

RESEARCH ARTICLE

Clinical Symptoms and Psychosocial Problems of Cancer Patients Attending Pain and Palliative Care Clinic

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Abstract

Palliative care is the total care which improves the quality of life of patients suffering from cancer and chronic incurable disease. Palliative care will start immediately after the detection of cancer and continue throughout the course of illness and till the end of life. This study was conducted to understand the common symptoms and psychosocial problems of cancer patients attending the pain and palliative care clinic, Medical College Hospital, Thiruvananthapuram, Kerala. A record based cross-sectional study included all new cancer patients registered in OP during Aug 1st to Oct 31st 2012. Incomplete records were excluded and 150 study subjects were randomly selected for analysis. Mean age of the participants was 55.8±1.36. About 57.3% were males and 42.7% were females. Among males, most common cancer was in gastrointestinal tract and lung cancer was the second commonest. Among females, cancer in breast was the most common followed by cancer in gastrointestinal tract. Regarding the symptom analysis, majority (94.7%) had pain, 48.7% had sleeplessness, 40.7% had constipation and 38% each had loss of appetite and tiredness. This study focused the need for palliative care clinic and importance of proper intervention of physical, psychological and socio-economic problems of cancer patients.

Keywords: Palliative care, cancer patients, cross-sectional study, lung cancer, breast cancer.

Introduction

In India, approximately 5 lakh people died due to cancer in 2010 (Dikshit *et al.*, 2012). Despite development in prevention, diagnosis and treatment, cancer is plaguing worldwide. Majority of cancer cases are detected and treated in the late stage, resulting in poor survival and increased mortality rate (Dinshaw *et al.*, 1999). Once the people are diagnosed with cancer, they are given chemotherapy or surgery or radiotherapy or a combination of these three. Many of them are suffering from myriad of problems like pain, anorexia, nausea, non-healing wounds, disfigurement, breathlessness, constipation, bleeding, mental problems like confusion, delirium, behavioral changes, sadness, depression, anger, fatigue, anxiety, social issues like loss of social roles, social isolation, financial difficulties and so on (Saini *et al.*, 2009). This vexatious disease not only affects the patient but also impoverish the family members. These problems are not cared properly and the majority of health care providers are poorly trained in handling these health issues. Chronic and incurable diseases are always associated with long term suffering. Palliative care is one of the important prevention modality which not only focuses on physical problems but also on psychological, social and economic difficulties of the patient. The word "Palliative" is derived from the Latin word pallium, meaning "cloak". In palliative care, symptoms are 'cloaked' with treatments whose primary aim is to provide relief from woeful situation.

There is no compartmentalization and no boundaries, it provide an integrated care which include physical, psychological, social and spiritual care through a single window (WHO, 2002). WHO define palliative care as "an approach that improve the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual" (WHO, 2014). Prime focus of palliative care is to provide quality of life to the patients along with their family members (WHO, 1980). It is designed as an interdisciplinary, multidimensional comprised of doctors, nurses, counselors, medico-social workers and volunteers. This also needs a good link between patient, care-givers and family members (Twycross, 2003). Despite the increase in the magnitude of cancer and other chronic diseases and also change in demographic structure, palliative medicine remains a huge unmet need. Majority of palliative services are started as individual initiation or in non-government sector in most parts of the world. In 1975, National Cancer Control program was started in India. In Kerala, scenario is entirely different from other states of India. In 1993, Pain and Palliative Care Society was started as a charitable organization which later developed into palliative Care Centre in Government Medical Collage, Calicut.

After this, lots of similar centers were started in various parts of Kerala. It is reported that only 30% of the needy are covered by this. In order to make this service more accessible, it must be integrated with general health service. Continuous training program must be necessary for health professional, nurses and volunteers. Another concern is to include palliative medicine in Medical Curriculum and initiate a Post graduate course in each medical college. Along with this, there is a need to increase the awareness among community about the importance of palliative care service (Murray *et al.*, 2005). Educating the community and administrators will help in sustain palliative care service in our society. Evidence based palliative care is essential to provide good quality care to the patients. Against these backdrops, this study was conducted to find out the symptoms and psychosocial characteristics of cancer patients attending palliative clinic.

Materials and methods

Experimental design: A record based cross-sectional study was conducted in Pain and Palliative Clinic at Govt. Medical College, Thiruvananthapuram. Pain and Palliative Clinic was started under the Dept. of Community Medicine in Nov 2010. Pain and Palliative clinic function 3 d in a week. Average number of new patients to this clinic is 2 to 5. This clinic is run by the Dept. of Community Medicine and Pallium India (NGO). All patients who needed palliative service were referred to this clinic. Cancer patients were only included. We included all new cancer patients who came to OP during Aug 1st to Oct 31st 2012. Each patient was clinically assessed by expert medical professional and symptoms and psychosocial problems were assessed by a trained medico-social worker and recorded in the case sheet. Incomplete records were excluded. About 150 data were selected for analysis.

Study variables: Age, sex, type and site of the cancer, presenting symptoms, type and intensity of pain, social background which included the socio-economic status, number of earning members, debt, patient's insight, previous treatment and present palliative treatment given were noted.

Visual Analogue Scale (VAS): In the clinic, the intensity of pain was assessed based on VAS in which the patient is instructed to give values from 0 to 10 for his or her pain, with 0 being no pain and 10 being the worst pain. We again categorized it into mild, moderate and severe pain. In patient's insight we took into account patient's own words when we considered their reactions at the time of diagnosis and at present. Patient's own words were recorded in the case sheets by trained medico-social workers. Regarding the data analysis, quantitative variables were expressed as mean with standard deviation and qualitative variables as percentages.

Table 1. Baseline characteristic of study participants.

| Characteristics | Frequency | Percentage |
|---|-----------|------------|
| Age | | |
| 15–29 | 5 | 3.3 |
| 30–44 | 18 | 12.0 |
| 40–59 | 67 | 44.7 |
| 60–74 | 49 | 32.7 |
| ≥75 | 11 | 7.3 |
| Gender | | |
| Male | 86 | 57.3 |
| Female | 64 | 42.7 |
| Income | | |
| APL* | 31 | 20.7 |
| BPL** | 119 | 79.3 |
| Debt | | |
| Yes | 78 | 52.0 |
| No | 72 | 48.0 |
| Number of earning family members in the family | | |
| Nil | 29 | 19.3 |
| One | 87 | 58.1 |
| Two | 26 | 17.3 |
| More than two | 8 | 5.3 |
| Type of cancer | | |
| Primary | 108 | 72 |
| Secondary | 42 | 28 |
| Know the diagnosis | | |
| Yes | 122 | 81.3 |
| No | 28 | 18.7 |
| Person who revealed the diagnosis | | |
| Doctor | 133 | 88.7 |
| Family member | 12 | 8.0 |
| Health staff other than doctor | 4 | 2.7 |
| Guess | 1 | 0.6 |

*Above poverty line; **below poverty line.

Results

The mean age of the study population was 55.8±1.36. Majority (44.7%) of our study subjects belonged to the age group between 45 and 59 years. About 57.3% were males and 42.7% were females (Table 1). About 79.7% belonged to a poor socio-economic background, i.e. they were below poverty line. Only 20.7% were above poverty line. About 52% of our sample had debt following the disease. Majority (58%) had just one earning member in their family and 19.3% did not have any earning member in the family. About 81.3% were aware of that fact that they have cancer, 18.7% were not. About 88.7% of the patient got the information from doctors, 8% from family members and 2.7% from other health staff. After hearing the diagnosis, 49.3% were sad, 15.3% were anxious, 4% had the fear of death. About 76.7% had under gone surgical or chemotherapy or radiation before attending palliative clinic (Table 1). In this study, 72% of our study subjects were diagnosed to be having primary cancer and 28% had secondary (Table 1). Oral cancer and cancer in the gastrointestinal tract (29.3%) are the most common cancers (pancreatic and liver cancers are excluded). Next commonest cancer found was lung cancer (15%) followed by breast cancer (12.6%).

Table 2. Site of cancer.

| Site | Frequency | Percentage |
|---------------------------------|-----------|------------|
| Oral and Gastrointestinal tract | 44 | 29.3 |
| Lung | 22 | 15 |
| Breast | 19 | 12.6 |
| Pancreas | 17 | 11.3 |
| Uterus/cervix/ovary | 6 | 4.0 |
| Liver | 4 | 2.6 |
| Prostate | 1 | 0.6 |
| Kidney | 1 | 0.6 |
| Others* | 36 | 24 |
| Total | 150 | 100 |

*Urinary bladder, hypo pharynx, larynx, bone, lymph node, skin, supraglottis and brain.

Table 3. Gender wise distribution of cancer site.

| Site | Male | | Site | Female | |
|----------|-----------|------------|---------------------|-----------|------------|
| | Frequency | Percentage | | Frequency | Percentage |
| GIT | 30 | 34.9 | Breast | 19 | 29.6 |
| Lung | 17 | 19.8 | GIT | 14 | 21.8 |
| Pancreas | 7 | 8 | Pancreas | 10 | 16 |
| Liver | 3 | 3.5 | Uterus/cervix/ovary | 6 | 9 |
| Prostate | 1 | 1.2 | Lung | 5 | 8 |
| Kidney | 1 | 1.2 | Liver | 1 | 1.6 |
| Others | 27 | 31.4 | Others | 9 | 14 |
| Total | 86 | 100 | Total | 64 | 100 |

Table 4. Presenting symptoms.

| Symptoms | Present (Percentage) |
|--------------------------|----------------------|
| Pain | 94.7 |
| Nausea and Vomiting | 26.7 |
| Cough or breathlessness | 36.7 |
| Drowsiness and tiredness | 38 |
| Constipation | 40.7 |
| Heartburn | 18 |
| Loss of appetite | 38 |
| Sleeplessness | 48.7 |
| Dysphagia | 18.7 |
| Skin problems | 26.7 |
| Delirium | 5.3 |
| Other symptoms | 18.3 |

Table 5. Pain score.

| Pain score | Frequency | Percentage |
|------------|-----------|------------|
| 0-4 | 15 | 10 |
| 5-7 | 46 | 30.7 |
| 8-10 | 89 | 59.3 |
| Total | 150 | 100 |

About 11.3% had pancreatic cancer (Table 2). Among males, the most common cancer was found to be GIT (34.9%) cancer. Second commonest was lung cancer (19.8%). Among females, the most common cancer was found to be breast (29.6%) followed by GIT (21.8%). About 16% of females had pancreas as the primary site of cancer. About 9% had cancer in uterus, cervix or ovary (Table 3). Regarding the symptom analysis, pain was the most frequent (94.7%) symptom (Table 4). According to visual analogue scale, 59.3% had pain score between 8 to 10, 30.7% had pain score of 5 to 7 (Table 5).

Other symptoms reported by the participants were sleeplessness (48.7%), constipation (40.7%), loss of appetite (38%) and tiredness (38%). Cough and breathless was there in 36.7% of patients, 26.7% had nausea or vomiting and skin problems. Very few (5.3%) had delirium (Table 5).

Discussion

We observed, 57.3% were male and 42.7% were female in our palliative clinic. A study conducted by Lal *et al.* (2012) reported that 56% (87/156) were male and 44% (69/156) were females in pain and palliative clinic at a tertiary institute in North India. Financial instability is the important consequence of cancer in addition to the physical and social dilemma. Cancer is a disease which makes the people jobless and economically insecure. If the disease hit below poverty line population, the problem will be unimaginable. In this study, majority (79.7%) of patients were below poverty line. Half of the patients in our study were in debt. Himmelstein *et al.* (2005) observed financial problems followed by the medical cost due to cancer. May and Cunningham (2004) also observed that 63% of the cancer patients suffered financial problems in paying rent, transport and food as a result of medical debt. Cancers of gastrointestinal tract is the most frequent cancer among both sexes in our study population. In males, most frequent cancer was in GIT and lung cancer was the second commonest. Among females, cancer in breast was the frequent cancer followed by cancer in GIT. Globally lung, stomach and colorectal cancers are the leading cancers in males (WHO, 2004).

Rao *et al.* (2002) found that oral cavity, lung, oesophagus and stomach are the common sites of cancers among males in India. Jagannatha (2005) and Reddy (2010) observed that in Southern India, stomach, oral, oesophagus and leukemia were the main cancers in males and cancers in cervix, breast, oral and oesophagus were the main cancers among females. There is variation in prevalence of cancers existing in India (Mohammed *et al.*, 2012). Symptoms analysis showed that pain (94.7%) was the most frequent symptom in our study this is in accordance with Lal *et al.* (2012) study. As per visual analog scale, 59.3% of patients had pain score between 8 to 10, 30.7% had pain score of 5 to 7. Other important symptoms in our study include sleeplessness, constipation, loss of appetite and fatigue. Lal *et al.* (2012) reported some important symptoms were insomnia (64.1%), loss of appetite (34.6%), nausea (32.7%) and vomiting (32.1%). But in our study, vomiting (26%) was less frequent. It may be due to the use of antiemetic along with anti-cancer drugs. Other studies also reported fatigue (77%), pain (75%) and lack of appetite (66%) (Riechelmann *et al.*, 2007). Majority (81%) of patients were aware of their condition and in majority of cases, this information was revealed to them by their doctors.

Conclusion

In this study, it was seen that 79.3% belonged to below poverty line and 52% was in debt and 58.1% having only one earning member in the family while 19.3% had no earning member. This highlights the need for financial assistance to these patients and their family members. Only in 88.7%, the diagnosis was revealed by the treating physician. From the study it was seen that 49.3% were sad, 15.3% anxious and 4% had fear of death. Breaking the bad news to the patients and their families and helping them to cope with the situation is an inevitable part in the management of the cancer which is usually ignored by most of the health professionals. It was seen that oral and gastro intestinal cancers followed by lung cancer and carcinoma breast is most common. We need further studies to identify the risk factors associated with these cancers in order to develop further strategies for their prevention. It was seen that during the palliative phase, majority of patients had complaints of pain, sleeplessness, drowsiness and nausea followed by vomiting and other symptoms. The patient and their care givers and family should be made aware about the common problems faced by the patients and how to cope up with it. This record based study conducted at Pain and palliative clinic highlight the importance of raising the awareness about the distressing problems faced by cancer patients and efforts must be made to formulate plans to improve the quality of care provided to them. A team work must be needed to tackle the problems suffered by cancer patients.

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References

1. Dikshit, R., Gupta, P.C., Ramasundarahettige, C., Gajalakshmi, V., Aleksandrowicz, L., Badwe, R., Kumar, R., Roy, R., Suraweera, W., Bray, F., Mallath, M., Singh, P.K., Sinha, D.N., Shet, A.S., Gelband, H. and Jha, P. 2012. Cancer mortality in India: A nationally representative survey. *Lancet*. 379: 1807-1816.
2. Dinshaw, K., Rao, D. and Ganesh, B. 1999. Tata memorial hospital cancer registry. Annual Report, Mumbai, India.
3. Himmelstein, D.U., Warren, E., Throne, D. and Woolhandlers, S. 2005. Market watch: Illness and injury as contributors to bankruptcy. *Health Affairs* 2005.
4. Hussain, M.A., Pati, S., Swain, S., Prusty, M., Kadam, S. and Nayak, S. 2012. Pattern and trends of cancer in Odisha, India: A Retrospective study. *Asian Pacific J. Cancer*. 13: 6333-6336.
5. Jagannatha, G.V. 2005. Oral cancer prevalence and assessment of various risk factors among oral cancer patients attending Kidwai Memorial Institute of Oncology-An epidemiological study. MDS Thesis submitted to Rajiv Gandhi Institute of Health Sciences, Bangalore, Karnataka.
6. Lal, M., Raheja, S., Kale, S., Das, N., Gogia, A.R. and Bhowmik, K.T. 2012. An experience with 156 patients attending a newly organized pain and palliative care clinic in a tertiary hospital. *Ind. J. Cancer*. 49(3): 293-297.
7. May, J.H. and Cunningham, P.J. 2004. Tough trade-offs: Medical bills, family finances and access to care Washington DC: Centre for studying Health system change, 2004.
8. Murray, S.A., Boyd, K. and Sheikh, A. 2005. Palliative care in chronic illness. *BMJ*. 330: 611-612.
9. Rao, Y., Gupta, S. and Agrawal, S. 2002. National cancer control program: Current status and strategies fifty years of cancer control in India. Director General of health services, MOHFW, Government of India, 2002. pp.41-47.
10. Reddy, K. 2010. Cancer epidemiology in South India. Bangalore: Dept. of Epidemiology and statistics Bangalore cancer registry. Kidwai Memorial Institute of Oncology.
11. Riechelmann, R.P., Krzyzanowska, M.K., O'Carroll, A. and Zimmermann, C. 2007. Symptom and medication profiles among cancer patients attending palliative care clinic. *Support Care Cancer*. 15(12): 1407-1412.
12. Saini, R., Saini, S. and Sugandha, S.P. 2009. Palliative care, its need and role in cancer patients, in the Indian scenario. *Ind. J. Med. Paediatr. Oncol*. 30(3): 119-120.
13. Twycross, R. 2003. Introducing palliative care. Harvest media services, Calicut. p.3.
14. WHO. 1980. Technical Report series 804. Geneva: World Health Organization; 1980. Cancer pain relief and palliative care.
15. WHO. 2002. National Cancer Control Programmes. Policies and managerial guidelines (2e). World Health Organization, Geneva. p.84.
16. WHO. 2004. Cancer mortality, the global burden of disease 2004 Update, World Health Organization 2004.
17. WHO. 2014. Geneva: World Health Organization; "WHO Definition of Palliative Care". Retrieved 17 Feb 2014 from <http://www.who.int/cancer/palliative/definition/en>.