Patient navigation pathway and barriers to treatment seeking in cancer in India: A qualitative inquiry

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A B S T R A C T

Cancer is a leading cause of mortality worldwide. Early diagnosis and treatment of cancer may curb the growing burden of the disease. Understanding cancer patients’ navigation pathways for seeking treatment is important in order to facilitate early diagnosis and treatment. With this background we conducted a hospital-based cross-sectional study comprising 68 randomly selected cancer inpatients in a tertiary cancer specialty hospital in Odisha, India, to explore the treatment-seeking pathways of the cancer patients and the barriers and enablers in seeking treatment. Financial constraint is one of the major reasons for the delay in accessing treatment, even when patients are suspected of or diagnosed with cancer. Low awareness of the presenting signs and symptoms of cancer and limited knowledge of the availability of cancer diagnosis and treatment facilities are major factors contributing to delay. Family and friends’ support is found to be the major enabling factor toward seeking treatment. Generation of awareness of cancer among the general population and primary-care practitioners – including those in alternative systems of medicine – is important. Information on diagnostic and treatment services appears to be a felt need.

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1. Introduction

Cancer, the second leading cause of death worldwide in 2010, is emerging as a global public health challenge. There were 8 million deaths from cancer in 2010, amounting to 15.1% of all deaths worldwide [1]. More than half (56%) of new cancer cases and two out of three cancer deaths occur in the less-developed regions of the world [2]. By 2030, the global burden is expected to grow to 21.4 million new cancer cases and 13.2 million cancer deaths owing to the growth and aging of the population [3].

Cancer contributes to about 6% of all deaths in India [4]. As projected by Murthy et al. it is expected that the number of cancer case in India could increase to 1.22 million by 2016 [5]. In a nationwide study it was found that in India 71% of the cancer deaths occur in the age group of 30–69 years, and among the same cohort carcinomas of the oral cavity, stomach and lung are the three leading causes [4]. Although tobacco use, lifestyle factors and alcohol have been well established as causal factors in cancer, barriers linked to treatment delays also substantially contribute to the burden of cancer mortalities [6–11].

For many diseases, awareness regarding the symptoms and treatment settings has been identified as one of the major contributors to treatment delay [12–15]. This is more cogent for cancer, where patients usually report at an advanced stage, thus making cure difficult [16]. People with lower financial capabilities are often observed to be more fatalistic and pessimist when they require health care [17]. Relating the symptoms of cancer to common and mild ailments is also a major reason for delay in consulting a physician and obtaining treatment [18–21]. Additionally, perceived severity regarding the disease is another factor that influences the turnaround time for seeking treatment [22]. Gaps in recognition of health professionals’ roles and responsibilities and inequitable access to healthcare services could also result in treatment delays [23].

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Early detection and treatment is one of the key strategies for combating the high mortality of cancer [24]. Identification of the barriers at individual, community and system levels is essential for designing and improving the current strategies for achieving effective diagnosis and treatment for cancer patients. The present study attempted to identify the treatment-seeking pathways of cancer patients and explore the reason(s) for delays in seeking treatment.

2. Methodology

This cross-sectional study was conducted in the Acharya Harihar Regional Cancer Center (AHRCC), Cuttack, which is a tertiary cancer specialty center (TCSC) in the state of Odisha, India. We included a sample of all patients admitted to the inpatient department of AHRCC between 5th April and 5th June 2011. Patients were both newly and previously diagnosed with cancer and were selected for inclusion on the basis of their bed number. Patients who were seriously ill or unable to speak (due to oral pathology) were excluded from the study, as were pediatric cancer patients.

We adopted a mixed methodology approach to data collection. A questionnaire was used to collect data on the following socio-demographic indicators: age, gender, marital status, residential status (urban/rural), monthly income, occupation and education. A semi-structured interview was then carried out with the patients, who were asked to describe their care-seeking pathways, the initial symptom, the cause for seeking medical care, enablers and barriers in access to treatment, their facility experiences, and the chronological order of facilities/providers visited before arrival at the TCSC; the time elapsed at each step was recorded. Interviews were conducted in the local language (Odiya) by one of the co-authors (DM), who is very familiar with this dialect.

Preliminary analyses were carried out for qualitative data while data collection was in progress, and results were discussed with the study team. The data collection process was stopped when information received from the respondents reached a stage of saturation and no new themes were emerging [25]. The interviews conducted with initial classified themes were recorded and transcribed by two of the authors (SP, MAH). Themes were prepared after classifying the themes from a review of the literature, and in consultation with the specialist in the field. To ensure the accuracy and quality of data transcription, as well as the interpretation of the transcripts, another co-author gave a final quality assessment for the necessary paraphrasing. Through both contesting as well as supportive responses while checking the interpretation, all authors – after necessary inclusions and exclusions – finalized the axial and selective coding. We used software NVivo Version 8.0 for analyzing the qualitative data, adopting a “thematic framework approach”. Final themes and key themes have been merged, and qualifiers were calculated to generate the findings and recommendations. Qualifiers are the representations of magnitude of similar kinds of open-coded responses falling under the same theme or family by different respondents. In the current study, if a certain type of open-coded response has been quoted by more than 50% of the participants, then the theme or family is denoted as qualifier *, between 25% and 50% as †, and less than 25% as ‡.

Quantitative data collected were entered into a Microsoft Office Excel spreadsheet and a master sheet was prepared. Descriptive statistics were calculated, and for continuous data, and summarized as means, medians or standard deviations depending upon the normality of distribution, whereas categorical data were presented as frequencies and percentages (%). The mean and median time elapsed was calculated for the following event intervals: between the patients’ first symptom and consultation with friends and family members; between the type of health facility contacted and finally getting diagnosed at a tertiary care center or cancer specialty center; from first consultation to hospital referral; from hospital referral to the first appointment with an oncologist; and from diagnosis to the start of treatment.

The study was approved by the Indian Institute of Public Health, Bhubaneswar institutional ethical committee. Patients were briefed about the study objectives before the interview and informed verbal consent was obtained. It was ensured that during the data collection and data analysis the identity of the respondents was kept confidential as names were not mentioned.

3. Result

Out of a total of 341 patients admitted to the hospital during the data collection period, 68 were interviewed. Mean age of the participants was 46.5 years, ranging from 26 to 85 years. The majority of the participants were housewives (42%), followed by laborers and farmers (25%). Respondents were predominantly females (69.1%). Thirty-six percent of the participants were illiterate. Nearly 80% of the respondents were married. Urogenital cancers were the predominant cancer among the respondents (30.8%) followed by cancer of breast and oropharynx (Table 1).

Half of the respondents had never heard about cancer. Only 13% knew about carcinogenic factors, while very few were aware of the availability of cancer treatment, and only two patients had undergone cancer screening. The navigation chains in seeking treatment are numerous, each one almost having same percentage of contributions to the total. However, it was observed that direct reporting to the TCSC (AHRCC) is very low (9%). The other navigation chains are from primary care to AHRCC (17.6%), private nursing home to AHRCC (20.6%), secondary care centers to AHRCC (16.2%), tertiary care centers to AHRCC (14.7%), and others (17.6%).

Table 1
Demographic profile of the participants.

<table>
<thead>
<tr>
<th>Demographic variable</th>
<th>Category</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male</td>
<td>21 (30.9)</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>47 (69.1)</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married</td>
<td>55 (80.9)</td>
</tr>
<tr>
<td></td>
<td>Unmarried</td>
<td>11 (16.2)</td>
</tr>
<tr>
<td></td>
<td>Widow</td>
<td>2 (2.9)</td>
</tr>
<tr>
<td>Monthly income (US$)</td>
<td>Up to 100</td>
<td>54 (79.4)</td>
</tr>
<tr>
<td></td>
<td>101–150</td>
<td>8 (11.7)</td>
</tr>
<tr>
<td></td>
<td>&gt;150</td>
<td>3 (4.4)</td>
</tr>
<tr>
<td>Residential status</td>
<td>Rural</td>
<td>48 (70.6)</td>
</tr>
<tr>
<td></td>
<td>Urban</td>
<td>20 (29.4)</td>
</tr>
<tr>
<td>Type of cancer</td>
<td>Urogenital tract</td>
<td>21 (30.8)</td>
</tr>
<tr>
<td></td>
<td>Breast</td>
<td>12 (17.6)</td>
</tr>
<tr>
<td></td>
<td>Oropharynx</td>
<td>10 (14.7)</td>
</tr>
<tr>
<td></td>
<td>Gastrointestinal tract</td>
<td>8 (11.7)</td>
</tr>
<tr>
<td></td>
<td>Ewing's sarcoma</td>
<td>4 (5.8)</td>
</tr>
<tr>
<td></td>
<td>Lung</td>
<td>4 (5.8)</td>
</tr>
<tr>
<td></td>
<td>Leukemia</td>
<td>3 (4.4)</td>
</tr>
<tr>
<td></td>
<td>Soft tissue sarcoma</td>
<td>2 (2.9)</td>
</tr>
<tr>
<td></td>
<td>Hodgkin lymphoma</td>
<td>2 (2.9)</td>
</tr>
<tr>
<td></td>
<td>Hodgkin lymphoma disease</td>
<td>1 (1.4)</td>
</tr>
<tr>
<td></td>
<td>Multiple myeloma</td>
<td>1 (1.4)</td>
</tr>
</tbody>
</table>

* Uterus, cervix, vulva, ovary, mole pregnancy, endometrium, pelvis mass.
† Mouth cancer, Tongue cancer, buccal mucosa, segment mandible.
‡ Gall bladder, hypopharynx, stomach, colon, esophagus duodenum, periaortic.
§ Acute myeloid leukemia, chronic myelogenous leukemia.
1 USD = 59.29 INR (15/7/2013).
The average time from first recognition of the unusual and unexplained signs/symptoms to having the first consultation with either family members or friends is 271 days (Fig. 1); an additional average time of 139 days is utilized in consultation with other health systems such as traditional healers and alternative systems of medicine such as ayurveda and homeopathy [26]. Alternatively, an average of 340 days, nearing 1 year, is the time taken to have a first consultation with an allopathic doctor before going for a proper diagnosis or meeting an oncologist, and then there is an additional 19 days before referral to an oncologist for investigations. After referral, respondents waited an average 52 days before being seen by an oncologist. A further 47 days passed between diagnosis and initiation of treatment. Due to missing data we could not calculate the time between consultation with other healthcare systems and the allopathic doctor, or between appointment with the oncologist and diagnosis.

Content analyses of the textual qualitative data led to the emergence of six themes, constituting both enablers and barriers to the treatment-seeking pathway of the patients: i.e. belief in alternative therapies, awareness and perceived seriousness of signs and symptoms, psychological stress and social inhibition, financial constraints, availability of treatment facilities, and support from family and friends. Financial constraints (qualifier 3+) were expressed as the major barrier for seeking treatment. Support from family and friends (qualifier 3+) was reported as the main enabler for early treatment seeking (Fig. 2). Verbatim quotes from the semi-structured interviews are listed under each theme in Box 1.

![Fig. 1. Time delay in treatment-seeking pathways.](image1)

![Fig. 2. Qualitative qualifiers affecting treatment-seeking pathways.](image2)
4. Discussion

Understanding how cancer patients seek treatment and walk through the healthcare system is important in facilitating early diagnosis and prompt treatment, especially in developing countries like India. Against this backdrop, this hospital-based cross-sectional study is the first of its kind to investigate the navigation pathways of cancer patients while seeking treatment and to identify potential barriers and enablers.

Most of our respondents were females, and the most common cancers were urogenital in origin followed by breast cancer. This skewed distribution of respondents could be due to the fact that female cancer patients outnumber males at the TCSC studied, and that carcinomas of female reproductive organs are the most common cancers among females while oropharyngeal cancers are common among males [27].

While analyzing the patient navigation pathways we observed some prominent factors, which have a direct or indirect influence on treatment delay (Fig. 3).

Timely recognition of cancer signs and symptoms is critical for early diagnosis and treatment initiation. In our study half of the patients had never heard about cancer before; less than a sixth knew about carcinogenic factors, and almost none of them knew about the availability of cancer treatment. Perception of the severity of the illness and low levels of knowledge are the leading causes of delay in the treatment of cancer [28]. Considering the fact that many of the cancer symptoms mimic those of other more common non-malignant conditions [29], and with this low level of

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Box 1. Verbatim quotes from semi-structured interviews

<table>
<thead>
<tr>
<th>Domain (qualifiers)</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial constraint (qualifier 3+)</td>
<td>“...I went back from the hospital as my husband doesn’t have enough money to get me treatment” [ID 59] “We don’t want to waste our money on treatment...” [ID 60]</td>
</tr>
<tr>
<td>Belief on alternative therapy (qualifier 1+)</td>
<td>“...My family suggested me to consult witchcraft, Ayurveda, &amp; homeopathic medicines...” [ID 21]</td>
</tr>
<tr>
<td>Awareness and perceived seriousness of the sign and symptoms (qualifier 2+)</td>
<td>“...I did not feel any discomfort &amp; didn’t think that I could suffer from this type of disease” [ID 55] “...I was not aware about the symptoms, when referred, I didn’t know where to go, what to do...” [ID51]</td>
</tr>
<tr>
<td>Family and friends support (qualifier 3+)</td>
<td>“...My nephew immediately took me to a hospital because I had difficulty in eating due to severe pain” [ID 13] “...My family member &amp; the villagers forced me to consult doctor...” [ID 53] “...The Sarpanch of my village forced me to meet doctor...” [ID 55]</td>
</tr>
<tr>
<td>Availability of treatment facility (qualifier 2+)</td>
<td>“I went to the hospital but no specialist was available; the doctor referred me to a hospital in the state capital...” [ID 34]</td>
</tr>
<tr>
<td>Psychological stress and social inhibition (qualifier 1+)</td>
<td>“...I was getting fear by listening from others that it will be operated...” [ID 11] “...I was feeling shy to consult a doctor as I had the problem in my breast...” [ID 48]</td>
</tr>
</tbody>
</table>

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Fig. 3. Enablers and barriers in treatment-seeking pathways.

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1. Raise public awareness regarding symptoms as well as the treatment facility.
2. Upgrading the treatment facility at secondary level. Distance from the settings has been observed as the main factor for the treatment delays in Odisha. Tertiary care with an enhanced patient admission capacity.
3. Comprehensive financial support package should be provided.
knowledge, it might not have been possible for the patients to relate their symptoms to cancer [30]. This could have been one of the contributing factors for prolonged watchful waiting and delayed consultation. Since the majority of our study participants were females, and cancers of the reproductive tract were the most common cancers, this could have resulted in feeling socially inhibited about discussing their symptoms with others. Similar observations have been made in a study conducted in Sri Lankan females with breast cancer [31]. The role of prevailing cultural norms and taboos on seeking cancer treatment in a local context merits further investigation.

The decision tree model in treatment-seeking behavior patterns among cancer patients is a complex interplay of various factors in the society showing a variegated pathway [16]. In our study none of the respondents had taken the decision by themselves to choose the path they would prefer to get treatment. All preferred to seek a second opinion either from their family members or friends. Some (19 out of 68) were asked to visit the alternative systems of medicine, while the rest were suggested to meet a nearby allopathic (modern medicine) doctor. Even though the family and friends could not guide these patients to the most appropriate facility, still, they encouraged them to avail themselves of some sort of primary care. Similar findings on the supportive role of family and friends were also noted by a Taiwanese research group [32]. This emphasizes the importance of raising public awareness of cancer symptoms, which would facilitate earlier treatment-seeking either by the patient or through their surrounding associates [33].

Out of 48 patients who sought treatment from a locally accessible allopathic doctor, only three could get diagnostic services there. The rest were referred to the nearby higher facility where diagnostic services were available; thus more time was incurred. Of those 45 referred, nine patients – instead of going to the referred facility – kept on trying with local healers, primarily because of lack of resources; 36 went to the referred facility where they were further referred to the TCSC for confirmation of the cancer diagnosis. Out of these 36, 22 complied with the advice and went to the TCSC without further loss of time. The remaining 14, owing to personal reasons, procrastinated and reported to the TCSC only after the condition worsened beyond tolerance. Finally, out of 68 patients, 28 had their own way of seeking treatment, thereby leading to undue delay in diagnosis and treatment.

Cancer patients with low socioeconomic status (SES) have more advanced cancers at diagnosis, receive less aggressive treatment, and have a higher risk of dying in the 5 years following cancer diagnosis [34–36]. As discussed above, financial constraint is the main reason for the delay in accessing treatment, even when the patient is suspected of or diagnosed with cancer. This has also been enhanced by the fact that most of our respondents belonged to low-income groups (monthly income <US$ 100).

About 40% of the patients had consulted first with traditional healthcare providers, which is a reflection of their mistrust of modern medicine and their inherent cultural belief system. The prominent alternatives were found to be homeopathy, ayurveda (an indigenous system of Indian medicine), and also witchcraft, a practice of using magical powers for treatment of disease. Furthermore, the easy availability and relatively low cost of these treatments might have caused these patients of rural, low socioeconomic background to prefer alternative therapies.

A focused and in-depth analysis of the patient navigation process indicates that the major contributing factors toward incurring delay are the low awareness of the presenting signs and symptoms of cancer and the limited knowledge of the availability of cancer diagnosis and treatment facilities. The mean time that elapsed at each stage is found to be prolonged, adding to the woes of the patients and the burden of the disease. Even though there is a time lag in the diagnosis of disease, still in the majority of cases family members and friends had a facilitating role in bringing about the first interaction between patients and treatment or diagnostic facilities. In this study it was also observed that psychosocial stress hinders some patients from seeking treatment.

5. Limitations of the study

Since we relied on information reported by patients, there may be recall bias. However, efforts were made to minimize the effects of recall bias by putting multiple and leading questions. The study could have had more generalizability if all cancer treatment centers – including private and various medical colleges and hospitals – had been included.

6. Conclusion and future implications

There is an appreciable delay in recognizing the signs and symptoms of cancer and initiation of treatment. This could have implications for the future survival of the patient as delayed diagnosis is thought to lead to poorer survival in some cancers, and may be associated with late-stage disease at diagnosis. From this study it has been noted that most of the preventable delays in seeking treatment among cancer patients is because of a lack of awareness about cancer signs and symptoms, their risks factors, and appropriate prevention and treatment facilities. Creating public and patient awareness of cancer could lead to earlier patient referrals in areas where technological and financial resources for early detection are not available or impractical on population-based levels. The need to sensitize alternative health-system practitioners on cancer and to disseminate information on available diagnostic and treatment facilities is important. Counseling of patients and their family members/associates on cancer seems to be a felt need.

Conflicts of interest

None of the authors has any conflicts of interest.

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