

Palliative care: A positive outcome for cancer patients?

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The development of palliative care in terms of recognizing the needs of the dying, palliative care becoming a nursing and medical speciality, the involvement of the World Health Organization in palliative care and the continuous development of treatment modalities available to cancer patients creates the expectation that the outcomes for the patient should also be positively influenced. The purpose of the study was to determine the most common symptoms of advanced cancer patients treated in a public and private hospital in Tshwane, and whether advances in palliative care improved the outcomes for these patients by decreasing the prevalence of symptoms experienced. The design of the study was a quantitative survey. The population consisted of patients with advanced cancer receiving palliative treatment as out patients in radiation and medical oncology clinics in a public and private hospital the Tshwane Metropolitan area. The sampling method was convenient and the sample size was 148 participants (n=148). Data was gathered by means of an interview and self report. Data analysis was done by means of descriptive statistics. The results of the study indicated that a high number of patients still experience problems that could have been prevented. Pain was found to be the biggest problem for patients (76.4%) followed by weakness and fatigue (65.5%), nausea and vomiting (65.5%) and a dry mouth (46.6%). Thirst was reported by 41.2% of the sample. The study provides evidence that the development of palliative care did not have a positive outcome for patients by reducing the prevalence of symptoms experienced.

Introduction

For many years, society has denied death by isolating the dying and the old. As reminders of our own mortality, we've sought to keep them out of sight and out of mind. Despite a series of articles by Dame Cecily Saunders in 1959, it was only in 1967 with the foundation of the St Christopher's Hospice in London that it was recognised that the needs of the dying were not being met and the principles of palliative care were established (Gamlin, 2001:4).

In 1990, the World Health Organization (WHO) (Johnson, 1999:2) defined palliative care as active total care of

persons whose disease no longer responds to treatment. According to the definition, control of pain and other symptoms, as well as the management of psychological, social and spiritual problems are of prime importance.

The need for palliative care is increasing and it is estimated that by the year 2020, 646 000 people living in sub-Saharan Africa will die from cancer compared to the 412 000 who died in 2002 (WHO, 2006). Taking the current disease burden into account, it is also estimated that one in 200 people living in Africa will need palliative care (WHO & UICC 2005). Of the estimated 720 000 000 people who currently live in Africa, (Fitch's African

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population page, 2006) 3 600 000 are in need of palliative care.

With the recognition of the needs of the dying and the WHO defining palliative care, development has world wide been ongoing to improve palliation for patients with cancer. These developments include palliative care becoming a speciality discipline in nursing in the early 1980s (Gamlin, 2001:5) and palliative medicine becoming a medical speciality in 1988 (Faull & Woof, 2002:7). Other developments include that in 1996 the WHO published guidelines for the management of cancer pain that was proven to achieve adequate pain relief in up to 90% of patients (Farrer, 2001:13; WHO, 2008), and since the beginning of the year 2000 until May 2006, 76 drugs were added to the list of approved oncology drugs by the United States Food and Drug Administration (Food and Drug Administration, 2006).

On paper, the expectation is created that the development of palliative care should have a positive impact on patient care and patient outcomes leading to a decreased number of symptoms. It would be expected that supportive care to manage the symptoms that accompany cancer - be it due to the disease, treatment or concurrent diseases - would also have evolved in the same way as new treatment modalities. As an aggressive disease, cancer often advances quickly in many patients, and its many diverse symptoms often impair not only the quality of life of the patient and family, but also the effectiveness of pain treatment (Meuser, Pietruck, Radbruch, Stute, Lehmann & Ground, 2001:1).

Considering the development in palliative care and the knowledge of patient symptoms the question arose: What are the most common symptoms that patients with advanced cancer treated in a public and private hospital in Tshwane experienced, and did the advances in palliative care improve patient outcomes for these patients by decreasing the prevalence of the symptoms experienced?

Purpose of the study

The purpose of the study was to determine the most common symptoms of advanced cancer patients treated in a public and private hospital in Tshwane, and whether advances in palliative care improved the outcomes for these patients by decreasing the prevalence of the

symptoms experienced.

Research methods and design

The research methods and design will be described in terms of the context, design, population, data gathering and data analysis.

Context of the study

A contextual study was performed (LoBiondo-Wood & Haber, 2006:561). Contextual means that the study results are only valid for the situation in which the study was done. The context for the study was the radiation and medical oncology clinics at a state hospital and private hospital where cancer patients are treated. Patients treated at these clinics come from all over South Africa and treatment takes place on an outpatient basis.

Population

The population consisted of all patients with advanced cancer receiving palliative treatment in radiation and medical oncology clinics at a state and private hospital in the Tshwane Metropolitan area. Convenience sampling, a form of non-probability sampling, was used. Convenience sampling refers to the use of the most conveniently available patients as study participants and was chosen for this study due to the fact that the patients were readily available when visiting the outpatient clinics. The sample size was 148 participants.

Design

A quantitative survey was conducted. According to Polit and Beck (2004:729), a quantitative survey is described as a process where data is gathered from the specific sample of a population in a structured manner. The ultimate purpose is to describe the phenomenon. According to LoBiondo-Wood and Haber (2006:240-242), an exploratory or descriptive survey design is applicable when the purpose is to gather accurate information about the characteristics of a phenomenon that is specific to a particular group.

Data gathering

The method of data gathering was a structured interview and self report using a checklist as the data gathering instrument. Illiteracy amongst patients did not allow for a self-completed

questionnaire. The checklist was designed using symptoms and problems that patients with advanced cancer experienced according to the literature (Atkinson & Virdee, 2001: 47; Fink & Gates, 2001:66 and Glass, Cluxton & Rancour, 2001: 37- 50). Four additional columns were provided to specify problems not reflected in the checklist. The checklist was designed to reflect both demographic data and the problems experienced. Participants were asked to respond freely to the following question: "What are the main problems and concerns that you are experiencing now?" Participants were not probed and the reported problems were recorded on the checklist. The checklist was pre-tested using 10 respondents and no symptom columns needed to be added.

One field worker conducted the interviews and was trained to use the checklist to indicate which problems participants identified. The field worker was monitored on a weekly basis to ensure consistency and a high standard of data gathering.

Data analysis

Descriptive statistics were used to analyse the results of the checklist and the results were presented by means of frequency figures and tables. Descriptive statistics summarises data to manageable portions and describe its various characteristics (LoBiondo-Wood & Haber, 2006:358). Data were analysed using the SPSS 13.0 programme.

Ethical considerations

It is every researcher's responsibility to ensure that the ethical code is maintained at all times (Brink, 2002:38). Permission to carry out the study was obtained from the Ethics Committee of Technikon Pretoria, the Ethics Committee of the University of Pretoria and the management of the hospitals where the outpatient clinics were located. A cover letter handed and discussed with the participants explained the purpose of the research. It also informed them that they could withdraw from the study at any stage and assured them that their responses would be regarded as confidential. Anonymity was ensured by numbering the checklists sequentially. Informed consent was obtained in writing from all participants. Privacy was ensured as participants were taken aside when interviewed.

Validity and reliability

Validity refers to whether an instrument measures what it is supposed to measure in an accurate manner. A valid instrument will truly reflect the concept which it is supposed to measure. Reliability can be described as the extent to which the instrument produces the same results when repeatedly applied (LoBiondo-Wood & Haber, 2002:338, 345). Measures that were taken to assure the validity and reliability of the study include:

- The checklist was pre-tested to ensure that participants understood the question and that the required information was gathered.
- The checklist was formulated and specifically planned to address the problems that patients with advanced cancer experience.
- One person collected all the data which avoided data-gathering variability.
- The checklist ensured that data were captured correctly as it allowed responses to be ticked off.
- Structural coherence was ensured through all 148 interviews by means of the checklist.

Results of the study

The format for the description of the results is the demographic profile of the participants, their disease status and problems most frequently experienced.

Demographic profile

The ages of the participants (n=148) ranged from 14 to 88 years of age, with the highest number of participants in the 50-59 year group (Figure 1). The 40-49 years age group represented 25.7% of the participants. Sixty percent of the group were female with 40% males.

Although approximately 70% of all cancers occur in people older than the age of 65 (Lemone & Burke, 2004:272), only 17% of respondents were older than 65. Three of South Africa's ethnic groups were represented in the study sample: 51.4% whites, 47.3% blacks and 2% coloureds. The majority of the participants (62.2%) were treated at the public hospital and the rest of the group (37.8%) were treated at the private hospital. Of the group, 57.4% was treated

with chemotherapy and 42.6% radiotherapy.

The participants came from five different provinces in South Africa, mostly from Gauteng (65.5%), Mpumalanga (18.2%) with the rest from North West, Limpopo and the Eastern Cape. The majority of the participants (66.9%) were from urban areas.

Disease status

The group of 148 participants had 33 different cancer diagnoses with the 10 most frequent presented in Table 1. Of the total group, 77% of the participants suffered from the 10 cancers as identified in Table 1. Less frequent diagnosis included chronic myeloid leukaemia, Hodgkin's disease, myeloma, acute lymphatic leukaemia, liver cancer, cancer of the nasopharynx or cancer of an unknown primary.

Lung cancer is the leading cause of cancer in South Africa and is responsible for the most cancer deaths (Medical Research Council, 2007). Lung cancer was the second most common cancer amongst the respondents. Cervical cancer is the most common cancer in females in South Africa with breast cancer the second most common female cancer. Breast cancer was the most common cancer found in the participants with cervical cancer fourth on the list of ten. Oesophageal cancer is the second most common cancer in the South Africa and the third most common cancer in the study group. Colorectal and prostate cancer is among the ten most common cancers in South Africa, with lymphoma, melanoma and bladder cancer all among the twenty most common cancers in South Africa (MRC, 2007).

Symptoms experienced

In Figure 2, the most common symptoms that the participants experienced are reflected. The largest percentage of participants indicated that pain was a problem (76.4%), followed by weakness and fatigue (65.5%), nausea and vomiting (65.5%) and a dry mouth (46.6%). Thirst was reported by 41.2% of the sample, followed by cough (35.8%), dyspnoea (32.4%), weight loss (30.4%), depression (28.4%) and insomnia (27.7%).

In Table 2 these results are compared with the results of similar international studies.

Both the first and second study was

conducted before the World Health Organization published guidelines on the management of cancer pain. It would be expected that the number of patients experiencing pain would dramatically decrease.

Neither of the studies conducted in 2002 (seven years after the publication of the WHO guidelines) show any improvement in the number of patients that experience pain. This result is supported by Beck and Falkson (2001:87) who state that in South Africa a significant number of cancer patients suffer from unrelieved pain. In contrast with the other studies reflected, constipation was not one of the 10 most common symptoms reported by the participants. Thirst and weight loss were among the most common problems in the study group, a finding not reflected in previous studies.

A comparison of each of the 10 most common symptoms experienced by public versus private patients is indicated in Figure 3.

It is clear that more participants being treated at the public hospital than participants being treated at the private hospital experienced pain. Weakness and fatigue, dyspnoea, and weight loss were mostly reported by participants treated at the private hospital and except for pain, more participants treated at the public hospital suffered from nausea and vomiting, a dry mouth, thirst, cough, depression and insomnia.

Discussion

The study provides evidence that developments in palliative care did not necessarily result in positive outcomes for patients as patients with advanced cancer still suffer unnecessarily. Studies have shown that the systematic application of the WHO's guidelines for the management of cancer pain achieved adequate pain relief in up to 90% of patients (Farrer, 2001:13). With 76% of patients (n=148) reporting pain, it is doubtful if these guidelines were applied. It is a well known that private patients have access to a larger range of medication, but even so, half of the patients indicated that pain is a problem. By using the relative inexpensive pain medication of the WHO's ladder for cancer pain, effective pain relief is possible. The high prevalence of pain reported by participants is unacceptable.

A shortage of nurses leads to patient care being compromised. The International Council for Nurses (2002) stated that the inadequate number of nurses has a significant negative impact on patient outcomes and that the health and wellbeing of millions of the world's people are impaired. The nursing shortage is part of the reality of nursing in South Africa. South Africa has 140 registered nurses per 100 000 people, while the United Kingdom, the leaders in palliative care, has 479 per 100 000. Canada has 748 nurses per 100 000 people (Munjana, Kibuka & Dovlo, 2005:40). Another factor that impairs the care of the cancer patient is the shortage of registered oncology nurses. According to Mr A Green of the South African Nursing Council (2006) there were 282 registered oncology nurses in 2006, which translates to one oncology nurse for approximately every 39 400 cancer patients. The unequal distribution of nurses in the public and private health care sector might explain the fact that patients being treated at the public hospital experienced more symptoms than patients receiving private health care. Mafu (2007) a spokesperson of Denosa stated that the nurse to patient ratio in the public sector has deteriorated to 1:50 whilst it is 1:3 in the private sector.

A matter for concern is that a large percentage of patients (42%) reported being thirsty. No evidence that patients in previous studies reported thirst could be found. Apart from thirst causing discomfort, it is associated with dehydration which is associated with an increased risk for bedsores and constipation (Kedziera, 2001:157). This could mean that the hydration status of the patient was neither assessed nor addressed; a serious accusation against the quality of nursing. Not only is the scientific process of nursing not applied, but the palliative care approach – control of pain and other symptoms and psychological, spiritual and social problems – is not practiced.

Conclusion

The study provides evidence that cancer patients still suffer unnecessarily. To improve patient outcomes and reduce the number of symptoms that patients with advanced cancer experience, a registered oncology nurse should be introduced to practice as symptom management consultant. These nurses should be deployed at all oncology out patient care settings to assess and manage patient

problems.

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TABLE 2: Percentage of patient symptoms

| Study | A* | B* | C* | D* |
|---------------------------------|------|------|------|------|
| Year published | 1989 | 1993 | 2002 | 2002 |
| Symptom | % | % | % | % |
| Pain | 62 | 84 | 60 | 77 |
| Weakness/fatigue/lack of energy | 39 | 95 | 50 | 66 |
| Constipation | 34 | 47 | 50 | |
| Nausea and vomiting | 30 | 51 | 40 | 66 |
| Dyspnoea | 26 | 47 | 40 | 32 |
| Fear/worry/anxiety | 20 | | 40 | |
| Sweats | | 60 | | |
| Oedema/lymph oedema | 7 | 60 | | |
| Dry/sore mouth | 4 | 50 | | 47 |
| Cough | | 30 | | 36 |
| Depression | | 38 | 45 | 38 |
| Anorexia | 14 | 71 | 60 | |
| Sleep disturbances | | 51 | 50 | 28 |
| Confusion | 16 | 33 | 30 | |
| Thirst | | | | 41 |
| Weight loss | | | | 30 |

(A*; Finlay, 1997:59, B*; Atkinson & Virdee, 2001:46, C*; Faull & Woof, 2002:64, D*; Current research).

TABLE 1: The 10 most common cancers

| Site | Cancer diagnosis Frequency (%) |
|------------|--------------------------------|
| Breast | 45 (30.4) |
| Lung | 12 (8.1) |
| Oesophagus | 10 (6.8) |
| Cervix | 9 (6.1) |
| Colon | 7 (4.7) |
| Lymphoma | 7 (4.7) |
| Melanoma | 7 (4.7) |
| Ovary | 7 (4.7) |
| Prostate | 6 (4.1) |
| Bladder | 4 (2.7) |

Figure 2: The most common symptoms experienced by the respondents

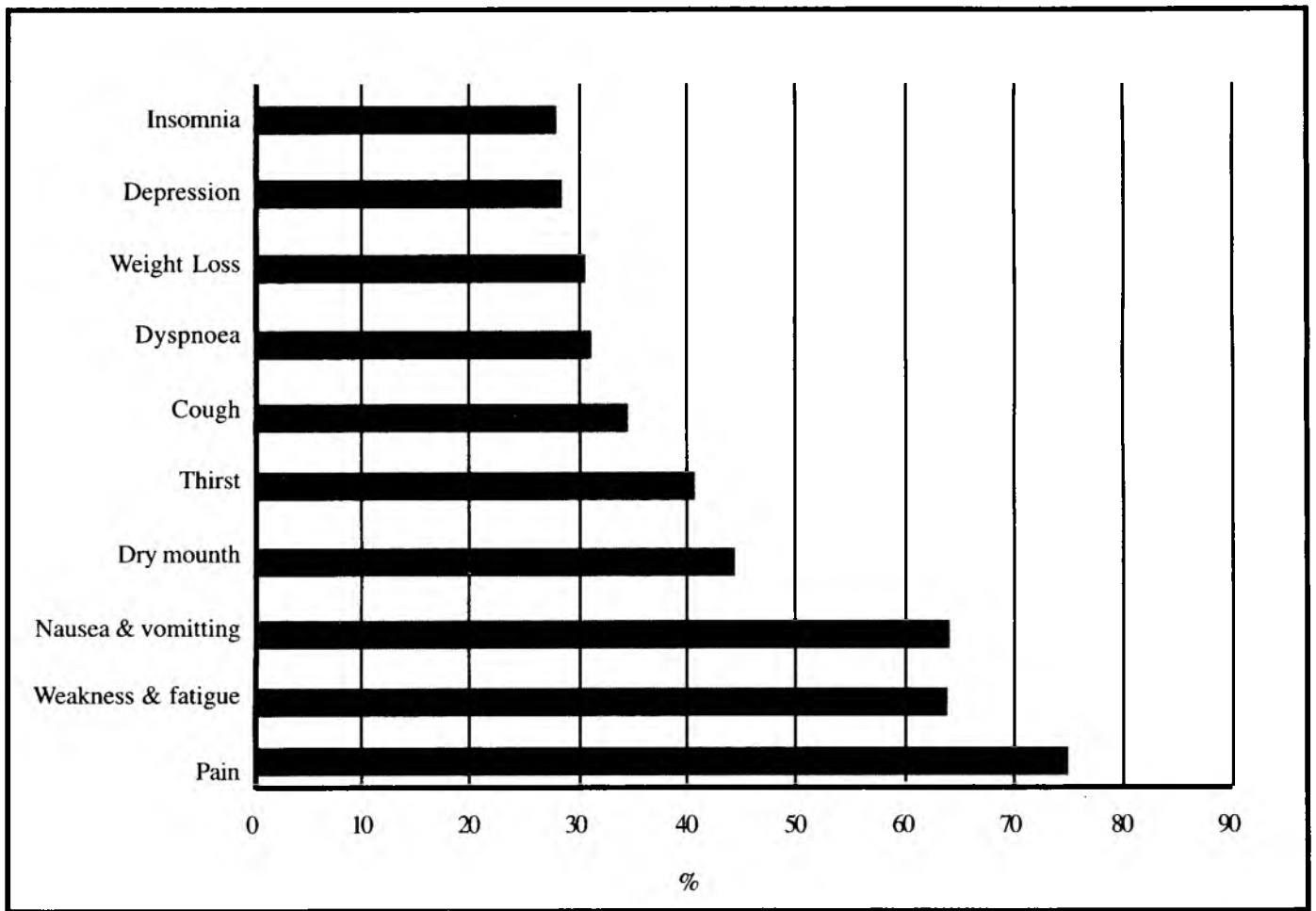


FIGURE 3: Comparison of symptoms of patients treated at a public hospital (n=62) versus patients treated at a private hospital (n=38) reflected as a percentage of the sample

