Original Article

Initial Perceptions about Palliative Care in Patients with Advanced Cancer: A Prospective Cross-Sectional Audit

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Abstract

Introduction: There is enough evidence to suggest that early introduction to palliative care (PC) for patients with advanced cancer is beneficial. However, despite this, the patients often come late to PC physicians. There are a number of studies examining the preferences and practices of the physicians with respect to PC. However, there is limited literature exploring the patients' preferences and awareness regarding the PC services. This audit was done to identify the understanding and perceptions of PC in patients visiting PC outpatient department (OPD) and identify strategies to enhance their understanding. **Materials and Methods:** This prospective cross-sectional study was conducted in 200 advanced cancer patients visiting PC OPD in a tertiary care hospital. The patients were asked to fill a questionnaire to assess their knowledge and expectations form PC on their first visit. **Results:** Majority of the patients were from nearby areas and around 20% of them had to travel more than 300 km to receive palliative consultation. Unfortunately, majority of the patients had not heard the term PC before and were not aware of its meaning. Most of them (90%) were send to control pain which was too severe to be managed by the oncologists. We think that the major reason for the lack of awareness about PC services is limited availability across the country and lack of coordinated approach. **Conclusions:** The main problem identified in the audit was the inadequate information, lack of PC setups, and late referral of the patients to PC. Hence, we should make a model where PC services are integrated with the curative services and offered throughout the illness after cancer diagnosis.

Keywords: Advanced cancer, palliative care, patient, perception, qualitative research

Introduction

The patients with advanced cancer want to know about the disease, have their symptoms controlled, and have a pain-free death.[1] All these preferences of the patients can be met with palliative care (PC) consultation. The PC team works with other specialties to develop treatment plans, manage pain and other symptoms, give emotional support, and help deal with the end-of-life (EOL) issues.[2] Furthermore, there is recent evidence to suggest benefits of early integration of PC in the management of cancer patients.[3-6] Despite this, even in countries with well-established PC services, the patients are often referred late to PC services even in developed countries.[7,8] The main problem with a late referral is that the patients are suddenly shifted from the point of treatment to the point that they are incurable and it may be difficult to counsel the patients emotionally and psychologically at this point of time. Furthermore, the awareness among the patients regarding the PC is limited, and even when they are referred, they associate PC with hopelessness, pain management, and EOL.

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A number of studies have identified the physicians perceptive regarding the reasons of this late referral to PC services.[9-11] However, there is limited literature on perceptions of patients about PC.[12]

This audit was done to understand perceptions about PC and identify barriers regarding the PC services reported by patients in a tertiary care comprehensive cancer center in India.

Materials and Methods

This prospective cross-sectional study was conducted in consecutive advanced cancer patients during their first visit

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to PC outpatient department (OPD) in a tertiary care hospital over a period of 6 months (June 2016 to December 2016). A questionnaire was designed [Appendix 1] to ascertain the awareness about PC, their disease status, the reasons for their referral, and overall experience in the PC. All patients were explained about the purpose of the research and patient confidentiality, and an informed consent was taken. The literate patients were asked to respond by filling the questionnaire themselves. If the patients were illiterate, the questionnaire was filled with the help of their literate relative or the doctor. The patients with cognitive or psychiatric abnormality were not included in the study.

We believed that at least 50% of the patients coming to our PC OPD were aware of the PC services. All the data were collected and analyzed using descriptive statistics. The answers given by patients were described as the percentages of the total number of answers given.

Results

A total of 250 consecutive patients coming for the first time in PC OPD were screened for inclusion in the study. Out of these, 50 patients were excluded (35 declined to participate and 15 had cognitive decline) and 200 patients filled the questionnaire. In majority of cases, at least one of the two (either the patient or the attendant) was literate. The age of the respondents ranged from 15 to 75 years and 63% were male. The patients who visited the OPD were from varied places. Although majority of the patients were from Delhi and nearby areas, 46% of them traveled more than 100 km to reach the OPD [Figure 1].

We had assumed that at least 50% of the patients will be aware of the PC services. But the standard set by us was not met as the majority of patients had not heard the term "PC" before and were not aware of its meaning. None of the patients was informed about the PC services in the beginning. Most of them (90%) were referred because of severe pain [Figure 2]. About 67% of these patients were started on pain medications by the oncologist (usually Ultracet™ SOS) and were sent because of inadequate pain relief. A small number believed that PC was EOL and their death was very near. Most of them were not aware of the status of the disease before sending to our OPD. Majority of them had no clue about the cure of other symptoms and EOL care planning. In fact, a small number thought that they would be cured of the disease by coming to the PC OPD.

In the PC OPD, all the patients who visited the OPD were attended by the physician within 20 min of the arrival [Figure 3]. During their first visit, the PC physicians clearly explained about the disease status and the management of symptoms including pain. The psychosocial issues and EOL care were discussed in some of the patients. A large number of patients were explained about the home care team and their role in the management of their symptoms [Figure 4].

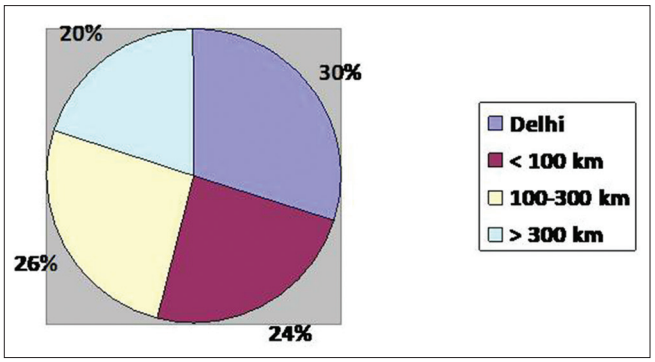

Figure 1: The native place of people visiting the outpatient department

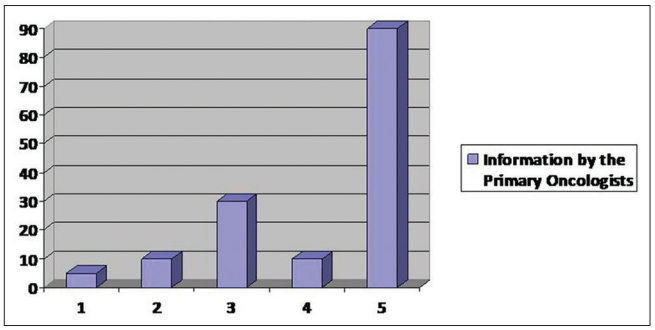

Figure 2: Information given by the oncologists before sending to palliative care outpatient department. (1) cure of disease, (2) cure of suffering, (3) guidance for further treatment, (4) end-of-life care planning, and (5) treat pain

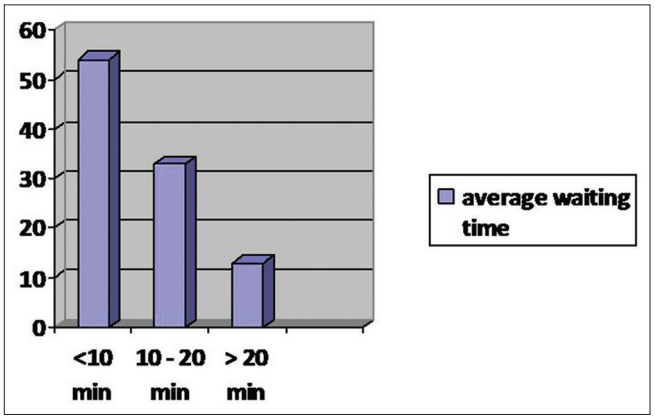

Figure 3: Average waiting times for the patients visiting palliative care outpatient department

Data analysis

As this was an exploratory study, only descriptive statistics were used.

Discussion

This is the first study in Indian population that addresses the perceptions of the patients with advanced cancer regarding PC on their first visit. A number of studies have highlighted the importance of integrating PC with curative services at an early stage.[3-6] It has been seen that an early introduction to

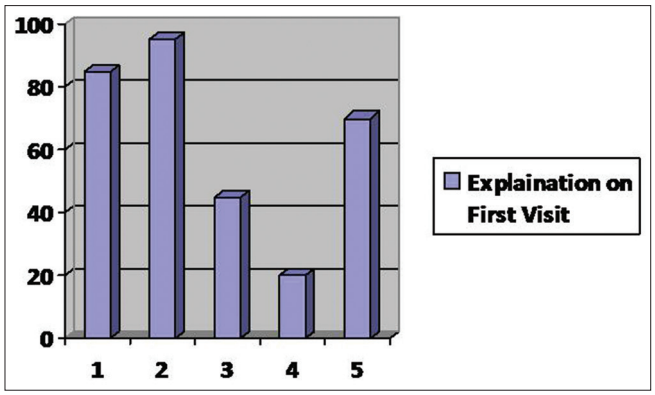

Figure 4: Interaction in the first visit with palliative care physician. (1) disease status, (2) treatment of pain and other symptoms, (3) psychological issues discussed, (4) end-of-life planning, and (5) an introduction with the home care team

PC improves the quality of life (QOL) and survival of the patients.[3,4] However, despite the said benefits, the perceptions of patients regarding PC have not changed and penetration of PC services remains low.

In our study, majority of the patients coming to PC OPD had not heard about the term before. There was a clear lack of familiarity and awareness about the meaning of PC. Most of them thought that they were sent for treatment of pain. A small number felt that their death was near and they were sent to prepare for death. The results of this study are in line with the emerging international literature on public awareness of PC, which has an inadequate awareness of PC among the general public.[1,2] We think that the major reason for this is limited PC services available across the country and lack of coordinated approach.

Majority of the patients were referred late in the course of disease and not aware of their disease status. The patients were not informed about the need for referral, and rather, they were still hopeful of disease cure. This may be due to lack of communication regarding the prognosis of the disease to the patients.

After consultation with the PC physician, most of the patients realized that their disease could not be cured for the first time and were unhappy that they were not primed about the reality earlier. Furthermore, they felt that a consultation with the PC physician to discuss the disease severity and EOL issues in the beginning along with the medical oncologists would have prepared them better.

Our findings are in concurrence with previous studies that confirm the late referral to PC by the oncologist.[9-11] The reasons for this include lack of awareness about PC as a specialty, lack of set protocols for referring the patients to the PC OPD, and inadequate training of the primary oncologists regarding the QOL and EOL issues in cancer patients.

Moreover, oncologists may not have sufficient time or training to discuss these sensitive issues in overcrowded OPDs. The lack of training in breaking bad news and discussing EOL issues has been previously cited as one of the common reasons for poor communication with the patients.[13,14]

We should try to integrate the concept of PC within the health-care delivery systems and should organize program to increase the awareness about PC among the general public so that the patients can have the advantage of optimizing their quantity of life (curative oncology) and QOL (PC) simultaneously and are not forced to choose one of them.[4,6,10]

After this audit, we have suggested setting up of comprehensive clinics with PC physician with other team members. Furthermore, a basic introduction to PC including discussion on "communication skills" and "prescribing the pain medications scientifically" is scheduled for the undergraduate students.

Conclusions

This study gives insight into the perceptions of patients regarding PC and suggests that despite a recent thrust regarding integrating PC services with the curative oncology services, the problem of improving perceptions of patients regarding PC services remains. Most of the patients are not aware of the term PC and equated it with pain clinic. Efforts need to be made to improve the understanding of PC among patients by means of public-targeted health campaigns.

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Conflicts of interest

There are no conflicts of interest.

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Appendix

Appendix 1:

Primary data questionnaire

Kindly fill the below-given information. The information provided by you will be kept confidential

Name:…… Age/Sex:……

Literacy state:……

Address (Delhi/outside Delhi):…….

Kindly tick the option which you perceive is correct:

1. Do you know the purpose of PC OPD? (Y/N)
2. Have you heard the term "PC before?" What do you mean by it?
3. Did you face any difficulty in finding PC OPD? (Y/N)
4. If yes, what was the difficulty faced?
   a. It was far from the other specialty OPD
   b. Not enough sign mark in the OPD
   c. By the time they reached the registration was over.
5. If yes, what do you expect by visiting a PC physician?
   a. Cure of disease
   b. Cure of suffering
   c. Guidance for the further treatment
   d. End-of-life care planning
   e. Treat pain.
6. Were you informed about PC services at the beginning of the treatment?(Y/N)
7. Were you given any special instruction before coming to the PC OPD
   a. Asked to get reports of all investigations before visiting
   b. Your disease cannot be cured
   c. Your pain is too much be controlled, and you need to visit a specialist.
8. Did you receive any pain medications before coming to the OPD? (Y/N)
9. Are you attended in time by the doctor?
10. What was the average waiting time?
    a. 0–10 min
    b. 10–20 min
    c. 20 min.
11. Were you explained in detail about the disease? (Y/N)
12. Were you explained by an earlier physician that the disease is incurable?
13. What all were you explained by the PC physician:
    a. The disease cannot be cured
    b. Your pain and other symptoms will be taken care
    c. You were explained about the end-of-life care
    d. You were told about home care team
    e. Your psychosocial issues were discussed in detail.
14. Any other suggestions/strategies to improve the knowledge about PC?
15. Are you satisfied with privacy in PC?(Y/N)
16. Are you satisfied with arrangements in the waiting area? (Y/N)
17. Are there arrangements for safe drinking water and toilets for the patients? (Y/N)