Fertility preservation is an important aspect of care provided by fertility experts to patients undergoing cancer treatment. We have tried to bring in more awareness on this aspect.

I hope that you may have enjoyed first volume of this series where an overview was presented. We present the second volume of this series where we present uptake of fertility preservation in India and also review efforts put in this sub-specialized field by various countries worldwide.

Oncofertility-Fertility preservation: an important aspect of care given by reproductive medicine specialist.

It has been endeavor of all of us to counsel, educate the masses about the nuances of fertility preservation and the outcome of the procedures. Many of them are experimental and have not an efficient outcome. Indian Fertility Society and Astra Zenac initiated bulletin- “Oncofertility Communications” to educate you all to do something for these unfortunate fighters and survivors and ease their pain and anxiety.

Continuing this educative endeavour forward, we present here the second volume of this series in which we discuss the understanding and uptake of this speciality in India and also review on various work done globally.
Dr Puneet Rana Arora
Guest Editor

Oncofertility communications was started with view to increase awareness among medical fertility regarding oncofertility services provided to patients undergoing cancer treatment. First volume was released in January, 2019. It is my absolute privilege to present the second volume of “Oncofertility Communications”.

Any new subspecialised field comes with its challenges and logistics. It is important to understand these challenges so that uptake can be maximised to larger population without any difference in economic status. In this volume we compare the Indian data and the western data with regards to understanding and availability of oncofertility services.

I hope this edition brings in further understanding from last overview volume.

Happy Reading!. 

Dr Jayesh Amin
SIG Chair - ONCOFERTILITY

Fertility preservation is an innovative technique which requires multi disciplinary approach. Our colleagues in the field of oncology as well as general public need more awareness about the subject and therefore lot of scope for training is the requirement.
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I. INTRODUCTION

Fertility preservation has moved from providing services related to preserving gametes (sperms/ooocytes) and embryos to “Oncofertility Care”. “Oncofertility Care “is a broad term including not only fertility preservation discussion and management, but also discussion regarding management of sexual dysfunction, hormonal dysfunction, complex contraception and fertility related psychosocial support. These effects are related to cancer and its treatment.

As per national cancer registry of India by 2020, 11.4 lakh people will have some form of cancer out of which 30-75% of males and 40-80 % of females have problems with fertility at some point after completion of cancer treatment.

II. WHY IMPORTANT TO DISCUSS UPTAKE OF ONCOFERTILITY CARE

As the number of long-term cancer survivors are increasing, fertility has become an increasingly important quality of life issue. However, aggressive cancer treatment, especially with alkylating agents or ionizing radiation can cause premature ovarian failure. The loss of reproductive potential is one of the most distressing adverse consequences of successful cancer treatment and can affect the quality of life of cancer survivors and can lead to psychological distress in some. Therefore, wherever possible, oncofertility care should be an integral part of cancer care from diagnosis through to survivorship.

If the risks of infertility are not discussed properly before cancer treatment, cancer survivors may experience prolonged anger and grief when they are unable to conceive.

Currently, several options are available for fertility preservation in young cancer patients; however, the only established option for male patients is sperm cryopreservation. For women both embryo cryopreservation and oocyte cryopreservation are considered as well established methods, but not ovarian tissue cryopreservation at the moment. Nevertheless, ovarian tissue cryopreservation is a good alternative option for women who cannot delay cancer treatment or with hormone dependent tumor. It is the only option for pre-pubertal girls who want to preserve fertility before cancer treatment.

There are various guidelines till date enforcing Oncofertility care naming few such as-
- Multi-disciplinary Working Group convened by the British Fertility Society, 2003
- French Association for the Care of Oncological Support, 2011
- National Comprehensive Cancer Network, 2011; von Wolff et al., 2011; Cardoso et al., 2012; Kim et al., 2012
Several barriers have been found to thwart the implementation of comprehensive and equitable fertility preservation practice. These include:

1. A lack of referral pathways and model of care for oncofertility services and collaboration between cancer and fertility doctors to deliver services;
2. Inequitable access based on cost;
3. Health literacy;
4. Lack of trained staff who can deliver these services; and
5. No consensus about the best way to deliver information to patients

All the guidelines recommends that health care providers should discuss fertility with their patients as a part of their counseling before cancer therapy, and should be prepared to refer for fertility preservation.

Even though fertility has been a significant issue expressed by cancer survivors, uptake of fertility preservation offered at the time of diagnosis is 10-12%.

There are several clinician and patient barriers which exist in providing oncofertility care and these barriers need to be quantified more accurately.

While fertility preservation is recognized as an important issue, work still needs to be done to educate care providers along with patients about the issues and options for fertility preservation.

A retrospective cohort study of female cancer patients aged 18-42 years in 2012 showed that overall referral rates for fertility preservation consultation are low (20.6%), with significant discrepancies in referral based on patient ethnicity, age, parity, and cancer type.

A population based study published in 2015 showed that the proportion of patients who were discussed about fertility preservation options before cancer treatment was 71% in young males and 44% in young women with cancer. However, actual fertility preservation arrangement was made only in 31% of males and 6.8% of females. Indeed, these low referral rates (confirmed by other studies) and under-utilization of fertility preservation are problematic even by now.
The main barriers among all include lack of knowledge on fertility preservation, attitude and behaviors of health care providers, and time constraint before cancer treatment.

In developing countries like India, the financial barrier (such as high cost and no insurance coverage) is a very significant issue. In spite of many barriers, a new global trend for fertility preservation is encouraging.

Rates of referral for fertility preservation remain relatively low, averaging 20–30% (Cohen et al., 2016; Scanlon et al., 2012), with women reporting lower uptake rates of fertility preservation (14.9%) compared to men (31.5%) in a recent study (Wang, Chen, Ruan, & Cheung, 2016). These low rates are a matter of concern, as clinicians have a ‘duty of care to provide the option of fertility preservation’ to patients of reproductive age (Logan, Perz, Ussher, Peate, & Anazodo, 2018b), and uptake of fertility preservation can improve quality of life and wellbeing post-treatment (Letourneau et al., 2012; Sobota & Ozakinci, 2014).

In addition, a lack of private health insurance or public healthcare funding for fertility preservation is associated with lower rates of uptake, due to financial barriers to accessing services (Inhorn et al., 2018; Shnorhavorian et al., 2015).

A lack of information about the consequences of cancer treatment on fertility from health professionals has been identified as one of the major barrier to accessing fertility preservation (Logan, Perz, Ussher, Peate, & Anazodo, 2018a).

### IV. DATA ON PUBLICATIONS RELATED TO FERTILITY PRESERVATION/ONCOFERTILITY SERVICES

Figure 1,2,4 depicts the total number of literature found on single source search engine-Pubmed. There were more articles with Neoplasms and infertility. Oncofertility search revealed few articles and were commonly after 2007 when this specific nomenclature was used formally. Number of studies in India were less in both categories. But still published data on other hand of whatever grade means the awareness and availability of Oncofertility service is available and what is needed is to streamline the services so that mass population can utilise when needed.

Existing research examining fertility preservation after cancer has focused on Western countries, with most studies conducted in the United Kingdom, United States of America, Canada and Australia. Figure 3 shows the different types of studies published related to Oncofertility or Neoplasms with fertility. Clinical Trials and laboratory based work was found less in Indian scenario than in western world. This is in line with other specialities of medicine. Studies have examined the distribution and quality of information by health professionals, utilisation of fertility services, as well as patient
Many people with cancer report receiving no information, or inadequate information from healthcare professionals about fertility (Benedict, Thom, et al., 2016; Ussher & Perz, 2018). Furthermore, fertility information from healthcare professionals is not uniformly distributed across gender, age group and cancer type (Shnorhavorian et al., 2015). Men, those who are nulliparous, heterosexual, with reproductive cancers, and who are AYA at the time of diagnosis, are the groups most likely to receive information from healthcare professionals and take part in fertility preservation studies/surveys (Barlevy et al., 2016; Logan et al., 2018a; Wang et al., 2016).

While previous studies have focused on health professional information and referral for specialist fertility care, other factors may influence uptake of fertility preservation (Flink et al., 2017). For example, the desire to have a biological child and being in a stable relationship at the time of cancer can motivate people with cancer to take part in fertility preservation (Baysal et al., 2015; Treves et al., 2014). Conversely, limited clinic times, urgency to act on fertility during cancer treatment, the wish to preserve survival for an existing child, and for women, the physical burden of fertility preservation, can act as barriers to uptake (Baysal et al., 2015; Flink et al., 2017; Lee et al., 2011).

Referral pathways between cancer and fertility clinicians can vary between different regions/countries and also institutions, relying sometimes on particular relationships between centers, between doctors rather than a formal referral system.
Fertility preservation strategies were initially developed and applied in Western Europe and North America, but ISFP (International society of fertility preservation) committee recommends that fertility issue should be addressed to all patients in reproductive age before cancer treatment, hence these applications are no longer limited to certain geographic areas or socio-economic classes.

A review of literature until December 2014 highlighted the lack of published data internationally from FP databases or registries collecting “whole of care” oncofertility information from male and female pre and post - pubertal cancer patients:

- The International Society of Fertility Preservation (ISFP) launched the Ovarian Cortex freezing registry in 2014, which is designed to collect ovarian cortex cryopreservation data.
- The Northwestern Oncofertility Consortium has an observational fertility information research study (FIRST Registry) collecting annual questionnaire data from women aged 18–44 years on the impact of cancer treatment on the reproductive health of young survivors.
- The Human Oocyte Preservation Experience (HOPE) is a prospective multicenter, observational oocyte cryo- preservation registry; however, this registry has not collected data from cancer patients.
- The FertiPROTEKT Network is the European oncofertility consortium set up in 2006 to provide expertise in oncofertility and standardized support and FP treatment recommendations for female cancer patients. Seventy registered centers in Germany, Switzerland, and Austria collect
and report on FP data before cancer treatment.

- A number of countries produce national reports about the success of assisted reproductive technologies, however, to date, these reports have not included specific data on FP in cancer patients.

![Figure 3: Type of studies published globally and in India](image)

**Figure 3-** Type of studies published globally and in India

**(NEOPLASMS OR CANCER) AND INFERTILITY AND INDIA (200 OUT OF 12315)**

![Figure 4: Literature review with keywords as Neoplasms/Cancer from India](image)

**Figure 4-** Literature review with key words as Neoplasms/Cancer from India
International and National Review of uptake of Oncofertility

V. CONCLUSION

Oncofertility Care/Fertility preservation is one of the most important quality of life issues in young cancer survivors worldwide. It is imperative to promote the global awareness of fertility preservation, to improve the global collaboration for fertility preservation and to expand fertility preservation service beyond the boundaries of geographic areas, socioeconomic status, ethnicity, nationality, age, parity, and cancer type.

One of the ways of promoting awareness among healthcare providers is publication of work being done on fertility preservation in various geographic areas. This is one of the good ways to connect between healthcare providers of various nationals. Also publication data is more directly related to work done in a particular region, it may not necessarily reflect the workload in an area. Network between oncologist and reproductive medicine specialist is must for a successful fertility preservation program.

VI. RECOMMENDED READING

Nelen, W. L. D. M. Decision-making in female fertility preservation is balancing the expected burden of fertility preservation treatment and the wish to conceive. Human Reproduction, 30(7), 1625–1634.


14. Flink, D. M., Sheeder, J., & Kondapalli, L. A. A review of the oncology patient’s challenges for utilizing fertility preservation services. Journal of Adolescent and Young Adult Oncology, 6(1), 31–44.


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