

THE INFORMATION NEEDS OF CANCER PATIENTS IN THE PRETORIA AND WITWATERSRAND AREA

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ABSTRACT

More than 48 500 South Africans annually are confronted with the diagnosis of cancer. (Sitas, 1994) Judging from the literature it would seem that the acquisition of information about the various aspects of their disease is a very important coping mechanism for the cancer patient. Various studies concerning the information needs of cancer patients have been published in the USA, the UK and Australia. Similar studies have not yet been published in South Africa.

In this article the information needs of cancer patients in South Africa are tabulated based upon research done for the fulfillment of requirements for a Masters degree in Information Studies at the Rand Afrikaans University. Information Services available to these patients are then also described in detail.

Because of the sensitive nature of the subject questionnaires were compiled in co-operation with medical professionals who treat cancer patients. The questionnaire mainly concentrates on the physical and therapeutic aspects of the disease. Surgery, radiation therapy and chemotherapy are looked at.

The research population consisted of 200 cancer patients who were receiving treatment at various treatment centres in the Pretoria -Witwatersrand area. The statistical processing of the results confirmed that the majority of the cancer patients need detailed information about the various aspects of their disease. For example more than 75% of respondents indicated that they would like to receive detailed information about reasons and possible side effects as well as ways of minimising the side effects of all the treatment methods ranging from diagnostic tests to surgery as well as radiotherapy and chemotherapy.

Above 80% of respondents wanted to be informed about the possible success rate of surgery, radiation therapy and chemotherapy in their specific cancer. It is interesting to note that 78.5% of the respondents wished to be informed about the prognosis/survival rate of their specific cancer. The two preferred methods of communication indicated were firstly personal contact and then a combination of personal contact and booklets.

An important conclusion which can be reached is that co-operation between the medical professionals, the information services and the patient and his family is

essential if the information needs of the cancer patient are to be met satisfactorily.

OPSOMMING

Meer as 48 500 Suid-Afrikaners word jaarliks gekonfronteer met die diagnose : kanker. Uit die literatuur blyk dit dat inligting oor die verskillende aspekte van die siekte 'n baie belangrike hulpmiddel vir die pasient is in die hantering van sy siekte. Verskillende studies is al in lande soos die Verenigde State van Amerika, Australie en Groot-Brittanje gedoen oor die inligtingsbehoefes van kankerpasiente en hulle families. Soortgelyke studies is nog nie in Suid-Afrika gepubliseer nie.

In hierdie artikel word die inligtingsbehoefes van kankerpasiente in Suid-Afrika getabuleer soos bevind in navorsing gedoen ter vervulling van die vereistes vir 'n Magister graad in die Departement Inligtingstudies aan die Randse Afrikaanse Universiteit. Inligtingsdienste beskikbaar aan die pasiente in Suid-Afrika word ook dan in detail beskryf.

Vanwee die sensitiewe aard van die onderwerp is die vraelys ontwikkel met die samewerking van medici wat kanker pasiente behandel. Met die vraelys word veral gekonsentreer op inligtingsbehoefes in verband met die fisiese en terapeutiese aspekte van die siekte. Chirurgie, chemoterapie en radioterapie word gedek.

Die proefpersone het bestaan uit 200 kankerpasiente wat behandeling ontvang het by verskillende sentra in die Pretoria-Witwatersrandgebied. Die statistiese verwerking van die resultate het bevestig dat die oorgrote meerderheid van kankerpasiente 'n behoefte het aan gedetailleerde inligting oor verskillende aspekte van hulle siekte. Meer as 75% van respondente het byvoorbeeld aangedui dat hulle gedetailleerde inligting oor die redes en moontlike nuwe effekte sowel as metodes om die nuwe effekte teentewerk van al die behandelings metodes van diagnostiese toetse tot chirurgie, chemoterapie en radioterapie wil ontvang. Meer as 80% van die respondente het aangedui dat hulle ingelig wil word oor die moontlike sukses van chirurgie, chemoterapie en radioterapie op hulle spesifieke kanker. Dit is interessant dat 78.5% van die respondente ingelig wil word oor die prognose van hulle spesifieke kanker. Die twee metodes van kommunikasie wat verkies word is eerstens persoonlike kontak en dat persoonlike kontak gekombineer met pamflette. 'n Belangrike gevolgtrekking wat gemaak word is dat samewerking tussen die mediese professie, die verskillende inligtingsdienste en die pasient

INTRODUCTION

Cancer is a word in the English language capable of striking fear into even the bravest of hearts. According to the report of the Cancer Registry of South Africa for 1989, more than 48 500 new cancer patients were diagnosed during that year. Although up to date statistics are not available as yet, it is reasonable to say that this figure can be safely projected to the present.

Each of these 48 500 newly diagnosed cancer patients will experience the fear traditionally instilled by this diagnosis. Lee, editor of the Medical Association of South Africa publications, points out that, as in most other dimensions of human experience, fear is always much worse if based upon ignorance.

A literature study made clear that the health care profession's approach to the patient with cancer has changed over the past decade. The trend in recent years has been one of greater patient participation in illness management decisions. In order for the patient to be able to participate positively in this process, he has to be provided with accurate information in the appropriate language at the appropriate time in the course of his illness.

This article aims to describe what the information needs of the South African cancer patient are in order to facilitate the provision of such information at appropriate times. A further aim is to describe the information services available to the cancer patient in South Africa.

METHODS USED IN THE STUDY

Because of the sensitive nature of the subject it would have been impossible to complete the study without the co-operation of several health care professionals in the cancer field. By combining input from these health care professionals with guidelines from a literature review, a structured questionnaire was designed. A chronological study of literature pertaining to the information needs of cancer patients demonstrates the growing importance of this aspect of patient care as an integral part of the treatment of the patient as a whole.

The content of the questionnaire was compiled using a combination of interviews conducted with the oncologists and doctors working in oncology surgery and guidelines from the literature.

Using the Derdarian Needs Assess Instrument devised by Derdarian (1986) as a basis, the questionnaire was compiled. According to this instrument the areas which need to be addressed are:

- i) Disease-related concerns such as diagnosis, treatments and prognosis.
- ii) Personal concerns such as physical and psychological well-being, job/career.

iii) Family related concerns including spouse, parents, children and siblings.

iv) Social concerns such as contractual, leisure and intimate relationships.

The five main subjects of enquiry to the Cancer Information Service in the United States as described by Meissner (1990:173) were then compared to the categories described by Derdarian (1986) and three additional aspects which needed to be investigated were identified:

- i) Referral/second opinion - names of doctors available for second opinions.
- ii) Counselling services - telephone numbers of counselling services and support groups.
- iii) Clinical trials in which patients can participate.

Adams (1991) describes what the content of education programmes should be. She focuses on the information/education needs of the patient during the following five phases of the disease:

- i) Diagnosis
- ii) Treatment
- iii) Rehabilitation and continuing care
- iv) Cancer survivorship/remission
- v) Recurrence or advanced disease

Adams concentrates on the practical information needed by patients such as side effects, pain management and physical limitations due to the disease.

Frith (1991) stresses the importance of written materials which should be made available and Schulmeister (1991:122) lists numerous teaching tools and methods like video tapes and booklets which can be used to educate the patient. It is important to ascertain which format the patient would prefer and therefore questions which address this aspect should be included.

Additional aspects were highlighted by the health care professionals interviewed:

- i) Information about complementary therapies such as aroma therapy and reflexology.
- ii) Counselling in conjunction with written material.

Using the guidelines for designing a questionnaire as set out by Berdie and Anderson (1974) and combining these with the above aspects as depicted in the literature and interviews, a questionnaire was developed.

The questionnaire is divided into three main sections and covers the following aspects:

Section A:

Sociographic data

Data on cancer site

Treatment modalities which the patient has undergone or is undergoing

Section B:

Physical nature of cancer

Prognosis

Information resources available to the patient

Self help/support groups

Diagnostic tests : all aspects pertaining to these tests

Surgery : all aspects pertaining to surgery

Radiation therapy : all aspects pertaining to radiation therapy

Chemotherapy : all aspects pertaining to chemotherapy

Complementary therapies

All forms of treatment available to patients

Counselling services available

Clinical trials

Second opinions

"Miracle" / "fad" cures

Spiritual and religious guidance

Diet and nutrition

Medical aid coverage

Health care system

Section C:

Communication with family members, friends and colleagues

Knowledge of services of CANSA

THE SAMPLE

The questionnaires were sanctioned by the ethics committees of the HF Verwoerd Hospital and the University of Pretoria, the Johannesburg General Hospital and the University of the Witwatersrand as well as the heads of the radiation therapy section of Sandton Oncology Clinic and the Rand Clinic.

Table 1 : Information needs of 200 cancer patients in the Pretoria and Witwatersrand area (a)

QUESTION:

DO YOU WISH TO BE INFORMED ABOUT?

	Not at all		Definitely		
	1	2	3	4	5
DIAGNOSTIC TESTS					
Reason for diagnostic tests	2.5 %	15%	3.5%	4.5 %	74.5%
Possible side effects of tests	2.5 %	0.5 %	2%	3%	92%
SURGERY					
Success rate of surgery in specific cancer	5%	2%	4.5%	5.5 %	83%
Need to provide booklet/ pamphlet explaining pre-operative procedures	4%	1.5 %	9.5%	12.6%	72.4%
Possible physical disfigurement from operation	5%	1%	4%	3%	87%
RADIATION THERAPY					
Success rate of radiation on specific cancer	3.5%	2%	3.5%	3%	88%
Treatment schedule to be discussed	3.5 %	1.5 %	5.5%	3.5 %	86%
Minimising of side effects due to radiation therapy	5.5 %	1%	3%	1.5 %	89%
CHEMOTHERAPY					
Success rate of chemotherapy in specific cancer	9.5 %	0	6.5%	3%	81%
Whether chemotherapy is having desired effect	7%	0	10.5 %	2%	80.5%
Option of stopping treatment if not having desired effect	7.5%	0.5 %	8%	2.5 %	81.5%
Minimising side effects due to chemotherapy	7%	0	8.5%	1%	83.5%
GENERAL					
Prognosis / Survival rate	11%	2%	6.5%	2%	78.5%
Details of Information Resources in South Africa	19%	3.5 %	10.5 %	10%	57%
Self help / patient support groups	24%	5.5 %	14.5 %	4.5%	51.5%
Complimentary therapies	11.5%	2%	8.5%	9.5 %	68.5%
All current forms of treatments in South Africa	5.5 %	1.5 %	9%	4%	80%
Counselling Services available in South Africa	11%	3.5 %	10%	8.5 %	67%
Clinical trials pertaining to specific cancer	5%	3%	9%	6.5 %	76.5%
Names of doctors / specialists for second opinions	5%	3%	4.5%	7.5 %	80%
Methods used in "fad" treatment or "miracle" cures	31.8%	3.7%	14.1 %	7.1%	43.4%
COMMUNICATION					
Resources available for help with communication	14.2%	4.6 %	11.2 %	5.6 %	64.5%

The research was started in 1993 and completed in 1994. The sample was made up of 200 patients being treated at the above centres. All questionnaires were handed to the patients personally at the treatment centres with a 100% response rate. There was an even spread of private and "hospital" patients as the questionnaires were completed at both Government Hospitals as well as private oncology clinics; 39% of the patients were

English speaking, 50% Afrikaans speaking and 11% were from other language groups. The questionnaire was given only to literate patients in either English or Afrikaans.

Of the respondents 132 had undergone surgery while 97 had undergone or were undergoing chemotherapy and 125 had undergone or were undergoing radiation therapy.

DATA OBTAINED FROM STUDY

Sociographic Data

The mean age of the group was 48, with the eldest being 85 and the youngest 13. Most towns in the Pretoria-Johannesburg area were represented. Both male and female respondents were represented.

RESULTS OF THE STUDY

The main body of the questionnaire can be divided into four main sections according to the format of the questions asked. These sections are subdivided according to the various diagnostic procedures and treatment modalities (Table 1 - 4).

It is clear that most respondents wish to be informed about all aspects pertaining to the diagnosis of their disease and the various treatment modalities. Where psychosocial aspects are concerned it is interesting to note that respondents showed less interest in receiving information about self help/support groups and details of information resources available to them. Another aspect which many respondents do not want information about is that of "fad" treatments or "miracle" cures. Many respondents show a great interest in obtaining information about clinical trials which pertain to their specific cancer.

Many respondents indicate that they would like to receive a great deal of information about the physical nature of their cancer as well as various aspects of the different treatment modalities.

Religious/spiritual guidance during the course of the disease is seen as being crucial to most respondents. Communication about their disease is crucial to most respondents where the spouse and children are concerned. Communication with colleagues is not seen as crucial to many respondents.

METHODS OF COMMUNICATION

According to the frequency study, personal contact is the preferred method of receiving information about the disease. A combination of personal contact and booklets was indicated as being the second most preferred method.

CONCLUSIONS

The results of this study clearly indicate that patients with cancer require a substantial amount of information about their disease and its treatment. The nature of the specific disease as well as all aspects of treatment as outlined in the tables need to be discussed with the patient. Personal communication with a member of the health care team as well as written information to enhance the

TABLE 2 : Information needs of 200 cancer patients in the Pretoria and Witwatersrand area (b)

QUESTION: HOW MUCH INFORMATION DO YOU REQUIRE ABOUT	No Information	Some Information	Basic Information	Quite detailed information	A great deal of information
	1	2	3	4	5
PHYSICAL NATURE OF CANCER					
Written information about physical nature of specific cancer	16.5%	1%	8%	4.5%	70%
SURGERY					
Detail about pre-operative procedures	4%	1.5%	10.5%	8%	76%
RADIATION THERAPY					
Purpose of Radiation therapy	5%	0.5%	6.5%	5%	83%
Effects (what it does) of Radiation therapy	5%	1%	6%	3%	85%
Treatment procedure followed by the radiation therapist	4%	5%	6.5%	9.5%	78.5%
Possible side effects of radiation therapy	5%	1%	4%	2.5%	86.4%
CHEMOTHERAPY					
Purpose of chemotherapy	10.3%	1.5%	6.7%	2.6%	78.5%
Effects (what it does) of chemotherapy	9.5%	0.5%	9%	3%	78%
Treatment procedure used by oncologist	6%	0	6.5%	4%	83.5%
Side effects of chemotherapy	8.5%	0	8%	4%	79.5%
Diet while undergoing chemotherapy	10.5%	1.5%	11.5%	5%	71.5%
GENERAL					
Diet and nutrition after treatments have been completed	4%	1.5%	7%	11.6%	75.9%
Coverage of specific medical aid for cancer care	17.6%	0	4%	7.5%	70.9%

Table 3 : Information needs of 200 cancer patients in the Pretoria and Witwatersrand area (c)

QUESTION: HOW MUCH DETAIL DO YOU REQUIRE ABOUT	No Detail				Full Detail
	1	2	3	4	5
DIAGNOSTIC TESTS					
Procedure used during diagnostic tests	5.5%	1%	5%	6%	82.5%
Results of diagnostic tests	0	0.5%	4%	6.5%	89%

Table 4 : Information needs of 200 cancer patients in the Pretoria and Witwatersrand area (d)

QUESTION: HOW IMPORTANT IS THE FOLLOWING ASPECT TO YOU?	Not at all				Crucial
	1	2	3	4	5
SPIRITUAL/RELIGIOUS GUIDANCE					
	2%	2%	8.5%	8%	79.5%
COMMUNICATION ABOUT YOUR DISEASE TO:					
Spouse / Significant other	9.6%	0.5%	4%	4.5%	81.3%
Parents	27.7%	1.5%	11.8%	4.6%	54.4%
Siblings	11.7%	4.6%	11.7%	6.6%	65.5%
Children	8.1%	2%	10.2%	9.1%	70.6%
Colleagues	24.7%	6.6%	25.8%	9.6%	33.3%
Friends	7.1%	6.1%	23.2%	12.6%	51%

information clearly is a preference with most patients.

These conclusions are in line with findings of Lancaster (1980); Reynolds' (1981); Derdiarian (1986, 1989); Freimuth (1989); Meissner (1990); Adams (1991); Frith (1991); Schulmeister (1991).

Respondents definitely want to receive full details about the procedures used during diagnostic tests and also the results of such tests.

Final Reflections

From the literature study conducted it is clear that the trend in recent years has been one aimed at greater openness between the doctor and the patient. Despite this trend, however, patients still express the need for more information about most aspects of their disease as indicated by the results of the empirical study. Respondents indicated that they need a great deal of information about most aspects covered in the empirical study. The lowest percentage of respondents, namely 43%, indicated that they definitely wanted information about fad treatments. This was the lowest percentage recorded. Most of the questions, however, revealed that the percentage of respondents who wanted information about the various aspects was above 70%, with many above the 80% mark. By equipping the health care professional with skills in communication and information provision, this need can be met.

The results of this study can be used to good effect by health care professionals dealing with cancer patients.

The role which the Cancer Association of South Africa as well as the other information services available in South Africa can play in the provision of information to the cancer patient cannot be stressed enough. Co-operation between CANSA, CISS (Cancer Information & Support Service) and the various health care professionals needs to be expanded. CANSA and CISS already have the basic information provision structures in place and there is generally a good relationship between CANSA and CISS and the various health care professionals, both in government-run institutions as well as the private sector. However, the specific information service offered by CANSA needs to be promoted more. Further study to evaluate the services offered at present is needed so that further recommendations can be made.

This study clearly highlights that fact that there is great need for structured information provision to the cancer patient in South Africa. In order to meet the needs of the patients as illustrated by the empirical study, co-operation between the various role-players in the cancer field is of paramount importance.

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