Being sick to a cancer patient: pathways of delay in help seeking and diagnosis of cancer in India

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Abstract
There is evidence that cancer mortality and morbidity could be reduced when the disease is diagnosed and treated at an early stage. The paper examines the pathways of delay of cancer diagnosis in an Indian setting. It draws on a qualitative study conducted among cancer survivors and family members of cancer patients in the city of Bengaluru, South India. The results show that a substantial part of the delay occurred at the stage of initial formal help seeking wherein patient and family-led, disease-related and systemic factors together played a major role. Patient-led factors included trivialisation and normalisation of symptoms as part of general fatigue and aging; unrealistic risk perceptions that linked causality of cancer merely to heredity and behavioural risk factors; fear of being diagnosed as cancer patient; gender related reasons including family’s gender performance expectation, lower agency of women to seek help and lower prioratisation of women’s health in the household and access related issues including financial constraints and unavailability of specialised hospitals nearby. Disease-related factors included the presence of comorbidity, cancer’s mimicking of symptoms of other diseases and absence of distinguishable symptoms at the initial stage for certain types of cancers. The practitioner-led and system-led factors such as trivialisation of symptoms by general practitioners, non cancer-specific referrals, and lack of cancer screening facilities accounted for a major part of delay after the formal help seeking. The paper argues that the mere knowledge of cancer symptoms did not always lead to early diagnosis due to the interplay of these factors. The ongoing cancer prevention and control interventions in India need to be informed of these micro level factors while developing strategies to prevent avoidable delays in cancer diagnosis.

Keywords Cancer · Formal help seeking delay · Diagnostic delay · Systemic delay · Disease-related delay · Gender-related delay
Introduction

Cancer has been a major cause of morbidity and mortality across the globe. Cancer accounted for nearly 10 million deaths globally during 2020 (Ferlay et al. 2020). There is evidence that the burden of cancer is increasing in India. Cancer prevalence in India is estimated to be 83 per 100,000 persons (Rajpal et al. 2018). The cancer incidence in India in 2020 was estimated to be 1.39 million (ICMR-NCDIR 2021). As per the mortality data of the World Health Organisation cancer accounted for 8.24% of the total deaths in India in 2015 and 13% of deaths within non communicable diseases (World Health Statistics 2019). The cancer mortality in India was the highest in the age group of 15–69 (George et al. 2018). Studies have also highlighted the growing morbidity and financial burden of cancer in India (Mallath et al. 2014; Dandona et al. 2017; Pramesh et al. 2014; Joe 2014; Rajpal et al. 2018).

There is evidence that cancer mortality and morbidity could be reduced when the disease is diagnosed and treated at an early stage (Rue et al. 2009; McPhail et al. 2015; McCormack and Aggarwal 2021). However, cancer is often diagnosed at an advanced stage for most of the patients due to various reasons. Studies conducted at several regional and cultural contexts across the globe showed that cancer diagnostic delays can be due to demographic, socio-economic and cultural reasons (Waller et al. 2009; Mwaka et al. 2016); lack of awareness and delayed presentation (Allgar and Neal 2005; Macleod et al. 2009), poor access to services (Petrova et al. 2020; McCutchan et al. 2021) and procedural delays (Olesen et al. 2009). These are generally classified as patient-led; practitioner-led and system-led delays. Similar reasons for delay in help seeking and diagnosis were reported from India as well. Studies showed that factors including lack of infrastructure facilities; financial constraints; gender related stigma; trivialisation of symptoms and lower awareness of the symptoms delayed cancer diagnosis in India (Broom and Doron 2012; Pati et al. 2013; Krishnatreya et al. 2015; Ganesan et al. 2020). These are further intersected with socio-economic background, education, gender, place of residence and age of the patients and the type of cancer. This paper attempts to understand the pathways of initial help seeking and diagnosis of cancer patients in order to delineate how delays are embedded in the social, economic, cultural and systemic milieus.

Methods

The study employed the qualitative method of in-depth interviews for data collection. Data were collected from cancer patients/family members depending on their willingness to participate in the study. Participants were purposively selected using the snowball method, initially from our personal contacts and through palliative care centres in Bengaluru city. Participants from all social, demographic and economic classes and across type and stages of cancer have been included in the sample. A total of 48 in-depth interviews were conducted till data saturation was achieved. The study used a semi-structured interview guide for in-depth interviews and traced the entire diagnostic pathways from the first notice of the symptoms of each case. Out of 48 interviews conducted, 12 were with the patients and remaining 36 were with the family members of patients. While 22 interviews were conducted face to face, 26 interviews
were conducted telephonically by following the prevailing protocols related to COVID 19. Interviews were conducted in English and the local language of Kannada.

The study used the grounded theory approach to analyse the data. All interviews were recorded and the verbatim transcribed and translated to English by a bilingual expert. Sufficient care was taken to reproduce the information in respondents’ own words, phrases and expressions. The data were analysed using qualitative software Atlas-ti. Both deductive and inductive codes were developed. Deductive codes were developed from the systematic reviews conducted and questions that had been asked to the respondents and inductive codes were developed based on the random reading of data and the new categories that emerged from the data. A total of 24 codes were developed. Axial coding was done to draw connections between the different codes. Further, sub-themes and themes were generated from the codes.

Ethical considerations

The study was approved by the ethics committee of the Institute for Social and Economic Change, Bengaluru conducted on 23 March 2021 (No. Regr/Ethics/8.15/2020–21). Consent for participating in the study was obtained. The data was anonymised to protect the identity of the participants.

Limitations

The selection of participants was based on snowball method due to the prevailing pandemic conditions. It led to the exclusion of two major types of cancers—oral and cervical cancers—in the sample. The paper does not discuss the reasons of diagnosis delay across all types of cancer due to the lack of data. Further, the diagnostic delays reported by the patients and family members at hospitals are not corroborated with the views of medical professionals.

Findings

Out of 48 participants, 30 were females and 18 were males. Most of them were currently married and from the age group of 50–59 (Table 1). There were ten participants who were from relatively lower economic backgrounds. There were no non-literate persons in the sample. The sample included breast, lung, stomach, endometrial, ovarian, liver, intestinal, pancreatic, brain, blood, lymphoblastic lymphoma, testicular and lymphoma melanoma cancer patients. Out of 48 cases, 14 were diagnosed at the fourth stage; 20 were diagnosed at the third stage and 10 were diagnosed at the second stage. Only four cases were diagnosed at the first stage of the disease.

Help seeking and diagnostic delays and their pathways

A substantial part of the delay in cancer diagnosis occurred in the period between appearance/notice of the symptoms and first formal help seeking/consultation (Table 2). The average delay occurred at this stage was nearly 180 days. The delay in first formal consultation varied across the categories of gender, type of cancer, stage of disease, and age. This was notably higher for females than males. Across age groups, delay in formal consultation was
| Characteristics                          | Number |
|-----------------------------------------|--------|
| **Gender**                              |        |
| Male                                    | 18     |
| Female                                  | 30     |
| **Age (when diagnosed)**                |        |
| 0–9                                     | 2      |
| 10–19                                   | 0      |
| 20–29                                   | 4      |
| 30–39                                   | 6      |
| 40–49                                   | 10     |
| 50–59                                   | 16     |
| 60–69                                   | 10     |
| **Marital status**                      |        |
| Currently married                       | 32     |
| Currently unmarried                     | 8      |
| Widowed                                 | 6      |
| Separated                               | 2      |
| **Occupation**                          |        |
| Student                                 | 4      |
| Working in government sector            | 2      |
| Working in private sector               | 14     |
| Retired                                 | 2      |
| Farmer                                  | 6      |
| Own business                            | 4      |
| Not earning                             | 16     |
| **Monthly income**                      |        |
| 0–24,999                                | 10     |
| 25,000–49,999                           | 2      |
| 50,000–74,999                           | 8      |
| 75,000–99,999                           | 2      |
| 1 Lakh and above                        | 8      |
| Income not declared                     | 18     |
| **Education**                           |        |
| Up-to secondary                         | 18     |
| Secondary                               | 10     |
| Graduate                                | 8      |
| Post graduate and above                 | 12     |
| **Type**                                |        |
| Breast cancer                           | 20     |
| Stomach cancer                          | 4      |
| Endometrial cancer                      | 2      |
| Ovarian cancer                          | 2      |
| Liver cancer                            | 2      |
| Lung cancer                             | 6      |
| Brain cancer                            | 2      |
| Testicular cancer                       | 1      |
| Lymphoma melanoma                       | 1      |
more in the age group of 40–59. Further, the delay was longest for patients with ovarian cancer (456 days), followed by lung cancer (321 days), intestinal cancer (234 days) and breast cancer (175 days). Majority of the patients sought the first formal help when the disease was at the 3rd or 4th stage. The average delay of diagnosis after the first formal consultation was nearly 32 days in the sample. The diagnostic delay after the first formal consultation was more than the sample average for patients with ovarian, lung, intestinal and testicular cancers and for elderly and female patients. It should also be highlighted that the average diagnostic delay of liver, lymphoma melanoma, testicular cancer patients in the sample was more in the second stage than the first.

The pathways of cancer diagnosis of participants are illustrated in Fig. 1. There were spells of negligence, informal help seeking and help seeking at small clinics and family doctors for all the participants before the first formal consultation. Further, most of the patients underwent non-cancer specific interventions and internal referrals before the oncology referrals. The instances of direct referral for cancer screening were very less.

Patient/family-led help seeking delay

Most of the participants related the symptoms to common problems of fatigue arising from work or other common ailments such as fever, cold, cough or body pain and resorted to informal help seeking and use of medicines bought over the counter (Table 3). Negligence and normalisation of symptoms were found among all categories of participants. For instance, there were instances where patients who were educated and employed tended to normalise the symptoms by attributing these to workload and work related stress. Further, there was a general tendency to attribute causality of cancer merely to heredity as well as to behavioural risk factors that include smoking, alcohol

| Characteristics         | Number |
|-------------------------|--------|
| Lymphoblastic Lymphoma  | 2      |
| Intestinal cancer       | 2      |
| Pancreatic cancer       | 2      |
| Blood cancer            | 2      |

| Stage when diagnosed   |        |
|------------------------|--------|
| 1st Stage              | 4      |
| 2nd Stage              | 10     |
| ‘A’                    | 0      |
| ‘B’                    | 2      |
| ‘C’                    | 4      |
| Don’t know             | 4      |
| 3rd Stage              | 20     |
| ‘A’                    | 2      |
| ‘B’                    | 2      |
| ‘C’                    | 10     |
| Don’t know             | 6      |
| 4th stage              | 14     |

Source: Fieldwork
intake, non-vegetarian diet and consumption of junk food. Those who did not have these risks and those who usually followed a “healthy lifestyle” [as they perceived it to be] hence did not anticipate cancer affliction and did not tend to attribute their symptoms to cancer initially. Participants, especially the breast and ovarian cancer patients, attributed the initial cancer symptoms to other normal life course events such as menstruation, menopause and ageing and such normalization delayed the help seeking. There were gender-related factors of anticipated stigma and fear of the inability to fulfill the expected gender performances at home that influenced the help seeking of female patients. For instance, a few female patients hid their symptoms from the spouse and family members and relied on over-the-counter medication for managing the symptoms, in order to reduce the conflicts of work and life, till the symptoms aggravated. A few participants also delayed the initial help seeking for the fear of being diagnosed as cancer patient.

Table 2  Average days of delay from the notice of symptom to formal consultation and diagnosis (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 of 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* Fieldwork
Practitioner-led delay

Trivialisation of symptoms by General Practitioners (GP) was also not uncommon, especially at the first stage of formal consultation. As the participants reported, a few GPs tended to resort to clinical diagnosis and trivialised the symptoms of pain and fatigue to conditions of excessive work, sleeping positions and presence of other chronic/acute health conditions that patients had (Table 4). In some cases, participants felt that overlooking of symptoms by the practitioners at the first consultation resulted in delayed cancer diagnosis. The case of a patient who was diagnosed with pancreatic cancer at an advanced stage is presented to illustrate the oversight of symptoms by GPs that led to cancer diagnostic delay. As reported by a family member of the patient, who participated in the interview, there was a delay of nearly three months from the date of first formal consultation to actual diagnosis since the GP tended to clinically diagnose the condition as sprain and muscle cramps. This had stopped further referrals and consultations since the patient tended to go by the first diagnosis, which was clinically conducted at a private clinic. Since the patient reported an increase of pain he was taken to another private hospital after three months where X-ray and biopsy were conducted. The patient was subsequently referred to a private cancer specialist hospital where pancreatic cancer was confirmed after undertaking a Positron Emission Tomography (PET) scan. The patient was diagnosed at the 4th stage of pancreatic cancer (see Table 4).
| Sub-theme                                                                 | Qualitative illustrations                                                                                                                                                                                                 |
|--------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Neglecting and trivializing initial symptoms                              | First, I experienced pain in my right shoulder; I couldn’t sleep and lift heavy weights. I couldn’t work because there was pain, and I would feel that pain is common. After 6–7 months I experienced pain in my legs, hands and knee cap, giddiness, vomiting sensation and I couldn’t get up and walk. I consulted a doctor locally and he gave me medicines for 15 days. But I didn’t go back again. I thought was it’s all happening because of the tension I kept quiet. (Breast cancer patient) |
| Informal help seeking                                                    | For almost one year it was like that...I had a cough. The pain was less. There was pain once in a while. When there was pain I would take tablets [over the counter painkillers] and I applied moov [pain balm]. I spent one year there. (Breast cancer case) |
| Never expected cancer since nobody in the family has                    | Nobody had this disease [cancer] in our family so we even did not guess that she is going to have this kind of disease (Stomach cancer patient)                                                                                 |
| Followed a ‘healthy life style’                                          | She was very slim, very active, very healthy, and a very brave and a gentle woman. She used to get up at 5[am]. This was her lifestyle and not even one day she might have had a panipuri [an Indian spicy street food]. She used to taunt people about why do they eat all such nonsense food. (liver cancer patient) |
| Seeing symptoms as a part of normal life course events                   | Due to hormone imbalance a lump was formed in my breast. I did not know about it. There was pain and pricking sensation in my breast during my [menstrual] periods. I felt like my breast was stiffened (bigidukonda haage aagodu). I did not know and I thought for everyone it will happen (breast cancer) |
|                                                                           | I neglected when I came to know about this [lump on breast]. I left it for about 11 months. I did not go to a doctor. I was like that it might be some other lump, may be due to my age and menopause and it’s not cancer. (Breast cancer patient) |
| Female patients hiding symptoms to spouse and family members             | She [patient] had some symptoms of leg pain, hand pain, something from quite some time. I understood it when one of the helpers in the bank [where the patient worked] told me that madamku thumba kiaal novam thare (Mdam has very bad leg pain). She [patient] never told me. She managed by taking a Crocin and continued work in the bank. This spell continued for long. If she told me earlier I would have taken her to the doctor. (Endometrial cancer caser) |
| Anticipated fear of cancer diagnosis and delay in help seeking           | Actually I could feel the lump in my breast. I had read all the symptoms and all like breast shape will change and all, I had read all that I knew that changes are happening but still I avoided going to the doctor because of fear. I did not go [to hospital] for the initial 4 months (Breast cancer patient) |

Source Interview transcripts
| Sub-theme                                                                                      | Qualitative illustrations                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|--------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Trivialisation of symptoms by practitioners at first consultation                            | She was just experiencing the pain in her left breast. It was actually a kind of cyst that she used to feel and she just told me that she has a small cyst here. We visited a general physician and the doctor told us it is normal and the pain is because of her excess work at home. He just gave me a small tablet. She was fine for one month. But she did not find the cyst getting smaller or disappeared. She felt it even grew to the size of a shirt button. We did not want to ignore it again and consulted a lady gynecologist (Breast cancer case) |
| Overlooking of symptoms and diagnostic errors by practitioners at the clinical level          | He had a pain near rib cage *(pakke novu anthidru)*. When he went to the doctor they said there might have been some sprain or something or it might be a muscle cramp. He ignored it for three months. Pain was still there. Later his cousin took him to another hospital. The doctor suspected there was some problem when they tested him. They did X-ray they came to know that it could be cancer (Pancreatic cancer case) I went to the doctor. They gave me painkillers. I waited for 10 days. My pain was not gone. I went to another government hospital. They also did not conduct any tests and I approached a private hospital. They doubted heart problems and conducted lot of tests and finally said that I must do a cancer screening, which I got done with a special hospital (Testicular cancer case) |
| Multiple referrals and non cancer specific diagnostic interventions                           | She met with an accident and had broken her left leg where she had to get an alignment surgery. She had leg swelling before and pain again and we took her to the orthopaedic who operated on her. The doctor told it (steel rod) should be removed, which is the reason for her swelling and pain. She has a stomach ache and all after that we took her to the local he family doctor. He asked us to get a scan. The doctor told that she has some water in lungs which has to be treated and it will be all fine with the medicines. After 45 days again she started [developed] urine problems like she never used to pass the urine so easily. The doctor told us it may be a bladder infection and asked us to get the bladder scanned again. We got the bladder scanned and they found that she has a urinary tract infection so after that she was admitted to …….. hospital in MC Layout. After that one doctor one doctor gave a hint about cancer again and asked to get the scan done. It was found that she has liver cancer in last stage and the doctor said we cannot do anything *(yella tindhbitidhe)* (Liver cancer case) |

*Source* Interview transcripts
Similar case of erroneous clinical diagnosis was reported by a participant who had testicular cancer. The patient was presented at a local government hospital with pain and discomfort in one testicle. The patient was sent back with pain killers. The discomfort and the size of the swelling increased, which led the patient to consult a private hospital where diagnostic interventions were initiated. However, initial interventions were Electro Cardio Graph (ECG) and Echocardiogram (ECHO) which were non-cancer specific. The patient was further referred to cancer specific interventions. The patient was finally diagnosed at stage 2 (B) in a specialised government hospital (see Table 4). Although the patient sought formal help within a week from the notice of symptoms, the actual diagnosis took nearly 30 days.

Multiple internal and external referrals and non-cancer specific diagnostic interventions were other important practitioner-led reasons of diagnostic delay. The case of a patient who was diagnosed with liver cancer at an advanced stage is presented to illustrate the pathways of referrals from GPs that led to delayed diagnosis. The patient was presented to a GP with a condition of broken leg subsequent to meeting with an accident. The initial intervention was an alignment surgery to fix the orthopaedic complications. The patient had a history of edema on the leg (leg swelling), but the same was not presented to the practitioner by the patient/patient’s family. Nor did the practitioner notice it. The edema increased after the surgery, which was diagnosed by the practitioner as part of the orthopaedic problem. Subsequently, the Intramedullary (IM) rods (steel rod inserted) were removed. The patient further developed symptoms like stomach ache, difficulty in micturition (poor stream of urine) and urinary tract infection (UTI). The patient was referred to the urology department and diagnostic interventions such as scanning of urinary bladder were undertaken. The diagnosis was UTI and the patient was given medicines. The symptoms progressed and the patient was referred to gastroenterology. Patient underwent a series of diagnostic interventions starting from routine blood test to stomach endoscopy. Liver cancer was suspected and the patient was sent for cancer-specific diagnostic interventions for confirmation. The disease was advanced to 4th stage by then (Table 4).

Disease-specific delays

As reported by a few participants, the absence of distinguishable symptoms of the disease delayed their formal help seeking and diagnosis. For instance, participants who had ovarian cancer, liver cancer and lymphoma melanoma could not recognise symptoms of cancer for a long period of time as these were not distinguishable enough. The only symptom that one of the patients who suffered from ovarian cancer had was skin allergy, which she did not recognise, was a possible symptom of cancer (see Table 5). The diagnosis in this case was made not due to help seeking for any symptom but as part of a general health check up underwent by the patient. By that time, the disease had advanced to stage 3C. Further, it was found that negligence of minor symptoms like rashes, itching and boils on the skin as well as lack of other prominent cancer symptoms led to delayed diagnosis for liver and lymphoma melanoma patients.

Cancer’s mimicking of symptoms of other diseases was another important disease-related reason for diagnostic delay. A participant (patient) was presented to a local private clinic with symptoms of cough and pain in the left side of the chest. The GP suspected cardiac problems based on the symptoms presented and suggested ECG. The patient was subsequently referred to a specialist cardiac hospital in the private sector where cardiac problems were ruled out. The patient was further referred to the
pulmonology department in order to rule out the possibility of tuberculosis (TB). The patient visited a specialist chest hospital in the public sector where X-rays were taken and the possibility of TB was ruled out. The patient was further referred to a general hospital in the public sector for detailed investigation. Patient underwent a CT scan and lung cancer was suspected for the first time. The patient was further referred to a specialist cancer hospital in the public sector to confirm the diagnosis. It took nearly 70 days for the proper diagnosis from the day of first formal consultation (Table 5).

Another important patient/family-led reason for delay was the presence of comorbidity, which led to non-cancer specific communication of symptoms to the practitioner by the patient. The delay was further increased by the practitioners since they tended to focus more on the symptoms of comorbidity, which led to non-cancer specific diagnostic interventions. For instance, symptoms of cancer such as lack of appetite and weight loss are symptoms of several other diseases such as Chikungunya, TB and metabolic disorders as well (Table 5). It turned out to be difficult for patients/family members and practitioners to suspect cancer when patients also had any of these co-morbidities.

### Table 5 Disease-led delay in cancer diagnosis

| Sub-theme                                                                 | Qualitative illustrations                                                                 |
|--------------------------------------------------------------------------|------------------------------------------------------------------------------------------|
| Absence of distinguishable symptoms and negligence of minor symptoms: Intersection of disease related reasons | She only had symptoms like skin allergies. She used to get rashes everywhere. By the time she was diagnosed, it reached the stage of 3 ‘C’ (Ovarian cancer case)  
She did not actually have any symptoms she only had leg swelling (Liver cancer case) |
| Mimicking symptoms of other diseases                                      | I had a cough and chest pain. It increased. I went to the doctor nearby where I usually go for a check-up. He did ECG. He told me to go to …….[private hospital]. I neglected for 1 week to 15 days and went to that hospital. I got a scan. The doctor told me that I have no heart problems. They referred me to Rajeev Gandhi hospital [chest hospital in public sector] from there we went to Rajeev Gandhi there they again did scanning and then they referred me to Victoria hospital [public sector]. They wrote for CT scan. I got it scanned and showed the results. They told me that I am showing symptoms of cancer and I should go to KIDWAI [cancer hospital in public sector]. I came here and got admitted (Lung cancer case) |
| Co-morbidity and non-cancer specific presentation of symptoms            | She [patient] got a fever and it was a serious fever that time she was admitted to a hospital nearby. It was a good hospital and there she was diagnosed with Chikungunya. Thereafter she lost her appetite. We were thinking we had an impression that it can be the aftermath effect of the Chikungunya (Stomach cancer patient) |

Source Interview transcripts
As it emerged from the interviews, the shortage of tertiary hospitals and diagnostic facilities at the vicinity lengthened the referral periods especially for patients who were from rural areas (Table 6). This has also intersected with patient-led and practitioner-led delays and considerably increased the total delay of diagnosis. The case of a lung cancer patient who sought help after the progression of the symptoms such as difficulty in breathing, fatigue and back pain is presented to illustrate the system-led delay. The patient visited a hospital at the nearby town, where no diagnostic facility was available. The GP also did not suggest any diagnostic intervention and prescribed medicines for 15 days. Further consultation of the patient was affected by the COVID-19 pandemic. On progression of symptoms, the patient approached a hospital in the nearby city. The patient underwent several internal referrals and diagnostic interventions and finally lung cancer was suspected. Lack of availability of cancer diagnosis facilities at the public sector was another reason for the diagnostic delay for economically weaker sections that emerged from the interviews. This on the one hand led the patients to rely on private hospitals, which increased the cost and on the other accessing public hospitals which were far away from their place of residence. Further, the public hospitals were crowded and the patients had to wait for a longer period of time for appointments and diagnostic tests which also led to the diagnostic delay. A few

| Sub-theme                                                                 | Qualitative illustrations                                                                                                                                                                                                 |
|--------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Unavailability of specialist hospitals and diagnostic facilities          | There are 4 hospital of ……..in Bagalkote. I went there for consultation, but they didn’t diagnose cancer. They gave me 15 days of medicines and I was normal and again the same thing happened and last year there was COVID. I went to Hubli. The same problem was there so I consulted a different doctor called……He did X-ray and MRI scanning and said there is a lump inside your lungs that is causing breathing problems. He suggested that you have to go to a cancer hospital. We took all that [reports] and came to cancer hospital in Bagalkote (Lung cancer case) |
| Lack of specific cancer screening interventions in public hospitals       | Public hospitals were crowded and it delayed completion of screening tests. When we went to Kidwai [public hospital] they asked to get an X-ray, biopsy and bone marrow test. They did a bone marrow test first, later they did X-ray and blood test when they got to know when they did bone marrow. For that report they took 20 days. I stopped going to KIDWAII and I came to HCG (Lymphoblastic Lymphoma case) |
| Lack of all facilities in one hospital, which led to switching between hospitals for all interventions | All facilities were not available in one hospital and we have used whatever was necessary for my treatment from different hospitals. For big scans like cancer detection—where it is in which stage it—where has it spread the facility was not there in Ambedkar hospital [public sector]. (Breast cancer case) |

Source Interview transcripts

**System-led delay**

As it emerged from the interviews, the shortage of tertiary hospitals and diagnostic facilities at the vicinity lengthened the referral periods especially for patients who were from rural areas (Table 6). This has also intersected with patient-led and practitioner-led delays and considerably increased the total delay of diagnosis. The case of a lung cancer patient who sought help after the progression of the symptoms such as difficulty in breathing, fatigue and back pain is presented to illustrate the system-led delay. The patient visited a hospital at the nearby town, where no diagnostic facility was available. The GP also did not suggest any diagnostic intervention and prescribed medicines for 15 days. Further consultation of the patient was affected by the COVID-19 pandemic. On progression of symptoms, the patient approached a hospital in the nearby city. The patient underwent several internal referrals and diagnostic interventions and finally lung cancer was suspected. Lack of availability of cancer diagnosis facilities at the public sector was another reason for the diagnostic delay for economically weaker sections that emerged from the interviews. This on the one hand led the patients to rely on private hospitals, which increased the cost and on the other accessing public hospitals which were far away from their place of residence. Further, the public hospitals were crowded and the patients had to wait for a longer period of time for appointments and diagnostic tests which also led to the diagnostic delay. A few
participants highlighted the lack of all diagnostic facilities in a single facility (hospital), which was true for both public and private hospitals. This had led to several external referrals, which were both non-cancer specific and cancer-specific diagnostic interventions. Patients had to switch between private and public hospitals in such cases as well. All these have contributed to the delay in diagnosis.

Factors helped the early cancer diagnosis

While delayed diagnosis was the major theme that emerged from the study, a few participants were diagnosed at an early stage of cancer (see Table 2). The most important patient-led factor that helped to reduce diagnostic delay was the alertness of the patient to the symptoms. This has been found to be true in the cases of breast cancer patients, where diagnosis was done within the 2nd stage of the disease. Alertness to symptoms was also related to the type of cancer. For instance, a few breast cancer patients could seek early help due to visible symptoms of breast cancer while those who had ovarian cancer, intestinal and stomach cancer could not. Further, it was found that the routine health check-ups and self referrals to specialists, bypassing the first referral for the fear that the symptoms could be that of cancer, reduced the delay of cancer diagnosis. A participant who was diagnosed in the first stage of cancer explained how her alertness helped the early diagnosis of the disease:

I went for a regular check-up and my gynaecologist [gynaecologist] sent me to the oncologist (Ovarian cancer patient)

Certain practitioner-led factors, especially the referrals by the GP were significant factors of early cancer diagnosis. For instance, the diagnosis was faster when the GP referred the patients directly to oncologist or suggested cancer screening interventions at the first consultation (see Fig. 1). Also, lesser number of internal and external references by GPs and lesser episodes of shifting between hospitals and system of medicines reduced the duration of diagnostic delay. One of the participants explained.

When I consulted family doctor she asked me to get a scan [done] and that there was some gedde (mass) in my right breast (Breast cancer patient)

Discussion

Similar to the studies conducted on delay in cancer diagnosis in India (Dwivedi et al. 2012; Broom and Doron 2012), the present study found that patient-led, practitioner-led and system led-delays explain a major part of the delay in formal help seeking and cancer diagnosis. The study found a common trajectory of help seeking for the patients that started from initially neglecting the symptoms for a brief period of time, informal help seeking, over the counter medication and consultation of local RMPs/doctors in local private clinics/government hospitals, which are categorized as patient/family-led and system-led delays. The patient/family-led factors such as negligence and normalisation of symptoms, reliance on informal healthcare, financial constraints, presence of other ailments, wrong presentation of symptoms and gender-related reasons accounted for the delay in formal help seeking (Fig. 2). Negligence (Ganesan et al. 2020) and normalisation of initial symptoms due to ignorance (Sathwara et al. 2017; Panda et al. 2020) were barriers for the early detection of cancer, especially for the female patients, in the present study as well.
Further, the study found that the self image as a person with lower cancer risks due to the absence of cancer patients in the close family line (genetic risk) and “having a healthy lifestyle” (without behavioural risks) led the patient not to suspect cancer and hence delay early help seeking. Similarly, trivializing symptoms as part of the natural life course events such as aging and menopause led patients to neglect the symptoms. The anticipated fear of cancer diagnosis led a few patients, especially those who were aware of the symptoms of cancer, to delay formal help seeking and diagnosis. Also, economic constraints and unavailability of persons to accompany the patients to formal healthcare facilities acted as barriers to early diagnosis for patients who were from economically weaker sections.

The findings also highlighted the gender-related reasons of delay in formal help seeking. This reiterates the existing gender-related reasons of help seeking and diagnostic delay pertaining to lack of women’s agency in health seeking, economic dependency and lower prioritisation of women’s health within the household (Nyblade et al. 2017; Chintamani et al. 2011). Further the study showed that the gender intersections of formal help seeking and diagnosis can be true for women who live in urban areas and for those who have better education (above graduation here) and economic backgrounds (read employed) as against the available evidence that these are true only for women from rural areas with less agency and education (Pakseresht et al. 2014; Deshmukh and Rathod 2017). Embarrassment to disclose the symptoms to family members and practitioners (Bodapati and Babu 2013) were also reported by the participants of the present study. The study notes that the gender-related factors of anticipated stigma and the expectations from women to perform multiple tasks often leads to neglecting their own health.
gender roles tended to subdue other enabling attributes such as knowledge of the disease, education or better economic and employment status of female patients and acted as barriers to the early presentation of symptoms to medical practitioners.

The formal diagnostic pathways began with GPs who initially conducted non-cancer specific interventions and internal referrals to other medical departments, which are categorized as practitioner-led and disease related delays. There is already evidence that a set of overlapping reasons, which include trivialisation of symptoms and medical negligence by practitioners are causes of cancer diagnostic delays in India (Miriyal et al. 2018). Studies also showed that practitioner-led delay, especially the diagnostic errors, delayed cancer diagnosis in India (Mishra et al. 2017). The present study highlighted the instances of negligence of symptoms and diagnostic errors by the practitioners, mostly at the initial consultation. It was found that reasons like trivialisation by practitioners, medical negligence, long and wrong referrals and non-cancer specific interventions added to the practitioner-led delay. It should also be highlighted that in some cases, practitioner-led delay overlapped with patient-led delays when the patients had comorbidity. For instance, the type of cancer, the stage when the symptoms were recognised and patients’ co-morbidity played a prominent role in the diagnosis. Studies have illustrated that cancer diagnosis can be delayed based on the type of cancer (Lytratzopoulos et al. 2014). The present study showed that diagnostic delay was the longest for ovarian cancer followed by lung cancer, intestinal cancer, breast cancer and stomach cancer (Table 2). Further, the study highlighted that disease-related reasons such as cancer mimicking of symptoms of other diseases, slow initial progression of the disease without distinguishable symptoms and comorbidity led the patients not to present cancer specific symptoms to practitioners and the practitioners not to conduct cancer specific diagnostic interventions.

Physical and financial access to specialist hospitals and modern diagnostic facilities was the major system-led barrier of cancer diagnostic delay in India (Dwivedi et al. 2012; Broom and Doron 2012; Pati et al. 2013). Available studies showed that healthcare delivery in India is constrained by insufficient infrastructure and diagnostic facilities, non-availability of qualified medical personnel, corruption, poor health management system and absenteeism of staff (Jaysawal 2015; Saikia 2018). Further, there is a substantial shortage of health infrastructure and personnel for cancer diagnosis and treatment both in the public and private sector. For instance, the oncologist-cancer patient ratio in India is estimated to be 1:2000 and as per the data provided by the National Cancer Grid there were only 62 dedicated cancer hospitals in India as of 2019 against an estimated prevalence of 2.25 million cancer patients in India (Sharma 2019). Our study found that the unavailability of specialist hospitals and diagnostic facilities, especially in the public sector; lack of all cancer diagnostic facilities in a single hospital and the burden and opportunity costs involved with the long travel for diagnosis were barriers to early cancer diagnosis, especially for patients who were lower economic background, outside the city limits of Bengaluru.

It should also be noted that in several instances, patient/family-led, practitioner-led, disease-related and system-led factors interplayed and led to the initial formal help seeking and diagnostic delay as illustrated in Fig. 2. Hence, the pathways of formal help seeking and diagnosis within these four broad categories often overlapped and led to a complex diagnosis pathway for several patients. The patient/family-led negligence intersected with gender reasons and system-led reasons of unavailability of hospital and diagnostic facilities. Similarly, the patient-led and practitioner-led delays related to oversight of symptoms intersected with disease-related reasons, including co-morbidity and absence of
distinguishable symptoms for certain types of cancer at the initial stage. Further, the economic background and gender [as woman] intersected with all four types of delay.

Conclusions

A considerable part of the delay in cancer diagnosis occurred during the period between appearance/notice of the symptoms and the first formal help seeking and most of these are avoidable. The ongoing cancer control and prevention interventions in countries like India focus on awareness generation on cancer symptoms, formal help seeking, access to clinical evaluation and diagnostic services and timely referrals to treatment services. The study highlighted that there are complex social, economic, gender and cultural embeddings existing in India wherein awareness of symptoms or availability of services would alone not always help patients to seek formal help immediately. The paper suggests that the ongoing early cancer detection initiatives need to be sufficiently informed of these complex issues. At present interventions such as information, education and communication and behavioural change communications are limited to the primary prevention in India. It is important to design a context specific behavioural communication model for cancer screening, diagnosis and initiation of treatment in the secondary cancer prevention interventions in order to reduce the avoidable delay in formal help seeking that occurs due to the interplay of social, behavioural, cultural, economic and gender factors. The factors that led to the early diagnosis that the study identified such as awareness and alertness to symptoms, prioritisation of women’s health within the household, routine health check-ups and prompt referrals by GPs could provide insights to the behavioural communication model to facilitate the active screening for cancer.

Avoidable delays after formal help seeking were mostly related to practitioner and system-led factors. The study, hence, suggests that the ongoing cancer control and prevention interventions in India need to cover the general medical practitioners who are at the first point of formal help seeking. It is important to enable the GPs to suspect common cancer at an early stage for patients who visit for other conditions, which could be related to cancer as well. Existing systemic barriers to access health care in India also need attention. Cancer hospitals are concentrated in big cities and in urban settings, which affects the accessibility of rural patients. Similarly, it was found that the number of cancer specialist hospitals in the public sector is less, which makes the patients wait for long periods for completing the diagnostic interventions or compels them to depend on expensive private sector services. The strengthening of peripheral hospitals to facilitate active cancer screening and setting up of more specialist cancer hospitals in the public sector are important steps to reduce the diagnostic delay that can happen due to problems of unaffordability.

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