LIVING WITH FACIAL DISFIGUREMENT: A PHENOMENOLOGICAL
STUDY OF INDIVIDUALS AFTER RADICAL SURGERY
FOR HEAD AND NECK CANCER

by

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We accept this thesis as conforming
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ABSTRACT

Head and neck cancer comprises four percent of all cancers. Clearly, individuals diagnosed with this type of cancer must cope not only with the diagnosis of cancer and the related fears, but also with the apprehension associated with the acquired facial disfigurement and related functional impairment resulting from the radical surgical treatment.

A review of the literature revealed that nursing research which focusses on understanding people’s perceptions and experiences with facial disfigurement after having had radical surgery for head and neck cancer is nonexistent. The impact of this type of cancer and its social implications must be far-reaching considering the emphasis placed on appearance, particularly by people in North American society. This study addressed the need for an increased understanding of the lived experiences of individuals with this type of acquired facial disfigurement.

The purpose of this phenomenological study was to explore and describe the perspectives and experiences of people living with facial disfigurement following surgery for head and neck cancer. In addition, the study examined and described the meaning of the disfigurement for these individuals and the impact of their altered facial appearance on their interpersonal relationships and functional abilities.
Four men and four women volunteers were selected as participants for the study from among patients being seen at the British Columbia Cancer Agency. Data collection and analysis occurred concurrently by means of indepth interviews, guided by open-ended questions. Field notes and the audio-taped interviews, which were transcribed verbatim, yielded the data for analyses.

Two principal themes constitute the research findings: loss and stigma. All of the participants experienced numerous, compound losses as a result of radical head and neck surgery. During the immediate postoperative period, the losses were primarily functional, but as recovery proceeded, the losses became more social in nature. The second theme, stigma, which is an attribute considered by others as discrediting, was experienced by the participants throughout the entire recovery period. Stigma protracted the illness experience and multiplied the losses, particularly social losses. In order to cope with their situations, the participants developed several coping strategies to deal with the losses and stigma associated with cancer and facial disfigurement.

The findings are discussed in conjunction with relevant literature. Implications for nursing practice and education are identified. Recommendations are made for future research based on this study.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td>ii</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>iv</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>vii</td>
</tr>
<tr>
<td>CHAPTER ONE: INTRODUCTION TO THE STUDY</td>
<td>1</td>
</tr>
<tr>
<td>Background to the Problem</td>
<td>1</td>
</tr>
<tr>
<td>Conceptualization of the Problem</td>
<td>4</td>
</tr>
<tr>
<td>Problem Statement</td>
<td>8</td>
</tr>
<tr>
<td>Purpose of the Study</td>
<td>8</td>
</tr>
<tr>
<td>Research Question</td>
<td>8</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>9</td>
</tr>
<tr>
<td>Assumptions</td>
<td>10</td>
</tr>
<tr>
<td>Limitations</td>
<td>10</td>
</tr>
<tr>
<td>Significance of the Study</td>
<td>10</td>
</tr>
<tr>
<td>CHAPTER TWO: LITERATURE REVIEW</td>
<td>12</td>
</tr>
<tr>
<td>Introduction</td>
<td>12</td>
</tr>
<tr>
<td>Impact of Cancer on Social Relationships</td>
<td>12</td>
</tr>
<tr>
<td>Facial Disfigurement and Social Reaction</td>
<td>17</td>
</tr>
<tr>
<td>Facial Disfigurement and Functional Impairment as a Result of Cancer</td>
<td>22</td>
</tr>
<tr>
<td>Summary</td>
<td>28</td>
</tr>
<tr>
<td>CHAPTER THREE: METHODOLOGY</td>
<td>30</td>
</tr>
<tr>
<td>Introduction</td>
<td>30</td>
</tr>
<tr>
<td>Overview of Phenomenology</td>
<td>30</td>
</tr>
<tr>
<td>Selection of Participants</td>
<td>31</td>
</tr>
<tr>
<td>Criteria and Rationale for Selection</td>
<td>32</td>
</tr>
<tr>
<td>Data Collection and Analysis</td>
<td>34</td>
</tr>
<tr>
<td>Recruitment</td>
<td>34</td>
</tr>
<tr>
<td>Data Collection</td>
<td>35</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>36</td>
</tr>
<tr>
<td>Means of Establishing Reliability and Validity</td>
<td>37</td>
</tr>
<tr>
<td>Ethical Considerations</td>
<td>39</td>
</tr>
</tbody>
</table>
# TABLE OF CONTENTS, Continued:

CHAPTER FOUR: FINDINGS AND INTERPRETATION .......................... 41
  Introduction ........................................................................... 41
  Characteristics of Participants .............................................. 41
  The Central Themes .............................................................. 45
    Loss .................................................................................. 45
    Stigma ............................................................................... 48
  Four Recovery Phases ......................................................... 52
  Losses and Their Management .............................................. 56
    Phase I: Initial Postoperative Period ................................. 57
      Eating ............................................................................. 58
      Communicating ............................................................... 60
      Body image .................................................................... 61
      Anatomical parts ............................................................ 63
      Social support ............................................................... 64
    Phase II: Initial Contact with Public .................................. 65
      Independence ................................................................. 65
      Eating ............................................................................. 68
      Facial appearance ......................................................... 69
      Certainty ......................................................................... 70
      Social support .................................................................. 72
    Phase III: Re-emergence into Society .................................. 72
      Functional abilities ....................................................... 73
      Optimism .......................................................................... 75
      Social support ............................................................... 77
    Phase IV: Living with Facial Disfigurement .......................... 77
      Social support ............................................................... 80
  The Impact of Stigma ........................................................... 80
    Phase I: Initial Postoperative Period .................................... 80
      Family reactions ............................................................ 80
      Public reactions ............................................................. 83
    Phase II: Initial Contact with Public ................................... 87
      Relationships with significant others ............................... 88
      Communication with significant others ............................ 92
      Altered facial appearance .............................................. 94
      Economic losses ............................................................ 95
TABLE OF CONTENTS, Continued:

<table>
<thead>
<tr>
<th>Phase III: Re-emergence into Society</th>
<th>96</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-confidence</td>
<td>97</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>98</td>
</tr>
<tr>
<td>Comfort with public</td>
<td>100</td>
</tr>
<tr>
<td>Concealing altered facial appearance</td>
<td>103</td>
</tr>
<tr>
<td>Financial support</td>
<td>106</td>
</tr>
<tr>
<td>Phase IV: Living with Facial Disfigurement</td>
<td>108</td>
</tr>
<tr>
<td>Sexuality</td>
<td>110</td>
</tr>
<tr>
<td>Public reaction</td>
<td>112</td>
</tr>
<tr>
<td>Adjustment over time</td>
<td>114</td>
</tr>
<tr>
<td>Summing Up</td>
<td>117</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CHAPTER FIVE: SUMMARY, CONCLUSIONS, AND IMPLICATIONS</th>
<th>121</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary</td>
<td>121</td>
</tr>
<tr>
<td>Conclusions</td>
<td>127</td>
</tr>
<tr>
<td>Implications</td>
<td>128</td>
</tr>
<tr>
<td>Nursing Practice and Education</td>
<td>128</td>
</tr>
<tr>
<td>Nursing Research</td>
<td>132</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>APPENDIX A: INFORMATION AND CONSENT FORM</th>
<th>145</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>APPENDIX B: TRIGGER QUESTIONS WITH ACCOMPANYING EXPLANATORY APPENDIX</th>
<th>148</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>APPENDIX C: DEMOGRAPHIC DATA SHEET</th>
<th>152</th>
</tr>
</thead>
</table>
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CHAPTER ONE: INTRODUCTION TO THE STUDY

Background to the Problem

Head and neck cancer comprises four percent of all cancers (National Cancer Institute of Canada, 1991). However, excision of this particular neoplasm often leaves the individual with severe facial disfigurement. "The term head and neck cancer refers to a malignancy which lies above the clavicle, but excludes the brain, spinal cord, axial skeleton, and vertebrae" (Dropkin, 1981, p. 103). "The diagnosis and treatment of these conditions exerts a major physiological and psychological influence on patients" (Krouse, Krouse, & Fabian, 1989, p. 789).

The diagnosis of cancer constitutes a severe as well as an acute threat to one's physical and emotional resources (Dropkin, 1989; Koster & Bergsma, 1990; Krouse & Krouse, 1982). Individuals diagnosed with cancer often experience feelings of helplessness, anxiety, fear, loss, and depression (Goldberg & Tull, 1983; Koster & Bergsma, 1990; Krouse & Krouse, 1982). Clearly, individuals with head and neck cancer not only have to cope with the diagnosis of cancer, and fears related to this diagnosis, but they must also cope with the apprehension associated with disfigurement and related functional impairment.

Surgical intervention for head and neck cancer is often radical, and involves removal of bony and soft tissue from the face and neck. The
surgical intervention frequently leaves the individual with a permanently altered facial contour and impaired sensorimotor function (Freelander, Espie, Campsie, Soutar, & Robertson, 1989; Koster & Bergsma, 1990). The ensuing disfigurement, depending on the extent of the surgery, may leave the individual with a number of physical impairments. These may include: speech and articulation abnormalities, weakness in facial movement and shoulder strength, dysphagia which leads to a decreased oral intake and weight loss, change in respiration, pain, and a decrease in the ability to taste and to smell (Krouse, Krouse, & Fabian, 1989; Strauss, 1989; Larsen, 1982).

The individual who has experienced disfigurement as a result of surgery for head and neck cancer often encounters psychological and social difficulties as well. These are varied but may include: depression, alterations in self-concept such as, decreased self-esteem and modified body image, problems with sexuality, difficulty coping with the chronic disease of cancer, decreased social interaction on a formal and informal basis, and economic difficulties (Koster & Bergsma, 1990; Krouse, Krouse, & Fabian, 1989; Shapiro & Kornfield, 1987; Strauss, 1989; West, 1977).

Most of the literature concerning individuals with head and neck cancer focuses on surgical intervention and radiation treatment of the neoplasms (Barbier, Luder, Schupfer, Becker, & Wagner, 1988; Burns,
Chase, & Goodwin, 1987; Flores, 1989; Flores, Nelems, Evans, Hay, Stoller, & Jackson, 1989), psychiatric problems such as anxiety, depression, and alcoholism (Davies, Davies, & Delpo, 1986; Harris, Vogtsberger, & Mattox, 1985; Shapiro and Kornfield, 1987), and identification of functional and psychosocial problems as a result of the surgery and disfigurement (Dhillon, Palmer, Pittam, & Shaw, 1982; Dropkin, 1990; Dropkin, Malgady, Scott, Oberst, & Strong, 1983; Krouse et al., 1989; Strauss, 1989; West, 1977). However, none of these researchers has adequately explored the meaning of this experience for these individuals.

Strauss (1989), an oral surgeon, completed a descriptive study utilizing a sociological participant-observation approach to identify psychosocial issues pertinent to this population of patients. Strauss (1989) makes specific recommendations for oral and maxillofacial surgeons to improve patients' psychosocial adaptation to treatment. These recommendations are as follows: be aware that the surgeon's ability to be helpful may be hindered by popular images of surgeons as omnipotent and infallible; do not blame patients for delay in seeking diagnosis and treatment; frankly discuss expected disabilities to reduce postoperative reactions to them; and provide truthful and realistic appraisals of the prospects for controlling the disease. Although many of these recommendations could be partially utilized by nurses, the concerns of
nursing are different than those of medicine. It is crucial that nurses develop a thorough knowledge and understanding of the meaning of this onerous event so that they can support and assist these individuals and their families in acquiring coping strategies for dealing with this type of cancer and its treatment and the numerous inherent social ramifications.

There is no nursing research which focusses on people's perceptions and experiences with facial disfigurement after surgery for cancer of the head and neck. The resultant disfigurement must profoundly affect the individual's social relationships, feelings, and perceptions of self and others, particularly in a society in which physical attractiveness is often passionately pursued. In fact, physically attractive individuals are often thought to be more socially desirable by our society (McKelore & Matthews, 1976). It is important that nursing research be completed in this realm, so that nurses can understand the essence of the patients' perspectives and experiences associated with the facial disfigurement. Research in this area will assist nurses in becoming more knowledgeable in identifying and assessing problems, providing support, and planning interventions with these individuals and their families.

**Conceptualization of the Problem**

The phenomenological method requires the researcher to approach the phenomenon with an unbiased viewpoint. This will assist the researcher...
in perceiving the phenomenon as it is truly experienced by individuals. The goal of phenomenology is not to validate a preselected theoretical framework; rather, it is to describe human experience as it appears (Sandelowski, 1986). The research question, however, is developed to focus upon a particular aspect of the experience, such as the impact of the surgical treatment of head and neck cancer on individuals' social relationships, psychological well-being, and functional abilities.

The literature regarding facial disfigurement in general revealed that individuals who are perceived as having a facial disfigurement were considered by others to be less attractive, less socially adequate, and less honest (Bull, 1982; Bull & David, 1986). Research has also indicated that people are less friendly to, and maintain considerably greater social distance from, individuals with facial disfigurement (Rumsey, Bull, & Gahagan, 1982). Studies have also established that people react to their own facial disfigurement with autonomic arousal and that women react with more negative emotions than men (Kleck & Strenta, 1985). Curley, Walsh, and Triplett (1982) found that individuals with facial disfigurement were less frequently employed, had lower incomes, and a lower level of education. These factors have grave ramifications for individuals trying to establish themselves in society after radical surgery for head and neck cancer. Not only must these individuals struggle with the stigmatizing
effects of cancer but they must also contend with a society which devalues individuals with a facial disfigurement.

The literature concerning facial disfigurement in individuals with head and neck cancer revealed that these individuals frequently experience functional difficulties (for example, loss of speech and difficulty swallowing) as a result of the disfigurement. People affected in this way were reported to express concerns regarding these difficulties and their alteration in appearance (Freelander, Espie, Campsie, Soutar, & Robertson, 1989). Dhillon, Palmer, Pittman and Shaw (1982) discovered that individuals who underwent a laryngectomy or commando procedure altered their social interaction and they frequently became socially isolated. It was also noted by these researchers that these individuals often experienced feelings of depression.

Other factors may play a major role in the individual’s psychological and social adaptation to the surgical eradication of head and neck cancer. One such factor, which to this author’s knowledge has not been explored, is the time since surgery. It is not known whether the length of time since surgery influences the individual’s coping. A second factor which may affect the individual’s adaptation is the age and developmental stage of the individual at the time of surgery. The impact and coping strategies utilized by a 25-year-old individual may be very different from those used
by the 75-year-old person. Gender may also affect the individual's perception of the experience. Finally, the availability and use of prosthetics for functional changes and/or enhancement of appearance may also modify the individual's perceptions of experiences pertaining to this life event.

After reviewing the literature and conceptualizing the problem, this author has identified that individuals with facial disfigurement as a result of surgery for head and neck cancer must adapt physically as well as psychosocially to their disfigurement. Social interaction and possibly social support from significant others may be modified because of the disfigurement and the disease process. It has been found that social supports not only benefit the individual's mental health, but they also have a stress buffering effect which is important in coping with life events (Cassel, 1976; Cobb, 1976; Hammer, 1983; Lynam, 1985, Syrotuik & D'Arcy, 1984). Lynam (1990) also states that social support is acquired through interactions with others and different events require different types of support. Individuals with facial disfigurement as a result of surgery for head and neck cancer may experience a change in the social support they need from significant others. Thus, acceptance of the disfigurement by the individual may also be dependent upon the reaction of the individual's family and friends and their acceptance of the disfigured individual.
Finally, it has also been found that social relationships can be a source of stress (Lynam, 1990). It is the researcher's intent to explore these issues in detail with the participants in the study to obtain the essence of the individuals' life experiences and their perceptions of living with a facial disfigurement.

**Problem Statement**

The prevailing problem to be addressed by this study is the lack of nursing literature and knowledge about the experiences and perceptions of individuals with a facial disfigurement resulting from radical surgery for cancer of the head and neck.

**Purpose of the Study**

The purpose of this phenomenological study is to explore and describe the perspectives and experiences of people living with facial disfigurement following surgery for head and neck cancer, to gain an understanding of the meaning of the disfigurement for these individuals, and to examine and describe the impact of the disfigurement on their social relationships and functional abilities.

**Research Question**

This research will explore, from the perspective of those who have undergone radical surgery for cancer of the head and neck, the meaning
of facial disfigurement and its impact on the individual’s social relationships and functional abilities.

**Definition of Terms**

**Head and Neck Cancer:** A neoplasm in the area that lies above the clavicle but excludes the brain, spinal cord, axial skeleton, and the vertebrae.

**Facial Disfigurement:** An alteration in the normal facial contour as a result of scarring and removal of soft and bony tissue during radical surgery for cancer of the head and neck.

**Radical Surgery:** Surgical excision of a cancerous lesion leaving the individual with an alteration in the normal facial contour.

**Meaning of Facial Disfigurement:** The perceptions and experiences of individuals who have experienced facial disfigurement as a result of radical surgical treatment of head and neck cancer.

**Functional Abilities:** The skills utilized by individuals to perform activities of daily living and instrumental activities of daily living; for example, the
ability to masticate and swallow food and the ability to obtain food.

**Assumptions**

For the purpose of this study, this researcher assumes that facial disfigurement, as a result of surgery for cancer of the head and neck, has an impact on the lives of individuals. This researcher also assumes that these people will be willing to discuss their life experiences candidly and sincerely.

**Limitations**

This study is limited to individuals in the Vancouver and Lower Mainland areas. The participants in the study are volunteers who are fluent in English. Participants were contacted through the British Columbia Cancer Agency. Therefore, these individuals represent a unique subgroup in the Vancouver and Lower Mainland areas. Participants who consented to volunteer in this research may represent only a limited number of people who have had disfiguring surgery for cancer of the head and neck.

**Significance of the Study**

This phenomenological study will provide the profession of nursing with insight into the perspectives of individuals with facial disfigurement after radical surgical treatment for cancer of the head and neck. Very little nursing research has been conducted in this area. A phenomenological
study will provide the foundation for further nursing research by revealing
areas of concern for these individuals. The study will augment nurses'
knowledge regarding nursing care for persons with facial disfigurement as
a result of surgery for head and neck cancer. It is hoped that the research
will also aid nurses in identifying and assessing problems, providing
support for, and planning interventions with these individuals. Finally, this
research may encourage other nurses to pursue further study in this area.
This and subsequent research will expand the theoretical body of nursing
knowledge which will ultimately increase the quality of nursing care.
CHAPTER TWO: LITERATURE REVIEW

Introduction

This chapter reviews the relevant literature about individuals who live with facial disfigurement and functional impairments as a result of surgery for head and neck cancer. The chapter is organized into three sections: 1) studies related to the impact of a cancer diagnosis on the individual's social relationships; 2) an overview of studies related to facial disfigurement and societal reaction; 3) a synopsis of research regarding facial disfigurement and functional impairments of individuals who have had surgery for head and neck cancer, and a summary of the literature review.

Impact of Cancer on Social Relationships

Individuals diagnosed with cancer are likely to become extremely anxious and uncertain about their futures. Many people who discover they have the disease feel that they need to clarify the meaning of their behavioural and emotional responses. This gives them an indication whether their reactions are normal and within acceptable societal limits (Dunkel-Schetter & Wortmann, 1982). Understandably, people with cancer commonly experience the need for additional emotional support from family, friends, and health care professionals. Nevertheless, they frequently encounter physical avoidance from others, evasion of open
communication, and contradictory and inconsistent behaviours from the public. Often the individuals interpret these ambiguous reactions as rejection. It is a very difficult period for them because it is often at this point in time when communication and support are of the utmost importance (Dunkel-Schetter & Wortmann, 1982).

Sontag’s (1978) essay “Illness as Metaphor,” outlines society’s view of cancer and how this view shapes responses to those who have cancer. She compares cancer to tuberculosis (TB) which, throughout history, has been considered a romantic and mysterious disease of the weak and artistic type of person. Sontag (1978) argues that society has developed many myths regarding TB and cancer. Among these are: TB makes the body transparent; the symptoms of TB are very visible, for example, there is progressive emaciation, coughing, languidness and fever; and TB is a disease which produces euphoria and increases appetite and exacerbates sexual desire. Cancer, on the other hand, was, and still is, viewed as silent and invisible until the final stages when it is too late and death becomes imminent. Cancer is also believed to cripple the spirit, deaden passion, and make eating and living an ordeal. Kleinman (1988) maintains that many people, even health care providers, still believe the myth that cancer is contagious. This is a major cause of avoidance and rejection of the individual with cancer.
Sontag (1978) asserts that these perpetuated myths shape society's views about illness and influence the individual's reaction to illness events such as cancer. She also argues that these outdated myths affect the treatment of the disease and the dialectic used to describe the disease and its progress. For example, cancer cells do not simply grow and multiply, they invade; cancer cells colonize from the original tumour site to outposts in the host; and the body's defenses are rarely adequate to obliterate the destructive cells. Chemotherapy treatment is like a chemical warfare against the invading cancer cells. Treatment is aimed at killing the cancerous cells and the side effects of treatment are frequently publicized as very unpleasant and something to be feared as well, giving the impression that if cancer doesn't kill you, the treatment likely will (Sontag, 1978).

In addition, Sontag (1978) concludes that the language about cancer must change. Sontag (1978) believes that it has already started to change as we become more knowledgeable about the disease and its rate of cure becomes much higher. Sontag (1978) states that, "It may then be possible to compare something to a cancer without implying either a fatalistic diagnosis or a rousing call to fight, by any means whatever, a lethal, insidious enemy" (p. 87).
Finally, Sontag's (1978) composition implies that individuals with cancer may subsequently adopt and incorporate others' images of cancer as well as dealing with their own view of their illness. As a result, they may experience isolation from family, friends, and acquaintances. The images described above must shape the process described by O'Connor, Wicker, and Germino (1990) who interviewed 30 people about their search for a meaning for cancer. These nurses found six major themes which provide an initial understanding of what is involved in the individual's search for meaning. The themes are as follows: 1) Seeking an understanding of the personal significance of the cancer diagnosis. This includes the frequently asked question, "Why me?" and the acknowledgement that it is cancer; 2) Looking at the consequences of the cancer diagnosis. This includes uncertainty about the future and the possibility of death; 3) Review of life. This includes looking back on life and reviewing achievements and events; 4) Change in outlook toward self, life and others. This includes focusing on relationships with others and a change in attitude toward life as a result of the cancer; 5) Living with cancer. This includes utilizing inner resources and drawing support from others; 6) Hope. The sources of hope for these individuals were spiritual beliefs, cancer treatment, caregivers, expectation of positive outcomes, and relationships with significant others. O'Connor et al. (1990)
state that "Social support, evident in the subjects’ descriptions of the significance of personal relationships with others, was considered for this study to be information, actions, and behaviours expressed as a positive effect of care and love in an ongoing reciprocal relationship" (p. 173). These researchers found that the participants described the closeness of family and friends and the need to reciprocate that love and care in some way.

Lynam (1990) studied twelve young adults diagnosed with lymphoma or sarcoma. The focus of this qualitative study was on social relationships which were perceived as supportive and the context within which such interactions occurred. Lynam (1990) includes many poignant excerpts from the interviews in her article. One example is an excerpt from a woman whose greatest fear was that she would no longer be able to maintain the relationships that she valued the most. This woman perceived that the support which she derived from her relationships with significant others enabled her to cope more effectively with her illness. It was also noted that social support can have a stress buffering effect when dealing with all life events, including the diagnosis of an illness (Cassel, 1976; Cobb, 1976; Hammer, 1983; Lynam, 1985).

Lynam (1990) found that cancer is an event that threatens both the individual’s identity and social relationships. Support from others was
found to control the extent to which the individual’s identity is threatened. Furthermore, all the participants in the study identified themselves by their feelings derived from their social roles and relationships. Lynam (1990) maintains that, "The focus of supportive interactions were interactions that assisted the individuals to redefine their views of themselves so they could see themselves as managing" (p. 178).

Lynam (1990) also discusses the importance of others seeing the individual with cancer as a whole person with other dimensions in life rather than continuously focussing on the illness. The study also revealed the importance of a shared understanding of the individual’s feelings about the illness event.

Finally, it is evident from the literature on facial disfigurement and cancer that both play a role in altering interpersonal relationships for those afflicted. It is possible that their suffering may be prolonged by the reactions of others after their surgery. These reactions may be related to negative perceptions of cancer, facial disfigurement, and the resultant functional impairments.

**Facial Disfigurement and Social Reaction**

"American society has been described as a society oriented toward a very narrow standard of beauty" (Hill-Beuf & Porter, 1984, p. 294). Physical attractiveness is initially evaluated by characteristics of the face
and head (Rumsey, Bull, & Gahagan, 1982). The face is also utilized for communicating, both verbally and nonverbally, to others. Studies indicate that attractive people of both sexes are perceived to be kinder and more intelligent than others (Dion, 1972), are liked more (Byrne, London, & Reeves, 1968), and are perceived as having better prospects for professional and social lives (Benson, Karabenick, & Lerner, 1976). "Of all the physical handicaps, none is more socially devastating than facial deformity" (Lefebvre & Barclay, 1982, p. 579).

A study completed by Rumsey, Bull, and Gahagan (1982) examined the effect of facial disfigurement on the proxemic behaviour of the general public. These researchers measured the distance between pedestrians and a person with a birthmark below the right eye, a person with a temporary scar below the right eye, and a person with no disfigurement. The same person was used in all three situations and make-up was applied by a professional make-up artist to simulate the facial disfigurement. The results of the study revealed that the subjects (pedestrians) stood further away from the person with the disfigurement. It was also noted that, if possible, the subjects stood on the side where there was no disfigurement. There were also differences noted between the person with the temporary scar and the person with the permanent birthmark. Subjects stood closer (22cms) to the person perceived to have the temporary scar. This research
confirmed the hypothesis that members of the general public avoid facially disfigured people by increasing their personal space zones. Rumsey et al. (1982) conclude that, "the results of the study seem to support the idea that the feelings of rejection and isolation that many disfigured people complain of may be well founded and are not necessarily a result of the disfigured people themselves (p. 146).

Bull and Stevens (1981) studied the effect of facial disfigurement on individuals' willingness to donate money to a charity. In this study, a researcher posed as a canvasser collecting money for a charity. Make-up was used to simulate a one-inch birthmark on the canvasser's face. The canvasser then canvassed half the homes with this simulated birthmark and the other half of the homes without it. It was found that people would not put money into the donation tin as often when the woman was facially scarred, and those that did donate to the woman with the birthmark gave less on average.

Bull and David (1986) investigated the effect of a facial scar on the stereotyping of both Negro and Caucasian faces by Nigerian Negro and English Caucasian nurses and office workers. The researchers also wanted to see if the occupation (helping versus nonhelping) influenced the extent and direction (positive versus negative) of the stereotyping. The results indicated that, regardless of occupation, in both Nigeria and England, the
women rated faces that had a minor scar as less sociable, less attractive, and more dishonest than did women who saw the same stimulus face with no scar. This research also implies that the stigmatizing effects of a facial disfigurement occur within different cultures and races.

Kleck and Strenta (1985) set out to determine the extent to which young adult males and females are disturbed by defects in their own and in other persons' facial appearance and the participants' perceptions regarding the social consequences of the defect. These researchers examined the differences in males and females and their autonomic and emotional responses to facial scarring. The participants viewed facial images of themselves; one image was "normal" and a second image had been manipulated to give the appearance of a facial scar. The subjects were also shown, in a stimulus sequence, images that were both facially normal and facially scarred. The autonomic responses, as measured by the Galvanic skin resistance test, of both the male and female participants were equal. Males and females were significantly more autonomically aroused when viewing facially disfigured images as compared to normal facial images. However, the emotional responses of the females and males differed when they viewed their own facially scarred faces, in that women chose more negative labels such as disgust, distress and fright. Males responded in a more humorous way saying that they found it "silly."
Most participants felt that their less intimate relationships would be disrupted and that, when conversing with others, the nonverbal behaviours of others would be altered. The results of this study demonstrate that young adult males and females expect facial disfigurement to have important consequences for social interaction and also indicate that there may be a change in the social relationships of individuals with facial disfigurement.

Curley, Walsh, and Triplett (1982) compared Vietnam veterans who had either maxillofacial wounds, an amputated limb, or no wounds, on several measures. Data were gathered with questionnaires which sought economic, social, marital, service, and attitudinal data. The results of the study indicated that members of the group with the maxillofacial wounds were significantly less often fully employed than members of the noninjured group. Of the three groups, the maxillofacial group had the lowest income, the lowest number of college degrees, and an 11% higher incidence of being in trouble with the authorities (narcotic and alcohol abuse, misdemeanors, and felonies).

Finally, Knudson-Cooper (1981) studied individuals with facial burns and their psychosocial adaptations. This researcher found that people with even severe facial disfigurement were not socially isolated. There was no significant relationship between low self-esteem (measured by the
Coopersmith self-esteem inventory and burns related supplement) and the cosmetic impact. However, several individuals found that the disfigurement was a problem because they felt restricted to wearing clothes that covered their scars. This indicates that individuals’ self-concept was affected. The major concern of the individuals in this study was their ability to adapt to the way other people reacted to them, particularly staring, asking questions, and avoidance behaviour.

**Facial Disfigurement and Functional Impairment as a Result of Cancer**

West (1977), a physician, studied the social adaptation patterns of cancer patients with facial disfigurements resulting from surgery. One hundred and fifty-two patients were interviewed at two head and neck clinics in Buffalo. As a result of her study, West (1977) concluded that 86% had adapted to their disfigurement.

West’s (1977) conclusions are based on the following findings. Of the people who did not return to work after the surgery, functional disability was given as the reason more frequently than the facial disfigurement. Of the people who did respond to the questions regarding adaptation to informal social groups, most people stated that they participated to the same degree as prior to surgery. Only one person stated that he or she participated less because of his or her appearance. However, only 52 of the 152 subjects responded to the questions
regarding adaptation to informal social groups. In response to the
questions regarding adaptation to public situations, more than 50% of the
104 who answered these questions went out less often in public after
surgery because appearance and speech problems were social deterrents.
Respondents also felt that people stared at them. On the basis of this
information, West (1977) came to the questionable conclusion that cancer
patients with facial disfigurements adapt socially. She does not explain or
elaborate on her criteria for adaptation. This author questions whether this
is in fact healthy or positive adaptation when 50% of the participants
venture to public places less often after surgery and feel self-conscious
when they do. This author also questions the validity of the study because
it appears that participants did not answer the questions related to
adaptation to informal social group functions. It is possible that the
participants chose not to answer some of the questions because the way in
which they were posed in the two questionnaires used was not meaningful
or did not entirely reflect the participants’ experiences. West (1977) does
not address these issues.

Freelander, Espie, Campsie, Soutar, and Robertson (1989), a group
of physicians, studied 41 patients and their spouses. The patients and their
spouses were assessed separately, via questionnaires, for their functional
problems and concerns regarding their appearance after surgery for
intraoral cancer. The results of this study indicated that 25% of the patients had functional difficulties related to eating, drinking, and speech. Twenty-five percent of the patients also reported concern regarding their appearance. However, coping strategies or prosthetics utilized by the patients to improve their functional abilities or appearance were not explored in this study. Interestingly, spouses reported that the patients had more functional difficulties and concerns about their appearance than the patients themselves reported. The researchers felt that the 25% of the patients who did report difficulties was a conservative estimate.

The findings of this study have several implications for nurses and other health care professionals such as, seeking a close relative’s appraisal during the assessment phase to obtain a more complete representation of the patient’s experience. It was also noted by the researchers that the women in the study were more concerned with their appearance than the men.

Krouse, Krouse, and Fabian (1989) studied 45 patients and their subsequent physiological, psychological, and social adaptation after surgery for head and neck cancer. The patients were assessed preoperatively, then three, nine and twelve months postoperatively. In a previous study (Krouse & Krouse, 1982), researchers hypothesized that impairment in physical functions, pain, and fear of recurrence were major
factors in the negative emotional reactions among cancer patients postoperatively. Krouse et al. (1989) justified completing this study by stating that, "Unfortunately, no prospective, longitudinal study has been performed to evaluate these issues in patients who have had head and neck cancer" (p. 789). Two self-report questionnaires were used to assess depression, body image, and self-concept. Semi-structured interviews were also utilized to evaluate limitations, pain, financial problems, and social interaction. These were completed preoperatively and at three, nine, and twelve months postoperatively.

The results of this study revealed that pain, fatigue, weakness, and loss of speech were the major concerns of these individuals. Patients who had composite surgical intervention for oral cavity and oropharyngeal cancer experienced more depression, were more physically limited, and had more persistent problems with speech than the other patient groups one year after surgery. Patients who underwent postoperative radiation treatments had the most difficulty adapting to their illness and its treatment. This group of patients had the most physical difficulties and financial concerns related to increased medical costs, complications that delayed return to work and strained financial resources, and experienced prolonged social isolation even longer than one year after surgery because of the prolonged cancer treatment.
Overall, these researchers found that issues related to appearance and body image played only a small role in contributing to adaptation. This study suggests that during this period, regaining lost functional abilities may be more significant to these individuals than appearance and body image. Once they have regained their functional abilities or they have learned to cope with their irrevocable functional disabilities, concern about body image and appearance may increase. Finally, this research indicates that the more radical the surgery for head and neck cancer the greater the degree of concern about lost functional abilities.

Dhillon, Palmer, Pittam and Shaw (1982) studied 49 patients who had undergone either a total laryngectomy or a commando procedure (resection of the primary lesion with a mandible and neck dissection) and were five months to fourteen years postoperative. The subjects were given questionnaires designed to obtain self-assessment of their resulting disabilities. Results indicated that while 54% of the laryngectomy patients achieved successful communication by esophageal speech, the remaining 46% had difficulty with speech. Dysphagia and "dribbling" were common problems reported by the patients who underwent the commando procedure. Eleven percent of the laryngectomy patients and 43% of the patients who had a commando became "social recluses." Forty-three percent of both groups reported a reduction in social activities. Fourteen
percent of the laryngectomy group and 21% of the commando group experienced frequent or constant feelings of depression after the surgery. Specific problems reported were related to changed facial appearance and self-consciousness when eating, especially when being viewed by the public in restaurants.

Strauss (1989), an oral surgeon, has completed the only descriptive study, to this author’s knowledge, to date. Strauss (1989) interviewed 28 patients who had disfiguring oral and maxillofacial surgery for head and neck cancer. The purpose of the study was to improve understanding about the social and psychological issues that affect the quality of life among head and neck cancer patients who have received extensive oral and maxillofacial surgery. These patients ranged from two to five years post-surgery.

The results of Strauss’s (1989) study indicate that 96% of the participants feared cancer prior to being diagnosed with cancer and 36% denied anything was wrong with them until family members or friends urged them to seek care. All of the participants indicated that they experienced considerable preoperative anxiety and 64% felt that effective preparation for surgery would help to alleviate the anxiety. All participants in the study described some social and family changes as a result of the surgery and altered social interaction. Fifty-seven percent of
the sample experienced being stigmatized because of their disfigurement. Even those who did not feel discounted because of their disfigurement had noted altered patterns of social interaction and 32% indicated that they considered themselves unable to work because of their functional disabilities. In the discussion section of the article, recommendations are given for oral surgeons regarding psychological preparation for surgery and postoperative adjustment of patients.

Summary

The review of the literature has indicated a definite lack of research related to facial disfigurement in head and neck cancer patients. According to the literature, facial disfigurement resulting from surgery for head and neck cancer has profound social, psychological, and physical ramifications. Individuals with this type of acquired facial disfigurement must adapt to an altered body image and self-concept. They often feel depressed, socially isolated, experience altered interpersonal interactions, and live with many functional difficulties. The literature related to the diagnosis of cancer revealed that society stigmatizes people with cancer. Individuals with cancer are often left alone, afraid, and confused, in their greatest time of need for supportive relationships, because of the stigma.

Although there has been some research concerning the disfigurement of head and neck cancer patients, there is an unequivocal
need for nursing research in this area. To this author's knowledge, there is no nursing research utilizing the phenomenological approach to understanding the meaning of disfigurement to these individuals. Exploring both the meaning of the disfigurement and their life experiences may reveal sensitive issues and concerns of these individuals, which were not unmasked in previous research. Not only is phenomenology the method of choice for exploring the research question, it will also give nurses and other health care professionals more knowledge and a better understanding of what it is like for individuals who live with facial disfigurement resulting from radical surgery for head and neck cancer. Ornery (1983) appropriately summarizes the importance of utilizing the phenomenological approach to elicit the true meaning of the phenomenon in question. The nursing profession is proud of its identification as a humanistic discipline. The profession's values and beliefs include a view that human phenomena are holistic and meaningful. Phenomenological methods support such values and beliefs. They consider all that is available in the experience under study, both subjective and objective, and strive to understand the total meaning of the experience for the participants.
CHAPTER THREE: METHODOLOGY

Introduction

This chapter describes the methods employed to conduct the study. The phenomenological approach was the most suitable means for exploring the research question. This chapter outlines this particular methodology and also includes the following: the process utilized for selection of the participants; the criteria for selection of the participants; the data collection and analysis; and measures taken for protection of human rights.

Overview of Phenomenology

Phenomenology, a form of qualitative research, was used for this study. Oiler (1986) states that, "the aim of phenomenology is to describe experience as it is lived by people" (p. 70). Omery (1983) asserts that "the phenomenological method is an inductive, descriptive research method" (p. 50) and suggests that the researcher utilizing this methodology is attempting to investigate and describe the phenomena and human experience as they appear in a holistic way. "The concern of the phenomenological researcher is to understand both the cognitive subjective perspective of the person who has the experience and the effect that perspective has on the lived experience of the behaviour of that individual" (Omery, 1983, p. 50). During this inductive process, the
researcher shifts back and forth between the subjective data and theoretical abstraction until he or she has an understanding of the meaning of the experience to the participants (Omery, 1983).

The researcher's role in phenomenology is to become absorbed in the phenomenon. The researcher customarily utilizes techniques such as interviewing and observation to collect data about the phenomenon (Oiler, 1982). The participant is considered an experienced and knowledgeable partner in the process and engages in cooperative dialogue with the researcher. In this way, the researcher gains an understanding of the perspective of this expert (Field & Morse, 1985).

Prior to beginning the research, it is important for the researcher to identify and bracket assumptions and preconceptions about the phenomenon. Bracketing does not eliminate bias but brings it into perspective (Oiler, 1982). In this study it is assumed that radical surgery for head and neck cancer resulting in a visible facial disfigurement will have an impact on the lives of these individuals and that they will be willing to share their experiences and perceptions with the researcher.

**Selection of Participants**

The researcher selected eight volunteers for the study from among patients being seen by health care professionals at two clinics within the British Columbia Cancer Agency. As planned, the researcher chose a
sample which consisted of equal numbers of women and men so that the data could be contrasted and compared between genders. Sample size is not predetermined in qualitative research; rather it is ordinarily based upon theoretical saturation of the data (Sandelowski, 1986). This researcher made a preliminary decision to choose eight to ten participants. This decision was based on time constraints and financial feasibility and because other researchers implementing this method have found eight to be an adequate number. The final sample size was eight because there was a limited number of volunteers and the data showed recurrent themes with all participants.

Participant selection depended upon the participants' ability to articulate their thoughts and feelings about experiences with the phenomenon in question. Sandelowski (1986) states that, "in qualitative research, any subject belonging to a specified group is considered to represent that group. Anyone's experience, if well described, represents a "slice from the life world" and is therefore appropriate subject matter for qualitative inquiry" (p. 32).

**Criteria and Rationale for Selection**

The participants spoke English fluently. This researcher is fluent in English only and it was not feasible to use a translator. The participants saw themselves as capable of speaking about the phenomenon of facial
disfigurement and what it meant to them as this is the essence of phenomenology. All lived within the Vancouver and Lower Mainland area.

The participants all had had radical surgery for head and neck cancer with a resultant visible facial disfigurement. This researcher intended to focus on the long-term issues and how they were managed, versus the immediate issues associated with the diagnosis and treatment of this type of cancer. Therefore, they were asked to participate if they were at least six months postoperative and had no known recurrence. During the acute phase of the illness several factors may influence participants’ adjustment to their illness. Thus, the participants selected for this study had had time to adapt to the chronicity of their illness, their facial disfigurement, and functional changes.

Interviewing was completed in the participants’ own homes with the exception of one participant who preferred to meet in a private office at the British Columbia Cancer Agency. This was more convenient for him because it was close to his place of employment. It was important that the participants were comfortable with the location and interviewing process. This enabled them to speak more spontaneously about the impact of the diagnosis and treatment of cancer on their daily experiences.
Data Collection and Analysis

Recruitment

As previously stated, subjects were recruited from the British Columbia Cancer Agency. Once approval was received from the University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies Involving Human Subjects and from the research committee at the British Columbia Cancer Agency, the researcher obtained information regarding interested volunteers from two charge nurses at the Agency. One nurse was in charge of the Ear, Nose, and Throat Clinic and the other nurse was in charge of the Head and Neck Clinic. Potential volunteers were given the Information and Consent Form (Appendix A) and, if interested, were asked to phone the researcher at their convenience. The researcher was then able to determine the participant’s suitability for the study over the telephone prior to the interview.

It took six months to find eight volunteers who met the selection criteria for the study. Several factors played a role in extending the anticipated time period. Some people who met the criteria for diagnosis and treatment spoke only Chinese. Others declined, failed to contact the researcher, or had changed their minds when the researcher contacted them. Finally, in an effort to facilitate the identification process, the researcher assisted the charge nurses of the two clinics by going through
charts and listing individuals who met the selection criteria so that they needed only to approach them the day of the clinic.

Data Collection

Following the subjects’ consent to participate in the study, the researcher collected data through in-depth, semi-structured interviews. Trigger questions were posed to guide the interview (Appendix B). These were formulated from recurrent themes in the literature and based on the research question, problem statement, and subsequent interviews.

All the interviews were audio-taped and transcribed by a designated typist to facilitate data collection. The length of the interviews varied from 50 to 150 minutes. Interviews were completed in participants’ own homes. This enabled the researcher to observe the participants in their home environment and the social interactions with their significant others. These observations facilitated the procurement of richer, more holistic data.

The researcher also recorded field notes following each of the interviews to retain the context of the interviews. The researcher maintained a personal diary during the entire research process to record and bracket preconceptions. This diary was also utilized to record the researcher’s thoughts and feelings experienced during the interviews and the subsequent data analysis. An example of one such thought which
recurred throughout the research process was whether facial disfigurement was the appropriate nomenclature for the title of the study. The researcher asked herself, does the term facial disfigurement evoke more negative thoughts and feelings in individuals which, in turn, perpetuate the stigma surrounding this phenomenon?

The researcher interviewed the participants twice, with the exception of one male participant who was unable to complete the second interview. The first interview was to gather data on the impact of facial disfigurement, as a result of radical surgery for head and neck cancer, on the lives of these individuals. The second interview took place following initial data analysis to clarify what the researcher did not understand, to elaborate on significant experiences and analytical categories, and to verify the interpretations made by the researcher from the initial interview. In this way, the data collection and analysis were concurrent and ongoing throughout the study.

Data Analysis

The researcher utilized Colaizzi’s (1977, as cited in Riemen, 1986) procedural steps for analyzing the data. The interviews were transcribed verbatim by a typist employed by the researcher. The transcribed interviews became the data for analysis. The participants’ descriptions of their experiences were read. Significant statements were extracted from
the transcripts and coded. Meanings were formulated from the significant statements. For example, many women talked of ways in which to conceal their facial scarring. Separate lists for men and women participants were formulated so that the data could be compared and contrasted. Clusters of themes were extrapolated from the meanings. An example of a cluster of themes which was extrapolated was coping strategies utilized by the participants in dealing with society's reactions to their facial disfigurement. These themes were then compared to the original transcripts to validate them. At this point, it was appropriate to validate these themes with the participants to ensure that the essence of the phenomenon had been captured by the researcher. A final exhaustive description of the phenomenon was formulated from the clusters of themes. The relationship of these clusters to the central concepts were identified. Finally, to further develop the concepts the researcher incorporated the appropriate literature which validated or opposed the findings.

Means of Establishing Reliability and Validity

"Qualitative methods are frequently viewed as failing to achieve, or to make explicit rules for achieving reliability, validity, and objectivity—criteria of adequacy or rigor in scientific research" (Sandelowski, 1986, p. 27). This view is often held by positivist-empiricists. However, Lincoln and Guba (1985, as cited in Catanzaro, 1988) state that ways do exist to
establish the trustworthiness of the study. Trustworthiness refers to
credibility, dependability, confirmability and auditability.

This researcher established credibility by validating the results of the
study with the participants of the study after all the data were collected
and analyzed. The results are credible because the participants felt that
the results were authentic descriptions of their experiences. A second way
in which the researcher established credibility was by having other people
involved with individuals who have had radical surgery for head and neck
cancer recognize the phenomena after reading the results of the study.

Lincoln and Guba (1985, as cited in Catanzaro, 1988) state that
confirmability is the means of establishing external validity in qualitative
research. They suggest that the descriptions acquired from the data must
fit the data from which they are derived. The findings must reflect both
the typical and atypical aspects of the life experience. This researcher
endeavored to do this.

Lincoln and Guba (1985, as cited in Catanzaro, 1988) suggest that
an inquiry audit be used to establish dependability and that a
confirmability audit be utilized to establish confirmability. An inquiry audit
is completed when an external research agent or expert in the field of the
phenomenon under study reads the report and confirms the findings. The
confirmability audit is accomplished when the reader of the report easily follows the researcher’s decision trail.

Sandelowski (1986) describes auditability. A study is auditable whenever all the steps of the research process are clearly outlined, the data analysis is clearly illustrated, and the conclusions derived are evident from the data. This researcher established dependability, confirmability, and auditability with the thesis committee members, with expert nurses at the British Columbia Cancer Agency, and with the participants.

**Ethical Considerations**

The ethical procedures in this study were approved by The University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies Involving Human Subjects. The research was also approved by the research committee of the British Columbia Cancer Agency. Participation in the research was voluntary. As mentioned previously, a consent form was signed by each participant stating that he or she would participate in the study and that he or she agreed to have the interviews audio-taped. A full explanation of the study and a letter stating the intentions and the role of the researcher were given to each participant prior to obtaining consent (See Appendix A). The participants were informed that they could withdraw at any time during the research.
process and that they could refuse to answer any of the questions posed by the researcher. The participants were also assured of confidentiality.

Confidentiality was maintained throughout the research process. Although direct excerpts from the data are used in this thesis and will be used in other papers developed from the research, all identifying features are removed. All taped and written material was kept anonymous to all except the researcher. Audio-tapes and transcripts were available only to the researcher and thesis committee members. Codes rather than names were used for the audio-tapes and written documents. This material will be destroyed after the research and thesis are complete.
CHAPTER FOUR: FINDINGS AND INTERPRETATION

Introduction

Can you imagine what your life would be like if, as a result of radical surgery for head and neck cancer, you had lost an ear, been paralyzed on one side of your face, with extensive scarring of your face and neck? Can you imagine being unable to eat in a restaurant because of your embarrassment with drooling, being unable to return to your previous profession, or to obtain employment, because of your changed facial appearance and cancer, or being constantly confronted by strangers who feel entitled to know why your facial appearance is different from theirs? It is unlikely that you could conceive of the devastating impact of this experience on your life. This chapter will describe the characteristics and lived experiences of the eight participants who underwent radical surgery for cancer of the head and neck and who at present live with profoundly altered facial appearances.

Characteristics of Participants

A demographic data gathering tool formulated by the researcher was utilized to gather information about the participants who volunteered for the study (See Appendix C). The following description of the participants is based on this information. Four men and four women were selected and agreed to participate in the study. The ages of the men at
the time of their surgery ranged from 49 to 69. The women’s ages ranged from 19 to 58 at the time of their surgery. All volunteers had been born and raised in Vancouver with the exception of one woman who moved to Canada from England 20 years earlier. The length of time since surgery varied from 18 months to 10 years. All participants underwent some form of radiation treatment prior to radical surgical treatment of the cancer. Radiation treatments ranged from laser beam radiation treatment, the swallowing of radioactive iodine for thyroid cancer to radiation implants in the mouth. As a result of the radiation treatment all of the participants developed longstanding side effects such as, problems with swallowing, pain, and dry mouth.

Prior to being diagnosed with cancer six of the eight participants had been very healthy with no underlying chronic illness. One participant had heart disease and a subsequent coronary bypass ten years prior to diagnosis of skin cancer. One other participant described himself as a chronic alcoholic prior to his surgery and had been drinking heavily until a year and a half after surgery at which time he abstained from drinking alcohol.

At the time of the first interview, none of the participants had experienced recurrence of cancer. However, at the time of the second interview one male participant had experienced a recurrence and had
undergone a radiation implant. The interviewer was unable to interview a second male participant a second time as the course of his illness changed and he was too weak to talk. Facial disfigurement as a result of radical surgery for head and neck cancer and its impact on his life had become secondary to his more acute life-threatening illness.

Each of the participants had undergone a different type of radical surgical treatment depending on the location, type, and extent of the cancer. Examples of the types of surgery are as follows: thyroidectomy with bilateral neck dissections, laryngectomy with bilateral neck dissections, partial removal of a mandible and partial glossectomy with a bone and vessel graft from the wrist and a muscle flap from the chest, bilateral neck dissections with removal of an ear, bilateral neck dissections and removal of palate, and removal of a mandible with a bone and muscle graft from the wrist. The length of time in the hospital after surgery varied depending on the extent of the surgery and postoperative complications such as infection. The average length of stay was two weeks. All of the participants had had or still require surgery for reconstructive or functional purposes.

As a result of the surgery, some of the participants utilized some type of prosthetic device such as a prosthetic ear, an artificial palate, or a
duckbill for esophageal speech. This assisted these individuals in carrying on the activities of daily living.

At the time of surgery and during the interviews all of the men were married and living with their wives and family members. In contrast, all of the four women were single at the time of surgery. One woman had been married after her surgery but was divorced prior to the interviews. Another woman was a single mother.

The employment status of the participants was varied. Two of the male participants were retired. The remaining two male participants were employed and found great difficulty returning to work after the surgery due to prospective employers' reactions to their altered appearance and cancer. As a result, one man took a substantially lower paying position because he was unable to return to his previous sales career. The four female participants were all employed prior to their surgery. One woman was not rehired because she had had cancer. She found employment elsewhere. Two other women were preparing to return to their previous employment but were still unable to do so because of many functional disabilities. Finally, one young woman had returned to her previous part-time job but gave up her aspirations for becoming an actress because of her altered facial appearance. She had, however, completed her high school education and finished a Bachelor of Arts degree since her surgery.
Some of the participants experienced financial hardships as a result of the barriers to finding employment after their surgery. Two participants had to maintain themselves and their families on welfare. One participant, although his financial status was precarious, refused to take welfare and attempted to find employment almost immediately after his hospitalization. Unfortunately, the employment he obtained was not enough to maintain his family and previous standard of living and he had to sell his home. For six individuals who did not have extended health benefits such as disability insurance there was no income assistance from the government other than welfare or their regular pensions. Two individuals had extended health and disability benefits.

The Central Themes

In the subsequent sections the lived experiences of the participants will be examined. As the data obtained from the transcribed interviews were reviewed it became clear that there were two central themes: loss and stigma. Both themes and their inter-relationship will be examined in the following sections.

Loss

Loss was the earliest theme which became apparent during the initial data analysis. All of the participants experienced multiple, complex losses as a result of the radical surgery. During the immediate
postoperative period, the losses were primarily functional. However, as time progressed and the participants began to have more contact with the public, their losses became increasingly more social in nature.

Buck (1984) defines loss as any situation in which an individual feels a valued object is actually, or potentially, rendered inaccessible to her or him. Loss also pertains to a situation in which the valued object is altered in such a way that its qualities are no longer perceived to be as valuable by the individual. Buck (1984) defines "valued object" as including "people, possessions, job, status, home, ideals, parts or processes of the body" (p. 337). People experience many losses during their lifetimes. Some are predictable and may be related to growth and development; these types of losses can be planned for. Others are completely unpredictable and unplanned, such as the diagnosis of cancer and subsequent loss of health (Buck, 1984). The emotional response to the loss depends on its significance. Some losses are considered more significant than others, depending on the social significance of the loss, the personal meaning that the valued object holds for the individual, age, gender, social roles, and culture (Schneider, 1984). The series of emotional reactions to a significant loss is generally called grieving (Buck, 1984).
The losses experienced by the participants in this study were completely unpredictable. They had not expected to become ill with cancer, and, consequently, they were not expecting to have radical surgical treatment and radiation. In addition, many of the losses experienced postoperatively were unexpected. One participant shared her experience with loss after the radical surgery for cancer:

I still couldn’t walk very far....I had someone look after me. You know my dad would take me for a walk up and down the sidewalk every day. He would make me get up even on a bad day and just walk around the apartment. The day he left I was really frightened being alone. I think the first meal I had by myself I thought: "I’m going to choke" and of course I did choke....But there was a lot of little things to get over. It wasn’t a lot of big stuff, it was little things to get over. And then you face the big things, then you face the world! But for the first you just have to learn to get up and, you know, take a bath by yourself, cook a meal yourself, and clean up afterwards. You know, everything is such an effort, really an effort....I was exhausted for so long and that had never really been explained to me before hand, so that was a real shock! Nobody said you were going to be disabled.
This narrative depicts the multi-faceted losses and the importance of establishing a new personal identity which encompasses the participants’ experiences with disability resulting from cancer and the radical surgery.

**Stigma**

The second theme which was manifest in the data was stigma. One participant described her experiences while job hunting after her surgery:

People who have cancer are discriminated against. I don’t know if you’ve looked on a whole lot of application forms but it will actually say do you have cancer. They’ll actually straight out and ask you if you do. And I’ve never gotten a phone call for a job ever because I had an illness. What I do for a living now is because my mom got me into it....All I needed to do was prove my ability physically and mentally to people but I was never given that chance because I was labelled right away because I did have cancer. Right away I was not going to be a good candidate for the job....it was very hard. Very, very hard. I know what it is like to be a minority now. I know what it is like to be prejudiced against.

Another participant stated that,
I used to get really upset about it....If it's someone I've been working with and they ask me in private about it, then it doesn't bother me. But it always, you know, the adrenalin speeds up a bit, makes me a little bit nervous but I can handle it better. Yeah, I used to get really hurt....I mean why should I feel embarrassed right for having a scar, for having cancer. You know, I shouldn't have to be embarrassed about that. Yeah, and I was, and I was because of the reaction, because of that, yeah, I seemed to be on the spot so many times, so many times in just all kinds of situations.

It is apparent from these accounts that stigma played a profound role in shaping the experiences of the participants. The participants were treated differently by the public because they had significant, visible, facial scarring, and worse, because they had also had cancer. The social losses they experienced were seen as directly linked to stigma, particularly when they began to become more involved in public activities after their surgery.

The participants' experiences are significantly different from those who experience other illnesses because of the stigma associated with cancer. Their experiences are also distinct from those who have cancer at
another site, owing to the visibility of the surgical treatment and the importance that society places on physical attractiveness. Hill-Beuf (1990) states that "America worships beauty. The culture stresses highly idealized images of both male and female attractiveness....smooth skin, silky hair, straight noses and dazzling smiles of models in the media set a narrow standard to which all must try to conform" (p. 6). Hill-Beuf further asserts, "The physically-impaired or disfigured person in America is deviant in two regards: failing to live up to the cultural standard of beauty, and failing to conform to the United States standard of 'normal' or unexceptional appearance" (p. 7). Although these authors are referring to the United States, this researcher maintains that the Canadian standards are very similar to the American standards. Goffman (1963) declares that "The term stigma, then, will be used to refer to an attribute that is deeply discrediting" (p. 3). Goffman (1963) continues by stating that the stigma is not the result of the attribute; rather, it is the attitudes of others which confer the stigma associated with the attribute. Thus, stigma is forced upon the individual with facial scarring rather than being an inherent characteristic of the facial scar.

Goffman (1963) describes three totally different types of stigma: various physical deformities; blemishes of individual character, such as mental illness or dishonesty; and tribal stigma of race, nation, and religion.
He states that the more visible or perceptible the stigma, the more the individual will be discredited by the public. One example is smoking. Smoking is now considered a "bad habit" and hence stigmatized. However, if the individual who smokes does so only while in isolation, the public is not aware that the individual smokes. On the other hand, facial paralysis is very visible and interferes with social interaction. Since this person's stigma is always very visible to the public, he or she is immediately, unnecessarily discredited. It is apparent that the participants in this study experienced the visible stigma of facial disfigurement as a result of radical surgical treatment of head and neck cancer and the less visible stigma attached to cancer itself. Hill-Beuf states that "There are degrees of discreditation, however, which rest mainly on the visibility of the impairment....From the social perspective, the face is by far the most critical of the body parts. It is almost impossible to hide facial impairment" (p. 64).

In addition, this entire experience of having cancer and consequently, radical head and neck surgery was so devastating for the participants that six of the eight participants experienced overwhelming feelings of sadness and despair associated with the length of the recovery process and society's negative reactions to their altered facial appearances and cancer diagnosis. As a result of negative treatment by society, the
participants relinquished many of their cherished hopes and dreams and had decreased self-esteem and less self-confidence. As one participant verbalized his despair:

You know there were times that I sort of, pretty bad times where I figured oh shit man I would have been better off, sorry [to the researcher because of his language], I would have been better off if I'd just died, you know. I didn't seem to be able to get over the hill....because of everything.

Another participant stated that "It's everything, you know, with the cancer, with your job, just everyday, a lot of things unanswered, unfinished. It gets me down." These feelings of depression began during the first phase, with several of the participants experiencing them more intensely when they faced the magnitude of the stigma attached to their experiences.

**Four Recovery Phases**

As the data were examined, it became apparent that the participants progressed through four phases as they recovered from the radical surgery for cancer. During each phase they learned to adapt to their chronic illness, numerous functional and social losses, their altered facial appearances, and the stigma associated with their illness. The phases began with the immediate postoperative period and progressed with time along a continuum toward the final phase of living with facial
disfigurement as a result of radical surgery for cancer of the head and neck. With time, the participants were able to cope with their many functional losses. Nevertheless, the stigma associated with cancer and their changed facial appearance continued, throughout their lives, to remind them that they were different from other members of society.

Prior to describing the four phases, it is important to note that the participants realized after the diagnosis of cancer, and before having their surgery, that they would look different from others and be treated differently by others following the surgery. One participant described a conversation prior to her operation: "Right out of the blue I said to my sister once, 'Oh don't worry I'm going to come out of that looking like the elephant man.' And she said to me, after the operation, that was just the way I looked." In addition, the participants were already beginning to become anxious about how they would be treated by others because of their altered appearance. Some participants recalled looking into the mirror just prior to the radical surgery and taking one "last look" at their facial appearance.

The first phase in the process is described as the initial postoperative period. This phase continued throughout the individual's hospitalization. Numerous, complex, functional losses were experienced by these individuals as a result of the radical cancer treatment. The main tasks for
the participants during this phase were associated with the recuperation of their physical health, functional abilities, and energy. The major functional losses which were most troublesome for these individuals were the losses associated with social skills, such as communication and eating in public. They devoted a great deal of time and energy to relearning these skills. This was the participants' first experience with facial disfigurement and they did describe some social losses related to stigma, such as isolation from friends and loss of former physical appearance.

The second phase in the process is that of the participants returning home from the hospital and establishing initial contact with the public outside the health care system. The length of time the individuals spent in this phase varied from two weeks to approximately one year and was contingent upon several factors: (1) the type and extent of the surgery; (2) whether they received radiation postoperatively; and (3) the presence of significant personal responsibilities, for example, the necessity to return to work for financial reasons. During this phase, the participants were continuing to recover their physical health and to cope with their many functional losses. They also recognized several additional losses which were beginning to be more social in nature. Thus, the participants began to experience the expanding role of stigma.
The third phase refers to the period of time when the participants were anticipating their re-emergence into society to the point where they were actually involved in social activities. Several of the participants were in this phase at the time of their interviews. During this phase, although the participants had improved physically and had adapted to their many functional losses, they recognized new losses as the result of being perceived differently by the public. For example, many felt reluctant to, or were unable to, return to their previous positions because of the stigma associated with their altered facial appearance and their having had cancer. Many of the tasks associated with this phase were related to concealing their changed physical appearances. Consequently, the losses identified in the third phase were the result of being treated differently by others in society.

The fourth phase in the process is best described as "living with facial disfigurement," a task that will continue throughout the individual's lifetime. During this phase the participants came to terms with the fact that their changed facial appearance was permanent. The role of stigma continued to increase during this phase. The tasks that the participants concentrated on were associated with developing coping behaviours which would minimize the effect of stigma on their lives. They also realized that this would be a lifelong process because they would continually be
meeting new people and responding to others’ reactions to their unique appearances.

An important point which should be noted is that some individuals in this study returned to the first phase after progressing along the continuum to subsequent phases. This revisiting of the earlier phases was due to the necessity for radiation therapy during the postoperative period. These radiation treatments were very physically taxing. Six of the eight participants also required numerous subsequent reconstructive surgeries. The reconstructive surgeries were less radical than the first so that after their return to the first phase, their progression through the subsequent phases the succeeding times was more rapid. In general, the first experience with the representative phases was the most dramatic for these individuals. It was their first encounter with cancer and facial disfigurement, and they were forced to develop the necessary coping behaviours.

In the following two sections of this chapter loss and stigma are discussed separately. The meaning of loss and stigma for these individuals is addressed in each of the four phases of recovery.

**Losses and Their Management**

In this section, the losses that the participants incurred as a result of the diagnosis and treatment of head and neck cancer are addressed. They
experienced numerous functional losses, particularly in the first two phases of the recovery period. As the participants progressed through the four phases they learned to cope with the many losses and by the time they reached the fourth phase they experienced no new functional losses.

**Phase I: Initial Postoperative Period**

During the initial postoperative period of the recovery process, the participants experienced numerous, complex, and diverse functional losses. All of the participants had undergone extensive surgery and were, as a result, medically fragile immediately after their surgery. One woman described this time period as: "It was like being in no man’s land!" As the participants began to recover their physical stability, they began the extremely long and arduous process of regaining and relearning lost functional abilities in order to recover their autonomy. The participants specifically spoke of focusing on relearning functional abilities that, as a result of the surgery, interfered with their social skills. Therefore, functional losses which the participants perceived as socially devastating were described as more significant than those that had fewer social consequences. For example, they experienced embarrassment because of their inability to eat neatly and their drastically altered facial appearances. This is consistent with Buck’s (1984) definition of loss which emphasizes the social significance of the loss.
Eating

All of the individuals in this study lost their ability to eat as before as a result of radiation therapy and the surgical treatment. The participants described oral pain, difficulty swallowing, dry mouth, loss of taste, partial facial paralysis, and difficulty chewing food because of multiple extractions. One participant described her ordeal of learning how to eat again:

In the hospital I would pull the curtains around and I never ate in front of anyone. I was just too self-conscious there because I really couldn’t eat very well. I couldn’t eat anything for about two weeks. They tried to give me some liquids, you know, to get me to swallow. I just couldn’t swallow at all so eventually an occupational therapist came to try and teach me to swallow properly, you know, bending the hand a certain way so that it would ease the throat and just let things slide down. Then I was able to start eating little bits but it was all pureed or really finely grated. Mandarin oranges were about the only solid things that I could swallow because they just slid down. Anything else was a struggle!...I’d say it was about two months before I could really safely feel I could eat.
It is evident from the previous narrative that the participants had to master eating again. It is also important to note that these individuals felt embarrassed or ashamed of their inability to master tasks that they had previously been able to accomplish. This embarrassment was also due partially to their altered appearance while eating. The participants learned to manage their difficulties with eating by utilizing various strategies such as, using special bottles for thin fluids, holding their heads at different angles while swallowing, avoiding foods that were potentially difficult to swallow, and taking smaller mouthfuls. For example one participant stated:

I have difficulty swallowing. Particularly liquids. You have to develop a new way of swallowing. Still if I take a large gulp of water it will come out my nose. Sometimes I do that inadvertently and it could become a social problem if I did that when I was dining out a friends. If I were to take too much water and the water came through my nose and lands on my plate or something.

Generally, this essential task was frustrating to relearn and took a great deal of skill and persistence to master. However, it was also an important task to master for the participants because of the social significance attached to eating in the presence of others.
Communicating

Another substantial loss experienced by one of the participants who had a laryngectomy was permanent loss of speech. Several of the participants experienced this temporarily because a tracheostomy was necessary during the immediate postoperative period and some of the participants had problems with articulation because of facial paralysis. One individual related his attempts at trying to communicate,

In the hospital, I couldn't talk at the time, and I had to write everything. And oh, it used to hurt my shoulder to write and so the visitors that came, well the fact that you were in the hospital, and you got cancer and you had your voice-box out, it bothered them more. And I also noticed that they didn't pay much attention no matter what you wrote down. They seemed tense....I've become a good listener. I couldn't talk for a whole year, so I had to sit and listen. I knew that a lot of times even when you wrote stuff down and people could read it, they still got the wrong idea. They'd agree to something when they should have been shaking their heads eh. And so I had to say: "no, that's not what I mean." You can't say a word, so you have to write everything.
In order to manage the loss of speech this participant wrote down his thoughts, but found the communication process frustrating because his messages were not being understood by the receiver and his shoulder was painful when he wrote. Many of the other participants also relied on alternate forms of communication. Typically, the methods utilized were writing, rudimentary sign language, gesturing, and lip reading. This took great effort as illustrated by the above account. This narrative also implies that his visitors may have been uncomfortable because of the diagnosis of cancer, the resultant radical surgical treatment, and his inability to communicate verbally.

Body image

An additional loss experienced by all of the participants was the loss of their previous body image. Initially, they all experienced extensive facial swelling, bruising, and stitches. The extent of the swelling and alteration in facial contour was contingent upon the type of surgical treatment of the cancer.

The participants’ methods of managing of this loss were similar during this phase. Most of their energy was expended on regaining their vigor and functional abilities. However, they all expressed concern, repulsion, apprehension, and discouragement over their altered appearances. They all described their appearances in very negative terms.
One individual related her shock and emotional pain when she first looked in the mirror:

When I first saw myself I was absolutely shocked! My neck was grotesque and my head was shaved. My face was drooping and my eye was staring and it was swollen. Of course I had this huge lump at the side because it was quite big [where the tumour was removed]. And all the scarring in the neck. At first I thought that’s not me. And I just stopped looking....and I mean you really saw people looking at you and thinking: "Oh my God, what has happened to her!" But, I was so ill that it was just a success to get through each day, to wake up, and not feel nauseous.

Another man described his appearance: "Well, immediately after, of course, it was absolutely ghastly; it looked like Frankenstein with the stitches and everything." A third individual described being apprehensive and incapable of looking in the mirror for two weeks postoperatively. These accounts indicate some of the understandably negative feelings, related to this particular loss, felt by these individuals during this phase.

Another way in which the participants were able to cope with their altered facial images during this phase was belief in the knowledge that their image would improve with time. They spoke of knowing that the
swelling would decrease, the bruising would disappear, and the stitches and tubes would be removed. This positive outlook assisted in sustaining them through this phase.

Anatomical parts

One person had an ear removed as a result of the cancer. Postoperatively, this individual was unable to hear on the affected side. She also became very dizzy, nauseated, and unsteady on her feet as a result of the removal of the inner ear. Another participant had his palate removed as a result of the cancer. All of the participants had severed facial nerves, some had muscle mass removed, and others had bone and vascular grafts from remote parts of the body.

In response to the loss of an ear and, subsequently, balance this individual eventually learned to regain her balance and live with the nausea and vertigo. She related her experience:

And the nausea, that was a problem that was really difficult. They [the nurses] used to try and get me to just sit up and I didn’t want to do that. They really had to poke me to do that...you know, having to make myself walk, get my balance, but it came. Before I left the hospital I was walking around. I was afraid to go too far. I had no confidence at
all in my balance. I wouldn’t go down the elevators myself.

Somebody had to be with me.

This account illustrates many responses to the losses. This woman faced feelings of frustration, discouragement, loss of confidence in her abilities, and loss of independence, all as a result of her loss of balance. In order to cope with the losses she had to learn how to walk in such a way that her vertigo was minimized. Initially, this process which began in the hospital meant relying on someone else for assistance. The process was lengthy and continued throughout the subsequent phases of recovery.

The individual who had his palate removed was eventually fitted for a prosthesis. In the meantime, his speech and ability to swallow were affected. Some of the participants received physiotherapy to improve muscle tone and strength. There was no assistance for the facial paralysis as a result of the nerve damage.

Social support

During this period the participants depended on health care professionals to assist them with performing the activities of daily living and medical treatment. However, as soon as they were able to function with minimal assistance, the participants were expected to be virtually independent. During this phase, some of the participants described having very little or no support from other essential health care professionals such
as physiotherapists. They generally depended on their families, close friends, and spiritual beliefs for emotional support during this time.

The losses and their management characterize the profound impact associated with radical surgery for head and neck cancer. Not only did these individuals lose anatomical organs, they also experienced numerous functional losses as well as pain and the loss of their health and well-being. The responses to the losses were complex, and many included learning to cope, an activity which extended into all phases of the recovery process.

**Phase II: Initial Contact with Public**

The losses which the participants identified during their initial contact with the public outside the health care institution were an extension of the losses initially experienced, as well as many that were newly identified. Many of the participants reported that they continued to focus on the extremely difficult process of regaining lost functional abilities and independence during this phase. Much of their effort was concentrated on regaining lost independence.

**Independence**

Achieving a balance between independence and dependence was a major task for the participants. Although independence was lost during hospitalization, this loss continued to play a major role in their lives at home during this phase. One individual recounted her experiences:
And eating, it was a problem, swallowing [upon discharge from the hospital]. My eyes got tired so you know, you couldn’t read as much and watch television as much. Thank goodness for television, you know; I always enjoyed it, but it sure came in handy when I first got home and couldn’t read at first. I couldn’t focus properly....I had to learn how to walk up and down stairs. I had to learn how to turn around without falling. Even squatting I still fall on my backside. I lose my balance. I am still learning how to cope [now thirty months since initial surgery]....I just think in a general way everything I did was affected; you had to do everything so carefully, because of the vision problem, your depth perception, you know, anything like that. I wouldn’t know where things were. I would have to be careful picking things up. I was always dropping things and that gets frustrating.

But, I think I coped all right, basically. I was dependent; I still needed to ask for help.

This narrative demonstrates the numerous functional losses that the participants continued to deal with. Every aspect of their lives was affected. Abilities that had previously been taken for granted had to be relearned so that they could function and live independently again.
During this phase the participants discussed how they allowed their family and friends to assist them with the activities of daily living even if they were used to living independently. One participant who required help, stated:

I think because of the support system, had I been on my own,...straight from the hospital I came here [living at sister's, 18 months since initial surgery]. The idea was that in a couple of months I could, maybe even weeks, I'd be fit and that would be it, I would go back to my apartment. But then this came [paralysis in hand], and of course I couldn't. I was weak, and I couldn't manage myself with one hand so I've stayed on....I've never had to struggle with transportation, my brother or my sister, somebody, has driven me down every time I need to go, three times a week for physio, every doctor's appointment, there's been somebody to pick me up and fetch me, you know.

An important concern, related to the loss of independence and expressed by six participants, was fear of choking while being home alone initially. In response to it, they established security systems with neighbours and family members until they were more comfortable on their own. One woman stated: *My sister and brother-in-law had to go out for
some reason. I was on my own, and I had to eat, and before I started eating, I made a mental note of what I would do in case I choked. Like who I would call or how I would get there." This account also suggests that it took considerable courage for these individuals to become independent again.

These narratives emphasize the importance that support from significant others played when these individuals were discharged home prior to living independently again.

**Eating**

Another set of frequently reported losses included the loss of enjoyment of eating, loss of variety and choice of foods, and loss of appetite and resulting weight loss. Related to the loss of enjoyment was drooling. This loss was socially devastating for the participants. The drooling was caused by nerve damage during the surgery and resulted in decreased facial sensation and paralysis. This loss of sensation and control of saliva was embarrassing and, as a result, several participants would only eat alone or with very close family members.

The participants learned to manage problem issues surrounding eating by a variety of means. In response to the loss of variety and choice in food selection, one participant illustrated his solution:
When you first get out you have to eat mush. So, I became a connoisseur of soups....I made some fantastic soups....I could have complained about it, but it wouldn’t have done any good. But it hurt like hell to eat anything....I lost quite a bit of weight.

Another participant described a similar process of creating many different types of nutritious thick liquified meals in a blender because he could only master thick fluids. Several participants described using trial and error as their approach to deciding whether they were able to consume the selected food. Many spoke about the many things that they found they could not eat, such as peanuts, chips, certain vegetables, and some types of meat, such as hamburger. All of the other participants spoke at great length about how the changes they had to make in their diet affected their lives.

Facial appearance

Generally, during this phase, the realization that they would never look the same as they did before became even more of a reality. This was perceived to be a tremendous loss, particularly for the women, and management was a major task for the participants.

In response to their altered facial appearance, three of the four women in the study described being unable to touch their scars, even
when the application of cream to the incision line was necessary for healing. Many participants enlisted the assistance of family members to carry out this task. Three participants described being unable to look at themselves in mirrors. One participant described her reaction to her changed facial appearance:

And mirrors I avoided and, even still today. I don’t look in mirrors the way I used to before all this happened. You still don’t want to see yourself. It’s not you. I keep thinking, when am I coming back? When is the real me coming back?

This statement portrays the devastation that this woman felt, and still feels, regarding her altered facial appearance.

Certainty

Another loss experienced by all of the participants was loss of certainty about the future. They had almost recovered from the physical trauma of the surgery and were finding ways to cope with their lost functional abilities. The participants were finally just beginning to consider the role of cancer in their future lives. Nevertheless, the future was obscure because of the possibility of the disease recurring.

The participants described several strategies for managing the uncertainty, such as not thinking about the possibility of recurrence until
they had follow-up appointments with cancer specialists. One participant stated:

And you think well, yeah, so it's cancer. It's another illness, you know. But I must admit that sometimes walking through those corridors at the Cancer Clinic [treatment centre] it suddenly shakes you up to think, you know, it could be serious. Like, it could come back again. It can be life-threatening, but if you worried about everything that was life-threatening, you wouldn't live very long....I guess like everything else if you've got it, yep, there's a certain amount of apprehension. It's amazing how you learn to cope.

Another participant revealed the optimism which was characteristic of all of the individuals in this study:

I feel that if you face the worst...it takes away a little of the fear, I think. Just you're better prepared. I've never had to face the worst yet in most cases....Generally, things have not been as bad as you've thought they would be. Now if they were I don't know how I'd react to that, but that's a whole new ball game. But I think it helps you to face whatever it is you're told.
These responses indicate the participants' ability to continue to live with such profound losses.

**Social support**

During this phase the participants' families were the mainstay of their social support. They had been discharged from the hospital and were no longer in constant contact with health care professionals except for follow-up appointments. Two of the participants required home-care nursing for a short period of time. The formal support for the participants was minimal. Several participants described depending on their families for assistance with the activities of daily living. However, they tended to cope with the complex losses independently and often concealed their true feelings surrounding the losses. This need to conceal their feelings may have commenced and been reinforced during hospitalization as all of the participants stated that they were never asked how they felt about all the changes as a result of the diagnosis and treatment of the cancer. They all stated that talking with the researcher was the first time that they had talked to a health care professional about their experiences.

**Phase III: Re-emergence into Society**

During this phase, the main goal of the participants was re-emergence into society and living in the manner to which they were accustomed prior to their surgery. Although some functional abilities were
adversely affected by the cancer treatments and remained disturbing, four participants were able to return to their previous employment. Two of the participants were retired and focussed on returning to their hobbies and leisure and volunteer activities. The remaining two were preparing to return to their previous careers. Concern about their futures continued to be an issue.

**Functional abilities**

All the participants continued to cope with functional losses which were improving with time. Some had difficulty accepting that they would never be able to do some things the way they used to. Others felt discouraged about their lack of energy. One participant described her feelings of frustration:

*What I think you have trouble accepting is that it may not get better than this. And you think, well is this good, or is this not good? I mean its pretty damn good compared to what it was but, it ain’t, you know, the top of the mountain. And you think: “gosh, is this for the rest of my life I’m going to be like this?” And you have to start accepting things and this is the hard part....It has been the last I’d say six months where I am able to get around well. You know, I mean really have no problem getting around and doing*
everything everybody else does, just a little slower....I think that it has taken so long. Am I ever going to feel better?

This individual continued to have difficulty with balance and facial paralysis two years after her surgery. Although this woman was able to live independently, she was doing so with difficulty and was becoming discouraged with her slow progress. At the time of the operation, she had had no idea that it would take two years to recover her strength and durability. Many of the other participants voiced the same concerns regarding the substantial number of functional losses and the length of recovery. One individual described her situation:

I was saying to Dr. [a particular physician], "Why do I have this, is it just me, am I imagining that I have this terrible salt taste in my mouth?" He said, "I can’t explain it. I’ve had several people tell me that. It will go away." And I said, "Yeah, but it’s one of those things you’ve got to learn to live with. She said, "Yeah, that’s just one of the things."

(laughs) Particularly tea and coffee which is such a common thing. This is one of the things I feel cheated on. I don’t enjoy a cup of tea anymore....These are the silly little things in life which you don’t place much importance on, but when
they're taken away from you they assume somewhat more
importance....It's stupid little things but they all add up.

It was also during this time period that some of the original
functional losses became less consequential. Some of the participants
described the return of some movement and sensation in areas that had
previously been paralyzed. These functional abilities had not returned to
the normal preoperative status and were considered by some to be
troublesome at times. However, they were not as disabling as during the
previous two phases and this allowed the participants to focus more on
issues surrounding contact with the public, such as returning to work.

Optimism

During this phase, the participants found it difficult to be optimistic
about their future. Several became discouraged with their own situations.
Many of them spoke about their thoughts and feelings related to the
cancer experience and the radical treatment regime and the impact it had
on their lives.

In order to manage their discouragement with their own situations,
all of the participants compared themselves to people whom they
perceived were enduring more difficult circumstances. Their own
circumstances became more bearable with this coping mechanism. One
participant stated, *How can anybody feel sorry for themselves when
there's kids this high [indicates little children], running around out there
with the same type of cancer [visited the Children's Hospital]." Another
individual related that "I remember looking at that [talking about a person
at the agency with shaved head and extensive head and neck surgery] one
day and thinking, you know, you've got nothing compared to what these
guys got....I've got no right to feel bad."

The gradual development of a more optimistic outlook is described
by one participant:

The first six months its almost like you're standing still and
you're not walking. You're healing, but you're kind of not
worried about the future, you're, just let me feel better now,
sort of business....I think as soon as the changes that have
taken place in you...for instance you're not hurting any
more. Your taste is maybe coming back somewhat. I went
through a period where eating was a real hell!! You know, I
couldn't taste a damn thing! It was like sawdust. Now the
moment that that sort of gets back to normal and you're
almost feeling like a whole person again, when you get to
that point, you kind of put all this other stuff behind you and
look forward to the day when it will be better. You know,
when life will be more normal.
Social support

During this phase the participants partially depended on their families for support; however, most of the pressure to function independently fell on the participants themselves. As in the previous phase, they tended to conceal their feelings and anxieties about returning to their careers. Several of them expressed apprehension about returning to work and the impact that their altered facial appearance would have on their clients and colleagues. They felt that additional support from trained health care professionals during this transition period would have been very beneficial. Some of the participants expressed a desire for assistance from health care professionals in helping them to develop strategies to deal with the reactions of others and assisting them with enhancing their altered appearance.

Several of the participants spoke of the lack of financial assistance to assist them with this difficult experience. One participant in particular was unsuccessful in his attempts to return to work almost immediately after discharge from the hospital. He felt that it was necessary to assist his wife with supporting the family financially.

Phase IV: Living with Facial Disfigurement

When the participants were interviewed by the researcher, not all of them had reached the phase of living with facial disfigurement. Two
individuals who were having difficulty recovering from their more recent surgery were unable to return to their careers at the time of the interview. There were no new losses which were a direct result of the diagnosis and treatment of cancer during this phase.

The participants had developed coping strategies to manage their functional losses prior to this phase and, indeed, no longer considered them to be major challenges. In fact, they described them as "bothersome" or more of a "nuisance."

A characteristic of this phase was that several of the participants had developed a new philosophy of life as a response to their uncertain futures, multiple complex losses, and the possible recurrence of cancer. Several of the participants spoke about the vast influence that cancer had upon their lives. They found its effect to be so far-reaching that it changed their ingrained values and philosophies. One participant described her philosophy: "You like all the little things a lot more. Like going for walks and being independent again....I think that’s one way I’ve changed, simpler things please me a lot now." Several participants also described becoming more aware of the value of their relationships with their friends and families and focussing more on their health and related issues.
For the women in this study, this new philosophy also pertained to their future career plans. One woman stated that "I want a job now, not a career, I just want to have a job." Another woman asserted:

Having cancer and dealing with it just made me more strong....I’ve changed drastically since my illness....I’m learning patience.....Not to lash out at people....I know every little stress affects my health...so I choose to go the route to minimize my stress level.

In contrast, the male participants maintained or increased their previous career aspirations—a more difficult task than they expected. For example, one man altered his career and resolved to earn a substantially higher income than he had earned prior to his surgery. He stated:

Assuming the best possibilities for my future, no matter how skilled I got in the... [name of the business] business I would never make it above the poverty level. Even if I got substantial raises....I figure well that’s no good....So I thought to myself, "If I put three years into learning everything about [name of new career] at least I’d have a chance of making a living above the poverty level." That’s when I signed up and started the course...I want to make more money. It’s just a matter of applying myself harder.
Social support

The participants were very independent by this phase. They had begun to work and support their families. There were virtually no formal support systems for the participants during this phase except for follow-up appointments with various physicians. Informal support systems had returned to the level of support that existed prior to their experience with cancer and its treatment.

The Impact of Stigma

In this section the impact of stigma on the participants' experiences is examined in relation to the four phases of the recovery process. Stigma's destructive role in the lives of these individuals increased over time and was directly responsible for numerous significant social losses.

Phase I: Initial Postoperative Period

The response of the participants' families during the initial postoperative period played a crucial role in their recovery process. All of the participants spoke about their appreciation for the support from significant others while they were hospitalized. Several described their families as being their principal support system during their recovery.

Family reactions

Seven participants described family members fainting or almost fainting when they initially saw their loved one after the radical surgery.
This reaction contributed to some of the feelings of self-consciousness and discomfort around visitors experienced by the participants. In addition to the negative reactions to the facial disfigurement, the negative feelings that others attached to cancer began to become evident during this period. The participants spoke about family and friends being extremely upset about their having cancer, an understandable reaction. However, they typically described family members’ reactions to cancer as more extreme than their own. One participant described her experience:

> It was because my friends and family treated me really weird. I felt that I had more AIDS or leprosy, than I did cancer. They were afraid of me. They were afraid, just afraid. I dealt with it better than anyone else, and I was the one that was ill, and, to this day, I really can’t understand that....Emotionally, yes, they were very distraught and upset, of course, but they always looked at me like so sad, like I was going to wither away, you know, like I wasn’t going to make it, and they didn’t know what to do.

This narrative illustrates several points. First, this participant felt that she was being treated differently because of the social meaning attached to the illness. She perceived that others were afraid of her. Second, her feeling that she was coping with her diagnosis, illness, and treatment better than
her family was left her hurt and confused. Finally, she had the distinct impression that her family automatically felt that she was going to die because she had cancer. These assumptions, held by society, are described in detail in Sontag’s (1978) essay. Sontag (1978) states:

Metaphorically, cancer is not so much a disease of time as a disease or pathology of space. Its principal metaphors refer to topography (cancer "spreads" or "proliferates" or is "diffused"; tumours are surgically "excised"), and its most dreaded consequence, short of death, is mutilation or amputation of part of the body (p. 15).

The individuals described in this study clearly have experienced the worst possible effects of cancer according to the assumptions held by our society. They have had cancer in a very visible area, it has been surgically "excised," and they have been "mutilated" by this "dreaded" disease.

Ironically, many of the participants perceived that they had to be emotionally strong for their families. This perception began at the time of diagnosis. Consequently, these individuals focussed on reassuring and supporting others rather than on their own feelings and coping abilities. Dunkel-Schetter and Wortmann (1982) assert that individuals diagnosed with cancer need additional emotional support from significant others and health care professionals. They frequently encounter physical avoidance
from others, evasion of open communication by others, and contradictory
and inconsistent behaviors from others. The individual with cancer often
interprets these reactions as rejection.

Public reactions

Although the participants had very little contact with the public
while hospitalized after their surgery, they were very aware that the brief
contact they did have with strangers was different and uncomfortable.
Several participants recalled the reactions of others when walking in the
corridors. One individual said:

You just have to tell yourself that people are going to stare
’cause you look funny....And let them stare and if they want
to talk, let them talk. Let them ask questions....I’d rather
have that than sort of peeking. But I think being so sick
helped because you are so sick you don’t give a damn. You
don’t care what you look like. And you just get through the
day. But you still don’t like to be stared at.

Another participant related his experience while on a daypass from the
hospital after his surgery:

I got mad at her [his wife because she would not pick him up
at the hospital]....I climbed on a bus with these tubes coming
out of my nose. And I went home....You feel kind of
conspicuous walking around with these tubes hanging out of your nose, you know, it was because I was mad at her that I was able to do this, because if I wasn’t mad there’s no way I would have got on a bus looking like that, with these tubes hanging out of my nose (laughs). Man, I kind of just looked out of the window so I wouldn’t see if anyone was looking at me.

It is clear from this statement that in order for this man to venture into the public eye at this point in time he had to be focussed on his extreme feelings of anger rather than on others’ behaviours towards him because, as he stated, it would have taken an enormous amount of courage to venture out under other circumstances.

As a result of the reactions of others, several individuals became uncomfortable around visitors and were inclined to avoid them. One individual related her feelings about visitors while in the hospital:

You want to see people, but you don’t want them to see you. It is almost as though if they could just stay on the other side of the curtain it would be nice, and hold your hand (laughs). But I think in a way it was good because I saw the way people looked, and I got over it, I think, faster than putting it off.
Another participant described her attempts to hide from the world in the hospital after her surgery:

I kept the curtains closed and the nurses would come in; like for the first couple of days they'd come in and whip open the curtains and everyone walking by would stare at me, and I'd crawl out of bed and close them and they'd keep opening them. It was hard to get up and close them. It was hard to go to the foot of the bed and do that.

Finally, a third participant described her attempts to shield a child from her facial disfigurement while in the hospital:

I have a great niece, she's five years old,...she was determined to come to the hospital to see me, and I was a little concerned that it would upset her because at the time it was very bad [talking about her appearance]....I didn't know what to do because (a) how would she be, you know, how would she like it and (b) how would it affect [name of the child]. And we decided that okay, she'd come, and I could just put a mask on or something at that time.

It became apparent from these statements that the behaviour and responses of others were beginning to shape the meaning that the participants assigned to their altered facial appearance. Early in the
recovery period the participants felt the need to hide with shame and embarrassment from society. The woman who felt that somehow her altered facial appearance could be harmful to a child was more concerned about the possibility of harming the child than her own feelings of sadness surrounding her perception of the need to wear a face mask. She interpreted society's messages about the value of physical attractiveness as meaning her appearance could be harmful to children. With further probing during our interviews, she admitted that she was, in fact, basing her view on the reactions from, and discussions with, other adult visitors. This view reinforced her fears that she was something frightening to look at. In fact, she described herself as "freaky."

Jones, Farina, Hastorf, Markus, Miller, and Scott (1984) note that people's behavioural reactions to an individual's facial disfigurement can in turn shape the affected individual's behaviour and personality. These changes may be harmful to the individual's self-concept. To further illustrate this point, another participant spoke about her feelings and reaction to visitors after she had been stared at by others:

It was my request...that nobody visit me, and she [her mother] made sure nobody came near me, and it upset a number of my friends who didn't understand that it was
because I didn’t want to see anybody...and they still don’t understand why I did that.

This statement further validates the important role which the societal response plays in shaping the meaning assigned to, and the significance of, the losses experienced by these individuals. This participant, anticipating that other people would react differently to her because of her altered facial appearance, attempted to shield herself from these reactions by isolating herself from others. Although embarrassed because of her appearance, this individual, like the others, depended on close family members’ supportive visits. After the initial shock and concern about their altered appearance, the family members continued to love and care for them as they had prior to the surgery, regardless of their appearance.

**Phase II: Initial Contact with Public**

During the time period when the participants had initial contact with the public outside the health care institution, stigma continued to pervade and shape their experiences. As the impact of stigma became greater, the participants experienced losses that were more social in nature than the functional losses resulting from the disease and radical surgical treatment.
Relationships with significant others

Several participants described altered relationships with their families. Typically, they perceived that others were uncomfortable visiting or helping them with their care at home. One man described his wife’s reaction to his laryngectomy stoma:

I think there’s a difference [in his relationship with his wife], but I don’t think she would say there is a difference. But I don’t know how to explain it....I think it has affected her, but I don’t know, yeah, I think it bothers her....See, my wife would never attempt to change that [talking about his duckbill].

This man had to rely on his daughter for assistance with changing his duckbill. He elaborated on this experience by describing his wife’s work as a homemaker prior to his illness. He described her ability to care for individuals who required palliative care but she felt unable to assist him with his laryngectomy. This man was unsure of her rationale for avoidance of assisting him with what he viewed as a small aspect of his laryngectomy care but it is possible that he perceived negative feelings regarding the appearance of his laryngectomy stoma. Other participants described similar situations when family members were uncomfortable assisting them with their care.
French (1984) discusses long-term relationships and the impact that stigma has on these relationships, in particular, on intimate relationships. Stigma can affect the previous role relationships which have characterized a marriage. These roles may be completely upset by the consequences of the disabling trauma. Both the husband and wife may feel conflicting emotions. The "marked" individual may feel both grateful and angry with the spouse; the "unmarked" spouse may feel deep love and compassion and also feel trapped, angry, cheated or guilty over contemplating desertion. French (1984) states that caretaking issues become dominant. Time and energy for physical caretaking may be overwhelming for the spouse if he or she takes on the role of primary caretaker. Finally, French (1984) asserts that social activities may also be curtailed because of the physical status of the disability and feelings surrounding the stigma, such as shame, embarrassment, and awkwardness in dealing with outsiders, as well as the attributional implications of the mark.

Some participants described a change in their relationships with their siblings. They perceived that their siblings were uncomfortable. One participant described her experience:

When I got out of the hospital, my sister came over to visit me, and I asked her if she would help me in the tub, if she would wash my hair for me. She said she would. She said
she wanted to go home and have a shower and she’d be back, but she never came back, ever!

This individual felt isolated and alone because of her sister’s reaction to her illness. With further probing she acknowledged that she did not know why her sister had rejected her request for assistance. Grossman (1972) found that siblings of a child with a disability were more likely to have problems than siblings of a normal child. Schreiber and Freeley (1965) found that siblings who do not have a disability may feel guilty for not being afflicted with the disability. These siblings may also feel overwhelmed and overburdened by the sibling with the disability. Thus, these factors may have been present in this relationship. The participant’s sister may have experienced ambivalent feelings towards her and reacted by rejecting her. This may be a result of the sister not having had support for dealing with her confusing feelings.

Another participant described her relationships, during this phase, with her sisters who were angry and resentful of her because their mother focussed her attention on her, the ill sibling, rather than equally among the sisters. French (1984) asserts that this is a frequent reaction of parents and siblings to an individual with a disability.

Several participants also perceived that their friends were initially uncomfortable with their altered facial appearance. The participants
described some friends as staring at the scars, unable to make eye contact, and occasionally asking "unreasonable" questions about the scars. In response to the discomfort they felt during these incidents, several participants developed strategies to increase their level of comfort. Many participants described humour as a useful strategy. One participant stated:

You've got to keep your sense of humour. I mean even at my worst, I'd make jokes about the way I looked. I mean it was hurting, but making the jokes helped and it helped other people when they were uncomfortable. I mean because they knew that you knew the way you looked and it was okay....I was always able to laugh about stuff even when it was the worst. Making jokes about the way I looked or my balance or what I couldn’t do.

This narrative illustrates that this woman felt that people felt uncomfortable about her appearance because she sensed the stigma society attached to her appearance. In joking about very sensitive issues, this woman concealed her true feelings about the changes in her facial appearance and functional abilities. This assisted her in interacting with others.
Humour as a strategy was also used by other participants when relating to friends as well as in other difficult circumstances. Jones, Farina, Hastorf, Markus, Miller, and Scott (1984) discuss the use of humour as one of the most effective strategies to reduce the potential discomfort and strain of others. They assert that forms of self-deprecating humour may be effective in helping the person with a disability keep the disability in perspective and to inform others that it is all right to talk openly about it. Such a strategy assists others in enjoying the disabled individual's company and assists the disabled individual with maintaining a social connection with others. It is also important to note that this type of humour assists the disabled individual in dealing with the uncomfortable situation as well. However, this author believes that it is imperative to recognize that self-deprecating remarks should not be used as a strategy if they are internalized by the disabled individual. This could be very detrimental to his or her self-concept.

Communication with significant others

Another way in which stigma was experienced by the individuals in this study was the manner in which their family and friends communicated with them during this phase. One individual recounted her experience with her family:
It was like don’t talk about it [cancer and resulting radical surgery] because you know, it would upset my mother. Like in the beginning, it would really upset my mother to talk about it and stuff like that, so I always found well, if I don’t talk about it, it makes her feel better. And I’d go around and be happy, for them. It makes them feel better, but sometimes that helped. But a lot of it I felt I was pushing everything inside.

This young woman suppressed her thoughts and feelings surrounding the illness because she felt that it upset her mother to talk about it, even though, at this time, her family was her predominant support system. Several other participants spoke about similar experiences in which they responded to their family’s needs for support rather than seeking support for and assistance with their own needs.

Barbarin (1986) discusses altered family relations and functioning in families with children diagnosed with cancer. He states that the heightened sensitivity of family members to the sick individual may build barriers between them because they feel compelled to disguise their sadness and pain so that other family members may be shielded. Even though this secrecy is well intended, this concealment of feelings will strain and distort genuine intimacy in the family. In turn, the individual with
cancer may wish to protect the family from his or her feelings and fears surrounding the illness. Barbarin (1986) states that "The unintended consequence of the lack of disclosure is experienced as withdrawal and estrangement at a time when family members most need support from one another."

**Altered facial appearance**

Despite limited contact with the outside world during this phase, several women became increasingly self-conscious about their altered facial appearance and described their initial attempts at concealing their scars prior to going out into the public. One young woman related her experience: "And going out was a big deal. To get ready was a big deal. I had to find something that I could wear, something with a collar to hide the scar."

In contrast, the men in this study reported that they were much less self-conscious about their appearance. One middle-aged man stated: "I've never really thought about it [changed appearance]. You know every now and then I'll notice it at a different direction. Every day I'm shaving I notice how concave it is there....I'm not conscious of it during the normal course of things." This individual continued:

The change was very superficial really....If I was a woman particularly if I had always been very attractive and I relied
on that more than other things, I would possibly have been devastated by even a minor imperfection. This is more so than a man. Appearance is more important I think to a woman in business or anything else. When a man gets wrinkles and what have you, it’s character; but when a woman does, she’s an old hag (laughs).

The other men made similar comments about their changed appearances. In fact, the men, even when encouraged to talk about their feelings regarding their altered appearance and its impact on their lives, tended to describe their altered appearance in more neutral terms than did the women. Kleck and Strenta (1985), in their study, also found that men tended to use more neutral terms about their altered appearance. This may be due to the fact that society does not place such a significant value on men’s appearances as on those of women. Men also have more options for concealing facial scars such as beards and moustaches.

**Economic losses**

Another loss which was the result of stigma was experienced by a middle-aged participant. This man and his family experienced financial difficulties. He was previously self-employed and able to stay at home for only a few weeks after his discharge from the hospital. In order to assist his wife with supporting the family it was important for him to find a job.
He had to cope not only with many of the losses discussed earlier but also with financial losses as a result of his seven-week hospitalization.

In response to this economic loss he became desperate, searching for a job almost immediately even though he had extensive dressings on his head and arm. He recounted his experiences while job hunting:

I didn’t look very nice [with the bandages]. I even went out for interviews with a head like that, you know. A guy just looked at me like wow, where’s this guy from Mars or something. Actually it was a stupid thing to do. I shouldn’t have done it but I was...not financially stable.

Unfortunately, this individual’s inability to re-establish himself as the provider led to conflict in his marriage, a common problem in families where an individual has become disabled (French, 1984). French (1984) discusses the possibility of permanent role shifts among members of the family and the importance of adjusting to the shifts in order to clarify ambiguity in task responsibility.

**Phase III: Re-emergence into Society**

Stigma continued to have an increasingly greater impact on the participants’ lives as they became more immersed in their social lives and came into contact with the public more often. They were more likely to be stereotyped by those who did not have facial disfigurement or cancer
than during the earlier two phases. Subsequently, the participants experienced several additional losses as a result of stigma. Jones, Farina, Hastorf, Markus, Miller, and Scott (1984) state that:

> Embarrassment, frustration, and anger are just a few of the unpleasant emotions we experience when we find ourselves being stereotyped by others. For stigmatized individuals, the pain of being stereotyped is especially acute. Indeed, stereotyping is at the heart of the stigmatizing process.

**Self-confidence**

One of the significant losses resulting from stigma experienced by the participants was the loss of self-confidence. Several described feeling less confident about their abilities as a result of negative reactions from others. One young woman described her feelings:

> My self-confidence definitely took a nose dive. I still have a problem talking in front of people....I think when I came out at the end of grade twelve there, I was really getting my confidence up. I definitely believe that. After the surgery it took a nose dive....I became reclusive. I didn’t want to go anywhere.
Another woman gave up her vision of becoming an actress after the surgery. She related her experience:

I just felt that because I had the scar you just can’t do that [talking about acting]. And then I didn’t have the confidence....And then I thought well,...if I did have the confidence to go that far well, you can only go so far because the scar would be noticeable....That was my perception at the time. It was like, no director is going to want me in a role like that.

**Self-esteem**

The participants’ self-esteem was also negatively affected as the result of society’s values and expectations about physical attractiveness. Facial disfigurement seemed to be particularly difficult for the women in the study. It can be argued that this is because society places such value on women’s appearance (Hill-Beuf, 1990). As one woman stated, "Looks are so important. You know every magazine or TV, it’s always beautiful people, and it just seems so important to people, and you think suddenly you’re not one of those anymore. You’re different. And that’s what bothers, I think." In fact this woman compared her experience with that of death because she felt it was so traumatic. Another middle-aged woman felt that she was not an attractive person to be with anymore, which affected her relationships with men:
I feel as though when I talk to a man I’ve never met before, he’s not going to think that I’m coming on to him. I mean why would somebody like me come onto him?...I feel as though I’m not attractive anymore the way I felt I was. Well, you know I wasn’t Elizabeth Taylor before but I felt I was OK. I was passable. But I don’t feel that way anymore....there’s nothing I can do about it. I can’t do a thing about it which is kind of sad. It makes me sad.

As a result of basing much of her self-esteem on her appearance, which is typically promoted by the mass media, this woman felt she had lost all hope of finding a husband:

I don’t expect I’ll meet anyone....I was getting older, you know, and I thought well it’s harder as you get older...There’s still hope, you know, you always go around with that attitude of well, you know, you never know, and now I don’t feel that. It’s just taken my hope away....That’s one of the sadder things of this whole thing.

The lost hope of future marriage felt by this woman and the lost vision of becoming an actress by the other young woman are losses related to these individuals’ perceptions of what is valued by society. They based their feelings on what they believed society values. This is supported by a study
by Ventimiglia (1982) who found that women who were considered unattractive came to expect very little from the social world, particularly men, after a very short period of time. As a result, these women were overwhelmed by very small gestures of courtesy from men.

Concerning the individual who is marked, Jones, Farina, Hastorf, Markus, Miller, and Scott (1984) discuss the emphasis that is placed on the mark by others as well as by himself or herself. If the marked person accepts the negative evaluation from others and comes to view himself or herself as unworthy, he or she will suffer a loss in self-esteem, especially if great emphasis is placed on the mark. Giving a great deal of emphasis to the mark by the marked individual and others is most likely to occur when the stigmatizing condition is relatively new, very visible, and knowledge about its full range of effects and the course it will follow is changeable and uncertain. Hill-Beuf (1990) refers to this process as "self-stigmatization."

**Comfort with public**

Stigma played a major role in decreasing the participants' comfort with public contact. Many of the participants experienced people staring at and questioning them, a situation they found very embarrassing. One individual described her embarrassment:
I remember being at school and I guess people didn't notice it at first [her facial scar]...we were in the cafeteria and I went to turn my head or something, and this girl in my class said, "Oooh! What happened to your neck!" And it's like...you just want to crumble, 'cause it's sort of like all of a sudden you feel like a million eyes are staring at you. It was the reactions of others that to me, were really embarrassing.

In his extensive discussion of the visibility of the stigmatizing mark, Goffman (1963) found that when the individual's mark can be visually perceived by others, the person who has the stigma may feel that when he or she is among unmarked individuals, this exposure "nakedly exposes him" to invasions of privacy. These feelings are especially heightened by staring. Feelings of displeasure and discomfort are increased by conversations that others feel free to strike up with the marked individual about the stigmatizing condition. Goffman (1963) states that "the implication of these overtures is that the stigmatized individual is a person who can be approached by strangers at will, providing only that they are sympathetic to the plight of persons of his kind" (p. 16).

It also became very apparent during this phase that the participants experienced discrimination not only because of the stigma attached to their altered facial appearance, but also because of having had cancer.
When two of the participants were prepared to return to work, they encountered many more obstacles in their search for employment related to their experience with cancer. This middle-aged person described his frustration and emotional pain:

But the unpleasant thing about cancer is, I'm sure people know the difference between cancer and AIDS, but I guess because cancer has got such a high death rate, and AIDS is terminal, the two are very similar in the way people treat you. It seems that in these interviews I'd get down to the last bit... where they seem excited about everything, and then they ask you, you know: "do you mind me asking what happened to you?" I should have said: "I was in a car accident or something." It seems as though after I told them I had cancer, that was the end of it. You know. They promptly got up and shook my hand and said: "Well, we'll let you know."

Therefore, it became evident that the participants in the study were doubly stigmatized, by facial disfigurement as well as cancer, yet society still expected them to return to work.
Concealing altered facial appearance

In order to decrease the likelihood of negative reactions from others, all of the participants discussed ways in which they attempted to camouflage their facial disfigurement. Several strategies follow. One participant stated:

I kept myself looking good. I became a fanatic about my hair. My hair always had to be done right. Always had to have makeup on. Always had to be dressed presentable. ... But just to make sure I was feeling good then I looked good. But I had to make sure I was feeling confident. So state of mind, right?

Another described her use of a prosthetic ear and sunglasses to conceal her altered facial appearance:

I wear those clip-on sunglasses, and I have to take these glasses off to fit them on and I will turn away from people. I won’t let them see my face. And even my family. I will very rarely face them without the dark glasses. They are, I guess, my safeguard against the world....I felt a lot better when I got the ear. That made a big difference. Even although a lot of people didn’t even notice. But it did to me. To me it
meant a little bit more normal. You know you've got two of everything.

Another individual described her plans for concealing her altered appearance prior to her return to work, where she was often required to give presentations to large numbers of people:

The neck scarring over here, that's a bit annoying. But that can be camouflaged with the right clothes. I am planning to, you know, wear clothes with long sleeves. Gone are the days where I can wear short sleeves [she had a graft taken from her wrist and is left with extensive scarring on that arm]. See it's, I guess, it's more not wanting to draw attention to yourself. For me, I couldn't care less, but it's, maybe it's just subconsciously you're trying to make yourself as normal as possible. I don't want people to, sort of have to stop and say: "Oh, what happened?" Or feel embarrassed.

One individual spoke about his attempts to find shirts that fit his neck after his laryngectomy and conceal his shoulder, which drooped as a result of the surgery:

So I shop, and shop, and shop, but it's hard to find a shirt that's the right size there [points to his neck] and the right
size here [points to his shoulders]. And the other thing is since my shoulder dropped this arm is lower. So a lot of clothes you buy you can see this shoulder is much lower.

Finally, another participant described how he hid his facial scar:

I lost that much of my jaw, you know quite a bit. Now no more chin. But you see I am very lucky in my situation that I'm a male. Because well, I grew this beard to cover it all up....they cut my lip in half right here....I was lucky insofar as that the hair grew right down the scar you know. And it's quite a mess under here. It's like a gross looking belly button there [pointing scar under his chin which is beneath his beard].

Although these individuals attempted to camouflage their altered facial appearance, it was impossible to conceal it totally. This was especially true for those whose difficulty with articulation brought additional attention to their faces. Goffman (1963) maintains that when the stigma is immediately perceivable the obtrusiveness or interference with the flow of interaction must be considered as another factor which contributes to the mark. For example, an individual in a wheelchair may have a visible stigma, but, when everyone is seated at the table in conversation, the wheelchair is overlooked. In the case of an individual with a facial
disfigurement and a speech impediment, the speech impediment cannot be overlooked as can the wheelchair. Consequently, the stigma is reinforced by its visibility and interference with the flow of conversation.

**Financial support**

Several participants described their attempts to obtain financial support from the government during their recovery period, prior to returning to work. However, the only financial support available to them during this time was welfare. Curley, Walsh, and Triplett (1982) found that Vietnam veterans with maxillofacial wounds were significantly less often fully employed, had the lowest income among others in their study, the lowest number of college degrees, and the highest incidence of being in trouble with the authorities. These factors all contribute to decreasing financial status. One man asserted:

I remember sitting in the hospital worrying about you know, the family. Like what the hell am I going to do. I haven’t got anything to leave them....The other thing was while I was in the hospital I wasn’t earning anything, you know, just zip. Whatever money I had, got used up. When I got out of the hospital I went through a series of exercises. I call them that because that’s all they turned out to be. I applied to the Federal Government for relief from medicare....Actually I
think it's through Canada Pension....I got an answer and I got a very short note back that I didn't, I was disqualified because they have a clause in it and she underlined it, but they wouldn't allow me to have it because I could go back in the foreseeable future. And I said, "what the hell is the foreseeable future, that could be anything?"...I won't go on welfare. So the next thing was, I said, "Well, I had better go back to work or something."

Understandably, this man became depressed. Unable to find satisfactory employment postoperatively, he eventually had to sell the dream home he had designed. The government had refused to assist him financially because it declared that he would be able to return to work in the future. He was not considered disabled according to the standards or criteria established for attaining financial assistance, yet society disabled him by not providing him with employment opportunities.

Stubbins (1991) critiques the current meanings applied to disability by social scientists and how these meanings affect funding and services for disabled people. He asserts that problems arise when able-bodied people define the criteria for disability and based on these criteria determine the allocation of resources for the disabled. Stubbins (1991) states "The
implications of conceptualizing disability as an issue in resource accessibility and allocation are far-reaching" (p. 15).

**Phase IV: Living with Facial Disfigurement**

It was during this final phase, living with facial disfigurement, that the participants realized that others would always behave differently toward them because of their altered facial appearances and the stigma associated with cancer. They also discerned that some of the pleasurable activities they had previously enjoyed were no longer as enjoyable. One individual stated,

> It bothers me a little to go swimming....I lost part of my chest up here. They took the muscle out and shoved it into my neck....I still go swimming and stuff, but it bothers me. The thing is I can’t do anything about it....there’s no sense in worrying about it too much or reacting negatively because there’s nothing I can do....I can’t wave a magic wand and put it back together again. I have to live with it and the hell if I’m going to give all those things up just because I’ve got a blinking scar!

Several participants discussed their discomfort with dining in restaurants. One individual recounted her experience:
We did go to a Chinese restaurant not very long ago...but the reason I don't go often is because I can't enjoy my food. It just seems a waste to go out. I don't enjoy it....I do have a problem with eating because I can't feel, my lip is numb. ...I don't dribble but you might find you know, particularly with pasta or something, you know, you end up with something on your chin....I'm a little self-conscious about that.

Another young woman described her strategies to conceal the fact that she has Fry's Syndrome. This rare condition occurs when a severed facial nerve from a salivary gland reconnects to a facial sweat gland. When the participant ate she started to sweat when the salivary gland was stimulated by food. This young woman stated that,

I don't like to eat out. I try not to eat out, and if I don't know the people I'm with, I definitely try to avoid it...If I do go out, sit me next to the wall. I hate sitting in the middle. You know, in a restaurant, in the middle where there is nothing around. I always try to get near a wall....I start dabbing it as soon as I start eating. There are times when I forget about it, you know, it's like I have to break out the
Kleenex and I have to dab it, (laughter) beyond normal sweating, you know my hair gets wet.

This woman continued with a description of her prior strategies for managing this syndrome. She stated that she used to eat breakfast and refrain from eating all day to avoid public exposure, but when she got home she would binge on food. She ultimately gave up this practice because she decided it was unhealthy and unsafe.

The loss of pleasure of dining out in restaurants was a result of the participants' discomfort with their appearance while eating. One individual experienced the loss of functional abilities and another had Fry's Syndrome as a result of the radical surgery. With further probing, these individuals admitted they perceived being stared at while in public restaurants. They found this to be embarrassing. Clearly this loss is not a result of the radical surgery or cancer but of others' responses to them. Such negative responses left them feeling uncomfortable and alien.

Sexuality

Two of the women in the study discussed their feelings about the impact that the stigma had on their sexuality. The first woman described her feelings:

I think at nineteen years old when you meet a man or you meet guys and you think about kissing guys, it's like well,
yeah, I have cancer in my mouth, right. You know, it's like you might have herpes or something. You know, it's just to me, it seems embarrassing just to get it in the mouth. So I don't usually mention that. People think that you can catch it, which isn't true.

The second woman described how her sexuality was affected by the radical head and neck surgery. This woman perceived that she was less sensual or less feminine because her neck had been permanently altered as a result of the radical surgery for cancer:

And the neck it's funny, because the neck to me was always one of the distinguishable features of people. Of women....I’ve got a stack of movie pictures up there and I’ll open every single one of them and they have these nice long, slender, white necks. I think that’s very sensual.

In discussing sexuality and the disabled, Knoepfler (1991) asserts that the prevailing feelings of society are that disabled people are not interested in sexuality or entitled to enjoy it. Many people also believe the underlying assumption that people with disabilities should not have children or that if there are no children there should be no sexual expression. Ducharme (1987) studied individuals who were disabled because of head injuries and found that health care professionals rarely discussed issues of sexuality with
these individuals during their rehabilitation. Subsequently, these
individuals often felt unattractive and asexual. These assumptions and lack
of support from health care professionals likely influenced the participants'
feelings surrounding sexuality.

Public reaction

Several participants discussed the public reaction to their altered
facial appearance during this phase. One participant appropriately
described the responses of others to her altered facial appearance: "It's
like taking your kid out in public and your child has something wrong with
it. People keep coming up and asking you stupid questions." In response
to this, the participants began to modulate previously developed coping
strategies to deal with the constant staring and questioning associated with
their altered appearances. Several individuals spoke of fabricating
nonsensical falsehoods as retorts to the challengers. One person described
how she and a friend sat down and discussed a possible rebuttal to a
discourteous question:

I think that people who didn’t know me should have had
more tact when they asked. I mean isn’t it obvious that I’ve
had some surgery? What do you think happened? I don’t
know, like such a damn question, you know and I’ll say that
just to bug them....I started talking to my friend to make
something up you know. Caught it in an electric blender or something like that. I shouldn’t have to, but I felt I should make something up just to sort of get across to them, you know how stupid their reaction was.

Another individual recounted:

1 get total strangers just walk right up to me. "What happened to you?"...It really depends [her reply] on how they approach me. It’s not necessarily what they say, it’s how they say it....if they make me feel really uncomfortable and they’re sort of matter of fact, like it’s their business to know, I basically turn around and tell them it’s not, it’s none of your business....If someone seems sympathetic...I will tell them the truth....I have to say that as time goes on I’ve known how to better know what to say to every different individual....In the beginning it was really hard....Some people I just lie to them. You know I told this one fellow I got attacked by a shark.

Although they continued to fine-tune their responses during this phase, they waged a never-ending battle with society as they were constantly meeting new people and being continually questioned. They described
never feeling totally comfortable with the various situations and their responses. However, as one individual angrily stated:

I mean why should I feel embarrassed right, for having a scar, for having cancer. You know, I shouldn't have to be embarrassed about that and I am because of the reaction! Because of that I seem to be on the spot so many times, so many times, and just all kinds of situations!

**Adjustment over time**

As the participants became more comfortable with their appearances, some described placing less emphasis on the stigma associated with their appearance and attempting to live their lives as usual and by enjoying leisure activities regardless of their altered appearance. One illustration of this is an individual, previously cited, who described going swimming even though he was embarrassed over the scars on his chest as a result of a skin graft. Another woman described getting her hair cut and the resulting positive feelings surrounding her decision:

I did get real brave...and I went out and got my hair cut short, just took it right off short. It was sort of my statement that this isn't going to bug me anymore....I always used to have short hair and I always looked better with short hair. ...And for me to do that it felt great! I felt really good.
Several participants described the process of becoming more comfortable with the responses of people to their facial disfigurement. One woman who had her surgery ten years ago stated:

I completely forget that I have it, you know until, I can be out and can be happy and on top of the clouds and walking around and I can see a picture or someone asks about it and it's like a complete sudden change of mood. You know, just 'cause all of a sudden it's there for real. You know, oh shit it's still there.

Thus, it became evident that while the participants in the study never became entirely comfortable with the stigma associated with their altered facial appearance, they were able to cope exceptionally well considering all the negative circumstances. It also became evident that they could forget about the alterations with time but they were also reminded very easily by the reactions and behaviours of others. Becker and Arnold (1986) discuss this process. They report that, as the stigma is integrated in the individual's identity, it may move from the foreground to the background of the individual's thoughts. In this way, it becomes tangible but nonintrusive. As the person's life becomes routinized, the stigma becomes less pronounced and negative. Social interaction becomes important because this process can readily emphasize the stigma. The
participants would not have experienced such acute emotional distress because of their changed facial appearance if the reactions of others were not there to remind them of their misfortune.

Finally, the participants continued to endure the stigma attached to cancer throughout this phase. One woman who had had her surgery ten years ago and had not had a recurrence described her experience: "I mean even now people come up: "How are you feeling?" which is an odd statement. I walk up to people and say, "How are you?" not "How are you feeling?" I get a lot of that. Several other participants experienced the same situation which is due to the stigma surrounding cancer. They were treated as though they were still ill several years after their cancer treatments. In fact, some of the participants described people being quite surprised that they had not died from cancer. Some people believed that everyone and everything died from cancer. One woman stated that,

She and I were talking about it [surgery for cancer] and she turned to me at the end of the conversation and she said, "Oh, you're the only person I know that's ever lived after having cancer." She goes, "even my cat died." (laughs) Just like, thanks a lot. You know, like months back, years back,
that would have really pissed me off but it was sort of like, I
kind of laughed about it because it was so stupid.

This narrative illustrates the damaging myths about cancer which pervade
society and which stigmatize individuals who have had the disease.
However, this account also portrays how the participants altered their
responses to the myths over time. In this instance, the woman used
humour rather than becoming hurt or angry because of others’ ignorance.

**Summing Up**

Based on the eight participants’ accounts of living with facial
disfigurement as a result of radical surgery for head and neck cancer, there
were two central themes which played a major role in their experiences.

The first was loss. The participants experienced and learned to cope
with numerous, complex, functional losses as a result of the treatment
regime for cancer.

The second theme was stigma. This was evident to some degree at
the beginning of the illness but grew to greater proportions as time
progressed. Stigma protracted the participants’ experiences with illness
and substantially increased their losses. The losses were ongoing, not
because of the cancer but because of others’ reactions to and views of, the
persons with the cancer. The participants’ abilities to get on with their
lives were hindered by other’s reactions and behaviours towards them.
One example was the difficulty they had finding employment after their surgery. These findings are consistent with those of previous studies. Benson, Karabenick, and Lerner (1976) found that physically attractive people are perceived as having better prospects for professional and social lives. Physically attractive people are liked more (Byrne, London, & Reeves, 1968) and perceived to be kinder and more intelligent (Dion, 1972).

It appears that the participants were more concerned with the functional losses which were visible and had social implications. In order to feel more comfortable in the presence of others they worked very hard at relearning these skills. For example, they expressed concern and frustration about relearning how to swallow food neatly or using a prosthesis to communicate with others.

The resources to assist the participants in coping with their functional losses as a result of the surgery were limited. Formal support from the health care system was available during the immediate postoperative period but, upon discharge from the hospital, the participants rarely had contact with health care professionals other than follow-up appointments with physicians and occasionally physiotherapists. The participants tended to rely on their families for support initially but this was usually limited to assistance with activities of daily living. The
participants tended to draw upon their personal resources such as problem-solving abilities and positive outlooks to deal with the many functional losses.

The losses as a result of the stigma were very distressing for the participants. Stigma was all-encompassing, interfering with their interpersonal relationships, ability to find employment, aspirations, and self-concepts. In order to manage these losses, the participants relied heavily on personal resources. There were no formal support systems and informal family support systems were minimal in assisting them with dealing with issues related to stigma. The onus was on the individual to adapt to the losses. The participants were alone in their battle against the stigma. Unfortunately, this solitary struggle led to sadness and despair for several of the participants and protracted all of their experiences with illness. One participant summarized her experience:

I guess it is a little bit like death in a way. You go through all the stages because something really, really traumatic has happened. It is not just a little thing....You’ve got to start loving yourself again. You’ve got to start looking at yourself and saying that it is OK. That’s me, and accept it. It takes a long, long time and you are all on your own....Some days you think you don’t look too bad and other days you think
you look awful....Some days you’ve been out with people and they have talked to you and it hasn’t made any difference and they don’t seem to have noticed too much. Those are the days you feel pretty good. But other days you sort of see people staring and wondering, "What’s happened to her?" and you start to feel very self-conscious. Those are the days you come home and think oh God, I don’t want to go out that door again! But you’ve got to keep on. Oh, what is it they asked Terry Anderson? "How did you make it through each day?" and he said, "You just do." That’s the way it is, I don’t know how or why, you just do.
CHAPTER FIVE: SUMMARY, CONCLUSIONS, AND IMPLICATIONS

Summary

This study was designed to explore and describe the lived experiences of individuals having an acquired facial disfigurement resulting from radical surgery for head and neck cancer. Facial disfigurement is believed to generate many personal and social difficulties; however, the impact of facial disfigurement on the lives of these individuals has been relatively unexplored. Individuals with head and neck cancer not only have to cope with the diagnosis of cancer and the fears related to this diagnosis but they must also cope with the apprehension and social ramifications associated with disfigurement and related functional impairment.

Much of the literature concerning individuals with head and neck cancer focusses on surgical intervention and radiation of the neoplasms, psychiatric problems, and identification of functional and psychosocial problems related to the surgery. None of these studies has adequately explored the significance and meaning of facial disfigurement for these individuals. Understanding the experiences and their social implications can provide health care professionals with invaluable insights and information.
The phenomenological approach was used in order to gain an understanding of the essence of the individual's perspective. This qualitative approach aspires to discover and describe the "human experience as it is lived" (Oiler, 1982, 178). The participants are viewed as co-researchers and knowledgeable informants who work with the researcher to explore and fully illuminate their perspectives (Omery, 1983). Since little is known about the impact of facial disfigurement and cancer on the social relationships and functional abilities of these individuals and phenomenology seeks to understand what is unknown, this particular methodology was suitable for the research question posed in this study.

Four women and four men volunteered to participate in the study. All had an altered facial appearance resulting from radical surgery for head and neck cancer. At the time of their surgery, their ages were between 19 and 69. The length of time since the surgery varied from eighteen months to 10 years. All were fluent in English and resided in Vancouver or the Lower Mainland. The participants responded to open-ended questions during in-depth interviews.

All the interviews were audio-taped and transcribed verbatim. These transcripts along with field notes were the data used for analysis. Data analysis was concurrent with data collection. As the participants described their experiences of living with an altered facial appearance
more questions and ideas were generated. Answering these questions and including the new ideas procured a better understanding of their experiences.

The researcher utilized Colaizzi's (1977, as cited in Riemen, 1986) procedural steps for analyzing the data. Significant statements were extracted from the transcripts and coded. Meanings were contrived from the significant statements. Separate lists for male and female participants were formulated so that the data could be compared and contrasted. Clusters of themes were extrapolated from the meanings. These themes were then compared to the original transcripts to validate them. At this point, it was appropriate to validate these themes with the participants to ensure that the essence of the phenomenon had been captured by the researcher. A final exhaustive description of the phenomenon was formulated from the clusters of themes. The relationship of these clusters to the central concepts was identified. Finally, the researcher incorporated appropriate literature which validated or challenged the findings.

Two major themes constitute the research findings: loss and stigma. The first theme identified was loss. All of the participants experienced multiple, complex losses as a result of the radical surgery. During the immediate postoperative period, the losses were primarily functional but as time progressed they became more social in nature. The losses
experienced by the men and women in the study were unpredictable. In order to cope with the losses, the participants developed various strategies for managing them. They attached greater significance to managing the functional losses that had social ramifications, such as learning how to eat without drooling or spilling food.

The second theme which was apparent in the data was stigma. The term stigma refers to *an attribute that is deeply discrediting; however, it is the attitudes of others which determine the stigma associated with an attribute, not the attribute itself* (Goffman, 1963, p. 3). Therefore, the stigma is forced upon the individual with facial scarring rather than being an inherent characteristic of the facial scar.

All of the participants were treated differently by others because they had visible, facial scarring and because they also had cancer. The social losses they experienced were associated with stigma and the role of stigma became more significant when they became more involved in public activities after their surgery.

The experiences of these men and women are significantly different from those of persons with other illnesses because of the stigma associated with cancer. Their experiences are also distinct from the experiences of those who have cancer at another site, owing to the visibility of the
treatment site and the importance that society places on physical attractiveness (Hill-Beuf, 1990).

In addition, six of the eight participants experienced overwhelming feelings of sadness and despair associated with the length of the recovery process and society’s negative reactions to their altered facial appearances and cancer diagnosis. Several participants also gave up future aspirations and experienced decreased self-esteem and self-confidence.

Time played a significant role in the participants’ experiences. It became evident that, as time progressed, the significance of the functional losses decreased while the significance of stigma increased. Four recovery phases were identified as the participants learned to manage and adapt to their chronic illness, functional losses, altered facial appearances, and the stigma associated with their illness.

During Phase I, the participants experienced several losses related to body functioning such as eating, drinking, and communicating. The tasks associated with this phase were related to regaining and improving bodily functions and becoming more comfortable with a new body image. In all circumstances, the strategies utilized for managing the changes were practicing new behaviours and drawing upon the knowledge, skill and support of others, as well as increasing their own personal vigor. Greater
significance was attached to those losses that were visible and had implied social ramifications.

During Phase II, the functional losses remained and the goals related to these losses were to regain their strength and endurance and to refine their functional skills. They also focussed on two newly-identified losses: lost independence and an uncertain future. During this and the two subsequent phases, management of their circumstances was centered on two aspects: outlook and support. They worked to develop a positive outlook within themselves and placed their experiences in perspective by reframing their situations. Support was derived from expanding their social networks beyond family and immediate friends.

Phase III was a critical period in which the participants became more involved in their previous public activities such as work and pleasure. They focussed on developing strategies to conceal their altered appearances and continued to work on interpersonal relationships.

Throughout Phase IV, the participants continued to maintain their positive outlooks and support systems. The tasks that they concentrated on were associated with minimizing the effects of stigma on their lives.
Conclusions

The research findings lead to several conclusions about the experiences of the eight participants living with facial disfigurement as a result of radical surgery for head and neck cancer.

1) These individuals experienced numerous, complex losses, many of which were functional and interfered with their activities of daily living, social lives, and careers.

2) These individuals experienced stigma because of their altered appearance and cancer.

3) The stigma associated with cancer and facial disfigurement protracted the illness experience and increased the number of social losses.

4) The functional losses and associated stigma contributed to the economic losses experienced by the participants.

5) After the surgery, as time progressed, the losses as a result of the cancer treatments became less significant and the losses created by stigma increased in significance.

6) There was very little or no formal support from the health care system to assist these individuals in coping with the numerous, complex losses when they returned home.

7) There were no formal resources to assist the participants with the impact of stigma.
8) The participants relied heavily on personal resources such as inner strength, family, and friends to assist them in managing the functional and social losses and stigma.

9) The participants learned to manage and live with their many functional losses but they were never free from the stigma associated with their altered facial appearances and the myths surrounding cancer. They were reminded continually by others' reactions that they were different.

**Implications**

The findings of this study suggest several implications for nurses working with individuals who have had radical surgery for head and neck cancer and a resultant facial disfigurement. The following sections discuss implications for nursing practice, education, and research.

**Nursing Practice and Education**

This phenomenological study provides a comprehensive sketch of what it is like for people who live with facial disfigurement as a result of radical surgery for head and neck cancer. One of the most disturbing findings was that these individuals, once discharged from the hospital, had very little or no formal support to assist them with adapting to their chronic illness and many complex losses. In fact, while hospitalized, all of the participants found that their physical difficulties were attended to but
psychosocial issues related to their surgery were never addressed by any of the health care professionals. All of the participants relied heavily on personal resources such as families, friends and inner strength to assist them with in coping.

In order to assist individuals who have head and neck cancer, nurses must become knowledgeable about the experiences of these individuals. Once knowledgeable about the effects of the cancer, its treatment, and others’ reactions, the nurse, in conjunction with the patient, can assess, plan, and implement nursing care with empathetic understanding and skill. Patients might then have more realistic expectations about the course of the illness and less anxiety which, in turn, would facilitate their recovery.

The findings of this study indicate that individuals with head and neck cancer who have had radical surgery experience many functional losses which impede their ability to perform activities of daily living and achieve a previous level of social functioning. Nurses need to assess, prior to surgery, their patients’ expectations and knowledge about their functional abilities and how these may be affected. If their expectations are incongruent with the anticipated outcomes, they should be re-educated in an empathetic manner. During the postoperative period, functional abilities should be reassessed and a care plan instituted in conjunction with the patient in order for functional skills to be relearned. Patients should
be given considerable support and reassurance during this learning process to prevent discouragement and frustration. Nurses should be partners in learning and take on some responsibility for the patient’s progress. Total onus should not be placed on the patient.

This study concluded that there is a definite lack of formal support for individuals with head and neck cancer, particularly when they are discharged. Formal support was required by these individuals for extended periods and should be available in the community upon discharge. Therefore, an assessment of community resources and patient needs is necessary followed by development of formal support systems.

Patients with head and neck cancer need to be aware that the stigma associated with their altered appearance and illness is presently the norm or standard of this society. It is important to assess their level of knowledge and abilities to deal with the stigma. Ongoing development of strategies to assist them in dealing with others’ reactions is necessary. It is critical for the nurse to incorporate positive feedback and reassurance throughout this process. Nurses should be viewed as empathetic supporters and advocates for patients.

Considering the results of this study, content related to the devastating impact of stigma on people’s lives should be incorporated into nursing education. The role that myths play, particularly in relation to
illnesses such as cancer, should be discussed in conjunction with their prevailing impact on the illness experience. Nurses should become aware that stigma protracts the illness experience and that there are very few resources available to assist individuals dealing with stigma. It is also crucial that nurses become aware of their own attitudes and beliefs about various illnesses and how these affect patient care.

It is also necessary to stimulate public awareness regarding the social consequences of this type of surgery. Others should be aware of the devastating effects of the stigma and the impact of the functional and social losses on economic stability. In order to facilitate recovery, economic assistance would be beneficial for those in need during the initial phases of recovery.

Health care professionals in the formal system such as a clinical nurse specialist working in conjunction with the Cancer Society and other groups with vested interests could lobby and take on an advocacy role for these individual. In this way social policies could be examined, ratified, and public awareness would be stimulated. A clinical nurse specialist may play a key role in the process of redefining disability to include individuals with this type of cancer so that they can obtain the necessary insurance.

Lack of formal support combined with the numerous losses led to feelings of sadness and despair for 75% of the participants in this study.
Nurses must be aware of the significance of these feelings and assess for their presence. If present, additional assessment is necessary and the appropriate supportive resources must be activated.

Finally, to give individuals with head and neck cancer support and understanding throughout their lives it is imperative that the emphasis be placed on members of society rather than on those with cancer. The public must recognize that their reactions to others have an impact on the other people’s lives. Nurses can be forerunners in this process by becoming powerful advocates for individuals who have had radical surgery for head and neck cancer.

**Nursing Research**

This study has focussed on the experiences of individuals who have had radical surgery for head and neck cancer. It provides a preliminary understanding of the experiences of these individuals. Additional research in this area would yield a greater degree of comprehension. Suggestions for further study follow.

Distinguishing between the different types of head and neck surgeries would build upon the present knowledge base. Studying the impact of specific types of surgery would describe the impact of a particular type of surgery on the participant’s functional abilities and relationships. Questions that could be posed are as follows: Do different
types of surgery produce distinctive functional difficulties? Do some types of surgery result in a greater degree of stigma?

Although this study explored the impact of facial disfigurement as a result of radical surgery for head and neck cancer on both men and women, it would be interesting and beneficial to study each gender separately in two different studies. The results of the two studies could be compared. This would provide in-depth knowledge on the impact of head and neck cancer on men and women. Similarly, it would be valuable to know the impact of this type of surgery at various ages. This would provide an excellent foundation for comparative data at different ages. Questions might include: Does the impact of head and neck cancer interfere with progression through various developmental stages? Are individuals at various ages affected differently by the stigma associated with head and neck cancer?

The need for support was a fundamental finding in this study. Future research could examine the impact of additional formal support on those living with facial disfigurement after surgery for head and neck cancer. Questions that could be addressed are: Does additional formal support alter feelings of sadness and despair? What impact does additional support have on the aspirations of these individuals? Does additional support affect the self-concept? What role might self-help
groups play in their recovery? Would a clinical nurse specialist facilitate the recovery process by providing necessary support, guidance, and advocacy within the health care institution and the home? Would support from the clinical nurse specialist improve the transition of the patient from the hospital to the home environment? What would be the impact on the recovery process if assistance were given by a clinical nurse specialist in resolving issues related to re-entry into the workplace?

It would be fascinating to study the impact of these individuals on family members. Most of the research examines the impact of this type of surgery on the individual who has had the surgery. However, significant others are involved in the process and are undoubtedly affected by the experience. Questions that could be asked are: How does the spouse view the partner’s altered appearance? How have the altered abilities and appearance impacted on relationships with each other and with friends? If they have children, how do the children feel? How is the family affected by the stigma associated with this type of cancer? What support do family members feel would be beneficial? How would educating family members about the phases of recovery and their length impact on the family and patient’s experience?

Finally, studying the effects of provision of information throughout the recovery process would be advantageous. What impact would accurate
information have on expectations about the experiences? Would information assist with alleviating feelings of sadness and despair? Would the provision of information give reassurance?

This study has described the subjective experiences of individuals who live with altered facial appearances as a result of radical surgery for cancer of the head and neck. It contributes to the knowledge base available to nurses and other health care professionals working with these individuals. The study has also generated additional questions the answers to which would support the provision of more effective health and nursing care for this group of patients.
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APPENDIX A: INFORMATION AND CONSENT FORM
Information and Consent Form for Research Project:

Living With Facial Disfigurement: A Phenomenological Study of Individuals After Surgery for Head and Neck Cancer

To ________________________,

My name is Kathryn Whitehouse. I am a Registered Nurse completing my master’s degree in nursing at the University of British Columbia.

My research study is looking at the changes in people’s lives after radical surgery for head and neck cancer. The effects of this type of surgery and the related life experiences have not been adequately described. I believe that an accurate description and understanding is necessary to improve nursing care. Therefore, describing your perceptions will greatly assist in describing these changes and this is the purpose of my research study. I am looking for volunteers to participate in this study and have asked the primary nurse from the clinic to give letters such as this one to people who might be interested. PLEASE UNDERSTAND THAT YOU ARE UNDER NO OBLIGATION TO PARTICIPATE IN MY RESEARCH AND THAT YOUR REFUSAL WILL NOT AFFECT YOUR FUTURE NURSING OR MEDICAL CARE.

If you do wish to participate in my research, I will need two, hour long interviews with you at your convenience to talk about your experiences and feelings related to changes in your life as a result of your surgery. During these interviews I will tape-record the two of us talking about your thoughts, feelings, and experiences after your surgery. One example of a question that I may ask you is, "Have there been changes in your interpersonal relationships as a result of your changed appearance?" You may refuse to answer any questions and you may also ask for any part of the tape to be erased. I will be sensitive to your thoughts and feelings. Your identity will be kept strictly confidential, and I will use code names and numbers on all materials. The accidental mention of names or other identifying information will also be erased.
PLEASE UNDERSTAND THAT YOU MAY ALSO WITHDRAW FROM PARTICIPATING IN MY RESEARCH AT ANY TIME WITHOUT PENALTY.

Please call me if you wish to participate or if you have further questions before agreeing to participate. My phone number is 264-0914. You may also contact my thesis advisor, M. Judith Lynam, who is an Associate Professor at the University of British Columbia School of Nursing. Judith can be reached at 622-7476.

Thank you,

Kathryn Whitehouse R.N.

I hereby give my consent to participate in Kathryn Whitehouse’s research for her master’s thesis. I agree that I have a copy of this information and consent form and that the study has been adequately explained to me.

Signed__________________________________________

Date____________________________________________

Witness__________________________________________

Date____________________________________________
APPENDIX B: TRIGGER QUESTIONS WITH ACCOMPANYING EXPLANATORY APPENDIX
TRIGGER QUESTIONS

1. Since your surgery do you feel differently about your facial appearance?
   If so, in what ways do you feel differently?

2. Do you feel that your changed facial appearance has changed your relationships with family, friends, co-workers, and acquaintances?
   If so, in what ways have your relationships changed?

3. If the individual feels that the relationships with others have changed, what reasons does he/she feel are the cause of the changed relationships?
   How do you feel about these changes?

4. What changes have you experienced in your activities of daily living as a result of the surgery, or your changed facial appearance? Some examples of changes may be in the way you eat or changes in the way you articulate your words.
   If you have experienced changes, could you please describe these changes?
   How do you feel about these changes?
   How have they affected your relationships with other people?

5. Overall, can you describe your thoughts and feelings about the changes in your:
   1) appearance,
   2) your relationships with others, and
   3) functional abilities.
ACCOMPANYING EXPLANATORY APPENDIX TO
THE INTERVIEW GUIDE

Demographic Data:

The purpose of the demographic data is twofold. Firstly, it will provide the researcher with the opportunity of establishing good rapport with the participants prior to examining the more sensitive issues such as, the changes in facial appearance after surgery and its impact on social relationships and functional abilities. Secondly, the data will provide the researcher with additional information which will augment the final data analysis.

Trigger Questions:

As previously stated, the phenomenological approach will be utilized in this research study. In order to evoke the participant's perspectives it is imperative to use an open interviewing style which allows the participants freedom to express their thoughts, feelings, and experiences related to the phenomenon in question. Therefore, open-ended questions are appropriate to guide the interview. An open interviewing style also enables the researcher to grasp the utter meaning of the participant's statements by allowing the interviewer to summarize the participant's comments in order to clarify intended meanings or to name a set of feelings that the individual has described.

The trigger questions in this interview guide are all general. The purpose for utilizing general questions is to generate candid discussion of sensitive issues. The trigger questions provide a frame of reference for the participant's response. However, little or no restraint is placed on how the individual answers the questions. This strategy elicits the individual's true position on the theme being discussed. Trigger questions also assist in highlighting the dimensions or qualities of the individual's experience.

Question One:

The intent of this general question is to explore with the individual his/her changed facial appearance. The individual may respond with positive or negative feelings. This question may also elicit the individuals changed feelings of self-esteem, self-concept and body image which may also be explored in more detail.
Question Two:
The purpose of this question is to extricate information from the participant regarding his/her personal relationships. Have these relationships changed? Has their appearance impacted on their relationships with significant others? For example, do they spend less time with their friends and spend more time at home?

Question Three:
This again is a general question which intends to elicit the participant's perceptions and feelings about the changes in their relationships. It also requires the participant to think about and discuss the personal meaning of the change.

Question Four:
The intent of this question is to elicit the changes in the participant's functional abilities and how this has affected his/her activities of daily living and social relationships. A possible response to this question may be that the individual is unable to masticate food and as a result require G-tube feedings. Previously, the individual frequently ate out in restaurants which was his predominant source of socialization.

Question Five:
Finally, this is another general question it is posed so that the participant can once again reevaluate his/her thoughts and feelings regarding these sensitive issues. It also allows the participant additional time to think about other areas of concern regarding this phenomenon. Lastly, this question encourages the individual to reiterate his/her perspective.
APPENDIX C: DEMOGRAPHIC DATA SHEET
DEMOGRAPHIC DATA

Code number _______________________

Date of Interview ___________________

Length of Interview ________________

Gender __________________________

Age ______________________________

Cultural Background__________________

When first diagnosed with cancer of the head and neck

___________________________________

Presence of other Illness _________________________________

Adjunct Therapy _________________________________

Date of Surgery _________________________________

Type of Surgery _________________________________

Type of facial scar _________________________________

Date of discharge from the hospital _______________________

Living Arrangements: Prior to Surgery

_____________________________________

Following Surgery (present)

_____________________________________

Artificial Aids Utilized by the Participant ______________________