

Women's Lived Experiences with Infertility

DIANA C. PARRY

Cet article nous parle des expériences des femmes et leur fécondité. L'auteure identifie un problème d'infertilité et suit sa progression à travers tous les stades et débouche sur un impact à long terme. Elle a voulu savoir comment les femmes vivent les différents stades, comment elles prennent les décisions, et comment elles se déplacent d'un stade à l'autre.

Headlines such as “Infertility: Who Pays the Price?” (Kaye) are bringing infertility issues to the forefront of Canadian health issues. The popular media coverage of medical research into the causes, and most recently, the technological solutions for infertility including drug therapy, egg donation, in-vitro fertilization, and the controversial practice of human cloning, have brought new awareness to the emotionally charged decisions that people with infertility face in their plight to conceive a child. Defined as the inability to conceive after one year of timely, unprotected intercourse or the inability to carry a live pregnancy to birth (Aronson), infertility is a health issue that affects approximately half a million Canadians (Kaye). Many of these Canadians are seeking medical assistance to conceive. This has resulted in research largely focused on the medical aspects infertility (Imeson and McMurray), leading to the medicalization of the health experience.

Medicalization “refers to an intricate social process involving the dominance of biomedical paradigms and authoritarian models of health in which illness experiences are understood as biological and individualistic” (Thomas-MacLean 630). Once a health issue becomes medicalized, it is described in medical language, treated in medical institutions, and people affected by the issue are regarded as patients (Greil). As issues are medicalized and dealt with in a medical domain, medical institutions and the medical world in general supply the major context for shaping health experiences (Lorber). This trend has been widely criticized by scholars and activists alike for failing to appreciate other factors and contexts that impact health (Boston Women's Health Collective). In particular, feminist scholars and activists argue that nowhere has the medical model been more invasive and harmful than in issues connected to women including pregnancy, childbirth, birth control, abortion, surrogacy arrangements and the mapping of the human genome (Woliver). Laura Woliver calls for feminist criticism, analysis and research that includes the voices and experiences of women and girls to add to medical model discourse viewpoints and aspects of health that are often overlooked, and specifically for feminist research that addresses women's re-

productive health. She states, “in reproductive politics, the women profoundly affected by the developments in science, politics and law are often not heard” (14).

Infertility is one such health issue that requires research grounded in women's lived experiences. The purpose of this article, therefore, is to direct attention away from the medicalization of infertility through the presentation of women's lived experiences with infertility. This article will explore women's progression through a series of stages beginning with the identification of their infertility through to its long-term impact on their lives.

Theoretical Orientation

Specific research questions I addressed included: At what point do women recognize a fertility problem? How do their experiences with infertility proceed after their recognition of a problem? What decisions do women make throughout their experiences with infertility and how do they make decisions? How do women feel about infertility and how do those feelings serve to inform their decision making process?

Feminism provided the guiding epistemological framework to answer the above research questions. I agree with Linda Thompson that: (a) all inquiry is value-sustaining, and femi-

nist work is politicized inquiry; (b) separation between researcher and researched does not ensure objectivity, and a closer connection between the two may reconcile objectivity and subjectivity; (c) women's experience can be considered a source and justification of knowledge; and (d) there may be no such thing as truth and objectivity (9).

Consistent with this feminist epis-

university. An additional 25 women were contacted through the online newsletter.

Because I appreciated and valued the effort these women made to reach out and contact me about such a personal and private issue, I chose to interview every woman who expressed her willingness to participate. In total, 30 interviews were conducted; each interview lasted roughly 50 min-

of the stages, for review and comment. All but a few women provided feedback. Their comments were incorporated into the stages identified.

Participants

The 30 women who participated had reached personal closure to their experiences (a conception, adoption or decision to remain childless) and were therefore able to reflect on the whole process of infertility and discuss the stages they perceived themselves as having experienced.

At the time of the interview, the women ranged in age from 30 to 53 years, with the majority in their late 30s to mid-40s. All of the women were Caucasian and married to men. With respect to employment status, three of the women were stay-at-home parents, while the rest were employed outside the home in a wide variety of careers, including lawyer, dental hygienist, secretary, graphic designer, journalist, and professor. The age at which these women first tried to conceive ranged from 17 to 41 years, with most having started trying in their late 20s to mid-30s. The length of time they tried to conceive ranged from a couple of months to 17 years. Most had tried to conceive from two to eight years. The treatments they pursued ranged from not doing anything at all to in-vitro fertilization. Most used infertility drugs and artificial insemination. At the time of the interviews, two were undergoing a final round of in-vitro fertilization, four had conceived with the aid of in-vitro fertilization, 12 had conceived with assistance other than in-vitro fertilization, eight had either adopted or were in the process of adopting, and four had decided to remain childless. The two participants who at the time of the study were undergoing a final round of in-vitro fertilization were included because they had decided it was their final attempt at conceiving a biological child. Moreover, both participants had decided if this final in-vitro attempt was unsuccessful they

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temology, this study was based on active interviews that are conversational in nature (Dupuis). Active interviews focus on mutual disclosure so that both the interviewee and interviewer contribute to the meaning-making process, creating a space where the women could share their own narratives and explain their own experiences (Kaufman). Thus, "knowledge was generated through dialogue, listening, and talking" (Thompson 10).

Research Design

Participants were initially recruited through snowball sampling. To ensure women felt comfortable to decline participation in the study, friends or family members were asked to contact women who had experienced infertility yet reached some sort of closure (a conception, an adoption, or a decision to remain childfree) to their experiences, share the purpose of my study, and, if interested, request permission for follow-up contact. In all cases, the first contact I made with participants was via email. Five women agreed to participate. In addition to the snowball sampling, an advertisement appeared in an online newsletter, a weekly email sent out to all faculty and staff at a large

utes to two hours. I explained to each participant that my interest in the topic stemmed from my sister's description of her experiences with infertility. All but one of the interviews were audio tape-recorded and later transcribed. To keep the data confidential, each woman was assigned a pseudonym and all other identifying information (names of partners, friends, family members, nurses, doctors, place of employment, etc.) was changed.

To analyze the data, I reread each transcript a number of times. Guided by my research questions and feminist epistemology, as I read, I underlined comments, questions, quotes, experiences, emotions, and stories that identified a women's progression through a series of stages with infertility. Within those stages, I noted how each woman felt, how she made decisions, and how she moved from one stage to another. Once the interviews were completed, the individual analysis from each interview was compared and contrasted to develop patterns of relationships among the women's comments, experiences, and stories. The analysis of data occurred with the help of the women who participated in the study. Each participant was sent her individual transcript, along with a description

would remain childless and therefore also described themselves as having reached closure. The findings of the study should be interpreted with the understanding that the participants were a homogeneous group. That is, the participants were all white, heterosexual women and thus, the study is limited to their experiences and is not necessarily reflective of women in other situations. Moreover, I have chosen to address the women's experiences in isolation, and focus on the individualistic aspects of the experience.

Findings

Throughout this section I will be using existing literature, especially the work of Arthur Griel, Judith Daniluk and Margaret Imeson and Anne McMurray, to contextualize the findings of my research.

All the women experienced the stages I identify below, albeit for varying lengths of time depending on their unique situation with infertility. It is to this progression I now turn.

Recognition of the Problem

For many of the women, the infertility experience began with the recognition of a problem. Most of the women were shocked to discover their infertility. As one woman commented,

We had been married three or four years and we'd been trying on and off for a few years and I hadn't been getting pregnant. I went to the doctor and said, "We've tried for long enough. Is something wrong?"

Similarly another participant stated,

I was only 26, 27 years old and I'm thinking why isn't this working? This should be working by now because I'm 27 years old.

However, not all women in the

study were surprised by their fertility problems. Several suspected they would have problems based on their gynecological history. As one participant noted,

I suspected I would probably have problems so I was very much in a hurry to get started [trying to conceive]. I had always had irregular periods, started my period late,

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and my cycles were way off so I already knew that it might be a problem. I read a great deal about infertility before I even got there.

Whether their recognition of fertility problems was a surprise or confirmed their suspicions, during this first stage most of the women felt anger, frustration, anxiety, sadness, and disappointment that pregnancy was unlikely to happen naturally. This sentiment was clearly summed up by a participant who stated, "I was absolutely and totally crushed." Another woman described her initial feelings thus:

I felt awful. And, if I heard that somebody was pregnant I would just cry, even if I was at work and I heard about it I would have to try really hard not to. It was very difficult for me to cover it up because I felt so terrible.

Cautious Optimism

After six months to a year of trying on their own, the women for whom infertility was an unanticipated shock entered the cautiously optimistic stage when they decided to see seek medical attention. Only one woman in the study decided against pursuing medical assistance to help her give

birth to a biological child. Similar to findings of other research on infertility (see Greil), most of the women in this study "felt" a problem well before the medically-mandated one year of unprotected intercourse. The decision of when to seek medical attention was therefore dictated by the medical definition of infertility as opposed to a woman's own intuition about the possibility of a problem.

Some of the women had always known they would need medical assistance to conceive. For example, one participant was married to a man with paraplegia and thus knew they would require medical assistance to conceive. These women bypassed the initial frustration that other women experienced, they tended to be much happier and more optimistic entering this stage of the infertility process. For these women, the cautiously optimistic stage was characterized by feelings of happiness, hope, nervousness, and faith in the medical technology and their ability to conceive.

To start the process, women initially made appointments with their regular gynecologist to determine why they were unable to conceive, solve the problem, and thus, gain control of their reproductive abilities. With this in mind, from the woman's point of view, the focus of the cautiously optimistic stage was characterized by a desire for a definitive diagnosis and treatment of the infertility (Shapiro).

However, not all the women were willing to pursue *any* medical treatment available to conceive. While most were eager to remedy their situation and submitted to many types of infertility treatments—despite their level of invasiveness or low probability of successful conception—a few

women made decisions about which treatments to pursue based on their financial situation, personal beliefs, and values. For example, one participant stated,

We chose not to go into the artificial insemination. We didn't do that because we didn't feel ... it was necessarily the right choice for us. We're Christians and we thought if God is trying to say "you don't need any more kids" then we didn't want to play God and try to manipulate things.

Thus, as noted by Judith Daniluk,

Individual beliefs and values about the importance of biological parenthood and the morality of and ethics involved in intervening with "nature" play a significant role in treatment decisions. (665)

Clearly there are also barriers posed by financial considerations for some of these treatments. For example, one woman stated, "we could afford insemination, but not in-vitro, so that is how we decided how far we could go along this path."

Ironically, while women sought medical assistance to gain some control over their reproductive abilities, they often found themselves embroiled in a process wherein they actually lost their sense of control. One woman commented,

My experience with infertility went very quickly. I went from in July of that year, they said "oh you might have a slight hormone imbalance, we're going to put you on Clomid," which is how I started, to by December them saying after a laproscopy [a surgical procedure] "we really think in-vitro is your only option to get pregnant." I just couldn't quite process that.

Thus, as Greil also determined, after seeking medical assistance the women found "themselves in a para-

doxical situation, because—to regain control—they have found it necessary to place themselves in a situation where they have very little control" (78).

The cautiously optimistic stage incorporated the entire period of time women sought a diagnosis of a problem and treatment for their infertility. This stage went on for a short or extended period of time, depending on the women's unique situation.

Regardless how long women spent in this second stage, all experienced emotional ups and downs. Infertility treatments seemed to

catapult [women] on to a cycle of hope and disappointment ... where hope is built up each month, only to be dashed with the onset of menstruation, which then resets the whole cycle. (Imeson and McMurray 1018)

The "emotional roller coaster" of infertility is well documented in the literature (Daniluk; Kaye). Where the women I interviewed were in this cycle of hope and disappointment determined how optimistic the women felt about their treatment. If a woman was hopeful, she tended to be quite optimistic about the potential for a successful conception. In contrast, if a woman had just suffered disappointment, she was more cautious. A small group of women, however, demonstrated a fierce determination to get pregnant, which acted as a buffer against negativity. As one participant said,

I think probably the most important thing was I never doubted it would work. It was just a matter of when it will work. So I didn't go insane thinking oh, I'll never have children, how will my life be? I just wondered how many attempts it would take.

Within the cautiously optimistic stage, many women experienced major setbacks, such as miscarriages. For example, one woman noted, "the

first month we were married we conceived twins but lost them at the end of the first trimester. It was horrible." Others experienced a tubal pregnancy, about which one woman commented, "I had an ectopic pregnancy which was just devastating. It was really traumatic." Many women experienced numerous failed in-vitro fertilization cycles. One participant described her infertility treatments as, "three unsuccessful in-vitros, I've lost track of how many laparoscopes and how many pergynol [an infertility drug] treatments. It was a wild ride."

Despite major setbacks on their paths to parenthood, many women continued with their infertility treatments because their desire for a biological child was very strong. Indeed, the strength of that desire influenced how long women continued with infertility treatments before looking into other options, such as adoption. A few women said their doctor "threw in the towel" before they themselves were ready to do so. Others commented the doctors gave them hope they would conceive when they were ready to stop trying to have a biological child. Ultimately, however, when women started losing hope that medical assistance would help them conceive, or if they did not like the next step in the reproductive technology process, they decided to stop trying to conceive a biological child. One woman commented,

It came to a point near the end where it just seemed like it shifted. It wasn't overnight "boom." I can remember even at the very beginning of the adoption process still thinking maybe I'll get pregnant right now, maybe it will just happen on its own. Even after all those failures it would still come into my mind but it just gradually subsided and it came to a point where the scales tipped in favour of, ok, the pregnancy thing isn't as important.

The shift in thinking as medical

treatments lost their promise was characterized, not by an abrupt change of heart, but rather by the slow, gradual realization that all the medical assistance in the world did not guarantee a biological baby. In short, as Greil has suggested, women

could not pinpoint a specific time or event when they began to see themselves as infertile. Rather they described the sense of themselves as infertile as something that just crept up upon them day by day. (75)

The Turning Point

Ultimately the cautiously optimistic stage led to a turning point, which arrived whenever one of two things happened: conception or the realization that conception was impossible. As Daniluk notes: "If treatment is successful, patients usually feel blessed in their good fortune and are extremely grateful for ...[their] precious 'gift of life'" (664). When repeated treatments were unsuccessful, women were forced into the realization that conception was impossible.

One woman described her realization that she was not going to conceive a biological child thus:

The way it ended, strangely enough, [was when] I was going in for the third in-vitro session ... and I just lost it. When [the doctor] finally arrived I told him "I can't do it." I told him "I can't go through with it." And after that I couldn't get myself to go back to the clinic any more. So we waited a few months and then we pursued adoption.

Women who realized they were not going to conceive or carry a pregnancy to term, in their words, "hit rock bottom." In doing so, they began the process of resolving their feelings about infertility. For some women this meant coming to terms with their inability to experience pregnancy and delivery. Others struggled with accepting their inability to con-

ceive a child that was a biological combination of herself and her husband. More specifically, it was at this point that many women needed to come to terms with their conceptualization of family based on a dominant ideology of two parents and children that are biologically related to both of their parents. At this stage, women experienced an identity shift whereby they stopped thinking of themselves "as not yet pregnant" and started thinking of themselves as "infertile" (Greil). In doing so, some women experienced a sense of relief that the experience of infertility was finished and felt "freed from the burdens of painful and humiliating medical procedures and invasive medications" (Daniluk 671).

Forging New Paths

Once they were freed up from the infertility process, many women forged new paths. For some, it meant exploring new paths towards parenthood. As the comments described above, some women decided their real desire was to be a parent and sought out other ways to extend their family by bringing children into it, however possible. A woman tended to make this decision in consultation with her husband and other close social contacts. Women in this stage developed a broader conceptualization of family and valued the presence of children in their lives and the opportunity to parent more so than conceiving biological children. For women who forged new paths towards parenthood, "stopping medical treatments did not mean giving up on parenthood, only on biological parenthood. Often the decision to call a halt to treatment was accompanied by developing or renewing a commitment to actively pursue adoption" (Greil 100). This sentiment was echoed by one woman who stated,

Just because we had stopped the infertility treatments didn't mean we didn't want to be parents. It just meant we were going to be parents in a different way. In fact,

I think stopping the infertility treatments made me more committed to being a parent in some ways.

For other women, forging new paths meant making and accepting a decision to remain childless and seek other avenues of fulfillment in life. As one woman commented

I came to the conclusion I was going to have find fulfillment in my life other ways. So when friends or relatives have babies, I will give a baby gift. I enjoy reaching out to others who are able to have children and trying to nurture that a little bit. I also volunteered for several years for the crisis nursery here in town. Also I get a lot of emotional comfort and pleasure from my husband certainly and from my pets. I have two cats and two dogs and I get a lot of emotional fulfillment from them.

Thus, women who had come to a realization that having children in their own nuclear family was not the most important aspect of life for them and found happiness by being involved in the lives of children in their extended family or agencies such as a daycares, enjoying a close group of friends, and seeking satisfaction through leisure pursuits and career opportunities.

Long-term Impact

Regardless of what happened at the turning point—conception or realization—all of the women commented that infertility was not simply an experience they "got over" and completely moved beyond, but rather it had a long-term impact. The experience of infertility became part of each woman and forever changed her. For some women the experience of infertility caused them to worry excessively about their children, making them over protective. Others remained sensitive about mother's day recognizing it as a difficult day for many women and taking care to ap-

preciate that it was not a celebration for everyone. Other women recognized that not everyone wanted or was able to have children and thus stopped asking people questions they found painful such as, "when are you two going to settle down and have kids?" many women appreciated how painful it was to experience infertility and made themselves available to help others struggling with such issues by making themselves available to talk to women in similar situations. One participant even decided to pursue a degree in social work so that she could counsel women regarding infertility. This participant stated,

I want to help others who go through infertility. I want to pass along any knowledge and experience I gained. If I can help even one person it will have made the whole experience worthwhile.

Perhaps Barbara Eck Menning, the founder of a support group called Resolve, sums up the long-term impact of infertility best with this comment:

My infertility resides in my heart as an old friend. I do not hear from it for weeks at a time, and then, a moment, a thought, a baby announcement or some such thing, and I will feel the tug—maybe even be sad or shed a few tears. And I think, "There's my old friend." It will always be a part of me..... (117)

Conclusion

While moving through the different stages of infertility the women took an active role in acquiring an understanding of their medical situation so that they could make informed decisions about their situation. The women discussed how they developed an internal strength and confidence to face life as a result of their encounters with infertility and use of reproductive technology. Empowerment was evident in our dis-

cussions, both as a process and an outcome of the women's experiences with infertility and use of reproductive technology (Braithwaite). For example, when asked what she has learned about herself as a result of her experiences with infertility, one woman responded, "I think the main thing is I'm stronger than I realize ... stronger as a person."

When we focus on women's lived experiences we learn much about women's health and well being. As the number of women accessing infertility treatments continues to increase, the importance of understanding all aspects of infertility will continue to grow as well. Clearly, issues beyond the physiological causes and technical solutions warrant attention since these factors also impact women's health. Because there is little doubt "the context in which women become mothers in Western societies is changing, reshaping, and sharpening issues of power and control over women's reproductive agency" (Woliver 1), perspectives from feminist researchers are needed now, more than ever, on the experience of infertility. Furthermore, identifying the stages associated with infertility is an important step in helping women and health care providers think about and develop any necessary stage-specific supports.

Diana Parry is an Assistant Professor of Recreation and Leisure studies at the University of Waterloo, Canada. Her research embraces a feminist epistemology and focuses on women's health and well-being from a quality of life perspective.

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