Review Article

"In Cycles of Dreams, Despair, and Desperation:" Research Perspectives on Infertility Specific Distress in Patients Undergoing Fertility Treatments

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Abstract

"Emotional distress in infertility" is a broad expression that loosely denotes anxiety, depression, grief, crisis, depleting psychological well-being, and all forms of affective and interpersonal disturbances faced by individuals with infertility. The distress is usually associated with involuntary childlessness as it is an unwelcoming event. The developmental crisis associated with childlessness poses a threat to one's sense of self at all levels (individual, family and social). Distress may begin before or during treatments as a person experiences the loss of control over attaining parenthood, anxiety or dejection after the diagnosis, treatments, its complications particularly its limited success rates. This paper reviews the basic concepts, theoretical models related to infertility specific distress (ISD). It elaborates on the effects of individual and treatment-specific variables on ISD with special highlights gathered from the national and international research.

Keywords: *Crisis, emotional distress, fertility treatment, grief, infertility, models, research perspectives, review*

Infertility Specific Distress

Infertility-specific distress refers to the degree of emotional strain associated with failure to conceive or experience childbirth. It has been identified as an important outcome variable in most of the evidence-based data across many countries.[1-12] It is also known to vary with time and phases of fertility treatments.[12] Studies have identified that there are two major sources of infertility distress. First of all, since most societies recognize mothering and fathering as essential social roles, infertility leads to an unexpected role loss (identified parent role, social role, biological role, and relational role). Second, as the treatment regimens, timings, strict scheduling coincides with the female partner's monthly menstrual cycles, every cycle brings in cyclic reactions of hopes, and despair.[13-19]

The paper is divided into two sections, out of which the first part elaborates the basic concepts and theoretical models related to infertility distress. The section of this article highlights the gender differences in experience of infertility and effects of individual and treatment specific variables on distress. Each section lays a special importance on findings gathered from the national and international research.

Nature of infertility specific distress

Infertility diagnosis becomes sources of chronic distress to both genders leading to emotional suffering in five major domains of daily life namely social, sexual, relational, needs for parenthood, and rejection of child-free life.[20]

Literature on psychology of infertility does not delineate between psychological consequences of infertility and consequences of infertility treatment as they are difficult to disentangle from each other.[21] Most of the evidence-based research emerges from clinic-based data (available from high resource countries) that primarily focused on treatment-related emotional stress.[22]

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Variability in infertility distress

Data from 25 population surveys and sampling over a lakh infertile women highlight that there are striking similarities in the trend of females seeking fertility treatments across less and more developed nations.[23] Nonetheless, evidences support that the experiences of all individuals facing infertility are dissimilar in nature.[24] There are studies that urge that almost 50% of women and 90% of men were minimally or moderately distressed,[25] and about a 20%–40% of patients are highly distressed.[25] It is also reported that before treatments and in the initial years, most of the subfertile couples may not have any significant psychopathology.[26,27] Nevertheless, a small subgroup among these do require psychological help.[28,29] Despite high pretreatment variability in infertile couples, when the same couples enter the treatment phase, these differences begin to blur. During treatments, emotional distress increases from the level initially reported by couples. Within a specific treatment module (intrauterine insemination [IUI], *in vitro* fertilization [IVF]-embryo transfer, intracytoplasmic sperm injection [ICSI], Donor program), most patients present with more or less similar psychological profiles.[30] Distress increases after treatment failures.[31] Consequently, over a period, distress interacts with several other variables that cause a change in its course and magnitude.[21,32,33] Pattern of variability in infertility distress can be explained by a plethora of factors present in one's cultural and sociocultural milieu.[25,34]

Research from the Indian database reports that infertility is impacted several domains of daily life and is thus experienced as a major stressor.[10,11,35-46]

The constellation of psychological reactions in infertility can be summarized as per seven major infertility specific frameworks[47] elaborated below.

Theoretical Frameworks on Infertility Specific Distress

Grief and bereavement approaches

Infertility involves the couple's shared loss. Loss is many-sided such as the loss of a biological role, physical and mental well-being, parenting ambitions, life goals, self-confidence, body esteem, control over one's body, social status, social role, and parenting role. Often women are reported to mourn more openly than men. The "28-day grief cycle of infertility" describes the five stages of grief in women subsumed under the 28 days of the menstrual period. This grief becomes cyclic for couples with infertility and periodically remerges and it does not end until they experience childbirth or renounce the desire for a child.[48]

Individual identity approaches

Children are viewed as an extension of oneself and one's family lineage. From these perspectives, infertility causes a blow to one's self-concept, self-image leading to narcissistic self-injury.[49]

Stress and coping theories

The self-regulatory perspective integrates the roles of cognitive representations, health beliefs, emotional representations in infertility.[24,50] The uncontrollability, ambiguity, and uncertainty associated with this medical condition are significant which explains why for a majority of patients, infertility turns into an unbearable stressor.[51]

Social construction perspectives

Infertility may also be a stigmatizing and shame-laden experience. Infertile men and women are perceived by others to be 'defective and socially deviant', adding to their feelings of guilt and inferiority.[21,52-55]

Family systems approach

Infertility prevents family expansion, interrupts the normal role-transition thereby blocking the progression of couples within their family life cycle. It can alter the existing dynamics, relations, boundaries, communication patterns, and tax the family's coping resources.[54,56]

Phase or stage theory

This theory talks of the psychological struggles and adaptation of the couple from pre-treatment to posttreatment stages. This model explains that there are five psychological phases of infertility through which couples progress.[57] The Dawning of realization is the first phrase in which the couples begin to speculate that they have conception issues and seek a medical evaluation. Mobilization of psychological coping resources marks the next phase in which the couple is informed about the fertility problems, diagnosis, and given a prognostic plan. This is the stage in which coping resources need to be mobilized as adjustment problems emerge. Immersion is the next phase as the couple chooses and decides to begin treatments. It is the most complex and demanding phase. Resolution is the fourth phase for couples who do not conceive or experience childbirth. It consists of decisions on ending medical treatments, acknowledging, and mourning the loss of not having a child, and finally rethinking on alternative reproductive possibilities. In the end, the Legacy is the last stage that represents the aftermath of new and old unresolved psychological issues.

Gender Differences in Response to Infertility

Response in women

Distress in women is higher than distress in men as historically the role of a female is considered to be more

important in reproduction.[47] Researchers explain that for women infertility is actually something that disturbs several aspects of her life for many years ahead.[52] In most of the developing countries, women are not only valued for their role in reproduction but are also blamed when they fail at living up to this role.[58,59] This may be the reason why men and women differ in their experience of infertility and their response to same. Studies suggest that women report higher feelings of guilt, shame, grief, dejection of not being able to meet the standards of the "desired social role."[26] Women perceive infertility more negatively with greater intrusiveness of fertility-related thoughts, goal blockage than their partners since they receive a more direct negative feedback about their fertility progress (negative pregnancy tests, menstruation, and physician's feedback). Psychological adjustment in women is reported to be related to both their own goal appraisals (as well as their partners') whereas in men, its related solely to their own goal appraisals.[60] Another research conducted in women in India reveals that irrespective of the cause behind a couple's childlessness, women by default carry a greater load of blame, responsibility, and guilt for reproductive failures.[61] This is referred to "courtesy stigma" as a favor on the male partner to save him from the disgrace to his personal and his family reputation.[61]

Response in men

Men on the other hand have been less investigated on their desire for parenthood, reactions to failed treatments, long-term adjustments and needs for medical support and structured psychological interventions. A recent systematic review of 92 studies on psychosocial aspects of infertility in men reveals that desires for parenthood, anxiety, and enduring sadness also prevails in men.[62] Men maintain high secrecy, anger, denial, powerlessness, personal inadequacy, and sexual inferiority regarding not being able to live up to "the idealized masculine image of self."[47,63,64] Men report experiencing greater distress when a defect is identified in them,[59,60] this is also true for pronatalistic societies.[10,11] However, women experience infertility as a greater loss and have a stronger and an enduring negative reaction to it.[65-68] Literature also suggests that men tend to underrate and women overrate infertility stress.[20-22]

Distress in Men and Women Undergoing Fertility Treatments

Literature reveals four major theoretical frameworks that have been used to describe the psychological response of individuals to infertility treatments.[47] These are namely: (i) the psychological sequel approach, (ii) the cyclical approach, (iii) the outcome approach, and finally (iv) the context approach**.** The psychological outcome approach integrates the most recent biopsychosocial perspectives to clinical practice.

The Biopsychosocial Viewpoint of Infertility Distress

From the biopsychosocial viewpoint, infertility distress is a by-product of the medical technology, individual and sociocultural, and treatment-specific factors.[47] Literature reveals that the individual specific factors and treatment-specific factors interactively contribute to levels of infertility distress described in sections below.

Effect of Individual-specific Factors on Distress

Psychological adjustment in infertility is affected by certain person-centric variables such as the following.

Personality factors

Personality characteristics predominantly color emotional and behavioral responses. Data from a recent systematic review suggests that neuroticism, trait anxiety, criticism, sensitivity to stress, dependency, escapist coping, intrusiveness, and anxious-avoidant attachment style is correlated with distress and low emotional adjustment. On the other hand, trait optimism, resilience, well-being, positive effect, and life satisfaction are associated with higher emotional adjustment.[69,70] Studies suggest that cognitive appraisals (helplessness, hopelessness, threat, loss, and uncontrollability) and irrational parenthood cognitions are risk factors for depression after treatment failures.[6,25,32,68,70] Protective factors for distress are coping measures such as seeking information and positive reattribution, compassionate acceptance, cognitive appraisal, social and spousal support, open communication about the infertility problem and developing an existential meaning out of the emotional experience.[32,33,71] Career-role salience, partner communication and dyadic coping predicts social, personal, marital harmony, mindfulness acceptance and cognitive-defusion, and alleviates stress.[25,72-75]

Sociocultural factors

The importance given to "biological parenthood" can stir identity struggles and contribute to internal and external shame in men and women experiencing infertility.[47,76,77] In developing nations, fertility and childbirth are perceived as social responsibilities.[78,79] Fertility treatments are thus quite popular as infertility is more of an unexpected life event and a major social issue rather than being just a medical disease. Despite the medical, financial, and emotional costs, couples who can afford these treatments go at quite a length to achieve

a childbirth rather than accept or adjust to involuntary childlessness.[78,79] In addition to this, there are gaps in literature on the experiences of men resource-constrained countries and its comparison with high-income countries.[62,73] Literature from Indian contexts depicts that women experience social hardships, personal and sexual inadequacy, low self-esteem, guilt, shame, loss of body-esteem, privacy, and integrity as a consequence of childlessness.[21,39,45,55,78,80] In addition, fertility defines womanhood. Infertility is a highly stigmatizing condition. Thus, in order to break out of this stigma, women go through all kinds and any extent of fertility treatments. In Indian context, patients lack the information on infertility, choice of treatments, and this makes coping with its consequences quite difficult.[79,81] Some of the social problems linked with infertility reported from the southern regions of India have been the unsolicited questioning by others, difficulty in guarding and keeping their sexual, intimate lives, politicization of reproductive failures, unwanted and unempathetic help, medical aids, suggestions, pressures to try out "the guaranteed cures and magico-religious solutions to infertility," social alienation, infertility being equated with "sexual weakness or impotency, lack of vigor, unattractiveness," and fimally adjusting within the "stigmatizing milieu" is the process of breaking mental barriers held by others.[62,82,83]

Coping with infertility

Meta-analytical reviews support that the infertility situation is unpredictable and minimally controllable and a problem-focused coping can lead to deleterious outcomes.[84,85] Coping with infertility occurs at two levels, namely individual and at dyadic level. Gender-wise differences are also evident. In addition to this, short-term coping is different from long-term adaptation to infertility.[69] As per the transactional theory of coping, individuals generally use distraction or avoidance to cope with low control situations such as infertility.[84] Limited distraction from ruminations or avoidance of anxiety-provoking fertility situations is adaptive as it curtails short-term treatment-related distress. However, overreliance on such strategies in the long run can lead to a recoil effect.[69]

Within Indian contexts, limited studies are available on the coping patterns in infertility. Evidences from cross-sectional studies suggest that coping difficulties are reported by nearly 57% of men (172 out of 300) and 72% of women (215 out of 300 women) seeking fertility treatments such as ovulation induction and assisted conception.[10,11] Studies report that both sub-fertile men and women mostly cope on their own or by seeking consolation, information, and advice from family and friends. However, they express an inconfidence in their coping capacities.[10,11,86] Women primarily adopt strategies such as use of self-controlling, seeking social support, venting, behavioral disengagement, and ruminative thinking. In addition, most of them report that they are unable to effectively employ the use of strategies such as problem-solving, mental mastery, positive appraisal, recreation of life around other goals, and seeking alternative rewards to resolve infertility distress.[87-90] Men report of employing the avoidance and escapist coping approach to deal with fertility-related stress.[11,86,91]

Another crucial step in the coping process is the acceptance of the diagnosis. Couples face higher levels of distress if they are unable to acceptance the condition.[47] Studies on coping processes in infertility also suggest that strategies that are beneficial to individual (distancing in men and self-controlling in women) are problematic to the partner.[92] Both genders benefit greatly from meaning-based coping as well.[93,94] Infertile men and women from lower social classes feel less compelled to conceal infertility from others and use more of active confrontative and meaning-based coping that men and women from middle- higher social class who use more of passive avoidance strategies.[95]

Effect of Treatment Specific Variables on Distress

Abiding by the medical definition of infertility,[95,96] a couple should ideally seek a medical evaluation if they have not conceived during 12 months of having regular, unprotected sexual intercourse. However, literature highlights that when and why a couple decides to seek an evaluation and treatment depends on their sociocultural background, economic condition, personal choice, and psychological comfort.[97]

Patterns of distress among treatment seekers

Within national scenarios, studies report that couples usually seek treatments between 1 and 3 years of not being able to achieve a pregnancy. Distress is highest when duration of infertility is 2–5 years. In addition, 80% of women and 72% of men undergoing initial infertility check-ups report being moderately or highly distress.[10,11,45] A study from India reports that primary infertility is a distressing condition, and pattern of seeking medical treatments for infertility is similar to that in other parts of the world, except that couples are reluctant to seek immediate evaluation and allopathic treatments for the same.[98,99]

Another cross-sectional study from India reports selected factors that hinder and foster psychological adjustment

in infertile women receiving IVF-ICSI treatments. In addition, intrapersonal factors have more prominence in the adjustment process than interpersonal factors. This study concludes that perceiving parenthood and children as essential entities of marriage, avoidance coping, ambivalence, low self-worth, low internal control leads to poorer adjustment whereas higher intrinsic religiosity, meaning-based coping, family, peer and social support, and marital and sexual satisfaction contribute toward better adjustment.[44]

The Treatment-specific Predictors of Distress

These include chronic uncontrollable stress,[10,11,65,66,100-104] increasing the duration of infertility,[104] repeated cycles of treatments and their failures,[15-18,21,22,32,33,103-106] gender-specific diagnosis and distress related to it,[10,11,63,66,100,104] treatment-related strain,[9,10,21,47,107] disturbances in daily life activities while taking treatments,[108] treatment side-effects and discontinuation[2,98-112] and stress-mediated biological changes.[102,107,113-118]

Treatment-specific Issues within Indian Scenario

A recent cross-sectional study from Indian setups reports selected factors that hinder and foster psychological adjustment in infertile women receiving IVF-ICSI treatments. This study concludes that perceiving parenthood and children as essential entities of marriage, avoidance coping, ambivalence, low self-worth, and low internal control leads to poorer adjustment whereas higher intrinsic religiosity, meaning-based coping, family, peer and social support, and marital and sexual satisfaction contribute toward better adjustment.[44]

Another recent study concluded that treatment-related distress is as high in IUI as it was in IVF in men and women. Gender differences exist on stress related to needs for parenthood, social and sexual concerns and female partners score higher on these subscales in comparison to their male counterparts.[119,120] In women indices of marital adjustment, sexual functioning and satisfaction tend to be stable in the first 2 years but are likely to deteriorate overtime.[43,45] Infertility distress is on a rise due to a plethora of medical, financial and emotional issues, exploitation from the healthcare sector, and low societal acceptance for "being in a state of involuntary childlessness."[41,42,82,121,122] Most couples are under the pressure to undergo a cocktail of treatments that comprises of less and more invasive protocols within a short duration of marital life. Several couples undergo magico-religious cures, and Ayurvedic treatment, Homeopathic therapies as a mainstay and they opt for Allopathic treatments alongside these.[10,11,41] Data also urges that pattern of seeking medical treatments for infertility is similar to that in other parts of the world, except that couples are reluctant to seek immediate evaluation and allopathic treatments for same.[98] Adding to this complexity, a recent survey of 470 Gynecologists in four major cities (in India) reveals that each clinic be it big or small follows a different yardstick for quality of care, patient management, costs, and ethical practices.[47,122-124] In addition, secrecy associated with undergoing third-party reproduction programs is high as these are publically perceived as obnoxious for violating the common cultural concepts of family, marriage, and kinship.[46,122,123] Under these conditions until about a couple of decades back, there were no clearly established guidelines for care of infertility patients and for professional counseling and therapy; however, more recently, the ICMR has taken stringent steps with regard to quality of fertility care in our country.[122]

Conclusions and Implications for Clinical Practice and Research

Fertility treatments are scientific marvels that began in 19 seventies. With increasing rates of infertility, globally,[23,39] medically assisted reproductive treatment and technology have become quite popular. Developments in these areas have also bloomed in our country simultaneously to its origins on other parts of the world.[47,121-126] Over the past 50 years, most countries have come up with an evidenced-based committee report that elaborates clear guidelines on addressing psychosocial needs in infertility specific to each phase of treatment. Systematic reviews and meta-analytical evidences from the western contexts support that there are personal, situational, and treatment-related risk factors for infertility distress. Personal factors include being a female, having a pre-existing psychopathology, a diagnosis of primary infertility, and avoidance coping style. Situational risk factors include poor marital relationship, impoverished social network, and frequent ruminations of infertility. In addition treatment-related factors that promote distress are the medical side effects, miscarriages, and treatment failures.[47] Evidence-based studies also point out that factors such as (a) the personality characteristics (neuroticism, pessimism, introversion, levels of resilience and hope), (b) increased threat, loss associated with infertility, (c) treatment repetition, procedural strain along with low perceived control over its course and outcomes, (d) frequent use of avoidant/escape coping strategies, (e) marital dissatisfaction and poor marital communication, (f) low social support and lastly (g) a combination

of clinic-specific factors such as treatment protocol, clinic environment, staff competency, and patient-staff interactions account for variability in infertility distress.

Research on these issues within the Indian setups is in its formative years. The local database reveals some empirical findings on psychosocial aspects of infertility. Nevertheless, it also reveals a dire need for primary research on role of mental health practitioner at infertility clinics, effectiveness of psychotherapy in infertile patients and systematically gathered meta-analytical evidences on patterns of distress, quality of life, treatment-related experiences, as well as on gender-specific predictors of coping efficacy in infertile patients.

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There are no conflicts of interest.

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