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THE IMPACT OF CANCER ON THE RELATIONSHIP OF THE COUPLE

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DTTSAN001

A minor dissertation submitted in partial fulfillment of the requirements for the award of the degree of MSOC SC CLINICAL PRACTICE IN SOCIAL WORK

Faculty of Humanities

University of Cape Town

2008

This work has not been previously submitted as a whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: _Signature_ Date: _Date_
Thank you Shona for supporting me and being so understanding.

Thank you Lily.
THE IMPACT OF CANCER ON THE RELATIONSHIP OF THE COUPLE

Sandra Hitchcock

ABSTRACT. This study aimed to investigate the impact that the diagnosis of cancer has on the relationship of couples where one of the partners have been diagnosed with cancer. In order to achieve this, the study explored the elements in the cancer process that were most difficult for couples to cope with and what supported them most in coping. There are already many stressors in couples’ lives without the added stress of cancer. When cancer is diagnosed in one of the partners, the couple is exposed to extraordinary challenges that they had never encountered before. It changes the appearance and the quality of the relationship. Their lives are disrupted by changes in all aspects. It was observed that the relationships of the couples were not adequately attended to during the cancer process. The study therefore attempted to assist couples and their medical teams to better understand some of the particular factors that could impinge on the relationship between patient and partner. Couple participants were conveniently selected. The study used qualitative methods to elicit thoughts and attitudes of couples experiencing the cancer process.
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5.1 Conclusions

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Chapter 1

1.1 INTRODUCTION

This chapter will cover the problem statement, rationale and significance of the study, the research topic, the questions, the objectives, clarification of concepts, the ethical considerations and reflexivity.

1.2 PROBLEM STATEMENT

Being part of a multi-disciplinary team as a social worker in an Oncology Unit, has alerted the researcher to the complexities couples have to face when one of them has cancer. There are already many stressors on the couple’s relationship without the added stress of cancer. In describing the common themes that couples encounter, Bulsara et al (2006) describes the impact of cancer on all the aspects of a couples’ life. It changes the appearance and quality of the relationship and challenges the couple’s beliefs. Situations arise that the couple has never encountered before. Couples describe cancer as the only crisis they have experienced in their relationship as the importance of other life events becomes less significant (Carlson et al, 2000).

The researcher has observed and experienced that some couples struggle with the overwhelming sense of losing control, while others have a more pragmatic way of going through the process. Some couples experience distance in their relationship, while others feel that they have achieved levels of intimacy that they would not otherwise have been able to achieve. In being involved with couples in different life stages and various diagnosis and prognosis of cancer, the researcher has noticed that couples utilize the support and coping mechanisms that already existed in the relationship before the diagnosis of one of the partners with cancer. Couples cope better if a supportive and satisfying relationship is already in place (Feldman and Broussard; 2005). Piccard et al (2005:127) support this suggestion by saying that “they had made a decision orientated towards the goal of adjustment and that this decision was motivated by the quality of the pre-existing emotional bonds.” It seems that a significant and satisfying relationship between partners before diagnosis may assist them with supporting each other and coping in their usual style. The opposite is also possible as Carlson et al (2000: 51)
found that couples whose relationship was characterized by “infrequent communal behavior” showed higher levels of depression and found it more difficult to communicate effectively. It is also noted by Feldman and Broussard (2005) that the emotional stress of cancer may cause pre-existing marital discord to crystallize.

Feldman and Broussard (2005) describe that a cancer diagnosis precipitates stress and chaos in the couple’s relationship. Health care professionals concentrate their attention on patient issues, not relational issues. The social worker, if part of the multi-disciplinary team, has to assist patients and their partners to effectively cope with the trauma in their lives (Feldman and Broussard; 2005). According to the Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (2003:1);

“Each patient will experience a range of practical, psychological and emotional challenges as a result of their diagnosis and treatment-related adverse effects. Their lives may also further be disrupted by changes in role and family functioning, occupational or employment status and financial status. Some patients will have to come to terms with progressive illness and approaching death, others may be faced with the physical, emotional and social changes of survival.”

Although it is the patient whose physical health is being affected, it is found that both patient and partner are experiencing the same emotional needs (Gillette Cancer Association; 2005)

As a result of the above information and experience in the field of psycho-oncology, the researcher has become cognizant of the need to assist distressed couples to cope with the crisis of cancer and the extraordinary challenges that their relationship is exposed to. This study is an attempt to contribute towards therapeutic work with couples who have to manage the illness and its adverse effects with the resources available to them.

1.3.1 RATIONALE AND SIGNIFICANCE

The researcher became cognizant of the fact that the relationship of the cancer couple was not adequately being attended to during the cancer process. In the researcher’s involvement, on a daily basis, with couples experiencing cancer it was noted that more assistance should be given
1.7 CLARIFICATION OF CONCEPTS

Cancer: A term for more than hundred diseases in which abnormal cells divide without control. Cancer cells can spread through the bloodstream and lymphatic system to other parts of the body.

Coping: Refers to the specific thoughts and behaviors a person uses in his or her efforts to adjust. (NCI, 2004)

Coping strategies: Conscious, rational ways of dealing with the anxieties of life. The term is used for those strategies designed to deal with the source of the anxiety (Reber: 164)

A chronic illness: A condition that persists for more than three months that is incurable, impacts on everyday physical, psychological or social functioning, affects patient and family members’ quality of life through obstruction of normal routines and activities, and at a patient level requires focus on symptom management rather than cure (Feldman and Broussard 2005:25)

Chemotherapy: Broadly described as drug therapy, but used specifically in terms of cancer treatment in the form of tablets, injection or by intra-venous method (GVI Guidelines)

Diagnosis: The identification of a disease from its signs and symptoms (GVI Guidelines)

Existential anxiety: The feeling of fear, even dread that can accompany a choice involving unknowns.

Radiotherapy: A form of treatment given by an energy source from a sophisticated machine such as a linear accelerator from which a carefully directed beam penetrates the body to reach the tumor (GVI Guidelines)

Tumor: A benign or malignant mass of cells within the body which serves no biological purpose. Benign tumors do not generally metastasize (GVI Guidelines)

Metastasis: The term describes the spread of cancer from the primary site to another site in the body. Cells in the metastatic (secondary) tumor are like those in the original (primary) tumor (GVI Guidelines).

Oncologist: A physician who specializes in the treatment of cancer (GVI Guidelines)

Palliative care: Relieving or soothing the symptoms of a disease without aiming for a cure (GVI Guidelines)
Primary site: Organ or position where cancer originated (GVI Guidelines)

Prognosis: Specifically, the predicted (in the sense of the best educated guess) eventual outcome of a disease or other disorder (Reber: 603)

Psycho-social aspects: Generally a grab-bag term used frequently to cover any situation where both psychological and social factors are assumed to play a role (Reber: 621)

1.7 ETHICAL CONSIDERATIONS

Strydom (2004: 62) quote Williams et al (1995): “The fact that human beings are the objects of study in the social sciences brings unique ethical problems to the fore that would never be relevant in the pure clinical laboratory settings of the natural sciences. For researchers in the social sciences, the ethical issues are pervasive and complex, since data should never be obtained at the expense of human beings.” Strydom (2004) also quotes Babbie (2001) who says that the researcher, as well as the respondents, should be aware of the general agreements to what is proper and improper in scientific research. According to Strydom (2004: 63) “Researchers sometimes tend to relate to respondents from a position of superior expertise and status and may think that the respondents do not need to be fully informed about the research goals, process or outcomes.” The researcher could identify with the viewpoint of Strydom (2004) stating that respondents should be seen as co-researchers. This study was undertaken to serve as a legacy for the couples participating in the research and to support couples in future with the complexities of cancer, not for the gain of the researcher. The researcher remained conscious of this fact in her contact with respondents.

The researcher and the focus group participants discussed the concepts of ethics, values and morality to serve as a foundation for the value system of the research project. The researcher quoted Levy (1993) as mentioned by Strydom (2004:63): “...views values as preferences for a certain form of conduct, while ethics imply preferences that influence behavior in human relations. Values indicate what is good and desirable while both ethics and morality deal with matters of right and wrong.” The ethical values that were agreed on by the group as a whole were confidentiality and respect. Both these values promote dignity preservation which was
seen as an important component in the cancer experience. Consensus was reached amongst the focus group participants that if their dignity was maintained throughout the process of research and afterwards, they would feel comfortable to proceed. They were assured that the researcher will contain emotions that might surface during the interviews, and post research, through therapeutic counseling.

As advised by Strydom (2004) the researcher was cognizant of protecting the respondents firstly from physical discomfort by ensuring that they were not experiencing strong treatment side effects like nausea or severe pain at the time of interviewing them. Secondly, it was important to protect respondents from emotional harm. Strydom (2004) say that this is not easily predicted or measured. The researcher’s involvement with cancer patients has sensitized her to the emotional intricacies that accompany the disease and motivated this research.

Strydom (2004: 65) cited Williams et al (1995) describing informed consent: “Obtaining informed consent implies that all possible or adequate information on the goal of the investigation, the procedures that will be followed during the investigation, the possible advantages and dangers to which the respondents might be exposed, as well as the credibility of the researcher, be rendered to potential subjects or their legal representatives.”

With this in mind the researcher informed the respondents as much as possible about the advantages of the study for themselves and patients to follow. The disadvantages, for example the impact of being confronted with emotional issues, were raised as previously said.

The researcher experienced trust from the respondents because they knew her as part of the multi-disciplinary team. Due to this fact and the small size of the study, it was emphasized that they should not feel morally obliged to participate. All the patients stated that they felt enthusiastic to be part of the project. They saw it as an attempt to make a difference in the lives of future couples where one partner would be diagnosed with cancer.
Two of the male partners indicated that they were not as enthusiastic as their patient partners to participate but that they would do it for their sake. On further discussion it became clear that they were dreading the emotions that it might evoke. They were reassured by both the group and the researcher that they could stop at any such time as they felt uncomfortable. It was reported back that they were grateful to have had the opportunity. It benefitted both relationships in a positive way.

The researcher held semi-structured interviews with the couples, which were complemented by written replies from the respondents. This was suggested by the group as they were of the opinion that they could fail to give information during an interview, but through written work they could have time to gather their thoughts and ensure that their perspectives were conveyed as they wanted them to be. They gave permission for their answer sheets to be used as appendices in the report, if the researcher needed to do that.

The researcher was never deceitful about the goal of the research and made it clear to all participants and colleagues that it was part of obtaining her degree. Strydom (2004: 66) cited Bailey (1994) saying that it is easy to lie about the purpose for research, especially in small qualitative projects, such as the one the researcher was involved in. The researcher was still involved in the participants’ treatment plan in a therapeutic setting as part of the multi-disciplinary team, requiring complete trust, which could not be achieved had there been any deceitfulness in the research process.

Due to the privileged position of the researcher as part of the multi-disciplinary team and thus having pre-knowledge of the respondents, she was aware of the element of personal privacy. “Privacy implies the element of personal privacy, while confidentiality indicates the handling of information in a confidential manner” (Strydom: 2004: 67). Sieber (1982) cited by de Vos et al (2004) viewed confidentiality as a continuum of privacy. According to Strydom (2004) information given anonymously ensures the privacy of the subjects. This argument is taken further by where Strydom (2004) who cites Rhodes (1986) that in reality no absolute rules about confidentiality exist. This makes the obligation of confidentiality the responsibility of the
researcher. The researcher was careful with information returned to her electronically and gained from interviews. Names were not linked with information, but coded for the researcher’s reference in the event of having to contact a specific respondent for clarity of or more information on certain aspects.

It was found that participants were honest and open with the information given. The researcher was convinced that they did not misinform or evade questions, but gave as much information as they could at that stage. It was at times as if they did not have the words to describe their emotions.

The attitudes of the participants were positive which assisted the researcher to conduct the research in the same manner. The researcher was aware of her own bias because the patients and their spouses were known to her, in some instances on an intimate level, as this could lead to misinterpretation of information. A mutual respect between respondent and researcher was experienced.

1.9 REFLEXIVITY

Reflexivity is “the ability to formulate an integrated understanding of one’s own cognitive world, especially understanding one’s influence or role in a set of human relations” (De Vos; 2004: 369) According to de Vos (2004) the researcher has to be cognizant of her own perceptions and ideas. The social work qualities of empathy and self-awareness are relevant in practicing reflexivity.

The researcher had to take into account that she knew all the participants from working with them therapeutically as their counselor, as part of the multi-disciplinary team. This could cause the researcher to calculate their responses and predict reactions into scientific research terminology. The researcher listened with an open mind, focusing on what the respondent was saying and not anticipating their answers.

It is difficult to translate feelings and emotions experienced as a researcher with these couples into scientific research terminology. This is not a cold scientific experiment. It is about feelings and emotions. The researcher felt privileged but at the same time touched about the level of
sharing that the couples were prepared to do. The researcher, at times, had the urge to stop them from sharing some of the raw personal emotions. It was as if the researcher was responsible for evoking these emotions.

The most difficult part for the researcher was the focus group discussion where one of the patients was in stage four of the cancer disease. All the other focus group participants treated him no differently, but debriefing was done with couples individually on the effect it had on them being made aware of their own vulnerability.

1.8 CONCLUSION

This chapter presented the introduction, the problem statement, the rationale and significance of the research, the research topic, the research questions and objectives, clarification of concepts, ethical considerations, and reflexivity. The following chapter will present the literature review that was done in order to inform the researcher about existing research on the topic.
Chapter 2

LITERATURE STUDY

Awareness concerning psycho oncology only started to become prevalent in the past twenty years as an element of cancer treatment (Holland; 1998). The information regarding the history of psycho-oncology has primarily been obtained from Jimmie Holland’s (1998) book, *Psycho-oncology*. Jimmie Holland established himself as leader in the field of psycho oncology. Although the publication date is 1998, the information is relevant and important to the current field of psycho-oncology. The researcher will be focusing specifically on the impact of cancer on the lives of couples where one partner becomes a patient and the other a caregiver.

2.1 BACKGROUND TO PSYCHO SOCIAL ONCOLOGY

According to Holland (1998) psychological and social issues related to cancer were not actively studied until the last two decades. Gradually small groups of clinicians started doing research in this field now known as “psycho-oncology”. This field addresses the psychological, social and behavioral dimensions of cancer from two perspectives; the psychological responses of patients at all stages of disease and their families (psycho-social); and the psychological, social and behavioral issues that influence morbidity and mortality (psychobiological) (Holland 1998).

Holland (1998) ascribed the slow development of research in this area to some extent to the stigma that has always been associated with psychological and emotional issues along with medical illness, especially cancer. Another contributing factor was the fact that limited funds are available for research and training. Holland (1998) continued to say that there were only a small number of psychosocial clinicians worldwide, limiting the chances of involvement in psycho-oncology due the availability of other fields of interest. There was also a need to develop valid instruments to quantify data in these domains which were viewed as “soft science” by the scientific community (Holland; 1998).

The focus in oncology was on cure and less attention was being paid to symptom control, quality of life and the well-being of the patient. As treatment and diagnostic methods increased over the years, patients have to cope with side effects like hair loss and vomiting. These
advances create new psychosocial problems requiring therapeutic assistance from trained clinicians (Holland 1998).

Holland (1998) said that clinicians working in the field of psycho-oncology have, by providing educational training, counseling and communication, drawn attention to the psycho-social issues experienced by patients and families. Behavioral and psycho-social interventions as well as measurement of subjective symptoms like pain, nausea, anxiety, depression and delirium have been developed. The quantitative measurement of quality of life, as an outcome variable in clinical trials research, has also been developed. Psycho-oncology has not only played a role in assisting patients to cope, but also in understanding how to reduce the risk of cancer and mortality through lifestyle choices (Holland 1998).

Holland (1998) says that no other disease has sustained such a strong negative stigma through the centuries as cancer. In the 1800’s an exact diagnosis of cancer was unusual and no treatment was available. It was only after general anesthesia came into practice that surgical extirpation became possible. Still, according to Holland (1998), cure was rare and death was the expected outcome for most cancer patients. Methods to control pain and other symptoms hardly existed. Information about the causes of cancer was notorious. The illness was feared due to the high mortality rate associated with cancer. Holland (1998) says that a cancer diagnosis was a death sentence causing stigmatization, isolation and humiliation. There were unique problems adding to the revulsion that accompanied cancer, like uncontrolled pain, foul smelling tumors, fatigue, loss of attractiveness and self-esteem. The visibility of breast and genital cancer, resembling syphilis, led to the belief that it was sexually transmitted. This added to the patient’s feelings of guilt, shame and stigma. Family members were mysterious about the information, withholding the truth from children. The patient was not advised about the condition (Holland 1998).

According to Holland (1998) the manifestation of cancer has changed with the reduction in cancer mortality, advances in treatment, increased global interest in palliative medicine, the incorporation of Quality of Life in outcome measures in clinical trial groups, the development of
supporting psycho-oncology services and public awareness around lifestyle choices like the dangers of smoking (Holland 1998).

As psycho-oncology is such a relatively new field and the impact of cancer as being experienced by couples currently not well understood, it may be helpful to refer to the following framework as suggested by Lauria et al (2001).

2.2 A FRAMEWORK FOR UNDERSTANDING THE PSYCHOSOCIAL RESPONSE TO CANCER

Lauria et al (2001) is of the opinion that the nature and sources of distress among cancer patients, their family members and significant others are understood by utilizing the framework of identifying common issues at different stages in the disease. These stages are as follows: the cancer diagnosis, treatment, post-treatment, recurrence and terminal illness. These stages are recognized as crisis points and require mastery of coping skills and adaptation tasks specific to the stage of the illness. It is helpful to discuss these different stages following this framework.

In addition there are other factors that affect an individual, couple or family’s psycho-social response to the cancer experience. These factors are included in the framework by Lauria et al (2001) as followed:

1. *The type of cancer, the stage and the prognosis:* Higher levels of distress and more consequences are experienced by patients who have cancer with a high risk of mortality and more intense treatment.
2. *The degree of disability the disease and treatment cause:* Patients can lose limbs or the function of a body part. They can also be disfigured as a result of cancer or the treatment of the disease.
3. *The intensity of the treatment:* The extent and aggressiveness of the treatment and the severity of the side effects can significantly affect physical and emotional functioning and a patient’s sense of well-being.
4. *The patient’s age and stage in the life cycle:* The impact of cancer differs according to the developmental life stage of the patient at the time.
5. **The person’s past experience with cancer**: The emotional and physical reserves available for employing coping strategies can be affected by the nature of previous experiences with cancer.

6. **The person’s current situation.** The individual’s current status as it relates to quality of life, personal relationships, financial stability, access to health care, quality of health care insurance, concurrent stresses, life expectations and existential outlook can affect the individual’s psycho-social response to cancer.

7. **Each person’s unique emotional makeup.** Pre-morbid functioning and personality characteristics can affect the individual’s response and ability to cope with the experience of cancer. Strong problem solving and communication skills, high self-esteem, success in personal relationships, trust in others and spiritual beliefs are predictors of positive coping.

8. **The degree of social support and caregiver availability**: The quality of the social support to the patient and family can affect the degree of distress. Support can provide a buffer against the harmful effects of stress.

9. **Typical ways of coping with stressful situations.** The patient’s response to previous crisis is predictive of coping strategies and skills that will be used to face cancer.

   (Lauria et al. 2001:28)

### 2.3 THE STAGES OF CANCER

It is desirable to comprehend the above framework in conjunction with the different stages of the illness. The different stages of cancer and the psycho-social issues accompanied with each stage will be recognized throughout the literature study. The stages according to Lauria et al. (2001) are as follows:

2.3.1 **The cancer diagnosis**: The patient and family members experience disbelief, shock and panic when confronted with the illness. They feel vulnerable, guilty, helpless and angry. Patients often direct feelings of hostility towards family members or other supporting people. Newly diagnosed patients are concerned about the impact their illness might have on their family members and loved ones (Lauria et al; 2001)
2.3.2 Cancer treatment: Lauria et al (2001:33) say that “Several factors influence the impact of treatment on patients, family members and caregivers. The aggressiveness of the treatment regime, side effects experienced, general physical health, disruption to routine and lifestyle, level of understanding about the treatment plan, age and point in the life cycle, tolerance and uncertainty, problem-solving capacity, relationship with the health care team and availability of social support will collectively influence the ability of each person to manage the rigors of therapy”.

2.3.3 Post-treatment: There are two perspectives on this stage, according to Lauria et al (2001), with the first being the patient considering the end of treatment as a milestone symbolizing their successful victory over cancer. The second outlook is one of fear and dread as they feel unprotected from cancer recurrence with the termination of active treatment. Patients often experience a combination of both perspectives (Lauria et al; 2001).

2.3.4 Recurrence or terminal illness: Lauria et al (2001) point out that recurrence of illness, as with all phases of the continuum, is a further individualistic experience for each patient. It is understandably a time of great distress for patients and families. It is known that some forms of cancer are treatable and curable despite recurrent episodes. The reappearance of disease in the primary site or as metastatic disease is indicative of resistance of the malignancy to front line treatment, lessening the chances of survival. Lauria et al (2001) hold the view that patients at this time turn to a spiritual connection to help them to come to terms with advancing disease or deny the implications for their long term survival. Patients might find alleviation of anxiety due to their knowledge of treatment and its side effects.

The terminal stage of the disease is understandably the most distressful to patients and family, according to Lauria et al (2001). Patients fear abandonment and their actual death. They are concerned about dignity preservation when they are no longer in control of their bodies. They are apprehensive about the well-being of their caregivers and loved ones after their death. The researcher is aware that much more information can be given about this stage, but as it is not the focus of this paper, it will serve to say that the presence of this stage is the reason for the immense impact cancer has on the existence of people.
2.4 THE STAGES OF THE FAMILY LIFE CYCLE

It is helpful to examine a concise version of the Stages of the Family Life Cycle as described by Erik Erickson (Becvar and Becvar: 2003: 113) to comprehend the diversity of the impact of cancer depending on the life stage of the patient and the stage of the cancer and to follow, also the stage of the marriage cycle the couple is in.
<table>
<thead>
<tr>
<th>STAGE</th>
<th>EMOTIONAL ISSUES</th>
<th>STAGE-CRITICAL TASKS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Unattached child</td>
<td>Accepting parent-offspring separation</td>
<td>Differentiation from family of origin, Development of peer relations, Initiation of career</td>
</tr>
<tr>
<td>2. Newly married adults</td>
<td>Commitment to the marriage</td>
<td>Formation of marital system, Making room for spouse with family and friends, Adjusting career demands</td>
</tr>
<tr>
<td>3. Childbearing adults</td>
<td>Accepting new members into the system</td>
<td>Adjusting marriage to make room for child, Taking on parenting roles, Making room for grandparents</td>
</tr>
<tr>
<td>4. Preschool-age child</td>
<td>Accepting the new personality</td>
<td>Adjusting family to the needs of specific children, Coping with energy drain and lack of privacy, Taking time out to be a couple</td>
</tr>
<tr>
<td>5. School-age child</td>
<td>Allowing child to establish relationships outside the family</td>
<td>Extending family/society interactions, Encouraging the child's educational process, Dealing with increased activities and time demands</td>
</tr>
<tr>
<td>6. Teenage child</td>
<td>Increasing flexibility of family boundaries to allow independence</td>
<td>Shifting the balance in the parent-child relationship, Refocusing on midlife career and marriage issues, Dealing with increased activities and time demands</td>
</tr>
<tr>
<td>7. Launching centre</td>
<td>Accepting exits from and entries into the family</td>
<td>Releasing adult children into work, college, marriage, Maintaining supportive home base, Accepting occasional returns of adult children</td>
</tr>
<tr>
<td>8. Middle-aged adults</td>
<td>Letting go of children and facing each other again</td>
<td>Rebuilding the marriage, Welcoming children's spouses, grandchildren, Dealing with aging of one's own parents</td>
</tr>
<tr>
<td>9. Retired adults</td>
<td>Accepting retirement and old age</td>
<td>Maintaining individual and couple functioning, Supporting middle generation, Coping with death of parents, spouse, Closing or adapting family home</td>
</tr>
</tbody>
</table>
It is only in the first developmental stage that an individual is generally not attached to another in a romantic way. For the rest of the developmental stages until death, people could be in meaningful relationships. The consequences of having cancer in any one of the family life cycle stages from two to nine, could be different for couples and have to be treated with a holistic approach. The researcher suggests that in order to understand the implications of the diagnosis of cancer for the relationship of the couple, it is significant to consider firstly the stage of the cancer disease, secondly the developmental stage of the family life cycle the couple is in at the time and thirdly the stage of their marriage. The permutation of the three variables could lead to a unique and complex situation for the couple with numerous intricacies to cope with. A table of the Stages of Marriage as according to Becvar and Becvar (2003:114) follows:

2.5 THE STAGES OF A MARRIAGE

Table 2 The stages of Marriage (Becvar and Becvar; 2004: 114)

<table>
<thead>
<tr>
<th>STAGE</th>
<th>EMOTIONAL ISSUES</th>
<th>STAGE CRITICAL TASKS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Honeymoon period</td>
<td>Commitment to the marriage</td>
<td>Differentiation from family of origin</td>
</tr>
<tr>
<td>(0-2 years)</td>
<td></td>
<td>Making room for the spouse with family and friends</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Adjusting career demands</td>
</tr>
<tr>
<td>2. Early marriage</td>
<td>Maturing of relationship</td>
<td>Keeping romance in the marriage</td>
</tr>
<tr>
<td>(2-10 years)</td>
<td></td>
<td>Balancing separateness and togetherness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Renewing marriage commitment</td>
</tr>
<tr>
<td>3. Middle marriage period</td>
<td>Post-career planning</td>
<td>Adjusting to midlife changes</td>
</tr>
<tr>
<td>(10-25 years)</td>
<td></td>
<td>Renegotiating relationship</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Renewing marriage commitment</td>
</tr>
<tr>
<td>4. Long-term marriage</td>
<td>Review and farewells</td>
<td>Maintaining couple functioning</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Closing and adapting family home</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Coping with death of spouse</td>
</tr>
</tbody>
</table>

2.6 PATIENT REACTIONS ON RECEIVING DIAGNOSIS

According to the National Cancer Database (2004) the process of adjusting to cancer can commence even before an exact diagnosis. Patients are concerned about unexplained
symptoms. They often start realizing that cancer might befall them when they undergo tests to determine the presence of cancer. On hearing the diagnosis, the crisis becomes an existential dilemma, making them speculate about their mortality and often verbalizing their worst fear that the disease can seize their lives. Their concern has now turned to distress due to the established presence of cancer.

"The diagnosis completely changed my life." (Holland and Lewis; 1999: 40). Patients and their families report that the sensation of uncertainty started at this point. The expectation of continued life and health is shattered. Patients report feelings of optimism and desolation succeeding one another with short intervals (Holland & Lewis 1999).

Similar to Lauria et al’s (2001) findings, Holland and Lewis (1999) note that patients and family experience feelings of shock and panic on receiving the diagnosis of cancer. They have found that it is often confirmation of a dreaded fear or it might come as an entire revelation. In both instances different degrees of denial may occur which can range from a healthy protective category of response to a pathological level of denial. Holland and Lewis (1999) continue to say that patients and family members describe experiencing a lack of lucid thoughts. They feel powerless, vulnerable and troubled. Patients fear death, pain and potential disfigurement. They describe a feeling of loss. They feel guilty about the trouble they bring on their loved ones. At the same time they fear that the people that they love most will abandon them or that they will become a burden to them.

The oncologist would normally outline treatment options immediately after informing patients of their diagnosis. It is therefore important to have another person, like a spouse or family member, present to help recall information at a later stage. Patients are anxious and often not able to comprehend or memorize what was said. (National Cancer Database 2004: 5)

According to Holland and Lewis (1999) patients experience guilt and blame themselves for making bad lifestyle choices like smoking or sun exposure. Patients feel guilty for waiting too long in search of medical counsel. Some patients believe that they are being penalized for sinful acts.
Holland and Lewis (1999) further say that patients experience a sense of helplessness that makes them feel out of control of their lives. The future suddenly becomes uncertain and unpredictable. They fear loss of autonomy and independence. Patients can experience feelings of anger about the fact that they have cancer and often direct their hostility towards their family members or people in supportive or helping roles. This can cause friction between spouses or partners.

According to Holland (1998) it is reported that an existential crisis can occur with the diagnosis of cancer. Patients experience a sense of loneliness causing them to feel isolated, alienated and desperate. On the other hand, existential exploration following the diagnosis can lead to spiritual growth enhancing the patient’s coping skills. This however, is an evolving process, guided by the direction that the illness takes.

Holland (1998) says that concern for family members are often the first thought that comes to mind, especially for patients with children or elderly parents. Patients are concerned about breaking the news and the response of the other. Patients are apprehensive regarding the level of disclosure. Heritable factors of cancer are a concern for people with children. They also envisage being a burden and placing heavy financial constraints on their partner. Communication about the diagnosis is a common concern (Holland 1998). While patients are experiencing these emotional difficulties, decisions have to be made about obtaining a second opinion and various treatment options.

The National Cancer Database (2004) divides the normal responses to the diagnosis into three phases. They should be read in conjunction with the four stages of cancer as described by Lauria et al (2001):

a. The initial response includes disbelief and often denial that the news is true. Patients might question the test results or want a second opinion.

b. The second phase is called dysphoria. Although it varies, depending on personal style and context, this period usually lasts about one to two weeks after the initial diagnosis. This is a time of great distress to the patient who might be experiencing depression, anxiety, insomnia.
and a loss of appetite. Intrusive thoughts around death and dying can occur. Usually patients start feeling more optimistic as they process the information and are more informed about treatment options. Feelings of hope start to emerge.

c. The third phase is the longer term adaptation and lasts for weeks, months or years. There is no single best way to cope. Patients cope according to their own individual established coping styles and short-term coping strategies, which are situation specific.

According to the National Cancer Database (2004), the challenges during the diagnostic stage of the illness are infinite and overpowering. If a patient masters these challenges, it contributes to their effective adaptation to the disease. It is further noted that nearly all patients have to deal with a variety of stressors, experiencing different levels of distress, shortly after receiving news of their diagnosis.

The Clinical Practice Guidelines for the Psycho-social Care of Adults with Cancer (2003) warn that not all patients are shattered or compliant about the diagnosis. Patients might react with anger or negativism or even rudeness. They will grieve in private, without admitting it to the medical team. It should be kept in mind that patients react differently and therefore an open mind and respect towards the patient’s individuality should always be priority.

2.7 COMMUNICATION OF DIAGNOSIS BETWEEN CLINICIAN AND PATIENT

It is evident from the above information that the diagnostic stage is one of great distress to patients and loved ones. It is also a stressful event for the clinician who has to convey the message to the anxious patient. According to the Clinical Practice Guidelines for the Psycho-social Care of Adults with Cancer (2003), the quality of medical care is dependent on both competences in interactional and medical skills. It is suggested through survey data that clinicians feel uncomfortable with their level of communication skills. “The way a clinician and the treatment team relate to, and communicate with a patient can significantly benefit the patient and their family, including improvements in psychosocial adjustment, decision making, treatment compliance and satisfaction with care.” (Clinical Practice Guidelines 2003: 7) These guidelines suggest that communication skills of expression of empathy and active listening
improve psychological adjustment. Patient satisfaction increases when techniques like these following are used; a summary letter as a follow up to the consultation, the presence of a support person and the active encouraging of questions. The Clinical Practice Guidelines (2003) suggest that clinicians should verbally communicate in comprehensible language when informing patients instead of medical terminology that is not familiar to them.

A view expressed by a health care worker: “The emphasis should lie with the professional in giving cancer information and that the health advocate (social worker) should support this and encourage the health care professional to speak in plain English without using jargon terms. This is a critical requirement in face to face encounters” (Cox and Lanceley; 2003:14).

“Surely a doctor should be expected to share...the skills of human sympathy...letting another creature know that his or her concern is honored and valued”. (Lauria et al 2001:13).

Regrettably, not all doctors hold this view. Lauria et al (2001) continue to say that if a patient is of the opinion that the clinician is all-powerful and infallible, they start with a serious misconception. It is important to keep in mind that doctors of medicine are ordinary people. This reality tends to get lost in the overwhelming diagnosis of cancer. Anxious patients might have unrealistic expectations of the clinician as an omnipotent being who is going to let the cancer disappear. This expectation is unfair towards both doctor and patient.

Lauria et al (2001) continue their plea for realistic expectations from doctors by stating that most clinicians care sincerely about their patients. Doctors are not supposed to reveal their nonprofessional selves, but they too have personal problems and sometimes ill health. Patients expect a self assured, commanding, focused and caring presence. Lauria et al (2001) are of the opinion that doctors receive little training on how to take care of people on a psycho-social level when they are in normal health or distressed. They are often overworked and exhausted and can make mistakes. Respect should be the main ingredient for the doctor-patient relationship, not by this indicating unquestioning acceptance.

Cox and Lanceley (2003) claim that interactions between a health care professional and a patient should be information orientated. According to Cox and Lanceley (2003) the health care workers tended to inform patients in detail about their diagnosis and treatment procedures
without assessing the patient’s knowledge, understanding or emotions. The health care workers uniformly indicated that they purposefully avoided emotional issues out of concern that patients may ask them uncomfortable questions that they cannot answer.

Cox and Lanceley (2003) ascribe the routine approach of health care workers to their anticipated stereotyped negative reactions from patients. Through this approach the health care workers might fail to recognize that informative communication could assist patients to adjust satisfactorily.

Runfola et al (2006) say that patients should begin to participate in medical decision making by being cognizant of their rights as consumers. Patients have the right to choose the health care provider of their choice. It is also patients’ responsibility to obtain information by asking questions and voicing their concerns. Patients must see to it that they are heard and addressed in an understandable and satisfactory manner. This viewpoint relates to that of Lauria et al (2001) who state that the patients must be the advocates for themselves and take control of their own illness through gaining information and knowledge. This approach suggests patients should make informed decisions about their own treatment.

In the study by Cox and Lanceley (2003) it is noted that patients experience medical terminology as a barrier and would like to be addressed in comprehensible language. This was also confirmed by Lauria et al (2001). A specialist nurse informant in the study of Cox and Lanceley (2003:13) highlights the importance of a face to face conversation with a person being diagnosed with cancer: “The situation can be so tragic you want face to face contact with someone who is going to answer your questions not just once but repeatedly”.

According to Cox and Lanceley (2003) patients value the provision of information and support through good access to and readily available advice. Patients and caregivers appreciate knowing that they could contact a health care professional for advice in a difficult situation.

Patients appreciate a kind and considerate health care worker who treats them with respect. A patient describes how thoughtful a doctor was in fitting her treatment around her holiday to her country of origin which she has been looking forward to for a long time. She reports that
she experienced that he understood how important it was to her. It was important for him to resume her treatment immediately on her return (Cox and Lanceley; 2003).

“I shall never forget the way the doctor handled telling us the news and how grateful I am to him for his kindness, empathy, wisdom and support. John and I sobbed our way through the appointment while he guided us through each step of the way” (Pistorius; 2001: 14). She says that the way their clinician managed the communication of the diagnosis to her did not take her sadness away, but it assisted her in coping with the dreaded news. She thanked him in a note; “Thanks for everything, except the news.” (Pistorius 2001: 14).

It is clear that the clinician plays a vital role in the lives of patients and their loves ones. It is therefore necessary to understand who this person is and what is expected of him/her. In the next section the task of the oncologist is explained.

2.8 THE ONCOLOGIST

The definition of “onco” according to Reber(1995: 510) is: “A combining form meaning mass, tumor or swelling”. An oncologist is a doctor that has studied how cancer and blood diseases affect and disrupt the body’s normal functions and the different ways of treating these conditions with radiation, chemotherapy, surgery and immunotherapy. Oncologists must master huge amounts of technical information like laboratory tests of body fluids, x-rays, CAT scans, MRIS, medications and their toxicities. They have to track the patients response to treatment and at the same time monitor salt and acid base balance, hydration and nutrition, immune system functioning, liver and kidney functioning, pain and other discomforts and infections (Lauria et al 2001:14).

According to Lauria et al (2001) numerous patients choose a specialist physician with little care. The patient is dealing with the quality of his life and ought to make an informed decision of the person that they are going to trust their lives to. Piccard et al (2005) found that couples stressed the importance of a bond of trust between them and the multi-disciplinary team, particularly the oncologist. They describe the relationship between patient and oncologist as follows: “This alliance is shaped or developed through a process in which knowledge is given an
the most intricate procedure or treatment to a patient on a level that the patient can understand.

According to Lauria et al (2001) numerous patients choose a specialist physician with little care. The patient is dealing with the quality of his life and ought to make an informed decision of the person that they are going to trust their lives to. Piccard et al (2005) found that couples stressed the importance of a bond of trust between them and the multi-disciplinary team, particularly the oncologist. They describe the relationship between patient and oncologist as follows: “This alliance is shaped or developed through a process in which knowledge is given an objective form to banish anxiety, integrate information, orient various forms of support and reduce feelings of powerlessness” Piccard et al (2005: 128).

Another key role the oncologist has is to ensure and facilitate effective communication amongst the multi-disciplinary team members, family and patient. A patient centered consulting style is preferred by the majority of family and patients (Clinical Practice Guidelines; 2003).

From all the above it is clear to the researcher that patients must be consumer activists for themselves, supported by their loved ones, family or partners if they are in a committed relationship. Latona (2005) says that it is most useful for a couple to manage cancer as a team. The support makes it more bearable for the patient and partner.

Bulsara et al (2006) says that due to the fact that patients experience loss of control, it could be helpful to ensure that the patient is involved in the management of their condition and in decision making regarding treatment options. “Regardless of prognosis, empowerment manifests itself in patients who have successfully regained a measure of control over their condition (Bulsara et al; 2006: 2). However patient empowerment remains a difficult concept to define in a measurable and objective way due to the complexities of cancer and its treatment regimes.

2.9 THE INFLUENCE OF CANCER ON THE RELATIONSHIP OF A COUPLE AFTER DIAGNOSIS

In the following sections the researcher will explore the influence that cancer has on the relationship of couples and the system in which they function. It is important to understand the
difference between the concepts “impact” versus “adjustment”. According to Carlson et al (2000: 1) the literature fails to distinguish between the two ill-defined constructs. “The term impact will refer to the immediate effects, both psychologically and practically, on the lives of patients and their families (up to approximately six months), and the term adjustment will refer to change and to longer term alterations in lifestyle, relationships, role function and outlook that often are the result of the cancer experience”. According to Latona (2005) the challenges and opportunities of the cancer experience change the relationship forever. Three human entities are affected; namely the patient, the partner and the relationship between them. The patient is defined as the patient through the diagnosis and the partner, by default, not (Latona; 2005).

When faced with the threat posed by the disease, Picard et al (2005) found that couples discovered the importance of simultaneously taking care of one self, the other and the couple. While the adaptability of the dyad is tested, the couple’s coping strategies intend to maintain a balance between these three components. Although these strategies support the adjustment of the partners, it is emphasized that each couple would develop their own unique way of balance. It would vary according to the life stage of the couple and the stage of the cancer disease. (Picard et al; 2005).

Because cancer has become a chronic illness rather than always terminal (see 1.7), especially with breast and prostate cancers, it is relevant to note that relationship problems are correlated with poorer chronic physical health (Halford; 2003). The link between poor physical health and relationship distress is only partly understood, but it seems that individuals in satisfying supportive relationships recover and cope better when ill health befalls them as opposed to couples in discontented relationships (Halford; 2003). It is suggested that one partner developing a major health problem puts couples at increased risk for relationship and sexual problems (Halford; 2003).

Couples will have unique experiences that will require compromising and adaptation to the different stages of the disease (Latona; 2005). In general couples could expect to have emotional fluctuations, experience grief and loss. Commitments will be tested and acquire new
meaning. When a couple faces cancer, these differences often take on a new intensity as the situation is affected by the unpredictable nature of cancer (Latona; 2005).

“The couples’ adjustment processes seemed to be structured around five major axes; a) building up of shared knowledge, b) mutuality, c) intimacy, d) constructing meaning and d) solidarity with the social network” (Picard et al; 2005: 127). These axes are represented in Figure 1. The result of Picard et al’s (2005) study suggests that focusing on these axes makes the adjustment process easier for the couples.

**Figure 1 Fundamental elements in the Adaptation Process** (Picard et al; 2005: 127)

**FIGURE 1. Fundamental Elements of the Adaptation Process**

![Figure 1](image)

2.9.1 RELATIONSHIP DISTRESS

Distress in long term committed relationships is a common problem in most Western societies. There is evidence that many of the 85 to 90% of currently married couples in the United States of America, indicating that they are in satisfying relationships, have unrealistic expectations of the relationship. The majority believe that they will never divorce their partner despite evidence of how common divorce is (Halford; 2001). Of the married people reporting high levels of relationship satisfaction, 40% also report having seriously considered leaving their partner. Relationship issues occur in satisfying partnerships even where both partners are physically sound. It is logical that the crisis of cancer can cause relationship distress, unsatisfactory functioning and in some instances even relationship separation. According to
Health on the Net (2007), 85% of marriages that have been complicated by a chronic illness eventually fail.

2.9.2 MUTUALITY

Few studies have specifically focused on understanding the couple’s ways and processes of adjusting. “The disruptions caused by a diagnosis of cancer and the way in which the couple reacts can increase or decrease the capacity of the partners to mutually support each other” (Picard et al; 2005: 117). The theoretical framework of their study is based within a dynamic and developmental perspective. The essence of it is derived from the developmental theories of the matrimonial relationship as described by Campbell (1988), Salome (1995) and Debigare (1995), cited by Picard et al (2005: 118): “These theories present the relational life of the couple from the perspective of the development of the commitment process and the dynamics of intimate relationships.” They refer to the different stages of married life as in 2.5 of this paper. Picard et al (2005) acknowledge that each phase has its own characteristics that structure the relational life of the couple in a particular way.

“Many couples’ narrative revealed that a primary strategy for controlling anxiety, is to more fully invest themselves emotionally in the conjugal bond by re-expressing their mutual feelings and giving assurance of unfailing support. This new bond of love is marked by diversity and creativity. Each couple develops their own way of demonstrating their mutual love” (Picard et al; 2005: 122). The renewing of the mutual commitment has a calming effect on their fears of abandonment and the threat of losing the other.

Mutuality is characterized particularly by a) interest and support shown towards the other, b) an attitude of openness and tolerance, c) reciprocal respect regarding the other’s physical state and d) progress and energy channeled into continuing to live together despite losses (Picard et al; 2005). It is suggested that the foundation of mutuality could make a positive contribution to the couple’s adjustment process by providing a reassuring basic emotional framework. “The assurance of unfailing support and continued commitment despite the risk of loss, disruptions and changes provides the partners with a defense against their psychological distress. In
renewing the mutual commitment, the couple reconfirms their bond, which has the effect of reinforcing the feeling of security within the relationship. This conformation of the bond reduces some of the uncertainty related to the future of their relationship and simultaneously increases their capacity for compromising and dealing with the changes that is introduced into the relationship by the disease” (Picard et al; 2005: 128).

According to Picard et al (2005: 129) other studies on mutuality has showed that when this is present in a marital relationship, “it testifies to the partners’ sensitivity to the other and the importance they give to mutually understanding one another, respecting each partner’s uniqueness and subjective experience”. Mutuality is associated with a greater degree of well-being and a willingness from the patient to take care of him/herself. It could also contribute to the reduction of the risk of symptoms of depression.

It has become clear that couples need supportive and therapeutic guidance to cope with the multiple changes that take place. The ripple effect of cancer and its treatment lead to considerable psychological stress in the relationship of a couple (Picard et al; 2005). Serious illness can bring couples closer or expose the shortcomings in the relationship. “Partners are concerned that the other might die” (Feldman and Broussard; 2005: 23), leaving them no time to rectify what was incorrect in the relationship.

2.9.3 ROLE CHANGES

Cancer can exacerbate pre-existing marital tension. The couples who cope better are the ones that do not allow the illness to intrude on the relationship between them (Fergus; 2006). They face the illness together, with the couple as a unit on the one side and the cancer on the other. Picard et al (2005) describes the relationship as a dyad dealing with the disease. It is often easier for a couple if the man is diagnosed with cancer as the women is typically the one in the relationship who plays many roles. A woman takes on the role as caregiver in a more natural manner than a man (Fergus; 2006). She notes that women find it difficult to accept care when the roles are reversed, as they are not used to requiring care. Women appreciate it when the
partner is available to listen to her concerns, accompanies her to treatment procedures and reassures her of his commitment.

Role changes take place that might make the male partner feel incompetent due to the unfamiliarity of his new role as opposed to his competency at work where he feels in control (Fergus; 2006). It is reported that male partners experience significant stress related to the role changes. They doubt their own capacity to ease their partner’s suffering (Picard et al; 2005). Because the male partners are often in a state of shock, they feel powerless and ill prepared to play a helping role due to their own psychological vulnerability (Picard et al; 2005).

2.9.4 DISTRESS IN PARTNERS

Although the partner of the cancer patient has not been studied in the psychosocial oncology field for many years, there is recently an increased awareness of the partner’s needs. (Carlson et al; 2000) “It is now recognized that the patient’s experience of being diagnosed with and treated for cancer can be as distressing, if not more distressing in some cases, for the partner than the patient” (Carlson et al; 2000: 40). In fact, a positive correlation was found between the distress of the patient and the partner – when one partner is distressed, the other seems to be similarly distressed (Carlson et al; 2000). Recent research has focused on the experience of male partners of patients with breast cancer across the various stages of the cancer process (Carlson et al; 2000).

Carlson et al (2000) found that the care giving burden for male partners decreases in recurrent disease as opposed to primary disease. This suggests that distress in male caregivers of terminally ill patients may be more related to existential issues than to the functional burden of care giving. The opposite might be true for women partners who suffer more from the functional demands than from the existential anxieties (Feldman and Broussard: 2005). “Husbands feel guilty about meeting their own needs and believe that concealing fears of their spouse’s death is best. Male partners use self control to hide their feelings of sadness and fear as they struggle to focus on their wives’ illness and care of their families” (Feldman and Broussard; 2005: 26). Their expected role as breadwinner is being challenged by unexpected

The experience of feeling powerless and out of control is extremely difficult for male partners (Carlson et al; 2000). It is therefore imperative to allow them to have as much control over decision making processes as is feasible. This might reduce the impact of the cancer experience on both partners.

It appears that little research has been done on the experience of the female partners of male cancer patients (Carlson et al; 2000). In two studies done with partners of men diagnosed with testicular and prostate cancers more distress was found on the wife’s part than on the patient’s part. However when measured by a Quality of Life Questionnaire the female partners’ scores were significant predictors of the patients’ scores, indicating again that the partners’ distress affects the patients’ psychological status as well (Carlson et al; 2000).

“For female patients, a higher level of perceived spousal support was associated with lower distress and greater well-being, but for male patients no relationship existed between perceived spousal support and well-being or distress” (Carlson et al; 2006: 47). The author’s findings indicated that it was more important for partners of female cancer patients to be supportive than it was when it was the reversed situation. Their results were consistent with the findings of Acitelli & Antonucci (1994) as cited by Carlson (2000) showing that women responded better than men to supportive behavior. Carlson’s (2000) study also showed the detrimental impact of the spouse’s negative behavior on the patient’s psychological well-being regardless of gender, hereby indicating that men are more responsive to their partner’s negative rather than supportive behavior.

2.10.5 COMMUNICATION

When one partner becomes ill, a couple’s normal pattern of relating is altered. The patient will likely give an indication if or when he wants to share emotions and information about his cancer (Gillette Cancer Ass; 2006). Due to these issues being very personal, depending on the individual’s style, the partner needs to be available. The timing should be determined by the
patient. Open communication is of the utmost importance in an attempt to counteract some of the misunderstandings, hurt and resentment that can arise in this stressful time (Talking to your Spouse; 2006).

“My relationship with my husband, David, was okay before the diagnosis, but afterwards, I felt like he put up some walls that were hard to leap over. I could not deal with that; I did not want to leap over them. I could not concentrate on his problems because I needed to concentrate on my own. It became very strained.” They moved further apart without communicating, as he tried to cope by being strong and keeping his emotions hidden from her, whilst she thought he did not care (Savard; 2004).

Couples ought to openly state their needs and ascertain how these impact on the needs of the partner. The couple needs to express their views on how they are experiencing each other’s style of communication (Gillette Cancer Association; 2005). It is also advised that couples should try to identify overlapping needs which will strengthen the mutuality (mentioned in 2.8.2) of the relationship.

2.10.6 SEXUALITY

Cancer has implications for the sexuality of a couple which includes physical, psychological and social changes. It is difficult to address sexual related issues when the patient experiences treatment side effects such as fatigue, pain, nausea, insomnia or constipation. Depression and anxiety can also interfere with sexuality. Other factors such as not being able to work or financial difficulties can distract the patient from sexual thoughts (Hughes; 2000).

According to Hughes (2000) sexuality is often overlooked by the health team as they focus on treatment. Because sexuality is such a sensitive issue, the topic is often not discussed by health workers nor raised by the couple. Couples sometimes stop having intercourse without any discussion. The healthy partner might be reluctant to raise the topic for fear of making the patient feel worse. When engaging in intercourse is terminated, other forms of intimacy change. Partners do not hug and kiss as easily as before for fear of arousing each other and then not being able to have sexual intercourse (Hughes; 2000). As intimacy changes, mutuality
changes and therefore a significant contribution to the couples’ conjugal relationship is changed (Picard et al; 2005).

“Intimacy has the effect of protecting against psychological distress and favoring adjustment by the couple inasmuch as it confirms the feeling of being valued by the other. The feeling of being loved and appreciated as one is, despite losses and limits (psychological or physical), help to reduce feelings of vulnerability, to support self-esteem, and to increase the sentiment of personal ability. These results corroborate the observations of Ghizzani et al (1995) concerning the importance of the quality of the intimacy between the partners in facilitating a satisfying revival of their sex life” (Picard et al; 2005: 129)

Shockney (2003; 2), a breast cancer survivor, suggests that couples may need to expand their ideas about sex. She provides a different perspective to Hughes by stating that; “Sex is very important in a marriage, but how each person defines it may be different. Embracing and hugging can be more intimate than the act of intercourse. Women respond to touch. Also emotion is very important. We as women, have to let men know it is safe to show emotion”. According to Shockney (2003) men generally do not have a problem adjusting to their partner’s changed shape after surgery. However, if he does not communicate this to her, she might think that he is not attracted to her any more. This could lead to the termination of their sexual life.

Certain medications can have sexual side effects like a decrease in sexual desire whilst receiving chemotherapy (Hughes; 2000). In addition medications for treating the side effects of chemotherapy can cause a decrease in libido or cause erectile dysfunction.

Fergus (2006) supports Hughes in saying that cancer treatment often has an immense impact on a couple’s sexuality. Men can be left with impotency and women with vaginal dryness causing intercourse to be painful. Hughes (2000) suggests that couples should discuss this with their physician who can advise them on other supportive devices or medication. Fergus (2006) and Hughes (2000) suggest that couples need to find more creative ways of experiencing and showing intimacy. They will have to plan sexual activities so that pain reducing or other medication can be taken in advance.
Cancer treatment may also leave the patient infertile adding the loss of the hope of having a family to the already distressed relationship (Hughes: 2000). This is another change that couples have to absorb and try to create new future plans and dreams. Lass (2001) advises sperm banking and other reproductive treatment, the content of which will not further be discussed in this paper.

2.10.7 COPING STRATEGIES

Urging patients to have a positive mental outlook can cause more harm than good. People have certain coping styles that assist them to get through stressful situations (Klotter; 2005). Some people focus on activity and problem solving while others would employ a fighting spirit. Stoic acceptance and fatalism, helplessness and hopelessness, denial or avoidance and even anxiety can be coping mechanisms. No reliable evidence has shown that any of these coping mechanisms increases or decreases survival time or cancer recurrence. Addressing the anxiety and depression may, however improve quality of life for the patient and partner. Klotter (2005) says that every doctor has seen patients with a positive outlook and fighting spirit die and patients without hope who survive.

In an effort to understand what assists couples to cope, Feldman and Broussard (2005: 26) found that “emotional support has been identified as the most beneficial support for patients because it helps to restore self esteem, decreases perceptions of inadequacy and helps patients to feel loved and valued. Conversely, the most frequent reported unhelpful behavior has been failure of husband to provide emotional support including avoiding the patient, minimizing her problems and employing forced cheerfulness”.

The case study of Mary Felstiner describes the patient’s search for ways to make meaning and cope, for them as a couple, with the presence of a chronic illness. The importance of emotional support, described by her as “caring commitment”, is illustrated by her account.

According to Yalom and Carstensen (2002) Mary Felstiner raised the following question: “If illness could set partners moving in two directions, what counterforce would keep them
parallel?” Mary started looking for predictions and reassurances of how their partnership was going to survive. She presented four questions:

**Case study: Mary Felstiner**

a. **Could they keep the relationship intact?** Mary tried to make social sense out of an unfair situation. They were a model couple when they got married. She felt guilty towards her partner because chronic illness changed her from whom she originally was when they married.

b. **Could they logistically manage the changes?** Studies have shown that women as caretakers care for their partners mostly themselves whereas male caretakers would more easily bring in help from outside. Women grow closer to their ill partners, ascribing this to the fact that they are brought up to care (Yalom and Carstensen; 2002).

c. **Would their relationship survive it?** The question of fairness continued to trouble Mary even after the couple found coping strategies that assisted them. She questioned the loss of their independency within the partnership. Her partner promised from the beginning to be a nurturer, not a nurse. She bargained on being a freelance person, not a patient. Mary started searching for a more imaginative system as their earlier model of equality was not applicable any more (Yalom and Carstensen; 2002). Mary realized that her healthy and able bodied partner was dependant on her skill in coping with her illness on a daily basis, as much as she was relying on him for assistance. This altered her viewpoint about her need for independence and her right to assistance from her partner. Mary says that she started accepting love with her illness, not because of it.

d. **What assisted them?** Their partnership consisted of different strategies coping with fear and fatigue, dependence, rage, humor, resilience and compassion. On reflecting how her life would have been without the disease and the possible disadvantages, Mary says that she might have missed out on the caring commitment from her partner (Yalom and Carstensen; 2002)

The researcher is aware that Mary’s narrative is not identical to all other couples experiencing the intrusion of cancer, but illustrates the distress caused by the illness. It also corresponds with
Latona’s (2005) viewpoint that one partner is a patient, only by default. As said before, the way in which couples cope depends on their personal style, but it is crucial to develop positive couple coping strategies. Feldman and Broussard (2005:39) found that couples seek assistance from a professional in this process. They advise that conjoint interventions are needed to assist couples to;

“1) Identify existing positive and/or negative coping patterns within their relationship; 2) evaluate effectiveness or harmfulness of coping patterns; 3) help couples modify or eliminate negative coping patterns; 4) allow couples to experiment with positive coping styles within the protection of the therapeutic environment”.

It is suggested by Feldman and Broussard (2005) that a conjoint approach can enhance a couple’s dyadic coping and relationship functioning.

Picard et al (2005) focus on understanding the support offered between the couple by observing the interactions between partners. The study reveals the influence of emotional interdependence of partners as to how their own vulnerabilities affect each other. They single out certain factors such as 1) the degree of marital satisfaction; 2) the degree of uncertainty and extent of the demands related to the disease; 3) the presence of external support; 4) the meaning given to the experience of the disease. The coping strategies that are in place for the couple will determine the degree of difficulty that they experience. Picard et al (2005) argue that the couple’s reaction to the disruptions caused by cancer will determine the capacity of the couple to mutually support each other.

The study of Feldman and Broussard (2005) support the relational model for couples therapy whereby the couple becomes more educated about the different types of support that would be most beneficial to their specific relationship style. The couple would thus be sensitized to “mutual exchange of feelings, thoughts and activities during the illness and suggest new ways to enhance the mutuality in their relationship” (Feldman and Broussard; 2005; 39). They argue that the fostering of relationship mutuality will enhance the resilience of the relationship to cope with when chronic illness or stress overload impede adjustment. Partners need help in
adjusting to the patient’s illness in order to benefit themselves, their partners and the entire family (Feldman and Broussard; 2005). (Also see 2.8.2).

2.10.8 SOCIAL SUPPORT

From the above it is clear that support from the partner and medical team are vital for the patient and partner who have to cope with cancer. The couple is however integrated into a larger social system consisting of family, friends, work colleagues, church fellowship relations, sport teammates and many more. These different spheres of the couple’s social system can contribute to support the couple. Uchino (2004: 9) asks the question; “What exactly is a socially supportive person?” The usual answer to that could possibly be “someone who is there for you”. He says that there is more to social support and defines it as follows; “ Social support is defined to include both structures of an individual’s social life (for example, group memberships or existence of family ties) and more explicit functions they may serve (for example, provision of useful advice or emotional support)” (Unich; 2004; 17).

The following table provides a description of the different support functions on how social support systems could be supportive of people experiencing difficulties;

Table 3 Definition and examples of different support functions (Unich; 2004: 18)

<table>
<thead>
<tr>
<th>TYPE OF SUPPORT</th>
<th>DEFINITION</th>
<th>EXAMPLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional</td>
<td>Expressing of comfort and Caring</td>
<td>Someone who makes you feel better because they listen to your problems</td>
</tr>
<tr>
<td>Informational</td>
<td>Provision of advice and Guidance</td>
<td>A person who can give you trusted advice and guidance on an issue</td>
</tr>
<tr>
<td>Tangible</td>
<td>Provision of material aid</td>
<td>A family member who could give you a personal financial loan</td>
</tr>
<tr>
<td>Belonging</td>
<td>Shared social activities, a sense of belonging</td>
<td>A friend with whom you enjoy just “hanging out”</td>
</tr>
</tbody>
</table>
Social support has been shown to decrease the negative effects associated with a wide range of stressful events such as unemployment, bereavement and medical problems (Unich; 2004). This model of support on adjustment to stress focuses on the buffering of stress for the patient, decreasing the negative effects of stress on both mental and physical health. “Even when faced with extremely stressful events (for example, death of a spouse), having individuals who can provide a person with support can help reduce the intensity of the stress response and facilitate coping over the long term” (Unich; 2004: 18). The benefits of being embedded in a social network are therefore not questioned.

Focus group informants indicated that support and practical help, for example, the filling of forms and accompanying them on hospital appointments, were meaningful (Cox and Lanceley; 2003). Some of these informants indicated that their husbands were not very supportive regarding tiredness and emotional distress due to their cancer illness. They did however experience the closeness of the wider family network as a positive form of social support that assisted them. One group member described it as follows; “The professionals should involve the families more. They are the ones who need to undertake the care and watch out for the person who has cancer”. (Cox and Lanceley; 2003: 13)

It is worthwhile to note that according to Unich (2004) the negative qualities of these support systems are sometimes ignored. In cancer patients the experience of negative interactions with their support systems are related to poorer coping and greater psychological distress. Spiegel (2001) as cited by Unich (2004) supported this notion that the patient might experience social alienation due to the actions of well meaning but anxious family and friends. For these patients support group interventions might counteract the negative effects of interactions with family and friends.

2.10.9 SPIRITUAL

In their search for “meaning making” during the cancer process, the researcher had often heard in her work with patients that they search for the solace that a deeper spirituality can include. According to Hersch (1998) developing the spiritual self frees the patient from any unusual feelings that might be experienced as a cancer patient. The patient realizes that he/she is fine
and that it is their body that has cancer. The patient’s life obtains more significance in the larger human context. Hersch (1998) claims that the patient will feel revitalized, if he/she starts opening up through his/her senses, to life beyond the immediate physical self. This is a philosophical perspective on how being more spiritual can assist a patient to cope with the shattered illusion of personal invulnerability. Hersch (1998:181) says that the diagnosis of cancer “and the subsequent treatments create an exaggerated focus on body that in and of itself can become a possible health problem”.

Hersch (1998) suggests that the human species organizes their existence and the understanding of that existence with imagery as well as symbols representing life, death and survival. Through this a unique awareness of life and death has been created. He asks the following questions: “How do we remain masters of life and death imagery rather than live in the terror of it? Through our contacts with death and the images we retain, how do we embrace life, fighting off fears of separation and loss of self?” (Hersh; 1998: 180) The answer lies in opening oneself up to spirituality. Hersch (1998:181) captures a dimension of this vision: “As I survived the black frustration of so many new forms of powerlessness, I partly learned to sit and attend, to watch and taste whatever...far more closely than I had in five decades. Spirituality is the process of celebrating life as you find it and to embrace it with all your senses, emotions and reason”.

Hersh’s (1998) suggests that striving for connectedness beyond the material, other living beings and the world beyond self, opens the patient to the possibility of moving beyond loss, separation and grief. Connectedness can open the patient to a condition of a mind untouched by suffering.

Hersch (1998: 182) is concerned that patients might live the remaining part of their lives in confusion and fear. He wants patients to experience life as a gift and not be concerned about the fairness of its length. “The salvation of self in life and death is found through acceptance of the limitations of our mortal selves”. According to Hersch (1998) patients who do not continuously attempt to stay connected can get lost in focusing on themselves, over-experiencing every sensation and fear. Patients should choose the means that work for them to
stay connected to a Being beyond themselves. He also advises to include a partner or other significant people in this search (Hersch; 1998)

The meaning of spirituality from a Christian perspective involves a process of becoming increasingly Christlike. This process goes beyond mere self-reflection to find hope, forgiveness, redemption, and ultimate meaning in the living Christ (Collins; 2001). He touches on the ultimate mysteries that surrounds peoples’ lives that therapy does not have answers for. It is suggested that Spirituality can assist in meaning making processes.

Moving away from the philosophical approach of Hersch to a more practical approach, Holland (2000: 162) supports Collins (2001) and Hersch (1998), agreeing that spirituality takes many forms, but “in all forms enables people to develop a perspective in which they feel better able to cope with unavoidable suffering and to come to terms with personal tragedy and loss.” Having something “to hold on to”, irrelevant of the belief system, seems to sustain people during a crisis or serious illness. These inner qualities of support and personal beliefs have normally served them well through life up to the point of the cancer diagnosis and should be reinforced through therapeutic counseling.

According to Holland (2000) many people grow up in a religious tradition, but neglect it as adults. The existential crisis of cancer often prompts patients and partners to re-explore their spiritual roots and seek meaning in the knowledge of their own mortality. Well known and new sacred sources like prayer, meditation, relaxation and reading from sacred and philosophical sources can become deeply comforting. Patients and their partners find hope in faith. Holland (2004) stresses that hope must be based on reality, taking into account the obvious meaning of a tragic life threatening event such as the diagnosis of cancer.

2.10.10 DIFFERENCE IN THE RELATIONSHIP AFTER A PERIOD OF ADJUSTMENT

Couples are at their most vulnerable in the period just after completing a treatment regime. Couples might think that life will return to normal again, but that is not necessarily true as the patient might receive further treatment and/or need a period of recovery from the physical and psychological impact of the illness (Fergus; 2006). The patient might still feel vulnerable and be
in need of ongoing support. Tension in the relationship might be the result of this disparity. The couples who adapt are often the ones who set new goals, implying that the relationship has changed irrevocably (Fergus; 2006).

A couple in a study at the Ohio State University Comprehensive Cancer Centre (2003) experienced that cancer has given them something intangible and priceless. According to the partner it felt as if they had been tested and survived. They felt that they were stronger after the experience, as if nothing could unnerve them. Being faced with the possibility of losing one partner through death, often unites a couple in new ways as they realize the impermanency of life (Fergus; 2006). This might bring about a positive change in the relationship, strengthening the bond between the partners.

Shockney (2003), a Patient Educator and patient, says that 98% of the couples she gets in touch with, develop a closer bond due to the challenges of breast cancer. In her own marriage it has brought their relationship to “a new level that I did not know existed” (Shockney; 2003:3). She supports Fergus’ statement: “When you realize that you could lose somebody, you want to show them how much you love them” (Fergus; 2006: 1)

Chapter two looked at literature that informed the topic of this research study. This included background information on psycho-oncology; a framework for understanding the psychosocial aspects of cancer; the stages of cancer; the stages of human development; the stages of a marriage; couple reactions on receiving the diagnosis; communication of diagnosis between client and patient; the oncologist; the influence of cancer on the relationship of the couple; coping strategies for the couples and the difference in the relationship of the couples after a period of adjustment. The next chapter will look at how the study was planned and executed through the research methodology that was followed.
The knowledge gained from the qualitative research with couples where one partner has cancer, was constructed by an inductive process through which the multiple experience of the same realities of the individuals was captured and understood. This was captured by way of emerging patterns and threats. The intension was to find richness and meaning concerning the difficulties couples have to endure, through interaction with the respondents. Because the sample was small, the data was used to interpret, not generalize, to the cancer public as a whole. Schurink (1998b: 240) says the qualitative approach is a “multi perspective approach (using different qualitative techniques and data collection methods) to social interaction, aimed at describing, making sense of, interpreting or reconstructing this interaction in terms of the meanings that the subject attach to it.”

3.2 SAMPLING

The researcher used purposive sampling, interviewing six patients and their partners. The eight couples were chosen because in each case one partner had cancer and were all receiving cancer treatment. The researcher, as part of the multi-disciplinary team, worked with them therapeutically. The researcher did not implement a probability sampling strategy and therefore cannot generalize findings to the cancer couple population at large. A purposive sample was used as described by Strydom and De Vos (1998: 198): “A purposive sample is based on the judgment of the researcher whereby a sample is composed of elements which contain the most characteristic, representative or typical attributes of the population.” By choosing the respondents, the researcher intended to get a better understanding of the challenges and requirements of the couples confronting the trauma of cancer.

The group consisted of couples where the patients had different diagnosis, were in different stages of the illness and also in different stages of the marital life cycle as well as the human developmental stages as according to Erickson (Becvar and Becvar; 2003). The similarities were that that they were all in a matrimonial relationship dealing with cancer diagnosed in one of the partners.

The respondents changed from the original group of eight couples as one of the patients died before the couple could be interviewed by the researcher. Another couple decided to
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The respondents changed from the original group of eight couples as one of the patients died before the couple could be interviewed by the researcher. Another couple decided to withdraw due to the fact that the patient in the relationship was in remission and they wanted to leave the experience behind them, starting a whole new lifestyle. The research was completed with the remaining six couples.

3.3 DATA COLLECTION METHODS

Mouton (2002) says that a first general principle in data collection is that if multiple sources of data collection are being utilized, it is likely to increase the reliability of the findings. The researcher has therefore made use of triangulation which is described in Mouton (2002:156) in the words of Denzinini, who coined the term, when multiple methods of data collection are used. The researcher therefore used the data collecting methods of collateral information from members of the multi-disciplinary team, a focus group and semi structured interviews with participants and their spouses.
3.3.1 The multi-disciplinary team as key informants (See Appendix 1)

The medical staff members were utilized as key informants due to their various positions in the multi-disciplinary team. They have a wealth of special knowledge and experience about the issues that couples struggle with and find helpful, when one of them has cancer.

The information gained from colleagues was primarily informing the research topic,” The Impact of Cancer on the Relationship of the Couple”. The researcher observed the reality of the patients and their partners and gained collateral from the multi disciplinary team to validate that the issue existed and was researchable (De Vos et al, 2004). The information gained from them formed the basis for the focus group discussion.

3.3.2 Focus Group (See Appendix 2)

A focus group is “a purposive discussion of a specific topic or related topics taking place between eight to ten individuals with a similar background and common interests.” (De Vos et al, 1998: 314). The researcher made use of this form of data collection first. As said before in this paper, the researcher became aware of the similarities in the needs of couples experiencing the cancer process. As stated in de Vos et al (2004) the focus group can be used in multi-method studies. The researcher wanted to learn more from and listen to the specific difficulties the patients and their partners experienced in their relationship during the cancer experience.

The researcher planned the focus group carefully as suggested by de Vos et al (2004). Input was obtained from colleagues in the multi-disciplinary team, as well as social workers in the other oncology units, to ensure a multi-faceted approach and meaningful questions to lead the group with. The participants were personally briefed by the researcher to prepare them for the focus group. As De Vos et al (2004) suggest, the researcher invited participants two weeks before the time to the focus group meeting. The meeting was arranged by the researcher at the home of one of the participating couples. The meeting was confirmed by a letter one week later and a phone call on the day.
The researcher identified eight couples and shared the aim of the study with them at a focus group meeting. The aim of the research was received with enthusiasm as the group was of the opinion that they could make a difference in the lives of couples who would in future share the same fate. It was mentioned that they wanted to share their experience and at the same time feel that the hardships they endured would not have been meaningless. The participants in the focus group formulated certain areas which they found particularly difficult or helpful through their involvement with the process of cancer.

The focus group allowed the couples the space in which to interact and the researcher to generate data from these interactions, relating to the topic of research. The focus group members were all strangers to one another, but after the initial discomfort, they related well and started sharing their experiences. The group members asked questions and were relieved to have their own emotions and uncertainties normalized within the group.

The researcher informed the group that the main objective of the focus group was to explore opinions around the feasibility of the study and the areas of concern to them as couples (De Vos et al; 2004). The questions for the semi-structured interviews were constructed during the focus group discussion, according to what the group experienced as the most pertinent areas of distress for them as indicated by Kritzinger and Barbour(1999:4): “Focus groups are group discussions exploring a specific set of issues. The group is focused in that it involves some kind of collective activity.”

3.3.3 Semi-structured interviews (See Appendix 3)

The researcher used a semi-structured interview schedule. This served as “a guideline for the interviewer and contained questions and themes that are important to the research (De Vos et al; 1998: 299). Through this method the discussion lent itself to openness that comes naturally and made the respondents feel comfortable. By guiding the respondents and having the interview schedule available, the researcher ensured that all topics were covered with each respondent in order to be able to have rich data covering the same topics. The interviews were conducted with partner and patient separately.
3.3.4 Written reflections on semi-structured interviews

The semi-structured interviews were complimented by written individual replies from the respondents using the interview schedule as a guide. This was suggested by the focus group as they were of the opinion that they could miss out on information during an interview. The other reason was that they might feel uncomfortable to verbally communicate their feelings or emotions but might be more open and honest in their writing. The end result was valuable information that the researcher could combine with the verbatim information from interviews. It will not be attached due to the confidentiality agreement.

3.4 DATA ANALYSIS

The researcher studied the interview material obtained from the participants several times to get a sense of the information as a whole before dividing it into themes and categories. De Vos et al (2002) suggest that the researcher familiarize herself with the data in intimate ways by re-reading, reflecting and making notes. The context, themes and comparisons that the researcher arrived at through this process, is documented in Chapter 4 of this paper. The themes that emerged were internally consistent but distinct from one another identifying the “salient grounded categories of meaning held by participants in the setting” (De Vos; 2002:344).

Through the emergence of the main themes and sub-themes (see table below), the researcher was able to interpret the information in a way that informed the original research objectives. As advised by De Vos et al (2002) one interview was used to analyze and code the information gained from the participant.

As according to Tesch (cited in De Vos et al 1998) the above process was completed with the rest of the interviews data until the main themes and subcategories were construed.

3.5 LIMITATIONS

3.5.1 The qualitative approach requires that “the researcher should be neither objective nor detached, but should rather be engaged” (Greeff; 2002; 299). This implies a willingness from the researcher to understand the response from the couple respondents in a wider context of the interview as a whole. The researcher was willing to understand the couples’ responses but
responses but it was difficult not to become involved in the emotional issues accompanying cancer. The subject of this research was all about feelings that were transferred to the researcher. It was difficult to maintain a professional distance. This could be limiting the way in which the data was analyzed as the researcher's own emotions and subjectivity could play a role.

3.5.2 The researcher made use of convenience sampling. This could be limiting to the research as all six the couple participants were white middle class, especially in South Africa with its various ethnical population groups.

3.5.3 The small size of the sample could also be viewed as a limitation as it makes it impossible to generalize the findings to the cancer population at large.

3.5.4 The researcher could have included more issues, as raised by the focus group, in the interview schedule. This could have brought about richer data that might have added value to the recommendations.

Chapter 3 presented the qualitative method of research used in this study; the research design; sampling; the data collection methods used; the data analysis and limitations of this methodology. The next chapter will look at the analysis of the data collected during the research. It is presented in three main themes with sub categories.
4.3.1.1 Honesty and transparency

These qualities were mentioned by couple respondents as of major importance to them.

“The relationship with the oncologist needs to be one of transparency and honesty. We would prefer to know what we are dealing with.”

4.3.1.1.2 Support including both patient and partner

Couple respondents indicated that a calm and encouraging style of working with them, are most beneficial. They need to experience that the oncologist is empathetic and patient towards them.

“He definitely transferred his calmness into us. We needed that at the time. He was very thorough in his consultation with us. He answered all the questions with a lot of patience.”

A partner respondent’s response to the way the oncologist included her in the treatment plan was as follows:

“He was always professional and patient. He communicated with patience and answered my questions efficiently. He never made me feel that I was in the way. He respected my husband’s wish that I had to receive the information directly from him and not through my husband”.

4.3.1.1.3 Knowledge and expertise from the oncologist

Couple respondents expected from their oncologist to be competent and informed about the latest research

“I have the best oncologist in the whole wide world and respect her knowledge and expertise. She treats all scares with great patience and seriousness and don’t take risks”.

“Competence and being up to date with the latest research (treatments, nutrition, etc) The oncologist also needs to be empathic and provide appropriate clear, concise information on treatment options including advantages, disadvantages, practical guidelines for how to prepare for treatment and practical information for what to expect and how to best counter the side effects”.

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4.3.1.1.4 A first-class relationship between couple and oncologist

All patient participants’ responses indicated the significance of a high-quality relationship between patient and oncologist; illustrated by quotes from the data:

“Open and honest discussion about my condition and treatment. An empathetic response to my reactions. I feel that the oncologist has my life in his hands and the best possibility for me to be cured is the formation of a strong and effective partnership between me, my partner and the team that he leads, based on trust. His attitude strongly influences my state of mind”

“One definitely feels more in control after you have spoken to your oncologist”.

Another partner respondent stressed the importance of information that needs to be given:

“The best information and support has come from the oncologist and it would be incredibly helpful if this level of information would come from the surgeon too”.

It is interesting to note that Picard et al (2005) similarly, as above, found that couples stressed the importance of a bond of trust between them and the multi-disciplinary team, especially the oncologist. This alliance serves to inform the couple and diminish anxiety by integrating the information and support to reduce the feelings of powerlessness (Piccard et al; 2005).

4.3.2.1 SUPPORTIVE COUNSELING

All the couple respondents indicated that the inclusion of a professional counselor as part of the holistic approach followed by the multi-disciplinary team to cancer couples’ treatment, was found to be meaningful and supportive. Two of the male partners said that they were uncomfortable with the concept of exposing their most private emotions to a stranger, but were surprised by the positive contribution it made to their adjustment process. The counseling did not only support the cancer process but facilitated open and honest discussion between patient and partner about their relationship before and after cancer. One couple respondent acknowledged that they were facing divorce at time of diagnosis but that the marriage is now better than ever with the assistance of relationship counseling during the cancer process. During the therapeutic process they unpacked unresolved issues from the past and dealt with the
complexities of cancer with their new ways of communication that was acquired during counseling.

Four out of the six couple respondents would have preferred the counselor to be present at the time of diagnosis already instead of only during the oncology treatment phase. As this was experienced as one of the most difficult parts of the cancer process, they might have been better equipped to deal with the uncertainties that were to follow had the diagnosis experience been contained with empathy and sensitivity. This supports the couple’s responses about the lack of empathic support and concerned communication from the physicians at the time of diagnosis. Having the counselor present from the beginning would allow for continuation of the process to the treatment phase.

Quotes from couple respondents about the contribution of counseling to their treatment plan:

“We were delighted to hear that the treatment model included a counselor. We had already decided that we needed counseling support, so having the counseling service offered as part of the treatment was most welcome. The counseling service has played a huge role in helping us to safely vent our feelings and issues, helping us to get back to the status quo”.

“Counseling; - that was the first time we actually sat down together to face and deal with our situation”.

“We never actually spoke to each other as to how we were feeling emotionally. The counseling was really wonderful in the sense that you have an opportunity to express your views”.

“Having the support of a counselor in the oncology department is a new and most welcome experience because it is possible for us to collect our thoughts and concerns and schedule a discussion”.

“It was wonderful that there were counselors available even specially for the children”.

“I also believe an oncologist should work in partnership with trained counselors”.

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4.3.2 SUPPORT FROM THE MULTI-DISCIPLINARY TEAM

All six couple respondents indicated that the support from the multi-disciplinary team was valuable and supported them through the cancer process. They felt secure in the care of the various members of the team with the oncologist leading the team.

This quote from a partner respondent summarizes the importance of the support of a multi-disciplinary team for patients and partners:

“Treatment team: Oncologist, surgeon, nursing staff, oncology nursing staff, radiologists, counseling support – professional people showing they care by doing their job efficiently, effectively and with empathy; providing information and support appropriate to our needs. The administration and reception staff has also played a positive role too, in that they are always helpful, friendly and patient even when it is obvious that they are being rushed off their feet, they still find the time to be helpful”.

A patient respondent’s viewpoint:

“I thought that there will be a negative atmosphere at an oncology unit. I was surprised by the positive attitude of the staff. It contributed a lot to my own feeling of being positive. I discovered that they were angels. All the healthy people that complain so often about nonsense, must visit the oncology unit and will see that the patients, doctors and other staff members are an example to everybody. They all are fantastic, even the parking attendant smiles to me!”

The information received from the couples about the importance of the support from the multi-disciplinary team is congruent with the clinical guidelines suggested for the field of oncology (Clinical Practice Guidelines; 2003).

4.3.3 SOCIAL SUPPORT

This section excludes the support from the partner and the multi-disciplinary team. All six couple respondents indicated family and friends as their most important source outside their marital relationship. Faith and prayer (see 4.3.4) was the other supportive factor that was mentioned by five of the couples.
“I feel that the most significant support comes from my family, friends and colleagues.”

“We received unbelievable support from our family, friends, colleagues and even strangers. We are still receiving it. Every sms, telephone call and visit is invaluable.”

“Being willing to chat about cancer and the treatment, especially as each new phase in the process occurs helps both of us to adjust.”

“Faith and my family.”

Uchino (2004) talks about the different spheres of the couple’s social system that contribute to support best. The data indicates that the different support functions of social support are present in the couple’s support systems. The types of support are emotional, informational, tangible and belonging. Cox and Lanceley (2003) emphasize the importance of family support in the care of cancer patients.

4.3.4 SPIRITUALITY

The data revealed that the couples did not suddenly become religious if they were not that before the diagnosis. All six couples continued their same style of spirituality as indicated in the responses below. The researcher would describe the responses as congruent to each couple’s style and belief system, but all of them became more aware of their life and the meaning of it within their specific contexts.

Four of the six couple respondents had meaningful relationships with God. They indicated growth in their spirituality, experiencing a deeper connection with God than before cancer. For them faith served as a supporting factor which gained depth as they proceeded with the process. The support through prayers from fellow believers was significant and added to their feeling of well being.

One couple said that spirituality has never been important to them and this had not changed through the diagnosis of cancer. They did feel more appreciative of life in general and became more aware of the important people in their lives.
In the other couple the partner has always had a questioning and cynical style of spirituality. This became more prevalent but a need to find answers exists. The patient has never pursued spirituality and this has not changed.

A quote (also in 4.3.3) from a patient respondent indicating the value of an integrated spiritual support system;

“Our church friends, family and all the staff were the best. Prayer groups as far as London started praying and offering support. Close friends took care of the kids and helped with food and transport arrangements where necessary.”

Another quote from a patient respondent describes the personal significance faith could have in these circumstances;

“I have become a lot more spiritual. I always believed in God, but did not feel or witness Him in my life. Now, I can see the golden thread of His presence in my life and feel him within me every day.”

A partner respondent;

“No major change. Maybe a bit more questioning – not quite as accepting as before. But to be honest this questioning process probably started before the cancer incident, however the cancer has fuelled the need to clarify and get answers to spiritual questions and long unattended issues.”

From the above findings it is evident that social support systems, as found by Unich (2004), serve different functions but are all interrelated. Couple respondents in this research mentioned all four types of support; emotional, informational, tangible and belonging.
4.3 Theme 3

THE INFLUENCE OF CANCER ON THE MARITAL RELATIONSHIP

4.3.1 CHANGES IN THE RELATIONSHIP

The data revealed similar but also different responses from patients and partners. The researcher noted the patient respondents all were positive and appreciative of their partners. It could be ascribed to their feelings of guilt due to the inconvenience of the illness of cancer and the changes it has brought about in the couples’ lives. Four of the six patient respondents indicated that the relationship was always satisfying, but that they are now more appreciative and aware of each other. Their partners have supported them throughout the process. One patient respondent said that their relationship was leading to divorce before the cancer diagnosis, due to work load and little time spent together. Unresolved issues from the past that resurfaced were resolved due to the realization that the one partner had a life threatening disease. One patient respondent said that cancer saved their marriage as there was distance and congested communication channels in their relationship before cancer.

The partner respondents agreed with the patient respondents that the relationship was satisfying before and became even more intimate due to the shared hardship of the cancer process. They were however more willing to also admit the negative changes that have taken place in the relationship. One partner respondent said that the quality of communication in the relationship was better before as the patient has become defensive, stubborn and emotionally unstable. One partner respondent said that the quality of the relationship was not satisfying before and that the patient has become increasingly irritated with the patients irrational fear.

The following changes in the relationships of the couple respondents were identified from the data;
4.3.1.1 A stronger relationship

**Couple respondents** noticed that their communication patterns changed from superficial to open and honest discussions of feelings and emotions. They feel closer and appreciate each other more than before the cancer experience.

“**My relationship with my wife has grown stronger and more appreciative – it is like having a second chance with my wife. I think we are much closer as well. The one thing I had to do was to forgive myself – I felt guilty for putting her through so much trauma even though it was not something that I did wrong or did on purpose.**”

“We had a great relationship before the cancer. Now we spend more time together – less time cross with one another and try to appreciate each other more.”

4.3.1.2 Partner's strength carried patient

**Patients** reported that the strength, courage, enthusiasm and honesty of their partners assisted them in coping with the difficulties of having cancer. They experienced a dependency on the partner which they never had before. They had to join forces in different new ways.

“**My husband stayed by my side right through everything and supported me in every way possible. He’s been absolutely amazing and I don’t think I would have been able to do it without him. He kept me positive, sane and laughing right through it all.**”

4.3.1.3 Tension experienced

**Couple respondents** reported having to cope with the fear and uncertainty accompanying cancer, amongst the routine of their daily lives, placed a lot of strain on their relationship. **Unresolved issues from the past returned which added to the tension that already existed due to the presence of cancer. Two of the partners mentioned that they were impatient with the cancer process and their partner’s response to it.**

“**The relationship was good, but this was the ‘first big test’. Relationship was strained for three years prior to ‘unexplained’ illness of patient.**”
“It has affected my wife’s confidence. She has irrational fears, somewhat paranoid about her health.”

“A minor change has developed, I have noted that as the chemo progresses, he is becoming more tetchy and less tolerant. He was always the tolerant, placid, calm one in the relationship; my rock – emotionally stable and logical versus my more emotional, feelings-orientated approach. Now at times he is as emotional as I am. This has been a little disconcerting and it took me a while to adjust – I think it also contributed to my feeling of helplessness.”

The relationship changes that couples experienced are similar to the changes as described by Fergus (2006). It also correlates with what Savard (2001) said about appreciating the second chance with her partner as the relationship is more significant after the cancer experience.

4.3.2 The couples’ experience of being different to other couples

All six couple respondents indicated that they feel different to “normal” couples who did not have to face cancer. They do however acknowledge that it could be due to the life changing experience, not necessarily only the cancer experience. It is true for each couple that they are more appreciative of the gift of life and each other. The following quotes describe the couples’ experiences best.

“It is difficult to compare us with other couples, but I think every couple that had to live through a difficult and unknown experience – think and act differently afterwards. This is what the old people refer to as ‘life experience’. We see ourselves as a couple who can talk about cancer with credibility.”

“We do feel that we are different from other couples. The feeling is almost a conceited feeling – we are better than them because we have done this. I am aware that you have no concept for something like this until you have experienced it.”

“We find that we do feel different from less close friends and couples who have not experienced any hardship in their lives. It is probably because there is no real sharing on a deep level and no frame of reference for them to understand that we have and are going through.”
A couple’s experience was recorded in a study at the Ohio State University Comprehensive Cancer Centre (2003) where they describe that cancer has given them something tangible and priceless. Shockney (2003) records that their relationship was taken to “a new level that she did not know existed”.

4.3.3 A new “connectedness”

Five couple respondents reported feeling more connected with each other. They ascribe it to the inter dependency that cancer forced upon them in order to cope with daily life and the treatment regimes. The couples that experienced a deeper “connectedness”, described it as a positive element that added value to the quality of their relationship.

In one couple respondent the patient indicated that she feels lost and sad and not closer to her husband. This is the couple that reported that their relationship was already strained before the diagnosis of cancer.

“We are closer than ever. We now spend more time on our relationship and communicating than ever before. I think it is because we give priority to our new relationship now and value it. We can see the long road that we have walked the past two years and that connects us more than anything. We both are witness to each other’s roads and know what it took from each of us to be where we are today.”

“We make time for breaks now and don’t focus so much on work. We have dealt with some outstanding issues and we definitely lead a more balanced life. He admits when he is tired and we take time out and have reduced our expectations of what can be achieved in a day – a lot more realistic. He talks more about how he is feeling and even understands some of the feelings I experience from time to time.”

“Of necessity it enhanced our connectedness because the treatment processes needed our full commitment for it to be successful.” “Yes, we have something stronger that bonds us together. We went through cancer together!!”

From the quotes above the similarity between “connectedness” from the data and “mutuality” (Picard et al; 2005) is clear. They describe the commitment of both patient and partner, as well
as the relationship between them, to the process of cancer diagnosis and treatment with the emotional intricacies that accompany it.

4.3.4 Sexuality

Three of the six couple respondents gave brief answers to this topic, indicating a discomfort to talk about the subject. Answers varied from “No” to “Not that I have noticed” on the question whether their sex life is different than before.

One couple ascribed an improvement in their intimate life due to the fact that they have revisited their relational life due to the cancer experience and therefore found an improvement in their sexuality as well.

“Yes, it is better. In a way the cancer was the catalyst for us to finally sort out our issues once and for all. We have both faced our demons and the intimacy problems we experienced before is now a thing of the past.”

One couple said that their sex life continued to be non-existing as before the diagnosis.

One couple reported that they were experiencing problems with their sex life due to the operation to remove the tumor. Their sexual relations together before the operation were satisfying. It has now become a frustration especially for the male patient. He sees it as follows:

“Our sex life is different due to cancer – I had complications due to the operation in removing the tumor. The operation should never have been done as the oncologist believes that it could have been cured with treatment.”

Although not much data was forthcoming in this study on the topic of sexuality, it is significant to mention the couple respondents’ indications that an improvement in intimacy between them could lead to an improvement in their sex life. This notion is supported by Picard et al (2005).
4.3.5 Finances

All six couple respondents had good medical aids and additional medical coverage, which covered most of the costs. Two couples mentioned hidden costs which had an influence on their financial positions. A few patients had a loss of income due to not being able to work.

One patient respondent explained the financial experience as follows:

“Yes, the medical bills were substantial and even though we had a medical aid, it was more a hospital plan. I don’t believe the financial situation influenced our relationship in any way. We would do whatever was required to ensure we were receiving the correct information and dealing with specialists in the field.”

Financial concerns are challenges that male patients have difficulty with (Carlson et al; 2000). It is merely mentioned in this study, but was not researched in depth.

Chapter four presented the findings that were revealed by the data as main themes, categories and sub-categories, as well as quotes from couple participants. The last chapter will look at conclusions and recommendations that followed from this research.
Chapter 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 CONCLUSIONS

The research explored the impact of cancer on the relationship of the couple. The study looked at the difficulties in coping with cancer, supportive factors and also how the relationship of the couples changed due to the cancer experience.

The data analysis will be discussed in relation to each objective (indicated on p 3)

5.1.1 To determine which elements in the process of receiving the diagnosis of cancer are the most difficult for couples to cope with

The data reveals that for most couples the way in which the diagnosis was conveyed to them was the most difficult element of the cancer process and determined their reaction to the news. Couple respondents strongly expressed disillusionment with the communication styles of their various general practitioners and surgeons. They were disappointed that they were treated without respect. Couples experienced that the physicians that conveyed the message to them did not exercise a containing approach, which left them feeling uncertain and uninformed about the future. Couples preferred a sensitive caring approach with knowledge about treatment possibilities and an immediate plan of action.

It would be reasonable to say that this is an emotional experience for both physician and the couple. It would also be fair to say that it is a difficult task for any physician to have to perform. It does not however allow them to communicate with disrespect to patients and their partners. Due to the content of the message that the couple receive from the physician, it is understandable that the couple might possibly perceive the physician in a negative way. This has to be taken into account when interpreting the results obtained from the participants. Usually the couple receives the diagnosis from another physician, not the oncologist.
The researcher observed in her work with cancer patients that if they feel uncomfortable with the style of the oncologist but believed in his/her capabilities, they would rather persist. Especially if they were referred to the oncologist by somebody they trust, like their general practitioner, another cancer patient or family member who has knowledge of the oncologist. The researcher often spent much time during counseling on assisting patients and partners in dealing with the style of the oncologist. Partners would be concerned about the patient, but do not want to add to the patient’s troubles by suggesting that they confront the oncologist or change to another. The experience might have been less demanding had the oncologist adhered to the requirements as indicated by patients in the data, which mostly is the case.

It was found that each couple has a unique experience depending on their specific relational style, developmental life stage, the stage of their marriage as well as the stage of the cancer. The findings describe these unique difficulties, indicating that although there are general factors that could be applicable to all couples, each couple should be treated with respect for their own unique experience. The researcher noticed that if the couple was given an opportunity to share their narrative and allowed to normalize it within the abnormal realm of the cancer experience, they discovered their natural coping strategies start to function.

The data also indicated that the couples would have preferred having a trained counselor present at the time that the diagnosis was conveyed to them. They found the support of the social worker meaningful through the rest of the illness and treatment, which causes them to believe that having the counselor present from the beginning, might have assisted them to deal with it differently. The researcher experienced that it is often meaningful for the counselor to sit in with the couple during their consultation with the oncologist as it assists with recollection of facts and meaning making of what was discussed. It also serves as a containing element when patients are anxious or dreadful news is being delivered. It is therefore most likely that having a counselor present on receiving diagnosis could add value to this difficult situation.

5.1.2 To determine what supported the couples in managing the course of cancer diagnosis and treatment
The data also indicated that the couples would have preferred having a trained counselor present at the time that the diagnosis was conveyed to them. They found the support of the social worker meaningful through the rest of the illness and treatment, which causes them to believe that having the counselor present from the beginning, might have assisted them to deal with it differently. The researcher experienced that it is often meaningful for the counselor to sit in with the couple during their consultation with the oncologist as it assists with recollection of facts and meaning making of what was discussed. It also serves as a containing element when patients are anxious or dreadful news is being delivered. It is therefore most likely that having a counselor present on receiving diagnosis could add value to this difficult situation.

5.1.2 To determine what supported the couples in managing the course of cancer diagnosis and treatment

The data revealed that the couple respondents perceived their relationship with the oncologist as the most important supportive factor. As the leader of the multi-disciplinary team, he/she leads the couple through the cancer experience. The couples require for the oncologist to be professional and competent, with knowledge of the latest research in the field of cancer. This person needs to make them feel safe in the midst of the uncertainty brought on by the diagnosis of cancer.

The couples found the multi-disciplinary approach supportive with regards to professional treatment and information provided. The couples’ social support system comprised of family and friends who comforted them with emotional as well as tangible support.

Spousal support is indicated throughout the data as the patients’ main source of support. Spousal support was perceived by the couple participants as the natural way of attempting to cope with the challenge of cancer. The relationship between the couples developed a new connectedness that was supportive to both patient and partner and made them mutually responsible for each other’s wellbeing. This mutuality is described by Picard et al (2005).

5.1.3 To determine what the relationship specific difficulties brought on by the presence of cancer were for the couples
The data reveals that most couple respondents had satisfying relationships before the diagnosis of cancer, but that the relationship changed for the better and became an even more satisfying and caring relationship. This was however an emotionally trying experience where they had to become focused on what was truly important and leave the trivial issues behind. They found that their styles of communication had to become more open and honest, allowing for the other to discern exactly what the other experienced throughout the whole process.

In addition to the unique life changing experience they realized that they feel different to “normal” couples. They describe a new quality of connectedness in their relationship that allowed for sharing on a deeper level than before the cancer experience.

The data reveals that couples’ financial positions changed due to added expenses as a result of the costly treatment and patients not always being able to continue working as usual.

5.2 RECOMMENDATIONS

5.2.1 Recommendations from the couple participants

The most significant recommendation that resulted from the data was to improve the way the diagnosis of cancer was conveyed to patients. It is therefore recommended that;

a) The physicians obtain better communication skills to be better equipped to deliver the diagnosis of cancer to patients and their partners. It is recommended that communication skills training be implemented at undergraduate level for medical doctors. It is further recommended that it should be compulsory to renew this kind of training to maintain their registration with the Medical Council.

b) That a cancer diagnosis should never be given to the patient alone. If the patient has a partner, the physician should arrange for such partner or other significant person to be present.

c) That an experienced and skilled counselor is involved when the diagnosis of cancer is conveyed to the couple to contain the process. The involvement should continue through the rest of the process.
d) That the physician is well prepared to inform patients and partners about future planning. It is further recommended that couples receive a concise information package that they can refer to at a later stage as they are often too overwhelmed to register facts at the time of diagnosis.

5.2.2 Recommendations from the researcher

The researcher supports the recommendations from the couples above. In addition, after careful consideration of the data combined with the researcher’s own experience in working with couples and cancer, it is recommended that;

a) Couples coping with cancer should receive relationship counseling after the completion of treatment in order to assist them to adjust to their new relationship.

b) Specific attention should be given to intimate and sexual aspects of the couple’s relationship through relationship counseling.

This final chapter presented the conclusions and recommendations by both couple participants and researcher that followed from the data analysis.
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*Talking to your spouse.* 2006. Teaming up to Take Action;


### Appendix 1

**DEMOGRAPHICS OF HEALTH CARE PROFESSIONALS CONSULTED**

1. Six oncology social workers from different hospitals
2. Four oncology ward nursing sisters
3. Four chemotherapy sisters involved with daily treatment of patients
4. Two radiographers involved in radio-active treatment of cancer patients
5. Three oncologists
6. One dietician involved with nutrition of cancer patients
Appendix 2

3.3.2 Focus Group Participants

<table>
<thead>
<tr>
<th>COUPLE</th>
<th>GENDER OF PATIENT</th>
<th>CANCER STAGE</th>
<th>DEVELOPMENTAL LIFE STAGE</th>
<th>MARITAL STAGE</th>
</tr>
</thead>
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<td>1</td>
<td>Female</td>
<td>Stage 1</td>
<td>Stage 5</td>
<td>Early</td>
</tr>
<tr>
<td>2</td>
<td>Female</td>
<td>Stage 2</td>
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</tr>
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</tr>
<tr>
<td>5</td>
<td>Male</td>
<td>Stage 3</td>
<td>Stage 8</td>
<td>Middle</td>
</tr>
<tr>
<td>6</td>
<td>Female</td>
<td>Stage 1</td>
<td>Stage 2</td>
<td>Early</td>
</tr>
<tr>
<td>7</td>
<td>Male</td>
<td>Stage 3</td>
<td>Stage 8</td>
<td>Long-term</td>
</tr>
</tbody>
</table>
INTERVIEW SCHEDULE

1. Describe your immediate emotions on receiving the diagnosis of cancer.
2. In which manner was this message conveyed to you and by whom?
3. Do you think this should/could have been done differently?
4. What do you expect from your relationship with the oncologist?
5. What was/is the most difficult part to deal with? Explain why?
6. How has your marital relationship changed after the news?
7. What was the relationship like before?
8. What role changes happened for you in your relationship?
9. Did cancer influence the level of connectedness between you and your partner?
   Indicate both negative and positive.
10. Is your sex life different from before? How is it different?
11. Did your financial position change? If yes, how did it influence the relationship?
12. Which support systems and resources were/are most meaningful?
13. Has your spirituality changed and in what way?
14. Do you feel different from other couples? If yes, explain how?
15. What do you know now that you did not know before?