Issue 7

Infertility and its management

The ethics & social issues in reproductive medicine

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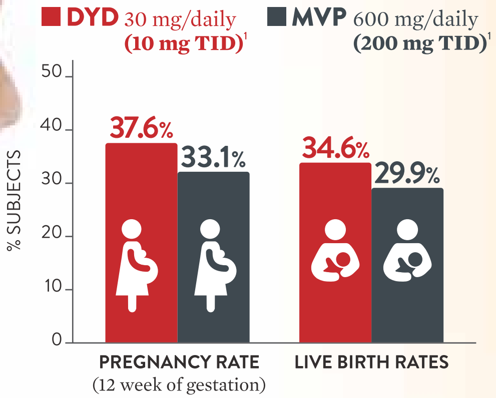

ORAL DYDROGESTERONE MAY REPLACE MVP

AS THE STANDARD OF CARE FOR LUTEAL PHASE SUPPORT IN IVF DUE TO:[1]

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Improved patient compliance[1]

ART: Assisted reproductive technology. **LPS:** Luteal phase support. **TID:** Ter in die (Three times a day). **IVF:** In vitro fertilisation. **MVP:** Micronized vaginal progesterone. **DYD:** Dydrogesterone. † Schindler AE. Progestational effects of dydrogesterone in vitro, in vivo and on the human incidence of miscarriage endometrium. Maturitas.2009; 65(1):S3–S11. ‡ Internal calculations based on Quintiles IMS database, IMS Health Analytics Link MAT03 2017. * Data on file.

Reference: 1. Tournaye H. Sukhikh GT, Kahler E, Griesinger G. Aphase 3 randomised controlled trial comparing the efficacy, safety and tolerability of oral dydrogesterone versus micronized vaginal progesterone for luteal support in in vitro fertilization. Human reproduction, Vol 32, no 5 pp.1019-1027,2017.

Abbreviated Prescribing Information: Dydrogesterone Tablets IP **Duphaston**®. **LABEL CLAIM:** Each film coated tablet contains: Dydrogesterone IP 10 mg, Excipients q.s. Colour: Titanium dioxide IP. **INDICATION:** Progesterone deficiencies: Treatment of dysmenorrhoea; Treatment of endometriosis; Treatment of secondary amenorrhoea; Treatment of irregular cycles; Treatment of dysfunctional uterine bleeding; Treatment of pre-menstrual syndrome; Treatment of threatened miscarriage; Treatment of habitual miscarriage; Treatment of infertility due to luteal insufficiency; Luteal support as part of an Assisted Reproductive Technology (ART) treatment and Hormone replacement therapy. **DOSAGE AND ADMINISTRATION:** Dysmenorrhoea: 10 or 20 mg dydrogesterone per day from day 5 to day 25 of the menstrual cycle. Endometriosis: 10 to 30 mg dydrogesterone per day from day 5 to day 25 of the cycle or continuously. Dysfunctional uterine bleeding: When treatment is started to arrest a bleeding episode, 20 or 30 mg dydrogesterone per day is to be given for up to 10 days. Secondary amenorrhoea: 10 or 20 mg dydrogesterone per day, to be given daily for 14 days during the second half of the theoretical menstrual cycle to produce an optimum secretory transformation of an endometrium that has been adequately primed with either endogenous or exogenous estrogen. Pre-menstrual syndrome: 10 mg dydrogesterone twice daily starting with the second half of the menstrual cycle until the first day of the next cycle. The starting day and the number of treatment days will depend on the individual cycle length. Irregular cycles: 10 or 20 mg dydrogesterone per day starting with the second half of the menstrual cycle until the first day of the next cycle. The starting day and the number of treatment days will depend on the individual cycle length. Threatened miscarriage: An initial dose of up to 40 mg dydrogesterone may be given followed by 20 or 30mg per day until symptoms remit. Habitual miscarriage: 10 mg dydrogesterone twice daily until the twentieth week of pregnancy. Infertility due to luteal insufficiency: 10 or 20 mg dydrogesterone daily starting with the second half of the menstrual cycle until the first day of the next cycle. Treatment should be maintained for at least three consecutive cycles. Luteal support as part of an Assisted Reproductive Technology (ART) treatment: 10 mg Dydrogesterone three times a day (30 mg daily) starting at the day of oocyte retrieval and continuing for 10 weeks if pregnancy is confirmed. Hormone replacement therapy: Continuous sequential therapy: An estrogen is dosed continuously and one tablet of 10mg dydrogesterone is added for the last 14 days of every 28-day cycle, in a sequential manner. Cyclic therapy: When an estrogen is dosed cyclically with a treatment-free interval, usually 21 days on and 7 days off. One tablet of 10 mg dydrogesterone is added for the last 12 -14 days of estrogen therapy. **CONTRAINDICATIONS:** Known hypersensitivity to the active substance or to any of the excipients. Known or suspected progestogen dependent neoplasms (e.g. meningioma). Undiagnosed vaginal bleeding. Treatment for luteal support as part of an Assisted Reproductive Technology (ART) treatment should be discontinued upon diagnosis of abortion /miscarriage. Contraindications for the use of estrogens when used in combination with dydrogesterone. **WARNINGS & PRECAUTIONS:** Before initiating dydrogesterone treatment for abnormal bleeding the etiology for the bleeding should be clarified. Breakthrough bleeding and spotting may occur during the first months of treatment. If breakthrough bleeding or spotting appears after some time on therapy, or continues after treatment has been discontinued, the reason should be investigated, which may include endometrial biopsy to exclude endometrial malignancy. If any of the following conditions are present, have occurred previously, and/or have been aggravated during pregnancy or previous hormone treatment, the patient should be closely supervised. It should be taken into account that these conditions may recur or be aggravated during treatment with dydrogesterone and ceasing the treatment should be considered: Porphyria, Depression and Abnormal liver function values caused by acute or chronic liver disease. **PREGNANCY & LACTATION:** It is estimated that more than 10 million pregnancies have been exposed to dydrogesterone. So far there were no indications of a harmful effect of dydrogesterone use during pregnancy. Dydrogesterone can be used during pregnancy if clearly indicated. Breastfeeding: No data exist on excretion of dydrogesterone in mother's milk. Experience with other progestogens indicate that progestogens and the metabolites pass to mother's milk in small quantities. Whether there is a risk to the child is not known. Therefore, dydrogesterone should not be used during the lactation period. Fertility: There is no evidence that dydrogesterone decreases fertility at therapeutic dose. **ADVERSE REACTIONS:** The most commonly reported adverse drug reactions of patients treated with dydrogesterone in clinical trials of indications without estrogen treatment are migraines/headache, nausea, menstrual disorders and breast pain/tenderness. Undesirable effects in adolescent population: Based on spontaneous reports and limited clinical trial data, the adverse reaction profile in adolescents is expected to be similar to that seen in adults. Undesirable effects that are associated with an estrogen-progestogen treatment (see also 'Warnings and Precautions' and the product information of the estrogen preparation): Breast cancer, endometrial hyperplasia, endometrial carcinoma, ovarian cancer; Venous thromboembolism; Myocardial infarction, coronary artery disease, ischemic stroke

Issued on: Date (27/06/2018)

Source: Prepared based on full prescribing information (version 6) dated 27/Jun/2018

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December 2018

Springer Healthcare

This edition is created in India for free distribution in India.

This edition is published by Springer Nature India Pvt. Ltd.
Registered Office: 7th Floor, Vijaya Building, 17, Barakhamba Road, New Delhi 110 001, India.
91 (0) 11 4575 5888
www.springerhealthcare.com

Part of the Springer Nature group

Printed and Bound by: Hi-Tech Printing Services Pvt. Ltd., Mumbai, India.

Preface

This book and its chapters argue to expand the definition of clinical infertility because the current definition is discriminatory, creating unequal access to assisted reproductive technology (ART) and preventing insurance coverage of ART for people not in heterosexual, cisgender couples. Others have argued that relational infertility should be recognized as its own diagnosis. The authors instead argue for an expansion of the current clinical definition of infertility to treat socially infertile people equally, rather than creating separate categories of infertility that may perpetuate stigma and barriers to healthcare. Specifically, the focus of discussion is on how the clinical definition of infertility is interpreted and applied by infertility specialists and insurance companies.

The authors have limited the discussion to single cisgender women and cisgender lesbian couples. Single men, gay male couples, and transgender individuals without internal female reproductive organs require the assistance of a gestational surrogate, which is not currently covered by infertility mandate of any state and is thus beyond the scope of this book. Furthermore, a lesbian couple consisting of a transgender woman and a cisgender woman may be able to use sperm from the transgender woman, which may not require medical intervention.

While infertility is often viewed as a woman's problem, past research has shown that infertility is not an individual experience, but instead it is a shared experience between a couple. As such, while this book is primarily an exploration of women's experiences of infertility, as authors we felt it relevant to discuss social and ethical issues in infertility in terms of their meaning in the women's journeys.

Happy reading!

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Expanding the Clinical Definition of Infertility to Include Socially Infertile Individuals and Couples

Weei Lo, Lisa Campo-Engelstein

Introduction

The Centers for Disease Control currently defines infertility as “not being able to get pregnant (conceive) after one year (or longer) of unprotected sex” (CDC 2017). “Unprotected sex” here refers exclusively to vaginal-penile intercourse. This definition is widely used in the medical literature and is used as the clinical definition of infertility by professional medical organizations like the American Society of Reproductive Medicine (ASRM); ASRM defines infertility as “the inability to achieve pregnancy after one year of unprotected intercourse” (ASRM 2012). Yet, this clinical definition of infertility excludes people not in heterosexual, cisgender couples. This means that heterosexual single cisgender individuals and lesbian, gay, bisexual, transgender, and queer (LGBTQ) individuals and couples are technically not able to be diagnosed and treated as infertile due to their relationship status. Infertility due to relationship status is known as relational infertility or social infertility (Murphy 1999) and can be contrasted with physiological infertility, which is infertility due to a medical condition (e.g., low sperm count, blocked fallopian tube). Individuals can have both social infertility and physiological infertility. For example, a

W. Lo
Albany Medical College, New York, USA
e-mail: low@amc.edu

L. Campo-Engelstein (✉)
Alden March Bioethics Institute, Department of Obstetrics and Gynecology, Albany Medical College, Albany, NY, USA
e-mail: campoel@amc.edu

lesbian woman can be socially infertile because she is in a same sex relationship but also physiologically infertile due to endometriosis.

In this paper, we argue to expand the definition of clinical infertility because the current definition is discriminatory, creating unequal access to ART and preventing insurance coverage of assisted reproductive technology (ART) for people not in heterosexual, cisgender couples. Others have argued that relational infertility should be recognized as its own diagnosis (Rank 2010). We instead argue for an expansion of the current clinical definition of infertility to treat socially infertile people equally, rather than creating separate categories of infertility that may perpetuate stigma and barriers to healthcare. Specifically, we focus our discussion on how the clinical definition of infertility is interpreted and applied by infertility specialists and insurance companies in the United States. We will limit our discussion to single cisgender women and cisgender lesbian couples. Single men, gay male couples, and transgender individuals without internal female reproductive organs require the assistance of a gestational surrogate, which is not currently covered by infertility mandate of any state and is thus beyond the scope of this essay.[1] Furthermore, a lesbian couple consisting of a transgender woman and a cisgender woman may be able to use sperm from the transgender woman, which may not require medical intervention.

Discriminatory Definition of Infertility

One major problem with the current clinical definition of infertility is that it automatically excludes anyone not engaging in vaginal-penile intercourse from being diagnosed as infertile. While heterosexual intercourse is the most common way people become pregnant and the failure to achieve a pregnancy through heterosexual intercourse can be an indicator of infertility, there are various medical technologies that can also demonstrate infertility in the absence of heterosexual intercourse. For example, healthcare professionals can test patients' hormonal levels and the quality

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[1] Although we will not discuss the ethical issues surrounding surrogacy, it is important to note that heterosexual couples who meet the current clinical definition of infertility may also benefit from surrogacy coverage. For instance, a woman who underwent a hysterectomy due to endometrial carcinoma may wish to start a family after she is cancer-free. Even if she has the foresight, opportunity, and means to preserve her eggs, she cannot carry a pregnancy due to her surgery and will need to seek the assistance of a surrogate.

and quantity of gametes in order to make a diagnosis of infertility. Yet, the definition of infertility requires patients to partake in a *specific* type of sexual activity—i.e., vaginal-penile intercourse—in order to make a diagnosis. The requirement to engage in heterosexual intercourse for the sole purpose of proving a medical diagnosis is discriminatory toward single, heterosexual women and lesbian women and couples. People's participation in a specific action that violates their personal beliefs and/or identity should not be mandatory for any medical diagnosis or treatment when alternative diagnostic tools and treatments exist. The heteronormative bias of this definition of infertility assumes that reproduction only occurs via vaginal-penile intercourse, thereby excluding single women and lesbians from consideration.

Although LGBTQ or single cisgender people are not forced to engage in vaginal-penile intercourse to establish infertility, the criterion of vaginal-penile intercourse has the de facto effect of excluding this population. For many individuals who have a strong desire for gestating genetically related children, especially those who live in states with limited ART access for people not in heterosexual relationships, the only way to conceive may be to engage in vaginal-penile intercourse. The strong desire for gestational and genetic parenthood may lead people to make choices they would not otherwise make if they had more options, including entering mixed-orientation relationship, when two partners have different sexual orientations (Clemons 2016; Tatlow 2015). In countries that criminalize homosexuality, refuse to recognize same-sex marriage, and have sparse ART access, a heterosexual relationship (i.e., vaginal-penile intercourse) remains the only plausible and legal method for their citizens to conceive a child. China is one such an example, where 80% of, or 16 million, gay men marry women to conceive children and/or fulfill cultural expectations. Although there is less data on lesbian women entering marriage with men for the same reason, it is a known practice in the LGBTQ community in China (Davison 2011; Tatlow 2015). Without plausible options to access ART, partly perpetuated by the discriminatory definition of infertility, people across the globe may engage in unwanted vaginal-penile intercourse to become genetic parents.

Some critics may argue that engaging in heterosexual intercourse is not an unfair demand because being single or lesbian is a "lifestyle" choice and women could just as easily choose to participate in vaginal-penile intercourse. This criticism is often based in religious or philosophical objections to homosexuality and “nontraditional” gender norms, rather than grounded in empirical data. The American Psychological Association asserts that most people have little or no sense of choice about their sexual orientation (APA 2008). Likewise, single heterosexual woman may not be able to find a suitable male partner, which has contributed to the burgeoning egg freezing market as a way to anticipate and prevent age-related infertility (Hodes-Wertz *et al.* 2013). Even if we were to grant these critics, their objection that being single or lesbian is a choice, this in no way justifies requiring people to engage in unwanted sexual activity to establish a medical diagnosis when other options exist. The objection that women can “choose” to engage in heterosexual intercourse is simply a way of affirming the heteronormative belief that reproduction should be limited to heterosexual couples and should exclude single women and lesbian couples.

We recommend changing the clinical definition of infertility to “a condition of an individual with intent of parenthood but unable to produce conception due to social or physiological limitations within a period of twelve months.” This expanded definition of infertility will push the medical community to recognize social infertility as a clinical diagnosis that is treatable with many of the same options already available for physiological infertility. Broadening the term will also inform and encourage the policy makers and insurance companies to cover social infertility under existing infertility insurance mandates.

Since the current clinical definition of infertility depends on heterosexual intercourse, it assumes that the only cause of infertility is physiological. Individuals with physiological infertility have reduced fertility due to factors indicated by physiological causes. Examples of physiological infertility could include a woman with chronic pelvic inflammatory disease secondary to a gonorrhea infection or a man with a low sperm count. This population is currently the only group recognized by the clinical definition of infertility. For 30% of heterosexual couples who are involuntarily childless, no medical cause can be identified after the standard infertility evaluation (The Practice Committee of the American Society for Reproductive Medicine 2013). These couples are diagnosed with “unexplained infertility,” with the presumption that there is a physiological etiology, but it cannot be identified. Because they meet the criteria of the clinical definition of infertility, heterosexual couples with unexplained infertility are presented with the same treatment options as other physiologically infertile heterosexual couples.

It is sometimes mistakenly assumed that physiological infertility affects only heterosexual couples, and social infertility is limited to LGBTQ couples. Yet, physiological infertility and social infertility are not mutually exclusive. While single women and lesbian couples are socially infertile due to their relationship status, they may also suffer from physiological infertility. Heterosexual couples can also experience both physiological infertility and social infertility. For example, take the case of a heterosexual couple in which the man has poor sperm motility (physiological infertility) and the woman has a strong preference against vaginal intercourse due to a history of sexual trauma (social infertility). Both their physiological and social infertility contribute to their difficulty conceiving as a couple. Heterosexual individuals can be physiologically fertile but socially infertile as in the case of a single heterosexual woman.

It was not until 2013 that the ASRM formally recognized the medical needs of socially infertile people and discouraged fertility specialists from restricting ART access to this population (The Ethics Committee of the American Society for Reproductive Medicine 2013). Although it was an important step for the ASRM to strongly recommend nondiscriminatory access to ART, regardless of a patient's sexual orientation or relationship status (The Ethics Committee of the American Society for Reproductive Medicine 2013), the organization stopped short of redefining clinical infertility. While this policy statement may influence the actions of healthcare providers, it does not necessarily affect the insurance industry. In fact, despite the reproductive medicine community's recent acknowledgment and acceptance of social infertility—including the World Health Organization's announcement in 2016 that it would expand its definition of infertility to include single individuals and LGBTQ individuals (Bodkin 2016)—health insurance companies in the United States still base infertility coverage on the narrow clinical definition, generally denying ART coverage to individuals with social infertility.

The Impact of Infertility

One common criticism of ART coverage is that infertility, and especially social infertility, is not a "real" disease because it does not cause physical harm. It is important to recognize that some diseases that cause physiological infertility may also manifest physical symptoms and are therefore indicated for medical interventions. For instance, in some cases, endometriosis can cause dyspareunia, or pelvic pain, and can also potentially cause infertility. A woman who is experiencing pelvic pain should clearly receive treatment for such pain. However, if this same woman has no physical symptoms, there would be no reason to undergo treatment unless she intends to conceive a child. Indeed, most physiologically infertile women will never know they are infertile until they attempt to become pregnant. Can a woman in a heterosexual relationship with no desire to have a biological child with her male partner suffer from infertility? The diagnosis of infertility and the decision to seek treatment rely heavily on social and situational factors and the individual's desire to become a parent. A diagnosis of physiological or social infertility may not have much impact on those with no desire to have children. However, the same diagnosis would keenly impact another woman whose identity and life goals include becoming a genetic mother. Both the intent to achieve pregnancy and the inability to conceive are necessary for a clinician to diagnose someone with infertility.

Some dismiss the desire to have biological children as unimportant or at least not within the medical purview. Yet, this criticism fails to recognize the psychological harms associated with infertility. According to a Pew Research Center report in 2011, 27% of childless men and 36% of childless women between ages 15 and 44 reported "it would bother them a great deal" if they never have children (Livingston and Parker 2011). In another 2010 survey, Pew found 60% of surveyed childless women under the age of 50 and 63% of childless men under age of 60 reported they want to have children one day, regardless of their marital status. Up to 83% of unmarried individuals who would like to get married in the future indicated that they wanted children one day. But even among single people who have no plans for marriage, 31% of them still reported a wish to have children some day (Pew Research Center 2010).

Infertility creates a low-control stress situation, in which individuals lack the ability to influence the outcome (Terry and Hynes 1998), and is a significant psychosocial stressor comparable to death of a family member or somatic disease such as cancer or HIV (Baram *et al.* 1988; Domar *et al.* 1993). In previous studies on involuntary childlessness, individuals who meet the clinical definition of infertility have shown increased risk of depression, anxiety, guilt, grief, sexual problems, reduced relationship satisfaction, and marital distress (Kraft *et al.* 1980; Möller and Fällström 1991; Lukes and Vacc 1999; Peterson *et al.* 2003; Sundby *et al.* 2007; Luk and Loke 2015). Infertility also contributes to social isolation, reduced self-esteem, loss of identity, and poor body image (Luk and Loke 2015; Whiteford and Gonzalez 1995; Wirtberg *et al.* 2007). Chronic adverse effects on interpersonal and social relationships secondary to distress precipitated by infertility have been reported even 20 years after failed pregnancy attempts (Whiteford and Gonzalez 1995). Despite significant emotional distress, many infertile women do not seek professional counseling or participate in support groups (Sundby *et al.* 2007), which may be because of the shame and stigma associated with infertility. Not surprisingly, involuntarily childless individuals reported reduced quality of life in comparison with individuals who have children (Chachamovich *et al.* 2010).

Much of medicine today focuses on treating conditions that may not be life-threatening but that significantly impact people's quality of life, such as seasonal allergies, back pain, anxiety, poor vision, and sexual dysfunction; and infertility is no different. The psychosocial harms of infertility are not limited to heterosexual, cisgender couples. All individuals, regardless of their relationship status, who want biological parenthood but are unable to achieve it may suffer from infertility. Socially infertile women have the same intent to become biological parents as their physiologically infertile counterparts and can suffer the same psychological harms associated with infertility. For these reasons, we believe social and physiological infertility should be recognized as the same illness with different etiologies.

Although heterosexual, cisgender couples are culturally elevated as ideal parents, or at least the norm, many single individuals and LGBTQ couples also desire parenthood. Furthermore, contrary to dominant cultural narratives, single individuals and LGBTQ couples can be good parents, and their children are generally just as well adjusted as children raised in heterosexual, two-parent households.

As of 2008, 25% of the American children lived in single-family homes (Pew Research Center 2010). The increase in single-parent households in the United States reflects changes in family structure. Many single families have extended social support such as aunts, uncles, grandparents, and Godparents that help the single parent to raise the children. Although single-parent households historically have faced significant stigma, 86% of participants surveyed in 2010 consider a single person with a child to be a family (Pew Research Center 2010), which shows that the cultural definition of family has expanded to include single-parent households. The majority of single-parent families are single mothers. Traditionally, these single-mother families have been associated with divorce, separation, or unplanned pregnancy. However, there is a growing trend of single motherhood termed "solo mothers." These are women without a partner who chose to enter parenthood and conceive children through donor insemination (Weissenber *et al.* 2007). A sharp increase of this "nonstandard request" at the fertility clinic has been observed in recent years as more single women decided to pursue single motherhood before their fertility declines (Golombok *et al.* 2016). Many of the 31% of surveyed heterosexual single persons who wanted children one day but did not want to marry would likely use ART if they were ultimately unable to find a willing and appropriate opposite-gender partner. Their desire to have biological children is no different than individuals in heterosexual relationships who are using ART due to physiological infertility.

Although children raised in a single-family home may face some disadvantages such as less parental time and lack of two-adult income, children raised in stable single family do not suffer from significantly worse cognitive development, health outcome, or school performance compared to children raised in two-family homes. In fact, family stability appears to be a more important factor in children outcome. Children raised in stable single-parent homes, after taking consideration of confounding factors, show no significant differences in cognitive development or behavior issues compared to children raised in stable two-parent homes (Waldfogel *et al.* 2010). Similarly, the maternal education level appears to have a stronger correlation to a child's school performance than the family structure (Amato *et al.* 2015). Children raised in a loving, supportive, and stable single-parent home with extensive social support network are therefore not at a significant disadvantage compared to children raised in other family structures.

Just like many heterosexual single individuals, many LGBTQ individuals desire biological parenthood. According to the Pew survey, 28% of childless LGBT adults under age 60 would like to have children one day, while 34% remained undecided (Pew Research Center 2013). Although the stigma in our society against single parenting appears to be in decline, the prejudice against same-sex couple parenting remains high. According to the 2010 Pew Research Center survey, only 63% of respondents considered a same-sex couple with children to be a family, compared to the 86% of respondents considered single parent with children to be a family (Pew Research Center 2010). This indicates a persistent bias against LGBTQ couples. The legalization of same-sex marriage in the United States has encouraged LGBTQ couples to engage in heteronormative activities, such as starting two-parent families and raising children (Hopkins *et al.* 2013). Interestingly, the public is more likely to classify a same-sex couple as "a family" when they are raising children together. Only 45% surveyed respondents considered same-sex couples without children a family, in comparison with 63% for same-sex couples with children. The presence of children in a same-sex household appears to have a legitimizing effect on the relationship and allows them to be further assimilated into society. This is yet another reason why same-sex couples may wish to have biological children.

Societal arguments against LGBTQ parents and families are often disguised as concern for the children but are constructed to justify discrimination against LGBTQ parents in an effort to maintain a heterosexist status quo (Clarke 2001). In a study reviewing 21 empirical studies on the outcome of children born to planned lesbian families compared to children born to planned heterosexual families, there have been no significant differences in the cognitive functioning, emotional development, or peer relationships. Children from the planned lesbian household, however, showed less aggressive behaviors. Mothers from these planned lesbian families also shared parenting responsibilities more equally, with a higher quality of parent-child interaction and parenting awareness skills (Bos *et al.* 2005).

Even if one is supportive of single women and LGBTQ couples having children, it is frequently suggested in public discourse that people suffering from infertility (physiological or social) should choose to adopt rather than undergo ART (Davenport 2016). However, the process of adoption is also costly and time-consuming. Depending on the type of adoption and adoption agency, it may cost up to $50,000 (Child Welfare Information Gateway 2016). Although there are loans, grants, and tax credits available to lessen the cost of adoption, the financial burden of adoption is comparable to the cost of undergoing at least two ART cycles. Since infertility is a long-term stressor associated with personal identity and the social expectation of one's ability to conceive a biological child, adoption may not necessarily resolve the psychological and emotional burden of infertility. Moreover, some couples highly value both partners sharing biological kinship with each of their children, thus making adoption a less appealing option to start a family. Lesbian couples can both share biological parenthood with their children, which is typically defined as experiencing gestation and/or being genetically related to the child, via in vitro fertilization (IVF) by fertilizing one partner's oocyte with donor sperm and transferring the embryo to the other partner for gestation (Marina *et al.* 2010).

Additionally, single women and lesbian couples may face additional barriers in trying to adopt since some adoption agencies will not place children with single parents and LGBTQ couples. A single individual may face significant difficulty adopting children due to the social stigma attached to single parenthood, especially against single women (Pakizegi 2007). LGBTQ couples may encounter homophobia and heterosexism biases present on the individual, interpersonal, and organizational levels of an adoption agency that prevent children placement (Ryan *et al.* 2004).

Insurance Coverage for Social Infertility

Demonstrating medical necessity is the main hurdle many single women and lesbian couples face when seeking reproductive assistance, especially in states without an infertility insurance mandate. Because social infertility is currently not a recognized medical condition nor is it part of the broader diagnosis of infertility, it is deemed medically unnecessary by the insurance companies. Broadening the current clinical definition of infertility to include social as well as physiological infertility recognizes that single people and LGBTQ couples will likely need the assistance of a fertility expert since they will not be able to conceive through sexual intercourse.

While this change in the clinical definition of infertility may seem too radical for some, it is worth noting that infertility is a relatively new medical condition. A heterosexual couple's inability to conceive a child was historically considered to be a private issue, not a public or medical problem. It was not until the 1950s, in conjunction with the development of fertility medications, that infertility became a recognized medical condition (Greil 1991). The labeling of physiological infertility as a medical condition meant that heterosexual couples were justified in seeking and receiving medical assistance in having biological children. Social infertility is slowly becoming recognized, especially as prominent lesbian celebrities, such as Wanda Sykes and Melissa Etheridge, publicly discuss using ART to have children (Long 2015). Similar to physiological infertility, social infertility has entered the public consciousness as a social issue that can be solved with the same medical technologies that many heterosexual couples have had access to for years.

Once social infertility becomes part of the clinical definition of infertility as a medical diagnosis, socially infertile individuals can become eligible for insurance coverage (though perhaps only in states where infertility is covered by insurance), and their reproductive goals would be legitimized by the medical community (Murphy 1999).Without insurance coverage, only the privileged and wealthy can afford ART (Greil *et al.* 2011; Bell 2016). A single round of IVF is estimated to range between $12,400 and $27,000 for women without insurance coverage (Nachtigall *et al.* 2012). The per successful outcome (i.e., a live birth baby), however, may cost over $61,000 (Katz *et al.* 2011).

According to the FertilityIQ employment report, less than 27% surveyed Americans who underwent fertility treatment received insurance coverage for the service (FertilityIQ 2017). In the states that mandate the group insurers to offer variable degree of infertility benefit to employers, religiously affiliated and small employers are generally exempted as well (Devine *et al.* 2014). Even in the states with a comprehensive fertility insurance mandate, ART is covered by insurance solely for heterosexual couples based on the current clinical definition of infertility. This narrow definition allows insurance companies to deny ART coverage to paying members who do not engage in coupled heterosexual intercourse while providing coverage to members who do. Without adequate insurance coverage, the unaffordability of ART procedures becomes a barrier to single women and lesbian couples seeking to start a family via reproductive assistance.

In the United States, only 15 states currently require health insurers to offer coverage for infertility diagnosis and treatment (RESOLVE 2017).[2] Of these 15 states, Massachusetts offers the most inclusive health insurance coverage due to the 2010 amendment that changed the definition of infertility to "a condition of an individual who is unable to conceive or produce conception during a period of year if the female is under the age of 35, or during a period of six months if the female is over the age of 35." The Massachusetts definition of infertility does not rely on the "married individual" qualifier found in the Rhode Island mandate or the "unprotected intercourse" requirement of the New Jersey mandate (National Conference of State Legislature 2017). The Massachusetts mandate also covers both the primary beneficiary and her or his spouse. There are also fewer limitations on the types of procedures or number of treatment cycles a woman can undergo under the Massachusetts mandate (Basco *et al.* 2010). The Massachusetts review system allows new medical technologies to be incorporated into coverage as they mature. Most importantly, Massachusetts has broadened the coverage for single women and lesbian couples who have attempted low-tech conception methods (Health Policy Commission Office of Patient Protection 2013).[3]

Besides Massachusetts, Illinois is another state to provide a potential pathway for lesbian couples and single women to resolve childlessness via ART. The Illinois mandate covers women after "efforts to conceive as a result of one year of medically based and supervised methods of conception, including artificial insemination, have failed and are not likely to lead to a successful pregnancy" (Illinois Department of Insurance 2014). In April 2017, New York State became the third state to mandate infertility

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[2] The 15 states that currently require health insurers to offer coverage for infertility diagnosis and treatment are Arkansas, California, Connecticut, Hawaii, Illinois, Louisiana, Maryland, Massachusetts, Montana, New Jersey, New York, Ohio, Rhode Island, Texas, and West Virginia.

[3] Although the Massachusetts infertility mandate has the most extensive ART coverage in the United States, it still does not include surrogacy. Single men and gay couples therefore will not receive coverage for all of the technologies and services they need to build a biological family.

coverage for lesbian couples and single women by insurance companies (New York State Financial Services 2017). However, the current clinical definition of infertility still perpetuates the stigma and bias against single women and lesbian couples, potentially delaying their access to ART. As of 2017, only Massachusetts, Illinois, and New York mandate broad insurance coverage of all women regardless of their relationship status. A more inclusive approach to infertility insurance coverage in other states would benefit socially infertile individuals throughout the country, especially for non-hetero, non-coupled, and nontraditional families.[4]

One potential concern with expanding the clinical definition of infertility is that it may cause insurance premiums to increase in states with infertility insurance coverage. If social infertility became a recognized and treatable medical condition, it would be hard to justify the continued exclusion of single individuals and LGBTQ couples, especially since these previously excluded populations have already been paying the same premiums to support the cost of infertility treatment for heterosexual couples. It is also worth noting that while ART is quite expensive for individuals, it makes up a very small percentage (only 0.06% in 2009) of the total healthcare expenditure in the United States (Chambers *et al.* 2009). Another potential concern with a broader definition of infertility is that the utilization of ART will also likely increase. Yet, many other factors have recently contributed to an increased utilization of ART, such as the normalization of such technologies, increased insurance coverage for ART (due to state mandates and insurance company policy changes), and "delayed" childbearing among women. Continuing to deny ART to single women and LGBTQ couples while simultaneously expanding its use among other groups does not seem to be a tenable position. Expanding the definition of infertility may entail financial implications. However, we should not allow speculative economic considerations to prevent us from upholding reproductive justice and providing access to ART for single and lesbian women.

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[4] Male infertility care is often overlooked in discussions of infertility. Although almost half of the infertility cases among heterosexual couples are caused by male factors, only six states (California, Connecticut, Massachusetts, New Jersey, New York, and Ohio) mandate coverage for male infertility care. Two other states (Montana and West Virginia) mandate undefined infertility services only for health maintenance organization plans. Among these states, Massachusetts once again provides the most comprehensive coverage for male infertility treatment, including sperm procurement, processing, banking, as well as reversal of elective sterilization (Dupree 2016). However, the Massachusetts coverage plan is designed only for males in heterosexual relationships.

Conclusion

In this chapter, we have claimed that social and physiological infertility may be viewed as the same illness with different etiologies. The recognition of physiological infertility as a medical condition has allowed some heterosexual couples to receive insurance coverage for certain types of ART. Only Illinois, Massachusetts, and New York provide some insurance coverage for the socially infertile women. The remaining 12 states that currently also require some insurance coverage for infertility unfortunately exclude single individuals and the LGBTQ community. The current definition of infertility is written under a heteronormative assumption of what constitutes a family and prevents socially infertile people from accessing treatments that may meet their medical needs.

We have proposed an expanded clinical definition of infertility that recognizes the contribution of both social and physiological factors to infertility. We asserted that a more inclusive definition of infertility will provide single individuals and LGBTQ couples in states with infertility insurance mandates improved access to ART. Future work is needed to examine and compare the psychosocial and emotional effects of involuntary childlessness among single individuals, LGBTQ couples, and heterosexual couples. The impact of infertility may have different or worse effects on the socially infertile as they face many different hurdles to achieving biological parenthood.

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Unconceived Territory: Involuntary Childlessness and Infertility Among Women in the United States

Kristin J. Wilson

“I was too busy having fun,” a co-worker in her mid-60s explained her childlessness to me though I had not asked. When I began researching childlessness, it became commonplace for women who were not mothers to justify their status to me. The co-worker went on to tell me that she never made a decision not to procreate. Instead, she enjoyed surfing with her partner and riding equestrian dressage and it did not occur to her until she entered menopause that she had not expended any energy weighing whether or not to have children. The prevailing pronatalist culture of the United States contributes to the social stigma of childlessness and, for many (but not all), to the emotional pain of infertility. This widespread expectation that women have children accounts for why I receive so many unsolicited explanations from women who do not have any and virtually none from women who do. Yet, to understand infertility and childlessness, it is important to recognize the diversity in these experiences.

Many women forgo motherhood but they still make children central in their lives, rendering problematic the common terms “childless” and “childfree.” Some women remain ambivalent about childlessness, whether or not they have chosen to be childless (Wilson 2014). Indeed, voluntariness is not always clear. And infertility is a surprisingly relative concept that can become meaningless in some circumstances and all consuming and life changing in others. The overlapping distinctions between fertility and infertility and voluntary childlessness and involuntary childlessness tend to belie and complicate research results. In this chapter, I outline and problematize these concepts, then argue for the crucial role of qualitative

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K. J. Wilson (✉)
Anthropology Department, Cabrillo College, Aptos, CA, USA
e-mail: krwilson@cabrillo.edu

research and some benefits of ontological analysis in exploring how childlessness and infertility operate in women's lives.

Infertile Conceptions

Am I infertile or not? Like many women, birth control helped me avoid pregnancy when I was younger, though not always as effectively as I would have liked. Then in my 30s my then-husband and I decided we wanted to have a baby only to discover his sterility. Artificial insemination (lots of it), along with an egg-boosting Clomid prescription, led to a few short-lived pregnancies. I declined further interventions like in vitro fertilization (IVF) and we pursued adoption. Post-divorce I was back to using birth control and now I am nearly 44 and perimenopausal. Infertility is a moving target, not a definitive diagnosis, not a static identity (Greil *et al.* 2011a).

The Centers for Disease Control and Prevention (CDC 2017) defines infertility specifically as the inability to conceive after a year of unprotected sex. The CDC goes on to expand the definition of infertility to include women over age 35, or women with irregular menstrual cycles, who have not conceived within 6 months of trying. The National Survey of Family Growth (2014) identifies "impaired fecundity" in about 12% of the U.S. women. This concept includes unmarried women as well as women who have "secondary infertility," or difficulty conceiving again after already having a child. These measures are necessarily imperfect due to the vagaries of human behavior and the differences in individual physiology. For example, the CDC rule-of-thumb cannot effectively figure in the frequency or timing of vaginal intercourse or whether the pregnancies result in a live birth. What is more, an individual person's fertility fluctuates, often for unknown reasons.

It can be difficult to identify the medical etiology of reproductive health problems but some of the most commonly identified reasons for infertility in women are polycystic ovarian syndrome (PCOS) and blocked fallopian tubes. Male partner infertility is another important factor; about 12% of men reported infertility in a national survey (Chandra *et al.* 2013). However, much of apparent infertility goes unexplained and is probably the result of a combination of factors.

A number of studies indicate nine to 12% of women worldwide encounter reproductive difficulties (see Mascarenhas *et al.* 2012 for a summary). A meta-analysis of disparate International survey data notes that the rates of infertility are remarkably similar among women in developed countries and in less industrialized nations (Boivin *et al.* 2007). The rates of reported infertility are also stable over time, as seen in comparisons across the decades from the 1980s to the early 2000s in the United States (Stephen and Chandra 2006). Although these results seem to suggest a steady rate of reproductive failure across populations, which one might be tempted to attribute to similar medical difficulties rooted in biology, a closer look reveals a wide variety in the mechanisms contributing to infertility.

As with most health conditions (see the National Healthcare Quality and Disparities Report 2015), infertility risk in the United States varies by class and race (Chandra *et al.* 2013; Green *et al.* 2001; Greil *et al.* 2011b; Nsiah-Jefferson and Hall 1989; Stephen and Chandra 2000). A 2013 analysis of NSFG responses found that 11.5% of married African American women experienced infertility as compared to only 7% whites and 7.7% of Hispanics (Chandra *et al.* 2013). Environmental racism that results in greater exposure to fertility-damaging toxins may contribute to these differences as may poorer quality medical care. Some data suggest that African American women as a group may experience under-diagnosis of endometriosis and erroneous over-diagnosis of sexually transmitted infection, thereby missing an opportunity to prevent a major cause of infertility (Nsiah-Jefferson and Hall 1989). Infertility rates seem to spike in some areas of the world. Parts of sub-Saharan Africa, for example, see 32% infertility probably due to untreated infection and male infertility is particularly high in places like Egypt, possibly due to schistosomiasis infection, water pipe smoking, and contaminants in work environments (Inhorn 2003: 6). Poor medical treatment techniques may also heighten infertility rates by damaging treatment-seekers, a particular problem for the less well-off in places where women feel compelled to get medical intervention but not be able to access quality care (Inhorn 2003).

The term "stratified reproduction" describes the relative value given to women's procreation depending on her social status (Ginsburg and Rapp 1995). Whereas middle class White women in the U.S. must contend with the "motherhood mandate" (Russo 1976)—the assumption that all women will take on the motherhood role as expected—(also see Veevers 1973), other groups experience intense negative scrutiny for their motherhood. Myths about poor women such as the one about overly fecund "welfare queens,"—who supposedly use public assistance to finance lavish lifestyles—remain entrenched in the culture (Zucchino 1997). Though single women and lesbians and queer-identified individuals are more likely to have children than ever before (Agigian 2004; Hertz 2006; Mamo 2007), their parenthood is still under public contention by political and religious conservatives. Their families and communities may withhold support. Women who are family-building without male partners may not be medically infertile per se but, because they utilize a range of fertility treatments to achieve pregnancy, their experiences are an important part of the American story of infertility. The experiences of those who are medically infertile but who are not trying to become pregnant—described as having "hidden infertility" (Greil and McQuillan 2010)—are also telling.

Not only do different groups of women encounter infertility at disparate rates—and for different reasons—among those who do become identified as infertile, there are distinct differences in help-seeking (Chandra *et al.* 2014). The NSFG statistics indicate that during the period of 2006–2010, about 13% of American women sought medical help for infertility; most of this was limited to medical advice, treatment to prevent miscarriage, and/or ovulation drugs. Only 0.7% of women in the population used any of the more involved techniques known as assisted reproductive technology (ART) such as IVF (Chandra *et al.* 2014).

Assisted reproductive technologies are notoriously expensive and lack guarantees. However, success rates continue to improve (www.cdc.gov) and these treatment strategies now represent a more routinized—if still relatively unusual—path toward pregnancy and parenthood. It seems that the percentage of the U.S. women on this trajectory is shrinking slightly, however (Stephen *et al.* 2014). Analysts have been unable to adequately explain this decrease, suggesting that perhaps women are misunderstanding the "need" for infertility treatment, optimistically assuming that they can delay childbearing to accommodate careers and the like without encountering problems (Stephen *et al.* 2014). These demographers go on to guess that fewer instances of treatment seeking "may also reflect other responses to childlessness other than medical help" but they point out that the data collected by the NSFG fail to account for the dip; not enough women are adopting or claiming that they chose to be childfree (Stephen *et al.* 2014: 10). A survey of 580 Midwestern women showed that those with infertility diagnoses rate the importance of motherhood along a continuum (Greil and McQuillan 2010). Perhaps diminished help-seeking for childlessness is less the result of a perceived clear choice between motherhood and nonmotherhood and more related to ambivalence. Whatever the reasons, the continuum also has depths and heights; age, culture, religiosity, sexual and gender identity, class, profession, region, medicalization, partner status, and family origin are but a few of the dimensionalizing factors that account for attitudes toward motherhood (Greil *et al.* 2011c).

Even with this modest cooling on the domestic front, the global market for infertility treatment continues to grow (Twine 2015). The interest in so-called "reproductive tourism"—perhaps less flippantly described as "reproductive exile" or "cross-border reproductive care" (Inhorn and Pasquale 2009; Mattoras 2005)—in which citizens in one country will seek out treatments elsewhere because the medical techniques and family-building opportunities are either unavailable, unapproved, or prohibitively expensive in their home country seems to be building. Although detailed numbers are hard to come by, health policy analysts estimate that somewhere between 50,000 and 121,000 Americans traveled abroad seeking medical treatment in 2007 (Noree *et al.* 2015); those seeking reproductive care specifically would represent a subset of this group.

Though an imperfect proxy for class, statistics on educational attainment provide some insight: of those who identified as infertile, only 10% of women with less than a high school diploma sought treatment whereas 23% of infertile women with a master's degree or higher did so (Chandra *et al.* 2014). Casual observers commonly assume that affordability is the primary barrier to treatment. A national population study that controlled for cost-based access still indicates unexplained variance in infertility help-seeking (White *et al.* 2006). In fact, one study that included only infertile women with the same military insurance coverage (and, also, similar employment circumstances) found that African American patients were still less likely than whites to take advantage of the treatments even when they were available at no additional cost to them (Feinberg *et al.* 2006). Infertile Latinas and African American women in Massachusetts, a state that mandates insurance coverage for infertility treatment, were much less likely to seek treatment than white women (Jain 2006). A number of social barriers such as difficulty in getting time off work for appointments and differences in conversations with doctors about diagnosis partly account for their avoidance in getting involved with lengthy, complicated treatment regimens (Bell 2010, 2014). There may be yet another reason: some women from marginalized populations in the U.S. are less apt to identify motherhood as an achieved status that one pursues in obeisance to the motherhood mandate (Wilson 2014). Rather, motherhood is ascribed and happens or not depending on unforeseeable twists and turns along one's life course. It follows that the concept of "infertility," as a pathology or medicalized condition that requires attention, falls outside this come-what-may (or, for some, "God's plan") framework.

Biomedical and cultural understandings of infertility get tangled together, frustrating researchers' attempts to operationalize "infertility" adequately. Infertility is widely understood to be not only a failure to conceive but also the inability to give birth to a viable baby as desired. Women can experience infertility differently depending on their cultural and social expectations (Inhorn 2002). For example, women in Vietnam or China who do not give birth to a son can be disowned as barren (Handwerker 1995; Pashigian 2002). The lack of healthy children can also be felt and understood as infertility (Greil 1991). My own ethnographic interview study outlined in the book *Not Trying: Infertility, Childlessness, and Ambivalence* (2014), which included women medically diagnosed as infertile in the United States, found that some wholly rejected the label "infertile" because it connoted a permanent state or a master status. This connotation notwithstanding, infertility is quite often temporary. The condition may be alleviated with treatment (but not necessarily "cured"), or, in the case of "courtesy infertility," in which a couple is labeled infertile, it may resolve itself by changing partners.

Sociologist Eviatar Zerubavel (1999) makes the case that individuals may belong to opposing "thought communities" at the same time. Those who do not consider infertility a viable descriptor for themselves recognize it as a legitimate condition for others—even when medical diagnoses are similar. Some people imagine infertility patients to be "yuppies"—those who seek medical interventions tend to be white middle class married women—who participate in the more competitive, "rat race" milieu in which motherhood is yet another marker of life success (Becker 2000). Discourses of ARTs (and international adoption) are fraught with class distinctions and debates about consumer culture (e.g., Franklin 1997; Jacobsen 2011). Further, women whose doctors might describe them as infertile disagree with the label simply because they are not trying to become pregnant. Indeed, infertility is more than a diagnosis for many; it suggests an identity and/or a social role, one that some women do not wish to take on.

Challenging Childlessness

Childlessness, or being "childfree," can be even more difficult to parse. Adrienne Rich argued in her influential treatise *Of Woman Born* (1976), published at the zenith of the Women's Movement, that "childless" makes it sound like a woman is less without a child (she half-jokingly proposed the less-loaded term "unchilded" which did not catch on). Many American women understand "childfree" to suggest the status was a deliberate choice and a rejection of compulsory motherhood. "Childless," by contrast, can signify that a woman's non-motherhood was involuntary. Both notions leave out the reality of many non-mothers who care for children in other capacities: as aunties, teachers, godmothers, neonatal nurses, and so on. My friend Brittany's situation illustrates the problem with categorization. She is 44 and has never given birth or adopted a child. She married a man 17 years older than herself and he already had a grown-up daughter. Brittany became a very involved step-grandmother of twins through no planning on her part. She is neither childless nor childfree in any literal sense. What is more, her fertility is irrelevant to her status as someone who does the work of parenting.

It is difficult to say for sure how many American women remain childless because the status is often in flux. Some estimates suggest that about 20% or so of American women never have children (Biddlecom and Martin 2006). Women who do not give birth during the expected childbearing window of 15–44 years may still become mothers; they may well become stepmothers later in life or they may end up adopting past the conventional fertile age.

To be sure, increasing numbers of women reject motherhood outright (Agrillo and Nelini 2008; Shapiro 2014) and others seek motherhood single-mindedly at all costs (Franklin 1997). The stereotype that women who purport to be childfree-by-choice are immature or selfish careerists persists (Carey *et al.* 2009), but the expansion of options for women outside of motherhood and shifts in social mores mean that fewer and fewer young women in industrialized nations expect to have children someday (Merz and Liefbroer 2012). The pattern seems to be consistent across ethnic groups. For example, the birthrate among Latinas in the U.S. dropped precipitously—by approximately 30%—in the period of 2007–2013, especially among younger women (Astone *et al.* 2015). Though having fewer children, or having them later in life, is not the same as not becoming mothers at all, this change, attributed to trends in marrying later and the economic recession, speaks to a loosening of pronatalist attitudes. It remains to be seen if the childlessness rates, which are increasing incrementally in the U.S., will begin to parallel those seen in other industrialized countries (Basten 2009). In Germany, for example, 30% of women remain childless, with an even higher percentage among university graduates (Harding 2006).

On the opposite end of the spectrum, *involuntary* childlessness connotes a woman who wants motherhood but cannot get there for some reason. This broader term stands in for "infertility" in much of social research because it is less pathologizing and less confined to a medicalized context (see van Balen and Inhorn 2002). It also includes single women and lesbians, whose fertility may be untested by the CDC standards.

There are a number of non-choices involved on the route to childlessness (see Greil *et al.* 2010). A summary of the literature on childlessness in the Western world (Basten 2009) reports that, more young European women express the intention that they will one day have children than actually do (Rowland 2007). Results from the NSFG surveys conducted from 2006 to 1010 suggest a similar pattern among the U.S. women (Craig *et al.* 2014). Some women may choose to wait to get pregnant and have a baby until the time is right—when they have the right partner and have reached financial stability, for instance—eventually discovering that they postponed past their fertile years. This waiting should not be seen as entirely accidental or noncommittal, with women remaining hapless victims of their circumstances, nor as gimlet-eyed, orderly, and wholly rational (see Krause 2012). For example, in the face of society and family pressure to produce a son, some Nepalese mothers who have only daughters, use contraceptives as an indefinite stalling technique to permanently delay having more children (Brunson 2016). It is important to once again underscore, however, that the U.S. data do not support delayed attention to childbearing as the definitive reason for a decline in fertility treatment and childlessness in the U.S.

(Stephen and Chandra 2006). There must also be other explanations. Some women report being fulfilled even absent the motherhood that they once desired and still others vacillate between satisfaction with their childlessness and longing for motherhood (Koropeckyj-Cox 2002; Koropeckyj-Cox and Pendell 2007).

Mary's story highlights the complex and sometimes transient nature of the experience. A childless, postmenopausal African American woman, Mary told me that she loves children. They are her whole life, in fact. She has cooked for decades at children's summer camps—she even met her husband there (he is similarly dedicated to children)—while also working full-time at a daycare during the school year. In her spare time she enjoys making baby clothes for friends. She became pregnant a couple of times but miscarried and never gave birth, never seriously considering seeking medical advice. Only after a spate of invitations to baby showers in celebration of her friends' coming grandchildren did she feel like she was missing out. Mary cried off-and-on for 6 months with regret over the missed opportunity to become a *grandmother*—not a mother—she emphasizes. Then, Mary explains, she snapped out of it, realizing she is utterly happy with how her life turned out. She contrasts her freedom and happiness with her friends' ongoing stress and worry over their children's lives.

Whether or not childlessness is voluntary may not even matter to the experience of it, as some researchers recognize (e.g., McQuillan *et al.* 2012). In fact, most childlessness among American women, if investigated closely, turns out to be the result of several factors, some of which can be considered matters of choice and some not (Chancey and Dumais 2009). Life circumstances may compel women to put off motherhood (Graham *et al.* 2013), resulting in a status that was neither expressly chosen, nor entirely unwelcome. Acceptance of childlessness may sometimes be a coping strategy (Becker 2000), but there are women, like Mary in the vignette above, for whom childlessness is an outcome that is just fine. A study of 25–45 year old American women who did not get pregnant after a year of unprotected intercourse found inconsistencies in answers about whether or not they wanted to get pregnant; as it turned out, many of the women were "okay either way" (McQuillan *et al.* 2011). Moreover, there are different types of ambivalence along a spectrum of "wavering noes," women who seem to be voluntarily childless but who reserve the right to change their minds about having children (Morrell 2000) and "perpetual postponers" who say they want children but who end up not becoming mothers partly through inaction (Berrington 2004). Because intentionality—reflected in the frequent narrative that a woman "always wanted" children—does not consistently reflect women's lived experience, the categories of voluntary and involuntary function as a false dichotomy that obscures the intricacies of childlessness.

Other Territories

Zara, a childless woman I interviewed, rejected the label of "infertility" outright. This vehemence might be puzzling to researchers given the fact that she had undergone a hysterectomy. It would be easy to dismiss her perspective as out of touch or a sad instance of being unable to move on from her pain. But she imagines future medical marvels in which her eggs might be harvested and rejuvenated years into menopause. She's a physicist who is by no means ignorant of modern science and she's an East African immigrant to the United States who sends money to Ethiopia to fund the schooling of children she claims as hers though they have never met. She expresses all of these ideas at once: she is not infertile but she might be and she is a mother but she is also not a mother. Foregrounding her worlds instead of the measurable realities that are the stuff of CDC surveys holds some potential for speculating different futures. Troubling the seemingly discrete categories of infertility and childlessness or fertility and motherhood may prompt researchers (and practitioners) to confront their assumptions. A simple reminder might be that counting the number of infertile women effectively discounts those who actively reject the diagnosis and completely misses those Teflon women to whom the descriptor will never stick.

Ethnographic research paired with an ontological view—in the anthropological sense—helps us access different experiences of infertility and childlessness. For example, the understanding that some women do not engage in the often-medicalized discourses surrounding infertility illustrates the primacy of subjectivity. We can choose to make fewer assumptions that there is an objective reality—always available for scientific testing—and instead leave open the possibility of encountering new "worlds" or territories that scholars have not imagined (Asberg *et al.* 2015; Holbraad *et al.* 2014).

Infertility and involuntary childlessness, socially constructed and intertwined, remain intensely meaningful and are worthy of thorough study by medical and social researchers alike. However, the two concepts do not merely represent an objective reality to which participants have varying responses depending on their social, cultural, and individual circumstances. It is useful to take the tack that what women say and do about infertility and childlessness may be accepted at face value. If motherhood is ascribed and not achieved, for instance, then an infertility diagnosis may be irrelevant and infertility treatment may not come up for consideration. Public health oriented research that aims to identify reproductive disparities and redress them could be misguided in such a terrain. To be clear, this is not to say that the work is at all unwarranted; it is merely to suggest that researchers take some time to consider how we come to discover what we know about infertility and childlessness.

Medical and public health studies, as well as work in psychology, make up the vast majority of research into infertility and involuntary childlessness. The work being done in these disciplines frequently presupposes that infertility and childlessness are negative statuses and unwanted experiences. Certainly medical intervention, prevention, and diagnosis are essential for women's health and reproductive freedom. And it is also important to address the disparities seen across lines of race, class, gender, sexual identity, able-bodiedness, and so on. Quantitative data analyses such as those stemming from the National Survey for Family Growth provide invaluable insights into reproductive trends.

Yet, teasing apart the "whys" of apparent statistical associations can be confounding. Why after economic recovery, are young Latinas still postponing motherhood? Qualitative research delves into the human stories behind these kinds of trends. And an ontological approach—whatever the theoretical perspective—respects the possibility that there are completely different realities of motherhood and otherhood—of childlessness and infertility. Asberg, Thiele, and van der Tuin (2015: 150, after Kirby 2011) suggest that we might attend to more than just "different expressions of the same phenomenon" but realities in which the phenomenon itself is different.

Infertility itself is ephemeral; it can disappear, only to appear again, sometimes in ways medicine cannot explain. Childlessness, too, can suddenly change. If we insist on seeing infertility and childlessness as things in and of themselves, we can argue that women engage with these things differently depending on their power position and on their culture. But these moving concepts are not just variable expressions of infertility or variable expressions of childlessness.

Also, importantly, it is dismissive to suggest that these concepts are merely misunderstood by those who would be identified with them. They simply may not always exist in ways that researchers assume or can readily access. And there is a growing recognition that native views may matter more than scientific ones (Holbraad *et al.* 2014).

An ontological approach is about being open to not knowing how those we study experience their worlds and about trying not to force our scientific or social scientific ways of knowing on to others. It is not our task to reinterpret others' realities based how we already understand the world. Some experiences are out of reach for researchers (Haraway 1988). When I first set out to interview "infertile" women who were not seeking treatment (representing a majority of women diagnosed but a minority of those participating in studies), I inadvertently offended some by asking them to participate on the basis of someone else having identified them as infertile. Several declined to be interviewed (saying they were not infertile) and others who did speak with me at length, confessed that they were not "really" infertile despite the accuracy of the designation per the CDC definition. Duly chastened, I decided to suspend judgement and hear them out rather than seek respondents who fit my predetermined categories. Messy results notwithstanding, I think I glimpsed something new (to researchers); I briefly stepped into other territory. Yet another researcher spent her time in still other territory in which infertility diagnoses were a welcome relief to the women she interviewed (Bell 2014). Both possibilities exist—women who cannot abide the stigmatizing concept of infertility and those who are happy to be able to move forward with a medical diagnosis they can then attempt to treat. The latter may benefit from public health oriented work—like lobbying to mandate insurance coverage for infertility treatment—meant to alleviate disparities in access to treatment. The others may be unreachable by such a campaign. Worse, the routinization of treatment and further medicalization of women's reproductive lives, where doctors offer prescriptions and referrals at the first sign of impending childlessness, may feel like unwanted pressure to some.

Feminist sociologist Barbara Katz Rothman (2000) makes the point that women should have the freedom to seek all manner of fertility help but that they should also have the freedom to decline infertility treatment. They should also be free to change their minds about reproductive choices, to waver, be ambivalent, or do nothing about it. Childlessness should not be seen as deviant and in need of remedy, as many researchers warn (Park 2005; Snitow 1992; Graham *et al.* 2013; Gillespie 2003). Empirical researchers—whether working with quantitative data or engaging in ethnography—need only be cognizant that a range of unconceived possibilities exist in the social and biological worlds of infertility and childlessness, and proceed accordingly. Only then, can divides (such as motherhood/non-motherhood or fertile/infertile), with all their connotations and consequences and angst, flatten into the mundane (to liberally paraphrase Donna Haraway 2008). Were ambivalence toward motherhood as well as toward childlessness to become the recognized norm, the poles of "voluntary" and "involuntary" would collapse and effectively lose all meaning? This sort of feminist speculative imagining (see Asberg *et al.* 2015) might just portend a hopeful future. A few scholars are already speculating. Stuart Basten (2009) locates online communities as sites for childless people to construct empowering virtual worlds where they understand others and are themselves better understood. And, on Mother's Day 2015, Donna Haraway gently offered her social media followers the motto "Make kin, not babies," which she later expounded on in a scholarly article (2015). It means no disrespect to mothers. Rather, it means to suggest a new cosmology—aware of overpopulation and aware of the overwhelming demands on contemporary mothers—in which a baby is more rare, more precious, and nurtured by a slew of caring adults, only one of whom gave birth.

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Source: Kristin J. Wilson. Unconceived Territory: Involuntary Childlessness and Infertility Among Women in the United States. In: Riley N., Brunson J. (eds). International Handbook on Gender and Demographic Processes. 1st ed. Netherlands: Springer; 2018, pp 95-104. DOI 10.1007/978-94-024-1290-1_7.

Partnering the Infertile: The Impact of Infertility on Women's Spousal Relationships

Paulina Billett

"Infertility is horrible… and it may end up ruining my marriage (which is only 4 months old). I may do this round of IVF (if the DH will still do it) and then call it quits. I don't want to live like this."—Patricia.

Introduction

The journal entry from which the above excerpt originated is highly significant. In it, Patricia describes in detail the almost love-hate relationship which many women hold with their infertility. Patricia opens her journal by describing this as the "worst day", she recounts advice from doctors which leads to attempting treatment she is not comfortable with, but feels obliged to try, as her partner may decide to strop treatment if she is unwilling "to try everything that the reproductive endocrinologist (RE) suggested". Patricia's entry relates a truly isolating experience, one where women "have to do everything" while husbands seem to do very little. This type of entry was not uncommon, and through our research we saw a number of examples which described the sometimes uncomfortable navigation many women undertake between their own and their partner's wishes and expectations. For many, these expectations were vastly different (or were perceived to be by the women) and were often the source of friction in the couple's relationship. However, when the couple's expectations aligned, the relationship provided what can be argued to be the single most important source of support during testing, diagnosis and

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P. Billett (✉)
La Trobe University, Melbourne, Australia
e-mail: p.billett@latorbe.edu.au

treatment and helped women to cope better with the demands of protocols and the disappointments of failed attempts.

Understanding the role which relationships play in the lives of infertile women is essential. As we have previously demonstrated, the support we receive from our relationships (be it our relationship to ourselves or to others) has the power to affect our capacity to deal effectively, even creatively, with life's many challenges. In this chapter, we deal with the third node of our relationship triangle: the couple relationship. In particular, we seek to explore how intimate partner relationships affect and enable the ability of infertile women to deal with the realities which treatment and the possible loss of motherhood entails.

While infertility is often viewed as a woman's problem, past research has shown that infertility is not an individual experience, but instead it is a shared experience between a couple (Greil 1997; Savitz-Smith 2003; Schmidt *et al.* 2005). As such, while this book is primarily an exploration of women's experiences of infertility, we felt it relevant to discuss intimate partner relationships in terms of its meaning in the women's journeys.

Relational Uncertainty, Partner Interference and Boundary Turbulence

Our research, like others before it (e.g. see Steuber and Solomon 2008 and 2012), found that the roller-coaster of emotion experienced during the infertility journey creates a shift in the couple's relationship leading to what Solomon and Knobloch (2004) term relational turbulence. Relational turbulence refers to how "relationship transitions (particularly life altering ones such as infertility) polarize emotions and cognitive appraisals and disrupt the exchange of messages between partners " (Solomon 2016, p. 1). Relational turbulence results in higher levels of stress for the couple emphasised by relational uncertainty in the form of uncertainty on the partner's commitment to the treatment and resolution of their infertile status.

The experience of infertility is a tough challenge for most infertile couples, who unlike "normal" couples, report the need to confront "new realities"; cope with financial pressures from treatment; learn a new "language" based on medical terminology and discourse; consider existential questions including the stresses of failed attempts, choices about changing or ending treatment, as well as contending with ethical questions such as what to do with unused embryos after treatment (see Matthews and Matthews 1986; Savitz-Smith 2003; Schmidt *et al.* 2005). This time of relational turbulence, requires couples to "re-adjust" to these new realities leading to periods of intense uncertainty, resulting in some women experiencing doubts about their partner's investment in treatment and its goals.

Unsurprisingly, the intense feelings of anger, resentment, depression and confusion experienced through the journey of infertility and fertility treatment can severely undermine a couple's relationship. In particular, reactions to the difficulties of this journey provoke intense reactions (both positive and negative) and create a veritable roller-coaster, one which couples reported feeling unable to "get off" no matter how hard they tried. For most, this was a difficult situation, with women frequently questioning their partners' commitment to treatment (and at times the relationship itself) and reporting intense feelings of isolation from their partner.

In terms of support, expectations and feelings of isolation, the earlier years seemed to present the most intense challenge for couples and led to greater levels of relational uncertainty. In the beginning, couples faced with the painful inability to conceive are confronted with an uncertain future which they must now negotiate. Once investigations begin, they are put through countless invasive procedures, which may or may not shed light on their condition. Upon diagnosis couples must make the choice of continuing to try "alone" or submitting to further tests and incredibly expensive procedures, such as IVF, which have unclear success rates. For women, this situation is even more challenging, as the majority of exploratory investigations, testing and subsequent procedures are undertaken on the female.

A consequence of this intense focus on the female body is that infertility is constructed as a woman's problem, which marginalises men from fertility treatment (Malik and Coulson 2008b; Hanna and Gough 2016, 2017). Previous literature on infertile couples has discussed that the feminine focus of infertility has rendered fertility treatment as a "second job" for women, (see for example Steuber and Solomon 2008) who take on the majority of the "infertility burden" including coordination of fertility related activities; such as timing of intercourse, channelling of large portions of the couple's funds into testing and procedures and the reshaping of everyday life to suit treatment cycles, while men see their primary role as one of support (Hanna and Gough 2016, 2017). This inevitably results in increased levels of anxiety due to misunderstandings and incongruent expectations, intensified levels of partner interference, which exacerbate existing difficulties, and higher levels of relational uncertainty. This heightened level of anxiety is further impacted by private boundary turbulence as the couple navigates the reshaping of boundaries and the sharing of intimate, and often sensitive, information between the partners and with others.

It is not surprising that, excluding discussion of treatment, the stresses of infertility and its impact on the couple's relationship was one of the most often encountered discussions in the women's journals. Journaling about the couple's relationship seems to take three forms; journaling about supportive behaviour, journaling to vent about what was perceived to be unsupportive behaviour or discussing protective attitudes and behaviours towards their partner. We deal with each in turn.

Feeling Supported

Infertile couples frequently do not receive support from friends or family because they often feel uncomfortable discussing their personal journey with others. Fear of being misunderstood or judged will keep many couples silent about their struggle. As a result, partners in a relationship commonly become each other's most important form of support (Abbey *et al.* 1995). For women undergoing fertility treatment, a partner's "appropriate" reaction to events and acceptance of partner interference during their journey can present a form of validation of their own feelings. Congruence in a couple's appraisal of the challenges posed by infertility lead to higher levels of marital adjustment and can help to reduce the stress they experience and increase the couple's ability to manage this highly taxing situation (Peterson *et al.* 2003). Not surprisingly, the joy felt by women when their partner assumed a congruent stance, and/or accepted partner interference in relation to treatment, was palpable. Many of the women rejoiced in what they considered to be the most supportive aspects of their partner's behaviours, such as taking time to research treatments and conditions, taking vitamins and other medication; demonstrating supportive behaviours such as attending appointments, and showing willingness to discuss fertility issues; and tangible displays of emotions, such as showing happiness at successes or displaying frustration due to failure. For the women of Stronger Together, these simple cues meant that their partner was as vested in their journey as they were, giving them a source of comfort and reassurance against an often unstable situation.

Sadly, while the entries which described supportive attitudes by partners were few, those that contained accounts of partner supportive behaviour were always greatly valued and celebrated. Of the entries made by the women, Joan's journal stands out. Joan and her husband Richard had been trying to conceive for around five years before joining Stronger Together. Throughout her two years of writing, Joan's husband Richard was often praised in her journal for his loving and considerate attitude to their struggle. To Joan, Richard often showed responsiveness towards their ups and downs, tolerated her demands, and is complimented by his wife for showing emotions such as happiness, excitement and sadness. His positive reactions and indeed acceptance of partner interference in their daily routine were seen by Joan as proof that he cares and that he is vested in the process just as much as she is. For example, in one of her entries, Joan shares her excitement at finally having a positive result in her ovulation test. As she suffers from PCOS and does not ovulate often on her own, she was excited at being able to share the good news with her husband. Joan shares that after texting him the news, he replied "saying that it definitely put a bounce in his step!"

Her journal moves on to comment on the ensuing "on demand" sexual activity (which is perceived by most women as further evidence of support) and medical symptoms which may spell out a pregnancy. At a later date, his positive reaction, once again, to ovulation is commented on by Joan, who writes:

> I got a positive LH test on Wednesday afternoon. DH was home, so he and I rejoiced a bit.

In each of Joan's entries, appearance of a "team effort" is demonstrated by each partner having internalised and enacted their expected "role"—Joan shoulders the responsibility of testing and setting the timing, while Richard performs emotionally and sexually when prompted by Joan.

For others, such as Lilly, the fact that her partner is able to feel the pain of childlessness like she does is important. In one of her entries she mentions her husband's sadness at hearing of new pregnancies and his angst at how this may upset her:

> DH and I sat down after I found out about his cousin's pregnancy. I was so angry with him for not telling me earlier! I just wanted to rage!!!!! He told me that he didn't want to tell me because it had really upset him, and he was so worried about how I would feel about it all after our loss. All my anger vanished, I just wanted to hug him so tight…

Joan and Lilly are not alone in perceiving certain action and reactions as evidence of support. On a thread post, Kerry comments with excitement on her husband's appropriate response, and writes that she "could not have picked out a better partner for this journey…" She goes on to suggest that his supportive behaviour, including his willingness to attend doctor's appointments, work extra hours to meet financial demands and "let me hang out in my PJs all day when I just don't feel like facing the day after my BFNs…" are evidence of his support for the journey they have undertaken. Kerry's husband, like Joan's and Lilly's, is appropriately enacting the role of supporter, one who is willing to limit his own role to that of follower and protector while accepting his partner's guidance in the process. In short, for these women, as for many others who responded on these threads, their husbands' supportive behaviours are evidence that they are vested in the process, making their struggled shared rather than one-sided.

However, the need to maintain a high level of support among the partners can be a high impact stressor and has been suggested as a predictor of poor marital outcomes (see for example Schmidt *et al.* 2005). It has been documented by those such as Hanna and Gough (2016, 2017) that like women, men also find the experience of infertility as deeply isolating. Often men find it hard to discuss emotions about infertility, even with other men in similar situations. Men, in their studies often felt at a loss as to how to help their female partners and often deployed stereotyped explanations of the differences between masculinity and femininity, including the need to prioritise their partner's needs above their own, as reasoning for their perceived shortcoming.

However, the pressure of always being "there" often became too much for even the most supportive of men. According to the women of Stronger

Together, the ensuing response was for men to simply “switch off” and attempt to withdraw from the onslaught of the infertility roller-coaster. For the majority of women, this shift in attention was often seen as abandonment, leading to anger and resentment. Inevitably, posts and journals were often dedicated to venting about a partner’s behaviour rather than singing their praises.

When Support Fails

Given the gender role expectations and the level of invasiveness of treatments, it is reasonable to suspect that males and females may have different responses to fertility treatment. For many women, the inability to fulfil societal roles and social comparison to women who have children can be a major contributor to depression (Newton *et al.* 1999); men, on the other hand, seem to see infertility as an unfortunate but resolvable issue (Greil 1991). The divide between a couple’s perceptions of the impact of infertility, as well as difference in the reactions between males and females, can create a gulf of understanding between the partners (Chachamovich *et al.* 2010). These differences were frequently perceived by women as unsupportive behaviour.

As discussed previously, women often perceived supportive attitudes as those in which their partner’s reactions mirrored their own. When a couple’s attitudes did not mirror one another, this was perceived as evidence of lack of support and was often a precursor to arguments and the inevitable, though usually temporary, breakdown of communication between the couple.

For many women, the lack of communication with their partner was a major source of angst. This was particularly troublesome during times of treatment, where much of the women’s attention was engaged in medical procedures and the process of conception. Lack of communication during this time in particular made the experience far more stressful for the women undergoing it. Mary discusses in her journal how her husband’s approach to infertility is making her feel isolated and reinforces her need for support at this time:

> I need to know that he is with me 100% in mind and body, it’s not a lot to ask for…

This resentment is mirrored by Catherine in response to another member's discussion, by highlighting her husband's lack of sensitivity to her struggle with the statement: "My DH just doesn't get it either." She goes on to quote what she felt was a particularly insensitive remark (regarding his perception of her obsession) as evidence of his lack of support.

The lack of support from a partner can be even more stressful for women who feel misunderstood by their partner in their search for an answer to their condition. The amount of time spent by many women researching their condition, its treatment and possible outcomes was frequently perceived by partners as an obsession. This unsurprisingly was often a point of friction for the couple. While for many of the women attempting to find answers became a compulsion, for their partners their perpetual engagement in the world of infertility was an obsession which needed to be controlled. Time and again, we encountered journals which lamented a partner's annoyance at the women's monotonous musings on treatment. These rebuffs often caused much sadness, as the apparent rejection was perceived as a lack of interest in having a baby and a withdrawal of emotional support. This was very evident in Mary's journal, where she discusses her husband's disengagement in their treatment through many of her entries. One in particular shows the depth of emotion that her partner's disinterest conveys to her:

> I said to him, are you excited about next week, YESSSSSSS in a long droned tone he said. I said to him why are you being like that—like you don't care, you need to give me 100% support and I need to feel your excitement, I also told him that I felt he was being negative and that we should be going into this with full excitement and 100% support for each other, he then got really defensive and told me, I was obsessed, and he didn't need to hear about it every day…

Mary also reports her husband's labelling of her need to discuss infertility as an obsession as a hurtful accusation, in response to a thread discussing partners' reactions to women's journeys. She writes that her partner often became frustrated by her constant discussion of IVF and infertility, telling her that she tended to over-analyse and needed to take just one day at a time. She concludes with the statement "THAT WAS HARD…"

Other women, such as Bethany, reacted with anger, rather than sadness at their husband's inability to show empathy. In a furious entry in which she discusses her partner's lack of support, both emotionally and financially, she closes with:

> You have to jack off in a cup. I have to be molested and probed. Wanna trade places?

To Bethany, her husband's failure to appreciate what she is going through is a source of anger and disappointment. She, as many other women, feels that the unfair burden placed on her body should be taken in consideration by her partner and was incensed when she felt attacked and misunderstood.

Deciding if and when to pause or end treatment can also be a major stressor for the couple, presenting a period of intense relational uncertainty. Undergoing fertility treatment is an ongoing stressful situation. For most women, the desire to continue treatment is based on their fear of giving up too early. The question of giving up was one often discussed in discussion boards and journals, particularly after failed treatment cycles. In these journals and posts the women often considered the possibility that pregnancy may never ensue. The message most frequently heard was: I don't want to give up because success could be just around the corner. In her post, Abigail discusses her desire to stop treatment but is concerned that "what if the next time is THE ONE!". Jacinta echoes this in her own post where she laments her devastation at yet another BFN and states "I don't want to give up, but it is hard" and "I am too scared to stop."

The decision to stop treatment is invariably a difficult one, even when this is for a short while. What complicates this even further is that infertility, unlike other illnesses, does not allow for unilateral decision-making and partners often found themselves at different levels of acceptance and understanding of their childlessness (see Leigh 2016). Penelope's post encapsulates this battle where she states that at 36 her husband is ready to give up, but she remains unsure as she knows that at 36 time is not on her side, and poses the question: "How do I know when enough is enough?"

While it is usually the female in the partnership who may not want to move on from treatment, at times it may be the male partner who may want to continue treatment or indeed "regress" to an earlier stage. Such was the experience of Jessie. After having tried for over a year to have a child, Jessie and her partner decided to move on to adopt, rather than to put their energy into continued diagnosis and treatment. During their adoption journey, they became pregnant, but unfortunately experienced the devastation of a miscarriage. They decided to attempt conceiving again. However, after four unsuccessful months, Jessie decided that she had enough and wanted to once again begin the process of adoption. She was left stunned when her husband professed a desire not to move on, but instead to begin testing in order to "search for answers":

> So DH now doesn't want to adopt… WTF I thought we were moving forward with this! I want to have a child, and I don't want to do this SHIT again!!!! I'm over the doctors, needles and the endless watching of the pee stick but no, now he wants to go back and begin looking for answers again! Like we haven't tried!!!!

It is unsurprising that so many of those undergoing fertility treatment find it so difficult to end their journey. Stories of success from group members coupled with the exaltation of advances by "claim makers" can make a couple uncertain whether to continue or discontinue their IF journeys. For many of the women, it is the "what if" which keeps them going: the expectation that one day they will achieve a family which keeps them pushing beyond physical, mental and emotional endurance. While many felt drained emotionally and physically by the never-ending cycle of testing, treatment and failure to conceive, their desperation to achieve "normalcy" through creating a family added a further level of pressure to already overstretched nerves.

As a result, infertility is more than a medical condition. Infertility affects how individuals feel about themselves, their relationships and their perspectives on life (Hart 2002). For the women of Stronger Together ceasing treatment was more than just a simple choice. It was the admittance of surrender, accepting that "normalcy" was beyond reach and seen as failure to persevere in the face of adversity.

As the years wore on and as the women developed a better understanding of procedures, and indeed grew more accustomed to failure, their need for reassurance also diminished making their partner's response less problematic. This finding is not uncommon; Gerrity (2001) suggests that the marital stress experienced by couples undergoing treatment may differ through different stages of the infertility journey and may ease as times progresses. One thing, however, remained relatively constant and changed little in terms of the women's reaction: their need to protect their partner from the trials of the infertility journey at all costs.

To Love and Protect

As discussed previously, women and men seem to take two different roles during the infertility journey—that of leader or supporter. While women almost exclusively appear to take the lead (meaning that they shoulder most of responsibility for testing and treatment during the infertility journey), at times they also take the role of supporter. This was particularly true of women attempting to shield their partners from the trials of the infertility journey. Protection of one's partners took two basic forms: protection from performance anxiety and loss of spontaneity; and, protection from the stress associated with the ongoing fertility treatment, including the discovery of male factor. We review each in turn.

Loss of Spontaneity and Pleasure in the Couple's Relationship

An important theme that was raised by the women was the loss of spontaneity and pleasure in the couple relationship. As entries progressed, and the women delved deeper into the world of fertility treatment, it was clear that life was very quickly reduced to monotony, something which many of the women deeply regretted. All those who shared their stories with us felt that their couple relationship had been greatly affected by the demands of treatment and a number of them voiced their need to take a break during the years in which they continued to journal and post on the general thread. For the majority of women, the feeling of being out of control was felt not only in terms of their own bodies, but also in terms of their couple relationship. A number of journals and posts discussed the impact that infertility and the treatment journey were having on their relationship. As time progressed a number of the women began to ask themselves if it was time to "take a break". This was often suggested as a way of regaining control, as well as allowing the couple some room to reconnect at a level other than conception.

An example can be seen in the following excerpt from Mary's journal who, after a number of unsuccessful attempts, discusses the impact the journey is having on herself and her husband and the need to take a break:

> As a matter of fact, my DH and I have discussed stopping this stuff altogether for a couple of months if we are not successful this month. It is just getting so exhausting and we both need a break and time to enjoy life! I will be sad, and may not be able to stop trying for more than a month, but I just can't deal with all of the bad news anymore.

However, it was not until the end of that particular cycle, and the crushing negative pregnancy test, that Mary felt ready to take time away from treatment, as she writes:

> Well I have NOTHING good to report. Christmas will be a sad one as I had feared. I plan on buying a few bottles of wine to drink over Christmas and New Years and just try to say goodbye to 2011… a year filled with horrible shots, pills, suppositories, early morning doctor appointments, tons of weight gain and not feeling attractive, mood swings, arguing with DH, tears, fears, headaches, acupuncture, cancelled plans because of how I was feeling, anger and some of the saddest news anyone can get (BFNs)… We plan on taking a break for a month or two at least before we decide if we can do this again. I hope that I have it in me, but I worry about becoming a totally depressed wife that my DH will not want to be around!

She once again writes after having taken time off and recounts the benefits and her subsequent trepidation at returning to fertility treatment, reflecting:

> Well this month has been quite enjoyable so far.
>
> Enjoyed some wine, good food, laughs with my DH!
>
> Enjoyed not feeling exhausted, moody, emotional!
>
> Enjoyed having the energy to get back to the gym for the first time in over a year (although I still despise the gym….it is a necessary evil!)
>
> Enjoyed having sex because I wanted to and not having to worry about abstaining before a procedure or being too tired to do anything.
>
> Enjoyed LIFE!
>
> AND THEN IT HAPPENED!
>
> THE TWO BIG BOXES OF MEDS SHOWED UP AT THE DOOR!
>
> REMINDING ME THAT THIS NIGHTMARE IS HARDLY OVER!

Similar to Mary, Erin also recounted in her journal her positive experiences after making the difficult decision to take time off:

> I have been feeling so much better since we made the decision to take a break. I'm still working on this round of Clomid, but I'm not thinking about it much at all. Occasionally, my brain will try to tell me that it is working, but I remind myself about the ultrasounds I have had recently and tell myself that there is almost no way it would work. My DH is having some issues with his medication as well, so it is nice to be on a break for a while until we get that straightened out. Our focus has just been on each other… not any of the crap that has been stressing us out. It's so nice! I'm reminded of when we were first married and didn't really worry about anything. We just took it all one day at a time.

Having time away also provided an opportunity to work on other aspects of their relationships. This was particularly true of their sex lives, which were often negatively affected by the experience of infertility and fertility treatment. Upon reading the women's journal entries and posts, it became clear that due to the demands of treatment, sexual intimacy took an obligatory character which was focused on conception alone, rather than something to be shared and enjoyed by the couple.

Sexual activity during treatments is always a difficult affair. Whether it is in the initial testing phase or during treatment with Clomid, IUI, IVF or other methods, medical protocols require sex to be timed to cycles during times of ovulation, pills or shots set by doctors and other treating clinicians. For the couple "baby dancing", as they call sexual activity, often becomes a chore, something which must be gotten over with rather than something which is intimate and pleasurable. This situation was often described as highly distressing to the couple. Joan explains that she and her husband often found it difficult to have intercourse on a regular basis, partly due to low libido on her part and partly due to the stresses of infertility. She goes on to recount that she is trying to get "interested in it" (though she does not explain what this may entail) so they can begin having intercourse every day. She concludes her entry by stating:

> I know it'll only be a week or so of BDing every day, but man does that seem daunting!

Performance anxiety also became an issue for some men, rendering them unable to perform and causing further stress and strain on the couple. In her post Megan relates to others her concern over her partner's inability to perform and particularly "not being able to perform and finish" when they only have "today and tomorrow". She states that she has asked her partner to "see a doctor".

Megan's partner is not alone in his response to the overwhelming pressure for sex on demand. In the replies to this and similar posts, a number of women discussed performance anxiety as an issue for their partners. Once again, taking on their role as leaders in their IF journey, women asked for advice as to how to rekindle passion in the bedroom, with answers ranging from ensuring date nights, taking time off for holidays to a number of women advising others to take on the responsibilities for treatment (such as monitoring ovulation) and keeping their partner as "shielded" as possible from these concerns. This, it was discussed, would take the pressure off their partner, allowing the man to regain enjoyment in sex. Such was Jane's suggestion to one woman's post, where she recommends not telling her partner but, instead, taking on the role of instigator. In her reply to the post, she details how she let her partner think that "he was this super-hot stud that I couldn't keep my hands off ALL of the time", even though "It was a little tiresome for me."

Another suggestion given by Wanda to the same post mirrored Jane's reply. In it, Wanda suggests "not [to] make a big deal about it… I said that it was just part of the process and the same way I had to take drugs to ovulate, he could take drugs for it too". In the end she relates how she not only solicited the prescription for erection pills from her doctor, but also filled the prescription "to save any embarrassment for my husband".

One of the curious themes in these discussions, as well as in many other similar discussions, is that while the women acknowledge their own discomfort and openly discussed their anxieties, their desire to conceive drove them to disavow their own needs in the hope of protecting their partner. These discussions also exemplify that, for women, conception is still very much a "woman's" domain. Whether or not they are the source of infertility, they felt obliged to lessen the burden on their partners by taking over responsibilities for treatment and absorbing the burden of reproduction in the hope that this cycle may prove to be their last.

Protecting from Disappointment and Judgement

For many couples, it is the male rather than the female who is faced with infertility. In fact, RESOLVE, the U.S. based national infertility association suggests that around 30% of all the cases of infertility involve partly or exclusively male factor due to "problems such as structural abnormalities, sperm production disorders, ejaculatory disturbances and immunologic disorders" (RESOLVE website). Nonetheless, society and medical practice continues to construct infertility as a woman's issue (Carmeli and Birenbaum-Carmeli 1994). It is not surprising that a diagnosis of infertility may come as a shock to many males, who often have not considered this possibility. For many men, there is a feeling of shame at being labelled infertile, for after all, male fertility is tightly linked to ideas of virility in most societies. Hanna and Gough (2016, 2017) found that participants in their studies often suggested that aspects of their masculinity had been compromised by infertility and saw it as invading all aspects of their lives. For many men, being "outed" as infertile was a difficult experience, and one which limited women's ability to share with others in an open manner. Peter's reaction to his wife's disclosure of their test results to her brother further supports this. Elisabeth writes in her journal how she is particularly close to her brother and thus felt comfortable confiding in him about the poor results she and Peter had received on their last semen analysis. Peter was greatly angered by this and Elisabeth writes that it is because:

> He says that it's an uncomfortable thing for guys, that it's a judgement on their virility.

In this instance of intimate boundary turbulence, the couple must come to terms with the impact of infertility on the male partner. In short, they must acknowledge that infertility is more than just a woman's problem and renegotiate what can and what cannot be permissibly discussed with others. Interestingly, most women were highly concerned about their partner's reaction in finding out that they were unable to provide their wife with a child. Unlike their fears of becoming "unwanted" because of their inability to produce a child for their husbands, women's reactions to diagnosis of male factor brought an intense preoccupation centred on their partner's mental wellbeing and the best manner to "treat" their infertility. Patricia gives a despairing account of the difficulties she faced in attempting to support her husband's struggle:

> I feel horrible for him too because he was told he has a very low sperm count and he is trying to do anything he can (bought boxers, eating foods that are supposed to help improve sperm count, etc…) to make this happen. It has to feel disheartening to him as well. I am sure we are both feeling like failures.

In a similar journal entry, Elisabeth expresses concern for her husband's well-being and discusses her attempts to shield him from her disappointment. In one such entry, she writes:

> I know he already feels bad enough as it is… I don't want him to feel like I'm blaming him, so I just sort of get quiet and crumple inside…

Further to protecting their partners from the anxiety of the male factor diagnosis, many of the women took on the role of protector from what they perceived to be personal attacks from friends and family. At times, parents, siblings, friends and even colleagues were discussed as having crossed the line when discussing men's infertility.

Feelings of sadness, anger and resentment were further complicated when they involved their partners. Unwaveringly, all posts and journal entries made by the women which dealt with this topic used language which showed a high degree of protectiveness over their partner. An example of this is Joan's anger at her mother's discussion about her husband's depression. In a scathing journal entry on her mother's interfering ways, she recounts how her mother's "instant reaction to the comment of my hubby being sad/depressed about the IF… is to diagnose the problem" (something that her mother blames on her husband's urinary tract infection). She ends her journal by stating, "Like we hadn't thought of that ourselves?"

Trudy's post provides another example. When her boss suggests that she would get pregnant if she "had sex with a real man", her reply is indignant. She firstly clarifies that her husband "is not the issue" (thus verifying his virility) and then suggests that her husband is "a really manly man". One interesting aspect about this post is that Trudy seems to be unconcerned with the level of inappropriateness displayed by her boss. However, she is incensed at the insinuation that her husband is not a "real" man.

For a few men, their infertility meant that they would never be able to produce a biological child . In cases such as these, the only options are either adoption or to take the more contentious approach of making use of a sperm donation. While for a number of men this was a perfectly acceptable option; for others, having a genetic link (and, thus having the ultimate proof of virility) is too significant, thus they are categorically against these options. The intense resistance of some partners drove women to consider an all or nothing approach. One such example is Tina, who, when advising another member of the community how to convince her husband that sperm donation may in fact be a viable option, suggests that "you can make the choice that if one can't be the biological parent, then neither of you will and you could adopt, or use a donor embryo…". In short, many women would rather sacrifice their own "genetic legacy" in order to secure their partner's agreement for the use of donor embryo or adoption.

Interestingly, egg donation and embryo adoption were seen as far less contentious. For many women with low ovarian reserves or low-quality eggs, embryo adoption or egg donation was felt to be a viable way of achieving pregnancy. A number of posts discussed men's much more relaxed attitudes towards adoption of a child or embryo and egg donation. This seems to be due to the stigma attached to male infertility, and these solutions afforded men protection in the form of secrecy of parental genetic identification.

Conclusion

The journey of the couples of Stronger Together was an eye-opening and, at times, heart-wrenching experience. It was hard not to feel deeply moved by the stories we read and the struggles these women and their partners faced. What these stories, as well as countless others demonstrate, is that infertility is a major life disruptor, which has deep effects on those who are intimately involved in it. The stories provided by the women further support current literature which suggests that the experience of infertility is not one-sided, or a "woman's journey", but is in fact a struggle faced by the couple, who must somehow overcome the devastation of diagnosis and unify as a team, to confront an uncertain future fraught with much sorrow and disappointment, in the hope of one day conceiving their much longed-for child. For women, this struggle is doubly hard, as they often feel isolated and seek solace and comfort in their partners, who may not fully understand their needs. Simultaneously, women also feel the need to support and protect their partners from the everyday stresses of the infertility journey as well as protect them from what they perceive as a brutal and uncompromising world.

No matter where in their journey couples found themselves, relationships were always affected by the journey of infertility. However, not all was lost: while this journey was difficult and trying for all, many couples were able to see the benefits gained from their difficult journey. A number of stories demonstrate that, while the journey to conception was indeed paved with many trials, this only made their relationships with their partners stronger. This finding is not unique. Other research, such as that conducted in Denmark by Schmidt *et al.* (2005), also suggests that while the journey of infertility may be disruptive to a couple, their relationship is often made stronger by the experience.

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Ethics and Reflexivity in Researching HIV-Related Infertility

Tam Chipawe Cane

Introduction

In this chapter, I draw on fieldwork conducted for my doctorate that explored the lived experiences of people living with HIV (PLWHIV). I was interested in PLWHIV who had accessed fertility treatment and child adoption services. HIV-related infertility and adoption are different to other forms of infertility or experiences of adoption because some of those affected may not be biologically infertile. When untreated, HIV can affect reproduction and increase the risk of HIV transmission during unprotected sexual intercourse to both a non-positive partner and potentially an unborn baby. Consequently, PLWHIV who wish to become parents are generally encouraged to access counselling in order to establish safer methods of having children. Fertility treatment or adoption are possible options that avoid the risk of HIV transmission to the unborn baby and partner (Savasi, Mandia, Laoreti & Certin, 2013). In this chapter, I discuss how I managed professional and personal relationships during fieldwork as I researched a small community of PLWHIV.

I was interested in the subjective experiences of PLWHIV and their inner life-worlds as they sought fertility treatment and/or adoption. I used Interpretative Phenomenological Analysis (IPA) as my methodological framework to achieve a reflexive stance during my research. I thought that bracketing my emotions and previous experiences was impractical. This was because I was a practising social worker who sometimes engaged with this client group. I found it crucial to find ways to maintain boundaries during the research process so that I could be in a safe

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T.C. Cane (✉)
Department of Psychology, Social Work and Counselling, University of Greenwich, London, UK

place to do my research. I spent time reflecting on my previous knowledge, practice experiences and conceptions using a process called internal dialogue (Maccarini & Prandini, 2010). I had internal dialogues with myself about the sensitivity of the data, and about what was potentially going to be shared with me. A typical dialogue went something like this: 'I am entrusted with information that has not been shared with others, can I emotionally cope with this and is my approach potentially harmful?' This internal dialogue enabled me to think about my capacities, ethics and boundaries as I knew my study was going to be emotionally challenging.

Many of the emotions I experienced were completely unanticipated and resulted from the participants sharing their experiences of secrecy and stigma in relation to adoption and/or fertility treatment. Their emotions raised profound feelings in me which I needed to reflect upon. As a consequence, I found that subjectivity *and* intersubjectivity were strong dynamics in the research between me and the participants. Since qualitative research involves dyadic interactions between people, reflexivity requires an interplay between the researcher and the participants' subjective worlds of experience, giving rise to intersubjective dynamics and understanding (Finlay, 2002). I used reflexivity as an active internal dialogue about a complicated situation (Maccarini & Prandini, 2010).

I developed my internal dialogue as a process of self-examination involving scrutiny and understanding of any assumptions and biases that could affect the interpretation of participants' experiences. This included looking into my personal opinions, feelings, emotions to understand how they were employed during the research alongside the interpretation of stories participants told me. For Wiley (2010), reflexive dialogues require researchers to see themselves as 'three legged stools, standing simultaneously in the past, present and the future' (2010, p. 19). In my internal dialogues, I reflected on my *past* self by exploring professional and personal experiences brought to the research, the knowledge and existing emotions associated with the emotive interviews (the *present*) and the analysis of the data, which offered me the opportunity to manage my emotions without causing harm to participants and self in order to formulate a better understanding of participants' life-worlds as they sought to move forward (the *future*). In addition, as part of an action-orientated research approach, Wiley supposes that reflexivity requires imagination about future actions and their consequences whilst, at the same time, engaging with the

I (present self), the me (past self) and the you (future or critical self), all of which depend on the purpose, and the projected and anticipated actions as part of the research. For example, the past self was myself as a researcher who is also social worker, to which was added the experience of working with PLWHIV who have lost the ability to achieve biological conception. Therefore, the sense of loss was an awareness I had through my professional role as a social worker but was also a constant presence in the research interviews—the *I* in the present. The participant's future included hope that PLWHIV would adopt a child or bear children through fertility treatment—future self. In that respect, reflecting beyond the wider features presented during data collection facilitated a deeper understanding of the impact of unique narrative accounts on participants' lives.

I recruited participants through charitable organisations that support PLWHIV. An online recruitment hub was created to promote and facilitate recruitment. Where appropriate, I visited support group sessions to talk about my research as well as using magazines and leaflets. Most interviews took place at the research hub (an HIV charitable organisation that offered me an honorary research contract) where I had a dedicated room and support staff available if required. One interview was conducted in the participant's home for their convenience. Wherever the location of the interviews, I re-visited the risk assessment strategy I had devised: to observe participant responses, monitor the emotional impact of the research questions and review participants' safety as well as my own (Holmes, 2010). Observations associated with emotional presentation of participants during interviews were noted in a research log and they formed part of the analysis.

All the participants in the study were committed to having their children through fertility treatment or adoption. Some had accessed adoption after a series of failed reproductive treatments, whilst others had only opted for adoption. Some participants had successfully adopted children, others were unsuccessful or in the process of re-applying to adopt through a separate agency. Given the intrusive, demanding and sensitive nature of both fertility treatment and adoption investigations, some participants were traumatised and challenged psychologically (Carroll, 2012). Participants felt that the reasons for failed adoption may be due to negative social work assessments and discrimination. In addition, even when accessed, fertility treatments are expensive and largely unsuccessful. Both fertility treatment and adoption have the potential to trigger feelings of anxiety and distress, and the assessments associated with both these processes may appear unsupportive. Childlessness itself had been a problem for the participants, who experienced stigma, and cultural and/or social pressures. Additionally, HIV-related childlessness had caused devastation, sorrow, segregation, guilt and sometimes powerlessness and frustration. During the interviews, participants described feeling emotionally fragile because the processes of applying for and undergoing fertility treatment and adoption were challenging. Those procedures frequently reminded them of how HIV contributed to their 'infertility' or childlessness. Some participants relived their experiences of how they contracted HIV and how this affected their ability or chance to have children using natural methods to avoid the risk of transmitting HIV.

Because of their emotional state during the interviews, rapport building was important in order to foster relationships with the participants so they felt comfortable with me and the interview environment. Thus, preparatory empathy created a gateway for participants to willingly talk about their experiences. I found that participants sometimes spoke about experiences they had not shared with others due to the fear of stigma. Consequently, when participants felt distressed, the rapport that had been built allowed participants to feel comfortable enough to elaborate on their feelings. Personally, I chose not to disclose my feelings in order to facilitate the researcher relationship. I wanted participants to talk about their experiences without worrying about my emotions. I wanted them to appreciate that their story was recognised within the research relationship and that my research was a way of doing something about it. My aim was to go beyond text but towards deeper interpretative psychological and psychoanalytic interests (Smith, 2008).

Subsequent sections in this chapter will explore the importance of engaging in pre-fieldwork reflexive activities, the conflicts that may arise between the research role against other responsibilities, such as being a practioner. Strategies to mange reflexivity are proposed before closing the chapter.

Pre-Reflective Activities

Processes of self-evaluation are subject to the researcher's philosophical position and the theoretical framework that grounds the research.

During self-evaluation, I acknowledged how my involvement and relationship with the phenomenon I was studying could be enmeshed with past experiences. I completed pre-reflective activities before the research commenced by taking an inventory of my experiences, beliefs and values, and experiences (Archer, 2012; Finlay, 2002) and then before each interview. I found this useful prior to interviewing participants even where they had provided a brief outline of their story during the recruitment phase. As a social worker who had supported service users through HIV-related difficulties, I carried my own perceptions and views regarding the subject. Prior to that, during my social work training, I had supported and advised PLWHIV on how and where to access fertility treatment and adoption services. Even then, I identified discrimination and problems faced by PLWHIV when seeking parenthood through fertility services. My choice and experience of research with PLWHIV was influenced by my professional experience. Awareness of my pre-existing knowledge, of how I was co-constituted and situated within the methodology helped me to unravel subjective and a priori assumptions. I examined my position during and after each interview in order to identify intersubjectivities that deepened the interpretations of the subject under investigation (Finlay, 2002; Holmes, 2010).

As a researcher, I had no lived experience of HIV and HIV-related infertility, nor had I gone through HIV-related fertility treatment or child adoption procedures but I had social work experience in matters around HIV. For this reason, reflexivity was an important element for being aware of what I brought to the research in order to become an introspective tool for the research process (Finlay, 2002). I went through a difficult process of shifting my positioning from practitioner to researcher, which required acknowledging the ethical and power differences between the different roles. To achieve this, I consciously detached my social work role from the research process. This meant relocating myself as a researcher at the heart of the research. On the other hand, I could not completely replace my prior experience as a social worker however hard I tried to achieve this. For example, as a social worker I had been an advocate to empower service users, to educate, support and represent those seeking to adopt children by helping them to navigate through various stages of an adoption process. As a *researcher* undertaking research in my own area of practice, I was more concerned with listening to participants' stories. I avoided being an advocate, educator, assessor or advisor at the same time as being a researcher. I also consciously avoided using my professional knowledge. Professional knowledge can be a way of gaining power over participants. Social workers are often seen as figures of power and authority when making professional judgements (Ruch & Julkunen, 2016) and when they make decisions about the suitability of prospective adopter's ability to adopt. I avoided this by bracketing my professional knowledge through maintaining a research log and taking down accounts of various challenges throughout the process.

Reflexivity is a process that requires researchers to acknowledge their social interactions, use of language and shared meaning, and in so doing create intersubjective dialogues and dynamics between the researcher and participant in order to produce research knowledge (Maccarini & Prandini, 2010; Noble & Mcilveen, 2012). Reflexivity may also be an inward examination of thoughts, feelings and the use of one's body as an object in the experience of others (Crossley, 2006). For Crossley (2006), this requires engaging in silences and in self-policing whilst consciously acknowledging their own embodied, tacit and practice knowledge. The researcher may mirror the participant's experiences and their emotional responses, responding by internally deploying conscious emotional responses to what the participant is reporting.

Emotions and Disclosure in the Research Space

It was imperative for me to acknowledge my own 'humanness', to examine my own emotions and behaviours within the research environment (Finlay, 2002; Holmes, 2010). This helped me to monitor my reactions and to be appropriate in my conduct in an endeavour to not influence the participants' reactions (Sandelowski & Barroso, 2002). I managed the intensity of emotions occurring in each interview by remaining emotionally and physically calm to avoid causing distress to the participant. For me, a sense of uneasiness about upsetting participants was always present. Part of me hoped, at a certain level, that participants would not revisit the circumstances through which they contracted HIV. I was unsure of how I would deal with this. I also did not wish to cause harm to people by getting them to relive how they became HIV positive. I knew some of the stories were likely to be distressing. Perhaps my reluctance was recognised by some participants who made efforts to avoid causing me upset when they spoke about their life experiences. One male participant in a same-sex relationship spoke about how he contracted HIV; it was particularly stressing as his sexual partner had not shared his HIV positive status with him. This description was emotionally challenging for me. It is possible that he observed my efforts to contain my feelings at that time and he questioned:

> How will you deal with what I told you if you do not talk to someone you trust about this? I understand you have to keep what I told you confidential but I also understand if you talk to someone about it as long as you do not reveal my identity. You do not have to respond to this but it is natural that we all share difficult experiences with others.

This conversation was powerful. I did not respond verbally or immediately. I realised that this participant empathised with my feelings and how I had responded emotionally to his devastating story. In an internal dialogue after the interview, I realised that in this situation that I did not know how to respond verbally as I felt lost for words and engulfed by the devastating story he had shared with me. Perhaps in the interview he could read my non-verbal language and was now reaching out to offer me support.

Smythe, Ironside, Sims, Swenson, and Spence (2008) highlight that interpretative work requires the researcher to explore that which remains unknown, by making it known. This includes understanding the meaning of silences, unspoken or concealed emotions and feelings. I suggest that in these silences, what remains unspoken is not only about the research participant but also intimately linked to the researcher. Understanding an individual's story requires curiosity. This involves asking the right questions to obtain new insights, acknowledging previous knowledge and sharing empathy (Smythe *et al.*, 2008). I was aware that, without using open-ended questions or probing even when I sense emotion, I would not access the unknown. I rehearsed sensitive questioning and how to manage emotions or unexpected responses. This is what I have already noted as preparatory empathy. When I commenced fieldwork, I had already appreciated that fieldwork would involve maintaining a balance in my physical reactions to maintain a stable emotional posture. Thus, reflexivity for me required going beyond my intellectual ability, emotional intelligence and critical thinking about historical influences, economic and political influences (Spence, 2016) about HIV, adoption and fertility issues. It required me to journey alongside the participants' personal journeys and to see through their eyes the experiences as they were told to me. However, the true feelings and thoughts of the other are never fully known, as empathy is limited; the researcher is trying to understand an experience that they perhaps may never really fully understand.

In one interview, a participant told me that because I was not HIV positive, I had not experienced his 'life-journey', I would never truly understand what it meant for him to be homosexual, HIV positive, to desire to become an adoptive parent for a child with learning disabilities and be told (directly) 'you will not live long enough to parent a child'. This was a disturbing message and of course it was absolutely true. As a person, a researcher and a social worker, I would never be able to fully comprehend what it meant to experience this range of factors but I was nevertheless emotionally affected by the enormity of the distress. This particular situation raises the importance of preparing for complex conversations during interviews. Engaging in emotional work is also important to ensure that participants feel safe and comfortable to question the researcher's own understanding of the sensitive subjects under investigation because qualitative interviews are conversational.

Conflicts Between the Research Role and Practitioner Role

Participants in my study described their lived experiences and I was 'the other' who had limited awareness and knowledge of how I would feel about, and what it is like to live with, being infertile and looking to adopt a child as a result of HIV. The following is a data extract from my research log:

> Mercy is a forty-five-year-old, HIV-positive female. Mercy was desperate to have a child with her husband who was HIV-negative. Mercy's fallopian tubes were blocked and this prevented her from having biological children. She was in denial about her infertility but was comfortable with her HIV diagnosis. Her unsuccessful application for NHS fertility treatment funding led Mercy to feel desperate for answers to her infertility. She became keen to adopt but had also been unsuccessful. (Research log)

Mercy knew I was a social worker and she was eager for my assistance and support. It seemed that in a way she wanted me to be her advocate. Following the interview with Mercy, she rang me almost monthly, seeking help and support. Mercy already knew where to access fertility treatment and adoption services but she was stuck behind what she believed to be *barriers* of HIV-related discrimination that firstly, prevented her from applying for fertility treatment funding; then secondly, her adoption application being rejected. Mercy had also received reproductive counselling through an HIV charitable organisation. My dilemma was that I could not give further advice—I was not acting as a social worker or indeed an advisor, I was a researcher. I had to maintain professionalism and to avoid giving Mercy false hope. For me, this was a clear dilemma because I had to maintain my role as a researcher first and a social worker second. Yet I was a social worker first; this role was embedded within me before I commenced the research.

Mercy's desperate state saddened and troubled me. The reality of someone struggling to have a child and feeling unsupported and desperate led me to empathise with Mercy. The sadness was increased by her (or my) powerlessness and helplessness. In an internal dialogue recorded in my field diary, I asked myself: am I a researcher, am I a practitioner or a support worker/advocate? Through reflexivity, I tapped into my social work skills around managing emotions, preparatory empathy, creating a safe research space in order to contain emotions in the interview but at the same time to continue with the interview. Here, I am suggesting that emotional regulation is a transferable skill that is also embodied. The management of feelings cannot be eliminated from the research process when attempting to make sense of human experiences. This means that I had to acknowledge Mercy's challenges and direct her sensitively towards further interview questions. I struggled with the conflict between being a researcher and an advocate. I experienced a great desire to be helpful; I imagined Mercy as my own service user to whom I felt a sense of responsibility. However, I needed to be honest about my limitations within the research role. I was lucky that I had access to clinical supervision to discuss this situation.

Maintaining the boundary between practice and research fuelled a sense of guilt as I felt (as a researcher) that I was denying support and assistance to someone who needed it. I also felt angry towards the social workers mentioned in the interviews and towards the system which the participants clearly felt was discriminatory. Some participants were adamant that their experiences had been discriminatory. As I had previously worked with social workers with minimal understanding of HIV, even some who had expressed judgemental views about HIV and parenting, I was unsurprised that some participants felt they had been discriminated against by social workers. However, I was shocked and angry about the extent to which discrimination was perceived by my participants to be at the heart of unsuccessful fertility treatment funding or adoption applications. Surely the stringent adoption procedures were necessary not discriminatory? I struggled to reconcile these experiences by wondering if some practitioners do not see things from the perspective of PLWHIV. Maintaining the boundary between professional social worker and student researcher was a real challenge.

Further conflicts between my practitioner and researcher roles arose during fieldwork as I continued to work as a social worker whilst I was completing my doctorate. I had an almost constant internal dialogue going on as I reflected on my practice in the light of the data collection. On the one hand, listening to participants in interviews made me aware of the subjective experiences of PLWHIV when seeking to become parents through fertility services or adoption and how they feel stigmatised and discriminated against by social workers. On the other hand, my colleagues could not understand how PLWHIV could be permitted to access fertility services or adopt. I found myself exasperated by what appeared to be the ignorance and prejudice I observed in my colleagues. However slowly, repeated informal discussions with colleagues about the nature of adoption for non-traditional service users (those with health issues) helped me to understand the knowledge gaps among practitioners. This ongoing internal conversation and external conversations with colleagues allowed me to reflect on the interaction between data and practitioner experiences as part of the analysis, to better enter and experience the life-world of PLWHIV who felt marginalised by adoption and fertility services. Consequently, I was able to view the situation from two contradictory positions: the first as a service provider and the second from the perspective of the researched who had either positive or negative feelings about the adoption or fertility systems and services. As the research progressed, I was better able to understand the perspective of the participants through similar internal dialogues. These dialogues involved examining myself (the social worker and researcher) as a researcher whose role was to work with the perspectives and experiences of the participants, and make meaning of those experiences on a case-by-case basis. By so doing, I made an attempt to avoid using practice experience not through bracketing but through reflexivity on those experiences (Binder, Holgersen, & Moltu, 2012). I focused on the rich life-stories told to me by the participants.

The more I interviewed the participants and listened to their stories, the more I saw a system that was non-inclusive; this insight was challenging to work with. It is important for researchers to rely on their interpretative resources to formulate meaning. I struggled to 'exit the worlds of participants' in order to re-engage with my interpretative resources and to analyse and interpret the data. In particular, when I conducted textual interpretation, I became overly sensitive towards participants' experiences (Smith, 2012). Academic supervision, where I questioned data against my own practice experience, a priori assumptions and prejudices, helped me to recognise how I was situated in the interpretation process. Supervision therefore improved textual construction, that is, how to write without making my own assumptions beyond what is located in a given data extract (Davies, 2008). Extra care and attention was paid to each individual participant's transcript by consciously engaging in an active internal dialogue to facilitate a balanced analytical process (Maccarini & Prandini, 2010). Through interpretative activities, such as rough note-taking, writing, re-writing and supervisory support, this process became easier.

Ethical Dilemmas when Researching a Shared Community

While I did not interview those I had known before the research commenced, as a researcher with an African background, the potential for interviewing people from my own community was always a possibility. By the time I commenced fieldwork, I quickly realised that researching HIV in the UK brought me into contact with people from various African communities including my own. Holmes (2010) describes this as relationality. Conducting research in a community where I had social relations created an unexpected power dynamic, which threatened to interfere with my researcher position. A personal dilemma that occurred during fieldwork is illustrative of ethical dilemmas that may occur in research in a shared community.

> During my data collection phase, I arranged a focus group meeting with PLWHIV through a third sector agency. This was for the purpose of research briefing and recruitment (data collection where appropriate). The meeting was scheduled an hour before a peer to peer support group. After the first hour, peer to peer support focused on issues around HIV diagnosis and associated concerns. Prior to the first meeting commencing, all introductions, information and consent forms were completed. Three quarters of an hour after the first meeting, a relative of mine joined the group. In order to provide information, to seek consent and for introductions to take place, it was vital to pause group discussions and welcome Lorry accordingly. This was Lorry's first time in attending a support group. He attended on that day to seek support about his new diagnosis. Upon Lorry's request and the groups' agreement, group discussions were deviated in order to focus on Lorry, who presented a troubled situation. He was worried, anxious and desperate for support. The research discussions were terminated and the support group was directed accordingly by the HIV Coordinator who was present throughout.

I was able to reflect and consider the appropriateness of continuing with data collection in a space where a relation of mine found comfort, help and support. My internal dialogue led me to question whether or not I needed to engage in a personal conversation with Lorry or to completely disregard Lorry's presence. I began to feel uncomfortable about the power that I had acquired over Lorry through my new role as a researcher about his position as a PLWHIV and what effect this had on my role as a family member. I have already highlighted earlier the dilemma I faced over the dual roles I found myself in, but in this case, I had three roles—a social worker, a researcher and a relative. As in other situations, in this space I was there as a researcher, not as a friend or family member, or a support worker/group facilitator. Had Lorry arrived early he could have opted out or I could have foregone my research briefing session. I sensed, during the session, that neither Lorry nor I could escape. Given the sensitive nature of HIV, my internal dialogue is presented in the box below:

I was concerned about Lorry worrying about his secret. Could Lorry trust that I would not disclose his secret? When he provided consent he was informed I was bound by confidentiality policies. However, I was not sure this would have been enough for him. In this case for me, reflexivity was not just an internal dialogue but negotiation of emotions that were physically sensed directly from Lorry. I could feel that physically, I was taking on Lorry's emotions and yet I was also managing my own emotions and my body language. Partly, I was shocked and overwhelmed by Lorry's story and his disclosures.

Lorry's story was dramatic as he revealed how he had contracted HIV and how this affected his physical health at the time as well as the impact of the illness on his closest family, (in fact, he kept his HIV status from his wife and wider family). As I tuned into Lorry's story, I made a conscious decision to make no contributions to avoid eye contact show no facial responses but to remain silent. Although I did not ask him directly about his feelings but as I reflected after the interview, I wondered how Lorry felt about my silence. I wondered if Lorry felt a sense of reassurance when sharing his personal and social experiences in my presence. He could have inaccurately assumed that I shared the same 'status' (HIV positive) as him. I found myself working on reproducing my social presentation throughout this meeting by engaging in emotion work so that my conduct remained professional and appropriate.

Holmes (2010) states that understanding the social self and reproducing the self requires paying attention to one's emotions through a reflexive process. For this reason, the generalised other played a part in how I made decisions to remain in the room, contain my emotions, kept silent and managed my physical reactions. I did this by asking: how would Lorry and the other group members feel? How would others view me? What would the group say about me and my conduct and how would this look professionally? In this dialogue, I was concerned about my reputation with the group members and how my behaviour would be scrutinised and observed.

Research can be complex. Without understanding one's position in fieldwork and in the interpretation of data, the researcher may misrepresent the stories told and create a false impression when research environments become messy, as in the situation with Lorry. I had to make a judgement about whether recruiting from such a complex group environment was appropriate. I concluded that using HIV support groups to recruit participants was no longer viable. I concluded that ethical codes for research and practice need to be flexible enough to address the difficult feelings that arise in the field. Codes of conduct that promoted reflexivity and patient safety (Haggerty, 2004) were key to addressing the dilemmas HIV researchers face (Skovdal & Abebe, 2012).

As data collection progressed, it became clear that I, as the researcher, needed support. Immediately after the group session related above, I was left with emotions that I could not process at that time of the night (9 pm). I felt constrained by confidentiality policies, as I could not seek support from close friends or family although eventually I was able to speak to a research buddy without breaking confidentiality. Writing about my feelings, observations and experience in my reflexive log helped me to manage some of my feelings. Writing a reflective summary about the group session above and how it had gone helped me to reflect and revisit methodological perspectives of my research. In an ideal world, immediate supervision with buddies and research supervisors who are bound to the research codes of practice will help the researcher to process immediate feelings and emotions that arise during fieldwork.

Learning from Managing Strong Emotions

Conducting HIV-related research required a strong capability in respect to emotional containment and resilience. I found that I had to manage my own feelings and remain professional even when I heard distressing stories. When preparing for research, I was ready to engage as the instrument for data collection and data analysis. I had pre-reflected on how to react when witnessing others' emotions using preparatory empathy. I would argue that this is more than personal introspection (Finlay, 2002), which involves internal searching (Archer, 2010). Despite my preparations, I had not imagined the intensity of my own emotions. My practitioner experience as a social worker and my previous work with PLWHIV as an HIV support coordinator was insufficient in preparing me for dealing with the uncertain and unpredictable stories that the participants told. I felt both angry and sad after the interviews. My research buddies were often helpful to me in managing my own feelings. Although supervision was also helpful, this was not always scheduled at the times that I needed support.

One example of an interview that was particularly emotional, which I found upsetting and disturbing, was with a serodiscordant couple whose partner had HIV and haemophilia. He was desperate to receive fertility treatment funding through the National Health Service and distraught about his condition. He just wanted the NHS to at least fund all their reproductive treatment cycles, but without success. The couple used all their savings and eventually gave up. They were turned down by a number of adoption agencies. They put this down to HIV-related prejudice. Listening to their moving story, I physically felt the pain and anger on their behalf:

> I felt, no matter how middle class you are, no matter how qualified and what your social status is, HIV has the potential to ruin a loving couple's desire for (biological) parenthood. Systemic procedures and practitioner knowledge in fact, does not cater for people's backstories and their desperation. Whatever they tried, they reached a 'brick-wall'. I respected the couple for challenging discrimination and remaining solid in their fight for parenthood. In my powerless position, I wondered, does it take a change in attitude for practitioners to realise that HIV does not always affect one's ability to bring up a child. After all, this couple is living well. They have now successfully adopted two children. It took only one agency and one practitioner with an open mind and open attitude to HIV. Did they have to fight through a plethora of agencies and fight against what they saw as discriminatory objections as much as they did? (Research log)

I was angry at how oppressive my participants found the systems they had to work with. One way of managing this was to use these feelings as clues for exploring the participants' experience further. Whilst it was appropriate to become attuned with participants' emotions, I was worried about my own feelings contaminating the pureness of the story as it was told and experienced by the participant. On the other hand, I needed to examine the meaning attached to their experiences and acknowledge why I had felt emotionally burdened by it. It was not about me but the experience of the participants. So, numbing my feelings, withholding comments, listening actively involved using emotion work but enabled me to access participant stories by asking probing questions to understand the meaning they had placed on their experiences increased participants' ability to narrate feelings and emotions about the troubling experiences encountered when seeking fertility treatment and adoption.

Maintaining a research log and using supervision when scheduled helped me to cope with unprocessed emotions and feelings. I found the research analysis and writing process both emotionally challenging and therapeutic. For example, through reflexive writing and analysis, I realised that the emotional demand I experienced was normal and that keeping an open mind facilitated my empowerment as a researcher. Initially, it was evident in my writing that my feelings directly affected my writing style. The ability to consciously negotiate and separate my practice and personal interests from the research role as I grew in confidence and was able to reflexively process feelings from the research interviews, allowed me to carefully and sensitively draw out important findings without being overly influenced by my personal or practitioner position.

Finlay (2002) argues that reflexivity is not about legitimised emoting but it develops insight about how the research space is managed and how this influences interpretation of data and research findings. The use of direct quotes to aid interpretation and meaning making was extremely powerful. This located the voice of the participants at the centre of their story/experience. Through self-reflective consciousness, I identified what my feelings were with regard to their experience, but also interpreted the meaning of the information and emotional reactions that had been reported (Finlay, 2002). I learnt that emotions cannot be shelved during research but can be used to enrich the analysis. And I came to appreciate that researching sensitive subjects is complex and unpredictable. I had to learn to manage my personal identity, professional identity and potential conflicts of interest between the researcher and professional role.

Researching PLWHIV constantly demanded sensitivity and active sensing of physical body responses as well as internal conversations. Although physical and verbal responses were evident as participants presented various emotions and feelings, these were absorbed within the interview room and transferred to my own 'container' of emotions. This emotional burden could not be avoided. I constantly questioned my responses, asking: is this the appropriate reaction? Is this the least destructive or the least harmful action? For me, being appropriate was about remaining neutral, fighting back tears and frustrations when listening to stories that were emotionally burdensome. I found that resisting the transference of the interviewee's feelings through reflexivity or counter-transference protected me as a researcher. I also learned that participants may empathise with researchers when they feel that their experience can be emotionally burdensome.

Strategies to Manage Reflexivity as a Researcher

- Clarify your own a priori conceptions.
- Allow data and the research process to trigger reflexive thoughts.
- Remain clear and focused on the research question when following participant stories and maintain an open attitude to participant responses.
- Have a clear researcher status and ability to adjust between conflicting roles to allow a transformation in self-identity as a researcher.
- Foster emotional resilience and find alternative confidential supervisory arrangements to address emotional disturbance during data collection.

Conclusion

This chapter explored processes used to engage in reflexive fieldwork when researching PLWHIV who experience HIV-induced infertility and seek adoption. I have described negotiating and renegotiating emotional and sensitive feelings and managing the boundary between researcher, practitioner relations. When tensions arise between the researcher or practitioner roles, personal or social relations can be managed through supervision, peer support and self sensitivity. Sensitive conscious engagement with data to account for a priori inferences with the interpretative process is important. In discussing these issues, I have emphasised that researching PLWHIV in a small research population may raise methodological and ethical challenges. It is also important to be open-minded, fluid and flexible about using alternative recruitment methods to manage ethical issues, boundaries and confidentiality.

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Source: Tam Chipawe Cane. Ethics and Reflexivity in Researching HIV-Related Infertility. In: Allan H.T., Arber A. (eds). Emotions and Reflexivity in Health & Social Care Field Research. 1st ed. UK: Palgrave Macmillan; 2017, pp 75-94. DOI 10.1007/978-3-319-65503-1_5. © The Author(s) 2018.

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* Prescribing Information of Letrolife | # Data on file
Ref: 1. American College of Obstetricians and Gynaecologists. Aromatase Inhibitor in Gynecologic Practice. Committee Opinion. Number 663. June 2016.

Prescribing Information: Letrozole™

COMPOSITION: Each film coated tablet contains:Letrozole I.P. 2.5 mg; Excipients q.s.; Colour: Tartrazine Lake & Titanium Dioxide IP. **INDICATION:** Letrozole is indicated for induction of ovulation in anovulatory infertility. **DRUG DESCRIPTION:** Letrozole belongs to a class of medications known as Aromatase inhibitors. Aromatase is an enzyme that is responsible for the production of estrogen in the body. **DOSAGE AND ADMINISTRATION:** Letrozole is given in the dose of 2.5 mg tablets from day 2 or 3 of the cycle for 5 days or as directed by the Gynecologist/ Registered Medical Practitioner. **ADVERSE REACTIONS:** Stop using the Letrozole and get emergency medical help if you have any of these signs of allergic reactions: difficulty in breathing, swelling of face, lips, tongue, or throat. Less serious side- effect may include hot flashes, warmth or redness in the face or chest, headache, muscle or joint pain,night sweats, weight gain, fatigue, weakness, nausea or swelling in hands, ankles or feet. **WARNINGS & PRECAUTIONS:** The medication is to be avoided if one is allergic to Letrozole or any of its ingredient or similar drugs. The medicine is likely to cause dizziness and hence driving is to be avoided. The medicines should not be taken with alcohol. Intake of Letrozole with tablets of Tamoxifen should be avoided because it can decrease the drug's effectiveness. Keep the drug out of the reach of children. **DRUG INTERACTION:** Some drugs that may interact with this drug include estrogens (such as ethinylestradiol, conjugated estrogens) and estrogen blockers (such as anastrozole,Tamoxifen). **MISSED DOSE:** Take the missed dose as soon as it is remembered. Skip the missed dose if it is almost time for the next scheduled dose. Do not take extra medicine or double dose to make up for the missed dose. **PHARMACOLOGICAL ACTION:** Letrozole works by inhibiting Aromatase thereby suppressing estrogen production, so the pituitary gland produces more of the hormones needed to stimulate the ovaries. These hormones, FSH (Follicle Stimulating Hormone) and LH (Luteinizing Hormone), can cause the development of ovulation in women who are anovulatory or increase the number of eggs developing in the ovaries of women who already ovulate. **STORAGE:** Store protected from moisture, at a temperature not exceeding 30°C.Keep all medications away from children. **Presentation:** One Blister of 5 Tablets.
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