

# **A Critical Literature Review of the Psychosocial Effects of Cervical Cancer**

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## Abstract

This study explores the experiences of women with cervical cancer. The illness affects the women physically, emotionally and socially. They face bodily mutilation that affects their body image, self-esteem and their sense of being feminine. They feel socially inadequate, as they can no longer contribute towards the society due to an illness. The emotional impact is so immense as the women are rejected by their partners, and sometimes friends and family that cannot bear the illness. They face various losses such as loss of bodily functions, loss of potential children, loss of jobs and loss of intimate relationships. As a result, the illness has been associated with different psychological disorders such as depression and anxiety as a result of fear of the future, particularly the impending loss of life.



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Diagrammatic Presentation of Patient's Fears and Concerns About Cervical Cancer and its Treatment



# **A Critical Literature Review of the Psychological Effects of Cervical Cancer**

## **1. Introduction**

Cervical cancer is one of the most prevalent cancers that afflict women and that lead to deaths worldwide. The illness is regarded as the second leading cause of cancer deaths among women, even though it is underreported (CANSAs Research, 2002). This is also the most common cancer in South African women, particularly those in their thirties (Fonn, Bloch, Mabina, Carpenter, Cronje, Maise, Bennum, du Toit, Jonge, Manana & Lindeque, 2002). Apart from the fatal nature of this illness, it attacks the most important organs of women, that is their genitals. Consequently, they tend to feel as though their feminine identity is damaged and their whole self-schema is negatively affected (Hamilton, 2001).

Failure to diagnose cervical cancer at an early stage results in the illness being chronic. It becomes irreversible and it also involves assaults on multiple areas of functioning beyond the physical body. The patients may face separation from family, friends and sources of gratification. There are losses of key roles, disruption of plans for the future, distressing emotions such as anxiety, depression and helplessness (Turk, 1979).

Even though the illness itself is fatal, it can be prevented through cervical screening tests. However, many women are skeptical about doing these tests because of social and psychological factors. They may include fear of positive diagnosis and its implications for the future, as well as others' evaluations and reactions to the affected person. In the case where one has a positive diagnosis, the treatment itself has side-effects that affect the psychosocial well-being of individuals.

The individual might also avoid screening because of a belief that this disease will never affect her. For some women it is just the perceived discomfort of having one's sexual organs handled by others that makes them avoid testing (Kowalski & Brown, 1994; Baileff, 2000). When the patient's body is exposed before a group of nurses and doctors, she feels personal violation and an invasion of privacy.

Several factors that place women at risk have been identified. Some of these factors include multiple sexual partners, sexual intercourse at an early age, smoking, the use of birth control pills and a history of sexually transmitted diseases (Kowalski & Brown, 1994; Chaves, McMullin, Mishra & Hubbell, 2001). Infection by the virus known as the human papilloma virus (HPV), which is sexually transmitted, is said to be one of the contributors in the development of cervical cancer. Furthermore, studies have found an association between human immunodeficiency virus (HIV) infection and cervical cancer. HIV-infected women are at a greater risk of developing this cancer than those not infected (Berman & Grosen, 1995; Shingleton & Orr, 1995).

There are different types of HPV. Most of them do not infect the genital organs but cause lesions such as common warts seen on children's fingers (Denny, 1999). The HPV that causes genital warts in men and women has been linked to cancers of the cervix, vulva, vagina, anus and penis (Castellsague, Bosch, Munos, Meljer, Shar, De Sanjose, Eluf-Neto, Ngelangel, Chichareon, Smith, Herrero & Franceschi, 2002). They argue that up to 99 percent of all cervical cancer cases may be attributed to infection by oncogenic HPV genotypes.

## **2. Physical Experiences and Emotional Distress of Cervical Cancer**

### **2.1 General effects**

Although a minority of cancer patients develop psychiatric illnesses, most of them experience psychosocial problems. These include fatigue, fear, problems with finances, employment, childcare, other family worries, and existential as well as spiritual doubts (White & MacLeod, 2002). It has thus been found that compared to the general population, patients with cervical cancer have a high risk of developing psychological distress that requires intervention (Klee, Thranov & Machin, 2000).

Psychological distress is defined as “an unpleasant emotional experience of a psychological, social or spiritual nature that may interfere with a patient’s ability to cope with cancer and its treatment” (White & Macleod, 2002: 379). Distress includes physiological arousal and subjective experiences. Associated experiences such as vulnerability, sadness and fear can result in depression, anxiety, social isolation and spiritual crises.

After being diagnosed with cancer, patients report problems in coping with work, caring for their family, as well as severe pain that interferes with their general social life (Baileff, 2000). They indicate less satisfaction with their affected ability to perform household duties due to fatigue and they report the difficulty of sharing their problems with others. A forced regression occurs requiring an individual to surrender at least temporarily the autonomy and environmental mastery that characterise the psychologically mature adult (Proshansky, Nelson-Shulman & Kaminoff, 1979).

Cervical cancer impacts on the family in many ways. Firstly, it affects the intimacy between partners, because it results in reduced libido. Moreover, depending on the stage and level at which the illness is diagnosed, the mother is at risk of dying and leaving young children behind (Eisemann & Lalos, 1999).

The illness has been associated with high levels of psychological stress as it affects women's sexual functioning and it also results in vaginal abnormalities. According to Whitehouse and Slevin (1996), the commonest symptom of cervical cancer is vaginal bleeding, especially after sexual intercourse. They argue that some women experience pain during sexual intercourse, especially if their cancer is advanced. Some women may even have a foul smelling discharge from the vagina.

### 2.1.2 Treatment of cervical cancer

The treatment of cervical cancer is determined by the stage of the disease. Microinvasive cancer (stage 1a) is the earliest stage of cervical cancer and only affects a small portion of the cervix. It can be managed by simple surgery like cone biopsy, which is the removal of a cone-shaped piece of tissue from the cervix of women who still desire future childbearing (Berman & Grosen, 1995).

Stages 1b and 2a are referred to as early invasive cancer. At this stage, the disease has spread to certain parts of the vagina, the pelvis and the uterus. The survival rate is still very high at these stages. The most effective treatment here involves radical surgery or hysterectomy and radiation. The former treatment includes the removal of certain portions of the uterus, the cervix, the pelvic wall and the vagina (Shingleton & Orr, 1995). Radiation therapy, on the other hand, uses high energy rays to kill and shrink cancer cells in the areas that are at risk.

There are stages 2b and 3 that can also be treated using radical hysterectomy

and radiation therapy. The disease in these stages still extends to the same parts that are affected in stages I b and II a (Berman & Grosen, 1995). However, in this case the parts are affected more severely.

The last stage usually indicates a poor survival rate and it is referred to as stage IV. At this stage a cervical tumour extends to the above mentioned parts, including the bladder and the rectum. In this case, radiation and surgery can still be used. However, chemotherapy is the most often used treatment at this stage. The treatment entails the use of drugs to fight cancer cells, and it is often used for women who have received maximum doses of radiation (Shingleton & Orr, 1995). Recurrent cancer or persistent tumour detected after radiation can also be managed by pelvic exenteration. This treatment involves the removal of bladder, rectum, vagina, uterus, ovaries, fallopian tubes and all tissues within the pelvis (Berman & Grosen, 1995).

Treatment of cervical cancer has major side-effects, particularly in the cases of radiation, pelvic exenteration and chemotherapy. These include tiredness, skin injury and emotional discomfort. Consequently, the side-effects of the treatment turn out to be a disruptive factor in the lives of patients (De Haes & Van Knippenberg, 1985; Grimiél & Freidl, 2000).

There is urinary and bowel dysfunction that causes a great amount of discomfort to the patients. The urgency to empty the bowel usually begins as an acute side-effect that often becomes a chronic symptom following external radiation (Klee et al., 2000). While bowel incontinence is usually experienced after radiation or chemotherapy, urinary pain and a feeling of urgency is predominantly evident in the patients who have had hysterectomy (Bergmark, Avall-Lundqvist, Dickman & Henningsohn, 2002). For some women the urinary urgency may be very severe and stressful that it impedes everyday activities

outside home as it defies prediction and control. In terms of pelvic exenteration, both bowel and urinary functions are affected.

Fecal leakage even has a greater impact on the level of distress, due to its social consequences such as having a bad smell around others and a feeling of uncleanness. An inability to control basic human functions such as urination and defecation seriously threaten a patient's dignity and violates the most basic foundations of adult personhood (Waskul & van der Reit, 2002). This powerlessness over the body reduces the patient to an infantile status, since it is only infants who cannot usually control these functions.

Waskul and van der Reit (2002) state that many women with cancer react to the loss of control of bodily functions by using the defense mechanism of dissociation. By distancing oneself from one's body, one avoids stigma and embarrassment. Patients go through psychological, physical and social adaptation when the disease affects their everyday life. There is also uncertainty about the prognosis and this causes pessimism, sadness and a sense of hopelessness (Velji & Fitch, 2001).

Some abnormalities have been reported, such as vaginal shortness due to radical surgical removal of tissue, insufficient vaginal lubrication for sexual intercourse due to damage to some nerves and blood vessels, as well a hormonal deficiency after surgery and radiation (Bergmark, Llundqvist, Dickman, Henningsohn & Steineck, 1999; Velji & Fitch, 2001).

There is reduction in the frequency of intercourse, and problems with arousal and orgasm that could be due to intrapsychic causes in addition to physiological ones. Vaginal changes tend to restrict coital pleasure and result in much distress when faced with having persistent problems with intercourse (Summers, 1998).

According to Hamilton (2001), it is the heightened preoccupation with the vagina, and a constant painful intercourse, that affects the personal meaning women attach to themselves. As a result, they report low self-esteem, and they tend to focus on the part of their body that underwent change.

## **2.2 Anxiety**

**Anxiety is a state of undirected arousal following the perception of threat or unresolved fear. It manifests as apprehension, uncontrollable worry, avoidance of people and of reminders of the threat. In the case of cervical cancer, a woman would for example try to avoid thoughts of the illness. Day (1979), describes anxiety as:**

- an awareness of being powerless to do anything about a personal matter
- the fear of impending and almost inevitable danger, a tense and physically exhausting alertness like one is facing an emergency
- an apprehensive self-absorption which interferes with an effective solution of reality problems and
- irresolvable doubt concerning the nature of the threatening cancer.

Anxiety in cancer patients emanates from the fear of the future and a dread of changes in one's self-concepts and body image (Summers, 1998). It also stems from the fear of death, apprehension about treatment and a dread of possible infertility resulting from the treatment. It also arises from the fear of abandonment, social isolation and anticipation of losses (Bohnet, 1986). Hence, anxiety is the emotional response when the self-concept is threatened. Although long-term chronic side-effects may not be a severe threat to the patient's life, there may be fear of some of the limitations the illness can impose on the

patient's general health and daily activities.

The degree of anxiety is related to the fears of the patient concerning anticipated adversity and severity of treatment side-effects (Derogatis & Wise, 1989). For instance, the patients may overestimate the risks associated with treatment and the likelihood of a poor outcome. There can also be post-traumatic stress symptoms following the diagnosis or treatment that has been particularly frightening (White & Macleod, 2002). Studies have therefore shown that cervical cancer patients present with significantly higher anxiety, tension, worry, irritability, social unease and somatic features of depression, compared to the healthy population or patients with other forms of cancer that are not gynaecological (Sevin, 1999; Summers, 1998).

At the end of an apparently successful treatment, some patients can experience distress associated with the fear that the cancer may recur or spread. Social phobia can also develop as a result of urinary and bowel incontinence. The women may start avoiding company because of their fear of social embarrassment (Klee et al., 2000). Even the patients whose cancer has been cured may experience psychological as well as social changes such as fear of recurrence that may induce a constant level of worry. Consequently, they find it difficult to cope with work or to return to work. This fear of recurrence may contribute to the feeling of loss of control, powerlessness, and unpredictability.

Apart from the fear of illness and its side-effects, there is also fear of death. Studies have shown that about 40 percent of people who develop cancer die from the illness (White & Macleod, 2002). The terminal phase of the illness often brings fears concerning uncontrolled pain, the process of dying, what happens after death and the fate of loved ones who are orphaned or left behind. Day (1979) indicated that in cancer patients where fear of death exists, it is often fear

in anticipation of death rather than fear of the event itself.

## 2.2 Depression

Lewinson (in Stonestreet, 1985) perceives depression as a consequence of inadequate reinforcement. The depressed person is viewed as being on a “prolonged extinction schedule”, because some reinforcer has been removed or withdrawn, weakening the patient’s behavioural repertoire. The individual comes to expect negative feedback in the face of her inability to perform a task at hand. Although the deficit of mastery in a situation may be the result of misconstruing reality, it can also result from the unresponsiveness of the environment. This could be lack of support and rejection from the significant others or the patient’s environment. Wherever lack of control exists in the environment or behaviour, the individual seems to develop negative self-statements.



The self-concepts of depressed patients tend to be significantly depreciated due to feelings of worthlessness associated with what they perceive as unredeemable failings for which they are responsible. According to Affleck (in Day, 1999), depressed individuals show a self-depreciating explanatory style in which they accept more responsibility for bad outcomes than good outcomes. It has therefore been postulated that depression can be due to inaccurate cognitions about the patient’s condition. The cognitions are marked by a negative view of the self and the future (Derogatis & Wise, 1989).

The cognitive hypothesis of depression, according to Beck (in Stonestreet, 1985), also includes certain idiosyncratic schemas that become activated and which lead to cognitive distortions. The cognitive schemas consist of a negative conception of self-worth producing an imbalance of thought content that causes feelings such as guilt, sadness, loneliness and pessimism. A woman with cervical cancer

may blame herself for the illness and feel as though she has failed her loved ones. She may also think that the illness implies the end of a satisfactory life, while in actual fact she can still cope and live relatively well despite the cancer.

A study by Missel and Somer, quoted by Stonestreet (1985), indicated that a group of depressed clients exhibited less self-reward and more self-punishment statements in their self-evaluation. Usually such patients experience more negative thoughts pertaining to themselves, but not to events concerning the world. They have higher expectancies of negative events and lower expectancies of positive events pertaining to the self (Stonestreet, 1985). Performance deficits of depressed people can thus be eliminated by encouraging them to blame failure on external factors (such as the harshness of the environment, or the misfortune itself), instead of blaming it on internal factors (such as one's incompetence or inadequacy) (Stonestreet, 1985).

Depression concerns an underestimation of the potential amount of control that one can exert. Usually the patient's judgment of control is an inaccurate reflection of the amount of control she can assert, and this results in motivational deficits. This causes learned helplessness, where patients undervalue their potential and give up trying to cope with the problem (Stonestreet, 1985).

Failure in itself or any other form of deficiency is not necessarily sufficient to produce helplessness, but failure that leads to a decreased belief in personal competence produces helplessness. Patients may view their illness as an act of fate that they cannot fight. They may also view themselves as victims of misfortune that they have no control over, and therefore surrender instead of trying to find some effective coping mechanism.

Helplessness also involves a syndrome of cognitive, emotional and motivational disturbances stemming from repeated exposure to uncontrollable events. Through exposure to such events, individuals come to believe that personal outcomes are independent of their behaviour. As a result, they reduce their attempt to influence the environment (Stokols, 1979).

Depression is also a response to perceived loss. As a result, the diagnosis of cancer and the awareness of loss may precipitate feelings of depression. Loss is the deprivation of something precious and valued (Bohnet, 1986). It may be loss of feminine body parts, and the loss of the family itself as one is separated from one's own family. Social losses occur with withdrawal of social contacts as well as dwindling relationships. Day (1979) observed that the familiar sights, sounds, touch and smells of home and belongings, together with the presence of family members, are all important to human beings. Hence, leaving home to live elsewhere, like being in the hospital for a long time, becomes a terrible loss for cancer patients.



There is also impending loss of life, as Bohnet (1986) asserts. Humans are unique in being able to grasp the concept of a future. Hence, the potential for non-existence is one of the most devastating of losses to face. The thought is actually frightening and awesome. The perceptions of death evoke heightened awareness of an individual's vulnerability, and the result is a shift to a weaker self-image (Horowitz, 1979). Reaction to the loss includes thoughts that lead to a shift from a strong self-image to an image of being weak, abandoned and helpless in the face of dangers.

Charmas (in Day, 1999) argues that despite disruptions and alterations caused by setbacks, complications, disability and impaired functioning, people with chronic conditions also struggle to have valued lives. Loss of status resulting from job

loss, diminished income and loss of social support can have a profound effect on the patient's identity, as she is challenged to adapt to these losses. In adjusting her identity, she tries to come to terms with the constraints and limitations of the illness.

Loss of independence also becomes a great concern for the person who values self-reliance and autonomy (Bohnet, 1986). It becomes difficult for someone who had been independent to become totally dependant on others for emotional, financial and physical support. Physical losses may begin with the deterioration of physical health. Emotional losses include the cessation of hopes and dreams of the future and threats to the core of one's existence.

Psychoanalytic theory states that life events involving psychological loss bring states of preoccupation alternating with periods of avoidance and emotional response that go beyond sadness. This includes symptoms of intense rage, self-hatred, fear, shame, guilt and significant emotional blunting (Horowitz, 1979).



Undergoing and witnessing loss is painful and it provokes feelings of helplessness (Fetsch & Miles, 1986). It has also been shown that severe and persistent depressive disorder is four times more common in cancer patients than in the general population (White & Macleod, 2002).

With patients who have undergone surgery, depression tends to worsen due to a disfigured body image (Bredin, 1999). Depression is also common in the terminal phase of cancer, especially in those with poorly controlled physical symptoms. Additionally, patients also suffer from severe fatigue, which is aggravated by the state of depression.

The fearful anticipation of chronic pain seen in cancer patients (particularly if is advanced) has also been associated with anxiety and depression. Leshan in Rosch (1984) argues that meaninglessness, helplessness and hopelessness are characteristic of the nightmare world in which a patient with chronic pain lives. The pain has different facets that can be physical, psychological, spiritual, financial and social, reminding the patient of her dismal prognosis and aggravating her agony.

## **2.4 Stress**

Stress refers to a challenge to a person's capacity to adapt to inner and outer demands, which may be physiologically arousing, emotionally demanding and call for cognitive and behavioural responses. It is a process of adaptation which develops as a reaction to a stressor (Rosch, 1984). The challenge implies opportunities for growth that may nonetheless cause disruption and uncertainty. Stress also entails loss and threat, which refers to perceived anticipated harm (Westen, 1999).

Looking at the threatening nature of cancer and its associated harm as well as loss, it is almost inevitable that cancer will produce considerable stress in patients. Some may only experience stress at a particular period of their illness, particularly before they learn how to cope with it. The stressors in cervical cancer may result in inability to cope with one's daily routine, role changes and disrupted sexuality.

It has been indicated that patients undergoing radiotherapy report a high level of anxiety, emotional distress and treatment side-effects, as well as long-term sexual dysfunction (Greimel & Freidl, 2000). The comparative studies showed that this emotional distress is higher in cervical cancer patients than in patients facing

other threatening diseases such as heart disease (Greimel & Freidl, 2000). Again, cervical and ovarian cancer patients became more distressed after surgery than endometrial cancer patients.

Stress has been associated with cancer in different ways. Older studies suspected that stress could cause or aggravate cancer. This was because breast cancer was particularly predominant among women showing signs of hysteric and nervous distress such as melancholy (Rosch, 1984). Researchers argued that the secretion of hormones related to stress may disturb the body chemistry, increasing the production of abnormal cells. This was believed to diminish the capability of the body to destroy these cells (in Rosch, 1984).

Some observed that exposure to various stressors such as loss of a significant person through death or separation can induce malignant growths that result in cancer (Tache, 1979). However, it has been shown that there is less evidence to support the assumption that stress can influence growth of tumours since, as Rosch (1984) argues, it is difficult to quantify and ascertain the start of the malignant growth.

Although stress is largely a psychobiological process, it also entails a transaction between people and their environment (Westen, 1999). It concerns the individual's perception that environmental demands exceed her available psychosocial resources. People also filter their perceptions of impinging events through a set of cognitive structures. For an event to become a source of stress, the individual appraises or judges it as potentially harmful (Turk, 1979). The individual's internal dialogue regarding the situation, attitudes and expectations concerning one's capacity to respond to the situation, determine the nature of cognitive and behavioural responses. These factors also affect the stress level she experiences. Through cognitive processes, the situation is interpreted, meaning is ascribed and significance is established (Turk, 1979).

Newell (1999) mentioned that stressful life events may impair the individual's coping ability. The stressed person is also unlikely to find either internal or external events reinforcing. However, stress depends on the meaning that the individual ascribes to the event. The extent to which an event is experienced as stressful depends on the person's appraisal of both her situation and her ability to cope with it (Westen, 1999).

Cervical cancer has proven to be one of the illnesses that affect the sufferer most severely and negatively. However, some patients can cope effectively with resilience while others may be devastated and worn out by the illness. There are those who cope with their illness because they perceive it as part of their life challenges. On the other hand, others may see cancer as punishment from a supernatural being that they are unable to fight. As a result, they can find the disease overwhelming and beyond their coping capacity.

Stavkary (in Rosch 1984) observed that the cancer patients with a favourable outlook on life are those that are able to express strong emotions under severe stress without loss of emotional control. However, there have been difficulties in attempts to prove a causal link between stress and cancer since what may be extremely stressful for one person may not necessarily be so for another individual.

It has been observed that social support mitigates the effects of stressful life events (Kaplan, Sallis & Patterson, 1993). Social relationships influence behaviours, and in turn promote desirable health outcomes. It is argued that individuals who experience significant life stress and yet have strong social support will be protected from developing psychosomatic illnesses associated with stress (Kaplan et al., 1993).

Deprivation of social resources on the other hand results in continuing, distressful, self-rejecting feelings. Supportive social networks may thus be expected to moderate the severity of the distress associated with stressful life events like cancer through the promotion of emotional and physical support (Day, 1999). A study done by Bloom (in Day, 1999) on breast cancer indicates that social support was found to be the strongest predictor of healthy adjustment. It had an effect on coping, sense of power and diminished psychological distress, which in turn resulted in a positive self-concept. It is the concept of self-concept that will form the focus of the next discussion.

### **3. The Self-Concept of Women with Cervical Cancer**

Cognitive social learning theory defines the self as a group of cognitive processes and structures that people use to relate to the environment (Engler, 1992). These structures influence a person's perceptions, evaluation and regulation of behaviour. The perceptions about the self that seem most vital to the individual are at the very core of personality and form part of the self-concept (Samuels, 1977).

Self emerges through socialisation processes within primary groups. It is thus comprised of a set of social identities which derive from social differentiations in society. Self therefore exists only until an individual has put herself into situational evaluation (Young, 1972). This is a presentation of self where one begins to be an actor in ways that are observable. The self becomes the organiser of behaviour, it scans the situation and matches one's behaviour role in appropriate ways.

According to Harock and Jackson (in Samuels 1977), the dimensions of self-concept include body self and cognitive self (mental representations about self). It also includes social self and self-esteem, which is the evaluative aspect of the self-concept. Self-concept is viewed as the sum total of the views which one has of oneself. The social learning theory defines a negative self-concept in terms of proneness to evaluate oneself negatively, whereas a positive self-concept would indicate a tendency to judge oneself favourably (Stonestreet, 1985).

The self-concept is a dynamic force in human life, which is shaped by the individual's experience. Experiences mould and shape the self-concept and the self-concept in turn shapes the experiences (Day, 1999). The influence that the self-concept exerts, determines behaviour because of the need to maintain self-consistency. It furthermore determines the meanings individuals give to their experiences.

Poor self-concepts are reflected in various actions that represent poor personal and social judgment, while good self concepts are associated with relatively better judgment (Day, 1999). The judgments that cancer patients make of themselves thus indicate how their experiences of the illness affect and alter their self-concept. Negative experiences such as lack of social support and the advanced stage of the illness may alter one's self-concept. Other factors such as loss of financial independence can also contribute adversely to poor self-concept.

The self-schema, or the way in which individuals view themselves, is often affected by the illness. The illness is experienced as an unwanted imposition, which in turn forces one to become identified with the disease. The thought of being worthless is usually a major concern in cervical cancer patients. By making comparisons with other people, the sufferers use beliefs and representations to

label themselves negatively (Day, 1999). These beliefs may trigger an unmanageable threat to the individual's self-concept and its consistency.

### **3.1 Self-schema: Rogerian Framework**

The schema is the manner in which people arrange knowledge of, and memory about, themselves, other people and things. The self includes the body, which is directly attacked by cervical cancer. It also includes the social identity, which can be a cluster of definitions that become attached to the body (Baumeister, 1995). The self-schema is therefore a cognitive structure that represents knowledge and perceptions about the physical and psychological attributes that are unique to individuals (Shaffer, 1999). It is formed as a result of evaluation and interaction with others.

Three kinds of self-schemas have been identified. The first is the actual self, which refers to a person's views of how they **really are**. It largely involves personality traits as perceived by oneself. There is secondly the ideal self that refers to the aspirations and hopes that define the way a person **would like to be**. Lastly, there is the ought-self, which includes the duties, obligations and responsibilities that define the way the person is **supposed to behave** (Westen, 1999). The ought and ideal selves are informed by one's perception of values that are important to society.

These kinds of selves are viewed from various vantage points, including one's own perception and that of significant others. For instance, a woman with cervical cancer may feel that the illness is incapacitating her and preventing her from fulfilling her ought-self-standards not only for herself, but also for her

sexual partner. As a result of being physically weak, the patient may fail to take care of herself. Since the illness affects the sexual organs, it can become difficult for her to be an effective sexual partner. In some instances it may be seen as failure to fulfill the ought-self standards of one's family, especially in the case where a woman becomes infertile due to the illness.

Consequently, for some women, their illness may affect other self-concepts as it results in discrepancies between the various self-schemas (Westen, 1999). For instance, some women may be infertile but physically strong. However, because they feel they are not fulfilling their duties as women, they may have distorted views of themselves as less feminine.

Westen (1999) indicates that when people perceive a discrepancy between their actual self and their ought-selves, they tend to feel negative emotions such as guilt and self-contempt. On the other hand, if the discrepancy is between the actual and ideal selves, there are feelings of embarrassment, shame and disappointment. This may entail feelings of worthlessness, because the desired and esteemed genitals, together with its associated sexual duties unique to a woman, are damaged or destroyed. As Hamilton (2001) indicates, the psychological impact of this disease intrudes into a woman's idea of what it means to be feminine, sexual and generatively powerful in the world. Discrepancies between self-schemas tend to influence not only mood, but also physical health.

### **3.1.2 Self-esteem**

Self-esteem is the desire to be worthy, to love, and to be appreciated, strong, secure and loved (Samuels, 1977). The self-esteem theory asserts that individuals have a need to increase and maintain their feelings of worth, effectiveness and self-satisfaction. According to Samuels (1977), these feelings may be manifested

either in a particular aspect of self-evaluation, or in global feelings. For instance, it may mean evaluating the self in terms of vaginal abnormalities or evaluating the self in terms of the overall abilities and strengths that one has.

Pervin and John (2001) assert that studies done on self-ideal congruence show that people's level of self-esteem can be defined as the degree of similarity between the actual self and the ideal self. People whose actual self is dissimilar to their ideal self present with low self-esteem. This is similar to Rogers' theory about the discrepancy between the real self and the self-concept. The discrepancy arises only when certain actions are approved by others, leaving the individual with conditional positive regard (Rogers, 1951). As a result, the individual experiences herself only in terms of what significant others approve of.

Consequently, defensive processes develop against the conflicting elements of the self that do not receive positive regard. This leads to rejection of elements of the real self, thoughts, feelings and actions (Rogers, 1951). This inhibition of the real self, according to Rogers (1951), leads to a state of incongruence. Looking at the physical abnormalities and behavioural deficits faced by cervical cancer patients, it is evident that they may have a very low self-esteem as their parts of self show discrepancy or incongruity.

The states of incongruence result in tension and internal confusion that consequently leads to anxiety. Rogers argues that when people become more aware of the discrepancy between their organismic experience and their self-perception, anxiety begins to evolve into threat. It is due to this awareness that self is no longer whole or congruent (Feist & Feist, 1998).

This problem can, however, be avoided by giving what Rogers calls unconditional positive regard, which is a need every human being has. He argues that when a person receives unconditional positive regard from important others, she in turn regards herself positively (Maddi, 1996). Positive regard is a prerequisite for positive self-regard but once established, positive self-regard becomes autonomous and self-perpetuating. The person then becomes in a way her own significant social other (Feist & Feist, 1998).

Positive self-regard includes feelings of self-confidence and self-worth, which results from social approval. Due to the fact that people have this need, they are sensitive to the approval or disapproval of significant others. Gender studies have indicated that women tend to be more sensitive to other people's approval. Andersen and Cyranowsky (1994) argue that gender differences in self-esteem suggest that women are more dependent on others for self-worth than men are.

According to Cooley (in Day, 1999), social support in the form of positive regard from significant others is the critical determinant of the self-concept. The approval and disapproval from others becomes incorporated into one's own esteem for self. An affection-giving network is a positive basis for self-evaluation and self-acceptance. Thotis (in Day, 1999) suggests that the social environment provides identity and sources of positive self-evaluation, thereby improving self-esteem. Consequently, this enhances the perception of control and mastery and reduces the experience of anxiety.

Cervical cancer patients need a supportive environment that shows acceptance. They need to feel important, regardless of their illness. They also need people who respect their sexuality and individuality. In most cases, instead of getting support from their loved ones, they suffer rejection by intimate partners.

Consequently, they are faced with feelings of worthlessness. The end result is incongruence that manifests itself in anxiety and threat.

#### **4. The Body Image of the Abject Body**

According to Bristow (1997), the body is the physical site of personal identity and this is socially constructed. Schonfeld (in Samuels, 1977) also argues that there are psychosocial components that determine the structure of the body image on both the conscious and unconscious level. These components are:

- the actual subjective experience of the body in terms of appearance and ability to function. Berdin (1999) refers to this as body perception, that is the way in which people sense their bodies physically through sensations and feelings. In terms of cervical cancer, this can be a painful body or a body with fatigue.
- there are also internalised psychological factors arising from an individual's personal and emotional experiences. This includes the ideal body image, which is formulated by one's attitudes towards the body. This is derived from the individual's experiences, perceptions, comparisons and identifications with other people's bodies (self-esteem).

Body image thus includes the physical, social, psychological and sexual self, and plays an important role in psychological well-being (Samuels, 1977). It is dynamic, and changes throughout the life cycle in response to even short-term alterations (Newell, 1999).

Body image has representations of the individual's current, past and fantasised

experiences of her own body. In most cases, the internalised mental image people have about themselves does not closely resemble their actual body structure. As Schindler in Newell (1999) observes, our physical appreciation of the body can be distorted, thereby influencing our confidence in, and satisfaction with, the body. People spend lifetimes integrating the perceptions of their own physical appearance with their perception of how others view them (Bohnet, 1986). Hence, the gradual deterioration in body image can cause great suffering.

Cervical cancer patients may be in a situation where their body image is different from their actual body structure. A cervical cancer sufferer may have positive feelings about her other abilities such as academic achievements, but consider herself a poor sexual partner. Her attitude may be more global, ranging from total acceptance of her condition or to total rejection of herself as a bad woman altogether. However, Samuels (1977) indicates that even though an individual does not accept or reject herself in a total sense, all concept dimensions correlate positively and significantly with total self-acceptance or total rejection.



Price (in Newell, 1999) identifies three related components of the body image. These are body reality, which is the actual structure of the body. There is also body ideal, which is the desired body that one wishes to have. Lastly, the body representation denotes the manner in which the body is presented to others and how it is perceived.

The alterations to body reality, such as surgery or disease, may lead to tension between that reality and body ideal. The person may attempt to reduce that tension by altering body representation through social withdrawal to compensate for the deficiency in body reality. A person may, however, also choose to change her attitudes as to what constitutes her body ideal, in order to invoke particular coping strategies (Newell, 1999).

One's knowledge of vaginal dysfunction, or the affected image of one's genitals can make the patient feel as though her whole body is visibly disfigured (Bredin, 1999). The patient may feel ugly, small or large at different times, when in fact her **external** physical appearance has not changed. She may also maintain a negative focus on the body part that underwent change (Hamilton, 2001). This is the picture of one's body, the mental representation about one's actual body image that may not be particularly true. Samuels (1977) says that if the cognitive construction of self-conflicts with the somatic perception of self, integration of self becomes difficult and this results in problem behaviours.

As Bredin (1999) argues, there is a subjective inner representation of how one thinks and feels about one's body, and it may bear no relationship to how one's body appears to others. She argues that such perceptions and feelings remain embedded in the realm of body experience and a body language that is beyond conscious thoughts and words. Bredin (1999) indicates that patients are aware that they do not look different to the outside world, but they feel as though they are not themselves anymore.

According to Bohnet (1986), body image is influenced by feelings, attitudes and conditioning. It appears that the meaning of the loss and violation of the body depends on various aspects. This could be the functional implications of the loss and emotional investment in the body part affected or the meaning attached to that body part. In this regard, cervical cancer has severely negative functional and emotional effects on one's body image. For example, the unpleasant odour of the disease aggravates the situation and it has a negative effect on a woman's perception of her sexual self (de Marquiegui & Huish, 1999). Furthermore, the patient loses weight and at the final stages as the cancer spreads to the limbs, it may cause immobility. This also has a negative influence on her physical self, as

well as her emotions.

It is when the body is regarded as shameful, damaged, polluted or invaded by an illness that it is named an abject body. This is when it causes suffering in the form of a sense of disorder, powerlessness, pain, torment and stigma (Waskul & van der Riet, 2002). In this way, the self has little control over the leaking of urine, faeces and other embarrassing body fluids. The cancer breaks the normative boundaries, making the body “unclean and unruly” (Waskul & van der Riet, 2002, p. 487). The results are a loss of body control and dignity. Having an abject body not only implies that one’s body is difficult to manage or control, but that it is a constant threat and source of discomfort to the self. Under these difficult circumstances, a patient has to try to preserve a dignified selfhood, despite the stigma, pain and suffering.

Bodies are objects, the centres of perspective, insight, reflection and desire. They function interactively and productively (Bristow, 1997). Their worth and value is thus determined through interactions with others. The body is both private and under social control, particularly when it comes to individuals’ sex lives. Looking at all these factors, it is understandable that the common reaction to the diagnosis of cervical cancer is a fear of perceived mutilation and a loss of body image that can result in rejection and devaluation by others. Newell (1999) mentions that people whose appearance deviates from the attractive body ideal of society have fewer reinforcement opportunities in various aspects of life such as socialising, dating and work.

It has, however, been argued that in some instances patients with a form of body disfigurement tend to expect rejection from others because of their belief that people are going to stigmatise and reject them. An additional source of distress stems from living in a culture where womanhood is bound up with the ideal of

having a perfect body and a blemish-free appearance (Bredin, 1999). Therefore, body image disturbances develop within a cultural context that emphasises the value of an attractive appearance for a woman. These values are reinforced by society through media and other powerful forms of persuasion (Bredin, 1999; Kent, 2000). As a result, women with cervical cancer may go to great lengths to conceal their condition to others, due to their fear of negative evaluation associated with their body image (Kent & Keohane, 2002). They can also conceal their loss physically and emotionally because of a desire to be seen as normal.

Disfigured cancer patients may avoid activities associated with the lost or damaged part such as dating and intimacy with sexual partners, because these provoke anxiety. The psychological difficulties experienced by people who have suffered a threat to body image are therefore mediated primarily by fear and avoidance (Newell, 1999).

Nonetheless, despite all these factors, some patients still experience acceptance from their loved ones, empathy and support, although support may be informed by pity.

According to Waskul and van der Reit (2002), body image and social interaction are interrelated to such an extent that distinctions between them are permeable. They argue that others negotiate one's body presentation and appearance in various ways. Bordo (1993) also argues that in some areas, biology may play an important role in our destinies. However, even in those areas, it is never pure and untouched by history or culture. She asserts that people are creatures circumscribed by culture from the moment they are designated one sex or the other. The bodies of sick women in this way offer themselves as a text for the interpreter. This text is read as a cultural statement about gender roles, for example, women should reproduce or bear children (Bordo, 1993). Hence, for

every woman, sexuality is inextricably entangled with reproduction and relatedness, and this is socially instituted.

#### **4.1 Social self**

People value themselves according to the contribution they make to society, such as working and studying. The social self also involves ethnic and cultural definitions of self. Samuels (1977) states that the social self can be internalised and it predisposes one to respond in predetermined ways. Studies have shown that the society in which cervical cancer patients live affects their sense of being, due to the expectations that they strive to live up to (Sevin, 1999). The significant people in their lives mostly convey these expectations to them.

Gergen states that an individual's self-feeling centers primarily around the social role status that is prevalent at the time (Samuels, 1977). The socio-cultural system describes standards of morality and behaviour patterns that structure the lives of individuals. Societal forces have a strong impact on the values and behaviour patterns of individuals. For instance, young women with cervical cancer who face the predicament of not being able to bear children may be labelled and blamed for misfortune they have no control over.

##### **4.1.2 Social self according to Bronfenbrenner**

Bronfenbrenner (1979) asserts that everything is linked to a whole ecological chain of associated environmental influences. These influences are not in static form, as they exist in a changing state. An individual becomes a change agent

within a given environment while she is also being influenced by both larger and smaller environments. Therefore, there is an interplay between an individual and the environment.

The healthy development of an individual is intricately entwined with factors such as the presence of family, friends and neighbours, the quality of health services, and others. These factors are referred to as systemic forms of influence (Hook, Watts & Cockroft, 2002). There are five environmental systems with a series of successive layers, each surrounding a smaller sphere that influences an individual. These are the microsystem, mesosystem, exosystem, macrosystem and the chronosystem.

The microsystem is the immediate situation that affects an individual. It involves relations between an individual and the important figures who exert an amount of influence on that person (Bronfenbrenner, 1979). There are three basic factors that an individual experiences in this systemic layer of influence. These are the role activities and expectations associated with a position in the society such as being a mother, partner, friend, patient and so on. It can also be the interpersonal relations that can depict either support or rejection from the family and friends towards a woman with cervical cancer.

The mesosystem involves interconnections between different facets of the microsystem. These can be extended family, neighbourhood and other social relationships, for example, the level of peer groups (Bronfenbrenner, 1979). This is where the norms of the community impact on an individual. That which is regarded as normal, is reinforced, and the abnormal is rejected and stigmatised. For instance, neighbours and peer groups can determine the manner in which a cervical cancer patient is to be treated. In turn, this will determine whether the patient is accepted or isolated. This will also depend on how people attach

meaning to the cause of the illness. It can be that the patient is seen as a victim of an illness she has no control over, or she is seen to have brought the misfortune upon herself. This then determines the kind of interaction that will occur between an individual and her mesosystem environment.

Bronfenbrenner (1979) refers to the exosystem as the social setting or organisation beyond the individual's immediate experience, that nevertheless affects her. This is an extension of the mesosystem embracing other social structures that encompass the immediate settings of the individual, and thereby influencing what happens there (Hook et al, 2002). It includes structures such as the world of work, the mass media, churches and government agencies. In some cases, a cancer patient's work is affected due to the inability to function well, and can result in retrenchment, or simply job loss. This on its own involves other factors, such as disruption of the patient's socioeconomic status. It becomes even worse if the patient has to care for dependants.

The mass media may serve to either protect patients or to stigmatise them. For instance, the media can create an awareness about the consequences of cervical cancer, and thereby increase sympathy and empathy towards the sufferers. However, it can also dwell on other causes of the illness, particularly its transmission through sexual intercourse. Consequently, society may start to view cervical cancer as an illness of people who are negligent and who deserve punishment (Chaves et al., 2001).

The church itself can serve to reinforce what the media advocates, by either rejecting or supporting patients. In cases where the church condemns, the consequences could be serious, since the person is made to feel that her whole existence is defiled and she deserves hell itself. The patient might feel that God does not want her, and the illness is a punishment from Him. The patient may

then fail to find even some form of inner comfort or strength as she thinks God has also abandoned her. In this way, the patient experiences herself as an outcast in every sense (Waskul and Van der Reit, 2002).

There is also the macrosystem that refers to the institutional patterns of the culture, such as the economic, social, educational, legal, and political systems, of which macro, meso, and exosystems are the manifestations (Hook et al, 2002). This is a level at which broad cultural patterns of ideology, dominant economic and political systems, general and popular discourses, values, laws, traditions and the customs of a particular society can be located.

The laws can include religious laws and customs such as abstaining from sex before marriage, as well as being loyal to one's spouse, so as to prevent the sexual transmission of illness. The values of the macrosystem can include the manner in which motherhood is esteemed in society. It can also be about the perceived importance of intimate relationships. These values are less likely to be actualised by women suffering from cervical cancer.

Macrosystems are also carriers of information and discourses that explicitly and implicitly motivate and endow meaning to social networks, roles, activities and their interrelations (Hook et al, 2002). In this regard, discourses of feminism and patriarchy concerning cervical cancer are part of this system. For instance, feminists argue that the stigma and social isolation that women with cervical cancer tend to face reveals a patriarchal ideology that still exists to oppress women and violate their rights (Bush, 2000).

Bronfenbrenner (1979) also counts the dimension of time as a fundamental influence on the person and he calls this the chronosystem. Time is important, as it entails the patterning of environmental events over the life course. It also

entails the unique psychosocial placement of the individual (Hook et al., 2002). Time can bring about diverse changes such as divorce, other illness within the family, and unemployment in the life of a cancer patient.

The change related to time, according to Bronfenbrenner (1979), is the ecological transition that occurs whenever a person's position in the environment is altered, due to a change in either role or setting. It can occur throughout the lifespan. Role changes are integral points in the history of an individual. They alter the way a person is treated, how they act, what they do and even what they think and feel (Hook et al., 2002). In the case of cervical cancer, role changes and its consequences are a part of the illness. In one way or another the illness impacts on the patient's physiological strength and psychosocial functioning.

Diagnosis of cancer may be felt like death itself, and from then on a patient may view life differently. Even symptoms such as pain or foul-smelling discharge (before actual diagnosis) can lead to disruption or change of some of the activities and roles of a patient. More help may be needed by the patient in order to carry on house duties, and it may just be the beginning of sexual problems that persist for the rest of her life. Time, therefore, constitutes a very broad level of ecological influence.

#### **4.2 Feminine identity: Eriksonian Perspective**

The socialised part of the self is called identity. Gender identities are assigned to individuals from birth, such as being a little boy or a little girl. From the time people are born, they are assigned a label, which determines how society understands them, as well as how they understand the society. Other identities are assigned later in life, such as the identity of "good woman" or "bad man". Other identities may be obtained by deliberate effort, such as teacher, mother, or

engineer (Berger & Berger, 1976). Whether identity is assigned or achieved, others will identify an individual in a certain way. People therefore confirm our identity. Hence, identity is shaped through interaction, and it is located between the self and the other (Potter, 1998).

Identity also implies a way of being, as it encompasses the meaning of one's life in the world (and not just the social environment). Feminine identity involves one's interests, behaviour and psychological characteristics that conform to one's own internalised definition of femininity (Hook et al, 2002). These definitions are prescribed by the society and are adopted by the individual.

Erikson (1959) states that identity is about self-realisation within a particular social environment and period. It is a two-way pull, where one aspires to be distinct from the social mass, yet also more fully a part of the society. Hence, the individual's innermost self may be unique, but it must at the same time be realised within a specific social environment.

A person typically goes through a socialisation process by which social identities are mapped out. This is then transferred to the social self-structure, which develops into social identity. This then constitutes what one is, and organises behaviour in ways that are compatible with specific social maps (Young, 1972).

Even though identity formation is largely manifested during the adolescent stage, it is a lifelong development. In achieving identity, potential options for work, beliefs, sexuality and social roles are explored within a cultural and personal context. Thus, identity involves the adaptation of individual skills, capacities and strengths to the prevailing role structure of the society in which one lives. Identity is a psychosocial process that involves one's values, but also social roles. This is about the social value of an individual, and the meaning of life to her. It includes answering the question, "Who am I?" (Hook et al., 2002).

The cervical cancer patient is also assigned the identity of being a woman from birth together with social roles, such as domestic roles in the household. She can be expected to bear children and show affection in her interactions with others. However, this may be hard, if not impossible to accomplish, due to the illness.

According to Erikson, the central task of young adulthood is to develop intimacy. He argues that that women are expected to show more affection, and this is often reinforced by societal expectations. Women are therefore expected to be more affective or intimacy-focused (Potter, 1998). Several studies have shown that identity-intimacy and early sex roles assigned to males and females lead to different views of identity and intimacy issues. It is argued that women significantly score higher on intimacy status than men do (Potter, 1998).

Some studies suggest that intimacy develops equally for both genders, but with a different focus. For men the focus is on shared activities, or companionship, and the possibility of sex without affection. For women, on the other hand, the focus is on emotional needs or affection (Potter, 1998). All these can, however, be a reflection of sex-role stereotypes. Hence, there have been some conflicting results on male and female sex-roles. Some studies in Potter (1998) show similar degrees of intimacy in peer relationships between adolescent males and females.

Erikson indicates that young adults are at the stage where they seek to invest in others, in order to find a healthy well-balanced and developed sense of love. This is done in order to share oneself with another, without fear of losing one's own identity. Hence, the success of having a healthy relationship depends on the strength of one's identity (Feist & Feist, 1998).

Erikson furthermore talks about an identity crisis that is usually the core conflict

in adolescence. He called this crisis identity confusion, which involves a divided self-image, an inability to establish intimacy and a sense of confusion (Feist & Feist, 1998). The objective and the subjective notions of self are also affected. This is the breakdown of the ability to co-ordinate present behaviour with future goals and thereby implies intrapsychic difficulty.

The result of threatened identity loss, according to Erikson, may include rage, which accumulates in the face of unfulfilled potentials, or a life that is not fully lived (in Potter, 1998). Considering the afflicted life of a cervical cancer patient, it is expected that she will face a similar kind of identity crisis. It can also involve the difficulty of identifying oneself as a cancer patient who cannot function like one did before the devastating illness occurred.

Identity change can be very disruptive, because well-defined and stable self-conceptions serving important functions are disturbed (Day, 1999). As a result, individuals may encounter a variety of cognitive, affective and interpersonal problems and conflicts. Identity confusion may take away the person's resources necessary to fight the illness. A patient may be caught up in a state where she is trying to make sense of her illness and experiences difficulty accepting the disease. In so doing, she may even deny the reality of cancer in her life and therefore ignore effective coping strategies.

### **4.3 Cognitive self and sexuality**

According to Samuels (1977), cognition is a process by which individuals become aware and gain meaning regarding events in their environment. Cognitive structures are comprised of beliefs, values, commitments and skills that determine individuals' perceptions about themselves and the environment (Turk, 1979). This implies that environmental factors are mediated by mental

processes, which are manifested through interaction between people in a social group. This interaction, in turn, is mediated by that group's accumulated cultural norms, values and cognitive resources (Hook et al., 2002).

Cognitive structures explain differences in people's reaction to objectively similar situations. Individuals may show different types of responses to the same event. Hence, it is possible to find women with cervical cancer diagnosed at the same stage, reacting and coping differently. Their cognitive structures enable them to screen, code and assess a range of internal and external stimuli and to decide on a subsequent course of action (Turk, 1979). Background and personality factors including emotional development, religious beliefs and previous coping experiences, contribute to each individual's set of cognitive structures or schemata (Turk, 1979).

Sexuality, on the other hand, consists of identities and social practices which are affected by beliefs and ideologies that regulate sexual activities. It involves the self-image, as well as the value that one places on being female or male (Bristow, 1997). Thus sexuality signifies the totality of being human, and it is an aspect of humanness that cannot be divorced from individuals. It is also defined in relation to sexual relationships (Bohnet, 1986). As a result, close loving relationships with their implications for sexuality create feelings of fulfilment and meaning in life.

According to Foucault (in Bristow 1997), sexuality is concerned with the body and its pleasures, or gratification. The body and sexual practices are socially constructed, involving assumptions about what is natural or normal. Hence, for most people, the body is a central object of personal concern, as well as a key social issue (Bristow, 1997).

The individual's cognitive representations of sexuality involve inferences about their sexuality based on observation of their sexual behaviour. Sexuality also involves the experience of sexual emotions and discovery of one's sexual attitudes and beliefs (Andersen & Cyranowski, 1994). Due to the fact that sexual events are interpersonal, individuals also tend to make inferences about their sexuality on the basis of their intimate relationships with others. The less they experience intimacy in their sexual relationships, the more they have negative cognitive representations about their sexuality.

Sexuality is furthermore shaped and influenced by life experiences. It is informed by previous sexual experiences and expectations. Constructions of sexuality encompass self-image, self-esteem, and perceptions of appearance and attractiveness to self and others. They also involve the affirmation and acknowledgement that women experience from others in their daily life (Koch, Kralik & Eastwood, 2002). Koch and others (2002) assert that acknowledgement from significant people not only provides meaning to women's lives, but it also positively influences their self-identity and perception of themselves as sexual beings.

Perceptions of sexuality for a woman with chronic illness may be shaped by her previous experiences of sex. It also includes having an available and supportive sexual partner who acknowledges her as a desirable woman (Koch, Kralik & Eastwood, 2002). Although in reality cervical cancer patients are often unable to be sexually effective, their partners' support and empathy can influence their positive self-view in terms of sexuality. Moreover, the patient and the partner may engage in alternative sexual practices that will not affect the patient's mutilated organs.

#### **4.3.1 Behavioural and emotional aspects of sexual identity**

According to Andersen and Cyranowski (1994), sexual self-concept includes positive aspects, such as an inclination to experience passionate-romantic emotions and a behavioural openness to sexual experience. It also involves a negative aspect, for example, embarrassment, which deters sexually relevant affects and behaviours. In most cases we find women with cervical cancer having a negative sexual self-concept. Due to the condition of their sexual organs, they tend to perceive their sexual identity as dysfunctional.

A woman with a positive sexual self-concept is viewed as one who experiences passionate and romantic emotions. She also shows behavioural openness to sexual or romantic experiences. Such a woman suffers little embarrassment regarding sexuality (Andersen & Cyranowski, 1994).

Considering the physical sexual dysfunctions that a cervical cancer sufferer has, it would be difficult for her to be open to sexual or romantic experiences. Corney, Everett, Howells and Crowther (1992) indicate that some women do not resume intercourse after surgery, while others engage in sexual activities less frequently. Some patients also report that they experience pain during sexual intercourse. As a result they become preoccupied with anticipated pain and they do not experience any sexual arousal.

As has been indicated, women who are most likely to survive cancer (especially at a youthful age) are often physically healthy. However, they are plagued by sexual side-effects for the rest of their lives (Hamilton, 2001). The sexual relationships of survivors of cervical cancer are disrupted by this illness. The disruption may result from the survivors' perceptions of unworthiness due to their affected sexual organs. The patients may feel as though they owe it to their sexual partners to be sexually active as they were before the illness. Usually

patients are aware of their partners' desire to have intercourse. However, since they cannot be sexually effective, they feel guilty and eventually avoid expression of all physical and sexual affection (Hamilton, 2001).

## 5. Stigma of the Sexually Transmitted Cancer and the Male Factor

Stigma refers to socially discrediting attributes towards others. The stigmatised individual is usually denigrated and avoided (Kats, 1981). Stigma also includes the relationship between a characteristic possessed by an individual, and the devaluation that society places on that characteristic. Regardless of what the stigma could be, it holds an element of threat for most people who are exposed to stigma. Goffman in Kats (1981) distinguishes between three different types of stigma:

- abomination of the body, that consists of different physical deformities, disabilities and chronic diseases
- blemishes of an individual which are inferred from a known history of socially deviant behaviour and
- inheritable tribal, sexual, gender identity or religious stigma.

There is enacted stigma, which refers to the actual incidents of rejection as well as felt stigma, which involves expectations of rejection. Although instances of enacted stigma can be rare, very often people experience felt stigma. These expectations of rejection can be extremely disabling. Individuals may constantly be concerned about self-representation and consequently avoid disclosure of their condition (Kent, 2000). Therefore, stigma involves anxiety about exposure and vigilance towards others' expected behaviour. Avoidance itself, or concealment, has a number of social and personal costs, including the loss of valued activities, as well as reluctance to develop intimate relationships (Kent, 2000).

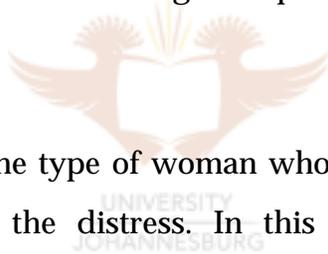
Developing cervical cancer has serious social consequences. As a result of the risk posed by sexually transmitted disease, there has been an assumption that the underlying causative agent of the illness is having multiple sexual partners (Chaves et al., 2001). This may therefore stigmatise the patient as she is viewed as morally questionable. A positive smear may be perceived as the result of promiscuous behaviour. As a result, many women have avoided attending cervical screening campaigns due to the fear of being labeled promiscuous. Those who are diagnosed with the illness mention that they felt dirty when their diagnosis came out positive (Baileff, 2000). Sexual promiscuity and sexually transmitted infections have been identified as a probable cause of the negative feelings women can experience about themselves and towards their partners after diagnosis (Baileff, 2000). This can include feeling defiled, and thereby cause resentment towards the partner, or guilt and anger towards oneself.

Lauver, Kruse and Baggot (1999) mention fear and anger that arise from the knowledge that the illness is sexually transmitted. As was mentioned earlier, the victims of cancer may feel blamed for having caused her own illness, and she may feel that the disease is a punishment for real or imagined improprieties (Fallowfield, 1991). Some religious women see themselves as entirely sinful and subsequently refuse treatment. They believe they have contributed to the cause of their suffering and deserve the torment of cancer (Waskul & van der Reit, 2002). This results in feelings of guilt and self-blame. As Waskul and van der Reit (2002) argue, an illness may be interpreted as a trial sent by God for the failure of taking proper care of oneself.

Kowalski and Brown (1994) indicate that during cervical cancer screening, some women refrain from discussing whether or not they are sexually active, or whether they have had a sexually transmitted disease (STD). They argue that many women become anxious and embarrassed due to their concerns over the

physician's evaluations and reactions. There is, therefore, shame and negative self-attribution related to having contracted an STD. Shame related to having contracted an STD and the negative self-attributions due to having affected sexual organs often inhibit the natural desire for sex, and lead to a self-consciousness that limits partner intimacy (Hamilton, 2001).

Despite all the shame and guilt that women are faced with, men carry the virus that causes this cancer. However, males are usually free of the symptoms, and can transmit the virus to their sexual partners without their knowledge (Sevin, 1999). A study done in South America showed that the high risk of cervical cancer was perpetuated by the patient's male partner's sexual interactions with prostitutes. This promoted transmission of HPV and other STDs. The socially accepted practice of male partners having multiple sexual contacts posed a great risk factor (Sevin, 1999).



The stereotypical views of the type of woman who is likely to develop cervical cancer may again add to the distress. In this regard, the role of female promiscuity appears to be more recognised than that of male promiscuity in the spread of cervical cancer. Men are excluded from the surveillance of their sexuality, and their responsibility for sexual and reproductive health issues is minimised (Bush, 2000). Additionally, should men develop cancer of their reproductive organs, they have an option of banking sperm in order to reproduce, whereas women cannot protect their fertility (Schover, 1999).

Bordo (1993) argues that female bodies become docile bodies which are subject to external regulation. Women take responsibility for the illness, or face the consequences of the illness, while their male sexual partners go free of blame. Since men often carry the HPV virus without their awareness, some of them get upset with their partners who are diagnosed with the illness. They may view

cervical cancer as their partners' fault, and therefore feel betrayed (Summers, 1998).

A study done by Adami and Trichopoulos (2002) shows that males may take the responsibility for avoiding HPV transmission by undergoing circumcision. They argue that circumcision reduces the risk of penile HPV infection and of cervical cancer since the glans of a circumcised penis has a thicker epithelium, making it more resistant to abrasions and less susceptible to HPV entry. According to Castellsague et al., (2002), monogamous women whose male partners are circumcised have a lower risk of cervical cancer than women whose partners are uncircumcised. It is argued that genital warts are more common among uncircumcised men, due to the reduced risk of penile HPV infection (Castellsague et al., 2002).

Other important ways of preventing transmission of the virus are to stick to one sexual partner and to use condoms since circumcision is only a modifying factor that protects against cervical cancer (Adami & Trichopoulos, 2002). Circumcision is not the ultimate protector against cervical cancer: it only reduces the risks of the acquisition and transmission of HPV and cervical cancer.

Nonetheless, whether it is circumcision, sticking to one sexual partner, or the use of condoms, women bear the consequences of infection and face the stigma of being promiscuous. Women tend to be passive sexual partners who consent to men's decisions about intercourse. For instance, women cannot engage in sex without condoms if their male partners do not want to use protection. As Halson (1991) states, sex is socially constructed in a way that perpetuates existing power imbalances between men and women.

## 6. Infertility and pregnancy complications

Infertility is emotionally painful, even as an isolated health problem. It is not surprising that cancer survivors have higher levels of distress over infertility than couples who are infertile due to other biological causes (Schover, 1999). Patients diagnosed before childbearing age are obviously more distressed about infertility than those who have already had children. Women, furthermore, tend to be more concerned over infertility than men. Schover (1999) argues that the distress results from the fact that women are more likely than men to see parenthood as an integral part of their socialised goals.

Infertility tends to injure the feminine self-image, due to the fact that from childhood many women are told that they will get married and have children. Some religious faiths focusing on the notion that people should multiply also reiterate the importance of having children. As a result, an infertile woman may unconsciously feel as though she is not fulfilling nature's law that requires a female to bear offspring.

Surgical procedures to fight cervical cancer include the radical removal of the uterus, fallopian tubes, the ovaries, the upper third of the vagina and the lymph nodes. All these structures are involved in child conception and childbearing, as well as sexual intercourse (Corney et al., 1992). Other forms of cervical cancer treatment such as radiation and pelvic exenteration also affect the reproductive system.

For various reasons infertility is additionally devastating to cancer survivors, as it becomes an insult added to injury. The grief of confronting infertility as a side-

effect of cancer is profound for the patient whose self-concept may have already been altered by the experience of cancer (Hamilton, 2001). Thus, fertility and femininity are often central concerns to the woman with cervical cancer during reproductive years. The illness itself may lead patients to worry about being rejected by their partners. Those that do not have partners may be anxious about dating due to their sense of unattractiveness (Schover, 1999). Being fertile is associated with feeling sexual and feminine. Infertility may impede the survivor's ability to find a mate.

Although the pain of infertility in cervical cancer is taken to be related to childlessness, it could also apply to interrupted family building. A couple might be faced with the disappointment of not being able to have more children and they may worry about an only child growing up without siblings (Schover, 1999).

Young (in Bristow, 1997) suggests that for some women, the experience of pregnancy produces a sense of power, solidity, validity and self-respect in a society, which tends to trivialise women. She states that pregnant women often feel a form of satisfaction or self-love for their maternal bodies. Infertility thus tends to cause a great deal of distress for women of childbearing age who still hoped to have children.

A study done by Bergmark, Avall-Lundquist, Dickman, Henningsohn and Steineck (1999) indicated that some women who had undergone surgical removal, reported that they missed their uterus, and they also related that infertility had a strong effect on their sexuality. Some women actually view their uterus as a repository of strength and vitality. Infertility has been characterised as an isolating and lonely experience and individuals may grieve alone for fear that others will not understand (Hamilton, 2001). Grieving has also been associated with intense feelings of anger, frustration, anxiety, depression,

disappointment and despair.

Many women see the uterus, menstruation and fertility as fundamental to their femininity. For many women who have undergone surgical removal of the uterus, this might mean that they have lost an important part of their feminine identity. Consequently, it becomes difficult for them to enjoy sexual intercourse (Harvey, Mack & Woolfson, 1988). Some women may feel bereaved, worthless and unfeminine, as this includes various losses such as the loss of a desired child and loss of identity as a mother (Harvey et al., 1988).

Women with cervical cancer who have not yet borne children might be at odds with the societal expectation of being mothers and 'worthwhile' sexual partners. They experience the disjuncture between what they believe they ought to be, and the actual reality of an infertile womb (Waskul & van der Reit, 2002).

Infertility may leave some women dissatisfied with any sexual relationships. They become doubtful of their ability to achieve a satisfying intimate life with anyone, given their inability to have a 'family'. The patients who have sexual partners even mention that after surgery they wished they were single (Corney et al., 1992).

Apart from these effects, these women tend to feel alienated from friends who are starting families. Some patients actually indicate that they do not feel woman enough when they are with other women (Hamilton, 2001; Corney et al., 1992). In this regard, group therapy or making friends with other women who are struggling with infertility could be beneficial to women with cervical cancer at a childbearing age (Lesch, 2002).

Apart from the surgical removal of the uterus, radiation treatment itself has

negative effects on the unborn fetus. Women who have abdominal radiotherapy, are at risk for delivering prematurely or having low birthweight babies (Schover, 1999). Radiation can also result in fetal injury, primarily affecting the developing central nervous system (Shingleton & Orr, 1995). The risks to the baby could include mental retardation, visual deficits and bone malformations. Consequently, women with cervical cancer are obliged to consider termination of pregnancy.

Hence, even survivors who are able to conceive and bear children may worry that becoming pregnant will not only increase the risk of cancer recurrence, but will also expose them to the risk of pregnancy complications. They may also fear that past radiation will cause birth defects, although this may not actually be the case (Schover, 1999).

Patients are usually advised to wait two years after their treatment is over before attempting to conceive since most recurrences of cancer happen within this time period. Most women, however, get to believe that this advice signals a risk that getting pregnant could cause cancer recurrence, even though this is not the case (Schover, 1999).

Miscarriages experienced by patients are another major concern (Eisemann and Lalos, 1999). It has been indicated that high doses of radiation result in miscarriage and stillbirth (Shingleton & Orr, 1995). The knowledge that this is caused by the illness makes a woman feel that she might be responsible for the miscarriage. This leads not only to self-reproach, but also to guilt feelings. A woman can actually be accused by her family or held accountable for the miscarriage, even being called a murderer.

Fallowfield (1991) indicates that the fear of abandonment in cancer patients is not

mere paranoia. Some patients actually report that people avoid them, and there is lack of understanding from family and friends, leading to social isolation.

Women with cervical cancer have to consider alternative ways of having children. For instance, they could conceive by using assisted reproductive technology, like the use of donated gametes. They could also get a surrogate mother to carry a child, or even consider adoption (Schover, 1999). However, all these options often provoke painful and confusing emotions, as women want to conceive their own children and want to be biological mothers. Apart from the above mentioned issues, religious faiths such as Catholicism, Orthodox Judaism and Islam forbid using donor gametes, and this leaves the patients with more conflict about spiritual issues in choosing such options (Schover, 1999).

The women experience the most profound loss of the dream of having one's own genetic child. They point out that it is often difficult for them to grieve adequately or to get empathy from family or friends, because they have lost a potential rather than an actual child (although for them the loss is no less real) (Schover, 1999).

In some cases patients consider adopting a child. This, however, becomes a problem as well. Biological mothers in open adoption programmes where the adoptive family is chosen are concerned about a history of cancer. These mothers may fear that their babies will be orphaned at an early age. The concern about the safety of children can, however, result from lack of understanding about the illness, since some cancer patients actually recover and live long healthy lives. The growing concern about late health risks after cancer treatment may evoke discrimination against survivors who want to adopt (Schover, 1999).

The picture is, however, not entirely negative. For example, children who are born after cancer may be more valued by their parents (Schover, 1999).

Furthermore, confronting the stress of a life-threatening disease can tremendously impact on one's resilience in coping with the challenges of daily family life. Even though some families break up as a result of cancer, marriages that have survived the illness are often strengthened, with spouses gaining a new appreciation of each other (Schover, 1999).

Despite all the disadvantages that are brought about by radiation and the surgical removal of the uterus, studies have shown that some women actually benefit from this surgery. De Marquiegui and Huish (1999) found that a hysterectomy may provide younger women with an additional relief in eliminating the nagging fear of conception, heavy bleeding and pain, thus allowing a freer sexual life. Some women may also use their condition or illness as an excuse for denying sexual contact to their more sexually active partners. Amias (1975) asserts that for married women the illness can be seen as a convenient escape from the matrimonial obligation of bearing many children. Apart from that, hysterectomy can come as a relief, because it will have removed the threat of cancer.



## **7. Family Support and Psychosomatic Family Dynamics**

Family and social support are necessary for the individual to acquire personal resources, the motivation to enhance life, and promote her development. Social support is the number of social contacts maintained by a person, or the cohesiveness of a social network (Kaplan et al., 1993). Cobb also defines social support as the perceived belonging to a social network of communication, mutual obligation where one can rely on others, and to be cared for and loved (in Day, 1999). Hence, social support is present to the extent that people perceive themselves as belonging to a particular network.

Often patients face either isolation, or undesired increases in social contact at their homes. The support can be too much or too little, and therefore fail to meet the patients' needs. Patients may experience too little or incorrect support because the family tends to misconceive their needs and priorities (Tempelaar, De Haes, De Brutter, Bakker, Heuvel & van Nieuwenhuijsen, 1989). Crowding causes tensions and prevents people from experiencing needed states of privacy. Similarly, social isolation equally produces tension, and it is psychologically threatening (Proshansky, Nelson-Shulman & Kaminoff, 1979). Crowding or social isolation imposed on a patient could alter the meaning of home. The patient is then more likely to perceive the household setting as a prison.

It has been suggested that chronic illness such as cancer can cause modifications in the support environment, or family interactions. Disturbance in marital relationships tends to follow the diagnosis and treatment of the illness (Kaplan et al., 1993). The family may not know how to behave in the patient's presence, spouses may be overly concerned, or the family may shy away from emotional involvement with someone who may not be likely to survive. The patient thus becomes a victim (Tempelaar et al., 1989). The family may furthermore be faced with feelings of separation, particularly if their loved one is in hospital. The family is forced to alter its expectations of the patient, while they may also miss her.

Summers (1998) indicated that women with positive pap smears said their partners were very upset, and this perpetuated the guilt and distress that they already had. Bergmark and others (1999) also observed that women who had cervical cancer were often single, suggesting that some relationships end as a consequence of the illness. According to Corney et al., (1992) the sexual problems in patients' marriages resulted in marked difficulties. Some of the relationships had actually ended since the women went for treatment. Women (particularly

young ones) suggested that they would have liked their husbands to receive more information on how the illness affects sexuality, and how to deal with it. Marital separation faced by the patients involves not only the disruption of relationships, but also the termination of familiar patterns and routines of activity (both inside and outside the home). The experiences of a woman's identity are in one way or another disrupted (Proshansky et al., 1979). The symbolic meaning of a home as a place of refuge and intimacy also changes drastically when one partner leaves. The home may come to represent loneliness, loss, emptiness and failure. This kind of environment can result in emotional loss, which in turn perpetuates the illness (Proshansky et al., 1979). Physical separation represents the most painful aspect of divorce and produces severe cognitive behavioural disturbances, which include depression, anxiety or substance abuse.



According to systems theory, some families tend to be open while others are closed. Those that are open tend to be characterised by a willingness to examine ideas, to test different options, to integrate new knowledge and to be receptive of new experiences (Becvar & Becvar, 2000). These families use resources, develop supportive networks and welcome outsiders who could provide support to the patient and the family. Warmth, caring and kindness are usually evident in these families. They are able to express feelings of grief, yet also maintain a sense of hopefulness. Emotional energy is directed toward maintaining acceptance, nurturance, dealing realistically with anxiety and relieving guilt (Fersst & Houck, 1986).

By contrast, families whose systems are more closed tend to block out or distort information from the environment in an effort not to compromise their sense of balance (Fersst & Houck, 1986). They are more reluctant to acknowledge new facts, are less open to strangers and are more resistant to change. Being less

flexible, such a system finds it more difficult to provide physical care and emotional support to the patient (Fersst & Houck, 1986). It becomes hard to accept help and support from someone outside the family and to adapt to changes precipitated by the illness. Sometimes family members flee, forfeiting their responsibility to the health care team.

According to Day (1999), families with a chronically ill patient are structurally like psychosomatic families. These families, according to Meissner (in Day, 1999), tend to be rigid and repressive. The patient may be infantilised, and the patient's symptoms become an externalisation of the pathology inherent in the family system. The family gets to be characterised by weak ego boundaries between members, over-protectiveness, rigidity of roles and rules, as well as a lack of conflict resolution.

Hudgens (in Day, 1999) also observed that the patient with chronic pain becomes dependent on the spouse or significant other. Communication between the family members also becomes indirect, social contacts are narrowed, and family members show an inability to handle anger effectively. Psychosomatic families furthermore are characterised by an absence of overt conflict. However, they tend to show a lack of closeness, intimacy and communication about personal matters.

Family members may deny their emotions concerning the illness, and therefore fail to utilise effective coping mechanisms. They may avoid their feelings by concentrating on unrealistic future plans, or they may be so overwhelmed by their own shock that they become unable to lend emotional support to one another (Fulton, 1979). As a result they may lack resources to adequately support the patient.

According to Fulton (1979), in Christian society there are psychological barriers to frankness in facing cancer and death. Fulton argues that the conspiracy of silence is still the accepted way of facing both cancer and death. Hence, the family members get to know that their loved one is dying, but by custom may not discuss it among themselves, or even with the patient.

Looking at all these challenges facing the patients and their respective families, it is evident that there is a need for supportive care and psychosocial intervention.

The discussion has been oriented at depicting the intricate relationship between different factors that affect patients with cervical cancer. See figure 1 below: patient fears and concerns about cervical cancer and its treatment, modified from Shingleton and Orr (1995).



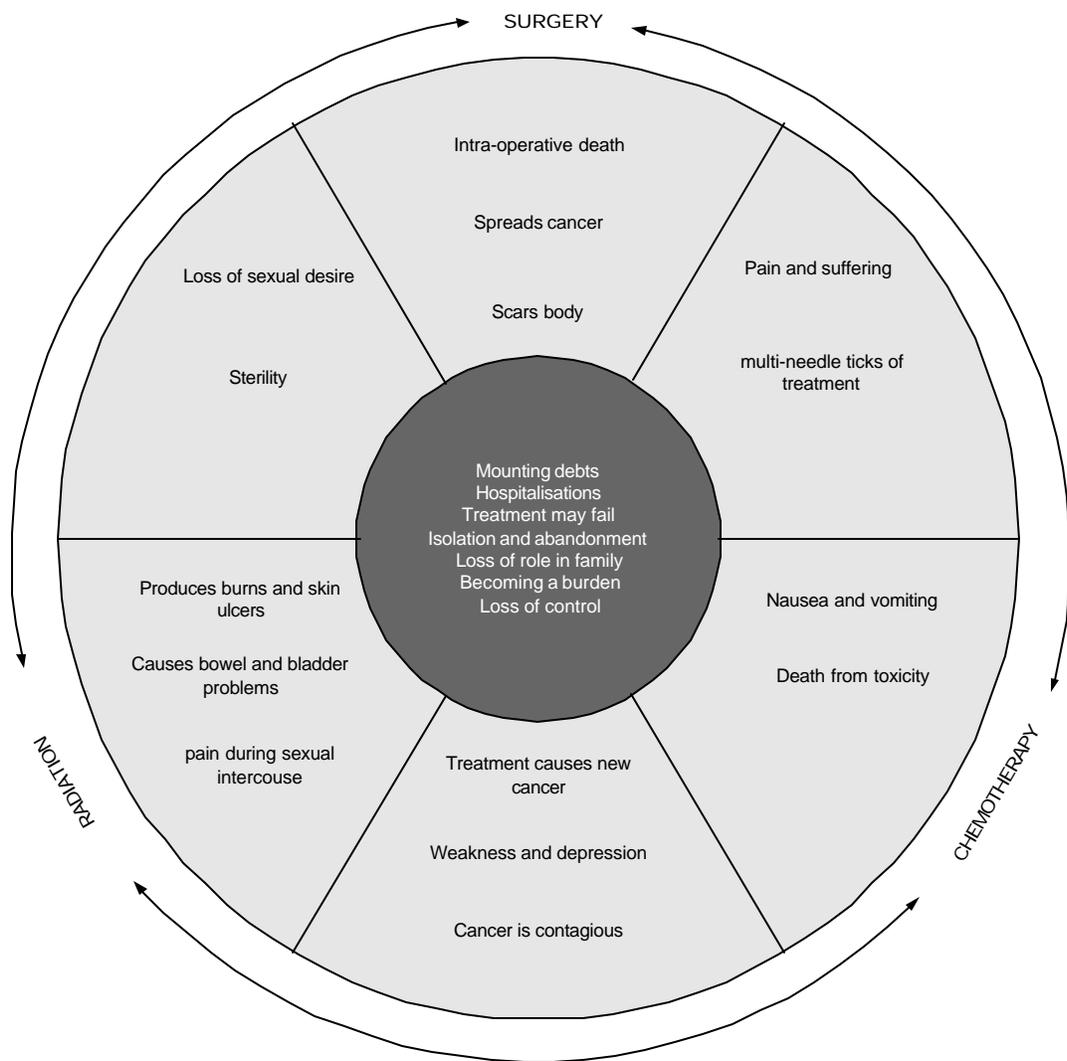


Figure 1:

## 8. Intervention

Psychological factors (such as poor family support, anxiety and depression), as well as physiological dysfunctions, suggest the necessity for an integrated psychosocial and medical intervention helping women to cope with cervical

cancer (Fallowfield, 1991). Issues relating to the sense of self can also be dealt with through psychological interventions.

The main objective of psychosocial intervention with cervical cancer patients is to enable the patient to function physically, socially and emotionally at the highest level possible, despite the constraints of the treatment and the illness itself (Wellisch & Surdam, 1995).

Patients should be able to know and understand the real facts about the illness they are suffering from. Research has shown that patients with chronic illnesses such as cancer complain about lack of information concerning their condition. In many cases the medical team fails to provide sufficient information about the reality of the illness. They either get scared to tell the patients the truth about an unfavourable prognosis, or they focus only on the undesirable side of cancer (Fallowfield, 1991). However, it has been shown that explanation and reassurance are fundamental in the management of cancer.



Therapeutic interventions such as cognitive-behaviour therapy can be of great help. The patient's idiosyncratic thinking can be challenged in order to alleviate depression and anxiety. Relaxation training and cognitive stress coping techniques can also be beneficial.

Family therapy and sex therapy are also of great importance. The former intervention can assist the patient's family in developing better mutual support (Wellisch & Surdam, 1995). The aim is to create the environment that will enhance the patient's effective coping. The latter intervention simply sheds some light on other effective ways of enhancing altered sexual functioning.

Even though intervention outcomes depend on the stage of the disease, the patient's emotional strength and the treatment that a patient may be undergoing, it has been shown that women benefit from psychosocial intervention. For instance, patients' self-image is enhanced and there is less sexual dysfunction (Fallowfield, 1991).

## **9. Conclusion**

This discussion has presented a survey of the collective effects of cervical cancer on patients. It is evident that the sufferer is challenged in various devastating ways. The relationships of these challenges complicate the efforts a patient may make towards leading a normal life. The pain, disruption of biological aspects of sexual functioning and coping with stigma are considered key problems for cervical cancer patients. Another important aspect is the feeling of worthlessness due to damaged femininity caused by the illness. The biological aspects may seriously affect women's view of themselves, how they think society views them and thereby affect their social interactions.

It is also evident that an understanding of the effect of these challenges by all parties involved – namely, the patient, the family and society – would go a long way towards eliminating some of the painful experiences that patients undergo.

Some of these issues may be prevented by psychosocial interventions such as providing enough relevant information. The ideal case would be for such education to take place before there is even the threat of such a diagnosis. This would help the newly diagnosed patient to approach the shocking news without any of the misconceptions that underlie so much trauma. It should thus be apparent that the medical interventions for physical management of cancer are only the first steps in the restoration of the patient's good health.

Patients need to be provided adequate relevant information in a non-threatening manner. They need to know the reality and the facts of the disease they are suffering from. The information may assist the patients and their families to understand what to anticipate and thereby consider various ways of coping effectively.

The interplay of the internal and external factors within which cervical cancer takes place, indicates that it is very difficult for an individual to manage the challenges in such way that complete recovery is achieved. This in turn informs the threat of the illness. However, like those with other life-threatening illnesses, patients who survive cervical cancer may reorder their life priorities and experience psychological benefits, including greater appreciation of some aspects of their lives.



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