



Charting the Course: A Policy Road Map for Preventing Avoidable Cancer Diagnosis Delays in the Indian Context

Sobin George¹

Introduction

Cancer has emerged as a significant global health concern, contributing to a substantial portion of mortality worldwide. According to the World Health Organization (WHO), cancer accounted for nearly 17% of global deaths in 2020. In countries such as India, the burden of cancer has become increasingly evident, with an incidence rate of approximately 100 cases per 100,000 population, as reported by the National Cancer Registry (Sathiskumar et al., 2022). Additionally, cancer-related mortality in India is notable, comprising approximately 8% of total deaths (George et al., 2021).

Research indicates that the burden of cancer in countries like India is exacerbated by delays in diagnosis, stemming from various factors including disease-related issues, patient/family dynamics, practitioner-related challenges, socio-economic and cultural factors, and systemic barriers (George, 2023). Many of these delaying factors are preventable, suggesting a crucial opportunity to alleviate the disease burden associated with cancer in terms of both morbidity and mortality.

This policy brief, drawing from a qualitative study involving 48 participants in Bengaluru city, aims to elucidate the underlying reasons for delayed cancer diagnosis and propose a policy roadmap to facilitate early detection of cancer.

Diagnosis delays: From identifying symptoms to seeking help

The present study found that a considerable part of the delay occurred in the first stage of the disease progression, which is the period between the appearance of the symptoms and the first consultation (see Table 1). The average delay at this stage was nearly 180 days. The average diagnosis delay in the second stage of progression, which is the period between first consultation and diagnosis, was nearly

32 days. Further, the cancer diagnosis delay among the participants varied across gender, type of cancer, stage of diagnosis, and age. While the delay at the first stage was substantially higher for females as compared to males, the longest delay in the first stage cross type of cancer was found for ovarian cancer followed by lung cancer, intestinal cancer and breast cancer. Across stages at diagnosis, the longest delay was found among those who were in the 3rd stage followed by the fourth stage. Early formal consultation within 50 days from the appearance of symptoms enabled the patients to diagnose the disease either at 1st or 2nd stage. Although there was no significant delay found between the first consultation and diagnosis, it took more than 50 days in certain cases. Also, in certain cases delay was more in the second stage than the first stage, pointing to practitioner-led delays and system-led delays.

Pathways of diagnosis

The typical diagnostic journey for most patients had both informal and formal pathways. They followed a fairly common pattern, starting with initial neglect of symptoms for a short period (ranging from one to three months), followed by self-medication with over-the-counter drugs. Subsequently, they sought consultation from local Registered Medical Practitioners (RMPs) or doctors in private clinics or government hospitals.

Figure 1 depicts the formal help-seeking pathways. The formal diagnostic pathway typically began with a visit to a general physician (GP), who initially conducted non-specific cancer detection interventions such as routine blood tests, X-rays, scans, ECGs, and sonography, depending on the symptoms presented. Internal referrals to non-oncology departments were also common leading to further non-cancer-specific diagnostic interventions. There were two cases (lung cancer and Lymphoblastic Lymphoma) in the sample in which diagnosis was confirmed after five consultations and several non-cancer-specific

¹ Assistant Professor, Centre for Study of Social Change and Development (CSSCD), Institute for Social and Economic Change, Nagarabhatta P.O., BANGALORE-560072, India. Email: sobin@isec.ac.in

Table 1 Cancer diagnosis delay across social, demographic, type and stages, average days (N=48)

Characteristics	Symptoms to 1st formal consultation	First formal consultation to diagnosis	Total
Gender			
Male	88.5	30.8	119.3
Female	244.3	34.2	278.5
Age			
0-19	60	20	80
20-39	41.4	32.2	73.6
40-59	256.9	29	285.9
Above 60	93.3	42.3	135.6
Type of cancer			
Breast Cancer	184.7	18.7	203.4
Ovarian cancer	456	76	532
Lung cancer	320.7	68.5	389.2
Lymphoma melanoma	7	30	37
Endometrium cancer	30	10	40
Glioblastoma (brain cancer)	30	15	45
Testicular cancer	30	45	75
Lymphoblastic Lymphoma	7.6	20.5	28.1
Intestinal cancer	234.3	67.4	301.7
Liver cancer	15	64	79
Pancreatic cancer	25	18	43
Stomach cancer	91	21	112
Blood cancer	82	14	96
Stage at diagnosis			
1st	45	18.5	63.5
2nd	51.1	25.6	76.7
3rd	484.6	69	553.6
4th	172.7	21.1	193.8
All	180.24	32.28	212.52

Source: George (2023)

diagnostic interventions. The lung cancer patient who made five visits to confirm cancer diagnosis underwent several non-cancer specific diagnostic interventions such as Electro Cardio Gram (ECG) and echocardiogram (ECHO) (non-cancer specific tests) at the government hospital during the second visit, Computed Tomography (CT) scan at the government hospital at the fourth visit and MRI and blood test at the government cancer hospital during

the fifth visit. There were no diagnostic tests undertaken in the case of the LL patient in the first three hospital consultations and the cancer-specific interventions started at the fourth consultation and were confirmed at the fifth consultation. To sum up, as is illustrated in Figure 1, in most of the cases the patients had to undergo three to four hospital visits for the final diagnosis causing considerable time lags. The study found that various tests were conducted for other illnesses before referral to specialised hospitals where cancer was diagnosed.

Further, the study revealed that aspects like negligence of symptoms, informal help-seeking and non-cancer-specific diagnostic interventions and referrals by the general practitioners considerably increased the period of cancer diagnosis (George 2023). As the study noted, factors for a delayed diagnosis led by patients included downplaying and considering cancer symptoms as mere signs of fatigue or ageing; having misconceptions about cancer's causes, often attributing it solely to genetics or certain lifestyle behaviours; financial constraints; fearing the diagnosis of cancer itself; and experiencing gender-related challenges. Disease-related factors encompassed co-morbidities, the resemblance of cancer symptoms to those of other diseases, and the lack of distinct symptoms during the initial stages of certain cancers. Practitioner-led and system-led factors played significant roles in delaying diagnosis after patients sought formal help. These included general practitioners downplaying symptoms, making non-cancer-specific referrals, and the insufficient availability of cancer screening facilities (George 2023).

Factors contributed to early Diagnosis of cancer

Although the number was less, a few participants were diagnosed at an early stage (see Table 1) mainly because the delay in diagnosis was shorter for them from the appearance of the first symptoms. It is hence, important to understand the factors that led to the early diagnosis of cancer.

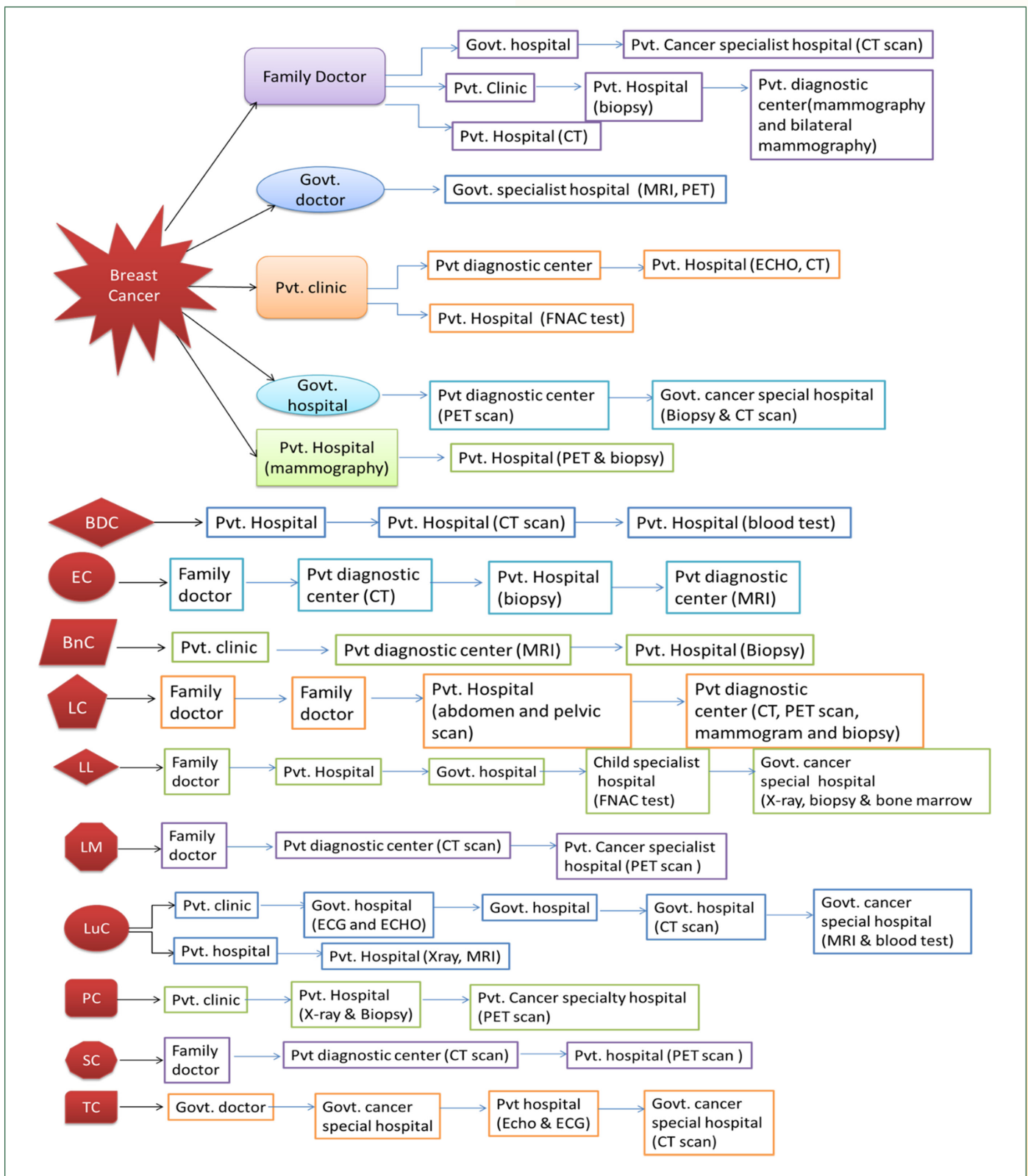
Knowledge and alertness to symptoms

The most important patient-led factor that helped to reduce diagnostic delay was the knowledge and alertness of the patient to symptoms. This was found to be true for the case of breast cancer patients, where the diagnosis was done within the 2nd stage of the disease due to visible symptoms while those who had ovarian cancer, and intestinal and stomach cancer could not. It was also found that early symptoms alerted the patients who had lymphoma melanoma, lymphoblastic lymphoma, liver cancer and testicular cancer to seek help (see Table 1).

Being male

It was found that diagnostic delay was comparatively shorter for male patients as compared to female patients (see Table 1), which further underscores the association between gender-based reasons for delay that included lack of women's agency in health-seeking, economic dependency and lower prioritisation of women's health within the household.

Figure 1 Formal diagnosis pathways of selected participants across types of cancer



BDC-Blood cancer, EC- Endometrial cancer, BnC-Brain cancer, LC-Liver cancer, LL- Lymphoblastic Lymphoma, LM- Lymphoma Melanoma, LuC-Lung Cancer, PC- Pancreatic cancer, SC-Stomach Cancer, TC-Testicular Cancer

Source: Primary study

Routine health check-ups and Self-referrals by patients reduced the delay

There were also instances when patients took the initiative to have regular check-ups and investigations. They also directly approached specialists and sometimes oncologists bypassing the first referral for the fear that the symptoms could be of cancer.

Cancer-specific interventions & short or direct referrals by the GP

One of the major factors in the early diagnosis of cancer was the cancer-specific interventions conducted at the first consultations. As it is clear from Figure 1 in a few cases, GPs at the first consultation undertook cancer indicative screening tests such as X-rays, CT scans, mammography and CA 125, which enabled them to directly refer the patients to oncologists. Also, in very few cases, GPs tended to refer directly to a specialist even at the first consultation based on clinical inferences. These happened in cases where GPs were previously known to the patient or were family doctors.

Further, less number of internal and external references by GPs and fewer episodes of shifting between hospitals and the system of medicines reduced the duration of diagnostic delay

Summary and Policy Recommendations

Results from the present study illustrate the patient, practitioner, disease-related and system-led delays in cancer diagnosis, which are avoidable. It underscores the urgent need to reduce the delay in diagnosis of cancer care, in the stage between the notice of the first symptom and formal help-seeking as well as after the formal help-seeking.

Developing a context-specific behavioural communication model for cancer screening, diagnosis, and treatment initiation in secondary cancer prevention interventions is crucial for mitigating avoidable delays in formal help-seeking. These delays often arise due to the relationship of social, behavioural, cultural, economic, and gender-related factors. Insights from factors associated with early diagnosis identified in the study, such as proper awareness of symptoms, prioritisation of women's health within households, regular health check-ups, and timely referrals by general practitioners, can inform the development of this behavioural communication model. By incorporating these insights, the model can facilitate active cancer screening and early detection efforts.

As the study revealed, diagnosis delays in the second stage are mostly centred on system and practitioner-related factors. Hence, it is important to ensure that cancer control and prevention efforts in India extend to include general medical practitioners, who serve as the initial point of contact for formal help-seeking. Empowering these practitioners to recognise common cancers early, especially among patients presenting with unrelated conditions that may also be indicative of cancer, is essential.

It is possible that the limited number of specialist cancer hospitals in the public sector results in prolonged waiting times for diagnostic interventions or forces patients to rely on expensive private sector services. Hence, it is extremely important to develop and increase affordable infrastructure facilities for cancer screening in India. Further, the problem of affordability can be addressed by expanding the network of specialist cancer hospitals in the public sector.

The rural-urban divide in cancer care with the higher concentration of hospitals in urban areas, is to be addressed by strengthening peripheral hospitals in rural areas to facilitate active cancer screening.

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Acknowledgements: This policy brief is developed from the findings of the research project titled "Informed choices and affordability: linkages of doctor-patient interaction, prescription practice and medical expenditure in cancer care in Karnataka", supported by the Indian Council of Social Science Research, New Delhi under the IMPRESS Scheme (P249). The policy brief also draws on the paper "Being sick to a cancer patient: pathways of delay in help-seeking and diagnosis of cancer in India" published by the author in the *Journal of Social and Economic Development*.

Institute for Social and Economic Change

Dr. V K R V Rao Road, Nagarabhavi PO, Bangalore 560072

Phone: 23215468, 23215519, Fax: +91-80-23217008; Web: <http://www.isec.ac.in>