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PEOPLE WITH INFERTILITY: THEIR OPPRESSION AND VULNERABILITY IN CANADA

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ABSTRACT
According to National Fertility Association (2014) infertility is a disease of the reproductive system where one third (30%) of infertility can be attributed to male factors, and about one third (30%) can be attributed to female factors. In about 20% of cases infertility is unexplained, and the remaining 10% of infertility is caused by a combination of problems in both partners. Female infertility can be caused by many factors including age, sexually transmitted diseases, obesity, use of intrauterine devices for birth control and pelvic surgery. Present paper surveyed the oppression and vulnerability related peoples with infertility.

INTRODUCTION

Infertility, defined by the failure to achieve a clinical pregnancy after twelve months or more of regular unprotected sexual intercourse, not only brings out societal pressures and a psychological burden to achieve procreation, the pinnacle for married couples, it also has a myriad of treatment options for each of its myriad causes, bewildering for most, physically uncomfortable, costly and without a guarantee of success which adds to the impact of the condition making it particularly stressful. Infertility is known to cause an impact on the mental health of the infertile couple, causing anxiety, depression, social isolation and sexual dysfunction. The triad of the condition, its investigation and treatment, the stigma associated with male and female infertility in traditional societal interactions cause a high level of psychosocial distress with a direct impact on the couple's marital and sexual relations. While several studies have proven this association between the impact of infertility and marriage and sex in couples, the unique societal circumstances and cultural settings require further investigation into this effect and quantification of the measure of impact. While the clinical effect and the direct impact of the condition are accurately measured, the subtler effects and multidimensional impact of the condition on holistic health, daily functioning, societal interaction and quality of life are often not evaluated while managing the condition. It has been postulated that the brunt of the condition is heavier in women and has more severe emotional and social repercussions than in men.

Size, Scope and Characteristics

Infertility is a medical condition that often requires a medical treatment. According to National Fertility Association (2014) infertility is a disease of the reproductive system where one third (30%) of infertility can be attributed to male factors, and about one third (30%) can be attributed to female factors. In about 20% of cases infertility is unexplained, and the remaining 10% of infertility is caused by a combination of problems in both partners. Female infertility can be caused by many factors including age, sexually transmitted diseases, obesity, use of intrauterine devices for birth control and pelvic surgery. Male infertility is attributed to factors such as age, heavy use of alcohol, injury to male reproductive system and cancer treatments. Medical problems associated with infertility often require treatment to overcome infertility. According to Johnston (2009) most women start becoming less fertile around age 30 and the process speeds up at age 35. In their 20s, women have a 20 to 25% chance of conceiving with their own eggs in a given month. By age 40, they have a 5% chance. By age 45, if she has not yet had any children, a woman's chance of getting pregnant with her own eggs is virtually zero. Men start becoming less fertile around age 40 as sperm count and sperm quality deteriorate. The risk of miscarriage, stillbirth and fetal abnormalities increases with the father's age. A 35 year-old woman trying to conceive with a 40 year-old man is twice as likely to miscarry as a woman of similar age who conceives with a man under 40.

As noted by Kirkey (2012) up to 16% of heterosexual couples where the woman is age 18-to-44 is experiencing infertility — a near doubling since the previous time infertility was measured in the nation in 1992. Not surprisingly, the older the woman, the higher the prevalence of infertility. Yet infertility appears to be rising among younger

women as well. In 1984, about 5% of couples with a female partner age 18-to-29 was infertile. By 2009-10, the prevalence for the same age group ranged from 7% to 13.7 %.(Kirkey, 2012).

The Ontario government is discriminating against those suffering from infertility because in order to receive treatment people in Ontario need to pay out of pocket for treatment. Following are some of the members from infertility group who often require assistance:

- Heterosexual couples when the male partner has no sperm or a low sperm count
- Single or lesbian women
- Women who are unable to provide their own eggs because of age, a genetic disorder, premature ovarian failure or treatment for a medical condition like cancer
- Fertile couples who are worried about passing along harmful genes to a child
- Single men and gay couples
- Women who have an irregular or missing uterus, or for whom other assisted reproduction services have failed

Many young working people cannot afford the costs of paying for fertility treatments or drugs. Aside from this, government also oppresses people who have a disability or an illness that seek government assistance to survive suggesting that if you do not have supplemental funds available then they cannot seek treatment for infertility. Nisker (2009) disputes that when the government revoked its funding for IVF treatments in 2004 "that allowed Ontario to "proceed" only for its wealthier citizens, and not to "care" for its socially less advantaged citizens" (para. 4).

Issues Associated

People who have experienced fertility problems or who have sought treatments face a number of issues including:

- It's difficult to get information: many people didn't know about the factors that affected their fertility.
- They are not sure where to go for help. Some facilities and practitioners offering assisted reproduction services are not accredited. Are the treatments safe? Where should they go to get the best care?
- The procedures are too expensive and are beyond the reach of most Ontarians.
- There isn't enough emotional support to help them deal with the grief over fertility problems, the stress fertility issues place on relationships or the challenges of treatments.
- Many people have trouble accessing services because of where they live.
- For same-sex and single people, and people with HIV, social and legal barriers can keep them from getting the services they need.
- The fertility needs of young cancer patients are often forgotten by treating cancer specialists.
- There is still a sense of failure or stigma about infertility that keeps many people silent and in pain.

With the exception of Quebec, Canada does not provide health care coverage for fertility treatments. As a strategy to reduce overall health care costs, Quebec currently funds 3 rounds of IVF for families struggling with infertility. As suggested by Bodnar (2011) due to the cost of IVF treatment families who do not receive government funding often transfer multiple embryos which can result in multiple births, complications during pregnancy and premature births which inevitably bears a cost on the health care system. The rate of having a child with a disability also increases with multiple births. Subsequently, woman who suffer from infertility have increased rates of depression and anxiety placing more financial bearing on the mental health system (Domar, Dusek & Paul., 2006)

Oppression at Personal Level

Couples with infertility suffer from low self-esteem, suppression of anger, isolation, powerlessness and guilt because of scarcity of resources and lack of support from government thus impacting psychological functioning of these individuals. Oppression negatively affects individual's psychology as it leads to loss of personal identity, fear, alienation and ambivalence. (Mullaly, 2010). Women who experience infertility report significantly higher levels of depressive symptoms and anxiety. People feel like there is something wrong with them, that there is a sticker on your forehead that says they're infertile. They don't want to be with people because they are depressed. In one study, 11%

of infertile subjects met the criteria for a major depressive episode, compared to 3.6% of fertile subjects. In another study of infertile women, half of the subjects reported changes in their sexual function, and 75% reported changes in mood, such as increased feelings of sadness (Domar, Dusek and Paul., 2006).

Due to higher costs of treatment and lack of government funding, those who are unable to afford costly procedures are not able to acquire this goal which means that only the rich can experience the benefits of medical advances in this area. This can further lead to resentment, anger, frustration and worthlessness. People may seek supernatural means as a way out of their oppressed condition such as astrology and superstitious beliefs thus living in denial and appealing to someone or something to fix what is wrong. There is shame and stigma associated with infertility which means some people never seek assisted reproduction services or feel supported. Many people are embarrassed or ashamed to admit that they are struggling with infertility. They may not be aware of how many other people are struggling with infertility right now. As noted by Johnston (2009) one in six couples has struggled with infertility at some point in their lives.

Oppression at Cultural Level

Culture exits in everyday life and one participates in cultural practices created by the dominant group. At times, many practices contribute towards relationships of domination or subordination. In some cultures, stigmatization around infertility is extreme where infertile people are viewed as a burden on the socioeconomic well-being of a community. Stigma extends to the wider family, including siblings, parents and in-laws, who are deeply disappointed for the loss of continuity of their family and contribution to their community. This amplifies the guilt and shame felt by the infertile individual. According to Sembuya (2010), in Uganda childless women suffer discrimination, stigma and ostracism and are banned from attending family gatherings. These are the moments when an individual feels extremely isolated as you are not regarded as a human. The situation is further exacerbated by the lack of support women face, both emotional and financial.

Women in some cultures are blamed, face social isolation, can be beaten, or worse for being infertile. They frequently remain silent about their husband's infertility. Infertility is an issue of profound human suffering, particularly for women. As noted by Sembuya (2010), women in less developed countries do not have the economic or job opportunities that are more available in comparison to Western Nations thus motherhood is a central part of their identity and self-worth. The inability to conceive a child has huge implications in terms of their identities and their ability to function in their societies.

Oppression at Structural level

Government policies in Ontario do not support public funding for assisted reproduction services based on their argument on validity and success of IVF treatments in addition to the fact that the procedure is not a medical requirement. This means that in 2009, for every cycle of IVF, people must pay about $10,000 for treatment alone and around $2500 for fertility medications every month. Even for patients whose treatment is covered under OHIP, costs range from $1,500 to $5,000 per cycle (depending on whether they go to a public or private clinic). Ontarians who need IUI, intra uterine insemination, a funded service, must still pay hundreds of dollars for sperm washing and administrative fees. These amounts do not include all of the other costs necessary for treatment – medications, travel, accommodation and time off of work – which add thousands more to the cost.

Current Federal laws restrict access to assisted reproduction in Ontario. Before the AHRA, Assisted Human Reproduction Act, many people who needed third party reproduction services had access to many professional services. Today, the Act makes it illegal to pay for sperm, eggs or surrogacy. Intended parents – the people who will raise the baby – will be allowed to pay for some costs of the pregnancy (e.g., travel expenses, fertility medications), but not all. This law is forcing some Ontarians to use dangerous alternatives and to use services outside of Canada. Thus Act makes it difficult for Ontarians to continue to use third party reproduction to build their families. The Act also makes it illegal to act as an intermediary – a person or company who finds potential surrogates and matches them

with people who need them – which means more people will have to find surrogates themselves. Before the Act, intermediaries helped people to find surrogates who would be a good match for them. Not only it is now difficult for people to find a surrogate at all, it is difficult to know if the surrogate is a good choice. Additionally, there is no law in Ontario that protects donors, surrogates and the intended parents. Donors and surrogates need protection so that it is clear that they do not have any parental responsibilities for the child that they helped to create. Parents need protection so that it is clear that a donor or surrogate cannot claim parental rights over the child. Currently, intended parents and donors face expensive legal costs to draft contracts that will protect the rights and responsibilities of everyone involved.

Addressing Oppression at Personal and Cultural level

The shame and stigma associated with infertility leaves many people embarrassed or ashamed to admit that they are struggling with infertility. As a social worker, the first step in breaking this stigma is to acknowledge and advocate that infertility is a medical condition and treat assisted reproduction, used to treat infertility, like other medical treatments. Currently, lack of public funding for IVF treatments is based on Government's perspective on how infertility is not a medical condition and validity and success of IVF treatments. This initiative can convince government to fund and provide additional support for people requiring fertility treatments.

Ontarians should be educated and made aware of how many people are struggling with infertility and that infertility is not a choice. Social workers can advocate for educating primary **care practitioners** about fertility and related issues including: the impact of age on fertility, male and female infertility, and the important risk factors that affect fertility; the reproductive needs of non-traditional families; and the complementary services available to enhance fertility or treat infertility. This education can then be translated as routine part of care for all patients, beginning in their 20s. This includes males and females, those in a relationship or single regardless of sexual orientation.

Early fertility education can further help Ontarians to make informed decisions about their reproductive health and childbearing decisions. Also, the sooner that Ontarians are aware they may have a problem with fertility, the sooner they can be referred for treatment. Steps can be taken to ensure that government enforces printed **and web-based educational materials** are developed and made available to primary care practitioners to share with their patients.

As social workers, one can work towards starting infertility support groups such as ones currently in operation in Niagara region. These groups provide support and strength to couples experiencing primary infertility through monthly meetings. Joining infertility groups can have many benefits: decreased sense of isolation, freedom to express negative feelings and emotions, learning to develop effective coping skills and enhanced self-esteem.

Addressing Oppression at Structural level

As social workers, we need to advocate for change in current federal legislations in Ontario regarding third party reproduction services. Under the current federal legislation, it will be very difficult to access any third party reproduction services. Ontario must develop a system that would support Ontarians needing these services – for example, through developing provincial regulations governing third party reproduction and establishing a province-wide donor and surrogacy bank. Quebec is currently challenging the law.

Since no current law protects intended parents looking into third party reproduction services and donors, advocacy is required in creating some kind of protection for these individuals so that face they don't have to face expensive legal costs to draft contracts that will protect their rights and responsibilities. Other jurisdictions have developed legislation that protects intended parents and donors that limits the need for individual contracts. Thus similar legislation is needed in Ontario.

Ontario is out of step with a number of other jurisdictions that fund IVF – including Belgium, Netherlands, Sweden, Denmark, Finland and Australia – all of whom have lower rates of multiple births than Ontario. The decision to fund IVF is usually driven by the desire to reduce multiple births and their health and social costs. By paying for

procedures like IVF, countries have been able to reduce the risk of people having twins or triplets while still containing health costs and maintaining the number of live births. (Johnston, 2009). The Government of Quebec has recently announced that it will soon fund three cycles of IVF and other associated medical services for its citizens. In the meantime, Quebeckers will continue to have access to a 50% tax credit for offsetting the costs of assisted reproduction. Social workers can work towards promoting a similar approach for Ontarians and help advocate that the government proactively provide health care coverage for infertility treatments.

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