

January 2013

Women's Experience of Infertility: A Multi-systemic Perspective

Roni Berger

Marilyn S. Paul

Lisa A. Henshaw

Follow this and additional works at: <https://vc.bridgew.edu/jiws>



Part of the [Women's Studies Commons](#)

Recommended Citation

Berger, Roni; Paul, Marilyn S.; and Henshaw, Lisa A. (2013). Women's Experience of Infertility: A Multi-systemic Perspective. *Journal of International Women's Studies*, 14(1), 54-68.

Available at: <https://vc.bridgew.edu/jiws/vol14/iss1/4>

This item is available as part of Virtual Commons, the open-access institutional repository of Bridgewater State University, Bridgewater, Massachusetts.

This journal and its contents may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, re-distribution, re-selling, loan or sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden. Authors share joint copyright with the JIWS. ©2022 Journal of International Women's Studies.

Women's Experience of Infertility: A Multi-systemic Perspective¹

By Roni Berger², Marilyn S. Paul³, Lisa A. Henshaw⁴

Abstract

This article describes a study that used a multi-system perspective to document the self-reported experience of women struggling with infertility and its treatment. A sub-sample of 56 participants from a parent study that examined posttraumatic growth in the context of infertility was used based on their answers to a single open-ended question about their infertility experience, which was included in the original questionnaire. Inclusion criteria were self-identified failure to achieve a pregnancy or carry it to term after at least one year of trying in the six years prior to the study and absence of a recent crisis unrelated to the infertility. Responses were content analyzed independently by a team of three researchers. The analysis yielded agreed upon 85 codes clustered in six themes: Challenges, perception of the experience, reactions, support, coping strategies and posttraumatic growth. The main overall finding points to the sense of being "trapped" in a web of multi-faceted, environmental and internal relationships between diverse systems involved in the infertility treatment. Implications for practice are identified and directions for future research suggested.

Key words: Women and infertility; infertility and psychosocial experience; single question

Introduction

And God blessed them, and God said unto
them, be fruitful, and multiply, and replenish
the earth and subdue it.
Genesis 1:28 (1)

¹ The authors wish to acknowledge Nancy Berlow, Harriette Rovner-Ferguson, Lesli Figlerski, Susan Gardner and Anne Malave for their assistance in the data collection as part of the original parent study.

² Born and raised in Israel, where she worked in direct practice and academia as well as supervisory and administrative positions, Dr. Berger holds a BSW, MSW and PhD from The Hebrew University of Jerusalem and a Diploma in Psychotherapy from Tel Aviv Medical School. She serves as a Professor at Adelphi University and a consultant to organizations nationally and internationally. She has published and presented extensively about trauma and Posttraumatic Growth, immigration, stepfamilies, group work and social work professional education.

³ Currently a Clinical Assistant Professor at Adelphi University School of Social Work, and an independent clinical practitioner in New York City, Dr. Paul was formerly a perinatal social worker at North Shore University Hospital where she created a community-based program for pregnancy and infant loss. Dr. Paul's research focuses on the experiences of infertility including third party reproduction within families, and is published in Human Reproduction, Family Process, Families, Systems and Health, and International Journal of Law, Policy and Family

⁴ Lisa A. Henshaw, MSW, LCSW is a doctoral candidate at Adelphi University School of Social Work where she also serves as a research assistant, advisor, field instructor, tutor and adjunct professor. She has experience in clinical practice working with those struggling with mental health and substance abuse and their families. She also served in supervisory and administrative positions. The focus of her scholarly and practice interests is on issues related to trauma and misdiagnosis.

The social demand for reproduction exists in all cultures. This study used a multi-system perspective to investigate the lived experience of women who are unable to meet this expectation due to infertility-related issues. Infertility is defined as the failure to achieve a successful pregnancy after 12 or more months of regular unprotected intercourse (ASRM, 2008). It is estimated that infertility affects about 80 million people worldwide (Nachtigall, 2006). While generally one in ten couples experiences primary or secondary infertility, its rates vary by socio-cultural contexts from less than 5% to more than 30% in developing countries (Vayena, Rowe, Griffin, Van Look & Turman, 2002). In the US, 2.1 million married women (7.4%) between the ages of 15–44 are reported to be infertile and 7.3 million women (11.8% of women ages 15–44) as well as approximately 3.3 – 4.7 million men (7.5% of those sexually active) have used infertility services (Anderson, Farr, Jamieson, Warner & Macaluso, 2009; CDC, 2002). Projections for up to the year 2025 suggest that these numbers are anticipated to increase (Stephen, & Chandra, 1998).

The use of infertility services in the US often requires navigating complex medical and financial systems. For instance, medical treatment for infertility typically occurs at a hospital or community-based fertility treatment center staffed with numerous personnel including insurance and payment coordinators, schedulers, lab personnel, nurses, doctors and mental health professionals as well as secretarial and support staff. In addition, there is the necessary negotiating with health insurance carriers, which may require completing and submitting a plethora of documentation as well as following up with telephone calls and/or e-mails for approval of procedures and reimbursement of expenses. Those who utilize third party reproduction (e.g. sperm, egg or embryo donation) have the added tasks of coordinating with a cryobank or agency. These medical and financial systems join the existing systems of family, friends, career, religion, and community of those struggling with infertility. The combination of input from these complex environmental contexts affects and is affected by the physical and emotional challenges caused by the infertility experience itself, and is experienced within each individual's unique coping style.

Cross-culturally, infertility is recognized as a stressor event with the potential to cause havoc in the lives of individuals, couples and families (Burns & Covington, 2006; Shapiro, Shapiro & Paret, 2001). Perceptions of and reactions to infertility as well as their correlates were studied. Previous findings showed gender-based differences such that men often internalize their feelings, obscuring emotional injury and loss (Abbey, Andrews & Halman, 1991; Snowden, 1990) whereas women perceived it as the worst crisis of their lives (Daniluk, 1997). Infertility was associated with depression as well as a sense of the loss of identity, self-esteem and social role (Carter & Carter, 1989; Deveraux & Hammerman, 1998; Domar, Broome, Zuttermeister, Seibel & Meidman, 1992; Ireland, 1993; Meyers, Diamond, Kezur, Scharf, Weinshel & Rait, 1995a, b).

Infertility-related distress was found to be associated with internal variables such as coping style and perceived locus of control (Berghuis & Stanton, 2002; Peterson, Newton & Rosen, 2006), and external variables such as the nature of the fertility treatment itself including the number of failed attempts (Braverman, 1997; Daniluk, 1996; Greil, McQuillan, Lowry & Shreffler, 2011; Leiblum, 1997). Studies also looked at the interaction between internal and external variables and identified associations between coping style, social support and infertility-related stress (Martins, Peterson, Almeida & Costa, 2011; Mindes, Ingram & Kliewer, 2003).

Until now, research utilizing a multi-systemic perspective that considers the interactions among the many internal and external systems in infertile women's lives has been essentially missing. Recently, Boivin and colleagues (2012) explored available knowledge about factors contributing to discontinuation of infertility treatment and concluded that "the discontinuation literature does make clear that the patient (individual, couple), the clinic (team, environment) and the treatment (type, effect) all have reciprocal influences on each other in determining willingness to continue with treatment" (p. 2). They posited that research is necessary to identify the challenges that those who need infertility treatment face in the context of the linkage between individual, clinic and treatment factors to inform strategies designed to minimize patient burden and dropout rate, and create a more integrated approach.

Such research is important especially in the US where medical treatment for infertility is dependent on private health insurance further complicating the maze of external variables for women who are infertile. Understanding of the nature and effects of these interactions among the diverse systems involved and their reciprocal influences on the lives of women with infertility can lead to improvements in the ways in which treatment is provided, and serve as a platform for further research and policy development. It is the role and effects of these systems on the experience of being infertile that was the focus of this study.

Method

The data presented was collected as part of a study of posttraumatic growth in the context of infertility (Paul et. al., 2010). The parent study researched the experience of both men and women of achieving benefits from the struggle with infertility. In addition, participants were invited to share further aspects of their experience. The current study focused on these reports from female participants who opted to elaborate on their experience.

Sample

Participants were 56 women who self-identified as failing to conceive or carry a pregnancy to term after one year of trying during the six years prior to the study and reported no recent crises unrelated to infertility. Recruitment of the full original sample of 121 participants was conducted via advertisements posted on infertility-related websites, in physician offices and through snowballing. The current sub-sample includes women who addressed the open ended question about their experience. Due to a small number of male respondents, the current analysis focused exclusively on women. Women in this subsample were relatively young ($M=35.5$, $SD=6.94$), educated (44.6% had a bachelor and higher degree) and employed (64.3% full time and 10.7% part time), and mostly Caucasians (83.9%). Most (87.5%) were diagnosed with primary infertility. Causes for infertility were female (46.4%), male (7.1%), couple (23/2%), and unexplained (23.2%) factors. Participants had spent one to four years trying to conceive ($M=3.2$, $SD=1.08$). Most ($n=47$, 83.9%) never had a live birth delivery and only one participants had adopted a baby.

Procedure

Individuals who expressed interest in participating and met the eligibility criteria were mailed a packet that contained the questionnaire, instructions, consent forms, and envelopes for returning the documents.

Measures

Two measures were used in this study; a background questionnaire and a single open-ended question about the infertility experience. The background questionnaire contained 22 items seeking information about demographic characteristics such as marital history and status, educational and occupational background, ethnic affiliation as well as about the history of the infertility, e.g. primary or secondary, duration of the condition and efforts to address it as well as the use of social, formal and other support systems. The single question invited participants to share anything they wanted about their infertility experience. In spite of potential validity issues, a single question has been commonly employed in qualitative and mixed methods studies. For example, Cesario, Nelson, Broxson and Cesario (2010) used a single question to study the worries of females with ovarian cancer. Perkins and Luster (1999) explored the experience of sexually abused adolescent females using a one question measure, Bartle-Haring and Arpita (2010) used single questions to assess relationship satisfaction and commitment in couples in marital therapy, and in a study measuring the availability of social supports for low income, Mexican immigrant women a single question was used by Vega, Kolody and Valle (1986).

Data Analysis

Written responses provided by participants were coded by a team of three researchers. Initially, each researcher coded the responses independently; then codes were compared and discrepancies resolved by consensus, leading to the construction of a codebook. In the second phase of "axial coding", hypotheses about relationships among the original codes were formulated inductively (i.e., how codes were associated with each other and with the research question) leading finally to the identification of core themes and the construction of a model regarding the links between the themes.

Findings

The content analysis yielded 85 codes, which grouped into six major themes: challenges, perception of the experience, reactions, support, coping strategies and posttraumatic growth. These themes are discussed and illustrated below.

Challenges

Two types of challenges emerged from the analysis: environmental and personal. The environmental challenges included logistics and socio-cultural issues.

Logistic challenges

A major issue mentioned repeatedly and by more participants than any other was the cost of medical procedures necessary for infertility treatment, the absence of insurance coverage for many of these procedures and the tremendous financial burden on the couple trying to conceive. One participant stated “Most of my infertility stress comes from not being able to afford in-vitro. I did research and found a study for in-vitro which cuts the cost in half but is still quite expensive for me”. Another stated “The most stressful part has been the financial aspect of the treatment”. More than one participant reported that they are forced to pace treatments by financial rather than medical considerations. Typical statements were, “The incredibly prohibitive high costs of treatment seemed to further exacerbate a situation that feels so-unfair overall”, “The most stressful part has been the financial aspect of the treatment”, “It is frustrating when you don’t have money to go for the kind of treatment that will yield you a baby”, “it is not covered by most insurance companies since they consider it a ‘lifestyle’ choice. I did not choose to be infertile”, “I think it is so unfair that treatment costs so much. It makes it very difficult for a lot of couples to afford it. Adding yet another stress to their lives”, “Our problem at this point is everything we do is ‘out of pocket’. NOTHING [emphasis in original] is covered by insurance including OBGYN visits related to infertility. In the past 5 years we have exhausted our funds and are currently at a standstill until we can save more money”.

Additional logistic challenges were the investment of time imposed by infertility treatment, the constant need to negotiate insurance companies that offer limited coverage and present those needing the treatments with numerous procedural and administrative hurdles. Access to current, trustworthy and sufficient information that may help inform decisions was also cited by participants as a barrier. One woman stated “I think the biggest issue is having competent healthcare advice and dealing with the healthcare insurance while going through one of the most personal and highly emotional life experiences”. Another posited “Not enough medical information given by an actual medical professional. Most information had to be obtained via my own means and research. Not enough medical providers can efficiently diagnose or positively treat symptoms/complications of my diagnosis of PCOS [Polycystic ovary syndrome; a leading cause of women’s infertility]. Not enough medical providers have knowledge of PCOS and its causes and effects”. Finally, the treatment process itself was described as posing challenges, including misdiagnosis and unpleasant procedures. One woman summarized her challenges in the following statement “It’s simple: there has to be a better way to absorb fertility meds/hormones than injections! I had major allergic reaction to the Repronex and then to discover it is derived by menopausal women’s urine I was floored! I would rather drink a nasty liquid than do injections again. There has to be a better way!”

Socio-cultural challenges.

Women reported diverse events and reactions that created painful problematic situations for them such as receiving other people’s baby pictures (“It is extremely difficult to get Christmas cards from friends with photos of their new babies”), being invited to baby showers and encountering pregnant women and babies. Sample reactions are “Part of what made our infertility treatment so hard was the fact that our sisters started getting pregnant”, “It’s painful when you see pregnant women, new babies celebrated and you see yourself still waiting”, “I became very sad whenever I heard of a friend being pregnant”. One woman discussed a supportive mind/body group for women struggling with infertility, with which she was affiliated and which “was a great help to me, but now I am looking for a new group because all the

members except me are now pregnant. That hurts”. Another participant who is a pediatric dentist described how “at this time of year all the mothers are bringing in their new babies along with their older kids and my front office staff they just go crazy over the babies, bringing them back to my office and showing the babies to me”.

Reactions from the environment were cited as insensitive, not understanding and posing challenges by probing about having babies, absence of validation, messages of stigmatization and exclusion from friends, family, medical staff and the public. Several women described how in family and social gatherings, there is always somebody who asks “When are you having a baby? Why wait?” Absence of validation was identified by many participants as a major challenge and was reported as manifested in numerous ways. Many women reported that their pain and loss was not acknowledged. For example, one woman wanted a formal acknowledgement claiming “IVF failure is indeed the same as miscarriage and the death of one or more children who lived, albeit briefly” is indeed a death of a human being. Another expressed the same sentiment “If anything, a couple who goes through so much time, expense, pain, agony to conceive through IVF, only to find at the end of two weeks post live transfers to not have been “technically pregnant” because the embryos did not implant, that couple should be able to equate their loss with other ‘societally’ or ‘medically’ accepted loss of life. The acknowledgement is not there and it is something I cannot accept to this day”.

Women further reported that the environment often manifested an attitude of discomfort and expectation for a quick solution. For example, one woman said “Most people want us to adopt or move on and not talk about it any longer”, another stated “People are uncomfortable and don’t know what to say”,

Often reported were experiences of being stigmatized, hushed (“the taboo nature of the diagnosis and treatment”), not understood (“no one acknowledges how stressful and hurtful having infertility is”, “it is completely isolating since no friend or family understand what this means to me”) and excluded.

Specifically, conduct by medical personnel was cited as a challenge. One woman who was concerned about the failure of the clinic to keep records in order as well as the absence of effective communication said, “the office seems very disorganized and I do not feel like they communicate very well with us and I was somewhat worried when we went in recently after taking a year off treatment and our file was not up to date with previous results”. Complaints were about refusal of clerical staff to leave for the physician (in a distant location) voicemail messages regarding the treatment and demanding that the participant pose her question in person, and being dropped from contact without follow up or support after a failed procedure.

Personal characteristics that were cited as main challenges were age and previous mental health diagnosis. One participant described the prolonged nature of the process of diagnosing infertility and identifying its nature and potential treatment, which led to the race against the “ticking biological clock” and becoming too old to conceive even with the help of advanced technology. Another difficulty cited by one woman was a diagnosis of bi-polar mood disorder which exacerbated the challenges of the infertility experience.

Perception of the Experience

Women perceived infertility and related treatment as a struggle, a loss, a failure, a stressor, a painful experience and an emotional roller coaster.

A struggle. Women described the demands of infertility as a constant struggle. Echoed in many respondents' description were comments such as "it is a daily struggle, when you cannot conceive", "the most demanding stressful and disheartening experience of my life... I don't know how I got through those six years".

A loss. Whether they were never able to achieve a pregnancy or conceived but lost the pregnancy to a miscarriage or a stillbirth and whether they suffered from primary (no children) or secondary (inability to conceive after having given birth) infertility, women felt in association to both the treatment itself and to its unsuccessful outcome, a deep sense of loss comparable to death of a loved one. This was expressed in statements such as "a part of me died with each pregnancy loss" and "going through infertility treatment was a lot like losing my first pregnancy". One woman spoke about the void created by the loss of her dream that infertility denied her of achieving "I feel a void in my life because I don't have kids and I remember as a child on career day at school when I was asked what I wanted to be when I grew up I would say I just want to be a mom".

A failure. Some women felt that the failure to conceive or carry a pregnancy to term speaks to their inadequacy. While struggling to view it as a medical issue, a few perceived infertility as a personal fault ("something is wrong with me").

A stressor. Not surprisingly, infertility and efforts to cope with it were perceived as continuing stressors. It was reported as combining various types of stressors. For example, one woman said "infertility is mentally and financially stressful". Another shared "trying to get pregnant became very stressful for me. Monitoring my eating, drinking, rest etc., monitoring blood, vitamin deficiencies -it felt like chasing reasons and trying different 'remedies' to address it and it began to impinge on my life - personally professionally. Trying to take care of myself in ways associated with getting pregnant in my 40's and to not stress out really ended up stressing me out each month that I didn't get pregnant." Statement such as "this experience has been the hardest, most demanding disheartening and most stressful and depressing experience of my life" were repeated again and again in numerous variations.

A painful experience. The loss, social reactions and additional challenges described above led participants to describe pain constantly and every step of the infertility journey, associated with diagnosis, negative test results and failed treatments and persistent even after treatment discontinued. One woman stated "The emotional pain and devastation appears to continue regardless if I have stopped treatment".

An emotional roller coaster. Participants described feeling their patience and ability to cope constantly tested by the struggle with infertility. They described it as "most personal and highly emotional life experiences", "an emotional rollercoaster very stressful! Emotionally draining" "extremely difficult and emotionally challenging", "I feel like I could really benefit from screaming to release all the hurt but I'm afraid that if I did, I would lose control and cry for days".

Reactions

Women described a wide and diverse array of reactions to the struggle with infertility. The majority of reported reactions were emotional; in addition, spiritual, personhood and relational reactions were described.

Emotional reactions. The dominant emotional reactions that women reported were misery, sadness and depression (12 women), and helplessness and vulnerability (6 women).

Participants described a broad range of sorrowful and devastating reactions. One woman spoke about “periods of extreme sadness” and another reported that “It eventually spiraled down into clinical depression”. One participant called her emotional reaction “an existential crisis”. Two participants discussed the fluctuating and escalating nature of negative reaction “I went from disappointed to unhappy to depressed to devastated”. Disappointment was often reported with every month with no pregnancy and every unsuccessful treatment cycle, as reported by one woman “I went from disappointed to unhappy to depressed to devastated as each negative test result came through.” Some women believed that having high expectations may set one to failure and the disappointment was described as difficult.

Women shared the feeling of “hopelessness over something we had no control” and “heartbreaking” because they could not achieve something that they so much longed for. A participant expressed the helplessness in the face of power beyond her control “In the meantime at age 30 my biological clock is more like a gong!” Several women described themselves as emotionally oversensitive and overreacting. For example, “I now even cry at dog commercial on T.V.... I don’t know what’s happening to me”.

Participants spoke of frustration, hopelessness (“it has brought me to tears with feelings of hopelessness”), irritability and hypersensitivity (“I became especially sensitive and nervous”), loneliness, anxiety, guilt, embarrassment and shame. While it is not surprising that most reactions were negative, a few women also expressed optimism and happiness with the good parts of their life, for example, one said “there are times of disappointment and sometimes a wonderful feeling”.

Spiritual reactions. Three participants described how the struggle of infertility affected their spirituality and religiosity such that all of them reported having lost faith in God. The strongest statement came for a woman who said “It [infertility] strained my religious faith; I was angry at God and didn’t go to church for years”. Two other participants stated “but I do have faith”.

Personhood. Several women reported that their reaction to infertility was self doubt, loss of trust in their body and the development of negative self perception. Sample statements were “Something is significantly wrong with me”, “You start questioning your womanhood” and “What’s been the most challenging is losing trust in my body”. Some negative self concepts were implied rather than stated openly. For example, “Having children defines us as women”, which suggests that the speaker concludes that because she does not have children, she is less of a woman, though she does not state so explicitly.

Relational reactions. Several participants recounted that the struggle with infertility negatively affects relationships with their husbands, friends and family. The effects on spousal relationships were related to the woman being irritated, the demands the treatment put on the time and financial resources of the couple (“very stressful on my marriage!”) and in one case, the disagreement between husband and wife regarding the use of treatment (“My first marriage ended as my husband was totally against fertility treatment”). Familial and social relationships were also impacted by changes in the women in connection with the treatment. One woman stated that “It has changed the way I look at a lot of things and affected many relationships for good and bad”.

Support

Participants reported relatively limited support as they were struggling with infertility, which may explain the loneliness that some experienced, as reported above. Those who did discuss support, found it from their spouse or partner, family and friends, faith and counseling.

Support from spouse, family and friends. Women emphasized the importance of the couple's mutual support. "Also support each other. From a woman's point of view, you need to realize you are not the only one going through this, your husband or special someone is also going through it to." How critical such support is was echoed in the report from several participants, such as "With the love and support of my husband and a few good girlfriends, I have done well.", "If you have the support and love of your partner, it is extremely helpful." and "I was lucky enough to have very supportive husband, friends and family." Some participants emphasized particularly support from friends, family and colleagues. Typical statements were "I have wonderful friends and a fantastic family who have helped me through very trying times", "Support from family and friends has been one of the most important factors in dealing with my infertility. Their support has been able to sustain me and give me hope – even in extreme periods of sadness".

Faith. While as cited above, several participants lost their faith in the process of coping with infertility, two participants cited their faith as important in their struggle with infertility. One stated "I have a very strong faith" and the other "I do have faith that I can conceive and bear children."

Counseling. Finally, one participant identified interaction with her mind/body group as very supportive and a great help; unfortunately, at the time of the study, she was looking for an alternative group as all the group members but her became pregnant and she could not tolerate the pain it caused her.

Coping Strategies

The three most frequently used coping strategies were taking action, reported by 10 participants, acceptance and selective sharing (5 participants each). Additional ways of coping included denial and avoidance (3), taking a break from treatment (2) and use of counseling services (2).

Taking action. Ten women reported that their way of coping involved becoming proactive by conducting extensive research about their condition, available treatments and recommended physicians, seeking second and third opinions, using alternative approaches including the most non-traditional ones and exhausting the exploration of options, not leaving any stone unturned. One woman's guidance was "What I have learned: Read but limit your reading because otherwise you will drive yourself crazy; get yourself to a Reproductive Endocrinologist as quick as possible; bypass your OB/GYN if you expect a problem- a lot have no clue and slow the process and check all clinic's results at Sart.org". The need to find a good doctor was repeated by several participants as they had disappointing experiences with physicians that they viewed as not informed well enough and making bad recommendations. For example "My Ob/Gyn recommended a doctor with the worst statistics in NYC. Only my husband read an article in the Wall St. Journal on finding a good clinic. [Otherwise] we would

have been screwed". Another woman concurred "My main point is do research and don't give up. Also support each other"; another stated "I've learned to always get second opinions".

In addition to traditional medicine, women pursued alternative routes. Participants used traditional Chinese medicine, acupuncture and a whole plethora of alternative medicine approaches. One woman shared "I drink an expensive Vietnamese tea twice a day and follow a vegetarian diet, affirmations and New Age kinds of remedies such as listening to CD's to encourage fertility".

Acceptance. "You have to be prepared for whatever outcome may occur", "I knew that I didn't want to end up going crazy chasing something that might not happen for me this lifetime", "I think I have accepted that maybe this is not meant to be" and "only now I'm relaxed and taking time for myself, for creative pursuits and some fun, to regain my balance". These statements represent women's coming to term with the status of their infertility, letting go of the dream to become pregnant and re-directing the incredible amount of energy invested in the struggle to conceive to other goals and living other parts of their life. One woman rejoiced in her role as a stepmother "[I am] grateful for the experience of being a stepmother to a child my husband had with ex-wife (after 13 years of trying to conceive with her and two failed fertility treatments, they had an unintended pregnancy). Feel extremely lucky to be weekend stepmom versus being no type of mother at all". Another said "I am working hard to accept a 'new me', an identity of a strong, capable woman who cares for others and myself and is a mother to two wonderful cats".

Selective sharing. To avoid uncomfortable reminders and pressure, several women reported that they opted to share their situation as well as their emotional experience with a selected few or, in extreme cases, with nobody. Participants stated "We have not told many of our friends nor any of my husband's family" and "I also kept it a secret from my family and friends since I'd told no one I was pregnant anyway, except my husband". One woman posited "I keep a lot of it [what she feels] to myself". Another explained the criterion for choosing with whom to share, "we only share our infertility experience with family and friends that are supportive".

Denial and avoidance. Some women reported coping with the emotional toll of infertility and treatments by avoidance. One typical reaction that captured this coping strategy was "I have tried to shove down, push out, suppress those feelings for the sake of my own emotional health and health of my marriage". Another stated that she refused to think that she may never conceive "Have I dealt with my true feelings?! My husband will not allow me to doubt-he thinks it only hurts to process; but when do we face the facts and set the timeline?" and yet another expressed longing to get away from the stress saying, "I think, I'll just go AWAY for the weekend to the nearby mountain town and just relax and reconnect with my hubby and forget about babies' meds". For some women the avoidance took the shape of taking a break from the treatment, "For the sake of my mental stability, my husband convinced me to take the past 8 months off from IVF treatments".

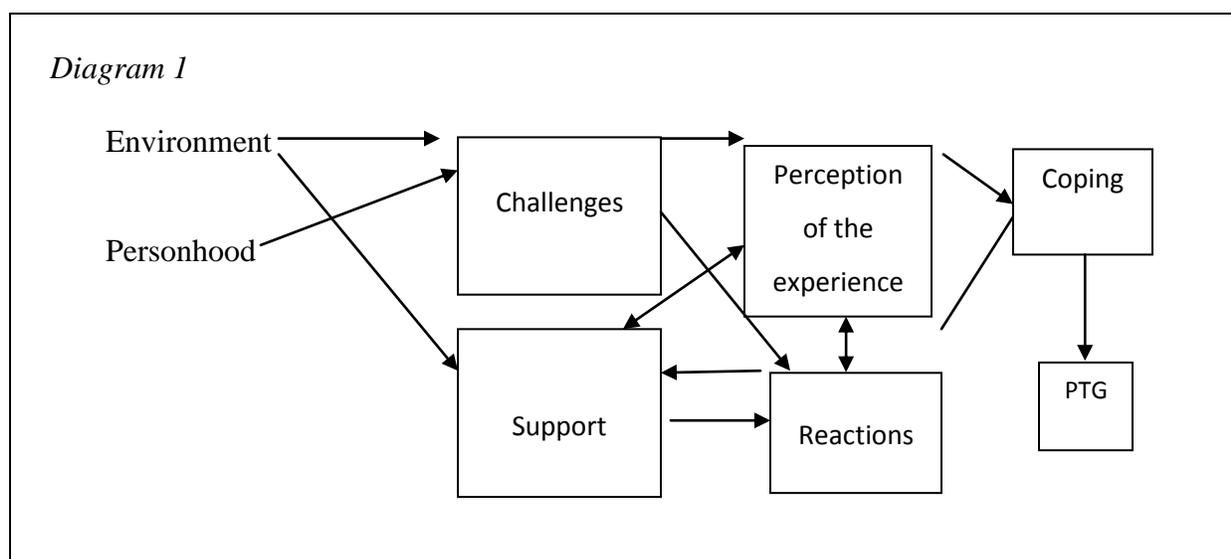
Posttraumatic growth

Three women expressed getting benefits from the struggle with infertility. Manifestations of growth were in the domains of self perception and interpersonal relationships. One woman

stated “I have found out that I am much stronger than I thought”. Another said “It has changed the way I look at a lot of things and affected many relationships”.

Discussion

The findings of this study suggest the multi-faceted and complex relationships between diverse systems in the environment and women’s struggle with infertility. This web of mutual relationships is depicted in Diagram 1.



The results of this study agree with previous research as well as expand and add to it, contributing to a more nuanced understanding of social effects of infertility treatment on women. This is of particular importance in light of previous findings that women experience greater social effects of infertility than men (Collins, Freeman, Boxer & Tureck, 1992). Specifically, this study highlighted the cumulative and interactive effects of multiple systems that infertile women encounter and must cope with. That such experiences may be shaped and intensified by cultural codes and social relations has been documented (Daar & Merali, 2002). Though to varied degrees, in many cultures, womanhood is defined through motherhood and the status of women in society is affected by their reproductive capacity. While this is more explicit in developing countries, reports from women in this study reveal that such perceptions are prevalent and manifested implicitly or openly by the various systems that affect their life. Pressures from peers, family, and society to have children often exacerbate the personal suffering and can lead to unstable marriage and stigmatization (Vayena et. al., 2002). Describing some of these pressures and their impact, Dill (2002) wrote, “The quality of life for some infertile people can become marginal when they have difficulty coping with a friend’s pregnancy, seeing babies and young children or watching television advertisements featuring babies. Events such as Christmas, Mother’s Day and Father’s Day can be painful reminders of other people’s fertility and success and are times to be endured. Many couples do not participate in these family celebrations” (261).

A major finding in the current study is that family, friends and others in the proximal social environment were viewed as a source of both stress and support whereas medical services, including doctors' offices and insurance providers, and infertility treatment policies were perceived as insensitive, harsh and unfair, adding to the stress of the condition itself and the physical and emotional challenges of the medical procedures involved in the treatment.

Systems responsible for funding policies appeared to be especially important, playing a critical role in the struggle associated with infertility and treatment related to it. Social policy relative to funding infertility treatment reflects the complex political and social processes of the various countries. For example, Israel is a very familistic and "pro-natalistic" society that highly values bearing children and where infertility treatments are accompanied by national and civil codes of bearing children as a "national demographic duty". This ideology is rooted in and nourished by the fear of extinction related to the Holocaust and the perceived need to "replenish" the six million exterminated by the Nazis, the perceived demographic threat posed by the surrounding Arab countries as well as the biblical imperative to be fruitful. Consequently, the eligibility for infertility treatment is highly inclusive and poses very few restrictions on Israeli citizens for infertility treatments in the context of the National Health Insurance system. Free, unlimited infertility treatments are provided until up to two live births (which may produce more than two children given the high frequency in which technology assisted fertilization yields multiple embryos) are achieved for women younger than 45 irrespective to marital status or sexual orientation. The policy has made Israelis the highest per capita users of infertility treatment in the world, although the procedures account for one of the country's largest public health expenditures (Shalev & Gooldin, 2006).

In the US in contrast, procedures are much more expensive (reflecting the overall health care system). The dominant policy for those with health insurance is of rationing infertility treatment and, despite the current health care reform movement, there still remain roughly 50 million individuals who are uninsured, and many more that are underinsured (US Census Bureau, 2012). The pain resulting from this policy and the conflicting values regarding the right for childbearing reflected were repeatedly and loudly voiced by the participants in this study who felt that the very systems they sought out for support became instead sources of stress and frustration. While there is no easy or quick solution for the current health care crisis in the US, there are incremental actions that can be taken within the current health care context while advocacy for a more equitable health care system continues.

Such actions have been discussed by Boivin and colleagues (2012) who, based on a cross-national review of patients' discontinuation of fertility treatment, noted reciprocal influences among patient, clinic, and treatment and recommended provision of comprehensive educational material, screening to identify highly distressed patients, provision of tailored coping tools and improvement in the clinic environment and medical interventions. These recommendations offer hope for a more supportive journey for women seeking treatment for infertility and are in line with the findings of this study. Future research is needed in order to better understand the connections between social support within all contexts (medical, financial, family, friends) and positive outcomes, i.e., post traumatic growth, for those with infertility. Additional qualitative studies utilizing more diverse groups, cross-national studies and intervention studies are recommended.

Many years of research on the experience of infertility confirm that for most who encounter it there will be an inevitable struggle and loss. In the parent study of 121 men and

women, from which the current sub-sample was drawn (Paul et. al., 2010), moderate degrees of post traumatic growth, availability of social support and high satisfaction with the support were reported. One possibility to explain the discrepancy between the relatively more positive outlook of participants in the original study with the larger sample and the more negative experience reported by the subgroup of women in this study is that the latter is comprised of those who endured infertility in a less supportive environment. Their choice to address the open question may indicate their feeling that the main questionnaire, which focused on benefits from the struggle with infertility, failed to capture the full gamut of the experience.

To address both the personal and environmental aspects of the multiple challenges, a combined micro-macro approach will be necessary. On the personal level, counseling efforts should be directed at helping clients to take control of what they can, including identifying and maximizing supportive others to help take active action and minimize the experience of isolation. On the environmental level, a potential challenge in making the medical, professional and funding systems user friendly lies in the resistance of current structures to embrace such change. The profession of social work is optimally positioned to address the combination of external and inevitable internal challenges involved because a person-in-environment perspective is at the core of understanding the effects of being at the intersection of multiple systems. Future research will help further our understanding of barriers to implementing such a combined intervention plan and point to effective strategies for addressing them.

Like all studies, this research has several limitations, which must be taken into consideration. First, the self-selected nature and small size of the sample require using caution in applying the conclusions. Future research should look at the effects of the multiple-systems involved in infertility treatment in additional diverse population groups. Second, because of the limited number of male participants, this study focused on the experience of women struggling with the experience. However, infertility can be caused by female, male, couple or unknown factors and the infertility treatments involve both partners and are thus a couple experience. Future research is needed to understand men's experience. Furthermore, the nature of the data is self-reported making it susceptible to bias. In addition, one question was used for seeking participants' report about their experience. While such strategy for data collection has been used in studies as indicated above, a more comprehensive qualitative research is anticipated to yield a better in-depth picture of the challenges involved in navigating the multi-systemic mine-field of infertility treatment.

References

- Abbey, A., Andrews, F. M., & Halman, L. J. (1991). Gender's role in response to infertility. *Psychology of Women Quarterly*, 15, 295-316.
- Anderson, J.E., Farr, S.L., Jamieson, D.J., Warner, L. & Macaluso, M. (2009). Infertility services reported by men in the United States: National survey data. *Fertility & Sterility*, 91 (6), 2466-2470.
- ASRM. (2008). Definitions of infertility and recurrent pregnancy loss, *Fertility & Sterility*, 89, 1603.

- Bartle-Haring, S. & Arpita, L. (2010). Using Bowen theory to examine progress in couple therapy. *The Family Journal*, 18 (2) 106-115, doi:10.1177/1066480710364479
- Berghuis, J. P., & Stanton, A. L. (2002). Adjustment to a dyadic stressor: A longitudinal study of coping and depressive symptoms in infertile couples over an insemination attempt. *Journal of Consulting and Clinical Psychology*, 70(2), 433-438.
- Boivin, J., Domar, A.D., Shapiro, D.B., Wischmann, T.H., Fauser, B.C.J.M., and Verhaak, C. (2012). Tackling burden in ART: an integrated approach for medical staff. *Human Reproduction*, doi:10.1093/humrep/der467
- Braverman, A. M. (1997). When is enough, enough? In S. R. Leiblum (Ed.), *Infertility: Psychological issues and counseling strategies* (pp. 209-229). New York: Wiley.
- Burns, L. H., & Covington, S. N. (2006). Psychology of Infertility. In S. Covington & L. H. Burns (Eds.), *Infertility counseling: A comprehensive handbook for clinicians* (Second ed.). New York: Cambridge University Press.
- Carter, J. W., & Carter, M. (1989). *Sweet grapes: How to stop being infertile and start living again*. Indianapolis: Perspectives Press.
- C.D.C. (2002). Fertility, Family Planning and Reproductive Health of U.S. Women: Data from the 2002 National Survey of Family Growth, tables 67, 69, 97. Retrieved September 2009 from <http://www.cdc.gov/nchs/fastats/fertile.htm>.
- Cesario, S.K., Nelson, L.S., Broxson, A. & Cesario, A.L. (2010). Sword of damocles cutting through the life stages of women with ovarian cancer. *Oncology Nursing Forum*, 37 (5), 609-617. Doi: 10.1188/10.ONF.609-617.
- Collins, A, Freeman, E. W., Boxer, A. S. & Tureck, R. (1992). Perceptions of infertility and treatment stress in females as compared with males entering in vitro fertilization treatment. *Fertility and Sterility*, 57 (2), 350-356.
- Daar, A. S. & Merali, Z. (2002). Infertility and social suffering: The case of ART in developing countries. In E Vayena, P. J. Rowe & P. D. Griffin, Eds., *Current practices and controversies in assisted reproduction* (15-21). Geneva: World Health Organization.
- Daniluk, J. C. (1997). Gender and infertility. In S. R. Leiblum (Ed.), *Infertility: Psychological issues and counseling strategies* (pp. 103-128). New York: Wiley.
- Daniluk, J. C. (1996). When treatment fails: The transition to biological childlessness for infertile women. *Women & Therapy*, 19, 81-98.
- Deveraux, L. L., & Hammerman, A. J. (1998). *Infertility and identity: New strategies for treatment*. San Francisco: Jossey-Bass.
- Dill, S. (2002). Consumer perspectives. In E Vayena, P. J. Rowe & P. D. Griffin, Eds., *Current practices and controversies in assisted reproduction* (255-270). Geneva: World Health Organization
- Domar, A. D., Broome, A., Zuttermeister, P. C., Seibel, M., & Meidman, R. (1992). The prevalence and predictability of depression in infertile women. *Fertility & Sterility*, 58, 1158-1163.
- Greil, A. L., McQuillan, J., Lowry, M., & Shreffler, K. M. (2011). Infertility treatment and fertility-specific distress: A longitudinal analysis of a population-based sample of U.S. women. *Social Science & Medicine*, 73(1), 87-94.
- Ireland, M. S. (1993). *Reconceiving women: Separating motherhood from female identity*. New York: Guilford Press.

- Leiblum, S. R. (1997). Love, sex and infertility: The impact of infertility on couples. . In S. R. Leiblum (Ed.), *Infertility: Psychological issues and counseling strategies* (pp. 149-166). New York: Wiley.
- Martins, M.V., Peterson, B.D., Almeida, V.M. & Costa, M.E. (2011). Direct and indirect effects of perceived social support on women's infertility related stress. *Human Reproduction*, 26 (8), 2113-2121
- Meyers, M., Diamond, R., Kezur, D., Scharf, C., Weinschel, J., & Rait, D. (1995a). An infertility primer for family therapists: I. Medical, social and psychological dimensions. *Family Process*, 34, 219-229.
- Meyers, M., Diamond, R., Kezur, D., Scharf, C., Weinschel, J., & Rait, D. (1995b). An infertility primer for family therapists: II Working with couples who struggle with infertility. *Family Process*, 34, 231-240.
- Mindes, E. J., Ingram, K. M., & Kliewer, W. (2003). Longitudinal analyses of the relationship between unsupportive social interactions and psychological adjustment among women with fertility problems. *Social Science & Medicine*, 56(10), 2165-2180.
- Nachtigall, R. (2006). International disparities in access to infertility services. *Fertility & Sterility*, 85, 871-875.
- Paul, M. S., Berger, R. Berlow, N., H. Rovner-Ferguson, Figlerski, L., Gardner, S. & Malave, A. F. (2010). Posttraumatic growth and social support in individuals with infertility. *Human Reproduction*, 25, 133-141. doi: 10.1093/humrep/dep367
- Perkins, D. F. & Luster, T. (1999). The relationship between sexual abuse and purging: Findings from community-wide surveys of female adolescents. *Child Abuse and Neglect*, 23 (11) 371-382.
- Peterson, B. D., Newton, C. R., & Rosen, K. H. (2006). Coping processes of couples experiencing infertility. *Family Relations*, 55(2), 227-239.
- Shalev, C., & Gooldin, S. (2006). The uses and misuses of in-vitro fertilization in Israel: Some sociological and ethical considerations. *Nashim: A Journal of Jewish Women's Studies & Gender Issues*, 12, 151-176.
- Shapiro, V. B., Shapiro, J. R., & Paret, I. H. (2001). *Complex adoption & assisted reproductive technology: A developmental approach to clinical practice*. New York: The Guilford Press.
- Snowden, R. (1990). The family and artificial reproduction. In D. Bromhan, N. Dalton & J. Jackson (Eds.), *Philosophical ethics in reproductive medicine* (pp. 70-78). Manchester, U.K.: Manchester University Press.
- Stephen, E. H., & Chandra, A. (1998) Updated projections of infertility in the United States: 1995–2025. *Fertility and Sterility*, 70 (1), 30–34.
- US Census Bureau (2012). *Income, poverty and health insurance coverage in the United States: 2010*. Retrieved from www.census.gov/prod/2011pubs/p60-239
- Vayena, E., Rowe, P., Griffin, D., Van Look, P. & Türman, T. (2002). Forward. In E Vayena, P. J. Rowe & P. D.Griffin, Eds., *Current practices and controversies in assisted reproduction* (XV-XVII). Geneva: World Health Organization
- Vega, W.A., Kolody, B.E. & Valle, J.R. (1986). The relationship of marital status, confidant support, and depression among Mexican immigrant women. *Journal of Marriage and Family*, 48 (3), 597-605.