

Review Article

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Exploring onco-fertility perceptions in India: a narrative review of psychosocial factors and implications for patients well-being

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ABSTRACT

Onco-fertility, the confluence of cancer and fertility preservation, is vital in modern healthcare. As global cancer survival rates rise, more patients aim to overcome cancer and safeguard their reproductive potential. This review explores onco-fertility in India, emphasizing psychosocial factors. It acknowledges cancer's profound implications on fertility, stressing informed decision-making and comprehensive care for dual challenges. The review explores various preservation options for both genders, highlighting India's evolving landscape. India's onco-fertility landscape, driven by rising cancer diagnoses and disparities, needs tailored services. Understanding psychosocial factors is crucial for addressing emotional distress, cultural contexts, and communication barriers. This review delves into factors influencing decisions and well-being, informing practices to better serve Indian cancer patients. Examining psychological distress and decision-making in balancing treatment and fertility preservation, it explores cultural, religious, and ethical considerations. It underscores the need for comprehensive psychosocial support. Addressing psychosocial factors is vital for enhancing cancer survivors' quality of life. The review emphasizes bridging information gaps, providing emotional support, promoting informed decision-making, and fostering collaboration. It calls for further research and initiatives to advance onco-fertility support, considering India's diverse psychosocial landscape.

Keywords: Onco-fertility, Cancer survivors, Fertility preservation, Psychosocial factors, Decision-making, Perceptions in India, Comprehensive care

INTRODUCTION

Onco-fertility, the convergence of cancer and fertility preservation, holds immense significance within modern healthcare. With the upward trajectory of cancer survival rates on a global scale, a growing number of patients aspire not only to overcome cancer but also to safeguard their reproductive potential.¹ This burgeoning field recognizes the profound implications of cancer treatments on fertility, addressing the pressing necessity of enabling individuals to make informed decisions regarding their future reproductive prospects. Onco-fertility involves a range of options and interventions. Women can opt for preservation methods like freezing eggs, embryos and ovarian tissue or explore techniques such as ovarian suppression and transposition. For male patients who have reached puberty,

preserving semen through cryopreservation is a standard practice, while the cryopreservation of testicular tissue is considered an experimental technique offered within the context of a clinical trial, specifically for pre-pubertal patients.² While the onco-fertility landscape in India is evolving rapidly in response to increasing cancer diagnoses and improved survival rates, it is also marked by awareness of fertility preservation, significant disparities in access and affordability of treatment.³ Comprehending and seamlessly integrating onco-fertility into cancer care remains imperative for enhancing patients' quality of life and overall well-being.

Understanding the psychosocial factors related to onco-fertility is integral to providing comprehensive care to cancer patients. It enables healthcare providers to address

emotional distress, ensure informed decision-making, respect cultural contexts, enhance communication and tailor support to individual needs. Ultimately, this understanding contributes to improving the overall well-being and quality of life for cancer survivors.¹

The purpose of this narrative review is to comprehensively explore the perceptions of onco-fertility in India, with a particular focus on the psychosocial factors that shape these perceptions. It aims to provide a deep understanding of the psychological implications of onco-fertility in the Indian context. By examining existing literature and research, this review seeks to shed light on how psychosocial factors influence patients' decisions and well-being. Ultimately, it aspires to inform healthcare practices and support systems to better meet the unique needs of cancer patients in India.

ONCO-FERTILITY: CONCEPTS AND CHALLENGES

Infertility, as defined by the World Health Organization (WHO), is the inability to achieve pregnancy after a year of regular unprotected sexual intercourse. Globally, approximately 1 in 6 adults, or 17.5% of the population, experience infertility.⁴ In India, primary infertility rates vary from 3.9% to 16.8%, with cases evenly distributed: 40% attributed to men, 40% to women, and 20% to both sexes.⁵

Cancer incidence in India is on the rise, with an estimated 14,61,427 new cases in 2022, expected to increase by 12.8% in 2025 and 57.5% in 2040 compared to 2020.⁶ This surge is attributed to lifestyle changes, improved detection, and increased life expectancy. In countries with robust healthcare systems, improved cancer survival rates result from early detection and quality treatment.⁷

Cancer and its treatments can lead to impaired fertility, affecting patients' family planning goals and overall well-being. Infertility can result from cancer or its treatments, such as chemotherapy and radiation.⁸ Cancer survivors, particularly those of reproductive age, may face infertility rates as high as 90%, influenced by factors like cancer type, treatment nature, cumulative chemotherapy dosage, radiation site, age, and reproductive history. Hypogonadism and androgen deficiency can lead to sexual dysfunction and infertility in male survivors, while female survivors may experience ovarian failure due to radiation and chemotherapy.¹

Onco-fertility, a multidisciplinary approach, aims to preserve or restore reproductive function in cancer patients. It goes beyond gamete and embryo preservation, addressing sexual dysfunction, hormonal issues, complex contraception, and psychosocial support related to cancer and its treatment.⁹ This innovative concept represents a shift in cancer care, focusing on mitigating adverse reproductive effects and offering comprehensive support

to those facing reproductive challenges due to cancer therapies.¹⁰

Despite the growing availability of fertility preservation options, evidence indicates that many female cancer patients feel the lack of sufficient support in decision-making, find it stressful and complex, and often do not pursue fertility care during this crucial period.

In a review published by Oxford University Press, several challenges encountered by female patients were observed, including: issues with fertility information provision (such as the timing and the lack of information and patient-provider communication); concerns about perceived risks related to pursuing FP (such as delaying cancer treatment, worsening hormone-positive cancer and potential consequences of future pregnancy); non-referral from oncology (due to personal situations, having hormone-positive cancer, FP not being a priority and service transition issues); the dilemma faced by patients (choosing one treatment over another while in survival mode); personal circumstances (including parity and relationship status); and financial concerns and costs.¹¹

PERCEPTIONS OF ONCO-FERTILITY: INDIAN CONTEXT

Perception of healthcare providers toward fertility considerations in cancer patients

Oncologists, as the primary healthcare contact for cancer patients, should take the initiative to communicate the potential impact of cancer treatment on fertility. Ideally, these discussions should commence upon confirming the diagnosis, prognosis, and treatment plan.

However, fertility considerations often receive limited attention, influenced by oncologists' personal biases, concerns about additional burdens on patients, and doubts about the success rates and viability of fertility preservation procedures. Moreover, time constraints and limited knowledge about these techniques can further impede discussions. Some oncologists may believe that such conversations should be the responsibility of specialists like reproductive endocrinologists, obstetricians, and gynaecologists.^{12,13}

Perception of patients

Patients often harbour numerous inquiries about fertility preservation prior to commencing cancer treatment. Their concerns encompass whether FP choices diminish the prospects of successful cancer treatment, elevate the risk of maternal or perinatal complications, or jeopardize offspring health, particularly regarding the potential transmission of cancer.

It is crucial to provide patients and parents of minors with realistic expectations regarding their cancer prognoses, elucidate the success rates and costs of FP interventions

and afford them the autonomy to decline such interventions.¹²

Cultural attitudes and religious beliefs towards fertility and cancer

Beliefs, influenced by religious traditions and cultural factors, exhibit regional and global diversity. These beliefs are deeply intertwined, making it sometimes challenging to differentiate between religious and cultural influences. Various religions offer distinct perspectives on health, disease, and healthcare. For example, Hinduism often links cancer to past sins or karma, while cultural factors in many societies are considered direct causes of cancer, sometimes overshadowing genetic or biological factors.¹⁴

To ensure patient autonomy and dignity in fertility preservation, healthcare providers must recognize that a patient's religious or moral convictions can significantly impact their acceptance of assisted reproductive technologies (ART). Understanding a patient's religious preferences related to cancer treatment and fertility preservation is vital. Neglecting these considerations may overlook the patient's profound spiritual perspective on illness and treatment.

Thus, addressing the religious dimensions of a patient's sense of meaning is crucial in discussions about fertility preservation options, enhancing the quality of care for cancer patients.¹⁵

PSYCHOSOCIAL FACTORS INFLUENCING ONCO-FERTILITY DECISIONS

Emotional distress and psychological impact of cancer diagnosis

Cancer treatments not only impact reproductive physiology but also trigger profound emotional distress. The psychological burden of cancer treatment extends beyond infertility, encompassing the symbolic loss of family completeness. It's important to clarify that this isn't a direct comparison of cancer and infertility's physical effects, but both disrupt the continuum of human existence. From an end-of-life perspective, infertility imposes an emotional burden, as life's continuity returns without the prospect of leaving behind a legacy through descendants.¹⁶

For women affected by cancer treatments, psychological distress arises from both the loss of their ability to conceive and the symbolic loss of fertility. Men, too, experience enduring distress due to impaired fertility from cancer treatments.¹⁷ Fertility concerns stemming from cancer induce profound existential distress, impacting life roles and cherished goals like motherhood and raising children, often causing uncertainty about the future.¹⁸

Infertility compounds the emotional strain of cancer, affecting self-esteem, causing feelings of defeat, and

intensifying distress, particularly for those desiring biological offspring.¹⁵

Decision-making under uncertainty- balancing treatment and fertility preservation

The choice to undergo fertility preservation is intricately entwined with a myriad of psychosocial factors. Firstly, individuals referred for fertility preservation often find themselves in the initial stages of grappling with their cancer diagnosis. In this vulnerable state, concerns about mortality, potential recurrences, implications of genetic testing, body image, sexuality, and the impact on present and future relationships loom large. Understandably, cancer patients frequently exhibit symptoms of depression and anxiety due to these anxieties. Moreover, the time-sensitive nature of the decision to engage in fertility preservation can intensify these anxieties. Additionally, the financial aspect comes into play, as many insurance policies do not extend coverage to these treatments.¹⁹

Research indicates that individuals make better decisions when they possess three key elements: a clear understanding of the relevant matters, a support network, and self-awareness regarding their personal values related to the decision.²⁰ Increasing evidence supports the use of decision aid tools in aiding fertility preservation decisions for cancer patients. These resources help inform patients about their options, reduce decision regret, alleviate decisional conflict and enhance overall satisfaction when used alongside therapeutic fertility counselling. This combination also improves patients' fertility knowledge and confidence compared to counselling alone.²

Gender roles and societal expectations in fertility decisions

Infertility carries significant social stigma in many Asian societies. Awareness of a woman's compromised reproductive capacity can result in challenges finding a compatible partner, divorce, or even abandonment.³ In India, patriarchy sustains gender inequalities and power disparities between men and women within the social system placing a significant burden on women in terms of procreation.²¹

Communication barriers with family members

A study found that the family environment significantly influenced patients' outlook on their illness.²² Those in negative family environments often faced the disease and financial burdens alone, leading to increased feelings of isolation and depression. Some patients withheld the truth about their condition from their aging parents to protect them, exacerbating their sense of isolation. The absence of family support intensified patients' emotional distress, negatively impacting their overall well-being.

Conversely, patients with strong family emotional support found it helped them confront the disease more calmly,

providing effective moral support and greatly reducing their anxiety and depression.

Knowledge and information gaps

In India, despite ASCO guidelines advocating fertility preservation for oncology patients, 85% of childhood cancer survivors lack information about treatment-induced infertility risks.²³ Knowledge gaps persist, especially in paediatric care.¹² Armuand et al study notes more men discussing fertility aspects with physicians than women, attributed to varied FP options.²⁴ Sperm banking, simpler for men, contrasts with complex and uncertain FP methods for women, hindering discussions. A study in India found primary care physicians cite 'lack of patient and physician awareness' as major barriers, underscoring the need for increased social awareness and education on onco-fertility programs.²⁵

Oncologists and gynaecologists are pivotal in onco-fertility program success. The frequency of their discussions with patients regarding both adult and prepubertal options is influenced by their knowledge and comfort.²⁵ A survey identifies gynaecologists' lack of awareness about FP techniques, emphasizing the need for in-house FP services and educational initiatives for long-term patient interactions.³ Educating patients empowers them to initiate fertility discussions, and for gynaecologists to fulfil this role effectively, staying updated with the latest information is imperative.

COPING MECHANISMS AND SUPPORT SYSTEMS

Defence mechanisms in coping

The role of defence mechanisms in adapting to physical illness should not be underestimated. Cancer often elicits intense emotions and the mobilisation of defence mechanisms serves as a crucial coping mechanism. These mechanisms help patients manage distressing emotions, allowing them to come to terms with their situation while excluding overwhelming and painful experiences from conscious awareness. The strategic use of flexible defence mechanisms not only shields patients from the fear and discomfort associated with a medical diagnosis but may also enhance their long-term survival prospects. Furthermore, the style of defence mechanisms employed has been shown to have a significant impact on the quality of life among oncology patients.²⁶

Importance of family support in onco-fertility decision-making

Cancer survivors found value in engaging in conversations about onco-fertility concerns with their spouses, friends and family members who offered emotional support and helped with decision-making.²⁷ Family support can influence a patient's choices regarding fertility. Unmarried women's decisions about fertility preservation may be guided by their mothers, while married women's decisions

about pregnancy can be influenced by their partners and their partners' families.²⁸ Parents play a crucial role in decision-making involving minors and post-pubertal boys and girls.²⁹

Importance of social support in onco-fertility decision-making

A study found that the assistance provided by healthcare professionals is of paramount significance.²² Patients, grappling with the dual challenges of survival and fertility, are keen to establish a solid trust-based rapport with medical personnel. A strong social support network can significantly ease the emotional distress and physical discomfort experienced by patients, instilling in them a sense of optimism about their chances of recovery and bolstering their trust in the treatment process.

Online communities and patient forums as sources of information and emotional support

At present, patients are increasingly turning to social media for accessing medical information and for fostering interactions among healthcare providers, healthcare facilities, patients and caregivers. Approximately one-third of patients use social media for health-related purposes, such as seeking information, advice and finding social support. Online communities dedicated to specific medical conditions, including cancer, facilitate interactions among various stakeholders, including patients, families, healthcare professionals, advocates and policymakers.³⁰ Patient-focused support groups and available resources are essential for maintaining comprehensive reproductive care.²⁸

Psychological counselling and interventions to alleviate distress

Providing medical information for fertility preservation counselling differs from fertility counselling alone where the therapeutic exploration of reproductive concerns and fertility treatment needs, conducted by a clinician with mental health training which has profound impact on emotional health.²

Psychosocial interventions designed for cancer survivors, some of which may incorporate web-based elements, often encompass a wide range of services and go by various names like survivorship care plans, self-management programs or multidimensional interventions. However, there's a noticeable gap in the availability of interventions that address both medical and psychosocial aspects of fertility and parenthood concerns in the context of cancer. An extensive review focusing on psychological distress related to fertility post-cancer treatment revealed that there are merely three documented psychological interventions for this specific purpose.³¹ The study indicates the effectiveness of therapies focused on existential and meaning-centred approaches and positive psychological therapies in the context of cancer. These therapies have

shown the potential to enhance psychosocial outcomes, including reducing anxiety, depression, hopelessness, while boosting optimism, self-efficacy and overall quality of life. Tailored interventions addressing existential and meaning-focused aspects have the capacity to alleviate existential distress stemming from fertility concerns related to cancer. These interventions aim to bolster the sense of meaning in life, promote psychological flexibility and foster adaptive coping mechanisms specifically tailored for individuals dealing with cancer.¹⁸

ETHICAL AND LEGAL CONSIDERATIONS

Ethical dilemmas in the convergence of cancer and reproductive concerns produce unique ethical challenges in cancer-related infertility: choice between experimental and established treatments, minors' capacity for informed consent, welfare of prospective offspring, prospects of posthumous reproduction, parental involvement in cryopreservation procedures for adolescents, legal aspects of testicular tissue preservation for pre-pubertal patients, access to fertility preservation for cancer patients with dim prognoses, challenges in establishing legal parentage for offspring from cryopreserved tissues, legal aspects of posthumous assisted reproduction, and legal ambiguities in cases of gestational carriers and divorce.³²⁻³⁴

IMPLICATIONS FOR PATIENT WELL-BEING

Psychological outcomes of different onco-fertility decisions

Cancer diagnosis and the consequential decisions about fertility preservation (FP) have significant psychological implications for patients. Opting for FP or not and the information received can result in various psychological outcomes. FP and fertility counselling have been associated with positive psychosocial effects, including improved quality of life, greater satisfaction and reduced feelings of regret.⁸ The choice to pursue FP is an expression of adaptability in the face of illness, reflecting forward-thinking and a concern for future well-being. This choice involves safeguarding life goals and personal growth, influenced by personality traits like self-directedness, reward dependence and harm avoidance.²⁶

Patients often find it challenging to address fertility concerns when dealing with an uncertain future. The complexity of treatment decisions following a cancer diagnosis, coupled with immediate discussions about FP to avoid treatment delays, can be emotionally overwhelming. This challenge makes it difficult to assume the ability to plan for the long term. Adaptive personality traits can aid in envisioning survival and future parenthood. Additionally, acknowledging future uncertainty is a valuable skill for prospective mothers, fostering a realistic and prepared approach to parenthood.²⁶

Long-term quality of life and survivorship considerations

Offering patients, the choice of FP and providing information about fertility is not only a medical concern but also a psychological one. Research shows that impaired fertility can significantly impact a survivor's long-term quality of life and is associated with a higher risk of mental health issues. It is essential to recognize the psychological needs of cancer patients and provide support to prevent long-term distress. This support should extend beyond the initial diagnosis and FP decisions, encompassing long-term survivorship. Young cancer patients may find it challenging to consider their future family desires at the time of diagnosis, making ongoing support crucial as they approach family planning. Fertility disruption can lead to psychological distress and an increased risk of conditions like depression, particularly when early-onset menopause is involved. Therefore, integrating fertility counselling into survivorship care is vital to assess risk factors and provide necessary support.²

Comprehensive psychosocial support programmes

In recent decades, psychosocial group interventions have emerged to aid cancer patients in better managing the psychological effects of their diagnosis and treatment. These support groups encompass various approaches, some concentrating on behavioural aspects and symptoms like pain and fatigue, while others emphasize emotional expression.

In addition to individual therapy, group interventions address cancer-related issues, facilitating emotional support among patients with similar experiences. This shared support helps alleviate the fear of death and an uncertain future. A primary therapeutic goal is to enhance the patient's personal coping resources. Consequently, these groups benefit not only the patients but also their partners and other family members, alleviating distress associated with cancer.³⁵

FUTURE DIRECTIONS AND RECOMMENDATIONS

Enhancing onco-fertility education is crucial in India. Healthcare providers should create educational materials and awareness programs for cancer patients, focusing on fertility preservation options and early discussions. Public awareness initiatives are needed to reach a broader audience. Integrating onco-fertility discussions into comprehensive cancer care, guided by standardized protocols, is essential. Embracing a multidisciplinary approach, involving oncologists, reproductive specialists, endocrinologists, mental health experts, nutritionists, yoga practitioners, complementary medicine experts, and support groups, is essential to address the complexity of onco-fertility challenges. Establishing onco-fertility consortiums can provide holistic support to patients and caregivers.

Further research in onco-fertility should explore patient, HCP, and survivor perceptions, as well as factors like personality traits, coping mechanisms, values, attitudes toward illness, and multidisciplinary research examining mental health, nutrition, yoga, existential, and spiritual aspects. This research can refine resources, protocols, and support services to better align with patients' diverse needs.

A psychosocial model incorporating various theories, such as the health belief model, theory of planned behaviour, coping theory, social support theory, resilience theory, and narrative theory, offers a comprehensive approach to studying onco-fertility perceptions in the Indian context. This holistic approach provides a deeper understanding of the complexities involved, contributing to more nuanced and context-specific insights. Psychosocial research is vital for developing evidence-based strategies to address the unique challenges faced by cancer patients in India effectively.

CONCLUSION

In this narrative review, we have explored the perceptions of onco-fertility in the Indian context, with a particular focus on the psychosocial factors that shape these perceptions. The review emphasizes the importance of addressing the psychosocial aspects of onco-fertility, as they play a significant role in the decision-making process and overall well-being of cancer patients. Key findings from this review include the need to improve patient education and awareness, integrate onco-fertility discussions into comprehensive cancer care, and foster multi-disciplinary collaboration to provide holistic support. Recognizing the influence of cultural, religious, spiritual and societal factors on onco-fertility decisions is also essential in the Indian context. In conclusion, addressing psychosocial factors related to onco-fertility is crucial for enhancing the quality of life and well-being of cancer survivors in India. It is imperative to take action to bridge information gaps, provide emotional support, and promote informed decision-making for patients facing the dual challenges of cancer and fertility preservation. Further research and initiatives are needed to advance onco-fertility support in India and ensure that patients receive the comprehensive care they deserve.

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