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The Psychosocial Challenges of Infertility and A.R.T

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ABSTRACT

Parenthood, considered a divine gift, becomes a source of profound distress when it eludes couples facing infertility. In the complex landscape of infertility and A.R.T., couples find themselves grappling with multifaceted challenges. It provokes many issues of an emotional, cultural, spiritual, moral and

ethical nature for the couple, leaving them in self-doubt. This chapter delves into the intricate psychological dimensions of infertility, exploring the feelings of inadequacy, frustration, and societal pressures that accompany the inability to conceive. Childlessness is associated with various negative outcomes for women and men, affecting their self-esteem, social roles, and overall quality of life. Many individuals may downplay their suffering, creating an impression of psychological well-being, especially when initial hopefulness and optimism are present. Nevertheless, research has shown that couples diagnosed with infertility and undergoing A.R.T. treatment experience symptoms of depression and anxiety. Major depressive disorders can be present, with an increased rates of suicidality i.e. suicidal thoughts or attempted suicide. Avoidance of family or other social gatherings, comprehensive psycho-social support for individuals undergoing infertility diagnosis and treatment.

Keywords: Assisted reproductive treatment, Childlessness, Emotional, Financial

INTRODUCTION

The World Health Organization (WHO) has indicated that 8–12% of couples worldwide experience infertility, and in recent years the number seeking treatment has dramatically increased. The diagnosis and therapy put a heavy psychological and physical burden on most of the couples. They can be flooded with many unanswered questions.

Unanswered Whispers: Navigating the Troubling Questions that Haunt Couples

- Why does everyone else seem to be able to get pregnant?
- Why can't we have a baby?
- Am I doing everything I should for a healthy conception?
- Are others judging me?
- Should I have tried to get pregnant earlier in my life?
- Is my partner resentful?
- Is this working?
- How long can we keep going with this?"
- Will we ever have a baby?"
- What will happen if we can't have a baby
- Can we afford fertility treatments?

These are just some of the many questions that can go through the minds of couples dealing with infertility

A journey through an emotional roller coaster of infertility and A.R.T.

The fundamental classification of infertility is that of an irreversible life crisis that jeopardizes one of the primary life goals—becoming a parent—puts strain on one's resources, and can revive unresolved issues from earlier in life. Stress can come from the social, marital, and personal lives of infertile couples. It was noted that the stress level throughout the A.R.T. procedures rose greater when these elements were present, either singly or together. The stress of infertility and ART has been rated as high as HIV and cancer even though there is no threat to the physical existence of the couple[7,8].

Distress, Depression and Anxiety

Nearly 40 % of the 122 women undergoing infertility treatment were diagnosed with either **depression or anxiety or both**. [1] These conclusions were confirmed by subsequent studies. Major **depression** was the most prevalent psychiatric symptom, with a 31% frequency [2]. This was confirmed by a study of 42,915 women who underwent ART treatment in Denmark from 1994 to 2009. They were screened for depression before treatment, nearly 35% screened positive [3]. Three-quarters of the 174 women in therapy for infertility fulfilled the criteria for **severe depressive disorder** [4] In northern California infertility clinics, 352 women and 274 men were evaluated [5]. Major symptoms of **anxiety** were reported by 76% of the women and 61% of the men, while significant symptoms of **depression** were reported by 56% of the women and 32% of the men. Lastly, 9.4% of the 106 women with infertility reported having attempted or thought of suicide [6].

The side-effects of medications

The medications used to treat infertility, including clomiphene, leuprolide, and gonadotropins, are associated with occurrence of symptoms of anxiety, depression, and irritability. It can be difficult to differentiate between the psychological impact of infertility versus the side effects of the medication. A detailed psychological assessment is needed for clarity. It can include measures of these symptoms before starting the medication, or after going off it. Questions regarding emotional reactions of the women to menarche and premenstrual mood fluctuations can be helpful. The studies which include these can be more accurate than those done only during the cycle.

Repeated cycles with long duration of ART

The longer the time spent in treatment, the higher the symptoms of depression and anxiety. Patients with one treatment failure had significantly higher levels of anxiety, and patients with two failures experienced more depression when compared with those without a history of treatment [3].

Miscarriage

Generally, anywhere from 10% to 25% of all clinical pregnancies end in miscarriage. One of the leading causes of miscarriage is the chromosomal abnormality of the fetus. Patients who experience pregnancy loss experience **post-traumatic stress disorder**; the majority of women report suffering from **anxiety and depression** [10].

The preimplantation genetic screening (PGS)is offered to patients to help. This procedure enables the clinicians to identify chromosomal defects through the biopsy of a blastocyst thereby increasing the chance of pregnancy by eliminating the embryos which would likely result in a miscarriage. However, this has uncertainties and challenges. The cost of PGS adds more financial burden for the couple. Some embryos don't survive to their fifth day, the time when the biopsy is done. If no

chromosomally normal blastocysts are found, the couple is affected negatively. Also, after the blastocyst is biopsied by day 5, it takes up to 2 weeks to get the result of the biopsy. All normal blastocysts are frozen after biopsy. The patient must wait for another month before she can undergo a thaw cycle to transfer the biopsied blastocyst. So PGS further increases the waiting period. Instead of waiting for the result between the transfer and pregnancy test, there is one more wait: waiting for the PGS results and then waiting between embryo transfer and pregnancy test. The uncertainty of the waiting period very stressful.

Repeat failure

Patients rarely conceive on their first cycle. For most, it may take more cycles and many years and despite that persistence and following all the medical protocols to the last detail, it still does not happen. The cause of infertility is not always clear. However, the diagnosis of unexplained infertility is one of the most difficult ones to accept. Knowing the cause of an infertility reduces the burden for couple. At least they can place the blame on "something.". With unexplained infertility, neither the clinician nor the patient understand what is happening. The couple may become obsessed with this diagnosis. [11]. They try many things - changes to lifestyle, exercise, diet, caffeine intake, sleep, and alternative medicines, etc. For some, these changes, along with ART may work; Others still do not achieve the desired pregnancy.

The stress at the infertility clinic

Lack of patient-centered care adds to already existing psychological distress of ART. The clinic's **organizational environment** as well as the **human interaction** component is important for the couple. An empathetic sensitive, attitude of the staff, involving the couple in the decision-making, involving the man, providing information, an opportunity to ask questions, and clearing doubts are all helpful in easing the long journey of ART. In terms of the organization, the continuity of care i.e., being seen by the same consultant on every visit, not having to wait too long, and clinics devoted exclusively to infertility treatment are preferred. Couples do not want to be part of a normal obstetrics' and gynecology set-up. [13,14,15]. Lack of patient-centered care can result in the couple changing clinics, or dropping out, thereby impacting the outcome.

The social burden of infertility: from connectedness to isolation

Infertility affects not only the couple experiencing it but also ripples through their interactions with friends and family. Couples do need the social support, however, there are challenges to interpersonal communication, resulting in isolation. The disclosure of infertility is difficult. It is a taboo subject. The talk is awkward, and inappropriate because of private nature of sexual and reproductive health. Also talking about infertility or its treatment makes it difficult to maintain the privacy and boundaries on related topics, such as financial, emotional, or relational difficulties. For similar reasons, family and friends also hesitate to enquire. Given these challenges, it is difficult for friends and family members to provide much needed support to someone with infertility. When couples do try to open up to disclose their diagnosis, they report feeling frustrated by conversations about infertility [53]

As a consequence, there is a rift from the social world. In some cultures, men are advised to leave the childless /infertile wife, women are blamed. Social pressure effects the marital relationship [38]. The social effects based on a cross-sectional study of 70 couples [21 20] is depicted in the Figure 1. Nearly half, 47 % of the respondents avoided family gatherings, 16% avoided meeting their friends, 13% avoided social invitations or gatherings due to their situation. 10% respondents said that they

don’t like to go out at all. Only 14 % reported no such effect. A total of total of 86% reported socially avoidant behavior. Studies have shown that active-avoidance coping has a negative effect on the mental health.

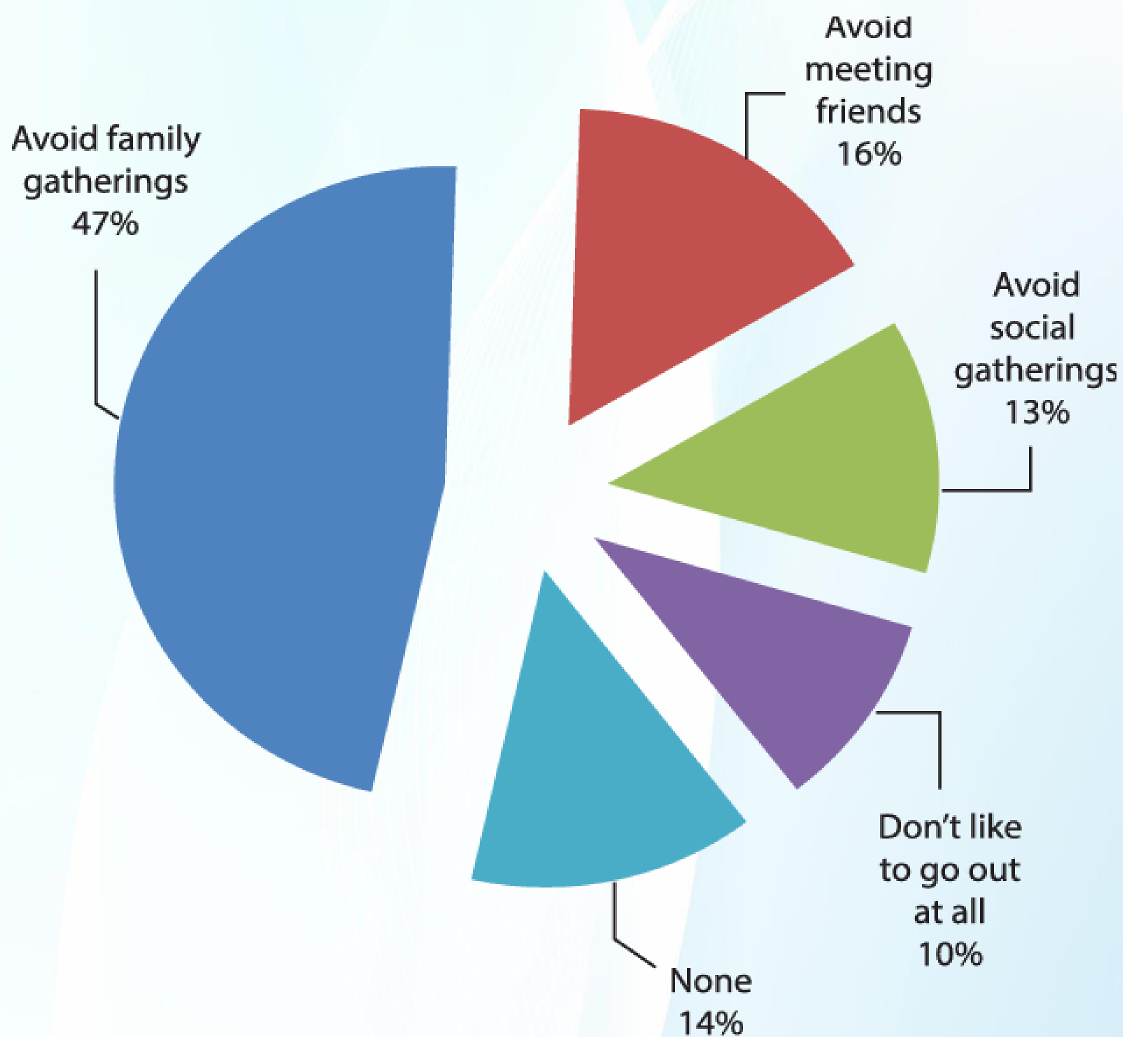


FIG .1(Mahmud et.al.2016)[20]

Gender Differences in Experience:

Psychology of men in the area of infertility remains an unexplored territory. Of 121 scientific papers on infertility published between 1948 and 1985, 56% referred solely to women, 29% to both the partners and only 15% exclusively to the men [57]. ART works mostly on the female body. They are direct recipients of major infertility treatments, procedures, its outcomes (cycles of ovulation induction, intra-uterine inseminations, in vitro fertilization, oocyte pickups, embryo transfers, fetal reduction, pregnancies, miscarriages, child-birth). Most of the studies in the existing literature thus focus on the female’s psychology. Men described their role in infertility settings as being overlooked

and ignored by the health care team and saw their role as a bystander. They felt marginalized during treatment process and report feelings of detachment and uncertainty.

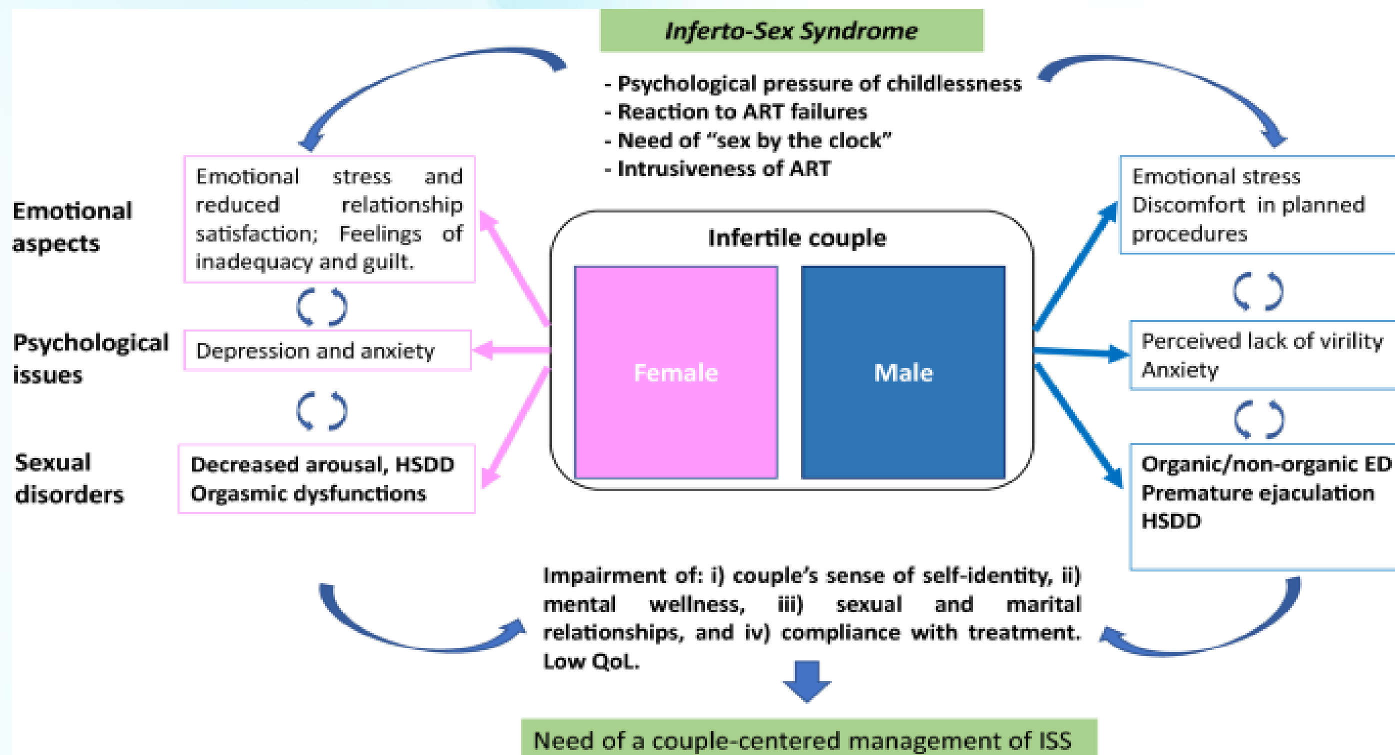
For many **women** motherhood is the primary culturally available identity, and sometimes the only one. [22]. Hence, infertility implies a role failure and social stigmatization. It can lead to physical and psychological abuse and in some cases life-threatening medical interventions [23]. In general, the women show higher levels of distress than their male partner. However, men's responses to infertility closely approximate the intensity of women's responses when infertility is attributed to a male factor [24]. Emotional stress and marital difficulties are greater in couples where the infertility lies with men. If the reproductive failure was caused by isolated male or combined male and female etiology, there was an immediate significant negative impact on the emotional status, the somatic or psychophysiological distress in men. It also effected negatively the marital relationship. This impact remained throughout the study period of nearly one year This distress was not seen in men for female factor or idiopathic infertility [57]

Communication and coping: There is a lack of openness about male factor infertility It is a taboo [25]. Media reports on sperm decline equate stereotypical masculinity and virility with fertility. Infertility is equated with impotency. **Secrecy** surrounds the diagnosis, sometimes to the point that women take the blame for the couples' infertility. Relatives of man are less likely to be informed about use of donor sperm than relatives of the woman even after successful treatment. Studies carried out in various cultural or ethnic settings demonstrate that males may find it difficult to disclose the outcomes of infertility testing or unsuccessful treatments, and display their emotions (e.g., shame, guilty feelings) even to their partners. They are also reluctant to share their feelings or concerns with the natural support networks in the family or at work (e.g., parents or -in laws, co-workers). Moreover, males from couples are even unwilling to openly discuss their health status or infertility issues with their fertility doctor or other medical staff. Women on the other hand tend to seek emotional support from others and may be more willing to discuss their feelings openly. For men, perhaps the greatest challenge is simply opening up and talking about the experience. Males may find it easier to connect with their peers using social media support networks or online discussion boards. Consequently, they are more likely to benefit from online social support networks. [18,57]

Sexual Intimacy in Infertility and ART

Sexual dysfunction in couples undergoing ART is a relatively new topic. The model depicting the interrelatedness of emotional, psychological issues is depicted in the "Inferto-sex syndrome "[26 25] Fig2 below explains the interrelatedness of the various factors contributing to sexual dysfunction in the couple during ART.

Fig 2: The Sexual Intimacy in infertility



ED (erectile dysfunction), HSDD (hypoactive sexual desire disorder), and ISS (Inferto-Sex Syndrome)*. Luca*

Infertility stress and sexual function

It has been found that up to 90% of infertile women had a reduction of sexual functioning as compared to 26% of the fertile control population, scoring lower in terms of sexual satisfaction and significantly higher (maladaptive) on all six domains of dyadic functioning (task accomplishment, role performance, communication, affective expression, affective involvement). Infertility is a specific 'crisis', in which the quality of sexual function is closely associated with treatment procedures [27]. The psychological burden of infertility is relevant for men as well, most commonly being associated with increased rates of depression [28].

Effect of ART on sexual adjustment

Attitudes to sexuality change through the course of the ART, affecting men and women differently. The constant focus on fertility and medical interventions affects the intimacy and sexual relationship between the couple. The intrusiveness of the procedures, medicalization of sex and intimacy, timing of sexual intercourse, and increased psychological pressure in case of treatment failures impact the sexual relations. It is reported 43.7% of women seeking ART had sexual dysfunction [29]. Studies carried out in other populations also gave similar findings [30], thus confirming the impact of the diagnostic and therapeutic procedures on the psycho-sexual function of the female [31].

During ART, medical investigations and female expectations have been reported to cause

sexual dysfunction in the male partner [32]. Men often felt uneasy with their involvement as "sperm donors": 11% of men cannot provide the sample on command, following transient erectile dysfunction or orgasmic disorder, in particular after detection of an abnormality in the results of semen analysis [33]. Giving semen samples in the IVF clinic is perceived as intrusive, thereby

contributing to the onset of erectile dysfunction or worsening of subclinical symptoms in subjects with a longer duration of infertility and with increased levels of anxiety [29,34 27]. In infertile men, a close association between erectile dysfunction and psychological burden has been demonstrated (especially anxiety and depression) [30 28].

The financial burden of A.R.T.

The journey through infertility is fraught with financial challenges at every turn. Fertility treatments like in vitro fertilization (IVF), intrauterine insemination (IUI), and hormone therapy can be incredibly costly, with expenses escalating based on the specific treatments. The financial challenges require couples to make tough decisions while seeking support and guidance to navigate this complex journey. There is a misconception that after paying so much, they must get the baby, as in a consumer transaction, hence the need to raise the level of awareness about the process of ART, and its limitations.

Difficulty in expressing the distress of infertility and art

Couples find it difficult to describe the depth of pain, anxiety, and sadness associated with infertility. They turn to metaphorical language to explain and frame the complexity of their experience. Thus, concrete conceptual metaphors such as ***emotional roller coaster, the job, war, empty inside,*** etc. help to communicate to a person who has never experienced infertility by choosing to compare it to a relatable experience. The metaphors are somewhere in between direct and indirect disclosures and a way to navigate the reveal-and-conceal dilemma when managing their infertility information while making themselves and others feel more comfortable [35]

Self-determination theory(SDT) and infertility metaphors.

According to SDT, people must meet three innate needs in order to achieve psychological well-being: **competence, autonomy, and relatedness**. These needs operate as a unifying, connective process; if one of these three needs is not met, negative outcomes occur. For example, if a person is in a situation where he or she is over-controlled, challenged, or rejected, he or she will begin to focus inward to cope with the issue and start withdrawing psychologically and socially from others [36]. The manner in which these components are disrupted in the infertility journey and ART are described below

1.Competence.

The metaphors of *Job, Roller Coaster and Game* expressed a feeling of incompetence experienced by the patients in controlling their emotions and treatment outcomes.

Job

Because of numerous doctors' visits, financial constraints, and physical pain from treatment, having a child was not about intimacy or connecting with a partner; it became like doing *a job* to achieve the goal of pregnancy. Everything was strictly followed, all instructions to the last detail. Thus, failure was particularly frustrating especially when they were doing "all of the right things." The feelings increased when others successfully become pregnant and when it seemed that the more they failed at conceiving, the harder they tried.

The Roller Coaster

The metaphor of *roller coaster* expresses the inability to control the direction and intensity of one's emotions.

…".. Tannu conceived, experienced great elation, but lost the baby a few weeks later, an emotional experience she was unprepared to deal with. ……. the crash of failure was awful…"

<u>Game</u>

The metaphor of game focused on the inability to control the outcome of infertility. The experiences were framed in terms of winning and losing, feeling cheated, of being unlucky in the game

"A patient's husband, 35, used game to explain their bad luck with infertility, such as his wife's diagnosis of ovarian insufficiency, "It's the luck of the draw, why does she have it? We don't know."

2.Autonomy

The loss of autonomy, freedom and choice was expressed as *Journey, Stalemate, Battle, and Illness* while trying to form an identity of infertility.

<u>Journey</u>

The long treatment procedures disrupt life plans. The life did not progress in a predictable path with specific normative milestones, such as completing studies, starting work, marriage, and birth of children

"Vinita, used metaphor of journey to compare her timeline to others her age." I was a step behind … everybody else is moving on with their lives…… unless I make a decision that I don't want children………"

<u>Stalemate or being stuck</u>

The patient's perceived themselves as existing in a no-win situation, which led them to unwillingly make decisions. They felt trapped, hopeless and being in a situation in which they had no choices.

"A couple made the difficult and unhappy decision to stop treatment during their secondary infertility experience. To continue on with treatment meant spending more money for another failure, while stopping meant they have ended treatment too soon because it was uncertain if they might have had more children…."

<u>Battle</u>

Some assumed the identity of being in a battle while protecting themselves and others from emotional pain. They were fighting for a joint cause, and experiencing an undesirable invasion of their body and personal life space during treatment procedures. They shared the experience of healing and surviving, being wounded, and dealing with scars.

<u>Illness or Disability</u>

Some framed infertility as a disability which deserves acknowledgement that other conditions receive. For example, comparisons were made to autism, terminal illness, cancer etc.

"Sangita equated her inability to have children to deformity or a handicap. She explained that people do not willingly choose to have a disability; therefore, others should be sensitive to her condition when talking to her."

3.Relatedness.

The third need for psychological wellbeing or relatedness was thwarted during ART. It was communicated through metaphors: *Infertility as Dirty Secret, Dance, And Club*.

Infertility as dirty secret

The predominant cultural view is that sexual and reproductive health is a matter of privacy. Disclosing infertility also makes it difficult to maintain privacy boundaries on related topics, such as financial, emotional, or relational difficulties. Women responded to questions about their infertility status with direct and indirect disclosures, lies, and responses that would point out others' rudeness. [37]. They feel frustration, awkwardness, discomfort, and tension, which often results in topic avoidance and a feeling of social isolation.

"Nirmala, 34, talked about how she and her husband had initially shared more information with others, but then after her first miscarriage and subsequent unwanted advice, she kept all information about infertility treatments and emotions between herself and her husband; it began changing how they interacted with others."

Dance

Metaphor of dance expresses the delicate ways people maintain connection when talking about infertility. There is a lack of consensus of how to talk about it. Some couples are very open about it but others don't want to talk about it at all because it's very intensely private and they may be in grief.

Infertility as a club

Some patients explained infertility as a club that no one joins by choice, but that also made it possible for them to share the difficulty of their experience with others who understood it and provided support for each other. It enhanced connection with those who experienced infertility, yet it is not a club that they felt good to join.

Practical Implications

An understanding of metaphors and narratives used by patients can help one to determine which needs are most important for their well-being. This enables them to reframe old metaphors as well as create new metaphors to positively structure their thoughts and actions about infertility.

Finally, analyzing metaphors within self-determination theory could explain why individuals experience infertility differently. Perhaps some women struggle with competency but feel autonomous and connected to others. Other women struggle with all three needs or a different combination of needs. It can help explain why infertility can be devastating for some and a challenge to overcome for others.

Use of Visual Metaphors [38]

Topic related with infertility and ART evoke complex experiences and emotions, and/or have strong cultural taboos and shame, making it difficult for the person to talk. In a novel method the drawings have also been used as method for data collection; and visual metaphors have been used as the main stimulus presented to women and used for understanding the deep feelings which could not be otherwise expressed. This is of great significance while developing specialized psychosocial care for the couple.

SUMMARY

Infertility and ART impact all aspects of a couple's life. The stress of infertility is very high, as high as in HIV and cancer ; this is so despite the fact that there is no threat to self-survival at the physical level .The impact is on the emotions , self identity , social , marital ,familial cultural expectations , the intensity of impact is fueled by basic evolutionary instinct of species survival .The unfulfilled dream , gets the hope from the rapidly developing medical sciences and technological advances . This hope propells the couple into repeated cycles, invasive procedures despite no gaurantee of success .Within the current state of knowledge this wish remains unfulfilled in many . They carry the burden of realigning their life , re-adjusting back and coming to terms with lost time , work opportunities and huge financial drain.Thus , no wonder , they experience anxiety , depression , sometimes even major one .The social isolation does not help , the marital problems may not resolve . The stress needs to be moderated and managed at all levels right from the beginning of the ART treatment . It is important to have conversations, show empathy, allow silences in order for healing to take place.

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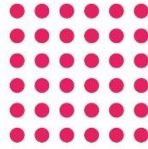

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