new immigrants or teen mothers, it is intended to provide prenatal and postpartum support, with a focus on nutrition, to help women have healthy pregnancies, improve the birth weights of infants, and support new families until the infant is 18 months (http://www.vch.ca/locations-and-services/find-health-services/?program_id=65, accessed November 26, 2016).

practice with parents in order to improve child outcomes.[32] Indeed, PPPSS's participation in this project had led the project to our video production professional, Chad Galloway, who had filmed the interviews with PPPSS staff members for Kids Care.

In January 2013, right as the project team was beginning work on our project, PPPSS staff were given rough cuts of three of the Kids Care videos to review because of the society's role as a community partner. At first, when PPPSS staff received the videos, there was concern that PPPSS's own planned video project would be unneeded or redundant because this Kids Care project existed (and was close to completion, while PPPSS's project was just beginning). However, when we reviewed the videos, it actually became quite clear that PPPSS's videos would be different from these and still fill a need. In fact, being provided with this comparative material, at this crucial point when we were just beginning our project, was an enormous gift that let the project team clarify what PPPSS really wanted to achieve with this project, and thus guided how we proceeded with the video production process.

During my first viewing of the Kids Care video drafts, I made the following observations in my notes:

> *Overall—They are all highly edited. Lots of stills of moms and babies (that look like stock art, nothing to do with these particular mums)— with moms and clinical experts talking over the pictures. Some white, at least one aboriginal, and some white but non-English as first language accents (so probably European immigrants?), voices. So far no East Asian or South Asian voices, and not many non-white faces in the stock art. Also where are the dads? Maybe a segment about*

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[32] The Kids Care series of videos on postpartum depression can be viewed here: http://www.kidcarecanada.org/video-section/postpartum-depression, accessed July 29, 2016. Kids Care official mission and vision can be viewed here: www.kidcarecanada.org/vision#vision, accessed July 29, 2016.

them will come, or maybe just focusing on the moms. Music in background. Each segment ends with take home points.

Video One: Not Just Baby Blues: Starts with a couple moms and their experiences, but mostly doctors/nurses talking. Discusses what perinatal depression and anxiety is and how it is different from just baby blues. Very educationally oriented.

Video Two: New Moms Need Support: Starts with moms talking about their experience and how things felt not right. More moms' voices than first video, then some clinicians.

Video Three: The Myth of Motherhood: Again starts with moms talking about their experiences. Lots of explanation by psychologists/clinicians about what the myth of motherhood is about.

First, knowing that these videos existed in the world gave PPPSS permission to proceed with the original vision of presenting longer segments of one person talking about their postpartum experience instead of making educational videos explaining postpartum depression. Someone was already doing that, and doing it well. Instead, it gave PPPSS the space to pursue what I and PPPSS staff felt the organization did best: share the direct experience of people who had experienced a PMAD and emerged from the other side in order to reduce isolation and encourage struggling new parents to reach out for support and treatment. In part this decision was made because it would be less costly than making highly edited video segments, but it was also a choice that fit with PPPSS's philosophy to put the parent first as a fully capable person who, given the right support and resources, can engineer his or her own recovery.

In the Kids Care videos, I felt that it was very clear that clinicians were the videos' creators and thus had the narrative power. This was demonstrated by the fact that the clinical experts were given the majority of screen time and because the clinicians were shown explaining what perinatal depression and anxiety is, discussing why it occurs, suggesting effective treatment options, etc. In contrast, the mothers who are featured just describe their own experience of

perinatal depression and anxiety, without making much meaning from it. In fact, on the Kids

Cares website, each video's written description has a section titled "Featuring," which lists the

names of all the clinicians who appear in the video. However, the names of the parents who

appear in the video are not mentioned. This situation, in which one set of people explains

everything and the other is used as an example, sets up an imbalanced power dynamic. I know

some of the featured mothers, and I am quite certain that they could explain nearly everything

about why PMADs occur and what effective treatment looks like just as well as the clinical

experts.

Figure 2. Screenshot of video description from Kids Care website[33]

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[33] http://www.kidcarecanada.org/media/postpartum-depression-not-baby-blues, accessed November 25, 2016.

This power dynamic in no way makes the Kids Care videos not useful, or not good (and it certainly does not make them bad), but it does mean they have a certain orientation and point of view that I would sum up as "we, the clinical and public health experts on this issue, want to help you." This approach makes sense for the Kids Care organization, which is run by doctors and public health professionals whose main concern is improving outcomes for young children, and is in keeping with their organizational values. Indeed, several of the videos from the Kids Care project are now part of the video collections on the PPPSS website and one is regularly used in PPPSS trainings.

By thinking about the Kids Care videos, the project team came to a much clearer understanding of our own project.[34] We realized that we needed to be mindful of who was given authority in the videos and in the overall project. In the PPPSS project, the primary creators of the videos, and experts on PMADs, would be parents who have experienced it. Most of the individuals involved, including both interviewees and project workers, also had educated themselves on the current research about PMADs, both to help in their own recovery and understanding, as well as to be able to better help others.

At this important moment when we were just beginning the project, we decided to be sure that we remembered that the interviewees were the primary video creators at every step of the process, not just during the interviews. In addition, it clarified that for the project to succeed we needed to keep the fact that those who have experienced PMADs are the most important experts in it and at the very forefront of everything that we were doing. In particular, we wanted to

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[34] At this point, the project team primarily consisted of Sheila Duffy, Georgie Hutchinson, Emma Lee, and myself.

carefully attend to who was given the air time to explain the big ideas (such as why PMADs occur or what treatments are effective) and to how we presented those explanations, as a way to be mindful of the power differentials present in any community project. Above all, we wanted to make sure that the videos reflected PPPSS's unique self-help orientation to treatment and support of those with PMADs. We felt that keeping true to the organization throughout the project, instead of trying to make the organization fit into some outside conception, was vital to making this project successful.

Recruitment of Participants

We required video interview participants to have experienced a PMAD in the past few years, but to not be currently attending a PPPSS support group (although in one case someone was supposed to be leaving group, but had an unexpected difficult life event and ended up still attending the group when her interview took place). We did not require that interviewees be a former PPPSS client, but in the end all were. Because these interviews would be professionally filmed and thus expensive, we wanted to carefully select and screen participants. We had budgeted funding to cover about eight on-location half-day shoots, and we would be able to conduct one to three interviews in a half day at each location.[35]

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[35] For three locations, we conducted interviews with the mom, the dad, and together as a couple. For one, we conducted two unrelated interviews in one interviewee's home because one of the interviewees was in the process of moving and conducting the interview in her own home was not a good option. In another case, we used the additional time in the location to film some segments on targeted topics, designed to fill the gap in our content, with the society's director, Sheila Duffy. And in one case, we

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The project team's criteria for selecting interviewees, which we shared with staff and volunteers, was parents who had experienced a PMAD, such as perinatal depression, perinatal anxiety, or post traumatic stress disorder (PTSD), were able to speak thoughtfully about their postpartum experience, and were willing to be interviewed on video and have parts of this interview be publicly available online. If the parent had a partner, it was desirable if the partner also would be willing to be interviewed, both separately and with the person who experienced a PMAD, and at least some interviews needed to include partners in order to meet the project goals.

In addition, for the project to be able to fulfill its goals the project team needed to recruit participants who represented diverse personal characteristics and a diverse set of experiences. The project team defined diverse personal characteristics as factors such as: culture/language group, immigration status/experience, sexual and gender identity, economic status, geographic location in the metro Vancouver area, and family size and composition. A diverse set of experiences was defined as: the type of PMAD (or combination of conditions), when in pregnancy or after birth the individual started not coping, type of pregnancy experience, type of birth experience, presence or absence of additional health problems for parent or baby, and path to recovery. The funding did not allow PPPSS to provide honorariums (Vancouver Coastal Health [VCH] policy does not allow paying patients). However, PPPSS did receive funding to offer child care reimbursement and all participants were also given copies of the interviews. But,

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were just able to conduct the one interview. This meant we ended up with fourteen interviews, but used just six days of our shooting budget (which later let us create another set of videos to support PPPSS's trainings).

clearly the primary motivation for participants would be the opportunity to give back to PPPSS and help struggling new parents and their loved ones.

The project team recruited eleven interviewees: seven mothers who experienced perinatal depression and/or anxiety, one father who experienced perinatal depression and anxiety, and three fathers whose partner experienced perinatal depression and/or anxiety. The three couples who participated were each interviewed separately and also interviewed together.[36] The project team was very careful to not over-recruit. We did not have funding to do additional filmed interviews, so we did not want to promise someone an opportunity that we would later have to back out of.

The project team recruited individuals with a diverse set of cultural and social backgrounds, including individuals who immigrated to Canada as adults (from Japan, Mexico, and the United States), an individual who immigrated to Canada as a child (from Hong Kong), and individuals who were born in Canada. In addition, we recruited interviewees with a wide range of perinatal experiences, with a focus on the kinds of experiences that are risk factors for PMADs. These experiences included: past history of mental illness, unstable family relationships during the parent's own childhood, difficult or high-risk pregnancy, traumatic birth experience, loss of close family member or friend during pregnancy or postpartum, significant postpartum pain, infant with colic or other high-needs behavior (such as only sleeping in arms), infant with a significant health condition, breastfeeding difficulties, and a difficult or unstable relationship with a partner. Because of the limited number of interviews time and funding allowed us to conduct, we were

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[36] We also filmed an interview on targeted topics (rather than about her own postpartum experience) with PPPSS Director Sheila Duffy.

not able to cover all topics. For example, suicidal thinking is not uncommon for those experiencing a PMAD, but we did not address it in this set of interviews.[37]

Participants took part for many reasons, but many expressed their desire to help other parents who were suffering as an important motivation. For example, in her follow-up interview, video interviewee Robin remembered that:

> I was nervous to be involved, for part of it. But also I felt that because of my own experience with postpartum and with the support group that, hearing other women talking about it, was such an integral part of my own healing. And was such an important part.
>
> Even just the first time hearing somebody speak about their experience affected me deeply. So if I thought if there was anyway I could say anything that might possible ring true to somebody else, then it would be worth it to talk about it. Because that's important. . . . Even if it was just one mom saw it and it maybe made her pick up the phone, or send an email, or talk to a friend, or something, it would be worth it.

PPPSS found that the video interviewees were incredibly generous with their experiences and insights.

Preparing for the Interviews

After careful consideration, the project team decided not to conduct any recorded interviews prior to the video interview (other than for those who chose to participate in an earlier focus group). This decision was made was so that the participants wouldn't feel that they had already told us parts of their experience and thus tend to leave aspects out during the filmed interviews. However, we did communicate our expectations and provide opportunities for the participants to ask questions multiple times via email and by telephone prior to the interview.

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[37] Although we later did in our videos designed to support professional trainings.

The project team used what we had learned conducting the focus groups to help guide the question formation for the video interviews. We used the expertise of PPPSS staff and volunteers to help edit the primary question lists and then modified it for each interview. The questions were designed to be open-ended and to allow the interviewee to control the narration, while still keeping the focus of the interview on their experience during the perinatal period (as opposed to a life history, for example). In addition, the interviewers, who were all trained PPPSS counselors who were given additional training in oral history interviewing for the project, were encouraged to treat the question list as a guide rather than something that had to be rigorously adhered to. This approach was influenced by the methodological work of folklore scholars such as Edward (Sandy) Ives (1995) and Charles Briggs (1986).

Conducting the Interviews

The project team worked with video production professional Chad Galloway to plan and film all the interviews. Chad brought his own experiences with fatherhood and difficult perinatal adjustment to his work and brought an artist's eye to the entire process. In most cases, we chose to record in the interviewees' home, as this was the location that they would be most comfortable in. When this was not possible, we found alternative locations and dressed them to look as homey as possible.

In conducting the interviews, although we had a set of broad questions to ask interviewees, we let the interviewees take the lead for much of the interview and share what they thought was important for struggling new parents and their loved ones and professional helpers to know. However, at times we did take a proactive approach in making sure we captured the material we had decided was important to the overall success of the project. For example, when about three-

fourths of the videos interviews were conducted, the project team looked at what we were coding and realized two areas were not really being addressed that we knew (from the focus groups and PPPSS's client feedback) were crucial for struggling new parents: lack of sleep and intrusive thoughts. The reasons that these were not being addressed turned out to be different. For lack of sleep, it seemed that interviewees were not talking about it because it was just an obvious part of everyone's experience (new parents often get very poor sleep, and this lack of sleep is a significant contributing factor to why some new parents get a PMAD). Almost all of the parents we interviewed could have spoken to this issue, but not all did because this obvious area had been ignored during the interview in favor of the more unique aspects of their experience. Therefore, for the last few interviews we let the interviewees know we really needed material on this topic and asked targeted questions to ensure we recorded it.

For intrusive thoughts, we knew that this was a sensitive topic for many people. For struggling new parents, intrusive thoughts can often be one of the most painful parts of their postpartum experience. We knew from our counseling work that it was often very freeing and healing when parents who were having them realized that they were not the only person having this thought, that these thoughts were actually common, and that having them did not mean they were going to happen or that they were going to act on them. Therefore, it was very important to include this material in the videos. We carefully recruited two participants, Linda and Robin, with the specific goal of speaking about intrusive thoughts. We spoke about what they would be willing to disclose ahead of time, talked about it during the interview, and paid close attention to it during the editing process.

In the end, the project team conducted, processed, logged, and transcribed fourteen video interviews. The original interview recordings ranged in length from about forty minutes to over

three hours. We then coded the transcriptions in order to identify themes and topics that emerged in the interviews, such as postpartum pain, isolation, intrusive thoughts, and what helps.

Production Phase

Project outputs during both phases of the project included: 1) Approximately 230 video segments from interviews with parents who have experienced PMADs. 2) Revised in-person support skills workshops, including substantial video content, and a new online version of workshop. 3) Revised editions of three core print publications. 4) Pilots of two new support programs targeting underserved populations: individual text-message and online group. 5) Culturally appropriate educational brochures and website content in Chinese (both simplified and traditional), Farsi, Hindi, Punjabi, and Spanish, and 6) Revised website with new content targeted at specific audiences and embedded video throughout.

Edited Video Segments

The project team, primarily myself and project assistant Emilie Irelan, coded the logged and transcribed video interviews in order to identify themes and topics that emerged (such as postpartum pain, isolation, intrusive thoughts, and what helps in recovery), and used those resources to create paper edits of the video segments. Videographer and editor Chad then used our paper edits to create the final segments. Each interview yielded an average of fifteen to twenty-five short segments (from thirty seconds to five minutes in length) on a wide variety of relevant topics. Most of the segments were used just as they were—as brief standalone stories. The 237 segments is a far greater number than we originally thought we would create, but there

was so much excellent material in these interviews that we wanted to have many options for future use.

The project team also created eight longer edited segments, each five to seven minutes long. Each segment focuses on a particular participant's perinatal experience in a way that also highlights targeted overall themes that are of importance to many parents who experience PMADs.

Table 3: Journey Videos

Title	Themes
Allen's Journey	Dad with perinatal depression and anxiety; relationship conflict resulting in an improved marriage; how to support someone going through perinatal depression and anxiety; advocating for changes to postpartum care for fathers.
Brianna's Journey	Postpartum PTSD; death in family during pregnancy; traumatic birth; anger; relationship conflict; role of psychiatric help, support group, and self-care in recovery.
Linda's Journey	Previous mental health conditions (in self and family); history of trauma and abuse; loss of relationship with own parents; relationship conflict resulting in divorce; role of support group and self-care in recovery.

Robin's Journey	Perinatal depression and anxiety with birth of second child; infant with serious medical condition; death of close friend in postpartum period; intrusive thoughts; role of support group and self-care in recovery.
Maria's Journey	Perinatal depression and anxiety with birth of first and second child (not diagnosed until second); sleep deprivation; anger; relationship conflict resulting in a stronger marriage; role of cultural difference in her perinatal depression and anxiety; importance of finding other Spanish-speaking moms to her recovery (immigrant from Mexico); role of support group and self-care in recovery.
Maria and Pablo's Journey	Impact of perinatal depression and anxiety on their relationship and on supporting partner; how to support someone with perinatal depression and anxiety; what they learned about their relationship and each other.
Mariko's Journey	Impact of cultural difference and language difficulties (immigrant from Japan) on her postpartum experience; relationship conflict resulting in a stronger marriage; role of stigma in not seeking help and having difficulty using available help; impact of stigma in her community; impact of having a child with someone from another culture.

Mariko and Kasimir's Journey	Impact of perinatal depression and anxiety on their relationship and on supporting partner; how to support someone with perinatal depression and anxiety; what they learned about their relationship and each other; role of stigma in not seeking help and having difficulty using available help; impact of having a child with someone from another culture.

The long segments went through several revisions as explanatory text was edited, video segments were added and deleted, and additional images and background music were added to help tell the interviewee's story in an effective way. These powerful journeys have also been designed to provide a video-mediated personal encounter with an individual who has experienced a perinatal mood disorder, with the overall goals of decreasing the isolation felt by those with these conditions and reducing the stigma that often surrounds them. They are intended to be somewhat similar to the experience of listening to a co-participant in a support group share their experience.

The project team worked closely with the interviewees throughout the editing process. We provided them with rough cuts of the longer edited segments for their feedback, and made changes to the content based on their assessments. For the final step, I met with all interviewees to review all of their segments. The interviewees approved each video clip for one of two types of uses, either public (on website and elsewhere) or controlled use (in PPPSS trainings, presentations, and support groups only). All videos are now stored on PPPSS's password

protected Vimeo account.[38] Segments have been selected and placed on the website and are used in PPPSS's training materials. Segments will continue to be added to the PPPSS website over time, so that fresh and updated content is available.

Video Production Concerns and Choices

In order for this project to meet its goals, PPPSS needed use a video production professional to record the interview footage and edit the final results. PPPSS had experimented with recording and editing interviews prior to this project, but the amateur quality had significantly detracted from the impact and limited their usefulness. For example, shooting in small spaces, like most of our interviewees' tiny metro Vancouver apartments, can be very challenging. Because of his experience in similar projects, Chad was able to quickly find the best location in a person's home, move furniture, objects, and lighting sources around, and, in the end, make it look like the best version of their own space. Making the visual setting calm, pleasant, and attractive was vital to doing justice to each person's story. We also carefully attended to the sound quality, which was more of a challenge in some locations than others. For example, in more than one case we conducted the interview on the weekend because during the week there would be noise from a nearby construction project.

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[38] Vimeo is a web-based platform designed to store and share video recordings. Designed by filmmakers, at the time of the project its available features were better suited for providing differential access to video recordings (such as only allowing staff members with a password access to particular videos) than other available video-sharing platforms (such as YouTube).

In documentary video production, the main subjects are often filmed doing things other than being interviewed (such as performing their work tasks, walking down the street, or playing with their kids). This type of b-roll footage is helpful in the editing process in order to provide something to show during transitions as well as relief from just looking at a talking head for the entire video. In our case, from a filmmaking perspective, the most obvious approach would have been to film the participants doing ordinary family things with their partners and children. However, most of the participants were quite concerned about protecting the privacy of their children and did not want them filmed in the present moment. This approach would have also required having the participant's families present for part of the shoot, and then getting them to leave to conduct the interview in peace. In addition, setting up for the additional type of filming would have taken more time and increased our production costs.

To deal with this editing problem, we chose to do some pickup shots at the end of each interview to help with editing transitions (what we ended up calling "hand shots" as most of them were close-ups of the interviewees doing something with their hands) and we also planned to use still images. We experimented with trying to find stock photography, but in the end what was available did not have the right emotional tone or level of visible cultural diversity. We did find some images (which we used in the website and print publications) but there were not nearly enough available to use in the video editing. In addition, using stock photography gave the videos a tone that was too impersonal.

Instead, we asked our interviewees to supply family photos. At first we just received standard happy snapshots and studio portraits that people tend to supply when you ask for family photos. But eventually we were able to communicate that we wanted a wide range of images, including ones that showed the difficulties that the interviewees had experienced. One participant was able

to understand my fumbling explanations of what we were looking for and supplied an incredible set of images. Chad then used those images to re-edit her journey video to be much more powerful and impactful. Once we had that video as an exemplar that demonstrated what images we were looking for and what impact those types of images would have, the rest of the interviewees were able to understand what we needed and most of them were able and willing to help. Two participants, for complex reasons, were never able to supply the needed photos. For those cases, we used the hand shots and some other images to complete the editing process. In some cases the participants chose to only provide images of their child as a baby, which most people would not recognize them from. Others were fine with including images that were more recent. In all cases we left the final choice of images up to the participant.

Use of Video

We have used these powerful interviews in a variety of ways, thus benefiting new parents and those who work with them far into the future. The publicly available ones (on the website) and privately shared ones (in trainings, support groups, and one-on-one) will serve purposes such as reducing stigma through providing personal mediated interactions with those living with PMADs, helping new parents to self-identify as having a PMAD, helping family and friends to understand what having a PMAD is like, and helping those with a disorder feel that they are not alone.

Web Resources

In the original grant, PPPSS proposed to redesign the website and make the content more interactive. As is true for many organizations, PPPSS's website serves multiple audiences and

purposes. Its most important function is to serve struggling new parents looking for information about and support for PMADs, as well as for those who are looking to find help for them, such as their friends, family members, and helping professionals. In addition, it serves as a way to keep donors, volunteers, and other members of the community informed about the society's activities, including trainings and fundraising events, and provides a way to obtain the society's publications.

At the time that we wrote the grant, the PPPSS website had just been redesigned in the previous year. Staff and board members were happy with the new visual design, but they were very frustrated with how the site functioned. The website was hosted on the web design company's servers using a proprietary content management system. PPPSS staff were not allowed access to the majority of the content in order to edit it. Instead the website management company charged PPPSS a fee for each requested update. When PPPSS had contracted with this company for the redesign, they were having significant problems with their current website and had limited funds to do anything about it. What the company was offering seemed like a good deal at the time, but unfortunately, PPPSS did not have the technical expertise to fully understand the problems that would be created by the new system. In addition, the website did not properly display on mobile devices, which at the time the grant was written in late 2012 accounted for 30 percent of site accesses and has continued to increase over time. Therefore, in this project we proposed to redesign the website to be compatible with a variety of viewing devices, migrate it to a common, easily modified content management system (such as WordPress), and move it to a server space that PPPSS staff could access themselves.
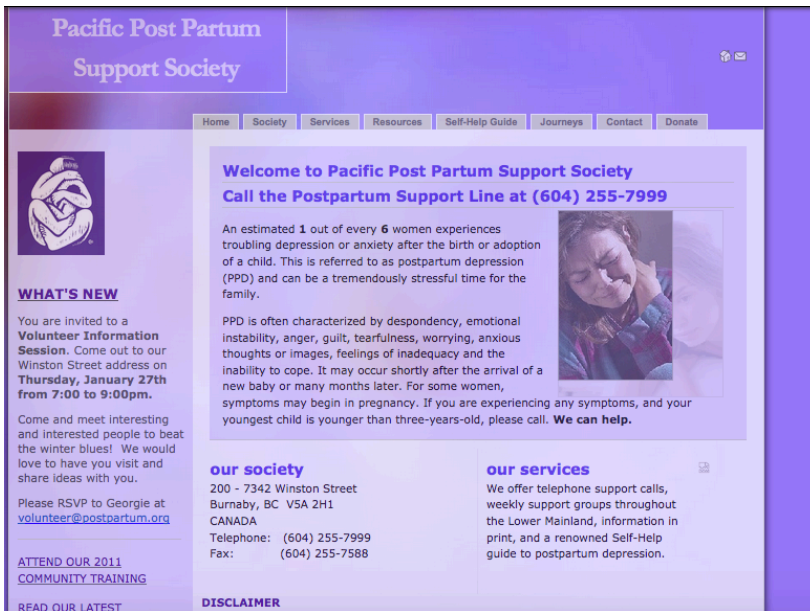
Figure 3: PPPSS site prior to 2011 redesign.[39]
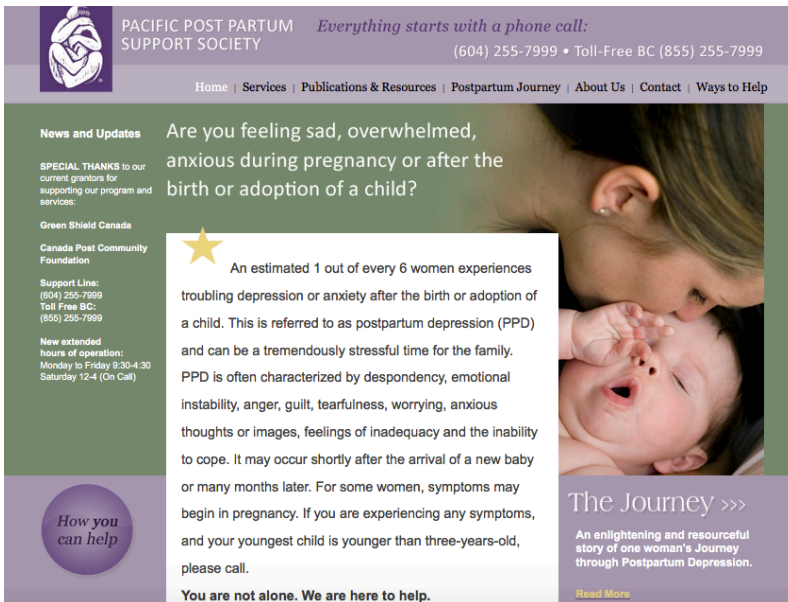
Figure 4: PPPSS home page after the 2011 redesign, but prior to the 2013 redesign.[40]

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[39] https://web.archive.org/web/20110127115419/http://www.postpartum.org/index.htm, showing page

on January 27, 2011, accessed July 20, 2016.
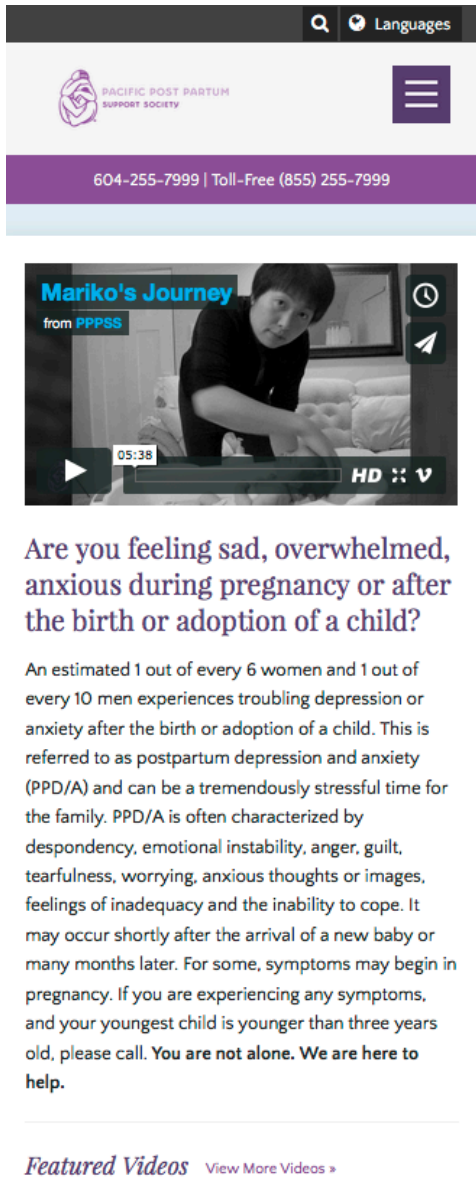
PPPSS also proposed to add new educational and outreach materials to make the site more engaging and interactive, including an events calendar, blog, and video segments, created from the interviews with families on topics such as adjustment to parenthood and how to seek help. These video segments would both provide valuable information and reduce stigma by providing users with personal mediated interactions with individuals who have had a PMAD. We also planned to develop culturally appropriate website sections in Chinese, Farsi, Punjabi, and Spanish, using the content developed for the informational brochures as well as links to vetted outside resources. Discussions with community members has indicated creation of culturally appropriate materials is more useful than simply translating the current website content. These sections would be easily accessed from the main page.

Figure 5: Redesigned home page, mobile device view.[41]

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[40] https://web.archive.org/web/20120913232136/http://www.postpartum.org, showing page on September 13, 2012, accessed July 20, 2016.

[41] http://www.postpartum.org, accessed October 11, 2016.
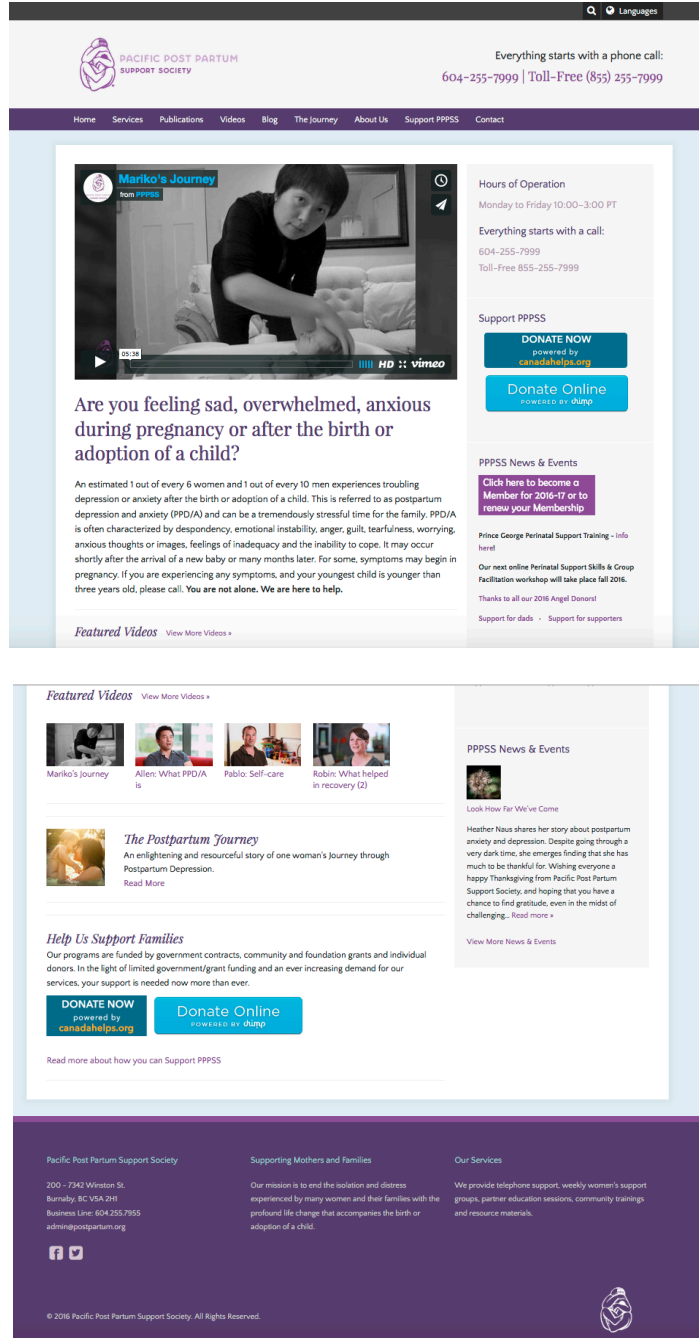
Figure 6: Redesigned home page, computer view.[42]

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[42] http://www.postpartum.org, accessed October 11, 2016.

The project team hired an outside contractor, Popgun Media, to redesign the website with the goals of making it cleaner and easier to use. In the first phase of the web project, the existing content was reorganized and migrated to the new content management system (WordPress) and moved to our own server space. This part of the project was live by August 2013. The redesigned site (fig. 5) keeps the core visual design of the previous site (fig. 4), so as not to confuse users (and the society was pleased with the visual look of the previous site), but with a cleaner, less cluttered look and improved navigation designed to help users easily find the resources they are looking for. Most importantly, authorized PPPSS staff members are now able to easily update any of the content on the site, without having to pay a content management company to do it for them. Therefore, it was now possible to keep the site up-to-date and to add new content as it is created. Popgun Media provided a user manual and trained PPPSS staff in use of the site.

During the redesign process, the project team encountered a few situations that we did not expect. For example, when we began to migrate PPPSS's current content from the current website to the new website we discovered that, contrary to our expectations, we did not own any of the stock images used on the existing site. Rather the images were licensed to our website designer and hosting service provider. This situation meant that we needed to select and purchase the rights to all new images for the site. We were able to do so for a reasonable cost, but the process of selecting new images did delay the redesign process. Some of the existing content had been developed in partnership with VCH, so changes to these images also had to be approved by the partner. During the project, a former client who is a design professional offered to create brand guidelines of official colors and fonts for the society, and the standards were applied to the website in March 2014. In addition, a search feature was added at this time.

In the second phase of the web project, the project team, especially writer and editor Linda Tobias, used what we had learned through our research to create new content. One approach was to review available online resources of other postpartum support agencies, such as the US-based Postpartum Progress, and Perinatal Anxiety and Depression Australia (PANDA), as well as organizations for other medical conditions, such as the Canadian Cancer Society, and Anxiety BC.[43] These exemplars helped us to see how such websites could be organized, what information and resources we might include, and what design choices made the sites useful and appealing. Through this research the project team also started to collect links to outside resources that we would later link to from PPPSS's site.

In the focus groups and interviews, the project team also asked what kinds of online resources would be useful for new parents. Parents that we interviewed, both as part of focus groups and individually, clearly stated that PPPSS needed to improve our informational resources for fathers who were going through a PMAD themselves as well as for partners/family members supporting those with PMAD. In the past, there was not a clear distinction between these two groups on the website and the materials often implied that all fathers were supporters (and not themselves perhaps experiencing a PMAD) and that all supporters were male partners (which, of course, left out both non-male partners as well as other friends and family members of both genders). Therefore, by March 2014 the project team added two new sections to the website, "For Dads" and "For Supporters." These sections consist of multiple pages with clear,

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[43] Postpartum Progress: www.postpartumprogress.org. PANDA: http://www.panda.org.au/. Canadian Cancer Society: http://www.cancer.ca/en/?region=on. Anxiety BC: https://www.anxietybc.com/. All accessed August 15, 2016.

easy-to-understand, and targeted information. The website now has embedded appropriate

segments from the project's interviews with parents who have experienced PMADs (either

themselves or their partners) and includes links to vetted outside resources. The pages are linked

to throughout the site and are also accessible through the top menu bar under "Services." With

the funding from the second grant, the project team was also able to add a dedicated "For Moms"

section in a similar style.

The project team also added video content throughout the website in a variety of ways. First,

the home page now features a highlighted video as the main image, which is regularly rotated.

Several other videos are featured at the bottom of the page, with a link to go to the main video

page. Second, users can go directly to the main video page via a prominent link in the main menu

bar. Once there, users will find videos organized by who they are about (about dads, about

moms, about supporters) as well as by general topic (common concerns, cultural difference,

relationships, supporting, and what helps). Third, video content is now integrated throughout the

site and will continue to grow in order to keep the site fresh and engaging.[44]

Videos are directly imbedded into the content pages for easy viewing (figs. 5 and 6). PPPSS

decided to use the paid hosting service Vimeo, rather than the free service YouTube, because of

more secure features that allow us safe storage of and differential access to non-publicly

available videos. Users can also click on a link to view the video with the full transcript

displayed below. This solution was much more cost-efficient that embedding subtitles directly

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[44] "For Dads": http://postpartum.org/services/dads/. "For Supporters":

http://postpartum.org/services/supporters/. "For Mom": http://postpartum.org/services/for-moms/. Main

video page: http://postpartum.org/videos/. All accessed August 2, 2016.

into the videos, but still allows users who need assistance to understand what the interviewee is saying, including second-language learners or those with hearing impairment, to access the materials.

Beginning in January 2014, with the functionality afforded by the new website, PPPSS began to publish regular blog posts. The blog posts are intended to serve a variety of audiences, including PPPSS clients (and struggling new parents who are not clients), potential donors and volunteers, and allies and other interested community members. Entries might publicize a fundraising event, share personal experience with PMADs, give tips for getting through an upcoming holiday, or share new research on PMADs. A few PPPSS board members and a practicum student developed a social media policy and a brief handbook for social media volunteers to guide this work. By mid-2016, the blog has successfully survived two changes in editors, continues to grow in scope and impact, and is well publicized on PPPSS's social media accounts.[45]

Culturally Appropriate Materials

Making use of the information that the project team gained during focus groups and one-on-one interviews, we wrote the culturally appropriate brochure text for the Chinese (both traditional and simplified), Punjabi, Farsi, and Spanish language brochures. In all cases, the majority of the brochure is in the relevant language. In this part of the project we were mindful of the limits of what PPPSS can currently offer by the way of services to those who either do not speak English or who are more comfortable with another language. At this point, due to a lack of funding and

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[45] All blog entries can be viewed at: http://postpartum.org/news-events/.

staff, PPPSS does not have staff members or volunteers who speak all of the languages that were included in the project (although PPPSS is always recruiting for such volunteers and is mindful of this issue when hiring staff). In addition, as a relatively small organization, there is no guarantee that a particular language will be supported long-term (as staff and volunteers come and go, taking their language and cultural skills with them). Therefore, PPPSS does not promise to provide telephone or group support services in any language other than English. Still, the organization felt that having culturally appropriate materials in a variety of languages was an important and useful step.

First, even though someone many speak English well enough to use PPPSS's services, when they are struggling with postpartum they may not fully understand informational materials if they are not in their own language. For example, video interviewee and Spanish-speaker Maria had been living in Canada for many years and was relatively fluent in English, but she did not really realize that she had postpartum depression until her mother directed her to some Spanish-language materials. In addition, PPPSS's goal was not just to translate our current materials into a variety of languages (which is relatively inexpensive and easy to do, but ultimately not that useful). Instead it was to create materials that specifically attended to the needs, concerns, and sociocultural situations of each particular cultural group. Therefore, the primary purpose of these materials was to provide information about PMADs and adjustment to parenthood to new parents from these cultural groups. For those who had some English-language skills, or were lucky enough to speak a language also spoken by one of PPPSS's current staff or volunteers, they would be able to access PPPSS's service if they wished. However, even if this was not the case, the parent would at least have a name for what they were experiencing and would be able to access help and support through other medical and social services where translation is

available.[46] To help mitigate this lack of support for non-English speakers in a sustainable way, PPPSS has a grant-funded multi-cultural training program to train professionals and volunteers, such as community support workers and public health nurses, to provide effective support to new parents in their own communities. Therefore, another purpose of these materials was to provide a useful resource for these community support workers. The project team also hoped these materials would help fulfill a need that had been identified in our focus groups to provide struggling new parents a way to communicate what they were experiencing with their own parents or other family members when there was cultural and generational difference.

In order to assist English-speaking health care professionals and community support workers, an English-language note is included on each brochure giving the English title and directing English-readers to our site for a full translation of the brochure content. Along with basic information giving PPPSS's contact information and describing their services, each brochure includes a section describing the signs and symptoms of perinatal depression and anxiety (with particular attention to how they may be likely to manifest in members of that community), particular concerns or risk factors surrounding adjustment to parenthood for members of that community, and quotations from members of that community about what it is like to be a new parent, and/or experience a PMAD.

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[46] Although the service is far from perfect, any medical professional or public health service in British Columbia can access translation services via telephone in almost any language. However, as a peer support nonprofit, PPPSS would have to pay a high fee for this service and so it is not a viable solution for the organization. To help with this, the website for each language also includes a list of vetted links to more information and community services provided in that language.

Linda Tobias, a professional writer, who immigrated to Canada as a child, wrote most of the culturally appropriate brochures. Most of the translations were done by Mosaic, a Vancouver nonprofit that provides services to new immigrants. However, the Chinese-language brochures were written and translated by Emma Lee, a Chinese-speaking PPPSS staff member, and have been reviewed by a Chinese-speaking public health nurse. We translated the content into both Traditional and Simplified Chinese versions to reach both the Cantonese and Mandarin speaking populations in metro Vancouver. The brochure content was reviewed and edited by our community partners at several points in the process before and after translation. This review process was vital in ensuring that the information was relevant for the intended audience and that the tone of the translation was friendly, warm, and welcoming, rather than overly official or medical.

The text of the culturally appropriate brochures also forms the core of the Farsi, Spanish, Punjabi, and Chinese webpages. Mosaic provided a plain-text version of each translation so that PPPSS could post the information online. The project team purchased stock photography depicting individuals who appear to be part of the cultural group who tends to speak the language to illustrate the content. PPPSS also received some donated images from staff and volunteers. In addition, users can also download a PDF version of each language's brochure in either English or the appropriate language. The second main component of each language's webpage is a list of recommended informational and community resources (all of which either have web resources available in that language or provide services in that language). These resource lists were complied in close collaboration with community partners (who know the relevant language). Once finalized in English, they were translated by Mosaic, checked by the community partner, and made available on the website. All of the content is available both in the targeted language

and in English (primarily included so that care providers can see what they are referring someone to). Prominent links make it easy to navigate back and forth between the English-language and translated versions.[47]

In phase two of the project, PPPSS received funding to translate the Punjabi materials into Hindi. When the project team was conducting focus group sessions for Punjabi speakers, we discovered that this was a difficult task in the VCH service area. Instead, we were successful at recruiting new mothers who were new immigrants from South Asia. Most of them spoke Punjabi and/or Hindi, but other languages were also represented. Census data confirmed Hindi was the second-most common South Asian language in metro Vancouver. Therefore, we decided to take the materials that we had created in phase one and translate them into Hindi, and then to find and vet Hindi-language resources in order to increase the reach of these materials beyond Punjabi-

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[47] Urls to culturally appropriate webpage (all accessed December 1, 2016):

Chinese (simplified): http://postpartum.org/translations/chinese-simplified/

Chinese (traditional): http://postpartum.org/translations/chinese-traditional/

   English version: http://postpartum.org/translations/chinese-english

Farsi: http://postpartum.org/translations/farsi/

   English version: http://postpartum.org/translations/farsi-english/

Hindi: http://postpartum.org/translations/hindi/

   English version: http://postpartum.org/translations/hindi-english/

Punjabi: http://postpartum.org/translations/punjabi/

   English version: http://postpartum.org/translations/punjabi-english/

Spanish: http://postpartum.org/translations/spanish/

   English version: http://postpartum.org/translations/spanish-english/

speaking individuals. Finally, it is important to reinforce that the most critical part of using these kinds of approaches in other applied folklore projects is that the methods of gathering information, the content of the educational and support materials, and the delivery method of materials and services must specifically be created in close collaboration with members of the particular community.

Publications

In phase one of the project, PPPSS received funding to redesign their flagship client publication, *Postpartum Depression and Anxiety: A Self-Help Guide for Mothers*, in order to transition to an e-book and print-on-demand model of distribution, and to make the publication available online through Amazon.com (instead of just available from PPPSS's websites and a couple of specialty health-oriented bookstores). The overall goal of this part of the project was to make this valuable publication more widely available and to improve the speed and efficiency at which orders were fulfilled. The need to create a new design that met the requirements of print-on-demand and e-book vendors gave PPPSS an opportunity to select updated images for the books (replacing some dated and poor quality line drawings) and to apply the society's new design guidelines to the publication.

This new model of distribution worked well for PPPSS's United States and international sales through Amazon.com. However, as we proceeded, we discovered that in Canada in 2013, print-on-demand distribution was not actually cost effective, in part due to much higher shipping costs. In addition, having Amazon.ca handle Canadian distribution was also not cost efficient, in part due again to the high costs of shipping books to their warehouse location and warehouse storage fees. Therefore, at the time of the project we decided to continue to use the current model

of print distribution in Canada (printing a run of books and fulfilling orders out of the PPPSS

office), while also making an e-book available through Amazon.ca.[48] In 2015, Amazon.ca

decided to make print-on-demand books created through Amazon.com available in Canada for

the standard Canadian shipping arrangements. Therefore, the initial goals of this part of the

project have now been met. After the changes to publication distribution were made, staff time

spent on publication distribution by PPPSS staff decreased about 25 percent. Volunteers are no

longer used for publication distribution, thus freeing them to focus on other areas.

Professional Training Materials

PPPSS delivers three one-day trainings on a regular basis: Perinatal Support Skills, Group

Facilitation, and Multicultural Focus. The Perinatal Support Skills training focuses on basic skills

for supporting parents during the perinatal period. The Group Facilitation training session builds

on the skills gained in the Perinatal Support Skills workshop to prepare participants to facilitate a

perinatal support group. The Multicultural Focus training provides support skills and basic

education about perinatal depression and anxiety to multicultural support workers who can then

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[48] The Kindle e-books can be viewed at:

US: Amazon.com: https://www.amazon.com/Postpartum-depression-anxiety-self-help-mothers-

ebook/dp/B00IADO8RU/ref=tmm_kin_swatch_0?_encoding=UTF8&qid=1480294461&sr=1-

1https://www.amazon.com/Postpartum-depression-anxiety-self-help-mothers-

ebook/dp/B00IADO8RU/ref=tmm_kin_swatch_0?_encoding=UTF8&qid=1480294461&sr=1-1

Canada: Amazon.ca: https://www.amazon.ca/Postpartum-depression-anxiety-self-help-mothers-

ebook/dp/B00IADO8RU/ref=tmm_kin_swatch_0?_encoding=UTF8&qid=1480294461&sr=1-1

Both accessed October 11, 2016.

reach out and support women in their communities, often in their own language. This Multicultural Focus training includes content also covered in the previous two workshops, revised to attend particularly to issues related to cultural difference, as well as including additional content designed to meet the needs of those working with diverse communities.

After completing a review of the current training materials for these three workshops, the project team identified the most effective existing materials (based on participant evaluations as well as staff assessments) to form the starting point of our revisions. We then revised our audiovisual presentations (PowerPoint slides with embedded audio and video) and workshop presenter documents (agendas and notes) with two primary goals. First, the project team worked to reduce written text and increase use of images and audiovisual materials to better support a wider variety of learning styles as well as to increase the visual impact and clarity of the presentations. Extra written content was used to create more robust handouts. These revisions have resulted in a much cleaner presentation. For example, figure 7 is a slide from PPPSS's previous version of the Perinatal Support Skills training:

Risk Factors for PND

- **Previous history of PND or history of depression:**
  - Self &/or family
- **Stressful life situations, such as:**
  - Partner conflict
  - Little support from family/friends
  - Past or current history of violence and/or substance use
  - Financial stress
  - Major physical move (e.g., immigration)
  - Death in the family
- **Difficulty adjusting to parent role, for reasons such as:**
  - Unwanted pregnancy / Difficult birth
  - High expectations for the role of mother from self or others
  - Colicky baby/health problems of baby and/or mother
- **Isolation due to:**
  - Social/cultural/linguistic/geographic factors

Figure 7: Slide from 2012 version of PPPSS Perinatal Support Skills training

And the same content from the revised version:
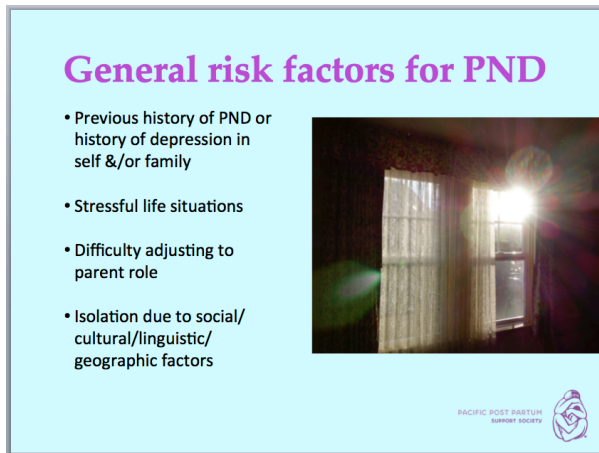
Figure 8: Revised slide from PPPSS Perinatal Support Skills training
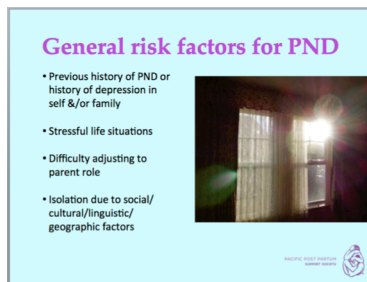
General risk factors for PND.

Stressful life situations, such as:

1. Partner conflict
2. Little support from family/friends
3. Past or current history of violence and/or substance use
4. Financial stress
5. Major physical move (e.g., immigration)
6. Death in the family

Difficulty adjusting to parent role, for reasons such as:

1. Unwanted pregnancy / Difficult birth
2. High expectations for the role of mother from self or others
3. Colicky baby/health problems of baby and/or mother
4. **Isolation due to:**
5. Social/cultural/linguistic/geographic factors

Image source: Paul Duffy

Figure 9: Revised handout from PPPSS Perinatal Support Skills Training

Figure 8 demonstrates how extra text has been removed from the slide, making room for an image that visually supports the content. In figure 9, the written explanation of the content has been incorporated into a handout for participants to use during the session as they wish and to take with them for future reference.

The second goal of the training materials revision was to update the content and organization of that content to make use of PPPSS's video segments and other resources as well as to reflect current research in perinatal support. The project team embedded video segments throughout all three presentations. Each video segment has been selected to support the workshop's learning goals, with an additional focus on reducing stigma by providing workshop participants with mediated personal interactions with individuals who have experienced PMADs. Because trainings are conducted in a mediated environment, we are able to use video segments on more sensitive topics that are not approved by the interviewee for use on our website. Each workshop's agenda are included in the appendices, which indicate all of the video segments that are now included. In addition, the transcripts of the video segments are included in the handouts so that participants can follow along during the workshop if they have difficulty understanding the speaker and so that they will have the content of the video available after the workshop.

Mock Support Group Session Video Segments

In PPPSS's Group Facilitation workshop, participants learn practical group facilitation skills in the context of nonjudgmental and peer-to-peer model of providing group support. The workshop structure offers many opportunities for participants to practice these skills, but depending on the nature of a particular workshop's participants, the effectiveness of this practice opportunity tends to vary from workshop to workshop. Often participants do not seem to know what they are

expected to do or are uncertain about how to begin. Demonstrations by the workshop leaders sometimes help, but were limited by the ability of those particular leaders to role-play the situation.

Therefore, on January 2014, the project team conducted an additional day of filming specifically to support the revision of this workshop's materials. We recruited several mothers who had experienced perinatal depression and anxiety (most of whom had participated in our support groups) and two PPPSS staff members who work as group facilitators to film mock support group sessions. We filmed several targeted scenarios designed to demonstrate our methods of support and useful techniques for addressing problems that can arise in support groups.

By using actual mothers and facilitators, rather than actors, we were able to operate without a script and obtained a more natural feeling to the interactions. Our filmmaker, Chad Galloway, was not sure how working with nonprofessional actors in this kind of situation would be, but at the end of the shoot he remarked that it had gone remarkably well given the situation. I believe this is because everyone involved was doing something they had done many times before and they were able to put the film crew in the background. In addition, this approach was much more cost effective as the mothers who participated were willing to donate their time and experience in order to help the society and other new parents. We did provide reimbursement for child care expenses as well as meals during the shoot. The footage from this day-long session was edited into ten training videos, each under ten minutes in length, on the following topics:

1. **Opening the group**: A group facilitator demonstrates techniques that can be used to set the stage for a successful group session and promote safety.

2. **Closing the group:** A group facilitator demonstrates techniques that can be used to help participants leave the session ready to continue with their day.

3. **Reflective statements 1**: A group facilitator demonstrates the support technique of reflecting back what the participant has said without judgment or advice.

4. **Reflective statements 2**: Features a different facilitator with a different approach who also demonstrates the support technique of reflecting back what the participant has said without judgment or advice.

5. **Providing support**: A group facilitator demonstrates general techniques for providing support.

6. **Risk management for suicidal feelings:** Shows the group facilitator's appropriate response to a group member discussing her suicidal feelings in a support group setting.

7. **Intrusive thoughts**: Shows the group facilitator's appropriate response to a group member discussing her experiences of intrusive thoughts in a support group setting.

8. **Keeping group on track 1**: Shows the group facilitator gently keeping a group on the needed topic.

9. **Keeping group on track 2:** Shows the group facilitator's ineffective attempt to keep a group on the needed topic.

10. **Advice-giving in the group:** The group facilitator demonstrates an appropriate response to one group participant giving unwanted advice to another participant.

PPPSS has the participant's permission to use these segments in workshops and trainings, but not to make them publicly available.

Phase Two Grant Application

The project team completed the outputs funded by the first grant and submitted the final reports in late spring of 2014. PPPSS was immediately encouraged to submit an application for a second grant application. The project team wrote a grant with the following goals and it was approved in June 2014, allowing for work to being immediately. The second phase of the project built on many of the resources created and lessons learned during phase one. Phase two had the following goals, which mirrored and expanded on the goals of phase one. The first goal was to create new patient education materials in Hindi. Guided by the population-specific focus groups and interviews with parents and community support workers that we conducted in 2013, the project team would create a culturally appropriate brochure and website section in Hindi that is engaging, culturally appropriate, and accessible. The second goal of phase two was to revise *Postpartum Depression and Anxiety: A Self-Help Guide for Mothers.*

Guided by the results of an online survey and in-person group discussions with past and current PPPSS clients, the project team would revise this valuable client support to be more accessible to readers with a wide variety of learning styles and reading abilities. In addition, the revision would work to be more inclusive and relevant to a wider segment of the population, including fathers, new immigrants, lone parents, parents in a same-sex relationship, and low-income parents. The third goal of phase two was to increase the convenience of and access to PPPSS's individual and group support, particularly for vulnerable and currently underserved populations. This goal would be met by developing infrastructure, policies, and methods needed

to deliver individual support via two-way text messaging and online, and group support online, conducting pilot programs to deliver services, evaluating the pilot programs, and creating documentation to guide future provision. The fourth goal of phase two was to increase the convenience of and access to our valuable training workshops for health care professionals and community support workers, particularly those with limited funding or who live in remote areas by developing infrastructure, policies, and methods needed to deliver workshops online, conducting a pilot program to deliver the online workshops, and evaluating the pilot program and creating documentation to guide future provision.

Implementation of Online Training

As part of phase one of the project, the project team revised PPPSS's training materials used for in-person workshops in order to increase their relevancy, cultural appropriateness, and accessibility. For a variety of reasons, some potential workshop participants cannot attend because they cannot travel to the workshop site. Karen Boley, an experienced education professional, joined the project team with the goal of transforming the existing training materials into an online course curriculum. The course is composed of seven weekly online lecture and discussion sessions (with participants primarily participating using the written chat feature) led by a PPPSS staff member, plus out-of-class work designed to prepare for each session, including watching videos about particular issues, completing short exercises, and participating in discussions about the videos and exercises in a private Facebook group.[49]

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[49] The online version of the training made extensive use of the video segments created during phase one of the project.

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Because PPPSS is a nonprofit with limited funds and no access to standard course management software, the project team chose to use a private Facebook group to conduct class discussions. In the future, PPPSS may try to find another venue, but in the present moment Facebook is a free platform that the majority of the participants were already using in a personal or professional capacity. The project team used the webinar service ClickMeeting to conduct the lectures, which had a reasonably priced rate for nonprofits that could be sustainably funded in future years by workshop fees. The project team set up a pre-class tech check to help each participant get set up with these tool, which 90 percent of our participants felt helped resolve any problems before the first class (according to our course survey). In the future, Facebook video services may be able to accommodate the online webinar component of the course.

With the grant funds, PPPSS was able to offer the first run of the online training at no charge to a pilot group of participants in order to test and refine the online format. The project team conducted the pilot online training with a group of thirteen participants and two PPPSS staff members, who had extensive experience delivering in-person trainings, serving as the training instructors. The project team had many more people express interest in participating, but felt we needed to cap it at this number in order to ensure a quality training experience. To evaluate the effectiveness of the training, the project team conducted two surveys, one at the midpoint and one at the end, to get feedback about the content and delivery of the course from participants. Project team and PPPSS staff hours spend delivering the workshop were tracked so that the project team could determine a sustainable fee for future sessions (which in 2016 seems to be about $300/participant).

The project team received generally positive feedback about the course. In regards to the online format, 90 percent of participants considered the fact that they did not have to travel to

take the course to be a benefit. In addition, 60 percent felt that not having to arrange child care was important, 60 percent felt not having to take time off of work was an important factor, and 60 percent felt that being able to spend one hour a week instead of two days all at once was an important benefit of the online format. In the class survey, half of the participants stated that they experienced technical difficulties (such as a loss of their own Internet connection) that affected content comprehension at least once. So in the future, PPPSS will record the lectures and make them securely available to participants to view later in case they had difficulties. The project team also found that the out-of-class discussions in the Facebook group helped with this issue because there was more than one opportunity to encounter and master the material. A few participants expressed concerns about the format of the Facebook group for discussion (such as threads tend to get hidden at the bottom of the page because there is no ability to show more than one at a time) but most appreciated that it was a convenient way to access the discussions because it was on a service they were using anyway. PPPSS will continue to evaluate if this is the best format for hosting the course discussions. In conclusion, the value of this training in the online format is shown by the fact that 100 percent of the participants felt the sessions were useful and that the instructors were knowledgeable and organized. Furthermore, 75 percent of them would not have been able to participate in PPPSS's in-person training due to logistical or financial barriers. Therefore, PPPSS feels that being able to offer the perinatal support and group facilitation training in this online format will meet an important ongoing need among those who work with new parents.

Overall, the experience of offering PPPSS's trainings in an online environment has been extremely positive. During 2015, PPPSS was able to offer the training three times to a total of 33 participants, with each session offering the project team a chance to make further revisions and

improvements to the course. The success of PPPSS's in-person trainings depends not only on accurate and useful content, but also on providing a warm and supportive environment in which participants can learn from the personal and professional experiences of the facilitators as well as their fellow participants. In order to meet PPPSS's training goals, it is not enough to simply present correct information about PMADs to participants. Instead, this approach to training supports PPPSS's broader goals of opening participants', encouraging understanding and compassion, and thus reducing the stigma that often surrounds perinatal mental health. Our formal evaluations of the trainings and informal discussions with participants indicate that we have been able to successfully translate these less concrete but extremely important qualities of our in-person trainings to the online environment.

Revised Publications

In phase two of the project, PPPSS also received funding to substantially revise the contents of the self-help guide, as well as the two manuals targeted at professionals. These revisions were informed by a survey and focus group with PPPSS alumni, as well as reviewing similar self-help publications. At the start of the project, the overall goals of the revision were designed to increase its effectiveness as a tool and to expand the number of vulnerable people being helped by: using simplified language and reducing reading difficulty; better representing diversity in culture, economics, family structure, and experiences of perinatal depression and anxiety;

supporting visual learning; and meeting the needs of fathers by including a chapter for men experiencing perinatal depression and anxiety. [50]

Talking with parents through surveys and a focus group, as well as a close reading of the current edition by the editorial team, allowed the project team to identify particular strengths of the current edition (such as the personal experience narratives at the end), discovered more about how readers actually use the self-help guide, and develop a plan to revise to structure, content, and design of the book. I took the lead in conducting research on new topics and updating existing sections with current research on PMADs. Writer Linda Tobias was primarily responsible for revising existing content and writing new content.

In order to make the book more accessible, we lowered the reading level to grade six, included numerous quotes taken from parents' real experience, and highlighted especially helpful information in "Did You Know?" text boxes throughout the book. New content includes a dedicated chapter for fathers, a discussion on the benefits and pitfalls of social media for someone living with perinatal depression and anxiety, and content designed to reduce the stigma of perinatal depression and anxiety (such as a list of well-known people who have also experienced the condition). Because individuals sometimes experience more than one perinatal mental health condition, we have also added basic information about other perinatal mental health conditions, such as postpartum psychosis, while keeping the focus of the book on perinatal depression and anxiety.

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[50] A grade five to six level is recommended for health materials (Cotugna, Vickery, and Carpenter-Haefele, 2005). The book was at a grade eight reading level, as assessed using several recognized tools.

The project team has worked to ensure the inclusiveness of this text by making mindful language choices and including dedicated content for unique populations, such as those who are parenting with a disability and parents who identify as LGBT. We greatly benefited from partnering with some mothers who have a disability for this part of the revisions, who generously shared their insights and helped the editorial team to be more inclusive of their experiences.

Being inclusive of gender identity was an especially challenging part of the revision process. PPPSS is an organization founded with the goal of supporting struggling new mothers, and many of the staff and volunteers identify extremely strongly as mothers. However, in the forty years since the organization was founded, our understanding of gender has become necessarily more complex, and we now know fathers can also experience PMADs. Therefore, the project team carefully worked to try to balance the need to make sure our core audience of individuals who identify as mothers continued to feel supported while also including individuals who may not identify as mothers or women, as well as those who identify as men and fathers, as we believe they could also benefit from this information and there are currently few resources available for them. PPPSS staff and parents who have experienced postpartum carefully reviewed the draft of the book and their suggestions were incorporated into the final version. Publication of the new edition is planned sometime in 2017, when the print run of the existing publication is exhausted.

As a pleasant bonus, the project team was able to create a new section for the PPPSS website, entitled "For Moms," using some of the new material developed for the book. The originally website was almost entirely for mothers, so in our phase one design we had not considered adding a section for this group. However, as the website got more complex, it was harder for this core audience to find basic information about PMADs that fit their needs. Therefore, the new For

Moms section was designed to be a clear and straightforward introduction to PMADs and sources of help for struggling new mothers.[51]

Professional Manuals

The *Telephone Support Manual* and the *Group Facilitation Manual* were originally developed with the goals of supporting PPPSS volunteers and serving as companion materials to the PPPSS training workshops. With this project, the society wanted to update the content of the materials to be in alignment with new research on PMADs, as well as to make the content more useful to individuals and organizations who were not part of PPPSS and had not attended PPPSS's trainings. Therefore, one of the first steps was to remove material that only pertained to PPPSS operations and use it to create a new internal manual for PPPSS volunteers. Then the project team revised both manuals with the overall goals of improving the readability and organizational structure, as well as updating existing content to reflect current research—for example, advice about coping with feelings of anger had substantially changed since the last edition. The project team also added substantial new content to the *Telephone Support Manual*, such as information about other perinatal mental health conditions. In addition, we incorporated what we have learned about providing support via text message during the text message pilot project into the manual (to be discussed in the next section). We worked to ensure the inclusiveness of this manual by making mindful language choices that acknowledge the diversity of parents who might need support. Pending approval by the PPPSS board, the formal name of the publication

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[51] View the "For moms" section of the PPPSS website at http://postpartum.org/services/for-moms/, accessed November 30, 2016.

will be changed from *Postpartum depression and anxiety: A Manual for Telephone Support Volunteers* to a title such as *Postpartum depression and anxiety: A Manual for Remote Support Workers*, in order to reflect that remote support is now being provided in ways other than by voice telephone calls, as well as by paid staff and volunteers. The *Group Facilitation Manual* had been revised in recent years, so the scope of new content was to add material about online-only group facilitation to the existing manual. The revised editions should be ready sometime in 2016, when the current imprints of the manuals are exhausted.

Pilot Project to Provide Individual Support via Text Message

Individual telephone support, provided by trained staff and volunteers, has been a core client service of PPPSS since its very beginning. When the society began more than forty years ago, a telephone landline was the most common communication tool. However, many individuals now only have a mobile telephone, and voice conversation may not be a person's preferred communication method.[52] Thus, as part of phase two of the project, PPPSS proposed to increase access to our services, particularly for vulnerable and underserved populations, by providing individual support via two-way text messaging and live online text and voice chat.

After close consultation with past and current clients (primarily through a survey and a focus group), a literature review, and consultation with other agencies, the project team created best practices and policies for providing individual support via text message. The project team

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[52] Many people (particularly low-income or otherwise vulnerable) no longer have a landline, and conversations on mobile phones may be limited by factors such as battery life, unclear signal, and cost-per-use (i.e., prepaid minutes).

selected iCarol as our vendor for SMS messaging services, which allows PPPSS to securely send and receive text messages from PPPSS's computers.[53]

One useful feature of the iCarol interface was the ability to save pre-set messages. This allowed PPPSS to set up stock text messages to use in common situations. These included series of messages such as: PPPSS's confidentiality and privacy policies for clients that begins each conversation, auto-reply responses for clients who texted outside of text message support hours letting them know what other resources were available, and helpful phases that would be likely to be repeated in many conversations, such as, "That sounds like a really difficult situation for you." Although the pre-set messages helped to make certain parts of the conversation more efficient (such as going through PPPSS privacy policies at the beginning of the session), for the most part the conversations required individual counselor responses and were highly variable with a minimal use of the pre-set responses.

The iCarol service also allowed PPPSS to customize a built-in system for tracking text message clients and text conversation sessions. The project team mapped this onto PPPSS's existing systems for tracking contact with telephone support and group support clients. After working with iCarol to customize our instance of the service, the project team conducted training with PPPSS staff members and began providing live texting service on April 1, 2015. PPPSS advertised the texting service through social media, the PPPSS website, announcements to public health nurses, in parent–baby groups, and to PPPSS's current clients.

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[53] Information about iCarol's services can be found at http://www.icarol.com/, accessed November 15, 2016.

During the pilot project, PPPSS staffed text messaging for ten hours each week (divided into two five-hour shifts) for sixteen weeks and conducted thirty-seven support conversations via text. The project team also produced an internal manual to guide texting. The texting team regularly discussed how the text messaging was going and made changes in the setup of the online texting interface and the internal texting guidelines and procedures. Although PPPSS did not conduct a formal evaluation with texting users due to privacy concerns and difficulty identifying individuals, we did informally discuss the service with clients as they were using it. Those who received support via text message indicated that they found the service valuable because it allowed them to privately and/or quietly receive support, such as while the baby was napping or while they were in a public place. We had several parents who made their initial contact by text and then went on to use voice call support and/or an in-person support group. PPPSS often receives feedback that it's hard for parents to make the initial call to ask for support. The counselors providing support via text message felt that it may have been easier and less anxiety producing for these individuals to reach out by text message than by voice.[54]

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[54] A September 2014 Gallup survey looked at how American adults were communicating with others throughout their day (Newport 2014). They found that for those under 50, most communication took place online or by voice call or text message on a cell phone. Most individuals giving birth or parenting a young child are under 50. Therefore, looking at this group, 68 percent of respondents aged 18 to 29 sent or read text messages "a lot" (compared to "a little" or "not at all") the previous day. For respondents aged 30 to 49, the texting rate was 47 percent. Fifty percent of respondents aged 18 to 29 made or received a phone call on a cell phone, while 41 percent of those between 30 and 49 did the same. For home landline phones, only 7 percent of those under 50 had used one the previous day. In contrast, only 26 percent of those 50–64 years old said they had sent or received a text message the

As the project team's research had suggested, we confirmed that individual support via text message took longer than individual support via a voice call. The average length of time that the parent and counselor participated in the text message conversation was eighty-seven minutes. This is not much different from the length of a voice support call; however, because of the nature of the medium, which included pauses between each message waiting for a response, text messaging counselors felt that less ground was covered compared to a voice support call. It is possible for staff to multitask during this waiting time, however, so we are exploring ways to do this without compromising the quality of the support. The text messaging team also discussed and implemented strategies for moving participants from a text message conversation to a voice call for complicated topics (which were more difficult to provide support for via text message). However, one advantage of some texting conversations, compared to voice conversations, was that the format allowed the client to more quickly get to their main concerns. Texting counselor Georgie Hutchinson stated that she found that, with some clients while texting,

> there was no, like fooling around. Moms were just texting right into what their issues were, instead of like dancing around the edges like we do on the telephone. 'How are you' and 'what brought you here.' They were just like, 'I'm really having a rough time.' And we'd be right there. Therefore, even though overall texting conversations took more time, for some clients they may have allowed them to get to the most important issues more quickly.

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previous day, compared to 40 percent who had used a cell phone to make or receive a call and 10 percent who had used a home landline. Clearly communication preferences are changing to favor text messaging and will likely continue to change as the cohort who were aged 18 to 29 in 2014 make up the largest percentage of likely new parents over the next few years.

Project evaluation also revealed that providing support by text message did not decrease the number of support contacts by voice calls and email (which increased by 21 percent compared to the same time period in the previous year). Therefore, this pilot project has confirmed that by providing support via text message, we are serving people who otherwise may never have asked for our support. This increase in overall volume also confirms that PPPSS needs to pursue additional funding for another staff member to be on duty to continue to provide support via text message in a sustainable way that does not contribute to staff and volunteer burnout.[55] After the pilot ended in June 2015, PPPSS was able to self-fund providing support via text-message until

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[55] The fact that support via text is more expensive than support via voice call is not the same as the experience of technical support providers. For example, Jonty Pearce cites proprietary marketing data from Forrester (a consumer research firm) that the average technical support call costs $12 or higher, while a web chat costs $5 or higher (2012). However, technical support chats also tend to take longer than technical support calls. The savings are realized because representatives are involved in multiple conversations at one time. Although this research is in the context of web chat, from the standpoint of the service provider the mechanics of conducting the conversation are essentially the same. However, in a mental health support chat, this would be much more difficult to manage. PPPSS model of care requires that the counselor mindfully focus on the individual they are assisting. Even in a written chat context, a client can likely tell when that attention is divided. In addition, the privacy and mental health consequences of confusing the content of one conversation with another would be more severe than in a technical support or customer service context. With practice, some counselors might be able to manage multiple conversations, but it seems unlikely. A more likely way to multitask during texting conversations might be to have the text-message support counselor to also be responsible for serving as a receptionist directing incoming voice calls to available counselors or taking messages for call backs.

the end of August. During July and August 2015, PPPSS conducted an additional twenty-four

support conversations via text message, for a total of sixty-one support conversations. PPPSS is

currently seeking ongoing funding to be able to offer this service again.[56]

Pilot Project to Provide Group Support via an Online-Only Group

Facilitated group support is a vital part of the services that PPPSS offers to new mothers

struggling with a PMAD. Demand for this service always exceeds the supply, and wait list times

have recently increased. In addition, PPPSS only offers support groups in metro Vancouver.

Therefore, in the grant, PPPSS proposed to increase access to group support with a twelve-week

pilot project to provide group support for mothers experiencing perinatal depression and anxiety

in an online environment. Online groups offering mother-to-mother support are extremely

popular, sometimes with thousands of members. However, unlike many peer-led Internet support

groups and forums, this group was guided by a trained facilitator and used PPPSS's proven

model of group support. We hoped that this approach would help to ensure participant safety as

well as allow participants to benefit from the expertise of the trained facilitator as they worked to

recover from a PMAD. Before the sessions began, we completed our standard intake process—

administered a pre-group Edinburgh Postnatal Depression Scale (EPDS), a standard assessment

tool to measure the likelihood a person may be experiencing postpartum depression— and

ensured that each member understood our confidentiality and privacy standards. At the end of

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[56] If enough funding were available, for an additional fee iCarol also offers an interface to provide support

via web chat. This service could be easily launched based on the policies and infrastructure developed to

provide support via text message.

the group, we completed a post-group EPDS and invited members to fill out an online feedback survey. All quotations and statistics are taken from this survey.

After confirming it met health care confidentiality and privacy requirements, we chose to use the same webinar software (ClickMeeting) that we had already been using for the online trainings. During the group session, one facilitator and one participant talked at a time (we used the Ask-a-question feature in ClickMeeting that allowed facilitators to grant one person speaking ability at a time) and other group members participated via written chat. This made for a much smoother experience than having an open audio discussion, which would be too chaotic for a group of this size.

The group met for twelve weeks beginning in April 2015 (with one week off due to a statutory holiday) from 7:45 to 9:00 pm on Monday evenings. Adapting PPPSS's time-tested meeting structure, the group facilitators started each group with a brief grounding exercise, such as a guided meditation. Then the facilitators presented a short psycho-educational lesson about a particular topic, such as relationships with partners. This set the stage for a time for each mother to share her own challenges during the week, receive support from other members and the facilitators, and make a plan for self-care during the following week. Then the facilitator briefly wrapped up before ending the group.

During the group sessions, there were some technical difficulties with the audio, which often seemed related to the quality of an individual's Internet connection on that day. The group facilitators found that the written chat was a useful backup when a participant was not able to get their audio to work. However, when the audio was working, participants found it much more personal and effective than just written chat. For example, one participant stated in her evaluation, "The facilitators were able to provide a full range of support using audio and video.

The group was able to connect." Therefore, although getting the audio to work sometimes took up valuable group time, we consider it worthwhile to continue to use it and keep finding ways to make it work better.

Five mothers completed the group. The two mothers who decided to leave the group before the end indicated that although they thought that the group was valuable, they decided online group support was not for them. They felt that there were too many distractions to allow them to participate from home and they found that the format did not give them the break and social experience that they needed (compared to going to an in-person group with child care, for example). PPPSS provided these mothers with referrals to other resources and continued to offer telephone support. It may be significant that in both cases the mothers who left had some other resources available in their respective communities. At the time they attended the group, members lived in Kelowna, Maple Ridge, North Vancouver, Sechelt, Victoria, and Whistler (all in BC), and Whitehorse, Yukon (fig. 10). Only the mother who lived in North Vancouver would have had an easily accessible in-person support group that focuses on PMADs. The majority of the group members had no other support groups for new mothers, let alone a group primarily intended for mothers with a PMAD, available in their area. As one participant stated:

> This experience was so essential to my recovery! I wish that all women (and men) who are suffering can find this resource and benefit from it. In remote areas it can be very difficult to access any kind of mental health support, so having the format of an online support group is ideal. It allows me to access health care that I would not otherwise be able to.
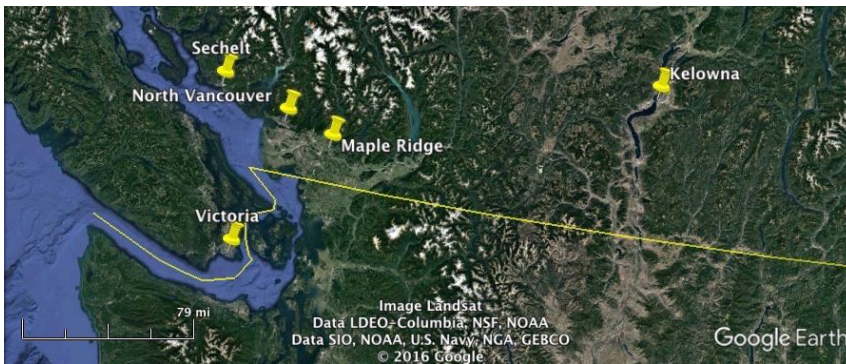
Figure 10: Maps showing PPPSS online group participants' locations.

The participants indicated that they found the fixed-length format of the group helpful (a total of

eleven sessions) because the same group of participants started and ended the group together;

however they wished that there had been more sessions. Participants who filled out the end-of-

group evaluation all indicated they felt very prepared by the facilitators to leave the group and be able to access resources and other supports when they needed them.

When asked if they would rather participate in an online group or an in-person group (if one was available), participants still found it valuable to have an online option available. As one mother shared, "being from such a small community, it can be difficult to remain neutral. I love the online forum and would love to see this offered to others."

The participants who stayed in the group found it very valuable. Three participants who finished the group experienced a substantial improvement in their EPDS scores; the other two had similar somewhat low EPDS scores when beginning and ending the group. All participants attributed at least 50 percent of their recovery from perinatal depression and anxiety to participation in the group. As one mother said: "The support from the online group and the facilitators has been the most helpful part of my treatment by far! I wish I could continue to be a part of an online group through PPPSS." Another told us that she experienced an immense change while participating in the group:

> My life is back on track. My anxiety and depression is minimal. I stopped the negative self-talk, the jumping to the worst-case scenarios. I check in with myself, I practice self-care, and I know what to do now if I relapse. I also have way less anxiety about the future and having more children. I don't feel guilty anymore.

Group participants gained tools that they felt would help them to cope in the future. One mother stated, as a result of her participation in the group, "I was able to have many tools to make changes and recognize the anxiety before it ramped up." Another pointed out how she learned helpful strategies in the group not only from the facilitators, but also from the other participants:

> I recognized signs and symptoms and triggers. I was able to learn different coping strategies from everyone else. And most importantly when you hear of others experiencing the same thing, I wasn't as hard on myself. As well, hearing of

others recovering gave me hope when I felt no hope that things would change in my life.

Thus, this pilot project confirmed that PPPSS was able to offer group support successfully in an online-only environment. Our evaluation of the project also showed that for this group of mothers, who were unable to attend an in-person support group for a variety of reasons, the online support group had many of the same benefits as our in-person groups.

For many reasons, it is often not practical to offer in-person support groups for PMADs in small communities. Individuals may live too far apart from one another to be able to easily meet in person, especially while caring for a new baby. And, even if they are able to get to a group meeting, stigma and the fact that everyone knows one another can make it difficult for struggling new parents to feel that they can attend a group specifically designed to address mental health and speak freely about their situation in that group. Therefore, we feel the online-only support group is in many ways the ideal format to serve struggling new parents who live in small and remote communities by allowing them to receive peer support from parents in other small and remote communities. The fact that this pilot online group had such a positive effect on the members' recovery from perinatal depression and anxiety is very encouraging evidence of the group's potential value and effectiveness for this population. In the fall of 2016, PPPSS received another small grant and in November 2016 is currently conducting another online support group. PPPSS is currently seeking funding to be able to offer online support groups on an ongoing basis.

Publicizing the Project Outputs

PPPSS publicized the new website and other resources throughout the VCH service area by demonstrating it at meetings for professionals (such as task force meetings) and events for community members (such as community health fairs). In addition, PPPSS worked to distribute the printed brochures throughout the community, through mail and in person, at places where young families congregate, such as at community centers, libraries, public health units, and health clinics.

Project Outcomes

Overall, evaluation revealed that the project had many positive outcomes for both parents with PMADs and for those who support those parents. Firstly, PPPSS received generally positive feedback from PPPSS's clients and community partners regarding new services and resources. Clients who participated in the online support group pilot improved their Edinburg Postnatal Depression Scale (EPDS) scores and all online group members attributed at least 50 percent of their recovery from perinatal depression and anxiety to participation in the group. In another measure of the project outputs, participants in the revised in-person and new online professional training workshops gave overwhelmingly positive evaluations to the sessions. In addition, although the project team did not conduct a formal evaluation, PPPSS staff received enthusiastically positive feedback about the effectiveness of the culturally appropriate materials, individual support via text messaging, and online only groups from allies such as public health workers and community support workers. Second, use of PPPSS's services and resources increased during and after the project. The number of people participating in PPPSS's professional training workshops has increased since the online delivery method was launched. In

2013–14, 111 people attended PPPSS's in-person training workshops. The following year, 100

people attended. In addition, in 2014–15 and the beginning of 2015–16, an additional 33

individuals participated in the new online training workshops. Therefore, PPPSS experienced

increased participation in training workshops with the implementation of online delivery. Third,

the use of PPPSS's web-based resources has greatly increased since it was redesigned and new

information resources, including video segments, were added (Table 5). From May to October

2014, website language in pages other than English received 640 views. These pages received

803 page views during the same period in 2015, an increase of 25 percent.[57]

Table 4: Use of PPPSS Web-Based Resources

	February to July 2013 (before redesign)	May to October 2015 (after full redesign)	Increase
Sessions/visits	4,594	16,331	255 percent
Unique visitors	3,142	12,864	309 percent
Mobile visitors	1,460	7,030	381 percent
Page views	12,110	34,053	181 percent

In addition, the overall number of contacts that were made with PPPSS (including phone calls

and emails, and requests for support and/or information) increased 21.5 percent from 7,991 in

fiscal year 2013–2014 (the year the website was being updated with extensive new content,

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[57] The free version of Google Analytics does not provide any data other than number of page views for

the non-English language sections of the PPPSS website.

including video) to 9,715 in fiscal year 2014–2015.[58] The increase in website use and contacts with the organization indicates that PPPSS's new resources and efforts to promote them were attracting attention to the organization and being used.

Finally, during the time of the project, PPPSS experienced increased use of all client support services. Voice calls largely held steady over the course of the project, but contacts via email increased greatly (see above). In addition, during the texting pilot in particular, in which use was closely tracked and PPPSS's services were being promoted, PPPSS's requests for individual support via voice telephone increased 21 percent in the VCH service area during the pilot project period. During that period, PPPSS also conducted 61 individual support conversations via text message. Increased use of PPPSS support services may indicate stigma-reduction strategies are effective and parents are more willing to seek help.

Next Steps

Some parts of this project, such as the culturally appropriate materials, revised publications, and online training, are either complete or are designed to pay for themselves through sales or fees, and thus will not require additional funding to continue. Other project components, in particular ongoing client services such as individual support via text message or the online-only group, require new funding in order to continue. It is often more challenging for non-profit organizations to obtain funding for existing services than it is to fund exciting new ideas. However, the success of these pilot projects have demonstrated the value of these services. In addition, the infrastructure and budget developed during the pilots have prepared PPPSS so they

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[58] Like many organizations, PPPSS's fiscal years run from June through July.

can now develop a sustainable long-term plan for such services. I am hopeful that they will be

successful in securing funding for the implementation of these services.

Chapter 4: Impact of Stigma on the Perinatal Experience

Robin: But I just remember, you know, [in my support group] there was one mum who was talking about how she was struggling so much.

And that, especially in the mum and baby groups, things were really, really hard for her because she looked around and all the mums seemed so put together and they seemed to have their lives all in order and everything is in place and had, you know, everything was going great for them and it wasn't for her.

And there was another mum on the other side of the room who looked at that mum and said: "did you know I met you before? I've met you at a mum and baby group. And you were that mum to me. I remember looking at you and saying: how does she have her shit together so, her stuff together so well, and I can't."

And it was sort of that realization that it's like: well, everybody's struggling in their own way and if we would all just talk about it, you know, it maybe would help break down some of the expectations and break down some of those myths that, you know, just keep carrying down through, you know, for all the mothers that are having babies right now. But . . .

Facilitator Emma: Yeah, that's a really big thing for me is to really sort of cut through that crap.

Robin: Yeah (laughs), I know, it is crap, it's all crap.[59]

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[59] http://postpartum.org/videos/video/robin-pressures-motherhood/, accessed October 16, 2016.

The stigma that impacts new parents during pregnancy and the postpartum period is multifaceted, pervasive, and profound. In addition, for parents with perinatal mood and anxiety disorders (PMADs), stigma remains a significant barrier to seeking and participating in effective treatment for mental health conditions (Corrigan, Druss, and Perlick 2014). In this chapter I will introduce the concept of stigma and discuss several of the areas in which project participants indicated that it had the most impact on their experiences as parents. I will also discuss how the project attempted to mitigate the impact of this stigma on parents' willingness to access and engage in support and treatment for PMADs.

As Diane Goldstein and Amy Shuman and other scholars have noted, research on stigma has primarily occurred in the field of social psychology and has tended to neglect the experience of those living with stigma (2012, 116). Although at the time the project was designed, I was not aware of this body of research, as a folklorist and as an individual who had recently spent a lot of time being a patient as well as the parent of a patient, I was aware that those who made policies or programs designed to help a particular group of people often did not meaningfully take into account the lived experiences of the individuals in that group. Therefore, the project's goal and methodology explicitly were designed to mitigate this situation: Pacific Post Partum Support Society (PPPSS) aimed to create educational materials and new services that were directly informed by the experiences of those living with a stigmatized condition, PMAD, in a life role, new parenthood, in which they were impacted by the potential of becoming a stigmatized person (a "bad parent") every day. In addition, to a more limited extent, the materials and services were created in collaboration with those individuals.

Project participants had a lot to say about stigma. Many participants expressed their belief that stigma keeps parents from talking about the more unpleasant realities of parenting and the

possibility of PMAD. In addition, many participants felt that this lack of information had contributed to their own distress and mental health difficulties. For example, video interviewee Mariko knew very little about mental health and how a new mother might feel before giving birth:

> So like other people said that having baby is just such a precious happy thing, nobody talking about difficulties or anything so I just thought: okay, it's going to be all good. I have no concerns other things just, you know, hoping to have a healthy baby when its time is come.

> We went back to see doctor after the labor and he asked me how I am doing, how I was feeling. Well, I just couldn't say: actually I feel not right, because of that whole myth that everybody should be happy. So I told myself that I should be happy because I have a healthy baby, a very supportive husband, why wouldn't I be happy, you know?

For Mariko, this lack of information about mental illness and her reluctance to share with anyone that she didn't feel like she felt a new mother should feel meant that she was not diagnosed with postpartum depression by her family doctor until nine months after giving birth. Mariko continued that her doctor finally:

> diagnosed me . . . but until then, because of the whole mental issues of stigma, it was hard to tell people that I'm not happy with my baby or I'm worried about everything.

> So if there is less stigma [it would] be good. . . . But [the medical professionals] didn't even talk about the high chance that mothers have postpartum anxieties and depression. They didn't give any information for that. So I hope, I wish, that they did so I couldn't just be in the darkness for nine months.

It is important to acknowledge that, especially for video interview participants, participants were taking a significant personal risk by participating in the project because of the stigma associated with being framed as a parent with a mental health condition. Although PPPSS only used the participants' first names to publicly label the videos, by including their image and voice, clearly

anyone who knows the individual will be able to identify them. Because of the risks of participating in the project, it was important that the project goals be transparent to participants and in alignment with the participants' goals.[60]

Increasing the visibility of individuals who have experienced PMADs as a way to reduce the stigma surrounding these conditions was an important motivation for all video interviewees. For example, as previously discussed, video interviews were specifically chosen as one of the project outputs because psychological research indicates that viewing such videos is an effective technique to reduce the stigma associated with individuals living with mental illness (Corrigan et al. 2007). Because PPPSS explicitly designed the project to mitigate the effect of stigma on accessing care for PMAD, and publicized this goal as part of the recruitment process, the fact that participants were motivated by this goal is not surprising. However, stigma was also a topic that participants brought up on their own, over and over again, as a significant factor in their own experiences of early parenthood and mental illness. For example, fifty-two sections of the video interviews were coded as discussing stigma, which was the seventh most common code assigned in the "experiences as a parent" field overall.[61]

In his seminal 1963 book, Erving Goffman states that stigma is an attribute that makes an individual "different from others in the category of persons available for him to be, and of a less

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[60] See Trevor Blank and Andrea Kitta for more on the importance of alignment between the project's goals and participants' goals (2015, 4).

[61] Compared to other terms in the "experiences as a parent" field. The more common terms were postpartum depression (139), postpartum anxiety (120), lack of support (106), communication with partner (101), isolation (100), caring for young children (66).

desirable kind—in the extreme, a person who is quite thoroughly bad, dangerous, or weak. He is

thus reduced in our minds from a whole and usual person to a tainted, discounted one." Not all

"undesirable attributes are at issue, but only those which are incongruous to what our stereotype

of a given type of individual should be" (1963, 3). In addition, stigma is the flip side of normal.

In this framework of stigma, the good mother or the good father is one version of normal, which

means being a bad mother or a bad father is the stigmatized attribute. As Goffman points out,

almost any attribute can be seen as normal or stigmatized (although he also notes there are many

attributes likely to be seen as a stigma for almost anyone in a particular society). The category

into which it is put depends on the relationship between the attribute, the individual, and

community standards.

The impact of stigma for new parents is often closely tied to cultural perceptions of

mothering and fathering. After interviewing fifty-two women and reviewing popular and

scholarly discourse on mothering and childbirth between 1975 and 1994, Verta Taylor found

that:

> For most women, the process of naming and reflecting on their experiences were
> closely tied to the competing representations of motherhood in popular culture,
> medicine, and psychology. Juxtaposing women's own experiences against the
> cultural myths allows us to see how the tensions in women's lives are important
> ingredients in their collective efforts to break apart the myths and their effects on
> women's mothering. (1996, 30–31)[62]

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[62] Verta Taylor interviewed fifty-two women, primarily white, slightly older, middle-class mothers from

the Columbus, OH area, about their experiences with postpartum depression (1996).

Although there has been less robust research on the topic, and the cultural expectations are likely different, fathers are also clearly impacted by their inability to meet those often conflicting cultural expectations in their own lives.[63]

PPPSS's project supported Taylor's findings and also showed that judgmental discourse about good parenting standards was a significant source of tension and distress in participants' lives. For example, in her interview Brianna stated:

> And I know that in a lot of parenting magazines and books and online there's a false positive sheen on everything that is just not reality. You don't love your child all the time, you don't like them all the time. Same goes for your partner. And that's just the reality of life. And especially when you're suffering with a depression you are allowed to feel that way. It's okay. Things will get better. But don't get sucked into that false positive vibe. Because those people who are expressing that positiveness, that's not their reality either. And so we need to believe that for ourselves as well. So that we can cope on a daily basis.[64]

Project participants discussed the significant impact of profound cultural expectations about new parenthood that tend to focus around the welfare of the baby and the parents embracing their new roles: at least you have a healthy baby, new parenthood should be a time of wonder and light, you should instantly fall in love with your baby, every moment you should remember how lucky

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[63] Verta Taylor is a sociologist, not a folklorist, so the term myth is being used here and in most cases throughout this work in the popular culture sense of an idea that is widely believed but probably untrue, rather than in the folkloristic sense of a tale that deals with supernatural beings, heroes, or ancestors that may contain religious meaning. However, both types of myths potentially can illuminate an individual or society's worldview. In its own educational materials, PPPSS tends to use the term Mothering Myths to label these problematic ideals because it is one that is widely understood in North American society (even if it is problematic term for folklorists).

[64] http://postpartum.org/videos/video/brianna-motherhood-myths/, accessed November 12, 2016.

you are to take care of this new being. If an individual does not feel this way, and believes that everyone else does, they tend to feel very isolated and alone.

Goffman also makes a useful distinction between being *discredited*, which is already being perceived as stigmatized by others, or as *discreditable*, which is being at risk of being perceived as stigmatized by others (1963, 4). As Goldstein and Shuman discuss, because discreditable individuals are not known to be part of a stigmatized group, but are at risk at being so labeled, then they may try to pass as normal (2012, 115). In the context of postpartum, struggling new parents often feel that they are passing as a "good parent," and that those around them are constantly observing and judging their mood and behavior and waiting for their chance to out them as a bad parent. Furthermore, as Goldstein and Shuman discuss, particular vernacular forms can be stigmatized and thus difficult to talk about. In addition, using these stigmatized forms also may put the individual at risk of being stigmatized. Depending on a parent's particular community standards, parenting practices such as co-sleeping (or having the child sleep in another room in a crib), or breastfeeding (or formula feeding), or having a protesting baby do tummy time anyway (or not), can all be stigmatized vernacular parenting practices. Because these standards are in flux as parents move from community to community, and are often in the process of negotiation within communities themselves, parents frequently feel they are constantly at risk of being judged a bad parent and being a stigmatized person because they are engaged in practicing a stigmatized vernacular. In addition, as Shuman later described her and Goldstein's 2012 discussion, "folklore research can make an important contribution to the study of stigma by attending not to the categories of what is stigmatized, but instead by observing this process of 'managing' how value is assigned, claimed and denied in social interactions." (Shuman 2015, 25). Therefore, in any social interaction in which a person is identified as a

parent, they might be engaged in managing how values are assigned to their parenting choices by

themselves and by those around them, a process that may be mentally exhausting.

In one of PPPSS's focus groups, Bobby shared his experience with unsolicited advice about

his parenting behavior when he was a new father:

> Bobby: We went to Toronto for Christmas and family and, it was nice because there was like: here you take the kid and we went to watch a movie. . . .

> But yeah it was like every little thing. And here I am, like: Hey, I've got a kid so they should leave me alone, that's what they wanted, right? A grandkid? (group laughter) No, it was like [the advice just] levels up.

> And it's not just family either, it's public. We were sitting in a coffee shop and we were out there and we were putting on her jacket and it was a little light drizzle. And there was a little ledge, so there wasn't really rain going on. And someone said: oh you should put that on—some random person on the street—(group laughter) oh you should put the hood up.

> And it's like: who are you? (group laughter)
> You know I was like, yeah, yeah some of it's funny. Everyone's got advice but [trails off].

> Facilitator Emma: But nobody's there to help.
> Bobby: Yeah. Exactly.

Many new parents struggle with this feeling that they are constantly being watched, evaluated,

and possibly found wanting. However, if a parent is also experiencing a PMAD, one of the

symptoms of their condition may be distorted thinking processes that cause the individual to

think more negatively about themselves and others. This can be a particularly toxic combination

that can keep a distressed mother or father from reaching out for support and treatment for their

PMAD. New parents with a PMAD are also impacted by the well-documented general stigma

that surrounds mental health conditions. As focus group participant Kevin stated, "there's the

natural stigma with mental health topics in, in I guess western culture; maybe in all cultures. That

it, they are more difficult to talk about and I think especially so when you are, when you are the guy."

In addition, combining the cultural expectations surrounding being a new parent with the stigma surrounding mental health can be particularly impactful. Focus group participant Bobby, whose wife had experienced severe postpartum depression after the birth of their child, shared:

> My wife Valerie was complaining about this. She was like: on the one hand it's like when we're all told: this [mothering] is a natural thing, you can do it no problem. But then on the other end it's like, you know, it's almost like a badge of dishonor to go through postpartum depression. Because this is something you should be able to do, you just kind of switch the mum button on and that's it. And, you know, that's not necessarily the case. So a crossed signal there.

This situation directly impacts how individuals experiencing PMADs feel about themselves, as well as their willingness to ask for and accept help, support, and treatment.

Video interviewee Linda, who had successfully undergone treatment for episodes of depression several times before becoming a mother, found that when she became a new mother and experienced a severe episode of postpartum depression and anxiety, it was much harder for her to ask for the help and support that she needed to recover.

> I felt debilitated a lot of the times, like I couldn't do anything, I couldn't function and I couldn't get out of bed and take a shower and take care of myself or take care of Ethan.

> And that was hard because I felt that was a reflection of my character, of my strength, or my willpower. Not that it had anything to do with [the fact] that I was going through depression. I felt that [it] was more just a reflection of me as a person.

> So I remember again not telling people about that, that I wasn't able to do things for myself or for Ethan and that's why we needed help. But we needed to get outside help.

> Again people have a hard time understanding that: why can't you do that? I mean don't you realize your son needs you? You know? Like you have a baby there that

needs you and that loves you, that should be enough. But for some strange reason it wasn't so.

As a person with a history of multiple episodes of depression, Linda understood that mental illness is just that, an illness. However, when Linda experienced postpartum depression and anxiety she felt that by experiencing depression at that particular moment, when she was supposed to be happy and in love with her new son, depression and anxiety were not an illness, but were rather a sign that she was a bad and weak person.

For Linda, the willingness of those around her to understand why she needed help and support in order to recover from this illness was significantly impacted by their cultural expectations around mothering and motherhood. In her marriage, she realized from the beginning that her husband expected her to take primary responsibility for caring for their child:

> I knew that when it came down to it, at the end of the day, it was all going to come down to me. And he always kept looking at me like: don't you know how to do that? I'm like: no, I'm learning just like you, right?

> You know, motherhood just doesn't mean you know how to do everything just naturally. And so it was really lonely and frustrating for me. And now when I look back at it and talk about it in therapy, I do understand that part of my postpartum depression was experiencing that loneliness. Of knowing that it was all going to come down to me and that I was the only person that was going to be able to take care of this baby. Even though I had, you know, my husband's family there, even though I had my husband.

Her husband's family also held the view that Linda should serve as sole caregiver for the baby:

> I remember them making comments to me that basically implied that it was my responsibility to always be taking care of this baby. It didn't fall on anyone else, right? It was me, because my husband had a job he had to go to, and I wasn't working, I was off. So it was all entirely up to me twenty-four seven.

> And I remember during the nights when, because Ethan was a colicky baby, he didn't sleep. So sleep was a huge factor in what was going on with us. And he was colicky for a long period of time, like for a good year of his life. . . .

> We were both sleep deprived. But it was mostly me, because my husband had a job he had to go to, you know, during the day and his parents and he felt that, right? It was an unspoken sort of understanding that it should just be me and it should come down to me. Because I'm the mum.

> And so, it was hard. It was a lot of pressure, and I was resentful and angry, and I felt very lonely. Yeah.

The different expectations that often exist for mothers and fathers in North American society also negatively impact fathers. For Allen, the pressure he felt to be a good economic provider, rather than to provide nurturing care for his wife and son, was one factor that led to both his wife and him developing postpartum depression:

> So you have a child and then all of a sudden the world turns upside down and then every decision you make you'd have to always worry about another person that's there in your life.

> And for me, let's say she didn't have a good night's sleep because the baby was crying or had a bad night. Well to me the easiest solution is: well, I'll take care of the baby and you can have a day on your own to sleep.

> But I think for her too, she wanted to be very active in the raising of our child. So she said: no, no I can do that too, I can do this. And with all good intentions she also didn't want to put the burden on myself.

Allen continued, sharing that both he and his wife felt a lot of pressure to meet society's expectations about the expected roles of a mother and a father in a young family:

> And perhaps that's also in my mind the way that society tells us that the mum is supposed to take care of the child and the dad is supposed to, you know, bring home the bread. So I think she put pressure on herself and I think that sort of built over the, you know, first year or two, of our son's life.

These expectations had a significant negative impact on how Allen thought of himself as a father:

Okay, for me, how that affected me was that I was thinking: well, I can do it. I don't need her help but she's saying that I can't do it. So I'm questioning my own abilities as a father and just a person to raise my child. And so I think that sort of had an affect on me. And I've always tried, you know, think that if she had a problem feeding our son then I would try to help but as a fix-it type of solution. But it seemed to not work.

In addition, these expectations about a father's proper role in family life also negatively impacted Allen's ability to care for and support his wife, who was struggling with severe postpartum depression:

So over the, you know, few months it just kept on going: Okay, I obviously can't fix this problem and so if she's got a, and she's getting into this depression mode and this is: How can I fix it. And it's always been: Problem–solution. And that's how I was thinking.

And so what, I think what happened is as she got more frustrated and more closed and more sort of focused on the baby. As the time went on she became more and more worried about the child, you know, whether he's going to get SIDS or something's going to happen. The beginning, you know, the doctor said he might have a jaundice. We were all worried about that. And then we tried, because he wasn't sleeping well at night, we tried different things and all the different sleeping solutions. And it never worked and he just kept on having a problem sleeping so it just added that stress and pressure.

Because they were unable to connect with and support each other in the hard work of caring for a newborn during postpartum, in part because of these rigid exceptions of the roles of mothers and fathers, Allen and his wife began to experience significant difficulties in their relationship:

And for me I was trying to fix it, fix it, fix it, fix it. For her, she's just trying to Band-Aid and trying to, you know, live through it. And we try bottle feeding him, but he wouldn't take the bottle, and just a lot of problems. And I think we, both of us, my wife and myself, we sort of got into our shells and just sort of, let's say separated, you know, ourselves from each other. And, we were having problems but I didn't realize the problems.

In this case, both partners were negatively impacted by how they were trying to meet society's expectations of new parenthood. Allan's wife felt she had to always be caring for their infant,

and thus she felt anxious and exhausted. Because of this expectation and their attempts to conform to it, Allen felt shut out, helpless, and disconnected. Their responses to these expectations were one of the factors that led to both of them developing depression and experiencing significant conflict in their relationship.

The stigma associated with having a PMAD and being an exhausted new parent also impacted project participant's relationships at their workplaces. New father and home renovation contractor Pablo shared that:

> People don't understand it. And it's understandable because if you're constantly dealing with somebody that never seems to be quite okay, just happens to be three full months in a constant tiredness mode . . . you start [to] question: Okay, what's wrong with this person?
>
> So, it's not like you meet a stranger: Oh, I have a kid and I had a rough night. Oh yeah, poor you. And off you go. [You start to lose] credibility because you are months and months and months of going with the same story.
>
> So it was like, even though in my case [I had] new customers every, let's say, month and a half or a month, whenever you go back to a previous job or to a site after six months and they see you the exact same way, you can tell that they don't trust you that much. Just because: Well, what's wrong with you? Like you told me that same story three months ago or four months ago, so how come you still the same?[65]

For Pablo, stigma around PMADs and the lack of understanding of what it was like trying to raise two children and support a spouse with a PMAD negatively affected his relationships with his clients and his ability to effectively do his job.

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[65] http://postpartum.org/videos/video/pablo-feeling-judged/, accessed November 12, 2016.

Stigma in Infant Feeding Choices

Just one example of a vernacular parenting practice that can become a stigmatized vernacular is infant feeding practices. In the context of metro Vancouver, breastfeeding infants is common and well supported by public health resources and a long maternity leave. This is the infant feeding practice that is seen as "normal." New mothers receive the message, as Janis stated in one of the focus groups for PPPSS alumni, that breastfeeding "is natural and you should be able to do this. [But] for some women it doesn't work. And that's not talked about. . . . I think people get in their mind that formula is bad and it makes women feel like they've failed if they can't exclusively breastfeed."

Therefore, those who choose not to or are unable to breastfeed may feel stigmatized for formula feeding.[66] For video interviewee Linda, she felt grief that her attempts to breastfeed her son were not successful, but also felt confident that her decision to switch to formula feeding was the right one for both her and her son's health. In her interview, she described one experience when the actions of a public health nurse leading a drop-in mommy and baby educational group at her local community center highlighted her feelings of stigma:

> So there'd be two mums out of those twelve, right? That had to be, you know, pulling out the bottle verses the breast. And it was weird.

> And they even split us up. They did a session, one of the nurses, it was a nurse, right? One of the Public Health Nurses that were running the sessions, they said: oh, let's split you guys up: who's breastfeeding and who's bottle-feeding? They split us up into groups!

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[66] See Suzanne Barston's Fearless Formula Feeder blog for just one example of an advocate for supporting parents in making infant feeding choices: http://www.fearlessformulafeeder.com/, accessed November 1, 2016.

Once Linda and the other formula-feeding mother got settled in their group of two, Linda began

to consider:

> And so there I am with the one other mum, (laughs) and they wanted us to talk
> about our experience and I'm like: this is so, this is like traumatic. You, you're
> actually, you're actually alleviating that stigma. Elevating that stigma, I mean.
> And so, that was a very bizarre experience.
>
> And I was so sleep-deprived that I didn't really couldn't process what was going
> on, but I remember thinking afterwards: that was just not right. Because that
> would make any mum feel horrible.

Linda continued, sharing that other mothers have shared with her that they feel so stigmatized by

not breastfeeding that they hesitate feeding their children in any setting where others might see

them bottle-feeding.

> It's intimidating. And I always hear about it from other mums when they have to
> be in public places they almost kind of shun from having to feed their baby in
> public, right? Because then that means you have to admit that you're not
> breastfeeding.
>
> Luckily it wasn't as horrible for me because, I guess, because I was more
> accepting of it. But it wasn't easy.
>
> Do I openly tell (whispers): "Oh yeah, I didn't breastfeed my child." Like, I don't
> openly tell people that, right?[67]

However, breastfeeding mothers who choose to feed their infants in public also experience the

impact of stigma when they are told to cover up or feed their baby in the bathroom (because their

infant feeding choice results in what others may perceive as public nudity or a lack of

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[67] View Linda's excerpt here: http://postpartum.org/videos/video/linda-breastfeeding-stigma/, accessed

October 18, 2016.

modesty).[68] In both cases, parents are told, by a wide variety of people, that they are good or bad

parents for their choice about the best way to feed their infant given their own family's particular

situation. Because of the well-publicized (but highly contested) public health implications of

infant feeding choices, everyone, from mother-in-laws to strangers on the street, feel they have a

right to get involved in this family health decision.

Stigma and Intrusive Thoughts

As discussed previously, when new parents experience unpleasant intrusive thoughts about harm

coming to their children, they can find this extremely distressing. Nichole Fairbrother and Sheila

R. Woody's study on intrusive thoughts showed that for the majority of parents, they had little or

no fear that what happened in the thought would actually come to pass. Instead the upsetting

nature of the thoughts and the guilt the individuals felt about having them were the most

significant impacts (2008). The experiences of project participants illustrate that some of this

upset and guilt seems to come from the fact that the nature of these thoughts do not fit with the

cultural expectation of what a good parent should be thinking about. Robin's experience with

intrusive thoughts illustrates this:

> When it came to disturbing thoughts around my children they just stayed with me
> and I obsessed about them. And there was so much guilt around that too. You
> know: "I'm a mother and I should love my children." And then these disturbing
> things would come into my head. I felt really guilty about them and then the guilt

[68] Although there has been extensive media attention to this issue in the past few years and many are

working to change this. Most US states guarantee the right of mothers to breastfeed anywhere children are

allowed. For example, mothers have staged nurse-ins to protest when a mother has been asked to leave or

nurse in a location such as a bathroom (see Adams 2015 for just one example).

just, you know, weighed so heavily on me as well. . . . And it was like, it made me
afraid . . . and it paralyzed me. And yeah, not a comfortable place to be at all. It
was really hard to deal with that.

A common fear for parents who are experiencing a PMAD is that if other people find out how

much they are struggling, social services will take their children away from them. As Robin

shared:

I have always been very good at presenting the façade of the perfect mother. That
everything was fine, everything was good. And that I was doing great if anybody
asked me: things were good. And that would really mean that things weren't
good. And it was terrifying to think, you know, what might happen if I said I was
feeling that way. You know? I was afraid that maybe somebody might take my
kids.

This fear comes in part from the incorrect perception that parents with mental illness are likely to

neglect or harm their children (as discussed in previous chapters). Therefore, parents who

experience intrusive thoughts about harm coming to their children, or, more distressingly,

intrusive thoughts about hurting their children themselves, feel at high risk of being perceived as

a child abuser or murderer (who are one of the most stigmatized individuals in our society).

This fear directly impacts how able they are to reach out for help and support. For example,

focus group participant Erin stated:

If there was one thing I could wish for the health care system, it would be that
more public health nurses and doctors and first-line workers were just more aware
of how common postpartum depression is. And it just so needs to be
destigmatized. That it's [not that] we're all going to drive our children into a lake
and kill them. That's not what postpartum depression is. But I think a lot of health
professionals still think that's what it is, so they won't even bring it up.

Many project participants describe the relief they felt when they learned what intrusive thoughts

were, that having these thoughts did not mean they were likely to act on them, and that many

new parents have these thoughts.

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During her postpartum period, video interviewee Linda had scary intrusive thoughts she

described as "violent" around her son. She did not understand these thoughts and so she was

afraid they indicated she had postpartum psychosis (although she felt very sure she would not

actually cause harm to her child). She also feared that these thoughts would make other people

think she had postpartum psychosis, report her to social services, and cause her child to be

removed into foster care. Therefore, Linda did not tell anyone about these thoughts. However,

when Linda began attending her support group at PPPSS, she:

> learned that these were classified as intrusive thoughts and . . . that these were
> normal for people experiencing postpartum. So that was reassuring. I remember
> when I first learned about that, it was just like this big light bulb that came on and
> it was very reassuring that this was normal.

Linda had a history of mental illness and had been receiving mental health care starting in

pregnancy, therefore she was surprised that:

> this was something that I'd never heard about and I had thought I had done my
> research and, you know, done my homework, and talked to my doctors. But none
> of them mentioned anything about these thoughts to me. I don't know if it was
> because they didn't want to feed, you know, that idea into my head. . . . But I
> remember I didn't get any information on . . . those types of symptoms. And I
> wish I had. Because it would have helped me understanding what I was going
> through was actually a normal symptom that many people [have who] go through
> postpartum and not the severe, you know, psychosis part of postpartum. So yeah.

Linda also found listening to the experiences that other mothers had with intrusive thoughts to be

particularly valuable:

> When I was sitting in the weekly support groups, and hearing the other mums that
> were experiencing these same thoughts it was a pattern, it was a dominant pattern
> that pretty much all the mums had intrusive thoughts. And for them to open up
> and share in a safe place, among other mums, people who were going through the
> same thing, that was really reassuring. That made the normal seem more normal.
> Like even though I was hearing from the facilitator saying that this is normal, it
> didn't seem normal until I actually heard it from other mums who were saying
> they were experiencing and hearing what those experiences were.

For Linda, listening to the experiences of other mothers with intrusive thoughts is what helped her to really accept that these thoughts were a normal symptom of postpartum depression and anxiety and not a sign that she was experiencing a psychotic episode. This acceptance provided her with an immense sense of relief and was important to her being able to recover from postpartum depression and anxiety.

Impact of Cultural Difference on Stigma

Informed by PPPSS's own anecdotal experience and research about mental health stigma in newcomer communities, the project also began with the orientation that the stigma surrounding mental health care particularly impacted individuals who were new to Canada (Morrow, Smith, Yuan, and Jaswal 2008). Project participants did talk about how being a good parent can be even more difficult and confusing when you have more than one cultural standard to meet. In video interviewee Mariko's home culture of Japan, a new mother is expected to go home to her mother's house for the first month after birth and be taken care of as she learns to be a new mother. However, Mariko was married to an Anglo-Canadian and living in Canada, where a new mother is told to "get out of the house" and resume her normal life as soon as possible:

> I was so afraid with taking my daughter outside and walking around the town. But for my husband that would be a normal thing to do for him. Or, I shouldn't say normal thing . . . it just came up to in his mind naturally that, you know, we can do such things. So I always had a like anxiety to get out of the door because [of my] culture background.

For Mariko, these differing cultural expectations about what new mothers should do after birth are illustrated in an incident that happened ten days after she gave birth:

> I got a phone-call from my mother ten days [after giving birth]. We were at a friend's house celebrating the friend's daughter's birthday. And my mum called

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me on the cell phone [and said]: Why are you not home? Like I'm worried about you, what happen[ed]? Something happen? Because you are not home.

So like I told my mother that: no, nothing happen, everything is good. We are just having a birthday party at a friend's place and for just dinner. It's not far from our place, you know, you've been there. But . . . my mum was so panicked [by] the fact that we weren't home.

So then [this incident] kind of supported me to stick with my original culture . . . getting out from the house is kind of a bad thing to do. But in fact though, you have to get out the house. . . . So that really caused me [to be] confused. And I think I lost whole confidence about who I am because I didn't know what is right.

Mariko brought ideas of what a good mother is from her own culture, but found it hard to live up to those ideals in the Canadian context and while experiencing postpartum depression and anxiety:

Because Japanese culture is, I don't say that in like a big part in Japanese culture, but the way I was brought up from my mother. I think in general wife/mother, we have to do everything. We have to take care of baby, we have to do the house chores, we have to do grocery shoppings, and we have to do everything by ourselves. So that's kind of common sense that I have to do. But I couldn't do any of that. So that's kind of one of the factors, I get the pressure from my conventional thinking.

Mariko felt stigmatized by being unable to meet all of these expectations. Thus, she was unable to accept the help and support that was being offered because doing so would have made her feel even more stigmatized.

So it becomes more embarrassing . . . and it becomes more big secret because . . . I can't do it. Why I cannot do the things that other people can naturally do? Being a mother is a natural thing to be. And why am I struggling with this? And why am I struggling with my partner who is supportive but I can't really take his supports?

Some project participants who were immigrants to Canada, such as Mariko, felt that because they had grown up in places where individuals with mental illness are highly stigmatized, it was harder to accept that they had a PMAD. Mariko stated that, for her, coming from Japan, "mental

issues, depression equal crazy. And then crazy equals hospitalized. Like whole that image of

being depressed was just like shocking. And I was, yeah, I was embarrassed."

After nine long months of feeling miserable and not knowing why, Mariko was relieved to

finally be diagnosed with depression because she finally knew why she wasn't happy. She was

excited to be able to share what she now knew with two Japanese friends, but the response she

received contributed to her feelings of being stigmatized:

> I didn't realize that [because of] the lack of education sometimes about
> postpartum depressions and [because] not many people knew or know [about it]
> still, they don't know how to respond.

> So one just laughed, lost their whole words. And one said: "Why did you go to
> see a doctor? If you go to see a doctor, they're going to diagnose you as
> depressed. Why did you go?"

> Those two experiences made me actually basically be so quiet. And after, I just
> didn't say I'm depressed. So that was the least helpful response from my friends.
> But on the other hand though, they were physically very supportive. They offered
> to [babysit my daughter] or provide meals and stuff.

> But, in that emotional part, people don't know how to express their feelings. They
> couldn't say: I'm sorry, I don't know anything about it, I don't know how to
> respond. . . . It feels like a stigma. I think that's the big barrier for mothers to
> actually talk about it.

Mariko also felt unable to tell her own family, who were still living in Japan, for three years,

"because of the cultural stigma. I know they are not going to understand it. And it's lucky [that I

had] that distance [so] I could keep it in secret for long time."

Generational difference was also a significant factor for many project participants, especially

those who came from East and South Asian cultures. Focus group participant Penny, who

emigrated with her family from China to Vancouver as a child, spoke about the impact that

cultural and generational difference had on her postpartum experience. Penny was diagnosed

with postpartum depression after the birth of her second child:

I was trying to explain to [my mom] what I was feeling. She didn't recognize it, she didn't know about it. She thought there was something definitely wrong with me and she just put on a different type of expectation. And so therefore I had to block her out and say: You know what? I can't talk to you. Don't come near me. Because she also created an extra stressor for me.

Because of significant differences between daily life in metro Vancouver and rural China, Penny found that her own mother's experience of early parenthood was so different from her own that it was hard for them to relate to each other during Penny's postpartum period.

Where [my mother] came from [in rural China], she even stated herself that when I was born she had the whole village helping her out. Yes, she slept with me until I was a certain age. And yes, I was close to her in the sense that day-in, day-out, I'd see her. But in terms of her healing process she had a month to rest, the Chinese thirty-day thing. And then after that, she says, because her job was to be in the fields, she just fed me and went to work in the fields and I was taken care of by an aunt or a cousin or what not. So, therefore, she didn't really take care of me, she said.

She even admits that, you know, once my brother came along (laughs) you know, I was sent away with my grandmother to even another city. So, she had the same process. She would just feed and sleep with him, but then in the morning she'd be off in the field working and my brother would be taken care of by another aunt or cousin. So she doesn't understand the isolation that's being felt.

Talking about the impact of that lack of understanding about the nature of postpartum depression and what it was like to parent young children in Canada, Penny added that "I don't expect [my parents'] support. Some times I wish they could give it to me because they are my parents, but because I know that they're not going to understand. And they're going to just give me an added stressor, it's not helpful at all to share with them."

Partners of individuals with depression also struggle with stigma. Video interviewee Pablo, who immigrated to Canada from Mexico, stated that in his childhood family:

There wasn't that much talk about depression. . . . My dad, when we moved from one city to another, it was a drastic change. He suffered quite a deep and long depression, which was never treated. I guess part of that was that taboo that:

Okay, I'm not bad. Everything is fine. Like if I go and see a psychiatrist or a therapist, they're going to think I'm crazy, or maybe they're going to tag me as a crazy person.

Pablo also had a distrust of psychological care because his grandmother had received inappropriate care for depression and greatly suffered as a result. However, when Pablo's partner, Maria, experienced severe postpartum depression, he was forced to confront his own beliefs about the condition:

Let's say twelve years ago, when [Maria and I] were just friends, I [would have] just said: what's wrong with you? You're crazy [for seeking psychological help]. But being able to see both sides of the story, and being able to see how good [Maria's] psychologist is and seeing how Maria reacted so well to his help, even before the depression, helped me to differentiate: Okay, this is a real thing, this is happening and it's not a bad thing. It's not that she's going to go nuts and just completely lose her mind; it's just a stage in her life.

And returning to it, that stigma, it's still a hard one to accept whenever you talk to people like friends and things like that. They still don't truly believe it and people still don't believe in postpartum depression. They will say: Ok, you're depressed. But they don't attribute it to a birth thing, having a kid. So they just think: Ok, maybe she was crazy before. This is just the excuse she needed.

But then on the other hand, there's people that really understand and really cope with you on that regard and try to help. So it's still way better, I would say it's better here than in Mexico, in my opinion. But, [even in Canada] probably a little bit more education that needs to be done in that regard.

Mariko's Canadian partner, Kasimir, also felt that the stigma surrounding mental illness impacted him as well:

Mariko: Yeah, the person who is having the depressions [is worried that their] partner probably could be embarrassed [by] that fact. That's what I was worried [about], like: our family might be embarrassed by the fact I'm depressed.

Kasimir: I think that maybe I was the person who was more worried about the stigma actually, because maybe [it impacts] men [more] to some degree.

Listening to Kasimir admit he'd been concerned about the stigma of Mariko having a mental

illness, she concluded: "Yeah, it's funny though, like mental health is really secret. We can talk

about cancers, we allow confessions, but come down to the mental conditions, it's still difficult."

Intersecting Stigmas

New parents bring other potentially stigmatized identities into their new role: cultural, racial, or

ethnic difference; body difference, such as obesity or underweightness; gender or sexual

difference; mental or physical health conditions; or visible or invisible disabilities. Before

parenthood, a particular individual may (or may not) have come to terms with what this

difference meant for themselves and likely had developed particular ways of being in the world

that worked for them. However, many individuals find that when they are a new parent everyone,

from perfect strangers to your own partner, now feels that they must comment on the impact that

this stigmatized attribute has on the baby and on the individual's ability to be a good parent, or,

indeed, even to be a parent at all. For example, one PPPSS client with a visible disability

reported that she was commonly asked when attending her local mommy baby group if she was

her child's "real mother," with the implication that someone with a disability could not be in a

romantic partnership and have a functional reproductive system. Because the focus of this

particular project was on representing the most common experiences of the perinatal period for

parents who experience PMADs, as well as the experiences of parents from particular cultural

groups, these intersecting stigmas are not well represented in this research and it remains a rich ground for future work.[69]

Conclusions

I would like to highlight three important themes that emerged in the project about the impact of stigma. First, participants often felt that they had to conceal the fact that they were living with a mental illness and/or they had thoughts and feelings that did not fit within society's expectations of what a good parent should think or feel. For example, video interviewee Linda shared that when she first started to attend a postpartum support group:

> It was really hard for me to get myself to the first group because I wasn't sure what to expect. And I was scared because I hadn't talked about it with anybody. So for the first year of my postpartum I didn't tell anybody. Probably [for the] first year and a half, I didn't tell [other] mums, I didn't tell like friends and

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[69] Unfortunately, given the focused nature of the project, the project team did not explore these kinds of intersecting stigmas during the video interviews and focus groups (beyond those related to immigration status). However, as the project continued the project team began to become more aware of these kinds of complicated intersections. When creating project outputs during phase two, we worked to fill some of our gaps of understanding the needs of particular populations, while also ensuring we kept the focus on the most common issues encountered during the perinatal period. For example, we reached out to an individual who participated in the PPPSS online training who had shared her experience of the stigma of parenting with a spinal cord injury during the course discussions. She enthusiastically volunteered to serve as an expert consultant for a section on parenting with a disability. However, this is an area that PPPSS needs to continue to grow, and if this kind of project is completed again in the future I hope PPPSS will continue to build on the diversity already represented.

family. I told maybe some select few what I was going through; I was very ashamed of what I was going through.

Even though I had done lots of reading about it, [and] I knew I was at a high risk to get [it], I still was ashamed. And so I didn't talk about it for the longest time.

So there was a lot of stigma for me surrounding having to admit that I had [postpartum depression and anxiety]. Again, maybe that [I had it was] some sort of reflection of my character, or some sort of weakness. But again that's the myth of it, right? It's not the truth of what it is.[70]

Furthermore, participants felt that the act of concealing increased their feelings of loneliness and isolation and impacted their ability to heal and recover. As Linda continued her story, she described the impact of being able to be honest with other women who were having a similar experience:

I found that that it was my only release, my only safe place. Because I didn't feel like I had anybody I could talk to. So there were days, weeks, where even if I couldn't get myself out of bed, I made sure I got myself out of bed to go to the support group meetings once a week. So I was able to get myself out of the house for that.

Because it, what I gained out of it was a sense of release, I felt like at least I wasn't being judged here. And whatever came out of my mouth somebody wasn't going to think I was crazy. And also being about to just sometimes just sit and listen to other people, even if I didn't want to talk. And being able to nod and say, you know, like we all understood each other, we all acknowledged where it all came from. And we could all relate. So that was a huge part of it.

I went to support groups for two years and I don't think I missed much of it (laughs. So I did it quite well, one of the only things I could do well, I think. Because it really helped me.[71]

Like Linda, many project participants described the sense of relief they felt when they found a safe environment to share their full experience of parenthood.

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[70] View Linda's video at: https://vimeo.com/91698005, accessed October 19, 2016.

[71] View Linda's video at: https://vimeo.com/91697805, accessed October 10, 2016.

Second, many participants discussed how the stigma surrounding mental illness and/or the stigma of being perceived as a bad parent negatively impacted their relationships. Struggling new parents often felt that other people, including those closest to them such as partners or their own parents, did not understand why the individual would want to be in this stigmatized condition. Therefore, because it was an undesirable state, the struggling parent should just decide to feel better. In addition, struggling parents expressed the fear that the fact they were experiencing a mental illness and/or being judged a bad parent would be embarrassing to and reflect badly on their family. Thus, many participants discussed how these factors negatively impacted their relationships with friends and family members. Project participants responded to these issues in a variety of ways, such as focus group participant Penny limiting contact with her own parents in order to protect herself, but these measures often meant that the individual was not able to fully access the physical and/or emotional support from their family at a time in which it was desperately needed. In addition, sometimes these relationships are so damaged that they do not recover after postpartum.

Third, because of the stigma, project participants were reluctant to seek help and treatment. For example, Mariko did not seek treatment for her postpartum depression for nine month in part because she was not familiar with the condition, but also because she felt ashamed for feeling the way that she did. This impact is well-documented in public health literature as it is obviously a key concern for public health workers' efforts to mitigate the impact of mental illness, including PMADs, on patients and their families (Corrigan, Druss, and Perlick 2014).

Participants Efforts to Manage the Impact of Stigma

As folklorist Sheila Bock discusses in regards to stigma and Type II Diabetes, "it is worthwhile to draw a distinction between stigma (the effect) and stigmatizing storylines (the naturalized connection between label and stereotype that lays the foundation for the effect). . . . I use the term storylines deliberately here: negative attributes associated with diabetes become connected to certain employments that are, in turn, projected onto the life stories of the stigmatized" (2012, 159). By sharing their stories, in their own way, I would argue that parents experiencing PMADs are attempting to disrupt the stigmatizing storylines related to their condition. Those pervasive misunderstandings include that: parents with PMADs are likely to abuse their children, children raised by a parent with a PMAD will have a negative psychological outcome, having mixed feelings about being a parent means that you do not love your children. As Darcy Holtgrave notes in her examination of YouTube Vlogs (video weblogs) by individuals living with bipolar disorder, "by telling their story of experience with mental illness, [the vloggers] are rejecting the notion that mental illness is a condition deserving of stigmatization." Instead they are positioning themselves as "just an ordinary person who happens to have a mental illness," a person-first formulation (2015, 188). Looking at this in light of Goldstein and Shuman's (2012) argument about how folklorists may most productively approach stigma, by participating in PPPSS's project, participants were actively managing how value is "assigned, claimed, and denied" to the act of parenting (Shuman 2015, 25). Instead of accepting that a good parent must be certain things or do certain things, participants are claiming that an imperfect parent with a mental illness could be, not a good parent (because that paradigm is the way that value is denied to so many), but a good-enough parent. For example, at the very end of her interview, in response to the standard end-of-interview question asking if there's anything else to share that we did not

know to ask about, Linda began to speak very quickly to share something that was clearly very important to her:

> Okay, so living with perinatal anxiety/postpartum depression was all those horrible devastating things for me. But I do want to add that there is light at the end of the tunnel. It was a long road for me and I remember reading something a while back, it was a book. And in that book this person was experiencing a lot of hopelessness and he kept telling himself two words: Hold on. So that's what helped me (sighs) was holding on. And that "this too shall pass," and it did. . . .

> So I think that one of the most important things is that we talk about it and share it. And as much as possible. To help with the stigma but also just to educate and make people aware what the experience is like for people who are trying to support family members who are going through this.

> And also to let the mums and dads who are going through this to know that they're not alone. It's a very lonely experience and I think it's important for them to know that they're not alone.

Linda concluded by advising struggling parents that, "talking about it is ok, it doesn't mean you're crazy and it doesn't mean there's something wrong with you."[72]

Impact of Project on Stigma

Project participants and staff members hope that this project will impact stigma in many positive ways, many of which we will not be able to identify clearly. Our efforts focused on two main avenues in which the video interview segments were used to provide mediated personal encounters with individuals with PMADs in order to reduce stigma. First, the project team created online and written resources, informed and populated by materials from the focus groups and interviews, which were designed to educate a broad audience on the broad range of

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[72] http://postpartum.org/videos/video/linda-hope/, accessed October 2, 2016.

postpartum experiences, the nature of PMADs, and the need for support for new parents. The project team promoted and delivered these resources through the PPPSS website, social media accounts, and in-person outreach. The target audience were new parents, their friends and family members, and health care providers and community support workers, but efforts were also made to reach the general public. Second, the revised professional training programs for health care providers and community support workers also made extensive use of video interview segments in order to provide mediated personal encounters with individuals with PMADs in order to reduce stigma. These in-person and online trainings were designed to increase awareness and understanding of PMADs, and to increase provision of evidence-based treatment and support for parents.

As discussed in chapter three, use of PPPSS's resources and support services has increased over the course of the project. It is difficult to prove causation, but a plausible contributing factor is that individuals struggling with postpartum depression and anxiety are more aware of PPPSS's services and/or more likely to reach out for help when they are in distress. Being willing to reach out for help and looking for information may be a sign of reduced stigma surrounding PMADs in Vancouver and in Canadian society in general. PPPSS's calls for help and support from the VCH service area increased 38 percent from 1,657 during the 2012 fiscal year to 2,090 during the 2013 fiscal year. Since PPPSS's newly designed site was launched in August 2013, use of PPPSS's website has increased about 60 percent, measured in several different ways (see chapter three for a detailed breakdown). During the text message and online support pilot projects (March 2015–August 2015), requests for individual support in all modes increased by 21 percent and website pages accessed substantially increased from the same period during the previous year.

In addition, project participants and staff have anecdotal evidence of the project's impact. In her follow-up interview, Robin shared:

> I had one friend write me, she was in Europe. She said that after her second baby was born [she had] been having a challenging time with her second child. And she'd seen the videos, specifically when I was talking about intrusive thoughts around my older child. And she's like, "that was really brave of you."
>
> And she said that, and I was like: "Whoa."
>
> [She said] "And I really appreciated seeing them and finding that."
>
> And so that was really nice to hear. Even one or two people saying that, would be worth it. Because if there'd been [trails off].
>
> I think about how long I waited, and I'm a person who, I was working in birth, like, I get this. And it took me so long to reach out finally, because I still was just like. There's still this stigma. . . .
>
> So maybe if I'd had somebody else that I knew, or a person who looked like a person that looked like me, you know what I mean, speaking about it out loud, it might have pushed me into speaking up sooner, so I didn't have to go so [long]. Speaking up sooner, reaching out, and getting help faster.

Of course this project was only one small effort in a wider universe of efforts to reduce the impact of stigma on parents experiencing PMADs. As discussed in chapter one, there are many people working to, and having success in, increasing the visibility and understanding of PMADs. In addition, there is much concurrent work with the goal of de-stigmatizing particular parenting behaviors and broadening the definition of what it means to be a good parent.[73]

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[73] One example of this advocacy work to decrease the stigma surrounding parents is in the context of infant feeding choices. In August 2013, the "I support you" campaign was launched. A collaboration between bloggers Kim Simon (Mama by the Bay www.mamabythebay.com), Suzanne Barston (author of *Bottled Up* and The Fearless Formula Feeder blog), and Jamie Lynne Grummet (author of I Am Not

the Babysitter blog, also well known as the mom who appeared nursing an older child on the cover of Time magazine in May 2012 http://time.com/3450144/behind-the-cover-are-you-mom-enough), this campaign encouraged moms to submit statements and images that were supportive of all infant feeding choices (under the #ISupportYou tag) on Twitter and to the Fearless Formula Feeder's Facebook page. Huffington Post also publicized the collaboration, and 184 of the supportive images can be seen at http://www.huffingtonpost.com/2013/08/07/i-support-you-movement_n_3719249.html. Simon's post can be viewed at: http://mamabythebay.com/2013/08/04/this-is-what-support-looks-like/, and Barston's post can be viewed at: http://www.fearlessformulafeeder.com/2013/07/announcing-the-i-support-you-movement/. As of October 2016, Grummet's blog was not available. All URLs accessed October 23, 2016.

For examples of projects working to broaden the definition of what it means to be a good parent, see The Good Mother Project: http://goodmotherproject.com/ (redefining what it means to be a good mother through writing and art), Fourth Trimester Bodies Project: http://www.4thtrimesterbodiesproject.com/ (just one of many projects to celebrate real postpartum bodies through photography), and Daddy Doin' Work: http://daddydoinwork.com/ (Doyin Richards' blog redefining the role of modern fathers).

Chapter 5: Healing from and Making Meaning of
PMADs through Narrative

Postpartum depression was one of the hardest times in my life ever. But, coming out on the other

side, I can say that I'm actually really thankful for having that experience. And that's simply

because I think that I would have been struggling with the ability to cope with things before. And

that I never really knew how to take care of myself or to handle emotions, but I was easily able to

sweep them under the rug or just put them aside.

But after, you know, having gone through postpartum depression and being able to gain

those tools, I am so thankful that I have them. And that would never have happened had I not

experienced what I did after my daughter was born.

—Robin

Providing a setting that allows individuals experiencing a perinatal mood and anxiety disorder

(PMAD) to narrate their experiences to an audience that is nonjudgmental and understanding is a

key part of the support and care that Pacific Post Partum Support Society (PPPSS) provides. In

addition, these kinds of narratives form the foundation of the project discussed in this

dissertation. This chapter will examine the process that happens for struggling parents when they

share their perinatal narratives and listen to other people's narratives, and when they give and

receive support during those acts of telling and listening. I will also look at some of the benefits

and challenges involved in using narratives to inform and create educational materials and

services in health care and social service settings. Finally, I will explore some examples of how

project participants used narrative to interpret their perinatal experience and move forward with

their lives.

As discussed in the introduction, in Canada, including metro Vancouver, most new mothers who have been working prior to giving birth or adopting a child qualify for up to a year of paid parental leave via a government-funded program. Some of this leave is designated as maternity leave and is available only to mothers who have given birth. However, over half of it is designated as parental leave and can be taken by an adoptive parent, the non-birthing co-parent, or split between both parents (Service Canada 2016). Although there are certainly individuals who encounter problems, an individual on parental leave is supposed to be guaranteed a comparable job with their employer upon their return. Some individuals choose to return to work after their parental leave is completed (making use of paid daycare or family support to care for their child or children), while others choose to leave their jobs and continue to stay home and serve as the primary caregiver. Therefore, for mothers who participated in the project, narratives of early parenthood most often took place in the context of being a fulltime primary caregiver of their infant. However, the fact that the mother was in that role for approximately the first year of her child's life does not mean that she was planning to continue with this family role in the future or that she considered her primary vocation to be a stay-at-home mom. Most project participants were working full or part time before the birth of their child and many of those participants returned to work at the end of their parental leave. [74]

Many of the narratives that are told each week in the context of PPPSS support groups and in individual support conversations fit within the genre of personal experience narratives. The types of narratives that might be told in this context include:

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[74] The focus groups also included one father who did not return to work at the end of his parental leave in order to serve as his children's primary caregiver.

What happened when my toddler had a fit at the grocery store.

What I felt like when my mother told me I am feeding my baby the wrong way.

How I was able to put on clothes and take my kids to library story time.

As Sandra K. Dolby defines the genre:

> The personal experience story is a prose narrative relating a personal experience; it is usually told in the first person, and its content is nontraditional. The plot of the story is based on an actual event—a single episode—in the life of the storyteller, and thus it is considered to be a "true" story rather than a fictional one. (1998, 504)

Like many personal experience narratives, these narratives are shaped by community standards on what makes a tale tellable and appropriate for the group. They often make use of humor, even when the topics are dark. Given the limited time available for each member, the tellers chose what to tell and what not to tell during their time, and they had a specific purpose for telling the narrative(s) that they chose. Within the groups, the narratives that are told during the introductions that were described in chapter two are perhaps even more shaped by these factors than the narratives describing what happened in the past week. The narratives that were solicited and recorded for this project were inspired by the postpartum journey narratives that were told during group introductions. As the product of a recorded interview discussing events that are personally known to the narrator and took place in the past, the project interview narratives also fit comfortably within the genre of oral history, with the targeted topic of the narrator's personal experience of a particular illness and of becoming a parent in a particular time and place.[75] The most significant source of authority for all of these narratives, including those told by group

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[75] See Trevor Lummis' (1992) definition of the genre of oral history, among others.

facilitators, is the individual's own personal experience with parenthood and perinatal mood and

anxiety disorders (PMADs).

What Does Sharing Narratives Do?

The PPPSS support groups are composed of a trained group facilitator and up to eight mothers

who are experiencing a PMAD. Video interviewee and former support group member Maria

remembers that feeling safe was essential to being able to participate in the group:

> I immediately felt safe in the group. I felt very, very welcome. I felt very, I don't
> know how to say this in English, but like, you're safe here. We are going to take
> care of you. We are going to treat you well. We're not going to judge you. We're
> not going to say anything that you may mention here. This is just a safe place for
> you and your babies. So I think that was very helpful because right away I started
> to talk and talk. And I learned so much from the mummies that went to there, to
> the group. So much, so much. In many, many, many different ways.

The group facilitator's role is to keep all group members safe by ensuring group guidelines are

followed, to encourage participation in the group by selectively sharing their own perinatal

experiences, and to ensure that all group members are able to share (if they want to) by

monitoring time and taking turns.

It is useful to consider four distinct actions that occur around sharing personal experience

narratives in the context of a PPPSS modified-peer support group and similar supportive

situations: telling, listening, receiving support, and giving support. In the group, any member can

take any of these roles at a particular time. When the group is working well there is also an

exchange of giving and receiving support through this exchange of talking and listening. This

positive exchange is in no way a sure outcome of sharing a narrative about difficult perinatal

experiences or feelings in the context of regular interactions with family and friends. Instead,

someone might be told what they should be doing, or that they shouldn't feel a certain way, or

what they should do to fix a situation. For someone who experiences a PMAD, these kinds of

responses are often unhelpful and quite possibly may cause harm. Instead, project participants

emphasized that what they needed was to have someone listen who was able to offer warm,

empathetic, and nonjudgmental support, or, at the very least, to just listen and nod. For example,

as discussed in chapter four, when video interviewee Mariko shared with two friends that she had

a PMAD, one friend just laughed and said nothing, while the other expressed dismay that Mariko

had gone to the doctor with these kinds of concerns. In response, Mariko stopped sharing her

experience with anyone, and thus felt even more isolated and alone. However, at the urging of

her doctor and husband, when she finally met with a counselor at PPPSS:[76]

> I started talking, introduced myself: my name is Mariko. I was diagnosed with
> postpartum depression, and I'm here. So the person quickly engaged with me,
> with no appointment. [She said] tell me about your stories.
>
> And, of course, a lot of tears through that conversation, but she is so calm, and
> peaceful, and no judgmentals. And I could finish my story without feeling I'm
> doing something wrong.
>
> That was really big turning point. . . . After that I got the phone call from the
> office regularly, maybe once a week. And, you know, very calm, no judgment,
> just listening, listening to my emotional talk.

In these narratives, the source of authority is the teller's own personal experience. This is true

even for PPPSS staff members. Although all PPPSS counselors have formal training in peer

support, their main credential and source of authority for being qualified to do the work is their

own personal experience with postpartum depression and anxiety.

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[76] Mariko was unsure about her ability to speak English on the phone, so in an unusual situation she met

her with PPPSS counselor in person the first time by just showing up at the office.

Act of Telling

Perhaps the most obvious action that takes place during support group is that one person at a time is engaged in the act of telling. This mere act of telling, even if the person does not receive support (but does not receive a negative response), may still be helpful for the individual. First, it allows the person to express and release their emotions, which can provide a sense of relief. Second, telling may allow the person to think aloud, which can help some people discover more about what has happened, how they feel about it, and what they would like to do next. Third, telling may allow the individual to explore ideas that might lead to a larger sense of what their thoughts and feelings mean to themselves. However, without a meaningful exchange between the teller and the listener, the impact of just telling may be limited.

Act of Listening

Many project participants described how listening to the experiences of other parents who were also experiencing a PMAD helped in many ways. Listening to other parents' stories placed their own experience in the context of a wide range of parenting experiences (rather than just positive ones), which helped to reduce feelings of isolation and loneliness. For example, video interviewee Noella shared about her PPPSS support group:

> Just having a place to come and talk and sort of normalize the feelings is huge. And I wish more people were more open about their anxiety. I think people sort of feel like if you, if you say anything bad about motherhood, or any of the process, that somehow means you don't really want to be a mother or you don't deserve your child.
>
> And I think we do a real disservice to women, as well to our own children. Because I don't think it would be fair to my son to think that everything was perfect all the time, because that would set him up with the expectation in life to think everything is going to be perfect all the time. And that's not what I'm here for. I'm here to teach him how to deal with it when it's not perfect.

Listening to the narratives of other members also lets group members learn about strategies that might help them to cope with their feelings and situation and to heal. Learning about what worked for someone else and therefore which might also work for you is a qualitatively different experience than being given unsolicited advice because the person who needs help keeps more of his or her own power and autonomy. That is, after hearing what worked for someone else, they can choose what to take and what to leave, instead of feeling that they must do this thing that someone told them to do. As video interviewee Linda described, in her support group sometimes she would:

> Just sit and listen to other people, even if I didn't want to talk. And being able to nod and say, you know, like we all understood each other. We all acknowledged where it all came from. And we could all relate. So that was a huge part of it.

In addition, by listening, individuals experiencing a PMAD can see people in other parts of the recovery process. Video interviewee Pablo remembers that when his wife, Maria, started to go to her support group:

> I really felt the changes when she started going. . . . And like everything, there are people that are in a better shape than you, and people who are in a worse shape than you. So that really helped her fit in, not to feel like she was the lowest of the lowest. So, that, that kind of help is always appreciated.

A person who is still severely impacted may gain hope from seeing others who have been in their situation earlier but who are now starting to recover. Those who are beginning to feel better, but who are still struggling, may realize how far they have come by listening to those who are currently having a more difficult time. Therefore, merely by listening to other group members' experiences, group members access many benefits that may help in their own healing and recovery.

Act of Receiving Support

When an individual receives support in the group, they may have the following experiences. First, the individual may feel that their emotions are real and valid. Second, they may feel supported, empathized with, and connected to other group members. Third, the person receiving support may feel that they are a good-enough parent, even if they are not feeling or (perhaps) behaving as they would like. Fourth, the individual may learn tools for dealing with the situation and their feelings about the situation from other group members, if such is desired and requested. Finally, receiving support may help them to determine what they would like to do, or not do, in response to the situation and their feelings about the situation.

Support can be given in a many ways. Perhaps the most obvious way is by having someone listen to your story and offer support in return, using methods such as kind words, empathetic expressions, and warm gestures. But another way is by listening to other's stories and feeling supported by realizing you have a similar experiences. Video interviewee and former group member Brianna realized, while recovering from postpartum post traumatic stress disorder (PTSD), that what she:

> was really craving, actually, was the support of other women who'd had similar experiences. Going to the psychologist was necessary for my mental health getting better, but having a group of women who just know, I think, was just as crucial for me.
>
> And I struggled with finding a group like that. . . . It was just through Googling over and over, and over again Vancouver, birth trauma, any combination of other words, that I found the Pacific Post Partum Support Society. And one phone call was all it took to get me into that group and it was essential, I think, to recovering. Even if you just sit and say nothing, you just listen.
>
> And that was one of the occasions where I might tell my story and see someone else was sort of thinking: Hmm, I had something similar. Or: I know how you feel. And that makes you feel a lot better. You feel like someone knows. [You feel] I'm not the only person who had to go through this. I'm sad for that person as well, but at least we can share our experience and our successes along the way.

Or, as another mom shared in the PPPSS alumni focus group:

> I didn't think a support group was going to be for me. . . . But that support group, that connection, that sitting there with the other women, and saying the things like: I don't want to be a mum. Or, you know: I want to divorce my husband. Or: I want to kill my husband.

> It was so powerful to have another mum be like: I know exactly how you feel. Or another mum just sit there and smile and be like: Yeah, I know. Like the power of that I think is why I feel like I've recovered mostly.

Participants also recognized that by asking for help and allowing other people to support then, they were in turn providing support. As video interviewee Robin shared:

> I ask for help now, and I never used to be able to do that, ever. It was always that I took care of everybody else. And I realized that it's actually really important that I ask for help. I love helping people, so [I realized that] other people love helping people too. . . . So I tell myself that sometimes, and it makes it easier to ask for help.

By reminding herself that letting others support her was in turn supporting them, Robin was able to encourage herself to reach out for help when she needed it.

Act of Giving Support

When an individual provides support to others in the group, they may have the following experiences: First, the individual may have an opportunity to practice the skills required to support others in a safe environment, which can then be applied in their own personal relationships. Second, providing support to other group members may help them feel connected by engaging in meaningful emotional exchanges. Third, individuals may gain a sense of satisfaction and competence by selectively sharing what they have learned through their own experience with PMADs with other members.

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In just one example of what can happen when a person provides positive support to another, video interviewee Noella talked about how what she learned in support group helped in interactions with her family:

> My family is, they're not the types of people that would talk about anxiety, or depression, or any sort of admitting to not being well and happy all the time. So it's been, it's been interesting. . . . But it's really helped with my brother, because my oldest brother doesn't really have anyone to talk about anxiety and depression, and I think he's experienced both. So me being able to talk about what I'm going through has kind of shown him that it's okay to say that life isn't perfect all the time and that, yeah, sometimes we need help.

Noella found that by using the skills she had learned and practiced in her support group, she was able to help and support her brother through his own struggles with depression and anxiety:

> It's been really good for him because he is able to talk to me about the things that he worries about in a way that he just really hasn't before. And he's always sort of thought that there was something wrong with him that he wasn't just happy. And seeing that, you know, no one is ever always happy anyway. And that the important part is to work on the tools, or learning the tools, to help facilitate being happy. And that even just talking about being unhappy makes you happier.
>
> So I know it's a big difference to him. He always tells me how much he enjoys talking to me. And I've learned a lot through what I've done with Pacific Post Partum Support Society. To be able to just share tools with him to, to help him just be more comfortable with himself, and more comfortable with the place he is in his life right now.

Noella was able to improve her relationship with her brother, which in turn gave her personal satisfaction and helped her to see how much she had grown and learned while recovering from postpartum depression and anxiety.

How to Use Narratives Responsibly

In the project, we used patient narratives to create a variety of outputs. This transformation process is not straightforward or free of risk to the project participants. Folklorist Diane

Goldstein discusses how scholars must carefully attend to how patient narrative is being used in medical situations. Although medicine has recently become more interested in patient narratives, Goldstein has found that many times these narratives are used for purposes other than making a meaningful difference for patients. For example, patient narratives of their experience of illness may be decontextualized and merely mined for diagnostic information or appropriated and used as evidence that the medical establishment is listening to and responding to patient concerns (without actually making meaningful changes to professional practice). She argues that in medicine "the ultimate goal is narrative management, wrestling narrative away from the teller and rewriting it to fulfill institutional needs and goals" (2015, 136–137).

However, Goldstein argues that the solution is not for folklorists to recuse themselves from being involved with how narrative is being used in the wider world. Rather it is to make sure that we are part of the conversation and to bring a critical lens to how the narratives of vulnerable people, such as parents with PMADs, are being used by those with more power. Folklorist Charles Briggs, when looking at the use of narrative in health care research, stated:

> I am struck by the extent to which scholars in anthropology, sociology, and other fields often read narratives in a flatfooted way, as if a narrative elicited by a stranger who just showed up to conduct an interview provides a transparent window into the social world of the person who tells it and/or the phenomena he or she portrays. I think that the "illness narratives literature (Kelinman 1988) and much recent work in the social sciences frequently reproduces this failure to document and analyze the social life of narratives (see Briggs 2011)." (Briggs 2012: 329)

That is, as folklorists have been doing for decades, we must look at aspects such as the context the narrative was created in, who is telling is, and what genres it is drawing upon, in order to begin to understand what it means.

For the narratives in this dissertation, the context of creation was conducting interviews with individuals who had a previous significant relationship with PPPSS with the main purpose of creating outputs intended to help other struggling new parents. Trained PPPSS GROUP facilitators conducted the interviews, so in that regards it was a bit like what happens in a PPPSS support group session. However, an interview has a much different flow and purpose than a support group. One person asks questions and the other answers. Even if those questions have been collaborated on by both parties and even if the person answering is allowed a great deal of freedom to answer the question in a manner of their choosing, this is still quite a different dynamic than in a support group.

We found that the narratives of PPPSS alumni and their partners (in the focus groups and video interviews) largely clarified and confirmed what project staff already knew about PMADs. This is not surprising because people at PPPSS typically spend much of their time listening to the narratives of people experiencing PMADs who are using their services. And, in formal and informal ways, listening and acting on the experiences of their clients and what clients say that they need has been the primary way that this grassroots organization has designed and implemented their programs. In addition, because these narratives were familiar, they were fairly straightforward for project staff to engage with and use.

However, during the project we were often surprised by what we learned about the experiences of members of groups currently underserved by PPPSS. As discussed in chapter three, in order to be able to learn what these narratives had to teach about community members' needs for perinatal support, project staff had to analyze them in a more nuanced way, as well as find different ways to talk with community members that fit better with their needs and that addressed their concerns about privacy,

With these kinds of issues firmly in mind, in this project's design we worked to make sure that the narrators were involved in creating the outputs at every step of the process. For example, the narrators edited and had the final approval for all video segments. They also designated how those segments could be used in a general sense and approved all actual use of the segments. For written outputs, we did not gain narrator approval for each quote (they had given permission for all content to be used in transcribed form) but the project team was careful to attend to the surrounding context of each quote to try to make sure that we did not alter the narrator's intended meaning. This effort does not, of course, eliminate these issues, but may help mitigate their consequences.

For video outputs, the way that the journey videos were edited was a form of the genre of journey narratives that I, and others, had noticed during introductions in PPPSS's support groups (described in chapter two of this dissertation). However, in the context of introductions during the support group, an individual's narrative would be shaped to meet the needs of that particular individual in that moment, as well as the needs of others in that small group. For the video journeys, the narratives also needed to be understandable and coherent to a broad audience and, as a group, provide a diverse set of overall experiences of postpartum that would be at least somewhat representative of the experiences of parents (at least in Metro Vancouver) experiencing PMADs as a whole. Although we were able to create approximately 250 more excerpts representing a broader range of each individual's postpartum experience, the storyline that is presented in these journeys is the most powerful and would be the version that is viewed by the most people. Editing the segments and putting them into an overarching story makes the interviewee's narratives, as well as their actual experience, seem more neat and tidy than they actually were. Each interviewee had a complex perinatal experience, but that experience was first

distilled in a one-to-two hour interview, and then was tightly edited into a six-minute journey video. Each journey simplifies the individual's perinatal experience into just a few elements, which were chosen not only to do justice to the narrator's experience and to meet the narrator's own goals, but also to provide a certain kind of content that PPPSS needed to meet the project's overall goals. Looking at the example of one journey video helps to illustrate this process. Video interviewee Brianna had postpartum PTSD as well as depression and anxiety. She received her diagnosis of PTSD relatively late, after being misdiagnosed with other conditions, and she felt that this situation had led to much suffering for herself and her family. Therefore, it was very important to her that her journey video emphasizes PTSD. This goal fit with PPPSS's goal of creating a set of videos that would represent a diverse set of perinatal experiences because she was the only narrator who had been diagnosed with PTSD. However, as is true for everyone, Brianna had many other aspects of her experience that could have been emphasized: she lost a close family member during pregnancy, she lived in a small isolated community, her husband went away to work for long periods of time, and more. Many of these factors are briefly addressed during the journey segment, but given the time constraints of the format, the emphasis of her video is certainly on PTSD, which was in keeping with her own goals for participation.

Because this was intended to be a resource for struggling new parents, there were certain parts of the narratives that we did not emphasize for this audience. For example, several interviewees have ongoing mental health concerns that may or may not have predated their experience of PMAD. However, PPPSS wanted to encourage new parents to reach out for help for PMADs. Therefore, the project team wanted to create videos with a realistic, but overall hopeful, narrative. Therefore, although we did put narratives that discuss the importance of previous mental health difficulties as risk factors for PMADs, we did not put any edited

segments specifically about ongoing, chronic mental health conditions on the website (although some of these videos are used in PPPSS trainings and could be used with individual clients). However, PPPSS did include videos on the website that discuss outcomes of PMADs that might be seen as less than desirable. For example, video interviewee Linda's decision to divorce her husband after experiencing postpartum depression and anxiety is an important part of her journey video.[77] Marital conflict is a common outcome of PMADs, and divorce is not an uncommon result of that conflict. Therefore, in order to support other parents who were also going through separation and divorce, the project team felt that it was important to present a narrator who had experienced this situation, survived, and felt confident that she had made the right choice for herself and her family.

For outputs such as the website content and informational brochures, narratives were used to inform both what kind of information should be included in the output and to provide engaging content for the output through the use of written and audiovisual quotations. This process, although not simple, is relatively straightforward and quite familiar to those in the public health world. However, by creating the video segments in this project, PPPSS was also trying to do something a bit different and less clear. PPPSS was trying to facilitate some of the social work that occurs when people share their postpartum narratives inside or outside of a support group for a much wider audience. First, as the project participants confirmed, just listening to the experiences of other people who share some similarity with your own experience helps to reduce feelings of isolation. In addition, these narratives provide a fuller range of the actual experience

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[77] Linda's Journey can be viewed here: http://postpartum.org/videos/video/lindas-journey/, accessed October 30, 2016.

of early parenthood, not just the positive aspects that are often highlighted in the media and on friends' and family's presentations of their lives on social media. PPPSS hopes the experience of listening to a more diverse range of actual experiences may change the listeners' perception of what a normative experience of early parenthood is. For individuals experiencing a PMAD, it was hoped that this representation of a broader range of perinatal experiences would help to reduce their feelings of isolation and concern that something was wrong with them because they did not feel the way about early parenthood that they were "supposed" to feel. For the family and friends of people experiencing a PMAD, as well as health care providers, community support workers, and members of the public, PPPSS and the project team hoped that listening to these narratives would also change the perception of what the range of actual experience of early parenthood is like and increase empathy for and understanding of those parents who struggle during this time, with the overall goals of increasing helpful support for those with PMADs and decreasing the stigma surrounding the condition and those experiencing it.

Second, from PPPSS staff members' experience in settings such as their support groups, training sessions for professionals, and outreach talks at parent–baby groups, when someone else talks about a difficult feeling, such as the difficulties associated with early motherhood, then other people in the group feel like they can talk about it, too. For example, video interviewee Robin teaches prenatal classes and co-facilitates a support group for those experiencing PMADs within her local public health unit. In those situations, she finds that:

> There are so many [parents experiencing PMADs]. And it's like, you're out there talking about it, and as soon as you bring it up, there's always somebody in a group . . . [who] had this experience, or [is having it].

> But they don't talk about it until somebody else talks about it. So I think that knowing that [helping to create the PPPSS video segments] actually could make some kind of difference is pretty rewarding.

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So, one goal of the project was to create a set of videos, that when viewed, might allow

struggling new parents to feel like they could talk about their own difficult experiences as well.

Unfortunately, it is difficult to formally measure or evaluate this type of impact, but anecdotal

evidence from PPPSS counselors indicates that clients are sharing the videos with friends and

family members with the possible goal of using them as a way to start a difficult conversations.

Project participants also felt that there is a significant emotional difference between

listening to someone's narrative and reading that narrative. From the beginning of its history,

PPPSS provided support through facilitating the sharing and listening to narratives in in-person

support groups and on telephone support calls. But, given the constraints of money and

technology, most efforts at education and outreach for a larger audience necessarily depended on

translating those narratives to print, first via books and pamphlets, and later through written

online resources. However, as video interviewee Robin shared in her follow-up interview,

listening to somebody's story is:

> totally different than just reading somebody's story. And I also think like that in that
> space, if you were in a space where you were despairing and feeling like there is not
> hope, you don't read. You're not going to read an article. You're not going to read
> somebody's story. But if it's like, you're just sort of like desperate, and there's a face,
> and you can press play and hear somebody speaking, I think that is huge. You know. So I
> think that's really valuable.

Therefore, the project grant provided by Vancouver Coastal Health enabled PPPSS to create

resources that made use of and boosted the signal of one of their most powerful tools: the voices

of parents who have experienced PMADs.

Making Meaning of PMADs through Narrative

As I discussed in chapter two, when I was a member of a PPPSS support group I observed how individual members shaped their perinatal narrative as they moved through their process of recovery from a PMAD. Having a space to tell their story, in whatever way that they felt that the story needed to be told in that moment, was an essential part of the healing that I, and other PPPSS staff, volunteers, and clients, observed. Because of the applied nature of this project, we did not collect multiple narratives from the same person as they were experiencing and healing from a PMAD in order to analyze how the narrative changes over time (which would be an extremely fruitful avenue for future research). However, we did ask participants to talk about why they felt it was important to share their narratives with others and observed how they brought meaning to what they had experienced through the process of sharing those narratives.

For most individuals, although they may have ongoing mental health conditions, with treatment and time their PMAD resolves. Some individuals chose (or are able to) to move on and to leave the whole experience behind. Because of the nature of this project, the experiences and words of those who chose to move on and do not consider it to be a part of their life that they need or wish to revisit are not really represented here (except, perhaps, in the client feedback forms, which are collected at the end of active support). However, others consider their journey through PMAD to be a transformative experience worth considering, rather than just a source of pain and anguish. Many individuals expressed that it was necessary that they learn more about themselves and gain new skills in order to recover from their PMAD. Furthermore, they often felt that what they had learned during their perinatal experience led to ultimately positive personal change and growth. PPPSS's support groups and individual support have been mindfully designed to allow for this kind of self-discovery and growth.

As David Hufford has discussed, for applied folklorists this process can, when done well, "expand our own knowledge and understanding" about health and healing, while at the same time "serving our natural constituency, ordinary people from all backgrounds, as they struggle to find consolation and meaning in disability, suffering and death" (Hufford 1998:310). In just one individual example, with the help of his (non-PPPSS) therapist, video interview Allen realized that, for him:

> In a tough emotional situation the doors are closed and that's it. And I take that emotion and bury it somewhere deep inside my body and leave it there and, and ignore it. So [learning that about myself] was a big help personally.

Realizing that this approach was harming his relationships, with the help of his counselor, Allen worked to find ways to be more open and comfortable with difficult emotions. In addition, Allen realized that in the past, when confronted with other people's difficult emotions, his primarily response was to try to fix the problem, which resulted in a lot of conflict with his wife. Therefore, one of the many things Allen learned on his postpartum journey was that one of the most important things he could do to really support someone else was to:

> Just listen. You don't need to do anything. And it works a hundred percent of the time. Even with my friends too sometimes, when I'm talking to my guy friends, I want to jump in and say: Oh, you got to do this. But sometimes just sit there and: Yeah. Nod and it works. And people just want to vent or do whatever. And I think it was a really good habit to get into. And I think that was the biggest thing, and the hardest thing.

> And no, I'm not perfect. I still say, you know, say the wrong thing (light laugh). But overall I would say: Yes, that was the biggest lesson I took away from the whole experience. And I still try to practice it, even with my son, try to practice that. And it helps a lot.

Although Allen's postpartum experience was very painful and challenging, he also found that it made his future life richer and more emotionally satisfying.

A common theme that emerged in the interviews was of profound personal change. Many narrators stated that, although their experience was very difficult, they would not give it back because they felt that the personal growth was worth it. Because this group of interviewees were selected only from among those parents who wanted to share their postpartum experience, this is, of course, not a sentiment that everyone who has experienced a PMAD would agree with. However, anecdotal evidence from the experiences of PPPSS staff and statements on the client feedback forms indicate that it is not an uncommon feeling. For example, as video interviewee Maria states in her interview:

> And now I can say thank you to so many people, to so many things, to so many. Actually thank you to postpartum depression, because now I know that because of what I went through I'm who I am right now. I'm a better mum, a better Maria, a better person, a better wife. And it definitely brought my family closer together. And my extended family closer too, as well. So it's been very intense, very difficult, many ups and downs but it's worth it, it's worth it.

At the beginning of the process, when the individual with a PMAD is struggling, overwhelmed, miserable, and immersed in intense and difficult emotions, growing as a person is likely not one of their concerns. Instead, a common sentiment is to just want to feel better, or to just have things back to normal, or to just have this all go away. For some people, when they recover they do return to a state that is relatively normal for them. However, for others their experience with PMAD is so profound and life-altering that they realize that they are never going to be the same person again. Instead they are faced with the reality of figuring out what person they are now, and what person they would like to become. In this task, narrative can be a powerful tool.

In her follow-up interview, Brianna said she had two main motivations to participate in the project. One was to support "women that have mental health issues after having a baby, because the information I gave would help the people, sort of on the front lines, who are helping these

women." The second reason was to help herself by "going through the experience of talking

about my birth experience and journey afterwards. And helping reduce my anxiety about it." Her

partner expressed a similar motivation for participation in the same follow-up interview, stating:

> I think for us it was part of the learning and coping process. It really was. She was
> talking about it. I was getting used to her talking about it. I was getting used to the
> idea that I also needed to deal with things, instead of just trying to be, I guess,
> there. Yeah, the support people need to take care of themselves. . . . Or [you are]
> just going to get into a dark, dark place. And I think, when we gave that interview,
> I was really starting to get awareness of that.

This act of sharing their narrative with others, with the expressed goals of helping their own

recovery as well as helping other parents who might be experiencing difficult emotions, was also

something that brought meaning to the difficult times that project participants had experienced.

Project participants expressed the hope that sharing their experience would help other struggling

new parents, and that this potential benefit would help make their own suffering meaningful.

Their hope was often twofold. First, they hoped that by encountering their narrative of illness

and recovery that a parent who currently had a PMAD might better understand what they were

experiencing, feel less isolated and alone, and/or be encouraged to seek out treatment and

support.

Second, project participants hoped that when potential supporters, such as family, friends,

health care providers, and community support workers, listened to their narratives that they

would better understand what the experience of new parents with PMADs was like and that this

knowledge would help them to become effective supporters. For example, in his follow-up

interview, Brianna's partner shared that his primary motivation to participate in the project was

to raise awareness of postpartum PTSD for other parents:

> I mean people never talk about how all pregnancies can go wrong, and do go
> wrong all the time. So when it actually happens, you're floored by it. Because

nobody ever wants to talk about it. Because they don't want to jinx anything, as though they're casting spells on it. So when it does happen, since nobody's ever talked about it, you're like: "What in the world is going on. I don't know why mine is going south." It happens. I mean, we know it happens. . . .

Like I see, you know some of the women at work. They get pregnant. . . . They have babies. So . . . you give them congratulations, but at the same time you try to say things. Pay attention once you have baby. Be aware of certain things.

Yeah, it's really important for me that people actually learn more about the things that can go wrong, that go wrong a lot, that nobody talks about. What a piss-off that doesn't happen. Because there's people like us that get swept up when it goes wrong.

By sharing their story, Brianna's partner also hoped to encourage health care providers to provide better information about the possibility of postpartum PTSD to their patients:

It wouldn't take two years to figure out what had gone wrong if someone had just said: "Oh, by the way, birth trauma can cause post traumatic stress disorder."

"Really? Oh?"

 "So here's some things to look for. And, by the way, have an evaluation, maybe, after you're done here."

I mean the nurse, when they stop by after a couple weeks, they're looking for signs of this. They're not just coming along to give the baby shots.

Yeah it's pretty stupid that we don't have more awareness on this stuff. So, just ridiculous, really.

For this dad, the hope of sparing other parents the suffering that not knowing about postpartum PTSD caused him and his wife was his primary motivation for participating in the project.

Given the stigma of parenting with a mental health condition, sharing these kinds of narratives on a public webpage was a significant personal risk for the video interviewees. And, even for some of the focus group participants, sharing any of these kinds of feelings with people that they did not know was not an insignificant act. They would not have taken this risk without

feeling like the potential benefits, for themselves and, especially, other parents, were significant and consequential. For many participants, the applied nature of this project was a significant motivating factor. That is, I do not believe that they would have been as interested to participate if they felt like the results would have simply been published in an academic journal. Instead they hoped for change to be effected in the world that they, and other new parents, live in. And they were willing to take risks and give up anonymity in exchange for the hope of contributing to this change. In addition, the work that has already been done by so many others in regards to raising awareness of and lowering the stigma around perinatal mood and anxiety disorders greatly contributed to the ability of these parents to step forward. They know they are not alone, and they want others to know that they are not alone as well. I share their hope that their narratives will continue this meaningful work in the world.

Chapter 6: Conclusions

When I began this project in late 2012, Pacific Post Partum Support Society (PPPSS) staff members told me I might want to look at a study that a social work student had done several years ago. I discovered that one of my project colleagues, Emma Lee, had completed a paper analyzing PPPSS's evaluation methods when she was completing her bachelor of social work. Therefore, I thought this was the project that PPPSS staff members were referring to. However, when writing this dissertation and doing a more in-depth literature review, I discovered that Kathy Berggren-Clive, a graduate student at the School of Social Work at the University of British Columbia, had conducted research with PPPSS clients for her masters thesis. She conducted interviews with eight PPPSS clients and used a feminist perspective to explore how using a medical model to understand postpartum depression did not offer some parents the tools that they needed to recover. Instead, treatment needed to address the personal, social, and cultural factors that may have led a particular person to have difficulties adjusting to parenthood and/or experience a perinatal mood and anxiety disorder (PMAD) (1996). In her 1998 journal article, adapted from her thesis, Berggren-Clive offered a list of eight recommendations for health care practitioners and community workers, developed from what she learned in the interviews, and designed to improve treatment and support for women during the perinatal period in order to help prevent PMADs and improve the outcomes for those experiencing them.[78]

Twenty years later, I seek to build on Berggren-Clive's previous work in this conclusion. I am another academic, writing another thesis based on research conducted with PPPSS clients,

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[78] Kathy Berggren-Clive has gone on to have a significant career in British Columbia's Ministry of Children and Family Development, with a focus on reducing child poverty.

and considering creating another list of practice and policy recommendations designed to help prevent PMADs and improve the outcomes for those experiencing them. This dissertation encourages additional applied folklore work to support struggling new parents and offers suggestions for how health care providers, community support workers, and friends and family members can better support new parents in the hopes of promoting positive outcomes for families. I believe that Berggren-Clive created a useful list of recommendations, many of which are similar to those I might have created to conclude this dissertation. Therefore, rather than make a completely new list of recommendations, I will instead examine those that Berggren-Clive made, consider what progress has been made in implementing them, and suggest ways to build on these recommendations in the context of the present day. One aspect of Berggren-Clive's recommendations that I would like to highlight is that they are made with the implicit assumption, common in the 1990s, that only women can have a PMAD. We now know that this is not the case, but care for new fathers still significantly lags behind that for new mothers. Therefore, although I do not explicitly discuss this aspect for each recommendation, I would expand each one to also include parents of any gender with PMADs. It is also important to note that Berggren-Clive's recommendations, and my discussion of them, are firmly placed in the context of Euro-American/Canadian culture and, more specifically, British Columbia, and that efforts to expand them to other cultural groups and places must be made cautiously.

Beginning in the mid-2000s, British Columbia engaged in a far-ranging and significantly funded provincial effort to improve the prevention of, care for, and outcomes of PMADs. This effort is commonly referred to as the BC Perinatal Strategy (BC Reproductive Mental Health Program, BC Ministry of Health, 2006; BC Reproductive Mental Health Program, Perinatal Services BC, Provincial Health Services Authority, BC Ministry of Health, 2014a, 2014b).

Given this significant effort to improve perinatal mental health care between the two projects, I asked PPPSS Director Sheila Duffy and Volunteer Coordinator Georgie Hutchinson to consider Bergrenn-Clive's recommendations and what progress that had been made in implementing them in the intervening twenty years. Both had been affiliated with the PPPSS during Berggren-Clive's study, which was conducted in the mid-1990s, as well as during the 2012–2015 project discussed in this dissertation.

Berggren-Clive's first two recommendations focus on educating health care practitioners and expectant parents about adjustments to parenthood.

> 1. Parenting groups for expectant and new parents are one avenue in which to begin deconstructing the myths of motherhood while also serving to educate couples about the potential for postpartum depression. In Western cultures, women and families receive little or no preparation for the postpartum period. All attention is focused on preparing them for labor and delivery (Kendall-Tackett 1993). These programs should be integrated into existing prenatal and postnatal programs.

> 2. Health care practitioners must become more educated about postpartum depression. Many professionals know little about postpartum depression or, if they do, dread informing pregnant women about the possibility of this phenomenon for fear of worrying them. Practitioners need to begin questioning the prevalent assumptions not only about postpartum depression, but with respect to the ideology of motherhood. (Berggren-Clive 1998, 116)

Both Sheila and Georgie thought that awareness of postpartum depression had improved in British Columbia, particularly in the past five to eight years with the creation and implementation of the BC Perinatal Strategy. However, education and awareness are still lacking regarding other PMADs for new parents, childbirth educators, and health care practitioners, particularly in regards to perinatal anxiety, which is now known to be the most common PMAD. Georgie identified a strong need for more education for health care providers and childbirth educators about perinatal anxiety. In particular, she stated that educating professionals about the

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common symptom of intrusive thoughts was a priority, given the potential for harm caused by misidentifying intrusive thoughts as a risk factor for child abuse and potentially referring families to child protection services when the children are not actually in danger.

Georgie and Sheila also agreed, even given the increased awareness about the potential for PMADs among childbirth educators and health care providers, there were still issues in conveying that message to expectant new parents. For example, Georgie shared that during a recent talk that she gave on adjusting to parenthood at a drop-in parent-baby group, one of the moms in the group said her adjustment has been made more difficult by the fact that prior to her baby's birth, "all the focus [was] on the delivery. But there was nothing about the actual reality of what this would be like. And now I'm isolated and have no support and no family." Sheila also felt that prenatal education was not serving expectant parents as well as it could, stating, "if this is one of the most common complications of pregnancy and childbirth, why are we not having more conversations about it?" During the project, many parents also discussed the lack of realistic information about early parenthood and how it negatively impacted their postpartum experience.

In addition, many expectant parents do not take prenatal classes, particularly those from vulnerable groups such as parents living in poverty or new immigrants, who may face significant barriers to being able to access classes (such as language, time, transportation, and cost). Therefore, it also seems necessary to find other avenues in which this education can take place, such as during routine prenatal visits. In Canada, free government programs for vulnerable pregnant women such as Healthiest Babies Possible, which offers nutritional information and support (including food distribution), seem a natural place to reach these populations. Working with these programs to ensure expectant mothers participating in them are receiving high-quality

information about how to prepare for adjustment to parenthood seems a potential way to begin to serve these groups better.

However, even when educators include this content about adjustment to parenthood and PMADs in their classes, and expectant parents attended those classes, Sheila stated that some expectant parents just "don't want to hear about it, so they just don't listen." Clearly, it is very important to present the message in a productive manner. Both Georgie and Sheila suggested that one way to better prepare expectant parents for the realities of early parenthood would be for childbirth educators and health care practitioners to focus on the fact that almost all new parents find the adjustment to parenthood to be an enormous life change, and that they all need social, physical, emotional, and financial support in order to successfully navigate this change. The risks of PMADs should also be addressed, but by focusing on the need for support that all new parents have during pregnancy and postpartum, rather than implying only those who might have something seriously wrong with them need support, may help to ensure new parents hear this message as well as make it more likely they feel like they can reach out for help when they first start to struggle.

The third recommendation focuses on the need for health care practitioners to attend as much to a new mother's emotional health as her physical health.

> 3. Maternal depression often goes undetected and untreated, yet is one of the most treatable and curable forms of depression (Gruen, 1988) and early intervention can prevent it from becoming a crisis. There needs to be as much focus on the new mother's emotional health as there is on her physical adjustment after the birth. Practitioners need to ask appropriate questions and provide a supportive environment in which women feel safe to talk about their feelings. New mothers are particularly dependent on advice from the medical establishment, yet they can often be labeled as overinvolved or dismissed with comments such as, "Oh, all new mothers experience that. It will pass." (Berggren-Clive 1998, 116)

Project participants agreed that there still was a need for health care practitioners to focus on caring for both the emotional and physical health of the whole family: parents and infant, rather than just focusing on physical health of the infant. One common example given by the 2012–2015 project participants was the focus given by public health nurses to promoting successful breastfeeding, even at the cost of the mother's own emotional and physical health. However, this was one area Georgie and Sheila felt might be improving, even since the project research was conducted in 2013. They felt that the public health community was beginning to understand that the health of the whole family needs to be considered, and the harm that was caused when parents felt that they were unable to meet the recommendations of health care practitioners. Georgie stated that she felt this change was coming in large part directly from mothers themselves, perhaps helped by supportive communities they found on social media platforms like Facebook. For example, she stated in a recent talk at a public health parent–baby group, a mother had shared how she left a pumped bottle of milk for her partner to feed to their six-week-old infant so that she would have a block of uninterrupted sleep from 8 pm to midnight. Georgie felt that, a few years ago, this mother might not have felt comfortable sharing that she was giving her six-week-old a regular bottle in this setting because she would have feared being judged by other mothers or by the public health nurse.[79] However, Georgie felt that orientation towards

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[79] The concern about giving young infants, such as a six-week-old, a bottle is that they will come to prefer the experience of bottle feeding over breastfeeding and refuse to nurse. This is often called nipple confusion. This is less of a concern once the infant is older and breastfeeding is well established. Although this is a real risk to successfully breastfeeding a young infant, lack of sleep is also a real risk to the mental health of a mother.

extreme judgment of other parents was perhaps starting to change, and that this change was being led by the mothers themselves: "I think that may be at the grassroots. It so often starts with the women themselves, supporting each other and having these conversations. And they influence each other." However, Georgie and Sheila also agreed that much work remained to be done in this area to ensure the emotional health of new parents is prioritized along with their physical health.

Berggren-Clive's fourth recommendation is:

> 4. There are two screening methods for postpartum depression available to practitioners; the Edinburgh Postpartum Depression Scale (EPDS) (Cox, Holden, and Sagovsky 1987) and the newly developed Postpartum Depression Checklist (Beck 1995b). These screening tools should be used by health care professionals during the first year postpartum to ensure that women experiencing postpartum depression receive treatment. (Berggren-Clive 1998, 116)

Sheila and Georgie agreed that this recommendation has been largely implemented, in large part due to the implementation of the BC Perinatal Strategy. Most new mothers in British Columbia are screened with the EPDS at least once during the postpartum period. Many are screened by their OB or midwife at their six-week postpartum appointment, prior to care being transferred back to their general practitioner. However, Georgie and Sheila agree with the mothers and fathers in the project focus groups that this screening needed to occur more times during the first year postpartum, as some parents feel okay in the early months but then begin to struggle. Some mothers are also screened by public health nurses when their baby is four months old if they are using the free vaccination clinics offered by public health centers, and it would be a routine matter to conduct the screening again at later clinics or at well baby visits with GPs. In addition, screening methods for perinatal anxiety, the most common PMAD, need to be improved as the EPDS is not as effective at predicting the possibility of anxiety as it is in predicting the

possibility of depression. Work is currently being done to develop more effective screening

protocols for perinatal anxiety, and when they are available, they should be implemented

(Fairbrother, Janssen, Antony, Tucker, and Young 2016).

I see Berggren-Clive's fifth and sixth recommendations as closely related, as a holistic

approach to treatment is likely one which takes into account the complex mixture of personal,

social, and cultural factors that may have led a particular person to experience a PMAD:

> 5. A holistic approach to treatment is needed. In order to be effective,
> interventions by professionals need to recognize and take account of mothers'
> own explanations of their problems and their ideas concerning what might
> constitute an appropriate solution. Medication, individual counseling, practical
> relief, self-help groups, and an intellectual understanding of their experience may
> all be required.

> 6. The clinical practice of social workers, mental health workers, therapists, and
> counselors can be informed by the model developed in this study as it provides a
> framework by which to better understand the experience of postpartum
> depression. (Berggren-Clive 1998, 116)

Reflecting on these recommendations, Sheila shared that when she first started as a counselor at

PPPSS, "the term self care? This was the only place I heard that. And now it's everywhere." She

felt that understanding of the causes of PMADs, and the supports and treatments that parents

with PMADs need to recover had improved quite a bit since the mid-1990s. She also stated that

the idea that one form of treatment, like medication, is "going to fix everything" is not accepted

anymore. "There's definitely more recognition that all of these things are going to make a

difference. And that's basically what we've been saying for a long time." Georgie agreed that

overall understanding of the complex causes of PMADs and need for holistic treatment had

improved, but also felt that a significant gap in understanding and treatment of PMADs exists at

the level of primary care physicians. Because of a lack of understanding of other treatment

options, as well as a lack of time to spend with individual patients, GPs are often just able to

offer parent with a PMAD a prescription for medication and perhaps a referral to reproductive mental health. However, Georgie had observed when PPPSS is offered an opportunity to promote their services and model of care to GPs, that they experience an increase in referrals from GPs as a result. Unfortunately, given the intense demands on GP's time, it is difficult for PPPSS to be able to reach them, but they continue to focus on finding ways to do so.

Berggren-Clive's sixth recommendation looks at improving support for new parents in the early postpartum period:

> 7. Due to the implementation of early discharge programs whereby women return home within 24 hours after the birth of their babies, comprehensive community services must be in place to assist new mothers and their families with their adjustment to parenthood and to potentially reduce the risk of postpartum depression. (Berggren-Clive 1998, 116)[80]

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[80] Although I was unable to find a source that discussed historical changes in maternity discharge recommendations specifically in the context of British Columbia, in most areas of North America beginning in the 1970s and accelerating in the 1980s, women started to return home from the hospital much earlier than they had in the past (when many stayed up to a week after a normal vaginal birth). In the context of the United States, economic pressure from health insurance companies meant that women were being discharged before they felt they were ready (with the women being forced to leave after being told their insurance would only pay for a certain length of stay). In response, federal legislation was passed in 1996 (which came into affect January 1, 1998) to guarantee that women be allowed at least a 48-hour stay for an uncomplicated vaginal birth and 96-hours after a C-section (Martell 2000). In the Canadian context it appears that women are encouraged to be discharged around 24 hours after an uncomplicated vaginal birth, but they are allowed to stay longer at their own request in order to address issues such as establishing breastfeeding.

When considering this recommendation, both Sheila and Georgie agreed that there are many places for parents with young children to go and be with other parents, such as community centers and family places. They also felt that the awareness of PMADs had increased among staff members at such sites. Therefore, once at these places, parents are more likely to encounter someone who might notice that they are having a hard time and know how to help the parent access appropriate mental health care than would have been the case twenty years ago. However, they felt that there was still an immense unmet need for more intensive support during the postpartum period. For support such as child care, or help with housekeeping or meal preparation, all of which can be essential for the well-being of an overwhelmed and exhausted new parent, there is very little help available. If more support was available to families during the early postpartum period, as Georgie reflected:

> It doesn't take a rocket scientist to figure out that, if a mom gets a lot of support in that first month, where she can get that sleep, and she can be taken care of and be nurtured . . . that's going to make a difference in their adjustment. And now people are doing it privately, and paying a lot, and they may be extending way beyond their budget to meet that need. Because there's so many families living in isolation, or far away from their own family. It's a big need.

Some new parents are fortunate and have nearby friends and family members who are able and willing to help. Others are able to financially afford babysitters, postpartum doulas, meal delivery, or house cleaners. For everyone else, low-cost and free programs that provide intensive support are in short supply and often have long wait lists. In addition, because of these wait lists, parents usually must prove that they are already experiencing a severe PMAD or another intense situation in order to access help. Often, they must also be low-income (although in Metro Vancouver, many middle-income families are also unable to afford to hire helpers). Therefore, this kind of essential support is often still not available. Sheila and Georgie agreed that if this

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area of early hands-on support for new parents were addressed, it would have an immense impact on the wellbeing of new parents.

Berggren-Clive's final recommendation looks at the larger societal issues around accepting the full range of emotional reactions individuals might be experiencing while adjusting to parenthood:

> 8. At a societal or more ideological level, we must begin normalizing emotional reactions to motherhood. We must begin dispelling the myths of motherhood so that women will feel that the emotional reactions they are experiencing are not signs of individual inadequacy. (Berggren-Clive 1998, 116)

This recommendation, more than the others, is extremely broad. But it also forms an essential part of the ongoing mission of PPPSS and has since it was founded in 1971. Sheila reflected that, outside of the work of PPPSS and similar organizations,

> There's more of that conversation happening, especially on social media. I'm watching the Good Mother Project and I'm seeing people posting some pretty open paragraphs of [how they are] feeling terrible, and I'm not good at this, and whatever. So that's a grassroots thing too. [81]

Georgie reflected that even when parents hear the message that there are a wide range of emotional experiences that are normal to have while parenting, it can be very difficult to internalize the message that someone who doesn't always feel positively about parenting can still be a good parent. Sheila shared that, when parents call into PPPSS for help, a frequent topic of conversation is that the caller feels that they are "inadequate, they feel like they're failing, and that hasn't changed. We've been having that conversation for a long time, right? So, yeah, it's a

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[81] The Good Mother Project, which is working to redefine what it means to be a good mother through writing and art, can be found at http://goodmotherproject.com/ .

long way to go." Georgie agreed that more realistic discussions of parenting were taking place, especially on social media. She reflected that new parents not only need these positive messages, they also need support to be able to internalize these messages and believe them in a way that helps to improve their own wellbeing and mental health.

Moving Forward

A new mother from metro Vancouver, Florence Leung, went missing on October 25, 2016, after slipping away from her home in New Westminster. From the beginning of the case, this mother of a two-month-old was identified as a person who might have postpartum depression, and thus was deemed at-risk. Her car was found the next day near one of her favorite spots, Stanley Park's beautiful Prospect Point overlooking the waters of Burrard Inlet. After an exhaustive search of the area, her family was left to wait (Dobie 2016). Public vigils were held in the hope of bringing Florence Leung home, and her case received intense local media coverage (Morton 2016). Tragically, on November 15 her body was found near Stanley Park in the waters off of Bowen Island. Law enforcement reported that foul play is not suspected (New Westminster Police Blog 2016). Over the weeks that she was missing, her case received intense attention on both traditional and social media. However, unlike many similar cases in the past, a great deal of attention was also paid to the general issues surrounding postpartum depression and other PMADs. In her follow-up interview, which took place not long after Florence Leung's body was found, PPPSS Director Sheila Duffy stated that she felt the media coverage of such sensational events was getting better:

> I've just done the last two months of, you know, crazy [numbers of] requests with media. And I found that [most reporters were], actually, really respectful. They were actually asking the questions I really hoped they'd ask, right? And talking more about the [motherhood] myths. And, you know, that kind of thing.

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There were a couple of really good radio interviews, where I thought, wow, they're asking really good questions that are actually going to help somebody. Instead of really being in the story of [the particular event that's] happened, and [just] making that the story. Because that is what I was really hoping, to talk about the [larger] issues.

Sheila felt that, at least in the context of metro Vancouver, media discussion of such cases and of the role of PMADs in these cases is becoming more accurate and concern with providing information that will help other struggling new parents, rather than just focused on the sensational details of these rare and tragic events. Furthermore, she hopes that this change will encourage other new parents, both now and in the future, to reach out for help and support themselves.

Sheila continued to reflect on what she saw as the relationship between PPPSS's work, including the project discussed in this dissertation, and the larger work of changing community attitudes about support for new parents:

Part of this project was about breaking stigma. I believe the more we talk about it, the more people are going to be able to identify well this is going on [with me]. You know, we have a long way to go, just in general, [in breaking stigma around] mental health. But certainly the more that we can understand as a society [about adjustment to parenthood and PMADs], it's going to be easier.

The problem with this situation that happened [Florence Leung's disappearance], the flip-side to it, is that is moms might be thinking: Well, I'm not that bad. And so now if I tell someone I have this, they're going to think I'm wanting to kill myself.

So that's why it's so important that we talk about that there's a spectrum and lots of different experiences. All those radio interview I did, I know that I said, every time, because I heard myself saying it: all new mothers need support. We all need support. Period. So I think that message, too, means that just because I'm asking for help doesn't mean that I have postpartum depression.

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By emphasizing that all new parents need support, Sheila hopes that the stigma of being a parent who needs help will begin to lessen, and that such change will allow others who are feeling like Florence Leung felt to reach out for help before tragedy occurs. Every day babies are born, and with these births new mothers and fathers come into being. And thus every day the work continues.

Applied folklorists have a great opportunity to make significant contributions to improving the understanding of and care for all new parents, from those who have the occasional difficult day to those who are experiencing a PMAD. At the conclusion of this dissertation, I come back to Dorry Noyes' call about the trinity of folklore that I evoked in the introduction:

> The field cannot theorize without strongly grounded, in-depth ethnography of particulars. The field has no purpose without engagement in the world, trying to understand and amend the social processes that created the F-word and other, far worse stigmas. Practice in the world has not lasting efficacy without theory to clarify its means and ends and make its efforts cumulative.

Theory, in-depth ethnography of particulars, and engagement in the world; all must work together, but time and resources are limited. As a folklorist with a propensity towards work in the world, when I am engaged in the world of academia, I feel very applied. But as a person doing work in the world, when I am working with my nonprofit colleagues, I feel very academic. That is the tension of doing applied folklore, to always be between both worlds, never quite in one or the other. This tension can make one feel stretched and out of place. However, I also hope it can drive one to do meaningful work that would not have happened otherwise. Of course, doing something with a real world application is not necessary or sufficient for meaningful work. But for me, partnering with communities to produce something of use and meaning to them brings great joy and satisfaction.

References Cited:

Abrams, Laura S. and Laura Curran. 2009. "And You're Telling Me Not to Stress? A Grounded Theory Study of Postpartum Depression Symptoms Among Low-Income Mothers." *Psychology of Women Quarterly* 2 (33): 351–62.

Adams, Char. 2015. "Moms State 'Nurse-In' at Oregon Marshalls After Mother Is Told to Breastfeed in the Bathroom." *People*, September 15. http://people.com/bodies/breastfeeding-mom-told-to-nurse-baby-in-marshalls-bathroom/, accessed November 1, 2016.

Altshuler, LL, V. Hendrick, and LS Cohen. 1998. "Course of Mood and Anxiety Disorders During Pregnancy and the Postpartum Period." *Journal of Clinical Psychiatry,* 59 (Supplement 2): 29–33.

American Psychiatric Association. 2013. *Diagnostic and Statistical Manual of Mental Disorders,* fifth edition. Arlington, VA: American Psychiatric Association.

BC Ministry of Health. 2015. *Rural Health Services in BC: A Policy Framework to Provide a System of Quality Care.* Victoria: BC Ministry of Health, http://www.health.gov.bc.ca/library/publications/year/2015/rural-health-policy-paper.pdf, accessed November 24, 2016.

BC Ministry of Health, Healthy Families BC. 2005. *Baby's Best Chance: Parent's Handbook of Pregnancy and Baby Care*, fifth revision, sixth edition. Victoria: BC Ministry of Health or online at http://www.health.gov.bc.ca/library/publications/year/2015/babys-best-chance-2015.pdf, accessed September 1, 2016.

BC Reproductive Mental Health Program, BC Ministry of Health. 2006. *Addressing Perinatal Depression: A Framework for BC's Health Authorities.*

http://www.health.gov.bc.ca/library/publications/year/2006/MHA_PerinatalDepression.pdf,

accessed September 1, 2016.

BC Reproductive Mental Health Program, Perinatal Services BC, Provincial Health Services

Authority, BC Ministry of Health. 2014a. *Consensus Statement: Screening for Depression in

the Perinatal Period.* http://www.health.gov.bc.ca/library/publications/year/2014/pnd-

consensus-statement.pdf, accessed September 1, 2016.

BC Reproductive Mental Health Program, Perinatal Services BC, Provincial Health Services

Authority, BC Ministry of Health. 2014b. *Best Practice Guidelines for Mental Health

Disorders in the Perinatal Period.* http://www.perinatalservicesbc.ca/Documents/Guidelines-

Standards/Maternal/MentalHealthDisordersGuideline.pdf, accessed September 1, 2016.

Berggren-Clive, Kathy Lynn. 1996. "Out of the Darkness and into the Light: Women's

Experiences with Depression After Childbirth." MSW thesis, University of British Columbia.

Berggren-Clive, Kathy Lynn. 1998. "Out of the Darkness and into the Light: Women's

Experiences with Depression After Childbirth." *Canadian Journal of Community Mental

Health* 17: 103–20.

Blank, Trevor and Andrea Kitta. 2015. "Introduction." In *Diagnosing Folklore: Perspectives on

Disability, Health and Trauma*, edited by Trevor Blank and Andrea Kitta, 3–22. Jackson,

MS: University Press of Mississippi.

Bock, Sheila. 2012. "Contextualization, Reflexivity, and the Study of Diabetes-Related Stigma."

Journal of Folklore Research 2 (49): 153–78.

Briggs, Charles L. 1986. *Learning How to Ask.* Cambridge: Cambridge University Press.

———. 2012. "Toward a New Folkloristics of Health." *Journal of Folklore Research* 3 (49):

319–45.

Brown, Seth A., Yolanda Evans, Kelly Espenschade, and Maureen O'Connor. 2010. "An

Examination of Two Brief Stigma Reduction Strategies: Filmed Personal Contact and

Hallucination Simulations." *Community Mental Health Journal* 5 (46): 494–99.

CBC News. 2011. "B.C. Cuts Back Nurse Visit to New Moms." CBC News British Columbia,

October 25. http://www.cbc.ca/news/canada/british-columbia/b-c-cuts-back-nurse-visits-to-

new-moms-1.1100144, accessed October 15, 2016.

Corrigan, Patrick W., Jonathon Larson, Molly Sells, Nathaniel Niessen, and Amy C. Watson.

2007. "Will Filmed Presentations of Education and Contact Diminish Mental Illness

Stigma?" *Community Mental Health Journal* 2 (43):171–81.

Corrigan, Patrick W., Benjamin G. Druss, and Deborah A. Perlick. 2014. "The Impact of Mental

Illness Stigma on Seeking and Participating in Mental Health Care." *Psychological Science

in the Public Interest* 15 (2): 37–70.

Cotugna, Nancy, Connie E. Vickery, and Kara M. Carpenter-Haefele. 2005. "Evaluation of

Literacy Level of Patient Education Pages in Health-Related Journals." *Journal of

Community Health* 30 (3): 213–19.

Dobie, Cayley. 2016. "[UPDATE] New West Police Continue Search for Missing Mom." *New

Westminster Record,* October 26. http://www.newwestrecord.ca/news/update-new-west-

police-continue-search-for-missing-mom-1.2374445, accessed December 9, 2016.

Dolby, Sandra K. 1998. "Personal Experience Story." In *Encyclopedia of Folklore and

Literature*, edited by Mary Ellen Brown and Bruce Rosenberg, 504–506. Denver: ABC-

CLIO Press.

Dubus, Nicole. 2014. "Permission to Be Authentic: An Intervention for Postpartum Women."

Affilia: Journal of Women & Social Work 1 (29):43–55.

Fairbrother, Nichole, and Sheila R. Woody. 2008. "New Mothers' Thoughts of Harm Related to the Newborn." *Archives of Women's Mental Health* 11: 221–29.

Fairbrother, Nichole, Patricia Janssen, Martin M. Antony, Emma Tucker, Allan H. Young. 2016. "Perinatal Anxiety Disorder Prevalence and Incidence." *Journal of Affective Disorders* 200: 148–155.

Foulkes, Michelle. 2011. "Enablers and Barriers to Seeking Help for a Postpartum Mood Disorder." *Journal of Obstetric, Gynecologic, and Neonatal Nursing: JOGNN / NAACOG* 4 (40): 450–57.

Frisch, Michael. 1990. *A Shared Authority: Essays on the Craft and Meaning of Oral and Public History*. Albany: State University of New York Press.

Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon and Shuster.

Goldstein, Diane E. 2001. "Competing Logics and the Construction of Risk." In *Healing Logics,* edited by Erika Brady. Logan: Utah State University Press.

———. 2004. *Once Upon a Virus: AIDS Legends and Vernacular Risk Perception*. Logan, UT: Utah State University Press.

———. 2015. "Vernacular Turns: Narrative, Local Knowledge, and the Changed Context of Folklore." *Journal of American Folklore* 508 (128): 125–45.

Goldstein, Diane E. and Amy Shuman. 2012. "The Stigmatized Vernacular: Where Reflexivity Meets Untellability. *Journal of Folklore Research* 49 (2): 113–126.

Gruen, Dawn. 1988. *The New Parent: A Spectrum of Postpartum Adjustment.* Minneapolis: Childbirth Education Association.

Harvey, Merryl, Helen M. Pattison. 2012. "Being There: A Qualitative Interview Study With

Fathers Present During the Resuscitation of Their Baby at Delivery." *Archives of Disease in

Childhood: Fetal Neonatal Edition* 97 (6): 439–43.

Hatfield, Jenna. 2016. "Bunmi Laditan on Postpartum Depression and Overcompensating."

Postpartum Progress blog, June 2. http://www.postpartumprogress.com/bunmi-laditan-

postpartum-depression-overcompensating, accessed October 15, 2016.

Holtgrave, Darcy. 2015. "Positioning Functions of YouTube Vlogs on Bipolar Disorder." In

Diagnosing Folklore: Perspectives on Disability, Health and Trauma, edited by Trevor

Blank and Andrea Kitta, 175–193. Jackson, MS: University Press of Mississippi.

Hufford, David. 1985. "Folklore Studies and Health." *Practicing Anthropology* 1–2 (7): 23–24.

———. 1998. "Folklore Studies Applied to Health." *Journal of Folklore Research* 3 (35): 295–

313.

Ives, Edward D. (Sandy). 1995. *The Tape Recorded Interview: A Manual for Fieldworkers in

Folklore and Oral History*, 2nd edition. Knoxville, TN: University of Tennessee Press.

Jones, Michael Owen, ed. 1994. *Putting Folklore to Use*. Lexington, KY: University Press of

Kentucky.

Kendall-Tackett, Kathleen. 1993. *Postpartum Depression: A Comprehensive Approach for

Nurses*. Newbury Park, CA: Sage.

Kirshenblatt-Gimblett, Barbara. 1992. "Mistaken Dichotomies." In *Public Folklore*, edited by

Robert Baron and Nick Spitzer, 29–48. Washington: Smithsonian Institution Press.

Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing, and the Human Condition.*

New York: Basic Books.

Lefkowitz, D.S., C. Baxt, and J.R. Evans. 2010. "Prevalence and Correlates of Postraumatic

    Stress and Postpartum Depression in Parents of Infants in the Neonatal Intensive Care Unit

    (NICU). *Journal of Clinical Psychology in Medical Settings,* 17 (3): 230–37.

Lovgreen, Tina. 2016. "Looking for Daycare in Vancouver? Good Luck." CBC News British

    Columbia, August 22. http://www.cbc.ca/news/canada/british-columbia/daycare-vancouver-

    struggle-no-space-expensive-1.3731536, accessed November 25, 2016.

Lummis, Trevor. 1992. "Oral History." In *Folklore, Cultural Performances, and Popular*

    Entertainments," edited by Richard Bauman, 92–97. Oxford: Oxford University Press.

Martell, Louise K. 2000. "The Hospital and the Postpartum Experience: A Historical Analysis."

    Journal of Obstetric, Gynecologic, and Neonatal Nursing 1 (29): 65–72.

Maxwell, Joseph A. 1996. *Qualitative Research Design: An Interactive Approach*, 2nd edition.

    Thousand Oaks, CA: Sage.

Montgomery, Phyllis, Sharolyn Mossey, Sara Adams, and Patricia H. Bailey. 2012. "Stories of

    Women Involved in a Postpartum Depression Peer Support Group." *International Journal of*

    Mental Health Nursing 6 (21): 524–32.

Morrow, Marina, Jules E. Smith, Lai Yuan, and Suman Jaswal. 2008. "Shifting Landscapes:

    Immigrant Women and Postpartum Depression." *Health Care for Women International* 6

    (29): 593–617.

Morton, Michelle. 2016. "Stanley Park Vigil Held for Missing Florence Leung." AM770 Online

    News, November 8. http://www.newstalk770.com/syn/112/240609/stanley-park-vigil-held-

    for-missing-florence-leung, accessed December 9, 2016.

Newport, Frank. 2014. "The New Era of Communication Among Americans." *Gallup: Economy*,

   November 14. http://www.gallup.com/poll/179288/new-era-communication-americans.aspx,

   accessed November 30, 2016.

New Westminster Police Blog. 2016. Update on High Risk Missing Person Florence Leung,

   November 16. http://www.nwpolice.org/blog/2016/11/17/update-high-risk-missing-person-

   florence-leung/, accessed December 9, 2016.

Noyes, Dorothy. 2008. "Humble Theory." *Journal of Folklore Research* (45) 1: 37–43.

Pacific Post Partum Support Society. 2014. *Postpartum Depression and Anxiety: A Self-Help*

   Guide. Burnaby, BC: Pacific Post Partum Support Society.

Paul, Ian M., Danielle S. Downs, Eric W. Schaefer, Jessica S. Beiler, and Carol S. Weisman.

   2013. "Postpartum Anxiety and Maternal-Infant Health Outcomes." *Pediatrics* (131) 4:

   e1218-e1224.

Paulson, James F. and Sharnail D. Bazemore. 2010. Prenatal and Postpartum Depression in

   Fathers and Its Association with Maternal Depression: A Meta-Analysis. *Journal of the*

   American Medical Association. (19) 303: 1961–69.

Pearce, Jonty. 2012. "Is Web Chat Cheaper than a Voice Call?" *Call Centre Helper,* November

   28. https://www.callcentrehelper.com/is-a-web-chat-cheaper-than-a-voice-call-33541.htm,

   accessed November 30, 2016.

Perinatal Services BC. 2016. Giving Birth in BC. http://www.perinatalservicesbc.ca/health-

   info/labour-birth/giving-birth-in-bc, accessed November 24, 2016.

Perrin, Maryanne. 2012. "Using Text-Messing to Support Breastfeeding in WIC." Lactation

   Matters: ILCA blog, April 3. http://lactationmatters.org/2012/04/03/using-text-messaging-to-

   support-breastfeeding-in-wic/, accessed August 3, 2016.

Segre, Lisa S. and Wendy N. Davis. Postpartum Depression and Perinatal Mood Disorders in the

DSM. Postpartum Support International web site. http://www.postpartum.net/wp-

content/uploads/2014/11/DSM-5-Summary-PSI.pdf, accessed October 15, 2016.

Service Canada. 2016. Having a Baby.

http://www.servicecanada.gc.ca/eng/lifeevents/baby.shtml, accessed November 25, 2016.

Song, Hayeon, Amy May, Vishnuvardhan Vaidhyanathan, Emily M. Cramer, Rami W. Owais,

and Susan McRoy. 2013. "A Two-way Text-messaging System Answering Health Questions

for Low-income Pregnant Women." *Patient Education and Counseling* 92 (2): 182–87.

Shuman, Amy. 2015. "Disability, Narrative Normatively, and the Stigmatized Vernacular of

Communicative (In)competence." In *Diagnosing Folklore: Perspectives on Disability,*

Health, and Trauma, edited by Trevor Blank and Andrea Kitta, 23–40. Jackson, MS:

University Press of Mississippi.

Statistics Canada. 2011. National Household Survey Profile, Vancouver Census Metropolitan

Area, British Columbia. http://www12.statcan.gc.ca/nhs-enm/2011/dp-

pd/prof/details/page.cfm?Lang=E&Geo1=CMA&Code1=933&Data=Count&SearchText=Va

ncouver&SearchType=Begins&SearchPR=59&A1=All&B1=All&Custom=&TABID=1,

accessed October 24, 2016.

Stewart, David W. and Prem N. Shamdasani. 2015. *Focus Groups: Theory and Practice,* third

edition. Thousand Oaks, CA: Sage.

Stone, Katherine. 2009. The Symptoms of Postpartum Depression and Anxiety (in Plain Mama

English). Postpartum Progress blog, November 15. http://www.postpartumprogress.com/the-

symptoms-of-postpartum-depression-anxiety-in-plain-mama-english, accessed October 15,

2016.

Taylor, Verta. 1996. *Rock-a-bye Baby: Feminism, Self Help and Postpartum Depression.* New York: Routledge.

Theriot, Nancy M. 1990. "Diagnosing Unnatural Motherhood: Nineteenth-Century Physicians and Puerperal Insanity." *American Studies* 26: 69–88.

———. 1993. "Women's Voices in Nineteenth-Century Medical Discourse: A Step Toward Deconstructing Science." *Signs* 19: 1–31.

Thomas, Lindsey J., Kristina M. Scharp, and Christina G. Paxman. 2014. "Stories of Postpartum Depression: Exploring Health Constructs and Help-Seeking in Mothers' Talk." *Women & Health* 54 (4): 373–87.

Westall, Carolyn and Prange Liamputtong. 2011. *Motherhood and Postnatal Depression: Narratives of Women and Their Partners.* New York: Springer.

Yow, Valerie. 1995. "Ethics and Interpersonal Relationships in Oral History Research." *The Oral History Review* 22 (1): 51–66.

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Education
Indiana University
> Doctor of Philosophy in Folklore, February 2017
> Master of Arts in Folklore, December 2008
> Master of Library Science, December 2008

Publications
Conference Papers and Posters

Perkins, Jodine and Sheila Duffy. 2016. Old Need, New Technology: Providing Perinatal Support via Text-Message and Online-Only Group. Paper presented at Perinatal Services BC's 2nd Biennial Healthy Mothers and Healthy Babies Conference: Advances in Clinical Practice and Research Across the Continuum, Vancouver, BC, 11–12 March 2016.

Perkins, Jodine. 2016. "Inside of each story was a piece of my story": Using perinatal depression and anxiety narratives to reduce stigma and educate clients and professionals. Poster presented at the Society for Applied Anthropology 2016 Annual Meeting, Vancouver, BC, 29 March–2 April 2016.

Perkins, Jodine. 2015. Engagement with Community Organizations in Digital Projects. Paper presented at the Digital Pedagogy Institute, Toronto, ON, 19–21 August 2015.

Perkins, Jodine. 2010. Exploring Similarity and Difference in Ethnographic Museum Collections. Paper presented at the American Folklore Society 2010 Annual Meeting, Nashville, TN, 13–16 October 2010.

Perkins, Jodine. 2009. Cooking in Place: Community Cooking and Identity in Community Cookbooks. Poster presented at the American Folklore Society 2009 Annual Meeting. 21–25 October 2009.

Perkins, Jodine. 2009. Exploring Similarity and Difference in Ethnographic Museum Collections. Paper presented at the Summer Institute in Museum Anthropology Research Symposium, Washington, DC, 22 July 2009.

Perkins, Jodine. 2009. Community Cookbooks. Poster presented at Public/Private: Indiana University/The Ohio State University Joint Student Conference, Bloomington, IN, 27–28 March 2009.

Perkins, Jodine. 2008. Context and Connection: Oral History at a Historic Site. Paper presented at the American Folklore Society 2008 Annual Meeting, Louisville, KY, 22–26 October 2007.

Perkins, Jodine. 2007. Oral History at a Local History Site. Poster presented at Translation/Transformation: Indiana University/The Ohio State University Joint Student Conference, Columbus, OH, 16–17 May 2008.

Perkins, Jodine. 2007. Ambrosia and Meatloaf: How Are Community Cookbooks Representational of Community Cooking?. Poster presented at the American Folklore Society-Folklore Studies Association of Canada 2007 Joint Annual Meeting, Québec, QC, Canada, 17–21 October 2007.

Exhibitions

Perkins, Jodine and Rebecca Cape. June–September 2008. Blue at the Mizzen: Patrick O'Brian and the 19th Century Naval World. Indiana University Lilly Library: Bloomington, IN.

Perkins, Jodine. May–November 2007. Liberty Recipes to Betty Crocker: American Cookbooks, 1918–1950. Indiana University Lilly Library: Bloomington, IN.

Perkins, Jodine. March 2006. Travel on the Overland Trails to the Pacific. Indiana University Lilly Library: Bloomington, IN.

Tedeschi, Anthony and Jodine Perkins. May–August 2006. Imaginary and Constructed Languages. Indiana University Lilly Library: Bloomington, IN.

Exhibition Catalogs

Perkins, Jodine and Rebecca Cape. 2008. Blue at the Mizzen: Patrick O'Brian and the 19th Century Naval World. Exhibition catalog. Indiana University Lilly Library: Bloomington, IN.

Harter, Christopher, Anthony Tedeschi and Jodine Perkins. 2006. Places of the Imagination: a Celebration of Worlds, Islands, and Realms & Imaginary and Constructed Languages. Exhibition catalog. Indiana University Lilly Library: Bloomington, IN.

Teaching

School of Library, Archival and Information Studies, University of British Columbia
ARST/LIBR 575 Graduating Couse Project (3 credits): Spring 2017.
LIBR 538b: Specialized Literatures: Theory and Practice of Oral History (3 credits): Fall 2011, Spring 2013, Spring 2014, Fall 2015.

Employment

Research Assistant/Tech 2   April 2016–present
University of British Columbia, Department of Physical Therapy
    Assisted with implementation and analysis of evaluation measures for the West Coast Interprofesssional Clinical Knowledge Evidence Disseminator (WICKED) project, designed to educate students on evidence-informed health care practices.

Oral History Consultant/Instructor   June 2016–August 2016
University of British Columbia, Faculty of Education
    Created and delivered a three-day workshop on oral history theory and methods for students enrolled in "Place-based learning in Huu-ah-ayht Territory." Collaborated with course instructor and the Bamfield Historical Society to design and implement oral history project with course students and community volunteers.

Project Manager   October 2012–November 2015
Pacific Post Partum Support Society, Vancouver, BC
    Wrote grant for and managed collaborative, community-led, and research-based project with PPPSS staff and outside contractors to create a wide range of project outputs including: edited video segments based on client interviews, new online client information resources in English and six other languages, online professional training workshops, pilot

projects to provide client support via text message and in an online environment, and revisions of all long-form publications.

Archives and Metadata Consultant   January–August 2013
Amber Ridington Folklore | Heritage Consulting, Vancouver, BC
  Created metadata and archiving standards and content management prototype for Traditional Land Use Study (TLUS) research outputs for a BC First Nation.

Museum Collections Research Assistant   September 2009–June 2010
Mathers Museum of World Cultures, Indiana University, Bloomington, IN

Editorial Assistant   September 2007–August 2009
Journal of Folklore Research, Indiana University, Bloomington, IN

Assistant Manager of Libraries   September 2006–August 2007
Library Supervisor   December 2015–August 2006
Residential Programs and Services Libraries (RPSL), Indiana University, Bloomington, IN

Service
Social Media Committee Member   September 2013–present
  Pacific Post Partum Support Society, Burnaby, BC.
Education and Outreach Committee Member   October 2011–October 2013
  American Folklore Society Archives and Libraries Section.
Prize Committee Chair   October 2009–December 2011
  American Folklore Society Archives and Libraries Section. Member: 2007–2011.
Farmstead Committee Chair   October 2009–June 2010
Museum Sub-committee Chair   September 2008–June 2010
  Hinkle-Garton Farmstead Project, Bloomington Restorations, Inc., Bloomington, IN.
  Member of committees October 2006–June 2010.
President   November 2008–November 2009
  Hoosier Folklore Society, Terre Haute, IN.

Honors
Travel Scholarship; August 2015. Digital Pedagogy Institute, Toronto, ON.
Fee Scholarship; 2014–2016. Digital Humanities Summer Institute, Victoria BC.
Beyond the Call of Duty Award; February 2010, Bloomington Restorations, Inc.
Student Service Award; Spring 2009, IU Department of Folklore and Ethnomusicology.
Daisy Garton Volunteer Award; February 2008, Bloomington Restorations, Inc.
Fee Scholarship; 2007–2009, IU Department of Folklore and Ethnomusicology.
Merit Scholar; 2005–2007, IU School of Library and Information Science.
Travel Award; Summer 2005, Indiana Chapter Special Libraries Association.
Bowen Scholar; 1992–1996, Grinnell College.