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## **Breaking the Silence** *Infertility, Motherhood, and Queer Culture*

*Narratives of infertility are neglected in our culture, and those of queer folks are further marginalized. Access to sperm is commonly believed to be the only obstacle lesbians face when trying to conceive, and yet it is not necessarily their only one. Queer experiences of infertility are innately different from those of heterosexuals due to the fact that we are “in a heterosexist society that questions [lesbians’] entitlement to [seek] motherhood in the first place” (Wojnar and Swanson, 2006: 8). Moreover, the literature and popular culture seem to lack the understanding that queer individuals may experience conditions of infertility. This is problematic as not only do the queer stories of infertility become erased, but it also perpetuates a belief among queer individuals that they are completely fertile. Unfortunately, queer folks are more at risk for and experience some conditions of infertility more often than heterosexuals. This article investigates the importance of studying queer experiences of infertility in a heterosexist, pronatalist, medicalized society, and particularly the link between infertility, motherhood, and queer bodies.*

“The idea of erasure is important to feminist and postcolonialist literary theory and cultural studies. Erasure is not exactly oppression or suppression, but rather being eliminated from the field of language, not being heard. Certain narratives are told over and over, making some realities visible while erasing others. This process is at the heart of political struggles over defining the canon and who gets to be part of the official story and who does not.” (Agigian, 2004: 51)

Between July 2004 and March 2005, while interviewing ten queer couples about their experiences of birthing in British Columbia,<sup>1</sup> three of the couples expressed narratives of infertility. Two of these couples disclosed that the non-

biological mother of their children had attempted to conceive without success, and the third couple told me at length about their almost six year journey of trying to conceive their first child, finally being successful using *in vitro* fertilization. In stark contrast to the joyful stories of birth that characterized the majority of my interviews, the narratives involving experiences of infertility were quite solemn, despite the fact that all of the couples now had children in their families.

Narratives of infertility are neglected in our culture, and those of queer folks are further marginalized. Access to sperm is commonly believed to be the only obstacle that lesbians face when trying to conceive, and yet it is not necessarily their only one. Queer experiences of infertility are innately different from those of heterosexuals due to the fact that we are “in a heterosexist society that questions [lesbians’] entitlement to [seek] motherhood in the first place” (Wojnar and Swanson, 2006: 8). Jaquelyne Luce (2002) explains:

The chapters on lesbians in books on reproductive technologies address the issue of lesbian parenting and the reality that lesbians do become parents by donor insemination. However, the processes and actual experiences of lesbians trying to become pregnant and/or parents are not the subjects of analyses. Thus, we have no sense of how many lesbians would have, like the presumably straight women using technology, faced difficulties conceiving or sustaining a pregnancy. (15)

This lack of acknowledgement and recognition of infertile queer folks was further demonstrated in my own experiences seeking services at a Vancouver fertility clinic, where nothing (image or printed word) reflected the fact that this clinic serves queer individuals and couples. It is no wonder that feelings of isolation prevail among lesbians “following a miscarriage, a late-term abortion, or [when experiencing] difficulties conceiving” (Luce, 2002: 49–50). This lack of acknowledgement of queer experiences of infertility is the focus of this article. More specifically, this article begins to address the importance of this representational absence of queer infertility by considering how Western culture’s notions of compulsory motherhood and the medicalization of (in)fertility—both steeped in sexist and heterosexist stereotypes—relate to the queer body and its apparent predisposition of being more susceptible to particular conditions of infertility. I argue that these ideas are important to consider not only for queer individuals, who undoubtedly most explicitly experience the effects of queer infertility, but also more generally for queer and Western cultures in order to revisit prominent assumptions regarding motherhood, reproduction, kinship, sexuality, and gender.

### **Compulsory motherhood**

While certainly not as pronatalist as they once were, western societies still often define women by their relationship to motherhood (Greil, 2002;

Letherby and Williams, 1999; Miall, 1994; Whiteford and Gonzalez, 1995; Woollett, 1991). Anne Woollett (1991) notes:

The meanings, practices and ideologies around motherhood are salient not only for mothers but also for childless women and those with fertility problems. Motherhood is important in all women's lives, whether or not they are or want to be mothers, because women are defined in terms of their relationship to motherhood. Women who do not become mothers are viewed negatively and have to account for their failure to achieve or their rejection of a social position to which, it is assumed, all heterosexual women in stable relationships aspire. (62)

In Tine Tjørnhøj-Thomsen's (2005) study of infertility in Denmark, she found that, "Several women felt that their own mothers did not consider them as real and responsible adults, because they had not yet made the transition into motherhood" (77). This expectation to become a mother is, however, seemingly not applicable to all women.

For many years, a prevalent notion in Western societies was that gay people do not want to have children and cannot biologically parent within same-sex relationships (Berger, 2000; Nelson, 1996; Slater, 1995). An innate infertility is and was seen to strike lesbian and gay relationships, due to the fact that our embodied selves cannot physically procreate within same-sex relationships. While queer folks can "get assistance" from those outside our relationships, our genetic materials will not, in and of themselves, merge to create a human being. This has been one of the arguments used against our relationships, marriages, and parental rights—gay and lesbian relationships do not lead to biological offspring (Agigian, 2004; Lewin, 1993; Nelson, 1996; Owen, 2001).

With the "gayby boom" of the last 30 years, many queer activists have gone to great lengths to prove our abilities both to become parents as well as to provide appropriate care for our children (Arnup, 1995; Owen, 2001; Slater, 1995). Queer folks have begun to be perceived differently with respect to their relationship to parenthood. For example, while 30 years ago it was not uncommon to perceive "lesbian motherhood" as a "contradictory," "dichotomous," and "oxymoron[ic]" phrase, by heterosexuals and queers alike (Berger, 2000; Lewin, 1993; Muzio, 1999; Slater, 1995), Kath Weston (1997) has pointed out that, "Are you planning to have kids?" has become a routine question directed at lesbian couples, even by heterosexual friends" (xiv). Over the last ten years in particular, various governments in Canada have passed legislation, thus recognizing the predominance, abilities, and rights of gay and lesbian parents. In most provinces, queer folks can legally adopt children, and in British Columbia Québec, Ontario, and Manitoba, two women can be listed as "parents" on birth certificates<sup>2</sup> (Epstein, 2005; Greenbaum, Hendricks and Piyalé-Sheard, 2002; Séguin, 2002; Wente, 2007).

Despite the legal changes, prominent notions regarding who should and should not be a mother still permeate our society, and reflect underlying social stereotypes of class, race, ethnicity, sexuality, and dis/ability, among other prejudices. Gayle Letherby and Catherine Williams (1999) note

...that the desire of a lesbian or disabled woman who wants a child is likely to be questioned in a way that an able-bodied heterosexual woman's is not. In these circumstances, a woman's inability or 'choice' not to have children may be welcomed by other people rather than defined as sad or selfish in the ways we have experienced, while women subject to racism face further complications. (727)

While it is illegal in Canada to discriminate or withhold publicly medical services based on race, ethnicity, class, sexuality, or dis/ability, American doctors "have typically maintained their right to do so" (Agigian, 2004: 57; also Mammo, 2002). Amy Agigian (2004) elaborates:

Although some physicians continue to 'hold the line' against lesbian AI, others have changed their practices over the years in the direction of equality for lesbians, sometimes stopping short, however, of equal access. (63)

Moreover, clinics and doctors can and do (consciously or subconsciously) make their offices and services not queer-friendly by refraining from publicly discussing or displaying any image or material referencing queer individuals or couples. Not surprisingly, this lack of acknowledgement fits well within the history of medicalization and infertility.

### **Infertility and its medicalization**

The historical and social context from which fertility treatments and the diagnosis of "infertility" have emerged—a context that has become increasingly medicalized—must be understood to completely comprehend the present context and debates. Medicalization "describes a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses or disorders" (Conrad, 1992: 209). Bryan Turner (1995) explains that the medicalization of society involved: "the growth of medical dominance under the auspices of the state, associated with the development of a professional body of knowledge" (208), and "a regulation and management of populations and bodies in the interests of a discourse which identifies and controls that which is normal" (210). While diverse bodies, conditions, and contexts exist, they are all compared to the "norm", and "[s]tanding for normality ... is [often] the white, heterosexual, youthful, middle-class, masculine body" (Lupton, 2000: 58). This undoubtedly sexist and heterosexist medicalized gaze has resulted in increased control over women's and queer bodies (Agigian, 2004; Inhorn,

1994; Luce, 2002; Mamo, 2002; Martin, 2001).

Agigian (2004) notes that, “women’s bodies have been pathologized and treated as inherently sick or sickening depending in the women’s socioeconomic status” (38) and “the medical profession has rarely hesitated to pathologize lesbians as both physiologically and psychologically ill” (46). Nowhere have women been medically managed more than in terms of their relationship to reproduction.

Childbirth and other issues related to reproduction, are often cited as the primary sites of medicalization (Conrad, 1992; Davis-Floyd, 2003; Davis-Floyd and Sargent, 1997; Martin, 2001; Parry, 2004).

[F]eminist scholars and activists argue that nowhere has the medical model been more invasive and harmful than in issues connected to women including pregnancy, childbirth, birth control, abortion, surrogacy arrangements and the mapping of the human genome (Woliver). (Parry, 2004:81)

Marcia Inhorn (1994) explains, “[t]hat women’s bodies are considered the locus of ‘disease’, and hence the site of anxious surveillance and intervention, is apparent in all of these studies of infertility” (460). But how did infertility become medicalized, or as Agigian (2004) asks, “At the risk of belaboring the obvious: Since when has childlessness been an illness?” (49).

Theorists note the switch from childlessness being a social to a medical phenomenon occurred somewhere between the 1960s and 1980s. Linda Whiteford and Lois Gonzalez (1995) explain that:

The development of infertility as a medical condition [was] dependent on medical advances in the understanding of human endocrinology and medical technology. Until the 1950s infertility was often thought of as emotional, rather than medical in origin. Not until the 1960s and 1970s, when the development of synthetic drugs allowed physicians to control ovulatory cycles and the technology of laparoscopy allowed them to see women’s internal reproductive biology, did infertility become medicalized. (29)

In a similar vein, Margarete Sandelowski and Sheryl de Lacey (2002) note that:

Infertility was ‘invented’ with the in vitro conception and birth in 1978 of Baby Louise. That is, in the spirit and language of the Foucauldian-inspired ‘genealogical method’ (Armstrong, 1990), infertility was discovered—or, more precisely, discursively created (Armstrong, 1986; Arney & Bergen, 1984)—when *in*-fertility became possible. Whereas barrenness used to connote a divine curse of biblical pro-

portions and *sterility* an absolutely irreversible physical condition, infertility connects a medically and socially liminal state in which affected persons hover between reproductive inability and capacity: that is, 'not yet pregnant' (Griel, 1991) but ever hopeful of achieving pregnancy and having a baby to take home. (34-35)

In short, medicalizing infertility meant being able to medically assist heterosexual couples so that they were no longer "social problems". In the twenty-plus years since infertility became medicalized, the diagnosis and treatment of infertility has expanded, yet its medicalized mandate to maintain a "norm" continues to be problematic for queer folks seeking treatment whether they experience a condition of infertility or not.

### **Infertility and the queer body**

When infertility is usually discussed and defined, it is in relation to the heterosexual couple. Alternatively, when spoken of in reference to queer folks, it is done so by referring to a lesbian couple needing access to sperm. The literature and popular culture seem to lack the understanding that queer individuals may experience conditions of infertility. This is problematic as not only do the queer stories of infertility become erased, but it also perpetuates a belief among queer individuals that they are completely fertile. Unfortunately, queer folks are more at risk for and experience some conditions of infertility more often than heterosexuals.

Social determinants affect various populations' risk to particular health conditions. "Demographic characteristics such as racial and ethnic minority group membership and lower education and socioeconomic status" have been linked to various conditions of infertility (Matthews, Brandenburg, Johnson and Hughes, 2004:105). Further, sexual orientation and gender identity have been shown to be social determinants of health in relation to conditions of infertility, particularly gynecological cancers, endometriosis, and Polycystic Ovaries (PCO) and Polycystic Ovarian Syndrome (PCOS) (Agrawal et al., 2004;; Bosinski et al., 1997; Futterweit, Weiss and Fagerstrom, 1986; Jussim, 2000; Matthews et al., 2004; McNair, 2003). Common themes throughout the literature relate to the late diagnoses of these conditions, the misinformation regarding screening queer folks for these conditions, and "negative attitudes and experiences within society and the healthcare system [towards queer individuals], which in turn influence[s] patterns of health-seeking behaviour, health-risk factors and specific health issues" (McNair, 2003: 643; see also Matthews et al., 2004; Quinn, 2003; Rosenberg, 2001). I will briefly review these conditions, and discuss their relation to queer folks who were born with a female reproductive system.

Polycystic Ovaries and Polycystic Ovarian Syndrome are conditions that seem to affect queer individuals the most frequently. Similarly, these conditions are among the highest diagnosed conditions of infertility in Western societies

(Agrawal et al., 2004: 1352), with Polycystic Ovarian Syndrome affecting an estimated “20 percent of women” (Kitzinger and Willmott, 2002: 349), and many more women affected solely by Polycystic Ovaries. Polycystic Ovaries (PCOs) are “ovaries with ten or more follicles of between two [and] nine millimetres in diameter” (Agrawal), typically diagnosed via ultrasound. Polycystic Ovarian Syndrome (PCOS) is diagnosed when someone has Polycystic Ovaries as well as hyperandrogenism and/or menstrual abnormalities, and is a condition often accompanied by obesity (Agrawal et al., 2004; Kitzinger and Willmott, 2002; Whiteford and Gonzalez, 1995). According to a report and study conducted by [FIRST NAME?] Agrawal et al. (2004) investigating the prevalence of PCO and PCOS among lesbian and heterosexual women visiting a fertility clinic in Britain, the “self-identified lesbian women had a significantly higher prevalence of PCO and PCOS compared with heterosexual women” (1355). More specifically, “polycystic ovaries were observed in 80 percent of lesbian women and in 32 percent of heterosexual women [, and further] analysis ... revealed that 38 percent of lesbian women and 14 percent of heterosexual women had PCOS” (1354). Moreover, other studies which have been conducted with female-to-male (FTM) trans-folks have also shown higher than normal rates of PCOS. In particular, a 1986 study revealed that PCOS “may be present in [between 25 and 33 percent] of [pre-testosterone treated] female [to-male] transsexuals” (Futterweit, Weiss and Fagerstrom, 1986: 70; similarly Bosinski et al., 1997). These high rates of PCOS and PCO translate into high numbers of individuals who may have problems conceiving and/or carrying babies to term. Agrawal and associates explain that besides having issues conceiving, “women with PCOS may miscarry at a rate of approximately 40 percent, compared with a 15 percent rate in the general population” (1356; also Kitzinger and Willmott, 2002: 349). While no particular explanation has been given as to why or how queer folks are more commonly affected with PCO and PCOS, this is not the case with endometriosis.

Endometriosis “affects between 4 and 10 million women in the United States” (Whiteford and Gonzalez, 1995: 32). It

... is a disease of unknown etiology in which misplaced menstrual tissue identical to the endometrium (the lining of the uterus) grows outside of the uterus in the pelvis.... Endometriosis can cause rubbery bands of scar tissue to form between surfaces inside the body, preventing the fallopian tubes from capturing the egg, thus causing infertility. (32)

Endometriosis is often managed through use of hormones, such as oral contraceptives (Hemmings, 2006; Jussim, 2000). As Judith Jussim (2000) explains, queer folks have a “higher rate of untreated endometriosis [which] may contribute to infertility problems” due to the fact that, “many straight women receive ‘accidental’ treatment for mild endometriosis by spending years on oral

contraceptives.” While PCO, PCOS, and endometriosis are directly linked to infertility, the link between the diagnoses and experiences of gynecological cancers and infertility must not be neglected.

While not a condition of infertility, per se, cancers and treatment of cancers can certainly affect a person’s fertility, especially if the cancer is diagnosed in a later stage and/or affects the cervix, ovaries, or uterus/endometrium. Given the fact that 1) queer folks are more likely than heterosexuals and gender-normative folks to have infrequent or delayed visits to physicians, and 2) more misunderstandings or ignorance exists about conditions and screenings relating to queer health, particular concerns arise regarding cancers and queer folks (McNair, 2003; Matthews et al., 2004; Quinn, 2003; Rosenberg, 2001). “Cancer of the cervix is the third most common cancer world-wide” (Quinn, 2003), and Matthews et al. (2004) identify factors that are closely linked to its predominance as:

failure to receive regular Pap tests, exposure to certain strains of the human papillomavirus (HPV), infection with other sexually transmitted diseases, older age, cigarette smoking, immunosuppressive disorders such as HIV/AIDS, and sexual risk behaviors.” (106; similarly stated by Quinn, 2003)

Further, Michael Quinn (2003) notes a positive relationship between obesity and uterine/endometrial cancer, and a negative correlation between ovarian cancer and pregnancy/birthing, breastfeeding, and consumptions of oral contraceptives (also noted by Rosenberg, 2001).

Unfortunately, most of these links place queer folks at higher risk, because as a population they have been shown to be more obese, have an increased incidence of smoking tobacco, engaging in sexual activity earlier and with less protection (in terms of STIs), have delayed or no childbearing and breastfeeding, and less consumption of oral contraceptives (Jussim, 2000; Matthews et al., 2004; Rosenberg, 2001). Moreover, in regards to cervical cancer screening tests, “findings from several studies suggest lower rates of cervical cancer screening among lesbian women ... [which] has been associated with lower perceived cancer risk [by physicians and lesbians, alike]” (Matthews et al., 2004: 106; also Marrazzo and Stine, 2004; Quinn, 2003; Rosenberg, 2001). In fact,

routine Papanicolaou test screening is performed less frequently among lesbians than national guidelines advise, although sexual transmission of oncogenic genital human papillomavirus (HPV) has been reported to occur between women, and genital HPV may be detected in up to 40 percent of lesbians. (Marrazzo and Stine, 2004: 1298-1299)

Clearly, more education of physicians and queer folks regarding risk factors and screenings for cancers, endometriosis, and PCO/PCOS would be



beneficial to queer folks' fertility and overall health. Moreover, physicians and the general public also need to understand that queer individuals and couples bring unique situations and perspectives to the table, in regards to diagnoses and experiences with infertility.

In "Opting in to Motherhood: Lesbians Blurring the Boundaries and Meaning of Parenthood and Kinship," Dunne (2000) brings up

... [a] fairly unique advantage for women who want to become mothers in a lesbian relationship—if one partner has fertility problems, the other may agree to go through the pregnancy instead. [Dunne cites four] examples ... of partners swapping for this reason, and several others [who] expressed their willingness to do so. (26)

While her point is valid and noteworthy, it is also problematic in that it oversimplifies the context and solution of fertility problems among lesbian couples. To suggest quite simply that if one partner has fertility problems than the other partner can conceive, sweeps over a very emotional issue, and neglects to give due care and attention to the fact that the couple is still dealing with the infertility of one of the partners.

Our society places a lot of emphasis on gender roles and fulfillment in parenting, thus, receiving a diagnosis of infertility is not easy. Guilt and shame are commonly cited feelings associated with infertility (Whiteford and Gonzalez, 1999; Inhorn, 1994). Arthur Griel (2002) notes:

It is clear that infertility brings with it a certain sense of demoralization for ... infertile women.... The experience of infertility is an experience of the failure of the body and self, and the experience of infertility treatment is an experience of frustration, loss of control, and mortification. (113)

I cannot imagine how the experience would be any less tragic for a lesbian, even if her partner could conceive. As one of the couples I interviewed in my research about birthing explained, having a physician and/or fertility specialist suggest that the 'more fertile' partner try to conceive, when the 'less fertile' one wants to, is inappropriate. Not only can the 'infertile' partner be offended because she wants to carry a child, but the 'more fertile' partner can be offended because she had no desire to be pregnant. For people who do not embrace a stereotypical 'feminine' identity, such as butches, genderqueers, or some trans-identified individuals, receiving a diagnosis of infertility may either support their incongruent gender identity, or cause further stress by seemingly stripping them of their agency to hold on to any level of 'female' identity. Either way, receiving a diagnosis of infertility does not seem any easier when one has a partner who *could*, hypothetically, conceive and/or maintain a pregnancy.

Kim Toevs and Stephanie Brill (2002) discuss another potential nega-

tive side-effect of having the second partner conceive and birth a child after the first partner has had problems with infertility. They explain that, “if one partner in a couple was unable to conceive or hold a pregnancy and now the second partner is ready to give birth, this can retrigger the non-pregnant mom’s feelings of inadequacy, resentment, or envy that she isn’t the one who’s about to have the baby” (431). Their point further illustrates another aspect that is often neglected in discussions of infertility—that the feelings of inadequacy or guilt of inability to successfully conceive, and/or maintain a pregnancy, do not end when the couple successfully conceives or takes another route to bring children into their lives. These are not temporary feelings but are instead long lasting, and often re-emerge.

### The non-conclusion

Given the relationship between infertility and queer folks, it is disappointing that no one has investigated the narratives or experiences of those most affected. This dearth, however, reflects a larger neglect that existed until recent years in social sciences, of both women’s voices and stories, and what Inhorn (1994) calls “reproductive morbidity.” She notes:

Within the past two decades, medical anthropology has contributed significantly to the exploration of human reproduction ... [yet] *reproductive morbidity*—including infertility, ectopic pregnancy, and pregnancy loss through miscarriage and stillbirth—has generated mostly silence in the medical anthropology community. (459)

Frank van Balen and Marcia Inhorn (2002) further point out and ask:

Given the utility of infertility as a lens through which so many other compelling issues may be brought into focus, the question becomes, Why the relative neglect of infertility as a legitimate subject of social science inquiry? (5)

Their point is strengthened through the minimal work that has focused on narratives of infertility.

Whiteford and Gonzalez (1995) are among the few social scientists who have researched narratives of infertility. They note that researching the narratives and experiences, and not simply the frequency of diagnoses, of infertility is important because:

the pain, stigma and spoiled identities of women like [the participants of their study on heterosexual women’s experiences of infertility] Laura, Cathy, Sarah and Megan reflect the hidden burden of infertility. Their narratives, their ‘truths’, their stories reveal the gulf that separates the medical industrialized ‘reality’ of infertility, from its lived experience...

[Moreover,] the story that biomedicine tells about women's experiences of infertility can be countered by the stories women tell about their own infertility. Their stories provide us with substantiation of alternative visions of reality; visions unlike the dominant medical story produced and propagated by those in biomedicine. (35)

Countering the “erasure” that has occurred with these previously untold narratives, and making them part of the “official story”, not only “provide[s] us with substantiation of alternative visions of reality” but it also offers unique insights to broader issues.

Due to race, ethnicity, class, culture, sexuality, and gender, a variety of realities exist. Moreover, people's experiences are further influenced by their diverse bodies, their access to resources, and negotiated relations within their cultural situations. Acknowledging the plethora of experiences and narratives, and ensuring none are erased is a daunting task. Its benefits with respect to the new perspectives and insights that can be gained are, however, immeasurable. With respect to queer infertility, the complex social ideas regarding sexual orientation and who should and should not become mothers, and the presence of two-women in a queer relationship striving to become mothers *together*, challenge the *status quo*. Studying queer folks' experiences of infertility, therefore, not only benefits queer folks who have or will experience infertility, but it also provides unique perspectives on gender and social expectations regarding sexuality, reproduction, kinship, and of course mothering. These unique perspectives allow us to challenge our deeply seated cultural and personal views, and to re-examine the stereotypes and assumptions that underlie them. This in turn, hopefully brings more understanding and acceptance of the diverse experiences and choices people make and live in our society. And ultimately, is that not what we all strive for?

<sup>1</sup>These interviews were conducted as part of my Master's research and thesis on “Queer Couples' Narratives of Birthing.” For more on that research, please see the completed thesis (Walks, 2007).

<sup>2</sup>While the possibility for two women to be named on birth certificates exists in these provinces, the situations in which this can legally occur differs from province to province, depending on whether the women are married (to each other) and/or the anonymity of their donor.

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