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Titled

THE FACTORS LEADING TO THE DELAY IN CANCER MANAGEMENT AND ITS IMPLICATION FOR TREATMENT OUTCOMES FOR OVARIAN AND GENITOURINARY MALIGNANCIES ACROSS TAMILNADU- A MULTICENTRIC MIXED METHOD STUDY

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ABBREVIATIONS

ADL	- Activities of Daily Living
ANOVA	- Analysis of variance
CIR	- Crude Incidence Rate
CHE	- Catastrophic Health Expenditure
CMCHIS	- Chief Minister's Comprehensive Health Insurance Scheme
DMER	- Directorate of Medical Education and Research
DPH	- Directorate of Public Health
CT	- Computed Tomography
EORTC QLQ -C30	- European Organization for Research and Treatment of Cancer - Quality of life Questionnaire Core 30
GCT	- Germ cell tumours
GLOBOCAN	- Global Cancer Observatory
GUC	- Genito Urinary Cancer
HRQoL	- Health related quality of life
IDI	- In Depth Interview
ICMR-NCDIR	- Indian Council for Medical Research - National Centre for Disease Informatics and Research
KII	- Key Informant Interview
NCD	- Non Commnicable Diseases
OC	- Ovarian Cancer
OPD	- Out Patient Department
PROs	- Patient Reported Outcomes
QoL	- Quality of Life
RCOPE	- Religious Coping Methods
SDH	- Social Determinants of Health
SEM	- Social Ecological Model
TNHSRP	- The Tamil Nadu Health System Reform Program
USG	- Ultra Sonogram
WHO	- World Health Organization

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Introduction

1. Introduction:

Cancer is a leading cause of death worldwide accounting for nearly one in six deaths globally according to WHO (1) and an important barrier to increasing life expectancy in every country in the world. The rate of new cases of cancer is 442.4 per 100,000 per year (based on 2013–2017 cases). According to World Cancer Research Fund International (2), 2020, globally, more than 18 million cases of cancer were diagnosed, of which 9.3 million cases are men and 8.8 million cases are women.

India has a cancer incidence of crude rate of 100.4 per 100,000 were reported, with one in nine people likely to develop the disease in 2022(3). In both sexes the percentage of total number of new urogenital and ovarian cancers cases diagnosed in 2020- prostate (7.8%) [4th rank], bladder (3.2%) [10th rank], kidney (2.4%) [14th rank], ovary (1.7%) [18th rank], testis (0.4%) [27th rank] and penis (0.2%) [30th rank]. In males the percentage of total number of new urogenital and ovarian cancers cases diagnosed in 2020- prostate (15%) [2nd rank], bladder (4.7%) [6th rank], kidney (2.9%) [9th rank], testis (0.8%) [20th rank] and penis (0.4%) [24th rank]. In females the percentage of total number of new urogenital and ovarian cancers cases diagnosed in 2020- ovary (3.6%) [8th rank], kidney (1.8%) [14th rank] and bladder (1.5%) [17th rank]. National Cancer Registry Programme (4), 2012-2016, India, reported that the projected cancer cases in India in 2025 is 5.1% for corpus uteri and ovary, 3% for prostate. Prevalence of prostate and ovarian cancer in Chennai, Tamil Nadu is 6.2% and 6.1%.

National Cancer Registry Programme ICMR-NCDIR(2021), reported that Out of 610084 cancers, 52.4% cancers were reported in males and 47.6% in females (5). The highest proportion of prostate cancer occurred in those over 65 years of age. Over 90% of the cancers in different organ sites got diagnosed by microscopic examination. Over one-third of patients with cancers of the kidney (including children) and bladder had localized disease at the time of presentation. In the younger age group (below 25 years), ovarian cancers were the commonest cancer types. Among all the gynaecological cancers, the proportion of patients presenting with distant spread was highest (nearly one-third) for ovarian cancer. Nearly 42.9% of the prostatic cancer patients were diagnosed with distant metastasis. Over a quarter of the male kidney cancer patients presented with distant metastasis. Proportion of ovarian cancer was 6.3%, followed by prostate (3%), kidney (2.1%) and bladder (1.9%). Close to one-third patients with bladder cancer regardless of clinical extent and prostatic cancer

patients with localised disease diagnosed at the reporting institution-initiated cancer directed treatment on the same day.

Based on Tamil Nadu Cancer Registry Project(6) 2021, 69517 new cases were diagnosed in year 2017 in the whole of Tamil Nadu. The estimated new cancer burden is 81814 in Tamil Nadu in year 2021. There were more women with cancer than men in Tamil Nadu for all cancers put together (1.2:1). The Crude Incidence Rate (CIR) of all cancers together was 87.9 per 1,00,000 population for both sexes together in Tamil Nadu state- Male: 79.2; Female: 96.6. Highest CIR of all cancers and both sexes together was observed in Chennai (143) and least was reported in Nilgiris (53.5) districts. Common cancers among men in Tamil Nadu: Stomach (CIR:7.0), Lung (6.6), Mouth (6.6), Large bowel (5.6) and Tongue (4.6). Common cancers among women in Tamil Nadu: Breast (CIR: 25.5), Cervix (CIR: 18.7), Ovary (CIR: 5.2). Incidence of various cancers among males in Tamil Nadu- prostate (4.1%), bladder (2.6), penis (1.8%), kidney (1.4%), testis (0.6%), renal pelvis (0%), ureter (0%) and urethra (0%). Incidence of various cancers among females in Tamil Nadu- ovary (5.4%), bladder (0.7%), kidney (0.6%), renal pelvis (0%), ureter (0%) and urethra (0%).

1.1 EPIDEMIOLOGY OF GENITOURINARY CANCERS (GUC):

The National Cancer Institute (part of National Institute of Health) classifies bladder(7), kidney, ureter, urethra, penile, prostate, testicular tumors of males under the Genitourinary cancers(8) **Genitourinary cancer** is one of the most common (20.79%) tumors encountered among both the genders. The morbidity and mortality caused by them as a significant impact on the death adjusted life years in middle aged population compared to other malignancies(9). Among males, genitourinary system constituted 17.48% of all the malignancies, where prostate cancer and urinary bladder had an incidence of 40.71% and 30.40% respectively.

Urinary bladder carcinoma has a relatively rare malignancy (17^{th} among most common cancers) among the Indian population contrary to the western world where bladder carcinoma is 4^{th} most common malignancy in men and 8^{th} most common in women. The 5-year prevalence is 3.57 per 100000 population and causes 11000 deaths each year(10). The incidence of bladder cancer is higher in males compared to females (Relative incidence being 4:1 in urban population). Among the identified risk factors for bladder carcinoma like industrial amines and carbon dust, tobacco consumption is the most important risk factor with 3–4-fold higher incidence

compared non-smokers and cause 31% of deaths among males and 16% in females. The most important fact is that the 2 major risk factors are in fact modifiable risk factors and have no genetic association(11). More than 90% of patients presented with painless visible haematuria. Other rarer symptoms may include frequency and urgency in urination and pelvic pain. About 26% presented with muscle invasion at the time of diagnosis(9). Transitional cell carcinoma was the most common histological variety (97.71%).

Renal carcinoma is carcinoma of the elderly presenting at a mean age of 56 where males were 4 times likely to present with renal tumours in our population than females in contrast to the western population where the ratio was 2:1. Clear cell carcinoma was the most predominant histological type of renal carcinoma in India whereas renal cell carcinoma was mor predominant in the western population(9). Most of the patients (67%) presented with symptoms of which haematuria and abdominal mass were the common ones, and 33% of the patients were asymptomatic and were diagnosed incidentally during USG or CT. A large proportion of patients (56.3%) presented with paraneoplastic symptoms(12).

Ureteric carcinoma are rare tumours with an annual incidence of 0.95-115/100.000 person-year(13). They are mostly urothelial tumours of the type papillary transitional cell carcinoma commonly involving the distal ureter. Concomitance with bladder tumours is also observed which occurred either synchronous or metachronous. Analgesic overuse is a risk factor as 22% of these tumours associated with analgesic abusers(14). In contrast to the findings of western world, the chief presenting complaints in the Indian patients were; pain, abdominal lump and haematuria with most neoplasms being single and histologically of squamous cell composition. Muscle invasion at presentation was associated with poor prognosis(15).

Penile carcinoma is a rare malignancy, especially in developed countries, where the annual incidence is less than 1 case per 1,00,000 men. Whereas India is one of the countries with the highest incidence of penile cancer in the world with rates up to 3.32 per 1,00,000 men in some regions(16). The incidence is multifactorial and associated with various factors such as circumcision practices, number of sexual partners, history of human papillomavirus infection, and exposure to tobacco products(9). Squamous cell carcinoma accounts for over 95% of penile malignancies. The most common presenting lesions for penile cancer are fungating growth, nodularity, and ulceration. The most common site for growth is the glans, followed by

the prepuce. Majority of patients presented with early-stage tumors, with T2 being the most common(17) This cancer is mostly seen in the elderly population between 50 and 70 years and maximum cases presenting in advanced stages of the disease. Almost one third of the patients presented with phimosis.

Prostate carcinoma is a global burden on the health-care system as it is the second most common cancer and sixth leading cause of cancer-related mortality according to GLOBOCAN 2008. Prostate cancer is primarily a disease of the elderly with more than three quarter of the cases occurring in men above 65 years of age. Prostate cancer is the second most frequently diagnosed cancer in men worldwide and the fifth most common cancer overall. It is also the sixth leading cause of cancer deaths in men.(18)

Testicular cancer is the most common solid tumour of young men, about 1% of all cancers in men. The cases has been increasing worldwide. Germ cell tumours (GCT)accounts over 95% of these cancers. 2% of individuals with testis cancer affected were first degree relatives, and concordant twin studies had also demonstrated a higher occurrence of testis cancer in monozygotic twins when compared to dizygotic twins.(19)

1.2 EPIDEMIOLOGY OF OVARIAN CANCERS (OC):

Ovarian cancer is ranked as the third most common gynaecologic cancer in various Indian cancer registries while globally ovarian cancer is the seventh most common type of malignant neoplasm in women and the eighth cause of mortality in them(20). In India, Ovarian Cancer is seen in the younger age group, with a median age, 55 years being reported by most of the studies. The majority of patients are diagnosed in advanced stage (70%-80%), where the long-term (10 year) survival rate is poor, estimated at 15%-30%. (2) Ovarian cancer ranks fifth in cancer deaths among women, accounting for more deaths than any other cancer of the female reproductive system. A woman's risk of getting ovarian cancer during her lifetime is about 1 in 78. Her lifetime chance of dying from ovarian cancer is about 1 in 108.(22)

Epithelial ovarian cancer represents approximately 90% of these malignant tumours, whereas sex-cord stromal, germ cell, and mixed-cell ovarian cancers account for the remaining 10%.All histological subtypes of Epithelial ovarian cancer have been defined, with the most common being the serous (68%–71%) subtype, followed

by clear cell (12%–13%), endometrioid (9%–11%), mucinous (3%), malignant Brenner (1%) and mixed histology (6%) subtypes(3)

Various factors affect the occurrence of ovarian cancer, from which genetic factor are among the most important ones. Pregnancy, lactation, and oral contraceptive pills play a role in reducing the risk of this disease. The risk of ovarian cancer is reduced in women with live birth or induced abortion ,and this risk decreases with an increase in the number of live birth cases (4)

1.3 FACTORS LEADING TO DELAY IN CANCER MANAGEMENT:

Nearly 60% of epithelial ovarian cancers are diagnosed at a late stage, at which time five-year survival is only 29%. In contrast, for the 15% of ovarian cancers diagnosed at a localized stage, five-year survival is 92% (25).Even a 4-week delay of cancer treatment is associated with substantially increased mortality across surgical, systemic therapy and radiotherapy indications for cancers and stated that the association between delay and increased mortality was significant& further concluded that policies focused on minimising system-level delays to treatment commencement could potentially achieve substantial improvements in population-level survival outcomes (26).

Various studies from all over the world had found out factors leading to delay in cancer management which were further categorised into presentation delay, referral time, health care delay.

The Andersen Model highlights the stages of appraisal delay , illness delay, behavioural delay, scheduling delay, treatment delay and is used in studies which assess cancer diagnosis.(27) In the expanded model, psychosocial determinants, an expanded component of the predisposing factors, follow rather than precede enabling and need factors(28). The WHO model for delay represents Access delay, diagnosis delay and treatment delay. The barriers being financial, logistics and psychological barriers for the above three delays.

Factors for delay: Decrease in awareness about risk factors, prognosis & symptoms, financial burden, unaware of right doctor to approach (29), misinterpretation of signs and symptoms, cultural influences, fear of losing body parts to surgery, health providers laxity, infrequent screening for cancer, no drugs available at government dispensary, spiritual reasons (30), denial of having a disease, prioritising various life events over seeing a physician (31), view that medical care is

nuisance, desire to surrender to the natural course of things(32), higher family income and smoking, self -treatment, increased referral time, employment status, increased travel time and distance to hospital, increase in number of consultations with surgeon before diagnosis (33), embarrassment of examination by a male doctor, fear of treatment and its side effects, alternate system of medicine, lack of family support. Survival rate of cancer could specify what proportion of patients with the same kind and stage of the disease are still living after a specific period of time, usually five years after their diagnosis. Although they are unable to predict the exact lifespan, they contribute in making informed decisions about effectiveness of various treatment modalities.(34) The prognosis is usually better with early discovery of cancer. The 5-year relative survival rate is 94% when the patient is diagnosed and treated in stage I. Nevertheless only 20% of cases of ovarian cancer are found to be in stage 1.(35)

Treatment delay and presentation delay contributes to the overall delay. It is also stated that women with delay of more than 3 months had shorter survival than compared to women who started treatment within first 3 months of symptom. Further presentation with late stages is associated with poor performance status (36) . An obstacle to cancer sufferers seeking care and support is the stigma associated with the disease. Stigma surrounding cancer may cause delays in both diagnosis and treatment (37). It is imperative to investigate the degree to which persons with cancer and those who provide care perceive, experience, and internalize stigma in a nation such as India (38)

One crucial component that gives cancer patients a framework to deal with their diagnosis, treatment, survival, recurrence, and death is spirituality. It can also act as a buffer against the worsening effects of stress in life and sickness(39). Spiritual well-being has been proven to be favourably correlated with both spirituality and health outcomes in cancer patients, making spirituality one of the most important indicators of quality of life(40) A person's experiences and symptoms of sickness may be influenced by spiritual distress and suffering, which may also worsen an individual's health and psychological consequences(41). Delay in the initiation of definitive treatment might lead to decrease in loco-regional control and overall survival. Elevated levels of fear of progression can affect patients’ well-being, quality of life and social functioning by psychological stress (42).

1.4. OUTCOMES OF CANCER MANAGEMENT AND ASSOCIATED FACTORS IN CANCER CARE CONTINUUM:

1.4.1. QUALITY OF LIFE:

The QoL is one of the most concerning health issues for oncology patients. It is a specific and multidimensional type of patient-reported outcomes (PROs) which is perceived by patients as something that encompasses the patients' social, financial, psychosocial, and physical activities (43). The association between HRQoL (Health related quality of life) and overall survival (OS), with post diagnosis HRQoL being more strongly associated with OS than pre diagnosis HRQoL or HRQoL changes. Interventions to improve HRQoL in patients with kidney disease include improving physical functioning, reducing fatigue and bolstering social support. (44)

1.4.2 STIGMA:

Stigma is now generally recognized as the fundamental determinant of inequality in health system and services. Disease specific Stigma is defined as a social process or related personal experience characterized by exclusion, blame or rejection as a result of the experience or reasonable anticipation of an adverse social judgement about a person or group identified with a particular health problem where the judgement is medically unwarranted with respect to the respective health problem itself. Stigma has been associated to reduced disease screening uptake, follow up and treatment compliance, mental health of the patient all of which result in a poor patient outcome (45,46)

1.4.3 SPIRITUAL COPING:

Spiritual care is an aspect of holistic medicine recognized by modern healthcare systems.(47) Empirical studies have demonstrated that many people turn to religion as a resource in their efforts to understand and deal with the most difficult times of their lives. Positive religious coping methods reflect a secure relationship with a transcendent force, a sense of spiritual connectedness with others, and a benevolent world view. Negative religious coping methods reflect underlying spiritual tensions and struggles within oneself, with others, and with the divine.(48)

Spirituality is associated with human strength to improve coping with pain, stress, and cancer. The majority of cancer patients receiving palliative care consider themselves spiritual and religious.(49) Cancer patients believed that they were able to reach calmness through their religious aspect of spiritual coping that included: Maintaining/ improving self-esteem, Positive appraisal/ Being optimistic and Self-

sustaining. (49) Spiritual distress is the opposite of spiritual wellbeing. Spiritually distressed patients appear sad, desperate, scared, anxious or angry. They may talk about loneliness, emptiness, uselessness, guilt, injustice, meaninglessness, helplessness.(47)

1.4.4 SURVIVAL

Cancer survival rate indicates the proportion of patients with the same stage of the disease still living after a specific period of time, usually five years after diagnosis which aids to make informed decisions about treatment effectiveness, although it cannot predict exact lifespan.

The prognosis is usually better with early discovery. The 5-year relative survival rate is 94% when the patient is diagnosed and treated in stage 1and just 20% of cases of ovarian cancer are found to be in stage 1. Ovarian cancer incidence and mortality rates have been declining over the past decade according to SEER data analysis. However, five-year survival for advanced stage disease remains less than 30% Over 80% of women diagnosed with ovarian cancer will recur, with an eventual progression to platinum-resistant disease. The majority of ovarian cancer patients will receive multiple lines of systemic therapy through their disease course.(50)

1.4.5 FINANCIAL OUTCOME

Currently, India has 13.9 lakh cancer cases, which are estimated to increase by 12% by the year 2025. Treatment of cancer inflicts a heavy cost of care and may even impoverish households. Geriatric population was found to be the most vulnerable to financial burden as it had the highest Out of pocket expenditure (OOPE) for both inpatient and outpatient care (₹7219, ₹10156).(51)

Households with members who underwent treatment for cancers and other chronic conditions spent a relatively high amount of their income on health care. Overall, 41.4% of the households spent > 10% of the total household consumption expenditure and 24.6% of households spent > 20% of health care expenditure for hospitalisation. Health care burden and impoverishment was higher in households who sought treatment in private health facilities than in public health facilities.(52)

Economic burden of cancer can be potentially significant in India, given that low public sector allocations to health (ranging from between 0.9% to 1.2% of GDP over the last few decades) and limited insurance options have forced households to rely on out of pocket spending to finance their healthcare.(53)

Rationale

2. RATIONALE FOR THE PROPOSAL:

Delay in the treatment of cancer carries foundational significance since it is proved to have adverse consequences on outcome in terms of increased mortality rates and poor prognosis affecting the quality of life of patients as revealed in systematic reviews in literature. Health seeking behaviour delays are profound among women for whom the commonest factors for delay were patient (presentation delay) followed by the health provider and healthcare sector delays. For surgery, there is a 6-8% increase in the risk of death for every four- week delay. This impact is even more marked for some radiotherapy and systemic indications. Such figures translate into significant population level excess mortality. The corollary is that the survival gained by minimising the time to initiation of treatment could potentially contribute to a greater magnitude and cost-effective benefit on patient outcomes than that seen with some novel therapeutic agents. Nevertheless, there is a dearth of research and lack of high-quality data on the impact of deferred and delayed cancer treatment on the patients and families in Tamil Nadu.

Hence the current study is contemplated to provide meticulous data on the various levels and patterns of delay and quantification of its impact on the patient and their families. The inputs of the study could contribute towards planning and better organization of zero delay cancer services in the state of Tamil Nadu.

Aims and Objectives

3.AIM & OBJECTIVES:

1. To study the sociodemographic characteristics and clinicopathological profile of the study participants with ovarian and genitourinary cancers.
2. To explore the factors leading to delay in cancer management among the study participants.
3. To assess the treatment outcomes and quality of life (QoL) among them.
4. To correlate the delay in cancer management and its outcome.

Table 1: Objectives and Study design

S.No	OBJECTIVE	Study Designs
1	Sociodemographic characteristics and clinicopathological profile	Quan: Analytical cross sectional
2	Factors leading to delay in cancer management	Quan: Analytical cross sectional Qual: IDI
3a	Treatment outcomes(in terms of health and Social Determinants of Health(SDH) such as economic issues, Social issues like stigma, Caregiver issues and Spirituality	Quan: Analytical cross sectional Qual: IDI
3b	Quality of life (QoL)	Quan: Analytical cross sectional
4	Correlation/ Association between delay in cancer management and its outcome	Merging of quan and qual analysis

Materials and Methods

4. MATERIALS AND METHODS

4.1. STUDY DESIGN:

The study was conducted at the community level as a Multicentric Convergent Parallel (Quan-Qual) Mixed methods study, the quantitative part with analytical cross sectional study design and the qualitative part through thematic analysis of the In-depth interviews and Key informant interviews.

4.2. STUDY SETTING:

The study was conducted in districts across Tamil Nadu.

4.3. STUDY DURATION:

The study was carried out for a period of one year, between December 2022 and December 2023.

4.4. STUDY POPULATION:

Quantitative component:

The target population included patients registered with genitourinary and ovarian malignancies between 2017 and 2021 at the districts across Tamil Nadu.
The study population was defined as follows: -

INCLUSION CRITERIA:

1. All women above 20 years registered with any type of urinary tract malignancies or ovarian malignancies between 2017 and 2021 at the districts across Tamil Nadu.
2. All men above 20 years registered with any type of genitourinary malignancies between 2017 and 2021 at the districts across Tamil Nadu.

EXCLUSION CRITERIA:

1. Participants who had migrated to other states and countries
2. Participants whose residence could not be traced due to various reasons viz, invalid phone number, incomplete address during line listing etc
3. Participants who were not willing to give consent or cooperate for interview.

Qualitative component:

To get first hand in-depth information on the delays in cancer management, the following categories were included for qualitative study:

1. Participants with malignancies of the genitourinary tract or ovary.
2. Primary care givers of participants who were deceased at the time of interview.
3. Health care providers (administrators, oncologists, social workers, post graduates working among cancer patients, ward boys) in the study districts.

Participants and the primary care givers of the deceased patients who were not

available and not willing to give consent or cooperate for interview were excluded from the study.

4.5. SAMPLE SIZE CALCULATION:

Table 2: Percentage of delay in health seeking for various cancers:

S.No	Type of cancer	Percentage of delay to seek treatment	References
1.	Bladder cancer	24%	Hollenbeck BK et al, 2010(54)
2.	Urothelial cancer	22%	Sundi D et al, 2012 (55)
3.	Prostate cancer	15%	Sun M et al,2012 (56)
4.	Penile cancer	45.7%	Gao W et al,2016(57)
5.	Testicular cancer	62%	Dieckmann KP et al, 1987(58)
		27%	Fossa SD et al, 1981(59)
6.	Renal cancer	21%	Mano R et al, 2016 (60)
7.	Ovarian cancer	45%	Allgar VL et al, 2005 (61)

From the above review of literature, the least delay proportion of 15% (prostate cancer) was considered for sample size calculation.

Sample size (n) = Z^2pq/d^2

p=15, q=85, d= 20% of p (relative precision) = 3

N = 3.84 x 15 x 85 / 3^2

N = 4896/9

N=544.

After adding non-response rate of 10%, N=544+54=598.

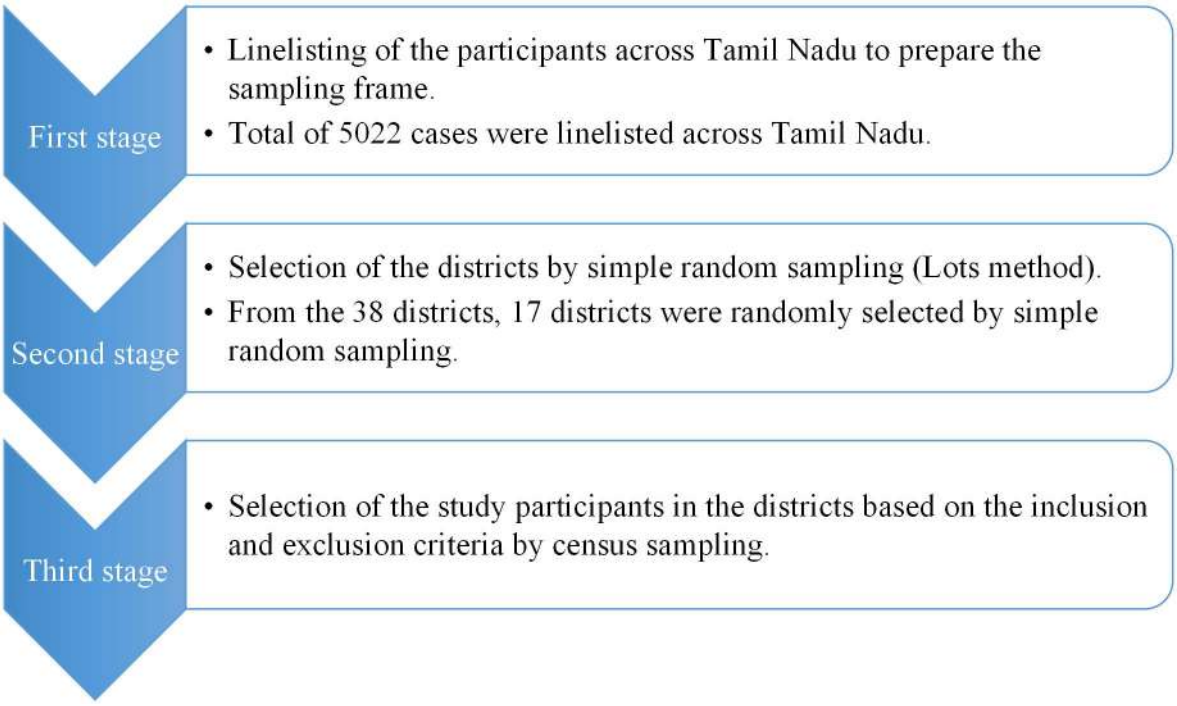
Collected samples = 606 participants.

4.6. SAMPLING METHOD:

Quantitative component:

Sampling frame

All men above 20 years registered with any type of genitourinary malignancy and all women above 20 years registered with any type of urinary tract malignancy and ovarian malignancy between 2017 and 2021 in the districts across Tamil Nadu were enrolled in the sampling frame. The required sample of 606 participants were selected from the sampling frame by Multi Stage Sampling.



Qualitative component:

Based on the geographical distribution, participants with each type of cancer at various stages at diagnosis and the primary care givers of the deceased participants at the time of interview were selected by non-probability sampling method – Purposive sampling method. **Maximum variation sampling** was employed to explore widest range of perspectives and factors contributing to patient, diagnostic and treatment delays. The participants were interviewed by In Depth Interviews (IDI) till redundancy of information was achieved. Totally 33 IDI s were conducted.

Key informant interviews were conducted among the primary health care providers at the study districts to get a detailed understanding on their perspectives towards delays in health seeking behaviour of cancer patients and cancer management. Individuals who had enriched experience in working among cancer patients were selected purposively by purposive sampling method based on their designation to ensure that they would provide rich study data. Invitations for interviews ceased when no further themes were identified (i.e., data saturation). Totally 5 KII were conducted.

4.7. STUDY TOOL:

Data on socio demographic and clinical details, medical history, reproductive history, personal habits, risk factors, details of treatment, details on factors leading to various delays in cancer management and outcome were obtained from a semi-structured questionnaire prepared based on previous literatures. Health Related Quality of Life was assessed based on the licensed version of standard European

Organization for Research and Treatment of Cancer - Quality of life Questionnaire Core 30 [EORTC QLQ - C30 (version 3.0)] English version(62). This questionnaire contains five functional scales (physical, role, cognitive, emotional, and social functioning), a global QoL scale, three symptom scales (fatigue, nausea and vomiting, and pain), and six single items (appetite loss, diarrhoea, dyspnoea, constipation, insomnia, financial impact). The questionnaire has a 1-week time frame and uses a four-point response format ("not at all," "a little," "quite a bit," and "very much"), with the exception of the global QoL scale, which has a seven-point response format. Spiritual coping level was assessed using brief RCOPE score(63). It is a 14-item measure of religious coping with major life stressors. It had questions on two overarching forms of religious coping, positive and negative. Details on the tumour related characteristics, its management and outcome were obtained from the patient case sheet and the hospital-based case reports. The questionnaire was translated into Tamil and again back translated to English to ensure appropriateness. The questionnaire was pretested among 20 patients at the hospital OPD and necessary modifications were made. (Annexure 1).

Detailed information regarding delays in cancer management was obtained through a semi structured interview guide. The questions were developed, guided by the five Social-Ecological Model (SEM) levels (individual, interpersonal, community, organizational, societal). The interview guide contained on outlined script and a list of open-ended questions, with probes beginning with easy to answer questions followed by questions on informant's opinions and beliefs regarding cancer, its management and its outcome, facilitators and barriers towards the health seeking behaviour for the disease, ending with questions on general recommendations. The interview guide was amended in an iterative process as new probes emerged during interviews.(Annexure 2)

Another semi-structured guide for the key informant interviews was prepared to enable the exploration of a consistent set of questions while at the same time providing the flexibility to probe on themes specific to the key informant. Key informants were asked questions about their perspectives on the cancer patient's health seeking behaviour and decision-making process; their attitudes towards the quality of services provided; the barriers and facilitators influencing their health seeking behaviour; their perceptions of the existing cancer management system and

their recommendations to improve the cancer management services. (Annexure 3) The semi structured interview guide was pilot-tested among cancer patients and health care providers at the hospital OPD for clarity, appropriateness and completeness.

4.8. DATA COLLECTION PLAN:

The line listing of patients with genitourinary and ovarian malignancies was obtained from the Oncology and Gynaecology departments of Government Medical College Hospitals across Tamil Nadu after obtaining approval from The Tamil Nadu Health System Reform Program (TNHSRP), Directorate of Medical Education and Research (DMER), Directorate of Public Health (DPH) and Institutional ethics Committee of Stanley Medical College and Directorate of Public Health. (Annexure 4,5,6,7) This line listing provided a geographical distribution of cases in various districts of Tamil Nadu. The line list collected from various institutions were compiled, duplicates were removed and data cleaning was done. The total cases line listed was 5022 across Tamil Nadu over the period of 2017 to 2021. (Annexure 8)

Multi Stage Sampling was employed to select the districts and the participants from those districts (Annexure 9). During the first stage of sampling, from the 38 districts across Tamil Nadu, 17 districts were randomly selected by using simple random sampling technique. The districts selected were Chennai, Kanchipuram, Tiruvannamalai, Vellore, Tiruvallur, Coimbatore, Tirupur, Namakkal, Salem, Dindigul, Madurai, Thoothukudi, Tirunelveli, Tanjore, Karur, Perambalur and Ariyalur. During the second stage, all the eligible participants who satisfied the inclusion criteria and were willing to participate in the study were recruited from the selected districts to achieve the required sample size of 606. The participants were identified from the master case sheets.

Prior to the collection of data, the data enumerators had orientation sessions in the Department of community medicine, Govt. Stanley Medical College about the study. Prior to the main study, a pilot study was done among 20 randomly selected cancer patients in the Oncology OPD on the hospital to identify the outcome and delays in the cancer management and to pretest the questionnaire.

An appointment was fixed prior to the visit with the consenting study participants or their caregivers (for deceased patients) and face-to-face interview was held in their place of confidentiality, mostly households, using the questionnaire ensuring strict confidentiality. Those with incorrect and incomplete contact numbers, those whose households could not be traced and those who were not willing were

excluded from the study. After ensuring privacy, each participant was given a brief introduction about the study and informed consent was obtained.

Relevant information was obtained from the respondent using the semi-structured questionnaire in the local language at their homes. Questionnaire was read out to the study participants in the same order as listed in the questionnaire and sufficient time was given to the subjects to respond. If the study subject did not understand the question, it was repeated in the same manner without probing for the answer. The details regarding the symptoms, management and outcome were crosschecked with the available hospital records.

In depth interviews were conducted concurrently among purposively selected participants and the caregivers. Interviews were conducted by the data enumerators who had detailed training sessions and hands on sessions on qualitative research methods. Interviews were conducted as face-to-face interviews in their households using the interview guide after fixing a prior appointment with the consenting study participants and the caregivers. Interviews were conducted until data saturation was reached, defined as no new concepts emerging over three consecutive interviews, and achieved after 24 interviews among the participants and 9 interviews among the caregivers. Probing questions were asked during the interview to help clarify informant's comments and get detailed information. Interviews were audio-recorded and professionally transcribed verbatim and field notes were taken during the interviews.Summary of the interview was read back to the participants to ensure participant validation.

Individual level key informant interviews (KII) were done among the purposively selected key informants from the study districts in the local language. The interviews were conducted at a convenient time in their offices after obtaining written informed consent. The purpose of the study, the procedure to be followed and its implications were explained to the participants. Although the core questions remained consistent throughout the data collection activities, probes were modified for in depth understanding of certain aspects and to follow-up on specific areas of technical expertise of the respondents. Proceedings were recorded on audio recorder enabled mobile phone. After the interview, summary of the interview was read back to the participants to ensure participant validation. Transcribed verbatim was proofread by a researcher who had native fluency with the local language and trained in qualitative research methods.

A subsample of 140 study participants were randomly selected to assess the patterns of religious coping using RCOPE questionnaire which was attached in Annexure(142). Mean and SD were computed. Similarly another subsample of 138 study participants were randomly selected to assess stigma and its types using questionnaire developed by Linda Squiers et al(141). The results were expressed in proportions and chi square was computed.

4.9.DATA ANALYSIS:

4.9.1. Quantitative data analysis

Data was entered in Microsoft Excel and quantitative analysis was done using SPSS v 27 and qualitative analysis with MS Excel and MS word. The sociodemographic characteristics, the clinicopathological profile and the outcome of the study participants were summarized using descriptive statistics. Continuous variables were expressed as mean and standard deviation and categorical variables were expressed as percentages. We used histogram, skewness value(-1 to +1 considered normal distribution) and Kolmogorov Smirnov test to evaluate the normality of considered quantitative data. Delays were summarized as median number of days(interquartile range)owing to skewness of the data. Outcome data were described using number and percentage with quality of life expressed as mean and standard deviation. Comparison between different groups regarding categorical variables was tested using Chi-square test. For normally distributed data, comparison between two independent parameters was done using an independent t-test, while more than two populations were analysed using an F-test (ANOVA). The significance test results are quoted as two-tailed probabilities. The significance of the obtained results was judged at the 5% level. Predictors for the delays and outcomes were analysed using multivariable logistic regression and the significance of the obtained results was judged at the 5% confidence level. Assuming the study population as a retrospective cohort, survival rates were computed using Kaplan Meier and life table statistics.

4.9.2. Qualitative data analysis:

Qualitative data analysis was done by thematic analysis which was done by using a two-phase deductive and inductive coding approach to identify and quantify themes from the text data. The procedure involved was document preparation, coding, grouping, categorization and theme abstraction. Deductive coding was completed by four independent reviewers using a priori codes from a code book which was

compiled by analyzing the literature reviews using the WHO 3 delay model using a conceptual framework depicting trajectory of cancer management continuum from symptom onset to end of life.

4.9.2.1. Process of deductive coding:

Deductive coding was done as an iterative process with a group of four coders who held meetings on day-to-day basis to improve consistency and relevance. Deductive coding was completed for all the 38 transcripts. Texts were labeled into codes; codes were further grouped into categories and sub categories and finally themes emerged.

4.9.2.2. Process of inductive coding:

Inductive coding was completed by two among those four independent reviewers. Both of them independently reviewed all the transcripts to derive themes based on the conceptual framework and incorporated within the 3-delay model. Following the preliminary identification of themes, the reviewers met to refine the codebook.

Trustworthiness of the data was assured in the data analysis process by having two independent analysts code the data and discuss discrepancies until a consensus was reached. All deductive and inductive coding was completed in Atlasti (version v5.17.3-2023-10-24). Analytical memos were written throughout the qualitative research process and the qualitative researcher's array of thoughts and reflections were noted down. The contradictory findings which emerged from IDI were also recorded.

4.9.2.3. About the qualitative researchers:

Both the primary qualitative researchers who participated in both deductive and inductive coding had more than 10 years of experience in qualitative research and trained in the same with previous experiences of conducting qualitative research. The other two qualitative researchers who participated only in initial deductive coding, were certified in a qualitative research workshop and acquired competency in coding methodology before undertaking the qualitative research.

The coding of transcripts was done as and when the IDIs were completed by the team of four independent qualitative researchers. (The interviewers who took qualitative interviews were not involved in the coding process. However, transcripts were returned to them for checking accuracy) and the codes were pooled together and refined by consensus.

While coding the last six transcripts, no further new codes emerged indicating data saturation or redundancy at which point the qualitative interviews were ceased.

4.10. OPERATIONAL DEFINITIONS FOR PARAMETERS USED IN THE STUDY TOOL:

1. Urban: Urban Unit (or Town):All places with a municipality, corporation, cantonment board or notified town area committee, etc. (known as Statutory Town)

- All other places which satisfied the following criteria (known as Census Town):
    1. A minimum population of 5,000;
    2. At least 75 per cent of the male main workers engaged in non-agricultural pursuits; and
    3. A density of population of at least 400 per sq. km (64)

2. **Rural:** All areas which are not categorized as urban area are considered as Rural Area(64)

3. Semi urban: There is also a third category, known as Urban Outgrowths, defined by the Census of India as, "a viable unit such as a village or part of a village contiguous to a statutory town and possess the urban features in terms of infrastructure and amenities such as pucca roads, electricity, tap water, drainage system, education institutions, post offices, medical facilities, banks, etc." (67)

4. Tribal: A community living in hilly forest or well demarcated areas having people with its own culture, religion, language and ethnic identity and having its own tribal chiefs (65)

5. Illiterate: A person who can neither read nor write or can only read but cannot write in any language is treated as illiterate. All children of age less than 6 years or less, even if going to school and have picked up reading and writing are treated as illiterates. (66)

6. Primary, Middle, High school and Higher Secondary school: The first 10 years is further subdivided into 8 years of elementary education (5 years Primary School and 3 years Middle School), 2 years of Secondary education followed by 2 years of Higher Secondary Schools or Junior colleges. (Education Commission of 1964–66)(67)

7. Graduate: A person who has a first degree from a university or college(68)

8. Professional degree: Professional degree, is a degree that prepares someone to work in a particular profession, practice, or industry sector often meeting the

academic requirements for licensure or accreditation. Professional degrees may be either graduate or undergraduate entry, depending on the profession concerned and the country, and may be classified as bachelor's, master's, or doctoral degrees(69)

9. Unskilled worker: One who does operation that involves the performance of simple duties, which require the experience of little or no independent judgement or previous experience although familiarity with the occupational environment is necessary. His/her work may require in addition to physical exertion familiarity with variety of article or goods(70)

10. Semi-skilled worker: One who does work generally of defined routine wherein the major requirement is not so much of judgement, skill and but for proper discharge of duties assigned to him/her or relatively narrow job and where important decisions made by others. His/her work is thus limited to the performance of routine operations of limited scope(70)

11. Skilled worker: A skilled employee is one who is capable of working efficiently of exercising considerable independent judgement and of discharge his/her duties with responsibility .He must possess a through and comprehensive knowledge of the trade, craft or industry in which he/she is employed.(70)

12. Family:

A family is the primary unit in any society defined as a group of individuals related biologically or by the institution of marriage living together and eating from the same kitchen.

13. Nuclear family: A nuclear family is the one which consists of married couple living with their children while the children are still regarded as dependent on the couple.

14. Joint family: A joint family is the one where in a number of married couples and their children live together live in the same house. The men are all related by blood and the women are their wives, unmarried girls and widows of their family kinsmen. The property is held in common. The most senior male member is the head of family and takes all the decisions.

15. Three generation family: It is a family where representatives of three generation are living together. Young married couples continue to stay with their parents and have their own children as well**.**(66)

16. Caregiver: A caregiver is someone who is responsible for looking after another person, for example, a person who has a disability, or is ill or very young.(71)

17. Primary caregiver: A primary caregiver is someone who's faced with the duty of taking care of a friend or loved one who is no longer able to care for themselves. Primary caregivers may be caring for children, a senior, a spouse with a terminal illness, or any friend or family member who requires assistance with daily activities**.**
An informal caregiver, often a family member or friend, gives care to someone they have a personal relationship with, usually without payment. They may or may not live in the same home or geographic area as the person they are caring for.(72)

18. Multiple caregiver: A person who is having >1 caregiver was considered as multiple caregivers.

19. Decision maker: A person who makes important decisions in the family.(66)

20. Smoked food: Smoking is a method of cooking meat and other foods over a fire. Wood chips are added to the fire to give a smoky flavor to the food. Smoking adds flavor to the meat, fish, and poultry, and provides a small food preservation effect.(73)

21. Processed food: A processed food is any food that has been altered in some way during preparation.**(** Freezing, Canning, Cooking or Drying)(74)

22. Early and late menarche: Menarche is considered early if it occurs at or before ten years of age and late if it occurs at or later than 15 years of age.(75)

23. Age at marriage: Under India's Prohibition of Child Marriage Act of 2006,the legal age of marriage for girls is 18 years and for boys it is 21 years.

24. Follow up regimen for various cancer in the study:

Cancer urethra: Urethral wash, urethroscopy every 6 months for 2 years, annually for 5 years(76)

Cancer prostate: PSAevery 3 months, abdomen thoracic imagingCT/MRI(77)

Cancer kidney: Clinical and physical examination, Abdominopelvic USG and CT every 3 months(77)

Cancer testis: Tumor marker every 3 months , chest x-ray every 6 months, abdominopelvic MRI(77)

Cancer penis: Physical examination every 3 months for 2 years(78)

Cancer bladder: Cystoscopy and urinary cytology every 3 months for 2 years, 6 months for 5 years, annually lifelong.(77)

25. Genitourinary cancers: Genitourinary oncology (GU Oncology) focuses on research and treatment of urinary system cancers in both genders, as well as malignancies affecting the male sexual organs (79)

TABLE 3: Delays in the Health seeking behaviour for cancer

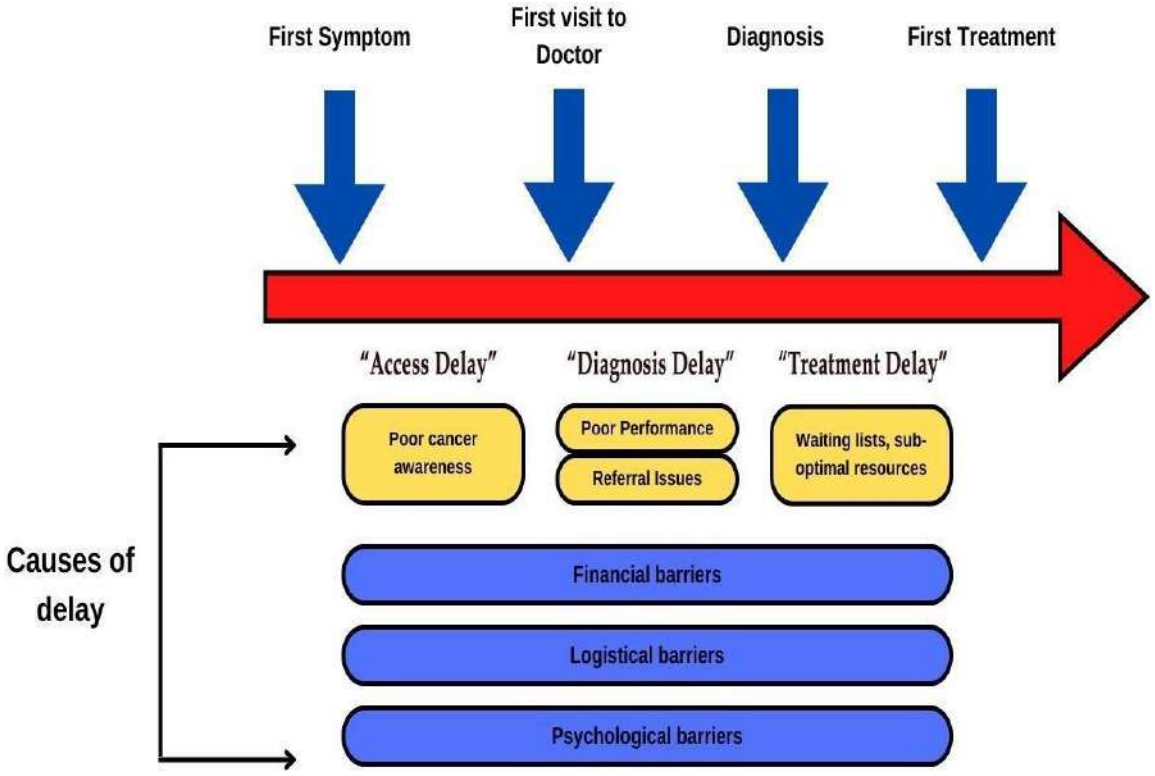
NAME	OTHER NAMES	DEFINITION	CUT OFF RANGE
26.Access delay(80)	Patient interval, Patient delay, Time from symptom onset to visit to health provider	Time interval between **onset of symptoms** and **first consultation** with health care provider	30 days
27.Diagnostic delay.(81)	Diagnostic interval/ System delay/ Provider delay	Time interval between **first consultation** with health care provider and **confirmation of diagnosis**	30 days
28.Treatment delay(82)	Treatment interval/ Diagnosis to treatment interval (DTI)/ Time to treatment initiation (TTI)	Time interval between **confirmation of diagnosis** and **initiation of definitive treatment**.	30 days
29.Global delay (80)	Total delay, overall delay, Delay in health seeking, Delay in 'Continuum of care'	Access delay + Diagnostic delay + Treatment delay.	30 days

Table 4: Delays in cancer care

Step of early diagnosis[a]	Component[a]	Potential delays[b]
Awareness and accessing care (patient interval)[c]	Population aware about symptoms (appraisal interval) Patients with symptoms seek and access health care (health-seeking interval)	Access delay[c]
Clinical evaluation, diagnosis and staging (diagnostic interval)	Accurate clinical diagnosis (doctor interval) Diagnostic testing and staging Referral for treatment	Diagnostic delay[d]
Access to treatment (treatment interval)	Treatment timely, accessible, affordable, acceptable and high quality	Treatment delay[e]

[a] Sample terms are used to designate various intervals within early diagnosis steps.
[b] The term "delay" is used to highlight a prolonged period of time within each step or component. Alternate terminology has been used to describe delays within each step and component of early diagnosis.
[c] Access delay has also been called patient delay. The term patient delay should be avoided because it suggests the cause of the delay is patient-related. In reality, there may be other contributing factors (such as societal or gender norms, economic factors, access barriers).
[d] Diagnostic delay can also be referred to as system or provider delay.
[e] Treatment delay can also encompass abandonment or discontinuation of treatment.

Figure 1: Delays in Cancer Care



(83)

30. Quality of life: The 30-item EORTC QLQ-C30 (version 3.0) was used to assess health related quality of life. This questionnaire contains five functional scales (physical, role, cognitive, emotional, and social functioning), a global QoL scale, three symptom scales (fatigue, nausea and vomiting, and pain), and six single items (appetite loss, diarrhea, dyspnea, constipation, insomnia, financial impact). The questionnaire has a 1-week time frame and uses a four-point response format ("not at all," "a little," "quite a bit," and "very much"), with the exception of the global QoL scale, which has a seven-point response format. The scores were linearly transformed to a score between 0 and 100. For the functioning and the global QoL scales, a higher score indicates better health. For the symptoms scales, a higher score indicates more symptom burden. The QLQ-C30 summary score is calculated as the mean of the combined 13 QLQ-C30 scale and item scores (excluding global QoL and financial impact), with a higher score indicating a better HRQoL. The summary score was only calculated when all the required 13 scale and item scores were available. (62)

31. Socioeconomic status: Calculated based on modified BG Prasad Scale classification for May 2022.

Table 5: Socioeconomic classification

Social class	Per capita income (in INR)
I	≥8480
II	4240-8479
III	2544-4239
IV	1272-2543
V	<1272

(84)

32. Perceived stigma: Perceived stigma encompasses the fear of discrimination and the awareness of negative attitudes or practices associated with a specific condition, such as cancer diagnosis. This includes the apprehension of enacted stigma, wherein individuals perceive that others feel prejudice against them due to their cancer diagnosis, resulting in reduced social acceptance. Perceived stigma involves assessing how the community thinks or behaves toward individuals with cancer and evaluating how collective beliefs about cancer impact both the affected individuals and patients' ability to access healthcare and disclose personal cancer diagnosis.(85)

33. Experienced stigma: Experienced stigma is the degree to which respondents experienced cancer-related stigma in the form of exclusion from social, religious, or family activities; received discriminatory remarks from family members; experienced verbal or physical harassment, loss of work or source of income; or had someone say they were worried they might contract cancer from them; denial of healthcare or insurance due to cancer diagnosis. (85)

34. Internalized stigma: Internalized stigma, also referred to as self-stigma is when the patient feels embarrassed or ashamed with his/her diagnosis; hides the diagnosis from family, relatives or society.(85)

35. Active cancer:"Active cancer" is defined as cancer not received potentially curative treatment, or when there is evidence that treatment has not been curative (e.g., recurrent or progressive disease), or when treatment is ongoing(86)

36. Tumor Progression Tumor progression is defined by irreversible change in the tumor characteristics reflecting the sequential appearance of a genetically altered subpopulation of cells with the new characteristics (Nowell 1986).(87)

37. Cancer cure: Cure means that there are no traces of your cancer after treatment and the cancer will never come back.(88)

38. Cancer remission: Remission means that the signs and symptoms of your cancer are reduced. Remission can be partial or complete. In a complete remission, all signs and symptoms of cancer have disappeared.(88)

39. Early stage and late stage of cancer: For ovarian malignancy, stage 1 was considered as early stage and other stages were considered as late stage of disease(89). For genitourinary malignancy, stage 1 and stage 2 were considered as early stage and stage 3 and stage 4 were considered as late stage of the disease.(90)

40.Catastrophic Health Expenditure (CHE): "if a household expenditure for hospitalisation exceeded 10% of the total annual household income"(91)

41.Visiting Multiple health care facilities: Patients who were visiting >2 health care facilities were categorized underpersons visiting multiple health care facilities.

Results and Analysis

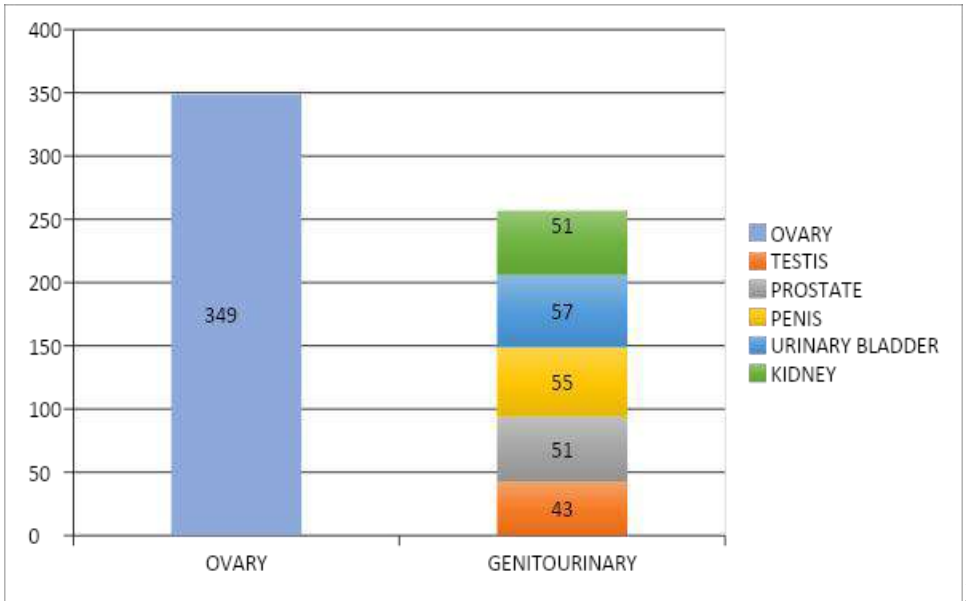
5. RESULTS AND ANALYSIS

This mixed method study included 606 participants across Tamil Nadu. From the 5022 samples line listed, 606 participants were interviewed across the selected districts by multistage sampling.

5.1. DISTRIBUTION OF CANCERS AMONG STUDY PARTICIPANTS :

Among the interviewed 606 participants, 349(57.6%) were registered with ovarian malignancy and 257(42.4%) with genitourinary malignancies during the study period. Among those with genitourinary malignancies, 51(19.8%) had renal malignancy, 51(19.8%) had prostate malignancy, 55(21.4%) had penile malignancy, 43(16.7%) had carcinoma testis and 57(22.2%) had malignancy of the urinary bladder and no participants had ureter and urethral malignancy. One participant presented with both malignancy of the urinary bladder and prostate at the time of interview, with urinary bladder malignancy being the primary malignancy. (Figure 2)

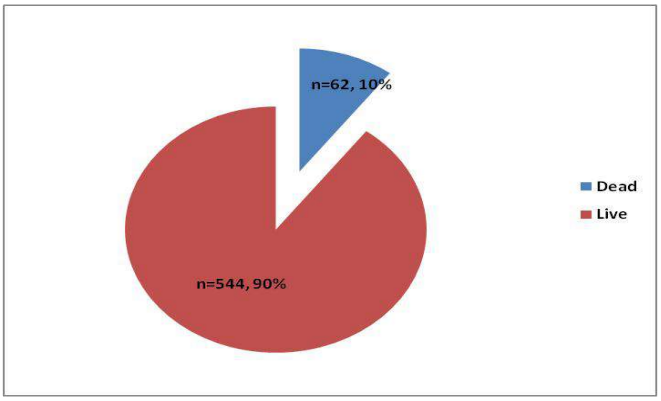
Figure 2: Distribution of cancers among participants (N=606)



2

Among the 606 participants, 544(89.8%) were alive and 62 (10.2%) were dead at the time of interview. Among those who were alive, 9 (1.65%) participants were bedridden and had difficulty in communicating. (Figure 3)

Figure 3: Status of the study participants (N=606)



Represented as n,%

5.2.SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE STUDY PARTICIPANTS

The mean age of the study participants was 55.27 ± 13.25 years ranging from 20 to 86 years. There were 383 (63.2%) females and 223 (36.8%) males among the study participants. More than half (60.2%) of the participants belonged to rural area and about 32.7% were illiterates. Among the study participants, most of them followed Hinduism (87.3%) and majority was married (81.2%). (Table 6)

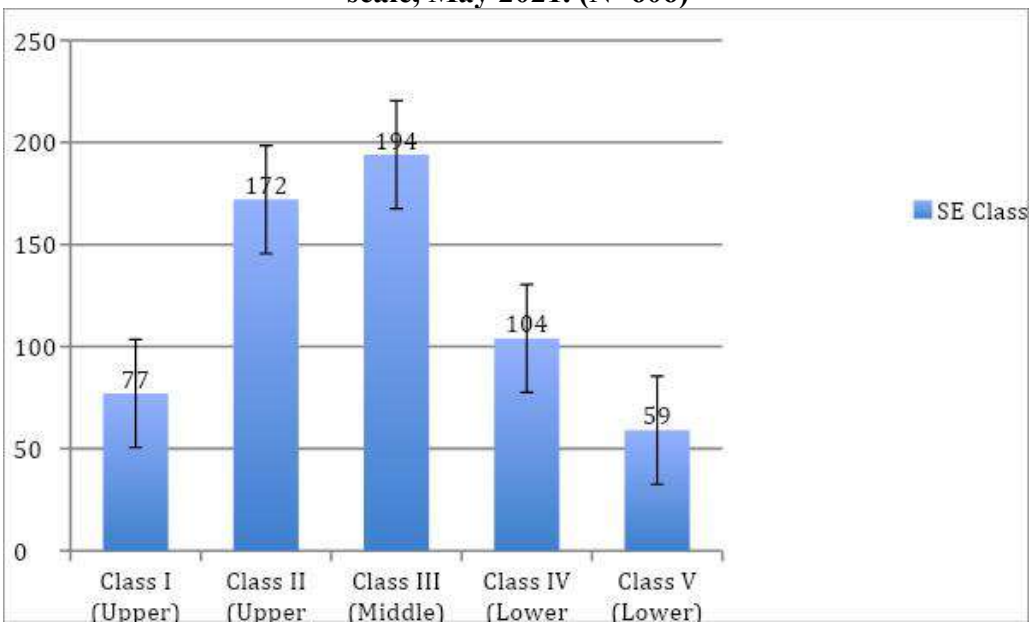
Table 6: Socio-demographic characteristics of the study participants (N=606)

VARIABLE	N	%
AGE GROUPS		
20-29 years	27	4.5
30-39 years	52	8.6
40-49 years	107	17.7
50-59 years	178	29.4
≥ 60 years	242	39.9
SEX		
Male	223	36.8
Female	383	63.2
LOCALITY		
Rural	365	60.2
Urban	208	34.3
Semi urban	33	5.4

MARITAL STATUS		
Married	492	81.2
Unmarried	31	5.1
Widow/widower	69	11.4
Divorced	14	2.3
TYPE OF FAMILY		
Nuclear family	386	63.7
Joint family	57	9.4
Three generation family	134	22.1
Broken family	8	1.3
Single	21	3.5
Total	**606**	**100**

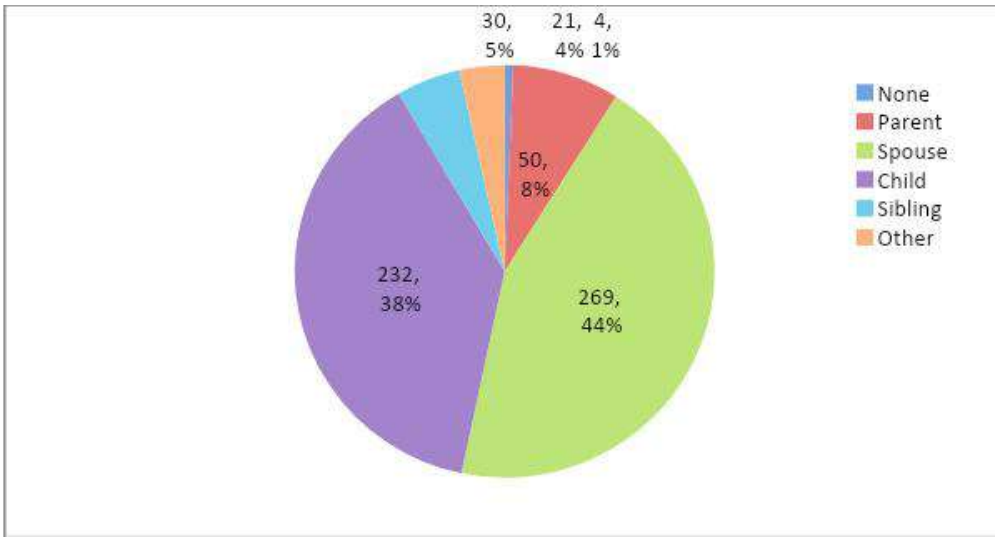
The study participants were commonly employed in farming, coolie work, driving, construction work, watchmen, tailoring, work in factories like asbestos, battery, beedi, brick kiln, weaving, doll making, paint, dye, shoe factories etc. More than half were unemployed (55.6%). More than half lived in nuclear families (63.7%) followed by three-generation families (22.1%). About 32% participants belonged to Social Class III (Middle Class) according to Modified BG Prasad Scale, May 2021. (Figure 4)

Figure 4: Socioeconomic scale classification according to Modified BG Prasad scale, May 2021. (N=606)



Primary care giver was the spouse for nearly half (44.4%) of the study participants followed by children (38.2%). Four participants (0.7%) reported that they did not have any primary care giver and took care of themselves (Figure 5). Around 186 participants (30.7%) had multiple caregivers. Most of them (95.2%) reported that they were satisfied with the support provided by their family members.

Figure 5: Details of the primary caregivers of the study participants (N=606)



Represented as n, %

Only 6 participants (1%) had practice of undergoing regular health checkup and only 41 participants (6.8%) had obtained cancer management guidance from a health care provider in the family. About 76 participants (12.5%) had history of previous hospitalizations. Around 233 participants (38.4%) had pre-existing comorbidities, the most common being hypertension in 127 participants (21%) followed by diabetes mellitus in 117 (19.3%) participants. One participant had HIV/AIDS and one participant had tuberculosis. Among those with comorbidities, 47 (20.2%) reported that the comorbidity influences their cancer management. The common reasons reported were additional expenditure for further investigations, postponement of surgery as the comorbidity was not under control and the complications of the comorbidity was to be managed along with the cancer.

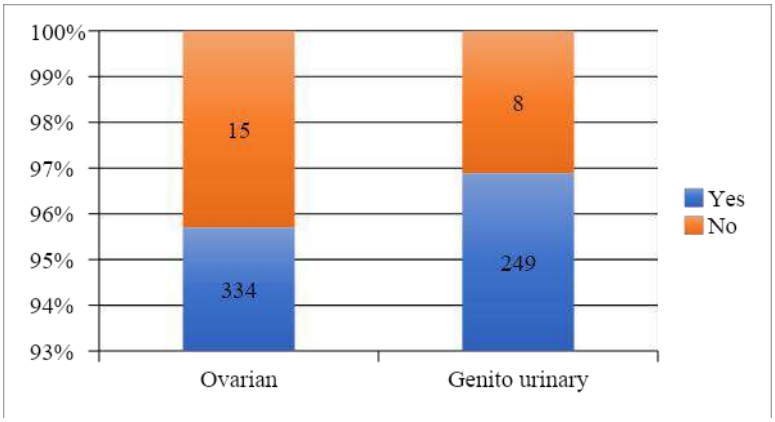
Among the study participants, 483 participants (79.7%) had visited multiple facilities before initiation of treatment. The distance travelled by the participants to obtain a health service for cancer management ranged from 0.5 kilometres to 253 kilometres. More than half of the participants (59.4%) had a health facility providing cancer management within 10 kilometres from their home. But most of them (91.1%) had the health facility within 50 kilometres.

5.3. CLINICO EPIDEMIOLOGICAL PROFILE OF THE STUDY PARTICIPANTS

Among those who were registered in the cancer registry between 2017 to 2021, one participant was initially diagnosed with cancer in 2003, one in 2014, 2 participants in 2015, 6 participants in 2016, 74 in 2017, 104 in 2018, 124 in 2019, 122 in 2020 and 172 in 2021. Among those registered with ovarian malignancy, one participant was initially diagnosed in 2003, one in 2014, 2 participants in 2015, 3 participants in 2016, 36 in 2017, 56 in 2018, 73 in 2019, 82 in 2020 and 95 in 2021. Among those registered with genitourinary malignancy, 3 participants were diagnosed in 2016, 38 in 2017, 48 in 2018, 51 in 2019, 40 in 2020 and 77 in 2021.

Among the study participants, 583 (96.2%) reported that they had some symptom before they were diagnosed with cancer. Among those with ovarian cancer, 334 (95.7%) reported the presence of symptoms before the diagnosis of cancer and among those with genitourinary malignancy, 249 (96.9%) reported the presence of symptoms before the diagnosis of cancer was made. (Figure 6)

Figure 6: Number of study participants who had symptom before diagnosis (N=606)



The epidemiology and the clinical features of ovarian and genitourinary malignancies are discussed below.

5.3.1. Epidemiology of Ovarian cancer:

Among the 606 interviewed, 349 (57.6%) were registered with ovarian malignancy during the study period. Among them, 320 (91.7%) were alive. The mean age was 52.9 $\pm$ 11.7 years with the maximum age of 84 years and the minimum age of 20 years. More than half of them (61.6%) were from rural area and most of them (75.9%) were married. More than half (59%) was living in nuclear families followed by 25.8%, living in three-generation families.

5.3.1.1. Risk factors for ovarian cancer:

i) Menstrual factors:

Two participants had early onset of menarche and 81 participants (23.2%) had delayed menarche. More than half of them attained menarche between 13-14 years. Most of them (89.1%) had regular cycles and more than half of them (56.4%) had attained menopause at the time of interview. Age at menopause (including surgical menopause) ranged from 26 to 55 years.

ii) Reproductive factors:

Around 97 participants (27.8%) had married before the legal age of 18 years and 8 participants had married after 30 years. Twelve participants (3.4%) were unmarried. There was one mother who had history of stillbirth in the study population. 69 women (19.8%) had their first childbirth before the age of 19 years and 9 women had their first childbirth beyond 29 years. 40 women (11.5%) were nulliparous in the study population. The number of children the women bore ranged from one to six. Among those who bore children, 8 women did not breastfeed their children.

iii) Hormonal factors:

Most of the women (95.4%) did not use Intra Uterine Contraceptive Devices. Eight women (2.3%) gave history of using oral contraceptive pills. 31 women (8.9%) gave history of treatment for infertility. Among them, 8 participants reported that they had taken ovulation-inducing drugs for infertility. Two participants reported of taking hormone replacement therapy.

iv) Gynaecological factors:

Two participants had history of precancerous lesion (benign mucinous cystadenoma, gestational trophoblastic disease) and one participant had history of complex cyst. Investigations for other gynaecological problems like endometriosis, chronic pelvic inflammatory diseases and ovarian cyst was done in 29 women (8.3%). Nearly half of the participants (46%) had undergone tubal sterilization.

v) Lifestyle factors

About 70.5% participants did not have the habit of doing any physical activity. Most of them (95.4%) were non-vegetarians. Among them, most of them reported of

consuming non-vegetarian food once a week. Among the study participants, only six (1.7%) had the habit of consuming smoked food and one fourth (25.8%) had the habit of consuming processed food. Five participants (1.4%) had history of exposure to asbestos. Two participants (0.6%) gave history of multiple sex partners. One participant was a smoker in the study population. Two participants gave history of hair dye usage and 3 participants reported of substance abuse among the study population.

vi) Genetic factors

Among the participants, 62 participants (17.8%) had history of malignancies running in their families. Fifteen participants had family history of ovarian cancer and 9 participants had family history of breast cancer.

5.3.1.2. Clinical features of the study participants with Ovarian cancer:

Among those diagnosed with ovarian cancer, 334 (95.7%) reported the presence of symptoms before the diagnosis of cancer. Nearly half of the participants (48%) reported of having some red flag feature at the time of diagnosis.

Among those registered with ovarian cancer, 181 (51.9%) had complaints of abdomen pain, 172 (49.3%) had abdominal distension, 55 (15.8%) had complaints of abnormal uterine bleeding (AUB), 31 (8.9%) complained of weight loss, 22 (6.3%) complained of bowel changes, 18 (5.2%) participants complained of bloating, 17 (4.9%) complained of dyspepsia, 13 (3.7%) complained of early satiety and 10 (2.9%) presented with low back ache at the time of diagnosis. Other common symptoms of presentation were nausea and vomiting, loss of appetite, frequency and urgency during micturition, painful micturition, flank pain, pain in the inguinal region, heaviness in the abdomen, leg pain, breathlessness, palpitation, painless mass in the inguinal region, pedal oedema and vaginal discharge. (Table 7)

In one participant, the malignancy was picked up incidentally during blood investigations, in 10 participants, the malignancy was picked up as an incidental finding during imaging and in one participant, the malignancy was picked up during master health check-up.

During the time of interview, 25 (7.2%) participants had abdominal pain, 17 (4.9%) had abdominal distension, 12 (3.4%) complained of weight loss, 8 (2.3%) had abdominal bloating, 7 (2%) had feeling of early satiety, 7 (2%) had low backache, 6

(1.7%) had dyspepsia, 3 (0.9%) had bowel changes and 1 (0.3%) participant had abnormal uterine bleeding (AUB). (Table 7)

Table 7: Distribution of 'red-flag' features among the study participants with ovarian malignancy

'Red-Flag' feature	At the time of diagnosis	At the time of interview
Abdominal pain	181(51.9%)	25(7.2%)
Abdominal distension	172(49.3%)	17(4.9%)
Abnormal uterine bleeding	55(15.8%)	1(0.3%)
Weight loss	31(8.9%)	12(3.4%)

*Multiple responses

5.3.2. Epidemiology of Genitourinary malignancy:

Of the 606 participants interviewed, 257 (42.4%) were registered with genitourinary malignancy during the study period. Among them, 224 (87.2%) were alive. The mean age was 58.51 $\pm$ 14.5 years with a maximum age of 86 years and a minimum age of 20 years. More than half of them (53.3%) were above 80 years and most of them were males (86.8%). More than half of them (58.4%) were from rural area and most of them (88.3%) were married. More than two-thirds (70%) was living in nuclear families and 6 participants (2.3%) were living alone.

5.3.2.1. Risk factors:

Among those registered with genitourinary malignancies, 9 participants (3.5%) had history of precancerous lesion and 1 participant had history of congenital anomaly (horse shoe kidney). One female had history of OCP intake and 3 female participants had taken treatment for infertility. Two participants had history of frequent dialysis, which is a risk factor for renal malignancy and 11 participants had history of bladder catheterisation for more than 2 months, which itself is a risk factor for bladder malignancy.

Regarding genetic factors, 8 participants had family history of breast cancer, 5 participants had family history of oral cancer, 2 participants had family history of

genitourinary malignancy and lung cancer and one participant had family history of ovarian malignancy, gastrointestinal malignancy and uterine malignancy.

Regarding lifestyle habits, only one-fourth participants (24.5%) reported of being physical active. Around 27 participants (10.5%) were vegetarians. Among the study participants, twelve (4.7%) participants had the habit of consuming smoked food and nearly one fourth (21.4%) had the habit of consuming processed food. Five participants gave history of asbestos exposure.

Regarding social habits of the study participants, 23 participants (8.9%) were current smokers and 88 participants (34.2%) had quit smoking currently. Around 25 participants (9.7%) were current alcoholics and 93 participants (36.2%) had currently quit consuming alcohol. Four participants (1.6%) gave history of hair dye usage and two participants (0.6%) gave history of multiple sex partners.

5.3.2.2. Clinical features

Of the 257 participants diagnosed with genitourinary malignancy, 249 (97%) had complaints before the diagnosis of cancer. Only 16.2% participants had some red flag feature at the time of diagnosis.

Among the symptoms, 70 (27.2%) had complaint of blood in urine, 47 (18.3%) complained of painful micturition, 42 (16.3%) had scrotal swelling, 32 (12.5%) had micturition disturbances, 24 participants (9.3%) had painless ulcers, 22 (8.6%) complained of abdominal pain, 20 (7.8%) complained of flank pain and 16 participants (6.2%) had painful ulcers. For 12 participants the ulcer progressed from painless to painful ulcer during the course of the disease. Fifteen participants (5.8%) had painless growth and weight loss and 5 participants (1.9%) had a painful growth. The other presenting features were vomiting, urinary incontinence, bone pain, constipation, bleeding ulcers, abdominal mass, abdominal distension, burning micturition, low backache, groin swelling and breathlessness.

At the time of interview, 3 (1.2%) had complaint of painful micturition, one participant had blood in urine, 4 (1.6%) had micturition disturbances, 7 participants (2.7%) had bone pain, 6 (2.3%) complained of abdominal pain, 3 (1.2%) complained of flank pain and 3 participants (1.2%) had weight loss. (Table 8)

In six participants, the malignancy was picked up as an incidental finding during imaging and in two participants, the malignancy was picked up during master health check-up.

Table 8: Distribution of 'red-flag' features among the study participants with GU malignancy

'Red-Flag' feature	At the time of diagnosis	At the time of interview
Hematuria	70 (27.2%)	1 (0.4%)
Flank pain	20 (7.8%)	3 (1.2%)
Abdominal pain	22 (8.6%)	6 (2.3%)
Weight loss	15 (5.8%)	3 (1.2%)
Abdominal mass	4 (1.6%)	-
Abdomen distension	3 (1.2%)	2 (0.8%)
Bone pain	2 (0.8%)	7 (2.7%)
Painful/ painless growth	21 (8.2%)	-
Painful/ painless ulcer	42 (16.3%)	-
Groin swelling	4 (1.6%)	-

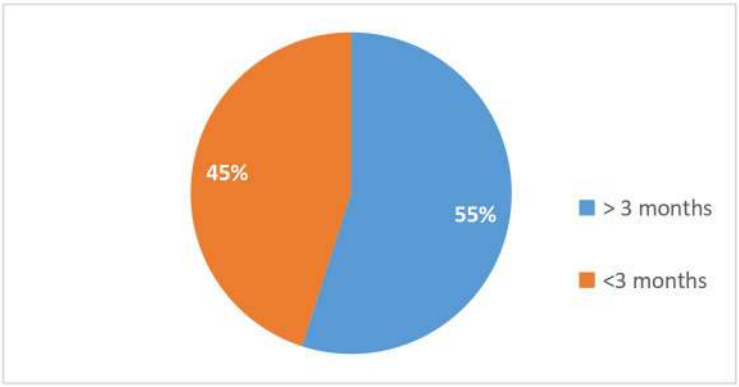
*Multiple responses

5.4. HEALTH SEEKING BEHAVIOUR AMONG THE STUDY PARTICIPANTS

5.4.1 Total delay/ Delay in health seeking/ Global delay/ Delay in 'Continuum of care'

The time from onset of symptoms to initiation of treatment was reported between one week to 135.3 months with a median of 3.46 months, with an extreme left deviation on the distribution curve. More than half (55%) of the participants (333 participants) had a delay of more than 3 months in seeking medical care for the disease. (Figure 7)

Figure 7: Distribution of delay in the study population (N=606)



Among those diagnosed with ovarian cancer, the time taken from the onset of symptoms to initiation of treatment was reported to range from one week to 121.5

months with a median of 3.53 months. More than half (55.3%) reported a delay of more than 3 months in seeking medical care. Among those diagnosed with genitourinary cancer, the time from the onset of symptoms to initiation of treatment ranged from 3 days to 135.3 months, with a median of 3.33 months. More than half (54.5%) reported a delay of more than 3 months in seeking medical care.

Table 9: Details of health seeking behaviour among the study participants (N=606)

Interval (In days)	Access Interval	Diagnosis delay	Treatment delay	Total delay
Median (Days)	39	7.5	12	104
IQR(Days)	144	26	24	185
Ovarian malignancy				
Median (Days)	59	8	12	106
IQR(Days)	163	26	23	185
Genitourinary malignancy				
Median (Days)	31	7	11	100
IQR(Days)	117	28	25	187.5

Table 9 shows the median (IQR) days of total delay, access interval, diagnosis interval and treatment interval in the study population. The median time taken for health seeking was higher among those with ovarian cancers than those with Genitourinary cancers.

Figure 8: Details of health seeking behaviour among the study participants (N=606)

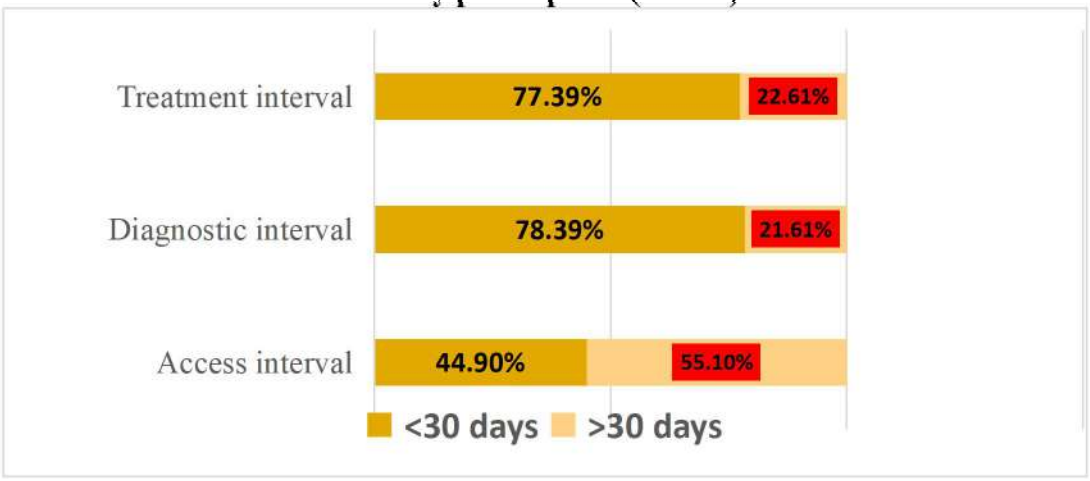


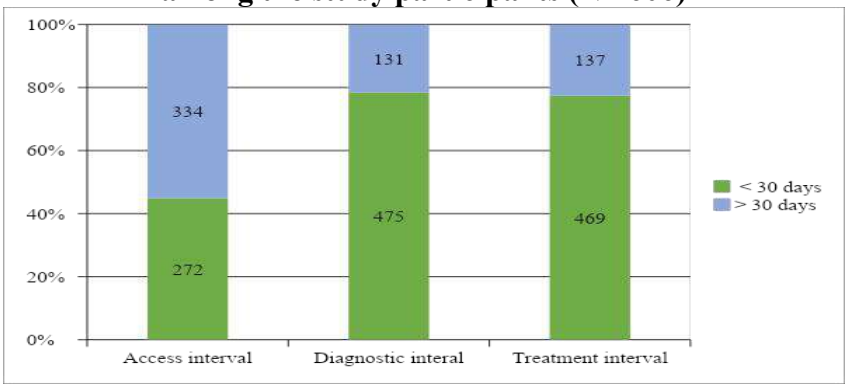
Figure 8 shows the distribution of health seeking behaviour among the study population.

The proportion of participants with Total delay was significantly higher among penile malignancy followed by testicular malignancy and renal malignancy The proportion of patients with access delay was significantly higher among penile malignancy followed by testis malignancy and ovarian malignancy. (Table 10). The access delay was higher than diagnostic and treatment delay in all the types of malignancies in the study population.

Table 10: Distribution of various delays in the study population:

Type of cancer	Total delay (>3 months)	Access delay (>30 days)	Diagnostic delay (>30 days)	Treatment delay (>30 days)
Ca Ovary	193 **(55.3%)** CI:(51.5%,59.1%)	204 **(58.5%)** CI:(54.7%,62.3%)	71 **(20.3%)** CI: (17.4%,23.2%)	75 **(21.5%)** CI: (18.6%,24.4%)
Ca Urinary Bladder	27 **(47.4%)** CI:(43.8%,51.0%)	21 **(36.8%)** CI:(33.2%,40.4%)	14 **(24.6%)** CI: (21.5%,27.8%)	12 **(21.1%)** CI: (18.2%,24.0%)
Ca Penis	42 **(76.4%)** CI:(73.1%,79.7%)	39 **(70.9%)** CI:(67.2%,74.6%)	15 **(27.3%)** CI: (24.0%,30.6%)	18 **(32.7%)** CI: (29.2%,36.3%)
Ca Kidney	19 **(37.3%)** CI: (33.7%,40.9%)	21 **(41.2%)** CI: (37.5%,44.9%)	8 **(15.7%)** CI: (13.0%,18.4%)	9 **(17.6%)** CI :(14.9%,20.3%)
Ca prostate	22 **(43.1%)** CI: (39.4%,46.8%)	19 **(37.3%)** CI :(33.7%,40.9%)	12 **(23.5%)** CI: (20.3%,26.7%)	16 **(31.4%)** CI: (28.0%,34.8%)
Ca Testis	30**(69.8%)** CI: (65.9%,73.7%)	30 **(69.8%)** CI :(65.9%,73.7%)	11 **(25.6%)** CI: (22.5%,28.7%)	7 **(16.3%)** CI:(13.6%,19.0%)

Figure 9: Distribution of various intervals in 'Continuum of cancer care' among the study participants (N =606)

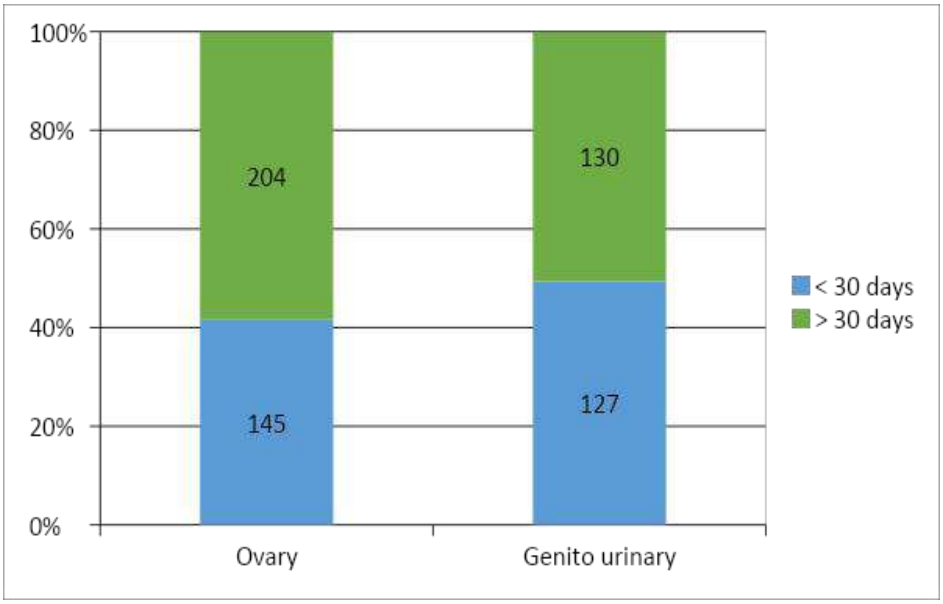


The distribution of various intervals in the 'Continuum of care' among the study participants is shown in Figure 9.

5.4.2 Access interval/ Patient delay/ Time from symptom onset to visit to health provider/ Access delay

The median time taken from the date of onset of symptoms to the date to visit the first provider among the study population was 39 days ranging from one week to 134.5 months and an IQR of 144. More than half of the participants (55.1%) had visited the health care provider for their symptoms after 30 days. This delay to seek the first health care provider was more in patients with ovarian malignancy than with genitourinary malignancy. (58.5% vs 50.6%)

Figure 10: Distribution of access interval among the study participants (in days) (N=606)



The most common reason for delay to visit the health care provider was misinterpretation of symptoms due to lack of awareness in 278 participants (45.9%), followed by COVID pandemic in 117 participants (19.3%), delay in decision making in 94 participants (15.5%), self medicating in 57 participants (9.4%), ignoring symptoms by 34 participants (5.6%), factors like prioritising other life events, financial constraints and following alternate medical care and treatments in 23 participants (3.8%), and stigma in 20 participants (3.3%). Other reasons for delay were lack of accompanying person, inaccessibility to health services, careless attitude, non-interference with daily activity, fear of cancer treatments, fear of surgery and shyness. (Table 11)

Table 11: Distribution of factors for Access delay in the study population (N=606)

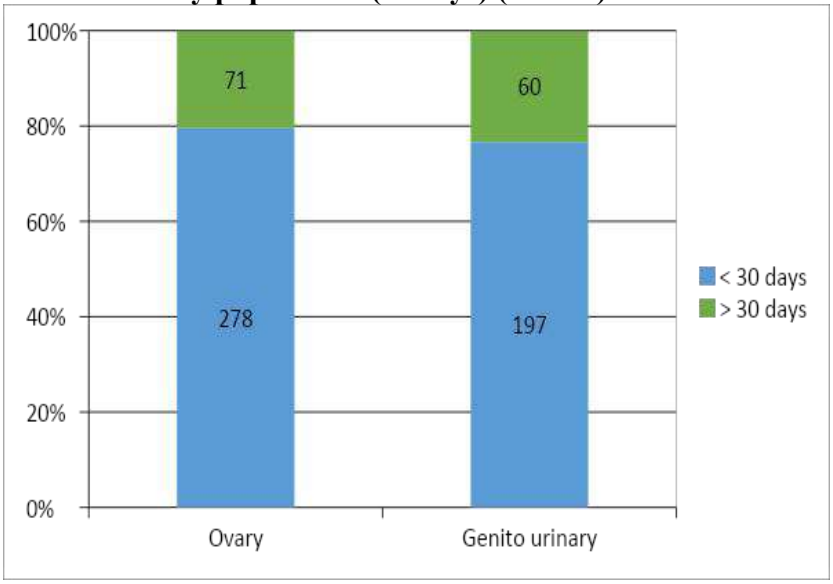
S. No	Factors for patient delay	Ovarian malignancy	Renal malignancy	Bladder malignancy	Cancer prostate	Cancer penis	Cancer testis
PATIENT FACTORS:							
1	Misinterpretation of symptoms due to lack of awareness	239 (68.5%)	23(45.1%)	29(50.9%)	28(54.9%)	**39(70.9%)**	29(67.4%)
2	Delay in decision making	49 (14%)	2(3.9%)	10(17.5%)	12(23.5%)	**14(25.5%)**	7(16.3%)
3	Self medication	28 (8%)	5(9.8%)	6(10.5%)	4(7.8%)	**8(14.5%)**	6(14%)
4	Financial constraints	**18 (5.2%)**	-	3(5.3%)	-	1(1.8%)	1(2.3%)
5	Prioritizing other life events	16 (4.6%)	-	2(3.5%)	1(2%)	2(3.6%)	**2(4.7%)**
6	Issues with caregiver	**3 (0.9%)**	-	-	-	-	-
7	Lack of accompanying person	**10 (2.9%)**	-	1(1.8%)	1(2%)	-	-
8	Sought alternate medical care	7 (2%)	2(3.9%)	2(3.5%)	3(5.9%)	-	**7(16.3%)**
9	Social stigma	6 (1.7%)	-	1(1.8%)	1(2%)	**11(20%)**	1(2.3%)
HEALTH SYSTEM FACTORS:							
10	COVID delay	**13 (3.7%)**	1(2%)	-	1(2%)	1(1.8%)	1(2.3%)
11	Inaccessibility to health services	3 (0.9%)	-	-	-	**1(1.8%)**	-

The median access interval was 59 (IQR -163) days ranging from 0 to 121 months among those diagnosed with ovarian malignancy and 31 (IQR – 117) days ranging from 0 to 134.5 months among those diagnosed with genitourinary malignancy.

5.4.3 Diagnostic interval/ Diagnostic delay/ System delay/ Provider delay

The median duration from the date to visit the first provider to the date of confirmation of cancer diagnosis was 7.5 days ranging from 0 to 76.2 months with an IQR of 26. More than three-fourth of the participants (78.4%) had a confirmation of the cancer diagnosis by a health care professional within 30 days of visiting the first health care provider. Delay of more than 30 days was seen in only 21.6% participants (131/606). More participants with genitourinary malignancy had a delay in the confirmation of the cancer diagnosis of more than 30 days than participants with ovarian malignancy (23.3% vs 20.3%) (Figure 11)

Figure 11: Distribution of diagnostic interval in the study population (in days) (N=606)



The common reasons for diagnostic delay include missed diagnosis by health care professionals in 89 participants (14.7%), seeking alternate care including native treatments by 43 participants (7.1%), lack of diagnostic facility in 22 participants (3.6%), financial constraints in 20 participants (3.3%) and difficulty in accessing diagnostic facility by 13 participants (2.1%). Other reasons included lack of family support, denial of insurance services, repetition of investigations, delay in obtaining investigation reports, careless attitude, long distance to travel, COVID pandemic, long waiting time, delay in decision making, lack of accompanying person, lack of trust on health professional, multiple investigations and misinterpretation of symptoms. (Table 12)

Table 12: Distribution of factors for diagnostic delay in the study population (N=606)

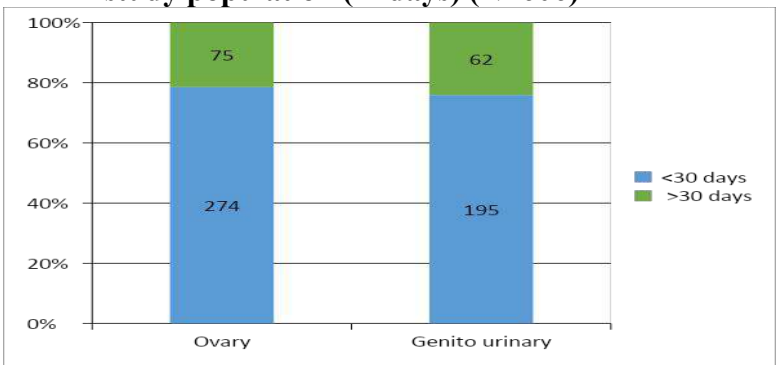
S. No	Factors for diagnostic delay	Ovarian malignancy	Renal malignancy	Bladder malignancy	Cancer prostate	Cancer penis	Cancer testis
HEALTH SYSTEM FACTORS :							
1	Missed diagnosis by health care professional (as perceived by the patient)	**40 (11.5%)**	**7(13.7%)**	**11(19.3%)**	**10(19.6%)**	**13(23.6%)**	**8(18.6%)**
2	Lack of diagnostic facility	16 (4.6%)	-	3(5.3%)	3(5.9%)	-	-
3	COVID pandemic	13 (3.7%)	-	1(1.8%)	-	-	1(2.3%)
4	Denial of insurance	1 (0.3%)	-	1(1.8%)	-	-	-
PATIENT FACTORS:							
5	Sought alternate medical care	28 (8%)	2(3.9%)	7(12.3%)	1(2%)	3(5.5%)	2(4.7%)
6	Financial constraints	10 (2.9%)	-	4(7%)	1(2%)	3(5.5%)	2(4.7%)
7	Difficulty in accessing diagnostic facility	9 (2.6%)	-	-	-	4(7.3%)	-
8	Lack of family support	4 (1.1%)	-	1(1.8%)	1(2%)	1(1.8%)	-
9	Self medication	3 (0.9%)	1(2%)	1(1.8%)	1(2%)	1(1.8%)	-

Among those diagnosed with ovarian malignancy, the median diagnostic interval was 8 (IQR-26) days ranging from 0 to 76.2 months and among those with genitourinary malignancy it was is 7 (IQR-28) days ranging from 0 to 73 months.

5.4.4 Treatment interval/ Treatment delay/ Diagnosis to treatment interval (DTI)/ time to treatment initiation (TTI)

The median time taken from the date of confirmation of cancer diagnosis to the date of initiation of definitive cancer treatment was reported as 12 days ranging from 0 to 48.5 months with an IQR of 24. More than three fourth of the participants (77.4%) had initiated definitive cancer treatment within one month of a confirmed cancer diagnosis. Delay of more than 30 days for initiating definitive treatment was found in only 22.6% participants (137/606). More patients with genitourinary malignancy had more than 30 days delay to initiate treatment after the cancer diagnosis than patients with ovarian malignancy (24.1% vs 21.5%) (Figure 12)

Figure 12: Distribution of treatment interval in the study population (in days) (N=606)



The treatment interval was further categorised into less than 4 weeks, 4-8 weeks and more than 8 weeks. The distribution of treatment delays among various cancers is given in the table 13 below

Table 13: Distribution of treatment delays in ovarian and genitourinary malignancies in the study population:

Duration of delay:	Ca Ovary N=349	Ca Urinary Bladder N=57	Ca Penis N=55	Ca Kidney N=51	Ca prostate N=51	Ca Testis N=43
< 4 weeks	274 (78.5%)	45 (78.9%)	37 (67.3%)	42 (82.4%)	35 (68.6%)	36 (83.7%)
4-8 weeks	43 (12.3%)	5 (8.8%)	7 (12.7%)	5 (9.8%)	9 (17.6%)	5 (11.6%)
> 8 weeks	32 (9.2%)	7 (12.3%)	11 (20%)	4 (7.8%)	7 (13.7%)	2 (4.7%)

The common reasons for treatment delay include financial constraints in 55 participants (9.07%), fear of surgery in 43 participants (7.1%), seeking alternate care including native treatments by 39 participants (6.4%), fear of side effects, lack of trust on health care professionals and poor health condition in 13 participants (2.1%), difficulty in accessing treatment facility by 9 participants (1.5%) and denial of insurance services in 7 participants (1.2%). Other common reasons for delay include self-medications, lack of family support, delay in decision making, lack of caregiver support during treatment, lack of accompanying person, non-disclosure of the condition to the family members, prioritising other family events, festivals, other comorbidities, misclassification of disease severity, lack of drug stock in pharmacy, multiple procedures after diagnosis, delay in pre-treatment evaluation, COVID pandemic, heavy case load in hospitals, long waiting time, waiting time at operation theatres in hospitals, multiple referrals, lack of bed facilities, festival holidays, and delay in availing fitness for surgery. (Table 14)

Table 14: Distribution of factors for treatment delay in the study population (N=606)

S. No	Factors for treatment delay	Ovarian malignancy	Renal malignancy	Bladder malignancy	Cancer prostate	Cancer penis	Cancer testis
	PATIENT FACTORS:						
1	Financial constraints	34 (9.7%)	2(3.9%)	6(10.5%)	**7(13.7%)**	4(7.3%)	2(4.7%)
2	Fear of side effects	5 (1.4%)	1(2%)	**4(7%)**	2(3.9%)	-	1(2.3%)
3	Sought alternate care	25 (7.2%)	4(7.8%)	4(7%)	-	**5(9.1%)**	1(2.3%)
4	Fear of surgery	22 (6.3%)	5(9.8%)	**9(15.8%)**	5(9.8%)	4(7.3%)	2(4.7%)
5	Poor health condition	8 (2.3%)	**2(3.9%)**	-	1(2%)	2(3.6%)	-
5	Lack of trust in health providers and treatment	7 (2%)	1(2%)	**3(5.3%)**	1(2%)	1(1.8%)	-
7	Difficulty in accessing treatment facility	6 (1.7%)	1(2%)	-	-	1(1.8%)	**1(2.3%)**
8	Lack of family support	1 (0.3%)	-	-	-	**1(1.8%)**	-
9	Self medication	-	-	**1(1.8%)**	-	-	-
	HEALTH SYSTEM FACTORS:						
10	Denial of medical insurance	5 (1.4%)	**1(2%)**	-	-	1(1.8%)	-
11	Misclassification of disease severity	1 (0.3%)	-	-	**1(2%)**	1(1.8%)	-
12	COVID pandemic	**69 (19.8%)**					
13	Non availability of drugs	-	-	-	-	-	-

The median treatment interval for ovarian malignancy was 12 days (IQR-23) ranging from 0 to 37.43 months and the mean treatment interval for genitourinary cancer was 11 days (IQR-25) ranging from 0 to 48.5 months.

5.4.5 Delay in follow up:

Among those participants who were alive, more than two-thirds (71%) were not compliant to regular follow up. The most common reason for irregular follow up was the absence of symptoms in 113 participants (20.8%), followed by difficulties due to COVID pandemic in 62 participants (11.4%) , financial constraints in 44 participants (8.1%) , lack of awareness on the need to follow up in 42 participants (7.8%), careless attitude in 41 participants (7.5), long distance of the health facility from the residence in 32 participants (5.9%), lack of caregiver and family support in 31 participants (5.7%), fear of complications in 20 participants (3.7%), hopelessness and giving up on self and difficulty in accessing health facility in 13 participants (2.4%). The other common reasons were COVID restrictions, rude attitude of doctors, prioritising other family events, inadequate communication regarding follow up, non-availability of health care professionals for follow up treatment and non-satisfactory behaviour of health care professionals.

5.5 Effect of COVID pandemic on cancer management

Delay due to COVID pandemic was reported in 177 participants (29.2%) with participants with ovarian malignancy affected more than participants with genitourinary malignancy (31.8% vs 25.7%). However, the difference was not significant (Chi square 2.684 p=0.05). It was reported from the study that 26 participants (4.3%) had postponed and cancelled consultations during the pandemic, 23 participants (3.8%) had a delay in the diagnosis of the disease, 112 (18.5%) had difficulty in availing treatment for their disease due to the pandemic and 62 (10.2%) had difficulty in follow up.

The most common reason for postponement and cancellation of consultation due to the COVID pandemic was lockdown restrictions (23%). Other reasons include fear of acquiring COVID infection (13%), inaccessibility to hospitals due to lockdown (7%), lack of beds in the hospitals (6%), financial crisis due to lockdown (3%), non-availability of health care professionals (3%) and lack of treatment services (2%).

The common reasons for delay in diagnosis of cancer due to the COVID pandemic includes lack of availability of diagnostic services (42%), lockdown restrictions (18%), fear of acquiring COVID infection (9%), lack of availability of hospital beds due to COVID (6%), inaccessibility to hospitals due to lockdown (5%), non-availability of health care professionals (3%), financial crisis due to lockdown (2%) and lack of treatment services (2%).

The most common reason for delay in treatment of cancer due to the COVID pandemic includes lockdown restrictions (84%), followed by fear of acquiring COVID infection (45%), lack of hospital beds due to COVID (35%), inaccessibility to hospitals due to lockdown (23%), financial crisis due to lockdown (16%), non-availability of health care professionals (12%), lack of treatment services (12%) and lack of availability of drugs (6%).

The common reasons for difficulty in adhering to follow up were non-availability of drugs (76%), non-availability of diagnostic services (75%), lockdown restrictions (52%), fear of acquiring COVID infection (32%), inaccessibility to hospitals due to lockdown (13%), non-availability of health care professionals (5%) and financial crisis due to lockdown (2%).

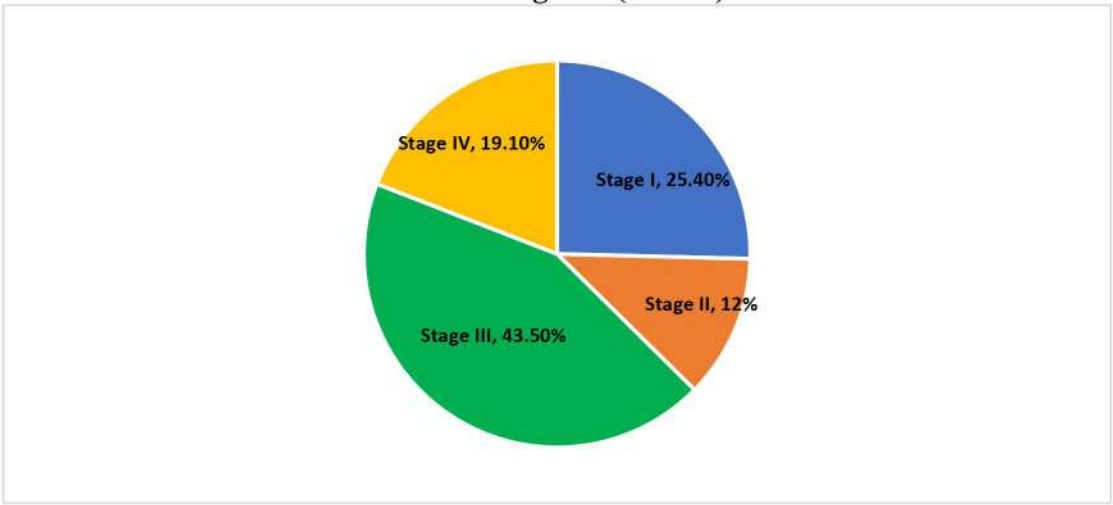
5.6. OUTCOME OF CANCER MANAGEMENT

5.6.1 Stage of the disease at the time of diagnosis

Among the 606 participants, the distribution of the staging at the time of diagnosis is as follows: Stage I: 124 (20.5%), Stage II: 112 (18.5%), Stage III: 208 (34.3%) and Stage IV: 143 (23.6%). Reports were not available with 19 participants. (Figure 19)

Among those diagnosed to have ovarian cancer, 85 participants had early cancer at the time of diagnosis and 250 participants had advanced cancer at the time of diagnosis. Among those with ovarian maliganacy, Stage 3 (43.50%) was found to be higher at the time of dignosis. The distribution of the staging of ovarian cancer at the time of diagnosis among the study participants is as follows: Stage I: 85, Stage II: 40, Stage III: 146 and Stage IV: 64. Records on staging details were not available with 14 participants. (Figure 13)

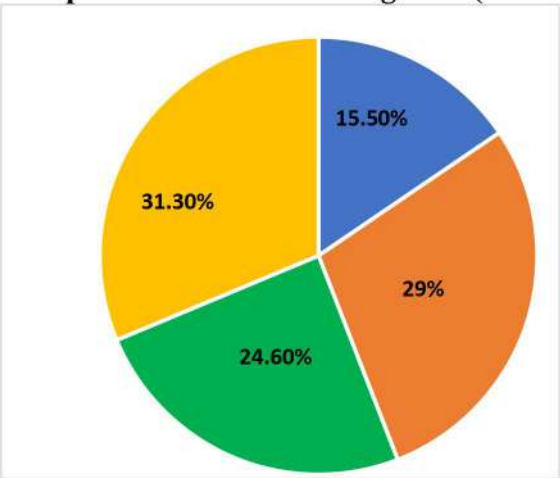
Figure 13: Staging of ovarian malignancy among the study participants at the time of diagnosis(N=335)



Among those diagnosed with genitourinary cancer, 111 participants were at early stage at the time of diagnosis and 141 participants were at advanced stage at the time of diagnosis. Among those with genitourinary maliganacy, Stage 4 (31.30%) was found to be higher at the time of Dignosis

The distribution of the staging of genitourinary cancer at the time of diagnosis among the study participants is as follows: Stage I: 39, Stage II: 72, Stage III: 62 and Stage IV: 79. Records on staging details were not available with 5 participants. (Figure 14)

Figure 14: Staging of genitourinary malignancy among the study participants at the time of diagnosis (N=252)



5.6.1 Clinical outcome

Among the 606 participants, more than half, 373 participants (61.6%) were in remission phase, 171 participants (28.2%) were under active treatment and 62 participants (10.2%) were dead at the time of interview. More participants with genitourinary malignancy were on remission than participants with ovarian malignancy (70.1% vs 67.5%). Among those 171 participants on active treatment, 113 (66.1%) were on primary treatment and 58 (33.9%) were on treatment for progression of the disease. Participants with ovarian malignancy had a higher tumour progression rate than participants with genitourinary malignancy (11.9% vs 8.9%). Year wise distribution of outcomes has been shown in Annexure 10.

Only one fourth of the study participants, 158/544 (29%) participants were on regular follow up. Among those on primary treatment, only 32/113 (28.3%) participants were compliant to treatment, among those with tumour progression, 22/58 (37.9%) participants were compliant to treatment and among those on remission, only 104/373 (27.9%) participants were on regular follow up of the disease. Participants with genitourinary

malignancy were on regular follow up than participants with ovarian malignancy (33% vs 26.3%).

Among those registered with ovarian malignancy, 216 participants (61.9%) were on remission, 104 participants (29.8%) had active disease and 29 (8.3%) were dead at the time of interview. Among those on active treatment, 66 (63.5%) were on primary treatment and 38 (36.5%) were found to be on treatment for tumour progression. Only 84 participants (26.3%) were compliant to treatment and on regular follow up among the 320 participants.

Among those registered with genitourinary malignancies, 157 participants (61.1%) were in remission, 67 participants (26.1%) had active disease and 33 (12.8%) were dead at the time of interview. Among those on active treatment, 47 (70.1%) were on primary treatment and 20 (29.9%) were found to be on treatment for tumour progression. Only 74 participants (33%) were compliant to treatment and on regular follow up among the 224 participants. (Table 15)

Table 15: Distribution of Outcome among the study participants

S. No	Cancer type	A) Active treatment	A1) Primary treatment	A2) Disease progression	B) Remission	C) Dead
1	**Kidney (51)**	12(23.5%)	8 (66.7%)	4 (33.3%)	34 (66.7%)	5 (9.8%)
2	**Ovary (349)**	104 (29.8%)	66 (63.5%)	38 (36.5%)	216 (61.9%)	29 (8.3%)
3	**Penis (55)**	10 (18.2%)	10 (100%)	-	40 (72.7%)	5 (9.1%)
4	**Prostate (51)**	21 (41.2%)	10 (47.6%)	11 (52.4%)	21 (41.2%)	9 (17.6%)
5	**Testis (43)**	8 (18.6%)	6 (75%)	2 (25%)	33(76.8%)	2 (46.5%)
6	**Urinary Bladder (57)**	16 (28.1%)	13 (81.3%)	3 (18.7%)	29 (50.9%)	12 (21.1%)
Total (606)		**171 (28.2%)**	**113 (66.1%)**	**58 (33.9%)**	**373 (61.6%)**	**62 (10.2%)**

5.6.3 Assessment of Activities of Daily Living (ADL)

Activities of daily living were assessed using Katz index of independence both at the time of diagnosis and at the time of interview.

Most of them (92.2%) did not report of having any ADL disability. Around 1% (6/606) had moderate ADL disability, and the remaining 3.5% (21/606) had severe ADL disability at the time of diagnosis. At the time of interview, more than three-fourths of the participants (85.6%) did not report of any ADL disability. Around 1.5% (9/606) had moderate ADL disability and 4% (24/606) reported of severe ADL disability. The severity of impairment was more at the time of interview among participants with genitourinary malignancy. (Figure 15)

Figure 15: Distribution of ADL disability (Severe, Moderate, Independent) among the living study participants (N=544)

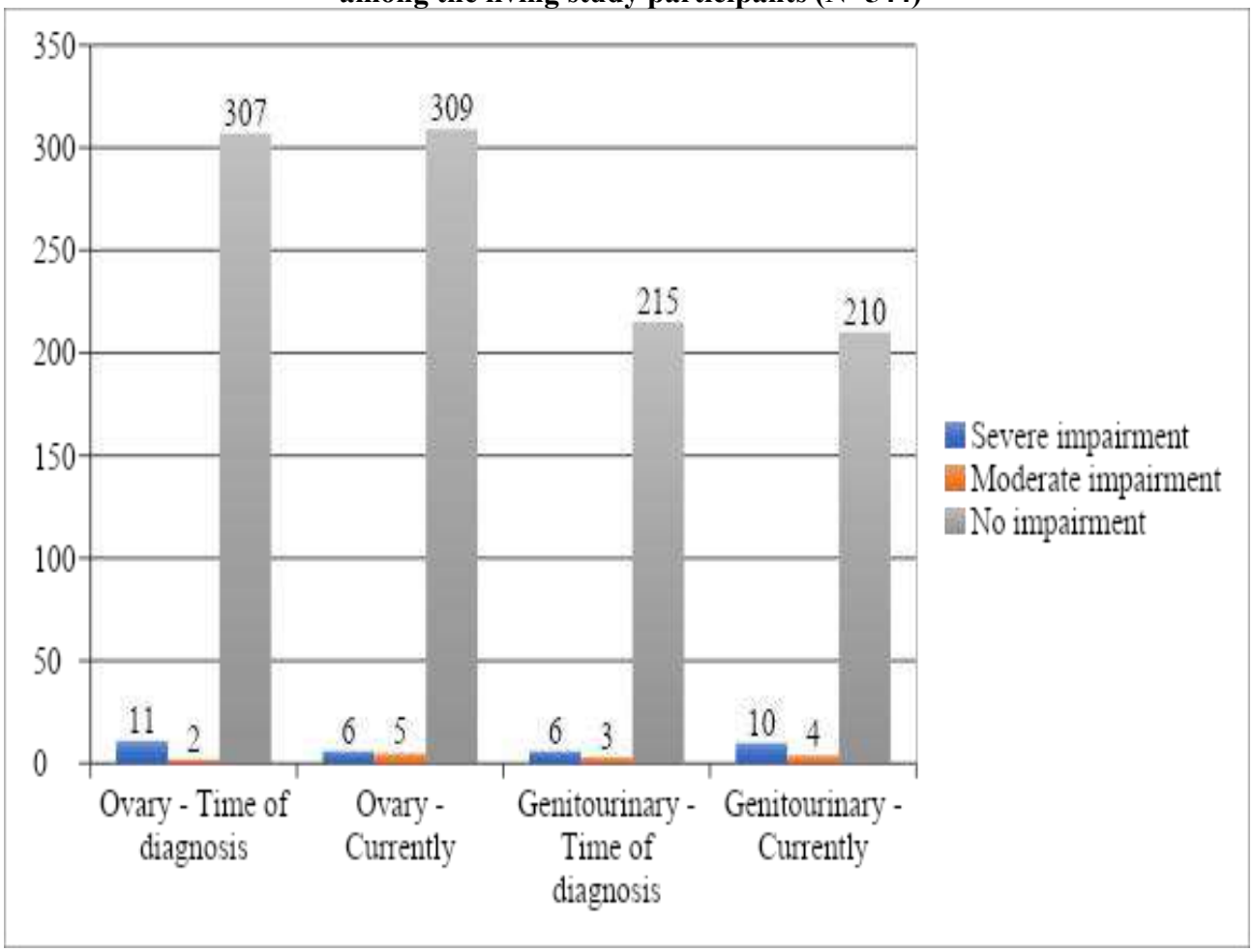


Table 16: Distribution of ADL disability (Severe, Moderate, Independent) among the living study participants (N=544)

S. No	Cancer type	Activities of daily living	At the time of diagnosis		At the time of interview	
			Frequency	Percentage	Frequency	Percentage
1	Kidney	Independent	43	93.5	43	93.5
		Moderate impairment	2	4.3	-	-
		Severe impairment	1	2.2	3	6.5
		Total	46	100.0	46	100.0
2	Ovary	Independent	307	95.9	309	96.6
		Moderate impairment	2	0.6	5	1.6
		Severe impairment	11	3.4	6	1.9
		Total	320	100.0	320	100.0
3	Penis	Independent	48	96	48	96
		Moderate impairment	-	-	-	-
		Severe impairment	2	4	2	4
		Total	50	100.0	50	100.0
4	Prostate	Independent	40	95.2	36	85.7
		Moderate impairment	1	2.4	4	9.5
		Severe impairment	1	2.4	2	4.8
		Total	42	100.0	42	100.0

5	**Testis**	**Independent**	41	100.0	41	100.0
		Moderate impairment	-	-	-	-
		Severe impairment	-	-	-	-
		Total	41	100.0	41	100.0
6	**Urinary Bladder**	**Independent**	43	95.6	42	93.3
		Moderate impairment	-	-	-	-
		Severe impairment	2	4.4	3	6.7
		Total	45	100.0	45	100.0

From the table 16 it was observed that more than 90% were independent at the time of diagnosis and more than 85% were independent at the time of interview irrespective of the type of malignancy. It was observed that the level of independence had worsened among participants with prostate and bladder malignancy and improved among those with ovarian malignancy.

5.6.4 Quality of life

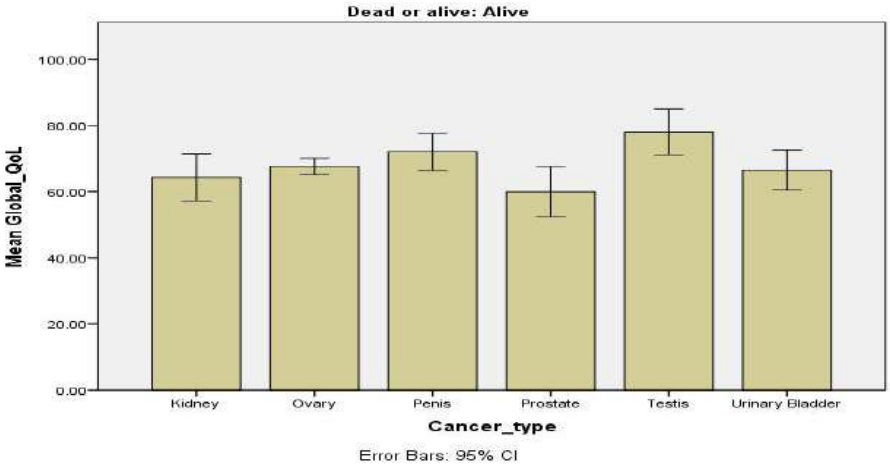
The quality of life of the study participants was assessed using EORTC questionnaire. For global quality of life domain and function scales domain, higher scores indicate better functioning. (Table 17)

Table 17: Distribution of global QOL among the live study participants(n=544)

S.No	Variable	All cancers (N=544)	Ovary	Genitourinary
1	Global QOL	67.80 ± 22.76	67.55 ± 22.83	68.15 ± 22.71
2. Functional scale domain:				
2. a.	Physical	73.95 ± 25.37	73.79 ± 24.14	74.17 ± 27.07
2. b.	Role	79.78 ± 28.89	80.67 ± 27.44	78.50 ± 30.85

2. c.	Emotional	78.48 ± 27.46	76.56 ± 27.62	81.21 ± 27.05
2. d.	Cognitive	84.99 ± 22.94	84.74 ± 22.87	85.34 ± 23.08
2. e.	Social	68.54 ± 31.14	67.71 ± 30.33	69.72 ± 32.30

Figure 16: Distribution of global QOL scores among the live study participants (N=544)



The above figure shows the comparison of global Quality of life among various subtypes of genitourinary and ovarian malignancies. The global quality of life was good in testicular malignancy and poor in prostate malignancies; (Figure 16) However, they were not statistically significant. (ANOVA, F=0.092, p=0.762)

5.6.4 Financial outcome

Among the study participants, 564 participants (93.1%) had medical insurance. Among them, 561 had government insurance and only 3 had private insurance. Among those who had insurance, 538 participants had utilised medical insurance for cancer diagnosis and treatment related expenses. Among them, 358 had utilised insurance for diagnostic services, 430 had utilised for surgery, 333 had utilised for chemotherapy, 62 had utilised for radiation and 14 had utilised for palliative services.

The various reasons cited by the participants (n=43) for non- availing of insurance include the following:

i. CMCHIS was not required since they went to private hospitals for subsequent treatment (n=20, 47.6%)
ii. Lack of awareness from the side of patient(n=7, 16.7%)
iii. Non-availability of documents like ration card, address proof and other proofs to avail insurance (n=6, 14.3%)
iv. Patient being ineligible to avail insurance due to their employment / socioeconomic class.(n=3, 7.1%)

v. Migrated to other states for treatment purpose(n=6, 14.3%)

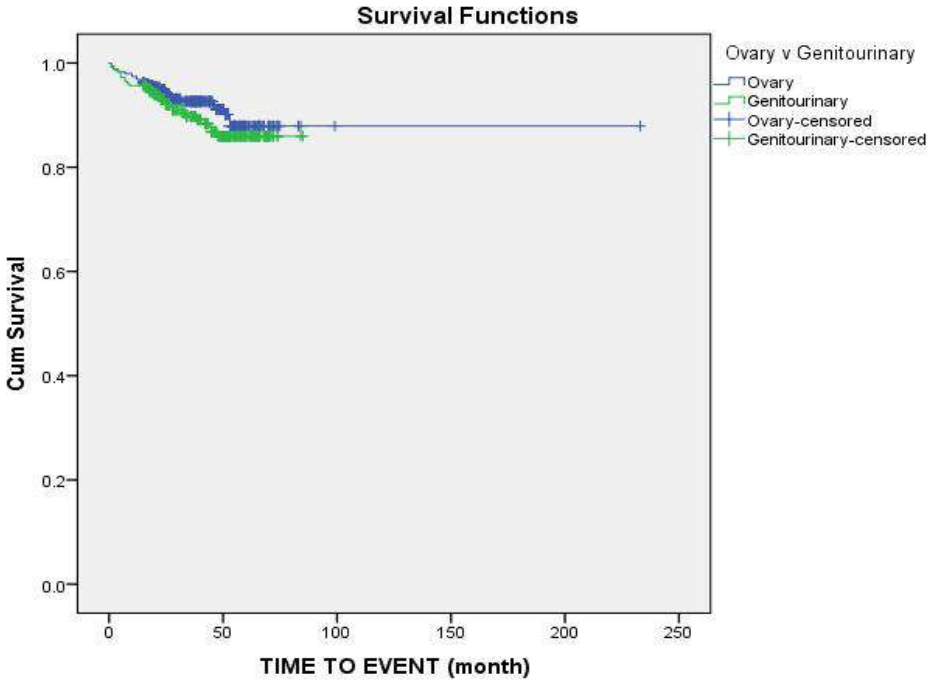
The total expenditure (including insurance) towards diagnostic services ranged from Rs.500 to Rs.10,05,000. The total expenditure (including insurance) towards surgical procedures ranged from Rs. 1,000 to Rs.10,08,000. The total expenditure (including insurance) towards chemotherapy ranged from Rs. 1,000 to Rs.10,50,000. The total expenditure (including insurance) towards radiation ranged from Rs. 1,000 to Rs.10,07,000 and the total expenditure (including insurance) towards palliative care services was around Rs. 56,000. Other expenses ranged from Rs. 50,000 to Rs. 60,00,000.

More than half (55.8%) participants reported that they have got debts due to expenses towards cancer management. Participants with testicular malignancy followed by ovarian malignancy had more debts than participants with other types of malignancies. The overall catastrophic health expenditure (CHE) rate was 71.9% (436/606) among the study participants. Catastrophic expenditure was highest among those with malignancies of the urinary bladder (80%) and testis (80%) and least among those with renal malignancy (67.4%).

5.6.5 Survival rates

The survival rates were analyzed using Kaplan Meier survival rates with log rank test.

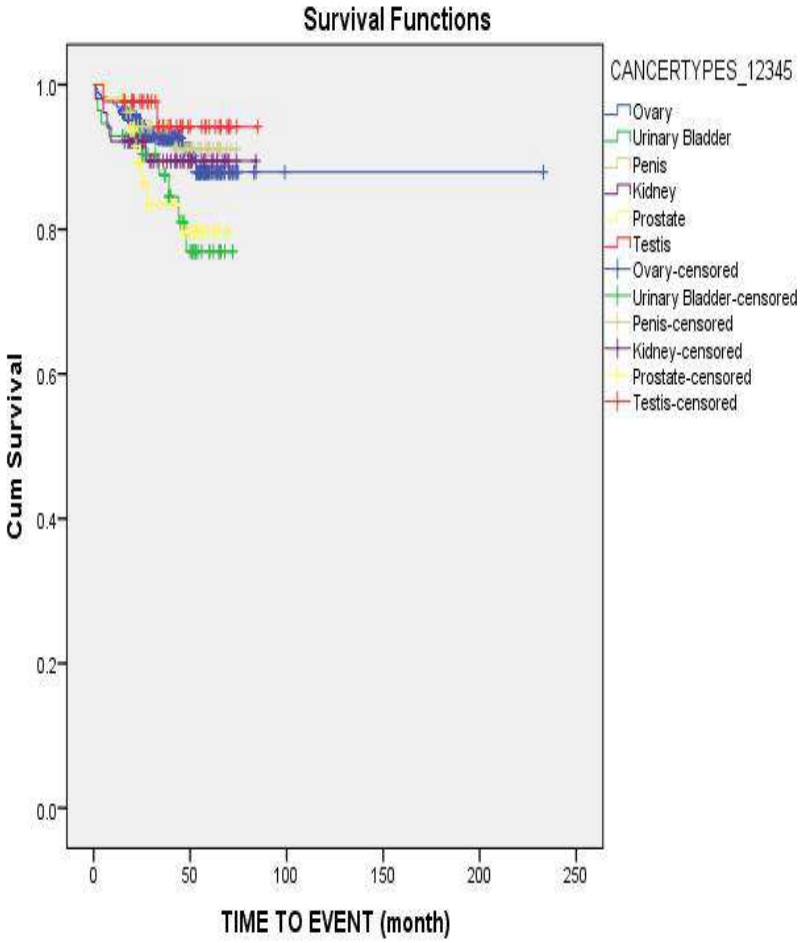
Figure 17: Plots of Kaplan-Meier product limit estimates of survival of a group of participants with ovarian and genitourinary malignancy



Log rank test - p value = 0.280

Participants with ovarian malignancies had a comparatively better survival than participants with genitourinary malignancy. Participants with testicular malignancy had better survival rates than participants with other malignancies. Participants with bladder malignancies had the least survival rates with worse survival prognosis. (Figure 17, Figure 18)

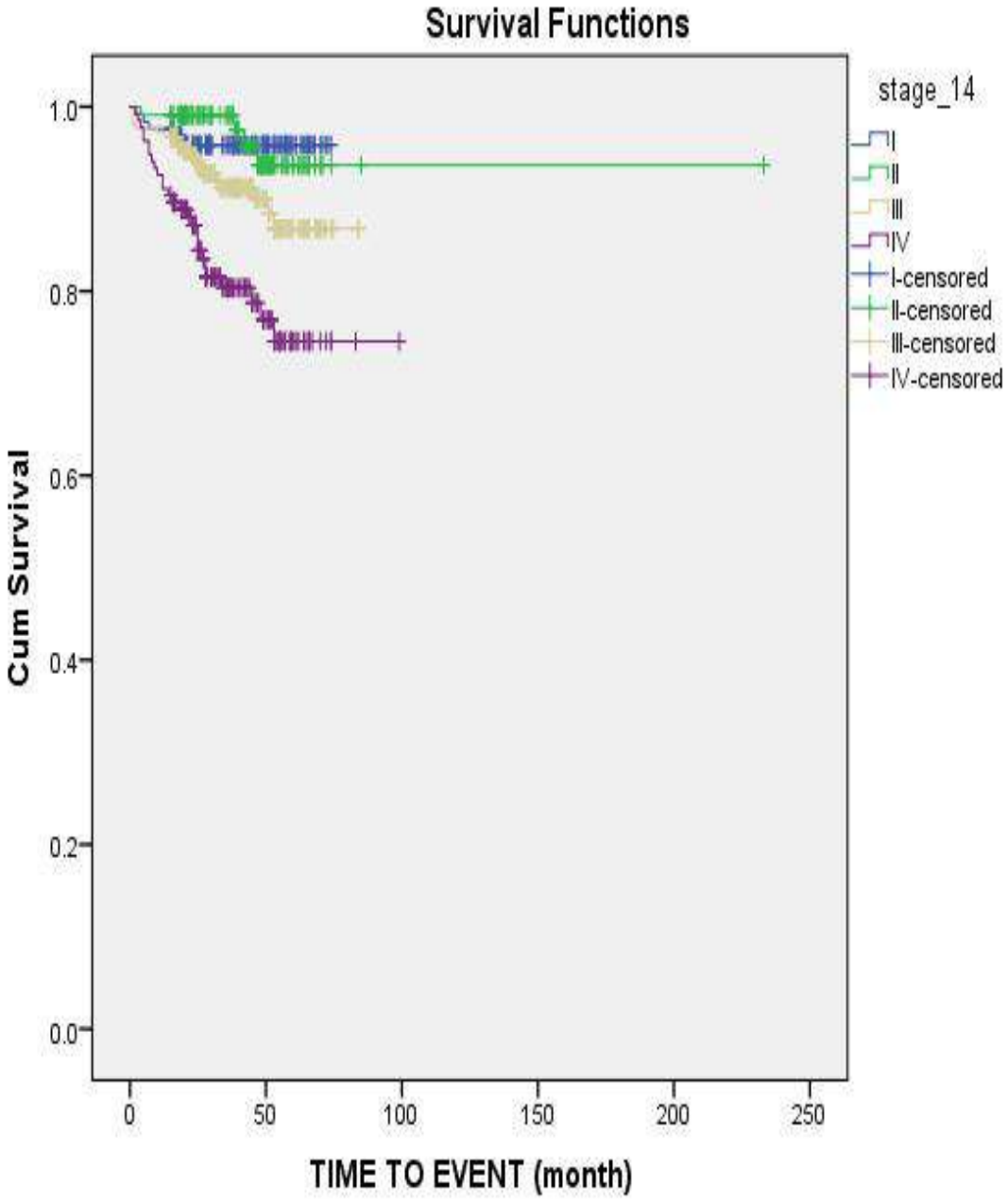
Figure 18: Plots of Kaplan-Meier product limit estimates of survival of a group of participants with various types of malignancies



Log rank test - p value = 0.727

As the stage of the cancer progresses, the survival rates worsen. This indicates a higher event rate with stage IV disease and therefore a worse survival prognosis as the stage of the disease progresses. This difference is found to be statistically significant. p= 0.0001 (S) (Figure 19).

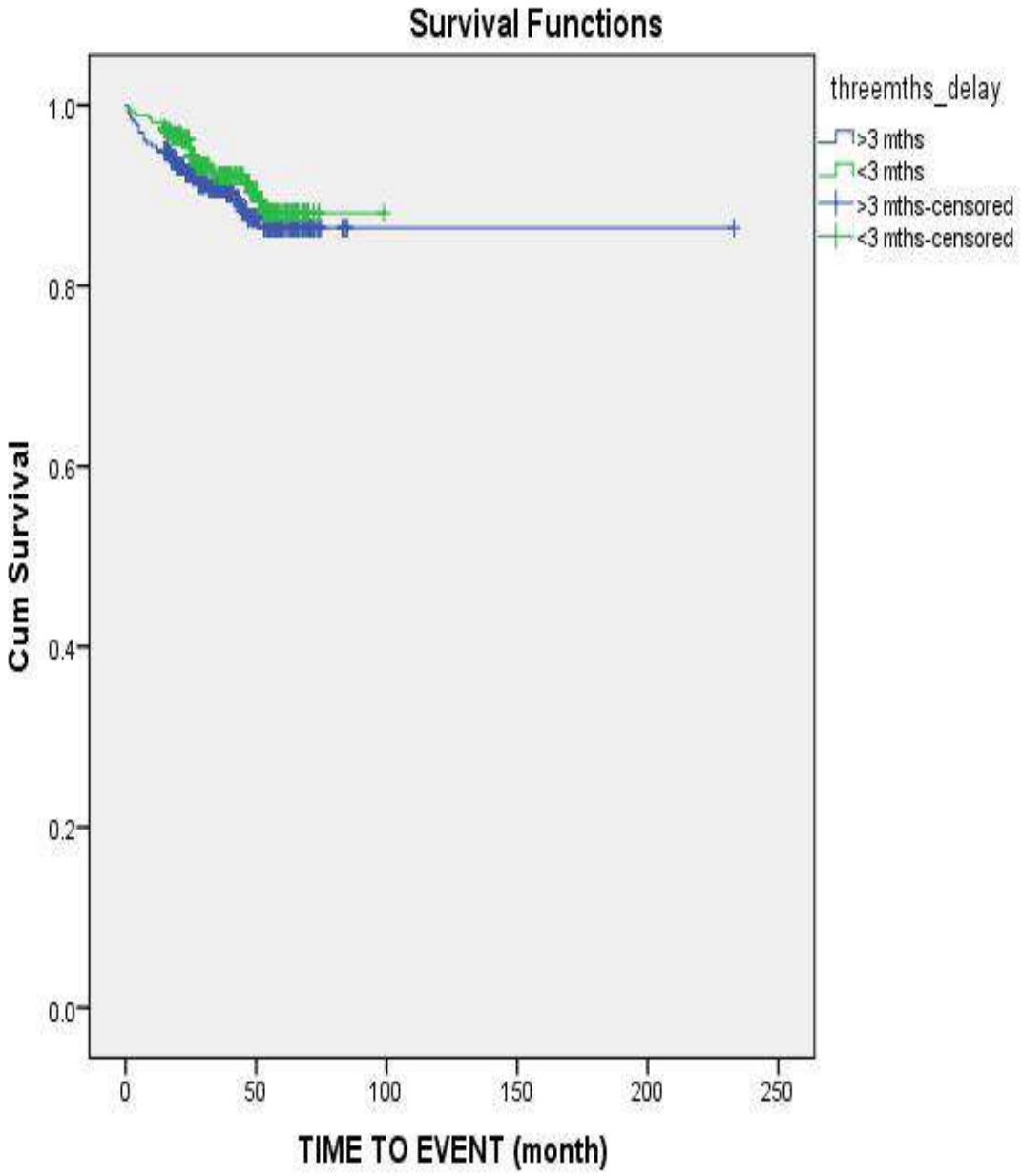
Figure 19: Plots of Kaplan-Meier product limit estimates of survival of a group of participants at various stages of cancer



Log rank test - p value = 0.0001 (S)

Participants with a total delay in cancer care of less than 3 months had better survival than participants who had a total delay of more than 3 months. This difference was not statistically significant. (Figure 20)

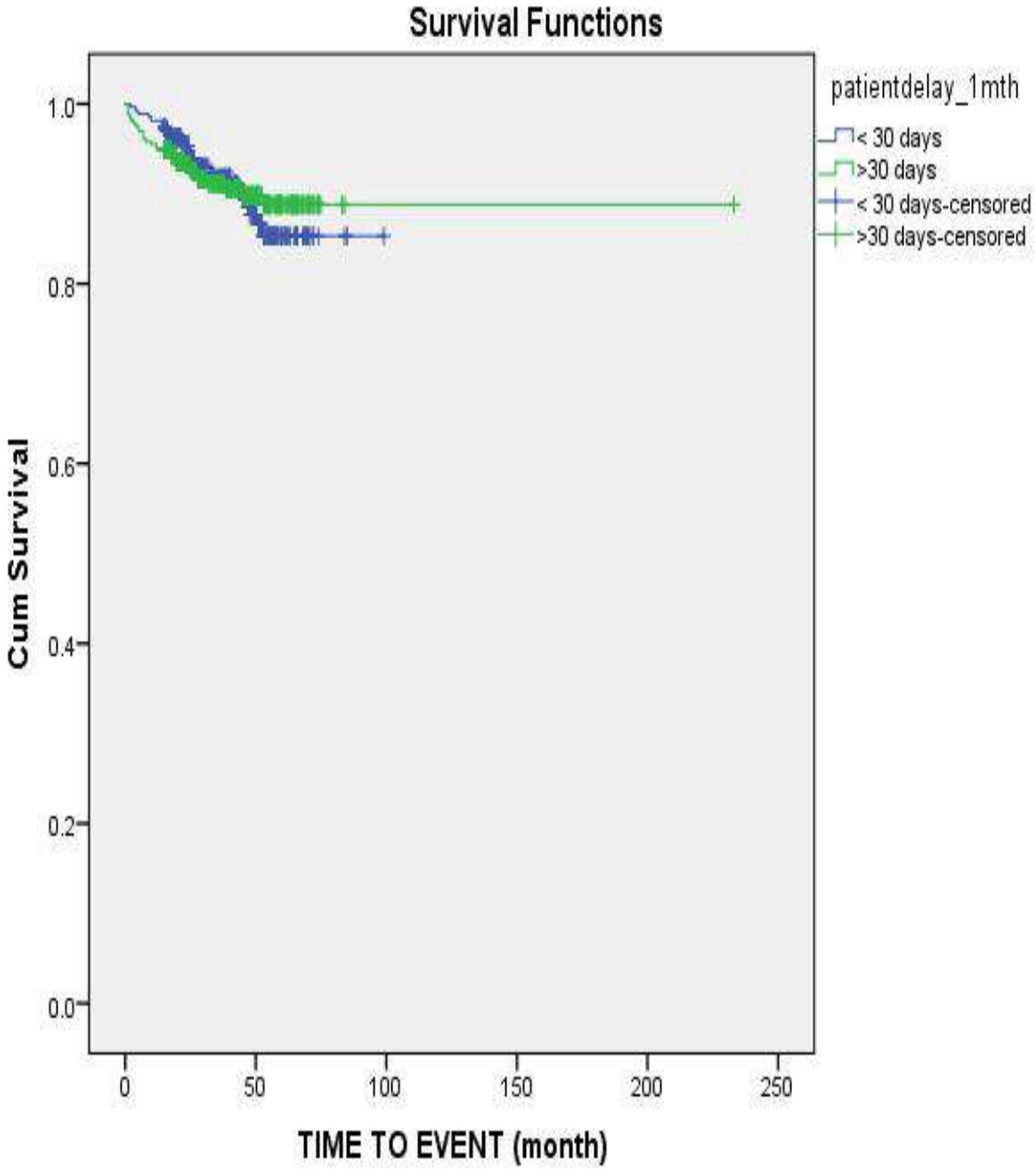
Figure 20: Plots of Kaplan-Meier product limit estimates of survival of a group of participants with a total delay of less than 3 months and more than 3 months



Log rank test - p value = 0.329

Participants with an access interval of less than 30 days had better survival than participants who had a delay of more than 30 days. But this difference was not statistically significant. (Figure 21)

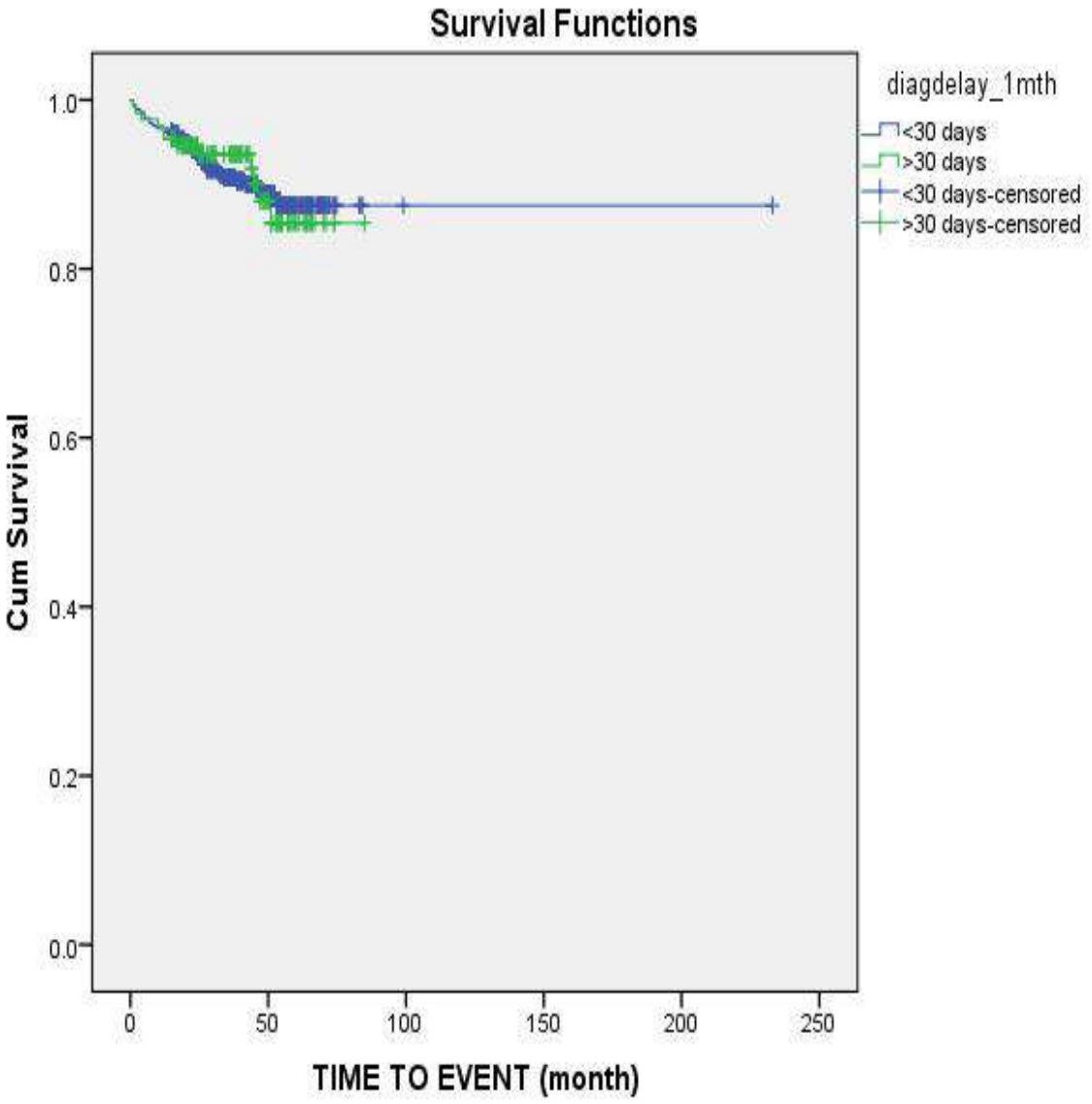
Figure 21: Plots of Kaplan-Meier product limit estimates of survival of a group of participants with access interval of less than 30 days and more than 30 days



Log rank test - p value = 0.883

Participants with a delay in obtaining a cancer diagnosis of more than 1 month had worse survival than participants who had an interval of less than1 month. This difference was not statistically significant. (Figure 22)

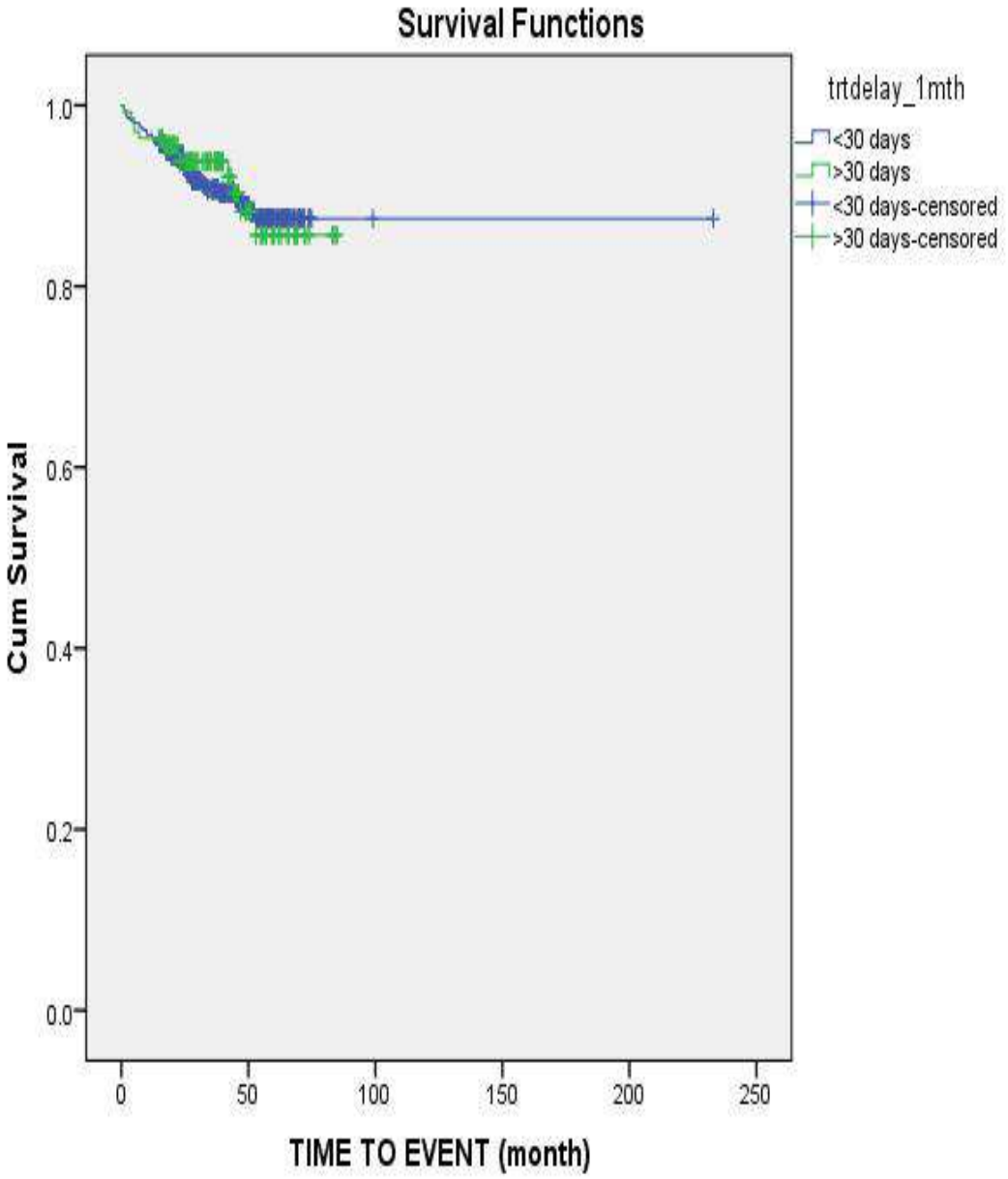
Figure 22 : Plots of Kaplan-Meier product limit estimates of survival of a group of participants with diagnostic interval of less than 30 days and more than 30 days



Log rank test - p value = 0.992

Participants with a delay in initiating cancer treatment of more than 1 month had worse survival than participants who had an interval of less than1 month. This difference was not statistically significant. (Figure 23)

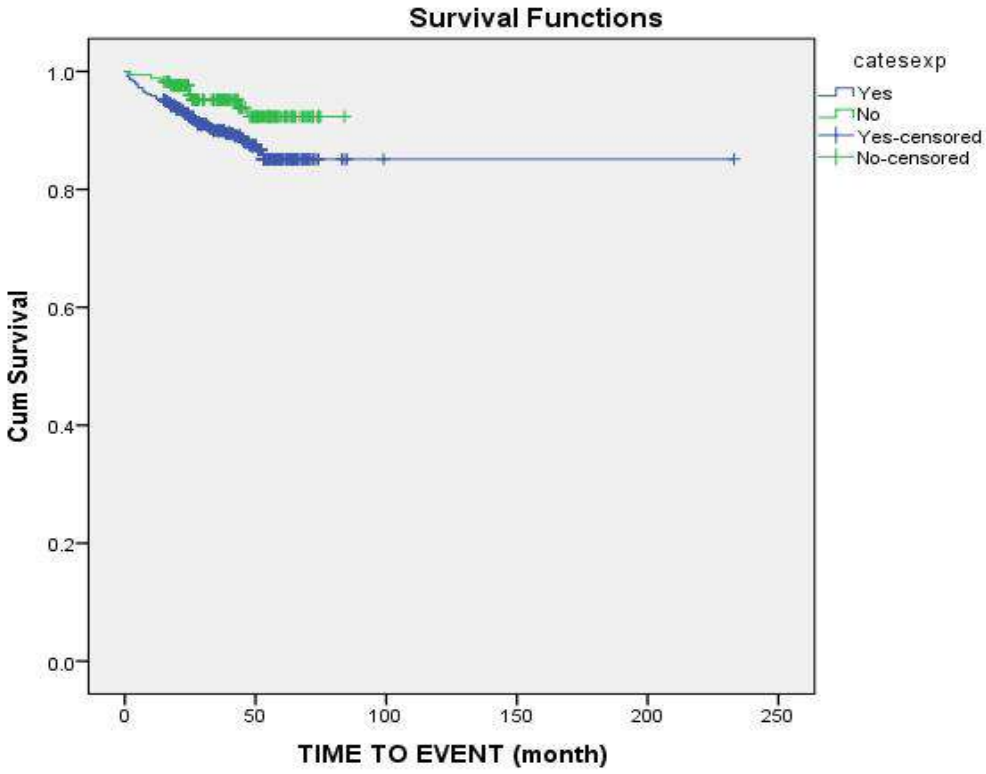
Figure 23: Plots of Kaplan-Meier product limit estimates of survival of a group of participants with treatment interval of less than 30 days and more than 30 days



Log rank test - p value = 0.880

Participants who suffered from high catastrophic health expenditure towards cancer management had a statically significant higher event rate, therefore had worse cancer survival prognosis than participants who did not suffer from catastrophic health expenditure. (p = 0.042) (Figure 24)

Figure 24: Plots of Kaplan-Meier product limit estimates of survival of a group of participants with catastrophic health expenditure and without catastrophic health expenditure.



Log rank test - p value = 0.042 (S)

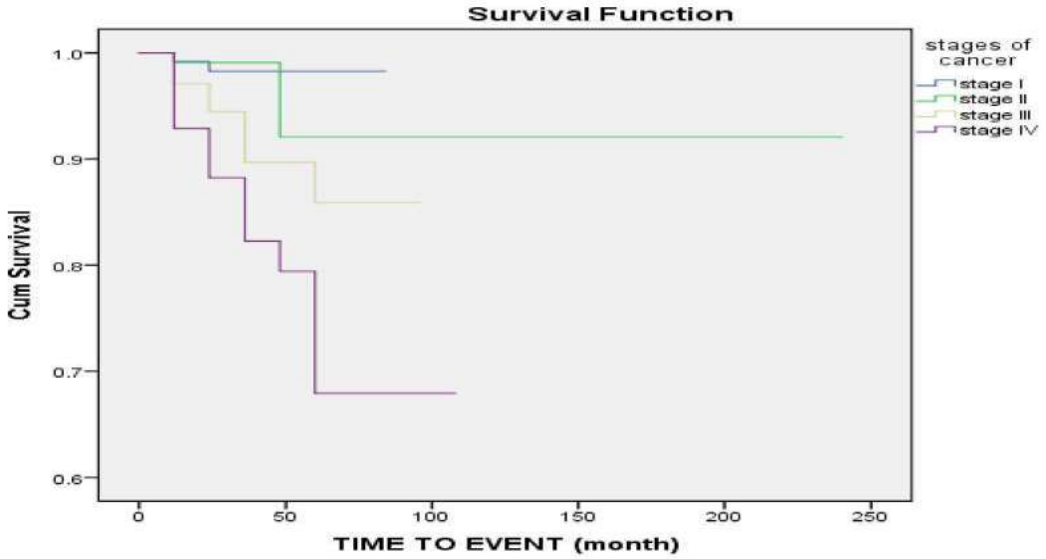
Considering the study population as a retrospective cohort, 5-year survival rates were calculated with lifetable analysis.

5-year survival of participants with various stages at the time of diagnosis is given in the Table 18 and figure 25 below.

Table 18: 5-year survival of participants with various stages at the time of diagnosis

CANCER STAGES	5 YEAR SURVIVAL
I(n=124)	98%
II (n=111)	92%
III (n=207)	86%
IV (n=140)	68%

Figure 25: 5-year survival of participants with various stages at the time of diagnosis

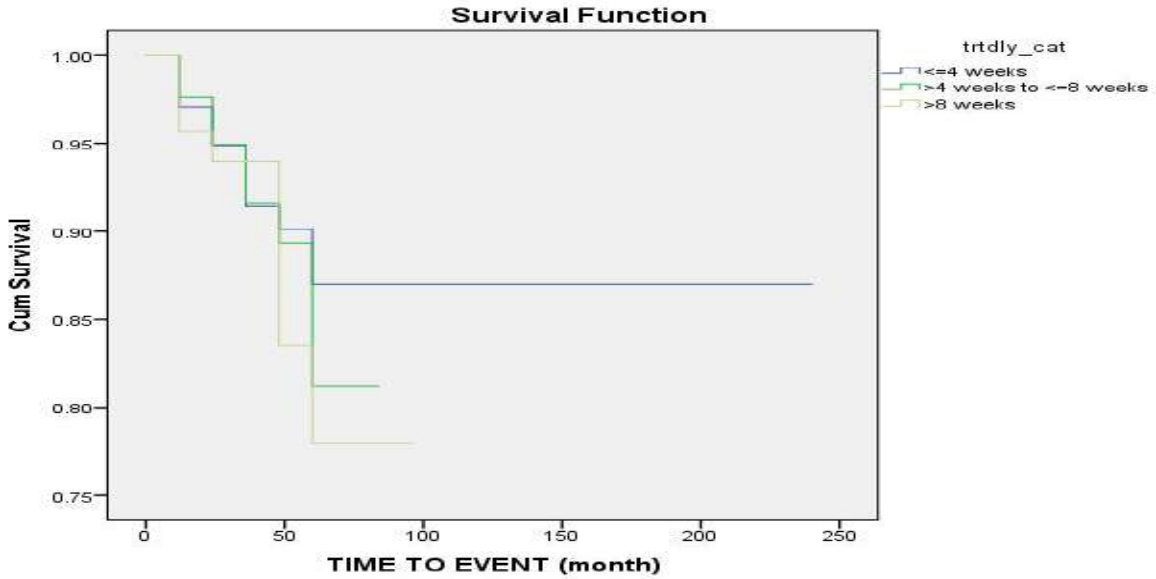


The 5-year survival of participants with treatment delay is given in the table 19 and figure 26 below.

Table 19:5-year survival of cancer patients with treatment delay:

Treatment delay	5 years survival
≤ 4 weeks (n=453)	87%
> 4 weeks to ≤ 8 weeks (n=84)	81%
> 8 weeks (n=69)	78%

Figure 26:5 year survival of cancer patients with treatment delay:



5.67. Spiritual coping:

The level of spiritual coping was assessed in a subset of the population (N=140) using RCOPE questionnaire. seven questions were asked on the positive coping and seven questions were asked on the negative coping and the mean and SD were computed. (Table 20)

Table 20: Distribution of positive and negative spiritual coping among the study participants:

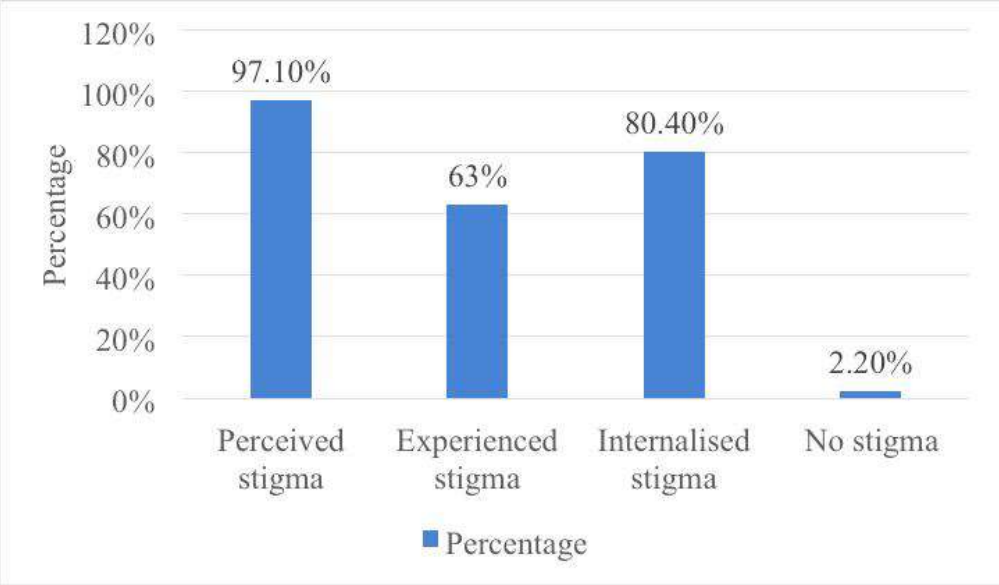
RELIGIOUS COPING	MEAN	SD
POSITIVE	13.08	5.247
NEGATIVE	11.16	3.845

The mean scores of positive religious coping and negative religious coping were 13.08 ± 5.247 and 11.16 ± 3.845 respectively.

5.6.8. Stigma:

Perceived stigma, experienced stigma and internalised stigma were assessed in a subset of 138 participants using a standard questionnaire.

Figure 27: Distribution of perceived, experienced and internalised stigma by the study participants:



The above chart (Figure 27) showed that among 138 participants, 97.1 % had at least one measure of perceived stigma. 63 % of the participants reported at least one form of experienced stigma. Majority i.e., 80.4 % had at least one measure of internalised stigma.

Table 21: Perceived stigma by the study participants

S. No	Questionnaire Item	Frequency (n=138)	Percentage (%)
1.	**Perceived fears in community about cancer spread. (Response = Yes)**	62	44.9
2.	**Perceived thoughts in the community about cancer being a curse or result of past sins. (Response = Yes)**	40	29
3.	**Perceived thoughts in the community to tell neighbours about cancer (Response = No)**	114	82.6
4.	**Perceived thoughts in the community to avoid talking or eating with a person having cancer (Response=Yes)**	31	22.5
5.	**Perceived beliefs in the community about the causes of cancer impeding healthcare access for the patient (Response = Agree or Strongly Agree)**	57	41.3
6.	**Perceived beliefs in the community about the causes of cancer offer difficulties in disclosing the diagnosis to others (Response = Agree or Strongly Agree)**	86	62.3
7.	**Perceived beliefs about revealing cancer diagnosis may ruin community respect. (Response = Agree or Strongly Agree)**	104	75.4

The perceived stigma by the patients is summarized in the table 21. Nearly half (44.9%) told people in the community believed cancer to be contagious.While 29% perceived that the community held the belief that cancer was a curse or a result of past sins. Majority (82.6%) had perceived stigma about disclosing to their neighbours about cancer diagnosis. Concerning social interactions, less than a quarter (22.5%) perceived people around would avoid talking or eating with cancer patients. Additionally, 41.3% believed that there would be difficulty in accessing healthcare due to perceived causes, and 62.3% believed there would be challenges in disclosing the diagnosis to others. A significant majority (75.4%) believed that community awareness of their cancer diagnosis would lead to a loss of respect.

Table 22: Experienced stigma by the study participants:

	Questionnaire item	Frequency (n=138)	%
1.	**Excluded from social or work gathering**	15	10.9
2.	**Excluded from religious activities or place of worship**	7	5.1
3	**Excluded from meals**	6	4.3
4	**Aware of family members making discriminatory remarks or gossip about you**	54	39.1
5	**Verbally harassed**	38	27.5
6	**Physical abuse/harassment**	5	3.6
7	**Worried people might contract cancer from them**	19	13.8
8	**Denial of health care**	15	10.9
9	**Denial of health insurance**	6	4.3
10	**Lost a job or source of income**	67	48.6

The experienced stigma by the participants is summarized in table 22. Among 138 participants, social exclusion affected 10.9%, 5.1% and 4.3% in work, religious and meal contexts respectively. Around 39.1% reported hearing gossip or offensive comments made about them by relatives. More than one fourth (27.5%) endured verbal harassment, 3.6% of the patients faced physical harassment and nearly 10.9 % were denied health care. Almost 48.6% lost a job or source of income.

Table 23: Internalised stigma by the study participants:

S.No	Questionnaire item	Frequency	Percentage
1.	**Not feeling comfortable telling others about my disease (Response = Agree or Strongly Agree)**	120	87
2.	**Hiding my cancer from others. (Response = Agree or Strongly Agree)**	110	79.7
3.	**Avoiding social gatherings because of cancer. (Response = Agree or Strongly Agree)**	53	38.4
4.	**Feeling ashamed to have cancer. (Response = Agree or Strongly Agree)**	49	35.5

The internalised stigma by the participants is summarized in the table 23. A significant majority, almost 87%, felt uncomfortable disclosing their disease. Fear for their child's future was a motivating factor in non-disclosure of diagnosis to the relatives or society. Nearly 79.7% actively hide their cancer from others. Around 38.4% avoided social gatherings and nearly 35.5% felt ashamed for having cancer.

5.7 ASSOCIATION OF TOTAL DELAY WITH VARIOUS FACTORS IN THE STUDY POPULATION

5.7.1 Association of total delay with various cancers under study among the study population

Participants with malignancy of the penis (p=0.0001), ovary (p=0.008) and testis (p=0.0001) had a statistically significant higher total delay in cancer care of more than 3 months. The estimated adjusted odd ratio (OR) for Carcinoma penis (OR: 6.57, 95% CI: 2.73-15.82), Carcinoma testis (OR: 5.18, 95% CI: 2.09-12.86) and Carcinoma ovary (OR: 2.33, 95% CI: 1.24-4.36) indicated that those with carcinoma penis, carcinoma testis and carcinoma ovary are 6.57 times, 5.18 times and 2.33 times more likely to have a total delay of more than 3 months as compared to participants with carcinoma kidney. This association is shown in table 24 below.

Table 24: Association of total delay with various cancers under study among the study population (N=606)

Variable		Total delay		Total	COR (95%CI)	p value	AOR (95%CI)	p value
		> 3 Months	< 3 Months					
Type of cancer	Ovary	193 (55.3%)	156 (44.7%)	349 (100%)	2.08 (1.14 – 3.82)	**0.018**	2.33 (1.24-4.36)	**0.008**
	Urinary bladder	27 (47.4%)	30 (52.6%)	57 (100%)	1.52 (0.70 – 3.27)	0.290	1.59 (0.72-3.53)	0.252
	Penis	42 (76.4%)	13 (23.6%)	55 (100%)	5.44 (2.34-12.63)	**0.0001**	6.57 (2.73-15.82)	**0.0001**

	Kidney	19 (37.3%)	32 (62.7%)	51 (100%)	1		1	
	Prostate	22 (43.1%)	29 (56.9%)	51 (100%)	1.28 (0.58 – 2.82)	0.545	1.28 (0.56-2.91)	0.555
	Testis	30 (69.8%)	13 (30.2%)	43 (100%)	3.89 (1.64-9.22)	**0.002**	5.18 (2.09-12.86)	**0.0001**
Total		333 (55%)	273 (45%)	606 (100%)				

Reference category: <3 months

5.7.2 Association of total delay with multiple factors among the study population

Participants who visited multiple health care facilities [OR- 1.63, 95% CI (1.03-2.58)] and participants who were physical active [OR - 0.56, 95% CI (0.37-0.85) had statistically significant association with predicted total delay. Participants who visited multiple care facilities were 1.63 times more likely to be in more than 3 months delay group holding all other variables constant. This suggests that as the patient visits more than two health care facilities, the odds of him falling into more than 3 months delay increases. Cancer patients who were physically active were 0.56 times less likely to have more than 3 months' delay holding all other variables constant. This result suggests us that as the person becomes more physically active, the odds of him falling into more than 3 months' delay decreases. (Table 25)

Table 25: Association of total delay with multiple factors among the study population (N=606)

Variable		**Total delay**		**Total**	**COR (95%CI)**	**p value**	**AOR (95%CI)**	**p value**
		> 3Months	**< 3Months**					
Age groups	**20-30 years**	17 (63%)	10 (37%)	27 (100%)	1.51 (0.67-3.44)	0.322		
	30-40 years	35 (67.3%)	17 (32.7%)	52 (100%)	1.83 (0.98-3.45)	0.06		

	40-50 years	61 (57%)	46 (43%)	107 (100%)	1.18 (0.75 –1.87)	0.48		
	50-60 years	92 (51.7%)	86 (48.3%)	178 (100%)	0.95 (0.65 –1.40)	0.81		
	>60 years	128 (52.9%)	114 (47.1%)	242 (100%)	1			
Gender	**Male**	123 (55.2%)	100 (44.8%)	223 (100%)	1.01 (0.73 –1.41)	0.94		
	Female	210 (54.8%)	173 (45.2%)	383 (100%)	1			
Residence	**Rural**	211 (57.8%)	154 (42.2%)	365 (100%)	1.86 (0.90-3.82)	0.09	1.40 (0.65-3.03)	0.389
	Urban	108 (51.9%)	100 (48.1%)	208 (100%)	1.47 (0.69-3.08)	0.31	1.12 (0.50-2.49)	0.777
	Semi urban	14 (42.4%)	19 (57.6%)	33 (100%)	1		1	
Education	**Literate**	222 (56.1%)	174 (43.9%)	396 (100%)	1			
	Illiterate	111 (52.9%)	99 (47.1%)	210 (100%)	0.88 (0.63-1.23)	0.45		
Occupation	**Employed**	151 (56.1%)	118 (43.9%)	269 (100%)	1			
	Unemployed	182 (54%)	155 (46%)	337 (100%)	0.92 (0.67-1.27)	0.60		
SES - BG Prasad scale	**I**	45 (58.4%)	32 (41.6%)	77 (100%)	0.96 (0.48 –1.92)	0.92		
	II	88 (51.2%)	84 (48.8%)	172 (100%)	0.72 (0.39-1.31)	0.28		
	III	111 (57.2%)	83 (42.8%)	194 (100%)	0.92 (0.51- 1.66)	0.77		
	IV	54 (51.9%)	50 (48.1%)	104 (100%)	0.74 (0.39-.41)	0.36		
	V	35 (59.3%)	24 (40.7%)	59 (100%)	1			

Primary care giver	**Present**	330 (54.8%)	272 (45.2%)	602 (100%)	0.40 (0.04 –3.91)	0.43		
	Absent	3 (75%)	1 (25%)	4 (100%)	1			
Multiple care givers	**Yes**	116 (63.4%)	68 (36.6%)	186 (100%)	1.66 (1.16- 2.36)	**0.005**	1.42 (0.95-2.12)	0.089
	No	215 (51.2%)	205 (48.8%)	420 (100%)	1		1	
	No	304 (53.8%)	261 (46.2%)	565 (100%)	1		1	
Comorbidities	**Yes**	130 (55.8%)	103 (44.2%)	233 (100%)	1.06 (0.76-1.47)	0.74		
	No	203 (54.4%)	170 (45.6%)	373 (100%)	1			
Presence of symptom before diagnosis	**Yes**	326 (55.9%)	257 (44.1%)	583 (100%)	2.89 (1.18-7.15)	**0.020**	2.06 (0.81-5.22)	0.128
	No	7 (30.4%)	16 (69.6%)	23 (100%)	1		1	
Visit multiple facilities	**Yes**	275 (56.9%)	208 (43.1%)	483 (100%)	1.51 (1.01-2.25)	**0.043**	1.63 (1.03-2.58)	**0.036**
	No	57 (46.7%)	65 (53.3%)	122 (100%)	1		1	
Physically active	**Yes**	75 (45.2%)	91 (54.8%)	166 (100%)	0.58 (0.41-0.83)	**0.003**	0.56 (0.37-0.85)	**0.006**
	No	258 (58.6%)	182 (41.4%)	440 (100%)	1		1	
Medical insurance	**Yes**	310 (55%)	254 (45%)	564 (100%)	1.01 (0.54-0.89)	0.98		
	No	23 (54.8%)	19 (45.2%)	42 (100%)				
Catastrophic expenditure	**Yes**	249 (57.1%)	187 (42.9%)	436 (100%)	1.36 (0.96-1.95)	0.088	1.13 (0.77–1.67)	0.536
	No	84 (49.4%)	86 (50.6%)	170 (100%)	1		1	
Total		333 (55%)	273 (45%)	606 (100%)				

Reference category: <3 months

5.7.3 Association of total delay with various factors among the study population with ovarian malignancy

Participants with ovarian malignancy residing in rural areas (p =0.02), having multiple caregivers (p=0.016), visiting multiple health facilities (p =0.005) and physically inactive (p=0.0001) were found to have a statistically significant greater total delay of more than 3 months. This association is found in the table 26 below.

Table 26: Association of total delay with various factors among the study population with ovarian malignancy (N=349)

Variable		Total delay		Total	Chi Square value	p value
		> 3 Months	< 3 Months			
Age	**20-29 years**	9 (60%)	6 (40%)	15 (100%)	4.003	0.41
	30-39 years	22 (68.8%)	10 (31.3%)	32 (100%)		
	40-49 years	44 (57.1%)	33 (42.9%)	77 (100%)		
	50-59 years	66 (55%)	54 (45%)	120 (100%)		
	≥ 60 years	52 (49.5%)	53 (50.5%)	105 (100%)		
Residence	**Rural**	130 (60.5%)	85 (39.5%)	215 (100%)	7.722	**0.02**
	Urban	55 (49.5%)	56 (50.5%)	111 (100%)		
	Semi urban	8 (34.8%)	15 (65.2%)	23 (100%)		
Education	**Literate**	112 (54.9%)	92 (45.1%)	204 (100%)	0.032	0.913
	Illiterate	81 (55.9%)	64 (44.1%)	145 (100%)		
Multiple care givers	**Yes**	73 (64.6%)	40 (35.4%)	113 (100%)	5.848	**0.016**
	No	120 (50.8%)	116 (49.2%)	236 (100%)		

Visit multiple facilities	**Yes**	172 (58.7%)	121 (41.3%)	293 (100%)	8.551	**0.005**
	No	21 (37.5%)	35 (62.5%)	56 (100%)		
Physically active	**Yes**	43 (41.7%)	60 (58.3%)	103 (100%)	10.859	**0.001**
	No	150 (61%)	96 (39%)	246 (100%)		
Catastrophic expenditure	**Yes**	140 (57.6%)	103 (42.4%)	243 (100%)	1.731	0.199
	No	53 (50%)	53 (50%)	106 (100%)		
Total		193 (55.3%)	156 (44.7%)	349 (100%)		

5.7.4 Association of total delay with various factors among the study population with genitourinary malignancy

Participants with genitourinary malignancy who get guidance from a health care provider for cancer management faced greater delay in cancer care and management. This association was found to be statistically significant. (p =0.007) (Table 27)

Table 27: Association of total delay with various factors among the study population with genitourinary malignancy (N=257)

Variable		**Total delay**		**Total**	**Chi Square value**	**p value**
		> 3 Months	**< 3 Months**			
Age	**20-29 years**	8 (66.7%)	4 (33.3%)	12 (100%)	3.903	0.427
	30-39 years	13 (65%)	7 (35%)	20 (100%)		
	40-49 years	17 (56.7%)	13 (43.3%)	30 (100%)		
	50-59 years	26 (44.8%)	32 (55.2%)	58 (100%)		

	≥ 60 years	76 (55.5%)	61 (44.5%)	137 (100%)		
Gender	**Male**	123 (55.2%)	100 (44.8%)	223 (100%)	0.316	0.585
	Female	17 (50%)	17 (50%)	34 (100%)		
Residence	**Rural**	81 (54%)	69(46%)	150 (100%)	0.138	0.975
	Urban	53 (54.6%)	44 (45.4%)	97 (100%)		
	Semi urban	6 (60%)	4 (40%)	10 (100%)		
Education	**Literate**	110 (57.3%)	82 (42.7%)	192 (100%)	2.429	0.149
	Illiterate	30 (46.2%)	35 (53.8%)	65 (100%)		
Multiple care givers	**Yes**	45 (61.6%)	28 (38.4%)	73 (100%)	2.113	0.166
	No	95 (51.6%)	89 (48.4%)	184 (100%)		
Physically active	**Yes**	32 (50.8%)	31 (49.2%)	63 (100%)	0.456	0.561
	No	108 (55.7%)	86 (44.3%)	194 (100%)		
Catastrophic expenditure	**Yes**	109 (56.5%)	84 (43.5%)	193 (100%)	1.253	0.311
	No	31 (48.4%)	33 (51.6%)	64 (100%)		
Total		140 (54.5%)	117 (445.5%)	257 (100%)		

5.8 ASSOCIATION OF ACCESS DELAY WITH VARIOUS FACTORS IN THE STUDY POPULATION

5.8.1 Association of access delay with types of cancer under study among the study population

Participants with carcinoma ovary, carcinoma penis and carcinoma testis had a statistically significant association with the access interval at the level of 5%. The estimated adjusted odd ratio (OR) for Carcinoma penis (OR: 5.12, 95% CI: 2.10-12.50), Carcinoma testis (OR: 3.14, 95% CI: 1.16-8.48) and Carcinoma ovary (OR: 2.04, 95% CI: 1.04-3.99) indicated

that those with carcinoma penis, carcinoma testis and carcinoma ovary were 5.12 times, 3.14 times and 2.04 times more likely to access the health facility after 30 days of symptom onset compared to participants with carcinoma kidney. (Table 28)

Table 28: Association of access delay with types of cancer under study among the study population (N=606)

Variable		Access interval		Total	COR (95%CI)	p value	AOR (95%CI)	p value
		> 30 days	< 30 days					
Type of cancer	**Ovary**	204 (58.5%)	145 (41.5%)	349 (100%)	2.01 (1.11-3.65)	**0.022**	2.04 (1.04-3.99)	**0.038**
	Urinary bladder	21 (36.8%)	36 (63.2%)	57 (100%)	0.833(0.38 – 1.81)	0.645	0.91 (0.39 – 2.12)	0.835
	Penis	39 (70.9%)	16 (29.1%)	55 (100%)	3.48 (1.56-7.79)	**0.002**	5.12 (2.10 – 12.50)	**0.0001**
	Kidney	21 (41.2%)	30 (58.8%)	51 (100%)	1		1	
	Prostate	19 (37.3%)	32 (62.7%)	51 (100%)	0.85 (0.38-1.88)	0.685	0.79 (0.33 – 1.88)	0.592
	Testis	30 (69.8%)	13 (30.2%)	43 (100%)	3.29 (1.39-7.77)	**0.006**	3.14 (1.16 – 8.48)	**0.024**
Total		334 (55.1%)	272 (44.9%)	606 (100%)				

Reference category: <30 days

5.8.2 Association of access delay with multiple factors among the study population

On analysing the influence of various factors on delayed access to healthcare facilities it was found that the participants who had symptoms before diagnosis, participants who visited multiple health care facilities, participants who were physically inactive and participants who had high catastrophic expenditure had statistically significant association with an accesss interval of more than 30 days considering p value as 0.05. The estimated adjusted odd ratio (OR) for presence of symptoms before diagnosis (OR: 8.03, 95% CI: 2.21-29.22), visiting multiple facilities (OR: 1.843, 95% CI: 1.16-2.93), physically active persons (OR: 0.56, 95% CI: 0.36-0.87) and catastrophic expenditure (OR: 1.58, 95% CI: 1.05-2.36) indicated that those presented

with symptoms before diagnosis, those who visited multiple healthcare facilities and people who had gone through catastrophic spending were 8.03 times, 1.843 times and 1.58 times more likely to access the healthcare facilities after 30 days of symptom onset respectively. Participants who were physically active were 0.56 times more likely to reach health facilities within 30 days of symptom onset. (Table 29)

Table 29: Association of access delay with multiple factors among the study population (N=606)

Variable		Access interval		Total	COR (95%CI)	p value	AOR (95%CI)	p value
		> 30 days	< 30 days					
Age	**20-29 years**	20 (74.1%)	7 (25.9%)	27 (100%)	2.76 (1.13-6.78)	**0.026**	1.91 (0.69-5.33)	0.216
	30-39 years	34 (65.4%)	18 (34.6%)	52 (100%)	1.83 (0.98-3.41)	0.058	1.60 (0.75 – 3.43)	0.229
	40-49 years	62 (57.9%)	45 (42.1%)	107 (100%)	1.33 (0.84-2.11)	0.220	1.00 (0.58 – 1.70)	0.982
	50-59 years	95 (53.4%)	83 (46.6%)	178 (100%)	1.11 (0.75-1.63)	0.606	0.97 (0.62 – 1.50)	0.881
	≥ 60 years	123 (50.8%)	119 (49.2%)	242 (100%)	1		1	
Gender	**Male**	114 (51.1%)	109 (48.9%)	223 (100%)	0.78 (0.56 -1.08)	0.775		
	Female	220 (57.4%)	163 (42.6%)	383 (100%)	1			
Residence	**Rural**	212 (58.1%)	153 (41.9%)	365 (100%)	1.30 (0.64-2.66)	0.47		
	Urban	105 (50.5%)	103 (49.5%)	208 (100%)	0.96 (0.46-2.00)	0.912		
	Semi urban	17 (51.5%)	16 (48.5%)	33 (100%)	1			

Education	**Literate**	218 (55.1%)	178 (44.9%)	396 (100%)	1			
	Illiterate	116 (55.2%)	94 (44.8%)	210 (100%)	1.008 (0.72-1.41)	0.965		
Occupation	**Employed**	149 (55.4%)	122 (44.6%)	269 (100%)	1			
	Unemployed	185 (54.9%)	152 (45.1%)	337 (100%)	0.98 (0.71-1.35)	0.903		
SES - BG Prasad scale	**I**	50 (64.9%)	27 (35.1%)	77 (100%)	0.95 (0.47-1.94)	0.887	1.20 (0.54-2.68)	0.656
	II	90 (52.3%)	82 (47.7%)	172 (100%)	0.56 (0.30-1.04)	0.068	0.60 (0.31 – 1.20)	0.149
	III	110 (56.7%)	84 (43.3%)	194 (100%)	0.67 (0.37-1.24)	0.200	0.69 (0.35 – 1.39)	0.300
	IV	45 (43.3%)	59 (56.7%)	104 (100%)	0.39 (0.20-0.76)	**0.006**	0.33 (0.16 – 0.70)	**0.003**
	V	39 (66.1%)	20 (33.9%)	59 (100%)	1		1	
Primary care giver	**Present**	331 (55%)	271 (45%)	602 (100%)	0.41 (0.04-3.94)	0.438		
	Absent	3 (75%)	1 (25%)	4 (100%)	1			
Multiple care givers	**Yes**	120 (64.5%)	66 (35.5%)	186 (100%)	1.75 (1.23-2.49)	**0.002**	1.411 (0.93-2.15)	0.11
	No	214 (51%)	206 (49%)	420 (100%)	1	1	1	
Comorbidities	**Yes**	127 (54.5%)	106 (45.5%)	233 (100%)	0.961 (0.691-1.34)	0.812		
	No	207 (55.5%)	166 (44.5%)	373 (100%)	1			

Presence of symptoms before diagnosis	**Yes**	331 (56.8%)	252 (43.2%)	583 (100%)	8.76 (2.57-29.79)	**0.001**	8.03 (2.21-29.22)	**0.002**
	No	3 (13%)	20 (87%)	23 (100%)	1		1	
Quit smoking currently	**Yes**	36 (40.4%)	53 (59.6%)	89 (100%)	0.499 (0.32-0.79)	**0.003**	0.70 (0.39 – 1.26)	0.24
	No	298 (57.6%)	219 (42.4%)	517 (100%)			1	
Visit multiple facilities	**Yes**	278 (57.6%)	205 (42.4%)	483 (100%)	1.60 (1.07 – 2.38)	**0.021**	1.843 (1.16 – 2.93)	**0.010**
	No	56 (45.9%)	67 (54.1%)	123 (100%)	1		1	
Physically active	**Yes**	75 (45.2%)	91 (54.8%)	166 (100%)	0.58 (0.40-0.83)	**0.003**	0.56 (0.36 – 0.87)	**0.009**
	No	259 (58.9%)	181 (41.1%)	440 (100%)			1	
Medical insurance	**Yes**	313 (55.5%)	251 (44.5%)	564 (100%)	1.25 (0.67-2.35)	0.490		
	No	21 (50%)	21 (50%)	42 (100%)	1			
Catastrophic expenditure	**Yes**	258 (59.2%)	178 (40.8%)	436 (100%)	1.79 (1.25-2.56)	**0.001**	1.58 (1.05-2.36)	**0.027**
	No	76 (44.7%)	94 (55.3%)	170 (100%)	1		1	
Total		334 (55.1%)	272 (44.9%)	606 (100%)				

Reference category: <30 days

5.8.3 Association of access delay with various factors among those with ovarian malignancy in the study population

Participants with ovarian malignancy belonging to upper socioeconomic class (p=0.005), having multiple care givers (p=0.027), visiting multiple facilities (p=0.005), following sedentary lifestyle (p=0.002) and suffering from catastrophic health expenditure (p = 0.025) had a statistically significant higher access interval of more than 30 days. (Table 30)

Table 30: Association of access delay with various factors among those with ovarian malignancy in the study population (N= 349)

Variable		Access interval		Total	Chi Square value	p value
		> 30 days	< 30 days			
Age	20-29 years	10 (66.7%)	5 (33.3%)	15 (100%)	2.1	0.72
	30-39 years	22 (68.8%)	10 (31.3%)	32 (100%)		
	40-49 years	44 (57.1%)	33 (42.9%)	77(100%)		
	50-59 years	68 (56.7%)	52 (43.3%)	120 (100%)		
	≥ 60 years	60 (57.1%)	45 (42.9%)	105 (100%)		
BG Prasad scale	I	32 (74.4%)	11 (25.6%)	43 (100%)	14.684	**0.005**
	II	56 (54.9%)	46 (45.1%)	102 (100%)		
	III	70 (61.9%)	43 (38.1%)	113 (100%)		
	IV	24 (40.7%)	35 (59.3%)	59 (100%)		
	V	22 (68.8%)	10 (31.3%)	32 (100%)		
Multiple care givers	Yes	76 (67.3%)	37 (32.7%)	113 (100%)	5.333	**0.027**
	No	128 (54.2%)	108 (45.8%)	236 (100%)		

Visit multiple facilities	**Yes**	181 (61.8%)	112 (38.2%)	293 (100%)	8.298	**0.005**
	No	23 (41.1%)	33 (58.9%)	56 (100%)		
Physically active	**Yes**	47 (45.6%)	56 (54.4%)	103 (100%)	9.892	**0.002**
	No	157 (63.8%)	89 (36.2%)	246 (100%)		
Catastrophic expenditure	**Yes**	152 (62.6%)	91 (37.4%)	243 (100%)	5.534	**0.025**
	No	52 (49.1%)	54 (50.9%)	106 (100%)		
Total		204 (58.5%)	145 (41.5%)	349 (100%)		

5.8.4 Association of access delay with various factors among those with genitourinary malignancy in the study population

Participants with genitourinary malignancy who obtained guidance from healthcare providers for cancer management (p=0.027), who continue smoking (p=0.013) and face catastrophic health expenditure (p =0.021) have a statistically significant higher access interval of more than 30 days. (Table 31)

Table 31: Association of access delay with various factors among those with genitourinary malignancy in the study population (N= 257)

Variable		**Access interval**		**Total**	**Chi Square value**	**p value**
		> 30 days	**< 30 days**			
Age	**20-29 years**	10 (83.3%)	2 (16.7%)	12 (100%)	8.549	0.075
	30-39 years	12 (60%)	8 (40%)	20 (100%)		
	40-49 years	18 (60%)	12 (40%)	30 (100%)		
	50-59 years	27 (46.6%)	31 (53.4%)	58 (100%)		
	≥ 60 years	63 (46%)	74 (54%)	137 (100%)		

BG Prasad scale	**I**	18 (52.9%)	16 (47.1%)	34 (100%)	2.167	0.709
	II	34 (48.6%)	36 (51.4%)	70 (100%)		
	III	40 (49.4%)	41 (50.6%)	81 (100%)		
	IV	21 (46.7%)	24 (53.3%)	45 (100%)		
	V	17 (63%)	10 (37%)	27 (100%)		
Multiple care givers	**Yes**	44 (60.3%)	29 (39.7%)	73 (100%)	3.83	0.05
	No	86 (46.7%)	98 (53.3%)	184 (100%)		
On regular follow up	**Yes**	31 (41.3%)	44 (58.7%)	75 (100%)	3.625	0.057
	No	99 (54.4%)	83 (45.6%)	182 (100%)		
Quit smoking currently	**Yes**	35 (39.8%)	53 (60.2%)	88 (100%)	6.257	**0.013**
	No	95 (56.2%)	74 (43.8%)	169 (100%)		
Catastrophic expenditure	**Yes**	106 (54.9%)	87 (45.1%)	193 (100%)	5.836	**0.021**
	No	24 (37.5%)	40 (62.5%)	64 (100%)		
Total		130 (50.6%)	127 (49.4%)	257 (100%)		

5.9 ASSOCIATION OF DIAGNOSTIC DELAY WITH VARIOUS FACTORS IN THE STUDY POPULATION

5.9.1 Association of diagnostic delay with the types of cancer under study among the study population

Participants with penile malignancy had higher diagnostic interval of more than 30 days. It indicates that those with carcinoma penis have 2.02 times higher chance of having their confirmed diagnosis beyond 30 days of initial visit to the health care provider as compared to participants with carcinoma kidney. (Table 32)

Table 32: Association of diagnostic delay with the types of cancer under study among the study population (N= 606)

Variable		Diagnostic interval		Total	COR (95%CI)	p value	AOR (95%CI)	p value
		> 30 days	< 30 days					
Type of cancer	Ovary	71 (20.3%)	278 (79.7%)	349 (100%)	1.37 (0.62 – 3.05)	0.437	1.51 (0.66-3.47)	0.328
	Urinary bladder	14 (24.6%)	43 (75.4%)	57 (100%)	1.75 (0.67 – 4.60)	0.256	1.87 (0.69 – 5.07)	0.221
	Penis	15 (27.3%)	40 (72.7%)	55 (100%)	2.02 (0.77-5.26)	0.152	2.72 (0.99 – 7.50)	0.053
	Kidney	8 (15.7%)	43 (84.3%)	51 (100%)	1		1	
	Prostate	12 (23.5%)	39 (76.5%)	51 (100%)	1.65 (0.61 – 4.47)	0.321	1.90 (0.68 – 5.332)	0.223
	Testis	11 (25.6%)	32(74.4%)	43 (100%)	1.85 (0.67 – 5.12)	0.238	2.53 (0.87 – 7.33)	0.086
Total		131 (21.6%)	475 (78.4%)	606 (100%)				

Reference category: <30 days

5.9.2 Association of diagnostic delay with multiple factors among the study population

Participants who visited multiple health care facilities [OR- 3.88, 95% CI (1.96-7.69)] and participants who had medical insurance [OR – 0.36, 95% CI (0.18-0.72) were statistically significant with a predicted diagnostic delay of more than 30 days. Participants who visited multiple healthcare facilities were 3.88 times more likely to have a confirmed diagnosis after 30 days of initial consultation holding all other variables constant. This result suggests us that as the patient visits more than two health care facilities, the odds of having diagnostic delay increases. Cancer patients with medical insurance were 0.36 times less likely to have a confirmed diagnosis

after 30 days of initial consultation holding all other variables constant. This suggests that if the participant has medical insurance, the odds of diagnostic delay decreases. (Table 33)

Table 33: Association of diagnostic delay with multiple factors among the study population (N= 606)

Variable		Diagnostic interval		Total	COR (95%CI)	p value	AOR (95%CI)	p value
		> 30 days	< 30 days					
Age	**20-29 years**	7 (25.9%)	20 (74.1%)	27 (100%)	1.42 (0.57 – 3.54)	0.458		
	30-39 years	13 (25%)	39 (75%)	52 (100%)	1.35 (0.67-2.72)	0.406		
	40-49 years	22 (20.6%)	85 (79.4%)	107 (100%)	1.05 (0.59 – 1.84)	0.876		
	50-59 years	41 (23%)	137 (77%)	178 (100%)	1.21 (0.76 – 1.94)	0.428		
	≥ 60 years	48 (19.8%)	194 (80.2%)	242 (100%)	1			
Gender	**Male**	53 (23.8%)	170 (76.2%)	223 (100%)	1.22 (0.82 – 1.81)	0.327		
	Female	78 (20.4%)	305 (79.6%)	383 (100%)	1			

Residence	**Rural**	88 (24.1%)	277 (75.9%)	365 (100%)	3.18 (0.95 – 10.67)	0.061	2.98 (0.84 – 10.61)	0.091
	Urban	40 (19.2%)	168 (80.8%)	208 (100%)	2.38 (0.69 – 8.19)	0.169	2.30 (0.63-8.42)	0.21
	Semi urban	3 (9.1%)	30 (90.9%)	33 (100%)	1		1	
Education	**Literate**	93 (23.5%)	303 (76.5%)	396 (100%)	1		1	
	Illiterate	38 (18.1%)	172 (81.9%)	210 (100%)	0.72 (0.47 – 1.10)	0.130	0.73 (0.46 – 1.13)	0.158
Primary care giver	**Present**	130 (21.6%)	472 (78.4%)	602 (100%)	0.87 (0.09 – 8.01)	0.869		
	Absent	1 (25%)	3 (75%)	4 (100%)	1			
Multiple care givers	**Yes**	43 (23.1%)	143 (76.9%)	186 (100%)	1.13 (0.75 – 1.72)	0.550		
	No	88 (21%)	332 (79%)	420 (100%)	1			

Presence of symptoms before diagnosis	**Yes**	128 (22%)	455 (78%)	583 (100%)	1.88 (0.55 – 6.41)	0.316		
	No	3 (13%)	20 (87%)	23 (100%)	1			
Comorbidities	**Yes**	53 (22.7%)	180 (77.3%)	233 (100%)	1.11 (0.75 – 1.65)	0.593		
	No	78 (20.9%)	295 (79.1%)	373 (00%)	1			
Visit multiple facilities	**Yes**	118 (24.4%)	365 (75.6%)	483 (100%)	2.96 (1.58 – 5.57)	**0.001**	3.88 (1.96 – 7.69)	**0.0001**
	No	13 (9.8%)	110 (90.2%)	123 (100%)	1		1	
Physical activity	**Yes**	29 (17.5%)	137 (82.5%)	166 (100%)	0.70 (0.44 – 1.11)	0.129	0.65 (0.40 – 1.05)	0.078
	No	102 (23.2%)	338 (76.8%)	440 (100%)	1		1	
Medical insurance	**Yes**	116 (20.6%)	448 (79.4%)	564 (100%)	0.47 (0.24 – 0.91)	**0.024**	0.36 (0.18 – 0.72)	**0.004**
	No	15 (35.7%)	27 (64.3%)	42 (100%)	1		1	
Total		131 (21.5%)	475 (78.5%)	606 (100%)				

Reference category: <30 days

5.9.3 Association of diagnostic delay with various factors among those with ovarian malignancy in the study population

Participants with ovarian malignancy who reside in rural locality (p=0.015) and visit multiple health care facilities (p = 0.01) have a statistically significant diagnostic interval of more than 30 days. (Table 34)

Table 34: Association of diagnostic delay with various factors among those with Ovarian malignancy in the study population (N=349)

Variable		Diagnostic interval		Total	Chi Square value	p value
		> 30 days	< 30 days			
Age	20-29 years	3 (20%)	12 (80%)	15 (100%)	0.514	0.979
	30-39 years	7 (21.9%)	25 (78.1%)	32 (100%)		
	40-49 years	16 (20.8%)	61 (79.2%)	77 (100%)		
	50-59 years	26 (21.7%)	94 (78.3%)	120 (100%)		
	≥ 60 years	19 (18.1%)	86 (81.9%)	105 (100%)		
Residence	Rural	49 (22.8%)	166 (77.2%)	215 (100%)	Fisher exact test	**0.015**
	Urban	22 (19.8%)	89 (80.2%)	111 (100%)		
	Semi urban	0	23 (100%)	23 (100%)		
Occupation	Unemployed	53 (23.3%)	174 (76.7%)	227 (100%)	3.617	0.057
	Employed	18 (14.8%)	104 (85.2%)	122 (100%)		

Presence of multiple care givers	**Yes**	27 (23.9%)	86 (76.1%)	113 (100%)	1.3	0.259
	No	44 (18.6%)	192 (81.4%)	236 (100% 0		
Visit multiple facilities	**Yes**	67 (22.9%)	226 (77.1%)	293 (100%)	7.173	**0.01**
	No	4 (7.1%)	52 (92.9%)	56 (100%)		
Total		71 (20.3%)	278 (79.7%)	349 (100%)		

5.9.4 Association of diagnostic delay with various factors among those with genitourinary malignancy in the study population

Participants with genitourinary malignancy who visit multiple healthcare facilities (p= 0.017) and continue smoking (p=0.045) have a statistically significant higher diagnostic interval of more than 30 days. (Table 35)

Table 35: Association of diagnostic delay with various factors among those with genitourinary malignancy in the study population (N=257)

Variable		**Diagnostic interval**		**Total**	**Chi Square value**	**p value**
		> 30 days	**< 30 days**			
Age	**20-29 years**	4 (33.3%)	8 (66.7%)	12 (100%)	1.92	0.979
	30-39 years	6 (30%)	14 (70%)	20 (100%)		
	40-49 years	6 (20%)	24 (80%)	30 (100%)		
	50-59 years	15 (25.9%)	43 (74.1%)	58 (100%)		
	≥ 60 years	29 (21.2%)	108 (78.8%)	137 (100%)		

Residence	**Rural**	39 (26%)	111 (74%)	150 (100%)	2.081	0.34
	Urban	18 (18.6%)	79 (81.4%)	97 (100%)		
	Semi urban	7 (70%)	3 (30%)	10 (100%)		
Presence of multiple care givers	**Yes**	16 (21.9%)	57 (78.1%)	73 (100%)	0.116	0.748
	No	44 (23.9%)	140 (76.1%)	184 (100%)		
Visit multiple facilities	**Yes**	51 (26.8%)	139 (73.2%)	190 (100%)	5.985	**0.017**
	No	8 (12.1%)	59 (87.9%)	67 (100%)		
Quit smoking currently	**Yes**	14 (15.9%)	74 (84.1%)	88 (100%)	4.136	**0.045**
	No	46 (27.2%)	123 (72.8%)	169 (100%)		
Total		59 (23%)	197 (77%)	257 (100%)		

5.10 ASSOCIATION OF TREATMENT DELAY WITH VARIOUS FACTORS IN THE STUDY POPULATION

5.10.1 Association of treatment delay with types of cancer under study among the study population

Participants with penile malignancy had a statistically significant higher treatment interval of more than 30 days at a 5% level of significance. The estimated adjusted odds ratio (OR) for Carcinoma penis (OR: 2.67, 95% CI: 1.03- 6.89) indicated that those with carcinoma penis have 2.67 times higher chance of having treatment beyond 30 days of diagnosis as compared to participants with carcinoma kidney. (Table 36)

Table 36: Association of treatment delay with types of cancer under study among the study population (N=606)

Variable		Treatment interval		Total	COR (95%CI)	p value	AOR (95%CI)	p value
		> 30 days	< 30 days					
Type of cancer	Ovary	75 (21.5%)	274 (78.5%)	349 (100%)	1.28 (0.60 – 2.74)	0.530	1.15 (0.53 – 2.52)	0.727
	Urinary bladder	12 (21.1%)	45 (78.9%)	57 (100%)	1.24 (0.48 – 3.25)	0.656	1.14 (0.43 – 3.06)	0.791
	Penis	18 (32.7%)	37 (67.3%)	55 (100%)	2.27 (0.91 – 5.66)	0.079	2.67 (1.03 – 6.89)	**0.043**
	Kidney	9 (17.6%)	42 (82.4%)	51 (100%)	1		1	
	Prostate	16 (31.4%)	35 (68.6%)	51 (100%)	2.13 (0.84 – 5.42)	0.111	2.27 (0.87 – 5.90)	0.094
	Testis	7 (16.3%)	36 (83.7%)	43 (100%)	0.91 (0.31 – 2.68)	0.860	0.93 (0.31 – 2.80)	0.900
Total		137 (22.6%)	469 (77.4%)	606 (100%)				

Reference category: <30 days

5.10.2 Association of treatment delay with multiple factors among the study population

Participants who visited multiple healthcare facilities [OR- 1.97, 95% CI (1.10-3.51)] had statistically significant higher predicted treatment delay. Participants who visited multiple healthcare facilities were 1.97 times more likely to be treated beyond 30 days of diagnosis holding all other variables constant. This suggests that as the patient visits more than two health care facilities, the odds of having treatment delay increases. (Table 37)

Table 37: Association of treatment delay with multiple factors among the study population (N=606)

Variable		Treatment interval		Total	COR (95%CI)	p value	AOR (95%CI)	p value
		> 30 days	< 30 days					
Age	20-29 years	5 (18.5%)	22 (81.5%)	27 (100%)	0.76 (0.27 – 2.09)	0.587		
	30-39 years	16(30.8%)	36(69.2%)	52 (100%)	1.48 (0.76-2.86)	0.294		
	40-49 years	21(19.6%)	86 (80.4%)	107 (100%)	0.81 (0.46 – 1.42)	0.466		
	50-59 years	39(21.9%)	139(78.1%)	178 (100%)	0.93 (0.59 – 1.48)	0.766		
	≥ 60 years	56(23.1%)	186(76.9%)	242 (100%)	1			
Sex	Male	54 (24.2%)	169 (75.8%)	223 (100%)	1.16 (0.78 – 1.71)	0.470		
	Female	83 (21.7%)	300 (78.3%)	383 (100%)	1			
Education	Literate	81 (20.5%)	315 (79.5%)	396 (100%)	1		1	1
	Illiterate	56 (26.7%)	154 (73.3%)	210 (100%)	1.41 (0.96-2.09)	0.083	1.34 (0.89 – 2.01)	0.167
Occupation	Employed	57 (21.2%)	212 (78.8%)	269 (100%)	1			

	Unemployed	80 (23.7%)	257 (76.3%)	337 (100%)	1.158 (0.78 – 1.70)	0.456		
SES – BGP scale 2021	**I**	11 (14.3%)	66 (85.7%)	77 (100%)	0.45 (0.19-1.06)	0.067	0.51 (0.21 – 1.25)	0.140
	II	37 (21.5%)	135 (78.5%)	172 (100%)	0.74 (0.37 – 1.45)	0.378	0.81 (0.40 – 1.62)	0.545
	III	44 (22.7%)	150 (77.3%)	194 (100%)	0.79 (0.41-1.53)	0.483	0.78 (0.39 – 1.56)	0.488
	IV	29 (27.9%)	75 (72.1%)	104 (100%)	1.04 (0.51-2.13)	0.916	0.98 (0.47 – 2.05)	0.964
	V	16 (27.1%)	43 (72.9%)	59 (100%)	1		1	
Presence of multiple care givers	**Yes**	45 (24.2%)	141 (75.8%)	186 (100%)	1.14 (0.76 – 1.71)	0.535		
	No	92 (21.9%)	328 (78.1%)	420 (100%)	1			
Presence of symptoms before diagnosis	**Yes**	132 (22.6%)	451 (77.4%)	583 (100%)	1.05 (0.39 – 2.89)	0.919		
	No	5 (21.7%)	18 (78.3%)	223 (100%)	1			
Visit multiple facilities	**Yes**	120 (24.8%)	363 (75.2%)	483 (100%)	2.04 (1.18 – 3.54)	**0.011**	1.97 (1.10 – 3.51)	**0.023**
	No	17 (13.9%)	106 (86.1%)	123 (100%)	1		1	

Medical insurance	**Yes**	127 (22.5%)	437 (77.5%)	564 (100%)	0.93 (0.45 – 1.94)	0.847		
	No	10 (23.8%)	32 (76.2%)	42 (100%)	1			
Debts	**Yes**	87 (25.7%)	251 (74.3%)	338 (100%)	1.51 (1.02 – 2.24)	**0.039**	1.44 (0.95 – 2.18)	0.086
	No	50 (18.7%)	218 (81.3%)	268 (100%)	1		1	
Catastrophic expenditure	**Yes**	104 (23.9%)	332 (76.1%)	436 (100%)	1.30 (0.84 - 2.02)	0.241		
	No	33 (19.4%)	137 (80.6%)	170 (100%)				
Total		137 (22.6%)	469 (77.4%)	606 (100%)				

Reference category: <30 days

5.10.3 Association of treatment delay with various factors among those with ovarian malignancy in the study population

Participants with ovarian malignancy who visited multiple health care facilities (p=0.004) had a statistically significant higher treatment interval of more than 30 days. (Table 38)

Table 38: Association of treatment delay with various factors among those with ovarian malignancy in the study population (N=349)

Variable		**Treatment interval**		**Total**	**Chi Square value**	**p value**
		> 30 days	**< 30 days**			
Education	**Literate**	38 (18.6%)	166 (81.4%)	204 (100%)	2.385	0.146
	Illiterate	37 (25.5%)	108 (74.5%)	145 (100%)		
Occupation	**Employed**	27 (22.1%)	95 (77.9%)	122 (100%)	0.046	0.891
	Unemployed	48 (21.1%)	179 (78.9%)	227 (100%)		

Visit multiple facilities	**Yes**	71 (24.2%)	222 (75.8%)	293 (100%)	8.138	**0.004**
	No	4 (7.1%)	52 (92.9%)	56 (100%)		
Total		**75 (21.5%)**	**274 (78.5%)**	**349 (100%)**		

5.10.4 Association of treatment delay with various factors among those with genitourinary malignancy in the study population

Among the participants with genitourinary malignancy, those who were illiterate and unemployed had a higher treatment interval of more than 30 days than literate and employed participants. (Table 39)

Table 39: Association of treatment delay with various factors among those with genitourinary malignancy in the study population (N=257)

Variable		**Treatment interval**		**Total**	**Chi Square value**	**p value**
		> 30 days	**< 30 days**			
Gender	**Male**	75 (21.5%)	274 (78.5%)	349 (100%)	0.008	1.000
	Female	8 (23.5%)	26 (76.5%)	34 (100%)		
Education	**Literate**	43 (22.4%)	149 (77.6%)	192 (100%)	1.239	0.314
	Illiterate	19 (29.2%)	46 (70.8%)	65 (100%)		
Occupation	**Employed**	30 (20.4%)	117 (79.6%)	147 (100%)	2.591	0.140
	Unemployed	32 (29.1%)	78 (70.9%)	110 (100%)		
Total		**62 (24.1%)**	**195 (75.9%)**	**257 (100%)**		

5.11 ASSOCIATION OF DELAYS WITH VARIOUS OUTCOMES IN THE STUDY POPULATION

5.11.1 Association of delays and compliance to treatment with the stage of the disease at the time of diagnosis

There is no statistically significant difference between the various delays and the stages of cancer presentation at the time of diagnosis. (Table 40)

Table 40: Association of delays and compliance to treatment with the stage of the disease at the time of diagnosis (N=587)

Variable		Stage of cancer at the time of diagnosis		Total	Chi Square value	p value
		Early	Late			
Total delay	**> 3 Months**	109 (33.9%)	213 (66.1%)	322 (100%)	0.068	0.860
	< 3 Months	87 (32.8%)	178 (67.2%)	265 (100%)		
Access interval	**>30 days**	111 (33.9%)	216 (66.1%)	327 (100%)	0.102	0.792
	<30 days	85 (32.7%)	175 (67.3%)	260 (100%)		
Diagnostic interval	**>30 days**	38 (30.9%)	85 (69.1%)	123 (100%)	0.436	0.521
	<30 days	158 (34.1%)	306 (65.9%)	464 (100%)		
Treatment interval	**>30 days**	39 (29.8%)	92 (70.2%)	131 (100%)	0.993	0.345
	<30 days	157 (34.4%)	299 (65.6%)	456 (100%)		
Total		196 (33.4%)	391 (66.6%)	387 (100%)		

5.11.2 Association between delay and the clinical outcome status of the study population

Table 41: Association between delay and the clinical outcome status of the study population (N=606)

Variable		Status		Total	COR (95%CI)	p value
		Live	Dead			
Total delay	**> 3 Months**	297 (89.2%)	36 (10.8%)	333 (100%)	1	
	< 3 Months	247 (90.5%)	26 (9.6%)	273 (100%)	1.15 (0.68 – 1.96)	0.603

Access interval	**>30 days**	303 (90.7%)	31 (9.3%)	334 (100%)	1.26 (0.74 – 2.13)	0.393
	<30 days	241 (88.6%)	31 (11.4%)	272 (100%)	1	
Diagnostic interval	**>30 days**	117 (89.3%)	14 (10.7%)	475 (100%)	1	
	<30 days	427 (89.9%)	48 (10.1%)	131 (100%)	1.06 (0.57 – 1.99)	0.846
Treatment interval	**>30 days**	122 (89.1%)	15 (10.9%)	137 (100%)	1	
	<30 days	422 (90%)	47 (10%)	469 (100%)	1.10 (0.60 – 2.04)	0.753
Total		544 (89.8%)	62 (10.2%)	606 (100%)		

Reference category: Dead

Table 41 shows that there is no statistically significant difference between delays among the living and the dead.

5.12 ASSOCIATION OF VARIOUS DELAYS WITH VARIOUS FACTORS LEADING TO DELAY IN THE STUDY POPULATION

5.12.1 Association of total interval for cancer management with various factors leading to delay

It was found that factors like symptom misinterpretation due to lack of awareness [OR-2.96, 95% CI (2.05-4.27)] and missed diagnosis by health care provider [OR – 2.26, 95% CI (1.33-3.86) were statistically significant with the predicted total delay. Participants who had factors like symptom misinterpretation due to lack of awareness and missed diagnosis by health care provider were 2.96 times and 2.26 times more likely to fall in more than 3 months total delay group holding all other variables constant. This result suggests that in participants with factors like symptom misinterpretation due to lack of awareness and missed diagnosis by health care provider increases, the odds of having total delay increases. (Table 42)

Table 42: Association of total interval for cancer management with various factors leading to delay (n=606)

Variable		Total interval		Total	COR (95%CI)	p value	AOR (95%CI)	p value
		> 3 Months	< 3 Months					
Delay in Decision Making	**Yes**	61 (64.9%)	33 (35.1%)	94 (100%)	1. 63 (1.03-2.58)	**0.036**	1.21 (0.73 – 2.01)	0.458
	No	272 (53.1)	240 (46.9%)	512 (100%)	1		1	
Symptoms Misinterpretation due to lack of awareness	**Yes**	255 (65.9%)	132 (34.1%)	387 (100.0%)	3.49 (2.46-4.94)	**0.0001**	2.96 (2.05 – 4.27)	**0.0001**
	No	78 (35.6%)	141 (64.4%)	219 (100.0%)	1		1	
Self medication	**Yes**	41 (71.9%)	16 (28.1%)	57 (100.0%)	2.26 (1.24 – 4.12)	**0.008**	1.42 (0.74 – 2.70)	0.290
	No	292 (53.2%)	257 (46.8%)	549 (100.0%)	1		1	
Social stigma	**Yes**	16 (80.0%)	4 (20.0%)	20 (100.0%)	3.39 (1.12 – 10.28)	**0.031**	2.14 (0.65 – 7.03)	0.211
	No	317 (54.1%)	269 (45.9%)	586 (100.0%)	1		1	
Prioritizing other life events	**Yes**	18 (78.3%)	5 (21.7%)	23 (100.0%)	3.06 (1.12 – 8.36)	**0.029**	2.02 (0.69 – 5.87)	0.198
	No	315 (54.0%)	268 (46.0%)	583 (100.0%)	1		1	

Financial constraints for consultation	**Yes**	14 (60.9%)	9 (39.1%)	23 (100.0%)	1.29 (0.55 – 3.02)	0.562		
	No	319 (54.7%)	264 (45.3%)	583 (100.0%)	1			
Inaccessibility to health services	**Yes**	4 (100.0%)	0 (0.0%)	4 (100.0%)		1.000		
	No	329 (54.7%)	273 (45.3%)	602 (100.0%)	1			
Sought alternate medical care	**Yes**	14 (66.7%)	7 (33.3%)	21 (100.0%)	1.67 (0.66 – 4.19)	0.277		
	No	319 (54.5%)	266 (45.5%)	585 (100.0%)	1			
Lack of family support	**Yes**	12 (85.7%)	2 (14.3%)	14 (100%)	5.07 (1.12 – 22.83)	**0.030**	3.01 (0.61 – 14.90)	0.176
	No	321 (54.2%)	271 (45.8%)	592 (100%)			1	
Lack of accompanying person	**Yes**	7 (58.3%)	5 (41.7%)	12 (100.0%)	1.15 (0.36-3.67)	0.812		
	No	326 (54.9%)	268 (45.1%)	594 (100.0%)	1			
Issues faced with caregiver	**Yes**	3 (100.0%)	0 (0.0%)	3 (100.0%)		1.000		
	No	330 (54.7%)	273 (45.3%)	603 (100.0%)	1			
Missed diagnosis by Health care	**Yes**	66 (74.2%)	23 (25.8%)	89 (100%)	2.69 (1.62 – 4.45)	**0.0001**	2.26 (1.33 – 3.86)	**0.003**

provider (perceived by the subject)	**No**	267 (51.6%)	250 (48.4%)	517 (100%)	1		1	
Difficulty in accessing diagnostic facility	**Yes**	12 (92.3%)	1 (7.7%)	13 (100%)	10.17 (1.31 – 78.70)	**0.026**	7.02 (0.86 – 57.45)	0.069
	No	321 (54.1%)	272 (45.9%)	593 (100%)	1		1	
Poor health condition	**Yes**	11 (84.6%)	2 (15.4%)	13 (100%)	4.61 (1.01 – 20.96)	**0.048**	4.65 (0.95 – 22.82)	0.058
	No	320 (54.4%)	268 (45.6%)	588 (100%)	1		1	
Delay due to COVID pandemic	**Yes**	110 (62.1%)	67 (37.9%)	177 (100%)	1.52 (1.06 – 2.17)	**0.023**	1.32 (0.89 - 1.94)	0.166
	No	223 (52%)	206 (48%)	429 (100%)	1		1	
TOTAL		333 (55.0%)	273 (45.0%)	606 (100.0%)				

Reference category: <3 months

Participants with ovarian malignancy had a statistically significant association of total delay with factors like symptom misinterpretation due to lack of awareness, missed diagnosis by health care provider, difficulty in accessing health facility, lack of family support, delay due to COVID pandemic and poor health condition ($p<0.05$). Participants with genitourinary malignancy had a statistically significant association of total delay with factors like symptom misinterpretation due to lack of awareness and missed diagnosis by health care provider ($p<0.05$).

5.12.2 Association of access interval with factors leading to delay (n=606)

Multiple logistic regression results showed that factors like symptom misinterpretation due to lack of awareness, [OR- 5.72, 95% CI (3.89-8.43)], prioritizing other life events [OR-3.96, 95% CI (1.09-14.38)] and poor health condition [OR – 5.64, 95% CI (1.11-28.65)] were statistically significant with predicted access delay. Participants who had factors like symptom misinterpretation due to lack of awareness, who prioritized other life events and with poor health condition were 5.72 times, 3.96 times and 5.64 times more likely to access health care facility beyond 30 days of onset of symptoms holding all other variables constant. This result suggests that in participants with factors like symptom misinterpretation due to lack of awareness, participants who prioritize other life events and have poor health condition, the odds of having access delay increases. (Table 43)

Table 43: Association of access interval with factors leading to delay (n=606)

Variable		Access interval		Total	COR (95%CI)	p value	AOR (95%CI)	p value
		> 30 days	< 30 days					
Delay in Decision Making	**Yes**	58 (61.7%)	36 (38.3%)	94 (100%)	1.17 (0.98 – 1.39)	0.164	1.19 (0.46-1.33)	0.372
	No	276 (53.9%)	236 (46.1%)	512 (100%)	1		1	
Symptoms Misinterpretation due to lack of awareness	**Yes**	273 (70.5%)	114 (29.5%)	387 (100.0%)	6.20 (4.30 – 8.96)	**0.0001**	5.72 (3.89 – 8.43)	**0.0001**
	No	61 (27.9%)	158 (72.1%)	219 (100.0%)	1		1	
Self medication	**Yes**	45 (78.9%)	12 (21.1%)	57 (100.0%)	3.37 (1.75 – 6.51)	**0.0001**	1.88 (0.92 – 3.82)	0.082
	No	289 (52.6%)	260 (47.4%)	549 (100.0%)	1		1	

Social stigma	**Yes**	15 (75.0%)	5 (25.0%)	20 (100.0%)	2.51 (0.90 – 7.00)	0.078	1.75 (0.56 – 5.41)	0.333
	No	319 (54.4%)	267 (45.6%)	586 (100.0%)	1		1	
Prioritizing other life events	**Yes**	20 (87.0%)	3 (13.0%)	23 (100.0%)	5.71 (1.68 – 19.43)	**0.005**	3.96 (1.09 – 14.38)	**0.036**
	No	314 (53.9%)	269 (46.1%)	583 (100.0%)	1		1	
Financial constraints for consultation	**Yes**	15 (65.2%)	8 (34.8%)	23 (100.0%)	1.55 (0.65 – 3.71)	0.324		
	No	319 (54.7%)	264 (45.3%)	583 (100.0%)	1			
Inaccessibility to health services	**Yes**	3 (75.0%)	1 (25.0%)	4 (100.0%)	2.46 (0.25 – 23.75)	0.44		
	No	331 (55.0%)	271 (45.0%)	602 (100.0%)	1			
Sought alternate medical care	**Yes**	17 (81.0%)	4 (19.0%)	21 (100.0%)	3.59 (1.19 – 10.81)	**0.023**	2.54 (0.77 – 8.43)	0.128
	No	317 (54.2%)	268 (45.8%)	585 (100.0%)	1		1	
Lack of accompanying person	**Yes**	8 (66.7%)	4 (33.3%)	12 (100.0%)	1.64 (0.49 – 5.52)	0.421		
	No	326 (54.9%)	268 (45.1%)	594 (100.0%)	1			

Issues faced with caregiver	**Yes**	3 (100.0%)	0 (0.0%)	3 (100.0%)	Fisher exact test	0.257		
	No	331 (54.9%)	272 (45.1%)	603 (100.0%)				
Denial of insurance	**Yes**	7 (100%)	0 (0%)	7 (100%)	Fisher exact test	**0.019**		
	No	327 (54.7%)	271 (45.3%)	598 (100%)	1			
Poor health condition	**Yes**	11 (84.6%)	2 (15.4%)	13 (100%)	4.58 (1.01 – 20.82)	**0.049**	5. 64 (1.11 – 28.65)	**0.037**
	No	323 (54.5%)	270 (45.5%)	593 (100%)	1		1	
Delay due to COVID pandemic	**Yes**	106 (59.9%)	71 (40.1%)	177 (100%)	1.32 (0.92 – 1.88)	0.130	1.08 (0.72 – 1.62)	0.701
	No	228 (53.1%)	201 (46.9%)	429 (100%)			1	
TOTAL		334 (55.1%)	272 (44.9%)	606 (100.0%)				

Reference category: <30 days

Participants with ovarian malignancy had a statistically significant association of delay in access interval of more than 30 days with factors like symptom misinterpretation due to lack of awareness, self medication, prioritising other life events, seeking alternate medical care and delay due to COVID pandemic. ($p<0.05$). Participants with genitourinary malignancy had a statistically significant association of delay in access interval of more than 30 days with factors like symptom misinterpretation due to lack of awareness, self medication and financial constraints ($p<0.05$).

5.12.3 Association of diagnostic interval with factors leading to delay

Factors like self-medication [OR- 7.28, 95% CI (1.16-45.90)], financial constraints for diagnosis [OR- 5.95, 95% CI (2.10-16.88)] and missed diagnosis by healthcare provider [OR – 6.72, 95% CI (4.04-11.28)] were statistically significant with predicted diagnostic delay of more than 30 days. Participants who were on self-medication, who had financial constraints for diagnosis and missed diagnosis by healthcare provider were 7.28 times, 5.95 times and 6.72 times more likely to have a confirmed diagnosis beyond 30 days of initial consultation by healthcare provider holding all other variables constant. This suggests that as the patient has predictors such as self-medication, financial constraints for diagnosis and missed diagnosis by healthcare provider, the odds of him having diagnostic delay increases. (Table 44)

Table 44: Association of diagnostic interval with factors leading to delay (n=606)

Variable		Diagnostic interval		Total	COR (95%CI)	p value	AOR (95%CI)	p value
		> 30 days	< 30 days					
Delay in Decision Making	**Yes**	24 (25.5%)	70 (74.5%)	94 (100%)	1.30 (0.78 – 2.16)	0.317		
	No	107 (20.9%)	405 (79.1%)	512 (100%)	1			
Symptoms Misinterpretation due to lack of awareness	**Yes**	87 (22.5%)	300 (77.5%)	387 (100%)	1.15 (0.77 – 1.73)	0.493		
	No	44 (20.1%)	175 (79.9%)	219 (100%)	1			

Self medication	**Yes**	5 (71.4%)	2 (28.6%)	7 (100%)	9.39 (1.80 – 48.94)	**0.008**	7.28 (1.16-45.90)	**0.034**
	No	126 (21%)	473 (79%)	599 (100%)	1		1	
Social stigma	**Yes**	5 (25%)	15 (75.0%)	20 (100%)	1.22 (0.43 – 3.41)	0.709		
	No	126 (21.5%)	460 (78.5%)	586 (100%)	1			
Prioritizing other life events	**Yes**	8 (34.8%)	15 (65.2%)	23 (100%)	2.00 (0.83 – 4.81)	0.124	1.33 (0.44 – 4.06)	0.614
	No	123 (21.1%)	460 (78.9%)	583 (100%)	1		1	
Financial constraints for consultation	**Yes**	9 (39.1%)	14 (60.9%)	23 (100%)	2.43 (1.03 – 5.75)	**0.043**	2.21 (0.75 – 6.50)	0.150
	No	122 (20.9%)	461 (79.1%)	583 (100%)	1		1	
Financial constraints for diagnosis	**Yes**	12 (60%)	8 (40%)	20 (100%)	5.89 (2.35 – 14.73)	**0.0001**	5.95 (2.10 – 16.88)	**0.001**
	No	119 (20.3%)	467 (79.7%)	586 (100%)	1		1	

Inaccessibility to health services	**Yes**	3 (75.0%)	1 (25.0%)	4 (100%)	11.11 (1.15 – 107.70)	**0.038**	10.02 (0.75 – 133.89)	0.081
	No	128 (21.3%)	474 (78.7%)	602 (100%)	1		1	
Sought alternate medical care	**Yes**	19 (44.2%)	24 (55.8%)	43 (100%)	3.19 (1.69 - 6.02)	**0.0001**	1.90 (0.90 – 4.00)	0.094
	No	112 (19.9%)	451 (80.1%)	563 (100%)	1		1	
Lack of family support	**Yes**	4 (57.1%)	3 (42.9%)	7 (100%)	4.96 (1.10 – 22.43)	**0.038**	1.50 (0.60 – 4.16)	0.518
	No	127 (21.2%)	472 (78.8%)	599 (100%)	1		1	
Lack of accompanying person	**Yes**	6 (50.0%)	6 (50.0%)	12 (100%)	3.75 (1.19 – 11.83)	**0.024**	2.08 (0.51 – 8.46)	0.308
	No	125 (21.0%)	469 (79.0%)	594 (100%)	1		1	
Issues faced with caregiver	**Yes**	1 (33.3%)	2 (66.7%)	3 (100%)	1.82 (0.16 – 20.22)	0.626		
	No	130 (21.6%)	473 (78.4%)	603 (100%)	1			
Missed diagnosis by Health care provider (perceived by the subject)	**Yes**	49 (55.1%)	40 (44.9%)	89 (100%)	6.50 (4.02 – 10.50)	**0.0001**	6.72 (4.04 – 11.28)	**0.0001**
	No	82 (15.9%)	435 (84.1%)	517 (100%)	1		1	

Lack of diagnostic facility	**Yes**	5 (22.7%)	17 (77.3%)	22 (100%)	1.07 (0.39 – 2.95)	0.897		
	No	126 (21.6%)	458 (78.4%)	584 (100%)	1			
Difficulty in accessing diagnostic facility	**Yes**	5 (38.5%)	8 (61.5%)	13 (100%)	2.32 (0.75 – 7.20)	0.147	1.09 (0.23 – 3.53)	0.899
	No	126 (21.2%)	467 (78.8%)	593 (100%)	1		1	
Delay due to COVID pandemic	**Yes**	7 (30.4%)	16 (69.6%)	23 (100%)	1.04 (0.68 – 1.58)	0.873		
	No	124 (21.3%)	459 (78.7%)	583 (100%)				
TOTAL		**131 (21.6%)**	**475 (78.4%)**	**606 (100%)**				

Reference category: <30 days

Participants with ovarian malignancy had a statistically significant association for delay in diagnostic interval of more than 30 days with factors like inaccessiblity to health services, lack of accompanying person, self medication and missed diagnosis by health care provider ($p<0.05$). Participants with genitourinary malignancy had a statistically significant association for delay in diagnostic interval of more than 30 days with factors like self medication, missed diagnosis by health care provider, financial constraints, sought alternative medical care, misclassification of disease severity and prioritising other life events ($p<0.05$).

5.12.4 Association of treatment interval with factors leading to delay

On analysing the influence of various factors on treatment delay it was found that factors like financial constraints for treatment and COVID 19 pandemic were statistically significant considering p value as 0.05. The estimated adjusted odd ratio (OR) for financial constraints for treatment (OR: 2.73, 95% CI: 1.48-5.05) and delay due to COVID pandemic (OR: 1.52, 95% CI: 1.01-2.30) indicated that those with financial constraints for treatment and delay during COVID pandemic period had 2.73 times and 1.52 times higher chances of being treatment beyond 30 days of diagnosis. As the factors like financial constraints for treatment and COVID pandemic delay are present in the participants, the odds of treatment delay increases. (Table 45)

Table 45: Association of treatment interval with factors leading to delay (n=606)

Variable		**Treatment interval**		**Total**	**COR (95%CI)**	**p value**	**AOR (95%CI)**	**p value**
		> 30 days	**< 30 days**					
Symptoms Misinterpretation due to lack of awareness	**Yes**	89 (23.0%)	298 (77.0%)	387 (100%)	1.06 (0.71 – 1.58)	0.760		
	No	48 (21.9%)	171 (78.1%)	219 (100%)				
Self-medication	**Yes**	17 (29.8%)	40 (70.2%)	57 (100%)	1.52 (0.83 – 2.78)	0.174	1.28 (0.68 – 2.43)	0.443
	No	120 (21.9%)	429 (78.1%)	549 (100%)	1		1	
Financial constraints for treatment	**Yes**	24 (43.6%)	31 (56.4%)	55 (100%)	3.00 (1.69 – 5.31)	**0.0001**	2.73 (1.48 – 5.05)	**0.001**
	No	113 (20.5%)	438 (79.5%)	551 (100%)	1		1	

Inaccessibility to health services	**Yes**	1 (25.0%)	3 (75.0%)	4 (100%)	1.54 (0.47 – 5.07)	0.480		
	No	136 (22.6%)	466 (77.4%)	602 (100%)	1			
Sought alternate medical care	**Yes**	14 (35.9%)	25 (64.1%)	39 (100%)	2.02 (1.02 – 4.00)	**0.044**	1.093 (0.40 – 2.18)	0.870
	No	123 (21.7%)	444 (78.3%)	567 (100%)	1		1	
Lack of family support	**Yes**	6 (42.9%)	8 (57.1%)	14 (100%)	2.64 (0.90 – 7.74)	0.077	1.91 (0.58 – 6.31)	0.291
	No	131 (22.1%)	461 (77.9%)	592 (100%)	1		1	
Lack of accompanying person	**Yes**	4 (33.3%)	8 (66.7%)	12 (100%)	1.73 (0.51 – 5.85)	0.375		
	No	133 (22.4%)	461 (77.6%)	594 (100%)	1			
Issues faced with caregiver	**Yes**	1 (33.3%)	2 (66.7%)	3 (100%)	1.72 (0.16 – 19.08)	0.660		
	No	136 (22.6%)	467 (77.4%)	603 (100%)	1			
Lack of trust on healthcare	**Yes**	6 (46.2%)	7 (53.8%)	13 (100%)	3.02 (1.0 – 9.150)	0.050	2.68 (0.73 – 9.81)	0.136
	No	131 (22.1%)	462 (77.9%)	593 (100%)	1		1	

Poor health condition	**Yes**	5 (38.5%)	8 (61.5%)	13 (100%)	2.18 (0.70 – 6.78)	0.177	1.51 (0.43 – 5.31)	0.522
	No	132 (22.3%)	461 (77.7%)	593 (100%)	1		1	
Delay due to COVID pandemic	**Yes**	51 (28.8%)	126 (71.2%)	177 (100%)	1.61 (1.08 – 2.41)	**0.020**	1.52 (1.01 – 2.30)	**0.047**
	No	86 (20%)	343 (80%)	429 (100%)	1		1	
TOTAL		**137 (22.6%)**	**469 (77.4%)**	**606 (100%)**				

Reference category: <30 days

Participants with ovarian malignancy had a statistically significant association for delay in treatment interval of more than 30 days with factors like seeking alternate medical care, financial constraints, lack of family support, fear of side effects, fear of surgery, lack of trust on health provider, and poor health condition ($p<0.05$). Participants with genitourinary malignancy had a statistically significant association for delay in treatment interval of more than 30 days with factors like inaccessibility to health services, financial constraints, lack of family support, misclassification of disease severity, fear of side effects and delay due to COVID pandemic.

5.12.5 Association of Compliance to treatment and follow up with various factors among the study population

It was found that participants who had guidance from healthcare provider [OR- 3.08, 95% CI (1.45-6.56)], participants with debts [OR – 0.59, 95% CI (0.38-0.91)], participants with carcinoma testis [OR – 3.07, 95% CI (1.06 – 8.93)], participants belonging to socio-economic class II [OR – 3.24, 95% CI (1.45-7.25)] and socio-economic class IV [OR – 2.55, 95% CI (1.09 – 5.96)] were statistically significant with the predicted compliance to treatment & follow up. Participants who had guidance from a healthcare provider were 3.08 times more likely to be compliant to treatment and follow up holding all other variables constant. This suggests that if the patient had guidance from a healthcare provider, the odds of him being compliant to

treatment & follow up increases. Participants who had debts were 0.59 times less likely to be compliant to treatment and follow up holding all other variables constant. This suggests that as the participant has debts, the odds of him being compliant to treatment & follow up decreases. Participants with carcinoma testis were 3.07 times more likely to be compliant to treatment and follow up as compared to participants with carcinoma kidney. Participants who belong to socio-economic class II and IV were 3.24 times and 2.55 times more likely to be compliant to treatment and follow up as compared to participants belonging to socio-economic class V. (Table 46)

Table 46: Association of Compliance to treatment and follow up with various factors among the study population (N=544)

Variable		Compliance to treatment and follow up		Total	COR (95%CI)	p value	AOR (95%CI)	p value
		Yes	No					
Age groups	20-30 yrs	8 (29.6%)	19 (70.4%)	27 (100%)	1.15 (0.48 – 2.76)	0.763		
	30-40 yrs	16 (33.3%)	32 (66.7%)	48 (100%)	1.36 (0.69 – 2.66)	0.371		
	40-50 yrs	28 (28.3%)	71 (71.7%)	99 (100%)	1.07 (0.63 – 1.83)	0.797		
	50-60 yrs	49 (31%)	109 (69%)	158 (100%)	1.22 (0.78 – 1.92)	0.386		
	>60 yrs	57 (26.9%)	155 (73.1%)	212 (100%)	1			
Gender	Male	66 (33.5%)	131 (66.5%)	197 (100%)	1.40 (0.96 – 2.04)	0.085	0.88 (0.29 – 2.65)	0.827
	Female	92 (26.5%)	255 (73.5%)	347 (100%)	1		1	
Residence	Rural	85 (25.2%)	252 (74.8%)	337 (100%)	1.69 (0.63 – 4.54)	0.301	1.49 (0.49 – 4.50)	0.476
	Urban	68 (38.4%)	109 (61.6%)	177 (100%)	3.12 (1.14 – 8.54)	**0.027**	2.05 (0.67 – 6.26)	0.206
	Semi urban	5 (16.7%)	25 (83.3%)	30 (100%)	1		1	

Occupation	**Employed**	75 (32.1%)	159 (67.9%)	234 (100%)	1.29 (0.89 – 1.87)	0.180	0.85 (0.55 – 1.34)	0.489
	Unemployed	83 (26.8%)	227 (73.2%)	310 (100%)	1		1	
SES - BG Prasad scale	**I**	24 (33.8%)	47 (66.2%)	71 (100%)	1.95 (0.85 – 4.45)	0.113	2.36 (0.965 – 5.755)	0.060
	II	58 (36.7%)	100 (63.3%)	158 (100%)	2.22 (1.06 – 4.63)	**0.035**	3.24 (1.45-7.25)	**0.004**
	III	36 (21.4%)	132 (78.6%)	168 (100%)	1.04 (0.49 – 2.23)	0.917	1.52 (0.67 – 3.44)	0.319
	IV	29 (30.9%)	65 (69.1%)	94 (100%)	1.70 (0.77 – 3.77)	0.189	2.55 (1.09 – 5.96)	**0.031**
	V	11 (20.8%)	42 (79.2%)	53 (100%)	1		1	
Types of cancer	**Ovary**	84 (26.3%)	236 (73.8%)	320 (100%)	1.36 (0.70 – 2.64)	0.365	0.87 (0.32 – 2.33)	0.781
	Urinary bladder	11 (24.4%)	34 (75.6%)	45 (100%)	1.50 (0.60 – 3.74)	0.390	0.68 (0.25 – 1.85)	0.676
	Penis	10 (20%)	40 (80%)	50 (100%)	1.94 (0.77 – 4.89)	0.163	0.48 (0.16-1.46)	0.196
	Kidney	15 (32.6%)	31 (67.4%)	46 (100%)	1		1	
	Prostate	21 (50%)	21 (50%)	42 (100%)	0.48 (0.20 – 1.15)	0.099	2.28 (0.80 – 6.52)	0.125
	Testis	17 (41.5%)	24 (58.5%)	41 (100%)	0.68 (.29 – 2.64)	0.393	3.07 (1.06 – 8.93)	**0.040**
Multiple care givers	**Yes**	61 (36.7%)	105 (63.3%)	166 (100%)	1.63 (1.14 – 2.49)	**0.009**	1.22 (0.78 – 1.93)	0.385
	No	97 (25.7%)	281 (74.3%)	378 (100%)	1		1	

Comorbidities	**Yes**	66 (31.4%)	144 (68.6%)	210 (100%)	1.21 (0.83 – 1.76)	0.332		
	No	92 (27.5%)	242 (72.5%)	334 (100%)	1			
Presence of symptom before diagnosis	**Yes**	151 (28.9%)	371 (71.1%)	522 (100%)	0.87 (0.35 -2.18)	0.770		
	No	7 (31.8%)	15 (68.2%)	22 (100%)	1			
Visit multiple facilities	**Yes**	121 (27.6%)	317 (72.4%)	438 (100%)	0.73 (0.47 – 1.15)	0.177	0.98 (0.58 – 1.67)	0.944
	No	37 (34.3%)	69 (65.7%)	106 (100%)	1		1	
Medical insurance	**Yes**	151 (29.7%)	358 (70.3%)	509 (100%)	1.69 (0.72 – 3.95)	0.228		
	No	7 (20%)	28 (80%)	35 (100%)	1			
Debts	**Yes**	71 (23.6%)	230 (76.4%)	301 (100%)	0.55 (0.38 – 0.80)	**0.002**	0.59 (0.38 – 0.91)	**0.016**
	No	87 (35.8%)	156 (64.2%)	243 (100%)	1		1	
Catastrophic expenditure	**Yes**	112 (29%)	274 (71%)	386 (100%)	0.99 (0.66 – 1.50)	0.982		
	No	46 (29.1%)	112 (70.9%)	158 (100%)	1			
Total		158 (29%)	386 (71%)	544 (100%)				

Reference category: Not on follow up

5.13Association of clinical outcome of disease to stage of the disease at the time of diagnosis (n=587)

There is a statistically significant association between the stage of disease at the time of diagnosis and the clinical outcome of the study participants. (p=0.0001) As the staging of the cancer worsens, the number of dead participants increases and as the staging of the cancer worsens, the number of participants in tumour progression increases. (Table 47)

Table 47: Association of clinical outcome of disease to stage of the disease at the time of diagnosis (n=587)

Variable	Stage of the disease at the time of diagnosis				Total	Chi Square value	p value
	I	II	III	IV			
Dead	2 (3.3%)	6 (9.8%)	21 (34.4%)	32 (52.5%)	61 (100%)	61.941	**0.0001**
Primary treatment	15 (14.2%)	21 (19.8%)	45 (42.5%)	25 (23.6%)	106 (100%)		
Tumour progression	7 (12.1%)	8 (13.8%)	19 (32.8%)	24 (41.4%)	58 (100%)		
Remission	100 (27.6%)	77 (21.3%)	123 (34%)	62 (17.1%)	362 (100%)		
TOTAL	124 (21.1%)	112 (19.1%)	208 (35.4%)	143 (24.4%)	587 (100%)		

5.14 Association of catastrophic health expenditure (CHE) with various factors among the study population

It was found that gender [OR- 1.79, 95% CI (1.16 – 2.76)], presence of multiple care givers [OR – 2.69, 95% CI (1.67 – 4.35)], presence of symptom before diagnosis [OR – 2.96, 95% CI (1.12 – 77.81)], visit to multiple healthcare facilities [OR – 2.88, 95% CI (1.81 – 4.57)] and debts [OR – 1.79, 95% CI (1.20-2.66)] were statistically significant with the predicted catastrophic health expenditure. Male participants, participants with multiple care givers, participants who had symptoms before diagnosis, participants who visited multiple health care facilities and participants who had debts were 1.79 times, 2.69 times, 2.96 times, 2.88 times and 1.79 times more likely to have catastrophic health expenditure holding all other variables

constant. This result suggests that with the chances of being a male, having multiple caregivers, presence of symptom before diagnosis, visiting multiple healthcare facilities & having debts, the odds of having catastrophic health expenditure increases. Participants who were in tumour progression phase had higher CHE than participants who were on active primary treatment. This association was found to be statistically significant (p=0.0001) (Table 48)

Table 48: Association of catastrophic health expenditure (CHE) with various factors among the study population (N=606)

Variable		Catastrophic health expenditure (CHE)		Total	COR (95%CI)	p value	AOR (95%CI)	p value
		Yes	No					
Age groups	**20-30 years**	23 (85.2%)	4 (14.8%)	27 (100%)	2.20 (0.73 – 6.60)	0.159	1.89 (0.60 – 5.98)	0.280
	30-40 years	39 (75%)	13 (25%)	52 (100%)	1.15 (0.58 – 2.29)	0.693	1.62 (0.75 – 3.47)	0.220
	40-50 years	79 (73.8%)	28 (26.2%)	107 (100%)	1.08 (0.65 – 1.81)	0.769	1.25 (0.70 – 2.23)	0.454
	50-60 years	120 (67.4%)	58 (32.6%)	178 (100%)	0.79 (0.52 – 1.21)	0.278	0.97 (0.60 – 1.56)	0.894
	>60 years	175 (72.3%)	67 (27.7%)	242 (100%)	1		1	
Gender	**Male**	170 (76.2%)	53 (23.8%)	223 (100%)	1.41 (0.97 – 2.06)	0.074	1.79 (1.16 – 2.76)	**0.009**
	Female	266 (69.5%)	117 (30.5%)	383 (100%)	1		1	

Residence	**Rural**	269 (73.7%)	96 (26.3%)	365 (100%)	1.40 (0.66 – 3.00)	0.385		
	Urban	145 (69.7%)	63 (30.3%)	208 (100%)	1.15 (0.53 – 2.52)	0.725		
	Semi urban	22 (66.7%)	11 (33.3%)	33 (100%)	1			
Education	**Literate**	279 (70.5%)	117 (29.5%)	396 (100%)	1			
	Illiterate	157 (74.8%)	53 (25.2%)	210 (100%)	1.24 (0.85 – 1.81)	0.262		
SES - BG Prasad scale	**I**	51 (66.2%)	26 (33.8%)	77 (100%)	0.61 (0.28 – 1.31)	0.205		
	II	120 (69.8%)	52 (30.2%)	172 (100%)	0.72 (0.36 – 1.42)	0.341		
	III	143 (73.7%)	51 (26.3%)	194 (100%)	0.87 (0.44 – 1.72)	0.694		
	IV	77 (74%)	27 (26%)	104 (100%)	0.89 (0.42 – 1.87)	0.752		
	V	45 (76.3%)	14 (23.7%)	59 (100%)	1			
Types of cancer	**Ovary**	243 (69.6%)	106(30.4%)	349 (100%)	0.96 (0.50 – 1.82)	0.889		
	Urinary bladder	45 (78.9%)	12 (21.1%)	57 (100%)	1.56 (0.65 – 3.75)	0.318		
	Penis	40 (72.7%)	15 (27.3%)	55 (100%)	1.11 (0.48 – 2.59)	0.807		
	Kidney	36 (70.6%)	15 (29.4%)	51 (100%)	1			

	Prostate	38 (74.5%)	13 (25.5%)	51 (100%)	1.22 (0.51 – 2.91)	0.657		
	Testis	34 (79.1%)	9 (20.9%)	43 (100%)	1.57 (0.61 – 4.07)	0.349		
Multiple care givers	**Yes**	157 (84.4%)	29 (15.6%)	186 (100%)	2.74 (1.75 – 4.27)	**0.0001**	2.69 (1.67 – 4.35)	**0.0001**
	No	279 (66.4%)	141 (33.6%)	420 (100%)	1		1	
Comorbidities	**Yes**	175 (75.1%)	58 (24.9%)	233 (100%)	1.30 (0.89 – 1.88)	0.172	1.38 (0.91 – 2.09)	0.134
	No	261 (70%)	112 (30%)	373 (100%)	1		1	
Presence of symptom before diagnosis	**Yes**	424 (72.7%)	159 (27.3%)	583 (100%)	2.44 (1.06 – 5.65)	**0.037**	2.96 (1.12 – 77.81)	**0.029**
	No	12 (52.2%)	11 (47.8%)	23 (100%)	1		1	
Visit multiple facilities	**Yes**	370 (76.6%)	113 (23.4%)	483 (100%)	2.87 (1.90 – 4.34)	**0.0001**	2.88 (1.81 – 4.57)	**0.0001**
	No	65 (53.3%)	57 (46.7%)	122 (100%)	1		1	
Medical insurance	**Yes**	406 (72%)	158 (28%)	564 (100%)	1.03 (0.51 – 2.06)	0.938		
	No	30 (71.4%)	12 (28.6%)	42 (100%)	1			
Debts	**Yes**	267 (79%)	71 (21%)	338 (100%)	2.20 (1.54 – 3.16)	**0.0001**	1.79 (1.20 – 2.66)	**0.004**
	No	169 (63.1%)	99 (36.9%)	268 (100%)	1		1	

Distance	**< 50 km**	391 (70.8%)	161 (29.2%)	552 (100%)	0.49 (0.23 – 1.02)	0.055	0.47 (0.21 – 1.06)	0.068
	> 50 km	45 (83.3%)	9 (16.7%)	54 (100%)	1		1	
Total		**436 (71.9%)**	**170 (28.1%)**	**606 (100%)**				

Reference category: No CHE

5.15 Association of catastrophic health expenditure (CHE) with stage of disease at the time of diagnosis among the study population

There was no statistically significant difference between the stage of disease at the time of diagnosis and catastrophic health expenditure (CHE) among the study participants. (Table 49)

Table 49: Association of catastrophic health expenditure (CHE) with stage of disease at the time of diagnosis among the study population (N=587)

Variable		**Catastrophic health expenditure (CHE)**		**Total**	**COR (95%CI)**	**p value**
		Yes	**No**			
Stage of disease at the time of diagnosis	**I**	89 (71.8%)	35 (28.2%)	124 (100%)	0.68 (0.39 – 1.18)	0.170
	II	79 (70.5%)	33 (29.5%)	112 (100%)	0.64 (0.36 – 1.13)	0.120
	III	147 (70.7%)	61 (29.3%)	208 (100%)	0.64 (0.39 – 1.06)	0.081
	IV	113 (79%)	30 (21%)	143 (100%)	1	
Total		**428 (72.9%)**	**159 (27.1%)**	**587 (100%)**		

5.16 Association of stage of disease at the time of diagnosis with various factors in the study population

Participants who had symptoms before diagnosis [OR – 0.27, 95% CI (0.08 – 0.88)], age between 30 to 40 years [OR-0.35, 95% CI (0.16 – 0.73)] and types of cancer – carcinoma ovary [OR – 4.02, 95% CI (1.67 – 9.60)] and carcinoma prostate [OR – 3.98, 95% CI (1.45 – 10.92)] were statistically significant with the predicted stage of disease at the time of diagnosis. Participants who had symptoms before diagnosis were 0.27 times less likely to be diagnosed with cancer at an advanced stage of disease holding all other variables constant. This result suggests that with the chances of having symptom before diagnosis, the odds of being diagnosed at advanced stage of disease decreases. Patients with carcinoma ovary and carcinoma prostate were 4.02 times and 3.98 times more likely to be diagnosed at advanced stage of disease as compared to participants with carcinoma kidney. Patients between 30 and 40 years of age were 0.35 times less likely to be diagnosed at advanced stage of disease as compared to participants above 60 years of age. More participants who died had presented at the late stage of the disease at the time of diagnosis. This association was found to be statistically significant. (p=0.0001) (Table 50)

Table 50: Association of stage of disease at the time of diagnosis with various factors in the study population (N=587)

Variable		**Stage of disease at the time of diagnosis**		**Total**	**COR (95%CI)**	**p value**	**AOR (95%CI)**	**p value**
		Early	**Late**					
Status	**Live**	191 (36.3%)	335 (63.7%)	526 (100%)	1		1	
	Dead	5 (8.2%)	56 (91.8%)	61 (100%)	6.39 (2.51 – 16.22)	**0.0001**	8.20 (3.06 – 21.96)	**0.0001**
Age groups	**20-30 yrs**	13 (48.1%)	14 (51.9%)	27 (100%)	0.49 (0.22 – 1.09)	0.081	0.60 (0.23 – 1.53)	0.287

	30-40 yrs	28 (53.8%)	24 (46.2%)	52 (100%)	0.39 (0.21 – 0.72)	**0.002**	0.35 (0.16 – 0.73)	**0.006**
	40-50 yrs	32 (30.8%)	72 (69.2%)	104 (100%)	1.02 (0.62 – 1.69)	0.938	1.02 (0.57 – 1.81)	0.946
	50-60 yrs	50 (29.4%)	120 (70.6%)	170 (100%)	1.09 (0.71 – 1.67)	0.700	0.97 (0.60 – 1.57)	0.915
	>60 yrs	73 (31.2%)	161 (68.8%)	234 (100%)	1		1	
Gender	**Male**	95 (43%)	126 (57%)	221 (100%)	0.51 (0.36 – 0.72)	**0.0001**	1.36 (0.52 – 3.55)	0.520
	Female	101 (27.6%)	265 (72.4%)	366 (100%)	1		1	
Residence	**Rural**	124 (34.9%)	231 (65.1%)	355 (100%)	1.03 (0.48 – 2.21)	0.951		
	Urban	61 (30.3%)	140 (69.7%)	201 (100%)	1.26 (0.57 – 2.80)	0.566		
	Semi urban	11 (35.5%)	20 (64.5%)	31 (100%)	1			
Education	**Literate**	147 (38.2%)	238 (61.8%)	385 (100%)	1		1	
	Illiterate	49 (24.3%)	153 (75.7%)	202 (100%)	1.93 (1.32 – 2.83)	**0.001**	1.36 (0.89 – 2.08)	0.153
Occupation	**Employed**	99 (37.6%)	164 (62.4%)	263 (100%)	1		1	

	Unemployed	97 (29.9%)	227 (70.1%)	324 (100%)	1.41 (1.00 – 1.99)	**0.049**	1.14 (0.75 – 1.72)	0.532
SES - BG Prasad scale	**I**	32 (41.6%)	45 (58.4%)	77 (100%)	0.78 (0.38 – 1.59)	0.496		
	II	52 (31.1%)	115 (68.9%)	167 (100%)	1.23 (0.65-2.32)	0.527		
	III	53 (27.9%)	137 (72.1%)	190 (100%)	1.44 (0.76 – 2.70)	0.262		
	IV	39 (40.2%)	58 (59.8%)	97 (100%)	0.83 (0.42 – 1.63)	0.583		
	V	20 (35.7%)	36 (64.3%)	56 (100%)	1			
Types of cancer	**Ovary**	85 (25.4%)	250 (74.6%)	335 (100%)	2.94 (1.60 – 5.39)	**0.0001**	4.02 (1.67 – 9.60)	**0.002**
	Urinary bladder	25 (46.3%)	29 (53.7%)	54 (100%)	1.16 (0.54 – 2.51)	0.706	0.87 (0.37 – 1.99)	0.742
	Penis	27 (50%)	27 (50%)	54 (100%)	1.00 (0.46 – 2.16)	1.000	1.04 (0.43 – 2.52)	0.919
	Kidney	25 (50%)	25 (50%)	50 (100%)	1		1	
	Prostate	9 (17.6%)	42 (82.4%)	51 (100%)	4.67 (1.88 – 11.58)	**0.001**	3.98 (1.45 – 10.92)	**0.007**
	Testis	25 (58.1%)	18 (41.9%)	43 (100%)	0.72 (0.32 – 1.64)	0.433	1.26 (0.46 – 3.41)	0.650
Primary care giver	**Present**	196 (33.6%)	387 (66.4%)	583 (100%)	Fisher exact test	0.307		

	Absent	0	4 (100%)	4 (100%)				
Multiple care givers	**Yes**	52 (28.3%)	132 (71.7%)	184 (100%)	1.41 (0.97 – 2.06)	0.076		
	No	144 (35.7%)	259 (64.3%)	403 (100%)	1			
Comorbidities	**Yes**	70 (31.5%)	152 (68.5%)	222 (100%)	1.15 (0.80 – 1.63)	0.457		
	No	126 (34.5%)	239 (65.5%)	365 (100%)	1			
Presence of symptom before diagnosis	**Yes**	192 (34%)	373 (66%)	565 (100%)	0.43 (0.14 – 1.29)	0.134	0.27 (0.08 – 0.88)	**0.031**
	No	4 (18.2%)	18 (81.8%)	22 (100%)	1		1	
Visit multiple facilities	**Yes**	148 (31.7%)	319 (68.3%)	467 (100%)	1.41 (0.93 – 2.13)	0.108	1.44 (0.90 – 2.29)	0.125
	No	47 (39.5%)	72 (60.5%)	119 (100%)	1		1	
Medical insurance	**Yes**	183 (33.5%)	364 (66.5%)	547 (100%)	0.96 (0.48 – 1.90)	0.902		
	No	13 (32.5%)	27 (67.5%)	40 (100%)	1			
Debts	**Yes**	104 (31.9%)	222 (68.1%)	326 (100%)	1.16 (0.82-1.64)	0.393		
	No	92 (35.2%)	169 (64.8%)	261 (100%)	1			
Catastrophic expenditure	**Yes**	138 (32.2%)	290 (67.8%)	428 (100%)	1.21 (0.82 – 1.77)	0.334		

	No	58 (36.5%)	101 (63.5%)	159 (100%)	1			
Total		**196 (33.4%)**	**391 (66.6%)**	**587 (100%)**				

Reference category: Early stage of cancer

5.17 Association of ADL scores with various factors in the living study population

Among the live participants, illiterates had more severe impairment than literates. This association was found to be statistically significant. (p=0.028), the unemployed had more severe impairment than the employed. This association was found to be statistically significant (p=0.046). Severe disability was more among participants with malignancy of the urinary bladder, followed by participants with malignancy of kidney. This association was found to be statistically significant. (p=0.021). Severe disability was higher among participants in tumour progression phase than participants on primary treatment and remission phase. This association was found to be statistically significant (p=0.0001). There was a statistically significant association between participants who had to travel longer distances (more than 50 kms) for cancer care and severe impairment. (p=0.024) (Table 51)

Table 51: Association of ADL scores with various factors in the living study population (N=544)

Variable		**ADL scores at the time of interview**			**Total**	**Chi Square value**	**p value**
		Severe impairment	**Moderate impairment**	**Independent**			
Age groups	**20-30 years**	0	0	27 (100%)	27 (100%)	Fisher exact test	0.144
	30-40 years	0	0	48 (100%)	48 (100%)		
	40-50 years	0	0	99 (100%)	99 (100%)		
	50-60 years	8 (5.1%)	3 (1.9%)	147 (93%)	158 (100%)		

	>60 years	8 (3.8%)	6 (2.8%)	198 (93.4%)	212 (100%)		
Gender	**Male**	10 (5.1%)	4 (2%)	183 (92.9%)	197 (100%)	5.254	0.068
	Female	6 (1.7%)	5 (1.4%)	336 (96.8%)	347 (100%)		
Residence	**Rural**	12 (3.6%)	4 (1.2%)	321 (95.3%)	337 (100%)	Fisher exact test	0.146
	Urban	2 (1.1%)	5 (2.8%)	170 (96%)	177 (100%)		
	Semi urban	2 (6.7%)	0	28 (93.3%)	30 (100%)		
Education	**Literate**	8 (2.2%)	3 (0.8%)	352 (97%)	363 (100%)	6.817	**0.028**
	Illiterate	8 (4.4%)	6 (3.3%)	167 (92.3%)	181 (100%)		
Occupation	**Employed**	4 (1.7%)	1 (0.4%)	229 (97.9%)	234 (100%)	6.116	**0.046**
	Unemployed	12 (3.9%)	8 (2.6%)	290 (93.5%)	310 (100%)		
SES - BG Prasad scale	**I**	0	1 (1.4%)	70 (98.6%)	71 (100%)	Fisher exact test	0.1
	II	5 (3.2%)	3 (1.9%)	150 (94.9%)	158 (100%)		
	III	4 (2.4%)	1 (0.6%)	163 (97%)	168 (100%)		
	IV	2 (2.1%)	2 (2.1%)	90 (95.7%)	94 (100%)		
	V	5 (9.4%)	2 (3.8%)	46 (86.8%)	53 (100%)		
Types of cancer	**Ovary**	6 (1.9%)	5 (1.6%)	309 (96.6%)	320 (100%)	Fisher exact test	**0.021**
	Urinary bladder	3 (6.7%)	0	42 (93.3%)	45 (100%)		

	Penis	2 (4%)	0	48 (96%)	50 (100%)		
	Kidney	3 (6.5%)	0	43 (93.5%)	46 (100%)		
	Prostate	2 (4.8%)	4 (9.5%)	36 (85.7%)	42 (100%)		
	Testis	0	0	41 (100%)	41 (100%)		
Multiple care givers	**Yes**	4 (2.4%)	4 (2.4%)	158 (95.2%)	166 (100%)	Fisher exact test	0.574
	No	12 (3.2%)	5 (1.3%)	361 (95.5%)	378 (100%)		
Visit multiple facilities	**Yes**	13 (3%)	7 (1.6%)	418 (95.4%)	438 (100%)	Fisher exact test	0.769
	No	2 (1.9%)	2 (1.9%)	101 (96.2%)	105 (100%)		
Clinical outcome	**Primary treatment**	5 (4.4%)	5 (4.4%)	103 (91.2%)	113 (100%)	Fisher exact test	**0.0001**
	Tumor progression	4 (6.9%)	4 (6.9%)	50 (86.2%)	58 (100%)		
	Remission	7 (1.9%)	0	366 (98.1%)	373 (100%)		
On regular follow up	**Yes**	4 (2.5%)	3 (1.9%)	151 (95.6%)	158 (100%)	Fisher exact test	0.883
	No	12 (3.1%)	6 (1.6%)	368 (95.3%)	386 (100%)		
Debts	**Yes**	11 (3.7%)	7 (2.3%)	283 (94%)	301 (100%)	3.136	0.193
	No	5 (2.1%)	2 (0.8%)	236 (97.1%)	243 (100%)		
Catastrophic expenditure	**Yes**	14 (3.6%)	6 (1.6%)	366 (94.8%)	386 (100%)	Fisher	0.286

	No	2 (1.3%)	3 (1.9%)	153 (96.8%)	158 (100%)	exact test	
Distance	**< 50 km**	14 (2.8%)	6 (1.2%)	479 (96%)	499 (100%)	Fisher exact test	**0.024**
	> 50 km	2 (4.4%)	3 (6.7%)	40 (88.9%)	45 (100%)		
Total		**16 (2.9%)**	**9 (1.7%)**	**519 (95.4%)**	**544 (100%)**		

5.18 Association of ADL scores with various delays in the living study population

There was no statistical significance between the various delays and activities of daily living. (Table 52)

Table 52: Association of ADL scores with various delays in the living study population (N=544)

Variable		**ADL scores at the time of interview**			**Total**	**Chi Square value**	**p value**
		Severe impairment	**Moderate impairment**	**Independent**			
Total delay	**> 3 months**	8 (2.7%)	5 (1.7%)	284 (95.6%)	297 (100%)	0.143	0.948
	< 3 months	8 (3.2%)	4 (1.6%)	235 (95.1%)	247 (100%)		
Access delay	**> 30 days**	6 (2%)	6 (2%)	291 (96%)	303 (100%)	2.615	0.289
	< 30 days	10 (4.1%)	3 (1.2%)	228 (94.6%)	241 (100%)		
Diagnostic delay	**> 30 days**	5 (4.3%)	3 (2.6%)	109 (93.2%)	117 (100%)	1.724	0.411
	< 30 days	11 (2.6%)	6 (1.4%)	410 (96%)	427 (100%)		
Treatment delay	**> 30 days**	5 (4.1%)	3 (2.5%)	114 (93.4%)	122 (100%)	1.395	0.502

	< 30 days	11 (2.6%)	6 (1.4%)	405 (96%)	422 (100%)		
Compliance to treatment and follow up	**Yes**	4 (2.5%)	3 (1.9%)	151 (95.6%)	158 (100%)	0.208	0.944
	No	12 (3.1%)	6 (1.6%)	368 (95.3%)	386 (100%)		

5.19 ASSOCIATION OF CLINICAL OUTCOME WITH VARIOUS FACTORS AND INTERVALS AMONG THE STUDY POPULATION

5.19.1 Association of clinical outcome with various factors among the study population

There is a statistically significant association between the clinical outcomes of cancer and the educational status of the study participants (p=0.015). More literates were in remission phase and more illiterates have died and are in tumour progression phase. More participants who are employed are in remission phase and more unemployed are in tumour progression phase. This association was found to be statistically significant (p=0.0001).

There is a statistically significant association between the types of cancers and the clinical outcome of cancer among the study participants (p=0.001). More participants with malignancy of the prostate were on tumour progression and more participants with malignancy of the testis were in remission phase. Higher number of participants with malignancy of the urinary bladder and prostate has died during the time of interview. More participants who had debts have died and are in tumor progression phase than participants without debts at the time of interview. This was found to be statistically significant (p=0.0001) (Table 53)

Table 53: Association of clinical outcome with various factors among the study population (N=606)

Variable		**Clinical outcome**				**Total**	**Chi Square value**	**p value**
		Primary treatment	**Tumor progression**	**Remission**	**Dead**			
Age groups	**20-30 years**	1 (3.7%)	1 (3.7%)	25 (92.6%)	0	27 (100%)	Fisher exact test	0.092
	30-40 years	9 (17.3%)	4 (7.7%)	35 (67.3%)	4 (7.7%)	52 (100%)		

	40-50 years	16 (15%)	10 (9.3%)	73 (68.2%)	8 (7.5%)	107 (100%)		
	50-60 years	39 (21.9%)	20 (11.2%)	99 (55.6%)	20 (11.2%)	178 (100%)		
	>60 years	48 (19.8%)	23 (9.5%)	141 (58.3%)	30 (12.4%)	242 (100%)		
Gender	**Male**	39 (17.5%)	19 (8.5%)	139 (62.3%)	26 (11.7%)	223 (100%)	1.399	0.706
	Female	74 (19.3%)	39 (10.2%)	234 (61.1%)	36 (9.4%)	383 (100%)		
Residence	**Rural**	75 (20.5%)	39 (10.7%)	223 (61.1%)	28 (7.7%)	365 (100%)	Fisher exact test	0.124
	Urban	33 (15.9%)	16 (7.7%)	128 (61.5%)	31 (14.9%)	208 (100%)		
	Semi urban	5 (15.2%)	3 (9.1%)	22 (66.7%)	3 (9.1%)	33 (100%)		
Education	**Literate**	73 (18.4%)	31 (7.8%)	259 (65.4%)	33 (8.3%)	396 (100%)	10.432	**0.015**
	Illiterate	40 (19%)	27 (12.9%)	114 (54.3%)	29 (13.8%)	210 (100%)		
Occupation	**Employed**	35 (13%)	15 (5.6%)	184 (68.4%)	35 (13%)	269 (100%)	23.647	**<0.001**
	Unemployed	78 (23.1%)	43 (12.8%)	189 (56.1%)	27 (8%)	337 (100%)		
SES - BG Prasad scale	**I**	7 (9.1%)	7 (9.1%)	57 (74%)	6 (7.8%)	77 (100%)	24.569	**0.017**
	II	31 (18%)	17 (9.9%)	110 (64%)	14 (8.1%)	172 (100%)		
	III	35 (18%)	16 (8.2%)	117 (60.3%)	26 (13.4%)	194 (100%)		
	IV	18 (17.3%)	13 (12.5%)	63 (60.6%)	10 (9.6%)	104 (100%)		

	V	22 (37.3%)	5 (8.5%)	26 (44.1%)	6 (10.2%)	59 (100%)		
Types of cancer	**Ovary**	66 (18.9%)	38 (10.9%)	216 (61.9%)	29 (8.3%)	349 (100%)		
	Urinary bladder	13 (22.8%)	3 (5.3%)	29 (50.9%)	12 (21.1%)	57 (100%)	Fisher exact test	**0.001**
	Penis	10 (8.2%)	0	40 (72.7%)	5 (9.1%)	55 (100%)		
	Kidney	8 (15.7%)	4 (7.8%)	34 (66.7%)	5 (9.8%)	51 (100%)		
	Prostate	10 (19.6%)	11 (21.6%)	21 (41.2%)	9 (17.6%)	51 (100%)		
	Testis	6 (14%)	2 (4.7%)	33 (76.7%)	2 (4.7%)	43 (100%)		
Presence of symptom before diagnosis	**Yes**	109 (18.7%)	56 (9.6%)	357 (61.2%)	61 (10.5%)	583 (100%)	1.098	0.778
	No	4 (17.4%)	2 (8.7%)	16 (69.6%)	1 (4.3%)	23 (100%)		
Medical insurance	**Yes**	110 (19.5%)	56 (9.9%)	343 (60.8%)	55 (9.8%)	564 (100%)	6.835	0.077
	No	3 (7.1%)	2 (4.8%)	30 (71.4%)	7 (16.7%)	42 (100%)		
Debts	**Yes**	58 (17.2%)	42 (12.4%)	201 (59.5%)	37 (10.9%)	338 (100%)	8.338	**0.04**
	No	55 (20.5%)	16 (6%)	172 (64.2%)	25 (9.3%)	268 (100%)		
Catastrophic expenditure	**Yes**	62 (14.2%)	49 (11.2%)	275 (63.1%)	50 (11.5%)	436 (100%)	23.758	**0.0001**
	No	51 (30%)	9 (5.3%)	98 (57.6%)	12 (7.1%)	170 (100%)		
Total		**113 (18.6%)**	**58 (9.6%)**	**373 (61.6%)**	**62 (10.2%)**	**606 (100%)**		

5.19.2 Association of clinical outcome with various intervals for cancer management among the study population

Participants who died had more total delay than participants who were alive. But there is no statistically significant association between various intervals of cancer care and the clinical outcomes of cancer. (Table 54)

Table 54: Association of clinical outcome with various intervals for cancer management among the study population (N=606)

Variable		Clinical outcome				Total	Chi Square value	p value
		Primary treatment	Tumor progression	Remission	Dead			
Total delay	**> 3 months**	66 (19.8%)	28 (8.4%)	203 (61%)	36 (10.8%)	333 (100%)	1.874	0.599
	< 3 months	47 (17.2%)	30 (11%)	170 (62.3%)	26 (9.5%)	273 (100%)		
Access interval	**>30 days**	63 (18.9%)	32 (9.6%)	208 (62.3%)	31 (9.3%)	334 (100%)	0.738	0.864
	<30 days	50 (18.4%)	26 (9.6%)	165 (60.7%)	31 (11.4%)	272 (100%)		
Diagnostic interval	**>30 days**	29 (22.1%)	14 (10.7%)	74 (56.5%)	14 (10.7%)	131 (100%)	2.039	0.564
	<30 days	84 (17.7%)	44 (9.3%)	299 (62.9%)	48 (10.1%)	475 (100%)		
Treatment interval	**>30 days**	31 (22.6%)	11 (8%)	80 (58.4%)	15 (10.9%)	137 (100%)	2.320	0.509
	<30 days	82 (17.5%)	47 (10%)	293 (62.5%)	47 (10%)	469 (100%)		
Total		**113 (18.6%)**	**58 (9.6%)**	**373 (61.6%)**	**62 (10.2%)**	**606 (100%)**		

5.20 Association of Global Quality of life and various factors among living study population

As the age advances the quality of life decreases among the living study participants. This association was found to be statistically significant. (p=0.0001). The quality of life was

better among literates than illiterates. This association was found to be statistically significant. (p=0.001). The quality of life was better among employed than the unemployed. This association was found to be statistically significant. (p=0.0001). The quality of life is poor among socio economically backward participants and this was found to be statistically significant (p=0.017).

Participants with testicular cancer had better quality of life and participants with malignancy of the prostate had a poor quality of life. This association was found to be statistically significant. (p=0.006). Participants with multiple caregivers had poor quality of life than participants with a single caregiver. This was found to be statistically significant (p=0.004). The quality of life worsens as the stage of the disease worsens. This was found to be statistically significant. (p=0.0001). Participants on tumour progression phase had poor quality of life than participants on remission. This association was found to be statistically significant (p=0.0001). (Table 55)

Table 55: Global Quality of life and various factors among the living study population (N=544)

Variable		**Global QoL**		**t-test/ F test**	**p value**
		Mean	**SD**		
Age groups	**20-30 years**	88.27	12.28	6.472	**0.0001***
	30-40 years	70.13	24.36		
	40-50 years	68.09	21.46		
	50-60 years	65.77	23.95		
	>60 years	66.03	21.92		
Gender	**Male**	68.78	22.26	0.757	0.449
	Female	67.24	23.05		
Education	**Literate**	70.68	21.21	-3.402	**0.001**
	Illiterate	62.01	24.64		
Occupation	**Employed**	75.60	18.65	-7.520	**<0.001**
	Unemployed	61.90	23.81		
SES - BG Prasad scale	**I**	63.02	23.34	3.037	**0.017***
	II	69.14	22.32		

	III	70.08	23.18		
	IV	69.41	21.70		
	V	60.06	22.00		
Types of cancer	**Ovary**	67.55	22.83	3.333	**0.006***
	Urinary bladder	66.48	20.06		
	Penis	72	19.76		
	Kidney	64.31	23.87		
	Prostate	59.92	24.50		
	Testis	78.04	22.10		
Multiple care givers	**Yes**	63.55	22.19	-2.903	**0.004**
	No	69.66	22.78		
Comorbidities	**Yes**	66.03	20.70	-1.486	0.138
	No	68.91	23.92		
Presence of symptom before diagnosis	**Yes**	67.65	22.75	-0.717	0.473
	No	71.21	23.24		
Stage of disease at the time of diagnosis	**I**	73.22	21.62	6.591	**<0.001***
	II	70.99	20.25		
	III	67.02	21.77		
	IV	60.96	26.11		
Clinical outcome	**Primary treatment**	53.98	23.41	67.153	**<0.001***
	Tumor progression	50.71	25.52		
	Remission	74.64	18.47		
Debts	**Yes**	68.16	23.57	0.412	0.681
	No	67.35	21.76		
Catastrophic expenditure	**Yes**	67.20	23.22	-0.951	0.342
	No	69.25	21.61		

Distance	**< 50 km**	68.32	22.65	1.777	0.076
	> 50 km	62.03	23.40		
Total		67.80	22.76		

*- ANOVA

5.21 Association of Global Quality of life and various intervals for cancer care among the living study population

The quality of life among those with higher total delay, access interval, diagnostic interval and treatment delay was poor than those who did not have delay. But this association was not statistically significant. (Table 56)

Table 56: Association of Global Quality of life and various intervals for cancer care among the living study population (N=544)

Variable		**Global QoL**		**t-test**	**p value**
		Mean	**SD**		
Total delay	**> 3 months**	67.48	22.89	-.359	0.720
	< 3 months	68.18	22.64		
Access interval	**> 30 days**	66.94	23.76	0.986	0.324
	< 30 days	68.87	21.44		
Diagnostic interval	**> 30 days**	65.31	21.35	1.335	0.183
	< 30 days	68.48	23.11		
Treatment interval	**> 30 days**	65.91	22.42	1.038	0.300
	< 30 days	68.34	22.85		
Total		67.80	22.76		

5.22 ASSOCIATION BETWEEN VARIOUS TREATMENT MODALITIES AND SURVIVAL AMONG PARTICIPANTS WITH EARLY AND LATE-STAGE CANCER

Table 57: Association between various treatment modalities and survival among participants with early and late-stage cancer

Stage of cancer	Treatment modalities	Status		Chi Square p- value
		Live	Dead	
Early	No treatment	56 (98.2%)	1 (1.8%)	0.695 (p=0.880)
	Non-surgical modalities	19 (95%)	1 (5%)	
	Surgery (With or without other modalities)	153 (96.2%)	6 (3.8%)	
Late	No treatment	50 (73.5%)	18 (26.5%)	13.8 (p=0.001)$
	Non-surgical modalities	41 (77.4%)	12 (22.6%)	
	Surgery (With or without other modalities)	207 (90%)	23 (10%)	

$- Significance

Among patients with late stage of cancer at diagnosis, a significantly higher proportion of patients (90%) remained alive at the time of interview compared to those who did not undergo any treatment(73.5%), p=0.001. However there was no significant association between treatment modalities and survival for those with early stage of cancer at diagnosis.

5.23 ASSOCIATION OF RELIGIOUS COPING WITH VARIOUS FACTORS IN THE STUDY POPULATION

5.23.1 Association of positive religious coping with various factors in the study population:

Table 58: Association of positive religious coping with various factors in the study population: (N=140)

S.No.	Characteristics	Category	Mean	P value
1	Age	< 45 years ≥ 45 years	14.42 12.62	0.076
2	Gender	Male Female	11.04 14.07	**0.0001**
3	Marital Status	Married Others	13.03 13.21	0.860

4	**Education**	**Illiterate** **Literate**	11.55 13.96	**0.009**
6.	**Occupation**	**Unemployed** **Employed**	13.18 13.03	0.872
7.	**Type of Cancer**	**Ovary** **Genito-Urinary**	14.25 11.04	**0.001**

Positive religious coping was significantly higher in females compared to males. Literate patients had better positive coping. Christian and muslim patients had significantly higher positive religious coping compared to hindus. It was also observed that ovarian cancer patients had better positive coping than patients with genito-urinary cancer. (Table 58) Negative religious coping was significantly higher in females compared to males. It was observed that ovarian cancer patients had significantly higher negative coping compared with genito-urinary cancer patients. (Table 59)

5.23.2 Association of negative religious coping with various factors in the study population

Table 58: Association of negative religious coping with various factors in the study population: (N=140)

S.No.	Characteristics	Category	Mean	value
1	**Age**	**< 45 years** **≥ 45 years**	12.06 10.85	0.104
2	**Gender**	**Male** **Female**	9.85 11.80	**0.004**
3	**Marital Status**	**Married** **Others**	10.95 11.69	0.308
4	**Education**	**Illiterate** **Literate**	11.14 11.17	0.965
5.	**Occupation**	**Unemployed** **Employed**	11.70 10.60	0.087
6.	**Type of Cancer**	**Ovary** **Genito-Urinary**	11.90 9.86	**0.002**
7	**Religion**	**Hinduism** **Others**	12.09 19.00	**0.0001**

5.24 Association between types of stigma and global quality of life

Table 59: Association between types of stigma and global quality of life (N=138):

Types of stigma	Global QOL (mean score)	
	Mean	P value
Perceived stigma	66.53	0.729
Experienced stigma	62.96	0.028
Internalised stigma	64.48	0.018

From the above table 60 it was observed that individuals who have experienced stigma tend to report lower global quality of life compared to those who have not. The independent t-test results for experienced stigma and global quality of life mean scores revealed a statistically significant difference (p = 0.028). Higher levels of internalized stigma are associated with a statistically significant decrease in global quality of life. (p=0.018)

Table 60: Association between perceived and experienced stigma

	Experienced stigma present	**Experienced stigma absent**	**Total**	**Fishers exact value**	**P value**
Perceived stigma present	87 (64.9)	47 (35.1)	134 (100)	7.027	**0.017**
Perceived stigma absent	0 (0)	4 (100)	4(100)		

The above table 61 showed that those who perceived stigma had experienced stigma and this association was found to be statistically significant. **(p=0.017)**.

Table 61: Association between experienced and internalised stigma

	Internalised stigma present	**Internalised stigma absent**	**Total**	**Chi square value**	**P value**
Experienced stigma present	76 (87.4)	11 (12.6)	87 (100)	7.166	**0.007**
Experienced stigma absent	35 (100)	16 (31.4)	51 (100)		

The above table 62 suggested that individuals who had experienced stigma were more likely to exhibit higher levels of internalized stigma and this association was found to be statistically significant **(p=0.007)**

Participants who perceived stigma had experienced stigma. This association was found to be statistically significant. (p=0.017) and individuals who had experienced stigma were more likely to exhibit higher levels of internalized stigma and this association was found to be statistically significant **(p=0.007)**.

B. QUALITATIVE REPORT

5.25 RESULTS

The following tables show the list of patients who participated in IDI, their caregivers and details of key informants who participated in KII:

Table 62: Baseline characteristics of Patients who participated in IDI

S.NO	Identifier	AGE	CANCER TYPE
1	OV1	47	Ovary
2	OV2	48	Ovary
3	OV3	43	Ovary
4	OV4	52	Ovary
5	OV5	33	Ovary
6	OV6	60	Ovary
7	OV7	48	Ovary
8	OV8	43	Ovary
9	OV9	56	Ovary
10	OV10	33	Ovary
11	OV11	42	Ovary
12	GU1	68	Urinary Bladder
13	GU2	36	Urinary Bladder
14	GU3	45	Urinary Bladder
15	GU4	61	Kidney
16	GU5	76	Urinary Bladder
17	GU6	68	Urinary Bladder
18	GU7	39	Penis
19	GU8	53	Penis
20	GU9	58	Urinary Bladder
21	GU10	71	Prostate
22	GU11	20	Testis
23	GU12	31	Testis
24	GU13	83	Prostate

Table 63: Baseline characteristics of caregivers who participated in IDI		
SR.NO.	**Identifier**	**CANCER TYPE**
1	OV_{CG1}	Ovary
2	OV_{CG2}	Ovary
3	OV_{CG3}	Ovary
4	OV_{CG4}	Ovary
5	OV_{CG5}	Ovary
6	OV_{CG6}	Ovary
7	OV_{CG7}	Ovary
8	OV_{CG8}	Ovary
9	GU_{CG1}	Penis

Table 64: Baseline characteristics of Key Informants who participated in KII			
IDENTIFIER	**JOB PROFILE**	**AGE**	**EDUCATION**
HCP_1	Oncologist	48	M.D radiation oncology
HCP_2	MSW	28	M.Phil MSW
HCP_3	M.O	35	MBBS
HCP_4	M.O	38	MBBS.MD
HCP_5	M.O	30	MBBS

Following eight themes emerged out of the thematic analysis:

The themes, categories & subcategories which emerged in chronological order are as follows:

Table 65: List of themes, categories and subcategories from IDI

S.no	Themes	Category	Subcategory
1	Symptom complex and perception vis-a-vis appraisal delay	Symptoms at presentation	Nonspecific symptoms
			Red flag symptom
			Metastasis at presentation
		Perception about symptoms	Patient perceptions
			Caregiver perceptions
			Doctor perceptions
2	Being diagnosed with cancer	Myriad of emotions	Emotional turmoil of patient and caregiver
			Cancer as death sentence
		Breaking the diagnosis-varied responses	Social stigma leading to concealment of diagnosis
			Spiritual struggle on being diagnosed with cancer
			Necessity to come to terms with poor prognosis
			Abounding fears and uncertainty

3	Facilitators and barriers in pathways to cancer care **Subtheme 1** Facilitators in pathways to cancer care	Patient factors	Desire to live for loved ones
			Peer comparison as a motivation
		Caregiver factors	Emotional support
			Holistic support
			Motivational support
			Acceptance of treatment
			Full and prompt consent to procedures
			Marital understanding
			Positive and practical attitude
			Resigned to fate
		Health care provider factors	Motivation to seek treatment
			Doctor's strong words of encouragement
			Focused advice on compliance
			Trust on doctors reassurance
			Conducive doctor patient relationship
			Viewing doctor as a God
			Divine guidance via doctor
			Soft disarming demeanor of doctor
		Spiritual factors	Clues to seek care
			Mutual prayer supports
		Insurance factors	Full support from CMCHIS

	Subtheme 2 Barriers in pathways to cancer care Follow up issues	Patient factors	Fear of surgery
			Avoidant coping strategy
			Reluctant attitude
			Fear of hospital
			Aversion to hospital set up
			Seeking symptomatic relief from OTC
			Perception of symptom related factors
			Procrastination till aggravation of symptoms
			Dismissal of symptoms
			Normalization of symptoms
			Misconception about symptoms
		Financial factors	Fear of expenses as a delay factor
			Multiple referrals (Shuttling)
		Health care associated factors	Healthcare services as a barrier in health seeking
			Informal health seeking
			Para medicals as a barrier to health seeking
			Transfer of healthcare provider
			Lack of communication as a barrier to health seeking
			Lack of chemotherapy drug supply in Govt hospitals
			Lack of electricity as a cause of delay in treatment

			Dismissal of patient concerns by healthcare provider
			Presumptive treatment
		Covid factors	Increased waiting time
			Lock down restriction as a barrier
			Vain efforts for transport
			Shutdown of services
			Expensive travel
			Fear of acquiring COVID
		Insurance factors	Grievances against insurance
			Unawareness about insurance
			Treatment delay caused due to insurance
		Family/Caregiver factors	Deranged family dynamics
	Barriers emerged in Key Informant interview	Time lag in acceptance of treatment	
		Resorting to native treatment	
		Collision of beliefs	
		Peer comparison as barrier	
		Lapses in communication about compliance	
		Lack of documentation	
		Challenges in utilizing CMCHIS scheme	
		Experienced stigma from spouse	
		Abrupt crude disclosure of survival and prognosis	

4.	Stigma	Perceived stigma	Mockery and fear of disclosure
			Doubts about marriage during health condition
			Fear of societal gossip and judgment about the health condition
		Experienced stigma	Family members expressing disapproval or mistreatment due to the health condition
			Restrictions on mingling with others and avoiding common interactions
			Experiencing different and discriminatory treatment, including criticism and inferiority
			Isolation from family functions due to the individual's health condition
			Work related consequences and family dispute arising from the inability to work post-cancer diagnosis
			Lack of emotional and social support during crucial health moments, such as surgery and last rites.
			Feeling uncertain about the sincerity of kind words expressed by different individuals.
			Poor treatment post diagnosis
			Financial exploitation demand

			Experiencing verbal abuse from the mother and uncle for seeking hospital treatment.
			Surviving an attempted homicide by the drunk husband during pregnancy
			Cruel treatment from the mother-in-law during a critical health condition.
			Restriction on the son visiting during a critical health period.
			Fear of societal repercussions and judgment related to health disclosure.
		Internalised stigma	Fear of societal repercussions and judgment related to health disclosure.
			Social deception
			Presenting a false narrative of a lymph swelling surgery instead of disclosing cancer to society.
			Avoiding social gatherings to evade questions about the health condition
			Neglecting personal appearance and avoiding mirrors due to the impact of the health condition.
			Coping with hair loss
5.	Economic issues in cancer care pathway	Determinants of financial burden	Baseline socio economic status
			Support from children/relatives
			Insurance as a boon
			Insurance as a barrier for

			cancer management
			Health care systems and services
			Social factors contributing to economic issues
			Role of Spiritual societies
		Components of economic burden	Direct burden
			Indirect burden
			Devastating viscious consequences
			Health issues and vocational inability
			Loss of work for caregiver
			Compromised quality of life
6	Multi dimensionality of care giver role and care giver burn out	Financial burden and vocational challenges faced by care givers	
		Emotional challenges in facing and accepting the diagnosis of cancer	
		Caregivers' multiple roles at stake due to care giving burden	
		Caregivers' worries on safeguarding emotional well being of patients	
		Challenges due to patient's non compliance	
		Encountering end- of life issues	

7	Spiritual aspects	Faith as a resilience factor for overcoming crisis situations	
		Resigning to God's sovereign will – As a coping resource	
		Spiritual beliefs superseded the death blow prognostic statements	
		Role of spiritual support groups	
		Commencement of spiritual journey after diagnosis of cancer	
		Religious struggle / spiritual distress	
8	End of life care	Emotional issues surrounding end of life care	Painful course of death and caregiver's hopelessness
			Sudden death and caregiver's guilt
			Lingering memories of death of loved ones
		Coping resources for end of life hardships	Healthcare providers
			Spiritual societies

5.25 THEME-1: SYMPTOM COMPLEX

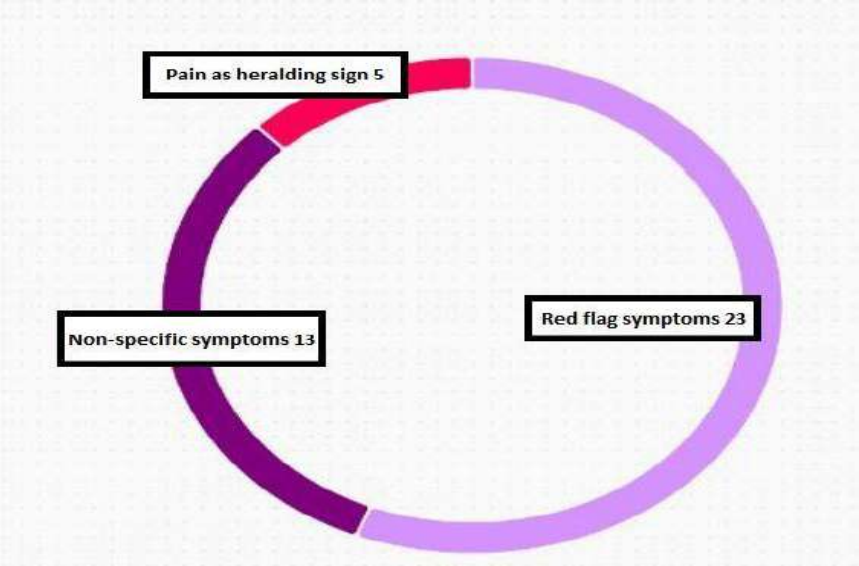
The symptom complex at presentation varied from red flag symptoms with pain as a heralding factor to nonspecific symptoms such as, dyspepsia, back pain, loss of appetite, etc. This is in congruence with the quantitative results.

Non-specific symptoms at presentation contributed to delay due to motivation to self medicate initially as quoted by Participant OV2 diagnosed with Ca ovary *"I had abdominal pain on and off for two years before that. I will get medicines from medicals or nearby clinic I will put injection and it will subside".*

There are patients who encountered the worst case scenario as they had presented at the stage of metastasis leading to a diagnosis with very poor prognosis as described by the caregiver of Participant OV_{CG5} who was diagnosed with ovarian carcinoma; *"the doctor informed us that it is cancer, we can't do much about it, it has already spread all over the abdomen".*

On the basis of the KII conducted, the radiologist and the Oncologist said that reporting an Ovarian tumour was a Diagnostic nightmare due to the complexity of the structure and its close structural similarity with benign conditions.

Fig 28: Doughnut graph of different categories of symptom complex among IDI participants



5.26 THEME-2: BEING DIAGNOSED WITH CANCER

The diagnosis of cancer was daunting and a devastating situation for the patient as well as their family. The following subcategories and codes emerged in IDIs

A) **Myriad of Emotions:**

(i) Emotional turmoil of patient and care givers

Disclosure of cancer diagnosis by the doctor caused a myriad of emotions both among the patient and caregiver ranging from shock, disbelief, devastation, crying, palpitations, fear, being traumatized, blaming attitude , questioning God, fear of death and even loss of will to live. It was a difficult situation to assimilate especially for the patients as stated by Participant GU 12 diagnosed with CA,*" I had Heart pounding feelings, Shivering, Nervousness I didn't understand*

*anything ,nothing was getting into my mind."*Caregiver of Participant OV_{CG2} diagnosed with CA ovary shared that, *"I was shocked, started shivering and was very upset. I was devastated and begged the doctors to save my mother's life, had a complete emotional breakdown. Even after some time I always felt like a wooden log. I used to talk to people outside but was worried all the time."*

(ii) Cancer as a death sentence:

Many patients and caregivers considered cancer as a death sentence causing a fear of death as an added emotional burden as experienced by Participant GU 2 diagnosed with Bladder carcinoma*, "I thought that I would die soon. I thought I would not be alive anymore and I would die soon. I thought my fate was finished, then and there. They said that the tumour had to be operated on. So, I was sure that I would die.I feel cancer is the main reason a lot of people die. They seem healthy initially, but suddenly they expire."*

(B) Breaking the diagnosis- varied response :

(i) Social Stigma leading to concealment of diagnosis:

Diagnosis of cancer gave birth to the fear of social stigma which worsened their emotional status even more as shared by Participant OV2 diagnosed with CA ovary, *"After thinking about what people would say I lost any will to live."* This fear motivated them towards non-disclosure of diagnosis to the relatives and society to avoid uncomfortable conversations. In some situations, the patients themselves were not told about their diagnosis as in case of Participant OV 11 diagnosed with CA ovary, *"We did not tell her that she has cancer we just told my mother that there was a small tumour in her uterus which needs to be operated."* Nurses and doctors also aided in nondisclosure of diagnosis as requested by the caregivers as stated by caregiver of OV_{CG2} diagnosed with CA ovary, *"The nurses also helped us in hiding the diagnosis from her by reassuring her that it has nothing to do with cancer."*

(ii) Spiritual Struggle on being diagnosed with cancer:

The diagnosis also led a shakedown of faith in God as experienced by 19 year old participant diagnosed with ovarian cancer, *"I was constantly questioning why all of this was happening to me while other kids of my age were carefree."*

(iii) Necessity to come to terms with poor prognosis:

Patients were also diagnosed with metastasis at firsts presentation itself which required the patient and caregiver to accept the diagnosis and come to terms with a poor prognosis and possible death at the same time as experienced by caregiver of Participant OV_{CG5} diagnosed with metastasis of ovarian carcinoma, *"The doctor informed us that it is cancer, we can't do much about it, it has already spread all over the abdomen."*

(iv) Abounding fears and uncertainty:

Avlodhaana nu bayam vandhuruchu started being afraid, not knowing what to do with 2 children around. I don't know any work, so I got scared. I thought to myself if this is the end.

wondering if they read someone else's result to me. cried on hearing. how I will safeguard my family and take care of them. (Participant GU 7 Penile carcinoma)

5.27 THEME-3: FACILITATORS AND BARRIERS IN PATHWAY TO CANCER CARE

Table 66: Categories and codes under the sub-theme: "Facilitators in pathways to Cancer care"

Sr.no.	CATEGORY	SUB CATEGORY/ CODES	QUOTATIONS
1.	Patient factors	Desire to live for loved ones	*"I have lived my life, it would not matter if I leave or not, but they are small children. I want to see my children grow up, settle and establish themselves" (GU2)* *For my two children, I must continue to live (OV10)*
		Peer comparison as a motivation	*"Patients who received chemo injection seems to be doing well which gave me some confidence. I got hope to live when I saw the people who become well after the treatment" (GU2)* *"I got hope as I know others who survived" (GU8)*

2.	Caregiver factors	**Emotional support:** Holistic support	*"Full support financially, mentally & physically*
		Motivational support	*Love, caring and motivating words by the people around gave her the hope & confidence to fight against the disease and to lead the life now" (Participant OV1 CA ovary)*
		Acceptance of treatment: Full and prompt consent to procedures	*"I did not hesitate even a bit to sign the consent document* *asked doctors to do whatever it takes to save their daughter. He didn't mind even the uterus getting removed but just wanted his daughter to be get cured of cancer" (Patient Caregiver OV_{CG4} CA ovary)*
		Marital understanding	*"I suggested that we avoid the surgery if she didn't want. She said all she wanted was for me to be alive" (Participant GU 8, CA penis)*
		Positive attitude: Practical attitude	*"We were not scared and were very practical about it. And were more focused about the treatment part" (Participant Caregiver* OV_{CG3} *CA Ovary)*
		Resigned to fate	*"We'll try our best, beyond that, it is up to fate." (Participant GU 8 CA penis)*

3.	Health care provider	**Motivation to seek treatment:**	
		Doctor's strong words of encouragement Focused advice on compliance	*"Doctor Encouraged and comforted, Convinced the care giver" (Participant OV2 CA ovary)*
		Trust on doctors reassurance	*"Doctor gave Specific advise not to drop out from treatment" (Participant OV 8 CA Ovary)* *"Reassurance by doctor Confidence of doctor gave hope to the patient to continue treatment Belief in doctor" (Participant GU 7 CA)*
		Conductive doctor-patient relationship:	
		Viewing doctor as a God	*"I always thought that God came in the form of doctors to treat me. I am incredibly grateful to him." (Participant OV5, CA ovary)*
		Divine guidance via doctor	*"Reassurance/ Moral support from consulting doctor Drs were soft and they will not show their anger on us"*
		Soft disarming demeanor of doctor	*"Reassurance by doctor Comforted by doctor Help from doctor I thought of the doctor as a form of God Kind words from doctor" (Patient Caregiver* OV_{CG5} *CA ovary)*

4.	Spiritual factors	Cues to seek care	*"My parents brought the Church father home to perform some prayers and then he asked us to consult a doctor immediately"* *(OV 5 CA ovary)*
		Mutual prayer supports	*"We thought that visiting Murugan gave us a sign that something was wrong with her body, and she had to treat it"* *(Patient Caregiver* OV_{CG1} *CA ovary)* *(Patient Caregiver* OV_{CG5}*, CA ovary)*
5.	Insurance factors	Full support from CMCHIS	*"Thanked the CMCHIS without which they would have not started and followed up the treatment regimen" (Participant OV 9 CA Ovary)*

5.28 FACILITATORS AND BARRIERS IN PATHWAY TO CANCER CARE

The sub theme of facilitators in pathways to Cancer care include categories such as patient factors, caregiver factors, health care provider factors, spiritual factors and insurance factors.

The sub categories under patient factors are desire to live for their loved ones - children and dependent mother, peer comparison as a motivation – getting hope from people who survived after the treatment. The sub categories under care giver factors are emotional support (holistic and motivational) in the form of physical, mental and financial support as well as love, care and motivational words gave hope and confidence; acceptance of treatment (full and prompt consent to procedures, marital understanding) – not hesitating to sign the consent form; positive attitudes (practical attitude and resigned to fate) – not scared and very practical about it; The subcategories under health care provider are motivation to seek treatment (doctor's strong words of encouragement, focused advice on compliance, trust on doctors reassurance) – encouragement, comfort, advice and reassurance by doctors gave hope to the patient to continue with treatment; conductive doctor – patient relationship (viewing doctor as a god, divine guidance via doctor, soft disarming demeanour of doctor) –

Doctors were soft and supportive in nature, patients thought that God has come in the form of doctors to treat them. The sub categories of spiritual factors are cues to seek care via church father, temple visits and mutual prayer supports. Under insurance factor, full support from CMCHIS in pursuing treatment emerged as a facilitator.

The sub theme of barriers in pathways to cancer care includes categories such as patient factors, financial factors, health care associated factors, covid factors, insurance factors, family/caregiver factors, treatment and follow up issues. The sub categories of patient factors are fear of surgery (avoidant coping strategy, reluctant attitude), fear of hospital, aversion to hospital set up, seeking symptomatic relief from OTC medicines, competing life priorities, perception of symptoms related factors (procrastination till aggravation, dismissal, normalization and misconceptions) – visiting hospitals only at later stages, pretending to be normal with symptoms, self-medication. The sub categories of financial factors include fear of expenses as a delay factor and multiple referrals.

The sub categories of health care associated factors are health care services a barrier in health seeking – long waiting hours, lack of investigations; informal health seeking – siddha treatment, alternative medicines; nurses as a barrier to health seeking – uncooperative, scolding nurses; transfer of health care providers; lack of communication as a barrier to health seeking; lack of drug supply in govt hospitals; lack of electricity as a cause of delay in treatment; dismissal of patient concerns by health care providers and presumptive treatment. The sub categories of covid factors are increased waiting time and lockdown restriction as a barrier (vain efforts for transport, shutdown of services, expensive travel, fear of acquiring covid). The sub categories of insurance factors are grievances against insurance and unawareness about insurance. The sub categories of family/caregiver factors are deranged family dynamics and treatment delayed caused due to insurance.

The summary of the codes under the subthemes of facilitators and barriers are depicted in the tree diagrams below. Among the barriers subtheme the specific challenges posed by health system were depicted in a separate tree diagram.

Table 67: Categories and codes under the sub-theme: "Barriers in pathway to cancer care"

Sr.no.	CATEGORY	SUBCATEGORY / CODES	QUOTATIONS
1.	Patient factors	**Fear of surgery:**	
		Avoidant coping strategy	*"My mother had to find some excuse to avoid operation and went back to Salem" (Patient Caregiver* OV_{CG2} *CA Ovary)*
		Reluctant attitude	*"My daughter was reluctant for the surgery second time as she was scared" (Patient Caregiver* OV_{CG4} *CA Ovary)*
		Fear of hospital	*"I was apprehensive to go to the hospital so I thought to stay at home" (Participant OV 11 CA ovary)*
		Aversion to hospital set up	*"Not willing for admission after Covid at Anna hospital due to Poor locality" (Participant GU 3 CA bladder)*
		seeking symptomatic relief from OTC	*"I had been trying to go on with pills bought from nearby medical shops on and off for my problems. But at one point of time my condition became severe and I went to doctor" (Participant OV2 CA Ovary)*
		competing life priorities	*"Didn't take CE-CT due to Pongal and COVID" (Participant OV2 CA Ovary)*
		Perception of symptom related factors:	
		Procrastination till aggravation of symptoms	*"Visits hospital when it affects daily activities" (Participant GU 7 CA penis)*

		Dismissal of symptoms	*"We asked her to come to hospital, she didn't come. She used to say, "I'm ok"(Patient Caregiver* OV_{CG2} *CA Ovary)*
		Normalization of symptoms	*"I thought the swelling and pain will be ok and it is due to injury. I did not take it seriously" (*Participant GU 12 *CA testis)* *"She didn't think that it was a big issue and refused to be taken to the hospital" (Patient Caregiver* OV_{CG1} *CA ovary)*
		Misconception about symptoms	*Due to consumption of analgesics for stomach pain (Sandhiya - Ca ovary)*
2.	Financial factors	Fear of expenses as a delay factor	*"We worried about the expenses at hospital" (Participant OV 11CA ovary)*
		Multiple referrals (shuttling)	*"We did not have much money so we were referred to many hospitals comparing costs"* (*Participant OV3 CA ovary)* *"Referred to govt hospital from initial private hospital due to high costs"* (Participant OV4 *CA ovary)*
3.	Health care associated	Healthcare services as a barrier in health seeking	*"Long waiting for scans" (Participant OV3 CA ovary)* *Lack of testing in the first surgery"* *(Participant GU 7 CA penis)*

		Informal health seeking	*"Initially we thought Siddha would be better than allopathy and got Siddha treatment for a year." (Participant GU 4 CA Kidney)* *"My husband asked me to try alternative medicines for three months and see if it gives any results. I tried it, but it gave me negative effects." (Participant* GU2 *CA bladder)*
		Para medicals as a barrier to health seeking	*"Nurses were not understanding and uncooperative Did not address the complaints of the patient at night and scolded the patient" (Participant GU 7 CA penis)*
		Transfer of healthcare provider	*"On arrival, we came to know that the doctor got transferred to another hospital. He was a very nice doctor, he explained everything to us, every scan. Doctor leaving the hospital was another sorrow for us." (Patient Caregiver* OV_{CG2} *CA Ovary)*
		Lack of communication as a barrier to health seeking	*"The other doctors barely explain the tests or scans done, they never bothered to let us know about those tests." (Patient Caregiver* OV_{CG2} *CA Ovary)*
		Lack of electricity as a cause of delay in treatment	*"Some days, there won't be any power, on other days, the machine would be in repair. So, my treatment was delayed by a few months". (Participant GU 8 CA testis)*
		Dismissal of patient concerns by healthcare provider	*"The doctors reassured me it was postpartum symptoms although my abdomen was still as big as 10-month gestation. Since the doctors reassured us about all the symptoms we decided to get discharged" (Participant OV5 CA ovary)*

		Lack of chemotherapy drug supply in Government hospitals	*"My only issue being that I didn't get my medications because they weren't in stock at the hospital (Sunitinib). (*Participant GU 4 *CA Kidney)* *Initially got in govt but had to stand in long ques and took time Later, could not get medicines due to no govt supply" (Participant GU 13 CA prostate)* *"We couldn't get that specific medication anywhere in the Govt Hospital. I went as far as Omandurar and MMC for that. Doctors in MMC again told us that this medication would not be available anywhere in the government setup" (Patient Caregiver OV_{CG1} CA ovary)*
		Presumptive treatment	*"Gave pain medications and injections without investigating cause". (Participant OV2 CA Ovary)* *"Took an x-ray there and sent us home saying that it was a wound." (CA Ovary)* *"When she had her pain once again, we went to the same doctor. He prescribed some medications and assured us that it was not a big issue". (Patient Caregiver OV_{CG1} CA ovary)*

4.	COVID factors	Increased waiting time	*"I had to wait for 1 month for treatment due to covid." (Participant OV2 CA Ovary)*
		Lockdown restrictions as a barrier:	
		Vain efforts for transport	*"She was praying daily that at least one bus should be working for her to visit a hospital". (Patient Caregiver* OV_{CG2} *CA Ovary)*
		Shutdown of services	*"Operation theatres shut down in 2 places (Anna Hospital and Salem GH) -non availability of beds" (Participant GU 3 CA bladder)*
		Expensive travel	*"Travel during COVID was difficult and expensive" (Patient Caregiver* OV_{CG3} *CA ovary)*
		Fear of acquiring COVID	*"During corona, due to crowding, he refused to go to hospital" (Patient Caregiver* GU_{CG2} *CA penis)*
5.	Insurance factors	Grievances against insurance	*"They made us write a letter complaining about the delay in the insurance scheme about how we paid in lakhs and were not given bills. Even for tablets we were not given bills. They had all the reports. We did not have anything." (Patient Caregiver* OV_{CG7} *CA ovary)*
		Unawareness about insurance	*"I Was unaware at that time about insurance benefits for us" (Participant OV 11 CA ovary)*

		Treatment delay caused due to insurance	*"There was no benefit for us from the insurance scheme. They even delayed the surgery by 2 days to get the insurance money but no benefit was obtained." (Patient Caregiver* OV_{CG7} *CA ovary)* *"Operation was also delayed due to insurance. It took me this long to get chemotherapy because of the date mix up in my insurance." (*Participant GU 8 *CA testis)* *"Though insurance is available, it was not useful for me to buy medicines and urine bags" (Participant GU 3 CA bladder)*
6.	Family/ caregiver factors	Deranged family dynamics	*"As years went by my husband and I always got into arguments, and he would use this fact against me. Once he came home drunk and started physically abusing me. (now separated from husband)".* Participant OV5 *diagnosed with CA Ovary* *"At the time of discharge, My wife, my wife's mother, my wife's older brother saying from Tirupur that if my brothers wanted to bring me home, I was to pay Rs5 lakh or else I should not be brought back" (Participant GU 4, CA kidney)*

COVID-19 pandemic posed an important barrier for cancer management among patients in the form of transport difficulties as coated by Caregiver of Participant OV_{CG2}; *"I used to pray every day that at least one bus should be functioning that day"* who was diagnosed with CA ovary, increase in waiting time and issues such as shutdown of Operation theatres and non-availability of beds

Other factors which emerged as barriers for cancer care in KEY INFORMANT INTERVIEWs were as follows:

Time lag in acceptance of treatment:

HCP4 during KII narrated an incident which portrayed the time lag in acceptance of treatment by patients acted as a barrier to timely cancer care: *"patient who had Ca ovary was not ready to accept when doctors recommended surgery, but at present, with post cervical lymph node metastasis, patient is ready to undergo surgery"*

Resorting to native treatment:

Native treatment was unevenly followed by both literates and illiterates alike. HCP3 during KII narrated *"We have a misconception that literates don't go for native treatment. Narikuravar colony, we visited was very difficult to reach by road. Those people stated that they visit doctor even for minor ailments. It's the rich and educated people who go for native treatment due to disbelief in doctors"*

Collision of beliefs:

Hereby illustrating that half knowledge is more dangerous than lack of knowledge. HCP2 narrated an incident about a 24 years old patient, Anjali (Ca Ovary). Anjali didn't believe that she was having an ovarian cyst which needs operation, since she was very young, healthy, didn't have any previous medical history. She thought that doctors lied to her. So, she went for several native treatments like acupuncture for a year.

Peer comparison as a barrier:

HCP2 narrated *"The patient was scared to undergo surgery as she saw other patients dying one by one around during her 6 cycles of chemotherapy. So, she refused surgery and managed with pain killers during covid lock down. Later, her condition worsened with extensive inguinal lymph nodal metastasis"*

Lapses in communication about compliance:

There were many instances of lack of awareness due to lapse in complete disclosure and communication between doctor and patient. HCP2 said *"The patients claim that they are not aware of their diagnosis and treatment even post -surgery. They are not aware of the CA-125. Doctors are not informing about follow up"*. HCP3 said *"Patient was not aware of the follow up and scans every year, she only visited for 3 weeks and then stopped getting checked. Six months later she developed dyspnoea due to metastasis and when she visited the hospital again, she was humiliated for not following up with the treatment. For treatment-sake, the patient accepted her mistake and continued with treatment"*. HCP5 narrated *"The disease and treatment course explanation can be better. Patient with ovarian ca. stated that they should be informed about the cure status of cancer earlier itself. After 12 cycles of chemotherapy, they are informed about the incurable state in a private hospital. Had she known earlier, she would have gone to government hospital avoiding all the catastrophic expenses."* So, the patient had to bear heavy costs due to deficiencies in proper communication.

Lack of documentation:

Deficiencies in proper documentation emerged as an important barrier for cancer care. HCP2 said *"The patients with documentations mostly don't have complicated problems regarding follow up. Patients see the dates mentioned in the documentation and visit the clinic accordingly."*

Challenges in utilizing CMCHIS Scheme:

HCP2 said, *"Patient have to wait for long time for approval of scheme for each and every cycle of chemotherapy and after that card was declined for palliative treatment"* M.O.5 said, *"One of the police applied for CM scheme insurance, due to delay in approval, patient spent their own money for surgery."*

Experienced stigma from spouse:

HCP5 narrated about a female CA kidney patient, *"After being diagnosed, her husband left the house, he also said, you have done a lot of sins. That is why, you are suffering."*

Abrupt crude disclosure of survival prognosis:

HCP2 narrated an incident about a Ca kidney patient, Manoharan. *"The doctors scared him that he will not live for many years and lose his kidney and his right arm. At present, he has undergone right nephrectomy and right arm amputation. He states that the way the doctors revealed the diagnosis was very mentally traumatic for him. So, he initially went for native treatment for 6 months."* HCP4 said *"People are scared of the way their diagnosis and life span explained. In certain cases, doctors don't even reveal the diagnosis and not following the proper treatment protocol. Some doctors over explain the diagnosis and were scaring the patients."* .

This underscores the fact that "Hard truth kills" and the prevailing deficiencies in competency among health care providers in disclosing survival prognoses to patients and their caregivers.

FIG-29: Tree diagram depicting overall barriers to health seeking (among IDI respondents)

FIG-30: Tree diagram depicting patient barriers to health seeking (among IDI respondents)

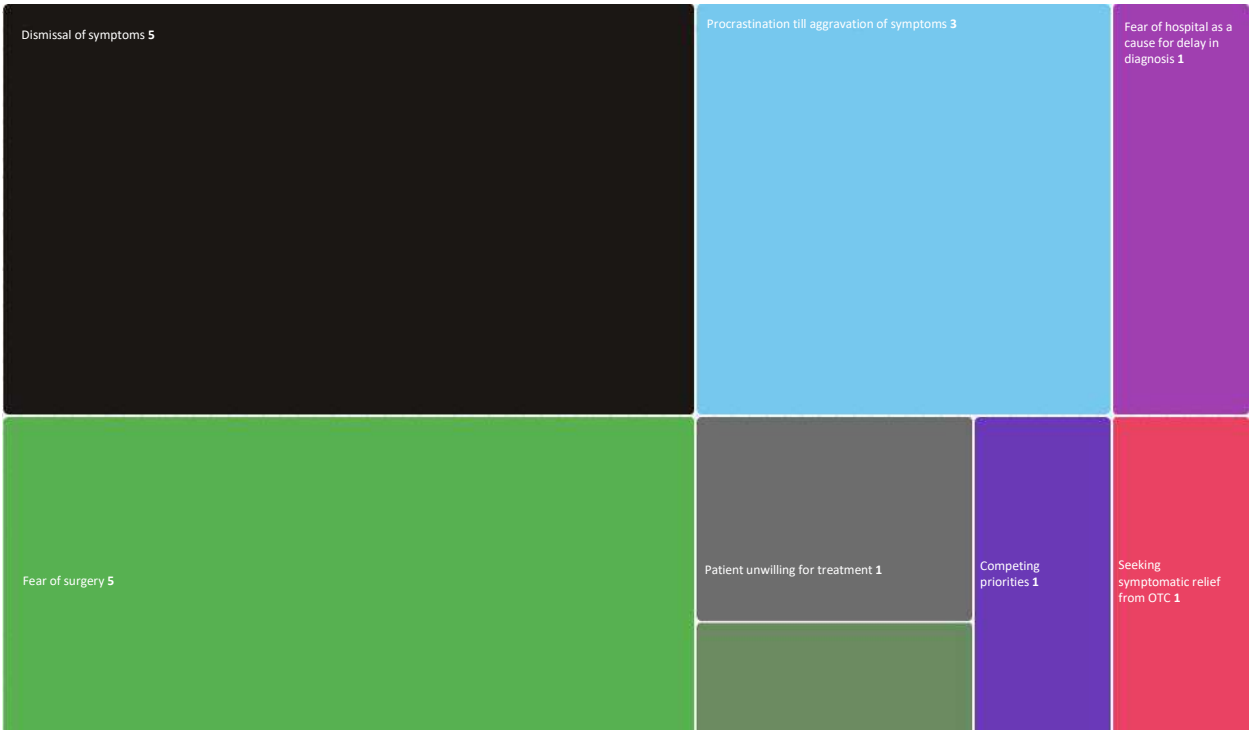
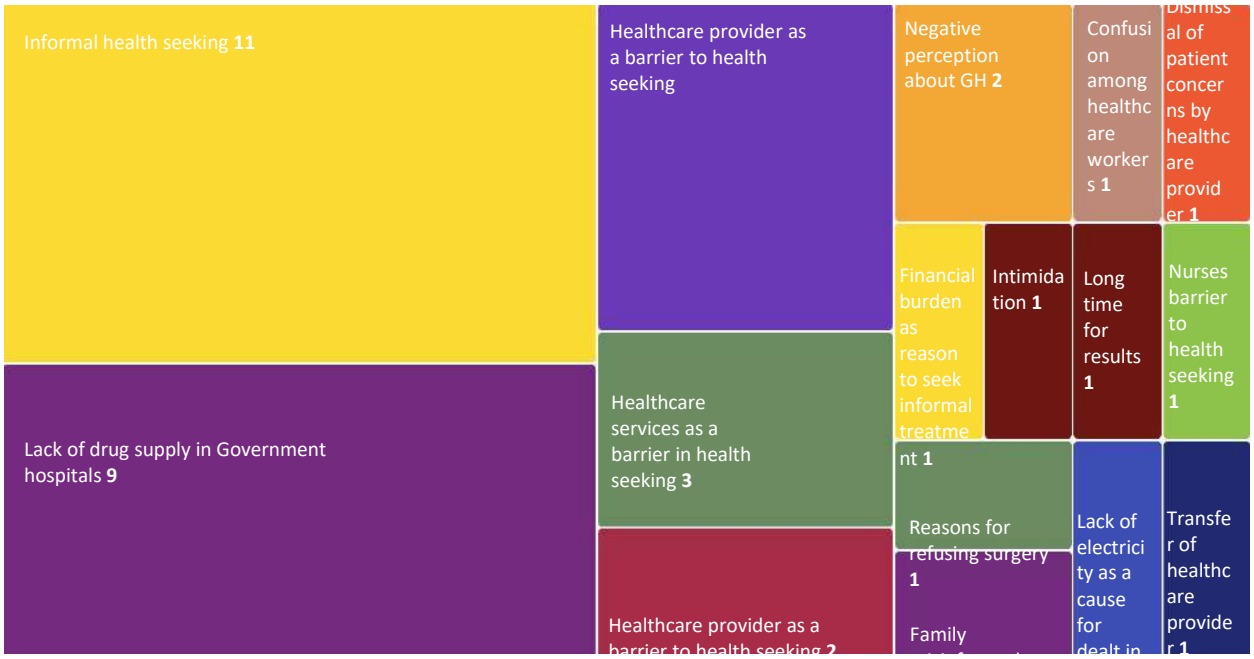


FIG-31: Healthcare system related barriers to health seeking (among IDI respondents)



5.30 THEME-4: STIGMA

Manifestation of stigma among Cancer patient ranges from social isolation within home or community, reduced marriage prospects and physical separation within home. Stigma has been reclassified as perceived stigma, experienced stigma, and internalized stigma. Perceived stigma is where we assess how community think about or behave toward someone with cancer and evaluate how "beliefs about cancer" affect their own or the patient's ability to get healthcare or tell others about a personal cancer diagnosis. Experienced stigma is the degree to which respondents experienced cancer-related stigma in the form of exclusion from social, religious, or family activities; received discriminatory remarks from family members; experienced verbal or physical harassment, loss of work or source of income; or had someone say they were worried they might contract cancer from them; denial of healthcare or insurance due to cancer diagnosis.

Internalized stigma, also referred to as self-stigma is when the patient feels embarrassed or ashamed with his/her diagnosis; hides the diagnosis from family, relatives or society.

On analysing our In depth interviews from 35 patients and categorising it as explained above the following results were obtained:

Figure 32 Stigma encountered among IDI participants: (n=35)

We observed that internalisation of stigma had the highest frequency of occurrence in our study. Non-disclosure of diagnosis of cancer to relatives and society was the most prevalent form of internalised stigma. Fear for their child's future was a motivating factor in non-disclosure of diagnosis to the relatives or society as said by the mother of Participant OV_{CG4} a 19 year old diagnosed with ovarian cancer; *"We didn't tell anyone about her*

condition as it may affect her in future". The alteration of physical appearance mainly in the form of hair loss following chemotherapy was a major cause of depression and embarrassment in female patients as quoted by participant OV 11 diagnosed with ovarian cancer; *"For 3 years I did not look myself in the mirror. I did not keep bindi. I used to look like a beggar*". Patients also suffered emotional trauma from the scarring post-surgery as felt by Caregiver of Participant OV_{CG4} diagnosed with ovarian tumour who underwent staging laparotomy, *"I still get affected by the scar i have from the surgery, it's very big and evident. I wanted to be as normal".* Patients and their primary caregiver misled the society and the relatives about the treatment and diagnosis to avoid scrutiny as cited by Participant GU 8 diagnosed with carcinoma penis; *"I didn't tell Society as cancer. I told them I had a lymph swelling and they did a surgery for that".*

Perceived stigma in the form of apprehension of stigmatisation or complicated conversations was most prevalent and a vital driving factor for internalised stigma. As quoted by Participant GU 8 diagnosed with penile carcinoma, *"Those who don't like use would throw in a few words. They would've mocked me if I told them where it was"* motivated him for non-disclosure of diagnosis. Fear of social reaction was a predominant finding which can be ascertained by the thoughts of Participant GU 12 diagnosed with prostate carcinoma*, "If I say I am having cancer then they will look down upon me".* Patients were also fearful for the future of their loved ones as quoted by mother of participant OV_{CG4}, *"I don't think anyone will agree to marry her knowing her condition."* due to the perception about marriage in the society which fueled the emotional trauma of the primary caregiver as well as the patient.

Stigma was experienced at different levels of the family and society. Stigma among family members was equally prevalent as in society which was a disheartening finding that emerged in our study. As experienced by the son (primary caregiver) of Participant OV_{CG5}, "*Even for the last rites, no one showed up. My sister had the operation. No one visited her. Would talk among themselves"* reflects the added emotional burden he had to undergo due to stigma associated with cancer. Fear of spread of cancer by touch was observed among the society and relatives as witnessed by the primary caregiver (son) of Participant OV_{CG5}, "No one would speak, they won't come visit us. Few people would come see us from a distance and go Afraid that it would spread". Patients were also subjected to social isolation as cited by Participant OV 8 diagnosed with ovarian cancer*, "Not allowed to touch the common pipe While walking on street, villagers used to wash the place with water."* Disengagement from family functions and gathering contributed to the isolation and emotional turbulence felt by

the patients in addition to their poor health which was experienced by Participant OV1 diagnosed with ovarian cancer, *"Relatives started isolating from family functions"*. Patients also experienced stigma associated with cancer at their workplace as stated by Participant GU 5 diagnosed with carcinoma penis, *"They treat me inferiorly which makes me feel that they are prohibiting my work"*.

Figure 33: Tree diagram depicting stigma

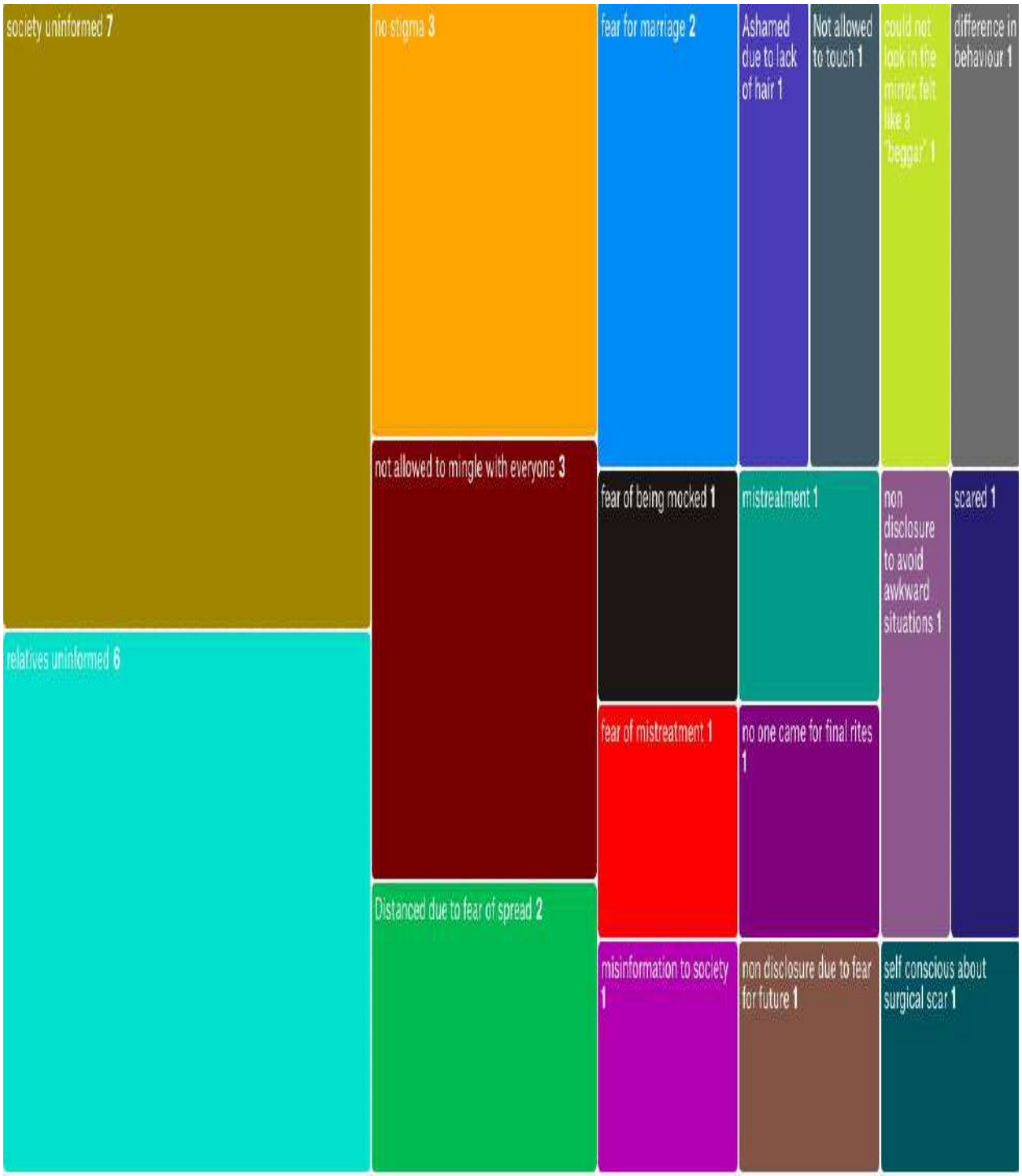


Table 68: Qualitative Codes that emerged for stigma among the study participants

Theme	Category	Codes	Quotes
Stigma among cancer patients	Perceived stigma	Mockery and fear of disclosure	***Those who don't like us would throw in a few words. They would've mocked me if I told them what it was (***Patient GU8 diagnosed with penile carcinoma)
		Doubts about marriage during health condition	**I don't think anyone will agree to marry her knowing her condition** (Mother of Patient OV_{CG4}aged 19 with ovarian cancer)
		Fear of societal gossip and judgment about the health condition.	***If I say I am having cancer then they will look down upon me(***Patient GU12diagnosed with prostate carcinoma)
	Experienced stigma	Family members expressing disapproval or mistreatment due to the health condition.	***No one would speak, and no one would come to see us. Few people would come to see us from a distance, scared that it would spread.*** (primary caregiver (daughter) of Patient OV_{CG5}diagnosed with ovarian cancer.
		Restrictions on mingling with others and avoiding common interactions.	***I was not allowed to mingle with everyone, not allowed to touch the common pipe. While walking on street ,villagers used to wash the place with water."*** (Patient OV 8diagnosed with ovarian cancer)
		Experiencing different and discriminatory treatment, including criticism and inferiority.	***People looked at me differently. People criticised me.They treat me inferiorly which makes me feel that they are prohibiting my work*** (Patient GU5diagnosed with carcinoma penis)

		Isolation from family functions due to the individual's health condition.	***Relatives started isolating from family functions*** (Patient OV 1aged 47, diagnosed with ovarian cancer)
		Work-related consequences and family dispute arising from the inability to work post-cancer diagnosis.	***I used to live and work with my brother. I was unable to work for several months following my cancer diagnosis due to surgery. As a result of this, there was a disagreement between our families, and we were separated. We had to sell our own home and migrate because people in the neighborhood started gossiping about me.*** (Patient GU3, aged 45, diagnosed with bladder cancer)
		Lack of emotional and social support during crucial health moments, such as surgery and last rites.	***Even for the last rites, no one showed up. My sister had the operation. No one visited her. Would talk among themselves"*** the daughter (primary caregiver) of Patient OV_{CG5}diagnosed with ovarian cancer.
		Feeling uncertain about the sincerity of kind words expressed by different individuals.	***Different people behaved differently. Even when they spoke kind words, I was not sure what they thought to themselves (***Patient OV 11, ovarian cancer)
		Poor treatment post diagnosis	***My wife and my wife's family members especially her brother treated me poorly after knowing my diagnosis. I took treatment in hospital without attender. My wife's brother abused me, "Why should my sister look after you when you only have one kidney and one***

		Financial exploitation demand	***hand? If you want my sister to stay with you and look after you, you must pay us 5 lakhs (***Patient GU4aged 61, with renal carcinoma with humerus metastasis)
		Experiencing verbal abuse from the mother and uncle for seeking hospital treatment.	***My husband would drink alcohol and abused me.My mother and my uncle yelled at me and abused me for taking treatment in hospital for a long time.*** (Patient OV 10, aged 33, diagnosed with ovarian cancer)
		1.Surviving an attempted homicide by the drunk husband during pregnancy 2.Cruel treatment from the mother-in-law during a critical health condition. 3.Restriction on the son visiting during a critical health period.	***Before marriage, I had my left ovary removed due to a benign condition. My drunk husband tried to kill me with a pillow while I was three months pregnant. After the birth of my son, I was diagnosed with recurrent cancer and was in a critical condition. My mother in law and husband was cruel to me. I slipped in my restroom, but she refused to assist me. They refused to allow my only son to visit me for almost a year*** (Patient OV 5 aged 33, diagnosed with ovarian cancer)
		Challenges in obtaining medical procedures due to insurance denial.	***The doctor has recommended me a PET scan every year, but the insurance section have rejected saying there is no requirement of PET scan*** (Patient GU4 aged 61, with renal carcinoma with humerus metastasis)
	Internalised stigma	Fear of societal repercussions	***We didn't tell anyone about her condition as it may affect her in future. Grandmother said not***

		and judgment related to health disclosure.	***to tell anyone as it might affect her marriage*** (the mother of Patient OV_{CG4}a 19 year old diagnosed with ovarian cancer)
		Social Deception Presenting a false narrative of a lymph swelling surgery instead of disclosing cancer to society.	***I didn't tell Society as cancer. I told them I had a lymph swelling and they did a surgery for that"*** (Patient GU8diagnosed with carcinoma penis)
		Avoiding social gatherings to evade questions about the health condition	***I mostly avoid social gatherings because people would ask me about my condition*** (Patient GU3,aged 45, diagnosed with bladder cancer)
		Neglecting personal appearance and avoiding mirrors due to the impact of the health condition.	***For 3 years I did not look myself in the mirror. I did not keep bindi. I used to look like a beggar*** (Patient OV 11diagnosed with ovarian cancer)
			I still get affected by the scar I have from the surgery, it's very big and evident. I wanted to be as normal (Patient OV_{CG4}diagnosed with ovarian tumour who underwent staging laparotomy)
		Coping with hair loss	***Due to falling of hair after chemotherapy, I felt awkward going out bald. So used purdah.(***Patient OV 5 aged 33, diagnosed with ovarian cancer)

5.31 THEME-5: ECONOMIC ISSUES FACED BY THE CANCER FAMILIES

The diagnosis of cancer and its impact on their careers often take a double hit on their finances. Out of pocket expenditures for diagnostic procedures, treatment like surgery and chemotherapy and travel expenses for the same combined with loss of income and sometimes even their jobs laid a foundation for catastrophic financial burden.

A. Determinants of financial burden:

The economic burden arising in cancer patients is of multifactorial etiology, roots originating from individual factors and extending till the societal contributions.

1.Baseline socioeconomic status:

Low socioeconomic status of the patient added to their troubles as experienced by Participant GU 13 diagnosed with CA was also financially supported by his son whose business went into losses at the same time of cancer diagnosis which lead them into taking debts.

2.Support from children/relatives:

In old age patients support from their children plays a vital role in determining the depth of their financial burden as in case of Participant OV 6 diagnosed with CA ovary, " *My children were worried a lot and asked me to come to Madurai and said that they'd take care. They themselves spent more than 1 lakh for the treatment and sent me back*." But there were families were they did not have any financial support from their relatives as it happened with Caregiver of Participant OV_{CG1} diagnosed with CA Ovary, "*We never got help from any of our relatives, nor our children got any help from our relatives. It's always been four of us*."

3.Insurance as a boon:

Insurance was a boon for the financially impoverished section, a majority in our study population. It aided in assessing diagnostic and treatment options in cancer patients which are highly expensive in private facilities and untouchable for the lower strata of the population.

Insurance played a major role in reducing the economic burden due to cancer on the patient as well as the caregiver family as experienced by Participant OV5 diagnosed with CA ovary*, "I got benefited from the govt insurance scheme, it would have costs around 3 lakhs in private but due to insurance we spent around 1 lakh."* The insurance schemes not only aided treatment in government hospitals but also in private hospitals as availed by Participant OV2 diagnosed with CA Ovary, "*The insurance facilitated my treatment in Ramachandra*."

Insurance was a motivation for seeking health facilities and continual of follow up as stated by Participant OV 9 diagnosed with CA ovary, *"I thank the CMCHIS without which we would have not started and followed up with the treatment regimen*."

4.Insurance as a barrier for cancer management:

On the other end of the spectrum there were instances were insurance became a barrier due to issues in acceptance of the documents as it happened with. Participant GU 4 diagnosed with renal carcinoma, *"I gave insurance forms for the 4th PET scan 3 times in Stanley. But my insurance got rejected all those times."*

Insurance was a reason of delay in availing cancer treatment in many instances as experienced by Caregiver of Participant OV_{CG7} diagnosed with CA Ovary, "*There was no benefit for us from the insurance scheme. They even delayed the surgery by 2 days to get the insurance money but no benefit was obtained*." This non acceptance of insurance was an added emotional burden to the patients and caregivers as stated by Caregiver of Participant OV_{CG7}, "*They made us write a letter complaining about the delay in the insurance scheme about how we paid in lakhs and were not given bills. Even for tablets we were not given bills. They had all the reports. We did not have anything*."

In many situations, patients were not benefited from insurances for their day to day medical needs as it happened with Participant GU 3 diagnosed with CA bladder, "*No insurance was given for medicines and urine bags.*

There were patients who were unaware of government insurance schemes as in case of Participant OV 11 diagnosed with CA ovary who had to pay for the expenses from her savings as she was unaware of such insurance schemes issued by both private and government organisations leading to the widening of her financial burden which is an avoidable cause of financial drain as quoted by her , "*All our savings was spent in the treatment*."

The dual role of insurance which emerged in IDI is depicted in fig.46

5.Health care systems and services:

Financial burden was also accentuated by the healthcare system and services. Non availability of drugs in the government set up forced the patients and their caregivers to enquire about medications in other hospitals causing them an added travel expenditure as stated by caregiver of Participant OV_{CG1} diagnosed with CA ovary, "*We couldn't get that specific medication anywhere in the Govt Hospital. I went as far as Omandurar and MMC for that. Doctors in MMC again told us that this medication would not be*

available anywhere in the government setup." This forced the patients to acquire these medications from private medical stores which were very costly and many a times cancer treatment becomes unaffordable to the common public as faced by Participant OV 11 diagnosed with CA ovary, "*we made multiple referrals due to lack of 1 stop facilities in government hospital with added cost of travelling due to lack of drug supply forced us get them from private stores.*"

6.Social factors contributing to economic issues:

There were many social factors which aided in reducing the financial burden. Cost cutting measures in the transport and food expenses were a blessing to the cancer patients and motivated them for continuous treatment and follow up. Food expenses were reduced by introduction of "Amma unavakam (canteen) "where meals were served at very affordable prices. Travel expenses were reduced due to concessions given on train and bus fares to the cancer patients. These were commented upon as cost cutting measures by IDI participant GU8 with cancer penis.

5 Role of Spiritual societies:

Spiritual societies also contributed in lightening the economic burden as stated by caregiver of Participant OV_{CG5} diagnosed with CA ovary were the Church paid for their surgery.

Insurance plays an instrumental role in aiding cancer families with reducing their financial burden henceforth acting as a facilitator in treatment seeking. It is essential that measures be taken to spread awareness about existence of insurance schemes and promoting it among all strata of population. It is important at the same time, that effort must be taken to remove all barriers in applying and availing insurance to ensure timely diagnostic and treatment facilities.

B. Components of economic burden:

The financial burden and constraints amid the diagnosis of cancer was a colossal component of troubles faced by the cancer families. There were both direct and indirect economic issues which emerged as a result of the diagnosis.

i) Direct burden:

The direct burdens presented in the form of travel and food expenses for both patient as well as caregiver during the treatment and follow up visits. The road to arrive at a diagnosis was not a direct path but a difficult and a very expensive one. The cost for diagnostic scans and procedures was very costly and practically untouchable for the

economically impoverished sections of the population, which inevitably force them to borrow money or take loans widening their debt as it happened with Caregiver of Participant OV_{CG2} diagnosed with ovarian carcinoma, *"we are very poor, we don't even have our own house. We had to take loan for full body scan*." The next step of management; the treatment part were humongous amount of money was spent on drugs and surgeries where lack of drugs in government hospital forcing them to approach private hospital which was just the tip of the cliff as experienced by Caregiver of Participant OV_{CG3}
diagnosed with CA ovary who was asked to outsource the chemotherapy drugs as they were not available in the government supply.

ii) Indirect burden:

Indirect financial issues faced by the families include the expenditures of transport for the caregiver and in acquiring the drugs for the treatment. This situation was faced by Participant GU 4 diagnosed with CA Kidney, "*During consequent months, the government hospital did not have those medicines, for which I had to go to Coimbatore (CMC)*".

iii) Devastating viscious consequences :

The various ramifications of the economic burden contributed to development of a series of devastating consequences both for the patient and the caregiver's family rendering the family dynamics off balance. Patients drown in the loans and debts taken for treatment and running their families as described by Participant OV 8 diagnosed with CA ovary, "*we spent all our savings on the treatment even then we were short of money so had to take loan to manage everything*."

iv) Health issues and vocational inability:

The diagnosis of cancer was accompanied with severe health issues both due to the cancer as well as the adverse effects of the treatment which ultimately resulted in inability to continue working as described by Participant OV4 diagnosed with CA Ovary, "I am an earning member of our family so I was worried about being unable to contribute for the family income". Participant GU 1 diagnosed with CA, " *I asked if I could go for my work but was advised to not go for any heavy lifting jobs.*" For many cancer patients the emotional trauma aside, it was a source of huge financial difficulty as they were the bread winners of their family. This crippled the financial status of the family. .

v) Loss of work for caregiver :

The loss of work for the caregiver as they were unable to go to work running between hospital during admissions and managing family responsibilities was an added burden to be carried as stated by Caregiver of Participant OV_{CG1} diagnosed with CA ovary, "*My wife had already given VRS (she was a VHN) and I also could not go for work. That one year I was completely by her side*." This resulted no source of financial income for the family leading to more loans and debts. Families were forced to mortgage their house, vehicles and even sell their jewelry as did by Caregiver of Participant OV_{CG7} diagnosed with CA ovary, "*we managed by borrowing money, selling land and vehicles to make the ends meet.*" Increasing debts and loans accompanied a sense of disparity and difficult emotions among the patients and caregivers as stated by caregiver of Participant OV_{CG5} diagnosed with CA ovary, "*Even now I have debts to pay. The lenders are pestering me to pay a lakh in a period of one month I had to take loan, I am in debt of around 4.5 lakhs*".

vi) Compromised quality of life :

The growing economic burden had its detrimental consequences even in the cancer treatment ultimately affecting the quality of life of the patient. Unaffordability of diagnostic scans, tests, procedures and treatment resulted in multiple referrals and healthcare providers before treatment was initiated which in itself contributed to the delay as experienced by Participant GU 13

diagnosed with Penile carcinoma, "*we went to Coimbatore GH for the treatment from initial private consultation due to financial constraints*". It motivated patients to opt for native medicine instead of going for diagnostic tests leading to further deuteriation of the health condition as experienced by Participant OV 9 diagnosed with CA ovary, "*Doctor advised ultrasound abdomen as it was costlier so we decided to choose indigenous medicine for a week but then the swelling burst*" Patients and caregivers opted options that reduced the expenses which compromised the diagnostic and treatment plan as did by Participant GU 13 diagnosed with Penile carcinoma, "*we had to take loan for travelling, for surgery and radiotherapy, food & drugs. So we were not willing for admission due to food and water expenses.*" There were extreme situations were patients were not able to afford further treatment even when they were made aware of the progression of tumor and a poor prognosis as it happened with Participant GU 3 diagnosed with genito urinary cancer.

Figure 34: Schematic diagram of economic issues faced by cancer patients and their families

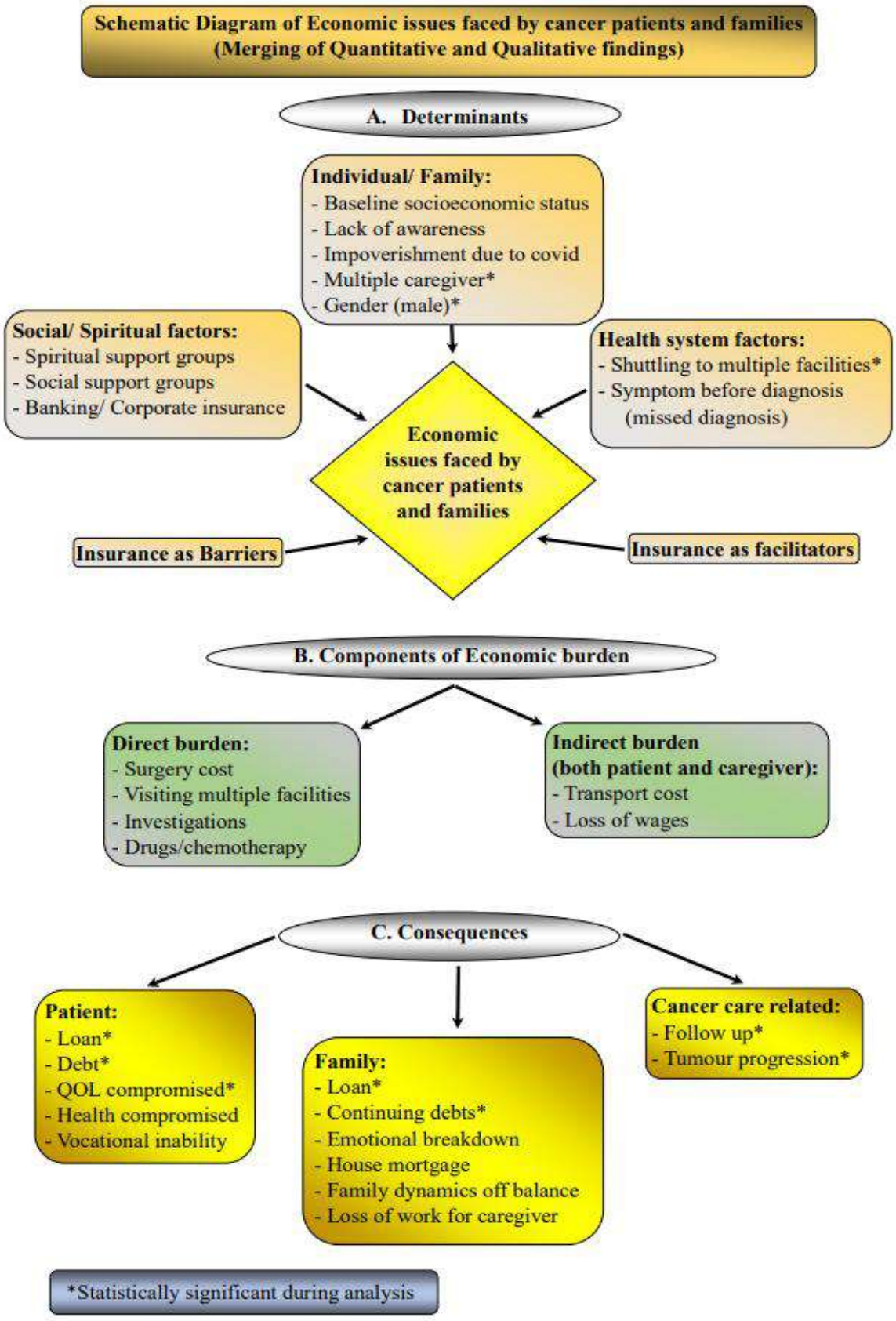
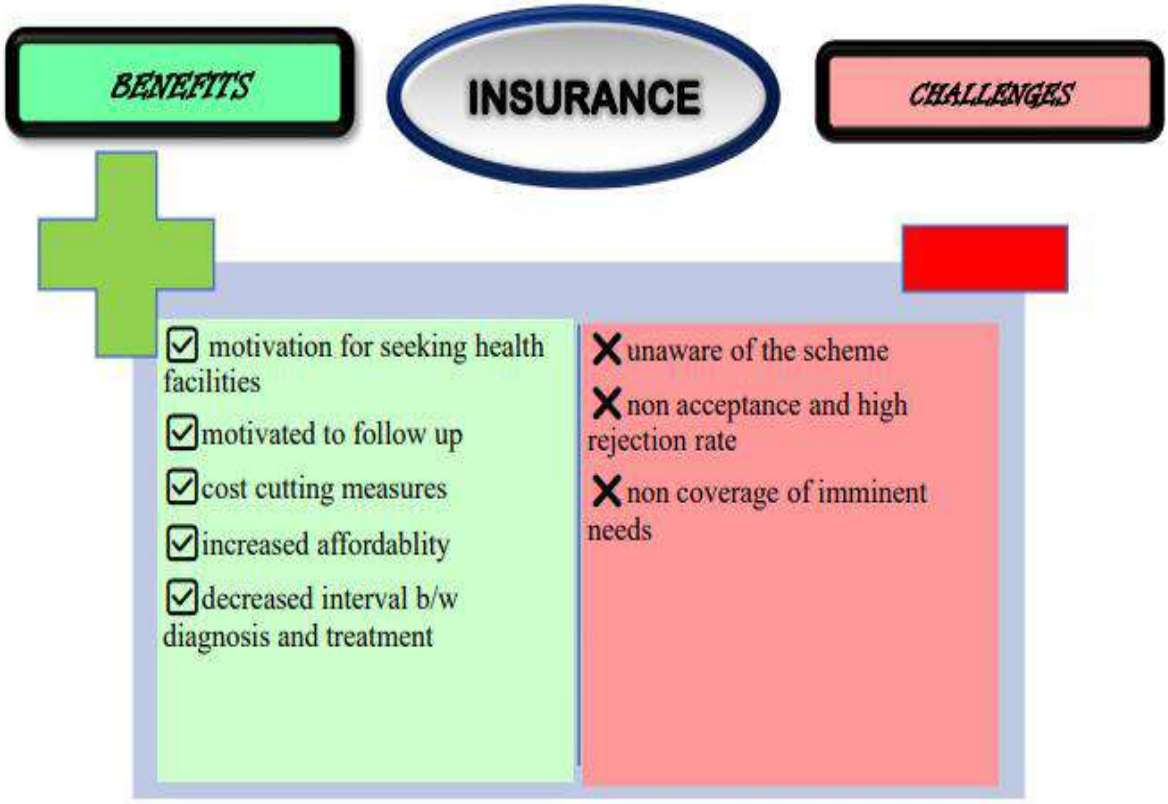


Figure 35: Dual role of Insurance as a boon and barrier among IDI participants



5.32 THEME-6: MULTIDIMENSIONALITY OF CAREGIVER ROLE AND CAREGIVER BURNOUT

Caregivers of cancer patients carry a humungous weight, a burden on their shoulder prevalent in all aspects of life, emotional, social, and financial which is neither identified nor addressed adequality. In our study, financial aspect was the most prevalent form of the caregiver burden.

Financial burden and Vocational challenges faced by Caregivers:

Caregiver had **financial** burden mainly in the form of loans, to repay the money borrowed mainly for treatment and travelling expenses for and as quoted by caregiver (son) of Participant OV_{CG5} diagnosed with CA ovary, *"Still I have debts to pay. The lenders are pestering me to pay a lakh in a period of one month I had to take loan, I am in debt of around 4.5 lakhs"*. Patients also relied for money from sources other than bank loans as did by Participant GU 8 diagnosed with Penile carcinoma,

"We used to borrow 500 from someone, pay it back next week. That's how we managed"

Participant GU 3 diagnosed with bladder carcinoma who made the ends meet by mortgaging house and selling gold jewelry. Financial difficulties were accentuated when the patient or the primary care giver was the sole earning member of the family or when patients who were the only earning member of the family passed away as quoted by primary caregiver of Participant OV_{CG3}, *"No I didn't go for work. That one year I was completely by her side."* Caregivers experienced vocational difficulties as stated by caregiver (husband) of Participant OV_{CG1} diagnosed with CA ovary, *"I stopped going to my regular work as I had to be with her. Petty jobs for 2-3 days in between. Did not borrow money as my wife did not like asking for money. Jewels were used for money".* They had to seek job opportunities in different places to meet the needs of the family as done by caregiver (husband) of Participant OV1 diagnosed with CA ovary, where he had to go to another state to support for the daily expenses and repay the debt due to cancer treatment. Patients and caregivers had to use their life savings for the treatment and associated expenses as said by Caregiver of Participant GU_{CG2}

diagnosed with penile carcinoma, *"I am still struggling to pay for my son's studies. He has money saved up, albeit little"*; caregiver of Participant OV2 diagnosed with CA ovary, *"Savings were Completely spent for her treatment so doing MNREGA to manage daily expenses."*

Emotional challenges in Facing and accepting the diagnosis of cancer:

Facing and accepting the **diagnosis of cancer** was a difficult emotion and hard to process as expressed by caregiver of Participant GU 7 diagnosed with penile carcinoma, *"Shocked and devastated on hearing his diagnosis. I had an emotional breakdown and started crying as I was afraid that he will die."* They were worried about the **patient's emotional state** and hence did not vocalize their emotions and fears in front of them as did by caregiver of Participant *GU 3* diagnosed with CA bladder. Some caregivers took the decision of **not revealing the diagnosis** to the patient and went great lengths to prevention suspicion as did by caregiver of Participant OV_{CG2} who was diagnosed with CA ovary, *"We were cautious that she*

didn't read the signs at test centers and nearby patients weren't being vocal about their condition or talk about the ward we were in. I sprayed room fresheners, but made sure I did it when she wasn't in the room. But slowly, she started to figure it out. I used to give excuses about dog stepping in, relatives coming home and so on." Caregivers supported their patients through **self-sacrificial acts** as done by caregiver (husband) of Participant OV_{CG6} diagnosed with ca ovary who shaved his head as his wife started to develop chemotherapy induced alopecia. They also consoled the patients and relieved them of their fears and their **perception of them being a burden** to the caregiver as quoted by Caregiver of Participant OV_{CG1} diagnosed with CA ovary, *"she was worried that all the money was being spent on her, but I consoled her".*

Seeing their **loved ones in pain** and not being able to help them was a significant emotional burden faced by the caregivers as expressed by caregiver (wife) of Participant GU 7 diagnosed with penile carcinoma, *"Unable to do anything when he was in pain. If it was some other place also I could have massaged or done something here what could I do. I could do nothing".*

On the contrary there were caregivers who felt caring for the patient as a burden as emerged in the **key informant interview** of MO2. The caregivers were not ready to give financial support and moral support to the patients. Such patients perceived care and concern by health care personnel in hospital to be relatively better compared to care at home.

Caregivers' multiple roles at stake due to care giving burden:

Caregivers face a lot of difficulties in balancing various responsibilities ranging from their children, family to the workplace difficulties all the while facing stigma from the society and relatives on several occasions. Participant OV5 diagnosed with CA ovary soon after delivery of her child had no one to take care of her or her newborn child except her parents. So, the aged parents had to care for their daughter post-surgery and chemo along with their grandchild. Caregiver of Participant OV_{CG5} diagnosed with CA ovary said that *"I have 3 children whom I must take care of and a sister who also has similar complaints (uterine mass)".* The stress and burden of caregiving also resulted in incidence of **healthcare issues in caregiver**

as experienced by caregiver of Participant OV_{CG2} diagnosed with CA ovary, *"All these tiring tasks made me weak. I was diagnosed with diabetes in between"* and caregiver of Participant GU $_{CG2}$ diagnosed with CA penis, *"I neglected my problems. [continues describing her condition, showing pictures of the lesion to the interviewers]. I took care of him with all these issues, limping all the way".*

Caregivers' worries on safeguarding emotional wellbeing of patients:

The caregivers had worries about **reaction of their relatives** and their perception leading to non-disclosure of diagnosis and refusal of support, as quoted by Caregiver of Participant OV_{CG1} diagnosed with CA ovary, *"I was worried that they will bad mouth me as I was unable to care for them, so I tried to refuse their visits".* Caregivers also had to face the backlash of the demotivating comments by the relatives who came to visit them as narrate by caregiver of Participant OV 6 diagnosed with CA ovary, "When they came to visit her in the hospital, they all used to ask, *"Did you have to end up with such a fate?"*Many relatives conveyed the worst outcome directly to the patient which would have devastating negative effects on patients emotional state as quoted by caregiver of Participant OV_{CG7} diagnosed with CA ovary, "*The relatives used to tell her that she would die because of the disease."* When I heard that, I used to feel bad as she used to ask herself the same after that."

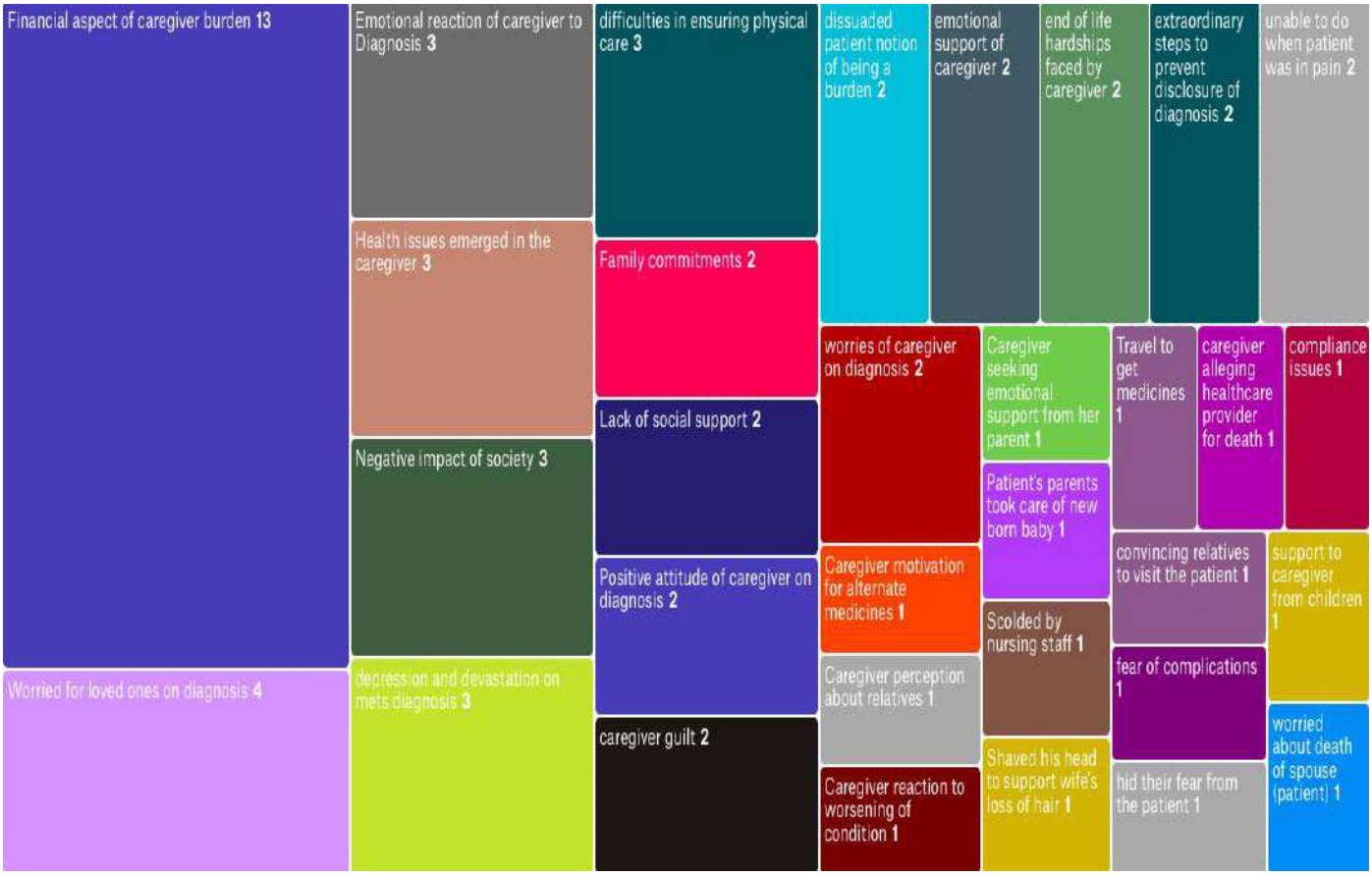
Challenges due to patient non-compliance:

Management of **Uncooperative patients** was another challenge for the caregiver as faced by caregiver of participant OV3 diagnosed with CA ovary, *"we brought her all the medications and tonics, but she refused to take them saying she believed in god and hence had no need of these tonics."* The **diagnosis of metastasis** added to the emotional burden of the patient as expressed by Caregiver of Participant OV_{CG1} diagnosed with CA ovary who was later diagnosed with metastasis, *"Re-surgery and chemo was done but even then, abnormal reports despite adherence and regular follow up was devasting".* **Hearing worsening of condition** of the patient for the caregiver despite their efforts, adherence to treatment was difficult and emotionally exhausting as said by caregiver of Participant OV_{CG2} diagnosed with CA ovary, *"They informed that the condition was worse and there's no use in chemo. I had to harden myself after hearing that."*

Encountering End-of-life issues:

Caregivers also had to face the **end-of-life issues** and come in terms with the death of their loved ones. Caregivers found it difficult to accept their death as felt by caregiver of Participant OV_{CG1} (Husband) diagnosed with CA ovary, *"she herself told me that chemotherapy would have done some good, but the medication which the doctor described did not do her any good. And the doctor who prescribed that medication (She had to take it both in the morning and the evening. So a total dose of 1200 was given to her in a day) had killed her."*

Figure 36: Tree diagram showing the codes which emerged under economic issues among cancer patients



5.33. THEME-7: SPIRITUAL ASPECTS INTERWINED IN THE CANCER CARE CONTINUUUM IN THE STUDY

Spiritual aspects (needs) were observed throughout the spectrum of cancer management among the IDI patients. It continues right from being diagnosed with cancer to end of life issues. Spirituality /religious beliefs, were a coping resource for majority as envisaged in the following instances:

Faith as a resilience factor for overcoming crisis situations:

Prayer came as an instant go to response ever since the disclosure of diagnosis to treatment process and beyond. As commented by Participant GU 8 diagnosed with bladder carcinoma, *"How would we make it this far without faith in God?".* There were others who admitted that their faith and beliefs gave them enough strength and courage to face difficult situations as expressed by Participant OV1 diagnosed with CA ovary, *"Self-confidence & faith in God helped her to fight against the disease".*

Resigning to God's sovereign will – As a coping resource

Certain patients derived strength and courage by surrendering to their lives and fate to the sovereign will of God which accelerated their acceptance of diagnosis ad prognosis aiding them in coping with life in a positive way. As said by caregiver of Participant OV_{CG5} diagnosed with CA ovary, *"I read the Bible for her all the time. we did not shun God. All His actions are justified. It was his thought that my mother should die. Even then someone will helps us in our mother's form".*

Spiritual beliefs superseded the death blow prognostic statements

For few patients their strong rooted beliefs over ridded the emotional burden of diagnosis of cancer at the time of breaking the diagnosis. Participant GU 6 diagnosed with bladder carcinoma expressed that, *"I consoled them stating that cancer or more dangerous disease will be looked after by Jesus"*

Role of spiritual support groups

When in crisis the patient either exercises their own beliefs or resort to other prayer support groups network. Participant OV5 diagnosed with CA ovary stated that, *"Everyone around me started to pray and I believe it's all their prayers that made out of the OT alive".* Relatives motivated them to pray and facilitate the patient to tap into spirituality as a coping resource as experienced by Participant GU 4 diagnosed with CA kidney physical who also received care through a spiritual devotee, *"My elder brother's son who is in Mysore told me to go to Coimbatore to meet Sai Baba*

follower. That Sai baba devotee took care of me like a God. Even my mother could not have given me that much care." The spiritual support network extended their support sometimes till their death as stated by caregiver of Participant OV_{CG5} diagnosed with CA ovary, *"A pastor used to come home and pray for her daily Then somebody used to come and pray for her the day she died".*

Commencement of spiritual journey after diagnosis of cancer:

A patient admitted that true faith in God commenced and increased a lot after he had been diagnosed with cancer. He stated: *"Oh okay before it was like my duty was to visit church on Sundays. this was my faith but after diagnosis it has been changed. First, I thanked God for giving me disease because now I started to search him a lot. I am grateful to God for giving me this disease".* (GU 6 CA bladder)

Religious struggle / spiritual distress

On the flip side, spiritual beliefs were a source of struggle especially in the process of accepting the fatal diagnosis of cancer. *"Why me?" responses: "Sometimes she'd be crying, asking why God is punishing her like this"* (Patient Caregiver OV_{CG2} CA ovary)

Prayed for death: "I once heard her pray to god to take her life" (Participant OV3 CA ovary)

Preferred death: Patient Caregiver OV_{CG2} CA ovary, *"God could've taken her life rather than torturing her like this"*

5.34 THEME-8: END OF LIFE ISSUES

Cancer is associated with a high mortality rate worldwide. High mortality rates mean a very high proportion of caregivers and patients facing the end-of-life issues; medically, financially, and emotionally. The following subcategories and codes emerged in IDI with respect to end-of-life issues:

8a) Emotional issues surrounding end of life care:

(i)Painful course of death and caregiver's hopelessness:

For many patients their final stages of life were very painful and emotionally taxing for the caregiver and family to stay and support them in their final moments as expressed by caregiver of Participant OV_{CG2} diagnosed with CA ovary, *"Her legs started to swell as they told her kidneys weren't functioning well. There wasn't much we could do, she complained of pain and she couldn't have solid foods she was able to consume only some water or coconut water."*

The course of death was very painful for many patients as in case of Participant OV_{CG1} diagnosed with CA ovary, *"Her condition worsened so chemo was stopped. She used to scream in pain and I didn't know what to do. She started vomiting continuously so I took her to Teynampet hospital where they found food pipe obstruction so a feeding tube was to be put but she became uncooperative and passed away after that shortly."*

(ii)Sudden death and caregiver's guilt;

For some patients the cause of death was sudden as in case of participant OV3 diagnosed with CA ovary. Many a times patients pass away when they are alone with no caregiver or family around which was an added emotional guilt for the caregiver as expressed by caregiver of participant OV3 diagnosed with CA Ovary, *"I am sad that I was not able to be with her in her last moment."*

(iii)Lingering memories of death of loved ones:

The aftermath of death in cancer patients left the caregivers with a state of confusion about the patient's health status and the course of treatment that finally resulted in their death as expressed by Caregiver of Participant OV_{CG1} diagnosed with CA ovary, *"I'm still confused about the drug. It severely injured her stomach. She was not able to take any food. Even the fluids came out as vomitus. She survived only through d rips. Even then, they. Had difficulty in finding veins."*

8b) COPING RESOURCES FOR END OF LIFE HARDSHIPS:

Healthcare providers also played a role in handling the final stages of life by giving appropriate advices and sharing the prognosis with the caregiver as in case of Caregiver of Participant GU_{CG2} with CA penis, *"The doctor told us that cancer had spread to brain. His mind was not under his control. Doctors in Omandurar told us 20 days earlier that his treatment was a futile effort and asked us to take him to home and keep him happy."* This helped to mentally prepare themselves for the incoming course of events and support the patient to their best.

Spiritual societies also provided some amount of emotional comfort in their moment of inconsolable grief in the form of prayers as stated by caregiver of Participant OV_{CG5} diagnosed with CA ovary, *"A pastor used to come home and pray for her daily Then somebody used to come and pray for her the day she died."*

Discussion

6. DISCUSSION

Ours was a mixed method study which included 606 participants across Tamil Nadu. From the 5022 samples line listed, 606 participants were interviewed across the selected districts by multistage sampling. Among the 606 participants, 544(89.8%) were alive and 62 (10.2%) were dead at the time of interview.

6.1 Distribution of Ovarian and genitourinary Cancer :

In the present study,57.6% were registered with ovarian malignancy and 42.4% with genitourinary malignancies. Among those with genitourinary malignancies, 22.2% of them presented with malignancy of the urinary bladder followed by 21.4%with penile malignancy, 19.8% with renal malignancy and prostate malignancy and 16.7% with testicular malignancy.Similar study done in North India also shows that prostate and bladder cancer are the most common genitourinary cancers (92) among the male.

6.2 Sociodemographic Details of study participants:

The study population comprised of 63.2% females and 36.8% males with their mean age of 55.27 $\pm$ 13.25 years ranging from 20 to 86 years. More than half ,60.2% are from rural area and 32.7% of them were illiterates. About 32% of the participants belonged to Social Class III (Middle Class) according to Modified BG Prasad Scale, May 2021.The mean age of the study participants in the current study was 55.27 ± 13.25 years ranging from 20 to 86 years. There were 383 (63.2%) females and 223 (36.8%) males among the study participants. About 32% participants belonged to Social Class III (Middle Class) according to Modified BG Prasad Scale, May 2021. More than half (60.2%) of the participants belonged to rural area and about 61.3% were literates. The data was comparable with world bank data on Indian Rural population which stated 64% literacy rate. (93) and Adult Literacy Rate of 69.1% as per Census 2011 (94). Among the study participants, most of them followed Hinduism (87.3%) which was in accordance with NFHS- 5 Survey(95)wherein the persons following Hinduism were 81.9%.

6.3 Clinico epidemiological profile of the study participants:

Majority of the participants in our study reported that they had some symptoms before they were diagnosed with cancer.But still, patients with symptoms before diagnosis had significantly higher delays. This is due to the clinical complexity of the symptoms at the onset of cancer. Literature has documented that most patients with cancer present to primary care with symptoms that have low or very low positive predictive values. Even red flag symptoms have

positive predictive values for cancer of less than 10% in men and even much lower in women.(96)

6.3.1 Clinico epidemiological profile of Ovarian cancer:

Results from previous study (97)showed that factors like multiparity, breast feeding, usage of OCPs, hysterectomy were seen as protective factors among the participants. The factors like family history of malignancy, nulliparity,early age at first pregnancy, early menarche, late menopause, infertility, hormone replacement therapy, physical inactivity, lifestyle anddietary habits(smoked and junk foods) were observed among the participants.

Many literature search says that ovarian malignancies presents with vague symptoms (98) like bloating, dyspepsia, nausea, changes in bowel habits (constipation or diarrhoea), early satiety, distension, abdominal or pelvic pain or discomfort, urinary frequency or urgency, constipationand dyspareunia.Many participantsin our study also presented with vague symptoms but majority of them around 50.7% presented with abdominal pain followed by 49% with abdominal distension and 11% with abnormal uterine bleeding (AUB).A study done by Christina Mary Dobson et al(99) shows that patients with vague symptoms takes time to reach the health care whereas patients with red flag symptoms like abdominal pain, distension and AUB reach the health care earlier for treatment of their symptoms.

6.3.2 Clinico epidemiological profile of genitourinary cancer:

87.2% of participants with GU cancers were alive at the time of interview. The risk factors for genitourinary cancers like precancerous lesions, long standing bladder catheterization, history of frequent dialysis, family history of cancer, congenital anomaly of kidney was mentioned by the study participants. Regarding lifestyle habits, only 24.5% of participants are physically active. Smoking increases the risk of bladder cancer and the risk for current smokers is high when compared to the former smokers(100), in our study we found that 8.9% were current smokers and 34.2% were former smokers.

Majority of the participants had symptoms before the diagnosis of GU cancer. The common symptoms were hematuria followed by dysuria and scrotal swelling. This finding was similar to the study result done in South India where majority of people with bladder cancer presented with hematuria. (93)

Qualitative component of the current study has revealed that many women with ovarian cancers had vague non-specific symptoms for many years before diagnosis and self medication

behaviour was rampant. Literature has documented that there is at least six months time lag between women with ovarian cancer reporting to primary care and diagnosis. One third of patients with ovarian cancer receive over-the-counter medications for alternate diagnosis like IBD, constipation prior to diagnosis of cancer..(101)(102) Failure to recognise symptoms of cancer and normalisation of symptoms are factors strongly linked with delays in help seeking as documented in other studies (103)(101)

These qualitative findings further reiterate the need to take a detailed history of the patient's symptoms and record these in the patient documents. This is further emphasized by NICE guidelines(101).

With respect to symptom complex, there is congruence of qualitative and quantitative findings. Though majority about (96%),had some symptoms before diagnosis, the dismissal of symptom, normalization of symptoms and procrastination of symptoms have contributed to delay in health seeking. This behaviour also led the patients to resort to informal health seeking like OTC drugs which indirectly contributed to delay in formal health seeking.

Similar findings were noted in our quantitative part of the study where symptoms misinterpretation due to lack of awareness and self-medication were significant contributors of access delay and overall delay .

6.4 TREATMENT SEEKING BEHAVIOUR

The time from onset of symptoms to initiation of treatment was considered as total delay and in our study we found that more than half nearly 55% of the participants had a delay of more than 3 months in seeking medical care. Total delay in our study for both the cancers ranged from one week to 135.3 months with a median total delay of 104 days for both ovarian and genitourinary cancers. This is slightly lower than the study in Northern India(104) has come out with a total delay time of 194 days for all type of organ specific cancers. Participants with carcinoma of the ovary, penis, and testis exhibited statistically significant total delay of more than 3 months, highlighting the urgency in addressing delays in these specific cancer types.

We found that 55.3% of participants diagnosed with ovarian cancer experienced a median total delay of 106 days and 54.5% of participants with genitourinary cancer had a median of total delay100 days. Among the genitourinary cancers the total delay time was more for penile cancer followed by testicular cancer and this association was statistically significant. Comparing our findings with those from other studies provides valuable insights. V L Allgar et al. reported

shorter total delays for ovarian cancer (mean 90.3 days) compared to prostate cancer (mean 148.5 days), suggesting differences in healthcare-seeking behaviours and diagnostic pathways between these cancer types.(105)Similarly, Rikke P Hansen et al. demonstrated relatively shorter total delays for ovarian cancer (median 60 days) compared to bladder cancer (median 134 days), further emphasizing variations in delay times across different genitourinary cancers. (106)Additionally, findings from D.M.A. Wallace et al. found that within genitourinary cancers, bladder cancer showed a median total delay of 110 days(107)Participants with carcinoma ovary, carcinoma penis and carcinoma testis had a statistically significant total delay of more than 3 months ($p < 0.05$).

Penile cancer, though relatively rare, presents unique challenges in terms of timely diagnosis and treatment. The associated social and psychological stigma often leads to delays in seeking medical attention, further exacerbating the problem(108)(109)

Another study by Öztürk Ç et al has found that the Median patient reported delay for testicular cancer was 30 (range 1–365) days. .Median patient reported delay was 30 (range 1–365) days(110)

Participants who had multiple care givers, presence of symptoms before diagnosis, multiple health care visits before diagnosis and those with sedentary lifestyle had total delay of more than three months and this association was statistically significant. AStudy done among cancer patients (111) states that the people are unaware of the cancer treatment facility centre and this might be one of the cause for participants visiting multiple health care facility for diagnosis and treatment. Earlier studies have shown that multiple consultations adversely affect the health care experience of patients with cancer.(112)

In our study if the time taken from the date of onset of symptoms to the date of visit to the first provider was more than one month, it was considered as access delay. we found that 55.1% had access delay with a median time of 39 days in our study which is slightly higher than a study from North India,(104) has come out with patient median delay time of 30 days for all the types of cancer. Various studies mentioned by the author (104) had wide range of delay time from minimum of 8 days to maximum of 900 days which are organ specific .

In our study in participants with both the cancer types who had multiple care givers, presence of symptoms before diagnosis, history of smoking in the past, who had visited multiple health care facilities before diagnosis, physically inactive, who had catastrophic expenditure had

delay time of more than one month and this association was statistically significant. Study by Mohammed(113) stated that where majority of the patients seek a primary health care physician for nonspecific symptoms and it's the concern of the physician to differentiate the urgent attention seeking from the self-limiting ones so this might be the reason for access delay in our study where they visit multiple health care facilities for their presenting symptoms.

Study by Montella et al (114)found significant association of age and literacy to access delay whereas other factors like occupation, residence were not significant .Study by Burgess et al (115) found no significant association between age, socioeconomic status and marital status to access delay. Education and upper SES to lesser access delay was significant in a study by Hansen ae al (116).various literate search gives varying associations between sociodemographic factors and delay.In our study we couldn't find any significant association between sociodemographic factors and delay except for residence whereby it was noted in current study that the ovarian patients residing in rural areas had higher total delay for cancer care.

Studies done across the world have documented that those living in rural areas have worse cancer results than those living in non-rural areas, including a lower overall survival rate.(117)(118)Wong ST et al., has documented that less access to health care services and poorer socioeconomic position act as contributors to the impact of rurality on cancer outcomes. Moreover, Cancer patients residing in Rural areas face challenges in accessing specialized surgical care and treatment after receiving a cancer diagnosis(119) The ability of an astute primary care physician to distinguish between the symptoms of ovarian cancer—which can be nonspecific and manifest months or years before a patient is diagnosed—is crucial for women who have not received a diagnosis.(120)

The association between factors for access delay of more than one month like misinterpretation of symptoms due to lack of awareness, self medication, prioritizing other life events, financial constraints for treatment, who sought alternate medical care, denial of insurance, poor health condition were statistically significant. Study by Anderson et al(121) have stated that misinterpretation of symptoms which is influenced by individual socio cultural context as a major patient delay factor in various cancer types.

If the time taken from date to visit the first provider to the date of confirmation of cancer diagnosis is more than one month it was considered as diagnostic delay and in our study we found that 21.6% of participants had diagnostic delay with a median time of 7.5days. This is

lower than the study done in North India(104) for all the cancer types which had stated that the diagnostic median time delay as 33 days.

The association between factors to diagnostic delay like selfmedication, financial constraints for consultation, inaccessibility to health services, who sought alternate medical care, lack of accompanying person, lack of family support, financial constraints for diagnosis, missed diagnosis by health care provider were statistically significant. A survey (122) found that patients visiting their general (family) doctor had comparatively longer diagnostic delay time when compared to others directly consulting the specialist. Diagnosis missed by the health care provider might have made the participants to visit multiple health facilities in our study. Our result was similar to a study done in Central India (111)were most of the diagnostic delay was due to patient inaccessibility and inappropriate referral by the health care provider.

If the time taken from the date of confirmation of cancer diagnosis to the date of initiation of definitive cancer treatment is more than 30 days it was considered as treatment delay which was a median of 12 days in our study. This is much lower thana study in North India(104)where among all the cancer patients treatment delay time of 59 days(median) was observed.

The common reasons for treatment delay included financial constraints, followed by fear of surgery, seeking alternate care including native treatments, fear of side effects and lack of trust on health care professionals.

The association between factors to treatment delay of more than one month like delay in decision making, misinterpretation of symptoms due to lack of awareness, self medication, social stigma, prioritizing other life events, financial constraints for consultation, inaccessibility to health services, lack of family support, lack of accompanying person, issues with care giver were not statistically significant.

In our study we found thatmore than half 57.2% of the participants were not adherent to regular post treatment follow up in their remission phase and the most reasons stated was the absence of symptoms, followed by financial constraints, lack of awareness on the need to follow up and careless attitude. Participants coming from urban area, upper middle class, who had prostate cancer, who had multiple care givers and those who don’t have debts had good compliance and better follow up ($p<0.05$). A study by Simoes F et al documented that treatment attrition was more common in patients with lower education levels and financial constraints like inability to pay(123)

6.5 Effect of COVID pandemic on cancer management

The COVID-19 pandemic had a significant effect on the diagnosis and treatment of cancer patients with 29.2% of participants being affected. We observed from our study that 4.3% had postponed and cancelled consultations during the pandemic, 3.8% had a delay in the diagnosis , 18.5% had difficulty in availing treatment and 10.2% had difficulty in follow up. A study regarding impact of Covid on cancer management in North India have come out with similar results classifying factors as patient related and hospital related(42). A study done by K.Kalpathi et al in Hyderabad on Impact of covid 19 and lockdown on adherence to treatment schedule among cancer patient has documented that 11% had treatment delay of these 50.6% due to fear of covid, 26% due to medical delay and 23.4 % due to transport and travel issues due to Covid 19.(124)

6.6.OUTCOME OF CANCER MANAGEMENT

Among the 606 participants, the distribution of the staging at the time of diagnosis was as follows: Stage I: 124 (20.5%), Stage II: 112 (18.5%), Stage III: 213 (35.1%) and Stage IV: 138 (22.8%).

Majority of participants in our study reported in advance stage of disease similar to the findings done in Central India(111) where most of them reported at advanced stage of the disease. We found a statistically significant difference in the mean survival rates and the stage of malignancy. As the stage increases, the survival rates worsen. From this we can infer that diagnosis at earlier stage should be done so that the survival rate of the patients being diagnosed can be improved.

More than half (55.8%) participants reported that they have got debts for cancer management.

Majority of the study participants nearly 93 % had medical insurance and among them 538 participants had utilized medical insurance for cancer diagnosis and treatment related expenses.Participants in age group of 40 to 50 years ,who are illiterate and unemployed, with multiple care giver, diagnosed in late stage of the disease, with prostatic cancer, in tumour progression stage, those who have debts and catastrophic expenditure have high financial burden and this association was statistically significant**.**

In our study the overall catastrophic health expenditure (CHE) rate was 71.9% (436/606) among the study participants. A study done in middle income countries(125) had found the CHE level of 54% among cancer survivors. A study done in Soth India by Swetha et al(126) have found the prevalence of catastrophic expenditure among population with chronic illness as 14%. In our study the catastrophic expenditure was high since the participants were spending money starting from diagnosis to follow up. In the same study (126) they have found significant association between lower economic class and catastrophic expenditure , in our study also lower economic class participants had more catastrophic expenditure but the association was not statistically significant.

Catastrophic expenditure was highest among those with malignancies of the urinarybladder (80%) and testis (80%) and least among those with renal malignancy (67.4%). Male participants, participants with multiple care givers, participants who had symptoms before diagnosis, participants who visited multiple health care facilities and participants who had debts were significantly more likely to have catastrophic health expenditure holding all other variables constant. A multicentric study done in India() has found that overall catastrophic expenditure was 90.1%

Literature has documented that out-of-pocket expenditure (OOPE) on cancer treatment is among the highest for any ailment.About 40% of cancer hospitalization cases are financed through borrowings, asset sales, and contributions from friends and relatives.(127)

Over 60% of households seeking private sector care spend more than 20% of their annual per capita household expenditure on cancer treatment. The high cost of cancer care often leads to substantial financial burden on patients and their families.(128)

Even among patients with health insurance coverage, cancer treatment results in catastrophic health expenses for more than 80% and impoverishment for over 60% of people. The financial burden associated with cancer underscores the urgency of comprehensive strategies to mitigate its impact on individuals, families, and society.(126)

In the present study, Positive religious coping was significantly higher in females compared to males. Literate patients had better positive coping. It was also found that Christian and Muslim patients had significantly higher positive religious coping compared to Hindus. In a study conducted among cancer patients in the state of Minas Gerais, in relation to the approaching of the issue of spirituality/religion by health professionals, 93% of the patients

consider it to be important as a way of helping in coping with the disease. The majority of the subjects (80%) stated that they would like to receive some type of spiritual care during the period of treatment.(48) In a study conducted in Vienna stated that women are more into religiousness and religious/spiritual practices and more frequently use R/S coping strategies than men.(129)The research postulates a far higher number of women engaging in religious coping as compared to their male counterparts. In a study conducted in India, it was found that Muslims utilized negative religious coping strategies the most, while Sikhs reported the highest usage of positive religious coping. Muslims, Hindus, Sikhs, and Christians reported comparatively high levels of gender traditionalism and religious coping.(130)

The findings of our study reveal a strikingly high prevalence of perceived stigma among cancer patients, with 97.1% of participants reporting at least one measure of perceived stigma. This rate is notably higher than the 85% reported in a study by Squires et al (1) and the 79% reported in a study conducted in Vietnam, (131)indicating that perceived stigma is a pervasive issue in the context of cancer in the studied population.The most common type of stigma was perceived stigma in our study, which was consistent with prior studies on perceived cancer stigma in India. Perceived stigma, particularly the belief that cancer is contagious, emerged as a prevalent theme in our study, with 44.9% of participants reporting that people in the community held this belief. This scenario was consistent with researches undertaken in India (132–135).Specifically, a higher proportion of females (35.5%) held this belief compared to males (15.6%). This suggested a strong- rooted cultural influence on perceptions of cancer and a potential gap in health education. A study among the general community in West Bengal on cancer found that (21.33%) believed that cancer was an infectious disease, which caused some cancer patients to be isolated from their families and society. (136). The perception that cancer is a curse or a result of past sins was held by 29% of participants, highlighting the complex interplay between cultural beliefs and the stigma associated with cancer.Our qualitative study supported the notion that societal perceptions of a family history of cancer as a curse. This was similar with research conducted by Gupta et al, Nyblade et al and Kaur et al.(132,133,135). The majority (82.6%) had perceived stigma about disclosing their neighbours about cancer diagnosis. Non disclosure of cancer diagnosis was rampant and emerged as an important inductive code in our qualitative research. Concerning social interactions, less than a quarter (22.5%) perceived people around would avoid talking or eating with cancer patients. Additionally, 41.3% cited difficulty in accessing

healthcare due to perceived causes, and 62.3% stated challenges in disclosing the diagnosis to others.

The main codes which were found in our qualitative research for the non disclosure of diagnosis would be fear of societal gossip, mockery and judgment about the health condition. A commonly expressed fear which we found in our qualitative study would be disclosing the cancer diagnosis would affect the marriage prospects of their daughter, this resonates with similar concerns identified in a study on cervical and breast cancer stigma in Karnataka.(8) .Another strategy would be concealing actual medical procedures to avoid negative repercussions and withholding information about the diagnosis to in law to prevent marital issues. A significant majority (75.4%) believed that community awareness of their cancer diagnosis would lead to a loss of respect This underscores the need for targeted interventions to address societal attitudes and promote understanding and empathy towards individuals facing a cancer diagnosis.

The findings presented in the study underscore the pervasive and complex nature of social stigma experienced by cancer patients within the study population. The quantitative data reveals significant proportions of individuals affected across different social contexts, with noteworthy percentages experiencing social exclusion in work (10.9%), religious (5.1%), and meal (4.3%) settings. The qualitative insights provide a deeper understanding of the various manifestations of stigma, ranging from disapproval and mistreatment by family members to exclusion from religious activities and restrictions on social interactions.

The participants' narratives shed light on the diverse ways in which social exclusion is manifested, including the verbal abuse, spread of gossip and offensive comments (39.1%), physical harassment (3.6%), and concerns expressed by others about contracting cancer from the patients (13%). The reported discriminatory treatment, such as criticism, feelings of inferiority, and isolation from family functions, further emphasizes the multifaceted impact of stigma on different aspects of patients' lives. A study on breast cancer treatment and social stigma in Thailand (137), a study on attitudes towards breast cancer among South Asian women living in the UK (138), a study on the quality of life of women with breast cancer in India (139), a

Nigerian study on the psychosocial concerns of women living with breast and cervical cancer (140)all describe similar manifestations

The high percentage (87%) of participants feeling uncomfortable disclosing their disease underscores the pervasive nature of the stigma surrounding cancer. This discomfort is further evidenced by the substantial majority (79.7%) actively hiding their cancer from others, reflecting a profound societal fear and a perceived necessity for concealment.

The findings of in depth interviews endorsed the quantitative data which indicated that 38.4% of participants avoid social gatherings and 35.5% feel ashamed of having cancer. This highlights the tangible consequences of such avoidance coping behaviours on individuals' social lives and self-perception. Avoidance of social gatherings can be seen as a coping mechanism to shield oneself from potential judgment or uncomfortable questions about the health condition. The emotion of shame associated with having cancer speaks to the internalization of societal attitudes, reinforcing the need for targeted interventions to challenge and change these perceptions.

The qualitative findings provide rich insights into the strategies employed by individuals to navigate the challenges of stigma. The fear of societal repercussions and judgment emerged as a common thread, leading to various forms of social deception. Participants reported presenting a false narrative, such as describing a lymph swelling surgery instead of disclosing the actual cancer diagnosis to society. This form of social deception reflects the lengths individuals are willing to go to protect themselves from potential stigma, emphasizing the urgent need for destigmatization efforts.

Avoidance of disclosure to neighbours and relatives due to concerns about potential gossip highlights the role of societal attitudes in shaping personal decisions around health disclosure. The qualitative data further reveals instances of strategic information sharing, such as informing relatives about a lymph node procedure instead of cancer to receive financial support. These strategies underscore the complex negotiations individuals undertake to manage the potential fallout from societal judgment.

Neglecting personal appearance and avoiding mirrors due to the impact of the health condition, as well as coping with hair loss, speaks to the profound psychological toll of cancer-related stigma on self-esteem and body image. These aspects further emphasize the need for holistic support systems that address not only the medical aspects of cancer but also the psychosocial challenges associated with stigma.

Despite the humungous nature of the burden, the coping resources and support network is direly lacking in our population. Planning and establishment of support network groups and counselling are the need of the hour to lighten the caregiver burden and ease the transition from acute illness to near normal life.

6.7 STRENGTHS OF THE STUDY:

1.The current study resolved to comprehensively and sequentially assess the continuum of care in cancer patients right from onset of symptoms to outcome

2.Both hard and soft outcomes were studied among the cancer patients.

3.The major strength of the study lies in the fact that the data were collected real time in the patients' household thereby ensuring liberty for them to vent out their real perceptions and emotions .

4.Apart from patient's perspectives, caregiver related issues and viewpoints were also collected in this study which enriched the underlying causes behind various delays .

5.The Social Determinants of Health- related outcomes which have an indirect but significant impact for patients and families, like economic impact,spiritual and social impacts were elucidated both in quantitative and qualitative study designs.

6.The delays in health seeking was segmentally analysed in the form of subcomponents both via quantitative (through preformed checklist) and qualitative approach(through in depth interview) to get an all-inclusive data about occurrence of delays and elaborate reasons underlying them .

7.The data on reciprocal impact of cancer on patients and their families were captured through the mixed method approach,thereby allowing scope for intervention at family / community level

8.The recall bias was maximally minimized in the current study by choosing registered patients of last 5 years (2017-2022)(rather than a long term cohort) and by employing data triangulation by taking multiple inputs by patients themselves , caregiver as well as patients records and data in the hospital registration system,wherever available.

6.8 LIMITATIONS OF THE STUDY:

1.Certain outcome factors like staging and risk factors had minimal data due to lack of complete records with the patient in certain instances and complete nonavailability of documents in case of deceased patients, in most instances (whereby the family member either discarded or even burnt the record in many instances).

2. A complete survival analysis could not be performed since the event rates (death) is only 10.2%. However there is scope for following up the same cohort and carrying out extensive survival analysis studies in future.

3.Though the delay factors could be comprehensively studied,its full-fledged implications for the treatment outcomes could not be studied since the follow up time is short (2017-2022) and hard outcomes like death have not occurred in 90% of the patients.

4. The factors leading to delay could be generalized as a whole for genitourinary cancers and ovarian cancers.However, due to smaller numbers when splitting into individual genitourinary cancers, they could not be generalized for individual subtypes.

5. The stage progression of cancers due to delay could not be elicited since the study is undertaken as a cross sectional study in community settings and data regarding stages of disease at various time intervals is not available. Moreover, employing diagnostic modalities to find out stage of disease at various time intervals is beyond the scope of the study.

7. SUMMARY AND HIGHLIGHTS:

- Among the 606 participants, 544(89.8%) were alive and 62 (10.2%) were dead at the time of interview;
- The mean age of the study participants was 55.27 ± 13.25 years ranging from 20 to 86 years. There were 383 (63.2%) females and 223 (36.8%) males among the study participants. More than half (60.2%) of the participants belonged to rural area and about 32.7% were illiterates. Among the study participants, most of them followed Hinduism (87.3%) and majority was married (81.2%). About 32% participants belonged to Social Class III (Middle Class) according to Modified BG Prasad Scale, May 2021
- 96.2% of participants had some symptoms before diagnosis (95.7% of ovarian and 96.9% of genitourinary).48% of ovarian and 16.2% of genitourinary cancer participants had red flag symptoms before diagnosis.
- Total delay :55% of the participants had a delay of more than 3 months in seeking medical care. Total delay for both the cancers were from one week to 135.3 months.
    - Participants with carcinoma ovary, carcinoma penis and carcinoma testis had a statistically significant total delay of more than 3 months ($p < 0.05$).
    - Participants who had multiple care givers, presence of symptoms before diagnosis, multiple health care visits before diagnosis, sedentary, had total delay of more than three months and this association was statistically significant. . Those who visited multiple care facilities were 1.63 times more likely to be in more than 3 months delay and those who were physically active were 0.56 times less likely to have more than 3 months delay.
    - The factors causing total delay of more than 3 months like delay in decision making, misinterpretation of symptoms due to lack of awareness, missed diagnosis by health care provider, were statistically significant. Participants who had factors like symptom misinterpretation due to lack of awareness and missed diagnosis by health care provider were 2.96 times and 2.26 times more likely to fall in more than 3 months total delay group.
    - 55.3% of participants with ovarian cancer, had delay time from one week to121.5 months,

- In participants with ovarian cancer who are from rural area with multiple care givers, physically inactive, who visited multiple health care facility before diagnosis, symptom misinterpretation due to lack of awareness, missed diagnosis by health care provider, difficulty in accessing health facility, lack of family support, delay due to COVID pandemic and poor health condition had delay time of more than three months and this association was statistically significant.
- 54.5% of participants with genitourinary cancer, had delay time from 3 days to 135.3 months
- In participants with genitourinary cancer who got guidance from multiple health care provider before diagnosis, symptom misinterpretation due to lack of awareness and missed diagnosis by health care provider is statistically significant to delay time of more than three months($p<0.05$).
- Among the genitourinary cancers the total delay time was more for penile cancer followed by testicular cancer and this association was statistically significant

- Access delay: 55.1% had patient delay of more than one month
  - In our study in participants with both the cancer types who had multiple care givers, presence of symptoms before diagnosis, history of smoking in the past, who had visited multiple health care facilities before diagnosis, physically inactive, who had catastrophic expenditure had delay time of more than one month and this association was statistically significant
  - Participants with symptoms before diagnosis, those who visited multiple healthcare facilities and people who had gone through catastrophic spending were 8.03 times, 1.843 times and 1.58 times more likely to access the healthcare facilities after 30 days of symptom onset respectively. Participants who were physically active were 0.56 times more likely to reach health facilities within 30 days of symptom onset.
  - The association between factors to access delay of more than one month like misinterpretation of symptoms due to lack of awareness, self medication, prioritizing other life events, financial constraints for treatment, who sought alternate medical care, denial of insurance, poor health condition were statistically significant. Participants who had factors like symptom misinterpretation due to lack of awareness, who prioritized other life events and with poor health condition were 5.72 times, 3.96

times and 5.64 times more likely to access health care facility beyond 30 days of onset of symptoms holding all other variables constant.

- In Participants with ovarian cancer who are in upper socioeconomic class, who had multiple care givers, who had visited multiple health care facilities before diagnosis, physically inactive, who had catastrophic expenditure, symptom misinterpretation due to lack of awareness, self medication, prioritising other life events, seeking alternate medical care and delay due to COVID pandemic had delay time of more than one month and this association was statistically significant ($p<0.05$).
- In Participants with genitourinary cancer with history of smoking in the past, who had catastrophic expenditure had delay time of more than one month and this association was statistically significant. Among the genitourinary cancers the access interval time was more for penile cancer followed by testicular cancer and this association was statistically significant.

- Diagnostic delay: 21.6% of participants had delay of more than one month
  - Participants who visited multiple healthcare facilities were 3.88 times more likely to have a confirmed diagnosis after 30 days of initial consultation. Cancer patients with medical insurance were 0.36 times less likely to have a confirmed diagnosis after 30 days of initial consultation, if the participant has medical insurance, the odds of diagnostic delay decreases.
  - The association between factors to diagnostic delay of more than one month like self medication, financial constraints for consultation, inaccessibility to health services, who sought alternate medical care, lack of accompanying person, lack of family support, financial constraints for diagnosis, missed diagnosis by health care provider were statistically significant. Participants who were on self-medication, who had financial constrains for diagnosis and missed diagnosis by healthcare provider were 7.28 times, 5.95 times and 6.72 times more likely to have a confirmed diagnosis beyond 30 days of initial consultation by healthcare provider holding all other variables constant.
  - In Participants with ovarian cancer coming from rural area ,who had visited multiple health care facilities before diagnosis, inaccessibility to health services,

lack of accompanying person, self medication and missed diagnosis by health care provider had a delay time of more than one month and this association was statistically significant ($p<0.05$).

- In Participants with genitourinary with history of smoking in the past, who had visited multiple health care facilities before diagnosis, self medication, missed diagnosis by health care provider, financial constraints, sought alternate medical care, misclassification of disease severity and prioritising other life events had a delay time of more than one month and this association was statistically significant($p<0.05$). Among the genitourinary cancers the diagnostic delay time was 2.02 times higher for penile cancer and this association was statistically significant.

- Treatment delay: 22.6% had delay of more than one month
  - In our study in participants of both the cancer types who visit multiple health care centres were 1.97 times more likely had a delay time of more than one month and this association was statistically significant.
  - In Participants with ovarian cancer who had visited multiple health care facilities before diagnosis, seeking alternate medical care, financial constraints, lack of family support, fear of side effects, fear of surgery, lack of trust on health provider, and poor health condition had a delay time of more than one month and this association was statistically significant ($p<0.05$).
  - Participants with genitourinary malignancy had a statistically significant association for delay in treatment interval of more than 30 days with factors like inaccessibility to health services, financial constraints, lack of family support, misclassification of disease severity, fear of side effects and delay due to COVID pandemic. Among the genitourinary cancers the treatment delay time was 2.67 times more for penile cancer and this association was statistically significant.

- The COVID-19 pandemic had a significant effect on the diagnosis and treatment of cancer patients with 29.2% of participants being affected.

- Outcome of the disease:

1. **Stage of the disease**: Majority of participants presented in advanced stages, There is a statistically significant difference in the mean survival rates as the stage of the malignancy increases. As the stage increases, the survival rates worsen.

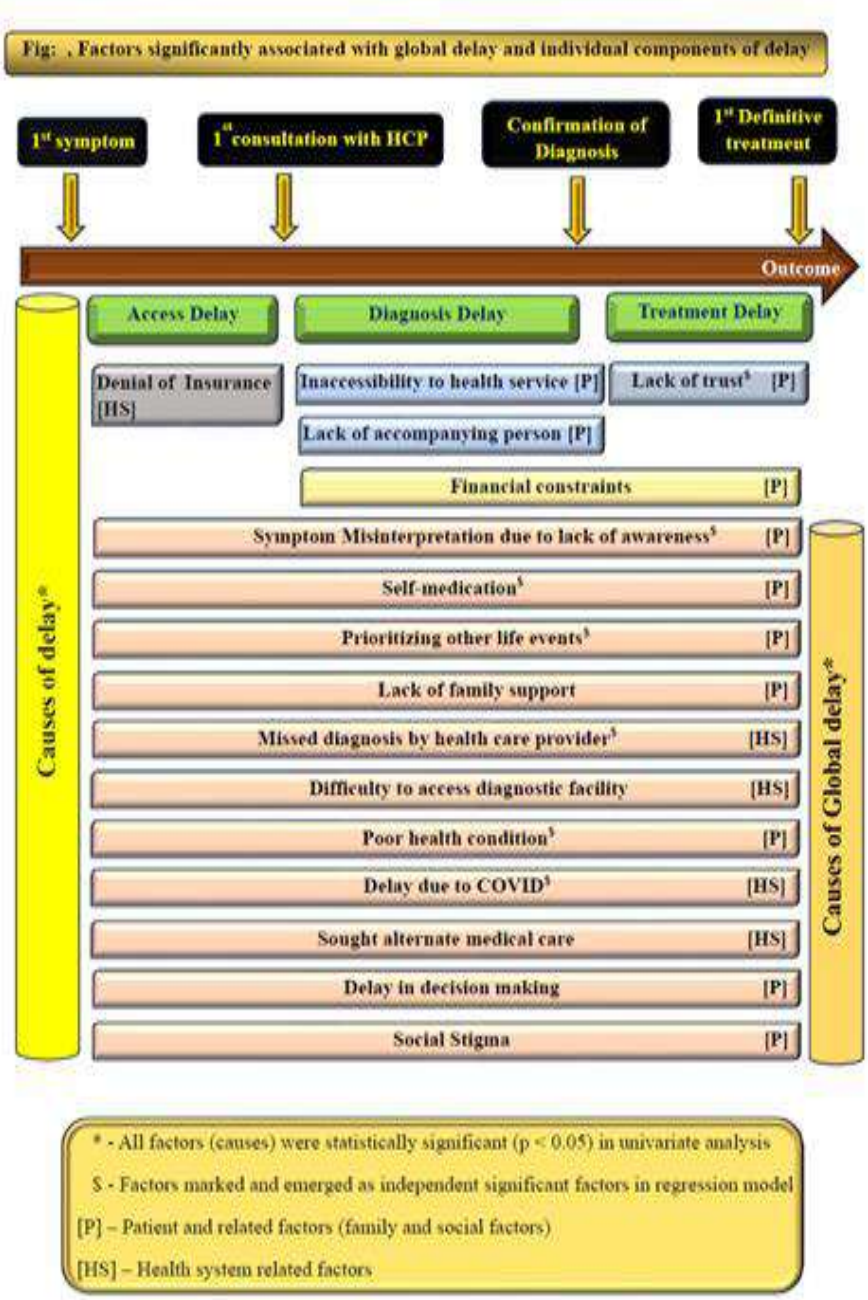
- Participants who had symptoms before diagnosis were 0.27 times less likely to be diagnosed with cancer at an advanced stage of disease holding all other variables constant. This result suggests that with the chances of having symptom before diagnosis, the odds of being diagnosed at advanced stage of disease decreases. Patients with carcinoma ovary and carcinoma prostate were 4.02 times and 3.98 times more likely to be diagnosed at advanced stage of disease as compared to participants with carcinoma kidney. Patients between 30 and 40 years of age were 0.35 times less likely to be diagnosed at advanced stage of disease as compared to participants above 60 years of age. More participants who died had presented at the late stage of the disease at the time of diagnosis. This association was found to be statistically significant. (p=0.0001)

2. **Clinical outcome**: 61.6% were in remission phase, 28.2% were under active treatment and 10.2% were dead. More participants with genitourinary malignancy were on remission than participants with ovarian malignancy (70.1% vs 67.5%). Among those on remission,42.8% participants were on regular follow up of the disease. Participants with genitourinary malignancy were on regular follow up than participants with ovarian malignancy (33% vs 26.3%). Participants who were on regular follow up and were compliant to treatment had statistically significant better mean survival rates than participants who were not on regular follow up. ($p<0.001$).Participants with ovarian malignancy had a higher tumor progression rate than participants with genitourinary malignancy (11.9% vs 8.9%).

- Majority of the patients at the time of diagnosis who presented in stage I and stage II are under remission phase whereas most of the patients who presented in stage III are under primary treatment of the disease and more than half of participants who presented in stage IV were dead and this association was statistically significant ($p<0.001$).

- Participants who were on regular follow up and were compliant to treatment had statistically significant better mean survival rates than participants who were not on regular follow up. ($p<0.001$)
- Participants who had guidance from healthcare provider were 3.08 times more likely to be compliant to treatment

Figure 37: **Pictorial representation of global delay and individual delays**



3. Assessment of daily living: Katz index was calculated at the time of diagnosis and at the time of interview. 90% were independent at the time of diagnosis and more than 85% were independent at the time of interview irrespective of the type of malignancy. The level of independence had worsened among participants with prostate and bladder malignancy and improved among those with ovarian malignancy

- Participants who are literate ,employed, with testicular cancer, in remission phase, with near by health centre within 50 km have independent ADL score when compared to those who are illiterate, unemployed, with bladder cancer ,in tumour progression phase with near by health care more than 50km having severe ADL score and this association was statistically significant.

4. **Quality of life:** Assessed byEORTC questionnaire- The global quality of life was found to be poor in participants with ovarian malignancy and participants with testicular malignancy had a poor functional score whereas those with prostate malignancy had good functional score.

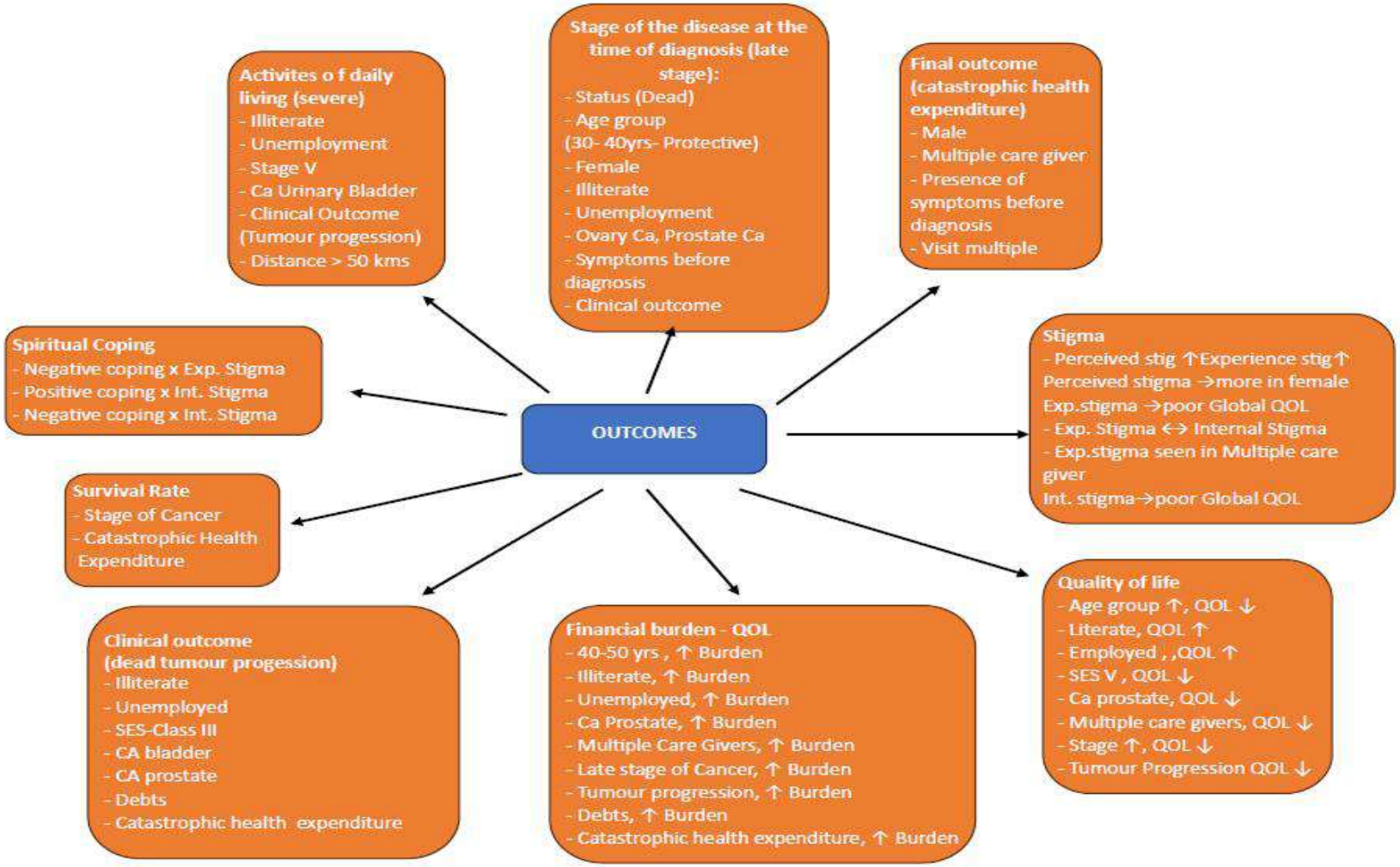
5. Financial outcome: 55.8% participants have got debts for cancer management:564 participants (93.1%) had medical insurance. The overall catastrophic health expenditure (CHE) rate was 71.9% (436/606) and it was high for GU malignancies especially bladder and testis.

- Male participants, participants with multiple care givers, participants who had symptoms before diagnosis, participants who visited multiple health care facilities and participants who had debts were 1.79 times, 2.69 times, 2.96 times, 2.88 times and 1.79 times more likely to have catastrophic health expenditure holding all other variables constant.

6. Survival:

Participants with ovarian malignancies had a comparatively better survival than participants with genitourinary malignancy. Among genitourinary, testicular malignancy had better and bladder malignancies had the least survival rates.

Figure:38 Outcome of the study at a glance



Recommendations

7. RECOMMENDATIONS:

1. Behavioural factors like physically active lifestyle was found to be an independent significant predictor for global delay especially access delay. Further, the healthy behaviour of quitting smoking was also significantly associated with access delay. Hence inculcating and promoting healthy lifestyle modification should be a part of focussed Behaviour Change Communication among cancer patients. This could be merged with the existing NCD control activities under the current NP-NCD programme.

2. Higher thrust and special emphasize to be given to patients belonging to lower socioeconomic status and compromised health conditions since these two baseline factors were independent predictors of patient delay. Further, cancer patients residing in rural areas need focused attention in view of their poor compliance and access delay.

3. Though Majority(96.7%) presented with symptoms before diagnosis,of which many had red flag signs, still those who were symptomatic before diagnosis had significantly higher percentage of delay than those whose cancer was diagnosed incidentally. This strongly reinforces the need for cancer screening and promoting master health checkup among the public .However for malignancies like ovarian cancer no proper and approved screening protocols exist as of date due to the inherent epidemiology of ovarian cancer. Therefore increasing awareness among general public as a whole on red flag signs for individual cancers should be widely disseminated through various health education modes and approaches.

4. Delay in access incurs heavy costs for the patients and their families as evidenced in current study that catastrophic expenditure is significantly higher among those with access delay. This impoverishment initiates a vicious cycle of accelerated tumour progression and lapse in compliance which further pushes them to debts and loans.Hence it is of dire necessity to provide financial assistance to patients diagnosed with cancer throughout their lifetime .

5. A significant association was found between those patients with severe compromise in ADL and the distance of their residence from the health care setting (residing >50kms). This finding reinforces the need for setting up palliative outreach services (community based palliative care) which is currently scarce in Tamil Nadu.

6. More than two thirds of the study participants were ignorant about their symptoms due to lack of awareness. So cancer awareness campaigns, programmes, websites, reels, melas and talks can be conducted to help recognise the early signs and symptoms of cancer enabling them to seek treatment at an early stage , to improve knowledge on warning signs, to educate about the key risk factors, to inform about the importance of regular screening and check ups and to help the community make healthier lifestyle choices.

7.It was perceived by 14.7% of the participants that the cancer diagnosis was missed by the first health care provider and it was a significant contributor for delay. To prevent this, periodic training and evaluation programmes to all primary health care providers on the warning signs of various malignancies should be planned. Special training sessions to all the secondary and tertiary care providers, to effectively improve some areas of cancer care professionals communication skills and to insist upon follow up and compliance of treatment.

8. To reduce stigma in the society, awareness campaigns should be launched utilizing various channels such as media, health talks, posters, audio and video presentations. These campaigns should aim to dispel misconceptions around cancer, educate the public on various aspects of the disease (from prevention to survivorship), and encourage empathy and understanding as more than two third of the participants experienced stigma in our study .

9. Networks of care can be created that extend beyond medical treatment, offering counseling services, support groups, and financial assistance to individuals and families affected by cancer.

10. As recommended by the caregivers and cancer survivors, support groups can be created specifically for families of cancer patients. These groups can serve as a platform for sharing experiences, exchanging advice, and building a community of understanding. Connecting with others facing similar challenges can be empowering and reassuring for family members.

11. Healthcare providers, policymakers, and communities need to collaborate to create an inclusive and empathetic environment that mitigates the adverse effects of stigma on cancer patients, fostering a society where individuals can navigate their health challenges without fear of discrimination or exclusion

12. Unique ID number should be generated for those who register with cancers at the initial point of registration, to maintain record linkage as they are referred to various health centres for various cancer care services and to keep a track of them for effective adherence to follow up.

13. To set up a toll-free helpline to provide support for fear, anxiety and stress related to cancer.

14. Importance of follow up should be reinforced to the patients and their care givers and protocols for follow up should be strictly enforced and adhered.

15. Patients frequently have to seek treatment from multiple institutions or healthcare providers, which makes the cancer journey fragmented and complicated. It can also be draining financially, especially when patients don't know how or where to go to for assistance. This warrants the need for one-stop cancer centres or integrated cancer care centres that can help ease some of these difficulties of the cancer journey. Patients would benefit from an integrated approach that provides the patient with the usual cancer management and treatments like surgery, chemotherapy, behavioural health services, nutritional support and other conventional tools, while also supporting their strength, stamina and quality of life with vocational therapies and counselling.

16. Need to employ clinical social workers in each primary health centre to counsel the patient and their family members from the time of diagnosis and provide continuum of care to provide psycho-social rehabilitation.

Table: 69 LIST OF KEY RECOMMENDATIONS AND SUPPORTIVE FINDINGS FROM THE STUDY

NO	RECOMMENDATIONS	SUPPORTIVE FINDINGS FROM CURRENT STUDY
1.	Inculcating and promoting healthy lifestyle modification as a part of focussed BCC (integrated with NP-NCD programme)	Physically active lifestyle.[AOR-=0.56, CI:0.36-0.87 (P=0.009)] and Quitting smoking [OR=0.49,CI:0.32-0.79 (P=0.003)] significantly lowers access delay
2.	Increasing awareness among general public as a whole on red flag signs for individual cancers	While 96% of patients exhibited symptoms before diagnosis, those symptomatic prior to diagnosis experienced significantly longer

		delays[AOR:8.03,CI:2.21-29.2 (P=0.002)] compared to those incidentally diagnosed, despite many showing red flag signs.
3.	It is of dire necessity to provide financial assistance to patients diagnosed with cancer throughout their lifetime	Catastrophic expenditure is significantly higher among those with access delay[AOR=1.58,CI:1.05-2.36(P=0.027)]. This impoverishment initiates a vicious cycle of accelerated tumour progression and lapse in compliance which further pushes them to debts and loans(emerged in IDI interviews)
4.	Need for setting up palliative outreach services(community-based palliative care)which is currently scarce in Tamil Nadu.	A significant association was found between those patients with severe compromise in ADL and all residence (residing >50kms)
5.	Periodic training and evaluation programmes to all primary health care providers on the warning signs of various malignancies should be planned.	It was perceived by about 14.7% participants that the cancer diagnosis was missed by the first health care provider in our study and it was a statistically significant contributor for delay(AOR:6.72, 95%CI:4.04-11.28)
6.	Stigma reduction campaigns through diverse media channels.	Widespread stigma in various forms among study participants(Both qualitative and quantitative)
7.	Unique ID number should be generated for those who register with cancers at the initial point of registration, to maintain record linkage as they are referred to various health centres for various cancer care services and to keep a track of them for effective adherence to follow up.	Multiple health care visits before diagnosis is significantly associated with global delay. (AOR:1.63, 95%CI:1.03-2.58)
8.	The need for one-stop cancer centres or integrated cancer care centres that can help ease some of these difficulties of the cancer journey.	

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Annexures

Annexure 1

THE FACTORS LEADING TO THE DELAY IN CANCER MANAGEMENT AND ITS IMPLICATION FOR TREATMENT OUTCOMES FOR OVARIAN AND GENITOURINARY MALIGNANCIES ACROSS TAMIL NADU – A MULTICENTRIC MIXED METHOD STUDY.

DEPARTMENT OF COMMUNITY MEDICINE
GOVERNMENT STANLEY MEDICAL COLLEGE
CHENNAI

INFORMED CONSENT

TOPIC : THE FACTORS LEADING TO THE DELAY IN CANCER MANAGEMENT AND ITS IMPLICATION FOR TREATMENT OUTCOMES FOR OVARIAN AND GENITOURINARY MALIGNANCIES ACROSS TAMIL NADU – A MULTICENTRIC MIXED METHOD STUDY.

The content of the information sheet dated _____ that was provided have been read carefully by me/explained in detail to me, in a language that I comprehend and fully understood the contents. I confirm that I have had the opportunity to ask questions.

The nature and purpose of the study and its potential risks/benefits and expected duration of the study and other relevant details of the study have been explained to me in detail.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal right being affected.

I agree to take part in the above study.

(Signature/Left thumb impression)
Name of the Participant:
Son/Daughter/Spouse of
Complete postal address:

Signature of the
principal investigator

This is to certify that the above consent has been obtained in my presence.

Date: Place:

2) Witness – 2
Signature:
Name:
Address:

2) Witness – 2
Signature:
Name:
Address:

****

ஒப்புதல் படிவம்

தலைப்பு : சூலகம் மற்றும் சிறுநீர் இனவள உறுப்பு புற்றுநோய்களால் பாதிக்கப்பட்ட தமிழ்நாடு முழுவதும் உள்ள புற்றுநோயாளிகளிடையே சிகிச்சையில் ஏற்படும் பல்வேறு தாமதத்திற்கான காரணிகள் மற்றும் அதன் விளைவுகள் பற்றிய ஒரு .ஆய்வு

_____ தேதியிட்ட தகவல் தாளின் உள்ளடக்கத்தை நான் கவனமாகப் படித்தேன்,எனக்கு விரிவாக விளக்கப்பட்டது. உள்ளடக்கங்களை நான் முழுமையாகப் புரிந்துகொண்டேன். கேள்விகளைக் கேட்க எனக்கு வாய்ப்பு கிடைத்துள்ளது என்பதை உறுதிப்படுத்துகிறேன். ஆய்வின் தன்மை மற்றும் நோக்கம் மற்றும் அதன் சாத்தியமான அபாயங்கள்/பயன்கள் மற்றும் ஆய்வின் காலம் மற்றும் ஆய்வின் பிற தொடர்புடைய விவரங்கள் எனக்கு விரிவாக விளக்கப்பட்டுள்ளன.

எனது பங்கேற்பு தன்னார்வமானது என்பதையும், எந்தக் காரணமும் கூறாமல், எனது மருத்துவப் பராமரிப்பு அல்லது சட்டப்பூர்வ உரிமை பாதிக்கப்படாமல், எந்த நேரத்திலும் இந்த ஆய்வில் இருந்து விலக எனக்கு சுதந்திரம் உள்ளது என்பதையும் புரிந்துகொள்கிறேன்.

மேற்கூறிய ஆய்வில் பங்கேற்க ஒப்புக்கொள்கிறேன்

கையொப்பம்/இடது கட்டைவிரல் பதிவு)
பங்கேற்பாளரின் பெயர்:
இன் மகன்/மகள்/மனைவி
முழுமையான அஞ்சல் முகவரி

முதன்மை ஆய்வாளரின் கையொப்பம்

எனது முன்னிலையில் மேற்படி சம்மதம் பெறப்பட்டதாகச் சான்றளிப்பதற்காகவே இது.

தேதி: இடம்:

1) சாட்சி – 1
கையொப்பம்:
பெயர்:
முகவரி:

2) சாட்சி – 2
கையொப்பம்:
பெயர்:
முகவரி:

QUESTIONNAIRE

I. SOCIO DEMOGRAPHIC DETAILS:

QUESTIONS	RESPONSE
1. Name of the patient:	
2. Name of the informant:	
3. Relationship of the informant with the patient:	
4. Reliability: 1. Good 2. Bad	
5. Condition of the patient 1. Alive and able to communicate 2. Alive, but unable to communicate. Specify reasons _____ 3. Dead. Date of death: ____ /____ /_____. Cause of death:	

II. DETAILS OF THE PATIENT:

6. Age (in completed years)	
7. Gender: 1. Male 2. Female 3.Transgender	
8.a. Residence: 1. Rural 2. Urban 3. Semiurban 4. Tribal	
8.b. Full Address:	
9. Contact Number:	
10. Educational status: 1. Illiterate 2. Primary school 3. Middle school 4. High school 5. Higher secondary 6. Graduate 7. Professional degree	
11. Marital status: 1.Married 2.Unmarried 3. Widow/Widower 4. Divorced	
12. Religion: 1.Hindu 2.Christian 3.Muslim 4. Others	
13. a. Occupation: 1.Unemployed 2.Unskilled 3.Semiskilled 4.Skilled 5. Clerical/shop owner 6. Semi professional 7. Professional	
13. b. Specify the occupation:	
13.c Duration of that occupation:	
14. Type of family: 1. Nuclear family 2. Joint family 3. Three generation family 4. Broken family 5. Others. Specify_____	
15. Total members in the family:	
16. Total family income:	
17. Decision maker in the family:	
18. Name of the primary care giver for the patient:	
19. Relationship of the primary care giver with the patient:	
20. Whether multiple care givers?	
21. Perception of the support provided by the family members for the cancer management: 1. Completely satisfied 2. Satisfied 3. Average 4. Dissatisfied 5. Completely dissatisfied.	
22.a. Do you do periodic health check ups? (Master Health Check up)	
22. b. If yes, how often?	
23. a. Did you have any guidance from health care providers in the family for the current symptoms and management? Yes/ No	
23. b. If yes, describe	
24. H/o any comorbidity: Yes/ No **24.a. If yes, mention the comorbidity:** 1. Diabetes. Duration: 2. Hypertension. Duration: 3. CVD. Duration: 4. COPD. Duration: 5. CKD. Duration: 6. Seizure disorder. Duration: 7. Others. Specify with duration _____	
25.a. Does the comorbidity influence the cancer management? 1. Yes 2. No	
25.b. If yes, How?	

III.SYMPTOM HISTORY:

26. History of precancerous lesions (CA Penis)/ Congenital anomalies: Yes/No	
26.A. If Yes, mention the lesion/anomaly	
26.B. If Yes, mention the duration	
27.When was the cancer first diagnosed? Year _____ Month _____ Date_____	

27. A) Did you experience any symptoms before diagnosis? 1. Yes 2. No	
27. B) If yes, what were the symptoms you had while approaching the health care provider? (Mention with duration)	
GENITOURINARY CANCER:	
1. Dysuria/ Hematuria/ Urinary Incontinence	
2. Sexual problems	
3. Abdominal pain/ Flank pain	
4. Abdominal mass	
5. Abdominal distension	
6. Vomiting	
7.Weight loss	
8. Constipation	
9. Bone pain	
10. Growth: Painless/ Painful / Progression (details)	
11. Ulcer: Painless / Painful / Progression (details)	
12. Disturbance in stream of urine	
13. Scrotal swelling	
14. Masculanisation/ Feminisation features	
15. Groin swelling	
16. Others. Specify _____	
OVARIAN CANCER:	
1. Abdominal pain	
2. AUB. Specify	
3. Abdominal distension	
4. Weight loss	
5. Bloating	
6. Dyspepsia	
7. Changes in bowel habits	
8. Early satiety	
9. Urinary frequency/ urgency	
10. Low backache	
11. Nausea	
12. Others. Specify _____	
27. C) If No, specify the situation that led to the diagnosis of cancer	
1. Incidental finding in blood test	
2. Incidental imaging finding	
3. Master health check up	
4. Health camp	
5. Others. Specify_____	
28. Did you visit multiple health facilities before confirming the cancer diagnosis? 1. Yes 2. No	
29. Narrate your experience in detail from the time of symptom onset/cancer detection till date (Type of facility visited, reasons for visit, time interval, investigations done if any, money spent) – TO FILL THE BOX IN THE ANNEXURE (TO FILL ALL THE 4 PARTS)	

IV.REASONS FOR DELAY IN MANAGEMENT:

30. Time interval between onset of symptoms and 1st consultation with health care provider? 1. Less than one week 2. One week to one month 3. One to <3 months. 4. More than 3 months.	
31. Reasons for delay in consultation? (For options 2 – 4) 1. Lack of awareness 2. Delay in decision making 3. Misinterpretation of symptoms. 4. Self medication 5. Social stigma 6. Prioritizing other life events 7. Financial constraints 8. Inaccessibility of health services 9. Sought alternate medical care 10. Lack of accompanying person 11. Other issues related to accompanying person/ caregiver. Specify _____12. Others. Specify_____	
32. Time interval between 1st consultation with health care provider and diagnosis? 1. Less than one week 2. One week to one month 3. One to <3 months. 4. More than 3 months.	
33. Reasons for delay in diagnosis? (For options 2 - 4) 1. Missed diagnosis by HCP 2. Self-medication 3. Denial of insurance 4. Financial constraints. 5. Lack of diagnostic facility 6. Difficulty in accessing diagnostic facilty 7. Lack of Family Support 8. Sought alternate Care/opinion 9. Others. Specify_____	

34. Time interval between diagnosis and initiation of treatment? 1. Less than one week 2. One week to one month 3. One to <3 months. 4. More than 3 months.	
35. Reasons for delay in treatment? (For options 2 - 4) 1. Sought alternate Care/opinion 2. Lack of Drug Stock in Pharmacy 3. Financial constraints 4. Lack of Family Support 5. Misclassification of Disease Severity 6. Self medication 7. Fear of Side effects 8. Fear of Surgery 9. Denial of insurance 10. Lack of trust in the treatment 11. Difficulty in accessing treatment facilty 12. Poor health condition. Specify _____ 13. Others. Specify_____	
36. a. Was there any delay in cancer management due to COVID-19 Pandemic? 1.Yes 2. No	
36. b. If yes, **- For consultation (C)** 1.Yes 2. No **- For diagnosis (D)** 1.Yes 2. No **- For treatment (T)** 1.Yes 2. No **- For follow up (F)** 1.Yes 2. No	
36. c. If Yes, What was the reason? (Reason with level of delay – C/D/T/F) 1. Inaccessibility of Hospitals 2. Financial Crisis 3. Lack of beds in hospital 4. Lack of diagnostic services 5. Lack of drugs 6. Non- availability of Health care professionals 7. Fear of COVID-19 risk 8. Lack of treatment services 9. Lockdown restriction 10. Others. Specify_____	
37. Stage of the disease at the time of diagnosis:	
38. Tumour sub type:	
39 a. Have you been following the pharmacological or radiation treatment as prescribed? 1. Yes 2. No	
39 b. If No why? 1. Side effects 2. Cost 3. No improvement in symptoms 4. Others (specify**)**	
40. Reasons for Delay in adherence to follow up after treatment completion: 1. Financial burden 2. Distance from residence 3. Absence/reduction of symptoms 4. Lack of awareness regarding need for follow up 5. Careless attitude 6. Lack of Family Support 7. Fear of complications 8. Giving up 9. Difficulty in accessing health facilty 10. Others. Specify _____	

V. HISTORY OF RISK FACTORS

If gender is male skip to question no. 52

41. What was your age when you attained menarche?	
42. Was your menstrual cycles regular? 1.Yes 2.No **Mention LMP (if applicable) _____**	
43 a. Have you attained menopause at the time of onset of symptoms? 1.Yes 2.No **43 b. Age at Menopause:**	
44. What was your age at the time of your marriage?	
45. What was your age when you gave birth to your first child?	
46. How many children do you have?	
47. Did you breast-feed your children? 1.Yes 2.No **If yes, mention the duration**	
48. History of usage of Intra uterine device? 1.Yes 2.No **If yes, mention duration**	
49. History of oral contraceptive pill intake? 1.Yes 2.No **If yes, mention the duration**	
50.a) History of infertility?	
50.b) History of intake of ovulation inducing drugs, HRT?	
51. History of previous USG? (Endometriosis, Chronic PID, Ovarian Cyst)	
52. History of previous surgeries? (Including circumcision, surgery for undescended testis, torsion testis, appendicectomy, hysterectomy, tubal sterilization, Bilateral tubectomy)	
52. a. If yes, When?	
53. History of asbestos exposure?	
54. History of physical activity?	
55. Nature of diet? 1. Vegetarian 2. Mixed diet. Frequency of Non vegetarian intake: _____ / Week	
56. History of smoked food intake?	
57. History of processed food intake?	

58. H/o multiple sex partners?	
59. H/o genital warts/ genital ulcer in the sexual partner?	
60. Did any of your family members had H/o **a.Ovarian Ca?** 1.Yes 2.No **b.Genitourinary Ca? (specify)** 1.Yes 2.No **c. Breast Cancer?** 1.Yes 2.No **d. Colon Cancer?** 1.Yes 2.No **e. Other cancers. Specify _____**	
60.a. If yes, how is that person related to you? * * *	
61. a. History of smoking currently? 1.Yes Duration:..... 2.No	
61. b. History of smoking in the past? 1.Yes Duration:..... 2.No	
62. a. History of alcohol intake currently? 1.Yes Duration..... 2.No	
62. b. History of alcohol intake in the past? 1.Yes Duration:..... 2.No	
63. H/o any other substance use? Specify **a._____** 1.Yes Duration:..... 2.No **b._____** 1.Yes Duration:..... 2.No	
64.a.Previous H/o hospitalisation prior to diagnosis?	
64. b. Reason for hospitalisation?	
65. H/o frequent dialysis? (CA kidney)	
66. H/o catheterisation for more than 2 months? (CA bladder)	

VI.OUTCOME:

67. Outcome of treatment A) On going treatment. 1. Compliant 2. Non-compliant. Reason? B) On Follow-up C) Cure D) Remission E) Tumour Progression F) Relapse G) Death	
68. Follow up regimen for each type of cancer	
Ca ovary - CA 125 every 3 months -	
Ca bladder	
Ca penis	
Ca testis	
Ca kidney	
Ca prostate	
Ca urethra	

VII. UTILISATION OF HEALTH INSURANCE SCHEMES:

69. a. Do you have medical insurance? 1. Yes 2. No	
69. b. If yes, specify the type of insurance: 1. Government 2. Private	
70. A. Have you utilised the above medical insurance for cancer related diagnosis and treatment? 1. Yes 2. No	
70. B. If yes, specify the purpose for its utilisation 1. Diagnosis 2. Surgery 3. Chemotherapy 4. Radiotherapy 5. Palliative care 6. Others. Specify	
70. C. If no, mention the reason for not utilising the scheme.	
71. Any debts due to cancer management?	

72. Expenses for cancer treatment	**Under insurance**	**Out of pocket**
1. Diagnosis		
2. Surgery		
3. Chemotherapy		
4. Radiotherapy		
5. Palliative care		
6. Others. Specify		

73. Total amount spent for cancer diagnosis and treatment:
Amount covered under insurance :
Amount spent out of pocket:

74. Quality of Life EORCP-QLC

S.No	Question	Not at all	A little	Quite a bit	Very much	Response
1.	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4	
2.	Do you have any trouble taking a long walk?	1	2	3	4	
3.	Do you have any trouble taking a short walk outside of the house?	1	2	3	4	
4.	Do you need to stay in bed or a chair during the day?	1	2	3	4	
5.	Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4	
During the past week						
6.	Were you limited in doing either your work or other daily activities?	1	2	3	4	
7.	Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4	
8.	Were you short of breath?	1	2	3	4	
9.	Have you had pain?	1	2	3	4	
10.	Did you need to rest?	1	2	3	4	
11.	Have you had trouble sleeping?	1	2	3	4	
12.	Have you felt weak?	1	2	3	4	
13.	Have you lacked appetite?	1	2	3	4	
14.	Have you felt nauseated?	1	2	3	4	
15.	Have you vomited?	1	2	3	4	
16.	Have you been constipated?	1	2	3	4	
17.	Have you had diarrhea?	1	2	3	4	
18.	Were you tired?	1	2	3	4	
19.	Did pain interfere with your daily activities?	1	2	3	4	
20.	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4	
21.	Did you feel tense?	1	2	3	4	
22.	Did you worry?	1	2	3	4	
23.	Did you feel irritable?	1	2	3	4	
24.	Did you feel depressed?	1	2	3	4	
25.	Have you had difficulty remembering things?	1	2	3	4	
26.	Has your physical condition or medical treatment interfered with your family life?	1	2	3	4	
27.	Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4	
28.	Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4	

For the following questions please circle the number between 1 and 7 that best applies to you							
29.	How would you rate your overall health during the past week?						
1	2	3	4	5	6	7 Excellent	
							
30.	How would you rate your overall quality of life during the past week?						
1	2	3	4	5	6	7 Excellent	
							

75. Assessment of daily life activities through Katz index of independence

Activities	Currently [Point (0/1)]	At the time of diagnosis [Point (0/1)]
Bathing		
Dressing		
Toileting		
Transferring		
Continence		
Feeding		
TOTAL		

Independence (1) - No supervision or personal assistance

Dependence (0) - With supervision, direction, personal assistance or total care

76. Would you like to give your additional opinion/ remarks regarding the diagnosis and treatment of your ailment?

_____
_____
_____
_____
_____
_____
_____
_____

77. Anthropometry

A. Weight: _____

B. Height: _____

C. BMI: _____

Q.29. 1. SEQUENCE OF STEPS IN TREATMENT SEEKING AND MANAGEMENT OF CANCER (All treatments including native medication and palliation)

Type of facility	**1st Provider**	**2nd Provider**	**3rd Provider**	**4th Provider**
29.1.a. Month/date of visit				
29.1.b. Distance from residence				
29.1.c. Reason for consultation/referral				
29.1.d. Duration of delay (if any)				
29.1.e. Reason for delay				
29.1.f. Investigation done if any				
29.1.g. Status of diagnosis				
29.1.h. Treatment advised and done (Explain) Surgery, Radiotherapy, Chemotherapy, Hormonal Therapy, Surgery+ Chemo+Hormonal, Chemo+Hormonal, Surgery +Radiotherapy, Surgery+Chemo, Palliation, Alternate system of medicine. Others. Specify _____)				
29.1.i. Total duration of management				
29.1.j. Subjective perception of outcome				
29.1.k. Other remarks				

Q. 29. 2. TIMELINE OF LANDMARK EVENTS IN CANCER MANAGEMENT IN PATIENT'S LIFE

Event	First symptom onset/ Incidental finding. Specify	Confirmation of diagnosis	Treatment plan advised. Specify	First treatment done date	Second treatment plan advised	Second treatment done date	Third treatment plan advised	Third treatment done date	Native treatment done date	Palliative treatment done date
Timeline (DD/MM/YYYY)										
Remarks (Specification of events)										
Whether underwent the treatment as per advice. If any delay, mention										

Q.29.3. DETAILS OF INVESTIGATIONS DONE

DETAILS	Done/Not done	If done, Date	Results/ Findings	Remarks
Clinical examination				
Biochemical markers (CA-125, PSA, B-HCG, AFP)				
PV, PR				
USG (TVS, Abd and pelvis)				
FNAC				
Biopsy (Truecut/ USG guided)				
CT/ CECT				
MRI				
PET - CT				
Xray				

Q.29.4. FLOWCHART OF SEQUENCE OF EVENTS FROM SYMPTOM ONSET TILL DATE WITH DD/MM/YYYY

The Factors Leading To The Delay In Cancer Management And It's Implication For Treatment Outcomes For Ovarian And Genitourinary Malignancy Across Tamil Nadu- A multicentric Mixed Methods Study

Name: Age: ID no: Date:

Address: Type of Cancer:

PERCEIVED STIGMA

1	Are people in your community afraid that cancer spread from person to person ?	Yes		No	
2	Do people in your community think that cancer is a curse or result of past sins?	Yes		No	
3	If someone in your community has cancer,do they typically tell the neighbours?	Yes		No	
4	Do people in the community avoid talking or eating with a person having cancer?	Yes		No	
5	Belief about how or why people get cancer make it difficult for (me/patients name) to get healthcare?	Strongly agree	Agree	Disagree	Strongly disagree
6	Belief about how or why people get cancer make it difficult for me to tell others(I/the patient)have cancer.	Strongly agree	Agree	Disagree	Strongly disagree
7	If people in my community found out (I/Patients name) had cancer,I would no longer be respected?	Strongly agree	Agree	Disagree	Strongly disagree

EXPERIENCED STIGMA -Family and community :Please indicate whether you have also had these experiences because you have had cancer

1	Have you ever been excluded from social or work gathering or activities - for exampe, wedding, funerals parties,club?	Yes	No
2	Have you ever been excluded from religious activities or place of worship?	Yes	No
3	Have you ever been excluded from meals or activities where only family is invited ?	Yes	No
4	Have you ever been aware of family members making discrimatory remarks or gossiping about you?	Yes	No
5	Has someone ever verbally harassed you-for example yelled, scolded or otherwise verbally abusive?	Yes	No
6	Has someone ever physically harassed or hurt you or otherwise physically abusive ?	Yes	No
7	Has anyone ever said they were worried they might contract cancer from you(you/patients name)?	Yes	No
8	Healthcare: have you ever been denied healthcare?	Yes	No
9	Healthcare: Have you ever been denied heath insurance?	Yes	No
10	Employment: Have your ever lost a job or a source of income?	Yes	No

INTERNALISED STIGMA

1	I don't feel comfortable telling others about(my/patients name) disease?	Strongly agree	Agree	Disagree	Strongly disagree
2	I hide that (I have/patients name has) cancer from others?	Strongly agree	Agree	Disagree	Strongly disagree
3	I often avoid social gatherings because (I have / patients name has)cancer ?	Strongly agree	Agree	Disagree	Strongly disagree
4	I feel ashamed (I have/patients name) has cancer	Strongly agree	Agree	Disagree	Strongly disagree

RCOPE- SPIRITUAL DISTRESS QUESTIONNAIRE

Name: Age: ID no: Date:

Address: Type of Cancer :

POSITIVE RELIGIOUS COPING

1.	Looked for a stronger connection with God	1. Not at all 2. Somewhat 3. Quite a bit 4. A great deal
2.	Sought God's love and care	1. Not at all 2. Somewhat 3. Quite a bit 4. A great deal
3.	Sought help from God in letting go of my anger	1. Not at all 2. Somewhat 3. Quite a bit 4. A great deal
4.	Tries to put plans into action together by God	1. Not at all 2. Somewhat 3. Quite a bit 4. A great deal
5.	Tried to see how God might be trying to strengthen me in this situation.	1. Not at all 2. Somewhat 3. Quite a bit 4. A great deal
6.	Asked forgiveness for my sins	1. Not at all 2. Somewhat 3. Quite a bit 4. A great deal
7.	Focussed on religion to stop worrying about my problems	1. Not at all 2. Somewhat 3. Quite a bit 4. A great deal

NEGATIVE RELIGIOUS COPING

1.	Wondered whether God abandoned me.	1. Not at all 2. Somewhat 3. Quite a bit 4. A great deal
2.	Felt punished by God for my lack of devotion.	1. Not at all 2. Somewhat 3. Quite a bit 4. A great deal
3.	Wondered what I did for God to punish me.	1. Not at all 2. Somewhat 3. Quite a bit 4. A great deal
4.	Questioned God's love for me.	1. Not at all 2. Somewhat 3. Quite a bit 4. A great deal
5.	Wondered whether my church had abandoned me.	1. Not at all 2. Somewhat 3. Quite a bit 4. A great deal
6.	Decided the devil made this happen.	1. Not at all 2. Somewhat 3. Quite a bit 4. A great deal
7.	Questioned the power of God.	1. Not at all 2. Somewhat 3. Quite a bit 4. A great deal

Annexure 2

In Depth Interview GUIDE

Among patients with GU and/ or Ovarian Cancer:

Greetings

Briefing about the study

Consent for the study and recording

1. Tell me more about yourself.

2. Can you tell us how this health problem started?
   Suggested Probes:
   - What happened next?
   - How did you perceive your symptoms?

3. What were your **treatment seeking experiences**? *(from symptom onset till diagnosis)*
   Suggested Probes:
   - How were you led to the final diagnosis of cancer?
   - Preferences of treatment
   - Financial hardships.
   - Interactions with health care workers

4. What were your **perceptions regarding** your **cancer diagnosis** ?
   Suggested Probes:
   - What were your feelings when you were diagnosed with cancer?
   - What are your concerns about disclosing your cancer to others?

   (Explore instances of stigma(perceived/ experienced/internalized)*

5. How did you perceive the **course of cancer management***(from diagnosis till now)*?
   Suggested Probes:
   - Self perceived facilitators *(for diagnosis and treatment of cancer)*
   - Self perceived barriers (*for diagnosis and treatment of cancer)*
   - Family concerns
   - Expectations and unmet needs
   - Preferences of treatment.

6. What has been your **lived experience with cancer**?
   Suggested Probes:
   - How is your daily routine after the diagnosis of cancer?
   - How do you perceive your personal outlook (*after diagnosis till now?*
   - How are your interactions at **family level?**
   - How is yourlived experience with cancer at **society level?**

   (Explore instances of stigma(perceived/ experienced/internalized)*

7. Can you tell about any **belief system** which is **driving your life**?
   Suggested Probes:
   - Religious beliefs
   - Spiritual support Systems

-Spiritual Distress[$] (Ask 3 evaluative questions: "Do you feel God has abandoned you?"; "Do you think God is punishing you?"
"Do you think the devil/evil force made this happen to you?")

8. What are your **current and future concerns about** your **cancer outcome**?
   Suggested Probes:
   - Concerns at Personal level
   -Concerns related to the family

9. What are your **perceptions about** accessing **palliative care** for your illness?
   Suggested Probes:
   - About felt needs for palliation for yourself
   -About expectations for palliative care
   - Experiences of utilizing palliative care (if any)

10. How do you idealize **an optimal cancer management system**?
    Suggested Probes:
    -What are your concerns/expectations about accessibility?
    -How do you perceive your interactions with health providers?
    -What are your expectations about optimal health infrastructure?

***Self-stigma/internalized stigma:** refers to negative attitudes of an individual to his/her own illness

Perceived(or anticipated) stigma An individual's beliefs about the attitudes of others towards his/her illness.

Experienced (or received) stigma refers to their actual encounter with stigmatising attitudes and behaviour from the general population

$Religious struggle / spiritual distress: Disruption in a person's belief or value systemwhen conflict occurs between his/her beliefs and what is happening in their life. Assessed by some evaluative questions.

References:

*1.Subu, M.A., Wati, D.F., Netrida, N. *et al.* Types of stigma experienced by patients with mental illness and mental health nurses in Indonesia: a qualitative content analysis. *Int J Ment Health Syst* **15**, 77 (2021)

*2.C. Simonsen, S.R. Aminoff, A. Vaskinn, et al.Perceived and experienced stigma in first-episode psychosis: a 1-year follow-up study
Compr Psychiatry, 95 (2019), Article 152134

$3.Pargament KI, Koenig HG, Tarakeshwar N, Hahn J. Religious struggle as a predictor of mortality among medically ill elderly patients: a 2-year longitudinal study. Arch Intern Med. 2001 Aug 13-27;161(15):1881-5. doi: 10.1001/archinte.161.15.1881. PMID: 11493130.

Annexure 3

KEY INFORMANT INTERVIEW

1.Can you please elaborate about yourself and your association(experiences) with cancer patients?
• Education • Designation • Reason for choosing oncology related career • Satisfaction/dissatisfaction in career – reasons for the same • Challenges/issues faced in your career in cancer care
2.What do you think are the perceptions regarding cancer among cancer patients &their caregivers?

• Perceptions about causes of cancer generally
  o Ca ovary
  o Genitourinary cancer
• How do patients and caregivers perceive being diagnosed with cancer
• Challenges in disclosing diagnosis of cancer to patients and caregivers
• Perceptions as a contributor for delay in cancer care
• Perceptions about modalities of cancer treatment
• Patients connotations about diagnosis of cancer (eg cancer diagnosis being equated as death sentence)

3.What do you think are the concerns in arriving at a cancer diagnosis ?
• Challenges in screening cancers • Challenges in confirming cancer diagnosis • Availability/accessibility/affordability for cancer treatment modalities • Facilities/barriers for prompt cancer treatment(with response to cancer ovary &genito urinary cancer in particular)
4.Can you elaborate on the treatment seeking experiences of the patient and his/her family?
• Challenges in risk communication to patient &family(disclosing about diagnosis of cancer ,implications,prognosis,survival rates etc.,) • Treatment preferences /aversions if any • Expectations/unmet needs of patients with response to cancer care • Treating doctors expectations/unmet expectations from patients and their family members for treatment compliance
5. What are the factors you think as important for a patient to initiate &complete the treatment successfully? (if feasible ask them to rank order these from 1 to 5)
6.What do you think are the reasons for gaps in treatment compliance among patients?
• Personal reasons • Financial reasons • Administrative reasons etc.,
7.How do you think the gaps in treatment compliance can be addressed?
8.What do you think are the psycho emotional perceptions about cancer & its management among cancer patients?
• Fears&worries • Self stigma • Spiritual beliefs influencing cancer perceptions and management • Any other belief systems driving their lives

9. What do you think are the social factors concerns with response to cancer diagnosis &treatment?
• Social stigma • Contributor for delay (if any)for cancer care • Facilitating factors (if any) • Social support systems
10.How do you perceive the interaction between cancer patients &health care providers?
• Communication(barrier of facilitations) • Rapport between patients nd providers • Concerns ands issues in followup • Ways to address loss to followup • Expectations &unmet needs • Factors promoting food &longterm patient provider relationship • Barriers/hindering factors for patient provider relationship
11. What do you think if the role of alternate systems of medicine in cancer treatment &how do patients utilize it?
• Say perceptions about its usefulness in cancer care • Say perceptions about its hazards for cancer care • Recommondations about integration of alternate systems in cancer care • Patient belief and practices with response to alternate systems in cancer care
12 what do you think are the financial concerns among patients and their families?
• Impoverishment/catastrophic expenditure occurrences • Role of insurance • Difficulties in availing insurance • Financial issues as a cause for delay in diagnosis ,treatment and followup
13. What is the current status of palliative care for cancer and what is the patient level awareness & uptake for palliative therapy?
• Availability/accessibility/affordability of palliative services • Awareness level among patients and providers • Gaps to be addressed • Ways and means to integrate palliation and provide holistic care
14.What do you think are the various treatment modalities for cancer &the concerns for each of these treatment modalities(with response to cancer ovary and genitourinary cancer)
• Availability/affordability/accessibility of each of these treatments • Patient preference/issues in compliance for each of these treatments • Challenges in each of these treatments
15.How do you idealize an optimal cancer management system?
• Health Infrastructure • Health manpower • Diagnostic Modules • Delay Minimization • Insurance

Annexure 4

From **02 December 2022**

Professor V R Muraleedharan,
Indian Institute of Technology (Madras),
Chennai - 600036.
[Coordinator, ORP – TNHSRP]

To
Dr. P. Seenivasan,
Prof &Head, Department of Community Medicine,
Govt Stanley Medical College,
Chennai – 600001.

Dear Dr. P. Seenivasan,

Subject: Your research proposal **"The Factors leading to the delay in cancer management and its implication for treatment outcomes for ovarion and Genitourinary Malignancies across Tamil Nadu – A Multicentric Mixed Method Study"** submitted to the **Operational Research Programme-Tamil Nadu Health System Reform Programme (ORP-TNHSRP)**

We are happy to announce that your proposal has been approved with financial support by the Selection Committee of the ORP – TNHSRP. The total amount sanctioned for the above study is **Rs. 25,32,000/-.**

The draft MoU to be executed between IIT Madras and Govt Stanley Medical College, is attached for your reference. We request you to kindly consult with your legal cell and let us know if you need any clarification/modification or further information in this regard. We shall then prepare the final version of the MoU and forward you the same for signature.

In the meanwhile, we request you to get the approval of your Ethics Committee for your proposal to enable us to transfer the funds to your account and complete other formalities.

We request you to furnish details of the Bank Account (of your Institution) in order to release the funds.

We thank you for your interest in being part of this pioneering initiative of the Dept. of Health and Family Welfare of the Govt of Tamil Nadu.

Sincerely,

V.R.Muraleedharan
Coordinator, ORP-TNHSRP

Government of Tamil Nadu

Tamil Nadu Health System Reform Program

From

Dr. S. Uma., I.A.S.,
Project Director,
Tamil Nadu Health System Reform Program,
3rd Floor, DMS Annex Building
359, Anna Salai, Teynampet,
Chennai – 600 006.
e mail: pdtnhsp@gmail.com

To

Prof. Muraleedharan,
Room No. 350,
Humanities and Social Sciences Department,
Indian Institute of Technology (Madras),
Chennai – 600 036.

Lr. Ref.No.: 1806/TNHSRP/ORP/2022 Dated:30.11.2022.

Sir,

Sub: Tamil Nadu Health System Reform Program (TNHSRP) – Supported by World Bank – DLI No. 7.3 - Operational Research Program (ORP) – 4th year (2022 – 23) – Selection Committee – Approved proposals – Communicated – For necessary action - Reg.

Ref:
1. G.O (Ms) No. 162, Health and Family Welfare (EAPI-1) Department, dated: 31.03.2020
2. G.O (Ms) No. 1058, Health and Family Welfare (EAPI-1) Department, dated: 03.10.2022
3. PSC meeting held on 24.11.2022
4. E – mail received from IIT (M), dated: 23.11.2022

Tamil Nadu Health System Reform Program (TNHSRP) supported by World Bank has been implemented by Government of Tamil Nadu and is in its 4th year of implementation. One of the Disbursement Linked Indicators (DLIs) of TNHSRP is Operational Research Program, under which each year the research proposals

under specific topics are called for and selected along with the budget required for the research study.

This year 6 broad themes were selected and a total of 68 proposals were received. The received proposals were reviewed and shortlisted by an Expert Group & Technical Committee. The Technical Committee meeting was held on 21.10.2022. The PIs were suggested to revise the proposals and resubmit it.

A discussion on revised proposals was held on 09.11.2022. Based on the revised proposals received and E - mail received from IIT (M) (ref 4)stating that the budget submitted by the PIs along with revised proposals exceeds the sanctioned budget of 1,85,00,000 for the proposals for the year 2033 – 23.

Budget sanctioned by the Government to TNHSRP:

S.No.	Activity	Budget in INR
1.	Budget proposed for research proposals	1,85,00,000
2.	Admin cost (IITM) – 7.5% of total budget of year 4 ORP	15,00,000
Total budget proposed for ORP year 4 activities		**2,00,00,000**

In the PSC meeting held on 24.11.2022 (ref 3), it was decided initially to sanction orders for 5 themes with 7 proposals.

Hence, IIT (M) is requested to award the proposals attached in the **Annexure** for the year 2022- 23 and sign the MoU with the selected Principal Investigators/ Institutions.

Annexure:

List of approved research proposals to be awarded for the year 2022 – 23

-Sd/-

Project Director

//True Copy Forwarded//

1/12/2022

Expert Advisor

List of approved research proposals to be awarded for the year 2022 – 23:

S.No.	Broad theme	PI of selected proposal	Institute of selected proposal	Topic	Budget (INR)
1.	What are the lessons learnt from the **quality accreditation** process and the challenges in sustaining the achievement?	Dr Jayanthi T P	Shree Balaji Medical College, Chennai	A situational Analysis of quality /accreditation of public facilities in Tamil Nadu	21,38,280
2.	What are the lessons learnt from the **quality accreditation** process and the challenges in sustaining the achievement?	Dr Subramania Raju Rajasulochana	NMIMS (Narsee Monjee Institute of Medical Sciences, Mumbai)	Managing & Sustaining accreditation for transforming health care in public settings. Evidence from Tamil Nadu	24,88,500
3.	Evaluation and functioning of **Health and Wellness centre** in Tamil Nadu	Dr Abhilasha Nair	St. John's Research Institute, Bangalore	Evaluation of functioning of Health and Wellness Centres in Tamil Nadu	35,26,950

4.	A study on **Equipment utilization** index and cost benefit analysis of major equipment provided to hospitals (such as MRI, CT scan, CATH labs, ECHO, LINAC machine etc) in Govt institutions	Dr Yuvaraj Krishnamoorthy	ESIC Medical College & PGIMSR, Chennai	Utilization and Economic Evaluation of Advanced Diagnostic and Therapeutic Healthcare Equipment in Public Healthcare Facilities of Tamil Nadu	24,19,939.50
5.	Correlation between delay in **Cancer Management** with respect to outcome for Solid tumors in Tamil Nadu	Dr. Rajkumar Kottayasamy Seenivasagam,	PSGIMSR, Coimbatore	Understanding the correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu using a multicentric mixed method study	24,36,000
6.	Correlation between delay in **Cancer Management** with respect to outcome for Solid tumors in Tamil Nadu	Dr.P.Seenivasan MD	Govt Stanley Medical College,	A mixed method study on the factors leading to the delay in cancer management and its implication for treatment outcomes for most common solid tumours among womenin regional	25,32,000

				cancer centre in tamil nadu.	
7.	Estimation of prevalence of **chronic kidney disease** of undetermined etiology (CKD) among workers in unorganized sectors in Tamil Nadu	Dr N Gopalakrishnan	Institute of Nephrology, Madras Medical College	Prevalence and risk factors of chronic kidney disease of uncertain aetiology among agricultural workers in different agroclimatic zones of Tamil Nadu – a cross-sectional study	24,56,120
Total					**1,79,97,789.50**

017181

Government of Tamil Nadu

Tamil Nadu Health System Reform Program

From
Dr. S. Uma, I.A.S.,
Project Director,
Tamil Nadu Health System Reform Program,
III Floor, DMS Annex building,
359, Anna Salai, Teynampet,
Chennai - 600 006.
E-mail: pdtnhsp@gmail.com

To
1. The Mission Director,
   National Health Mission,
   Chennai – 6.
2. The Mission Director,
   Integrated Child Development Services (ICDS),
   Chennai – 113.
3. The Director of Public Health and Preventive Medicine,
   Chennai – 6.
4. The Director of Medical and Rural Health Services,
   Chennai – 6.
5. The Director of Medical Education,
   Chennai – 10.

Ref.No.: 1806/TNHSRP/PMU/2021 Dated: 17.02.2023

Madam/ Sir,

Sub : Tamil Nadu Health System Reform Program (TNHSRP) – Operational Research Program (ORP) – 4th year (2022 – 2023) research proposals – Approved and study to be initiated – Permission requested - Reg

****

Tamil Nadu Health System reform program has implemented Operational Research Program (ORP) as one of its DLI to study the existing services and performances of the hospitals of Government of Tamil Nadu. Indian Institute of Technology, Madras [IIT(M)] is the nodal agency in the selection and monitoring of ORP study. Memorandum of Understanding (MoU) has been signed between IIT(M) and TNHSRP for the implementation of ORP.

S.No.	Year	No. of proposals awarded	Status
1.	2020 – 2021 (2nd year of ORP)	7	Completed and results disseminated
2.	2021 – 2022 (3rd year of ORP)	8	Awarded and studies are in progress
3.	2022 – 2023 (4th year of ORP)	7	Awarded, MoU signed and Study to be initiated

For this year 2022 – 2023, 7 proposals were selected by the Selection Committee headed by the Principal Secretary, Health and Family Welfare Department. Memorandum of Understanding (MoU) has been signed between individual institutions and IIT (M) and Ethical Clearance obtained for all the 7 research studies.

Research proposals selected:

S.No.	Name of the Topic	Name of the institution	Study Participants	Study Area
1.	**Quality accreditation** – A situational Analysis of quality /accreditation of public facilities in Tamil Nadu	Shree Balaji Medical College, Chennai PI – Dr. Jayanthi T. P.	Quality Committee members, Hospital administrators, Nodal officers, Trained assessors, Medical Officer, Staff Nurse, Pharmacist, Lab Technician, Paramedical staff, Nodal officer - Quality of NHM, TNHSRP, DDHS, JDHS and Patients	Annexure I

2.	**Quality accreditation** - Managing & Sustaining accreditation for transforming health care in public settings. Evidence from Tamil Nadu	NMIMS (Narsee Monjee Institute of Management Sciences), Mumbai PI – Dr. Subramania Raju Rajasulochana	Patient Welfare Committee members, NHM coordinator, District level Quality team, Reginal Quality Circle, Community leaders, Anganwadi workers, Panchayat leaders and Patients	Annexure II
3.	**Health and Wellness Centres** – Evaluation of functioning of Health and Wellness Centres in Tamil Nadu	St. John's Research Institute, Bangalore PI – Dr. Abhilasha Nair	Households, MLHP, NHV, HI, VHN, Anganwadi workers, Anganwadi helpers, Representative from Panchayat, Self Help Groups, Patients and Care givers	HSCs of The Nilgiris, Kanyakumari and Nagapattinam
4.	**Equipment utilization** - Utilization and Economic Evaluation of Advanced Diagnostic and Therapeutic Healthcare Equipment in Public Healthcare Facilities of Tamil Nadu	ESIC Medical College & PGIMSR, Chennai PI - Dr. Yuvaraj Krishnamoorthy	Doctors, Health care providers and Technicians	Annexure III

5.	**Cancer Management** - Understanding the correlation between social determinants of delays in diagnosis and management and outcomes for solid cancers in Tamil Nadu using a multicentric mixed method study	PSGIMSR, Coimbatore PI - Dr. Rajkumar Kottayasamy Seenivasagam	Doctors, Health care providers and Patients	Royapettah Kilpauk Medi college and Medical colleges of Coimbatore, Madurai, Tirunelveli, Thanjavur, Trichy districts
6.	**Cancer Management** – A mixed method study on the factors leading to the delay in cancer management and its implication for treatment outcomes for most common solid tumours among women in regional cancer centre in Tamil Nadu	Government Stanley Medical College, Chennai PI - Dr. P. Seenivasan	Patients, Health care providers and Care givers	All Medical Colleges of Tamil Nadu
7.	**Chronic Kidney Disease** - Prevalence and risk factors of chronic kidney disease of uncertain aetiology among agricultural workers in different agroclimatic zones of Tamil Nadu – a cross-sectional study	Madras Medical College, Chennai PI – Dr. N. Gopalakrishnan	Farmers (Farming related manual labour)	Tamil Nadu

As the studies are being done by the above said institutions in the above-mentioned study area, the HODs are requested to permit the Investigators to conduct the study in the specified area and do the needful.

-Sd/-

Project Director

//True copy Forwarded//

Program Officer

Copy submitted to

The Principal Secretary,

Health and Family Welfare Department

Copy to,

1. Deans/ JDHS/ DDHS of the concerned districts
2. Concerned institutions

Annexure I

List of institutions of study by Shree Balaji Medical College, Chennai:

S.No.	District	Type of Health facility	Health facilities chosen for Study	
			Certified	Non-Certified
1	Kancheepuram	DH	GH Kancheepuram	-
2		SDH	GH Tambaram	GH Sriperambudhur
3		CHC	Thirupakuli	Paranthur
4		PHC (Rural)	R. Sembakkam	Chinna Kancheepuram
5		PHC (Urban)	NA	Kaliampoondi
6	Trichy	DH	GH Manaparai	-
7		SDH	GH Lalgudi/ Musiri	Thuraiyur
8		CHC	Inamkulathur	kulumani
9		PHC (Rural)	Petavathalai/ Nagamangalam	Tumbalam/ Thirunakulam
10		PHC (Urban)	Subramaniapuram	Periyamilagu paarai
11	Coimbatore	DH	GH Polachi	NA
12		SDH	GH Mettupalayam	Sulur
13		CHC	SS Kulam	Somanur
14		PHC (Rural)	V. Kaliayapuram	Tirumalayampalayam
15		PHC (Urban)	Ganapathi managaram	Selvapuram / Velankurichi
16	Kanyakumari	DH	Padmanabapuram	-
17		SDH	Kullithurai	Kulasekaram
18		CHC	C R Pudhur	Kurunthakodu
19		PHC (Rural)	Thovalai	Olavillai
20		PHC (Urban)	NA	Vattavillai
21	Chennai	PHC (Urban)	NA	NA
22	Madurai	DH	-	Ussilampatti (Common for all districts)

Annexure II

List of institutions of study by NMIMS, Mumbai:

S.No.	Type of institution	Accredited (N1=20)	Non-accredited (N2=20)
1.	District Hospital	DH Mettur Dam (Salem)	DH Thirukovilur (Villupuram)
2.		DHQH Kumbakonam (Thanjavur)	DH Gudiyattam (Vellore)
3.		DH Cheyyar (Tiruvanamalai)	DH Uthamapalayam (Theni)
4.		GHQH Wallajapet (Ranipet)	DH Thiruvotriyur (Thiruvallur)
5.		DH Tenkasi (Tenkasi)	DH Kangeyam (Tiruppur)
6.	Taluk Hospital	GH Harur (Dharmapuri)	GH Ponneri (Thiruvallur)
7.		GH Rasipuram (Namakkal)	GH Avinshi (Tiruppur)
8.		GH Hosur (Krishnagiri)	GH Denkanikottai (Krishnagiri)
9.		GH Aruppukottai (Virudhunagar)	GH Ettayapuram (Tirunelveli)
10.		GH Thiruchendur (Tuticorin)	GH Srivaikundam (Tuticorin)
11.	Community Health Centre	CHC Kunnur (Virudhunagar)	CHC Zamin kollankondan (Virudhunagar)
12.		CHC Mugaiyur (Cuddalore)	CHC Mailam (Tindivanam)
13.		CHC Sayalkudi (Ramanathapuram)	CHC Devipattinam (Ramanathapuram)
14.		CHC Kadugur (Ariyalur)	CHC Andimadam (Ariyalur)
15.		CHC Perungattur (Tiruvannamalai)	CHC Anakkavur (Tiruvannamalai)
16.	Primary Health Centre	UPHC Therespuram (Tuticorin)	UPHC Fathima Nagar (Tuticorin)
17.		UPHC Belrampatti (Dharmapuri)	UPHC Pammal (Chengalpattu)
18.		PHC Avatti (Cuddalore)	PHC Sirumangalam (Cuddalore)
19.		PHC Thiruvalampozhil (Thanjavur)	PHC Swamimalai (Thanjavur)
20.		PHC Agasthiarpatti (Tirunelveli)	PHC Koodankulam (Tirunelveli)

Annexure III

List of institutions of study by ESIC Medical College, Chennai:

S.No.	District	Medical Colleges	Government Hospitals
1.	Chennai	Rajiv Gandhi Government General Hospital	Government Royapettah Hospital
		Government Stanley Medical College Hospital	
		Government Medical College, Omandurar Government Estate	
2.	Coimbatore	Coimbatore Medical College Hospital	Government Medical College and ESIC Hospital
3.	Madurai	Madurai Medical College Hospital	Government Hospital, Melur
4.	Tirunelveli	Government Tirunelveli Medical College and Hospital	-
5.	Trichy	KAP Vishwanathan Government Medical College and Hospital, Trichy	Government Hospital, Srirangam
6.	Thanjavur	Government Medical College Hospital, Thanjavur	Government Hospital, Pattukottai
7.	Salem	Government Mohan Kumaramangalam Medical College and Hospital, Salem	Government Headquarters Hospital, Mettur
8.	Sivagangai	Government Sivagangai Medical College and Hospital, Sivagangai	Government Hospital, Karaikudi
9.	Villupuram	Government Villupuram Medical College and Hospital	Government Hospital, Tindivanam
10..	Theni	Government Theni Medical College and Hospital	Government Hospital, Periyakulam
11.	Nilgiris	Government Medical College, Nilgiris	Lawley Government Hospital, Coonoor
12.	Thiruvarur	Government Thiruvarur Medical College	-

Annexure 5

Ref.No.017181/ME1/1/2023

Directorate of Medical Education
Kilpauk, Chennai -10.
Dated :23.02.2023.

Sub: Medical Education – TNHSRP – Operational Research Program (ORP) – 4th year (2022-2023) research proposals – approved and study to be initiated – Permission requested – communicated - Regarding

Ref: Ref.No.1806/TNHSRP/PMU/2021 of the Project Director, Tamil Nadu Health System Reform Program, Chennai dated:17.02.2023.

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A copy of letter in the reference cited received from the Project Director, Tamil Nadu Health System Reform Program, Chennai, is enclosed and the Deans / Head of the Institution`s are directed to permit the investigators to conduct the study in the specified area at their respective Institution.

Encl: As in the ref. cited.

for Director of Medical Education

To:

1. The Dean, Rajiv Gandhi Government General Hospital, Chennai
2. The Dean, Government Stanley Medical College Hospital, Chennai
3. The Dean, Government Medical College and Hospital, Omandurar Government Estate, Chennai
4. The Dean, Coimbatore Medical College Hospital, Coimbatore
5. The Dean,Government Rajaji Hospital and Madurai Medical College, Madurai
6. The Dean, Tirunelveli Medical College and Hospital, Tirunelveli
7. The Dean, Mahatma Gandhi Memorial Government Hospital and KAP Vishwanatham Government Medical College, Trichy
8. The Dean, Thanjavur Medical College Hospital, Thanjavur
9. The Dean, Government Mohan Kumaramanagalam Medical College and Hospital, Salem

10. The Dean, Government Sivagangai Medical College and Hospital Sivagangai
11. The Dean, Government Villupuram Medical College and Hospital, Villupuram
12. The Dean, Government Theni Medical College and Hospital, Theni
13. The Dean, Government Medical College and Hospital,The Nilgiris
14. The Dean, Government Thiruvarur Medical College and Hospital, Thiruvarur

Copy to:

1. The Project Director,
   Tamil Nadu Health System Reform Program,
   Chennai

2. The Mission Director,
   National Health Mission – Tamil Nadu,
   Chennai

Annexure 6

INSTITUTIONAL ETHICS COMMITTEE
DIRECTORATE OF PUBLIC HEALTH AND PREVENTIVE MEDICINE
CHENNAI – 600 006.

CDSCO Registration No. ECR/1648/Inst/TN/2022
DHR Registration No: EC/NEW/INST/2021/2446 Date: 28.04.2023

CERTIFICATE OF APPROVAL

IEC No. DPHPM/IEC/2023/117

To
Dr. P. Seenivasan,
Prof. and Head,
Department of Community Medicine,
Govt. Stanley Medical College,
Chennai - 600 001.

Sir/Madam,

With reference to your Submission letter dated on 25.04.2023, the Directorate of Public Health and Preventive Medicine, Institutional Ethics Committee discussed and reviewed your application for Research Project proposal.

The research project proposal details

Protocol No.	DPHPM/IEC/117/V2 Date: 25.04.2023 and 29.04.2023
Title	The factors to the delay in cancer management and its implication for treatment outcomes for ovarian and genitourinary malignancies a cross Tamil Nadu – A multicentric mixed method study.
Name of the Investigator	Dr. P. Seenivasan
Study Design	Multicentric Convergent Parallel (Quan – Qual) Mixed methods study design with both quantitative (Analytical cross – sectional study) and qualitative (In – depth interview – Key informant interview) components.
Institution/Organisation	Department of Community Medicine, Govt. Stanley Medical College, Chennai - 600 001.
Study Place	Districts across Tamil Nadu
Type of review	Full Review
List of documents reviewed	1. Covering Letter 2. Details of the project 3. Protocol (Detailed Description) 4. Methodology 5. Informed Consent form (English & Tamil) 6. Participant Information from (English & Tamil) 7. Questionnaire
Approval status	Comments – Good Proposal
Approval Certificate Validity	1 Year (28.04.2024)
Date of Progress Report Submission	Final report to be submitted at the closure of project.

The Committee earlier suggested the following:

1. Share district details
2. Extend as a prospective study if possible.
3. Please submit other approval documents.

➢ **Good protocol**

The Committee received now approved the proposal after the corrections were made with the following conditions:

1. Any protocol deviations – including those in the patient's informed consent forms and Serious Adverse Events (SAE), occurring in the course of the study should be reported within seven working days.
2. Any significant change in the protocol.
3. Serious Adverse events and action to be taken within 24 hours of the event.
4. Any change in the research personnel and their delegation of the work.
5. Final report to be submitted at the closure of project.
6. The Final Report of study closure to be submitted to Ethics Committee.
7. Members of IEC have right to monitor the study at any point with prior intimation.

Yours Sincerely,

Dr. A. Somasundaram MBBS., DPH., M.D., MAE.
Member Secretary,
Institutional Ethics Committee,
DPH&PM, Chennai – 600 006.

Yours Sincerely,

Dr. K. Surendhiran MBBS., DPH,.
Vice-Chair Person,
Institutional Ethics Committee,
DPH&PM, Chennai – 600 006.

Annexure 7

INSTITUTIONAL ETHICS COMMITTEE

GOVERNMENT STANLEY MEDICAL COLLEGE & HOSPITAL

EC Registration No : ECR/131/Inst/TN/2013/RR-22

DHR Registration Number : EC/NEW/INST/2022/TN/0102

3.04.2023

To

Dr.P.Seenivasan MD
Prof &Head ,
Department of Community Medicine,
Govt Stanley Medical College,
Chennai

Project Title- The factors leading to the delay in cancer management and its implication for treatment outcomes for Ovarian and Genitourinary malignancies across Tamil Nadu – a Multicentric mixed method study.

Subject – Ethics Committee Communication for modification of protocol

Dear Dr.P.Seenivasan ,

Based on the expedited opinion obtained from the Chairperson of the committee Dr.Arun Kumar and the Member secretary Dr.M.Kulandaiammal , the committe approved the modifications in the proposal .

1. Change in inclusion criteria
2. Change in Data collection plan.

- The Principal Investigator shall promptly report to the IEC:
  - Any changes to or deviations to the protocol approved by this ethics committee that the PI might implement to eliminate hazards to the trial subjects.
  - New information that may affect adversely the safety of the subjects or the conduct of the trial.

- Also submit:
  - The status report of the study at every 6 months interval.
  - A report to the Ethics Committee on completion of the study.

INSTITUTIONAL ETHICS COMMITTEE

GOVERNMENT STANLEY MEDICAL COLLEGE & HOSPITAL

EC Registration No : **ECR/131/Inst/TN/2013/RR-22**

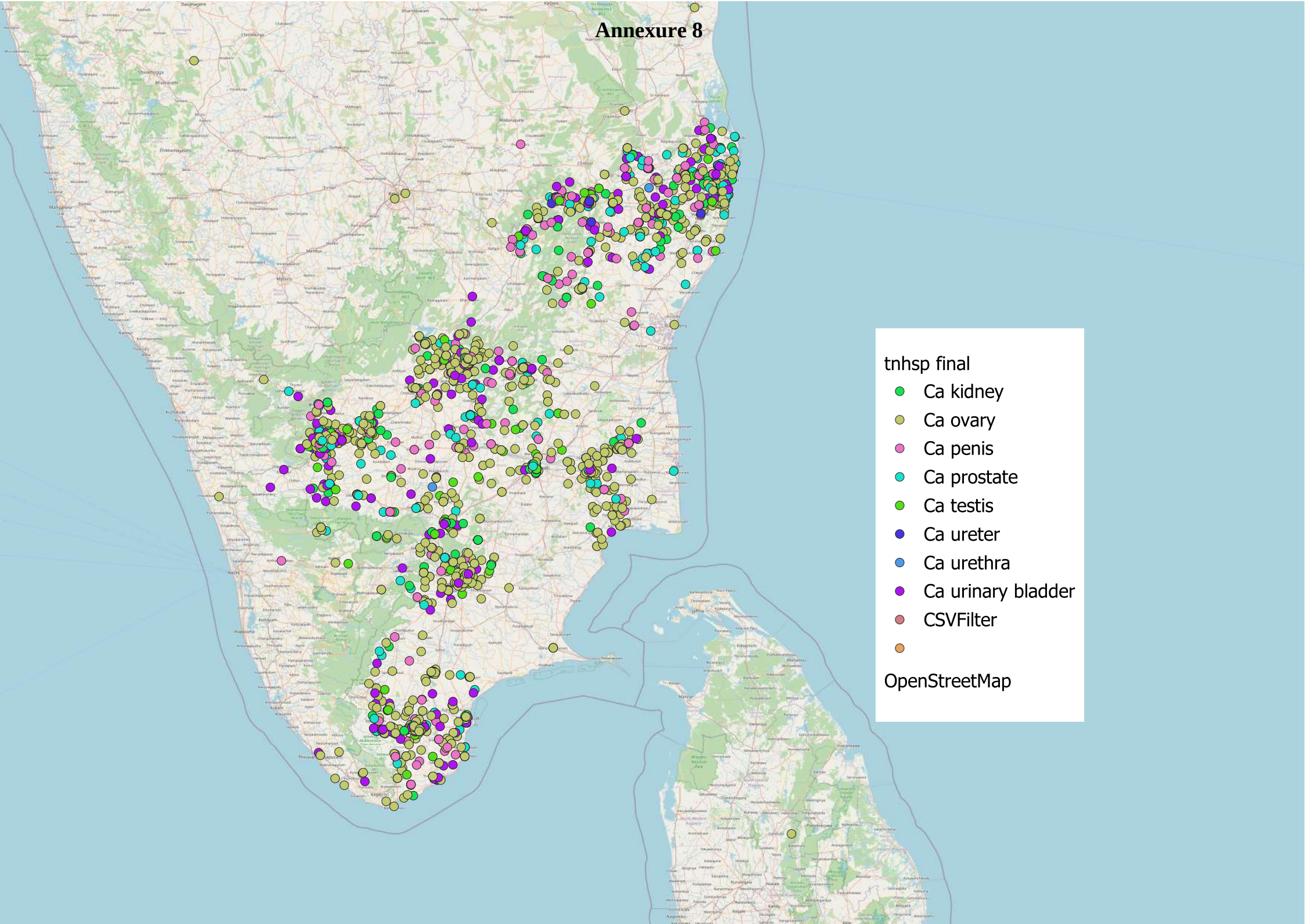
DHR Registration Number : **EC/NEW/INST/2022/TN/0102**

Yours sincerely

3/4/23

The Member Secretary
Institutional Ethics Committee,
Govt. Stanley Medical College
No.1, Old Jail Road, Chennai,
Tamil Nadu – 600001, India.

Annexure 8


tnhsp final
Ca kidney
Ca ovary
Ca penis
Ca prostate
Ca testis
Ca ureter
Ca urethra
Ca urinary bladder
CSVFilter
OpenStreetMap

Annexure 9

List of Districts Selected

S No.	Name of the District	No. of cases
1	Chennai	115
2	Thiruvallur	2
3	Kanchipuram	47
4	Karur	18
5	Salem	48
6	Coimbatore	53
7	Tiruppur	29
8	Namakkal	32
9	Perambalur	5
10	Ariyalur	15
11	Thanjavur	42
12	Dindigul	19
13	Madurai	44
14	Thoothukudi	17
15	Tirunelveli	46
16	Vellore	30
17	Thiruvannamalai	44
	Total	**606**

Annexure 10
Year wise summary of study participants

Year of Diagnosis: 2017 (n=74)			
Variables		Dead n (%)	Alive n (%)
Cancer types	Ca ovary (n=36)	5(13.9)	31(86.1)
	Ca kidney (n=9)	1(11.1)	8(88.9)
	Ca bladder (n=8)	2(25)	6(75)
	Ca testis (n=9)	0	9(100)
	Ca penis (n=8)	0	8(100)
	Ca prostate (n=4)	1(25)	3(75)
Cancer stages	Not available (n=5)	0	5(100)
	Stage I (n=17)	0	17(100)
	Stage II (n=10)	0	10(100).
	Stage III (n=25)	4(16)	21(84)
	Stage IV (n=17)	5(29.4)	12(70.6)
Treatment status	No treatment (n=11)	4(36.4)	7(63.6)
	Surgery (n=20)	0	20(100)
	Radiotherapy (n=4)	0	4(100)
	Chemotherapy (n=2)	1(50)	1(50)
	Surgery and chemotherapy (n=31)	4(12.9)	27(87.1)
	surgery and radiotherapy (n=6)	0	6(100)
	surgery, chemotherapy and radiotherapy	0	0
	chemotherapy and radiotherapy	0	0
Treatment	No treatment (n=11)	4(36.4)	7(63.6)
	ongoing treatment (n=7)	0	7(100)
	alive and completed treatment (n=51)	0	51(100)
	dead and had treatment (n=5)	5(100)	0

Year of Diagnosis: 2018 (n=104)			
Variables		Dead n (%)	Alive n (%)
Cancer types	Ca ovary (n=56)	2(3.6)	54(96.4)
	Ca kidney (n=7)	0	7(100)
	Ca bladder (n=13)	2(15.4)	11(84.6)
	Ca testis (n=5)	1(20)	4(80)
	Ca penis (n=9)	0	9(100)
	Ca prostate (n=14)	2(14.3)	12(85.7)
Cancer stages	Not available (n=2)	0	2(100)
	Stage I (n=24)	0	24(100)
	Stage II (n=21)	1(4.8)	20(95.2)
	Stage III (n=33)	2(6.1)	31(93.9)
	Stage IV (n=24)	4(16.7)	20(83.3)
Treatment status	No treatment (n=17)	3(17.60	14(82.4)
	Surgery (n=23)	1(4.3)	22(95.7)
	Radiotherapy	0	0
	Chemotherapy (n=11)	0	11(100)
	Surgery and chemotherapy (n=38)	2(5.3)	36(94.7)
	surgery and radiotherapy (n=9)	0	9(100)
	surgery, chemotherapy and radiotherapy (n=6)	1(16.7)	5(83.3)
	chemotherapy and radiotherapy	0	0
Treatment	No treatment (n=17)	3(17.6)	14(82.4)
	ongoing treatment (n=16)	0	16(100)
	alive and completed treatment (n=67)	0	67(100)
	dead and had treatment (n=4)	4(100)	0

Year of Diagnosis: 2019 (n=124)			
Variables		Dead n (%)	Alive n (%)
Cancer types	Ca ovary (n=73)	6(8.2)	67(91.8)
	Ca kidney (n=13)	0	13(100)
	Ca bladder (n=9)	2(22.2)	7(77.8)
	Ca testis (n=9)	1(11.1)	8(88.9)
	Ca penis (n=13)	0	13(100)
	Ca prostate (n=7)	0	7(100)
Cancer stages	Not available (n=5)	0	5(100)
	Stage I (n=30)	1(3.3)	29(96.7)
	Stage II (n=25)	1(4)	24(96)
	Stage III (n=42)	4(9.5)	38(90.5)
	Stage IV (n=22)	3(13.6)	19(86.4)
Treatment status	No treatment (n=25)	1(4)	24(96)
	Surgery (n=35)	2(5.7)	33(94.3)
	Chemotherapy (n=8)	2(25)	6(75)
	Radiotherapy	0	0
	Surgery and chemotherapy (n=41)	4(9.8)	37(90.2)
	surgery and radiotherapy (n=8)	0	8(100)
	surgery, chemotherapy and radiotherapy (n=6)	0	6(100)
	chemotherapy and radiotherapy (n=1)	0	1(100)
Treatment	No treatment (n=25)	1(4)	24(96)
	ongoing treatment (n=25)	0	25(100)
	alive and completed treatment (n=66)	0	66(100)
	dead and had treatment (n=8)	8(100)	0

Year of Diagnosis: 2020 (n=122)			
Variables		Dead n (%)	Alive n (%)
Cancer types	Ca ovary (n=82)	6(7.3)	76(92.7)
	Ca kidney (n=7)	3(42.9)	4(57.1)
	Ca bladder (n=9)	3(33.3)	6(66.7)
	Ca testis (n=8)	0	8(100)
	Ca penis (n=11)	2(18.2)	9(81.8)
	Ca prostate (n=5)	1(20)	4(80)
Cancer stages	Not available (n=3)	1(33.3)	2(66.7)
	Stage I (n=25)	0	25(100)
	Stage II (n=17)	2(11.8)	15(88.2)
	Stage III (n=43)	4(9.3)	39(90.7)
	Stage IV (n=34)	8(23.5)	26(76.5)
Treatment status	No treatment (n=31)	5(16.1)	26(83.9)
	Surgery (n=25)	1(4)	24(96)
	Chemotherapy (n=18)	3(16.7)	15(83.3)
	Radiotherapy (n=2)	1(50)	1(50)
	Surgery and chemotherapy (n=38)	3(7.9)	35(92.1
	surgery and radiotherapy (n=3)	0	3(100)
	surgery, chemotherapy and radiotherapy (n=5)	2(40)	3(60)
	chemotherapy and radiotherapy	0	0
Treatment	No treatment (n=31)	5(16.1)	26(83.9)
	ongoing treatment (n=30)	0	30(100)
	alive and completed treatment (n=51)	0	51(100)
	dead and had treatment (n=10)	10(100)	0

Year of Diagnosis: 2021 (n=172)			
Variables		Dead n (%)	Alive n (%)
Cancer types	Ca ovary (n=95)	8(8.4)	87(91.6)
	Ca kidney (n=14)	1(7.1)	13(92.9)
	Ca bladder (n=17)	2(11.8)	15(88.2)
	Ca testis (n=11)	0	11(100)
	Ca penis (n=14)	3(21.4)	11(78.6)
	Ca prostate (n=21)	5(23.8)	16(76.2)
Cancer stages	Not available (n=4)	0	4(100)
	Stage I (n=28)	1(3.6)	27(96.4)
	Stage II (n=37)	2(5.4)	35(94.6)
	Stage III (n=60)	5(8.3)	55(91.7)
	Stage IV (n=43)	11(25.6)	32(74.4)
Treatment status	No treatment (n=44)	5(11.4)	39(88.6)
	Surgery (n=28)	1(3.6)	27(96.4)
	Chemotherapy (n=24)	5(20.8)	19(79.2)
	Radiotherapy (n=3)	0	3(100)
	Surgery and chemotherapy (n=59)	4(6.8)	55(93.2)
	surgery and radiotherapy (n=5)	0	5(100)
	surgery, chemotherapy and radiotherapy (n=6)	2(33.3)	4(66.7)
	chemotherapy and radiotherapy (n=3)	2(66.7)	1(33.3)
Treatment	No treatment (n=44)	5(11.4)	39(88.6)
	ongoing treatment (n=42)	0	42(100)
	alive and completed treatment (n=72)	0	72(100)
	dead and had treatment (n=14)	14(100)	0