QUALITY OF LIFE AND NEED OF PALLIATIVE CARE SERVICES AMONG TERMINALLY ILL CANCER PATIENTS ADMITTED IN A TERTIARY HEALTH CARE CENTRE OF EASTERN INDIA

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ABSTRACT:

Background: Cure in cancer patients is difficult, they can be given palliative care which minimize their sufferings and help them to die with dignity.

Objective: To assess the need of palliative care among terminally ill cancer patients admitted in a tertiary health care centre.

Methods and Material: The study was a cross-sectional study conducted in a tertiary care hospital during July 2015 to September 2017. Study population comprised of 110 Terminally ill cancer patients. The schedule consisted of socio-demographic status, disease condition, need of palliative care.

Results: In the present study, majority study participants were in the elderly age group (mean - 55.7 years). Major clinical symptoms observed among terminally ill were pain, dyspnoea, fatigue, bladder and bowel incontinence, constipation, depression etc. About 60% of the patients were dissatisfied with the care provided. Almost 3/5th of the participants complained of problems in relationship with their spouse or children. General satisfaction for the care provided by general physicians was about 65% while that for specialist medical care provider was 52%.

Conclusions: Psychological, social, financial, autonomy and spiritual issues of terminally ill cancer patients were poorly managed. Patients demanded more compassionate and benevolent care from their family members and physicians

Keywords: End of Life Care, palliative care, quality of life.

I. INTRODUCTION

Palliative care provides comfort and enhances the quality life.¹ World Health Organisation (WHO) suggests that palliative care should be both disease-orientated and palliative treatments should be available over the spectrum of disease stages, and availability of palliative care services should be based on need and not on life expectancy. Palliative care should not be associated exclusively with terminal care or with cancer care. Sometimes patients need palliative care during early phase of disease, starting from the moment of diagnosis.²,³ For patients with cancer and other progressive, incurable non-cancer diseases, palliative care is an important and sensitive issue.⁴,⁵ Palliative Care not only improve the quality of life and but also the quality of death. Therefore, it offers health gain by offering to patients, family members and carers, a better quality of life. Studies have shown that physical symptoms are inadequately controlled and that psychological and spiritual issues are neglected.⁴,⁵ There is also evidence to support the case that most patients would prefer to die at home.⁶

An estimated 40 million people need palliative care every year, 78% of whom live in low- and middle-income countries.⁷ The prevalence of cancer in India is estimated to be around 2.5 million. In India, out of one million...
newly diagnosed cancer patients, more than 50% will die within 12 months of diagnosis and another one million cancer survivors will show progressive disease every year. Among them, 1.5 million need palliative care and less than 0.1 million patients can be covered by the existing facilities. Majority of patients in India present with late-stage disease and have limited access to palliative care and effective pain-relieving medications, such as morphine. Cure in cancer patients is difficult, they can be given palliative care which minimize their sufferings and help them to die with dignity. Some State Governments (Kerala) have simplified legislation or policies of governing opioid availability for cancer patients so that they can access to the medication to control their pain and mental distress, however still availability of Oral Morphine even in the Government Hospitals is lacking in many States.12

In Odisha, the paucity of palliative care units has severely affected thousands of cancer patients and their family members. In the state, palliative care for terminally ill patients is provided by only one Cancer Centre. There are 50 beds dedicated to palliative care which have been running since last one decade in the same hospital.13

Community health care professionals like general practitioners and nurses need to provide general palliative care in the community. Palliative care affirms that death should be dignified and the existing is to be fulfilled by a joint commitment of the medical fraternity and family members, and appropriate government policy.14,15 Palliative care not only focuses on the family but it also provides support to the family after the death of the patient (bereavement care). This current study was conducted to assess the need of palliative care among terminally ill cancer patients admitted in a tertiary health care centre.

II. MATERIALS AND METHODS

A Hospital based Cross-sectional study was conducted in Oncology (Medical and Surgical) and Haematology Departments of a tertiary care hospital of Eastern India. The study was conducted over a period of two years and three months, from July 2015 to September 2017. Study population comprised of Terminally ill cancer patients. The sample size was calculated to be 110 depending upon the prevalence of terminally ill patients among all cancer patients which was 80% taken from a multi centric study by Seamark D et al. (9) Considering allowable error of 10% and 15% nonresponse rate, the sample size was calculated to be 110. So, 110 Patients were included in the study. Seriously ill patients who are clinically non-responsive were excluded from the study.

Data collection and analysis: On each day of data collection, the register consisting of names of admitted patients in oncology and hematology wards were collected and the detailed list was presented to the respective treating physicians. Based on their clinical assessment the physicians would identify terminally ill cases (with survival less than one year) and those cases were interviewed. The process was repeated till the desired sample size was achieved. In the process of data collection, 152 patients were approached to get the desired sample of 110.

The schedule was used for interviewing terminally ill cases. The subjects were explained in detail about the study and the expected outcome. They were assured of privacy and confidentiality of data. Informed written consent was obtained from the subjects/surrogate. The interview was conducted in the local language after establishing a good rapport with subjects and in a very friendly manner. First part of the schedule consisted of socio-demographic status & onset of disease. Second part of the schedule was on the need of palliative care in terminally ill cancer patients. It aimed at understanding the current palliative care services and how the terminally ill is being benefitted out of it, moreover the focus was to elicit the need of the cancer patients onto their terminal stages of illness. Considering all the aspects of palliative care and satisfaction levels for these services among patients were divided into 10 domains like quality of life, clinical symptoms, financial issues, social issues, psychological issues, role activities, autonomy, spiritual issues, quality of care and informational needs. Separate questions were included to elicit satisfaction level.

The data collected were entered in Microsoft Excel spreadsheet. After proper data cleaning data were imported and analyzed using IBM SPSS Statistics software version 20 licensed to the institute. Descriptive statistics were expressed as frequencies (percentages), means, median, standard deviations, standard error of means at 95 confidence intervals.

Ethical considerations: The study was approved from the Institutional Ethics Committee of Institute of Medical Sciences & SUM Hospital, Siksha ‘O’ Anusandhan University, Bhubaneswar.
III. RESULTS:

In the present study, the mean age of the study participants is 55.7 years with a standard deviation of ± 20.066. The minimum age of the study participants was 8 yrs. while the maximum age was 84 yrs. Among study population, 57.3% were male and 42.7% were female. Majority were Hindu (85.45%), followed by Muslim (6.36%), Christian (5.45%) and Jain/Buddhist (2.74%). About 2/5th (43.60%) of the participants were married, 40.90% were widowed and the remaining were either never married (10 %) or separated/divorced (5.50%). Most of the patients had no formal education (20%), followed by a few who were having some form of primary education (19.10%). A very small portion of the participants were graduate (10%) and postgraduate (10.9%). Mostly participants belonged to rural area (49.10%), followed by semi-urban (30%), urban (15.5%) and slum (5.40%) dwellings.

For majority of the participants the cost of treatment was incurred by the family members (53.64%) which included costs for both medical & ancillary care (transportation, nourishment). Pension schemes (20%) was a support in the needy times for the terminally ill patients and that levied off their family members in terms of financial burden. Although some had their terminal illness overpowering their health till being moribund they kept themselves employed (16.36%) and some were salaried (5.45%). Only a few had pre-planned retirement schemes (4.55%) Socio economic status was assessed according to modified BG Prasad scale. Maximum of the study participants belonged to middle class (62.7%), followed by lower class (27.3%) and only a few belonged to upper class (10%).

Based on histopathological classification, carcinoma was the most frequently (n = 75, 68.18%) observed form of cancer among study participants followed by lymphoma (n = 12, 10.90%), leukaemia (n = 11, 10%), sarcoma (n = 10, 9.10%) and myeloma (n = 2, 1.82%). The most common form of cancer on basis of site was oral carcinoma (18 %), followed by breast carcinoma (7.2%). (Fig 1)

More than half (55%) of the patients didn’t go for regular health check-ups, while only 45% went for regular health check-ups. Out of those who went for regular health check-ups (75.5%) didn’t assess their health parameters (like routine biochemical, haematological and pathological examinations) whereas only 24.5% assessed health parameters regularly but all tests that were prescribed by their respective physicians were not done. (Fig 2)

Near about half of the population had problems with pain (43.6%), nausea / vomiting (46.4%), lack of appetite (40%), pricking / numb sensation (40%), sweating / hot flushes (48.2%) and pressure sores / wound (45.5%) and satisfaction among them concerning the care provided was low and about 30% to 40% people wanted more of care form their concerned care providers. Other associated issues which were not considered a problem by almost 1/3rd of the population are as follows, problems with stoma (46.4%), sexual dysfunction (32.7), itch (35.5) and difficulty in concentration (33.6%). Patients expressed utmost satisfaction in care provided on issues like taking care of sleep (71.5%) and care of oral ulcers (71.6%). (Table 1)

The terminally ill patients were troubled and overburdened (50.9%) with the financial expenses that are incurred in the course of their health management. Reduced income because of the disease was found in 82.7% of the participants and only 32.3% of them were satisfied with the help received on such issues by the family members. Planning for the last will / death testament was somewhat an issue among 41.8% of the participants and almost 35.7% of the people among them wanted help on this issue. The dying patient couldn’t furnish their best (30.0%) in making their spouse or family members acquainted with their financial issues. About 2/5th of the population wanted more help in dealing with their financial and administrative issues.

Almost 3/5th of the participants experienced no issues with their spouse (28.2%) and 34.4% of them were satisfied with the help received by their spouse. Roughly participants endured difficulty in interacting with their children (65.5%) and friends/colleagues (82.7%), and wanted more of help (43.9%) and belongingness from them. It was an obvious problem in experiencing too little support from family, practical help from near & dear ones and loneliness was seen in 28.2%, 48.2% and 28.2% respectively. Family members of some patients (26.4%) dramatized/exaggerated the situation while some other family members (39.1) denied the severity of the situation. With differences in opinion (30.9%) of what should be the better treatment provided, of them 50% of people wanted help to deal with such state of affairs. 34.5% were forsaken by the attitude of others (near and dear ones) towards them but still then 19.2% were passable with their behaviour.

Difficulty in filling the day and able to relax throughout was a delinquent matter among mainstream (35.5%) of study participants. To help fill their day 40.9% wanted more help and keep themselves relaxed (out of the woes of

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the progressing disease) 52.7% needed much of support. Problems like employment (seen among 29.1%) and caring for the children (36.4%) was seen in patients but majority of them were satisfied with what help they receive. (Table 2)

Depressed mood (51.8%), fear of physical suffering (27.3%), fear of metastasis (38.2%), difficulty in coping the unpredictability of the future (39.1%), difficulty in showing emotions to other (41.8%), difficulties to see positive aspect of the situation and being overwhelmed by the decisions that must be made (28.2%) people experienced some sort of difficulty and were more or less satisfied with the care received was mentioned that there is a lot of scope or ways that they can be helped (almost 2/3rd agreed upon this) while 1/3rd needed much help and were not satisfied with the contemporary care they are being provided. Prime issues included fear of treatment (38.2%), metastasis (34.5%), death (50.9%); feeling of guilt (46.4%) and changing bodily appearances (40.0%). (Table 3)

People found it difficult to be engaged usefully (37.0%) and difficulties in keeping confidence in God or religion (37.3%) while some sort of problem was seen in issues like being available to others (33.6%). To accept the disease and get engaged usefully (40.9%) and coping with difficulties in accepting the disease (40.9%) people wanted more of help from their near and dear ones. 18.2% were in self-distress for not being able to keep confidence in God and needed a hoisted care to deal with it.

It was somewhat an issue in spheres like continuing usual activities (40.9%) and social activities (52.7%); while being dependent upon others was a major issue which contributed to almost 37.3% of the total study population and of it 49.1% needed more of help to overcome this issue. Other major issues included loss of control over one’s body (46.4%), loss of control over one’s life (31.8%), inability to make one’s own decision (28.2%) and difficulty in asking help to others (46.4%). Major dissatisfaction was seen for issues like difficulty in continuing one’s social activity (38.2%) and experiencing loss of control over one’s own body (30.0%). (Table 4)

Most (35.5%) of the participants found it difficult to show their disagreement to certain procedures or care plan that are being taken for them. And of them exactly 50% were not satisfied with the help provided to them and some rather needed more help (32.7%).

Almost halve of the population experienced difficulties in saying things that were not understood by others (44.5%) and remembering what was said to them (46.4%). Majority of the patients wanted to have another care provider (35.5%) but almost 50% were satisfied with their current care provider. 81.8% of the patients agreed upon that there was no help provided or received outside of family by any organisation or charitable institution. Having too many caregivers around the patient was a matter of concern for 40.9% of the participants. 52.7% of the participants experienced too slow professional reaction from the medical care providers at times when they needed and 38.2% were completely displeased with the care.

Almost half of the people experienced much of difficulty in handling daily to daily circumstances like self-care (47.3%); self-mobilisation (44.5%); able to cook (40.0%), shop (48.2%); personal transportation (45.5%) and in even doing light (46.4%) to heavy housework (46.4%) and on asking them that whether they are satisfied with the care they are provided on these aspects, only 1/3rd of them were satisfied while there remained another halve of terminally ill who still wanted more of help and on an average 1/3rd of the population were not satisfied with the help they are receiving from their family members and physicians. It is notable that near 47.3% of the population who considered body care to be a problem were dissatisfied (59.9%) with the care they are receiving. (Table 5)

Patients were eager to know more on about places and agencies that provide help (57.3%); many wanted to know the outcome of the treatment (54.5%) and the possible side effects obtained out of it. It is a notable fact that 60% of the study partakers wanted to know about euthanasia and how could it affect them. Many wanted to learn about alternative healing methods (59.1%) and what physical symptoms can be expected in future (60%) with the current prognosis of the disease. Patients were also interested in learning about certain issues like sexuality of people with cancer (41.8%), nourishment towards terminal stages (49.1%) and artificial aids (47.3%) like wigs, prosthesis, special beds (to avoid pressure sores), etc.

The general physician / resident doctors imparted a greater role in the caregiving process. Many of the patients (about 40 – 60 %) were satisfied with the care or help they received from the GP’s on these troubled areas like to understand what went wrong in the past (50.0%), helps the patient in taking difficult decision (54.5%), and supports the patient if the patient proposes a different opinion in the ongoing health care plan (53.6%). But major flaws as
mentioned by the patients in concern or view of the general physician were that the GP never announces a home visit (98.2%), doesn’t actively involve my family in care providing during hospital stay (82.7%) and doesn’t provide a personal counselling if required (80.0%). There were also some matters on which if the GP could emphasize more then the patients could be more benefitted like giving attention to what the family members of the patient want (60.0%), having a little empathetic attitude during difficult times (57.3%), listen more to what the patient says (57.3%) and show interest in the patient as an individual person (52.7%). The specialists involved in the care providing play a pivotal role. There has been good satisfaction among patients in term of care provided by the specialist. In aspects mentioned underneath there was prodigious positivity observed amid patients like taking care so that the patient doesn’t undergo unnecessary procedures (58.2%), supporting the patient during hard times (53.6%), keeping the GP informed always (51.8%) and maintaining privacy during medical consultation, check-up and counselling (60.9%). There is always scope for betterment and this was also mentioned by the patients that if these certain issues are taken a bit care then caregiving would be at its best. Issues included like shuttling the patient to the hospital should be less (53.6%), treatment shouldn’t be over threatening or burdened to the patient (56.4%), not let the patient wait for long for the consultation (55.5%), the specialist should help in taking difficult decisions (61.8%), the specialist is expected to answer the patient honestly & in simple words regarding the current medical situation & prognosis (57.3%) and moreover the specialist should arrange a good follow up when there is an obvious bad news for the patient (54.5%).

IV. DISCUSSION

The present study was conducted to assess the need of palliative care among terminally ill cancer patients admitted in a tertiary health care centre of Odisha.

Only 45% of the study group went for regular health check-ups even in their terminal stages of illness and of them only 24.5% did all investigations as required and as advised by their treating physicians. But there lies a major chunk of study participants who were either negligent or had financial issues in not going for regular health check-ups and not doing the laboratory investigations. A study published in Canada, almost 92% people went for regular physician consultations and did necessary investigations as directed.16

For, most patients, suffering is not purely physical and pain is only one of several symptoms. Pain relief should be therefore seen as part of a comprehensive pattern of care which encompasses the physical, psychological, social and spiritual aspects of suffering.17 Published reports indicate that between 30% and 50% of cancer patients are experiencing pain or being treated for it. An analysis of 12 surveys covering nearly 2600 patients in developed countries suggest that more than 50% of patients suffer unrelieved pain.3 This study shows that about 72.7% people suffer from cancer pain and out of which 27.5% are completely dissatisfied with the care being taken for them in controlling pain and only 40% are somewhat satisfied with the care, which is much higher than the published reports. Hence, it is clearly indicative that pain in terminally ill patients is poorly managed and needs to be abridged with a benevolent approach. Treatment of multiple symptoms is demanding and needs a collective care by physicians of diverse specialities and moral backing & prompt caregiving by family members. Dyspnea was the cause of major distress (seen in 74.5%) among the terminally ill and when associated with other major symptoms like pressure sores (70%), Edema (seen in 74.5%), Numbness (70%), Bladder and bowel incontinence (68.2%) lead the patient into a pitiful state of affairs. However, about 30% - 40% of patients complained of not being satisfied with the help or care provided by the physicians. Only about 2/5th of the patients showed some gratification to the care provided.

When one is aware about his / her state of terminal illness he/she suffers from the dreaded pathology of the disease and gradually gets moribund then it is obvious that he / she won’t be able to carry out the usual activities and so also will have difficulty in filling the day (which was seen among 74.6% participants) and relaxing throughout the day (71%) and for such condition around 4/5th of the participants disclosed displeasure for the care received.

Cancer patients experience a number of challenges which include psychological distress; difficulties in communicating with health providers, family and friends; obtaining the required health information; physical changes in body functioning and appearance; sexual dysfunction; and disruption to family functioning and occupation.18,19 Major depression was found among 16.7% participants in a study conducted by Tatsuo Akechiet al.20 But results of our study showed 34.5% of study participants obviously suffering from depression which may be due to the fact that only pain and other clinical symptoms relating to the cancer are being taken care whereas psychological symptoms are poorly managed. About 49.1% did not experience pleasure on anything anymore and
45.1% of them were not satisfied with the care provided to them and a similar proportion wanted more care from their family and physician. Fear of many adverse health outcomes are imminent among the one who is in an advanced stage of carcinoma. Fear of physical suffering (27.3%), fear of metastasis (38.2%), fear of being alone (41.8%) and fear of death (50.9%) were the most common fears observed. Symptoms can begin to resolve within a few weeks as the patient receives support from family, friends in addition to the support and outline provided by the medical oncologist, of a treatment plan that offers hope and reduces part of the uncertainty that is so difficult to deal with in oncology. The psychological mechanisms involved in the disease process can be influenced by either the calming effects of secure and harmonious family attachments or the disruptive effects of family enmity and criticism. A negative change in one’s body is always dreadful and about 40% of study participants found it difficult to accept and as much as 71.5% were unhappy with the care received for this.

People found it difficult in keeping confidence in God and religion (61.8%), many found difficulties in concerning the meaning of death (75.5%) and accepting the disease (70.9%). Dissatisfaction to any form of care provided to these spiritual concerns were pretty higher, ranging from 30% to 60%. People facing death suffer from an inability to find meaning in this last chapter of their lives; from a bleak, narrowly confined and abbreviated future; from inability to deal meaningfully with family and loved ones at this final opportunity, from total dependence on others; from loss of capabilities; from being turned from a contributor into a burden on others (seen in 28.2%); from the indignity of being unable to take care of even basic bodily functions; from a sense that their bodies or their minds are betraying them; from being cast out of the world in which the healthy live; from guilt; from a sense of abandonment and difficulties in accepting the disease (29.1%); from anger about all of this; and from isolation due to the reluctance of the healthy to broach the subject of dying.

Safeguarding the dignity of patients at the end of life has become a key objective of clinical practice. According to Chocinovet et al., about 40% people have lost their autonomy in life and consider their life to be of no use and often have experiences of frustration and even may develop suicidal tendencies. Our research reports that 30.9% people find it difficult in continuing their usual activities, 26.4% in continuing social activities and about 37.3% showing displeasure on being dependent on others. Many experienced loss of body control (46.4%), loss of control over one’s life (31.8%) and 46.4% had difficulties in asking for any form of help. Numerous studies have clarified that what is meant by dignity, to identify the variables associated with it, to examine how it is perceived by patients, families, and professionals, and to explore ways of assessing and enhancing it. The illness experience, the transformation of identity and the influence of the social context are aspects that have been referred to in numerous settings, and in this regard the present synthesis, which takes multiple factors into account, can help to clarify the different ways in which the concept of dignity has been used in relation to autonomy.

Needing help for personal routine activities at many a times is not welcomed by the terminally ill patient and is seen to cause low self-esteem. Difficulties in body care was seen in 47.3% participants and of them 60% were not satisfied with the care received. Difficulties and definitive problems were seen in almost 40% - 50% of those participants. Carrying out light house activities and heavy household activities was a problem for 46.4% study participants. And to this issue broad displeasure was seen among 30% people and more of help was demanded from about 50% of study partakers. The reason for displeasure or dissatisfaction may be due to lack of trained palliative care nurses in hospital and physicians not giving insight into such matters.

In Western cultures, in which autonomy reigns, the wishes of the patient receive priority over those of the family members about what is told and to whom concerning prognosis. Patients from other cultural backgrounds may prefer nondisclosure, or disclosure negotiated through the family, when life expectancy is short. But there lies the art of the physician to extract what more can be done for the terminally ill and how better can the physician support the patient. It is notable in my study findings that maximum of the participants wanted to learn about alternative healing methods (59.1%), physical symptoms that can be expected (60%) in further course of illness and knowledge about euthanasia (60%). It thus evidently suggests that much is yet to be catered to the terminally ill. To our knowledge, little is known regarding what expert clinicians, terminally ill cancer patients, and their caregivers think about these issues.

End-of-life care presents many challenges for clinicians, as well as for patients and their families. Unfortunately, clinicians who are responsible for the treatment of patients at the end of life commonly lack adequate training to help guide end-of-life decisions and to deliver bad news to patients and families. Our study results indicate that the GP lacks skills in areas like understanding what went wrong in the past (50.0%), helps the patient in taking difficult decision (54.5%), and supports the patient if the patient proposes a different opinion in the ongoing health
care plan (53.6%). The way we set up the system right now, primary care physicians don’t have time to spend an hour with you, see how you respond, if they wanted to adjust your medication. So, the easiest thing for everybody up the stream is to admit you to the hospital. And once someone is admitted to the hospital they’re likely to be seen by a dozen or more specialists who will conduct all kinds of tests, whether they’re absolutely essential or not. The GP was appreciated for helping the patient take difficult decisions (seen in 54.5%) and in even taking difficult decisions when the patient is jumbled (53.6%) to choose which is better. Studies by Rodriguez-Prat et al. showed that GPs are more concerned for the terminally ill patients rather than the specialist medical care provider as they tend to be in close proximity with the patients.

Satisfaction in terms of care provided by the specialist physicians is seen to range from 40% to 60% which is at par with results from Kerala and U.S. Specialist care in terminally ill plays a prime role in care for the terminally ill as for the patient they are their saviours. Certain dissatisfaction was observed in issues like need of involving the family more in care giving (60% patients wanted more of family involvement), helping in taking difficult decisions (61.8%) and discussing what went wrong in the past (55.5%). The one thing that could be done by either the specialist physician or the GP is to arrange home visits to evaluate and counsel the terminally ill would be a much benevolent approach.

V. CONCLUSION

Although palliative care encompasses a wide variety of services, our observations shows that clinical symptoms experienced by cancer patients during their terminal stages of illness were appropriately managed but other aspects like psychological, social, financial, administrative, autonomy and spiritual issues were poorly managed. Patients demanded more compassionate and benevolent care from their family members and physicians. There should be arrangement of home visits by physicians so as to minimize shuttling of the terminally ill patients.

REFERENCES

4. Rome RB, Luminarias HH, Bourgeois DA, Blais CM. The Role of Palliative Care at the End of Life.
11. Editorials: Ten Commandments for the Care of Terminally Ill Patients - American Family Physician [Internet]. [cited 2017 Mar 24].
13. Cancer patients: Palliative care in critical state | Orissa Post [Internet].
15. Gopal KS, Archanas PS. Awareness , Knowledge and Attitude about Palliative Care , in General , Population and Health Care Professionals in Tertiary Care Hospital. 2016;3(10).
16. The DEATH test: Doctors’ check list spots patients most at risk of dying within 30 days | Daily Mail Online [Internet]. [cited 2017 Oct 13].
19. Psychosocial issues for people with advanced cancer [Cancer Forum [Internet]. [cited 2017 Oct 15].
23. Spiritual Issues at the End of Life [Internet]. [cited 2017 Oct 16].
25. Americans too often lose autonomy at the end of their life [Internet]. [cited 2017 Oct 16].
34. Roles of the Family and Health Professionals in the Care of the Seriously Ill Patient | American Hospice Foundation [Internet]
Figure 1: Distribution of various types of cancers among terminally ill cancer patients on basis of histopathological origin

- Carcinoma: 61, 55%
- Sarcoma: 49, 45%
- Lymphoma: 37, 75.5%
- Leukemia: 12, 24.5%

Figure 2: Regular health check-up and assessment of health parameters

- Did not have regular health check-up
- Did not check health parameters regularly
Table 1: Clinical symptoms and management among terminally ill cancer patients

<table>
<thead>
<tr>
<th>Clinical symptoms and management</th>
<th>PROBLEM yes</th>
<th>somewh</th>
<th>No</th>
<th>SATISFACTION Satisfied</th>
<th>Want</th>
<th>Not satisfied</th>
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<td>Number (Percentage)</td>
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<tr>
<td>Pain</td>
<td>48 (43.6)</td>
<td>32 (29.1)</td>
<td>30 (27.3)</td>
<td>26 (32.5)</td>
<td>32 (40)</td>
<td>22 (27.5)</td>
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<td>Difficulty in concentration</td>
<td>40 (36.4)</td>
<td>33 (30.0)</td>
<td>37 (33.6)</td>
<td>25 (34.4)</td>
<td>24 (32.8)</td>
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<tr>
<td>Fatigue</td>
<td>41 (37.3)</td>
<td>55 (50.0)</td>
<td>14 (12.7)</td>
<td>14 (15.2)</td>
<td>54 (59.2)</td>
<td>27 (25.6)</td>
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<tr>
<td>Sleeping problems</td>
<td>31 (28.2)</td>
<td>46 (41.8)</td>
<td>33 (30.0)</td>
<td>55 (71.5)</td>
<td>7 (9)</td>
<td>15 (19.5)</td>
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<td>Nausea or vomiting</td>
<td>51 (46.4)</td>
<td>27 (24.5)</td>
<td>32 (29.1)</td>
<td>23 (29.5)</td>
<td>22 (28.2)</td>
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<td>Constipation or diarrhoea</td>
<td>35 (31.8)</td>
<td>38 (34.5)</td>
<td>37 (33.6)</td>
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<td>Incontinence</td>
<td>39 (35.5)</td>
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<td>13 (17.3)</td>
<td>26 (34.7)</td>
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<td>Mouth problems or swallowing problems</td>
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<td>Lack of appetite or change of taste</td>
<td>44 (40.0)</td>
<td>33 (30.0)</td>
<td>33 (30.0)</td>
<td>15 (19.5)</td>
<td>7 (9)</td>
<td>55 (71.5)</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>34 (30.9)</td>
<td>48 (43.6)</td>
<td>28 (25.5)</td>
<td>22 (26.8)</td>
<td>19 (23.2)</td>
<td>41 (50)</td>
</tr>
<tr>
<td>Cough</td>
<td>31 (28.2)</td>
<td>52 (47.3)</td>
<td>27 (24.5)</td>
<td>23 (27.8)</td>
<td>30 (36.1)</td>
<td>30 (36.1)</td>
</tr>
<tr>
<td>Itch</td>
<td>35 (31.8)</td>
<td>36 (32.7)</td>
<td>39 (35.5)</td>
<td>19 (25.3)</td>
<td>50 (66.7)</td>
<td>6 (8)</td>
</tr>
<tr>
<td>Loss of hair</td>
<td>38 (34.5)</td>
<td>39 (35.5)</td>
<td>33 (30)</td>
<td>17 (22)</td>
<td>10 (13)</td>
<td>50 (65)</td>
</tr>
<tr>
<td>Impaired vision or hearing</td>
<td>46 (41.8)</td>
<td>45 (40.9)</td>
<td>19 (17.3)</td>
<td>20 (21.9)</td>
<td>40 (43.9)</td>
<td>31 (34)</td>
</tr>
<tr>
<td>Sexual dysfunction</td>
<td>41 (37.3)</td>
<td>33 (30.0)</td>
<td>36 (32.7)</td>
<td>66 (60.0)</td>
<td>38 (34.5)</td>
<td>6 (5.5)</td>
</tr>
<tr>
<td>Prickling or numb sensation</td>
<td>44 (40.0)</td>
<td>33 (30.0)</td>
<td>33 (30.0)</td>
<td>55 (71.5)</td>
<td>15 (19.5)</td>
<td>7 (9)</td>
</tr>
<tr>
<td>Swelling of arms, legs or abdomen (Edema)</td>
<td>34 (30.9)</td>
<td>48 (43.6)</td>
<td>28 (25.5)</td>
<td>22 (26.8)</td>
<td>41 (50)</td>
<td>19 (23.2)</td>
</tr>
<tr>
<td>Sweating or hot flushes</td>
<td>53 (48.2)</td>
<td>24 (21.8)</td>
<td>33 (30.0)</td>
<td>21 (27.3)</td>
<td>33 (42.8)</td>
<td>23 (29.9)</td>
</tr>
<tr>
<td>Wounds or pressure sores.</td>
<td>50 (45.5)</td>
<td>27 (24.5)</td>
<td>33 (30.0)</td>
<td>33 (42.8)</td>
<td>11 (14.4)</td>
<td>33 (42.8)</td>
</tr>
<tr>
<td>Problems with a stoma</td>
<td>23 (20.9)</td>
<td>36 (32.7)</td>
<td>51 (46.4)</td>
<td>20 (23.9)</td>
<td>29 (59.2)</td>
<td>10 (16.9)</td>
</tr>
</tbody>
</table>
Table 2: Role activities

<table>
<thead>
<tr>
<th>Role activities among terminally ill cancer patients</th>
<th>PROBLEM</th>
<th>SATISFACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
<td>somewh</td>
</tr>
<tr>
<td></td>
<td></td>
<td>at</td>
</tr>
<tr>
<td>Difficulty in filling the day.</td>
<td>39 (35.5)</td>
<td>43 (39.1)</td>
</tr>
<tr>
<td>Difficulty in relaxing.</td>
<td>39 (35.5)</td>
<td>39 (35.5)</td>
</tr>
<tr>
<td>Difficulties in employment or following a study.</td>
<td>32 (29.1)</td>
<td>48 (43.6)</td>
</tr>
<tr>
<td>Difficulties in caring for children or babysitting.</td>
<td>40 (36.4)</td>
<td>33 (30.0)</td>
</tr>
</tbody>
</table>

Table 3: Psychological issues

<table>
<thead>
<tr>
<th>Psychological issues among terminally ill cancer patients</th>
<th>PROBLEM</th>
<th>SATISFACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
<td>somewh</td>
</tr>
<tr>
<td></td>
<td></td>
<td>at</td>
</tr>
<tr>
<td>Depressed Mood</td>
<td>38 (34.5)</td>
<td>57 (51.8)</td>
</tr>
<tr>
<td>Not experiencing pleasure anymore.</td>
<td>54 (49.1)</td>
<td>39 (35.5)</td>
</tr>
<tr>
<td>Fear for physical suffering.</td>
<td>30 (27.3)</td>
<td>50 (45.5)</td>
</tr>
<tr>
<td>Fear of treatments.</td>
<td>42 (38.2)</td>
<td>41 (37.3)</td>
</tr>
<tr>
<td>Fear of metastases.</td>
<td>38 (34.5)</td>
<td>42 (38.2)</td>
</tr>
<tr>
<td>Fear of being alone.</td>
<td>46 (41.8)</td>
<td>37 (33.6)</td>
</tr>
<tr>
<td>Fear of death.</td>
<td>56 (50.9)</td>
<td>37 (33.6)</td>
</tr>
<tr>
<td>Difficulty coping with the unpredictability of the future.</td>
<td>43 (39.1)</td>
<td>48 (43.6)</td>
</tr>
<tr>
<td>Difficulties in showing emotions.</td>
<td>31 (28.2)</td>
<td>46 (41.8)</td>
</tr>
<tr>
<td>Feelings of guilt.</td>
<td>51 (46.4)</td>
<td>27 (24.5)</td>
</tr>
<tr>
<td>Feelings of shame.</td>
<td>35 (31.8)</td>
<td>38 (34.5)</td>
</tr>
<tr>
<td>Loss of control over emotions.</td>
<td>51 (46.4)</td>
<td>30 (27.3)</td>
</tr>
<tr>
<td>Difficulties to accept a changed bodily appearance.</td>
<td>44 (40.0)</td>
<td>33 (30.0)</td>
</tr>
<tr>
<td>Difficulties to See positive aspects of the situation.</td>
<td>34 (30.9)</td>
<td>48 (43.6)</td>
</tr>
<tr>
<td>Being overwhelmed by all decisions that must be made.</td>
<td>31 (28.2)</td>
<td>52 (47.3)</td>
</tr>
</tbody>
</table>
### Table 4: Autonomy

Autonomy among terminally ill cancer patients.

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>SATISFACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
</tr>
<tr>
<td>Difficulties in continuing the routine activities.</td>
<td>34 (30.9)</td>
</tr>
<tr>
<td>Difficulties in continuing social activities.</td>
<td>29 (26.4)</td>
</tr>
<tr>
<td>Difficulty in handing over tasks of another person</td>
<td>44 (40.0)</td>
</tr>
<tr>
<td>Being dependent on others</td>
<td>41 (37.3)</td>
</tr>
<tr>
<td>Frustrations because one can do less than before.</td>
<td>31 (28.2)</td>
</tr>
<tr>
<td>Experiencing loss of control over one’s own body.</td>
<td>51 (46.4)</td>
</tr>
<tr>
<td>Experiencing loss of control over one’s life.</td>
<td>35 (31.8)</td>
</tr>
<tr>
<td>Experiencing difficulties in asking for help.</td>
<td>51 (46.4)</td>
</tr>
<tr>
<td>Experiencing difficulties in making one’s own decisions.</td>
<td>31 (28.2)</td>
</tr>
</tbody>
</table>

### Table 5: Different aspects of quality of life

Different aspects of quality of life among terminally ill cancer patients.

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>SATISFACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
</tr>
<tr>
<td>Difficulties in body care, washing, dressing, use of toilet</td>
<td>52 (47.3)</td>
</tr>
<tr>
<td>Difficulties in rising, walking, climbing stairs</td>
<td>49 (44.5)</td>
</tr>
<tr>
<td>Difficulties in preparing meals or cooking</td>
<td>44 (40.0)</td>
</tr>
<tr>
<td>Difficulties in shopping (groceries, clothes)</td>
<td>53 (48.2)</td>
</tr>
<tr>
<td>Difficulties in personal transportation (cycling, bike riding)</td>
<td>50 (45.5)</td>
</tr>
<tr>
<td>Difficulties in doing light housework (tidying up, etc.)</td>
<td>51 (46.4)</td>
</tr>
<tr>
<td>Difficulties in doing heavy housework (cleaning, gardening)</td>
<td>51 (46.4)</td>
</tr>
</tbody>
</table>