

**TEAM-PATIENT COMMUNICATION OF INFORMATION AND SUPPORT
AT THE BREAST CANCER CLINIC OF THE JOHANNESBURG HOSPITAL**

by

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ABSTRACT

This study addresses the effectiveness of communication between the team (doctors, sisters and social workers) and patients at the Breast Cancer Clinic of the Johannesburg Hospital.

The needs of patients were highlighted, as well as the role of care-giver, both as a group and in their separate disciplines, in attempting to meet these needs.

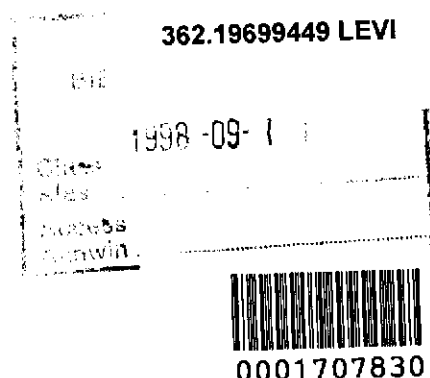
The empirical survey was carried out through the use of questionnaires as well as interview schedules. Patients, doctors, nurses and social workers were used as respondents.

Results indicated that the majority of patients' needs for information and support were met by the team in general; however, a need for further social work intervention seemed to be apparent. In addition, several barriers were found to inhibit both team-patient and inter-team communication.

The researcher used the information gathered in this study to make recommendations that will facilitate improved communication in the clinic, with specific reference to the role of the social worker.

KEY WORDS

Patient, Breast Cancer, multi-disciplinary team, information, support, communication, doctor, nurse, social worker, roles.



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DECLARATION

I declare that

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is my own work and that all the sources that I have used or quoted have been indicated and
acknowledged by means of complete references.

.....*Levin*.....

SIGNATURE

(MRS D LEVIN)

.....*2 December 1997*.....

DATE

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CHAPTER ONE

THE RESEARCH PROBLEM

1.1 PROBLEM FORMULATION

The issue being addressed in this research is the effectiveness of communication between the team (i.e. doctors, sisters and social worker) and patients at the Breast Cancer Clinic of the Johannesburg Hospital.

The matter under investigation is three-fold:

- (a) What aspects of communication with their patients do the team perceive to be important, and are they able to practice these aspects?
- (b) What aspects of communication with the team do patients perceive to be important?
- (c) The role of different team members for meeting the needs of the patients

Ireland (1993: 120) says that a comfortable, honest, friendly relationship with a doctor is something of tremendous benefit to the patient during the counselling, decision-making and adapting stages of breast cancer. His or her support and empathy can help or prevent many problems which may arise later. The researcher would extend this comment to the whole treatment team at the Johannesburg Hospital.

The research focuses on two areas of concern:

- * The patient's understanding of the illness, and sense of having enough information regarding treatment and treatment options.
- * Emotional support which the patient receives from the treatment team.

A good relationship with the staff is an important aspect of a patient's medical care and will influence the way in which patients and family members cope with the illness (Chesler and Barbarin 1987: 66).

The following broad areas will be investigated:

Transmission of information

Perceptions of the team and the patient regarding:

- * how information should be transmitted
- * who should transmit information
- * how much information needs to be transmitted, at different stages of the illness
- * do patients perceive the information received to be helpful?

Honesty and clarity of information

- * the degree of accurate and forthright information, as opposed to false reassurances
- * the patients' feeling of ease to ask questions and state needs

Quality of interpersonal contact

- * To what extent are these contacts characterised by mutual respect, empathy, sensitivity and caring?
- * How satisfying or stressful is the relationship?

Ability to resolve conflict

- * Can areas of conflict be raised and negotiated with mutual respect and concern?

1.2 Reasons for choosing the area of investigation

The researcher worked at the Breast Clinic of the Johannesburg Hospital for two-and-a-half years. During this time she became aware of the fear and turmoil confronting these patients, especially at the initial stages of the illness.

The word 'cancer' conjures up in the minds of the lay public, images of mutilation, pain and suffering, dependency on health-care teams and family and friends, loss of sexual attractiveness, loss of potency and death (Krumm 1982:729).

The researcher held discussions with these patients and it seemed that many were ill-equipped to deal with their illness, in that they lacked information and support from the health-care professionals with whom they were involved.

Communication may make the difference between a composed functioning person and an anxious and depressed one. The difference lies not in the nature of the disease, but in the information and support given to the patient in the physical, emotional, spiritual and social spheres (Lichter 1987: 1).

It was with this in mind that the researcher sought to clarify the needs of the patients, as well as the role of the team members in meeting these needs.

The researcher's experience was also that the team was not co-ordinated in their efforts at meeting the needs of the patients. Nason (1983: 25) claims that team co-ordination is necessary to ensure that both the needs of the team and the patient are being met. The researcher, therefore also sought to understand why the team was not working in a co-ordinated way and how team relationships could be improved, in order to better meet patients' needs.

The value of the research would therefore be, to clarify to the medical team what the needs of the patients are. Recommendations for change would follow from this, both from the viewpoint of the team and the patients. The results of the research will be used to facilitate changes in the clinic, where an improved structure could be established to better meet the needs of the patients.

1.3 AIM AND OBJECTIVES

1.3.1 AIM

The aim of the research is to examine:

- (a) the needs of breast cancer patients for information

- (b) the needs of breast cancer patients for support
- (c) the role of the different team members for meeting these needs

1.3.2 OBJECTIVES

In order to achieve the above aim, the following objectives were set for the study:

- (a) to investigate the perceptions of breast cancer patients regarding the information they receive from the team.
- (b) to investigate the perceptions of breast cancer patients regarding the support they receive from the team.
- (c) to explore the views of doctors, sisters and social workers in the clinic, regarding the type of communication with their patients which they feel to be important.
- (d) to establish whether barriers exist to good communication.
- (e) to establish whether barriers exist to inter-team communication.
- (f) following the above, to clarify the role of the social worker in the clinic, both with the multi-disciplinary team and with the patients.
- (g) to conduct a literature study on the role of communication between the team and the cancer patient in holistic healing.

1.4 ASSUMPTIONS

- * The needs of breast cancer patients for information are not being met adequately.
- * The needs of breast cancer patients for support are not being met adequately.
- * Barriers to communication exist among team members, which block effective communication from taking place.

1.5 RESEARCH DESIGN

1.5.1 TYPE OF RESEARCH DESIGN

According to the criteria of Rubin and Babbie (1989: 86-88) this study has elements of an *exploratory*, *explanatory* and *descriptive* design.

It is *exploratory* because:

- * it explores what patients and the team perceive good communication to be.

- * it explores reasons for current patterns of communication
- * it explores alternatives in which more constructive communication can take place

Hence a new area is being explored in order to generate information on a topic about which little is known.

It is *descriptive* because:

- * it describes the type of communication presently taking place in the clinic

The research is *explanatory* in that it seeks to explain the reasons for some of the difficulties in communication. According to Rubin and Babbie (1989:88) this type of research design looks at the 'why' of certain phenomena.

1.5.2 GUIDELINES FOR THE INVESTIGATION

The guidelines for structuring the investigation in such a way that relevant information could be obtained were as follows:

Sources of information

The sources of information included reviews of the published literature on the needs of the breast cancer patient and the role of the team in terms of imparting information and support.

In addition, questionnaires were filled out by breast cancer patients, and interviews were held with doctors, sisters and social workers at the Johannesburg Hospital.

1.5.3 THE RESEARCH PROCEDURE

The research conducted comprised the following steps:

- * A comprehensive theoretical and literature study was conducted. Aspects that were researched were :

- communication
 - reactions of the breast cancer patient
 - the need for effective communication and support
 - the need for information
 - the role of the multi-disciplinary team in general
 - the role of each member of the multi-disciplinary team
-
- * The researcher obtained permission to carry out the study from the head professor at Johannesburg Hospital Breast Clinic.
 - * A questionnaire was designed by the researcher for the patients.
 - * An interview schedule was designed by the researcher for doctors, sisters and social workers
 - * A pilot study was undertaken using three patients and two doctors.
 - * Both the questionnaire and interview schedule were then modified on the basis of the pilot study.
 - * A sample was selected.
 - * The questionnaires were explained and personally handed to the patients for completion.
 - * The data was recorded and tables comprising the responses of the respondents were evaluated, analysed; inferences were made in terms of the existing literature and theories.
 - * On the basis of the results, recommendations were made in terms of how communication could be improved on between breast cancer patients and the medical team.

1.5.4 DATA REQUIRED TO TEST THE RESEARCH ASSUMPTIONS

In order to test the assumptions in section 1.4, the following information was obtained:

*** PATIENT QUESTIONNAIRE****- Psycho-social factors**

Various psycho-social particulars of the breast cancer patient were identified such as:

- Age
 - Sex
 - Race
 - Home Language
 - Level of Education
 - Previous need for psychological/psychiatric treatment
-
- Transmission of Information
 - Patients' understanding of diagnosis and treatment
 - How patients would have preferred information to be put across, if relevant
 - Members of the team from whom patients would like to obtain information and support
-
- Patients' needs
 - Information needs
 - Support needs

*** TEAM QUESTIONNAIRE**

- Features of good team-patient communications
- Barriers to communication
- Features of good team communication
- Barriers to team communication
- Role of the social worker
- Recommendations to improve communication

1.5.5 DATA COLLECTION METHOD

Data was collected using two methods:

* QUESTIONNAIRES

Questionnaires were administered to a sample of patients (described below). The researcher explained the purpose of the questionnaire to the respondents and was available to answer questions. In addition, a covering letter was attached which explained the research in terms the respondent could understand. Rubin and Babbie (1989: 316-317) state that where there is a covering letter to motivate people, and in addition, the researcher monitors the distribution and collection of questionnaires, this will result in a high level of return. The questionnaire consisted of open-ended and closed-ended questions, as well as a Likert-type attitude scale.

• Open-Ended Questions

Open-ended questions do not have any structure for replying. They allow for probing and eliciting the depth of emotions that would be sought in a study of this nature. According to Grinnell (1993: 228), an advantage of open-ended questions is that it allows people to respond without constraint. It allows respondents to go into detail and to express greater depth in their answers. This was considered by the researcher to be appropriate in an exploratory study.

• Closed-ended questions

According to Grinnell (1993: 229) in closed-ended questions, respondents are to choose from a number of specified choices. Responses from closed-ended questions are more likely to be reliable and are far simpler to code.

• Likert-type attitude scale

The Likert-type scale begins with a series of statements each of which provides an opportunity for respondents to indicate their agreement or disagreement on

a continuum from low to high. The score received on an attitude scale indicates the direction and intensity of an individual's attitude, thoughts and feelings towards a phenomena or issue of concern (Anastasi 1990: 584). It is particularly relevant to this study, as patients' attitudes and feelings on an issue are being measured.

Due to the individualised and exploratory nature of the research, the researcher was unable to find an appropriate questionnaire in the literature, and therefore one was developed specifically for the needs of the population at hand. (See Appendix 1, page 127).

*** INTERVIEW SCHEDULE**

A face-to-face interview schedule was administered by the researcher to the doctors, sisters and social workers in the clinic. The interview schedule allowed the researcher to explain questions more clearly and allowed for in-depth probing. Face-to-face interviewing allows for more open-ended questions. Grove (in Grinnell 1993: 268) adds that the sensitive personal questions are more likely to be answered freely in a face-to-face situation. (See Appendices 2,3 and 4 on pages 140, 144 and 148).

1.5.6 VALIDITY AND RELIABILITY

► External Validity

External validity is "the degree to which the results of a research study are generalizable to a larger population or to settings outside the research situation or setting" (Grinnell 1993: 228). Grinnell (1993: 224) specifies certain criteria to maximise external validity. Those relevant to this study were:

- The inclusion of a full explanation of why the study was undertaken. Grinnell (1993: 224) explains that where subjects are unsure as to the motives of the researcher for undertaking the study, their responses may prove inhibited or inaccurate.

- Respondents were assured that there were no 'right' nor 'wrong' answers so as to avoid what Grinnell (1993: 225) terms "socially desirable responses".

► **Internal Validity**

According to Grinnell (1993: 225) internal validity is concerned with reducing or eliminating measurement error. Some of the ways that internal validity were maximised, according to Grinnell's criteria, were as follows:

- Questions were constructed as clearly as possible.
- Simple language was used. According to Grinnell (1993: 225), this ensures that both educated and uneducated people would be able to relate to the questions asked.
- Double-barrelled questions were avoided. According to Grinnell (1993: 226) these are questions which contain two questions in one.
- The researcher kept questions short and to the point. Grinnell (1993: 227) claims that in this way the clarity and precision of the instrument will be maintained.

A pilot study was administered to three patients and three doctors. On the basis of this, some of the questions were reorganised or changed.

1.5.7 SAMPLING

► **Breast Cancer Patients**

Breast cancer patients attending the breast clinic at the Johannesburg Hospital were randomly selected over a period of one month. This period of time was used, as most patients undergoing treatment come to the clinic every three to four weeks. Patients coming to be checked up come three monthly or six monthly. A one month period of time was used in order to attempt to avoid duplication.

A condition for their selection was that they were to have already undergone a mastectomy operation. This condition was set forth in order to ensure some uniformity.

Patients were chosen according to their availability and willingness to participate. According to Grinnell (1993: 162) this type of sampling is known as availability or accidental sampling. It also has an aspect of what Grinnell (1993: 663) terms 'quota sampling', in that the condition mentioned above is present.

Forty-two patients completed the questionnaires, the average age being 53 years. The majority of respondents are women, with only one male respondent. The racial group of most of the respondents is either Black or White with 19% being Coloured or Asiatic. The home language of the majority of respondents is English or Afrikaans, while 29% of respondents speak other languages.

► **The Team**

A sample consisting of eleven doctors, 91% of whom are White, with 9% being Asian; six sisters, 100% of whom are Black; and two social workers, 50% of whom are Black and 50% White, were selected on the basis of their availability and willingness to participate. This would also fall into the category of availability sampling.

1.5.8 PRESENTATION OF DATA

Findings were analysed in terms of quantitative data analysis and presented in tabular or graph form. Where applicable, commentary was added to add clarity and make interpretations of the findings. According to Rubin and Babbie (1989: 414), this means that descriptive statistics were employed.

1.6 LIMITATIONS

- * It was difficult to ensure external validity, as a subjective and emotive experience is being measured using open-ended questions.
- * The sample was restricted to the Johannesburg Hospital. The information received was therefore limited and not generalisable.
- * A small sample was used which restricts the relevance of the findings.
- * A non-probability sample was used thus limiting its representativeness of the entire population from which it is drawn.
- * Patients may have felt uneasy about reporting negative experiences they had had in the clinic, which may have caused them not to respond completely honestly.
- * Patients' perceptions of communication with their doctors at the time of diagnosis may have been clouded or even blocked by the emotional turmoil and shock they experienced at the time.
- * Cultural and/or language factors may have inhibited full understanding of information communicated.
- * The interview schedule using open-ended questions is very time consuming to administer, as well as to code and analyse.
- * The direct interaction in face-to-face interviews may bias the responses of participants and therefore may lead to measurement error. This may be due to participants wanting to please the interviewer and give the 'correct' answer, or they may be influenced by verbal or non-verbal cues given consciously or unconsciously by the interviewer.
- * The patient questionnaire was very long, taking into consideration the illness of the patients and the fact that many of them were feeling tired when answering the questionnaire.
- * Following from the above, using closed-ended questions only may have been more appropriate for these patients.
- * Questions should have been asked in the same way, from doctors, sisters and social workers.

1.7 DEFINITION OF TERMS

► Breast Cancer

Stage 1 - Uncontrolled growth which starts in a single cell in the breast.

Stage 2 - Localisation as a mass

Stage 3 - Invasion of local tissues

Stage 4 - Metastasis (spread) to other parts of the body via blood stream or lymph system or both (Ireland 1993: 23).

► Communication

The development of shared meaning through verbal and non-verbal messages (Anderson and Ross 1994: 3).

► Treatment and treatment options

The type of information that can be discussed with patients, are the advantages and disadvantages of the following treatment or procedures (Ireland 1993: 60-61).

* Excision Biopsy (mini-lumpectomy)

The small lump is totally removed at the time of doing a diagnostic biopsy.

* Lumpectomy (with gland removal) and radiation

Lumpectomy involves surgical removal of the lump with some surrounding breast tissue. This is usually done together with gland removal and radiation of the area.

* Partial Mastectomy (with gland removal)

Part of the breast is removed with the glands

* Modified Mastectomy (with gland removal)

The whole breast is removed with the glands

* Radical Mastectomy

Removal of the whole breast plus the large muscles of the chest wall. This is the most disfiguring of the operations. After the operation, chemotherapy and/or breast reconstruction may need to be discussed.

- * **Support**

The communication of concern, support, reassurance, trust and care (Lichter 1987: 2).

- * **Team**

At the Johannesburg Hospital Breast Clinic, this refers to the doctors, sisters and social workers.

- * **Active and passive patients**

According to Hack et al (1994: 279-287), 'active' patients refer to those patients who desire detailed information regarding their illness, as well as an active role in treatment decision-making. 'Passive' patients on the other hand, wish to remain relatively uninformed and prefer their doctors to make treatment decisions for them.

1.8 PRESENTATION OF CONTENTS

This thesis is divided into four parts: Chapter 1 formulates the problem and defines key terms in the problem area that forms the research basis of the study. It also contains the research design of the empirical study.

In Chapter 2, relevant previous research and the theoretical background are outlined and discussed, including a review of the literature.

The results of the study are presented in Chapter 3.

The last chapter contains the conclusions and recommendations derived from the study.

CHAPTER 2

THEORETICAL AND LITERATURE STUDY

2.1 REACTIONS OF THE PATIENT TO A LIFE-THREATENING DISEASE

Krumm (1982: 729) discusses the psycho-social reactions occurring in cancer patients, explaining that the word 'cancer' itself, results in images of mutilation, pain and suffering, dependency on health-care teams, family and friends, rejection by certain friends or family, loss of sexual attractiveness, loss of potency and death.

Breast cancer shares common elements with all cancers but is specific in certain ways. It is primarily a 'woman's' disease, and the loss of a breast can cause difficulties of adjustment for her on many levels. It can affect her body image, her perception of her identity as a woman, her social image and the way in which she presents herself to others, and her marital or other sexual relationships (Ray and Baum 1985: 20).

Due to the fact that the adjustment to the disease and needs of the breast cancer patient are similar to other cancers or life-threatening diseases, this study will focus on life-threatening diseases in general.

The researcher is aware that some of the material she has used is not recent, but many of these are either 'classic' works in the field, or of a highly relevant and useful nature.

2.2 ADAPTATION TO A 'CANCER' DIAGNOSIS

The diagnosis of a life-threatening disease is described by several authors as a crisis (Gyllenskold 1982: 72; Doka 1993: 2; Barton 1977: 19; Poss 1981: 13). Adaptation to the illness occurs as a process over time.

Perhaps the best-known contribution in the literature to this adaptation process was given by Kubler-Ross (1969). She conceptualises the person's adaptation to dying,

death or intense loss, as occurring in five stages. In the first stage, the person's initial response to a serious illness is one of shock and denial. Shock may be evident in high levels of stress, confusion, disorientation and numbness (Buckman 1992: 114; Doka 1993: 4). Denial is the 'blocking out', or refusal of the patient to accept what is being told to her. Several authors speak of the functional and healthy role of denial, certainly at the beginning stages of the illness, as it helps the person to mobilise other more adaptive strategies (Poss 1969: 13; Doka 1993: 6; Barton 1977: 18).

The second stage is anger, which can be expressed indirectly towards family, friends or hospital personnel. The next stage is one of bargaining. The patient acts as if he will be spared if he behaves in a prescribed, pleasing manner. Following the stage of bargaining is depression, in which the impact of the illness is felt and the losses perceived evoke sadness and despair. Finally, there is the stage of acceptance in which the person accepts her illness and its possible ultimate outcome. Barton (1977: 20) and Doka (1993:1) warn against expecting all people to respond in the same way and in the same sequence. Care-givers need to respond to people as individuals, keeping the relevant information in mind for purposes of guidance.

Pfeiffer and Mullikan (1984: 168) and Barton (1977: 19) point out that a person will adapt according to past life experiences, current circumstances and the anticipated future.

2.3 PATIENT NEEDS FOR INFORMATION

Following a review of 200 papers, spanning 20 years, relating to communication with cancer patients, Northouse and Northouse (in Luker et al 1995: 136) concluded that seeking information was one of the major areas of importance for individuals with cancer. Empirical evidence suggests that there is a difference in perception in what the patient wants to know, and what the health-care professional thinks the person wants to know, with information often being perceived by patients as unhelpful, rather than constructive and supportive (Luker et al 1982: 135; Givio 1986: 322 and Thorpe 1988: 170).

Hack et al (1994: 280) write about a useful theory described by Taylor, explaining the patient's need for information. He speaks of three ways in which psychological adjustment to a life-threatening situation can occur:

- (a) extracting meaning out of the situation
- (b) maintaining a sense of mastery and control
- (c) maintaining self-esteem through self-enhancing evaluations.

Two important ways in which cancer patients may gain a sense of control over their illness include:

- (i) acquiring information about their illness and its treatment
- (ii) playing a more active role in decision-making about treatment.

(A) SOCIAL FACTORS

Patients' needs, and the way the professional team deal with these needs, will be dependant on the following factors:

(i) Age

According to Doka (1993: 59) perceptions of health-care professionals and the patient may be influenced by age. He asserts that both parties may be more prone to ignore symptoms and thereby delay diagnosis, attributing them to age.

In studies conducted by Hack et al (1994: 287) and Beisecker et al (1994: 506) it was found, contrary to their expectations, that age did not play a role in the patients' desire to be actively involved in the treatment process. They found that older patients (over 60) wanted all the information they could get; however, they left decision-making in the hands of the physician. This was in contrast to younger adult patients (under 60) who were more in favour of joint decision-making.

(ii) Gender

Ireland (1993: 22) states that breast cancer is very uncommon in men. For every hundred women with breast cancer, there will be less than one case occurring in a man. Doka (1993: 58) asserts that there will be differences in the way a male

perceives risks and responds to symptoms, compared to his female counterpart. There may also be differences in the way male doctors respond to symptoms presented by males in contrast to those of females.

(iii) Culture

Culture will influence the needs of patients in several different ways. Culture frames one's entire belief system about the nature and cause of illness, the efficacy of treatment, or the process of seeking outside assistance, eg. in some cultures traditional or alternative healers may be consulted instead of, or prior to, turning to conventional medicine (Doka 1993: 57). Nunnally and Moy (1989: 152) add to this by comparing Western and Asian culture. Oriental philosophy underplays individuality, (a strong Western value), and subordinates individual needs to family needs. Further, they strive to accept their environment. Western culture places prime value on choice and the uniqueness of the individual and emphasises coping by changing the environment, changing one's behaviour and learning to manage stress. Nunnally and Moy also speak of the culture of Black Americans which can be likened to Black South Africans. This group has had centuries of social, economic and political hardships, largely due to colour discrimination. Despite their heritage, Black people have shown an ability to survive and develop culturally characteristic strengths. One of these is the emphasis on strong kinship connections which results in the development of a lifelong network of co-operative domestic exchange, linking generations and multiple households. For example, if a mother became ill with breast cancer, she could, in many cases, rely on a network of relatives to care for her children.

It is therefore important for care-givers to be aware of cultural factors as they can then assist their patients with more insight and create a 'culturally sensitive' treatment regime. Where cultural awareness is absent among team members, cultural barriers may inhibit both the process of health-seeking and subsequent treatment.

(iv) Language

As in culture, Trenholm (1995: 87) theorises that people from different language communities perceive the world differently. For example, certain concepts and ideas that are easily expressed in one language, are difficult to translate into another. The use of words or expressions by one language group that are unfamiliar to another, may not allow the full impact of what is being said to be 'heard' by the other. Cohn (in Trenholm 1995: 87) comments on the difficulty of expressing one's own ideas and values in a language that is not one's own.

Strano (1984: 28) delineates certain barriers to communication created by language, i.e. a person communicating in a foreign language may become inarticulate and lack verbal skills.

Often translators are used to avoid the types of problems mentioned already. However, Tatro, in Ruben (1984: 297) warns that language can become lost in its translation. Translators could give meanings to words that are out of context, and not intended by those who uttered them, and hence misunderstandings can occur.

(v) Education

In a study presented by Hack et al (1994: 287) it was found that poorly educated patients preferred their doctors to make treatment decisions for them, while well-educated patients had more of an ability to determine the kind and amount of information they needed to make informed, rational decisions. They do not define 'well-educated' and 'poorly educated'. Doka(1993: 58) agrees with the above contention and adds that disparities between the educational level of the patient and the health professional may inhibit the communicative process.

2.4 INFORMATION NEEDS AT DIAGNOSIS

Patients will have different information needs at different stages of their illness. According to Doka(1993: 2) and Gyllenskold (1982: 71) the diagnostic stage is perhaps

the most traumatic, and it is therefore important to look at patients' needs at this time.

Often denial and shock occur at the time of diagnosis, as part of the patient's initial response to bad news. According to Buckman (1992: 121), however, denial may be prolonged over an extended period of time, despite the evidence that the patient is deteriorating. According to Gyllenskold (1982: 79), during this phase the patient has no way of absorbing information and processing it. The patient may also find it very difficult to remember what she was told afterwards. Giving information at this stage, therefore, may be completely ineffective for such patients.

Hack et al (1994: 287) suggest that if important information has to be conveyed to the patient at this time, a useful procedure would be to provide patients with a written copy of their diagnoses, using the same wording conveyed during their diagnoses. Doka (1993: 67) describes diagnosis as a process, rather than a one time event. The seeking of information may also, therefore, be a process in which the individual is involved, at her own pace.

2.5 PATIENTS' SEEKING OF INFORMATION AND INVOLVEMENT IN DECISION-MAKING

Several reasons are described as to why a person may not be able, or want, to seek information during the diagnostic stage, or later during the course of her disease. Hack et al (1994: 287) did a study measuring how much detail patients prefer in:

- (a) the disclosure of their diagnosis
- (b) the disclosure of available treatment options with the degree of risk attached to each alternative
- (c) the exploration of treatment procedures
- (d) the relay of all possible treatment side-effects and how to remedy them.

The results of their study show that most patients want detailed information about their diagnosis, illness and its treatment, and seek an active role in treatment decision-making.

However, there was a group of patients who they term 'passive' patients. These patients did not want to receive their diagnoses and did not want to be kept informed regarding their illness and its treatment.

They give certain hypotheses as to why these patients are passive with regard to their illnesses. One of them is that patients may find it easier to remain hopeful if they know little about their disease and its possible outcome. As mentioned in 2.3(v), a poor educational level may also contribute to a patient not having a need to seek further information.

Doka (1993: 68) adds that patients may be intimidated by the social status or authority of the physician or other medical personnel, causing them to hesitate to ask questions. Ray and Baum (1985: 41) agree that the hierarchical nature of the doctor-patient relationship creates fear in the patient; she does not ask questions or challenge the doctor, nor does she make her needs known, as she considers them peripheral to the consultation. Therefore, it is ignorance that, as well as the factors already mentioned, that can foster passivity, which in turn, reinforces ignorance.

Hack et al (1994: 286) and Buckman (1992: 74) point out a very important point; caregivers should assess how much each individual patient wants to know, and at what level, before deciding on the type and amount of information they will give.

Buckman (1994: 82) provides guidelines on how to give patients information:

- (a) he warns against using medical or psychological jargon, which the patient will not understand
- (b) he advises caregivers to check on the reception of information frequently. Connell & Connell (1995: 36) agree with this assertion
- (c) information should be reinforced and clarified frequently
- (d) information should be given in small amounts at a time, to give the patient an opportunity to absorb it
- (e) the patient should be respected and not patronised
- (f) Doka (1993: 230) adds to this the importance of being truthful to patients with regard

to giving information. Very often care-givers or family members try to shield the patient from the truth of the nature or implications of their illness. This often creates further anxiety for the patient as she perceives the seriousness of her illness. However, as described above, the individual patient has to be taken into account, as well as her needs and ability to take in direct information.

Hack et al (1994: 280) differs with Doka where he says that doctors do tell patients the truth, but differ in the way they do so.

Imparting the right type of information is of great importance. It would be prudent to examine the priority of information needs at key points in the process of the patient's illness to prevent overloading patients with information that they will not be able to recall at a later date. An extensive review of the literature carried out in Canada identified items of information that were important to people with cancer generally, and more particularly, with breast cancer. The literature revealed nine major areas of importance. These areas included physical, psychological and social aspects of care and treatment, spread of the disease, likelihood of cure, impact on social life, effect on family and friends, sexual attractiveness, treatment options and side-effects of treatment (Degner et al, cited in Luker et al 1995: 136).

Time is a valuable resource for health-care professionals; being able to use the limited time with an enhanced awareness of what the individual considers to be important in terms of information, would increase the benefits derived from such communication.

Luker et al (1995: 135), urges professionals to encourage patients to be active in making decisions regarding their health, as he claims this to be important in the total healing of the patient.

Several authors write of the positive benefits for the patient in taking control and participating in decision-making regarding treatment, in terms of long-term adjustment to the disease. Hack et al (1994: 288) assert that benefits associated with active

decision-making include decreased anxiety and depression compared to patients not included in this process. Doka (1993: 78) believes that not only will active patients cope better, but many actually live longer.

The above research correlates with Taylor's theory, as described in a previous section (2.3), where he states that playing an active role in treatment decision-making gives patients a feeling of psychological control over their health.

Sutherland et al (1989: 262) note, that although information is an important aid to decision-making, it should not be assumed that non-participation in decision-making relates to a wish for less information. Information may still be required to function autonomously, even if that information is not being used to make decisions.

2.6 PATIENT NEEDS FOR EMOTIONAL SUPPORT FROM THE TEAM

The word 'support' is a frequently used one, but is often undefined and non-specific. Buckman (1992: 93) asserts that it is important to define the word in behavioural terms. He defines it as "hearing" what the patient says and identifying her emotions in a non-judgmental way. To extend this concept further, the researcher will describe what Carl Rogers in Koch (1959) the founder of the person-centred approach to counselling, identified as essential conditions that free interaction to become effective dialogue.

- (1) **Congruence:** Rogers found that communicators more easily facilitate understanding if they can generally achieve a congruence, a matching of their inner experience, with their outer behaviour.
- (2) **Positive Regard:** This condition has sometimes been termed 'acceptance', 'regard', 'respect' and 'confirmation'. Rogers found that when communicators do not attach conditions to their acceptance of others, their relationships result in more effective understanding. The positive regard in Rogers' system attaches to the person, and not necessarily to the behaviour. One does not need to like the other person in order to

have a positive regard for her 'humanness' or potential.

- (3) **Empathy:** Rogers in Koch (1959: 210) talks of empathy or "entering the internal frame of reference" of another. This can be explained as being able to sense the emotions of another as he, himself, feels them.

Attempts at empathy send positive relational messages because one person shows his/her willingness to grant full validity to another's uniquely different experience (Anderson and Ross 1994: 196).

Effective communication of empathy and support can make the difference between a composed functioning person and an anxious and depressed one. The difference lies not in the nature of the disease, but in the support that is given to the patient in the physical, emotional, spiritual and social spheres. The quality of interpersonal relationships protects people from the effects of stress (Chester and Barbarin 1987: 65; Lichter 1987: 1; Guex 1989: 15 and Doka 1993: 48).

Lichter (1987: 1) quotes Stedeford who states: "More suffering is caused in the terminally ill patient by poor communication about illness, than any other problem except unrelieved pain."

2.7 ATTITUDES TOWARDS DEATH AND DYING

Several authors speak of the individual's and society's attitude towards death. This is central to how care-givers will communicate with patients confronting death. Contemporary men and women are extremely fearful about confronting death and hence it has become a taboo subject, which people avoid confronting at any cost (Kubler-Ross 1969: 4; Poss 1981: xi; Barton 1977: 76; Guex 1989: 69). According to the literature, care-givers are no exception. Kubler-Ross (1969: 12) explains this avoidance as man's unconscious inability to perceive his own death and therefore his need to defend himself from his own mortality. In the medical sphere, this manifests itself as continuous

advancement in scientific and technical know-how, while the emphasis on interpersonal human relationships has almost become redundant. Barton (1977: 75) extends this further when he describes death or the inability to cure a patient, as a failure for the physician. He raises the possibility that some health-care professionals, in fact, entered the profession because of a fear of their own deaths; they hoped to resolve this through experiencing themselves as having mastery over death through curing all illnesses. Predictability, order and organisation are sought after as a means of gaining control and avoiding anxiety. Mistakes are poorly tolerated and a sense of 'omnipotence' is reinforced both by the profession and society. This is obviously a generalisation and differences certainly are found among medical personnel; but the desire for mastery and control, according to Barton, is a commonly found one. Therefore, when faced with a patient who is possibly dying, the care-giver is forced to confront the reduction of his control over the situation. Barton (1977: 77), examines the kinds of defences medical personnel guard themselves with, in order to avoid uncomfortable emotions. He speaks about physical distancing, emotional distancing and using scientific explanations which are difficult for the patient to understand. Different disciplines may use different techniques to impose some type of order. For example, the doctor may focus on his technical skills and hence focus only on the physical dimension of the disease, whereas the nurse may use her busy administrative schedule to stop her from focusing on the individual patient. These defence mechanisms would obviously be an obstruction to true empathy taking place.

Barton (1977: 82) further emphasises that without shared support of the intense emotions the care-giver is experiencing, he may be lead into a "painful state of isolation, meaninglessness and despair".

2.8 THE MULTI-DISCIPLINARY TEAM

For the purposes of this study, the three disciplines which will be discussed are the doctor, the nurse and the social worker.

Good patient care requires the combined efforts of a team of health-care workers, collectively concerned with the total well-being of the patient and her family. In a multi-disciplinary team, each member works within his professional sphere of training and provides his particular insights and skills to meet the patients' physical, social, psychological and spiritual needs (Barton 1977: 39; Lowe and Herranen 1978: 1; Nason 1983: 25 and Kane 1975: 3).

The communications and relational patterns involved with the ill or dying person, and all the people connected to that individual, combine in a specific way in order to create the total care process. The patient, the family and the care-givers are all subgroups within this interactional triad (Barton 1977: 39; Poss 1981: 4; Doka 1993: 96).

In studying multi-disciplinary teams, it is possible to delineate several characteristics that influence team functioning as described by Lowe and Herronen (1989: 324); Kane (1975: 31); Iles and Auluch (1990: 162); Blues and Zerwekh (1984: 70):

- (a) group purpose
- (b) role expectations - internal and external
- (c) decision-making process
- (d) communication patterns
- (e) leadership
- (f) norms.

Nason (1983: 26) adds that in order for the group to maintain itself, it needs to meet regularly and have agreed-upon methods of resolving conflict.

The advantage of working in a team is that it has the potential for gathering in a wider knowledge base, of making decisions that take into account what other providers can realistically do, and of extracting a commitment from each provider who will be participating in the care plan. A team brings together a range of talents, interests and coping styles and does not permit the exclusion of less interesting or less manageable problems (Nason 1983: 27).

In order to understand whether a team functions adequately, it is important to analyse the different elements:

(a) Communication

Team work requires close communication between the various members about all matters relating to the patient's welfare. This is best achieved by means of frequent team meetings attended by all members involved with the patient. The purpose of these meetings is the exchange of information about the patient, support of team members for each other, as well as a time to resolve any conflict that may arise between team members. At these meetings, roles and expectations can also be clarified (Lichter 1985: 186; Guex 1989: 75; Nason 1983: 31).

(b) Goals

Specific goals can be outlined by defining the tasks to be accomplished. Several questions are raised in relation to this: how are goals defined; who sets and evaluates them, and how committed is the team to these goals? (Lowe and Herranen 1978: 325 and Blues and Zerwekh 1984: 70).

(c) Roles

Each person has a set idea of how he or she should act, as well as how other team members should respond to achieve the stated goals. Role and function never develop in a vacuum, but are influenced by external role expectations. According to Lowe and Herranen (1978: 325), there is little congruence in the way a profession defines its own roles and the way others define them. For example, physicians who see themselves high on the status ladder may see a social worker's role as arranging concrete services with little other input into patient care.

Internal and external role expectations can lead to role ambiguity (expectations not clearly defined and communicated), role conflict (incompatible or conflictual expectations), and role overload (inability to meet multiple expectations). In order to function within the team, each member attempts to maintain an equilibrium between his internal values and external expectations (Lowe and Herranen 1978: 325; Blues and Zerwekh 1984: 70).

(d) Leadership

Leadership of the medical team has traditionally assumed to be the function of the physician. Social, economic and prestige gulfs can separate the physician from other team members and make effective interaction difficult (Lowe and Herranen 1978: 327).

(e) Norms

Group norms are the unwritten rules governing the behaviour of people in groups. They govern leadership, communication patterns, decision-making and conflict resolution (Lowe and Herranen 1978: 327).

(f) Decision-Making

Decisions can be made in several ways: decision by default, unilateral decision, majority vote, consensus and unanimity. Each form will have different results in various situations influencing team functioning (Lowe and Herranen 1978: 327).

2.8.1 THE PATIENT AND FAMILY AS PART OF THE TEAM

The patient is part of the caring team as she is the expert about her own feelings and the reactions of her body to the disease and its treatment (Lichter 1985: 185).

However, the patient exists as part of a system, and therefore changes in the patient will not only affect herself, but the whole family system of which she is a part.

An illness, and certainly a terminal illness, will place acute demands on the family, including caring for the ill person, rearranging priorities in personal lives, dealing with multiple emotions raised by the illness, dealing with the possibility of death, difficult decisions, and each member must come to terms with the meaning of the illness in his or her own way Walters (in Blues and Zerwekh 1984: 246).

Different families will have different levels of awareness regarding the illness of their family member. However, according to Barton (1977: 64), "whatever the

level of awareness, families have an understandable and intense need to retain active lines of communication with health-care professionals". They need clarity, structure and predictability, which care-givers cannot always provide. However, Barton stresses the importance of the 'presence' of the team and their availability and support for the family. In addition, Poss (1981: 58) calls for working with the patient and family as a unit or separately to help them work through unresolved feelings.

Family are also an important resource for patient support and Ireland (1993: 56) emphasises that if possible they should be there for the patient and become part of the caring team from the moment of diagnosis.

According to Hayes-Bautista (in Blues and Zerwekh 1984: 6), research has indicated that patients and families involved in decisions and plans for their care, are far more committed to and supportive of such treatment. According to Blues (in Blues and Zerwekh 1984: 73), it is the responsibility of every team member to listen carefully to patient-family concerns, to interject those concerns into team decision-making, and to keep the patient and family informed about choices and outcomes. She adds that families' opinions should lie at the very centre of team decisions.

2.8.2 THE HOSPICE TEAM

Hospice is a programme for palliative and supportive care which recognises the physical, social and spiritual needs of terminally ill people and their families. This care is provided by an inter-disciplinary team of professionals and lay volunteers. It is available without regard to the patient's ability to pay on a 24-hour-a-day, seven-days-a-week, basis. Hospice care continues into bereavement. Palliative care provides the most modern and sophisticated treatment to relieve the symptoms and distress process. According to Blues (in Blues and Zerwekh 1984: 6), at the core of such care is the recognition of patients as valued, loved, supported human

beings with a right to dignity and control in their dying.

Blues (in Blues and Zerwekh 1984: 72) outlines some differences in Hospice teams as opposed to traditional medical teams. The purpose of the Hospice team, which is the comprehensive care of the patient and family, varies constantly because it is dependant on ever-changing needs. The tasks are often unclear. The roles of those who perform these tasks must clearly be overlapping and flexible in order to evolve in ways that keep individual patient needs at the centre of team function. This is in contrast to the medical team where the purpose and functions are often clear, i.e. to operate and to heal. The area of decision-making is where the greatest differences between traditional medicine and Hospice lie: i.e. in the medical team there is usually a hierarchy for decision-making, whereas in Hospice, decision-making is a group process or is delegated first to one or two members and then to others, depending on a matching of their skills and expertise to patient-family needs.

2.8.3 OBSTACLES TO TEAM COMMUNICATION

Conflict is a natural and inevitable development in inter-disciplinary team life (Sands et al 1990: 55). Conflict in teams reflects more than a clash of perspectives among team members. Sometimes the conflict mirrors the emotions experienced by patients and their families or contradictions at the systems level (Nason 1983: 42). By looking at its own emotional reactions, the team can diagnose and clarify patient issues, provider issues, institutional practices and social impediments that underlie the conflict (Nason 1983: 38).

Conflict in inter-disciplinary teams is associated with a number of sources. Barton (1977: 81) describes it as resulting from preconceived stereotypes held by caregivers about each other, varying sets and levels of knowledge and differences in language. Disciplines that have overlapping functions may perceive each other as competitors (Lowe and Herranen 1978: 326). Differences in professional values,

professional socialisation, philosophy or theoretical perspectives are other sources of conflict (Sands et al 1990: 56). Role competition, role confusion and turf issues also cause inter-disciplinary tensions because each discipline must sacrifice some degree of autonomy for collaborative problem-solving to take place (Lowe and Herranen 1978: 325).

Role definition poses problems as well. A number of studies have identified discrepancies between the perceptions of social workers and those of physicians regarding functions assigned to social workers. In particular, counselling activities are more often seen as a prime social-work responsibility for social workers than for physicians (Abramson and Mizrachi 1996: 271).

Conflict can also arise from variations in professional socialisation processes. Members of each profession define their role and the goals of services to clients differently. Communication difficulties then arise and are often ascribed to interpersonal dynamics rather than recognised and addressed as inter-professional in nature (Abramson and Mizrachi 1985: 34-35).

Physician dominance of team and inter-professional decision-making has remained a critical issue for other health professions. Nurses, pharmacists and social workers face comparable issues in collaborating with physicians, including a lack of acceptance by physicians of the full breadth of other professionals' roles, continuing status and gender differences, contradictory expectations regarding the autonomy of non-physicians, and a commonly expressed need for physicians' recognition of their competence (Baggs & Schmitt 1988; Cowen 1992; Fagin 1992; Koeske et al 1993; Lamb 1991; Mullaly 1988; Pike 1991) - cited in Abramson and Mizrachi (1996: 271).

In a study conducted by Abramson and Mizrachi 1996, measuring how physicians and social workers collaborate, the following results were found:

- (a) social workers seemed to seek validation from physicians, whereas physicians were unconcerned about receiving validation from social workers
- (b) physicians were found to be willing to give up authority in exchange for sharing some burdens of patient care with social workers, at least those whom they respect and deem competent
- (c) an interesting contradiction was found. Social workers perceive physicians as inaccessible or as valuing brevity in their communication with social workers. However, according to some doctors who participated in the study, it was the social worker who was unavailable or withheld information. According to the researchers, social workers may have lacked clarity regarding what to communicate or the confidence to express their views effectively
- (d) both social workers and physicians stressed the importance of communication. This finding suggests that professional training needs to focus more on interactional skills
- (e) both groups stressed the importance of respect for their collaborator.
- (f) Social workers tended to stress a counselling role for themselves much more than did physicians
- (g) social workers indicated that physicians did not fully understand the breadth of their contribution to patient care.

In summary, social workers can be encouraged to be more assertive and confident in their approach to collaboration with physicians, as results of the above study definitely showed an increase in physicians having more interest in a reciprocal relationship with the social worker than has been shown in previous studies. Abramson and Mizrachi recommend that social workers address remaining inequalities in their relationship with physicians, while at the same time relinquishing a quest for autonomy when collaborating with physicians whose interactions seem based on assumptions of equality and inter-dependence rather than hierarchy and control.

It seems clear from the above that the health care system is moving towards an inter-disciplinary approach with more emphasis on the 'whole' patient. Success in developing a collaborative practice requires that all team members understand common barriers and the strategies needed to minimise them. Abramson and Mizrachi (1996: 280) stress that social workers can assume leadership in shaping, rather than merely responding to, changing conditions, and in the process contribute to the development of new and more effective models of inter-disciplinary patient care. The effectiveness of inter-disciplinary collaboration will directly affect patient care.

2.9 THE ROLE OF EACH MEMBER OF THE MULTI-DISCIPLINARY TEAM

A. THE ROLE OF THE DOCTOR

The doctor traditionally has the dominant role within the team, in the treatment of the patient (Serero 1987: 23; Poss 1981: 4).

The interpersonal relationship between physician and patient involves a highly affective component. Several authors assert that the patient's satisfaction with medical care, her compliance with treatment regimes, and the outcome of treatment, tend to be substantially related to the physician's ability to satisfy her socio-emotional needs in the health-care encounter. This critical aspect of health-care can be termed 'rapport' or 'relationship' (Di Matteo 1979: 16; Farrow et al in Blitzer 1990: 2; Ray and Baum 1985: 52; Lichter 1987: 8; Chesler and Barbarin 1987: 66). Chesler and Barbarin (1987: 65) emphasise the importance of physician-patient communication, right from the time of diagnosis, as this will have enormous implications for their future relationship. Lichter (1987: 2) talks about doctor-patient communication as something 'more than words' - it involves communication of caring, understanding, respect, support and reassurance. It is the sharing of a human relationship and a commitment to the welfare of the patient and his family in every respect.

The factual information given to the patient may be forgotten, but the assurance of continuing care and concern by the caring team, will never be forgotten. He adds, that the manner in which information is imparted may be more important than the words. Farrow et al in Blitzer (1990: 2) stresses the importance of the supportive communication of information from the diagnostic phase onwards, and he feels that it should be the physician who delivers the initial information as he will ultimately determine the treatment and care of the patient.

Barton (1977: 172) refers to this supportive relationship as the 'humanitarian' approach to patient care. Barton, a medical doctor himself, gives certain characteristics he has found to be important for the physician when dealing with the ill or dying patients. Some of these include: compassion (real empathy); genuine concern (the ability to identify patient needs); warmth; communication skills (the ability to communicate with the patient on her level); integrity (honesty in dealing with the patient's problems, and the physician's ability to deal with his successes as well as his failures); forthrightness (giving of information as it really is); patience (the ability to spend adequate time on problem solving); generosity (giving time and effort); unconcern with one's self-image; attentiveness - this Barton describes as not only giving the patient enough time, but making the patient feel comfortable, keeping the patient in touch with where she is in the disease; he even stresses the importance of such things as sitting while talking to a patient. This shows an openness towards the patient as opposed to somebody who is disinterested and 'on the run'. Barton stresses the importance of the availability of the doctor to the patient. This he defines as letting the patient know that he cares and is always available to his patients. Barton also speaks against many doctors sharing one patient. Latimer (1991: 860) describes lack of continuity of care as 'subtle abandonment' by the physician through physical withdrawal of contact with the patient. According to Ray and Baum (1985: 54), not only does the patient suffer, but the physician is unable to identify with the patient as his, and thus cannot feel the same personal involvement in her welfare.

The conditions Barton speaks about are closely aligned to Carl Rogers' (1957) specifications for effective counselling, i.e. (a) the communication of warmth and unconditional positive regard; (b) an understanding of the person's feelings and a communication of that understanding and (c) the communication of genuineness and sincerity. According to Di Matteo (1979: 23), patients' perceptions of the caring and concern, warmth and positive feeling coming from their physicians, can strongly influence their desire to continue the relationship, and their tendency to comply with the physician's orders. He quotes Haase and Tepper, who claim that in the communication of empathy, non-verbal cues have been found to be extremely important, possibly even more important than the message itself.

The development of doctor-patient rapport, according to Farrow et al in Blitzer (1990: 2), minimises the amount of misinformation the patient may receive and leaves the patient with a sense that, while she is still having to come to terms with her physical condition, she is dealing with a real person, who understands her situation, and is beginning appropriate treatment. Appropriate communication skills act as a therapeutic tool in that they:

- (a) reduce the patient's uncertainty as to what to expect
- (b) strengthen the relationship between doctor and patient
- (c) may alter the patient's perception of her illness, from one of hopelessness to one of hope.

Pfeiffer and Mulliken (1984: ix) explain similarly that the word 'doctor' is derived from the word 'teacher', i.e. the doctor teaches her how to live with, understand, accommodate and cope with her disease.

The ideal doctor-patient relationship described above does not often materialise in many medical settings. Some of the obstacles to this type of communication can be described as follows:

(a) Time

Buckman (1992: 41) describes several studies that were done of doctors' interviews with patients. They reveal that on average, the time that a patient is allowed to talk before being interrupted by the physician is eighteen seconds, and only 23 percent of patients ever finish their opening statements.

In a hospital setting, especially where there is understaffing, staff often work under tremendous pressure in order to have the time to attend to the patients' basic physical needs. This factor would therefore affect certain conditions mentioned above. For example, it is difficult for doctors in this situation to be constantly available to their patients, as recommended by Barton above. In addition, if doctors are confined by lack of time, listening attentively and generously may become difficult. Ray and Baum (1985: 54) comment that the difficulties of time and work pressure facing doctors is felt by patients and hinders them from confiding their concerns. However, as described in 2.6, several authors maintain that doctors spend little time with their patients, especially dying patients, in order to avoid having to focus on issues around their own mortality and sense of competence. Guex (1989: 68-69) asserts that 'listening' means preparing one's self to analyse one's own reactions, in the face of suffering and death. Doctors who allow themselves to become involved in the emotions of their patients may fear losing their clear-headedness and may have to confront feelings of inadequacy or impotence in the face of not being able to cure a patient.

In order to escape from a flood of contradictory feelings, some doctors hide behind a facade of a meticulous treatment regime and spend as little time as possible with their patients. Ray and Baum (1985: 55) agree with Guex in that they believe that the doctor may fail to communicate because of uncertainty about the diagnosis and outcome of the disease.

Latimer (1991: 86)) remarks that although a physician's desire to withdraw may be a normal human response in the face of suffering and sadness, "professional responsibility requires that it not occur!"

(b) Lack of communication skills

Di Matteo (1979: 16) asserts that a physician's ability to establish rapport with his patients is at least partially dependent on his communication skills, especially his ability to decode and encode non-verbal messages of effect.

Furman (1990: 281) laments that the basic training at Medical School involves dealing with diseases, not people. He describes that on entering General Practice, some 15 years previously, ".....I found that I had to deal with human beings and not organ systems..... I found myself faced with feelings of strong anxiety and inadequacy in having to deal with more complex interpersonal problems....."

Ray and Baum (1985: 56) recommend that interpersonal skills be given an important role in the medical curriculum, where the 'whole' patient's needs should be stressed and not just the physical needs.

Latimer (1991: 862) agrees that developing skills in the art of communicating is a very important "clinical challenge".

(c) The hierarchical nature of the doctor-patient relationship

As mentioned in 2.4, the hierarchical nature of the doctor-patient relationship may prevent communication from taking place. According to Ray and Baum (1985: 41), there are several bases to the powerful role the physician often does assume.

- (i) The doctor can provide resources which promise some hope for the patient to be cured, or at least to be relieved of suffering. The patient is the receiver of these resources.

- (ii) Doctors are seen as authority figures having the right to make important decisions, within certain limits.
- (iii) Doctors have training and expertise, which the patient obviously lacks. Ray and Baum comment that patients see the doctor as an expert, even in matters in which they don't have specific training, e.g. in the social, psychological and moral spheres.

This concept of an authoritarian doctor and passive patient is acceptable and even convenient for some patients as it relieves them of the burden of having to cope with their own problems and make their own decisions. However, some patients do question this authority and challenge the physician on different levels. Some do so directly, others more indirectly e.g. non-compliance in terms of treatment or medication.

This can be seen to correlate with Hack et al's (1994) concept of the active or passive patient, as described previously.

There are also variations in terms of doctors' needs for the authoritarian position. According to Ray and Baum (1985: 43) the degree of control assumed by the doctor depends on the patient's behaviour as well as the doctor's own particular preference.

Hence it can be seen that for some patients, the hierarchical nature of the relationship may be comfortable, while for others it may block the real communication of issues and concerns that are important to the patient.

(d) Cultural and Linguistic Barriers

As described in 2.3 (A) (iii) and (iv), counselling people who do not share the same culture or language can be particularly difficult. For communication to be effective, both the care-giver and the individual cared for must be able to correctly interpret each other's verbal and non-verbal messages. According to Doka (1993: 216), this

process can become very difficult when different cultural groups exhibit different verbal and non-verbal behaviours. It can be especially complicated when linguistic barriers further complicate the process. Interpreters may also complicate interaction, as they may seek to shield those for whom they interpret, changing the message to make it more palatable.

(e) **The Hospital Environment**

The hospital as a "complex social institution", termed by Buckman (1977: 4), can create obstacles to communication for both the patient and doctor. This is characterised by social hierarchies, highly specialised role designations, and complicated, sometimes burdensome, administrative protocols. The efficiency and 'humanness' of the supportive administrative protocol, varying from friendliness of clerks to the length of queues patients have to stand in, and the effectiveness of communication systems for doctors, will affect how doctors and patients ultimately relate to each other, given the stresses of the environment.

It seems clear, therefore, that while the relationship or 'rapport' between doctor and patient remains vital as a basis for their interaction, there are many obstacles - be they external as part of the environment, or inherently part of the relationship, which prevent good doctor-patient communication from taking place.

B. THE ROLE OF THE NURSE

According to Ray and Baum (1985: 58) the nurse has a double role:

- (a) a technical function (physical treatment and care)
- (b) assisting in reducing the patient's emotional tensions, i.e. informing the patient, reassuring her, conveying warmth and interest and helping to clarify problems and solve them.

Wiernik (1953: 8) defines the oncology nurse as the "on the spot" supporter of the patient and family. Similarly, Guex (1989: 74) asserts that because nurses are in direct contact

with their patients, they are in the best position to listen to their concerns, especially when the patient feels intimidated about going to the doctor. This is supported by Lichter (1987: 168); Perachi in Pfeiffer and Mulliken (1984: 169) and Calzone et al in Harness (1988: 335).

Lichter (1987: 166) quotes Hacking, who agrees that more than any other team member, the nurse is in a position to gain the patient's trust and establish a relationship. In a study by Pallson and Norberg (1995: 277), where emotional support was offered to patients by nurses, it was concluded that confirming relationships and emotional contact are closely related to the patient's sense of control and his/her ability to cope. According to Barton (1977: 185), the supportive nurse-patient relationship includes spending time with the patient, listening, accepting and reflecting the patient's feelings and creating an environment in which the patient is free to express her anxieties and feelings. Barton stresses that the patient should know that the nurse is available and that she is not alone. This aspect is reinforced by Lichter (1987: 167).

As with the doctor, Kroehl in Pfeiffer and Mulliken (1984: 36) stresses the importance of effective nurse-patient communication during the diagnostic phase. She states that communication during that time can establish a pattern of coping and adaptation that continues throughout the disease. The nurse plays a vital role by offering the patient support, reassurance and a chance to ventilate her feelings about the diagnosis and perceived problems with regard to it. The patient's family also need education and encouragement. According to Kroehl, at this stage, the nurse answers the patient's and her family's questions, describes procedures and gives appropriate instructions.

In a study done by Suominen et al (1994: 278), patients reported that support was insufficient before and after hospitalisation. Patients primarily expressed the need for informative support, whereas nurses underlined the role of psychological support. The study also confirmed that patients consider the attitude of health-care staff as important for their recovery.

Beisecker et al (1994: 570), supports the need for nurses to educate patients, stating that patient education has become a primary activity for oncology nurses. The study found that nurses advocated greater patient input in decision-making, than did doctors or patients.

However, several authors disagree that all nurses can transmit the necessary information and support to the patient, regarding the disease. Luker et al (1995: 36) suggests that it may fall into the scope of the specialist breast care nurse (which has become available in certain countries, the United Kingdom, for example). He maintains that despite this, all nurses can act as facilitators, enabling patients to gain access to information by, for example, making medical colleagues aware of patient's information needs. Guex (1989: 77) backs this argument when she speaks about the "monitoring role" of the nurse and her ability to be alert to the need for patient referral. She may act as a back-up to a psychological or psychiatric service.

As in the case with doctors, obstacles can exist in the relationship between nurse and patient. Barton (1977: 186) and Stockwell in (Ray and Baum: 1985: 58) speak of time pressure for the nurses in a hospital setting. A high degree of organisational skill is often required to complete the administrative and physical aspects of care. The psychological needs of patients may indeed be greater than their physical ones, but do not receive as much attention. Barton maintains that the nursing profession places more emphasis on "getting things done, and the organisation running smoothly", than it does on talking to the patient.

Another obstacle to a good nurse-patient relationship is related to the nurse's own feelings. Several authors agree that nurses can tend to avoid an intimate relationship with patients due to feelings of guilt and inadequacy that they cannot take away the patient's illness (Barton 1977: 186; Guex 1989: 75; Ray and Baum 1985: 59; Blues and Zerwekh 1984: 351). According to Ray and Baum (1985: 59), an additional factor in the case of breast cancer patients is that female nurses can identify with their patients, awakening

their own fears of cancer and disfigurement. Lichter (1987: 172) adds that nurses may avoid discussion with the patient about her illness because they fear that dealing with the true facts may destroy the patient's hope, and may lead to emotional reactions which become uncomfortable for the nurse. Lichter describes several ways in which the nurse attempts to avoid the patient. Some of these are: denying the seriousness of the illness; changing the subject; ignoring the patient or adopting a formal, professional manner, distancing herself from the patient.

Physicians and surgeons, according to Ray and Baum (1985: 59), may have expectations on the nurse that inhibits her interactions with the patients. For example, a nurse may be warned about having discussions with patients, as she senses the disapproval of the physician who regards himself as being in control of what to disclose and what guidance to give. Nurses may feel unskilled in counselling and ill-equipped to undertake this task. Ray and Baum (1985: 59) cite Gyllenskold who says that an unskilled counsellor may be encouraging a patient to deny or suppress her feelings, rather than to work through and come to terms with her negative emotions.

Finally, Blues and Zerwekh (1984: 351) state that the nurse's own personal stresses may inhibit her ability to give of her emotional energy to her patients at work.

Many of the obstacles already mentioned call for the nurse's awareness of self in order to be effective in her dealings with the patients; this also assumes that she receives support from other members of the team in order to allow her to deal with the many stresses she is faced with.

In summary, the nurse is faced with several roles. Among these are her technical duties, emotional support for the patient, her role as educator, although this is a controversial one, and her role as liaison or monitor between the team and the patient. However, several obstacles to these roles become apparent, and self-awareness on the part of the nurse is required to overcome these.

C. THE ROLE OF THE SOCIAL WORKER

As already mentioned, both the patient and her family go through a range of emotions as a response to the diagnosis of a life-threatening disease.

A crucial factor for recovery is an available and active human support system. The ability to activate such systems is a major priority for social workers in the health field (Stolar 1982: 33).

There are several roles for the social worker in dealing with the ill or dying patient. Bergman et al (1982: 1) cite several studies which were done, which confirm a general lack of understanding about what social workers can do. She must therefore perform two roles simultaneously: education of staff and patients about her clinical skills, and the actual provision of service.

An important role of the social worker in the medical milieu in general is that of helping the patient, the family and the medical team involved in caring for the patient, to recognise the psycho-social impact and the intra-psychic disequilibrium ensuing from physical illness (Bergman et al 1984: 2). Poss (1981: 4) speaks of the social worker as the 'primary care-giver' the person who will, on behalf of the entire team, carry out the major part of the psycho-social and spiritual work in facilitating the patient to resolve the 'terminal crisis'. The social worker's intervention should begin at diagnosis when the patient often is at her most vulnerable (Hughson and Cooper 1982: 1430; Stolar 1982: 32, Doka 1993: 80).

The patient should be given an opportunity to ventilate her feelings, and deal with her anxieties regarding mutilation as a result of surgery, and possibly death. Families also need information and counselling to help prepare for the physical outcomes of the patient's surgery and her process of recovery. Significant others are the most important factor in the patient's recovery, and support to family members may turn out to be a primary service (Doka 1993: 80; Stolar 1982: 32).

Poss (1981: 46) describes the subsequent skills that the social worker uses as being similar to the skills used in general social work practice. She quotes Younghusband (1973: 47) describing the skill of the social worker as embracing a

"capacity to listen - and to hear - to be reliably alongside people, to understand what it feels like to be in their situation - and why - and to convey some kind of strength that makes it possible for the other person to begin to cope". The social worker 'holds' the emotions of the patient, eventually enabling her to bear those feelings herself.

The social worker normalises the stages the patient will go through, as well as providing information and encouragement regarding problem-solving and strives to decrease stress by identifying strengths and resources. An empathetic, non-judgmental attitude encourages reassurance that the situation can be managed (Connell and Connell 1995: 33).

Poss (1981: 45) emphasises an additional skill specific to work with the dying patient, and that is the importance of the social worker coming to terms with her own feelings regarding death, so that she can better tolerate close contact with the dying patient.

The role of the social worker is not only with the patient herself, but she should focus on the family and also on the medical team as they interact to treat the physical illness (Connell and Connell 1995; Black 1989; Kane and Kane 1987; Kleinman 1988; Goldberg and Tull 1983).

Connell and Connell (1995: 34) add that her role is to facilitate a viable relationship among all groups by facilitating communication, normalising patient and family reactivity to illness and navigating the contextual world of hospitalisation. She may also encourage the whole team to deal openly and honestly with each other for the benefit of the patient.

The social worker, in addition, plays an educative role with the patient and family. She may clarify information for them and empower them to take a more active role in

decision-making regarding treatment (Connell and Connell 1995: 34; Black 1989: 103; Stolar 1982: 32).

Goldberg and Tull (1983: 20) talk of the social worker as the liaison team member, i.e. one who would pick up psycho-social problems and somatic preoccupations which can present as medical issues, and present them to the team.

Similarly, Connell and Connell (1995: 36) refer to the social worker as an advocate for the patient, making the team more aware of the patient's needs and feelings, especially where the patient may be too sick, tired and frightened to balance her needs and resources during the crisis.

Poss (1981: 108) and Black and Rosen (1983: 94) speak of the interpretative role of the social worker in which she leads team discussion regarding the particular problem of the patient, the implications thereof for patient care and the effects of the work on the care-givers. In order to ensure optimal patient care, care-givers need to be aware of their feelings and to support each other in dealing with them.

Poss (1981: 113) and Bergman et al (1984) agree that the social worker is, by virtue of her training, equipped to integrate medical and psychological aspects of care, and provide a comprehensive approach to the evaluation and treatment of patients and their families.

In addition to the emotional aspects of care and liaison between the patient, family and team, the social worker may also deal with practical aspects of care and assist the family in mobilising social services where necessary.

Poss (1981: 115) refers to the need for social workers to guide their colleagues towards selection and referral of patients for social work services. Many complicated issues are involved: patient needs, scarce resources, quality of service, accountability, role clarity, priorities, referral procedures and team agreement of conflict in these areas. Without

formulated criteria, barriers of conflicting expectations, blurred role boundaries and unclear goals are likely to interfere both with the team's communication and the direct help eventually given to the patient.

Bergman et al (1984: 4) stress that there must be institutional acknowledgement of the role of the social worker which should then be conveyed to the patient in order to establish receptivity and willingness to utilise the social worker's particular expertise.

"Until social work is visible and accessible throughout the patient's entire term of illness and recovery, complete care is not being offered." (Stolar 1982: 33).

According to the opinions cited above therefore, the social worker has a multi-faceted role. She balances the needs and resources of the patient, the family and the team in her role as counsellor, educator, consultant and advocate.

2.10 SUMMARY

In this chapter, certain aspects of patient needs and the role of care-givers as a group, and in their separate disciplines, to meet these needs, were highlighted.

Psychological reactions to cancer and specifically to breast cancer and the losses involved for the patient, were discussed. The stages of adaptation to a life-threatening disease were enumerated, especially the first one, of shock and denial, which is especially relevant in the beginning stages of the disease.

An attempt was made to outline the importance for the patient of gaining the right amount and type of information. Social factors affecting the patient's need and ability to take in information were described. Patients differed in their desire to be involved in the decision-making process; one of the most important ways of understanding this, as described in the literature, was the 'active' and 'passive' patient. Patients' preferences in this area need to be understood and respected by medical personnel.

The theoretical concept of emotional support was discussed, with all its implications for the ill patient. Society's attitudes, and especially those of the care-givers, towards death and dying can sometimes be responsible for blocking the emotional support required by the patients.

The importance of the multi-disciplinary team with reference to the doctor, sister and social worker, was highlighted as contributing to the overall well-being of the patient. Obstacles to team communication can directly affect the patient and her family. The Hospice Team, as an example of the multi-disciplinary team, was described.

The interpersonal 'rapport' between doctor and patient is vital to the well-being of the patient from the time of diagnosis. Significant aspects of this relationship were analysed. Attention was given to the obstacles which can interfere with the building of a sound basis between doctor and patient. Education in communication skills was recommended for doctors.

The different roles of the nurse as discussed in the literature were observed. These range from her practical or technical duties to counsellor, educator, liaison team member and patient monitor for referral purposes. Self-awareness of the nurse is described as vital for recognising and/or avoiding obstacles which may arise in her multi-faceted roles.

The many and different roles of the social worker were described. The importance of the social worker gaining the confidence to sell herself to the team and hence to the patients, was emphasised in order for the social worker to be effective as a team member. The literature emphasises the need for the social worker to take an active role in team leadership as well as in patient, family and team support and counselling. In addition to these, her roles include education, advocacy and consultancy to the patient and team.

The following chapter contains the results of the empirical study.

CHAPTER THREE

RESULTS OF THE EMPIRICAL STUDY

3.1 INTRODUCTION

The following chapter outlines the results of the data that was gathered in this empirical study. Results have been presented mainly through the use of tables, and a graph. Accompanying commentaries, explanations and/or linkages to existing theory were employed. In Section A, 42 patient respondents handed in completed questionnaires. However, as there were many questions in which fewer than 42 patients responded, percentages were therefore worked out according to the total amount of people who responded to that particular question.

The sequence in which the data will be presented is as follows:

- A. Patient questionnaire
- B. The doctor, sister and social worker interviews will be presented together

A. PATIENT QUESTIONNAIRE

3.2 IDENTIFYING INFORMATION

3.2.1 Age

The table below describes respondents' ages:

TABLE 1 : AGE DISTRIBUTION

Age	NO.	%
30 - 39	9	21
40 - 49	10	24
50 - 59	11	26
60 - 69	5	12
70 →	7	17
TOTAL	42	100

The following information can be derived from Table 1:

21% of respondents are between the ages 30 and 39.

50% of respondents are in the age group 40 to 59.

29% of respondents are 60 years and above.

The average age of respondents is 53 years, while the minimum age is 30 and the maximum age 89 years.

Hack et al (1994: 28) conducted a study which found that older breast cancer patients (those who were 60 years and above) would be more likely to prefer a passive role, whereas younger patients, (below the age of 60) were expected to desire active involvement in their treatment. This is discussed further in section 2.3 (A) (i).

3.2.2 Sex

The vast majority of respondents (97.6%) were female, while only one respondent, aged 35, was male. According to Ireland (1993:22), for every one hundred women with breast cancer, there will be less than one case occurring in a man.

Although the needs of men and women may be different in relation to breast cancer, the needs of women will be focused on, as they are by far the majority who suffer from this disease.

3.2.3 Race

The table below describes the distribution of different races in this study:

TABLE 2 : RACE DISTRIBUTION

RACE	NUMBER	%
Black	11	26.2
Coloured	3	7.1
White	23	54.8
Asiatic	5	11.9
TOTAL	42	100

The majority of the respondents (81%) fall into the White and Black group, while the remaining 29% are Coloured and Asian.

Nunnally and May (1989: 152) point out that, working with such a large range of cultures, the team would need to be aware of the different cultural issues facing different groups. For example, Oriental philosophy underplays individuality and stresses interdependence, whereas the Western culture places prime value on choice and the uniqueness of the individual. On the other hand, Black culture emphasises the flexibility of family roles and individuals rely on each other in times of need. It is very important that the team should be aware of such factors when helping a person to deal with a life crisis, and when planning a treatment regimen. In this case, the team would need to be aware of the culture of all four groups.

In addition, Doka (1993: 57) and as discussed in section 2.3 (A) (iii), adds that a person will view his illness through the lens of his particular belief system.

3.2.4 Language

The home language of 25 (61 %) of the respondents is English. Four people speak Afrikaans (9.8%), 8 (19.6%) respondents speak an African language and 5 (11.9%) of the people in the sample speak one of the Asian languages.

Eight people who were requested to fill in the questionnaire, refused, as they were not able to communicate in English or Afrikaans.

The above information implies that the team at the clinic need to communicate with a large percentage of people who do not speak the same language as them. Even in cases where English or Afrikaans was spoken, for 30% of respondents neither English nor Afrikaans was their home language. In section 2.3 (A) (iv), Trenholm (1995: 87) states that the use of words or expressions by one language group which are unfamiliar to another, may not allow the full impact of what is being said to be 'heard' by the other. Cohn, in Trenholm (1995: 87) points out how difficult it is to express one's ideas and feelings in a language that is not one's own. Even when an official translator is used, Tatro in Ruben (1984: 297) discusses how language can become lost in its translation and that translators can give their own meaning to what is being translated. This is discussed further in section 3.3.4.

3.2.5 Education

Thirty two (78%) respondents in the study, by far the majority, have a high school education. Five (12,2%) respondents got up to standard 5 or below in the school system, and 4 (9,8%) have tertiary education.

Hack, Degner and Dyck (1994: 287) found in a study done on 'decisional control and information needs' as discussed in 2.3 (A) (v) that patients who are poorly educated, which in this study can be defined as Standard 5 or below, preferred their physicians to make treatment decisions; on the other hand, patients who had received more education were more likely to have the ability to determine the kind and amount of information they needed to make informal rational decisions. The above theory may become evident in this study in the form of a significant proportion of patients, who would be less interested in seeking information and being involved in decision-making (i.e. those who did not receive a high school

education).

3.2.6 Duration of Illness

The duration of the patients' illness, as described in the table below, is relevant in terms of patient needs as well as in their reaction to the illness. For example, the emotional disposition of a patient ill for one month will be vastly different from a patient who has been ill for 23 years.

TABLE 3 : DURATION OF ILLNESS

DURATION	NUMBER	%
Less than 1 year	10	28
1 - 2 years	10	28
3 - 4 years	7	19
4 years	9	25
TOTAL	36	100

Fifty-six percent of patients have been ill for 2 years and less, while the remaining 44% have had cancer for over 2 years. The shortest duration of illness in this sample is one month and the longest, 23 years.

Kubler Ross (1969) writes about five stages a person goes through in reaction to terminal illness, which would correspond largely to the duration of time in which they have been ill. These stages are as follows : denial, anger, bargaining, depression and acceptance and is discussed in detail in section 2.2.

The fact that as many as 44% of patients have been ill for over two years, and more, (the longest time being 23 years) influences respondents' needs for information, as discussed in section 3.2.15. . On the other hand, the aforementioned theory should be taken into account when looking at patients' ability to absorb information presented at diagnosis. The majority (56%), may

still be in the beginning stages of shock and denial.

3.2.7 Previous need for psychological/psychiatric treatment

Five out of thirty-three patients who answered this question (15.2%) responded that they have had previous psychological/psychiatric treatment.

A person who has had emotional difficulties in the past may be more affected by their diagnosis of cancer, and may have more need for support in the clinic.

3.2.8 Patients' understanding of information given at diagnosis

The table below describes how well patients understood or absorbed their diagnosis.

TABLE 4 : PATIENTS' LEVEL OF UNDERSTANDING AT TIME OF DIAGNOSIS

LEVEL OF UNDERSTANDING	NUMBER	%
Understood	31	86.1
Unsure if Understood	4	11.1
Did not Understand	1	2.8
TOTAL	36	100

The majority of patients understood what was explained to them at diagnosis. However, 14.7% of patients were unsure or did not understand.

Twenty-six patients commented on the above. Eleven (68.8%) reiterated that they understood clearly. Four patients (25%) said they were too shocked to absorb the information and one patient (6.3%) sought different opinions before she could grasp the illness.

From the explanations patients gave for not grasping the diagnosis, 5 patients altogether (31.3%) described shock and an emotional inability to take in the

information.

Kubler Ross (1969: 35) describes shock and disbelief as the first reaction to the diagnosis of a terminal illness as described in section 2.2. This would seem to be the logical explanation for a patient being unable to absorb a lot of information at this stage of her illness.

3.2.9 Re-asking questions after diagnosis

Patients were asked whether they would have liked to have asked their questions again at subsequent consultations. Twenty-four out of 42 patients (57%), the majority, said yes; while 18 patients (42.9%) said no.

This would seem to affirm the above, that patients have difficulty taking in information at diagnosis, and have a need to ask their questions again.

Similarly, Hack et al (1994: 287) found in their study that patients are extremely anxious when receiving a diagnosis and do not remember what their physicians told them. A recommendation was made that patients be given a written copy of their diagnosis after their consultation with the doctor as detailed in section 2.4.

Twenty-seven out of 36 (75%) respondents, said they were given an opportunity to ask their questions at subsequent consultations, while 9 patients (25%) said they were not. Northouse and Northouse in Luker et al (1995: 136) maintain that seeking information is one of the major areas of importance for individuals with cancer. Fear and apprehension often mean that individuals are reluctant to ask for specific information, believing they will be told everything they need to know. The implications for this study are that either fear of authority inhibited them from asking their questions; or these patients were the 'passive' ones, as described by Hack et al (1994: 287). This is described in more detail in sections 2.4 and 3.2.15.

3.2.10 Would patients like to have been given their diagnosis differently?

The majority, 33 out of the 37 patients who answered the question, (89,2%) were satisfied with the way they were given the diagnosis, while only 4 (10,8%) were not. Only one patient commented and said she needed someone to continue the discussion with, for her and her family.

Despite such a high percentage of patients who were satisfied with the way they were told, it seems that some patients still need the approach to diagnosis to be different, as seen also in section 3.2.9.

As described in section 2.3, despite the shift to informing people of their illness, it appears that people are not receiving as much information as they wish in the areas they perceive to be important (Luker et al 1982: 135; Givio 1986: 322 and Thorpe 1988: 17). It is also possible that patients wish to be told in a different way, as described by Buckman (1994: 82).

3.2.11 People present at the diagnosis

Nineteen out of 40 people (47,5%) said that the doctor alone was present at the diagnosis.

Two people (5%) said that a family member alone was present (this may have been a misunderstanding of the question as it was not possible for a family member to give the diagnosis). Nine people (22,5%) said that the doctor and sister were present, 4 people (10%) said that the doctor and a family member were present, 1 person (2,5%) said that the doctor and social worker were present, 1 person (2,5%) said the sister and a family member were present and 1 person (2,5%) said that the doctor, sister and a family member were present.

The significant results therefore were the doctor being present, the doctor and sister being present, and slightly less frequent, the doctor and a family member.

3.2.12 Patients' preference for people present at diagnosis

The table below shows patient preferences regarding who they would have liked to have with them at diagnosis:

TABLE 5 : PREFERRED TEAM MEMBERS AT DIAGNOSIS

	NO.	%
Doctor	5	27.8
Sister	3	16.7
Social Worker	6	33.3
Family Member	2	5.6
Doctor and Social Worker	1	5.6
Doctor, Sister and Family Member	1	5.6
TOTAL	18	100

Significant results in the above table showed the following:

Five out of 18 patients (27,8%) prefer the doctor to be at the diagnosis. Three patients (16,7%) would like a sister to be at the diagnosis. Six patients (33,3%) would like a social worker to be at the diagnosis.

The procedure in the Johannesburg Hospital is that the doctor gives the patient the diagnosis. The researcher's assumption, therefore, is that patients may have misunderstood the question and where they have stated a preference for a sister, social worker or family member, this includes the doctor.

It seems that some of the patients' needs were therefore met by having the sister present. Four patients altogether (22,3%) requested a sister to be present and in 3.2.11, we see that 9 people (22,5%) said that a sister was present with the doctor at the diagnosis.

The nurse, according to Kroehl in Pfeiffer and Mulliken (1984: 36) is an especially important source of support, reassurance and education at the time of diagnosis. This concurs with results shown above, where almost one-quarter of the patients felt a need for the sister at diagnosis.

However, patient needs were not met in terms of the social worker. Seven people altogether, (38,9%), had a preference for the social worker to be present at diagnosis, while in 3.2.11 only four people altogether (10%) said that the social worker was present. Patients did not show a strong preference for the presence of a family member.

The above results do not confirm the importance Ireland (1993: 56) places on a family member being at the diagnosis as seen in section 2.8.1. Poss (1981: 47) does stress the role of the social worker as being a strength for the patient in time of crisis, discussed in section 2.9 (c), confirming the patients' needs for the social worker to be present at diagnosis.

3.2.13 Patients' desire for a social worker at the diagnosis

To confirm the above result, 15 out of 33 patients (45,5%) would have liked the social worker to be at the diagnosis. Eighteen patients (54,5%) did not deem this to be important.

When patients were asked to explain their reasons for wanting a social worker, 7 out of 13 (53,8%) said they needed her for support, encouragement and strength, while 6 patients (46,1%) said they needed a social worker to obtain additional information and further explanation of the disease from her.

This is supported by Younghusband, quoted by Poss (1981: 47) who speaks of the social worker as being able to "convey some kind of strength...." The second reason given (to assist with explanation and information) could be due

to a patient's sense of intimidation at asking the doctor questions. This is confirmed by Ray and Baum (1985 :4) and is described further in section 2.9 (c). In addition to the social worker providing support, as described previously, she also has a role in patient education as described by Connell & Connell (1995: 34); Black (1989: 10) and Stolar (1982: 32).

3.2.14 The stage at which the patient would like the social worker to become involved

TABLE 6 : SOCIAL WORKER INVOLVEMENT AT DIAGNOSIS

	NO.	%
Before the diagnosis	9	28.1
At the time of diagnosis	3	9.4
Straight after diagnosis	9	28.1
At the clinic following diagnosis	11	34.4
TOTAL	32	100

The above result does seem to contradict patient responses in sections 3.2.12 and 3.2.13, where a large amount of respondents said they wanted the social worker to be at the diagnosis. In contrast, the above results indicate that only 9.4% of patients wanted the social worker to be present. This could possibly be explained in terms of patients perceptions of diagnosis as an ongoing process, and not a once-off consultation. This concept is confirmed in the literature, by Doka (1993 : 6), who describes diagnosis as a process. Hughson and Cooper (1982: 1430) and Stolar (1982: 32) confirm the importance of social work intervention from diagnosis onwards, but do not specify the exact stage. The high percentage of patients wanting to see the social worker at the clinic following diagnosis (34,4%), as well as the low percentage of patients wanting the social worker to be at the 'actual' diagnosis interview, could be explained in terms of the shock patients may be feeling, having received their

diagnosis, as described in sections 2.2 and 3.2.8. In the researcher's own experience, some patients needed to go home and absorb the shock before feeling ready to discuss the issues with the social worker (myself). On the other hand, others, especially those who did not have the support of a family member with them, needed to release their emotions after they had received the diagnosis. This would confirm the result of the nine patients (28,1%) who wanted to talk straight after they were given the initial diagnosis.

The above results confirm the importance of the presence of a social worker at diagnosis, but the exact stage of diagnosis seems to depend on patient preference.

3.2.15 Sufficient information supplied for patients to plan their lives

The table below shows patients' satisfaction or dissatisfaction with the amount of information given:

TABLE 7 : SUFFICIENCY OF INFORMATION

	NO.	%
Information was sufficient	19	61.3
Unsure if information was sufficient	5	16.1
Information insufficient	7	22.6
TOTAL	31	100

The majority of patients (61.3%), felt the information given was sufficient to be able to plan their lives, while 38.7% felt that information was insufficient, or they were unsure.

According to Taylor in Hack (1994: 280) one of the ways in which psychological adjustment to a life-threatening situation occurs is when people

have a sense of mastery or control. Hack interprets this control in health matters to include acquiring information about their illness and treatment and playing a more active role in decision-making regarding treatment. In a study conducted by Hack et al (1994: 287), it was found that although many patients want this type of information (active patients), there was also a significant group (passive patients) who would not seek further information as discussed in section 2.4.

It can be concluded that the 38.7% of patients who were not completely satisfied with the information received, could have possibly comprised the 'active' patients who desire more information about the illness and its treatment.

3.2.16 Aspects of the disease important to patients

The table below shows which aspects of breast cancer were most important (i.e. rated as 1, in a scale from 1 to 10) for patients to gain information about:

TABLE 8 : IMPORTANT AREAS OF INFORMATION

	No.	%
Treatment	11	39.3
Spread of the disease	7	25
Likelihood of cure	2	7.1
Impact on social life	0	
Effect on family and friends	0	
Self care	0	
Sexual attractiveness	0	
Treatment options	2	7.1
Side effects of treatment	0	
Emotional reaction to having cancer	6	21.5
TOTAL	28	100

Results show that aspects which patients feel to be important are as follows:

One quarter (25%), of the patients said spread of the disease, six patients (21,4%) said emotional reaction to cancer, two patients (7,1%) said treatment options, two patients (7,1%) said likelihood of a cure. Other aspects listed above were not rated as being important. The above results concur to some degree with a study conducted by Degner et al (1987), described in section 2.5, where they discuss aspects of the disease that patients find to be important. However, some of the aspects which they found to be important for patients were not confirmed in this study, e.g. aspects to do with the patient's social life, family and friends, sexuality, self care and side effects of treatment.

It seems that although patients want information about their treatment (39,3%) only 7,1% wanted more information about treatment options. This confirms Sutherland et al's (1989: 262) findings in section 2.5, which are that information may be required to function autonomously, even if the information is not being used to make decisions.

The high percentage of patients who sought more information about emotional aspects (21,4%) confirms results in sections 3.2.12-14, where patients were seen to have a need for further involvement from a social worker.

3.2.17 Aspects of the disease discussed with patients

The table below indicates aspects of the disease that were discussed with patients by a member of the team. Some patients mentioned several aspects.

TABLE 9 : ASPECTS OF THE DISEASE DISCUSSED WITH PATIENTS

	NO.	%
Treatment	26	20.5
Spread of disease	15	11.8
Likelihood of cure	18	14.2
Impact on social life	6	4.7
Effect on family and friends	8	6.3
Self care	11	7
Sexual attractiveness	6	4.7
Treatment options	13	10.2
Side effects of treatment	11	7
Emotional reaction	13	10.2
TOTAL	127	100

Results indicate the following significant areas that were discussed with patients:

Treatment	-	20,5 %
Likelihood of cure	-	14,2 %
Spread of disease	-	11,8 %
Treatment options	-	10,2 %
Emotional reaction	-	10,2 %

With reference to section 3.2.16 therefore, the following areas that were important for patients to gain more information about, were actually discussed with them.

- Treatment was well covered by the team

- Spread of the disease was discussed with 11,8% of the patients, but perhaps not covered as fully as patients would have wanted, i.e. 25% of patients wanted this aspect to be covered, as seen in section 3.2.16.
- Likelihood of cure was not rated as very important to patients - only 7,1% of patients rated it important. However, it was discussed relatively fully by doctors, with 14,2% of patients.
- Treatment options were also discussed more fully by doctors, i.e. with 10,2% of patients, than what was required by patients (7,1%) as seen in section 3.2.16.
- Patients' emotional reaction to having cancer was rated very highly in section 3.2.16; however this was not an area that was thoroughly discussed by the team, i.e. it was only discussed with 10.2% of the patients.

Patients' needs for the social worker is discussed with further detail in sections 3.2.12-14.

3.2.18 Discussion of treatment methods with the patient

Table 10 describes the different patients' views regarding whether the treatment methods were discussed with them.

TABLE 10 : DISCUSSION OF TREATMENT METHODS

	NO.	%
Treatment methods were discussed	21	65.6
Unsure if treatment methods were discussed	5	15.6
Treatment methods were not discussed	6	18.6
TOTAL	32	100

The above results confirm that the majority of patients have their needs met as far as information regarding treatment is concerned, as seen in section 3.2.16. However, 34.2% are either in doubt or feel they do not have their needs met.

Five people commented on the above. Two people (40%) said that nothing about treatment was discussed with them. Three people (60%) said that although it may have been explained, they did not always understand the doctor.

Findings here could confirm Kubler-Ross's (1969: 35) theory regarding shock and denial of the disease, which cause people not to absorb what the doctor told them, as seen in section 3.2.8 and 2.2. Findings could, on the other hand confer with Northouse and Northouse (in Luker et al 1995: 136) on patients' intimidation about asking questions, as described in section 3.2.9. The other possibility is that the 34.2% of patients were the 'passive' ones described by Hack et al in sections 2.5 and 3.2.15.

3.2.19 Patient involvement in decision-making

Twelve out of 30 patients who answered the question (40%) said they would like to have been more active in choosing treatment; eighteen patients (60%) said they did not feel a need to be part of this process. Ten people commented on the above: seven people (70%) felt that it is the doctor's choice and they have trust in his decision. Three people (30%) felt that it is important to know the advantages and disadvantages of the treatment.

As discussed in section 3.2.15 the majority of patients who do not want to be involved in making treatment choices, would fall into Hack et al's definition of a 'passive patient'.

Hack et al (1994: 287) stress very importantly, that all patients should have their information preferences respected. It seems clear that more patients seek information in general about treatment as seen in Table 8, than those who actively desire to be involved in making choices. Ray and Baum (1985: 41) in section 2.9 (c) assert that some patients see the doctor as an 'authority figure' and therefore are happy for them to make decisions on their behalf, this being

another explanation of why patients do not feel the need to be involved in decision making.

3.2.20 Explaining procedures

Thirty-one out of 35 patients (88,6%) felt that procedures were adequately explained to them before they were carried out, and four patients (11,4%) did not feel that there was adequate explanation.

Four patients commented on the above.

Two patients (50%) said that the doctor was too hurried to explain adequately, one patient (25 %) said she was too anxious to absorb the information and one patient (25 %) said she did not need explanations.

The above results concur with sections 3.2.15 and 3.2.18. In all three, it seems that the majority of patients are satisfied with the amount of information and explanation they are given, with a significant amount, although a minority, in all three sections, feeling dissatisfied with information given. This would seem again to represent Hack et al's passive vs. active patients. The active patient probably wants more information than the doctor has time to devote to her. Buckman (1992: 41) concurs with this argument, asserting that the average doctor allows the patient to talk for 18 seconds before interrupting her. Different reasons for this are described in sections 3.2.28 and 2.9 (A). Cultural and linguistic barriers can also account for patients not understanding all the information given to them as detailed in section 2.3 (A) (iii) and (iv).

3.2.21 Truthfulness of diagnosis

Thirty-seven patients (100%) felt that they had been told the truth about their illness.

Only one person commented that she was told the truth on her insistence.

As described in section 2.5, Hack et al (1994: 280) acknowledge that most doctors do tell their patients truthfully about their diagnosis, however they may differ from each other in the way they do so. In addition, Doka (1993 : 230) speaks of the importance of being truthful with patients.

3.2.22 Understanding of doctor's language

The table below describes how well patients understood the language doctors used when communicating with them.

TABLE 11 : DOCTOR'S LANGUAGE

	NO.	%
Patient understood	28	77.7
Unsure if understood	6	16.7
Did not understand	2	5.6
TOTAL	36	100

The majority of patients (77.7%) did not have problems from a language perspective.

The patients (22.3%) who were unsure, or did not understand the language the doctor used can be explained in two ways:

- (a) the patients spoke a different language to the doctor and therefore could not understand the actual language, as described in section 3.2.4.
- (b) the doctors used language that was too technical and therefore beyond the scope of the patients.

Connell and Connell (1995: 36) state that patient concerns should be addressed in understandable language and information should be presented simply and frequently. Buckman (194 : 82) warns against using psychological or medical jargon which the patient will not understand.

3.2.23 Empathy of team members towards patients

The table below describes patients' perceptions of empathy conveyed to them by the team.

TABLE 12 : EMPATHY FOR PATIENTS SHOWN BY TEAM MEMBERS

	NO.	%
Patient felt understood	29	85.3
Patient unsure if understood	4	11.8
Patient did not feel understood	1	2.9
TOTAL	34	100

Twenty-nine patients (85,3%) felt understood by the team members as a whole. Four patients (11,8%) were unsure if they were understood. Three patients (1%) did not feel understood.

Most patients (85.3%) did feel understood by the team, while 14.7% of patients did not feel completely understood.

As described in section 2.6, team communication of support with the patient will make a very big difference to the way the patient will cope with her illness (Chesler and Barbarin 1987, Lichter 1987, Guex 1989, Ray and Baum 1985, Blitzer 1990 and Lichter 1987).

3.2.24 Discussion of sensitive issues

Sixteen out of 35 patients (45,7%) did want to discuss sensitive issues, e.g. death, with the team. Nineteen patients (54,3%) did not wish to.

Six patients out of 19 patients (31.6%) said the team were willing to discuss these issues, while 8 patients (42.1%) said the team were not willing to enter into this type of discussion.

A significant proportion of patients did not want to discuss sensitive issues, such as death, with the team. However the majority of patients wished to discuss these issues.

Similarly it seems that a significant proportion of team members were willing to discuss these issues, however the majority avoided this type of discussion.

Kubler-Ross (1969: 13) speaks of fear and denial of death, that most people suffer from. This could explain why both patients and doctors avoid this painful subject. However, several authors discussed in section 2.7, speak of the importance of medical professionals facing and examining their own mortality in order to assist patients to work through their fears of dying (Kubler-Ross 1969; Guex 1989; Ray and Baum 1985; Barton 1977 and Poss 1981).

3.2.25 Respect for the patient by the doctor

Twenty out of 22 patients (93.5 %) felt that the doctor spoke to them as an adult and did not patronise them. Two patients (6.5 %) did not feel respected by the doctor. The majority, therefore, did feel that the doctor spoke to them with respect.

Rogers (1959), discussed in section 2.6, speaks of the importance of one person having 'positive regard' or respect for another, which will promote effective understanding. Lichter (1987: 2) backs this up in his description of doctor-patient communication as the conveying of caring, understanding, respect, continuity and availability. This is discussed further in section 2.9 (A).

3.2.26 Sufficient time in consultation with doctors

The table below describes the above variable.

TABLE 13 : TIME SPENT WITH DOCTORS

	NO.	%
Patients had enough time	25	80.6
Unsure if time was enough	3	9.7
Not enough time	3	9.7
TOTAL	31	100

The majority of patients (80.6%), felt they were given enough time with their doctors. There was a significant number of patients, however (19.4%), who stated that there was not enough time, or that they were unsure about this.

Several authors speak of this obstacle to communication. Guex (1989), Ray and Baum (1985) and Lichter (1987) do not confirm the above result and comment that doctors may spend little time with their patients as a way of avoiding difficult issues, described in section 2.9 (A), and discussed further in section 3.3.4 (i).

3.2.27 Doctors' enquiry regarding psychological well-being of patient

Twenty-three patients (65.7%) responded that doctors did ask them whether they were feeling low or depressed.

Twelve patients (34.3%) responded that they were unsure.

This uncertainty could be interpreted to mean that some members of the team enquired, while others did not.

3.2.28 Doctors' reaction to the patient being low or depressed

The table below describes the doctors' reaction to the patient being in a low or depressed mood.

TABLE 14 : DOCTORS' REACTIONS

	NO.	%
i) Discussed the problems with patients	12	52.2
ii) Refer patients to social worker	4	17.4
iii) None of the above	2	8.7
iv) Other	1	4.3
v) i) and ii)	4	17.4
TOTAL	23	100

Significant results showed that the doctor either spoke to the patient about problems him/herself in the majority of cases (52.2%), or referred the patient to a social worker (17.4%). (This result was less significant).

On the one hand it is important in holistic healing that doctors discuss issues of psychological import with patients. However, both patients and doctors have found that often there is not enough time for the consultation they would wish for, as seen in Sections 3.2.26 and 3.3.4(i). This would seem to imply that the social worker could be an aid to the doctor when issues of this nature arise. Poss (1981: 4) states that although doctors may be responsible for the patient's 'total' care, the social worker can be seen to be responsible for enhancing the patient's emotional, social and spiritual health. This is discussed in more detail in section 2.9 (C).

3.2.29 Patients' need for doctors to enquire about their emotional health

Eleven out of 14 patients (78.6%) who responded to the question in section 3.2.27 as negative, said they would have liked a doctor to enquire about their emotional health, while 3 patients (21.4%) did not have this need.

It appears from this information therefore, that patients have a need for 'holistic care' as seen in section 3.2.27.

3.2.30 Team request for patients to bring families to the clinic

Eight out of 33 patients (24.2%) said they were asked by a member of the team to bring their families to the clinic.

Twenty-five patients (75.8%) said they were not asked to bring their families to the clinic.

The table below indicates which members of the team spoke to the patients' families.

TABLE 15 : COMMUNICATION BETWEEN TEAM MEMBERS AND THE FAMILY

	NO.	%
Doctor	7	58.3
Social Worker	3	25.0
Other (not specified)	1	8.3
Doctor and Sister	1	8.3
TOTAL	12	100

It can be seen from the above, that the majority of patients are not being asked to include their families in issues regarding their illness.

Significant results show that either the social worker (25%), or doctor (58.3%), consult with family members when they do come to the clinic.

Poss (1981 : 95) sees the family as part of the 'treatment team'. She adds that work with the family is vital in order to work effectively with the patient. She

is backed in section 2.9 (C) by Doka (1993) and Stolar (1982) and by several authors discussed in section 2.8.1.

3.2.31 Discussion of Hospice with patient

Twenty-two out of 34 patients (64.7%) said they were told about Hospice or the Cancer Association.

Twelve patients (35.3%) said they were not told of these resources.

The majority of patients therefore, were told about Hospice as an important resource, especially for the terminally ill patient, (although they do provide services for those who are not terminally ill as well). Hospice is often perceived as an organization only for the terminally ill, which is a possible reason that a significant amount of patients were not informed about it. Further discussion about the Hospice team can be found in section 2.8.2.

3.2.32 Patients' perception of being 'listened to'

The table below indicates whether or not patients feel they are being listened to by the team.

TABLE 16 : PATIENTS' PERCEPTION OF 'BEING HEARD'

	NO.	%
Patients feel heard	26	86.7
Patients unsure	2	6.7
Patients do not feel heard	2	6.7
TOTAL	30	100

Twenty-six patients (86.7%), the majority, felt that the team does 'listen' to them.

The two patients (6.7%), who felt 'unsure' may be indicating that some members of the team listened to them, while others did not, while 6.7% of

patients did not feel heard by the team.

Most patients, therefore, did feel the sense of team support, stressed in sections 2.6 and 2.9 (A), (B) and (C) and discussed in sections 3.2.13, 3.2.23 and 3.2.25.

3.2.33 Patients' 'ability' to disagree with doctor

The table below describes whether or not patients felt they could voice their disagreements with their doctors.

TABLE 17 : PATIENTS' COMFORT WITH DISAGREEING WITH THEIR DOCTORS

	NO.	%
Patients felt comfortable to disagree	17	58.6
Patients unsure whether they could disagree or not	9	31.0
Patients did not feel comfortable to disagree	3	10.3
TOTAL	29	100

A significant proportion of patients (58.6%), felt confident enough in their relationships with their doctors to argue an issue with them. However, a large proportion of patients (41.3%) felt uneasy about this.

As described in section 2.9 (A) (c), several authors speak of the hierarchical nature of the doctor-patient relationship, and hence, the patient's feeling of inferiority and sense of intimidation in challenging their doctors (Ray and Baum 1985). This phenomenon may also be explained by Hack et al (1994) in terms of the 'active' and 'passive' patient. The 'passive' patient may feel so confident in her relationship with the doctor that she does not feel a need to challenge him.

3.2.34 Patients' perceptions of the role of the sister

The following table indicates what patients perceive the role of the sister to be.

TABLE 18 : PATIENTS' PERCEPTIONS OF THE ROLE(S) OF THE SISTER

Role of Sister	NO.	%
a) Answering questions about any illness/treatment	1	3.3
b) Giving me emotional support	2	6.7
c) Helping me with practical information	1	3.3
d) Referring me to appropriate professionals	2	6.7
e) B, C and D	3	10.0
f) C and D	4	13.3
g) A and C and D	2	6.7
h) A and B and F	9	30.0
i) A and B and C	1	3.3
j) A and D	2	6.7
k) A and B	2	6.7
l) A and B and D	2	6.7
TOTAL	30	100

Significant results show what the majority of patients deem the role of the sister to be.

Nine patients (30%) perceived the role of the sister to fulfil all four functions listed above (A and B and C and D).

Four patients (13.3%) saw the sister in more practical terms - to give practical information (C) and refer the patients to relevant resources (D).

Three patients (10%) saw the sister as having all three functions, except information giving regarding the patient's illness.

Seven patients altogether (23.3%) saw the nurse in terms of giving information

regarding the patient's illness, as well as having other roles.

The majority of patients therefore, saw the role of the sister as needing to fulfil all four functions listed above.

As seen in section 2.9 (B), these roles are discussed by several authors. Ray and Baum (1985) describe the technical role of the nurse, while several authors speak of the supportive role of the sister (Ray and Baum 1985; Wiernik 1983, Lichter 1987, Perachi in Pfeiffer and Mulliken 1984; Calzone in Harness 1988, and Guex 1989: 74).

Others speak of the informative role of the sister (Pallson and Norberg 1985, Suominen et al 1994 and Beisecker 1994). However, some authors disagree with this role of the sister and question her ability to transmit the necessary information (Luker et al 1995 and Lewis and Bloom 1978). The aforementioned authors, as well as Guex (1989), agree that the role of the nurse should be one of co-ordination for physical and psychological care and to be alert to the need for patient referral.

3.2.35 Roles fulfilled by sisters

The following table describes patients' perceptions of the roles actually fulfilled by the nurses/sisters in the Breast Clinic.

TABLE 19 : ROLES FULFILLED BY SISTERS

	NO.	%
a) Answered questions about my illness/treatment	0	0
b) Giving me emotional support	1	5.9
c) Helping me with practical information	2	11.8
d) Referring me to appropriate professionals	2	11.8
e) b, c and d	3	17.6
f) c and d	3	17.6
g) a and b and c and d	4	23.5
h) a and b	1	5.9
TOTAL	17	100

Significant results describe which roles are actually fulfilled by the sisters.

Four patients (23.5%) said that all four roles were fulfilled (a and b and c and d). This correlates with results in 3.2.34, where a significant amount of patients perceived the above to be the role of the sister.

Three patients (17.6%) perceived the sister to fulfil the roles of b, c and d. This again, concurs with what patients perceived the role of the sister to be in 3.2.34, i.e. 7 patients altogether (23.3%) perceived the sister to have these three roles.

Three patients (17.6%) said the sisters fulfilled their role in terms of practical information (c) and referral (d). This confirms the above result.

Three patients (17.6%) felt the sister did fulfil the role of information giving, together with other roles. This was a lower percentage than in 3.2.34, where patients saw a further role for sisters in terms of information giving. These results confirm the literature in 3.2.34, as well as the ambivalence several

authors feel regarding the sister's role in giving information, described in section 2.9 (B).

3.2.36 Patient comfort at talking to the sisters

The following table discusses how comfortable patients feel, at chatting to the sisters.

TABLE 20 : EASE WITH WHICH PATIENTS TALK TO SISTERS

	NO.	%
Patients feel comfortable	25	83.3
Patients unsure	2	6.7
Patients feel uneasy	3	10.0
TOTAL	30	100

Twenty-five patients (83.3%), the majority, said they felt comfortable chatting to the sisters. This concurs with results in section 3.2.35, where 9 patients out of seventeen (52.9%) said that one of the roles fulfilled by the sisters was that of emotional support.

Several authors see at least one of the roles of the sister as a support to the patient, especially when the patient feels too intimidated to speak to her doctor (Ray and Baum 1985; Wiernik 1983; Guex 1989; Lichter 1987; Perachi in Pfeiffer and Mulliken 1984; Calzone in Harness 1988 and Lichter 1987). This is discussed in section 2.9 (B).

3.2.37 Patients' awareness of a social worker in the clinic

Twenty-four patients out of 30, (68.6%), were aware of the existence of a social worker and eleven patients (31.4%) were unaware of her existence. It appears from the above, that there is not enough being done in the clinic, both by the social worker and the rest of the team, to make patients aware of the

social worker and her role. The above results are confirmed by Bergman et al (1982: 1), discussed in section 2.9 (C). They assert that there is a general lack of understanding about what social workers can do, by both staff and patients.

3.2.38 Number of patients who have consulted the social worker

Eleven out of 30 patients, (33.3%), replied that they had consulted the social worker, while 22 patients (66.7%) had not.

The above results imply that out of those patients who were aware of the existence of the social worker, less than half consulted with her.

As in 3.2.37, this seems to be the result of poor marketing of the social worker, as discussed in sections 3.3.9 and 2.8.3.

3.2.38(a) Social worker's support of patients

The table below indicates whether or not patients who saw the social worker felt supported by her.

TABLE 21 : PATIENTS' PERCEPTIONS OF SOCIAL WORKER SUPPORT

	NO.	%
Felt supported	8	57.1
Unsure	4	28.6
Did not feel supported	2	14.3
TOTAL	14	100

Fifty seven point one percent of patients, the majority, felt emotionally supported by the social worker. The rest, 42.9% of patients, felt unsure or unsupported by her.

In the section above, (3.2.38), only eleven patients said they had consulted with the social worker, whereas in 3.2.38 (a), fourteen people responded. The possibility exists that those patients who replied that they were unsure, did not actually consult with the social worker.

3.2.38(b) Patients' ease at asking the social worker questions

The table below shows the patient's level of comfort at asking the social worker questions about her illness.

TABLE 22 : PATIENTS' PERCEPTIONS OF THE SOCIAL WORKER AS EDUCATOR

	NO.	%
Felt at ease	10	76.9
Unsure	2	15.4
Felt uneasy	1	7.4
TOTAL	13	100

The majority of patients (76.9%), felt at ease asking the social worker questions regarding their illness, while 22.8% felt unsure or uneasy.

A significant number of patients therefore felt comfortable asking the social worker questions regarding their illness.

3.2.38(c) Helpfulness of the social worker's intervention

Eleven out of sixteen patients (68.8%) felt social worker intervention was helpful and five patients (31.3%) felt it was not helpful.

Comments on the above question were:

- "She gave me support, objectivity."
- "She assisted me with information."

3.2.38(d) Interest in speaking to the social worker

The patients who replied that they had not consulted the social worker were asked if they would have been interested in speaking to her.

Eighteen out of 25 patients (72%) said yes, while seven patients, (28%) said they would not have been interested.

A significant amount of patients therefore, who were not formerly aware of the social worker in the clinic, would like to have consulted with her. The majority of those who did consult her felt comfortable speaking to her about their emotions, as well as their health.

Stolar (1982: 26) comments on how medical personnel separate emotional and physical health and do not treat the 'whole' patient. This could be one of the reasons that patients are not referred often enough to the social worker. Other reasons are described in sections 3.2.38 and 2.9 (C).

Results of Sections 3.2.38 (a-d) confirm the multi-faceted role of the social worker commented on by several authors in section 2.9 (C).

Poss (1981: 45-50), speaks of the extremely important counselling role of the social worker. Black (1989), Corbin and Strauss (1988), Connell and Connell (1995) and Stolar (1982), speak of empowering the patient to become more active in the decision-making process.

In addition, Connell and Connell (1995) see the role of the social worker as advocate between the patient and the medical team.

3.2.39 General Comments

Patients made the following general comments:

Two patients said:

"I was not aware of a social worker in the clinic. Patients should be made aware of this."

Two patients said:

"If you have cancer you need someone to talk to."

Seven people said they were very happy with the clinic.

One patient said that there was good team work and she appreciated the care. However, she would have appreciated less anxiety expressed by the team regarding the use of alternative treatment in addition to orthodox treatment.

3.3 ANALYSIS OF DOCTOR, SISTER AND SOCIAL WORKER INTERVIEWS

3.3.1 INTRODUCTION

As in Section 3.1, most of the questions were analysed in terms of numbers and percentages and presented in the form of tables.

The researcher had three options in terms of how to work out percentages, due to the fact that, in most cases, respondents could give more than one response.

The three options were as follows:

- (a) Percentages could be worked out, out of the total number of respondents, i.e. 11 doctors, 6 sisters and 2 social workers. Responses would then be presented under certain headings, with the combination of applicable responses under that heading. In this case, percentages would not add up to 100%.
- (b) The researcher could have worked out a percentage for each response out of the total number of responses. This percentage would add up to 100%.

- (c) The researcher could have worked out a percentage for each combination of responses out of the total number of responses. This too, would have totalled 100%.

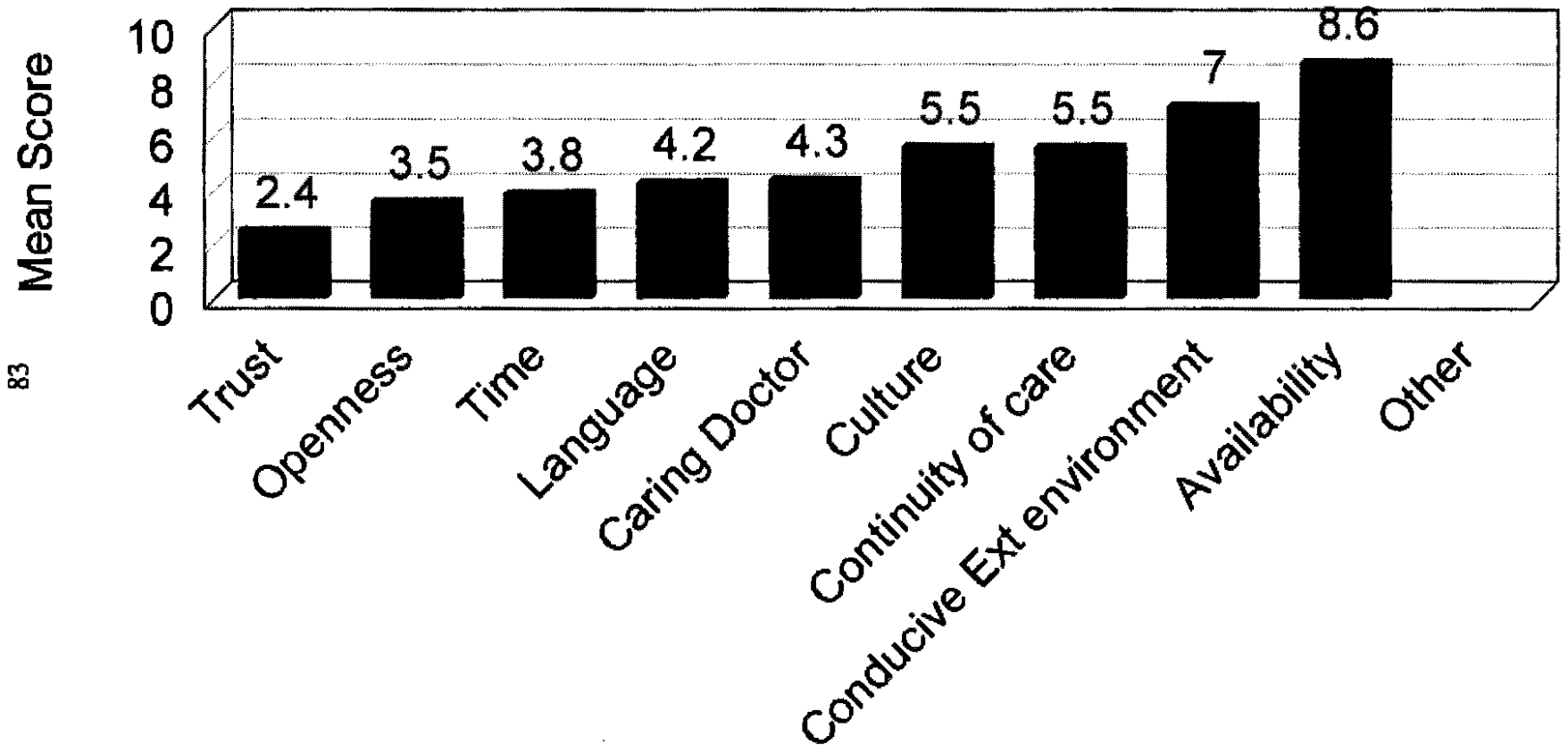
The researcher chose option (a) as she felt that working out a percentage out of the total number of responses would not be as meaningful in this study as being able to provide data on what the respondents said. In addition, the researcher felt that working out percentages from each combination of responses, as in (c) could create very small and insignificant percentages.

In the sections where the same questions were asked of doctors, sisters and social workers, these responses were tabulated together, for the purpose of comparison. The researcher had the option of cross-tabulation but decided against it, due to the small number of social workers, which would have skewed the results.

3.3.2 FEATURES OF GOOD DOCTOR-PATIENT COMMUNICATION

This section was analysed as the mean score for each response. It was analysed in this way because all responses were supplied to the respondents (doctors) in the interview, and they were asked to rank them in order of importance. This is different from the other questions where the respondents (sisters and social workers) volunteered their own answers so that they could be analysed in percentages. The reason for the difference in the way the questions were asked of the doctors versus the sisters and social workers, was that during the pilot study, several doctors said they would not have time to think up responses themselves and would prefer to rank them.

FIGURE A DOCTOR - PATIENT COMMUNICATION



Most Important-----Least Important

■ Features of good Doctor - Patient Communication

NOTE: Scores are ranked in decreasing importance, i.e. the feature with the lowest score has the most importance.

In Section 3.2.2 the respondents (doctors), were asked to rank 'Nine features of good doctor/patient communication in order of importance', with 1 being the most important. The results can be seen from Figure A on page 83, where a mean score was calculated for each response. Obviously the lower the score, the more important the response. From Figure A, the most important features, in descending order, were Trust, Openness, Time, Language, Caring doctor, Culture, Continuity of care, Conducive external environment and availability. There were 2 'other' responses, i.e. responses which were not mentioned in the question and they were: 'Doctors' experience' which had a score of 6 in that doctor's opinion and 'Denial', which was unranked.

Several authors, discussed in section 2.6, speak of the importance of establishing a good relationship or rapport with the patient, of which trust, openness to questions and discussion and a caring doctor, are certainly a part (Ireland 1993; Di Matteo 1979; Ray and Baum 1985; Lichter 1987 and Chesler and Barbarin 1987). These aspects of communication were seen to be extremely important by the doctors. One could surmise from this, that establishing a good relationship is the cornerstone of any future communication that will take place between the doctor and patient.

Having enough time to spend with patients was rated third highest, after trust and openness. It would seem obvious that spending time with patients is a prerequisite for establishing a good relationship with the patient (i.e., a trusting and open one).

Despite the fact that doctors see time as an important element of communication, findings in the literature contradict this, as discussed in sections 3.2.20, 3.2.26 and 2.9 (A).

Language and cultural factors were rated as less important. Despite the importance that many authors place on these two factors (Trenholm 1995; Strano 1984; Ruben 1984 and Nunnally and May 1989; Doka 1993), for doctors it appears that they come secondary to a good basic relationship with the patient. This is discussed in section 2.3 (iii) and (iv).

Interestingly, doctors did not rate continuity of care for the patients as very high. This would seem to contradict what was earlier said regarding the importance of doctor/patient rapport. It would be difficult to establish this type of rapport if the doctor the patient is consulting with, continuously changes. In section 2.9 (A), Barton (1977: 172) contradicts doctor responses. He sees continuity of care as vital to the patient's sense of interconnectedness and feeling of aliveness. A lack of this quality with care-givers can lead to a feeling of isolation and abandonment. Latimer (1991: 860) concurs with Barton's opinion.

Finally, the scores with the lowest rating, was a 'conducive external environment' and availability. Several doctors explained this to mean, the environment patients are exposed to while waiting for doctors, i.e. friendliness and efficiency of clerks, waiting in long queues etc, as well as the environment for doctors, i.e. telephones that work, an efficient pager system and efficient secretaries. These factors affect the way doctors and patients relate to each other. However, it would seem from the doctors' responses that they see these factors as secondary.

Barton (1977: 4) sees the hospital environment as being inseparably intertwined with psycho-social stresses for patients, their families and the care-givers, as discussed in section 2.9 (A). This contradicts doctors' responses.

3.3.3 FEATURES OF GOOD SISTER-PATIENT AND SOCIAL WORKER-PATIENT COMMUNICATION

As mentioned above, sisters and social workers were asked to supply their own ideas regarding good communication. It would have been better for purposes of comparison had the questions all been presented in the same way.

Table 21 on page 87 indicates what both sisters and social workers described as good communication within their respective disciplines.

TABLE 23 : ASPECTS OF GOOD COMMUNICATION

SUPPORT	SISTERS		SOCIAL WORKERS	
	NO.	%	NO.	%
Support alone	2	33.3		
Support, education, referral to other professionals	1	16.7		
Support, education	3	50		
Support, education, referral, mediation			1	50
Support, mediation, education			1	50
SUB TOTAL	6	100	2	100
EDUCATION	SISTERS		SOCIAL WORKERS	
	NO.	%	NO.	%
Education, support, referral	1	16.7		
Education, support	3	50		
Education, support referral, mediation			1	50
Education, support, mediation			1	50
SUB TOTAL	4	66.6	2	100
MEDIATOR				
Referral, support, education	1	16.7		
Referral, mediator, education, support			2	100
SUB TOTAL	1	16.7	2	100

(a) SUPPORT

Six sisters (100%) said that they saw emotional support for patients as an important aspect of communication. Two social workers (100%) also saw support

as very important.

These results correlate with the roles that patients see nurses as having; this can be seen in sections 3.2.36 and 2.9 (B). In addition, Poss (1981: 47) speaks of the counselling and "holding" role of the social worker, as described in sections 3.2.40 and 2.9 (C).

(b) EDUCATION

The high percentage of nurses who saw their role as educator can be correlated with patients' perceptions described in section 3.2.34, where 23.3% of patients saw the nurse's role as giving information. Further details of the nurse as educator can be found in section 2.9 (C).

As seen in section 3.2.13, 46.1% of patients said they would have liked the social worker to assist them with further explanation of the disease and additional information, especially at diagnosis. In the above table it can be seen that social workers also see this as their role. The literature described in section 2.9 (C), (Connell and Connell 1995; Black 1989; Stolar 1989) confirms these findings, and argues for the social worker as educator of the patient, family and inter-disciplinary team.

(c) REFERRAL TO OTHER PROFESSIONALS AND/OR RESOURCES/MEDIATOR

One sister (16.7%) and two social workers (100%) saw their roles in communication with the patient as mediating between the patient and his/her environment. Despite the low percentage of sisters who saw this aspect as important, many authors see this as an important role for the sister. This is discussed in section 3.2.34 and 2.9 (B). Several authors speak of the social worker as the mediator between the patient, the family and the medical team (Connell and Connell 1995; Black 1989; Kane and Kane 1987; Kleinman 1988;

Goldberg and Tull 1983; Guex 1989). Connell and Connell (1995) also speak of the social worker as an advocate for the patient, as described in section 2.9 (C).

3.3.4 OBSTACLES TO COMMUNICATION IN THE CLINIC

The following table indicates what doctors, sisters and social workers experience as obstacles to communication.

TABLE 24 : OBSTACLES TO COMMUNICATION

(i) NOT ENOUGH TIME	DOCTORS		SISTERS		SOCIAL WORKERS	
	NO.	%	NO.	%	NO.	%
Time only	3	27.3	3	50	1	50
Time, language	1	9.1				
Time, uncondusive hospital environment	1	9.1				
Time, culture			1	16.7		
Time, depression			1	16.7		
Time, culture					1	50
SUB TOTAL	6	54.5	5	83.4	2	100
(ii) LANGUAGE & CULTURE						
Language, time	1	9.1	1	16.7		
Culture, time			1	16.7		
Culture alone			1	16.7		
Language, culture	2	18.2				
Language, culture hospital environment	4	36.4				
Culture, time					1	50
SUB TOTAL	7	63.7	3	50.1	1	50

(iii) UNCONDUCTIVE HOSPITAL ENVIRONMENT						
Unconductive hospital environment alone	1	9.1				
Unconductive hospital environment, language, culture	2	18.2				
Hospital environment, time	2	18.2				
SUB TOTAL	5	53.4				
(iv) DEPRESSION DUE TO NATURE OF WORK			1	16.7		
SUB TOTAL			1	16.7		

(i) Time

The biggest obstacle to communication seemed to be that all the different team members (doctors, sisters, social workers), do not have enough time to spend with their patients, due to the pressures of work.

Six doctors (54.5%), found time to be an obstacle; five sisters (53.4%) and both social workers (100%), agreed.

Interestingly, in section 3.3.2, doctors also found time to be a very important component of good communication. Many of the factors mentioned in Table 24 could be contributing to the shortage of time that staff are experiencing; i.e., where team members and patients are from different language and culture groups, it would take longer for them to understand each other. Also, where an unconductive hospital environment exists, i.e. poor conditions of work, every task will take longer to be completed. The importance of time as an obstacle to communication is described in more detail in section 2.9 (A) (a).

(ii) Language and culture

The researcher decided to discuss these two obstacles together, as there is often an interplay between them, i.e. where problems of language exist, problems of culture often exist.

Seven doctors (63.7%), found language and culture to be obstacles in the communication process; three sisters (50.1%) and one social worker (50%) agreed.

Figures for time and language and culture are both high, and as mentioned above, can be seen to affect one another.

In the Breast Clinic, the team has to deal with at least four different cultural and language groups (as well as their subgroups), as demonstrated in 3.2.3 and 3.2.4. The literature described in sections 2.3 (iii) and (iv), as well as 2.9 (A) (d) confirms the difficulty of communicating across the language and culture barriers. Doka (1993: 216) specifically mentions the complexity of decoding verbal and non-verbal behaviour which is culturally specific.

(iii) Unconducive hospital environment

Five doctors (53.4%), found the above factor to be an obstacle. No sisters or social workers rated this as an obstacle.

One of the factors that several doctors mentioned under the above heading, was that the breakdown in the hospital environment, e.g. inefficient pager system, often caused doctors to be unavailable to their patients. A lack of efficiency in the environment, therefore, creates difficulties in doctor/patient relationships.

The researcher surmises that doctors, as opposed to sisters and social workers, found this to be a problem because doctors often work in several wards or even hospitals, whereas sisters and social workers can usually be found in their own wards or departments. This would make them more available and less affected

by the general hospital environment. This obstacle is discussed in section 3.3.2 and 2.9 (A) (c).

(iv) **Depression due to nature of work**

One sister (16.7%) mentioned this to be an obstacle in communication with the patients. Doctors and social workers did not state the above as an obstacle. As can be seen in section 2.7, several authors agree that where the care-givers are themselves not confronting their own mortality, these issues are avoided or mishandled with patients (Poss 1981; Kubler-Ross 1969; Barton 1977). The researcher would therefore use the above to explain the low percentage of professionals who stated this as an obstacle, i.e. a very low level of self-awareness of how they are being affected by issues of suffering, death and dying.

3.3.5 SOCIAL WORKERS' ASSISTANCE WITH BARRIERS TO COMMUNICATION

Doctors were asked whether a social worker could play a role in the barriers to communication mentioned in 3.3.4. This question was only asked in the doctors' questionnaire. The researcher sees this as a flaw in the questionnaire, as this question should have been asked of the sisters as well.

The table below indicates doctors' responses to the above question.

TABLE 25 : SOCIAL WORKERS' ASSISTANCE WITH COMMUNICATION

	NO.	%
YES	9	82
NO	2	18
TOTAL	11	100

The majority of doctors therefore, (92%), felt that the social worker does play a role in assisting with doctor-patient communication. The way in which she could assist will be discussed further in section 3.3.10.

3.3.6 TEAM COMMUNICATION IN THE CLINIC

Doctors, sisters and social workers were asked to rate team communication in the clinic. The table below describes their responses.

TABLE 26 : LEVEL OF TEAM COMMUNICATION

	DOCTORS		SISTERS		SOCIAL WORKERS	
	NO.	%	NO.	%	NO.	%
GOOD	6	75	2	33.3	0	
FAIR	2	25	2	33.3	1	50
POOR			2	33.3	1	50
TOTAL	8	100	6	100	2	100

The majority of doctors, (75%), felt that team communication was good. A third of the sisters, (33.3%) agreed, while no social workers found team communication satisfactory.

The remaining quarter of doctors (25%), stated that communication was fair, while a third of the sisters agreed and one social worker (50%) also felt it was fair.

None of the doctors felt that communication was poor, a third of the sisters felt it was poor, and one social worker (50%), agreed.

According to section 3.3.7, doctors did not see the social worker as a functioning member of the team at the time of the interview. It is very possible therefore, that doctors', and possibly sisters' responses reflected team communication between doctors and sisters only. This would account for the difference between

doctors and sisters, versus social worker perceptions of team communication.

It seems clear from the above therefore, that there is a discrepancy in the team as to the nature of their communication, the majority of doctors feeling satisfied, while the sisters and social workers feel much less so. In section 2.8, the literature describes leadership of the medical team to be traditionally assigned to the physician. Gaps in social, economic and prestige status can separate the physician from other team members, making effective interaction difficult. Lowe and Herranen (1978: 327), Sands et al (1990: 56) and Abramson and Mizrachi (1996: 271) assert that differences in professional values, socialisation and philosophy can create conflict in a team. According to several authors cited by Abramson and Mizrachi (1996: 271), nurses and social workers face comparable issues, including a lack of recognition of their competence. The above factors, detailed in section 2.8, may account for the above discrepancy.

3.3.7 FACTORS AIDING COMMUNICATION

Both doctors and social workers stated that at the time of the research, there was no communication between the social workers and the rest of the team (i.e. doctors and sisters). The researcher, therefore, asked doctors and sisters what factors they believe are present that make their team function. The table below describes their responses.

TABLE 27 : FACTORS AIDING COMMUNICATION

i) OPEN COMMUNICATION	DOCTORS		SISTERS	
	NO.	%	NO.	%
Open communication only	1	9.1	2	33.3
Open communication, formal meetings, efficiency, availability	1	9.1		
Open communication, availability	2	18.2		
Open communication, continuity, efficiency	2	18.2		
Open communication, continuity	1	9.1		
Open communication, formal meetings			1	16.7
Open communication, continuity, formal meetings			1	16.7
SUB TOTAL	7	63.7	4	66.7
ii) FORMAL MEETINGS				
Formal meetings, open communication, availability	1	9.1		
Formal meetings, continuity	1	9.1		
Formal meetings	3	27.3		
Formal meetings, open communication			1	16.7
Formal meetings, continuity, open communication	1	18.2	1	16.7
SUB TOTAL	6	63.7	2	33.4
iii) AVAILABILITY				
Availability, open communication	2	18.2		
Availability, continuity, open communication	1	9.1		
SUB TOTAL	3	27.3		
iv) CONTINUITY OF STAFF				
Continuity, formal meetings	1	9.1		

Continuity, formal meetings, open communication	2	18.2	1	16.7
Continuity, open communication	1	9.1		
SUB TOTAL	4	36.4	1	16.7

(i) **Open Communication**

Seven doctors (63.7%) and four sisters (66.7%) said that open communication, care and respect of team members for each other aid in team communication. This factor was rated as most important by both doctors and sisters.

Several authors, discussed further in section 2.8, confirm the above, that the team needs to deal honestly and openly with each other for the ultimate benefit of the patient (Lichter 1985: 186; Guex 1989: 75; Nason 1983: 31).

(ii) **Formal meetings**

Six doctors (63.7%) and two sisters (33.4%), felt that formal meetings were an important aid to team communication. Two doctors added under this heading, that in order for the team to function effectively, definite policies and roles needed to be set in place. This result is confirmed by certain authors in section 2.8, who see the importance of team conferences and exchanges of information in order to meet the needs of the patient at every stage of the disease, as well as to work through their own feelings about different issues (Lichter 1985: 186; Guex 1989; Nason 1983: 31).

Lowe and Herranen (1978: 325) and Blues and Zerwekh (1984: 7) emphasise the importance of clear role expectations and goals in the team.

(iii) **Availability of team members**

Three doctors (27.3%) commented on the above factor as a way of maintaining the smooth functioning of the team. The sisters did not mention this.

This can be linked with the importance of having regular meetings, where team members are available to each other for discussion. As discussed in 3.3.3 (c), it is possible that sisters do not see the above as an important factor due to the fact that they are less scattered than the doctors.

(iv) Continuity of staff

Four doctors (36.4%) and one sister (16.7%) found continuity of staff valuable in good team communication. It would seem that the longer people have functioned together as a team, the better they would know each other and therefore what is expected from them, and the easier it would be to co-operate together.

3.3.8 FACTORS HINDERING TEAM COMMUNICATION (Medical doctors and sisters)

As mentioned above, the doctors did not see the social worker as part of the team. The researcher therefore, split this question into: factors hindering communication between the medical doctors and sisters, and those between the medical team and social worker.

Table 28 describes factors hindering communication between the team comprising doctors and sisters.

TABLE 28 : OBSTACLES TO TEAM COMMUNICATION

i) NO HOSPITAL SUPPORT STRUCTURE	DOCTORS		SISTERS	
	NO.	%	NO.	%
No hospital support structure only	2	18.2		
Work pressure, inexperience with team involvement, No hospital support	1	9.1		
SUB TOTAL	3	27.3		
ii) WORK PRESSURE				
Work pressure alone	4	36.4	3	50
Work pressure, inexperience with team involvement, No hospital support	1	9.1		
SUB TOTAL	4	45.4	3	50
iii) NO PROBLEMS	4	36.4		
iv) INEXPERIENCE WITH TEAM INVOLVEMENT			1	16.7
Inexperience, work pressure, No support structure	1	9.1		
SUB TOTAL	1	9.1	1	16.7

(i) No hospital support structure

Three doctors (27.3%), saw the above factor as a hindrance to team communication. Similarly, in Section 3.3.3 (c), this was also seen by doctors as an obstacle to their communication with their patients.

Under this heading, several doctors mentioned lack of availability of other team members due to the poor hospital back-up service (i.e. clerks, lifts, pagers, telephones) that is overused or does not function well. (See also Section 3.3.3).

(ii) Work pressure

Four doctors (45.5%), and three sisters (50%), found work pressure to be the greatest hindrance to team communication. Some of the pressures that professionals spoke about were: non-productive attitudes and difficult personalities among team members; stress leading to burn-out, and language and cultural barriers, keeping staff separate from each other.

Many of these factors contributing to work pressure, i.e. difficult personalities, stress and burn-out, can be explained by the nature of the work that care-givers are exposed to. Working with people who may be very sick or dying, forces them to confront issues regarding their own mortality. As described in sections 3.3.4 (iv) and 2.7, each profession deals in their own way with the stresses taking place. Barton (1977: 82) stresses that without shared support and a setting for the expression of feelings in the care-giving milieu, care-givers can be left in isolation and despair, leading to a sense of estrangement from other care-givers.

The area of language and culture as a cause of team divisiveness is confirmed by Barton (1977: 81), who states that conflict arises due to pre-conceived stereotypes held by care-givers about each other as well as differences in language, among other factors. This is discussed in section 2.8.3.

(iii) No problems

Four doctors (36.4%), a fairly large proportion, felt there were no problems in team communication.

(iv) Inexperience with team involvement

One doctor (9.1%) and one sister (16.7%) felt that several problems arose in the team, simply due to inexperience of certain team members in working in a multi-disciplinary team.

3.3.9 FACTORS HINDERING TEAM COMMUNICATION

(Between social worker and medical team)

TABLE 29 : OBSTACLES TO TEAM-SOCIAL WORKER COMMUNICATION

i) IGNORANCE RE: ROLE OF SOCIAL WORKER	DOCTORS		SISTERS		SOCIAL WORKERS	
	NO.	%	NO.	%	NO.	%
Role of social worker, availability	2	18.2				
Role of social worker, visibility, availability	2	18.2				
Role of social worker, visibility	1	9.1				
Availability, visibility	1	9.1				
Role of social worker alone			2	33.4		
SUB TOTAL	6	54.6	2	33.4		
ii) LACK OF AVAIL- ABILITY OF SOCIAL WORKER						
Lack of availability alone	3	27.3				
Ignorance re: role of social worker, lack of availability	3	27.3				
Role of social worker, visibility, availability	2	18.2				
SUB TOTAL	8	72.8				
iii) LACK OF VISIB- ILITY OF SOCIAL WORKER						
Lack of visibility alone	2	18.2	1			

Visibility, role of social worker, availability	2	18.2				
Role of social worker, visibility	1	9.1				
Visibility, availability	1	9.1				
SUB TOTAL	6	54.5				
iv) SOCIAL WORKER PERSPECTIVES						
Doctors don't get involved in psycho-social issues						
Doctors unavailable to discuss psycho-social issues with social workers Few referrals					2	100
SUB TOTAL					2	100

(i) Ignorance regarding the role of the social worker

Six doctors (54.6%) and two sisters (33.4%) said that one of the factors hindering their relationship with the social worker was that they were ignorant about what she has to offer. Some of the doctors said there had never been any formal introduction to her, adding to their lack of knowledge about her role. As can be seen, the doctors experienced this more strongly than the sisters. A study conducted by Bergman et al (1982: 1) within a medical milieu, detailed in section 2.9 (C), found a general lack of understanding of what social workers can do.

(ii) Lack of availability of the social worker

Eight doctors (72.8%) felt that the social worker was not available when they needed her. Judging by the high percentage, this was the greatest hindrance doctors experienced in their relationship with the social worker.

None of the sisters experienced this problem with the social workers.

Abramson and Mizrachi (1996: 271), described in section 2.8.3, confirm this, that doctors find social workers to be unavailable.

(iii) Lack of visibility of the social worker

Six doctors (54.6%) said that the social worker was not visible to them on a formal or informal level. Some of the doctors described it as not feeling the 'presence' of the social worker. This is linked to the doctors' sense of not experiencing the availability of the social worker. As in (ii) above, the sisters did not state that they experienced this difficulty at all.

(iv) Social workers' perceptions

Both social workers (100%) explained their isolation from the rest of the team as follows:

The social workers experience the doctors as having a lack of concern for psycho-social issues affecting the patients, and deal with the medical aspects of the patients only.

Secondly, they feel that the doctors are unavailable to them to discuss patients' concerns.

Thirdly, social workers get very few referrals from doctors which leads to a vicious cycle in that they come to the clinic less and less often.

From the above it seems there is a stark contrast between the doctors' and sisters' perceptions of the same social workers at the same clinic. The doctors feel unclear about the role of the social worker, and feel that she is unavailable and lacks a presence. However, only two sisters felt unclear about the role of the social worker and did not state any other problems.

The above conflict concurs with a study conducted by Abramson and Mizrachi (1996: 271), as mentioned in section 3.3.9 (ii). They found that

social workers found physicians to be inaccessible or as valuing brevity in their communication with social workers. However, according to the doctors, it was the social worker who was unavailable or withheld information. According to the researcher, social workers lack clarity regarding what to communicate, or they lack the confidence (due to the lack of recognition they receive), to express their views effectively.

3.3.10 SOCIAL WORKERS' ROLE IN ASSISTING WITH TEAM COMMUNICATION AND DOCTOR-PATIENT COMMUNICATION, AND TEAM COMMUNICATION

The table below indicates whether doctors feel that social workers have a role to play in assisting with their communication with patients, and in team communication in general.

Only the doctors were asked to comment. Section 3.3.3, it would have been useful to get a response from the sisters as well.

TABLE 30 : DO SOCIAL WORKERS HAVE A ROLE IN ASSISTING WITH COMMUNICATION?

	NO.	%
YES	10	91
NO	1	9
SUB TOTAL	11	100

The table which follows describes doctors' responses on the varied role the social workers would be able to take up.

TABLE 31 : DOCTORS' PERCEPTIONS OF ROLE OF SOCIAL WORKER

PROBLEMS	NO.	%
1. Social worker to deal with emotional issues leaving more TIME for doctors	3	30
2. Social workers to help with language and culture problems	2	20
3. Social worker to play role of facilitator in the team	1	10
4. Social worker to monitor patients' need for information and refer back to doctor where necessary	2	20
5. Social worker to run communication courses	1	10
6. Social worker to work through treatment options with patients	1	10
SUB TOTAL	10	100

(a) Significant results show the following:

Three doctors (30%) said that they would have more time to deal with patients if social workers would take over the psycho-social aspects of patient care. This confirms patients' feelings in 3.3.26 where a significant number of patients did not feel they have enough time with their doctors. The conflict discussed in 3.3.9 (iv) is highlighted here, where doctors state that they want social workers to become more involved, and social workers perceive doctors to be disinterested. In the study conducted by Abramson and Mizrachi (1996: 271), they confirm this result, that doctors are willing to give up authority in exchange for sharing some burdens of patient care with those social workers who they respect and deem competent. This is discussed further in section 2.8.3 (b).

- (b) Two doctors (20%) felt that it would be beneficial to have a social worker of the same language and culture group as the majority of patients, as they could assist with these areas; these difficulties have been described in Section 3.3.4 (ii).
- (c) Two doctors (20%) felt that the social worker could monitor how much the patient understood, and then refer the patient back to the doctor, where necessary, to answer further questions. This would assist with those problems discussed in section 3.2.5, where patients were unable to absorb all information given to them at the time of diagnosis.

Other aspects mentioned by the doctors were:

- Communication courses to be run by the social worker. Poss (1981), Kubler-Ross (1969), and Barton (1977) speak of the importance of communication skills and self-awareness on the part of all care-givers.
- Social worker to facilitate team communication. This is backed up by several authors (Connell and Connell 1995; Black 1989; Kane and Kane 1987; Kleinman 1988; Goldberg and Tull 1983).
- Social worker to work through treatment options with the patient. This would facilitate enhanced understanding of options for the patient, and in addition, would save the doctor time, which, as mentioned already, creates much difficulty for him. Several authors agree with this notion of the social worker empowering the patient to be more active in her treatment (Connell and Connell 1985; Black 1989; Stolar 1982). Sections 3.2.15 and 3.2.21 discuss this issue further.

The following chapter is the final one, containing conclusions and recommendations for the study.

CHAPTER 4

CONCLUSIONS AND RECOMMENDATIONS

4.1 CONCLUSIONS

From the results of the research outlined in Chapter 3, it would appear that the objectives of the study have been attained. It would further appear that some of the assumptions described in Chapter 1.4 were supported and some were not. A discussion of these statements will follow.

4.1.1 PERCEPTIONS OF BREAST CANCER PATIENTS REGARDING INFORMATION THEY RECEIVE FROM THE TEAM

Patient responses indicate that in the majority of cases, patient needs for information from the team are being met.

During the process of diagnosis it can be concluded from sections 3.2.8 and 3.2.9 that patients understood information conveyed to them by the doctor, and felt comfortable to seek further information. However a significant proportion, 14.7% and 25% respectively, did not have an adequate grasp of information and did not feel able to seek further information. The inability to absorb information at diagnosis due to shock and denial is described by Kubler-Ross (1969: 35); Buckman (1992: 114) and Doka (1993: 4). Various factors such as 'passivity' as described by Hack et al (1994: 287) or fear of authority suggested by Ray and Baum (1985: 41) could have prevented patients' seeking further information.

Results of sections 3.2.15, 3.2.17, 3.2.18 and 3.2.20 lead the researcher to conclude that needs for information were met for the majority of patients; however in section 3.2.17, information needs regarding 'spread of the disease', and 'emotional reactions' to a cancer diagnosis and discussion of death, were

not sufficiently met. Northouse and Northouse (in Luker et al 1995: 136) concur with the above conclusion, that there is often a difference in perception of what the patient wants to know and what the health professional thinks he or she wants to know. In this study the lack of information seems to be in the 'emotional' sphere of the disease.

As evidenced in section 3.2.19, seeking information was more important to patients than actively being involved in decision-making. This is backed up in the literature by Hack et al (1994: 287) who argue that certain patients are 'passive' and do not want to be active in seeking information and making decisions, whereas others may want to rely on the 'authority' of the doctor (Ray and Baum 1985: 41).

In this study, information needs seem to be met by the doctors, as already described. The sisters do not meet this need, as shown in section 3.2.35 where only 17.6% of patients perceived sisters to fulfil the educative role. The majority of patients, (84 %) however, felt comfortable with asking the social worker questions regarding the disease.

4.1.2 PERCEPTIONS OF PATIENTS REGARDING SUPPORT THEY RECEIVE FROM THE TEAM

Patient needs for the social worker to be available for support during the process of diagnosis were not met, as shown in sections 3.2.12 and 3.2.13. This concurs with the literature where several authors agree that the social worker's intervention should begin at diagnosis when the patient is at her most vulnerable (Hughson and Cooper 1982: 1430; Stolar 1982: 32; Doka 1993: 80).

However, in general, the majority of patients (85.3%) felt understood and 'heard' by the team, as seen in sections 3.2.23 and 3.2.32. According to the

literature, team communication of support will make a big difference to the way the patient will cope with her illness (Chesler and Barbarin 1987; Lichter 1987; Guex 1989; Ray and Baum 1985; Blitzer 1990 and Lichter 1987). This was manifest by the truthfulness with which the doctors conveyed the diagnosis, (section 3.2.21), the language he used in speaking to the patients (section 3.2.22), the amount of time spent with the patient (although 19.4% did not feel they were devoted enough time by the doctor, (section 3.2.26) and respect shown to the patient by the doctor (section 3.2.25). Barton (1977: 172) refers to the supportive relationship between the patient and the team as the 'humanitarian' approach. The doctor-patient relationship referred to above, concurs with Barton's characteristics for an effective doctor-patient relationship. However, the one area that patients (41.3%) did not feel comfortable with, was that of disagreeing with their doctors. This indicates a sense of intimidation perhaps due to the hierarchical nature of the relationship as described by Ray and Baum (1985: 41).

The patients therefore felt positive about the supportive way the information was transmitted; however, the majority (78.6%) would have liked the doctors to enquire further into their emotional health.

Most patients (83.3%), felt comfortable receiving support from the sisters as confirmed in the literature by Ray and Baum (1985); Wiernik (1983); Guex (1989); Lichter (1987); Perachi in Pfeiffer and Mulliken (1984) and Calzone in Harness (1988).

The majority of patients (57.1%) felt emotionally supported by the social worker. However, only 33.3% of patients in the sample actually consulted the social worker. Several authors speak of the supportive role of the social worker (Bergman et al 1982: 1); Poss (1981: 4); Connell and Connell (1995: 33). However, Bergman et al (1982: 1) confirm that there is a general lack of

understanding about what social workers are able to do, and therefore adequate referral does not take place.

4.1.3 VIEWS OF DOCTORS, SISTERS AND SOCIAL WORKERS, REGARDING THE TYPE OF COMMUNICATION WITH PATIENTS THEY FEEL TO BE IMPORTANT

Doctors felt that the establishing of a good relationship with patients includes building trust, being open to questions and discussion, having enough time for patients, being 'caring' and being able to overcome language and culture barriers. These were the five most important aspects that were rated by doctors, out of a choice of ten features of communication.

Nurses rated giving patients support and education about their illness as the most important aspects of communication.

Social workers rated support, education and mediation between patients and the team as most important. The role of the social worker is not only with the patient herself, but she should also focus at the interface between the patient, family and medical team as they interact to deal with the physical illness (Connell and Connell 1995; Black 1989; Kane and Kane 1987; Kleinman 1988; Goldberg and Tull 1983).

4.1.4 BARRIERS INHIBITING TEAM-PATIENT COMMUNICATION

Doctors, sisters and social workers all agreed that lack of time due to work pressure is one of the major factors encroaching on good team-patient communication. This is acknowledged as an obstacle to communication in the literature (Buckman 1992; Ray and Baum 1985; Guex 1989).

The majority of doctors, sisters and half the social workers experienced language and culture as a major barrier to communication. This is especially

relevant in this study where a variety of language and culture groups were found to be present in the patient population. Doctors out of all the team members, experienced this most strongly as the majority are White and English-speaking. The sisters interviewed were all Black but nevertheless encounter this difficulty, and half the social workers are Black, with only half having experienced this as an obstacle. For communication to be effective, both the care-giver and the patient must be able to correctly interpret each other's verbal and non-verbal messages (Doka 1993: 216).

The majority of doctors experienced an '**unconducive hospital environment**' to be an obstacle to communication. Sisters and social workers did not experience this as a problem. The researcher surmises that only doctors experienced this factor as problematic because they often work in several wards, making communication difficult, where essential hospital communication services, e.g. telephones, pagers, lifts, are not in working order. It is easier to contact sisters or social workers who have fixed wards or departments in which they can be found or contacted.

A minority of nurses described '**depression due to the nature of the work**' to be an obstacle. None of the sisters or social workers experienced the same problem.

Several authors agree that where the care-givers are themselves not confronting their own mortality, these issues are avoided or mishandled with patients (Poss 1981; Kubler-Ross 1969; Barton 1977).

4.1.5 **BARRIERS INHIBITING INTER-TEAM COMMUNICATION**

There was considerable disparity between how the different disciplines experienced communication within the team, as seen in section 3.3.6. The majority of doctors felt it was good, while sisters and especially social workers

did not find it satisfactory. An inhibiting factor for doctors and sisters was work pressure, while doctors also experienced ignorance regarding the role of the social worker, and her lack of availability and visibility as major barriers. Social workers, on the other hand, experienced doctors as disinterested in psychosocial issues and unavailable to discuss patient concerns with them, (section 3.3.9). According to Abramson and Mizrachi (1996: 271) social workers perceive physicians as inaccessible or as valuing brevity in their communication with them, while physicians perceived social workers to be unavailable.

4.1.6 THE ROLE OF THE SOCIAL WORKER IN THE CLINIC

Almost half the patients (45.5%) stated a need for a social worker to be present during the process of diagnosis for her **support** as well as to clarify **information** about the disease. More than half the patients saw this role as a continuous one, even after diagnosis. The majority of patients who had not been referred to the social worker (72%), would have wanted to consult with her.

The above roles, as defined by the patients, were confirmed by the social worker, i.e. **support**, **education**, and in addition, she saw her role as a **mediator**.

Doctors saw additional roles for the social worker as follows:

- (i) The social worker to run communication courses. Poss (1981); Kubler-Ross (1969); Barton (1977), speak of the importance of communication skills and self-awareness on the part of all care-givers.
- (ii) Social workers to facilitate team communication. This is backed by several authors (Connell and Connell 1995; Black 1989; Kane and Kane 1987; Kleinman 1988; Goldberg and Tull 1983).

- (iii) Social workers to work through treatment options with patients. The following authors agree with this notion of the social worker empowering the patient to be more active in her treatment (Connell and Connell 1985; Black 1989; Stolar 1982).

4.1.7 LITERATURE ON THE SUBJECT OF COMMUNICATION OF INFORMATION AND SUPPORT BETWEEN THE TEAM AND BREAST CANCER PATIENT

The researcher found limited information on this subject in South Africa. There has however, been much written on the subject in international publications, although some of them are not of a recent nature.

The literature study clearly showed the role that adequate information played in the way the cancer patient coped with her illness, namely that it gives patients a sense of control over their illness and decreases anxiety and depression (Hack et al 1994: 288). Support for the patient by the team was seen to protect patients from the effects of stress (Chesler and Barbarin 1987; Lichter 1987; Guex 1989 and Doka 1993), and it created a more 'humanitarian' approach to patient care (Barton 1977: 172). The functioning of the multi-disciplinary team, and whether it could overcome the obstacles to its effective functioning were found to be vital to the total well-being of the patients. The roles of the doctor, sister and social worker within the team were explored with reference to patient communication.

4.2 ASSUMPTIONS AND IMPLICATIONS FOR SOCIAL WORK

4.2.1 The needs of breast cancer patients for information are not being adequately met.

This assumption was not proved to be completely correct by the research conducted. As seen in section 4.1.1, the majority of patients did perceive

themselves to have been provided adequate information by the team in the clinic. However, patients' perceptions of gaps in information were mostly in the emotional spheres, i.e. not absorbing information fully at diagnosis due to shock, not receiving enough information on the emotional aspects of cancer and feeling that doctors avoid discussion on death and dying. It seems clear that more social work input could assist patients in all these areas.

4.2.2 The needs of breast cancer patients for support are not being met adequately

As in section 4.2.1, the above assumption was also not proved to be fully correct. According to the conclusions reached in section 4.1.2, the majority of patients did feel adequately 'heard' and supported by the team.

However, as in 4.2.1 patients felt that there were certain inadequacies in support received from the team:

- (a) Patients need more social work support, especially during the diagnostic phase;
- (b) Patients do not feel comfortable about disagreeing with their doctors;
- (c) Patients need their doctors to express further concern regarding their emotional health.

The implications for social work of these findings are as follows:

- (a) Social workers should get more involved with patients on a supportive level, especially during diagnosis.
- (b) There is a role for social workers to act as mediators between doctors and patients to assist them in voicing their concerns or disagreements.
- (c) Social workers could become involved earlier with identifying patients' emotional problems and assisting them. This would free already overburdened doctors from needing to become involved on this level.

4.2.3 Barriers to communication exist which block effective communication from taking place between team members and patients

This assumption was proved to be correct, as concluded in 4.1.4. The barriers to communication experienced by doctors, sisters and social workers with their patients were:

- (a) not having enough time for patients due to work pressure;
- (b) difficulties with **language and culture**;
- (c) doctors experienced an **unconducive hospital environment** to be an obstacle to communication, and
- (d) a minority of nurses experienced '**depression**', due to the nature of the work which impeded good communication.
- (e) In addition, the major barrier to communication within the team was doctors experiencing lack of clarity regarding the role of the social worker as well as her lack of availability and visibility. Similarly, social workers experienced doctors as disinterested and unavailable.

The **implications** of these findings for social workers are as follows:

- (a) As mentioned above, further social work involvement with patients may allow doctors more time to deal effectively with patients.
- (b) Social workers who have a similar cultural and language background to the majority of patients could possibly assist with these issues.
- (c) The view of the researcher is that social workers alone cannot make an impact or bring about changes in the entire hospital structure.
- (d) social workers can create a supportive environment for the team to express emotions and work through problems.
- (e) Social workers need to educate doctors regarding their role, and improved communication channels need to take place between social workers and the rest of the team.

4.3 RECOMMENDATIONS

Recommendations will now be made, based on the conclusions mentioned in 4.1, as well as recommendations made by doctors, sisters and social workers in the clinic.

A. RECOMMENDATIONS BASED ON CONCLUSIONS IN THE STUDY

4.3.1 SOCIAL WORKERS TO BE AVAILABLE TO PATIENTS DURING THE PROCESS OF DIAGNOSIS

Patients should be referred to the social worker in the clinic at the pre-diagnostic stage in order to begin to build a rapport with her; also the social worker would be able to identify any existing psycho-social problems. Thereafter, patients will have a choice if and at what stage they would like further intervention from her.

4.3.2 PATIENTS TO BE GIVEN A WRITTEN COPY OF DIAGNOSIS

During the diagnostic phase the patient has no way of absorbing information and processing it (Gyllenskold 1982: 79). An idea suggested by Hack et al (1994: 287) is that patients be given a written copy of their diagnosis after their first diagnostic interview, in order to assist them in absorbing the information.

4.3.3 SOCIAL WORKERS TO ASSIST DOCTORS WITH 'EMOTIONAL' ASPECTS OF THE DISEASE

Doctors who identify emotional problems in their patients, which have not previously been assessed by the social worker, should refer these patients to the social worker for further intervention. According to Poss (1981: 4), the social worker is the 'primary care-giver', who should carry out the major part of the psycho-social and spiritual work. This would also relieve already overburdened doctors.

4.3.4 SOCIAL WORKER AS MEDIATOR

Social workers should act as mediators in areas where patients find it difficult to speak to their doctors. Connell and Connell (1995: 30) refer to the social worker as an 'advocate', making the team more aware of the patient's needs and feelings.

4.3.5 SOCIAL WORKER TO EDUCATE TEAM REGARDING HER ROLE

The social worker should educate the team regarding her role, as well as about the referral procedure. Bergman et al (1982: 1) confirm a general lack of understanding regarding what social workers can do. In addition, Poss (1981: 115) recommends that social workers guide their colleagues towards selection and referral of patients for social work services.

4.3.6 SOCIAL WORKER TO ASSIST WITH LANGUAGE AND CULTURAL BARRIERS

Where possible, social workers who have a similar language and cultural background to the majority of patients, should be appointed to the clinic. They would be able to assist with meaningful translation of language, as well as interpreting significant facts regarding the culture of the patient for the team member concerned. This is important, as culture frames one's entire belief system about the nature and cause of illness, the efficacy of treatment, or the process of seeking outside assistance (Doka 1993: 57). In addition, Tatro in Ruben (1984: 297) asserts that a translator inexperienced in a particular field, can give inappropriate meanings to certain words or concepts, creating misunderstandings. Hence it seems appropriate that somebody with a background in social work, assist in this area.

4.3.7 SOCIAL WORKER TO FACILITATE EXPRESSION OF FEELINGS FOR TEAM MEMBERS

Working with ill and dying people on a long term basis is stressful for care-

givers. Barton (1977: 82) emphasises that without the shared support of the intense emotions experienced by the team members, individual members of the team may enter a "painful state of isolation, meaninglessness and despair". Due to the social worker's training in group work, she is in an ideal position to lead the team in discussing the emotional effects their work has on them.

4.3.8 COMMUNICATION SKILLS AS PART OF THE MEDICAL SCHOOL SYLLABUS

Ray and Baum (1985: 56) recommend that inter-personal skills be given an **important** role in the medical curriculum. Although in recent years, doctors are being taught communication skills at medical school, it does not seem that this aspect of their work is being stressed enough.

4.3.9 SOCIAL WORKERS TO RUN COURSES ON COMMUNICATION

The researcher recommends that continuous courses be run on issues related to communication, stages of emotional adaptation to dying, how to break bad news, etc. This will give the medical team the confidence to deal more effectively with these emotive issues which face them daily.

B. RECOMMENDATIONS MADE BY DOCTORS, SISTERS AND SOCIAL WORKERS IN THE CLINIC

In addition to the following recommendations, recommendations 4.3.3, 4.3.5 and 4.3.6 were also made by the team. The following recommendations were made:

4.3.10 APPOINTMENT OF ADDITIONAL STAFF

Additional staff should be appointed in order to ease staff pressure. This is a recommendation on the administrative level, which would involve additional funding. This may not be possible due to the shortage of funds.

4.3.11 SISTERS TO PROVIDE MORE SUPPORT FOR PATIENTS

Some of the sisters stated that they would like to provide more support for patients where this is practical in terms of time.

4.3.12 PATIENTS TO RECEIVE LECTURES REGARDING THEIR ILLNESS

Some of the team members felt that on-going lectures should be provided by medical staff, to inform patients of details regarding their illness. This would create a more informed patient and would also remove some of the pressure on staff.

4.3.13 SOCIAL WORKERS TO WORK THROUGH TREATMENT OPTIONS WITH PATIENTS

This would empower the patients to become more active in their treatment. This aspect is also recommended by the following authors: Connell and Connell (1985); Black (1989) and Stolar (1982).

4.3.14 DOCTORS TO CONSULT WITH PATIENTS AND THEIR FAMILIES AFTER DIAGNOSIS

It was suggested by one of the doctors that after the patient is given her diagnosis, she should consult with the same doctor a second time to discuss treatment options, with the support of a close relative or friend.

4.3.15 THE BREAST CANCER CLINIC TO BE SPREAD TO OTHER DAYS

At present all breast cancer patients are seen by doctors on one day of the week at an extremely busy clinic. Some team members recommended that the breast cancer patients should rather be seen among other cancer patients, and spread through the week, allowing them to spend more time with the patients. This change, were it to take place, would be an administrative one.

4.3.16 REGULAR TEAM MEETINGS TO BE HELD

Regular team meetings would improve communication channels amongst the various disciplines. According to Lichter (1985), Guex (1989) and Nason (1983), the purpose of these meetings is the exchange of information about the patient, support of team members for each other and the resolution of conflict which may arise between members. At these meetings, roles and expectations can also be clarified.

4.3.17 SOCIAL WORKERS TO BE MORE VISIBLE TO PATIENTS

Social workers could become more visible to patients by chatting to them informally while they are waiting for their appointments with doctors. (There are no set appointment times in the clinic and patients sometimes wait for up to four hours).

4.3.18 FEWER PATIENTS TO BE BOOKED PER CLINIC

As in section 4.3.17, this would serve to ease pressure for staff. However the researcher is not sure whether this is plausible, due to the large numbers of breast cancer patients that need to consult their doctors.

4.3.19 SOCIAL WORKER TO MAKE HER PRESENCE FELT

It was recommended that social workers spend more informal time with the rest of the team in order to make her presence felt, e.g. in the tea room.

4.3.20 SOCIAL WORKERS TO BE DEDICATED TO ONE DEPARTMENT ON A LONG-TERM BASIS

Social workers at present work in several areas in the hospital, as part of their work load. Several team members therefore, recommended that it would be better for team communication if the social worker was dedicated to one area only.

4.3.21 FORMALISED MEDICAL TRAINING FOR SOCIAL WORKERS

As mentioned above, an important role for social workers is in-patient education; it was therefore recommended that she be well-versed in the medical aspects of her work in order to be a more effective educator. Formal medical training should be provided to social workers for this purpose.

4.3.22 HOSPITAL BACK-UP SERVICE TO BE IMPROVED

As mentioned in 4.2.3 (c), this would need to be improved on an administrative level. However, it does warrant further investigation, due to the many obstacles to patient care that it creates.

4.3.23 COURSES TO BE RUN IN BLACK LANGUAGES

Some of the team members suggested that courses be run for team members in the relevant Black languages, in order to assist with language and cultural barriers.

BIBLIOGRAPHY

Abramson J s and Mizrachi t (1985). **Sources of strain between Physicians and social Workers: Implications for Social Workers in Health Care Settings** in Social Work in Health Care 10(3): 33-51.

Abramson J S and Mizrachi T (1996). **When Social Workers and Physicians collaborate: positive and negative interdisciplinary experiences** in Social Work 41(3): 270-281.

Anastasi A (1990). **Psychological Testing** (6th edition). MacMillan Publishing Co Inc: New York, London.

Anderson R and Ross V (1994). **Questions on Communication**. St Martins Press: New York.

Barton d (ed) (1977). **Dying and Death: a clinical guide for caregivers**. Williams and wilkins: Baltimore.

Beisecker A, Helmig L et al (1994). **Attitudes of oncologists, oncology nurses, and patients from a women's clinic regarding medical decision making for older and younger breast cancer patients** in The Gerontologist 3(4): 505-512.

Bergman A S, Contro N, Zivetz N (1984). **Clinical social work in a Medical setting** in Social Work in Health Care 9(3): 1-12.

Black R B (1989). **Challenges for social Work as a core profession in cancer services** in Social Work in Health Care 14(1): 1-13.

Blitzer A (1990). **Communicating with Cancer Patients and their families**. Charles Press: Philadelphia.

Block R, Rosen J B (1983). **Head and Neck cancer: impact of radical surgery on patients, families and the treatment team** in Social Worker Travailler Social 51(3): 92-95.

Bloom M and Fischer J (1983). **Evaluating practice: Guidelines for the Accountable Professional**. Englewood Cliffs: Prentice Hall.

Blues A G and Zerwekh J V (1984). **Hospice and Palliative nursing care**. Grune and Stratton: Orlando.

Buckman R (1992). **How to break bad news: a guide for health care professionals**. University of Toronto: Toronto.

Chesler U and Barbarin O (1987). **Childhood Cancer and the family**. Brunner/Mazal Publishers: New York.

Connell G M, Connell L C (1995). **In-hospital consultation: Systemic interventions during medical crisis** in Family Systems Medicine 13(1): 29-38.

Di Matteo M R (1979). **A social psychological analysis of Physician-Patient rapport** in Journal of Social Issues 35(1): 12-33.

Doka K J (1993). **Living with life-threatening Illness**. Letington Books: New York.

Furman S (1990). **Doctor, are you listening?** In South African Practice Kime 1990: 281-283.

Goldberg R S and Tull R (1984). **Defining discipline roles in consultation psychiatry: the multi-disciplinary team approach to psychosocial oncology** in General Hospital Psychiatry 6(1): 17-23.

Grinnell R M (1993). **Social Work Research and Education** 4th edition. F E Peacock Publishers Inc: Itasca, Illinois.

Givio (Interdisciplinary Group for Cancer Care Evaluation, Italy) (1986). **What doctors tell patients with Breast Cancer about diagnosis and treatment in British Journal of Cancer** 54(2): 319-326.

Guex P (1989). **An introduction to Psycho-Oncology**. Routledge: London.

Gyllenskold K (1982). **Breast Cancer**. Tavistock Publications: London and New York.

Hack T F, Degner L F, Dyck D G (1994). **Relationship between preferences for decisional control and illness information among women with breast cancer in A quantitative and qualitative analysis. Social Science and Medicine** 39(2): 279-289.

Harness J K (1988). **Breast Cancer/Collaborative Management**. Mich Lewis Publishers: Chelsea.

Hughson A V M and cooper A F (1982). **Psychological aspects of breast cancer and its treatment in Practitioner** 226(1370): 1429-1435.

Iles P, Auluck R (1990). **Team building, inter-agency team development and social work practice in The British Journal of Social Work** 20(2): 151-164.

Ireland J and J (1993). **Beating Breast Cancer**. Oxford: Cape Town.

Kane R A (1975). **Interprofessional teamwork**. School of Social Work, Syracuse University: Syracuse, New York.

Kane R A and Kane R L (1987). **Long Term Care: Principles, Programmes and Policies.** Springer: New York.

Kleinman A (1988). **The illness narratives: suffering, healing and the human condition.** Basic Books: New York.

Koch S (1959). **Psychology: A study of a science: Study I. conceptual and systematic. Vol. III. Formulations of the person and social context.** McGrawhill: New York.

Krumm S (1982). **Psychosocial Adaptation of the Adult with Cancer in Nursing clinics of North America.** Woods M E and Kawalsky J D (editors). 17(4) 729-737.

Kubler-Ross E (1969). **On death and dying.** Chaucer Press Ltd: Bungay, Suffolk.

Latimer E J (1991). **Caring for seriously ill and dying patients: the philosophy and ethics in Canadian Medical Association Journal:** 144(7): 859-864.

Lewis F M, Bloom J R (1978-79). **Psychosocial adjustment to breast cancer: a review of selected literature in International Journal of Psychiatry in Medicine** 9(1): 1-17.

Lichter I (1987). **Communication in Cancer Care.** Churchill Livingstone: New York.

Lowe J I, Herranen M (1981). **Understanding teamwork: another look at the concepts in Social Work in Health Care:** 7(2): 1-11.

Lowe J I, Herranen M (1978). **Conflict in teamwork: understanding roles and relationships in Social Work in Health Care:** 3(3): 323-330.

- Luker K A, Beaver K, Leinster S J, Owens R G, Degner L F, Sloan J A (1995). **The information needs of women newly diagnosed with Breast Cancer** in Journal of Advanced Nursing 22(1): 134-141.
- Messerli M L, Garamenoi C, Romano J (1980). **Breast Cancer information as a technique of crisis intervention** in American Journal of Orthopsychiatry 50(4): 728-731.
- Nason F (1983). **Diagnosing the hospital team** in Social Work in Health Care: 9(2): 25-45.
- Nunnally E and May (1989). **Communication basics for human service professionals**. Sage: Newbury Park.
- Palsson B E, Norberg A (1995). **Breast Cancer Patients' experiences of Nursing Care with the focus on emotional support: the implementation of a nursing intervention** in Journal of Advanced Nursing 21(2): 277-285.
- Pfeiffer R N and Mulliken B (1984). **Caring for the patient with Breast Cancer: An Interdisciplinary/Multi-disciplinary Approach**. Reston Publishing Company Inc: Reston Virginia.
- Poss S (1981). **towards death with dignity**. National Institute Social Services Library No. 41. Billings and Sons Ltd: London and Worcester.
- Ray and Baum (1985). **Psychological Aspects of early Breast Cancer**. Springer-Verlag: New York.
- Ruben R (1984). **Communication and Human Behavior**. Macmillan Publishing Company: United States.

Rubin A and Babbie E (1989). **Research Methods for Social Work**. Wadsworth Publishing Co: Belmont.

Sands R G, Stafford J, McClelland M (1990). **'I beg to differ': Conflict in the interdisciplinary team in Social Work in Health Care**: 14(3): 55-72.

Serero K (1987). **Teamwork in Medical Social Work in Social Work Practice**. Iss 2: 22-23.

Siminoff L A (1989). **Cancer patients and physician communication: Progress and continuing Problems in Annals of Behavioral Medicine** 11(3): 108-112.

Stolar G (1982). **Coping with Mastectomy: Issues for Social Work in Health and Social Work** 7(1): 26-34.

Strano Z (1984). **Communicating**. Harcourt Brace Javonovich Group: Australia.

Suominen T, Leino Kilpi H, Laippala P (1995). **Who provides support and how? Breast Cancer Patients and Nurses evaluate patient support in Cancer Nursing** - 18(4): 278-285.

Sutherland et al (1989). **Cancer Patients: their desire for information and participation in treatment decisions in Journal for the royal Society of Medicine**: 82(5): 260-263.

Thorpe S (1988). **Helpful and unhelpful communications in cancer care: the patient's perspective in Oncology Nursing forum**: 15(2): 167-172.

Trenholm S (1995). **Thinking through Communication: an introduction to the study of human communication**. Allyn and Bacon: Needham Heights, Massachusetts.

Wiernik P H (1983). **Supportive Care of the Cancer Patient**. Futura Publishing Company: New York.

5 June 1997

Dear Patient

**TEAM - PATIENT COMMUNICATION OF INFORMATION AND SUPPORT AT THE
BREAST CLINIC OF THE JOHANNESBURG HOSPITAL**

I am undertaking the abovementioned study in part fulfilment of my Masters degree in Social Work at UNISA.

The objective is to provide meaningful results which would contribute to enhancing team-patient relationships at the clinic.

Please answer the questionnaire which follows, as accurately as possible. There are no right, wrong or ideal answers.

All information will be treated confidentially.

I would appreciate it if you could return the questionnaire to me as soon as it is completed.

Thank you for your participation.

Kind Regards

Debbie Levin
SOCIAL WORKER

Please use the following scale to assist with the questions.

- 1 = AGREE (this is the way I think/feel)**
- 2 = UNSURE (I don't know what I think/feel)**
- 3 = DISAGREE (this is not the way I think/feel)**

PATIENT DETAILS**PATIENT'S NAME:**

.....

TELEPHONE NUMBER:

.....

AGE:

.....

SEX:

MALE

FEMALE

RACE:

BLACK COLOURED WHITE ASIATIC OTHER

HOME LANGUAGE: ENGLISH AFRIKAANS ZULU SOTHO OTHER**RELIGION:**

.....

LEVEL OF EDUCATION: STD 1-5 STD 6-10 TERTIARY EDUCATION**DIAGNOSIS****STAGE****DURATION OF ILLNESS** MONTHS**TYPE OF TREATMENTS THUS FAR**

.....

PREVIOUS NEED FOR PSYCHOLOGICAL/PSYCHIATRIC TREATMENT:

YES

NO

PATIENT QUESTIONNAIRE

Please circle the appropriate responses:

1) I understood everything that was explained to me when I was first diagnosed.

1

2

3

Please comment

2a) Would you have liked to discuss your questions over and over at subsequent consultations?

YES

NO

b) Were you given the opportunity ?

YES

NO

3a) Would you have liked to have been told differently?

YES

NO

b) If yes, what would you have liked to have been different?

4) Who was present when you were told the diagnosis? (You may circle more than one)

- A) Doctor
- B) Sister
- C) Social Worker
- D) Other (please specify)

5) If any of the above were not present, which of them would you have liked to have been present? (You may circle more than one)

- A) Doctor
- B) Sister
- C) Social Worker
- D) Other (please specify)

6a) If the Social Worker was not present, would you have like her to have been present?

YES

NO

b) If yes, please state why?

7) At what stage would you have like the social worker to get involved?

- a) Before the diagnosis (while tests were being done)
- b) At the time of diagnosis
- c) Straight after you were given the diagnosis
- d) At the clinic after diagnosis

8) I was given enough information so that I could plan my life?

1 2 3

9) Please number the aspect(s) of the disease which are important for you to know about, in order of importance (1 being the most important, and 10 being the least important).

Treatment
 Spread of the disease
 Likelihood of cure
 Impact on my social life
 Effect on my family and friends
 Self care
 Sexual attractiveness
 Treatment options
 Side effects of treatment
 Emotional reaction to having cancer

10) Please tick which aspect(s) were discussed with you.
 By whom? (ie doctor, sister, social worker)

Treatment
 Spread of the disease
 Likelihood of cure
 Impact on my social life
 Effect on my family and friends
 Self care
 Sexual attractiveness
 Treatment options
 Side effects of treatment
 Emotional reaction to having cancer

11a) Would you have preferred any of the above to be discussed with you by someone different?

YES

NO

b) If yes, who and why?

12) My doctor discussed the different treatment methods with me.

1

2

3

Please comment:

13) I would like to have been more active with my doctor in choosing a treatment course.

YES

NO

Please comment

14) All the procedures or treatments were explained to me adequately before they were done.

YES

NO

If no, please comment

15) I was told the truth about my illness.

YES

NO

If no, please comment

16) I could understand the language my doctor used.

1 2 3

17) The team at the clinic understood my feelings.

1 2 3

If 3, please state why.

18a) Did you want to discuss sensitive issues (eg possibility of death) with the team?

YES NO

b) If yes, was the team willing to discuss them with you?

YES NO

19) My doctor spoke to me as an adult and did not speak down to me.

1 2 3

Please comment

20) At the consultations with the doctors they allow me enough time to say or ask what I need.

1 2 3

21) My doctor enquires if I am feeling low or depressed.

YES NO

If yes, please answer 21(a)

If no, please answer 21(b)

21a) If yes, does he:

- i) discuss the problems with me
- ii) refer me to the social worker
- iii) none of the above
- iv) other (please specify)

21b) If no, would you have liked him to enquire?

YES NO

22) I was asked to bring my family to the clinic to discuss my illness with them.

YES NO

If yes, please answer 22(a) and (b)

If no, please answer 22(c)

22a) If yes, who spoke to your family:

- i) doctor
- ii) sister
- iii) social worker
- iv) other (please specify)

22b) Would you have liked someone different to have spoken to your family?

YES

NO

If yes, who would you have preferred?

22c) If no, would you have liked them to have been spoken to?

YES

NO

23) Hospice/Cancer Association was discussed with me.

YES

NO

24) The team at the clinic are always willing to listen to me.

1

2

3

25) I could tell my doctor anything I disagreed with him/her about.

1

2

3

26) Please tick the appropriate answer/s:

I see the role of the sisters in the clinic as:-

- a) answering questions about my illness/treatment
- b) giving me emotional support
- c) helping me practically with information about where to go or what to do
- d) referring me to the appropriate people to speak to about the issue on hand

27) Which of the above do you feel were fulfilled by the sisters?

28) I feel at ease chatting to the sisters and/or asking them questions.

1 2 3

29) Do you know that there is a social worker in the clinic?

YES NO

30) Have you ever consulted the social worker?

YES NO

If yes, please answer 30a) - d)

If no, please answer 30e)

30a) I feel emotionally supported by this social worker.

1 2 3

30b) I feel at ease asking this social worker questions about my illness.

1 2 3

30c) Was this social worker's intervention helpful for you?

YES NO

30d) If the answer to 30c) is yes, in what way?

30e) If the answer to 30 is no:

Would you have been interested in speaking to her had you known?

YES

NO

31) Do you have any other general comments?

5 June 1997

Dear Doctor

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Thank you for your participation.

Kind Regards

Debbie Levin
SOCIAL WORKER

PLEASE USE THE FOLLOWING SCALE TO ASSIST WITH QUESTIONS

1 = Good

2 = Fair

3 = Poor

DOCTOR'S INTERVIEW

- 1) What are the most important features of good doctor-patient communication in the clinic?
(Please rank in order of importance, 1 being most important.

Trust between doctor and patient
Language
Culture
Enough time for patient
Openness to questions and discussion
Conducive external hospital environment
Continuity of patient care environment
Caring doctor
Availability
Other

- 2) Which of the above are not possible to fulfil in the clinic?

- 3) Please give reasons why not?

- 4) Could a Social Worker assist with any of the barriers to communication mentioned in (2)?

YES

NO

- 5) How would you rate communication among the team in the clinic (ie doctors, sisters, social worker)?

1

2

3

- 6a) What factors help team communication
(Medical Team & Sisters)?

- b) What factors help communication
between the Medical Team and
Social Worker?

1)
2)
3)
4)
5)

1)
2)
3)
4)
5)

7a) What factors hinder team communication
(Medical Team & Sisters)?

- 1)
- 2)
- 3)
- 4)
- 5)

b) What factors hinder communication
between the Medical Team and
Social Worker?

- 1)
- 2)
- 3)
- 4)
- 5)

8) What recommendations would you make to improve team communication?

- 1)
- 2)
- 3)
- 4)
- 5)

9) What recommendations would you make to improve doctor-patient communication?

- 1)
- 2)
- 3)
- 4)
- 5)

10a) Could the Social Worker play a role in 8) or 9)?

YES

NO

b) Please comment on the above.

5 June 1997

Dear Sister

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Kind Regards

Debbie Levin
SOCIAL WORKER

PLEASE USE THE FOLLOWING SCALE TO ASSIST WITH QUESTIONS

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2 = Fair

3 = Poor

SISTER'S INTERVIEW

- 1) In your opinion, what are the most important features of good nurse/sister/patient communication in the Breast Clinic?
- 2) What factors, if any, inhibit this type of communication from taking place?
- 3) How would you rate communication among the team members (eg doctors, sisters, social worker) in the clinic?

1 2 3

- 4) What factors aid team communication?
 - 1)
 - 2)
 - 3)
 - 4)
 - 5)
- 5) What factors hinder team communication?
 - 1)
 - 2)
 - 3)
 - 4)
 - 5)

6) What recommendations would you make to improve team communication?

1)

2)

3)

4)

5)

7) What recommendations would you make to improve sister-patient communication?

1)

2)

3)

4)

5)

5 June 1997

Dear Social Worker

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Thank you for your participation.

Kind Regards

Debbie Levin
SOCIAL WORKER

PLEASE USE THE FOLLOWING SCALE TO ASSIST WITH QUESTIONS

1 = Good

2 = Fair

3 = Poor

SOCIAL WORKER INTERVIEW

1) In your opinion what are the most important issues in social worker-patient communication with the breast cancer patient?

1)

2)

3)

4)

5)

2) In the Breast Clinic, what factors inhibit good communication between staff and patients?

1)

2)

3)

4)

5)

3) How would you rate communication among team members in the clinic?

1 2 3

4) What factors aid team communication?

1)

2)

3)

4)

5)

5) What factors hinder team communication?

- 1)
- 2)
- 3)
- 4)
- 5)

6) What recommendations would you make to improve social worker-patient communication in the clinic?

- 1)
- 2)
- 3)
- 4)
- 5)

7) What recommendations would you make to improve team communication in the clinic?

- 1)
- 2)
- 3)
- 4)
- 5)