Original Article

A qualitative exploratory study of delay in the presentation of gastrointestinal cancer

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ABSTRACT

Introduction: Patients with gastrointestinal (GI) cancers often present late in the advanced stages, due to various reasons and may experience delays in treatment. Hence, we have attempted to find the factors leading to this delay. **Methods:** This was an exploratory qualitative study, in a tertiary care hospital, including 20 patients with advanced GI cancers. They were interviewed to assess the reasons for delays in presentation, diagnosis and treatment, and the factors were analysed based on the interval of delay and the cause. **Results:** This study found that there was an interval of delay of 8 months from the onset of symptoms till primary treatment, more than half of which occurred in the pre-hospital phase (56.4%). We classified the causes for the delay into different intervals such as the appraisal interval, health-seeking interval, diagnostic interval and the pre-treatment interval. Lapses at the individual, societal and institutional level lead to the delay. The major causes included ignorance, substance abuse, poverty, social stigma, vague symptoms and missed diagnosis, miscommunication, resource constrain, very poor doctor-patient ratio and delay in investigation and treatment. **Conclusion:** This study noted a significant delay in the treatment of patients with advanced gastrointestinal cancers. Reasons for delay have been noted at various levels. Further action based on this study, at the community and hospital level could potentially reduce the delay and result in better survival and improved quality of life.

Keywords: Advanced cancer, gastrointestinal cancer, pathway to care, patient perspective, qualitative study

Introduction

Cancer is the second leading cause of mortality around the world and contributes to a large amount of healthcare expenditure of most countries. Gastro-intestinal (GI) cancers are among the most common malignancies and is increasing in incidence and mortality in Asia.[1] Cancer related mortality and the proportion of patients presenting with late stage malignancies in the developing countries are higher than the developed countries.[2]

Many factors have been shown to impact access of patients to cancer screening, early diagnosis and treatment. Various studies have been conducted to assess the pathways to care from the first presentation to the hospital to diagnosis and initiation of treatment.[3,4] However, it is difficult to analyze the reasons for pre-hospital delay using descriptive studies. These include socioeconomic, cultural factors, fear about cancer, and social stigma associated with cancer.[5,6] Delay in presentation is an important aspect to be tackled to improve the cancer survival and outcome.

Very few studies are noted in the english literature which assess the pre-hospital pathways to care and mostly included breast and cervical cancer.[6-8] This study was designed to explore the pathways to care and health seeking behaviour of patients, to identify the interval which was responsible for the delay in

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treatment. This study also explored the perceived factors affecting the time period by means of an in-depth interview.

Methodology

Study design

This study was conducted as an exploratory qualitative study in the Department of Surgery at a tertiary care centre in India, between April and May 2019. Institute Human Ethics Committee approval (JIP/IEC/2019/188) and informed consent was obtained. This study was conducted in accordance with the Declaration of Helsinki. The Entire information recorded was kept confidential, and the patient was given full freedom to leave from the study at any point. All ethical principles mentioned in the Declaration of Helsinki were followed in this study.

Study patients

Patients diagnosed with advanced (stage 3 and above) gastrointestinal (GI) cancers based on investigations, who were under treatment or follow-up during the study period were included. Patients who were unable to recollect information on their symptoms, who were unfit for interview, age less than 18 years and patients with incomplete records were excluded.

Sample size

Since it is an exploratory study on awareness, treatment seeking behavior and treatment pathways a sample size of 20 was chosen for convenience. We have included 10 patients with Upper GI cancer and 10 patients with colorectal cancer.

Sampling technique

Purposive sampling was done to choose eligible, willing and vocal participants for the study.

Theoretical framework

This study used the Model of Pathways to Treatment, based on an improved version of the Anderson's model.[9,10] It identifies four time-intervals to treatment: appraisal interval (from onset of symptoms to the time the individual decides on the need to consult a doctor), help-seeking interval (from the decision to consult to the first visit to a doctor), diagnostic interval (from the first visit to a doctor to diagnosis), pre-treatment interval (from the diagnosis to initiation of treatment). In this study, we assessed the time period between the first symptoms to the initiation of treatment, in each of the intervals described, and the factors affecting them.

Procedure

Semi-structured, in-depth, face-to-face interviews were conducted by the investigator, at a time and place that was comfortable to the patients. The interview was audio recorded and notes were taken, and the interview was carried out for approximately one hour. A patient caretaker was allowed to be present at the time of the interview if the patient so desired, with consent. An interview guide, reviewed and discussed by the investigators, was used and included open-ended questions on the time elapsed between the first symptoms to initiation of treatment, and various factors leading to delay, if any. Time periods were noted in terms of 'days' or approximated to the closest 'week'. Data on investigations and hospital visits were corroborated with patient records. In case of a palliative-intent treatment decision, the date of the decision was considered the end point of the pre-treatment time interval. The period of neo-adjuvant treatment, if any, and treatment related mandatory or recommended waiting periods were excluded from the pre-treatment interval. At the end of the interview the key discussion points were summarized verbally for participant validation. The interview was transcribed in English on the same day by the interviewer.

Statistical analysis

Manual content analysis was done and reported according to COREQ guidelines.[11] Codes were generated and categories were identified as the unit of analysis. Inferences were drawn, and meanings were derived from the data. Conceptual framework was derived from the categories and codes which were based on the patient's statements.

Results

We interviewed 20 patients with advanced (Stage III and IV) gastrointestinal malignancies, with equal distribution of upper and lower gastrointestinal malignancies. The study participants included five women and fifteen men with a mean age of about 52 (11.3) years [Table 1]. Seventy percent of the patients had Stage III malignancies and the rest had metastatic disease. We found that most patients had a significant delay in diagnosis as well as treatment. A mean delay of about 32.5 weeks was noted from the onset of symptoms till the start of primary treatment [Table 2].

After the interview, the causes for delay were coded into three categories, namely, individual lapses, societal lapses and system lapses, with their effects on different intervals of the model of pathways to care (an improved version of the Anderson model) [Table 3]. Information saturation was attained on certain causes with respect to ignorance, poverty and missed diagnosis.

The appraisal interval

The subjects reported that they weren't aware that such symptoms could be harbingers of cancer or that cancer is treatable when detected early. Men, who were addicted to alcohol and smoking thought that the symptoms may be due to that habit. Some patients reported that they self-medicated themselves with over the counter medications until the symptoms were unbearable. Also, women with lower gastrointestinal symptoms such as bleeding per rectum refrained from complaining of such symptoms to their family or friends, for fear of being segregated, shame and social stigma.

The health-seeking interval

Lack of family support was a major factor in women and elderly men, who were dependent on other family members to accompany them for medical care. This resulted in long avoidable

Table 1: Characteristics of the patients interviewed to assess for pathways to care with advanced gastrointestinal cancers (*n*=20)

Characteristic	Value (in number)
Age (in years)*	51.9 (11.3)
Gender	
Male	15
Female	5
Tumor location	
Esophagus	2
Gastro-esophageal junction	3
Stomach	5
Colon	3
Rectum	7
Stage of the disease	
Stage III	13
Stage IV	7

Table 2: Delay noted in pathways to treatment

Intervals in the treatment pathways	Delay in weeks (mean, SD)
Appraisal interval	12.3 (10.4)
Health seeking interval	5.8 (8.1)
Diagnostic interval	6.8 (6.1)
Treatment interval	7.2 (5.0)
Total time delay	32.5 (11.5)

SD=standard deviation

delays after the symptoms started. Women who were involved in household work were expected not to complain about the symptoms. Many of our patients were from lower socioeconomic status and reported that they could not afford to lose a day's pay to visit the doctor and they were also afraid of loosing their job if they were diagnosed with cancer. Elderly patients reported that they were in denial of the diagnosis and refused to visit the hospital until the symptoms were insufferable.

The diagnostic interval

Patients reported that when they visited a primary care doctor, they were given medications and symptomatic treatment after a cursory examination. Most of the centres they visited were crowded with very few doctors. Also, the symptoms of malignancy are very similar to those of benign diseases in the early stages and this leads to a delay in the referral or diagnosis of these patients. There were also issues of alternative medical practitioners who were not trained to treat malignancy and unqualified medical practitioners treating them symptomatically for extended periods of time reulting in delay in presentation.

Even when asked to review after a period of time, the patients at times refused to review with the same doctor again because of the fear of unnecessary investigations as propagated by some media. After referral to higher centres, most patients did not experience significant delay in diagnosis. However, long travel to the referral centres made it difficult for them to come on different dates for multiple investigations.

The pre-treatment interval

Many patients experienced delay in the start of treatment, mainly due to delay in operating room and radiotherapy appointments. There were also delays in dates for radiological investigations which led to delay in some cases. A few patients reported that they experienced miscommunication regarding the plan of management and review dates, which led to significant delays in treatment. Two patients also reported that they had difficulty in navigating the different buildings of the hospital and could not meet their treating doctors despite multiple visits. Some patients reported that they experienced delays as they were unable to visit the hospital for their appointments due to their work.

Discussion

Patients with gastrointestinal malignancies often present in the advanced stages due to significant delays in diagnosis and treatment.[12] The survival rate in gastrointestinal malignancies drops significantly with regional and systemic spread.[1] During the course of study we found that it was a difficult task to ascertain with certainty the time interval from the start of first symptom to the first visit to a health care facility. This was because most of the times the symptoms were vague and did not obviously point to a suspicion of cancer. While in literature, the period of delay in treatment is partitioned into different intervals, as used by Brousselle A, *et al.*, the concept is rather difficult to assess in practice.[7] This is due to the current trends of individualisation of treatment protocols in malignancies, and the varied presentations of these conditions. We found that patients with advanced GI malignancies had a striking delay from the onset of symptoms, before they underwent treatment. More than two-thirds of this delay occurred before seeking medical attention.

We have identified many factors such as misinterpretation of symptoms, substance abuse, stigma, gender inequalities in our patients. These factors resonated with a study by Broom A, *et al.*, wherein they had found that patients had a delayed presentation due to perceiving the disease symptom as normal for their age, gender inequalities, diminished access to care and cultural stigma.[5,12] This was more pronounced with cervical and breast cancer, as noted by Nyblade L, *et al.*, where women were especially noted to defer seeking medical attention due to social stigma.[6] Similar results were pointed out by van Erp NF *et al.* which highlighted upon the huge impact of appraisal interval due to their limited awareness of the cancer symptoms, on the overall delay in gastric and oesophageal cancers.[13]

GI malignancies have non-specific symptoms that may skip the radar of primary care physician in primary health centre where the doctors are overburdened with too many patients per day. They also require specialised testing like endoscopy and imaging that is not available at peripheral centres in a resource limited setup. According to the study conducted by Tata MD, *et al.* early endoscopy has a great impact in reducing the delay in diagnosis of stomach cancers.[14] Also, there is a disbelief among patients

	Individual lapses	Societal lapses	System lapses
Table 3: Patient's perspectives on the various causes for delay in treatment of advanced gastrointestinal cancer			
Appraisal interval	Ignorance Substance abuse Self-medication	Social stigma	-
Health-seeking interval	Poverty	Lack of family/societal support Job insecurity	-
Diagnostic interval		Refusal to undergo testing due to misinformation.	Missed diagnosis Unqualified Long travel to referral centres
Pre-treatment interval	Depression or denial of the illness.		Difficulty in navigation within the hospital Miscommunication regarding plan and subsequent visits. Delay in dates for investigations Delay in dates for surgery or radiotherapy.

regarding the need for such investigations suggested by doctors, as a result of media propaganda. This leads to a delay in diagnosis of these conditions.

Delays in treatment occur in tertiary care hospitals such as ours due to a mismatch between the patient load and the infrastructure, resulting in delay in imaging, operating room availability and starting chemoradiotherapy. According to Allgar VL, *et al.*, based on data of six cancers from the National Survey of the NHS (UK), the lengthy pathways to care have been attributed to insufficiency in diagnostic capacity and logistics.[3] From this article we can clearly say that resource limitation is not only a problem in developing countries but also in developed countries.

There is a need for better awareness among the general public regarding the symptoms of cancer and the treatment options available when diagnosed early. There is also a need for social activism to eradicate social stigma and to empower women. Steps must be taken to allow for employees to undergo medical check-ups and treatment without fear of discrimination or being dismissed at work. Awareness and possibly legislation is needed to reduce the rates of substance abuse in the population which may, apart from removing potential risk factors for cancer, result in a better improvement in their health seeking behaviour which may lead to early diagnosis and treatment. Also, unqualified medical practice and the availability of the over-the-counter medications needs to be to be curtailed, which could encourage patients to seek healthcare early.

A number of patients were managed symptomatically at presentation in the primary care centres and by the primary care physicians, which caused a significant delay before referral or diagnosis after worsening of the symptoms. This delay could possibly be prevented by the availability of screening investigations at peripheral centres and by increasing the number of doctors in these centres to reduce the burden. There is also a need to address the psychosocial component – the emotional stress that the patients endure with a diagnosis of cancer, in order to improve their compliance and quality of life. Our patients reported a significant delay after the diagnosis, as a result of miscommunication and difficulty in navigating the hospital. This

may be specific to this institution where we have to improve the proper communication with the patient and the hospital navigation system with proper signage.

The study was conducted to help us provide an insight about the various factors and causes that at a cumulative scale causes the delay in the treatment of gastrointestinal cancers. The delay is very disastrous to the overall survival of patients. Since the primary care physicians are the first contact of these patients, increased awareness about this diagnostic delay and the cancer related symptoms will help in reducing the delay in getting the definitive treatment.

There are some limitations to this study: The onset of symptoms is extracted from the patient's memory and is not easily determined, especially over a long period, which may lead to "recall bias". The cause for in-hospital delays are difficult to assess by considering the patient's perspectives alone, as there may be some logistic reasons which the patient may not fully understand and not all the causes noted here are applicable to all countries and regions, as a few causes at the health care system level maybe specific to our centre.

Key points

- The present study shows that there is a considerable delay (average delay of 8 months) from the onset of symptoms till primary treatment for patients with malignancy
- Significant delay in the treatment for malignancy occurs in the pre-hospital phase (56.4% in the present study).
- Lapses at the individual, societal and institutional level lead to the delay.
- The major causes includs ignorance about the early symptoms of cancer, substance abuse, poverty, social stigma, missed diagnosis at the primary care level, miscommunication, resource constrain, very poor doctor-patient ratio and delay in investigation and initiation of treatment.
- The Causes for the delay can be classified into appraisal interval, health-seeking interval, diagnostic interval and the pre-treatment interval for improving and addressing the shortfall in each phase.

Conclusion

We have noted a significant delay in the treatment of patients with advanced gastrointestinal cancers. Many potentially correctable causes of this delay, have been noted at various levels which is correctable by the health policy makers, conducting cancer awareness programme and active reformation of the society. The quantitative effect of each of these causes is difficult to assess and is likely to be region specific. Conducting continued medical education for general practitioners and alternative medical practitioners, increasing the number of doctors and facilities in primary care setting, and creating awareness for general public, could potentially reduce the delay and result in better survival and improved quality of life among patients with gastrointestinal cancers.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

Conflicts of interest

There are no conflicts of interest.

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