

PERCEPTIONS ABOUT CANCER TREATMENT: A BLOEMFONTEIN PERSPECTIVE

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ABSTRACT

Cancer patients have varying perceptions about their treatment. The aim of the study was to investigate the different perceptions that patients have about their treatment, and how these perceptions are influenced by their social and cultural backgrounds. The impact of these perceptions on patient responses was also investigated. Eighty-five patients were selected for the study and interviewed using a questionnaire to explore their perceptions and the possible impact of these perceptions on their responses to treatment. An analysis of the perceptions is provided.

Keywords: Perceptions; Cancer treatment; Information.

1. INTRODUCTION

Bloemfontein is the capital city of the Free State province, one of nine provinces of the Republic of South Africa. The oncology facilities in Bloemfontein service the entire Free State, Northern Cape, parts of the Eastern Cape and North West provinces, and the Kingdom of Lesotho. The regions that the Bloemfontein oncology facilities service represent a vast, predominantly rural, geographical area of the Republic of South Africa and Lesotho, and constitute a population of approximately 10 million people (Statistics South Africa, 2008). Patients in this region represent diverse social and cultural backgrounds, with different knowledge, experiences, beliefs, behaviours, and expectations.

Ever-evolving trends in medical science and the emergence of new technology have the consequence of disparities in the oncologists' approaches to the treatment and management of cancer and patients diagnosed with cancer. The disparities in the treatment approaches by oncologists, coupled with the dynamics amongst patient composition, pose interesting challenges to the oncology landscape. These challenges relate to the individual expectations that patients have when they are set to receive treatment, the quality of treatment that they receive, and their perspectives about the treatment that they receive.

The stress and anxiety associated with the diagnosis and treatment of cancer can result in significant reductions in patient quality of life (Fawzy et al, 2007). Patients who have been diagnosed with cancer often face emotional and spiritual distress, which can result in patients becoming vulnerable and emotionally challenged (Kvale, 2007). Fortunately, numerous psychosocial interventions for patients with cancer have been found to be quite effective in assisting with such stress (Fawzy et al, 2007). Interventions aimed at assisting

patients to gain insight into the treatment of their disease have proven successful in improving the psychological and physical health of patients with cancer (Schofield et al, 2003). These interventions include education, stress management, coping-skills training, and support (Schofield et al, 2003). If patients are not appropriately informed on the extent of their disease and the required treatment, such patients can experience heightened anxiety and depression, poor psychological adjustment, ineffective coping, hopelessness, reduced quality of life, and perceptions of reduced control over the disease (Thorne et al, 2008). The importance of appropriate information cannot be overstated since too much or too little, or even inaccurate information can generate negative energy which induces unwanted vigilance and paranoia, making patients sensitive to even the slightest effects of their disease or treatment (Mayer et al, 2007).

Cancer treatment is known to cause adverse effects (Spiegel, 1993). The extent and frequency of adverse effects varies for different patients, cancer types, treatment modalities, and treatment doses (Spiegel, 1993). In order to provide optimal care for cancer patients, health-care professionals need to have adequate insight into and a proper understanding of the precise impact of the disease and cancer treatment (Carelle et al, 2002). The insight of health-care professionals is not only valuable in the administration of treatment, but particularly useful in the interventions of educating, counselling and supporting patients.

According to the South African Patients' Rights Charter, (Constitution of the Republic of South Africa, Act No. 108 of 1996), patients have the right to be given full and accurate information about the nature of their illness, diagnostic procedures, proposed treatment, and the costs involved, for them to decide on any elements relating to their treatment. By implication, patients only consent to treatment once they've been given a clear understanding of their illness and the required treatment, with possible implications of such treatment. Patients who are due to receive treatment for cancer would ideally require a session of pre-treatment counselling where all aspects of treatment are discussed and all possible implications of treatment are communicated to the patient prior to granting informed consent for treatment.

However, practical experience in Bloemfontein oncology treatment facilities seems to contradict the ideals of informed consent. It is common for radiotherapists to be confronted by distressed patients and family when they experience even the slightest adverse effects encountered during the treatment process. The concerns that patients or their loved ones raise often relate to matters that would be assumed to be addressed during the pre-treatment counselling and informed consent phases of consultation. These concerns often translate to despair, loss of hope, and misperceptions that their health has deteriorated rather than improved, resulting in negative attitudes, which could have an impact on the patients' response to treatment. The questions then arise:

If patients are appropriately informed about their treatment, and given a hope of extended and improved quality of life, what suddenly evokes these negative attitudes, and how do they impact on the patients' treatment?

Through this study it was envisaged to address this question by investigating the patients' perceptions about the treatment they receive for cancer at the oncology treatment facilities in Bloemfontein. The objective of addressing this question was to establish the impact of socio-cultural influences on these perceptions, the relationship between patients' perceptions and their responses to treatment, and the relationship between patient attitudes and treatment responses.

2. METHODOLOGY

The study was conducted at two oncology treatment facilities in Bloemfontein over a period of six months. Eighty five patients (n=85) were included in the study, and care was taken to have representation of all diagnoses, race, gender, language, age, literacy levels, and geographical origin. Patients had to have completed at least four weeks of their treatment cycle, to make provision for the manifestation of adverse effects, if the patients did encounter any such effects.

Data collection was done over a period of 6 months between September 2007 and February 2008. Individual interviews were conducted with all the participants by members of the research team. A standard data source form (questionnaire) was used to conduct the interviews. The questionnaire was essentially used to structure the interview process and to make sure that all the participants were asked the same questions in the same way. The use of structured interviews was helpful in ensuring that participants received clarification and clear explanations of the questions, and in preventing the participants and the members of the research team from placing their own interpretation on the questions. All the interviews were conducted in the participants' language of preference.

The questionnaire was developed to capture data relating to the patients' knowledge about their treatment at three levels. Firstly, data relating to participants' prior knowledge about cancer and the treatment thereof had to be captured. Secondly, data relating to participants' knowledge about adverse effects accompanied by treatment for cancer, as well as the participants' expectations of these adverse effects. Finally, data relating to participants' response to adverse effects, their general tolerance of the treatment, and their perceptions to the treatment after having first-hand experience of treatment.

Data that was acquired from the interviews was captured on a spreadsheet using Microsoft Excel® software. A coding system was used to transcribe the data that was acquired from the interviews into codes on the spreadsheet. With the coding system, parameters relating to the participants' knowledge about their treatment were presented in the form of codes. An example of the coding system can be provided in the case where patients were questioned about whether they had

received pre-treatment counselling prior to commencing treatment. Participants could respond by selecting one of several options, which was represented by a code. If the participant acknowledged that s/he did receive pre-treatment counselling the member of the research team selected option (1) by making a cross in the extreme right column, which meant that the participant receiving sufficient information prior to the commencement of treatment. An example of the coding system and the process of selecting the appropriate option are provided in figure 1.

1. Before commencement of your treatment, to what extent were you provided with information relating to your treatment, and the possible effects of the treatment? (Acknowledge receiving pre-treatment counselling)

1	Provided with sufficient information	X
2	Provided with limited / unclear information	
3	Not provided with any information	

Figure 1: Coding system and options as provided in the questionnaire

Descriptive statistics were used to analyse the data collected in the study through summarising the overall patterns and trends regarding the patients' experiences of their treatment. Data collection and analysis yielded various patterns and trends relating to patients' prior knowledge, their expectations, and how they experienced their treatment. In sharing their experiences participants reflected their perceptions about their treatment, and the impact of these perceptions on the outcome of treatment. Data was used to compare different perceptions between differing demographic groupings.

3. RESULTS AND DISCUSSION

The focus of the interviews was to investigate the impact of patient perceptions on their treatment. The impact of patient perceptions was extrapolated from data that was reflected in the questionnaires. The data were also used to compare differences between differing demographic groupings. Of the 85 patients that participated in the interviews 47 were black, 28 were white, and 10 were coloured. With regards to literacy levels, 44 participants were literate, 25 semi-literate, and 16 totally illiterate. Participants were classified as literate if they could read, write and communicate without any difficulty. Semi-literate participants were those who showed limited or basic reading and writing skills, but had the ability to interpret and understand basic concepts relating to their illness and treatment. Participants who could not read or write, or who had difficulty in understanding most concepts that were explained or communicated to them were regarded as illiterate.

When participants were asked if they had received pre-treatment counselling prior to commencement of treatment, 23 (27%) responded that they never received any information, 34 (40%) said they received limited information, while the remaining 28 (33%) said that they were thoroughly informed (see Figure 2).

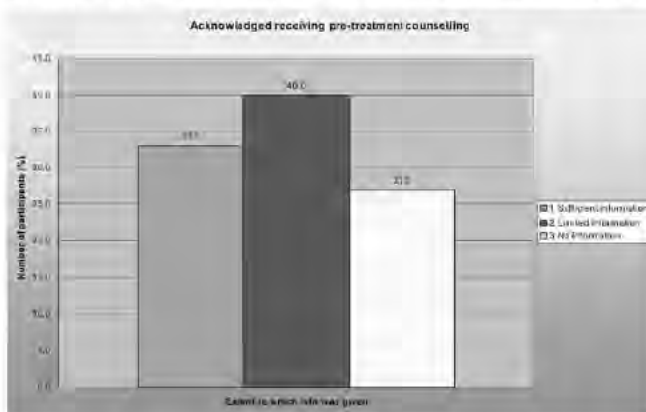


Figure 2: Summary of acknowledgement of pre-treatment counselling

When asked if they had any prior knowledge about cancer, 53 (62.4%) indicated that they had no prior knowledge about cancer, 17 (20.0%) indicated that they had limited knowledge about cancer, while 15 (17.6%) indicated that they did have prior knowledge about the disease (see Figure 3).

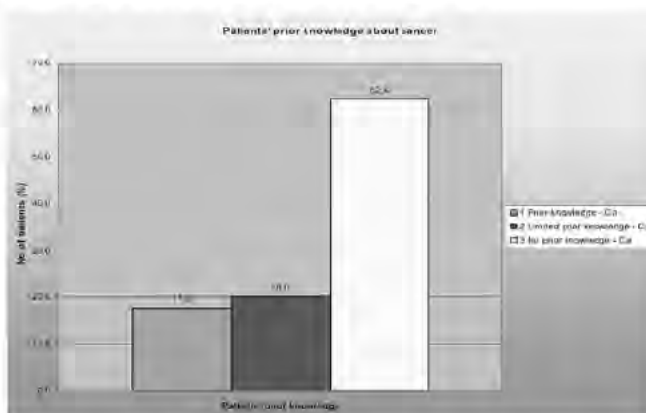


Figure 3: Summary of patients' prior knowledge about cancer

Participants were also asked if they expected any adverse effects from the treatment after pre-treatment counselling. Of the 85 patients 27 (31.8%) did not expect any adverse reactions, 9 (10.6%) did not know, while 49 (57.6%) expected some kind of adverse reactions to the treatment (see Figure 4).

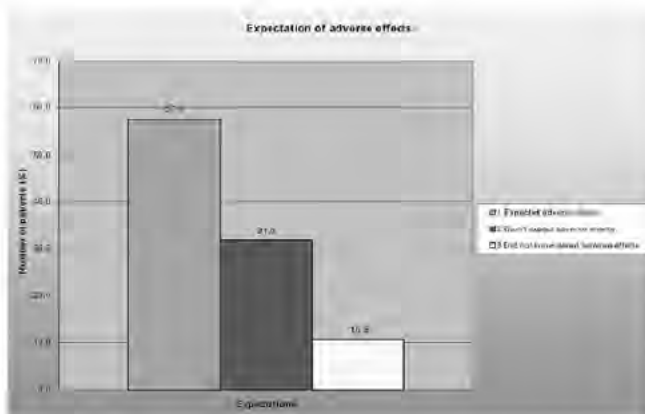


Figure 4: Summary of patients' expectations of adverse effects

Participants were requested to give a general view of their experience of the treatment, under the classification of good, bad or uncertain. Twenty five (29.5%) patients experienced the treatment to have a good or positive effect, 15 (17.6%) were uncertain, and 45 (52.9%) claimed to have bad or negative experiences (see Figure 5).

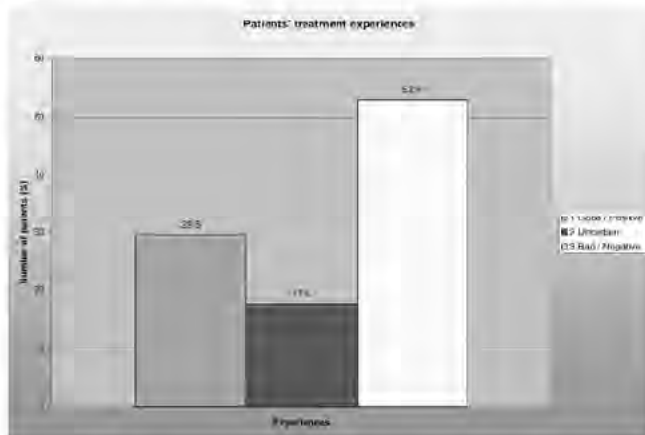


Figure 5: Summary of patients' experiences of their treatment

On the question relating to whether the patients did experience any adverse effects, patients reported as having experienced noteworthy to severe, negligible or no adverse effects from the treatment. Of the 85 participants, 55 (64.8%) reported noteworthy to severe, 15 (17.6%) reported negligible, and 15 (17.6%) reported no adverse effects incurred from the treatment (see Figure 6).

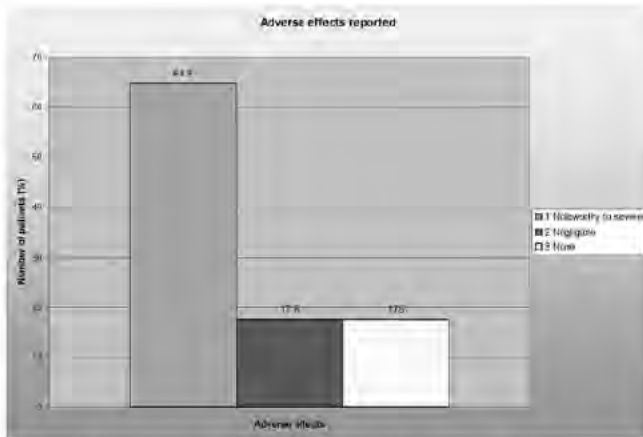


Figure 6: Summary of adverse effects reported by patients

Participants were also asked whether they felt better or worse after receiving treatment. Of the 85 participants 49 (57.6%) reported that they actually felt worse after receiving treatment, 13 (15.3%) were not sure, and 23 (27.1%) reported that they felt better after commencing with their treatment (see Figure 7).

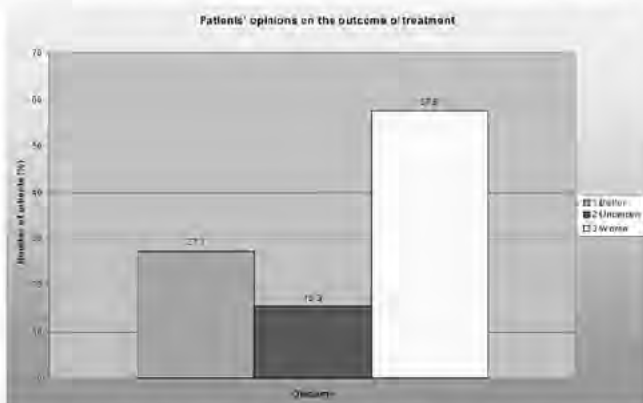


Figure 7: Summary of patients' opinions on the outcome of treatment

Similar to the studies conducted by Mager et al (2002:39), Siminoff et al (2006:358), Ward et al (2004:81), and Thorne et al (2008:37), this study was aimed at analysing the relationship between patients' perceptions and their responses to treatment, and the relationship between patient attitudes and treatment responses. The results showed a close correlation between the patients' expectation of adverse effects and the adverse effects that were actually reported by patients in the study. From the results it would seem that

most of the patients who reported adverse effects (64.8%) might have actually expected the effects (57.6). It would also seem that the patients who reported adverse effects held negative opinions about the outcome of the treatment (57.6%), stating that they felt worse after treatment than before treatment. The patients' opinions on the outcome of treatment seem consistent with their general experiences of the treatment, with 52.9% patients reporting bad or negative experiences.

The results also offered some evidence on the role of participants' socio-cultural conditions. Unlike the participants from the rural areas, the participants from the urban areas seemed to show more ease in grasping and conceptualising information relating to their disease and treatment. The same observation was made with regards to the participants' literacy levels. The illiterate and semi-literate participants either struggled to grasp or didn't grasp at all, even after several consultations and interventions. Participants, mainly urban-based and literate, who had access to other sources of information such as the internet, other sources of literature, knowledgeable friends, colleagues and significant others, acknowledged consulting these sources at some point. The participants who easily conceptualised and grasped the information relating to their treatment also showed an inclination to expect adverse effects from the treatment, and eventually did experience such effects.

All patients sign their treatment files before commencing with their cancer treatment. This is done in accordance with the South African Patients' Rights Charter, (Constitution of the Republic of South Africa, Act No. 108 of 1996). By signing their files patients acknowledge that they have been duly informed about their treatment and therefore grant consent to the administration of such treatment. It was notable during the interviews that even though patients granted informed consent for their treatment, some participants in the study claimed not to be informed about their treatment and possible adverse effects. However, from discussions with the participants in the study, they seemed to reveal a reasonable understanding of the possible consequences of terminating or withdrawing from the treatment. From these discussions it was also observed that some patients granted consent for reasons other than the objectives of the Patients Rights Charter. Some of the reasons that participants cited were as expressed in their own words: "I'm prepared to go through this...as long as its going to help me live longer...life is far more worth a bit of pain...if I don't sign I wont receive treatment...I come from far so I have to take this treatment...if they don't burn the cancer, then the cancer is going to consume me..." Despite the belief that the treatment made them sick and did more harm than good, the conviction to complete treatment was strengthened by the fear of death and the belief that there is still much to live for. The conviction to complete treatment was evident amongst all demographic groupings.

Throughout the study it was notable from dialogue with patients that any visit to the hospital is a challenging and sometimes overwhelming experience which

induces anxiety and fear. Participants stated that a diagnosis of cancer and subsequent referral for treatment made such a visit terrifying. Participants identified the improvement of healthcare workers' communication skills and the emphasis on the possible adverse effects of cancer treatment during pre-treatment counselling and throughout treatment, as a vehicle to help patients overcome their anxiety and fear. It was also evident from the study that the principles of holistic care based on treating the patient with cancer, rather than treating the cancer are still valid, even in the modern era of digital technology.

The observations from this study also re-affirm the principles of holistic care based on treating the patient with cancer, rather than treating the cancer. When treating patients in a diversified environment such as Bloemfontein, the uniqueness of individuals and the socio-cultural dynamics of the region should always be taken into account. Counselling of patients should not be a process that is limited to the acquisition of informed consent from patients, but rather as a continuous process of communication and counselling that seeks to address patient fears and anxieties, and to maintain a positive attitude towards treatment. The findings of the study seem to correlate with the findings of other similar studies by Finset et al (1997:175), Ward et al (2004:85), and Ong et al (2000:147), that patients need to be well informed about their treatment, not only to make informed choices with regards to their treatment, but also to be adequately prepared to deal with the consequences of the treatment. However, when patients are inappropriately informed such information can have the opposite effect. Too much information can result in patients being over-prepared, resulting in patients responding to even the slightest indication of what they anticipate on the basis of knowledge or information at their disposal.

4. CONCLUSION

From the data analysis it could be concluded that patients who were better informed about the adverse effects, had actually expected to experience adverse effects themselves. There was concurrence between the adverse effects that patients expected and what they experienced. The incidence of adverse effects also seemed to impact negatively on the patients' general perceptions about their treatment, which in turn affected their attitude towards the treatment. Patients who had negative perceptions about the treatment did not tolerate their treatment well, which resulted in an increase in the incidence of adverse effects. The relationship between patients' perceptions, attitudes and tolerance of treatment can be summed up as: Positive perceptions of treatment result in positive attitudes towards treatment, which in turn, result in increased tolerance levels or thresholds for adverse effects of treatment.

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