

**TO BREASTFEED OR NOT TO BREASTFEED?: AN
ETHNOGRAPHIC EXPLORATION OF KNOWLEDGE
CIRCULATION, MEDICAL RECOMMENDATIONS ON
HIV AND INFANT FEEDING, AND RELATED 'GOOD'
MOTHERING DISCOURSES IN SASKATOON,
SASKATCHEWAN**

by

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ABSTRACT

This thesis looks at how knowledge on HIV and infant feeding is circulated, shaped, and then disseminated into a medical recommendation in Saskatoon, Saskatchewan. It explores good/ bad mothering discourses linked to women with HIV who are feeding infants in this city. Guided by Bruno Latour's actor network theory, I interviewed 31 community and health professionals to ethnographically locate "key actors" involved in knowledge circulation on HIV and breastfeeding. The interviews revealed two patterns of knowledge circulation in which different information on HIV and breastfeeding is being shared. I suggest that contrasting good/bad mothering discourses position women with HIV in a "tension zone" that characterizes them as both 'good' and 'bad' mothers. I situate my observations in literature on medicalization of reproduction and science studies writings on social movements and "experts". I argue the tension zone overshadows challenges facing women with HIV navigating poverty and trying to access baby formula.

Keywords: knowledge flows; good mothering discourses; HIV and infant feeding; medicalization of infant feeding

Subject Terms: Knowledge, Sociology of; Breastfeeding – Canada; HIV Infections – Transmission – Infant; Medicalization; Motherhood – Canada

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CHAPTER 1: METHODOLOGIES AND SITUATIONS

In June 2007 I ran an Ovid MEDLINE search for “HIV AND breast feeding.” My search yielded 265 articles. A year later, I ran this search again to see how many new articles had been published; there are now 309 articles on this topic. The earliest article in this search is from 1987 (“Breast-feeding and HIV infection”: 1987). Between 1987 and 1990 there were only six articles on this topic. Including commentaries, editorials and reviews, within the past 18 years 304 articles have been written about HIV and breastfeeding and the writing is exponential with every year. This subject is a growing hot topic with still many questions unanswered.

One of the findings in this thesis is that different groups of health professionals are reading very select clusters of research drawn from this pool of 309 articles and other resources. Before looking at each of these clusters of knowledge individually and exploring the pathways that led to this finding, I want to situate the knowledge and the topic of the comments that are included and discussed in this thesis. To do this, I give a bird’s eye view of the research that has unfolded on pediatric HIV, and HIV and breastfeeding. Then I outline the methodology used in my fieldwork to determine who constitutes a key actor in HIV and infant feeding knowledge flows in Saskatoon, Saskatchewan as well as my key working conceptualizations. I explain; 1) how I conceptualize my fieldwork site and location; 2) “who” I recognized as a key actor in this research and how this designation was established; 3) the way I conceptualize knowledge and its movement between actors, and finally; 4) the main ideas illustrated in this thesis.

Situating The Reader

In her book *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*, Paula Treichler (1999) poignantly highlights how homophobia, racism and sexism within medical discourses on HIV infection and transmission positioned women outside of medical research in the initial years following the discovery of the AIDS disease. Medical anthropologist Paul Farmer adds that despite documented cases of women with AIDS from the beginning of the

epidemic, the US Center for Disease Control (CDC) 4-H list that named homosexuals, hemophiliacs, heroin addicts, and Haitians as the high-risk categories was emphasized as the public understanding of “who” got AIDS (1992: 210).

Women were only recognized in the AIDS epidemic in North America after risk analyses declared certain behaviours, such as prostitution and anything “exotic”, as “contaminated” (Treichler 1999: 20). As a result of this new risk focus, medical research explaining HIV presentation in women talked exclusively about their association with sex or “exotic” places like Africa (Treichler 1999, Farmer 1992). The limitations of this focus became apparent when hemophiliacs and infants started presenting with HIV, despite not having multiple sexual partners or using injection drugs. Following this observation greater attention was paid to the social, economic and political factors that render women vulnerable to HIV (Preda 2005: 23; Stillwaggon 2006).

Today, infants presenting with HIV is an international medical concern. As one scientist emphasizes in a recent article; “with more than 15 million human immunodeficiency virus (HIV)-infected women living in developing countries and more than 500,000 HIV infected infants born each year, the HIV/ Acquired Immunodeficiency Syndrome (AIDS) epidemic presents an unprecedented challenge to maternal and child health” (Abrams 2007: S101).

HIV-specialists and public health officials are now actively working towards understanding, controlling and preventing HIV transmission occurring between mothers and their infants. From the medical side, scientists are in consensus that HIV transmission can occur “during gestation (in utero), during delivery (when the fetus makes contact with maternal blood and mucosa in the birth canal), or after delivery (through breast milk)” (Public Health Agency of Canada 2007: 41; Coutsooudis et al 1999; Thorne and Newell 2007; Abrams 2004; Abrams 2007; Pai 2007; Coovadia 2007).

Some researchers are seeking to identify the factors that increase so called “vertical” transmission, that is the transmission, which occurs during pregnancy and delivery. They agree that a lack of antiretroviral (ARV) drug therapy in combination with increased levels of RNA viral load correspond to advanced stages of the disease and a greater risk of vertical transmission (Garcia et al 1999; Thorne and Newell 2003; Abrams 2004; Arvold et al 2007). Other scientists working in this area indicate that even if RNA viral load is maintained at undetectable levels, HIV transmission has still been observed, suggesting there is no

threshold below which transmission will not occur (Thorne and Newell 2003; Arvold et al 2007).

There is further consensus in this field that increased vaginal fluid, ruptures to cell membranes and low CD4 counts increase vertical transmission (Landesman et al. 1996; Newell and Thorne 2007). Some scientists have proposed that elective caesarean section (ECS) be used as an intervention of mother to child transmission of HIV. These researchers argue that mode of delivery could help eliminate the risk of cell membrane rupture and increased vaginal fluid typically part of vaginal deliveries (European Collaborative Study 2005; Fowler 2007; Abrams 2004). However, one review study raises questions related to the safety and effectiveness of ECS by weighing the risks of maternal and infant mortality attached to performing caesarean sections against the risks of HIV transmission (Read and Newell 2005). The authors recommend that ECS be used only when the pregnant woman has either taken no ARVs and her viral load is high, or if she has only taken the one ARV called Zidovudine (7). They also argue that ECS should only be performed if the risks attached to this surgery are outweighed by the benefits of reducing HIV transmission (7). The effectiveness of ECS when performed in the presence of ARVs, when the viral load is low and the risk of infection is low is still contested (Fowler 2007; Read and Newell 2005).

The prevention of pediatric HIV through the appropriate management of viral loads and CD4 counts, measures varied success depending on access to ARVs. In “resource-rich settings” access to highly active antiretroviral therapy (HAART) and ECS have greatly reduced vertical transmission (Foster and Lyall 2008; Newell and Thorne 2007; Abrams 2004; Gibb et al 2003; European Collaborative Study 2003). However, in what are termed resource-rich settings the access and feasibility of using ECS or HAART has been very limited. The major intervention being used is a weaker drug treatment called single-dose nevirapine (SD-NVP) (Abrams 2007, Newell and Thorne 2007). Despite the progress observed in preventing vertical transmission of HIV as a result of HAART, there are now questions being raised around the unknown side effects of this drug regimen on infant growth and development (Foster and Lyall 2008).

Without any intervention, vertical transmission measures between 15 and 30 per cent (Public Health Agency of Canada 2007: 41). From the perspective of public health, the prevention of mother-to-child-transmission (PMTCT) has focused on HIV prevention in women by encouraging safe sex through condom use; increasing prenatal HIV testing and counselling; and encouraging access to more multidrug interventions that extend beyond SD-

NVP in places where this is the only drug available (Epi-Updates 2007; Pai 2007; Abrams et al 2007; Fowler 2007).

Prenatal HIV testing is especially important in the prevention of pediatric HIV. Interventions can only be implemented if there is access to appropriate resources and if the mother is *known* to be HIV positive. Thus, in some places in the United States prenatal testing for HIV is mandatory (Scott 2003:9). In Canada, however, HIV testing of pregnant women remains ultimately the choice of the woman (Public Health Agency of Canada 2007: 43). Prenatal testing approaches also vary across the country. In some jurisdictions, women are automatically tested unless they ask not to be, and in others, including Saskatchewan, they must give consent before being tested (43).

While researchers are confident about recommending ARV treatment worldwide as a prevention strategy for vertical transmission, recommendations to prevent HIV transmission through breastfeeding are still contested within medical literature.

To date there have only been three randomized control trials (RCTs) looking at the rate of transmission of HIV through breastfeeding (Otieno et al 2007, Gray and Saloojee 2008). The first took place in Kenya and determined that the rate of HIV transmission through breastfeeding was 16.2 % (Nduati et al 2000). Subsequent studies on this topic have been predominantly observational cohort studies conducted in similar resource-poor countries including Tanzania, Zambia, South Africa, Zimbabwe and Brazil (Coutsoudis 1999; Breastfeeding and International Transmission Study Group 2005; Kuhn 2005). Notably all of these studies suggest HIV transmission through breastfeeding is significantly less than 16.2 per cent.

The Kenya RCT has been criticized for not properly defining the mode of breastfeeding. Coutsooudis and Rollins (2003) and Smith and Kuhn (2000) note that if a mother practices mixed breastfeeding then she is feeding her baby breast milk along with additional fluids and solids. In contrast, if she is an exclusive breastfeeder the baby only receives breast milk. The subsequent observational studies purport the rate of transmission of HIV to be significantly less than the RCT suggests when the mother practices exclusive breastfeeding (around five per cent), and higher (around 20 per cent) when a mother is mixed feeding (Coutsoudis 1999; Illiff 2005; Coovadia 2007).

The other two trials have only recently been published. One looked at HIV-transmission rates through breast milk when antiretroviral prophylaxis (Kumwenda et al 2008), the other at mortality rates and HIV-transmission as a result of early cessation of

breastfeeding (Kuhn et al 2008). The findings from these trials suggest that ARV treatment during the breastfeeding period as well as an extended period of breastfeeding can effectively reduce HIV transmission (Gray and Saloojee 2008).

Accounting for the varying reports on HIV transmission through breastfeeding and the limited number of RCTs are the ethical and logistical challenges of randomizing breastfeeding as a behaviour (Coovadia 2007; Coutsooudis 2003). Medical and social science research report both exclusive formula feeding and breastfeeding are hard to practice due to social, cultural and economic values and pressures tied to mixed feeding or breastfeeding (Leshabari and Koniz-Booher 2006; Coutsooudis 2007; Morrisson and Greiner 2000; Murphy 2003; Yeo et al 2005; Knaak 2006; Malacrida 2002, Murphy 2000). If a person is randomly assigned a form of infant feeding that is inappropriate to their lifestyle, there is a greater likelihood that they will turn to mixed feeding. Coutsooudis (2003) makes the point that randomizing a behaviour like breastfeeding is challenging because it is so “inherently part of a woman’s motherhood” (440). The benefit of an RCT is that it creates equal samples that can be used in comparison to each other. In the absence of RCTs, HIV and infant feeding studies have been limited to observation and the hope that enough women will pick mixed feeding, exclusive breast or formula feeding within the studies so comparative data can emerge.

The national and international infant feeding recommendations for women with HIV are therefore—unsurprisingly—incongruent. In the medical literature formula feeding is given as the main alternative to breastfeeding. Several scientists maintain that this alternative is not itself free of risk, pointing at the overwhelming health benefits for both mothers and infants directly associated with breastfeeding (Morisson and Greiner 2000; Coovadia 2007). Coutsooudis and Rollins highlight that exclusive breastfeeding for the first six months significantly reduces infant and child mortality from gastrointestinal and respiratory diseases, particularly in resource poor areas (2003: 438). Bryce et al also add “the [World Health Organization] WHO estimate that diarrhoea and pneumonia are responsible for 17 per cent and 19 per cent of deaths in children younger than five years, respectively” (Bryce et al 2005: 1150). Therefore, in the literature, determining health policies around HIV and breastfeeding presents itself as a dilemma; the risks of not breastfeeding need to be weighed against the risks of contracting HIV.

In 2001, the WHO addressed the infant feeding dilemma facing HIV-positive mothers by establishing a set of criteria designated to help local and national health officials

determine an appropriate infant feeding recommendation. Recognizing the risks attached to breastfeeding in the presence of HIV, the importance of exclusive breastfeeding to infant health, and acknowledging that this feeding pattern presents a reduced rate of HIV-transmission in comparison to mixed feeding, the WHO states that “when replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS), avoidance of all breastfeeding by HIV-infected mothers is recommended; otherwise, exclusive breastfeeding is recommended during the first six months of life” (World Health Organization 2001). Then, in 2006 the WHO adjusted its guidelines in response to studies indicating that early and abrupt cessation of breastfeeding was dangerous to HIV-transmission and infant health. The new guidelines emphasize that if AFASS criteria is still not met by six months of life exclusive breastfeeding should be continued until an AFASS diet is available (Coutsoudis 2008; Lunney 2008).

In Canada AFASS has been evidently met, for the existing Canadian HIV health policy on infant feeding advises that if a mother is known to be HIV positive, she is to be prenatally recommended not to breastfeed and to take up “replacement feeding” instead (Burdge et al 2003: 9). Significantly, there are no studies on whether women living in poverty in developed countries meet the AFASS criteria. Discussion of HIV transmission through breastfeeding is limited to debates on the dilemma facing HIV-positive women in developing countries, and stresses the availability of preventative treatment and the avoidance of breastfeeding in developed countries like Canada (Jackson et al 2003: 121; Burdge et al 2003: 1686; Kuhn and Peterson 2002).

From the medical literature on HIV and infant feeding we can conclude that (1) qualitative data on HIV transmission through breastfeeding is being generated out of observational studies, then turned into a series of objective medical recommendations; (2) underlining these recommendations is the assumption that the only – and therefore best – alternative to breastfeeding is formula feeding; (3) based on the national recommendation, in Canada it is assumed that all women with HIV meet the World Health Organization’s AFASS criteria.

My Questions

Reviewing this medical literature, I am left with the following question: Is there controversy underneath this apparently solid recommendation on HIV and breastfeeding in Canada, and if

so, for whom? In this research, I explore this question by looking at *how* the Canadian HIV and breastfeeding recommendations at a municipal level came to be. The methodology of this thesis was therefore centred around answering two overarching questions: (1) Who are the influential actors involved in shaping, disseminating and receiving knowledge (the “knowledge flows”) on HIV and infant feeding in the form of a standardized medical recommendation in the context of the City of Saskatoon; and (2) how do these actors impact on other actors involved? I use the information gained from identifying who is a key actor in HIV and infant feeding “knowledge flows” to answer the following three questions around which the chapters of this thesis are shaped:

- 1) What is the infant feeding recommendation for women with HIV in Saskatoon, and why?
- 2) How and where is information about this infant feeding recommendation circulating in Saskatoon?
- 3) How does the infant feeding recommendation for women with HIV shape good and bad mothering discourses and why?

Why pick a city where there is a low prevalence of HIV?

Most women with HIV in Canada live in large urban centres like Toronto, Montreal, Calgary and Vancouver (Public Health Agency of Canada 2007: 43). As a result, most research on HIV takes place in these larger places with many of the same people. I chose to conduct this fieldwork in a smaller city with a lower prevalence of HIV to gain a different perspective on the issues facing people living with HIV in Canada.

There are practical benefits to conducting research on HIV in a smaller city where HIV is less prevalent. In such a city, there will be fewer “experts” and organizations available for support and treatment. My study traces knowledge flows on HIV and infant feeding between people, places and documents, and therefore fewer places to visit and people to follow makes this project more manageable and, ultimately, doable. In a smaller venue where HIV is less researched, there is also more opportunity for my work to be of greater interest and use to the community where this study is conducted.

Even though prevalence of HIV is not as high in Saskatoon as it is in other places in Canada, I quickly learned that this disease is still a concern. When I arrived at the start my fieldwork in June 2007, I was told that I arrived at a “good time” for someone researching women HIV because Saskatoon was observing an unprecedented number of women with HIV who were pregnant. A nurse I spoke with from the Positive Living Program, at the HIV-clinic at the Royal University Hospital elaborated; “this spring we had seven moms deliver, we have two or three who are pregnant right now”. Before these deliveries, there was an average of about one case of pediatric HIV a year.

Why Saskatoon?

The Royal University Hospital in Saskatoon is currently engaged in the “Baby-Friendly Initiative”. According to the Saskatoon Health Region website, this initiative is an international program developed by WHO/UNICEF for “the protection, promotion and support of breastfeeding as a strategy aimed at increasing the health and well-being of children and families” (“Baby-Friendly Initiative”). The overall goal is to help create a health environment where breastfeeding is considered the norm. Saskatoon’s involvement in this initiative indicates the value this city has placed on breastfeeding and suggests that it will be engaged in visible breastfeeding promotion. This city then becomes the ideal context for conducting this study on knowledge flow and good mothering discourses. Several questions arise as one considers Saskatoon’s bid for Baby-Friendly status: Do new mothers face increased pressure to breastfeed? How do women with HIV, for whom breastfeeding is contraindicated, feel when faced with so much evident promotion of breastfeeding “as best”? What information do groups that promote breastfeeding have about HIV in Saskatoon, what recommendations do they offer?

Conceptualizing Knowledge

While, as a researcher, I physically follow knowledge in a linear form, given that I can only be in one place at once, this is an inaccurate representation of how knowledge truly travels and exists in time; between multiple human and nonhuman actors in time, place and space. Borrowing partially from Donna Haraway (1996) I view knowledge as “diffracting” whereby ideas are shaped and produced on multiple levels either at one or multiple times while

spreading, and transforming continuously across place and space (436). In this way knowledge is conceptualized as organic, and never crystalline or static. Knowledge from this perspective does not travel or exist in a fixed singular form from one point to another in a linear fashion.

Conceptualizing the Field Site

Reflecting the dynamics of being in a constant state of change, in multiple places at multiple times, I characterize the site where knowledge is produced, transformed and diffused similar to the way Caroline Nordstrom illustrates and positions the ambiguous “warzone” in her research. Nordstrom suggests that in her research “war” serves as “the ‘locating’ topic of this study” rather than a traditional “locale” (1997: 78). Blurring the traditional ethnography of a locale, Nordstrom stresses that her ethnography is grounded “in a topic and a process, not a place” (78). Thus, in this thesis, I ethnographically locate the influences of key actors on the flow, shape, sharing, transforming and production of knowledge related to HIV and infant feeding recommendations in Saskatoon.

This conceptualization of an anthropological field site steers away from traditional models grounded in one physical location. Sets of relationships — like violence, international trade relations, transnationalism and war — often cannot be observed from a single location. Consequently, similarly engaged anthropologists have re-conceptualized the ethnographic notion of the field location as “multisited” (Marcus 1995; Nordstrom 1997; Caldeira 2000; Scheid 2002; Nordstrom 2004; Brennan 2004). While my research looks at how actors produce, change and share knowledge and impact on other actors in not one single location, it is also not occurring in multiple physical sites either, like the ones Scheid (2002), Marcus (1995) and Caldeira (2000) conceive of in their fieldwork. My “field site” is not the City of Saskatoon itself but rather the points, spaces, nodes and zones of interference and juxtaposition of knowledge that occurs, or is found within its boundaries. The knowledge I examine in Saskatoon should be viewed as a cross section of larger knowledge flows on infant feeding and HIV happening in Saskatchewan, Canada, North America and around the world. This is because knowledge cannot be contained physically to one particular location; it is abstract and does not have a physical appearance.

The City of Saskatoon, defined by physical boundaries, therefore acts as what I will call a “meeting ground” for the knowledge examined in my fieldwork. A piece of ground

refers to soil, or a fixed physical attachment to some part of the Earth. A ground must be characterized by a fixed timeline, relative to one fixed space and place. This time-space-place relationship is different from the relationship that characterizes knowledge: there can be multiple copies of one “fact” within one timeline. A meeting can be an assembly, a gathering or a congregation of more than one thing or person. A “meeting ground” is therefore an assembly of more than one thing over a fixed timeline relative to a fixed physical location and space. Saskatoon as a “meeting ground” acknowledges therefore that the knowledge transformations, diffusions and diffractions illustrated in this thesis are shaped partially but not uniquely by the characteristics of time, place and space that made up Saskatoon over the summer-fall of 2007.

What is an Actor?

Medical knowledge comes out of the mouths of patients, laboratory technicians, non-governmental organizations, physicians and nurses. It can appear in the doctor’s office, in textbooks, on internet sites, articles, posters and on medicine bottles. Knowledge is constantly exchanged between, and carried by, people and texts. How do we explore the relationship occurring between these different knowledge mediums? Recent science and technology theorists looking at actor networks posit that studies examining and looking for cultural constructions of scientific standards, recommendations and the production of knowledge, fail to take into account the changes that occur to and between non-human and human “actors” when they interact together (Latour 1987; Callon 1986; Latour 1999; Star 1991; Timmermans 1999; Law 1999). Constructivist science authors historically and temporally position nonhuman actors outside of their studies and histories of science in support of modernist dichotomies that explain the making of science and knowledge in terms of object-subject or nature-society dualities (Latour 1999: 156).

In this thesis I move away from social constructionist explanations of how recommendations are created. I identify a network of human and non-human actors that are simultaneously involved in influencing and shaping each other in the process of creating, sharing and receiving medical recommendations on infant feeding for HIV-positive mothers. In this thesis, I follow knowledge through the perspectives of multiple *actors*, including articles, websites, people and institutions. I illustrate multiple angles of a Saskatoon HIV and infant feeding knowledge flow actor-network.

Early actor-network theorists Bruno Latour and Michel Callon, conceptualize an actor as “any element which bends space around itself, makes other elements dependent upon itself and translate their will into a language of its own” (1986: 286). Proponents of actor-network theory, like Guunarsson, highlight the methodological benefits of this approach noting that an actor network “seeks to unfold the world as consisting of heterogeneous relations where humans and non-humans alike are treated as possible actors and are thereby ascribed agency” (2005: 138). Agency becomes the capacity of either a non-human or human to have or take action (139).

This thesis conceptualizes scientific articles and other relevant texts as non-human article actors. Consider the following questions: Are articles always read by the audiences they are intended for? Does the meaning of an article remain the same over time? Can an author predict what meaning the reader will glean? By considering an article as an actor, I make analytic room for the possibility that the social action accorded to articles *can be* independent of the social action accorded to humans. This thesis is in part an exploration of how the social actions of humans *are or can be* independent from the articles they create (see Chapter 4 for this discussion).

In addition, humans and non-humans are not confined by the same space, time and place limitations. It is physically impossible for one human to be in two places at once. It is also impossible for a younger version of a human to physically sit next to a later older version of itself. Humans are bound by the present period. In order to communicate with each other outside of the present, humans must engage a type of communicative intervention. These interventions can include tape recording, video recording, journal writing, letter writing, e-mailing, publishing, or any other medium for storing information. These interventions are useful because they allow *representations* of human ideas to exist in time, space and place dimensions that go beyond the limitations of human confinement to the present. Multiple copies of the exact same article *can* appear in many different places at the same time or at different times. Multiple editions of the same textbook *can* be lined up next to each other. The exact same article published in 1986 *can* be looked at in its entirety in 2008. These interventions therefore take on different social paths in time, than humans do.

When we think of objects we think of lifeless, static, neutral entities. However an article or a piece of writing differs from other “objects”—or non-human actors—as they generate and store symbolic meanings based in linguistic representation. The symbols work and rely on each other to give meaning. Timothy Mitchell (1988) draws on Jacques Derrida’s

work when he explains that the meaning of a word is determined by other words through a paradox of sameness and difference. Mitchell argues that meaning emerges out of repetition in a double sense: “the sense of something non-original, something that occurs by modifying or differing from an other; and a repetition in the sense of the-same-again” (145). While a human is required to witness or to look at the text to give it meaning, as Mitchell stresses, that there is still action occurring between the symbols. Yet, the action between symbols cannot be described as the same kind of physical actions ascribed to humans.

If I was to conceptualize an article only as an extension or part of a human actor, my observations of knowledge flows and social action would be limited to the way humans interact and exist. This would overlook a whole other level of action that could be occurring. Thus I interpret articles as actors with the aim of observing the way knowledge flows change as they pass from human mediums to non-human textual mediums. I further discuss the action of non-human article actors in Chapter 4.

The Spider and the Web: Conceptualizing Ethnography and the Ethnographer

Given the time restrictions of this study and the lack of participant observation that my research supposes, data was examined under an ethnographic *analysis*. The analysis and insight explored in this thesis shares with ethnography the view that knowing, understanding and sharing peoples’ perspectives is contextually located, and makes valuable contributions to knowledge. This view forwards that an ethnographic analysis, is able to problematize Eurocentricism and dichotomies of ‘West and the rest’ (Caldeira 2000; Fabian 2000; Hall 1996). In this research I contextually locate, through ethnographic analysis, the multiple perspectives of and the imagined space where, actors act on each other within discussions of HIV and infant feeding recommendations.

I located and became familiar with the different actor perspectives as if I were watching a spider’s web take shape around me. In this case, the spiders on the web represent the various key actors. The threads of the web represent other actors and their interconnected nature. The completed spider’s web is the ethnographic analysis and I am the fly, the ethnographer, stuck to and thus part of the web. Ultimately, I affect the way the web is built, though I predict neither the shape it will take nor who will be involved.

Thus in this thesis I take the position that conceptualizes ethnography as a form of performance (Denzin 2001; Fabian 2000; Castaneda 2006). Johannes Fabian contextualizes this epistemology arguing that knowledge presented in discursive statements, as elicited in interviews, can only be represented “through action, enactment, or performance” (1990: 6). When interviews are viewed in this way, the ethnographer’s role, then, “is no longer that of a questioner; he or she is but a provider of occasions, a catalyst in the weakest sense, and a producer (in analogy to a theatrical producer) in the strongest” (Fabian: 7). In my fieldwork I assume the role of “producer” to find out which actors are connected to each other and an influence in the web.

By viewing interviews as functioning as a performance, Fabian blurs the power hierarchies that emerge between observers and observed or interviewer and interviewee, or spider and fly, when one person is viewed as informing and the other as extracting (11). Instead, performance is seen as “giving form to” something, which, as Fabian explains “only occurs whenever communicative exchanges are initiated that involve all participants, including, of course, the ethnographer” (12).

Locating Actors: Who did I interview and why?

To locate an “actor,” Latour emphasizes, is to look at the set of processes, institutions and relations that envelope it; “there is no other way to define an actor but through its action, and there is no other way to define an action but by asking what other actors are modified, transformed, perturbed, or created by the character that is the focus of attention” (1999: 122). Drawing from Latour and Emily Martin (1994) I approached the task of locating actors by crossing back and forth between the traditional lines of the laboratory and the surrounding community. I look at knowledge on HIV and breastfeeding as it circulates in the community, amongst breastfeeding organizations and organizations that support women with HIV. I also look at clinical settings and how knowledge on HIV and breastfeeding emerges in a community clinic and in the offices of HIV specialists.

Actors and “key actors” were determined by looking at and noting the number of referrals to and the subsequent “recursivity” around certain actors. I use “recursivity” to mean that I paid attention to the number of times an actor was mentioned or referred to me by other actors.

As an outside “fly” I had to choose some part of the web to land on before I could start to see how the threads would take shape around me. I decided to start by approaching people who obviously interacted with HIV-positive women; organizations designed to support those with HIV. From internet searches I discovered that in Saskatoon there are two major organizations of this genre: AIDS Saskatoon and People Living with AIDS (PLWA). For no particular reason other than looking for a place to land I started by calling AIDS Saskatoon, this call resulted in an invitation to a community barbeque. This barbeque hosted a mostly health-centered community resources fair, equipped with display boards that introduced me to many if not most of the resources available to women living with HIV in Saskatoon. At this event I handed out information about my project and was directed by several people to contact the Westside Community Clinic because, according to those at the barbeque, most people with HIV go to the Westside Community Clinic for medical advice.

I wouldn’t know it until later, but both AIDS Saskatoon and the Westside Community Clinic were “spiders,” or key actors, on my web because of the sheer number of times that each of these places was cited by other actors as a key resource used by women with HIV or that the actors used themselves. Many threads of the web spanned between these two organizations. Each thread represented a person, place, organization or document named by an actor as a “go-to” resource related to infant feeding recommendations for women with HIV. Thus, in order to find all of the spiders, I followed every thread introduced to me.

Using recursivity as a marker for key human actors was reliable because the number of people working in healthcare and focusing on HIV and infant feeding, as separate or related topics, is limited, thus narrowing the possibility for actors at the outset. For example, when interviewing people at the Westside Clinic several mentioned the Saskatoon Food Bank and Learning Center as a place to acquire free infant formula. I learned that there is only one food bank in Saskatoon meaning that I was being directed to a main resource. People Living with AIDS, La Leche League, the YWCA, the Salvation Army and Kids First were all threads of some part of this web, but were not directly related to the knowledge flows pertaining to infant feeding recommendations for women with HIV and were not pursued.

With respect to locating documents as actors and key actors I was limited by the time restrictions of this study. While I did not actively attempt to determine key article actors, or key actors within the articles, in Chapter 2 I point out that in some cases the article actors were made very obvious to me through recursivity, and in that case a key article actor was named.

In total, I interviewed 31 professionals working in the community. These people are affiliated with breastfeeding organizations, organizations providing support to women with HIV and medical settings in the community clinics and the Saskatoon Health Region (SHR). Below is a list of the organizations or institutions from where I drew my informants . Consent was obtained to use all of the names that appear.

In alphabetical order: AIDS Saskatoon, Breastfeeding Centre, Breastfeeding Matters, CHEP, a community services worker, EGADZ, Food For Thought, Healthy and Home, health librarians, Healthy Mother Healthy Baby, BC Women's Milk Bank Vancouver, a midwife, Moms for Milk, Saskatoon Food Bank and Learning Center, Royal University Hospital (RUH) Infectious Disease specialists, RUH Positive Living Program, an RUH postpartum nurse, and RUH postpartum social worker, and the Westside Community Clinic.

My fieldwork officially spanned from September 2007 to January 2008. At the end of January 2008 I had held interviews with people from a spectrum of areas in the community and healthcare network in Saskatoon. Many potential actors were situated in other parts of Canada or internationally. However, with the exception of BC Women's Milk Bank and Moms for Milk I limited my interviews to those situated in Saskatoon in order to provide some form of boundary to the interview process. The topic of milk banks became an important component for understanding HIV and breastfeeding knowledge flows. I felt it was necessary to include an interview with someone connected to human milk banking in my research. BC Women's Milk Bank is the only human milk bank in Canada; I conducted one interview with a person from this organization in Vancouver. Breastfeeding actors mentioned moms for Milk so many times that I also could not ignore this group.

Women with HIV

My study does not include interviews with any women living with HIV. As this thesis illustrates, I held interviews with multiple people and include as many perspectives on HIV and infant feeding knowledge flows as were introduced to me. Notably, these people and perspectives are all concentrated within the professional paid sectors of healthcare and community, breastfeeding and HIV support. I originally thought this thesis would be able to create a space for the perspective and experiences of HIV-positive women. I realized when I started that an entirely separate research project is warranted in order to do justice to the

perspective of women living with HIV regarding the medical knowledge they receive on infant feeding, and the relationships they have with the purveyors of this information.

At the earlier stages of my project, I established contact with a woman with HIV; for reasons out of my control, the interview never happened. After reconsidering the focus of my thesis, I did not attempt to arrange for any more interviews with women with HIV. Instead, the focus became an examination of what knowledge is flowing in Saskatoon amongst the people who might be contacted by women with HIV about infant feeding. Consequently, the perspectives expressed to me concerning the experience and context in which HIV-positive women live are often anecdotal, sometimes speculative, and otherwise directly formulated based on observation by professionals.

This thesis therefore gives insight into what the health care, community support and breastfeeding support systems all *perceive* to be the experience of women with HIV and infant feeding. When we look at the actors as gatekeepers of knowledge, then we can understand why some knowledge is transferred and some is not.

I use this thesis to draw attention to a need for research that reflects the perspectives of women with HIV within knowledge flows. I do this by illustrating; 1) how much of the patient's perspective is absent from the webs presented and 2) how perspectives on the experience of HIV-positive women who are infant feeding in Saskatoon are different or even contrasting across the community and the healthcare system.

Interview Questions

The spider's web I illustrate in this thesis, as I mentioned before, is in part my creation. I provided an opportunity for specific people to comment on a topic I chose, by asking specific questions.

I asked variations of these four main questions:

- 1- What challenges/successes face women with HIV in Saskatoon in terms of infant feeding?
- 2- Where do you send women with HIV for information on infant feeding?
- 3- Where do you get your information on HIV and infant feeding?
- 4- Take me through the information you give on infant feeding and HIV.

My questions varied only slightly from person to person depending on whether I was interviewing community organizations, breastfeeding-related groups or healthcare providers. Some additional questions were also added based on whom I was talking with. For the healthcare providers I asked about the process involved in formulating a medical recommendation. For the breastfeeding groups I asked about the success people in Saskatoon have had in initiating and sustaining breastfeeding as well as about breastfeed versus mixed feed statistics. I asked health librarians to illustrate how they would conduct an information search on infant feeding and HIV. Additionally I was interested to learn about the interactions between health librarian and physicians, and how they choose which references to send and when to send them. From the BC Women's Milk Bank representative I asked about the process of human milk banking at the BC Women's Hospital. I asked about cost, accessibility, whether women with HIV use the facility, and about their Priority List for allocation of donated milk.

Two additional questions were integrated into my interviews. Early in the interview process, I became aware of an initiative being led in Saskatoon to reinstate a human milk bank. Because a human milk bank provides an additional infant feeding option for women with HIV, I included a question that looked at what people thought of such an initiative. The second additional question was related to Saskatoon's "economic boom" as reported in city newspapers and at the heart of a provincial election campaign. Within two months of moving to Saskatoon, this economic boom boosted my monthly rent by \$100. Like many, I was in the middle of a housing crisis. Rent increases were common and alarming rates of condominium conversions continue to diminish the availability of affordable rental property. The result for many, since at least May 2007, has ranged from evictions to increased financial burden. Many women with HIV live in poverty, I thus included a question asking about the housing crisis, and to describe if any, the impact this has had on women living with HIV who are trying to feed infants.

Thesis content outline

In Chapter 2, I make three observations about how knowledge on HIV and infant feeding circulates in this city amongst professionals working with women with HIV in both clinical and community settings. I illustrate how some of the professionals working with women with HIV are more connected to each other than others through different referral patterns. I

explore how institutional and organizational agendas influence the way knowledge becomes compartmentalized. I argue that compartmentalization of knowledge shapes the information different groups are interested in, and are able to access and work with. I illustrate how different variations of the Canadian infant feeding recommendation for women with HIV emerge because of this process.

In Chapter 3, I illustrate that when medicalization of reproduction, childcare and infant feeding are applied to women with HIV ambiguous boundaries between the legitimate intervention of medicine and the social control over motherhood start to form. I identify corresponding good mothering discourses that shape around women with HIV who are upholding the medical infant feeding recommendation established by the Infectious Disease Department. I highlight that the multiple discourses present in Saskatoon paradoxically characterize women as both “good” and “bad”. I explore the implications this paradox for these mothers.

In Chapter 4, I evaluate the usefulness of characterizing articles as actors. I situate my observations about knowledge flows in recent science studies writings on social movements and the establishment of experts. I argue that the good/bad mothering paradox and the formation of multiple variations of a medical recommendation are best explained by examining the relationship human actors have to nonhuman article actors.

I conclude this thesis in Chapter 5 by suggesting that the compartmentalization of knowledge on an international level upholds the competing discourses of good mothering, and the ambiguity of medicalization of the reproduction and infant feeding. I illustrate how justification of the medical recommendation for infant feeding with reference to Canada’s development status overshadows the challenges women face when navigating poverty and accessing formula. I provide some key questions and observations that this thesis highlights with respect to knowledge flows, communication between institutions and infant feeding options for women with HIV.

CHAPTER 2: VISUALIZING ACTOR ENTANGLEMENT IN SASKATOON

Huddled around a computer monitor a health librarian takes me through the steps of how a librarian would respond to a physician's request for a literature search on breastfeeding and HIV. I watched 31,000 articles on HIV dissolve into 20 "really good" articles ready for launch through cyberspace, via e-mail to an imaginary physician. When we got to about 260 articles, the librarian started talking about how they narrow the search:

I would say English for one thing, because MEDLINE has a lot of foreign-language stuff. And even if they hadn't asked me to, I might start limiting my years. A lot of this is going to be from, maybe stuff from the 80s. Even if they didn't tell me to, and most don't, initially I will just limit it to 1990... 256 articles, well that got rid of almost nothing!

There are endless possibilities when it comes to literature searches. New articles are uploaded every day and there are innumerable combinations of key word searches, limitations, and word trees to be explored. Information is publicly accessible through a multitude of avenues, from library journals and databases to fliers and word of mouth. How does the search process influence what people choose to read or not read? Who knows what about HIV and infant feeding in Saskatoon and why? Who is reading what, and who is talking to whom? This chapter will reflect on these questions.

In this chapter, I illustrate how knowledge on HIV and infant feeding circulates among actors in Saskatoon. I look at why certain people share information with some actors but not others. I outline the different interactions that journal articles have as non-human article actors with other key actors both human and non-human to highlight how different variations of the Canadian recommendation on breastfeeding and HIV are favoured. Finally, I illustrate how knowledge is filtered mechanically through search processes and philosophically through the institutional compartmentalization of knowledge.

The Set Up

“Where do you find your information?” This question allowed me to understand how all of the people I interviewed connect to each other and to medical knowledge in general. Below is a diagram that I pieced together by keeping track of the names of the places and resources that the people I interviewed would or do use to assist a woman with HIV enquiring about infant feeding. The arrows connect resources to each other and represent the direction of the referral. The arrows always start from the place that was referring me. Only the key actors are included. Using this drawing, I will outline some focal observations I made about how knowledge about HIV and infant feeding flowed in Saskatoon from June 2007-Jan 2008. Do all the “key” actors connect to each other in Saskatoon? The next section will answer this question.

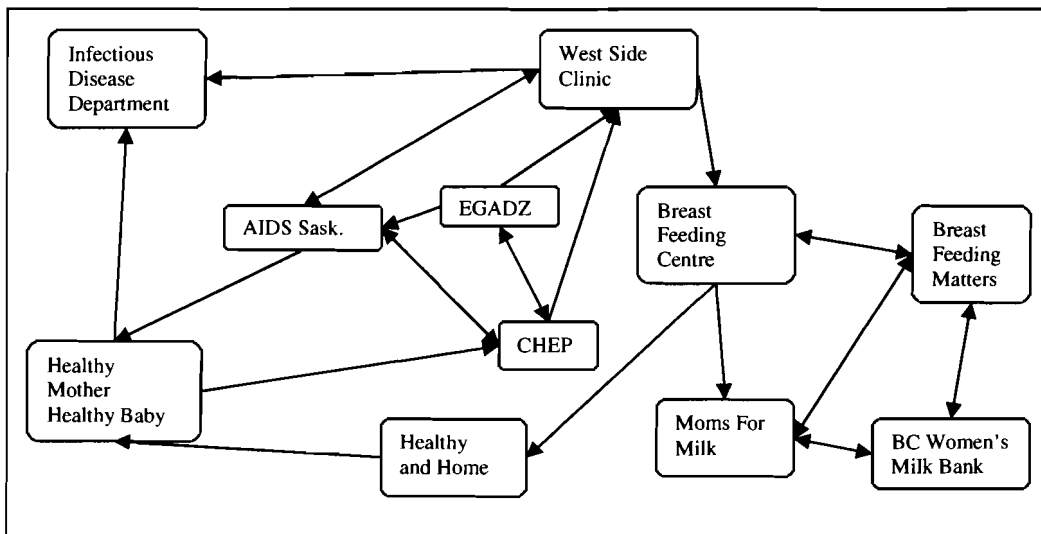


Figure 1: HIV and breastfeeding knowledge flows between “key” human actors in Saskatoon. Note all the above actors connect to multiple article actors. However, this figure is unreadable when all the arrows are drawn connecting to an icon representing this type of actor so I left it out.

Observation #1: By locating “key” actors, distinct referral clusters start to take form¹

A Cluster of Referrals Revolves Around the Infectious Disease Department

AIDS Saskatoon is in an old house in the west side of Saskatoon at the corner of Avenue F and 33rd. There is an immediate feeling of cosiness as you walk through the doors and across the hardwood into the visitor drop-in centre. A rack of flyers, the day's *Star Phoenix* and a television welcome visitors to enjoy a free coffee and snacks on one of the couches. There are also two computers and a telephone that are available for anyone can use. Both of these resources are well used. Beyond the visitor's lounge, the centre has a full kitchen that is put to use for monthly events, as well as laundry facilities for public use. The upper floor of the building house several offices for AIDS Saskatoon staff. It's a busy place; aside from supporting many, if not most, of Saskatoon's HIV-positive population, their families and friends, the organization manages a national 1-800 info line serving all of Western Canada.

I held two separate interviews with AIDS Saskatoon staff. During these conversations I learned about the types of education outreach and support resources operating out of the organization. In both these domains, AIDS Saskatoon acts a referral hub. As a person working there put it to me,

I don't do on-going therapy with people. It's providing support information, referrals, advocacy, that kind of thing. There can be referrals to a family doctor who is skilled at working with folks with HIV, it can be to dentists, things like that. There are referrals obviously to social services but also referrals around Healthy Mother Healthy Baby- making sure that people have the knowledge of those resources. We work very much on the philosophy that we can provide people with the information but they need to follow through on it themselves, so any of those kinds of resources we have ourselves.

AIDS Saskatoon pointed out to me that most of the women visiting the organization do not seek information about infant feeding or receive adequate prenatal care. Some information

¹ For this chapter I limit my illustration of the articles as actors to pointing out the different textual materials that certain human actors are being connected with. I originally intended to create a similar drawing as the human actor flow diagram, to represent which articles, pamphlets, and other written documents were considered “key” and being circulated either inside the articles themselves or between people.

about HIV and infant feeding will come from doctors; women might also be directed to social services, but AIDS Saskatoon underlined that Healthy Mother Healthy Baby (HMHB) has been a particular asset for some of the moms.

HMHB is a community-based program in Saskatoon that provides prenatal and limited postnatal support to pregnant teens and women who live in the community with risk factors like poor nutrition, substance abuse, abusive relationships or low-income housing. The organization is in the West Winds Primary Health Centre in Saskatoon, located at 3311 Fairlight Drive West of 20th Street a half-hour bike ride from AIDS Saskatoon. HMHB nurses drive to their homes for prenatal visits, which are every two weeks leading up to delivery. The nurses' visits start as soon as a woman has enlisted in the program. HMHB offers in-home support sending nurses for prenatal visits every two weeks leading up to delivery and for a few weeks postpartum. During these visits, the nurses give mothers information about pregnancy, fetal growth and development, body changes, labour and delivery, breastfeeding, birth control and nutrition. Women receive free milk coupons or vitamin and mineral supplements. Anyone can refer women to the HMHB program, including women themselves.

HMHB nurses are not hands-on nurses; instead, they ask many questions and fill out forms about the mother's height, weight and lifestyle. They take information on mental and physical health, finances, substance abuse and addictions. The nurses find out what issues the women face during pregnancy and determine how to best support them. The program operates on a harm reduction model, focusing on making information on the harmful effects of substance abuse and addictions available, with the aim decreasing and eliminating harmful usage.

While AIDS Saskatoon relies heavily on people coming into the centre itself for referrals, the organization also makes referrals through education presentations around the city. As someone from AIDS Saskatoon explained to me the staff directs people to local community health resources; "I will talk about an HIV specific social worker and about talking to her about things, talking to a doctor, plugging community places, so checking out the Westside Community Clinic or come down to AIDS Saskatoon where we have emergency assistance funds".

I followed the referral from AIDS Saskatoon and went to the Westside Clinic. This clinic is one of a select number of health cooperatives in Saskatchewan. It receives government funding but is separate from the Saskatoon Health Region (SHR). The SHR is

the largest health region and health delivery agency in the province and overseas areas concerned with public health, short and long-term care and health promotion and surveillance in Saskatoon. In the community clinics, physicians receive a salary rather than fee for service. The SHR gives special permission to physicians from community clinics to use the SHR facilities.

The Westside Clinic serves a large number of Aboriginal persons, the elderly and the poor and functions primarily on a drop-in basis. It is the primary medical venue for people with HIV in Saskatoon. The Clinic eschews the sterile unwelcoming feeling of a hospital. Upon my visit in October 2007, the waiting room was covered in posters and art celebrating Aboriginality and handmade baby blankets for sale were on display. Comfortable chairs, water and free coffee also made the place inviting and I observed several people come in just to have a coffee and read the paper. The Clinic has a kitchen, a conference room and houses the youth organization called SWITCH (Student Wellness Initiative Toward Community Health).

The staff at the clinic work together as a team to deliver primary health care. There is a nurse practitioner, a dietician, two family doctors, counsellors, a receptionist and administrative staff. Some of the government funding the clinic receives goes towards developing specialized health programs designed to suit specifically the population visiting the Westside Clinic.

Another organization referring women with HIV to the Westside Clinic is EGADZ. EGADZ is also known as The Saskatoon Downtown Youth Centre Inc. but got its name from the building's former occupant, the EGADZ dance club. The young people who first started visiting the centre voted to keep the name, and the old sign has been the same since. The centre is located a block away from the downtown bus depot at 1st Ave. and 24th Street. EGADZ spreads over two floors. A large "safe space", the old dance floor, is used for programs and hanging out. Children can run around in while teenage parents catch their breath. Like AIDS Saskatoon, EGADZ is a community-based organization. Its resources include a drop-in centre, legal advocacy and classes on teen parenting. As from AIDS Saskatoon, EGADZ is about a 10-minute bike ride from the Westside Clinic—a clinic the EGADZ staff highly recommends;

For us, and for the vast majority of the people here, *the* clinic to access would be the West Side Community Clinic. Dr [name withheld] is fantastic—we've just have a fantastic relationship with them for probably the last 15 years. We used them before anybody else used them.

EGADZ and AIDS Saskatoon both have a direct relationship with the Westside. The Westside Clinic also works closely with the Infectious Disease Department (IDD) in Saskatoon. The IDD includes half a number of HIV-specialists. Through the referral cluster, AIDS Saskatoon and EGADZ therefore *indirectly* connect with information from IDD when they send their visitors to the Westside Clinic.

Almost an hour-long bike ride that goes across one of Saskatoon's seven bridges gets you from AIDS Saskatoon to the IDD on the East side. The IDD is at the Royal University Hospital (RUH) on the University of Saskatchewan campus. The IDD shares the third floor of the RUH with the Positive Living Program. The nurses working in this program are the primary hospital contacts for patients attending the HIV-clinic. New HIV patients spend three months visiting the clinic for blood-work monitoring and updates on CD4 counts before they get to see an HIV specialist.

The IDD is a principal resource on HIV for the Westside Clinic. Once a month, an HIV- specialist makes a visit to see patients with HIV who will only visit the Westside clinic—an issue I will come back to in Chapter 3. Some of the prenatal patients with HIV see this physician. The specialist gives guidelines on medications these women should take. Although the Westside Clinic does not receive many questions about HIV and infant feeding, I was told that this visiting specialist would be a resource the Westside Clinic would go to.

The IDD is also a resource for the Clinic outside of monthly visits. One of the physicians explained to me that in addition to checking the Canadian Medical Association or the Canadian Pediatrics Association websites they would call the nurses working at the Positive Living Program and go over what they use.

Like the Westside Clinic, Healthy Mother Healthy Baby maintains a direct relationship with the IDD and the Positive Living Program. When I asked about where I could access information about infant feeding and HIV I was referred *only* to the IDD:

There is no specific guideline given to Healthy Mother Healthy Baby when encountering HIV-positive mothers, because it [the recommendations] changes because of the drugs that they are using. If you wanted a policy I guess our policy is to check what the current recommendation is with the HIV specialists in town.

While the IDD connects directly with only the Westside Clinic and HMHB it also taps into the client base of AIDS Saskatoon and EGADZ because of the referral system illustrated above. After interviewing people who advocate or provide support for women who breastfeed, I started to see another distinct referral cluster take shape around me.

A Second Referral Cluster Links Together all of the Breastfeeding Groups

As I explained in my methodology I had to put myself on to the “spider’s web” before I could start looking around. In the case of AIDS Saskatoon and Breastfeeding Matters, I was the initiator—I did not follow a referral. Over time, I confirmed that these actors *are* “key” parts of the knowledge flow picture in Saskatoon. I was introduced to Saskatoon Breastfeeding Matters after a Google search of “breastfeeding in Saskatoon,” brought me to the SHR website. Under “Breastfeeding Matters”, I found a paragraph explaining that the group advocates breastfeeding as *any* woman and child’s right. I wondered whether women with HIV and their infants are included in this mandate and whether Breastfeeding Matters Breastfeeding Matters had had to face the issue of HIV-positive women and infant feeding. This group became my entry point into understanding knowledge flows on HIV and infant feeding passing through organizations that support breastfeeding.

Saskatoon Breastfeeding Matters is dedicated to the promotion and normalization of exclusive breastfeeding. The group holds community events and educational sessions as part of its efforts to create a supportive, breastfeeding-friendly mothering environment in Saskatoon. Breastfeeding Matters operates outside of the Saskatoon Health Region as an advocacy group for mothers who feel they have not received equal support or opportunity when it comes to breastfeeding. Women and health professionals connect with this group either at monthly meetings at one of the city’s malls, through the Saskatoon Health Region website or at their home base in the Public Health Services building on Idyllwild and 25th Ave—about halfway between the Westside Clinic and the RUH.

When I asked a person from Breastfeeding Matters how they connect with new information on breastfeeding and HIV I was introduced to several articles which I will look at more closely in the next sections, and two organizations in particular; the BC Women’s Milk Bank in Vancouver and Moms for Milk.

The BC Women's Milk Bank is the only milk bank in Canada. Milk bank donors are lactating mothers who produce more milk than their baby needs. They freeze their milk and bring it to the milk bank. The milk bank pasteurizes (heats) the milk in order to ensure its safety. All women are screened before they become donors. The screening process includes a questionnaire, an interview, a consultation with the woman's family physician or midwife and a set of blood tests testing for infectious diseases like HIV, Hepatitis and Syphilis. The BC Women's Milk Bank operates using the Human Milk Bank Association of North America (HMBANA) priority list. This list stipulates that when there are more requests for donor milk than there is milk available, milk is given to the smallest and the sickest babies first. Occasionally milk is distributed outside of the province for very sick babies. Breastfeeding Matters is currently working with BC Women's Milk Bank in efforts to learn how to re-establish a similar milk bank in Saskatoon.

I learned from talking with the BC Women's Milk Bank that there were 22 other milk banks in Canada in the early 1980s. Some of these were donor banks and some were storing mother's own milk. They all closed by the mid 1980s as a result of the HIV scare, leaving the BC Women's Milk Bank as the solo bank in Canada. One of the reasons why it did not close like all of the other milk banks across the country is because it has been pasteurizing its donor milk almost since it opened back in 1974.

Following a referral from Breastfeeding Matters, I met with someone from the BC Women's Milk Bank to find out if they provide any donor milk to women with HIV. When it came to the subject of where to get information, I was directed back to Breastfeeding Matters and, again, to Moms for Milk.

Continuing with the referral chain, I followed up with Moms for Milk. This grass roots organization also promotes breastfeeding as a right of all mothers and infants. Moms for Milk publishes an online newsletter and manages the listserv through Yahoo Groups called *Breastfeeding Canada News*. This listserv sends updates, news articles and journal articles on breastfeeding to over 700 health professionals and mothers currently signed up to the mailing list. Breastfeeding Matters, the HMBANA representative and the Breastfeeding Centre—another group I interviewed—are all members of this listserv. To join the list people must express an interest in breastfeeding and provide some information about their background, for example, whether they are a mother or a health professional.

The informational services provided by this group aim to give women access to detailed information on birth and infant feeding choices. Pressure is then placed on health

services to support these choices. Moms for Milk is a volunteer-driven operation, run out of an individual's home a few hours outside of Saskatoon. Our interview took place over speakerphone while this person was at the computer in their house and I was in a friend's office.

As mentioned above I also connected with a service in Saskatoon called the Breastfeeding Centre. However, unlike the BC Women's Milk Bank, Moms for Milk and Breastfeeding Matters the referral came not from another breastfeeding group but from Westside Clinic. In an interview with a physician at the Westside Clinic, I presented a hypothetical situation where a mother with HIV was adamant about breastfeeding and wanted information. I wanted to know what the physician would do. This physician's reply highlights the recommendations that the Westside clinic follows in the case of HIV and breastfeeding. The primary resource available to women looking for breastfeeding support in Saskatoon is also underlined:

You would need to ask AIDS Saskatoon. I don't know anywhere where they would support that idea [of HIV-positive women breastfeeding]. ... I already talked about that whole thing about social services and putting the child at risk, like Jehovah's Witness and not giving blood transfusions and asking 'where do you draw the line?' I've never run into that particular scenario so I can't really comment on what I would do until I'm faced with it. My hunch right now would be that I would be reporting this to social services and saying, "is this a legitimate reason to take this child into care?" If the mother was adamant, and if social services say, "no, we are not going to do anything and if she wants to breastfeed then so be it," then if she ran into problems with breastfeeding I would treat her like I would any other woman and I would send her off to the Breastfeeding Centre.

After talking with the physician at the Westside Clinic, I went straight to the Breastfeeding Centre to explore what *the* resource on breastfeeding in the city knew about HIV and infant feeding. The centre is in West Winds Primary Health Centre in Saskatoon and staffs certified lactation consultants. These consultants are trained to help women overcome challenges they face with breastfeeding, as well as answer any questions or concerns they might have about nursing. As the next section will outline in more detail, I learned in this interview that lactation consultants are very connected with recent scientific and academic journal articles. Some of the articles, the representative explained, arrived via the Moms for Milk listserv and Breastfeeding Matters. Thus, while I was not directed *to* the Breastfeeding

Centre directly through other breastfeeding groups, I was directed *back* to these groups, highlighting the existing connections between them all.

Evidently, there is a referral cluster connecting Breastfeeding Matters, Moms for Milk, the BC Women's Milk Bank and the Breastfeeding Centre. This cluster is distinct from, and not connected to, the IDD.

Importantly the two above referral patterns were constructed for me partially with reference to a hypothetical situation where a woman with HIV would ask a question about infant feeding. While there are instances where this question has come up in all of the organizations I talked with that connect with IDD, it was overall an uncommon inquiry. Aside for the BC Women's Milk Bank, a woman with HIV approached none of the breastfeeding groups for information. In the next chapter, I examine some of the reasons why there is a silence around this topic.

Observation #2: Within Different Referral Clusters Actors have Different Health Agendas

The visibility of two referral clusters around information on infant feeding and HIV reflects the effect that different institutional and organizational mandates, philosophies and health agendas have on actors' responsibility and interest for specific information.

In Saskatoon, HIV research is instrumental in the efforts to re-establish the human milk bank. As I was told by a person from Breastfeeding Matters, "HIV issues drive our need for human milk banking in Saskatoon, it's one of the reasons we're going for it." In this context, HIV research upholds a platform from which breastfeeding and access to breastmilk can be ethically promoted as "the right of every woman" and her child.

As it was explained to me, any form of support for a human milk bank upholds a major philosophy and goal of the organization, the promotion of exclusive breastfeeding. HIV intimately connects to this goal: "We use the evidence there to show that exclusive breastfeeding makes a big difference and that the research on HIV particularly shows how anything but breast milk can damage the gut and therefore HIV can enter."

I was also reminded that in order to re-establish the human milk bank it is *necessary* to keep on top of information on HIV because, as a Breastfeeding Matters representative emphasized "it was HIV that did the human milk bank in." As a result, Breastfeeding Matters

follows information on HIV and is weary of the ways that “breastfeeding can be undermined”.

Breastfeeding Matters also employs HIV research to question the dominant popular infant feeding construction of “women producing human milk for their own babies with no alternatives for their babies other than formula.” In the Canadian Guidelines and in Saskatoon, as we will see, breastfeeding is contraindicated for women with HIV; replacement feeding (infant formula) is recommended instead. In contrast, Breastfeeding Matters cites research suggesting breast milk can be successfully and safely pasteurized to eliminate HIV². This organization subsequently raises the question: “why should we stop women from expressing milk and pasteurizing it before giving it to their babies?” While Breastfeeding Matters seems open to exploring pasteurization of milk of mothers with HIV, they do not seem to be advocating for this route. They are interested more in the idea that women with HIV could use breast milk donations instead of formula if a human milk bank was available.

To elaborate, with a secure milk bank, women who cannot breastfeed or advised against breastfeeding, or are not allowed to breastfeed will still be able to exercise their right by giving their baby donor breast milk. Then, from Breastfeeding Matters’ perspective, they can “ethically” promote breastfeeding as a right for every woman. At the present, the right to breastfeed exists but cannot be exercised.

Notably, the breastfeeding groups differ in their breastfeeding promotion. In order to maintain professional status as lactation consultants, staff at the Breastfeeding Centre must keep up to date on HIV and infant feeding information:

As board certified lactation consultants working in the Breastfeeding Centre, we are required by our organization to maintain certification. And so, what that involves is the accumulation of certified education hours. We have to have 75 hours every five years of certification in order to be recertified. So that requires a great deal of conferences, a great deal of self-learning; we subscribe to two journals in our breastfeeding centre. We definitely stay current with what the current recommendations are because that is a requirement for our job. ... I did an hour talk on viruses in breast milk and different guidelines around that. And so I did present that information [on HIV] to the staff that was there. We discussed the implications of that for us as lactation consultants. I

²I was directed to two article-actors that illustrate this information:

- 1) Arnold, Lois “Global Health Policies that Support the Use of Banked Donor Milk: a Human Rights Issue” *International Breastfeeding Journal* 26 (1) 2006.
- 2) Coutsoudis, Anna, “Infant Feeding Dilemmas Created by HIV: South African Experiences” *American Society for Nutritional Sciences* 135(4) 2005: 956-959.

wanted them to be aware of this information because it is really difficult for us to say where this will take us, if anywhere. But it is just for us to be aware, because this is new research.

Rather than promoting breastfeeding as a human right, this centre turns to the medical-scientific institution—as represented in “the latest research”—to support why breastfeeding should be followed as a maternal practice. Unlike Breastfeeding Matters, the Breastfeeding Centre is part of the SHR. Within the SHR health rubric lactation consultants turn to the latest research because they are specialized health professionals, often nurses, trained to support mothers who are breastfeeding.

The Breastfeeding Centre’s affiliation with the SHR illustrates and supports what Bernice Hausman (2003), Jacquelyn Litt (2000) and Rima Apple (1987) describe as the phenomenon of the medicalization of infant feeding. I will come back to this point when I explore medicalization in the next chapter. Through the health affiliation, the agenda of the Breastfeeding Centre becomes promoting breastfeeding as the *healthiest* nutritional infant feeding option for babies reflecting its position within the medical institution.

While the Breastfeeding Centre and Breastfeeding Matters have distinct differences in their approaches to breastfeeding promotion and in their reasons behind their interests in HIV research, they do share a common agenda: the promotion and support of breastfeeding. This agenda unifies the breastfeeding referral cluster. Information related to breastfeeding promotion, breastfeeding support, breastfeeding as a human right, and exclusive breastfeeding would interest all of these groups.

Conversely, the IDD is interested mostly—if not strictly— with the HIV half of the HIV and breastfeeding equation. Within the SHR, the IDD is composed of infectious disease specialists. These specialists are physicians who narrow their focus but deepen their medical knowledge and expertise around communicable diseases like HIV and Hepatitis. A mother seeking information about infant feeding from the IDD would be seeing an HIV specialist who has then further specialized in pediatrics. Even within the IDD, knowledge on HIV is compartmentalized. Like lactation consultants, HIV and pediatric HIV specialists are tasked with knowing and advising patients around their *specific* specialty. Consider the response of one HIV specialist after I asked about how they look for information about HIV:

I must say I don’t as a general rule look out for nutritional issues because I am not a gastroenterologist so I don’t do that. However, if it’s anything to do with improving the health of the child or preventing transmission those titles would certainly grab my attention.

What the HIV specialists do is concern themselves with the specific area of controlling and preventing HIV transmission:

[Regarding HIV transmission] for the first six weeks after birth for the first six weeks, our own statistics in Saskatchewan is zero transmission so far. The going rate across North America across Canada is two per cent. In the last 12 years I've had something like 42-45 infant-mother pairs. So the cases we've known about, is so far zero. ...So, should I concentrate on pushing no breastfeeding? Do I feel like I want to increase my transmission? No. And it's zero in the sense that I only have 42 pairs and if you say it's two per cent than 1/100 is less than zero- so zero might look better than it is. The average, going across- is less 2%. What's 2 % of 40 cases? So I should have zero, a less than 2 percent rate.

Because of the referral cluster, women with HIV are treated specifically for their HIV and not with consideration for their infant feeding preferences (if any). The Westside Clinic and HMHB will be passing on information reflecting this HIV focus to their clients. Vivid in this specialist's comments is the medical rhetoric around risk mitigation. Interestingly risk rhetoric is also present in the support Breastfeeding Matters offers for pasteurization of milk as an alternative to formula feeding:

Many women, for many reasons like sexual harassment, breast reductions and possibly HIV—where the physician is saying that breastfeeding is a contraindication—would find that that option is not there for them [to breast feed] and that the other option is formula. And formula has a whole range of risks attached to it and not breastfeeding has a whole range of risks attached to it.

The risk rhetoric used here suggests that Breastfeeding Matters and the IDD are upholding their commitment to their specialist/organization agendas, with a shared moral responsibility for controlling specific but different unhealthy risk behaviours as determined by different “expert” knowledge.

Social scientists writing on risk rhetoric have extensively illustrated the ways culturally constructed risk categories often emerge around specific people who are associated with culturally constructed “risky” behaviours and ethnicities (Hausman 2003; Malacrida 2002 etc). Other writers like Mary Douglas (1992) and Deborah Lupton (1994) have outlined how a system of ‘blaming’ shapes around these socially constructed risk categories.

For instance, Lupton argues that “the opportunity to blame others for their misfortune occasioned by risk discourse serves to ensure social conformity, acting as a technique of

coercion and legitimating moral principles” (1994: 136-7). In the case of women with HIV, infant feeding is the behaviour in question of regulation; blame is attributed to the person or people not controlling the way the baby is fed. The expert is the one establishing guidelines against which acceptable feeding is measured. From this angle, both Breastfeeding Matters and the HIV specialist are experts.

As Douglas explains “blaming” acts as a gatekeeper for institutions and organizations, whereby information passes only when it is “wearing a badge of loyalty to the particular political regime which the person supports” (Douglas: 19). Thus, risk is constructed differently by different groups of people separating ‘public’ perception of risk from that of the ‘experts’ (Douglas: 11). This suggests that breastfeeding groups, according to their agendas, will pay special attention to knowledge that wears a badge of loyalty to breastfeeding, while the Infectious Diseases Department will champion information favouring a zero transmission rate. In the next section, I illustrate whether or not Douglas’s suggestion bears truth in Saskatoon.

Observation #3: Almost all of the Actors in this Knowledge-Flow Diagram Connect with ‘Articles’—the ‘Biggest’ of the Key Actors

What variation of the Canadian guideline on breastfeeding develops in each cluster and why? In this section I will illustrate that every human actor is connected to different article-actors that in some cases become shared within a referral cluster. I argue that both the agenda and search method used in each cluster are reflected in the kinds of article-actors being connected with.

Different Actors Link to Different Nonhuman Actors

Medical and health institutions are so big that the tendency is to compartmentalize people into specialties and disciplines. Following this compartmentalization, knowledge is streamlined and separated by subject, topic and category. Thus, every discipline has its own reference books. HIV specialists, lactation consultants, and midwives each named a specific textbook they would go to first for information about HIV and infant feeding. None of these textbooks were the same and all of them concentrated on a separate specialty. One HIV specialist from the IDD selects “*Harrison’s Textbook of Internal Medicine, 16th Edition*, pg.

1082 part 6, chapter 173, introductory part.” A midwife³ chose either the *Miles Textbook for Midwives* 14th edition, or the 2003 *Midwives Handbook*.

Importantly, the Positive Living Program uses an HIV protocol manual that acts as a “textbook.” Under the section “HIV and breastfeeding” the only information listed is the name of an HIV specialist I interviewed. This person is referenced as holding the hospital recommendations on HIV and breastfeeding. This reference book suggests that an HIV specialist is a central human actor in one of the referral clusters through which HIV and infant-feeding knowledge sharing occurs in Saskatoon.

Where does this specialist’s knowledge come from? In the health institution, in addition to specialized textbooks, there are specialized websites. For example, the HIV specialist referenced to in the manual, drew heavily from one website, the National Institute of Health (NIH) AIDS information site. As I was told, all of the drug dosages that are used in the HIV protocols in the IDD come from this one internet site. During my conversation with this specialist, I learned that the medical knowledge in these sites is specific and compartmentalized for HIV. For example, the HIV specialist remarks that the NIH AIDS information website displays, “a really small section on nutritional aspects” because “that’s not necessarily an HIV-specific issue, a part from transmission through breast milk.”

The Breastfeeding Centre, integrated into the SHR health institution similarly reflects a loyalty to following breastfeeding-specific knowledge. They subscribe to the *Academy of Breastfeeding Medicine Journal* and *Human Lactation*. These journals are unsurprisingly different from the ones that an HIV specialist listed as the key journals the IDD subscribes to:

I get *Journal of New England Medicine*; *Clinical Infectious Diseases*; *Known Infectious Diseases* and a few others. There’s some Canadian stuff too like the *Canadian Medical Association Journal*. I follow the AIDS journals; *AIDS*, *Lancet*, not so much *Lancet*, *Journal of AIDS*, *AIDS* (basic science) *Clinical Care*...

³ I contacted a midwife because I wanted to know whether pregnant women with HIV in Saskatoon seek care from midwives. In Saskatchewan, midwifery is illegal. There are only a few practicing midwives available. I learned from one of these women that no, there had not been any instances where HIV had come up. All of the referrals she gave sent me outside of the network of actors I had been introduced to. There was one small connection; this person mentioned talking with a doctor at the Westside Clinic who was supportive of midwifery. The midwife was therefore an actor but not a key part of the web. I did find out that the effect of medical specialization is very evident in this group. Midwives are taught to be resourceful and research their own information. I was therefore directed to predominantly other midwives, midwifery networks and textbooks, thus I include an example of this above.

Because of specialization and knowledge funnelling, many actors are reading different and specific journals, textbooks and websites and connecting with different non-human article actors. Not bound by a health institution Moms for Milk, Breastfeeding Matters and AIDS Saskatoon are not limited by institutional knowledge requirements and compartmentalization of their professional specializations in health care in Saskatoon. However, as I will now illustrate, knowledge is filtered mechanically as much as it is philosophically.

Searching: a Filtering Process

I learned from a physician at the Westside Clinic that doctors in searching for articles, often call on health librarians for assistance. This suggested that perhaps the HIV specialist is not the only actor in the centre of the referral cluster. I was told that librarians, who are adept at finding articles through trained search techniques, are a great resource for physicians who are too busy to run their own searches or unfamiliar with databases. I interviewed four health librarians working in the city to understand more about what is involved in searching and sifting through medical articles and how this process impacts on what people read or don't read.

During the interviews I gave the librarians mock search titles "HIV and breastfeeding" and "HIV and infant feeding" that they could use to take me through the steps of searching a topic for a physician. I learned that performing a search can be more specific than simply typing in key word searches. Typically, physicians are given a form to fill in. This form guides librarians in picking and choosing relevant articles to send back to a physician. The form is broken down into, "contact information"; "purpose of research" from "patient care" to "personal" etc (you can tick multiple boxes); "limits" in which you can limit by "sex", or "review articles only"; "age groups" where you specify from a list the age of the people you are researching; "years to be searched" where you specify the range of the article publication dates you are interested in and "search request" where you state the question or topic you are interested in researching⁴. This form suggests that before typing any words into

⁴I acquired one of these sheets in time to give to an HIV specialist. Time did not permit, but an interesting activity would be to give a physician completed form to a number of different librarians and compare the articles that they find in the end. This exercise would illustrate the way knowledge is filtered electronically, mechanically and personally through databases and word searches.

a database, a physician's search is filtered. In order to find information on a precise topic, its specifications must be stated and a question posed.

Two librarians talked to me about how to formulate 'search questions'. The librarians I talked with referred to the "PICO" method. PICO stands for *population, intervention, comparison and outcome*. Librarians ask doctors questions around these four categories to understand what to look for.

Database searches started to look like the sorting of water that occurs when it is being rushed through a canal that is riddled with gates and channels and side passages. At the other end, there are different amounts and stains of water based on the pathways the water is forced to take. As I was shown, even the database itself adds its own gates through customized searching templates and thus the avenues for searching vary. When using MEDLINE, for example, you have the option of expanding your keyword search to look for all of the related terms under that tree; this is called "exploding" a term. You can run a "Core Clinical Journals" search to locate only articles that are part of a set list determined by the Abridged Index Medicus⁵. MEDLINE also publishes its own search terms, called MeSH terms, or Medical Subject Headings. MeSH essentially illustrate that information is filtered even before it is accessible, and sorted through a database because it needs to be classified and labelled by a person, an indexer, or even a scientist first. One of the librarians explained that a committee at the National Library of Medicine determines these new search words publishing them in a newsletter.

Following a database search, the health librarians then have to choose "good" articles to send back for review. I gathered that between 20 and 40 articles is an acceptable number. When choosing these articles, some librarians employ—and strictly abide by—a hierarchy of knowledge that suggests some articles are worth sending more than others:

⁵ From the summer to fall 2007, I tried to find out the criteria used to select the core clinical journals. I contacted the National Library of Medicine a number of times. I received the following response from the Head of the Indexing Section; *I'm very sorry not to be of help, but I did already check with my management and others about this matter. The core list was selected long ago, and there is no record or memory of the exact process. Our users seem entirely satisfied with the existing list (Fri Oct 12, 2007)*. Out of interest, with the purposes of illustrating how "limits" and database templates alter literature search results, I determined which articles were most cited within a search on HIV and breastfeeding. From this search, I took the most cited articles and looked at which journals they were published in. I marked all of the articles that would not appear after running a "core clinical journals" search. The journal "AIDS" is not on the "core clinical journals" list and therefore does not appear in a search that uses this limit. This would eliminate a number of frequently cited journals, and part of the research story related to HIV and breastfeeding.

I would look for things called overview articles. So those are things that would include but are not limited to systematic reviews. ... You are basically doing evidence-based medicine literature searches and your gold level is your systematic review. Clinical trials all fall underneath there, human clinical trials but not animals and I will just [clicks something on a website]... so that's your quantitative model. You're not really looking at qualitative articles, so that's what I would find out first, what he wanted, date range, what level of evidence, those are two big ones.

Preference for systematic reviews is part of an emerging phenomenon within medicine whereby evidenced-based medicine (EBM) drives patient care. EBM urges physicians to look at the latest information, and not just textbooks, for information on how to treat patients. Librarians are becoming even more useful. One librarian remarked that the use of librarians in an EBM context was an argument made to justify employing librarians at a medical school this person used to work at.

Because of EBM and article-type preferences some articles on HIV and breastfeeding might circulate amongst breastfeeding groups whereas they wouldn't even be sent to HIV specialists. The breastfeeding groups, as I will soon discuss, do not illustrate any preference for Randomized Control Trials. Going back to the introduction, there is only one RCT measuring HIV transmission through breastfeeding. Health librarians would have broaden their search parameters if they want to find more than this single study, but this preference still illustrates how knowledge is filtered.

Based on all the possible avenues for searching, it is not surprising that two librarians can yield different results for the same search. One librarian stressed that even one decision about whether to “explode”⁶ a search term can result in the difference between finding 12 or 212 articles.

I learned that health librarians are aware of the subjectivity inherent in their searches and the role they play in finding the ‘right’ information. Gesturing towards the computer screen while scrolling down a list of article titles, one of the librarians reflects this awareness by pointing out their lack of “expert” physician status:

Again, a lot of these articles are not based in North America, but I would include it anyways. And so, I don't know—and I'm not the physician—so that's the point where I know that I am going to send it to them. This is a research evaluation study, it's probably not the highest level, but I'll

⁶Exploding a term, as it was explained to me refers to when a search looks for a term and checks off anything under the tree. So if you put in HIV, to explode the term would be to look at all of the related terms to do with for example physiology, transmission, different meanings of HIV.

probably send it to them. This one is on certain drugs stopping mother-to-child transmission, that sounds pretty relevant and it's a comparison. ... Actually it is a Randomized Control Trial so it sounds like it's pretty bang on, so I would send that to them as well.

References to how the librarians were not physicians came up a number of times with most if not all of the librarians. One way of mitigating this lack of expertise, is by keeping open communication with the expert. Sometimes the list of 20-40 articles will go back and forth between the physician and the librarian a number of times until the search brings up information the doctor finds relevant. Some searches can take up to eight hours to complete, others only one. Health searches are a filtration process.

Overall EBM underlines that while a physician might be the person named as the centre of a referral cluster there is invisible work that occurs around this actor keeping them in this position. Actor networks that look for nonhuman and human actors like this one, suggest that the NIH website, the articles sent to the physician by librarians, and the librarians themselves are all integrated into the centre of the referral cluster and act on the physician. In this case, however, the HIV-specialist listed in the HIV protocol manual explained that they conduct all their own literature searches and does not use librarians. Regardless, many physicians do.

Within the breastfeeding groups, Moms for Milk has some filtering influences comparable to those of the librarians. Over the phone I listened as this person explained how articles are located and selected for the mailing list;

I don't really go looking for them. I have Google News Alert set up for "breastfeeding" and "breastmilk", "breastfeeding + Canada" and "infant formula." Those are my keywords that I stick to. So if it hits the Canadian media then often I would send that to *Breastfeeding Canada News* [the listserv]. If I had the time I would go back, and research back to that article and find it in the journal, find the link and do the leg work for the health professionals. And I would also monitor Lacnet [a breastfeeding chat room predominantly used by professionals] because there the professionals are talking about that study and they are discussing how strong it is, and what are the holes in it and what are the other considerations. I would take that and summarize that and put it in a full package and send it to *Breastfeeding Canada News*. So when the media coverage comes out they also have the original article and some of the things to consider when assessing how important this study is and conveying that information back to their clients or their peers who may be discussing that same study.

Later in an e-mail, this person mentioned that after checking back through *Breastfeeding Canada News* they got 29 hits for HIV and breastfeeding, which means at least 29 articles on this subject, have been sent to the people on the list serve. Evidently, these searches are less stringent when it comes to filtering by article type in comparison to health librarian searches. However, this listserv is provided on a volunteer basis only. The person behind the list serve is sending out information because they have a passion for promoting breastfeeding. Thus, sometimes this person found themselves filtering some information based on content preference:

The thing I do have to admit to is that I probably do have some bias in what I send out. I am a big supporter of breastfeeding and my personal bias to like- Well I know about the author Anna Coutsooudis. To me that was really profound and it struck me that we don't have the answers on this [HIV transmission through breastfeeding]. I would rather air on the side of breastfeeding if we don't have the answers. So if there was ... something negative toward breastfeeding then I would forget to forward that thing or I would be too busy to forward that thing on.

Here the agenda of this grassroots organization is evident. Breastfeeding is every woman and infant's right and women should have all of the information on this subject. Because the risk of HIV transmission is not 100 per cent guaranteed, breastfeeding, in this person's eyes, is still an option. At the very least, the strong feelings this person has for breastfeeding is enough to consider all sides of the research. The perspective of this person is different from the stance the Breastfeeding Clinic is *allowed* to take. This group is bound by the medical guidelines established by the Canadian Pediatrics Society and the Dietician's of Canada as per their affiliation with the SHR. They cannot advocate for both sides of this research; they can only be aware of them. The agenda of Moms for Milk is evidently not rooted in a desire to promote breastfeeding from a medical standpoint. In further conversation with Moms for Milk we discussed about how, if this person was paid for the service they provide, they would be obligated to send out information on both sides of the HIV and infant feeding "debate." As a volunteer, who searches and sends exciting information that supports breastfeeding as part of a passion and a hobby, this person is not obligated to send *everything* they find.

Like the health librarians, Moms for Milk illustrates the behind the scenes mechanics of knowledge flows. The articles sent and the person that selects them is as important as the ones that deliver and analyze the messages tied into this process.

There are Common Nonhuman Actors Being Shared Within Referral Clusters

Reflecting the mechanics of referral systems, in particular the links that exist between the breastfeeding groups through the *Breastfeeding News Canada* listserv, a particular author appeared in this cluster. All of the breastfeeding groups named scientific author Anna Coutsooudis as a resource for information on breastfeeding and HIV. Infectious Disease Department HIV specialists did not mention this author once.

Breastfeeding Matters follows this author because her work reflects a shared goal noting that, “I was just interested in the exclusive breastfeeding period.” For the Vancouver Milk Bank, Coutsooudis’ studies represent important research that should be followed up on. She writes, “I do think we need more research, so that we feel that we are really giving that woman an informed choice on how she should feed her baby.” This person also told me about how Coutsooudis has an orphan’s home for six children with HIV. At this orphanage, “she uses pasteurized donor milk with them.” Again, the mandates of this person are reflected in Coutsooudis’ work. As mentioned above, Moms for Milk also favours Coutsooudis’ work, given that this author indicates breastfeeding could be possible in some exclusive breastfeeding/pasteurization contexts.

Given the ties within the breastfeeding groups, we can understand why they share a common knowledge of Anna Coutsooudis’ work. Why isn’t her work mentioned in any of the conversations I had with the IDD? If we recall, going back to one of the HIV-specialists comments I include earlier in this chapter, the specific journals followed and shared amongst HIV specialists does not really include the *Lancet*, the journal that published Coutsooudis’ most popular works⁷. Again, we see the effect of the specialization of knowledge within medical institutions. For Breastfeeding Matters and Moms for Milk, whether Coutsooudis publishes in the *Lancet* or in *Time Magazine* her work will be considered significant because it is useful for the purposes of promoting breastfeeding as every woman’s right.

⁷In June 2007 I conducted a MEDLINE OVID search on HIV + Breastfeeding. I determined a list of “key article actors” within the search by (1) counting the number of times an author published an article in that particular search, and (2) looking up the statistics on how many times every article in the search was cited. It turned out that Coutsooudis was amongst the top five authors with the most number of articles published and cited. I noticed that most of her most cited articles were all printed in the *Lancet*.

Conclusion

I have illustrated that there are distinct referral clusters in Saskatoon and that they circulate specialized and less-specialized information about HIV and breastfeeding. The question remains, how does this knowledge filter into a recommendation? As I pointed out earlier, one specialist in particular is positioned in the centre of one cluster, and *Breastfeeding Canada News* supplies information that is commonly shared among the breastfeeding groups. In one cluster, we have groups who connect with a set of institutionally established guidelines determined by the HIV specialist. In the other, we should expect some flexibility in these guidelines, given that at least two of the organizations are not constricted by the compartmentalization of knowledge associated with being affiliated with a health institution.

In line with these expectations, the IDD HIV specialists have developed a variation of the Canadian “recommendation” for infant feeding that is less forgiving and stricter. Together the HIV specialists and nurses at the Positive Living Program decided over the summer I started my fieldwork, to change the Canadian guideline on infant feeding and HIV from “recommended not to breastfeed” to “no breastfeeding.” The HIV specialist from the policy manual provided me with the reasoning behind this change, highlighting the agenda of zero HIV transmission:

Obviously if the nurses see that “no breastfeeding” order and the mother says, “I’m going to breastfeed” then you know the nurses are going to call somebody and say “hey you know it’s contravening this order we need to do something about it.” Whereas, if it’s “not recommended,” then it leaves some room for manoeuvre. Whether somebody would actually notice it, [the change in policy] and whether somebody from La Leche League will say, “what are they doing?”—I would like to see them fight me about the HIV story because one thing trumps the other. It’s only for babies of women who are confirmed to have HIV, or about to be confirmed, or about to rule out HIV that would apply to that scenario. The moment a woman is proven not to have HIV those orders are null and void.

The information given out by the Westside Clinic, EGADZ, AIDS Saskatoon, and HMHB will soon be “no breastfeeding.” This stricter policy reflects an “HIV trumps all” agenda. I argue that this may result from institutional and mechanical compartmentalizing of knowledge in medicine and the fact that specialists are not reading about the effect different modes of breastfeeding have on HIV transmission. This HIV focus also reflects their mandate to stop HIV transmission at all cost.

This specialization may also explain why conversely, groups like Breastfeeding Matters and Moms for Milk, who are not bound by compartmentalized knowledge, are very familiar with research on HIV, which is technically outside of their “field.” Hence, Breastfeeding Matters from its position outside Saskatoon’s Public Health Agency expresses a more-flexible variation of the Canadian guideline on HIV and breastfeeding:

Canada as a developed country hasn’t gone that route [of promoting exclusive breastfeeding for women with HIV] and has suggested that HIV women not breastfeed. On the other hand we know that if there is HIV in breast milk it can be pasteurized. Why should we stop women from expressing milk and pasteurizing it and giving it to their babies? And that’s what we would promote if we came across any cases; to stay within the guidelines of Canada but let women know the information so they can make their own choices.

The gap between the referral clusters that separates communication between IDD and Breastfeeding Matters can evidently have significant consequences. Social services might become involved at the probable expense of the mother if the breastfeeding group were to recommend pasteurization or exclusive breastfeeding. I look more closely at these implications and the significance of opposing variations of infant feeding guidelines for women with HIV in the next chapter. Evidently, the clusters and the knowledge circulating within these patterns are separated by mechanical filtration processes and by institutional/organizational agenda focuses. A communication bridge between at least Breastfeeding Matters and the IDD would open the floodgate separating these two referral clusters in Saskatoon. This would allow each group to understand the other’s point of view and allow for a more complete understanding of HIV and breastfeeding issues to be.

Importantly, with the exception of AIDS Saskatoon staffers who list social scientists among resources they would contact if asked about HIV and breastfeeding, most of the information that is circulated and put into use in Saskatoon is written by scientists, physicians and clinical researchers. The variations of the Canadian Guidelines on breastfeeding and HIV are both derived through this close bond between human actors and article actors. In Chapter 4 I take up this observation and evaluate the implications it has for supporting the conceptualization of articles as actors. Before this, in Chapter 3, I look at how the variations of the Canadian guideline for infant feeding in the presence of HIV, when analyzed for good mothering discourses, paradoxically frames women as both good and bad mothers.

CHAPTER 3: GOOD AND BAD MOTHERING AND INFANT FEEDING RECOMMENDATIONS FOR WOMEN WITH HIV IN SASKATOON

In the summer of 2007, Child Hunger Education Program (CHEP) published a study on infant feeding methods and challenges in Saskatoon (Partyka and Grunerud 2007). CHEP is a community-based organization in the city that advocates for food security for infants and children. In the study, interviews were held with 81 women, key stakeholders and focus groups to understand the infant feeding challenges facing women in the city. When I interviewed two people about this study I learned a bit more about the infant feeding culture that exists in Saskatoon:

I think one of the things you could infer from the high initiation rate [85 per cent]⁸ is that most people know that “breast is best.” Maybe everyone knows that “breast is best” and there should be a way between knowing that “breast is best” and feeling like “breast is the only option” and that if you don’t breast feed your baby you are somehow inferior. There is a difference between “oh you should breastfeed your baby” and “oh you should breastfeed your baby you’re a bad mom” and I think that that’s what Saskatoon needs to balance.

Feminist writing on women’s experiences negotiating medical knowledge about childbirth, reproduction and childcare highlight that the choices women make for their children become subject to a set of moral discourses about “good” and “bad” mothering (Craig and Scambler 2005; Mitchell 1998; Rapp 1998; Lock 1998; Tapias 2006; Blum 1987, 1999; Knaak 2005; Apple 2006).

I noted in Chapter 2 that the Infectious Diseases Department in Saskatoon has changed its policy from a “recommendation” that women who are HIV positive not to breastfeed to simply “no” breastfeeding. Formula feeding is the infant feeding alternative specified. But in Saskatoon, as the person from CHEP highlights, “most people know that

⁸ CHEP shared this statistic with me during our interview; it is not included in the actual 2007 report. The staff at CHEP calculated this statistic after the publication of the report and included it in their follow up presentation. The statistic reflects the number of women who initiated breastfeeding not how many breastfed past nine months, this statistic is much lower (37%).

'breast is best'." This context raises the question: What kind of "good" and "bad" mothering discourses relate to women with HIV who "choose" to formula feed their baby in Saskatoon?

In this chapter, I illustrate the different perspectives health care professionals and people working in the community have of the experience faced by women with HIV who are told that they cannot breastfeed. I contextualize the perspectives shared with me in literature on the medicalization of infant feeding, reproduction and childcare. I illustrate how, as a result of being medical subjects and mothers, competing good mothering and medicalized discourses take shape around women with HIV who are following the medical guideline to formula feed their babies in Saskatoon. I argue that from within this tension zone, the challenges women with HIV face when trying to uphold the medical recommendation for infant feeding is going unheard.

HIV in Saskatoon: The Latest Trends

In this thesis, I refer to good and bad mothering *discourses*. I take discourses to be "a specific series of representations, practices and performances through which meanings are produced connected into networks and legitimized" (Johnston, Gregory, Pratt and Watt 2000: 180). Here meanings are produced out of the interaction between symbolic processes like power and ideology with human social practices (Levinson and Ember 1996: 351). Before looking at good/ bad mothering discourses around women with HIV who are formula feeding, I start by exploring how these discourses figure around women with HIV who are *not* infant feeding.

In conversation with AIDS Saskatoon, I found out about the "recent trend" of HIV infection in the city. I was told that there are "young women under the age of 18, who are HIV positive and finding out through getting pregnancy tests." As I indicated in the introduction, the Positive Living Program told me the same. Later in my interview with the Positive Living Program I asked about where these patients live or come from. I was told; "we've got women from Reserves, we've got women who are aboriginal and living off reserve, we've got women from Saskatoon, people who live in small communities, women for whom this is their birth country and women who have immigrated".

I learned more about this trend from a second nurse from the Positive Living Program whose job mostly takes place on the streets in the "core" neighbourhoods of Saskatoon. These "core" areas include the Riversdale and Pleasantville neighbourhoods located on the

city's west side along 20th and extending west. This nurse primarily works with "street health clients" like "injection drug users, people who are in and out of corrections, street youth, at risk youth and women and men in the commercial sex trade". The daily routine includes giving out information on various health topics, testing people for Sexually Transmitted Infections (STI's) like Chlamydia, HIV and Gonorrhoea, and then notifying anyone who tests positive for one or more of these infections. This nurse will also make house calls to patients with HIV to do blood work and collect information on CD4s and viral loads. The nurse also refers and connects patients to the Positive Living Program HIV clinic at RUH.

In our conversation, the nurse explained that in 2005 an "HIV cluster" was discovered in the city. Out of this cluster, I was told, the majority of the people with HIV were IV drug users "and a good half of them were women." A physician from the Westside Clinic succinctly told me that HIV has become "a disease of poverty."

From the interviews I had in Saskatoon, I gathered that a typical mother with HIV is either on social assistance or among the working poor. She is young, single, using injection drugs, and is either native, or has immigrated to Canada. Writers looking at good and bad mothering discourses suggest that possessing any of the above traits would qualify a woman as a "bad" mother.

For example, feminist writers have stressed that one of the core assumptions of the "good" mother is that she can only exist within the "two-parent heterosexual family form" as Krista Robson puts it (2005:220; Ladd-Taylor and Umanski 1998). Linda Blum emphasizes that in the 1990s, moral guilt was imposed on single mothers because Western society deemed women disrespectful when deviating from the normative expectation of being married and having children (1999: 159).

Anthropologists and sociologists writing about breastfeeding as a trait of good mothering observe that welfare and working poor mothers are constructed as "bad" mothers. Christina Bobel (2001) underlines the racialized and class-based constructions of the "good" mother in La Leche League International (LLL). She argues that their definition of good mothering assumes "an intact, stable family, preferably supported by a breadwinning father," which excludes single mothers, women receiving federal aid and others who do not fit this mould (2001:146). Conversely, Stephanie Knaak's (2005) research on baby-book explanations on proper infant feeding suggests that "good" mothers don't work, regardless of whether they breastfeed or not (207).

Rebecca Koch et al (1998) argue that poor and homeless women are pitted as bad mothers regardless of breastfeeding and good mothering discourses. These authors remark that permeating all of the stories they heard was “the stink of blame from a society that views poor mothers and their poverty with suspicion and fear” (1998: 62). Blum (1999) on the other hand suggests that black women in the United States have historically been even less “predisposed” to “good mothering” than poor women. She explains that this is because black women have “represented the most essentialized ‘other’ of all groups to white Americans, their sexual and reproductive bodies cast as dangerous and impossible to rehabilitate” (1999: 167-168).

Scholars looking at colonialism and its effect on health illustrate that black women are not the only “others” that have been racially constructed as bad mothers, and as having ‘bad’ mothering practices. Margaret Jolly (1998) argues that although there were several reasons for the decline in population in Fiji and Vanuatu, British colonialists blamed bad mothering practices and the ‘helpless’ and ‘hopeless’ mothers in these places (199). Fijian “ancestral maternities” such as collective responsibility for children, intimacies in breastfeeding, seemingly clandestine nature of birthing and active postures of birthing was observed as deficient and undisciplined forms of mothering (200). Patricia Kaufert and John O’Neil (1990) similarly argue that high infant mortality rates were attributed to Inuit childbirth practices in the Keewatin Region of the Northwest Territories in Canada. These authors underline that infant mortality rates were based on data largely composed of guesswork that consistently overestimated infant deaths in this area and that poor housing, infectious disease, relocation were all transferred onto the body of the Inuit woman (439).

In addition to upholding a racialized, heterosexual, married and class-based construction of the ‘good’ mother, dominant good mothering discourses suggest that “good” mothers “self-sacrifice” and put their children’s needs before their own (Robson 2005; Gottschang 2007; Ladd-Taylor and Umanski 1998). These discourses position mothers who use drugs as bad mothers because, as Margaret Kearney explains, “mothers who smoke crack cocaine are viewed as selfish and uncaring, pursuing their own pleasure while neglecting their children” (1994: 351). Christa Craven (2005) adds that her work emphasizes that drug-addicted mothers are characterized as bad mothers and “pathological criminals” if found using drugs during their pregnancy (203).

Frequently a person from AIDS Saskatoon gives education sessions on HIV at an addictions treatment centre in Saskatoon. During this presentation, one presenter told me,

there is always a debate that stirs when the topic of HIV-transmission through breast milk is raised. Before being able to listen to the details around this subject, the women are confronted by the men in the audience who announce, as this presenter recounted for me “well a woman who is HIV positive should never have kids in the first place because it’s selfish of them to procreate.” Casting some insight on this reaction, Karen Fraser Wyche suggests that these simultaneous identities of drug user, poverty, minority and woman combine to stigmatize and marginalize women with HIV (1998: 176). She suggests that these marginalities fit the public idea of who is “unworthy” and “should” have HIV (176). Regardless, the reaction of the men at the treatment centre highlights that once women become mothers they seemingly join a moral category separate from the rest of society, free for anyone to judge.

Based on the above comments and the literature situating marginalized people in good and bad mothering discourses, we have a sense of where mothers who have HIV “start off” when it comes to being judged as being good and bad mothers. This context is intended to create further understanding of the depth of the good bad mothering discourses that envelope women living with HIV who are formula feeding. What are the additional good and bad mothering discourses that emerge in the dynamics of having HIV and formula feeding in a breastfeeding society? This question will be addressed over the course of looking at the different steps involved in receiving and executing the HIV-specialist’s infant feeding directive not to breastfeed.

‘An Appointment with the Doctor’

As I mentioned in the previous chapter, women with HIV in Saskatoon seek medical advice from AIDS Saskatoon, EGADZ, the Westside Clinic and Healthy Mother Healthy Baby (HMHB). No matter where the woman seeks advice she is inevitably, through the referral cluster, sent to make an appointment with the Positive Living Program at some point over the course of her pregnancy. According to the staff of these organizations, both women and men with HIV have trouble keeping these appointments; there are social and economic barriers that prevent people with HIV from going to see the doctor. The first reason is that the HIV-specialists and the Positive Living Program are located in the Royal University Hospital (RUH), which is far from the downtown core.

The labyrinthine RUH is the biggest hospital in the city and located at the end of the University Bridge leading from 25th Street. My first visit to this hospital I got lost because they were rerouting the main entrance. The old entrance looks more like it is part of the university campus and new entrance is in a huge parking lot. My first impression of RUH was that it was confusing, massive and had inadequate signage.

AIDS Saskatoon reports their clients find hospitals to be very intimidating places, and not just because they are jungles to navigate through. One staff member describes the RUH as “a middle class white hospital,” while most of the people visiting the Positive Living Program are neither white nor middle class. A lot of their aboriginal visitors experience racism in this environment and are reminded of the poverty they live in:

People don't have easy access to having clean clothes. I mean that is why we have a washer and dryer. To get up in the morning and not have clean clothes to put on, I wonder how that would make you feel. It wouldn't make you feel good. So, you feel not clean, you're First Nations, you're hungry but you don't have enough money for food. And, if you are a woman, your hair is kind of, I mean, you haven't had a fresh haircut for a long time. And you know, you are supposed to go trekking off to RUH where people are walking around in business suits and you know, hospital white jackets and you're looking... you know its really difficult.

Because of the intimidation associated with race and class hierarchies that are experienced in hospital settings, many of the people visiting AIDS Saskatoon do not visit RUH unless they absolutely have to.

Another challenge facing patients with HIV who are seeking medical help is the distance to travel to get to RUH. As I mentioned in the previous chapter it would take almost an hour to bike to RUH from AIDS Saskatoon. As I learned, most of the people AIDS Saskatoon sees do not own a bike, have bus passes, or have access to a car; they walk everywhere. This winter, Saskatoon experienced a week where the temperature dropped to -50 centigrade. I cannot imagine biking in this weather let alone walking for an hour. Even finding appropriate winter wear is challenging. Many women with HIV in the city rely on the Salvation Army or the AIDS Saskatoon clothes bins.

AIDS Saskatoon noted that even without this distance to travel some people would downright refuse to go to a hospital. St Paul's for example, is much closer to AIDS Saskatoon. Located at Avenue Q and 20th Street, it is only a ten-minute walk from the

Westside Clinic. As AIDS Saskatoon underlined some people absolutely refuse to go to emergency at St Paul's Hospital because "they feel like they are being looked down on."

There are also logistical challenges in keeping appointments. A person from the Westside Clinic pointed out that finding housing or a baby-sitter are additional factors that prevent some women from making appointments. As a result, the Westside Clinic sees as many drop-in visits as appointments in the run of a day. Emphasizing this point, a nurse remarked that in 20 years of working at the Westside Clinic "we've only had one half day where everybody has showed up to meet the doctor at their appointment". The difference between missed appointments at the Westside Clinic and RUH is that people seem to reschedule or "drop-in" at the Westside Clinic whereas there is a consistent reluctance to follow up with the Positive Living Program. This same nurse explained why she thought this resistance exists:

RUH, or St Paul's – they hate it. Part of the reason we do so much programming out of here, is not because it is better or anything like that but because particularly around HIV and diabetes and some of these things, when you try to bring them to RUH, where they have diabetes and ID specialists, we could just not get them there. We'd take them, we'd go with them one time, but we could just never get them there the second time. We would give them bus passes- we would help them with whatever we could.

Denise Spitzer (2004) would suggest that the Westside Clinic "drop-in" flexibility reflects the Clinic's adaptation to the needs and challenges facing a culturally and economically marginalized demographic. In her article on health care reform in Canada and the impact on minority women she argues that hospital inflexibility in hours of operation and scheduling of appointments are a result of the healthcare system's attempt to normalize "Euro-Canadian values and sensibilities into the 'common sense' operations of the institution" (492). I will come back to this point later in this chapter. I raise this point to underline that because of racism and Euro-Canadian normalization of values and sensibilities in hospitals, the Westside Clinic has become the major health facility supporting a demographic of the city that in some cases is critically ill.

Accordingly, the Infectious Disease Department sends an HIV specialist to the Clinic one a month to visit patients. Staff at the Westside Clinic, knowing which of their patients have HIV, schedule whomever they can find in the waiting room on that day to talk with the

specialist. While I was conducting my interviews, I heard discussions about the IDD increasing these visits to twice a month.

This specialist sees some of the prenatal patients and gives them the appropriate medications they should use. However, reflecting the compartmentalization of knowledge that is characteristic within medicine, there can be multiple specialists even within a specialty of medicine. Unfortunately, not all of the HIV sub-specialists, like the pediatrics HIV specialists, visit the Westside Clinic. Mothers with HIV must then bring both themselves and their infants to RUH for this consultation.

The IDD is evidently aware that patients with HIV dislike or find it challenging to come to the hospital, given their action to send a specialist over to the Westside Clinic. However, missed appointments are sometimes interpreted as a deliberate form of “risky behaviour.” Consider the reasoning a person from the Positive Living Program gives for justifying advocating for one mother to keep her child:

We have advocated for one mom who social services thought should take and that we had seen such an amazing turn around in her that we didn't see a risk. She has actually kept all of her appointments and baby is doing great, and she is doing great.

Note how this comment suggests that if the mother was not keeping her appointments she would be a “risk” to her baby. The street health nurse I talked with similarly underlines the value that is placed on keeping appointments in her description of a ‘successful’ mother with HIV who is able to keep the custody of her children;

You know she has been clean for a long time, she has made all of her appointments and she does have custody of that child. She is working on gaining custody of the older one, which I am pretty sure that she is going to be well on her way. Foster mom supports her and everything, they are really close. But, I think out of six of seven who were pregnant at the same time, she's the only one that I know of who took charge [and got to keep her child].

By listing “being clean” and keeping appointments on the same level, this nurse is characterizing appointment-keeping as a behaviour that is monitored. The implication is that deviance from this behaviour is considered intentional and “bad.” Failing to display good behaviour is interpreted as a deliberate act to put the baby at risk. However, we know based on the comments coming from the professionals in the community that there are social and economic barriers that deter people, not just mothers with HIV, from going to RUH to see

specialists. Would it not be safe to assume that the mother is not *intentionally* trying to put her baby at risk? I will come back to this question.

I found that appointment-keeping was most clearly identified as a behaviour that can be used to judge a woman's mothering capabilities in the criteria used in social worker psycho-social assessments. My initiative to contact a social worker emerged out of a visit with the Positive Living Program. During one of the interviews a nurse went through the statistics on the apprehension of babies from mothers with HIV with me: "I'll tell you from 19 babies that were born from May 2006 to September 25, 2007 was our last pregnancy, so of those- apprehended, apprehended, apprehended, apprehended, apprehended, 10 out of 19, were apprehended". After finding out that over 50 percent of the babies born to mothers with HIV were apprehended I wanted to know more about the process that was involved in determining the "safety" of a mother.

Importantly, there is no HIV-specific social worker working at RUH. Rather the nurses working at the Positive Living Program have added social work-type tasks to their jobs⁹. These jobs include connecting people with the needle exchange van, addressing housing issues, arranging for transportation for their patients coming from out of Saskatoon and who have Treaty status¹⁰, as well as assuring that connections with HIV social workers outside the hospital are made. Whether it is to assist in trying to fill this departmental gap, or whether all mothers with HIV are "high risk," a hospital- based postpartum social worker is automatically assigned to a mother if she has HIV. The in-hospital social worker I interviewed was such postpartum worker.

Because women with HIV typically have Caesarean sections, keeping them in hospital for two or three days after delivery, the postpartum social worker is on a fast track for this short time. Once women are discharged from delivery on the postpartum ward, and out of the hospital, the job of the postpartum social worker is over. In that short window of

⁹ One of the reasons why there is no HIV in-hospital social worker is a result of funding issues. Outside of this, the person I asked from the Positive Living Program was not sure why the hospital has not created this position.

¹⁰ According to the Health Canada website, a person with "Treaty status" is a registered Indian under the *Indian Act*. The Canadian federal government provides "Non-Insured Health Benefits (NIHB) including prescription drugs, over-the-counter medication, medical supplies and equipment, short-term crisis counselling, dental care, vision care, and medical transportation" to registered Indians ("Benefits Information" ...). Under this government health plan, persons with "Treaty status" are provided with ARV's like Zidovudine, and with transportation to the Positive Living Program (Drug Benefit List 2007: 19). This suggests that women with HIV who do *not* have Treaty status may face additional challenges economically than those that do.

time the social worker needs to determine whether or not the baby will be safe with the mother and should be allowed to go home, or whether the child should be recommended for apprehension and referred to Child Services. To assist the postpartum social worker in determining the safety of the child, a psychosocial assessment is conducted with the mother. As the social worker I talked with expresses, a key indicator of the potential a mother has for being “successful” is how well she has kept her appointments:

When I do a psychosocial assessment, I always look at the history. Lots of times it’s a good indicator if a woman has been taking really good care of herself prenatally. She has been taking her own HIV medications as directed, she is taking really good care of herself and seeing the doctors when she is supposed to—that’s usually a good indicator that she will take care of the baby. *But if she hasn’t taken any medications at all and misses most of her doctor’s appointments* then that would be a red flag that she may be *non-compliant* with her baby’s meds. So I look at the history as well and try to gather the history flags [italics added]

In this situation, the postpartum nurse infers that a mother will only do for her child what she will do for herself. The assumption is that if a woman with HIV does not keep her appointments she will not make the effort to keep those of her baby. This psychosocial assessment factors out the economic and social barriers that would deter or *prevent* most people from going to the hospital. An HIV specialist makes a similar assumption when telling me about a case that took place a number of years ago where a mother with HIV decided to breastfeed her child:

As I understand it, she simply expressed her decision to do that—to do alternative and complementary therapy other than conventional therapy for herself too. So there’s a point where she was consistent; she was doing the same things for herself as for her child. There’s no question that she was not wanting to off the child. My child will do as I do.

The above case is the only case I heard of where a mother with HIV was found breastfeeding her child. I was told that it happened around three or four years ago, around 2003. Note how breastfeeding is considered “complementary therapy”. Conventional therapy is evidently defined locally and not internationally because breastfeeding in the presence of HIV can be conventional in other parts of the world. Chapter 2 of this thesis suggests that breastfeeding is not conventional in Saskatoon because HIV ‘trumps breastfeeding’ in this city. If the mother had not been giving herself “complementary therapy” breastfeeding would have been

viewed as deviant behaviour. This suggests that some of the specialists have a limited understanding of the reasons why some mothers want to breastfeed.

Notably, physicians did not question this mother's status as a "good" mother. Social Services were not contacted; the "behaviour" she imposed on her baby was consistent with what she imposed on herself. But as the literature I included earlier in this chapter indicates, one of the fundamental values of "good mothering" assumes that "good" mothers will self-sacrifice and put her children's needs before her own: a value that *expects* inconsistent behaviour. While the good mothering discourse on selflessness establishes some impossible mothering standards, it gives the benefit of the doubt to all mothers; all mothers have the potential to be selfless. This discourse suggests that if the mother with HIV is a "good" mother, even if she could not make her own appointments, she will surely go out of the way to make the ones for her baby. In practice here, the physicians and the social workers do not give this benefit of the doubt. For the nurses, the benefit of the doubt that she is not making her appointments because of social and economic barriers is missing. Why is there no room for doubt and for seeing the economic and social barriers that are facing women with HIV?

Literature on the medicalization of reproduction and childbirth provides some insight into the reasons behind the contrasting expectations of the physician and the good mothering discourse on "self-sacrifice" around appointment-keeping. This literature highlights that because of medicalization during pregnancy, reproduction and childbirth women's actions are placed under medical scrutiny. The question to keep in mind is: "At which point do physicians, nurses and social workers see women with HIV as pregnant women and mothers that need to be managed or as medical subjects that need to be managed, or both?"

In North America, "medicalization" has traditionally described processes where "medicine" (as an institution and system/body of knowledge) incorporates more and more aspects of everyday life under medical scrutiny, dominance and surveillance (Zola 1986; Conrad 1992). Problems in these everyday areas are defined in medical terms using medical language, adopting a medical framework for solving issues in these everyday areas (Conrad 1992: 211). Irving Zola for example, names reproduction as the best illustration of the "medicalizing of society" and medical expansion over everyday life (1986: 519). He points out how it was not so long ago that "virtually all births and the concomitants of birth occurred outside the hospital as well as outside medical supervision" (1986: 519).

Stemming from this body of writing is a concept some social sciences writers call "scientific motherhood" (Hausman 2003; Litt 2000; Apple 1987, 2006). The rise of scientific

motherhood is a form of medicalization. Mothering, feeding children, raising children and children's health—once considered “daily life”—have come under medical scrutiny. As historian Rima Apple documents, looking at infant feeding at the turn of the twentieth century, “scientific motherhood increasingly emphasized the importance of scientific and medical expertise to the development of proper childrearing techniques” (1999:97). Women's studies writer Bernice Hausman adds that the increased value placed on medical expertise, under the regime of scientific motherhood, “destabilized maternal authority and replaced it with the figure of the doctor” (2006:22). As a result, many of the standards of “good” motherhood evolve out of scientific motherhood and the “crucial” value placed on the relationship between women and their physicians.

Apple and Litt both argue that at the turn of the twentieth century physicians and medical experts were concerned with the spread of disease in order to address astronomical rates of infant mortality and morbidity (2006:6, 2000:22). At the time, infant mortality was closely linked with “erroneous” infant feeding practices, and so physicians sought to control these rates through the control of mothering practices; in particular infant feeding (Apple 2006:166). Central to Apple's arguments is the idea that women's compliance with medicine, including respect and attentiveness to expert advice was key to addressing infant mortality, for as she states, the problem was thought to be linked directly to “maternal ignorance” (38). Litt further emphasizes, “Medical authority was increasingly solidified while mothers' lack of compliance with medical regimes came to be seen as a sign of maternal neglect, even abuse” (2000:35).

Apple supports this idea explaining that medicine and physicians constructed the image of the “good” mother, the “proper” mother, to be “a woman who sought out experts for advice on childrearing and who followed the advice she was given” (9). And, as Litt puts it, “the ideal mother made routine medical visits” (2000:34). The literature on scientific motherhood, therefore suggests that a “good” mother is one who has submitted her mothering practices to medicalization. Thus, by the standards of ‘scientific mothering’, a woman with HIV would be treated as ‘good’ if she attended the appointments she makes, or ones that are made for her. However, are women with HIV only under surveillance for their mothering practices?

One section of literature on the medicalization of reproduction focuses on what Conrad (1992) calls the “fourth category of medicalization”: surveillance (216). This line of thinking draws on concepts like Michel Foucault's concepts of the “medical gaze” and of

“biopower” to explain how medicine exerts a form of social control over certain types of behaviours, like appointment-keeping, causing bodies to become ‘pliant’ to power (Lock and Kaufert 1998; Murphy 2003; Foucault and Sheridan 2003). Medical experts are portrayed as assuming authority and control, and reproductive technologies are viewed as disciplinary tools through which normative mothering practices become created and upheld (Sawicki 1999). This writing emphasizes that those women, marginalized either by race or socially and economically, are more likely to be vulnerable to the power exerted by these reproductive technologies or procedures (Rapp 1998; Mitchell 1998; Martin 1992).

For example, those writing on prenatal genetic testing emphasize that the stories they record are almost exclusively limited to white or middle-class women’s experiences (Britt 2000, Rapp 1998). Margaret Lock’s (1998) examination of women’s experience with genetic testing in Japan, and Rayna Rapp’s (1998) work in East Harlem United States are notable exceptions. Rapp’s work suggests that the lack of prenatal genetic testing on women who are not middle class and white can be attributed to the absence of “respectful health services” available to women when they are from a minority or lower class like the women she interviews in East Harlem (1998:150). Emily Martin (1992) argues that when this lack of respect is transferred into the hospital at the time of delivery in the form of racism, some women like black women or other socially marginalized groups become incapable of resisting procedures like Caesarean sections (C-section) when they are “exerted” upon (1992:40). This literature would suggest that the emphasis placed on women with HIV to keep their appointments is an illustration of the medical exertion of authority over risky marginalized mothers, who are in this case generally aboriginal teen women, single mother or drug users.

Importantly, anthropologists like Victor Turner (2002) and Mary Douglas (2004) have noted that even outside the onset of the “medicalizing of society” pregnancy is a state of transition that attracts intensified social concern that needs to be monitored by society. Turner, drawing on Van Gennep’s earlier work on rites of passage, argues that during periods of “liminality” people find themselves in an “in between” state, slipping through networks of classification that normally locate people in cultural spaces (2002: 359). Turner lists “being in the womb”, as one of these periods of liminality. Pointing at the social control accompanying liminality, he argues that “liminal entities” possess normally passive or humble behaviour and “must obey their instructors implicitly, and accept arbitrary punishment without complaint” (359). For Douglas marginalized states like pregnancy are

dangerous “simply because transition is neither one state nor the next, it is indefinable” and therefore prone to “pollution” (2004: 119). She remarks that when a person is marginal all of the preventative measures against dangers of pollution must come from others (121). In this sense, Douglas and Turner view all medical surveillance over reproduction as extensions of cultural management over liminal rites of passage.

Anthropologist Lisa Mitchell (1998) writes about how certain reproductive technologies manage this “liminal state” of pregnancy¹¹. She argues that ultrasound technology monitors, controls and alters women’s behaviour during pregnancy by visually transforming and personifying the embryo or fetus into an “individual” through the effect of “body permeability”. Mitchell explains, “Even during the earliest routine ultrasounds observed is the image of an idealized infant, rather than that of a fetus or embryo with its distinctive appearance, uncertain subjectivity, and contested personhood” (109). As she puts it, women are monitored for “their own shortcomings-failure to monitor their bodies and behaviour, failure to be compliant and selfless- in short failure to be ‘good mothers’” (112). Importantly, Mitchell’s observations indicate that ultrasounds collapse the liminality around pregnant mothers as much as they serve to uphold it: through ultrasounds, one person is not being viewed as in a bodily state of transition, but rather as two individuals who are then assigned equal value. The mother’s womb and state of liminality have greater visibility and yet become invisible with the focus on the “individual” inside. Mitchell’s observation that reproductive technologies give the fetus status as an individual is essential for understanding the clash between good mothering and scientific good mothering discourses.

Women with HIV have a deadly infectious disease that can be transmitted to their infants before, during and after birth *if it is not controlled*. As we saw in Chapter 2, the HIV-specialist is entirely consumed in controlling and preventing the transmission of HIV. The *pediatrics* HIV-specialist is similarly preoccupied with this goal but with ‘special’ focus on one type of “individual”: the fetus. However, as this specialist pointed out to me, in Canada

¹¹ Within anthropology there is a distinct branch of writing dedicated to medicalization and reproductive technologies under the rubric of “cyborgs” (Dumit and Davis-Floyd 1998).

the fetus is not recognized as having any individual rights¹² “which means you can’t force a C-section on anybody”. If a mother is HIV-positive, she still has the right to refuse the treatment. However, the HIV-specialist cannot even recommend a C-section unless the mother is known to be HIV-positive.

Because of medical specialization of knowledge, the IDD also does not have the right to administer prenatal testing. This is the job of the Obstetrics Department at RUH. The IDD is therefore reliant on obstetricians to locate women with HIV so that they can then do their job. But, in Canada, women must also consent to being tested for HIV. From the perspective of the HIV-specialist I talked with, this test is not offered routinely to every woman as it ought to be. This specialist is frustrated with the lack of initial control they have over their medical specialty. Compartmentalization of knowledge within medicine has its side effects, even for professionals integrated into its structure.

Because the fetus lacks the legal status of ‘individual’, the pediatrics HIV specialist assumes even more responsibility on behalf of the ‘client’ than usual. This person becomes the fetus’ agent and the only paid advocate that exists for this ‘patient’. This means that a mother known to have HIV during pregnancy is doubly monitored for her actions in order to prevent HIV transmission. From this angle, reproductive technologies are used to give agency to the fetus and to the pediatrics HIV specialist; the pediatric HIV specialist’s client, the fetus is given a ‘body’ and the doctor is given a job. While the HIV-specialist cannot force a woman with HIV to do anything when she is pregnant, the risk of HIV is still present after pregnancy when the neonate is now an individual. Unfortunately, because the medical treatment for HIV carries over from pregnancy onto the infant after it is born—for the first six weeks after birth the baby receives a regime of ARVs—a rigorous medicalization of motherhood also becomes justified. Consequently, during pregnancy the woman is evaluated even more than what is otherwise “routine” due to the added evaluation of her potential as a mother who can prevent HIV transmission.

The boundaries between medicalization per se and medical management of HIV are evidently blurry. Importantly, analyses of the medicalization of reproduction and motherhood

¹² On the Supreme Court of Canada website, I found a court case that outlined the rights of the fetus. In the case of a woman that was pregnant for five months and found addicted to glue sniffing, the Supreme Court Judge decided to force this mother into an addictions treatment centre until the birth of her child. This decision was then “set aside” on the grounds of tort law whereby “the law of Canada does not recognize the unborn child as a legal person possessing rights” (Winnipeg Child and Family Services 1997: 3). This law also indicates that “once a child is born, alive and viable, the law may recognize that its existence began before birth for certain limited purposes” (3).

highlight the unreasonable control of medicine over “everyday life” and over mothers. As I illustrated above, these analyses can even bring voice to these mothers. However when the medicalization boundaries are rendered blurry—as they are in the case of women with HIV—it is harder to identify whether the mother’s “behaviours” are being unjustly submitted to medical surveillance, scrutiny and control. This suggests that women/mothers with HIV have even less capacity to resist medical authority and power. I suggest that the high rates of apprehension in Saskatoon from mothers with HIV reflect this compounded vulnerability to medical supervision. A doctor cannot take away the fetus from a woman, but she can remove an infant from its mother. Are all of these apprehensions justified? Because of the blurry boundaries, this justification is ambiguous. The efforts of women with HIV to be “good” mothers are ignored in the name of ‘medical management’ of HIV.

High rates of child apprehension therefore may be one of the reasons why many of the people I talked with working in the community rarely or never received questions about infant feeding in the context of HIV; there are few mothers with HIV asking these questions in the first place.

Following Doctor’s Orders: Let’s go Buy Formula

Once a woman with HIV makes it out of the hospital (and if she has been allowed to keep her child) like all mothers she now has to focus on feeding her baby and keeping it alive. In Chapter 2 I explained that women with HIV are told “no” breastfeeding. In order to maintain her good medical subject status she must comply with this recommendation. No problem, she will just go to the store and pick up some cans of formula and whip the stuff up, simple right? Not at all. One of the major findings of the 2007 CHEP study is that poor women face a pronounced lack of access to baby formula in Saskatoon. Before I spoke with CHEP about its findings, I heard about the lack of access to this resource from HMHB, AIDS Saskatoon and the Westside Clinic. In each interview, I asked where women go to get baby formula in Saskatoon. I was told that they could go to EGADZ, the Salvation Army and to the Saskatoon Food Bank. The Food Bank got the most referrals so I went to have a look.

The Saskatoon Food Bank is located on Avenue C and 20th Street. The building is only a ten-minute walk from the Westside Clinic. I learned in my interview that this facility is the only food bank in Saskatoon and serves 12,000 people from the city and up to a 50 km radius outside of this area. Food hampers are arranged in the following sizes; single for

individuals, small for families of 3-5 people and large for six people and more. The Food Bank is open for pick up Monday to Friday from 8:30 to 11:45, and 12:30 to 3:30. In order to receive a hamper a person must physically produce a health card (it is not enough to memorize the number). Through this system, the Food Bank is able to track and make sure that a person is not coming more than every two weeks. The majority of the people who visit the Food Bank are from the “core” neighbourhoods.

During my interview with the Food Bank, I learned of the extent of the emergency formula shortage in Saskatoon. I was told that quite a few mothers come through the Food Bank looking for food and formula and sometimes, just formula. Because the physical handing out of food operates on a volunteer basis the staffing cannot handle a line-up for only formula. Therefore once a mother has received her hamper, regardless of whether there is formula included, in this package she cannot return for another two weeks. Because of the formula demand, the Food Bank looked into the cost of providing a more reliable source of formula by talking to formula suppliers. I was told that it would cost \$100,000 a year to meet the demand.

Like the rest of the food at the Food Bank, formula is donated. When I visited the Food Bank, I was brought to look at the shelf that holds the formula. That day it was full because a donation had just come through. The person showing me around was shocked and exclaimed, “Usually the shelf is empty, we’ll just have one or two cans and we’ll go through that in a day!”

Through my interviews, I learned that People Living with AIDS does not have free formula; AIDS Saskatoon does occasionally; the Salvation Army will donate only to those who have a social insurance card and who provide their welfare information; and EGADZ offers formula only to those less than 25 years of age. I was therefore not surprised to hear from AIDS Saskatoon that women with HIV immensely appreciate formula it is available to them:

We had eight cans of formula, basic formula I can’t remember the kind. And there’s one mom in particular in here who’s [HIV] positive and who has a little one. [She] was just so ecstatic that we had it, “Can you keep it here? I can’t get it all today, but can you keep it here I’ll come back another day and get the cans when I need them” – she was just floored.

While the awareness of this formula shortage was widespread among the community organizations and the Westside Clinic, this was news for some of the HIV specialists with

whom I spoke. As doctor [name withheld] said, “the ones who have gone on to formula feed have not brought up any specific concerns.” One of the reasons behind this lack of awareness points directly back to the compartmentalization of knowledge. Each physician has his or her own focus:

Obviously if they are not familiar with the formulas, they would have discussed this with their own physicians. We are a consultation service so I don’t actually provide a general pediatric service as well. So they either have their own pediatrician or a family physician who follows them. So I would think that they would discuss those with their own physicians at first and then if they have specific problems they might then forward them to me. But I’ve been lucky in that no one has said that you know I can’t afford it or the child’s not tolerating this particular formula, I haven’t had that in the last ten years.

I find it interesting that the person who would make the infant feeding recommendation would not be aware of the infant feeding challenges facing their patients. The Westside clinic where most of the family physicians for these women with HIV would be located is certainly aware of the challenges facing access to formula. I learned at the Westside Clinic that women with HIV who are on welfare could access a formula feeding supplement if their family physician writes a note stating that she has HIV¹³. In this, the women falling through the cracks are working poor. A person from the Positive Living Program commented to me on this context:

Again it’s the working poor we find often fall in the middle; they aren’t on social assistance but still don’t make enough. What we do then is we don’t say go get this one formula that we recommend, but we make sure they know that you can go get a no-name brand for less. Or, we do also refer them to AIDS Saskatoon. Not always but sometimes they have some money available as a one-time to help people buy formula. Other places? I don’t know if the food bank does or not, and I don’t know specifically any place else. Those are the places that we send people—AIDS Saskatoon and People Living With AIDS.

As I mentioned above, the options to find formula are limited. While the Positive Living Program seems aware of the challenges facing women with HIV in terms of formula access,

¹³ Section 16.2 in the “Social Assistance Policy Manual” supports that with a physician’s recommendation an allowance for special diet is provided, (Saskatchewan Ministry of Health Services 2008: 68). All persons with HIV or AIDS are automatically assigned an extra 140\$ per month for products like “Ensure”, or other dietary needs. However, *children* of women with HIV are treated the same as other infants with mothers on Social Assistance. A mother must submit her receipts, and from the total cost, \$70 is deducted and the rest is refunded. Mothers still have to find a way to pay for the entire cost of formula until they can be refunded.

they are evidently not aware of the extent of these issues, nor where to send people to address them. The difference between the knowledge held in the community organizations and in the hospital is underlined here. We are reminded that while knowledge flow connections might exist in theory they do not always exist in practice.

Time to Feed Baby

Assuming that women with HIV have located formula and are still keen on keeping up their good medical subject status, they should find themselves “over the infant feeding hump” so to speak, right? Wrong. My first experience with giving a baby a bottle of formula was as a volunteer for the “cuddle program” at the RUH. There were only women in this program and I was one of two under the age of 30. I did not grow up around babies so I had never ever given a baby a bottle before. Our job was to provide comfort to babies and infants up to two years of age in the form of holding, feeding, singing and playing. When I was handed the bottle and tried to feed the baby, I realized that there was no food going out of the bottle and into the baby. I asked the nurse and she looked at me with a slightly stunned face and answered, “push the bottle in further, the baby has no latch.” There was an assumption that because I was a woman I should have innate knowledge of how to properly feed a baby—even if I had never fed one in my life. These assumptions, as I learned from my fieldwork, come up again when a woman gives birth to her newborn.

Women with HIV receive minimal instruction on how to feed their babies while in hospital at the RUH. At the Positive Living Program they talk about not putting medicine in bottles because it is harder to know how much of the medication has been taken. They tell mothers not to breastfeed but, as I was told, “we don’t actually go into the “what to feed,” “how to feed,” “what specific brand to feed,” “how much,” “how often,” we leave that to the postpartum nurse.”

I followed up with a postpartum nurse to find out about what information they share with the mothers who have HIV. I met with this person on the 5th floor of the RUH on the postpartum ward. At our meeting, I was handed a green sheet of paper with the words “Formula Feeding and Preparation” on the top. The list includes a chart that illustrates the amount of food and number of feedings that should be given according to a baby’s age. The sheet also contains a list of “equipment” needed. On the back, I found instructions for preparing formula and sterilizing utensils.

Missing from this sheet are diagrams illustrating how to formula feed, an explanation of what sterilizing means, what baby formula is made out of, what kinds of formula are available for purchase outside of the hospital, its cost and where it can be found. After looking at the sheet of paper, I asked the postpartum nurse to take me through the teaching she does with the women she talks with. As her reply illustrates, this teaching is very limited;

Me: Other than the sheet of paper is there anything else that you use?

No our focus here is really on breastfeeding, so these sheets are kept in a drawer so that when a mother decides to bottlefeed. [We give it out] to all of our mothers who are bottle feeding. ... We get them to read it and if they have any questions then ... You see it tells them everything they need to buy, it tells them the amount of the feedings, for how many months and weeks the baby is, and on the back here it tells them how to prepare it, how to sterilize it. Just different notes like that. Basically its pretty self explanatory and if the mother has questions we go back in, after she has had time to read it, and we just say "do you have any questions" and she will answer "yes" or "no" or whatever and then if we need to spend more time we will.

Note how this nurse assumes that all mothers *decide* to use formula. Framing infant feeding practices as being a choice automatically assigns a moral "right" and "wrong" option. This assumption overlooks a category of people who do not have this choice but absorb the moral consequences of whatever option they have been assigned.

The other built-in assumption in the concept of "choice" is the idea that women consciously choose to breastfeed as though they are free of the influence of the Baby-Friendly Initiative, good mothering discourses and the many posters that promote breastfeeding as the best way to feed a baby. The implication that a "choice" occurs during a clear moment of conscious decision blurs all of the day to day negotiations including logistics, health issues, economic and social considerations that legitimately influence on a person's options and *feelings* about those options. These factors and the context of women living with HIV highlight that "choice" is an on-going negotiation, not a time specific decision.

The second assumption this nurse makes, other than how all women should know how to prepare formula, is that all women are literate. In this interview, I was told four times that this handout was "pretty self-explanatory". As a person from EGADZ describes, this not the case with everyone who is given a sheet full of numbers, measurements and specifications;

I had one mom where you could tell there was a significant literacy issue. But she is obviously compensating because when you tell her what the amount is *and show her...* When she was around here, this was probably quite some time ago, she actually etched her plastic cups with two separate marks. She had formula this one, water this one. Obviously she was concerned enough about it that she would never remember it, and so that was her way for compensating and remembering how to do it [italics added for emphasis].

I want to point out that when a woman is uncomfortable, intimidated and vulnerable in a hospital—as I have established is the likely case of a woman with HIV—there is a chance that she will not feel comfortable asking any follow-up questions. In addition, at this time, if she has not yet tried to mix formula, she may not be aware of the challenges she might face. This may be another reason behind the lack of questions some health and community professionals receive for information and clarification on HIV and infant feeding. A postpartum nurse offered me a different explanation:

A lot of the HIV patients that we see here are usually the lower socio-economic scale and they tend a lot to not verbalize that kind of thing to us [concerns over not being able to breastfeed]. They are very umm quiet, and a lot of them are [from the] Aboriginal community and they tend not to question things that happen here. We occasionally get someone that is Caucasian but most of the time it's our Aboriginal community. That's just their culture not to make waves or argue about anything.

While the above nurse recognizes that her Aboriginal patients do not ask questions because (as she assumes) “that’s just their culture”, she further presumes that they will ask her to explain something that they do not understand. Spitzer (2004) would suggest that the Euro-Canadian expectation on “self-reliance and self-care” is being employed in this situation. Evidently, the hospital lacks *useful* resources that can help a woman with HIV comply with her doctor’s orders not to breastfeed. I learned that the public resources outside of the hospital are also lacking.

While talking with HMHB I learned that they organize and teach prenatal classes, for the city. When I asked them to tell me about the formula feeding information covered in the classes they said they give very little detail in compliance with the Baby-Friendly Initiative guidelines adding, “We really have to promote breastfeeding”. This means that they cannot show women how to formula feed in front of others, but they can provide them with help “if

they have specific questions or if they are mentally challenged.” Once again, the onus is on the mother to speak up and ask her questions. Basically, as Healthy and Home clarified for me, with respect to the Baby-Friendly Initiative “formula feeding and breastfeeding are not to be seen as equivalent.”

When I asked HMHB, more questions about formula feeding I was faced with knowledge delegation and my questions about “postpartum care” were redirected to a different program called Healthy and Home. Healthy and Home is a program in the Saskatoon Health Region and is designed to provide postpartum support for mothers once they have left the hospital. Nurses make house calls in order to go over any questions mothers have about postpartum women’s health and infant care. The nurse will visit usually two days after the mother is discharged from hospital and can make a couple of trips if one is not enough. Again, the feeling that expressed to me was that women do not experience any challenges with formula feeding. I was told:

We don’t tend to see as many problems because that’s generally a lot more straight- forward. You know, stick the bottle into the baby’s mouth and he drinks. There aren’t usually any problems.

Whether it is an effect of the Baby-Friendly Initiative or because women are assumed to already know how to give a baby a bottle, there is very little public information that is made available to women who “choose” to formula feed in Saskatoon. Instead, publicly she is reminded that her “choice” for feeding her baby is inferior and bad for her baby. I elaborate on this point in the next section.

Baby’s Fed. Job Well Done, Right?

In Theory

Once a mother with HIV gives her baby formula she will be complying with the IDD recommendation and by medical standards should be considered a good medical subject and by proxy a good mother. However, as I learned in Saskatoon, whether you have HIV or not, if you are formula feeding you are subjected to discourses of “bad” mothering related to your “choice” in infant feeding. Recall the comments that the people from CHEP shared with me from the introduction of this chapter. They felt that most people in the city knew that “breast

is best.” We know from the last section that the Baby-Friendly Hospital Initiative also reminds people inside and outside of the hospital, that formula is not equivalent to breastfeeding.

Inside this message is the implication that there is a danger attached to formula feeding. As Elizabeth Murphy states in her study on population health regulation and the government of women through breastfeeding promotion, “when mothers are warned of the dangers of formula feeding, the implicit message is that the good mother will breast feed” (2003: 438). Through these warnings, breastfeeding is highlighted as a standard of good mothering. Glen Wall (2001) suggests there are multiple discourses of good mothering around breastfeeding, implying that the “dangers” of not breastfeeding are not uniformly defined. She argues that at the heart of infant feeding discourses is the control of mothering, emphasizing that caught up in this rubric are notions of “naturalness and purity of breastfeeding and breast milk but also the scientific and medical colonization of reproduction and child rearing” (2001: 593).

In Saskatoon, several people I talked with indicated that not being able to breastfeed would be hard, pointing at women’s awareness of the different “dangers” of not breastfeeding. However, as I will now illustrate these dangers stem from scientific evidence suggesting that the dominant good mothering discourse around infant feeding in Saskatoon is medicalized.

For example, in Saskatoon even though the specialists said that they had never talked with a woman with HIV who expressed feeling bad about not breastfeeding, they both thought this recommendation would still be a challenge for her. Underlining the effects of the medicalization of infant feeding, one specialist sensed that for these women “it would be very hard” because normally breastfeeding is what is recommended and most people know that. The other specialist elaborated on this point suggesting that because most people know that doctors recommend breastfeeding; “for some [women] it is an impairment of their motherhood if they can’t do for their child what should be done for their child.” Litt (2000) and Apple (1987) both highlight that scientific and medical support for breastfeeding exemplify the medicalization of infant feeding. By extension, this discourse signifies that a scientific “good” mother should breastfeed.

In the community, I was again pointed towards resonances of medicalized discourses around infant feeding. EGADZ has done a lot of work with women who have drug addictions. A person from this organization talked about how, in some situations, these

women are also recommended to not breastfeed and “a lot of times they are upset about it.” This person said that for these women often “they’ve felt that they let that child down,” and fear that they are not going to be able to bond as fast with their child, feeling disappointed in themselves as a result. One HIV-specialist argued that a mother might feel bad depending on how she felt about breastfeeding; “many women like it, it’s a bonding thing.”

Notably, Blum (2001) and Wall (2001) argue good mothering discourses that promote breastfeeding for its important role in mother-child bonding are rooted in scientific evidence. Wall explains that mother-infant bonding research was initiated in the 1970s but it “has since broadened beyond its narrow scientific definition to become deeply embedded in popular constructions of motherhood” (2001: 600). The comments from both the HIV specialist and EGADZ reflect how this scientific research has been fashioned as a standard of a “good” mother.

Outside of these speculations, actors from HMHB, and CHEP also mentioned that they imagined women with HIV would feel guilt over not being able to breastfeed. Unlike EGADZ and the HIV specialists, they did not reference exact reasons why they thought this, other than pointing out that in Saskatoon breastfeeding is so clearly promoted. CHEP for instance emphasized that “if you have visited the postnatal maternity ward at RUH you can see that promotion of breastfeeding is front and centre.” Is this breastfeeding promotion medically based? The posters on the walls of the postpartum ward certainly were. When I interviewed the postpartum nurse I found only posters about breastfeeding on the wall. This infant feeding method was listed as the “normal” way of feeding a child listing all of the negative health side effects of giving a baby formula like increased risk of ear-infection and allergies and poor digestion, allergies, diabetes—all backed up with scientific evidence. Part of my interview with the postpartum nurse took place in front of the biggest poster on this ward, one that indicated how the hospital fared in its initiative to achieve Baby-Friendly certification. Based on the references to the Baby-Friendly Initiative, mother-bonding, and medicine’s support of breastfeeding, in Saskatoon the dominant good mothering discourse on infant feeding appears to be one that is medicalized.

Underlining the presence of scientific evidence-based breastfeeding advocacy in La Leche League promotion, Bernice Hausman (2003) points out what she sees as the dangerous consequences. Hausman writes that dependence on scientific writing “serves to subordinate women’s practices to the paradigm of scientific motherhood, in which mother’s own views and experiences take second place to the advice of (male) experts” (153). Like Hausman, I

also found that the dominance of the medical discourse of breastfeeding indicates that a medicalized discourse of good mothering continues to subordinate women's mothering practices to medicine.

A tension zone appears in the good mothering discourses. Susan Star argues that a tension zone is "the zero point between dichotomies or between great divides: male/female, society/technology, either/or" (1991: 47). Because women with HIV are told to breastfeed *and* not to breastfeed on the grounds of medical scientific evidence they are placed in the middle of the continuum of n/either "good" n/or "bad" mothers.

However, when we are reminded that HIV is an infectious disease that can be transmitted through breast milk this, tension zone highlights once again the ambiguity located in boundaries between medicalization of infant feeding and 'medical management of HIV'. The medical discourse that good mothers breastfeed is in theory dissolved and replaced by medical management. In this case, HIV trumps breastfeeding and a 'good' mother, in the eyes of the scientific medical institution, does not breastfeed.

Importantly social scientists Stephanie Knaak (2005) and Hausman (2003) would argue that the dominance of the medicalized discourse around breastfeeding is reflective of the progressive decline of the promotion of breastfeeding as "natural mothering." Knaak highlights how there was a visible decline in the emphasis on "natural mothering" in Dr. Spock baby books. Up until the early 1990s, "natural mothering" was emphasized in baby books as the number one reason to support breastfeeding when it was then replaced by "baby gets immunities" as Knaak explains (205).

The "danger" of not breastfeeding is different depending on the reasons upholding its promotion. Take La Leche League promotion, again for example. Blum suggests that their philosophy of mothering emphasizes breastfeeding "naturally" fulfils the need of both mother and baby for an intimate, physical relationship (1999: 65). From this angle, Wall suggests, "breast milk, given its status as natural substance, as opposed to an artificial one, is understood to be essentially, and unquestionably, pure and good" (2001: 596). Women who do not breastfeed then become constructed as bad mothers for failing to uphold their "natural" maternal duty to give pure and good breast milk and a "natural" closeness. Writers looking at this angle of breastfeeding promotion suggest that natural signifies "easy," and that all women should be able to breastfeed leading to feelings of inadequacy when women cannot (Blum 1999; Bobel 2001; Wall 2001; Knaak 2005).

This discourse might explain why an EGADZ representative says they would not hesitate to say that breastfeeding for a woman with HIV “leads to a certain level of feeling of incompetence or inadequacy. It becomes like ‘just one more thing that I’m failing at’.” This discourse also relates to the findings of a recent Brazilian study. In this study, mothers with HIV were asked how they feel about not breastfeeding. The authors report that for mothers, the recommendation not to breastfeed, “which they felt placed restrictions on the mother-infant contact, resulted in a feeling of incompetence as mothers” (Hebling and Hardy 2007: 1097). Echoes of this discourse could therefore be present in Saskatoon.

Regardless of whether both discourses are present, because scientific evidence supporting breastfeeding has been usurped by *popular* discourses of good motherhood and not just ones that are scientific, not breastfeeding can still signify bad mothering when society does not know that women have HIV.

This points to a key assumption imbedded in discourses of good motherhood on infant feeding. As we saw with the comment of the postpartum nurse, good mothering discourses assume that all women have the ability to *choose* the infant feeding practice that best suits her context and needs (Gottschang 2007; Tapias 2006; Knaak 2005; Murphy 2000, 2003; Malacrida 2002; Bobel 2001; Wall 2001). Absent in this discussion are reflections on the situations and feelings of women who are not given a *choice* about the form of infant feeding they adopt. Notable exceptions are Hebling and Hardy’s research on women with HIV in Brazil (2007) and Gillian Craig and Graham Scambler’s (2006) discussion about women’s feelings of good or bad mothering when physicians’ recommend gastrostomy tubes for babies with Cerebral Palsy who have difficulty orally feeding. The tension zone therefore results from this assumption. Women with HIV in Saskatoon are subjected to good mothering discourses formulated under the pretext of “bad decisions” to use or not to use formula.

Star highlights that within standardized networks like good/bad mothering continuums is located the “private suffering of those who are not standard—who must use the standard network, but who are also non-members of the community of practice” (1991: 43). Star also suggests that “one source of suffering is denial of the co-causality of multiple selves and standards, when claims are made that the standardized network is the only reality that there is” (48). Women with HIV are not standard within the medical network because they are mothers and medical subjects and their subordination to medical authority is ambiguously justified. Because the medical interventions are considered justified, women’s protests to their experiences of racism and discrimination and inappropriate surveillance of ‘deviantly’

missed appointments may result in the consequential loss of their infants as going unheard. This constitutes a private suffering. Further, in Saskatoon, women with HIV are also not part of the “community of practice” because they don’t have a “choice” about how they feed their infants and yet they are still judged against good mothering discourses that assume that “choice” exists.

The research I present here records the speculation of people who work with women with HIV. This means that people might have been sharing opinions reflecting their own positions within dominant discourses of good mothering in Saskatoon. What is evident from this study is that the voices of women with HIV are startlingly silent. Thus, this research points to the need for a study that shares the perspectives and opinions of women with HIV and their experiences with having *no* “choice” in how they feed their baby.

The topic of “choice” also raises important questions about how breastfeeding advocacy that promotes breastfeeding as a woman and infant’s right generate constructions of good mothers and “choices”. People from Breastfeeding Matters, Moms for Milk, and the Vancouver Milk Bank all advocate for women with HIV to have an ‘informed choice’ under the slogan that it is every mother and infant’s right to breastfeed. Advocating for the human right to breastfeed, according to Hausman, is a recent form of breastfeeding promotion. The rights language moves away from earlier discourses of biological determinacy which focuses on bonding between mothers and children, medicalization and naturalness (2003: 28). How does a mother with HIV measure against good mothering discourses if she is given the “right” to use breast milk and then “chooses” not to? Do you have a “choice” not to give your infant what is considered “a right”? Once again HIV poses a challenge to breastfeeding advocacy . Where once HIV closed milk banks, now HIV will pose conundrums of justifying mothers rights over breastfeeding.

In Practice

Regardless of the diverse motives behind breastfeeding promotion, research on the internalization of these discourses suggests that women experience a deep sense of moral loss, and guilt as a result of “failing” to live up to the “gold standard” of breastfeeding (Wall 2001; Malacrida 2002; Murphy 2000, 2003; Bobel 2001; Knaak 2005). Buried in these descriptions is the assumption that all women are impacted by good mothering discourses to the same degree. Scholars and actors in Saskatoon, however, find that this guilt is missing

when they reflect on low rates of breastfeeding amongst some minority populations including African Americans and aboriginal communities.

Litt (2000), Blum (1999) and Hausman (2003) all argue that in the United States, many African American women adamantly support formula feeding. Litt posits that this support for formula feeding among Jewish women and African American women stems from the ways these groups embraced medicalization in the first half of the twentieth century. Medicalization positioned formula feeding as scientific and became a sign of Americanization for Jewish women, and for African American women, as a way of detaching oneself from “primitive” “southern practices” for African Americans (61, 68). Blum and Hausman both note that African American women continue to resist sexualized stereotyping and discrimination, and that it is this resistance that is at the root of low rates of breastfeeding in amongst this population (2003: 43). Suzanne Zhang Gottschang similarly argues that, in China, women’s decision to formula feed was rooted in a desire to achieve “modern” status as a mother (2007: 74).

A person from AIDS Saskatoon suggests there is strong support for formula feeding among women with HIV similar to the African American women that the above authors write about. She explains:

It is very acceptable, I’ve had people sitting around and say “oh do you want me to just warm that up for you” and it’s just ingrained. [...] It was a really cool day, it was all moms it was probably five or six moms all kids, lots of infants and most of them were formula feeding. One young woman didn’t have any and one woman said I have an extra bottle you can keep it. I’ll even mix it up for you. Like it was even this little like bonding that “I have formula; who needs some?” It’s like tobacco and even now when people come in, even for her to be like “oh I saw a bottle,” and they go and look through the clothing depot and “here’s one we’ll just wash it and I’ll send it with you.” People do that over tobacco. It’s like, “I have a pouch of tobacco, who needs some?” Sometimes that happens. It’s that camaraderie except it’s all mothers and it’s all based around formula.

A second person from AIDS Saskatoon reasons that the acceptance of formula feeding is a result of poverty and marginalization, noting, “Many of the women probably come from lives where breastfeeding would not have been the norm.” On the other hand, or possibly related, Healthy Mother Healthy Baby, CHEP and a person I interviewed who had many years of experience in the service industry and working with women with HIV, all suggested that women with HIV might not want to breastfeed because of their aboriginal background. These

actors pointed at the tumultuous history of oppression of aboriginals through residential schools in Saskatchewan that led to a high rate of sexual abuse amongst women in this population. While these actors are offering speculation, this observation is inline with Litt, Hausman and Blum's comments about women who are trying to distance themselves from a history of sexualization as a racialized "other."

Intrigued by these actors' comments and confused by the high initiation rate of breastfeeding that CHEP recorded in Saskatoon, I talked with sociologist Karen Wood about a publication she and anthropologist Penny Van Esterik currently have in press. Wood interviewed six aboriginal women with a history of sexual abuse from Saskatoon about their experiences with breastfeeding. Wood argues that out of this group four initiated breastfeeding. She explained that these women eventually stopped breastfeeding when they could not support the physical reminder of their past experience with being abused (Wood and Van Esterik 2006). While this study supports the speculation of the community service actors, it also suggests that women with this background still have a strong desire to breastfeed. Evidently, infant feeding preferences and choices among aboriginal women in Saskatoon are indefinite and require further investigation. This uncertainty suggests that while there is tension zones formed out of contrasts in medical discourses on breastfeeding, not all women with HIV may be sitting in the middle.

Conclusion

In this chapter, I illustrated that in the context of HIV ambiguity forms along the boundaries between what appears to be the 'medical management over medicine' and the medicalization of reproduction, child birth and infant feeding. I suggest that as a result of their dual identity of being marginalized mothers and medical subjects, women with HIV experience "silent suffering" offering even less resistance to medical intervention and surveillance than already faces them.

Similarly, I located a tension zone within good mothering discourses on infant feeding. This tension zone illuminates, as Star says "the properties of the more conventionalized, standardized aspects of those networks which are stabilized for many", in this case how to be a "good" mother (1991: 53). I argue that in Saskatoon this tension zone is created out of competing medicalized discourses of infant feeding, while pointing out that

there are other discourses that could be present. This tension zone underlines the key interactions that are occurring between human actors and article actors.

In the next chapter, I conceptually explore the partnership between human actors and article actors to better understand how tension zones, controversy and contrasting recommendations are shaped.

CHAPTER 4: DETANGLING ACTORS IN HIV AND BREASTFEEDING KNOWLEDGE FLOWS IN SASKATOON

In Chapter 2, I suggested that an HIV specialist at IDD is centrally positioned within the referral pattern that supports the medical directive “not to breastfeed”. I pointed out that this person draws heavily from specific articles and websites to support this recommendation. At the same time, Breastfeeding Matters, reading different scientific material, arrived at an opposite recommendation. Controversy was located. Similar interactions between human actors and articles were noted in Chapter 3 when I highlighted that the root of the tension zone that forms around women with HIV upholding the HIV specialist’s directive is based on connections with scientific evidence.

Taking into consideration the relations between articles and librarians, Moms for Milk, HIV and lactation specialists and breastfeeding advocates, should the HIV- specialist still be considered the central actor? How should the act of articles “influencing” a human actor be conceptualized? In this chapter, I answer these questions by situating my observations of knowledge flows in Saskatoon in science studies writing on actor networks, social movements and the creation of “experts”. I argue that envisioning articles as actors is useful for highlighting and understanding the fluid and organic character of knowledge.

Scientist in the Lime Light

Over the past two decades within science studies writing, there has been a debate over the position ‘the scientist’ holds in the process of knowledge production. In the early years of science studies, sociologists occupied themselves with observations of what scientists actually do in the laboratory (Hess 1997:103). As a result, this field did not examine other social factors and actors that might be involved in shaping knowledge.

Sociologists and philosophers like Bruno Latour (1987), Steven Shapin and Simon Shaffer (1985) underlined that science is a social practice that does not evolve inside an airtight vacuum-sealed environment free of influence. “Laboratory studies”, as they were

called, were replaced by more dynamic examinations of the relationship between knowledge production and society. To illustrate this social action, Latour introduced the idea of actor networks. He argues that actor networks are composed of human and nonhuman actors that together form a process of knowledge formation based on the enrolment of actors, translation of agendas and the stabilization of ideas (Latour 1987, 1988). The agency of the varying actors depends on the point each entity holds within the network (Hess 1997: 108).

Theoretically, actor networks can be written from the point of view of any actor, but, as Stefan Timmermans and Marc Berg remark, “in most case studies the perspective of scientists or engineers is chosen” (1997: 274). As they point out, for Latour it is the “scientist”, Louis Pasteur, who is seen as standing with his hand on a lever ready to “raise the world” as opposed to the endorsement of any of the other actors, like the farmers, or the laboratory assistants (274).

Subsequently, feminist science studies writers point out the limitations of actor-scientist centred networks. Emily Martin highlights that scientists are portrayed in actor-network theories as the “active agents” who are “attempting to change an essentially passive world” (1994: 6). Susan Star similarly points out the drawback in scientist centric actor networks by making the analogy between the scientist that Latour describes, and an executive business man. She argues, “Much of the work is attributed back to the central figure, erasing the work of secretaries, wives, laboratory technicians, and all sorts of associates” (1991: 29). Star adds that when this work is recovered, by looking at the perspectives of those who are marginalized or in the ‘background’, a very different network is discovered.

Joan Fujimura (1996) uncovers a different weakness in Latour’s actor-network. She argues that science studies have not been able to explain how “the scientist” is acted on by other actors and undergoes changes within the network. Fujimura argues that actors are co-enrolled with the help of a “theory-methods package”- a process in which “tools, practices, and theories circulate through and across worlds of practice (not only scientific worlds) and both change and are changed by their circulation”, (1996:16-17). For Fujimura, this concept is useful for highlighting how power and authority are concentrated among different actors, objects and social worlds as opposed to in the hands of a few scientists (153). Marc Berg and Stefan Timmermans (1997) similarly see processes of universalization and destabilization of an idea as “a *distributed* activity” in which “non-docile actants may well be a *sine qua non* for universality in practice” (1997: 275).

Collectively feminist science studies writings on actor-networks redirect the field to look at points of view outside of that of the scientist. The attention this thesis gives to the role Moms for Milk and health librarians play in accessing, filtering and sending knowledge to other actors like physicians and breastfeeding advocates therefore supports a feminist science studies perspective; the scientist is not the centre of the network. However, the observations I make regarding the interactions that occur between human actors and articles also resonate with the observations illustrated in current science studies writing on social movements. Are articles actors?

Human and Nonhuman Collaborations: “Seeing” the Knowledge Flow

Current science studies research also builds from the groundwork of feminist science studies writers by questioning “who” is an expert and how this title is achieved (Hess 2007). As I will illustrate, interactions with scientific articles are key to this process.

Steven Epstein’s (1995) work on AIDS activism in the US, and Krista Harper’s (2004) work on Genetically Modified Organisms (GMO) controversy in Hungary both draw attention to the role scientific articles play for equipping lay activists with tools that can be used to gain credibility within political and scientific circles. Epstein remarks, “while activists have also insisted on the need to bring ‘nonscientific’ language and judgments into their encounters with researchers, they have nonetheless assumed that the capacity to speak the language of the journal article and the conference hall is the sine qua non of their effective participation” (417). Harper echoes this comment pointing out that Hungarian environmentalists gained public support for challenging GMO’s, by enlisting the writing of a Hungarian scientist who criticized GMO research (2004: 484).

Peter Redfield (2006) offers a slightly different set of observations on how expertise is being shaped by looking at the notion of “témoignage”, meaning, “witnessing”. Redfield suggests the non-governmental organization Médecins Sans Frontières (MSF) uses witnessing to establish itself as an international “expert” moral voice on humanitarianism. Credibility forms out of a partnership between the collective narrative (of witnessing in this case) and scientific knowledge, through nonhuman article actors. For example in 1987, MSF-France launched “Epicentre” to collect data that would hopefully, as Redfield explains, “resonate in expert circles, enhancing the organization’s credibility within a wider world of public health and improving its ability to ‘speak to the institution’” (14). Redfield points out

that uniquely, MSF challenges the idea of the individual expert because it produces a “collective” knowledge; only the organization is listed as an author, thereby dissolving any one person as key or expert within MSF itself (16). The organization stands as an actor.

Timothy Choy’s (2005) exploration of a local anti-incinerator debate in Hong Kong, and Heather Paxson’s (2008) observations of Cheese of Choice Coalition lobbying of the Food and Drug Administration in the U.S. suggest that knowledge employed by activists and lay people constitute articulations of “counterexpertise”. Choy’s research suggests that we will only be able to understand how some counter knowledge succeeds and others fail by paying attention to “articulated knowledges” and “unarticulated knowledges” in the politics of knowledge (2005:10). Similarly, Paxson draws attention to how advocates must pay attention to sorting through “good” and “bad” science when making claims legitimate (2008: 38). Her observation suggests that becoming “experts” through the cooptation of science means voicing some ideas and silencing others. I suggest that these unarticulated knowledges are not just located in the thoughts and unvoiced thoughts of people, as Choy and Paxson would suggest, but in articles as well.

The above authors underline the key role of article-human interaction for making a scientific or local layperson into an expert. Missing from this writing is a key *description* of the unique interactions that lay people and professionals have with articles. How are certain arguments more convincing than others? How do the articles relate to each other and other knowledge in the same field? Who are key authors and why?

Understanding and Situating Nonhuman Article Action

The above literature suggests that controversy, a public display of opposing views, emerges from the collaboration of lay individuals, scientists and other professionals with articles. While previously only one “truth” or “fact” would have been represented, many start to emerge. For example, Breastfeeding Matters and the IDD voice contrasting recommendations on HIV and breastfeeding. Both groups were partnering with scientific articles on the topic of HIV. Controversy, therefore illustrates that knowledge as fact, a truth or as “black boxed”—to use Latour’s term— is an illusion. Controversy highlights that knowledge is organic, changing, instable and growing; not static, stable and “true”. But in order to fully appreciate the organic nature of knowledge we have to be able to see its movement by looking at the actions of the articles being used to make people into experts.

Several science studies authors have limited the conception of knowledge as organic by configuring its formation and movement as linear; departing from one point and arriving at another (Timmermans and Berg 1997; Timmermans 1999; Latour 1987, 1999; Hogle 1995). Behind this linear conceptualization of knowledge-formation is a lack of willingness to attribute action to nonhuman actors. For example, Timmermans and Berg (1997) and Timmermans (1999) base their linear time specific conceptualization of knowledge “crystallization” and “trajectory” on sociologist Anselm Strauss’ idea of “trajectory”. However, Strauss assumes that an actor can only be human noting that an actor “will be the agent of an action—a person, a group, an organization, or other social unit” (1993: 23).

Hess, like Strauss, also sees action as being limited to humans noting that for many trying to understand the action of a nonhuman actor is a challenge because; “action in classical Parsonian social theory involves the idea of a goal state or intention, nonhuman entities cannot be actors because they do not have intentions and goals” (1997: 108). While Hess is correct in saying that nonhuman actors don’t have the same amount of conscious agency that can translate into physical actions, I argue that this is not the only way to have action.

Latour for example describes action that exists between authors that are cited within texts. He locates and looks within sentences for what he calls “modalities” (1987: 22). Positive modalities are defined as “sentences that lead a statement away from its conditions of production, making it solid enough to render some other consequences necessary”, negative modalities do the reverse to a statement (23). Modalities are, and generate actions, by “transforming each other’s statements in the direction of fact or fiction” (Latour: 25). From this angle, an author picks up an article and finds themselves *directed* to another article or idea.

Interestingly, Latour does not integrate the action he sees as existing in texts, in his own application of actor-networks. By limiting the action that can be recognized within the text, Latour is able to position the scientist as writing the text free of influence, and therefore as centre of the actor network. For example, Latour refers to the reader located outside texts as “the dissenter”. He suggests that the dissenter has three ways of reading a text and all of these inevitably end up with the reader being ‘turned away’ from the literature (60). Latour never explains how the dissenter became dissented before appearing in front of the text in the first place. He does not explore the possibility that—as a result of the action occurring in the text between nonhuman actors and the interactions between human and non human actors—

the text has been able to “act” on the reader making them dissented. Latour indirectly dismisses the action he wants to attribute to nonhuman actors.

Like Hess and Strauss, Latour seemingly struggles with assigning the same kind of agency to nonhumans as humans. Are subjects the only actors that can have action at the bottom of this philosophical exploration? Perhaps Latour’s hesitation arises because of not factoring in that humans make articles in the first place. Acknowledging that humans create articles automatically establishes a subject-object divide. This has the risk of undoing Latour’s (1999) attempt to dissolve the constructionist subject-object dichotomy. On the other hand, by conceptualizing objects as having action separate but *equal* to that of subjects, we run the risk of losing sight of how the objects are made in the first place. This scenario resonates with Karl Marx’ (2000) discussion of “commodity fetishism” whereby the value assigned to products becomes separated from the value of the labour used to produce them. Following Marx’ argument there is the additional fear that we, like the economists he talks about, will become unaware of our own “fetishisms” (14). The fetishisms are the value we attribute to objects outside of their production value, suppressing the work that went into making them. Where is the balance between conceptualizing objects as objects, but with the capacity to “interact” with humans?

There are important differences between the commodities Marx writes about and articles as objects that writers produce, which need to be considered. Unlike the commodities Marx describes which, over time are *assigned* religious-like fetish symbolic qualities, articles are both *inherently* symbolic and in a lower hierarchical position to humans because they are composed of words. Timothy Mitchell draws on the work of Jacques Derrida and Saussure, arguing that from a constructivist perspective signs are composed of two sides: one is a “‘material’ image” and the other, a “non-material thought” (1988: 142). Mitchell argues that these two sides are inseparable but not equal. The material element of the word is the representation of the meaning, and the sound- image originates in the mind of the author. Mitchell suggests that the conceptual element comes first and is closer to the original thought being communicated (144). In this sense, Mitchell argues that a hierarchy is formulated between original meaning and secondary representation (144). The hierarchy means that articles as representations of ideas, by nature remind us that they are secondary to human concept. This means that if we conceptualize articles as actors that have action we do not run the same risk of “fetishism” as the commodities Marx describes.

The second difference between Marx's commodity objects and articles as objects is that articles, in the sense of being composed of words, are not really objects. Mitchell, referring here to Derrida, suggests that words are neither "things" nor "events" "in the sense of a unique and empirical particular" (Mitchell: 144). In his explanation of how words gain meaning, a set of actions that occur between words as symbols is uncovered. Mitchell explains, "Language is something made possible by the movement of repetition and differing" (145).

Importantly, acknowledging action in articles does not necessitate forgetting that a person composed the article. Star elaborates, echoing Latour's response to criticism of the political implications of levelling human/nonhuman differences, by noting that, "heuristic flattening does not mean the same thing as empirical ignoring of differences in access or experience" (1991: 43). As I expressed in the introduction, the action in articles is not the same as action for humans, or action for other objects, as both Mitchell and Derrida essentially point out. In recognition of the above symbolic qualities of words, I am not arguing for an acceptance of the action for all objects. Instead, I ask for a conceptualization of action that looks at movement and difference between words and texts for the purposes of understanding how controversy is shaped. By including articles as actors, we can explore the knowledge flows of, and between both their concept and representation forms.

By accepting to move beyond constructivist division between concept and object, and object and subject, Derrida argues that a system of differed reality takes shape. He argues that the meaning of words emerges through a process of differing and sameness. In this system of deferral, the point of origin of truth becomes "ungraspable" because "the reflection, the image, the double, splits what it doubles" (1976: 36).

Scientific referencing within a scientific reference is like the reflection that continues to split when two mirrors are placed facing each other. Suddenly the depth of action that is created from scientific referencing, that defers reality to yet another deferred reality, starts to appear¹⁴. In this way, the scientific author as an actor is never real, suggesting its action cannot be understood as existing within the same time- space continuum as human actors and

¹⁴ Symbols have elsewhere been conceptualized by anthropologists as having action. Victor Turner in the chapter "Symbols in Ndembu Ritual" suggests that the structure and property of a symbol become dynamic within its "appropriate context of action" (1967: 20). He therefore puts forth the idea of "symbolic interactionism" to describe symbols producing action whereby, the "dominant symbols tend to become focuses in interaction" (22). Turners ideas are closer to the discussion in this thesis than Clifford Geertz' ideas of "symbolic action" whereby humans have actions that 'signify' (1973: 10).

their actions. The actions of human actors are limited by linearity because they can only move forward in time appearing only in the present. There are no duplications of a human. Representations on the other hand, like the article actors named inside a scientific text, can assemble in the *same* place representing several periods of time in the form of “Simone 2001; Jacques 1994; Anna 2008”. Or, multiple copies of the same actor can also appear in many different moments in many *different* places. Suddenly a *network* of deferred realities and symbols is visible. By seeing articles as actors and action within and between articles, knowledge cannot appear as static or stable; it appears as constantly changing and growing.

Therefore, to map knowledge production we have to work with two different time-space parameters, one for human actions and the other for article actions. Then, we can compare the two. For example, this thesis highlights that “Anna Coutsoydis” emerged as an important purveyor of information on HIV and infant feeding in a number of scientific articles breastfeeding groups are reading. This author is a representation of a deferred reality in which we find more concepts on HIV and infant feeding. If time had permitted, I would have taken one of her articles and looked for citations to find the other authors that are present and linked with more concepts on HIV and infant feeding. Following authors as actors through texts would have told me about the ideas, institutions, writers and settings that surround this author that can be found by looking at the authors this actor interacts with in the text. The article is a deferred reality of knowledge production. If articles are taken as extensions of humans and *not* as actors then Anna Coutsoydis is merely the name of a well published scientific writer. Naming her as popular does not prove, explain or illustrate *how* she is influential, as an actor in a text interacting with other actors in the text and then with a human, it becomes clear how she is frequently cited. If we conceptualize articles as actors, anthropologists have a whole other world that they can describe.

Conclusion

I have argued that this thesis and science studies writings on social movements highlight the importance that nonhuman scientific article actors play in creating experts and understanding knowledge as organic. By looking at articles as actors, social action that occurs in multiple spaces, times and places become visible; the changing organic state of knowledge can be visualized and subsequently the formation of multiple types of human actors into experts is explained. Controversies then become understood as illustrations of the organic character of

knowledge because it becomes a collection, presentation, navigation, contestation and changing of ideas.

In the next chapter, I suggest that the international compartmentalization of health contexts is also in “action” in Saskatoon. I look at the repercussions of this process and conclude with practical applications and implications of this thesis for understanding knowledge flows and for offering support to women with HIV who are feeding infants.

CHAPTER 5: CONCLUSION: NEW QUESTIONS, NEW STEPS FORWARD

To conclude my thesis discussion on HIV and infant feeding knowledge flows in Saskatoon, I want to draw more attention to the “silent suffering” of women with HIV in this city. This suffering occurs when daily negotiations of poverty are not recognized within the standardized construction of international health contexts where formula feeding is assumed not to be a problem.

I focus on some of the contextual details related to poverty established in my fieldwork. I discuss how these contexts become overlooked in the face of assumptions that are made surrounding Canada’s “developed” country status—assumptions that become integrated into translations of international health policy by several different health professionals in the form of local and national health recommendations. I end by reflecting on some questions and actions that, as this research suggests, can help cast light on the good/bad mothering tension zone positioned around women with HIV in Saskatoon now and potentially in the future.

We Have Clean Water

“Where did you learn your information?” Answers I gleaned from asking this question illustrated that infant feeding recommendations for women with HIV are embedded and understood within dialogues about differences in international health contexts. For example, several people highlighted that in Saskatoon formula feeding is recommended for women with HIV because Canada is a “developed” country, and that “we have clean water”. These reasons suggest that formula feeding is a viable alternative to breastfeeding. Take the comments from one Breastfeeding Centre employee;

It is recommended “no breastfeeding” in Saskatoon, the reasons being that the HIV virus can be transmitted through the breastfeeding. Although, there is some newer research coming out now that seems to indicate that if women exclusively breastfeed their babies with no introduction of any formula for the first six months, there seems to be some indication that there may be

protective qualities against the infant developing the virus. However, once you introduce any type of supplementary food—so, [that means] any additional bottles that protection is lost. So for that reason in our country, which is a developed country, where women *do* have access to clean water, and theoretically have access to artificial baby milk or infant formula, the recommendation has remained that those women would bottle feed those babies infant formula. This is of course a different recommendation than what we currently suggest for women in the developing world, where they do not have access to infant formula often.

By emphasizing that “theoretically”, women will have access to formula; the person from the Breastfeeding Centre underlines the assumption that every Canadian has the same “developed” standard of living. However, when she states, “in our country, which is a developed country, where women do have access to clean water,” she places water access as a direct result of Canada’s “developed” country status. In this sense, she assumes that a developed country status and access to clean water go hand in hand. One person I talked with at the Westside Clinic also attributed the formula feeding recommendation based on the assumed access to clean water:

Basically, all I really know is that it [breastfeeding] is not recommended. In Canada, where we have clean water, it is formula for HIV positive moms. I don’t know if it’s a formal sort of thing it’s more what I intuited along the way, I guess, and from the doctors here at the clinic. Things trickle down from them to me, and back and forth I guess.

Not everybody believes Canada is free of water issues. A person from BC Women’s Milk Bank spoke about the international differences between the recommendations on infant feeding and HIV. This person points out the high-profile water crisis in Walkerton, Ontario evidence that a developed nation such as Canada is not without its problems. “When you think [about] the Walkerton crisis—and I would be willing to bet once you’ve seen footage of some living conditions Canadians are living in—certainly clean bottles and washing bottles would be an issue.” While a person from CHEP portrays water issues as mostly issues for other countries, there is still awareness that safe water is not necessarily accessible to all:

If I had a daughter who was HIV positive I would work so she felt just fine about feeding perfectly good formula to that baby. We have water ... in Saskatoon that is safe. I know how to boil water. I can sterilize things. I wouldn’t want that person to feel bad at all. I think my criticisms of formula feeding are more for countries where there might not be a safe water supply, where the practices of

the formula companies may be manipulative and exploitative. In Canada I don't feel that strongly about it, I think you can accomplish that close bond and relationship [without breastfeeding].

This comment also underlines (and argues with) the dominant good mothering discourse that only breastfeeding leads to closer bonding.

I am including the above references to clean water to emphasize that a health recommendation is justified with reference to a generalized assumption that formula feeding can happen safely in Canada. I suggest we take a closer look at the housing crisis that is currently in full force in Saskatoon and the housing quality and arrangements people have. Does everyone have access to a stove to sterilize water? Do all houses on reserves or in rural and remote areas have safe wells or adequate water treatment? Developed status implies uniform access to clean water. But according to a CBC News report "a recent government report showed that tap water poses a significant risk in three-quarters of the water systems on Canada's reserves." ("Minister Vows..." 21st Feb. 2006).

We are not Africa

Justifications for formula feeding are constructed by placing HIV in Saskatoon in direct contrast to health, poverty and resources issues in Africa. Consider the comments from someone at the Westside Clinic:

The recommendations I learned in school are that if anyone is HIV positive then no breastfeeding because the incidence of passing it on through breastmilk is there. In school, we were basically taught that those with HIV should not breastfeed. No basic information on HIV and breastfeeding. I don't think it's that well taught or covered in school because it's still a low incidence. I mean we're getting there, but it's still not something you encounter everyday. It's not like if we were in Africa and it would be a daily occurrence for you.

[Question: Do you ever hear about what is happening in Africa?]

Just what you hear in the news, basically you know, I know that those countries don't have clean water, they don't have access to formula, they don't have money. Poverty is really big. I mean we have some of the same things here like poverty and women have to pay for formula and formula is expensive, it's sort of similar. But I mean you can't even compare prevalence between here and there. So I mean for those countries you either feed your baby breast milk or let it die 'cause no one is going to give you formula. And so you have to choose. Those women who have HIV and are already compromised, immune compromised, will it break down their immunity? Will the

extra energy of breastfeeding be a detriment to their health? I mean they are dealing with different things. They don't have the social safety nets that we do here.

Importantly, this person suggests there are issues that are similar between Africa and Saskatoon. The people at the Westside Clinic are all very aware of the poverty that exists in their community; they see it everyday. But ultimately this person suggests that breastfeeding *has* to be acceptable in Africa “‘cause no one is going to give you formula”. As I mentioned in Chapter 3, emergency formula is hard to access in Saskatoon. The implication is therefore somehow women with HIV in Saskatoon will find someone who will help them out. As I learned later in the interview, this person would ensure that a mother had enough formula for her baby;

Here we would go above and beyond our means to try and find formula for that mom. Borrowing somebody money, two dollars, co-pay for antibiotics for people who are on assistance: I'm not going to see that kid go without antibiotics, especially when they need it. So here's a toonie if that's what it takes. Or, you know, making phone calls and making connections and you know, what's the cheapest route we could go to then? You know what I mean? I say it happens fairly often. The clinic has an emergency fund so we cover medication for people who really, really need it. For formula feeding it would be the same thing, and trying to find it for them.

Like the person from Westside Clinic, a person from the Positive Living program also described to me how the challenges facing women with HIV “here” do not compare to those facing women in “other” countries:

We have discussions about how it must be very difficult for a woman who already has no money to try to find money for formula when she can't feed herself. It becomes 'do I starve everybody else to find formula, if I can find it to feed my child?' Or 'do I breastfeed and take the risk?' And if I have formula; I'm mixing it with contaminated water so either way I am putting my child at risk. But that's not because it comes from any research, its just discussion we have. We talk about other countries and their risk because we talk about how people here have so many more options but they don't seem to always want to use them. If you had no money and you had to walk ten miles to get your formula and find out that they are out and the baby is growling it would be tough.

By distinguishing between “here” and “there,” the person from the Positive Living Program sets particular issues or challenges apart and distant from “here.” For example, when she says

“we have discussions about how it must be very difficult for a woman who already has no money to try to find money for formula when she can’t feed herself” and “it becomes ‘do I starve everybody else to find formula’” it is implied that women in Saskatoon have enough money for formula and do not find themselves in the position of having to starve themselves in order to feed their baby. However, as I heard many times Saskatoon is facing an unprecedented housing crisis that is forcing economically marginalized women to creatively juggle their finances. A person from the Westside Clinic elaborated on this for me;

When we say that women should be looking at bonding with the baby, they are actually looking for a place to live. It is so hard to find a place to live right now. When they are formula feeding it’s good because they can leave the baby with someone else, they don’t have to be there all the time. Some have come in to say that they found a place but they have to pay \$250 more than they are given. So, they take from the food budget. And you know for the most part I really see that in the community here they really see how—know how important it is to give the baby good nutrition. So the last thing to be cut is the baby’s food, because they know that and they believe in it. But I have seen adults who haven’t eaten for days...

As this person notes, formula feeding is a double-edged sword during a housing crisis. Formula costs more than breastfeeding and yet mothers are more mobile and able to look for housing. Recall that women on social assistance who have HIV can receive a supplement for their baby. These women might not have to juggle their food budget as much as women who have HIV and do not have a supplement. As I mentioned in Chapter 3 women who are part of the working poor are caught between the cracks.

When the person from the Positive Living Program mentions that it would be a challenge for a woman to “walk ten miles to get your formula and find out that they are out and the baby is growling,” another shadow lies over the infant formula challenges facing women in Saskatoon. In Chapter 3, I underlined that the food bank does not have a reliable source of infant formula and it is therefore quite possible that a woman will walk several kilometres to be turned away because there is no formula available. What’s more, it is possible that women with HIV—as AIDS Saskatoon and CHEP both noted—who do not have cars or money for bus passes will walk this distance in -40 centigrade.

In Saskatoon, some of the perceptions people have of the severity of poverty in their own communities are shaped out of processes of differentiation whereby the perceived international context is contrasted against then distanced from the local community. This

differentiation appears to render the local context invisible to people who see only how different the two contexts appear to be: Saskatoon is not Africa. Rather, how “here,” is not “there.”

Invisible Impact

As a person from AIDS Saskatoon described it to me, this invisibility can mean less community donations for the people who live “just down the street”:

The other thing we see is that people just don't have the money for the formula. We had a case of formula donated from a church that actually sent formula to international countries. That was their fundraiser, and they had some left over so they gave it locally. I have a big problem with that. I completely support and encourage people to do international work, like, of course that's my mentality as well, but a lot of people don't look at their own communities first, so we got the leftovers from that.

Similarly, a person from Moms with Milk, mentioned that they had read about a milk bank organization in the United States called Prolacta, that sends donated human milk overseas;

The International Breastmilk Project: That organization has been featured by Oprah and they just got on ABC news and had a feature this last week or two. So they are collecting. This not-for-profit International Breastmilk Project is headed up by a woman who had extra breastmilk and she wanted something to do with it. And she wanted it to go to Africa to AIDS orphans so she established this. ... But now she is affiliated with Prolacta and she collects the milk under this charity and it all gets turned over to Prolacta who processes it. But they are sending 25 per cent of the milk that she collects to Africa and they are keeping 75 per cent of the milk [to sell to hospitals]. That kind of information does not come out clearly in the ABC news items or Oprah. So this milk is actually being sent to South Africa to the charity that Coutsooudis did her work in. [...] Why can't the women just get the milk in Africa? If the women could they could supply their own milk. The amount of milk going over is small. They just sent a shipment of 55,000 ounces and that's what got on ABC news. So they are claiming that that is enough to feed six infants for a year, it's a drop in the bucket for what's going on over there.

The above example of Prolacta and the International Breastfeeding Project is an excellent illustration of how the perception of what is happening overseas can overshadow what happens in the local community. In this case, there are people donating breast milk to AIDS

orphans in Africa when there are many infants being born from women with HIV in North America who would gladly use free donated breast milk if given the opportunity.

While some people unconsciously distance the local context of poverty from ideas of international poverty, there are just as many “bridges” between the two. For instance, during my fieldwork a nurse who typically works with people on the street walked me through one of the “core” neighbourhoods. At one point, she turned to me and said, “We have our own little Africa right here in our backyard.” It is interesting that “Africa” is the descriptor used to signify the extent of the poverty in the Saskatoon “core” neighbourhood was. Even though the comment is used to highlight that there are similarities between “here” and “there” contexts, the descriptor still establishes some distance; it suggests that the fact that the contexts shouldn’t be similar.

This person and someone from AIDS Saskatoon both commented on one international trend in particular. A person from AIDS Saskatoon mentioned that while running education sessions in the northern part of Saskatchewan, she observed “a lot of the grandmothers were raising the babies,” explaining that “of course a whole generation is affected by HIV /AIDS”. The nurse who waked me around one of the “core” neighbourhoods made the same observation commenting, “it’s interesting it almost parallels some of the stuff that goes on over in Africa where there is a whole generation that isn’t caring for the children, it’s the grandparents.”

I also talked with people who challenged the assumption that all women have access to formula in “the developed world.” For example, a person from the Breastfeeding Centre described to me what women do in situations where they cannot afford formula:

Well I know for women living in poverty, [access to formula] is a huge issue. I have visited in homes where babies are not being fed formula. We know that babies are sometimes fed things like Coffee Mate, Kool-Aid and juice because there’s not the money to buy the formula because it’s expensive for families to purchase. I’ve visited at homes where they have only a very limited amount and we were questioning where they were going to obtain the next amount. So that’s why I know that in our “developed” world theoretically women have access to that, but in fact for women in poverty that’s a struggle.

A person from AIDS Saskatoon made some similar observations:

The trend here that I have noticed is everyone is formula feeding. And if they don’t have access to formula they use whatever they can find, like creamer, coffee creamer, and water- because it looks

like milk—all kinds of things. Sometimes they go to the 7/11 or the Mac's and are getting little creamers and putting that in the bottle and filling the rest up with water. People don't have access to it. I think there's that big gap between not only public health and community groups, but between the people living in our community and actually accessing services- so people are getting swept along.

From my interviews, it is unclear whether any of my interlocutors were absolutely certain women with HIV are finding themselves in need of using creamer, Coffee Mate or other non-formula substances. From the perspective of the physicians and the Infectious Disease specialists I talked with, accessing formula has not presented itself as a challenge for their patients. I asked two of the HIV specialists whether they had ever heard of women substituting formula with other liquids. Both were surprised at this idea. For example, one physician responds;

Ew! I would certainly look at the nutritional contents. I would wonder where they came up with the combination. It would certainly give you enough fructose and glucose and refined carbohydrate energy. But in terms of antibodies, nutritional content—not that breast milk is complete—I imagine it would be horrific. But that leads to another problem, that's not a problem about HIV recommendation, that's a problem of poverty. [HIV specialist #1]

Another specialist suggested that the issue of substituting formula with creamer would need to be addressed through education;

Well that would be a problem. I hope that we can educate them otherwise. I haven't seen that in particular yet. But you know I would probably put them in touch with a dietician about the right ways to feed your child. I still wouldn't put the child at risk of HIV even though, I agree, the risk is small. HIV to me is a life and death situation as opposed to saying that a person absolutely breastfeed. [HIV specialist #2]

The above emphasis on education illustrates blindness to the many other factors that might lead a mother to feed creamer to her baby. As the people from the Breastfeeding Centre and AIDS Saskatoon highlight above, turning to creamer may not be a result of not knowing the “right” way to feed a baby. Lack of access to formula and an inability to cover its cost are also reasons. There is an obvious need for a closer look at this issue.

In the above pages, I have illustrated how the recommendation for infant feeding and HIV in Saskatoon is being justified, in some cases, by negotiating a differentiation between

local “us” and international “them” contexts of health and poverty. The murmurs of the challenges women in Saskatoon face accessing and using infant formula suggest that the World Health Organization AFASS criteria are not all being met. Yet in Canada, a policy has been standardized for a health context that is assumed uniform because of its association with a geographic and political entity—the nation—without regard for intra national disparity.

A 2006 epidemiology report conducted in Saskatoon highlights that even within a city, health contexts are far from uniform. Dr. Lemstra et al. measured health disparity by neighbourhood income and suggested that the rate of infant mortality was five times greater in the “core” neighbourhoods than in affluent neighbourhoods in Saskatoon (437). The authors add that the rate of suicide in this part of the city was five times greater (438). Denise Spitzer points out that health context across Canada are similarly diverse. She stresses that a history of oppressive and repressive actions against Aboriginal people in Canada has resulted in “current unequal conditions such as high infant mortality rates and living conditions that rival the poorest of nations among some First Nations communities” (2004: 493).

I point out the assumptions imbedded in the standardization of the infant feeding health policies for women with HIV in Canada and in Saskatoon not to debate whether women with HIV should be formula feeding or not, but rather to point out the silent suffering that is overshadowed as a result. I advocate that we dissolve the generalized “here”/ “there” Africa versus Canada HIV- poverty dichotomy in place of a closer analysis of the local contexts within which individual women with HIV reside. We are standardizing “development” region health contexts, and national health contexts, which overshadow city and neighbourhood contexts. Essentially, I am calling for a focus on what Eileen Stillwaggon describes as “the ecology of poverty” (2006).

Implications: “The Microbe is nothing, the Environment is everything.”

Stillwaggon points at Louis Pasteur’s famous quote “the microbe is nothing, the environment is everything” to draw attention to the way some health paradigms overlook how “regions of vastly different economic and ecological conditions” are the ground from which “real risk” emerges (2006: 11). She argues that by looking at the unique contexts within which patients with HIV find themselves, we start to see the knowledge that explains the spread of epidemics. By looking at the ecology of poverty in cities or neighbourhoods when making

health recommendations, we can start to provide patients—like women with HIV who are told not to breastfeed—with the appropriate compassion, understanding and support needed for them to effectively and safely carry out these medical directives.

When I arrived in Saskatoon I stepped into a web and watched the geometry of the strands come into focus. Multiple angles of Saskatoon as a context started to take shape. After talking to the actors in this web, I have come to endorse some of the initiatives that were introduced to me. These initiatives act towards addressing certain infant feeding issues present in this context and that have been explored in this thesis.

1) Efforts have been made to secure an emergency formula bank

In Chapter 3, I mentioned that CHEP conducted an extensive study on infant feeding practices and challenges for women in Saskatoon. Here is one of their major findings:

With few resources available, and limitations around them (such as SAP [Social Assistance Program] deductions or unusable varieties [of formula]), many mothers were left scrambling to find accessible infant food. These families emphasized the value of providing a consistent variety of formula, as many infants cannot tolerate certain kinds (or suffer gastrointestinal upset because of them). Respondents suggested a reliable, accessible source, without the restrictions of SAP deductions and the necessity of receiving SAP in order to be eligible (as at the *Salvation Army*) (Partyka and Grunerud:18).

CHEP also remarked, that stakeholders have identified that substances like Kool-Aid, Creamer, Coffee Mate and water are being used in the community (Partyka and Grunerud 2007: 24). CHEP reports stakeholders say “the current practice for providing emergency formula in Saskatoon was inadequate” (29). They indicated in their report that stakeholders would like to see both a centralized phone number where people can call during formula feeding emergencies and a centre for emergency formula that they can access (29). Saskatoon is a smaller city and there is a limited set of key stakeholders with regards to infant feeding and social and economic support networks, it is probable that I have interviewed many of the same stakeholders. Unsurprisingly I have come to some similar conclusions as the CHEP study; women cannot access infant formula as easily as it might be assumed and that emergency formula provision is inadequate in this city.

Thus, this thesis also endorses the suggestions made by the stakeholders and CHEP, it underscores that an emergency formula bank would be of great benefit to many of the women

who are on social assistance as well as the working poor in Saskatoon (who are especially compromised in the current housing crisis). I am focusing here on issues that are relevant to women who have HIV. While it is evident that a lack of access to formula exists, it is unclear to what degree women with HIV are affected. Without the social assistance supplement for formula HIV-positive mothers in the lower-working class will no doubt face many of the same challenges in finding formula as reported in the CHEP study. Going back to Chapter 3 and the anecdote from AIDS Saskatoon, about one woman with HIV who benefited greatly from some formula donations suggests that women are still struggling to find formula for their infants. Evidently, this issue needs more attention.

British Columbia has a model that guarantees women with HIV can get the formula they need to feed their baby. It is a model that Saskatoon should consider. In conversations with BC Women's Milk Bank, I learned that the women in question do not need to go through the effort of filling in forms, applying for supplements or social assistance:

Over at the Oak Tree Clinic the dietician works out with the mother where to find a pharmacy that would be convenient for HIV mothers to visit. She then goes into the pharmacy and they give the mother a letter or something that enables her to get formula from that pharmacy for a year and she doesn't have to go the ministry and through all the hoo-hah.

Ideally, a similar uncomplicated system could be made available not just in Saskatoon but across Canada. In Saskatoon, formula provision is an irony for mothers with HIV who want to be "good" and give their child what they need: foster mothers are given free formula from social services but women with HIV are only given a supplement.

2) Human milk donations as a breastfeeding alternative

If we recall, the World Health Organization specified that alternatives to breastfeeding are advised when replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS). Replacement feeding and alternatives to breastfeeding are assumed by this policy, by Canada and Saskatoon to mean formula. As I learned during this fieldwork, there are other options. As I mentioned in Chapter 3, I spoke with breastfeeding advocates who are pushing for the establishment of a human milk bank in Saskatoon. Underpinning this application is the research on HIV transmission and exclusive breastfeeding. Women with HIV are instrumentally put forth as people who could largely benefit from this service. Conversations with one HIV specialist and a person from the BC Women's Milk Bank also confirm that a

human milk bank in Saskatoon could be greatly beneficial to women with HIV looking for options outside of formula feeding.

During our interview the person from BC Women's Milk Bank spoke with a nurse at Oak Tree Clinic, and asked about whether women with HIV used the milk bank. I was told; "they certainly had a lot of women in the past who were doing it [using donated human milk] but with the processing fee, of course, it is too expensive now, so that is an issue." Importantly, the BC Women's Milk Bank operates on a priority scale when the demand for breastmilk outstrips the amount available. This priority scale, which provides milk for the sickest baby and the smallest baby, does not favour a baby from a mother with HIV. If the milk bank in Saskatoon decides to adopt this priority model, the babies from mothers with HIV will not actually benefit from the milk bank. This would be unfortunate considering breastfeeding advocates are using the case of mothers with HIV to garner support for the milk bank. An HIV specialist also talked about the viability of having human milk as an option for women with HIV:

The interesting question would be how foster parents feel about that. As you know, if the child is in foster care the formulas are provided by social services. The funding is provided, so it is not an issue from a monetary standpoint. So how would banked human milk be viewed and who would pay for it etc. All those aspects have to be explored I guess. If cost was not an issue I would have no problem recommending it.

As both of these individuals note, this milk bank project will only benefit women with HIV if the costs are affordable. Otherwise, there are the same access issues observed with formula feeding. I add that the milk bank would also need to be geographically accessible to women with HIV. As I illustrated in Chapter 3, women with HIV do not feel encouraged or have the desire to go to big hospital settings if it can be avoided. A milk bank in a hospital setting that is far away from the "core" neighbourhoods would be equally as inaccessible as baby formula is right now.

This fieldwork highlights that women with HIV are positioned in a tension zone surrounded by multiple medicalized contrasting discourses on good and bad mothering. A benefit of human milk bank in *any* city would be that it would provide women with HIV the opportunity to make an "informed feeding choice". I make this comment recognizing that having two options to choose from does not mean that you have a "choice" as so many good mothering discourses point out. Depending on cost and physical location, at least these

women could have infant feeding *options to consider*. This choice addresses the tension zone because women are placed on an equal playing field with other mothers who are judged based on the *choices* they are making. The advent of a human milk bank in Saskatoon would pose an interesting set of questions concerning discourses of good mothering around breastfeeding: we would be able to answer whether breast is really best, or whether it is the breast *milk*.

If human milk becomes an equal option for women with HIV to choose in Canada, the question will be which discourses of good mothering will these women be subjected to then? Breastfeeding advocates in Saskatoon, in particular, will have to be sensitive to this impending question considering they are relying so heavily on the HIV research and the fact that they can “help mothers exclusively feed their children breastmilk” and exercise their “right” as argument for the implement the human milk bank.

3) Increasing the flows of knowledge

In Chapter 4 I highlighted that by conceptualizing knowledge flows as organic multi-dimensional human and nonhuman interactions, actors in *any* web can start to see how different people are able to argue different “expert” perspectives. By examining these key interactions more about the social action involved in creating a recommendation is known. Actors within articles and actors locating articles for other actors to use become illuminated. Suddenly it becomes obvious that a physician or a scientist can never be in the centre of an actor network.

In this thesis, I illustrated that by following knowledge on HIV and breastfeeding many groups are reading different pieces of information related to the same topic. As a result, conflicting ideas about appropriate health recommendations about infant feeding emerged in Saskatoon. I suggest that to resolve “controversy” we need to embrace it, and encourage it, by allowing for all of the perspectives on this topic to be shared. Ultimately, the health of women and their infants is a goal shared by all parties, by exchanging information between referral patterns this goal can be reached more effectively and efficiently. With some collaboration between breastfeeding groups and HIV-specialists, women will not face conflicting health recommendations, discourses and instructions.

In order to facilitate collaboration, compartmentalization of knowledge needs to be surpassed. This context is not specific to Saskatoon. In places where information about HIV

transmission has not been shaped into a standardized recommendation and is even more contested, competing knowledges are potentially more visible. This fieldwork illustrates that many of the ideas in controversies are never exchanged between opposing sides. A website, newsletter or listserv that is made common to breastfeeding advocates, community medical clinics, community organizations and HIV-specialists alike would be an example of this. Conferences inviting the perspectives of multiple actors are another way of opening the knowledge floodgates. Venues that encourage “controversy” dissolve illusions of standardization and silent suffering starts to be heard. “Developed” and “developing” labels get pushed to the side and the intricacies of poverty navigation in multiple settings become explored.

In 2006 while completing my undergraduate degree at York University in Toronto I assisted in organizing a similar venue; a three day conference called “Gender, Child Survival and HIV/AIDS: From Evidence to Policy.” This conference assembled a range of stakeholders including women with HIV, HIV support groups, breastfeeding groups, international HIV specialists, family doctors, nurses, social workers, anthropologists, and other social scientists from over 25 countries for an open discussion on infant feeding and HIV. During the conference questions were voiced that otherwise would not have been asked, because of the lack of connectedness between these groups. A major conclusion from this conference—that my thesis will also advocate here—is that if community perspectives, advocates for the right to give babies the best nutrition available, and efforts to prevent HIV transmission all work together, then babies born into poverty will have a much greater chance at survival than if all of these groups work in isolation.

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