

**Role of Perceived Illness, Self-Blame and Type D
Personality in Physical and Psychosocial
Adjustment among Cancer ‘In-Patients’, Assam**

A Dissertation Submitted

To

Sikkim University



In Partial Fulfilment of the Requirement for the
Degree of Master of Philosophy

By

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December 2019

CERTIFICATE

This is to certify that the dissertation entitled “**Role of Perceived Illness, Self-Blame and Type D Personality in Physical and Psychosocial Adjustment among Cancer ‘In-Patients’, Assam**” submitted by Ms. Kinnari Kashyap (Roll No. 18MPPS02 and Reg. No. 18/MPhil/PSY/02) in partial fulfilment of the requirement for the award of MPhil Degree in Psychology of Sikkim University has not been previously submitted for the award of any degree/diploma of this or any other University and it is her original work. She has been working under my supervision.

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DECLARATION

The work embodied in the dissertation entitled “**Role of Perceived Illness, Self-Blame and Type D Personality in Physical and Psychosocial Adjustment among Cancer ‘In-Patients’, Assam**” was conducted at the Department of Psychology under School of Human Sciences, Sikkim University, in partial fulfilment of the required for the award of MPhil degree of Sikkim University. The work has not been submitted in part or full to this or any other university or institution, for any degree or diploma.

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**“ROLE OF PERCEIVED ILLNESS, SELF-BLAME AND TYPE D
PERSONALITY IN PHYSICAL AND PSYCHOSOCIAL ADJUSTMENT
AMONG CANCER ‘IN-PATIENTS’, ASSAM”**

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per 100,000 (Sunderam et al., 2016). Cancer has become a major health concern among the public in India with 1.01 million new cases of cancer per year. This indicates that India as a single country contributes to 7.8% of the global cancer burden ((Sunderam et al., 2016). Around 2.5 million people live with cancer with the mortality rate 5, 56,400 per year in India (Nandakumar, 2001). The frequency of cancer in India varies from 44-122 per 100,000 populations in men and 52-128 per 100,000 populations in women (Akca et al., 2014). The International Agency for Research on Cancer GLOBOCAN project states that the number will double in the next 20 years (Mallath et al., 2014).

Head and neck cancer vary depending upon the sex, country and its sub-types (Bloomerg et al., 2011; Chaturvedi et al., 2013; Subhashraj et al., 2009). Approximately 30 -40% of all cancers are HNC in India, accounting for 23% of all cancers in males and 6% in females (NCRP, 1988-89), highest among the north-east states of Assam, Manipur, Mizoram, Tripura, and Nagaland with

Receiving a cancer diagnosis has been called a 'teachable moment' (Demark-Wahnefried et al., 2005), but it appears that few survivors make

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LIST OF ABBREVIATION

HNC: Head and Neck Cancer

CONS: Consequence

TL: Timeline

PC: Personal Control

TC: Treatment Control

IDE: Identity

CON: Concern

UND: Understanding

ER: Emotional Responses

SI: Social Inhibition

NA: Negative Affectivity

CSB: Characterological Self-Blame

BSB: Behavioural Self-Blame

HCO: Health Care Orientation

VE: Vocational Environment

DE: Domestic Environment

FE: Family Environment

SO E: Social Environment

SE E: Sexual Environment

PD: Psychological Distress

PHC: Positive Health Changes

ABSTRACT

Patients with Head and Neck cancer are at a greater risk of suffering because of the obstructions due to cancer related factor, yet little is known about the factors contributing to psychosocial and physical adjustment. The present study examined the association of the Cognitive attribute such as illness perception and self-blame and type D personality with psychosocial adjustment and positive health changes among the head and neck cancer patients. For this purpose, 66 eligible in-patients (34 male and 32 female) with Mean= 51.68 and S.D. = 15. 26 from early stage: Stage I and II, were selected from 4 different hospitals of Assam. The patients were divided into two groups: patients below 45 years and above 45 years based on the head and neck cancer features in Assam. Purposive sampling technique was used for sample selection. The participants were assessed by using brief illness perception questionnaire, self-blame questionnaire, type D personality questionnaire, psychosocial adjustment to illness scale and Positive health changes questionnaire. The results of the study revealed that head and neck cancer patients reported different causes for their illness such as environmental exposure, bad habits, physical injury/accidents/infections, religious cause and luck. In addition, most patients reported positive health changes such as healthy food habits, physical activity, meditation, proper hygiene and better sleep after the diagnosis of their illness. However, a significant correlation was found among the variables and their dimensions undertaken. The patients who believed that their illness would last longer, had more personal control over the illness as well as they were able to identify more symptoms that resulted in influencing their psychosocial adjustment. Findings suggested that identifying the symptoms and having negative emotions significantly predicted positive health changes in the in-patients as well. Furthermore, gender differences and age wise differences were found regarding adjustment among the patients. Therefore, encouraging for positive beliefs and thoughts among the cancer survivors at a very initial stage would promote them to have a healthier future.

Key Words: Cancer, illness perception, self-blame, personality, adjustment

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CHAPTER I

INTRODUCTION

“There are no psychological problem without biological features and no biomedical problems without psychosocial features”

-McDaniel, Hepworth, & Doherty (1992, pp1-2)

In the recent decade, even in the face of good progression of diagnosis and treatment there is an increase in the prevalence of cancer and its detrimental effects. These factors have drawn much attention of specialist to cancer more than ever, cancer being a big peril to the society (Akbari, 2003; Kotnis et al., 2005). According to the World Health Organization (WHO), report, cancer is one of the most vital diseases of the current period and the second most common disease leading to maximize death next to cardiovascular diseases. However, more than 10 million people are diagnosed with a variety of cancer every year (Momeni et al., 2012).

Cancer is a life-threatening illness touching all aspects of an individual's health. Diagnosis of cancer causes psychological pressure where patients undergo fear of uncertainty about the future (Dankert et al., 2003) contributing to numerous problems in Physical, functional, psychological/cognitive, social, economic, spiritual and family dimensions exposing the patients to a wide array of threats, trouble and potential losses (Alonzo, 2000; Zemestani et al., 2013). Problems related to the disease include nausea, vomiting, pain, constant fatigue, loss of appetite as well as libido, anemia and structural and physical changes. Along with it, the patients suffer from alopecia, mastectomy, and amputation (Zemestani et al., 2013). Furthermore, even though

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patients do not develop any clinical symptoms they may experience worries, fears that might make psychological distress common among them. These may be due to the type of cancer, physical and role impairment, the amount of pain and prognosis and other related issues (Zabora et al., 2001). The chronic illnesses such as cancer can bring guilt, loss of control, anger and confusions among the patients (Stanton et al., 2001).

1.1 Cancer Defined

Cancer can be defined as a group of disease that occurs due to uncontrolled growth and propagation of abnormal cells leading to death if not controlled. However, current believes state that cancer is a multi-step disease that instigates from a single abnormal cell with an altered sequence of DNA (Mallath et al., 2014). Cancer is derived from the Latin word crab i.e. they adhere to any part of the body that they hold in a determined manner, similar to the behaviour of a crab. Consequently, the growth of the cancerous cells can attack and destroy the adjoining structures causing death (Thakur & Rao, 2016).

Additionally, cancer has been recently categorized as a chronic illness. Like the other chronic illness, cancer can cause intense pain, can be disabling, cause embarrassment and be stigmatized (Department of Health, 2001; Koller et al., 1996), as it persists for a longer period of time. A person with chronic illness develops a chart of their life course to navigate the challenges that remain constant within themselves, so as cancer patients. Patients rely on health care services such as pharmaceuticals, machines and other technologies (Tritter & Calnan, 2002).

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1.1.1 Head and Neck Cancer

Head and neck cancers (HNC) are a general name for a group of different types of cancer. The National Cancer Institute defined Head and neck cancers as

“Cancer that arises in the head or neck region (in the nasal cavity, sinuses, lips, mouth, salivary glands, throat or larynx)” (National Cancer Institute, Dictionary of Cancer c.f. Macfarlene et al., 2012). Cancer of the head and neck is globally considered the ninth common cancer (Ferlay, 2010).

The causes of HNC seem to be very complex, and the epidemiological evidence has pointed out several risk factors that increase HNC. Some of the factors may not be the direct cause of HNC, but might individually or in combination increase cancer (Dobrossy, 2005).

1.1.2 Etiology of HNC cancer

Although several factors were identified as risk factors for HNC cancer, only a few were categorized to be the major factors. Smoking tobacco is a dominant risk factor for HNC, where risk is correlated with intensity and duration of smoking habit (Hashibe et al., 2007; Torrente et al., 2011). Since the cigarette contains nitrosamines and polycyclic hydrocarbons carcinogen elements that have toxic effects. It increases the risk of the disease. Alcohol consumption strongly indicted the risk of cancer development especially the cancer of oral cavity, pharynx, and larynx (Bagnardi et al., 2001). There is a strong relationship between the quantity of alcohol use and increase risk. Moreover, consumption of tobacco-associated with alcohol increases the HNC cancer risk to 40- folds (Marur & Forastiere, 2008). Other food habits like betel nut/quid chewing have been identified as a factor in the Asian population (Montero &

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Patel, 2015). Betel quid (also referred to as paan) contains betel leaf, lime, tobacco. Some common forms are khaini (tobacco and lime), zarda (boiled tobacco) and mawa (tobacco, lime, and areca) are consumed in different parts of India. These products lead to oral cancer development (Axell, 1987).

The remaining were classified as emerging risk factors such as poor hygiene (Mayer et al., 1993), dietary deficiencies (Shildt et al., 1999), red meat and salted meat consumption (La Vecchia et al., 1997) can be the etiological factor. The frequent use of mouth wash can also be a causal factor for oral cancer as mouth wash contains alcohol as preservatives (Hasbibe et al., 2000). Environmental factors such as viral infection (herpes virus, human papillomavirus, and herpes simplex virus) (Negri et al., 2000) or fungal infection (*Candida* species) (Stryker, 1988) are strongly implicated in the development of oral cancer.

Treatment for HNC is very complex. Patients undergo various surgeries, radiotherapy, chemotherapy or a combination of the treatments (Argiris et al., 2008). These treatments are associated with experiencing side effects that result in deformity of the facial appearance and disruption of vital functioning of the health such as complications in breathing, eating, swallowing, hearing, sight as well as speech and decrease sensation (Brockstein & Masters, 2010). Patients with HNC require rehabilitative treatments such as speech therapy, swallowing, and facial rehabilitation, physical therapy and occupational therapy (Ward & Van, 2006).

1.2 Prevalence of Cancer among Worldwide and India

An estimation of about 21 million is considered to be a burden of cancer worldwide (Prasanna, 2015). However, the worldwide burden is expected to increase to 21.4

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million new cancer cases and 13.2 million cases of cancer deaths by 2030. Worldwide cancer deaths are anticipated to increase by 60% from 2012 to 2030 (SEER cancer statistics review 1975-2013). These might be due to the increase in the size of the population as well as acceptance of western lifestyles such as smoking, poor diet, physical inactivity and reproductive factors (American Cancer Society, 2011).

However, according to the American Cancer Society (2015), globally 16% of cancer is caused by infection.

Cancer mortality is found to be higher among men (207.9 per 100,000) than women (145.4 per 100,000). Cancer has become a major health concern among the public in India with 1.01 million new cases of cancer per year. This indicates that India as a single country contributes to 7.8% of the global cancer burden (Sunderam et al., 2016). Around 2.5 million people live with cancer with the mortality rate 5, 56,400 per year in India (Nandakumar, 2001). The frequency of cancer in India varies from 44-122 per 100,000 populations in men and 52-128 per 100,000 populations in women (Akca et al., 2014). The International Agency for Research on Cancer GLOBOCAN project states that the number will double in the next 20 years (Mallath et al., 2014).

Head and neck cancer vary depending upon the sex, country and its sub-types (Bloomerg et al., 2011; Chaturvedi et al., 2013; Subhashraj et al., 2009).

Approximately 30 -40% of all cancers are HNC in India, accounting for 23% of all cancers in males and 6% in females (NCRP, 1988-89), highest among the north-east states of Assam, Manipur, Mizoram, Tripura, and Nagaland with an incidence rate of 54.48% (Bhattacharjee et al., 2015). Recently, the National Cancer Registry Program (NCRP) has circulated a 3-year report from 2012-2014. The highest inhabitants with

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cancer were found among North-eastern states of India compared to the other parts (NCRP, 2016). According to NCRP (2016) northern and western Assam such as Kamrup, Dibrugarh, Barpeta and Nalbari districts have the highest incidences of cancer with leading sites such as the oesophagus, hypopharynx, lung, stomach, and mouth in male while breast, oesophagus, gall bladder and ovary in female (Varshney, 2015).

In the north-eastern states of India, the risk is associated with the practice of betel quid, areca nut chewing (Adhikari, 2013), chewing of smokeless tobacco products (Stepanov et al., 2008) and smoking of bidis (Mondal et al., 2013). Around 200,000 cases of HNC occur every year in India. Almost 80,000 cases of oral cancer are diagnosed each year mostly because of the quid of betel-nut kept in the oral cavity for a longer period of time (National Cancer Registry Program, 2009). The most important factor for HNC are smoking, chewing tobacco and/or taking alcohol, as three-fourth of the cancer is attributable to the use of these substances (Freedman et al., 2007; Hashibe et al., 2007). In India, 40,000 cases of pharyngeal cancer and 29,000 cases of laryngeal cancer occur every year. India stands in second place after China in oesophageal cancer with 77,000 cases every India.

HNC has become a major public health problem, with distinct demographic profile, risk factors, food habits as well as personal and family history (Mishra et al., 2009). Approximately 650,000 HNC cases are diagnosed every year, globally making it the 6th common type of cancer (Parkin et al., 2005). Grounded on the visibility of the disease and treatment squeal, HNC is found to be perhaps the most emotionally distressing cancer to experience (Bjorklund et al., 2010). Therefore, the changing situation has brought out quite unfavourable impact among the patents.

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Some consequences of chronic illness such as cancer are rapid and unexpected while others are gradual (Thompson & Kyle, 2000). The decline in day-to-day activities, vitality, relationships may lead to an irregular course of life. These variations may present actual challenges among people to adjust to the disease. This led to a growing focus in psycho-oncology research during all stages of treatment and recovery.

The appearance of HNC coupled with the visibility of the illness, HNC is debatable the most traumatic cancer to experience (Bjorklund et al., 2010). This led to raising the focus of the researchers on the ways they are coping and adjusting with the unwanted situations of their life. Therefore, in the urge of becoming a healthier and finest nation, coordinated and need-based research to understand the threat to the nation from HNC and ways to challenge those dangers are increasingly important.

1.3 Conceptualization of Adjustment to Cancer Patients

In our day to day life, there has been constant struggle sandwiched between the needs or desires of an individual and the demand of the external forces. Regardless of personal illness or death of the loved ones, people facing such blows achieve a better quality of life as most of them find effective ways of accepting such situations (Sadjadian et al., 2011; Silver & Wortman, 1980) and making positive health changes. According to Darwin’s theory of evolution, species that adapted successfully to the external forces lived while others who did not have bought an end to their lives. Therefore, changing oneself or one’s environment on the basis of the demands are the basic needs of our survival. This evidence can be used to improve the knowledge of understanding about the individual’s adjustment to the demands of the external environment (Viquruddin et al., 2012).

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Adjustment can be defined in the following ways:

“Adjustment is a response to change in the environment that allows the individual suitably adapt to that changed situation”

-Sharpe and Curran (2006, p. 1154)

“Adjustment is a continuous process of maintaining harmony among the attributes of the individual and the environmental conditions which surround him. It involves the fulfilment of potential for a personally and socially satisfactory”

-Arkoff (1968, p.4)

From the above definition, it is apparent that an individual has to change the behaviour in order to go well with the unwanted changed situation, to maintain a satisfactory and harmonious relationship with the individual’s needs and environment. Researchers are trying to question the type of individuals that make an adjustment, factors that lead to adjustment/maladjustment and psychological changes occurring during adjustment. Therefore, several attempts have been made by the researchers to measure adjustment in relation to social, cognitive, physical, emotional and personal adjustment. In personal adjustment, personality factors have been investigated as correlates of adjustment. In the present study effect of Type D personality on adjustment is examined. Moreover, satisfactory adjustment can be developed if a person has a realistic perception of the world and himself. Additionally, some patients adjust to the disturbing environment successfully while others could not. This means that there some crucial factors that facilitate adjustment while others hinder the adjustment. In order to develop an adequate understanding of how people adjust it is essential to become accustomed to specific models regarding human nature.

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Adjustment is the continuous process as most patients suffering from cancer are faced with many challenges to solve cancer-related problems (Ahangar et al., 2013). In cancer patients, adjustment can be defined as a cycle of attitudes and functions accepted by the individual for nourishing health, well-being, and overcoming cancer-induced stresses (Sadjadian et al., 2011).

It facilitates the patient to meet the physical needs i.e. mostly described as physical adjustment. However, adjustment to illness can be explicated as a good quality of life, well-being, vitality and positive affect.

Effective adjustment to the disease enhances performance, encourages better living, and improved quality of therapy (Samadzade et al., 2015). Receiving a cancer diagnosis has been called a ‘teachable moment’ (Demark-Wahnefried et al., 2005), but it appears that few survivors make adjustment in the form of positive health changes (PHCs) (Hawkins et al., 2010) despite evidence suggesting that several health behaviours (e.g. striving for a healthy weight, eating more fruits and vegetables, and increasing physical activity) produce ‘probable’ or ‘possible’ benefit by extending disease-free or overall survival (Doyle et al., 2006). However, knowledge about the psychological predictors of PHCs is limited (Park & Gaffey, 2007). Studies such as the NHANES research (Jung et al., 2015; Sutherland & Gee, 2015), EPIC study (Ford et al., 2009) and INTERHEART study (Yusuf et al., 2004) showed how health behaviour change affects an individual’s both mental and physical health. The studies demonstrated that fulfilling factors such as not smoking, 3.5 hr/week of physical activity and maintaining a healthy diet leads to lower risk of cancer, heart disease and myocardial infarctions.

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Adapting and making positive changes to the illness depend on a series of factors, such as the individual’s belief about the illness, the psychological and emotional inferences of the disease, specific characteristics of the disease such as symptoms, and its progression, communication with the family members, and other socio-cultural context (Popa-Velea, 2010). Therefore, it is essential to look at the external and internal factor that influences adjustment and health changes to any worrying life events.

An array of psycho-social aspects is essential, for a person with a severe disease like cancer to adjust. In order to consider the interplay between these aspects and the adjustment, it is necessary to make assumptions that cancer contains multiple stages with specific challenges. Hopefully, relevant information will be emerged about how the patients adjust to both stages I and stage II and how different psychosocial aspects influence the patient’s adjustment.

1.4 Psychological Factors in Adjustment among Head and Neck Cancer Patients

Traditionally researches focused on the association between psychiatric symptoms (such as depression, anxiety, stress) and physical illness, in both medical and behavioural science (Folkman & Greek, 2000). The studies do not reveal how chronic illness patients adjust to illness. In fact, psychological adjustment plays a vital role in disease resistance and course of the illness for the patients (Turk & Okifuji, 1997).

Researches indicated that there is variability in the psychological and physical outcome that may be due to differences among the individuals (Maunder & Hunter, 2001; Smith & Wallston, 1996). Since adjustment covers multiple components such as cognition, emotion, physical, social and intrapersonal factors. Therefore, the

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present paper will include psychological frameworks for adjustment among cancer patients.

Cognitive factors for illness adaptation to threatening events such as illness was proposed by Taylor (1983), which argued that adjustment centres on 3 themes: search for meaning, gain a sense of control and mastery over the illness. Therefore, laying emphasis on illness perception, control over the illness and consequences shows the way to psychological adjustment. This standpoint of psychological adjustment may be helpful for conducting researches among chronic illnesses. Researchers have focused on the significant theoretical work regarding the concept of meaning that is appropriate for any negative life events (Antonovsky, 1980). Researches indicated that individuals suffering from cancer go through a route of constructing meaning regarding cancer (Taylor, 1983) and how the development of the meaning impacts their psychological adjustment (Barkwell, 1991; Taylor, 1983). Additionally, acceptance of the condition, its implications and learning to live with them is an optimal component in gaining a sense of control (Austin et al., 1991). Taylor (1983) brought to light the importance of having control and mastery over the illness such as symptoms, course, and treatment in the process of cognitive view of adaptation. Therefore, according to the cognitive viewpoint, good adjustment is the potential of the individual to infer meanings in a realistic and positive manner. This will guide us to a self-fulfilling behaviour rather than self-defeating.

1.4.1 Attribution of Blame

Cognitive attribution has surfaced as one of the determinants of adjustment (Allison, Guichard, & Gilain, 2000; Friedman et al., 2006). As individuals adjust to distressing events such as cancer, they often struggle to understand, manage and predict the

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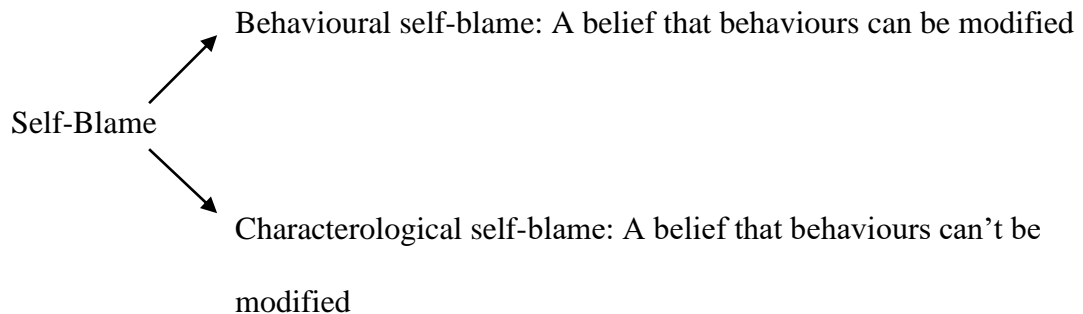
environment by finding a causal explanation of the event (Ferrucci et al., 2011). Although such cognitive appraisals are highly subjective (Faller, Schilling, & Lang, 1995), they may have a profound influence on psychosocial adjustment and behavioural changes following the painful event (Butler et al., 2001; Janoff- Bulman, 1979; Roesch & Weiner, 2001). As patients with head and neck cancer are mostly linked to poor health behaviour such as smoking (Sasco et al., 2012), chewing tobacco, betel-nut and eating smoked food. Therefore, patients may blame themselves for developing cancer. Self-blame attributions are those in which an individual assigns the cause of an event to oneself.

Self-Blame Theory

Furthermore, the type of attribution that the patients make may signify the difference between poor and good adjustment. Janoff-Bulman (1979, 1992) distinguished two types of self-blame: Behavioural self-blame is defined as blame directed at specific habits or behaviour in which a person is engaged. For e.g. in the case of cancer, attributing one disease to eating habits may allow them to believe that the disease might be prevented through changing the eating habit. When an individual attribute blame for the current stressor to the behaviour and perceived those behaviours to be modifiable, it enhances the perception of control that positively affects psychological adaptation. On the other hand, Characterological self-blame is defined as blame directed to stable personality traits and characteristics. For e.g. a cancer patient who believes that the disease is to happen in their life and they have no control over the course of cancer. Characterological self-blame is linked to poorer psychological adjustment because this type of self-blame elicits a sense of helplessness- a belief that

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nothing can be done to change the stable aspect of the trait. Individuals believe that the characters are more fixed and more controllable (Janoff- Bulman, 1992).



1.4.2 Illness Perception

Moreover, the way people perceive their illness may affect their adjustment to the environment (Hagger & Orbell, 2003). Illness perceptions are thought to be mental construct or cognitive beliefs that might bring changes in the patient’s life (Moss-Morris et al., 2007; Petrie et al., 2002) to make psychological and physical adjustment to the illness. These perceptions are thought to be a vital determinant of behaviour and treatment outcome as well as functional recovery (Leventhal et al., 1997; Weinman & Petrie, 1997). However, there are two crucial features to be noted: firstly, the patient’s belief about their condition is different from those who are treating them. Secondly, patient’s perceptions about the illness vary as patients with the medical conditions may have different view of their illness.

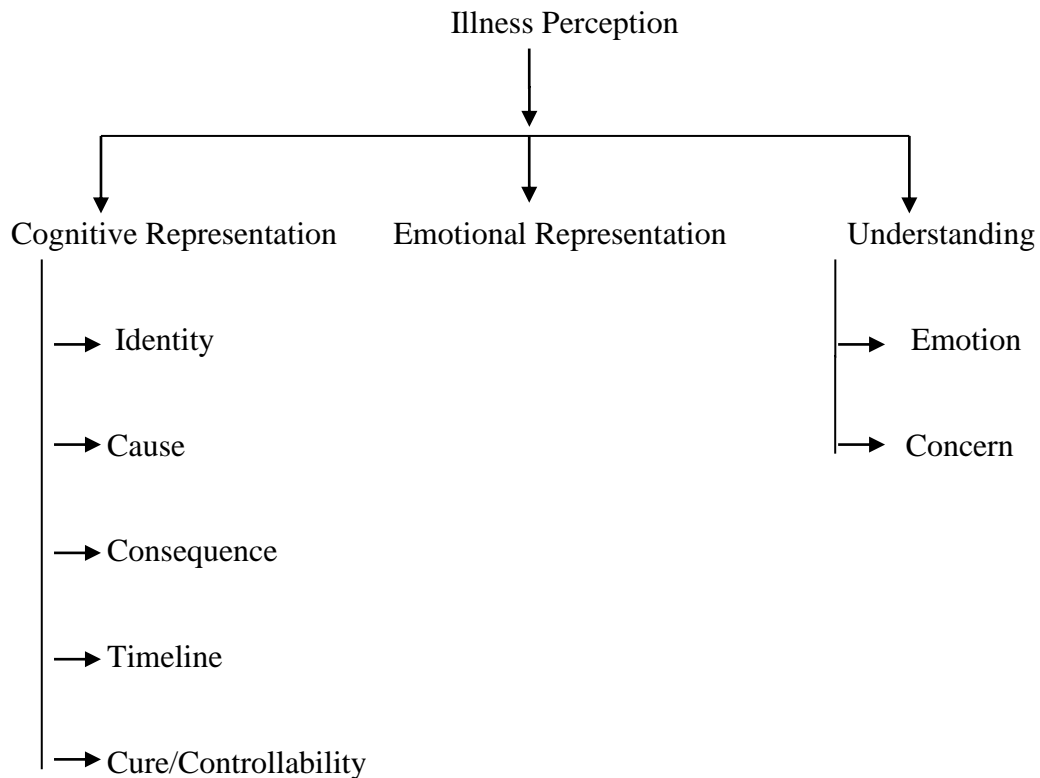
Common Sense Model of Illness Perception

The Common-sense Model (Leventhal, Brissette, & Leventhal, 2003) is used to understand the role of illness perceptions to adapt to the health threat by developing cognitive and emotional representations about their illness. It facilitates to make sense of and develop strategies to manage the illness. This model explains how individuals

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diagnosed with the same illness can have widely different beliefs about and reactions to their medical condition (Petrie & Weinman, 2006). In the case of illness, patients cluster their ideas around five central themes that provide a framework for making sense of their symptoms and for directing action (Buick, 1997). The cognitive representations of the illness and treatment are based on the five formulated dimensions: Identity: the label placed on the disease by the patient and the symptoms associated with it ; Cause: the individual’s ideas about how one gets the disease ; Consequence: the perceived physical, social, financial and emotional effects of the disease; Timeline: expectations about the duration and course of the disease; Cure/controllability: patients’ ideas about what they themselves, or their medical carers, can do to promote recovery or manage symptoms. The model extended by adding more themes (Moss-Morris, 2003): Splitting the control dimension into personal control: individuals belief on how much control they have over their illness and treatment control: individuals belief on how much the treatment would have control over their illness, understanding illness factor: patients understanding of the illness , Concern: concern experienced regarding the condition of the illness and emotional representation: the extent to which the patients experience the symptoms of depression, fear or anxiety (Broadbent et al., 2006; Moss-Morriss et al., 2002; Weinman et al., 1996).

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1.5 Personality Defined

People differ in their tolerance of dissatisfaction, conflicts and adjustment mechanisms that they employ to any unwanted situation. Such differences are in variation to personality (Shaffer & Shoben, 2019).

However, personality plays an important role in health and disease (Friedman, 1990).

Association of personality and cancer has become a crucial area of research as it is quite nascent. The type of personality can have a major impact on the cancer incidence, course, and progression, outcome of the disease and health status.

However, personality can be defined in various ways:

“Personality is a dynamic organization within the individual of those psychophysical systems that determine his characteristics behaviour and thought”.

-Allport (1961, p. 28)

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“Individual differences in characteristic patterns of thinking, feeling and behaving”

-American Psychological Association (2015)

Hence the above two definition consider personality as a structure and process that triggers stability in human affect and behaviour (Gangestad & Snyder, 1985). Besides emphasising the psychological risk factors, there is an urgent requirement to adopt a personality approach in the early stage of cancer that is vulnerable to stress related events. Different models of personality have till date categorized two, three or five traits. However, the current paper is based on two global traits that can be linked to the physical and psychological outcomes of HNC. Therefore, the present study will selectively focus on distressed personality type.

1.5.1 Type D personality

Certain characteristics have been identified as salient predictors for cancer adjustment (Allison, Guichard & Gilain, 2000; Friedman et al., 2006). One such trait might be Type-D or Distressed personality recently identified trait, emerged in the 1990s. Type-D personality is defined as a combination of two stable personality constructs: Negative affectivity (NA) and Social Inhibition (SI). Individuals that experience greater NA (greater negative emotion and cognition) and lower SI (inhibiting social expression of the negativity) tends to be defined as Type-D personality (Denollet et al., 1996). People with NA experience negative view of oneself, world, others, and future (Larsen et al., 1991; Mols et al., 2010). They are more likely to experience negative affects across time and despite any situation. This trait can be conceptualized as neuroticism (Eysenck, 1991; McCrae & Costa, 1987). People with NA are associated with exposure and reactivity to negative events (Bolger & Zuckerman,

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1995). People with intense SI have fewer personal bonds and become uncomfortable while socializing with others (Emons et al., 2007). As a result, people with type D personality frequently report a feeling of dysphoria, worry, and tension. They feel insecure, feared rejection and disapproved (Denollet, 2000).

A theoretical justification of D as distressed has been provided in a paper by Denollet, Sys, and Brutsaert (1995) which portrayed that distress is not the result of experiencing negative emotions but chronic psychological distress from holding back the negative emotions.

Therefore, in order to have a complete understanding of the way patients adjust to any distressed situation, it is important to account for the effects of various factors.

Therefore, in our course towards become a healthier and wealthier nation research based on need and coordination is required to comprehend the threats to the nation that appears from chronic illnesses such as HNC. Assam being a stock house for several types of HNC and high incidence of HNC highlights the importance of research to defy the threats by consideration of cancer patient's adjustment to the changing situations. There is also a need to identify the factors that affect the psychological and mental health has been predominantly the matter of interest for many researchers. Little evidence is identified whether cognitive appraisal and personality lead to a wide array of positive impact on adjustment.

Therefore, the present study examines the patients from Head and Neck Cancer of Assam. The study explores how various factors such as the perception of illness, self-blame and Type D personality functions in the process of psycho-social and physical adjustment among the patients. It also investigates how the variables differ by age, gender and intake of substances.

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1.6 Operational Definition

- *Perceived illness*: The way people perceive their illness in the form of cognitive and emotional illness representation.
- *Self-blame*: Self-blame attributions are those in which individuals assign the basis of an event to selves either blaming their behaviour or character.
- *Type D personality*: Type D personality is characterized by the tendency to experience negative emotions and cognitions, simultaneously experiencing negative affectivity and social inhibition.
- *Health changes*: Health changes is defined as the changes that people make regarding their health behaviour such as diet, exercise, habits after the diagnosis of any illness.
- *Psycho-social adjustment*: Patients perception of their ability to overcome the effects of illness in relation to various personal, environmental and emotional factors.
- *Head and neck cancer*: Cancer that mostly occurs in the mouth, nose, throat, larynx and salivary gland because of the intake of tobacco-related food and smoking as well as smoked food.
- *Early stage cancer*: Cancer at its initial growth and is aggregate in a specific area of the body during (Stage of I and II).

CHAPTER II**REVIEW OF RELATED LITERATURE**

The review of literature in research provides one with the means of getting to the frontiers in a particular field.

-Borge (1964)

An effort to conduct research would not be ideal without outlining the studies that are applicable to the present study. The review may be defined as an examination of something with the intention of changing it if necessary. It may also be defined as to carefully examine or consider something or subject matter again, especially to that one can decide if it is necessary to make changes or to think about past events, for example, to try to understand why they happened. A review of literature that compliments or contradicts supports or opposes will be of immense help in understanding the present study from a various different perspective. Therefore, an effort is given to go through studies that are done previously in the field of the present study.

Research takes advantage of the knowledge that had accumulated in the past as a result of constant human endeavour. The theoretical and empirical framework, which the problem arises, must be reviewed for this purpose. The latest research trends pertinent to the problems should be mentioned. The researched have to be clear that his problem has root in the existing literature, but it needs further research and exploration. A brief summary of related studies found in journals, magazines, articles, abstracts, and reports should be made. This provides evidence that the research is familiar with what is already known and what is unknown and improved. The existing

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literature review portrays us with the picture reflecting the home environment, psychosocial competence and parent-child relationship. The studies are divided into the following headings:

1. Perceived illness and Adjustment
2. Self-Blame and Adjustment
3. Type D Personality and Adjustment
4. Gender and adjustment
5. Stages of cancer and adjustment

2.1 Perceived Illness and Adjustment

The way people perceive their illness can shed some new light on this area. However, studies on illness perception considering cancer do not apprehend the perception of cancer patients but people place perception of cancer (Figueiras & Alves, 2007), health behaviours to put off cancer (Cameron, 2005) as well as response to the screening of cancer (Hagger & Orbell, 2005). Although most of the study centres on the miscellaneous group of cancer patients (Husson et al., 2013), limited studies have been done on specific types of cancer such as head and neck cancer (Johansson et al., 2011; Llewellyn et al., 2007) and colorectal cancer (Mols et al., 2012). Since patients' illness perceptions are believed to determine the behavioural and emotional self-regulation following a health threat, it facilitates to reappraise in a feedback loop (Leventhal et al., 1984). It has been shown to affect adaptation to illness in patients with a wide range of conditions, including multiple sclerosis, rheumatoid arthritis or other chronic illnesses (Groarke et al., 2005; Jopson & Moss-Morris, 2003).

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However, analysis based on common sense model by Leventhal et al. (1984) (suggesting illness perception to be formed by present and past experiences), shows that patients going through an indistinguishable type of cancer have similar perceptions because of the familiar experience of the disease type. Other features such as illness duration and treatment status might affect their experience and shape illness perception although patients suffering from a common or different type of cancer (Mols et al., 2012). Furthermore, according to the model, adjustment is associated with cognitive and emotional beliefs about the illness.

Investigation of a study revealed that adaptive outcomes, namely role, social and physical functioning, psychological well-being and vitality are associated with lower perceived consequences and a weaker illness identity (William et al., 2011). Groarke et al. (2005) found that high illness identity, more serious consequences and lower illness cure/ control were related to adaptive illness outcomes. Conversely high perceived control over the illness is positively correlated with psychological well-being and vitality (Hagger & Orbell, 2003). Hopman and Rijken (2015) conducted a longitudinal panel study among heterogeneous cancer 325 patients, in Netherland. Results suggested that almost all the cancer patients perceive their illness to be chronic in nature and long-lasting with lower perceived personal control compared to treatment control. Moreover, findings suggested that patients might be benefited and better adjusted when alleviating severity in the perception of illness. So far, studies investigated the relationship between adjustment and illness perception. Yet measurement of illness perception differs across studies. Negative beliefs such as stronger illness identity, higher perceived consequences, and negative emotion representation are associated with poorer adjustment. Positive beliefs such as higher illness coherence and personal as well as treatment control are related to better

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psychological adjustment. Belief about the illness to be chronic in nature leads to poorer adjustment (Hagger et al., 2017; Spain et al., 2007).

Price et al. (2012) investigated illness perception among 301 palliative care populations. The findings highlighted that the dimensions of Mental Adjustment to cancer such as helplessness-hopelessness was correlated with the items of illness perception. Several causal attributions were identified: don't know, personal responsibility, exposure, intrinsic personal factor, fate or luck was associated with depression.

The association of illness perception with outcomes has been found in various illnesses. Kaptein et al. (2006) found that in patients with Huntington's disease illness perception influenced physical and psychological well-being. In patients with Rheumatoid arthritis, consequence beliefs of illness perception impacted the well-being such as physical adjustment and life satisfaction (Treharne et al., 2005).

Another study on rheumatoid arthritis found that women reported illness perception associated with adjustment and physical functioning (Groarke et al., 2005). Macros et al. (2007) reported that patients who displayed a larger quantity of symptoms, their illness were expected to have worst functioning at school/work, suffer from sexual problems, have poor family functioning and have less global adjustment. Patients who stated a sense of cure was like to have better functioning at work/school, better health care orientation, better family relationship, and better global adjustment. Illness perception was not associated with domestic and social adjustment.

Health behaviour can also vary according to the perception of illness. As a result, positive illness perception is linked to higher self-care ability and behaviour such as cardiac rehabilitation participation, diet, exercise and reduces smoking (Broadbent et

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al., 2009). The association between illness perception and health behaviour can be explained through the self-regulatory theory of health. According to the theory (Leventhal & Carmeron, 1987), cognitive and emotional representations are developed by the individual when faced with illness. Subsequently, they take up the behaviour to cope with it and finally evaluate the effectiveness of their own health behaviour. In this continuous self-regulatory process of behaviour, illness representation plays a crucial role. The emotional representation such as fear, anger, distress and cognitive representation such as identity, consequences, cause, timeline, and control of the illness directs the health outcome/behaviour such as confirming to prescribe health suggestions.

Study regarding gender differences based on illness perception of patients suffering from heart disease found that women perceived heart conditions to be more chronic than men, while men had more personal and treatment control beliefs than women (Grace et al., 2005). Moreover, male patients with lung cancer characterized their illness to personal responsibility than the females as they gave smoking as the prime cause (Price et al., 2012).

In contrast to the previous studies, illness perception has little association with adjustment. Therefore, it is crucial to understand that the way individuals perceive their illness is likely to impact the course of the illness, the type of treatment sought, adherence to and response to treatment as well as making a physical and psychological adjustment.

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2.2 Self-Blame and Adjustment

Identifying the cause of illness emerged to be an outstanding component in the process of adjustment to stress and trauma, even in certain circumstances where the etiological factors are unidentified (Taylor, 1983). A large amount of work based on causal attribution in serious illness emphasizes some patient's tendency to attribute the cause of their condition to some aspect of themselves. Mixed results were found when researchers explored self-blame processes among cancer patients. Some researchers argued that blaming oneself for negative occurrences can cause undesirable psychological consequences, including poorer psychological adjustment, exclusively with depressive symptoms (Abramson et al., 1978). Contrasting with the previous finding, the result demonstrated that blaming self can as well positively affect adjustment outcomes in accident victims (Janoff- Bulman & Wortman, 1979). However, other studies have found no association between self-blame and psychological adjustment (Taylor et al., 1984). These studies encouraged both theoretical and empirical work to realize why, how and when self-blame might be adaptive in nature.

In an attempt to resolve the contradictory and diverse findings, Janoff-Bulman (1992) argued that the propensity of patients to ascribe the cause of their condition to the past actions or behaviours "behavioural self-blame" (Malcarne et al., 1995) is a common adaptive self-blame. It has more adjustment consequences as the behaviour being blamed is out looked as changeable leading to invulnerability in the future. In contrast, Characterological self-blame increases psychological distress over time (Judith & Bruce, 1999) because the patients view their characters more fixed leading the way to maladjustment.

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The difference between Characterological and Behavioural self-blame can be inferred from the theoretical perspective, conceptualizing internal, global and stable attributions for negative events. According to the Learned Helplessness Model, Characterological self-blame is detrimental to mental health than behavioural. Although both are internal, Characterological self-blame as it is global and stable.

Several researchers have found an association between self-blame and psychological adjustment. Research on post-mastectomy cancer patients, Taylor et al. (1985) found that self-blame was positively associated with the perception of adjustment, between 17 to 36 months after surgery. But beyond that or prior to it no association was found with adjustment. Gotay (1985) conducted a study on 42 early-stage and 31 late-stage cancer patients. The result indicated that both behavioural and characterological self-blame was not correlated with adjustment (i.e. positive or negative mood). In a study with a heterogonous sample of cancer patients, ascription of characterological self-blame predicts poorer adjustment during the time of diagnosis, whereas behavioural self-blame showed no relationship (Malcarne et al., 1996). However, in a study by Houldin et al. (1996) indicated an association of both the kinds of self with worse psychological adjustment.

One interpretation for inconsistent findings among behavioural self-blame and adjustment can be given on the basis of cognitive-social differences that moderate the association between them. For example, individuals might hold expectancies about their future health-related outcomes that may influence the relationship between self-blame and adjustment. Patients who believe that future health-related outcomes are dependent on their own actions may display better adaptive behavioural outcomes. Alternatively, when individuals blame themselves in the absence of the belief that

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they can control the future, their behaviours may not be adaptive i.e. there is less likely to make any behavioural changes.

A study among the sexual assault indicated that characterological self-blame was associated with negative outcomes, especially psychological distress. But behavioural self-blame was found to have no association with psychological distress (Breitenbecher, 2006). Moreover, though characterological self-blame may have adaptive consequences, when the characterological self-blame is also made the benefits of blaming one-self may be lost. Once character is blamed, the behaviours are overshadowed (Janoff-Bulman, 1992). In a study, Malcarne et al. (1995) found that Characterological self-blame was related to distress only after 4 months of post-diagnosis in a mixed sample of cancer patients, not immediately after the diagnosis. In contrast, behavioural self-blame was not related to distress immediately after the diagnosis or after 4 months of post-diagnosis. Glinder and Compass (1999), reported that among the breast cancer patient, behavioural self-blame was associated with poor adjustment near the time of diagnosis and characterological self-blame was related to poor adjustment after 6 months and 1-year post-diagnosis.

The relationship between behavioural self-blame and Positive Health Changes has seldom been examined but preliminary evidence suggests that they may be positively correlated. Attributing one’s cancer to diet, stressor environmental toxins are associated with positive dietary changes (Costanz et al., 2005; Rabin & Pinto, 2006) but no evidence bears on the question of whether attributing cancer to smoking and/or drinking alcohol relates to making other PHCs. Many survivors of lung cancer or head and neck cancers are found to engage in PHCs, but those patients who do not feature the cause of the disease to their behaviour are less expected to make health changes.

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The most common health changes are changes in diet, exercise, stress management, getting better sleep and reduce tobacco consumption. Therefore, survivors who attributed their disease to their own behaviour reported making more positive health changes (Lebel et al., 2013). Survivors of breast cancer who have attributed their cancer to insufficient exercise, unhealthy behaviour, alcohol consumptions were more likely to modify their behaviour (Rabin & Pinto, 2006). Since, diagnosis of cancer can be a teachable moment where the survivors recognize their risk producing behaviour of health, which may motivate them to improve their health behaviour.

Evidence suggests that there is a link between substance use (tobacco use, alcohol use, and chewing betel nut) and HNC. Continued use of tobacco or alcohol following treatment is also associated with a higher rate of cancer recurrence with lower patient's survival (Falk et al., 1989). For example, Steven et al. (1983) reported an increase in the recurrence of HNC for patients who continued smoking as compared to non-smokers. Similarly, continuous use of substances following treatment among patients with HNC has been associated with a poorer survival rate (Deleyiannis, 1996). The patients who had a history of substance use makes behavioural outcome for HNC patients. However, less work has been done to understand the individual differences in behavioural self-blame among patients with a history of substance use.

There are several factors that might explain the divergent outcomes of the studies related to self-blame. Firstly, the measurement of self-blame varies across different studies, where some studies simply recognize the presence or absence of self-blame (e.g. Newsom et al., 1996), while others categorize the self-blame into Characterological self-blame and Behavioural self-blame (e.g. Timko & Janoff-Bulman, 1985). Secondly, adjustment differs across the studies. Thirdly, the samples

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were heterogeneous taking into account the type and stage of cancer and the time since diagnosis.

2.3 Type D Personality and Adjustment

It is important to find better ways to identify those patients for impaired adjustment and mental health status. Individual differences in personality are important in this context.

Type D Personality characteristics have been identified as the most salient predictor for cancer adjustment. Negative affectivity is a tendency to experience negative feelings and Social inhibition is the tendency to experience boundaries in behavioural interactions and emotional expressions (Denollet, 2005).

Hence, people with Type D personality have been reported to have a low performance of health behaviours such as smoking cessation, an increase in physical activity, and dietary control (Pedersen & Denollet, 2003; Williams et al., 2008).

Type D survivors have lower levels of general health, less physical activity like exercise and less walking, more smoking (Mols et al., 2012; Pederson et al., 2006; Wienciers et al., 2017) as type D personality is associated with health-damaging behaviours and have lower psychological adjustment. However, studies on Type D personality among cancer survivors are scarce (Mols et al., 2010).

Kwon and Kang (2018) conducted a study among the coronary artery disease patients, results revealed that type D patients were observed to have low health behaviours and health outcomes leading to a lower adjustment in their lifestyle.

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According to a study on diabetic patients (Nefs et al., 2015) with Type D personality did not maintain the prescribed health diets and avoided counselling with the health care professionals. Patients with Type D personality are tensioned about their illness, have less understanding and are emotionally depressed.

Another study among Coronary Artery Disorder (Ginting et al., 2016), Type D personality was associated with lower health behaviour. Studies have reported that Type D personality among the patients with coronary artery disease has shown below average for the awareness of health status or change in health status, satisfaction on health status and physical activity (Son, 2009). Type D patients were shown to have lower on regular exercise, regular breakfast, resting after work and balance diet. However, patients without Type D personality led a healthier life with more physical activity (Lee & Kim, 2006).

A way in which Type D may predict negative health outcomes due to its relation with health behaviour (Williams et al., 2015). For example, compared to non-type D individuals, type-D individuals are less expected to stick to medications (Wu et al., 2015) and do not report their illness symptoms to the health care professionals (Pelle et al., 2010). Moreover, Type-D individuals are more engaged in negative health behaviour such as consumption of alcohol (Bruce et al., 2013), smoking cigarettes (Ginting et al., 2014), and having a poor diet (Booth & Williams, 2015). However, there is a lack of research investigating the relationship between Type-D personality and Adjustment among the cancer patients.

A plausible way in which Type D may predict negative health outcomes is through its established relations with health behaviour (Williams et al., 2015). For example, compared to non-Type D individuals, Type D's are less likely to adhere to medication

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(Wu & Moser, 2013; Wu et al., 2015) and to report their symptoms to healthcare professionals (Pelle et al., 2010). Furthermore, Type D individuals have been shown to engage in significantly less positive health behaviours (Williams et al., 2015), consume more alcohol (Bruce et al., 2013), spend less time outdoors (Williams et al., 2008), smoke more cigarettes (Ginting et al., 2014) and have poorer diets (Booth & Williams, 2015) than their non-Type D counterparts.

2.4 Gender and Adjustment

While considering gender differences in adjustment among patients with chronic illness, it can be believed that the differences are the reflection that is observed among the general population, for example, women reporting depressive symptoms more than men (Stommel et al., 2004). Moreover, as men and women are moulded to perceive and respond differently, their adjustment to illness also differs accordingly. Women are expected to adjust to illness more easily due to their acceptance and submissive nature and traditional women's gender role (Cameron & Bernardes, 1998). Yet the findings of gender differences in adjustment are contradictory. Kim (2011) conducted a study to investigate the gender differences on daily physical activity among individuals with chronic illness. The result highlighted that greater risk of daily physical activity disability was found among men than women. Another study by Robin et al. (1996) reported gender differences among individuals with chronic pain. The findings portrayed women's adjustment in relation to cognitive factors more than men. Moreover, women used more health-care services than men. Peleg-Oden, Sherer, and Soskolne, (2003) conducted a study to examine the gender differences in the social and psychological adjustment among cancer patients with chemotherapy and radiation. Men undergo many difficulties in social adjustment than women.

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Fife et al. (1994) found that females adjusted more positively in vocational and social adjustment and sexual relationships. Sneed et al. (1992) found no differences between males and females in adjustment. Reports from various countries revealed no gender differences among social adjustment (Vickberg et al., 2001). The conflicting findings regarding gender differences in adjustment to cancer lead to raise another question.

2.5 Stages of Cancer and Adjustment

However, late-stage cancer patients are complicated. Patients with cancer at the late stage are often undetected, shown a rapid progression or recurred, have limited treatment options and received mixed messages or insufficient information (Zhang et al., 2009). During that period the patients are physically as well as mentally unfit for participation. Therefore, it is not feasible for the researcher to go with late-stage cancer patients. Illness perceptions have been found to predict psychological adjustment within individual patients with acute and chronic illnesses (Hagger & Orbell, 2003), including late-stage cancer (Price et al., 2012). However, little is known about the factors that predict psycho-social adjustment and positive health changes of patients in the early-stage of cancer.

Moreover, the common age group, 45-65 years and patients 65 years and older reported more cancer-related impairments than those aged 45 years and younger (Greimel et al., 1997). Another study showed that most of the cases of head and neck cancer were from 40 to 69 yrs. Very few cases were from below 20 years (Bhattacharjee et al., 2006). A study showed that the incidence of head and neck cancer patients increases with age, especially after the age of 50 years (Ridge et al., 2016).

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The above studies do not provide with sufficient quantity of information as there were no enough studies showing the relationship among the variables such as illness perception, self-blame, Type D personality and physical and psychosocial among the cancer patients. However, studies on different locations will provide us with overall different results. Even fewer studies emphasized the gender differences and stages of cancer, which is an important contribution to the patients ‘healthy promotion of well-being. The basic needs to be examined are to understand the variables and make a comparison of male and female patients.

CHAPTER III**THE PRESENT STUDY****3.1 Need and Justification of the Study**

The prevalence of cancer has increased in recent years enhancing a wide variety of psycho-social and health challenges among the patients. The lens of viewing cancer is determined by numerous factors within as well as outside the individual as each individual brings his/her own uniqueness to the illness such as illness perception, personality traits, past experiences to influence directly or indirectly the process of adjustment in their own way. Previous research indicates clinically significant adjustment difficulties among a certain group of cancer patients, mostly ignoring a very sensitive area of Head and Neck cancer in the Indian context.

While taking into account the parts of India, the northeast region is turning to be the stock house of HNC due to different kinds of food habits like the tradition of chewing betel nut and addiction to other sources of tobacco. Hence, there is a requirement of enthusiastic help to provide an opportunity for the patients to understand the cause of the illness and create cognitive and emotional representations about their illness. This will help them make sense to manage the illness and provide a better environment for adaptation.

The study of belief has been focused on the interpretation of internal and external experiences of people as well as its contribution to the maintenance of the symptoms. However, there has been less examination done on the important beliefs, highlighting the literature on physical health such as the causes of illness, beliefs about the

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treatment/personal control, belief about perceived consequences and the length of the experiences (Lobban et al., 2003).

After the diagnosis of the illness among the patients, it is reasonable to wonder how they experience the life-limiting chronic conditions. Therefore, this is an important area of research as there is involvement of researchers making the patients realize the cause of cancer and comprehend the necessities of adjustment to the illness at an early stage of cancer will help them better adapt and increase the longevity of the patients. Thus, focusing on the early stage of cancer (stage I and stage II) might facilitate in improving the health and for better adjustment.

It is understandable that cancer sufferers encounter mental, social and physical problems. However, till date, most of the researchers are trying to emphasize the factors that hinder the physical as well as mental health and lead to a distressed life. As people have a tendency to study something that troubles the well-being of life. Therefore, it is vital for the researchers to shift their focus towards features that helps them adapt to the illness through internal as well as external environment.

Moreover, for the patients with physical symptoms (cancer) emphasize is given more on the physical conditions rather than the psychological factors, which might trigger the severity of the illness. Furthermore, it is essential to understanding the positive health changes among the patients and the causes behind those healthy behaviour.

Therefore, the motivation behind the present investigation is to find out the correlates of psycho-social adjustment and positive health changes among head and neck cancer patients in the Assam state of India. Furthermore, although the present study proposes to explore variables including perceived illness, self-blame and type-D personality on

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adjustment, these variables have received little empirical consideration. The study will provide a better understanding of the disease adjustment in different areas of adjustment such as social, psychological, family, workplace and predict the positive behaviours adopted by the patients.

3.2 Statement of the Problem

The actual trouble of head and neck cancer in India is much larger than the reflected existing literature and thus can be considered as a 'tip of iceberg' situation. In India, there is an excessively higher incidence of head and neck cancer patients as compared to other common malignancies leading to poor hygiene, and poor diet (Bhattacharya et al., 2006; Elango et al., 2006). The problem under investigation in the present study was to explore the process of adaptation as well as to emphasize on the factors that encourage the patient to bring alteration in diet, exercise and food habits after the illness diagnosis. Moreover, researches have shown that self-blame and personality is associated with the patients' welfare. Yet the mechanism behind the relationship is unclear. Therefore, the study will help us visualize the pathway for change in both mental and physical health that is very much essential to lead a better life among the patients.

The statement of the problem is “role of perceived illness, self-blame and type D personality in physical and psychosocial adjustment among cancer ‘in-patients’, Assam”.

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3.3 Hypothetical Framework

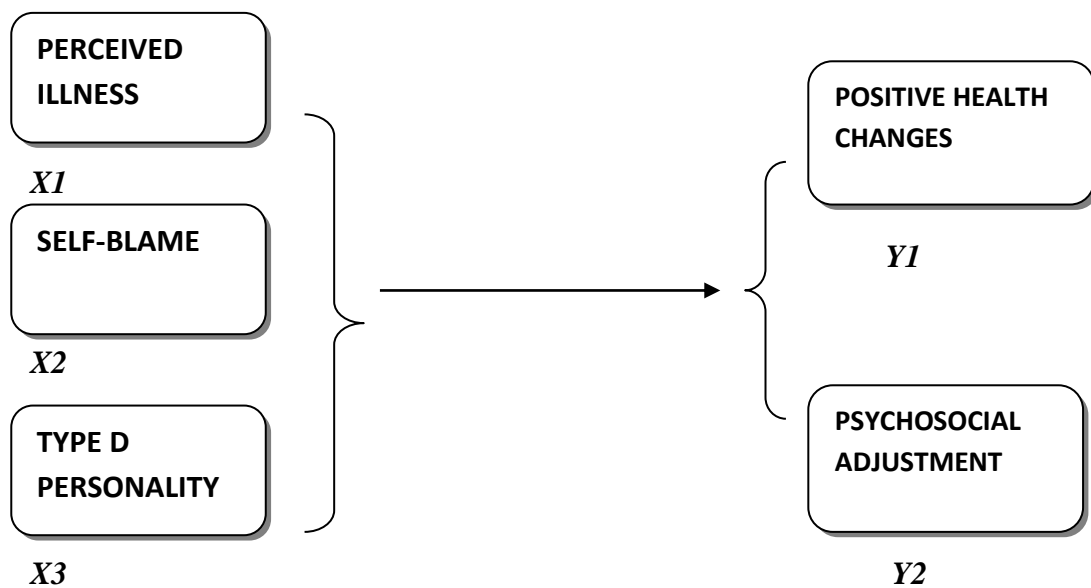


Fig 3.1: *Self-blame (X1), type D personality (X2) and perceived illness(X3) is associated with psychosocial adjustment (Y1) and positive health changes (Y2).*

3.4 Objectives of the Study

O1: To explore the relationship between self-blame, type D personality, perceived illness, psychosocial adjustment and positive health changes among the cancer in-patients.

O2: To determine the significant predictors of self-blame, personality trait, perceived illness and other selected demographic variables on adjustment and positive health changes among cancer in-patients.

O3: To make a gender-wise and age-wise comparison on variables of psychosocial adjustment and positive health changes among cancer in-patients.

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3.5 Hypotheses of the Study

H1: Selected dimensions of Self-blame, type D personality and perceived illness would significantly relate to psychosocial adjustment and positive health changes among the head and neck cancer in-patients.

H2a: Selected dimensions of Perceived illness, self-blame, and type D personality would be a significant predictor of psychosocial adjustment and positive health changes among the cancer in-patients.

H2b: The hierarchical model would predict selected dimensions of adjustment and positive health changes among the cancer in-patients.

H3a: There would be a significant gender difference between selected dimensions of psychosocial adjustment and positive health changes among the cancer in-patients.

H3b: There would be a significant age difference between selected dimensions of psychosocial adjustment and positive health changes among the cancer in-patients.

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CHAPTER IV

METHODOLOGY

This chapter deals with the research approach method and procedure followed in this study, the sampling design, a brief discussion of tools in the study and statistical design employed for analysis and interpretation of data. Research is equally as important as reading books. Both scientific and non-scientific fields of study require research for a better reality with knowledge. The everyday problems that arise seek their solutions and suggestions. Scientists are among several ordinary people who take initiatives to find their causes, explanations, and implications. The effective yet abstract phenomena are undertaken to both understand and realize by research. Avenues of research open a door for the readers to know about the phenomena in a systematic way. The foremost aims of the research are to invent new and relevant facts, to verify and test them and to analyze an event in order to see its cause and effect relationship, to develop new scientific tools, concepts, and theories to solve and understand problems, to find solutions to them and to overcome upcoming ones (Rajasekar, Philominathan & Chinnathambi, 2013). Research is a technical term that is priory used as an academic activity. Clifford Woody suggested that research is a collaboration of the systematic steps: to define a problem, formulate a hypothesis, collect, organize and evaluate data, make deduction, draw conclusion and finally testify they are similar to the formulated hypothesis (Fisher, 1930). Adding to these, research is a scientific study focused on an inquiry aiming to learn new facts, an idea with a systematic collection, analysis, and interpretation of data. All of the activities lead us to generate new knowledge and solve problems (Degu & Yigzaw, 2006).

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Chapter IV included research design, variables, sample, tools, procedure and statistical techniques for analysis.

4.1 Research Design

Descriptive research design is adopted for the present study, where primary data was collected using specific questionnaires. The logic behind implementing a quantitative study is that the study is based on some previously developed theories. Those theories would facilitate to come to a conclusion. However, the present section would assist to look into the operating arrangement and preparation of population, sample, methodology, tools and so on.

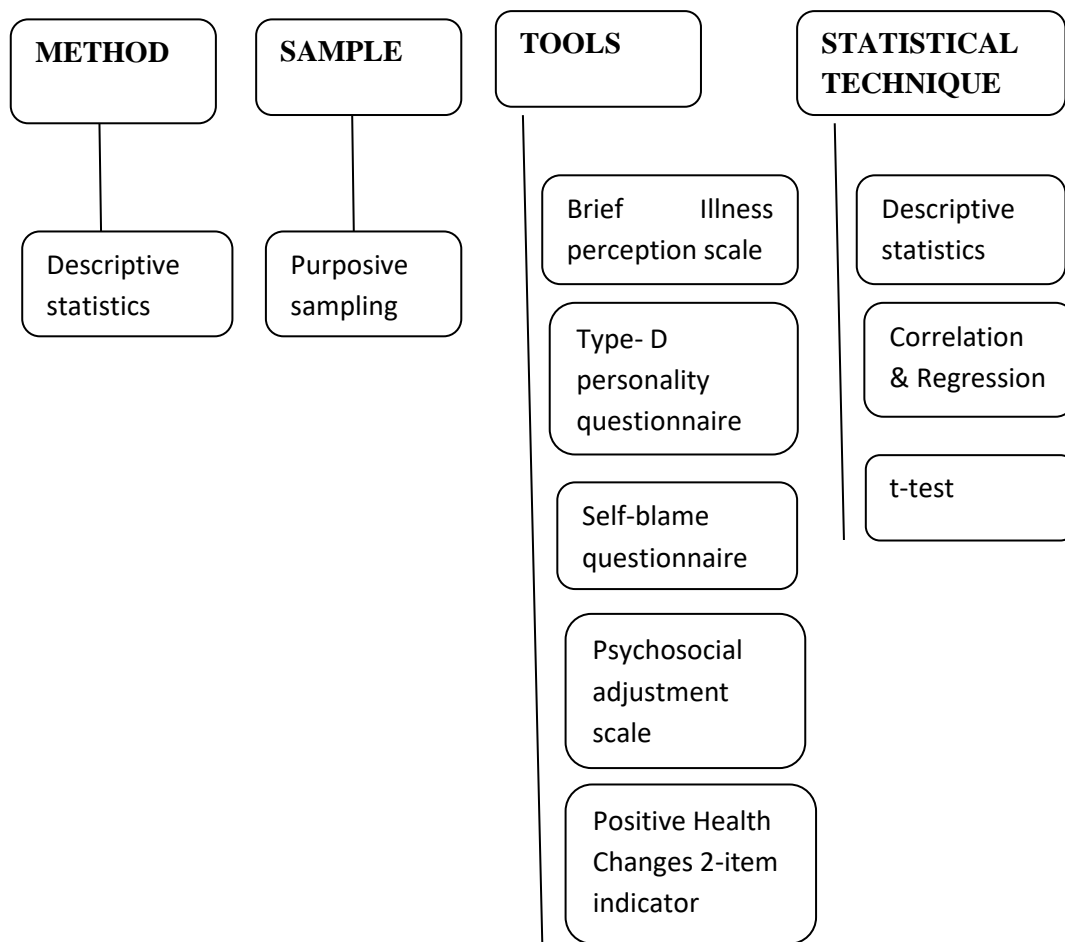


Fig. 4.1: Exhibiting the plans and procedures for the study

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Table 4.1: *Variables used in the Study*

<i>Independent Variables with Dimensions</i>		<i>Dependent Variables with Dimensions</i>	
Gender	Male	Psychosocial Adjustment	Health care orientation
	Female		Vocational environment
Age	Above 45 years		Extended family environment
	Below 45 years		Domestic environment
Substance use	-		Social environment
Illness perception	Consequence		Sexual environment
	Timeline		Psychological distress
	Personal control		Positive health changes
	Treatment control		
	Concern		
	Identity		
	Emotional response		
	Understanding		
Self-blame	Behavioural self-blame		
	Characterological self-blame		
Type-D personality	Negative affectivity		
	Social Inhibition		

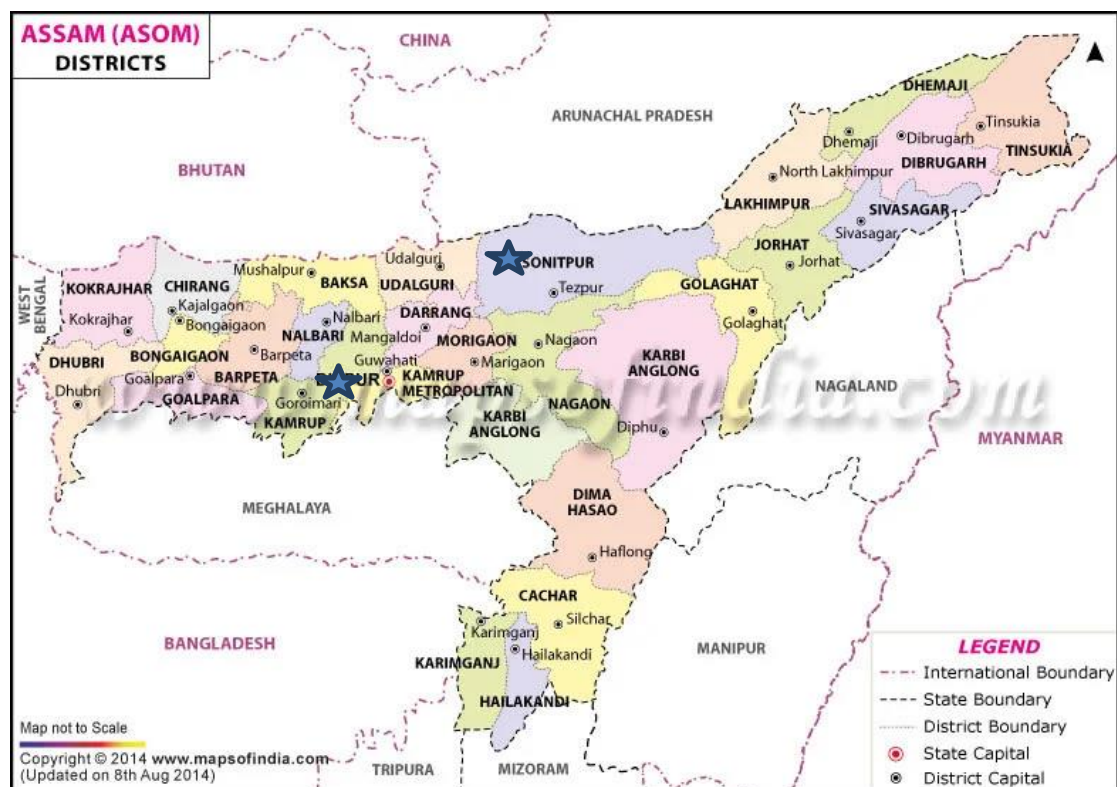
4.2 Geographical Area

The geographical location used for the study is Assam, a north-east state of India. Out of 33 districts, two districts, namely, Kamrup and Sonitpur, were taken into consideration for collection of data. Studies showed that Kamrup district has witnessed a remarkable growth of cancer cases since the last few years increasing mortality rate due to oesophageal cancer, larynx cancer, liver cancer and so on (Sharma et al., 2016). However, few studies have been carried out categorising the districts, where cancer cases were reported from Kamrup and Sonitpur districts and screening procedures were carried out (BBCI, 2019, 15th Feb). There is an alarming rate of increasing cancer incidence in Sonitpur district (Boro, 2018, 9th Aug). Moreover, Assam is the central portion of Northeast region and Guwahati is the

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gateway. The medical facility has the highest standard among all the other seven states, especially for cancer treatments. Therefore, data was collected from four different hospitals, including cancer hospitals and multispecialty Hospitals of Assam, India.

4.2.1 Map of Assam



Source: www.mapsofindia.com

4.3 Sample

The sample was delimited to the participants who were reachable and restricting the possibility of randomization. For the present study, 66 clinical samples (Mean= 51.68 and S.D. = 15. 26) (Early-stage: Stage I and II) were taken comprising of 34 male and 32 female head and neck cancer patients. The age of the participants has been grouped accordingly < 45 yrs. and >45 yrs. Participants suffering from cancer were selected

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from three different institutes of Guwahati and one institute of Tezpur, Assam.

Purposive sampling technique was used for the sample collection.

4.4 Participant Inclusion Criteria

- Patients with stage I and II
- Patients suffering from head and neck cancer
- Age group (45 years above and below)
- Both male and female
- Permission was taken from the directors of all the cancer hospitals
- Residence of Assam

4.5 Participant Exclusion Criteria

- No prior /present history of physical/psychiatric illness
- Patients who didn't give their consent

4.6 Ethical Considerations

- Permission was taken from the institution/hospital for data collection
- Informed consent of the participants as well the caregivers were taken
- Confidentiality: Ensuring privacy and confidentiality of personal information
- Non-inclusion of subject's personal information in data files

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Table 4.2: List of Cancer Hospitals of Assam for the Present Study

Sl. No.	Name of the Hospital	District	No. of Participants
1.	Civil Hospital, Tezpur (Assam)	Sonitpur	8
2.	Guwahati Medical College Cancer Hospital, Guwahati (Assam)	Kamrup	28
3.	North East cancer institute, Guwahati (Assam)	Kamrup	23
4.	Night angle hospital, Guwahati (Assam)	Kamrup	7

4.7 Tools Used

1. *Socio-demographic Datasheet (Self, 2019)*: Socio-demographic datasheet consists of the personal record of the participants like age, sex, and intake of substances like drinking, smoking, chewing tobacco, or any other substance.

2. *Brief Illness Perception Questionnaire*: Brief illness perception questionnaire was developed by Broadbent et al. (2005). The questions assess 9 dimensions:

Consequences: the expected outcome of the condition, *Timeline*: the persons believe about how long the condition might last, *Personal control*: individual’s belief on how much the illness can be kept under control, *Treatment control*: individual’s belief on how much the treatment would have control over their illness, *Identity*: the labels or names given by the patient to describe the illness/symptom, *Concern*: concern experienced regarding the condition of the illness, *Understanding*: patients understanding of the illness, *Emotional response*: Illness-the extent to which the patients experience the symptoms of depression, fear or anxiety, *Causes*: identifying the causes of the illness. The reliability of the items ranges from 0.42 to 0.73.

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3. *Self-blame Questionnaire: Behavioural and Characterological self-blame* will be accessed via two questions used during individual structured interviews. A portion of this interview will be based on prior research on the psychological adjustment of cancer patients (Compas et al., 1994; Taylor et al., 1984). Embedded in the structured interview will be questions about both behavioural and Characterological self-blame. Questions will be presented as follows:

“We have found that some people blame themselves for their cancer and some people do not blame themselves at all. I would like to ask you two questions about whether and how much you blame yourself for your cancer:

(1) How much do you blame yourself for the kinds of things you did, that is, for any behaviours that led to your cancer?

(2) How much do you blame yourself for the kind of person that you are (that is, for being the kind of person that has things like cancer happen to them)?”

Both questions will be answered on a 4-point Likert scale, with 1=not at all, 2=somewhat, 3= very much and 4=completely.

4. *Type D Personality Scale:* Dutch 14-item Type D Personality Scale (DS14) is a self-report questionnaire used for the study to assess personality traits (Denollet, 2005). It consisting of 2 dimensions with 14 items, each dimension with 7 items:

Negative affectivity: the tendency to experience negative feelings regardless of situation or time. For example: “I make contact easily when I meet people”. *Social inhibition:* the tendency to experience limitations in emotional expressions and behavioural interactions. For example: “I am often irritated”.

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The items of the scale are measured on a five-point Likert scale ranging from 0 (false) to 4 (true). An individual is categorized as type D personality if the score is 10 or higher for both the dimensions. The reliability of the scale is 0.88 for NA and .86 for SI scale.

5. *Positive Health Changes*: Positive health changes (Lebel et al., 2012; Mullens et al., 2004; Rabin & Pinto, 2006) for PHCs measures were measured using a 2-item indicator: (a) ‘I take better care of my health’ and (b) ‘I have made some PHCs’ (this item allowed space to describe adopted changes). The scoring of the 2 items is done on a Likert scale ranging from 1(not at all) to 4 (completely). The reliability of the items is 0.86.

6. *Psychosocial Adjustment to Illness Scale*-Self report multi-dimensional scale considered to assess the psychosocial adjustment of the patient to illness. The scale measures an individual’s interaction with families, spouse, friends and the organization that constitutes the socio-cultural environment. The scale as developed by Derogatis and Derogatis (1983) has 7 domains with 46 items. The domains are as follows:

Health care orientation: respondent’s perception about the quality of health care in general, patients expectation’s about the illness and treatment and motivation to involve in healthy belief and behaviour (8 items), Vocational environment: impact the illness has on the respondent’s perceived quality of vocational performance, vocational satisfaction, vocational interest at home/work/school (6 items), Domestic environment: illness-related difficulties at home/family such as financial aspect, family communication, aspect of family living (8 items), Sexual relationship: changes in a sexual relationship, sexual interest, frequency, performance and level of satisfaction, (6 items), Extended family relation: disruption in the extended family

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relationship associated with illness, the negative impact of illness upon communication, help expected/needed (5 items), Social environment: impairment in the social/leisure activities associated with illness(6 items), Psychological distress: dysphonic thoughts, feeling including anxiety, depression, worry, body image related to illness (7 items) Reliability of the items ranges from 0.47 to 0.85 and the internal consistency of 0.92 on individuals with chronic physical illness. “Better psychosocial adjustment is indicated by lower scores “and “poorer psychosocial adjustment” is indicated by higher score. The score of 0-35 indicates “good” adjustment; 36-51 indicates “fair” adjustment and scores 52 and above indicates “poor” adjustment.

4.8 Procedure

The concerned authorities in the GMC, NECI, Night angle hospital and Civil hospital were contacted for permission to collect data from the respondents. After the consent was taken from the respondents, good compatibility was established and the purpose of the study was explained before the survey was initiated. The questionnaires were distributed and the instructions were given in details for completing the questionnaire. All the participants were assured that the responses would be kept confidential and would be used for the study purpose. Moreover, the respondents were asked to clarify any doubt without hesitation. Data was collected individually along with the socio-demographic data with co-operations. The time taken for completion of the questionnaire was an hour to two, as the participants were physically disturbed. The duration of data collection was 1.5 months. It was really a very tough task to find out the sample as it required selecting the patients with HNC and most of them refused to participate due to their unhealthy condition.

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4.9 Statistical Techniques Used

Keeping in view of the objectives and hypothesis, different statistical techniques were used for analyzing the data. The quantization data was analyzed using SPSS version 23. For the descriptive statistics techniques like mean, SD, the frequency was used. For the inferential statistics techniques like correlation, t-test and regression was used to measure the significant relationship, significant differences and significant prediction among the variables and groups.

CHAPTER V**ANALYSIS AND INTERPRETATION OF THE DATA**

After collecting the data from the participants, it has to be analyzed. It is a fundamental step in research only after which the results can be out-streamed. The data may hold the characteristics of adequacy, validity and reliability; however, it does not provide any valuable purpose unless it is carefully and systematically classified, tabulated, scientifically analyzed, interpreted and rationally inferred.

In this study, an attempt has been made to ascertain the influence of different dimensions of self-blame, illness perception and type D personality on the physical and psychosocial adjustment among the HNC patients. The data were arranged and analyzed in six sections. The socio-demographic characteristics with descriptive statistics of the selected HNC patients for the study are profiled in Section I. In Section II, the descriptive statistics, illness causes and behavioural changes of the selected variables such as illness perception, psychosocial adjustment and positive health changes are presented. Section III deals with the results of inter-correlations carried out for all the variables. Section IV has been presented with hierarchical regression equations for psychosocial adjustment whereas Section V deals with hierarchical regression equations for positive health changes. In Section VI, gender differences on variables of psychosocial adjustment and positive health changes have been discussed. Similarly, in Section VII age wise differences of patients on psychosocial adjustment and positive health changes have been discussed.

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SECTION I: Descriptive statistics of selected socio-demographic characteristics

Table 5.1: Descriptive statistics of selected socio-demographic variables (N=66)

<i>Variables</i>	<i>Sample</i>	<i>Categories</i>	<i>Frequency (%)</i>
Age	66	Above 45	39 (62.10)
		Below 45	27 (37.90)
Gender	66	Male	34 (51.50)
		Female	32 (48.50)
Substance use	66	Chewing betel-nut	25 (37.90)
		Chewing /smoking tobacco	20 (30.30)
		Multiple use	10 (15.20)
		None	11 (16.60)

Age level-wise Distribution

Data presented in the Table 5.1 reveals that the participants were divided into two groups, below 45 yrs. or younger and above 45 yrs. or older based on earlier studies. The data showed that 62.10 percent were above the age group of 45 yrs. and 37.90 percent were below the age group of 45 yrs. Therefore, the highest portion of the sample was above the age group of 45yrs.

Earlier studies have shown that patients older than 40 yrs. reported more HNC cancer. However, very few HNC cancers patients were found below 20 years (Bhattacharjee et al., 2006). Another study showed that the incidence of head and neck cancer patients increases with age, especially after the age of 50 yrs. (Ridge et al., 2016).A

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study by Sharma et al. (2019) also found that patients with 39 yrs. and above reported more HNC.

Gender-wise Distribution

Among the 66 participants from Table 5.1, 51.5 percent were male and 48.5 percent were female. Hospital records of patients have shown that buccal mucosa and tongue cancer (HNC) have been increasing among the males (Malik et al., 2018). Moreover, males were found to be prone to almost all types of HNC cancer when compared to females, as diagnosis showed that males are prone to squamous cell carcinoma (Guru et al., 2015). However, among the male participants, cancer was found to be increasing among various sites of Head and neck such as hypo pharynx as the leading site followed by mouth, tongue and tonsil. Among the female participants, cancer was found to be increasing among various sites of Head and neck such as mouth as the leading site followed by tongue and hypo pharynx (Das et al., 2017). Moreover, differences in prevalence of HNC among male and female was found in various studies with male higher in number than female (Bhattacharjee et al., 2006; Das et al., 2017; Hesham et al., 2017; Mehrotra et al., 2005).

Substance Consumption of Participants

In the substance use category from Table 5.1, it can be observed that 37.0 percent among all the participants were involved in chewing betel-nut, 30.3 percent were involved in chewing/smoking tobacco, 15.2 percent involved in multiple use and 16.6 percent were engaged in consuming none of the substance. Therefore, highest participants were involved in chewing betel-nut followed by chewing/smoking tobacco.

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Studies show that consuming tobacco (chewable and non-chewable) is responsible for majority of oral cancer. According to global adult tobacco survey, 34.6% of adults in India, 47.9% male and 20.3% female consume tobacco (Malik et al., 2018). A study has shown that the incidence of HNC is related to the major risk factors such as tobacco, betel quid chewing, smoking cigarette (Mehrotra et al., 2005). Betel-nut chewing with lime is one of the highest traditional risk factors for HNC in India (Hesham et al., 2017). A comparative study showed that tobacco smoking was associated with an increase in the risk of HNC as compared to non-smokers (Perdomo et al., 2016). Moreover, the study has shown that consuming a mixer of the highest level of alcohol and smoking were associated with the joint effect of developing cancer than non-smokers/drinkers and were 10 times higher than never users. The independent effect of alcohol consumption and tobacco use were seemed to be less as compared to joint effect (Hahibe et al., 2009).

SECTION II: *Descriptive Statistics of Selected Variables undertaken*

5.2 Perceived Causes of Cancer

Regarding the open-ended question of the IPQ-brief questionnaire, various cancer causal attributes has been extracted from the answers: a) environmental exposure such as use of plastic, chemicals in the food, harmful inhalation of smoke, b) bad habits such as intake of harmful substances (tobacco, gutka, betel-nut), wrong food habits, poor hygiene, lack of physical exercise, poor life style leading to weight gain/loss c) physical injury/accidents/infections, d) religious cause such as karma, punishment by the God, e), luck or fate and f) don't know. For the purpose of the analyzing the causes in the study, the patient's first three answers were considered to be the most important causes. However, the most frequently referred causes of cancer

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by the participants were bad habits (29), followed by physical injury/accidents/infections (17), and followed by religion causes and environmental causes (13) and luck/fate (10), don't know (4). These findings facilitate in assuming how participants differ in conceptualizing the causes of illness.

These findings seemed to be related to studies of Castro et al. (2012) and Price et al. (2012) where emotional causes, modern life, post traumatic causes, biological malfunctioning, genetic factors, old age, work related causes and failure life choices was not reported in the present study. This shows that even with the sample of the same disease, the causes of illness greatly differ and is challenging for them to make assumptions on how they perceive the illness Price et al. (2012). However, Llevellyn et al. (2007) reported that perceptions do not change with the course of illness and treatment. The change is yet related to the belief about the causes of cancer, which might increase the frequency of cancer or diminish the bad habits or maladaptive behaviour.

The causes if illness such as intake of harmful substances (tobacco, gutka, betel-nut), wrong food habits, poor hygiene, lack of physical exercise, poor life style leading to weight gain/ loss can be related to internal locus of control. The other causes such as fate/chance, environmental exposure, physical injury, infection can be related to an external locus of control.

The majority of the participants after the diagnosis of the illness have made some positive health changes. The frequency of the types of PHC reported by all the participants is mentioned in Table 5.3.

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Table 5.3: *Positive health changes among the early stage cancer patients (N=66)*

Positive Health Changes	N (%)
Healthy food habits	48 (29)
Regular physical activity	34 (20)
Cessation or decrease of tobacco/betel-nut/smoking/alcohol intake	26 (16)
Better sleep quality	15 (9)
Maintaining a proper hygiene	15 (9)
Meditation and Therapy	12 (7)
Getting rest	8 (5)
Active participation in social activities/groups	8 (5)

The findings indicated that survivors of head and neck cancer reported making several positive health changes. The most frequently reported changes are food habits, regular exercise and substance use behaviour. This finding line up with earlier studies where patients are encouraged for positive health behaviour in addition to stress and connecting with people, social support (Hawkins et al., 2010; Label et al., 2013). Few of health changes, such as meditation and therapy, active participation in social activities/groups were not reported in any of the earlier studies.

Table 5.4: *Psychosocial adjustment among the early stage cancer patients (Higher score indicates lower adjustment) (N=66)*

Dimensions	Min	Max	Mean	SD
HCO	1	15	5.90	2.68
VE	0	17	8.34	3.46
DE	1	15	6.31	2.45
FAM	0	13	5.75	2.91
SO E	0	17	9.37	2.66

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SE E	0	17	19.33	4.09
PD	0	18	11.17	3.66
Total	29	98	55.17	14.26

It can be observed from Table 5.4, that out of a possible 138 points, the participant's psychosocial adjustment score ranged from 29 to 98 with the mean being 55.17 and SD being 14.26, indicating poor adjustment. The total score indicates that they have low, moderate and high adjustment to illness. In a study by Cinar et al. (2009), the mean score of Haemodialysis patients was 68.94 with SD 14.77. In a study by Swain et al. (1996) the patients with breast cancer had a mean of 51.46 and SD of 9.97. The scores revealed by the present study are in similar with those studies. This might attribute that human beings who are the bio-psycho-social creatures might produce a comparable response to the illness across cultures (Rizalar et al., 2014).

However the total score in the present study suggested that most of the patients were poor in psychosocial adjustment to illness. The findings go in opposite to the earlier studies by Cam et al. (2009) where they found that patients with breast cancer had a normal psychosocial adjustment to illness and Butler et al. (2006) reported good psychosocial adjustment by breast cancer. The present study showed participants had poor psychosocial adjustment which might be because of religion, culture, socioeconomic and individual differences.

The total mean score is 55.17 is relatively high, with a higher score indicating lower adjustment. Out of the seven domains, non-adjustment (indicated by higher mean score) was related to the area of Vocational environment, social relationship, Sexual Relationship and Psychological distress. In a study by Akin and Durna (2006), vocational and social adjustment was found to be significantly impaired.

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One possible explanation for low adjustment to vocational environment (individual’s inability to function in their vocational setting) could be that most of the participants might experience detachment in the workplace (Morgan, 2019). Cancer diagnosis and active treatment (chemotherapy/radiotherapy) can affect work ability (Duijts et al., 2014 ; Taskila et al., 2007) as they might have a poorer health condition, experiencing fatigue, pain (Velthuis et al., 2010), lack of mobility, cognitive impairment, sleepiness (Sun et al., 2016) and emotional distress (Nerenz , Leventhal, & Love, 1982).

Moreover, non-supportive work environment, employer discrimination and manual work of the patients in work place might cause lower vocational adjustment (Taskila et al., 2007), whereas employers’ accommodation, flexibility and co-worker/supervisor support (Hansen et al., 2008) were found to be crucial facilitator.

Moreover, changes in appearance, such as losing hair, weight loss, and nail change might have made the patients uncomfortable to interact with the co-workers. As well as the physical demanding task, job challenges such as travelling and driving and unable to use technology at work might cause poorer adjustment in a vocational environment (Sun et al., 2016).

Intensity of chemo/radiotherapy required to treat head and neck cancer may cause patients to experience functional side effects such talking and socializing (Epstein et al., 2001) and increasing social isolation (Gritz et al., 1999). HNC patients undergo surgical treatments that make them experience physical alteration of the body that are highly visible, such as face and neck creating challenges for social interaction.

Therefore, studies focused on the changes in speech (Penner, 2009) feeling embarrassed with bodily changes such as scar, disfigurement, loss of teeth and hair, drooling, social eating and speaking related issues (Fingeret et al., 2012). These factors might decrease the interest among the patients for social activities. Rogers,

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Hummer, & Nam (2000) reported that patients utilizing leisure time for socializing and physical activities lead to higher well-being.

Sexual issues are frequently reported by HNC patients, which lower their sexual adjustment. Sexual functions such as decrease sexual desire, decrease arousal, vaginal dryness, and orgasm dysfunctions and sexual activities are altered among the patients (Mercadante, Vitrano, & Catania, 2010). Changes in neck and visible area due to surgery, skin problems due to chemotherapy may decrease the feelings of sexual attractiveness (Hung et al., 2017; Rhoten, Murphy, & Ridner, 2013). Moreover, problematic oral section, oral pain and inability to move one's neck may be a barrier in sexual activities. The reasons for lower adjustment in sexuality may be due to treatments which cause vomiting, sticky saliva, fatigue decreasing sexual interest and enjoyment (Melissant et al., 2018). Studies have also shown that patients with weight loss and constipation reported less sexuality (Lees, 1999). However, sex and intimacy often require social interaction. This makes sense that poor social functioning due to treatment interferes with social activities leading to socially withdraw not only from the family/friends, but also from their partners (Melissant et al., 2018).

The study reported that pain, xerostomia and fibrosis induced by radiation, depression, the presence of tracheotomy tube were related to poor sleep quality (Shuman et al., 2010). This might cause a lower adjustment in psychological distress. Studies showed that mutilation of facial surgery was associated with high level of depression (Dropkin, 1986). Higher complications in pain and nutrition also result in psychological distress (Hammerlid et al., 1997). However, long term survivors who have achieved successful organ maintenance reported less pain and depression

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(Nguyen et al., 2001). Distress and fear could have been less among the non-surgical patients as they might have communication abilities.

Patients are found to be higher in health care orientation adjustment. It might be possible that patients have created an environment in which much of the information's are provided regarding symptoms, illness and management, which may facilitate them to recognize selves as they are concerned about their personal health. Information's related to the problems of the patients, such as symptoms, beliefs, concerns, information's about treatment such as how the treatment will work, uncertainty about effectiveness are often discussed among the patients and doctors (Linden et al., 2017). Patients supplemented with adequate information increases the positive rehabilitation outcomes (Boer et al., 1995). The patients may be provided with good health care teams and professional that keeps them up-to-date with relevant information's. Studies have shown that patients are dissatisfied with informational received about body image and appearance after surgery. However, patients who believed greater informational resources to be helpful were able to manage concerns about their illness (Fingeret et al., 2012). Most of them, especially younger patient's preferred internet-based programs to receive information while others prefer to receive information delivered in-person by a health care specialist (Fang et al., 2012). Patient's health care orientation mostly concerns, financial matter, access to health care services, complexities of treatment side effect, rehabilitation and care that may be needed during and after treatment (Fang & Heckman, 2016). Patients might be satisfied with the information regarding managing treatment, maintaining one's health and healthy life style after treatment. As they are concerned with their health care, they leave no stone unturned to make their health better.

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SECTION III: Correlation Coefficients of Different Variables among the early stage cancer patients

Hypothesis 1: Selected dimensions of Self-blame, type D personality and perceived illness would significantly relate to psychosocial adjustment and positive health changes among the head and neck cancer in-patients.

Table 5.5: Correlation Coefficients among different dimensions of perceived illness, type D, self-blame and psychosocial-physical adjustment among the cancer in-patients (N=66)

<i>Dimen sions</i>	<i>CON</i>	<i>TIM</i>	<i>P C</i>	<i>T C</i>	<i>IDE</i>	<i>CON</i>	<i>UND</i>	<i>ER</i>	<i>SI</i>	<i>NA</i>	<i>CSB</i>	<i>BSB</i>
	<i>C</i>											
HCO-	-.42**	-.49**	-.43**	.21	-.31**	-.29*	-.30*	.19	.13	-.28*	.18	-.53**
VE	.29*	.47**	-.002	-.55**	.30*	.42**	-.50**	.30*	.14	.18	.12	.21
DE	.13	.18	-.36**	-.34**	.07	.49**	-.32**	.11	.03	.11	-.05	.02
FE	-.14	-.11	.19	.04	-.12	.22	.19	.21	.23	.18	-.07	-.08
SO E	.11	.19	-.31*	-.32**	.02	.13	-.10	.29*	.31*	.45**	.25*	-.21
SE V	.14	.23	.23	.08	.23	.17	.20	-.18	-.09	-.27*	.09	-.10
PD	.25*	-.40**	.29*	-.08	.19	-.33*	-.12	-.44*	.18	.33**	.24*	.42**
PHC	-.29*	.19	.34*	.43**	.11	.14	.13	-.04	-.28*	-.31*	.13	.25*

* $p < .05$; ** $p < .01$

Pearson’s correlation coefficient in Table 5.5 demonstrated an inverse and significant relationship among the dimensions of psychosocial adjustment and perceived illness ($P < 0.05$), such as higher adjustment led to higher perceived illness. A correlation was observed between dimensions such as consequences, time line, personal control of illness, identity, concern and understanding of illness to have a negative and significant relation with health care orientation (Lower health care orientation indicates higher adjustment). More severe perception of consequences, higher

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personal control, identifying with the symptoms, more concerned about the illness and having a better understanding about the illness were associated with more adjustment in health care use and behaviour. This result is comparable to studies by Frostholm et al. (2005), MacInnes (2013) and Thong et al. (2018). In those studies, a belief in serious consequences of illness, a long timeline standpoint, cure/control, a strong illness identity, concern and emotional representation was associated with higher health care behaviour and better self-care. In contrast, Kim and Kim (2017) reported that negative illness perception has been lined to worst health care behaviour.

However, according to the Dutch guidelines, patients who do not have a regular supervision with the negative or severe perception of illness, believe their illness would last longer may increase the fear about the possibility of recurrence which might encourage the patients to visit the doctors, get enough information about their present illness health, and pays attention to the needs of the illness and health.

Therefore, this implies that severe illness perception among the patients may facilitate in adaptive self-management techniques. Another study showed that health information seeking was associated with patients having more concern about the illness and more able to understand the illness (Stanarevic et al., 2016). Although understanding of the illness was found to be associated with higher adjustment to health care orientation, earlier studies showed vice-versa that poorer understanding of illness was associated with higher health care use (Ninou et al., 2016). As written information, verbal explanation and even follow up can increase health care behaviour leading to adjustment. NA is associated negatively with health care orientation.

People with stronger tendency to worry have poor compliance with treatment schedule (Mensink et al., 2003), decrease motivation to follow necessary self-care routine and below average awareness of current health status (Lee & Kim, 2016).

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Behavioural self-blame is associated with health care orientation. Individuals have their own power on health. Therefore, people might take personal initiative to promote/maintain health, seek proper medical care, and gather more related information when they recognise and blame their unhealthy behaviours leading to health problems such as smoking, use of alcohol, physically inactive and so on. Therefore, Behavioural self-blame prompts an individual to look at the behaviours that becomes an obstacle to achieve optimal health.

Similarly, consequence, timeline, identity, concern and emotional response is shown to have a positive and significant relation with vocational environment, while treatment control and understanding is found to have a negative relation with vocational environment (Higher vocational environment indicates the lower adjustment). Perception of illness such as greater labelling of symptoms, more serious consequences, and emotional impact of the illness has been reported to be associated with longer duration of missing from work and less likely to return to work (Giri et al., 2009) compared to those who have lower score for those variables. Studies have shown how an individual’s belief about the symptoms and meanings attached to the illness is crucial for work/occupational outcome (Hoving et al., 2010; Main et al., 2010). In general, patients with negative illness perception failed to adjust in their vocational/work environment leading to more absenteeism, decreased work performance, loss of motivation and poor relationship/conflict with colleagues. This indicated that negative perception of illness is to be identified for adjustment in the workplace. There are some evidences reporting that facilitating patients to be aware of the negative illness perception and influencing them can encourage for better behavioural change. Therefore, an intervention program if designed to change the negative illness perception of hospitalized patients may speed up their return to work

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(Petrie et al., 2002). However, having a better understanding of the illness and believing in the treatment might increase the awareness of the symptoms and side effects of the therapies. This might in turn facilitate the patients to handle the various work-related issues with high self-esteem.

Many areas relate to an individual's life. Among all family is the most crucial one. Personal control, treatment control and understanding of illness are found to be inversely correlated with Domestic environment and concern to be positively related. Patients who are optimistic and belief they have more control and have a better understanding of the illness are less distressed than patients who do not have a positive frame of mind (Currie, Hermes & Phipps, 2009; Fotiadou et al., 2008). This optimistic belief of the patient may influence the adjustment in the family. Insight into patient's cognition regarding the illness may help the therapist understand the (mal) adaptive adjustment in the family. Hager and Orbell (2003) found that greater perception of control was associated with problem focused coping. This might facilitate the patients to regulate the illness related problems at home rather than denial. Although there are frequent changes in the daily activities of the patient, because of the traditional family structure less conflict among the family members and supportive relationship would be a stronger expectation for better understanding and control over the illness. Thus, patients might be hopeful, who in turn encouraged for family/home adjustment. However, being more concerned about the illness, physical appearance, and health might reduce adjustment in the domestic environment. Concern among the patients might encourage them for various other treatments and more discussions which might increase financial assistance and worries among the family members. Moreover, a person expanding knowledge about

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self, their needs, their illness, abilities and change in behaviour tends to improve adjustment.

Upon careful examining social adjustment contributing factor, personal control was identified to have an influence on adjustment. The patients might attribute the causes to internal factors leading to personal control rather than treatment control and personal control is associated with more adjustment. Therefore, internal control is associated with positive orientation towards a social-problem encouraged for social activities (Aubut & Belanger, 2017). However, the negative impact of illness has been found on the social adjustment (Raty et al., 2005, 2007). Compared with control, patients with epilepsy had few friends at school, fewer leisure hobbies and other unexpected behaviour. Patients might respond emotionally to the unpleasant events such as illness leading to increase in emotional distress such as experiencing depression and fear about the illness symptoms, pain complains and future. This might lead to variation in adjustment impairing the social adjustment (Groarke et al., 2004), where they might not enjoy leisure and recreational activities (Mueser et al., 1990). Type D personality was found to be associated with lower social adjustment. As a type D personality increases the level of loneliness lowering relationship adjustment (Spek et al., 2018). Individuals generally feel uncomfortable around other people (Gest, 1997), do not seek for help (Williams & William, 1983), and are found to be more avoidant. Studies showed that the individuals mostly internalise problems leading to poor sense of belongingness, social impairment and social isolation (Bohlin, Bengtsgard, & Andersson, 2000).

Although sexual adjustment was found to be associated with Type D personality at 0.05 level, studies have shown negative affectivity to be associated with sexual

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problems (Shakeriana et al., 2014). As type D personality people with cancer are accompanied by negative emotions such as hatred, lack of emotional stability, feeling guilty, and anger about the illness. Those traits might interfere with the sexual desires and leads to reduction in their sexual adjustment. Patients with negative affectivity are theoretically characterized by an overactive automatic system that makes them less likely to involve in sexual behaviour (Eysenck, 1967). The patients might lack sexual desires rather than sexual functioning due to worst mental health, body image concern and chemotherapy/radiotherapy (Christie et al., 2010). However, Costa et al. (1992) have shown an insignificant association between the two dimensions. Factors that might be associated with poor sexual adjustment might be due to old age, concern about the relationship and depression (Speer et al., 2005).

In the present study, a positive correlation was observed between duration of cancer, serious consequence and adjustment in psychological distress. The study reported higher duration, serious consequences related to lower psychological adjustment. A study by (McCorry et al., 2013) shows similar result, where women with breast cancer reported lower level of distress when they belief the illness will not last for a longer duration and they do not believe their cancer will cause serious consequence. Tol et al. (2012) showed an inverse result portraying higher adjustment related to higher duration of illness. This could be attributed to the time of measuring the adjustment during where most of the patients were administered chemotherapy. Stewart et al. (1997) showed that patients with heart disease when repeatedly hospitalized for a longer duration increases likely to see their illness more threatening. Moreover, perceived high concern towards the illness is related to higher psychological distress as the patients might be concerned about the financial problems, the impact of the illness upon the family members or they could not perform their duty at home causing

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more discomfort and distress (Nur et al., 2018). Negative affectivity is associated with psychological distress, which is reported in other studies (Howard et al., 2012; Pederson et al., 2009). People with higher NA scores are more prone to experience negative emotions, such as a greater tendency to worry, experience anger, frustration, guilt, sadness, hopelessness and feel less able to cope with stress (Mensink et al., 2003) and higher on depression (Denollet et al., 2000). Moreover, higher Characterological self-blame and behavioural self-blame is associated with lower psychological adjustment (higher psychological distress). Earlier studies reported Characterological self-blame to be associated with lower psychological adjustment and no association of behavioural self-blame was found with psychological distress (Breitenbecher et al., 2006). However, the study of (Malcarne et al., 1995; Bennett et al., 2005) showed both the types of self-blame to be related to distress and anxiety. Studies showed that Characterological self-blame might have a long term effect on cancer, whereas behavioural self-blame might be maladaptive for the present moment. Since, Janoff-Bulman (1922) hypothesized that the effect of self-blame on adjustment may not be comprehended until several years after diagnosis of the illness or understanding the stressor. This may be attributed the cause of behavioural self-blame to be adaptive as the stressor may be identified at a point of time. However, helping the patients to identify the modifiable aspects of the behaviour may help them more in the psychological adjustment process.

Behaviour is associated with illness perception. Thus, an illness perception promotion program improves behaviour in patients with renal disease (Rasani et al., 2015) and has significant association with health behaviour (Mosleh et al., 2016). Previous studies have reported that patient’s illness perception influences the health behaviour (Broadbent et al., 2009). A significant relationship exists between positive health

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changes and consequences, indicating higher threatening perception i.e. severe consequences of illness are related to better health behaviour. Health changes behaviour was related to treatment control. It might be because the patients receive the knowledge of the doctors and ways to control in the future, as they don't want their health to deteriorate (Nur et al., 2018). Personal control was also related to positive health changes. Studies show that patients must have self-control and think about the behaviour to adopt positive health behaviour until the behaviour becomes habit for them such as smoking cessation, diet management, taking medicine at times and physical activity (Nur et al., 2018). NA is inversely associated with positive health behaviour as psychological distress deteriorates positive health behaviour (Mensink et al., 2003), report more negative physical health symptoms and there are less positive health changes among the patients. Therefore, overall type D personality, reported more unhealthy behaviour, and less healthy behaviour (Ginting et al., 2014) with less health status change (Lee & Kim, 2016). Behavioural self-blame is associated with positive health changes. Attributing one causes of cancer had been associated with positive health changes such as smoking cessation and decrease alcohol consumption (Costanzo et al., 2010; Label et al., 2012; Rabin & Pinto, 2006). However, this indicated that survivors who accept their health risk producing behaviour and identify the behaviours are motivated to improve their health that may produce psychosocial perception of control over the illness (Maunsell et al., 2002) and reduce cancer recurrence (Stewart et al., 2001).

Therefore, the hypothesis 1“Selected dimensions of Self-blame, type D personality and perceived illness would significantly relate to psychosocial adjustment and positive health changes among the head and neck cancer patients” is partially accepted.

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SECTION IV: Hierarchical regression equations for psychosocial adjustment among the early stage cancer patients

Hypothesis 2: The hierarchical model would predict selected dimensions of adjustment and positive health changes among the cancer patients.

Table 5.6: Prediction of psychosocial adjustment by socio-demographic variables, perceived illness, self-blame and type D personality (N=66)

Psychosocial adjustment to illness												
	Model I			Model II			Model III			Model IV		
(I)Socio-demographic Variables	SB	SE B	t	SB	SE B	t	SB	SE B	T	SB	SE B	T
Age (above 45)	-.22	2.31	-1.83	-.13	1.56	-1.56	.13	1.6	1.51	.17	1.60	1.18
Gender (female)	.61***	2.34	-4.82	-.11	1.54	-1.32	.11	1.6	1.31	-.10	1.58	-1.17
Substance use	.12	1.10	.97	.03	.65	.44	.01	.70	.17	.04	.71	.54
(II) Illness Perception												
Consequence				.11	.5.86	1.46	.14	.61	1.61	-.16	.61	-1.87
Timeline				.38**	.80	2.55	.39**	.83	2.56	.41**	.81	2.76
Personal control				-.39**	.64	3.41	-.39**	-.67	3.27	-	.66	-3.42
Treatment control				-.08	.59	.74	-.03	.68	-.31	.40**	.67	-.34
Identity				.47***	.96	5.23	.43***	1.04	4.31	.46**	1.09	4.51
Concern				.29	1.00	1.81	.31	1.08	1.86	.13	1.02	1.94
Understanding				-.18	.58	1.38	-.15	.62	-1.08	*	.60	-1.14

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Emotional responses	.13	.59	1.94	.20	.61	1.87	.24	.41	1.18
(III) Self-blame									
Behavioural self-blame				-.07	.67	-.79	-.06	.67	-.70
Characterological self-blame				-.03	.65	-.38	.04	.70	.45
(IV) Type D personality									
Social inhibition							.13	.15	1.9
Negative affectivity							-.03	.21	.43
R	.62	.92		.92			.93		
R2	.38	.85		.86			.87		
Adjusted R2	.34	.81		.81			.82		
R ² change	.38	.47		.002			.01		
F	9.68***	21.05***		17.22***			15.88***		

*p<.05; **p<.01

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A hierarchical regression analysis was carried out to identify the predictors of psychosocial adjustment to illness among the patients suffering from HNC. Variables used for the analyses were demographic variables (age, gender, and substance use), illness perception, self-blame and type-D personality. The results of the analysis were shown in the Table 5.6, where psychosocial adjustment included aggregation of all the 7 subscales. After the first model with age, gender and substance use in the equation, gender explained 38% of the variance (change in $R^2=.000$) and the variables contributed significantly to the model ($F=9.68$, $p<.001$). In the second model, the overall model remained significant ($F=21.05$, $p<.001$) with the addition of subtypes of illness perception. The subtypes timeline, personal control and concern were significant contributors to the model, explaining additional variance of 47% to psychosocial adjustment to illness (change in $R^2=.000$). However, in model 3 and model 4, subtypes of illness perception significantly predict psychosocial adjustment similar to model 2 in spite of the additional variables of Self-blame and Type D personality (change in $R^2=.002>.05$; change in $R^2=.01>.05$) and 2, $p<.001$; $F=915.88$, $p<.001$) respectively. Therefore, model 3 and model 4 are not increasing the prediction level and are not significantly predicting to change the R^2 value.

Since adjustment is defined as a power to accept the changes in the external and internal factors and display appropriate attitude and behaviour, it requires the interplay of mind and body. Adjustment can be studied from various grounds such as biological, psychological and social-cultural. Thus, psychosocial adjustment to illness is influenced by all the factors. It has been reported that psychosocial adjustment to cancer patients is affected by social support, psychological support, sense of control, stage of illness, symptoms, physical fitness and perception of illness (Cam et al.,

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2009). However, gender and the four subtypes of illness perception i.e. timeline, personal control, concern and emotional responses significantly predicted 87% of the variability in psychosocial adjustment. The most important predictor of psychosocial adjustment was identity of illness perception. However, the four subtypes were found to be constantly predicting psychosocial adjustment indicating stronger predictors of adjustment. Overall the 4 models are significant at .001 levels.

Results indicated that female participants predicted lower adjustment (lower score higher adjustment). Male and female patients may face different problems in adjustment. Researchers have scanned the relationship separately by taking gender into account and some disparity was found between them with respect to gender norms assuming women as nurturers by nature with a greater burden of fulfilling the role of caretaker (Ashing et al., 2003; Greimel et al., 1998). Although females can communicate more easily with others as they can express their emotions related to illness. This might not facilitate them to adjust to their different corners of their life. Females might have perceived greater impact of physical disabilities such as impaired speech, eating, disfigurement upon their lives.

The result indicated that patients who believed their illness will last for a longer time, displayed a large number of symptoms related to their illness and experience more emotional responses related to their illness are more likely to have overall lower psychosocial adjustment such as worse functioning at work, reduced self-care, suffer from sexual problems, have poor social and family relationship with more psychological distress (Higher score indicates lower adjustment). As patients were repeatedly hospitalized for a longer period perceived their illness to occur for a longer period of time enhancing fear and worries among them (Stewart et al., 1997).

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The tendency to attribute symptoms to cancer was associated with lower psychosocial adjustment. These symptoms might act as a warning sign for the patients, indicating that their HNC is in progress and active state. These may smooth the progress of psychological distress such as worries, tension and fear among the patients. These impressions may reduce their adjustment in various fields of their life (Jopson & Moss-Morrison, 2003).

Belief about cure demonstrated an interesting relationship with psychosocial adjustment. Having faith in self for control and cure of illness was associated with positive benefits for the patients. Patients with a strong belief in self may likely to have better global adjustment than the treatment control. Patients who reported feelings of control over the illness were more likely to have better functioning at work, better healthcare orientation, experience less sexual issues, and practice healthy social and family relationship with better psychological health. Dunn et al. (1996) found that patients with optimistic believe and feeling of greater control was associated with adjustment. This finding goes opposite to the findings of Marcos et al. (2007). These findings recommend that the patients are needed to be educated regarding the belief in self as well as the positive effect of treatment.

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SECTION V: Hierarchical regression equations for positive health changes among the early stage cancer patients

Table 5.7: Prediction of positive health changes by socio-demographic variables, perceived illness, self-blame and type D personality (N=66)

	Positive Health changes											
	Model I			Model II			Model III			Model IV		
(I) Socio demographic Variables	SB	SEB	t	SB	SEB	t	SB	SEB	t	SB	SEB	t
Age (above 45 years)	.06	.01	.49	.15	.01	1.08	.15	.01	1.08	.07	.01	.51
Gender (female)	-.11	.17	-.85	-.16	-.20	-1.05	-.13	.20	.87	.11	.20	.74
Substance use	-.23	.16	-1.79	-.17	.17	-1.52	-.20	.18	1.36	.25	.18	1.80
(II) Illness perception												
Consequence				-.29	.15	-1.96	.32	.16	1.82	.26	.16	1.73
Timeline				-.21	.24	.71	.18	.25	.60	.25	.24	.85
Personal control				-.37	.16	-1.91	-.36	.17	-1.80	.31	.16	1.60
Treatment control				.37	.16	1.72	.31	.17	1.40	.29	.17	1.28
Identity				.64*	.27	2.04	.59*	.28	2.09	.64**	.27	2.04
Concern				.24	.27	1.40	.28	.28	1.55	.31	.28	1.73
Understanding				.31	.16	1.13	.25	.16	.87	.431	.16	1.09
Emotional responses				-.12	.23	-.56	-.12	.23	-.57	-.006	.23	-.02
(III) Self-blame												

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Behavioural self-blame		.11	.14	.82	.09	.15	.63
Characterological self-blame		-.02	.18	-.19	-.03	.17	-.27
(IV) Type D personality							
Social inhibition					-.06	.006	-.43
Negative affectivity					-.32**	.03	-2.35
R	.29		.51		.52		.59
R2	.08		.26		.27		.35
R ² change	.08		.18		.01		.07
Adjusted R2	.04		.11		.09		.15
F	1.93		1.79		1.54		1.81*

*p<.05; **p<.01

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A hierarchical regression analysis was carried out to identify the predictors of Positive health changes after the diagnosis of illness among the patients suffering from HNC. Variables used for the analyses were demographic variables (age, gender, and substance use), illness perception, self-blame and type-D personality. The results of the analysis were shown in the Table 5.7. After the first model with demographic variables such as age, gender and substance use in the equation, none of the variables predicted PHC (change in $R^2 > .05$) and the variables did not contribute significantly to the model ($F=1.93, p > .05$). In the second model, the overall model remained insignificant ($F=1.79, p > .05$) with the addition of subtypes of illness perception although the subtype of illness perception i.e. Identity was significant contributor to the model, explaining variance of 18% to PHC (change in $R^2 > .05$). In model 3 subtype of illness perception is significantly predicting PHC similar to model 2 but the additional variable of Self-blame did not predict PHC, overall explaining 1% variance of PHC (change in $R^2 > .05$). The overall model remained insignificant ($F=1.54, p > .05$). In the model 4, addition of subtypes of Type-D personality significantly predicted PHC among the patients. Negative affectivity explained addition of 11% of the variance thereby, increasing the prediction level and is significantly predicting to change the R^2 value (change in $R^2 < .05$), thereby significantly predicting the model ($F= 1.81, p < .05$). Therefore, only model 4 is found to increase the predicted level and is significantly predicting to change the R^2 value.

However, studies have shown that representation of illness motivates for self-management behaviour (Fostholm et al., 2005). The association of illness perception and health behaviour could be explained through the self-regulation system theory of health. According to the model given demonstrated by Leventhal and Carmeron

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(1987), individuals first form representation of the illness such as identity, concern, consequence, understanding, fear etc. These representations help them to adopt certain behaviours to cope and adjust to it and finally they evaluate the effectiveness of their own health behaviour.

The present result indicated that identifying symptoms of the illness are positively predicting positive health changes among the patients. However, a study by (Fostholm et al., 2005) showed that identifying symptoms, illness worry, emotional distress and belief in serious consequences encouraged the patients for higher health care use. Previous studies demonstrated that if the patients have a positive perception of illness, they will adapt higher self-care ability such as participation in rehabilitation centres, better diet, exercise and smoking (Broaden et al., 2009; Park et al., 2014). This might encourage them for better healthy behaviour. Identifying the illness symptoms and being more concerned about the illness might make them aware of their present health as they might not want their health condition to deteriorate. This might encourage them to take advice from the doctors and perform good healthy behaviours.

Illness perception associated with health behaviour might also be influenced by culture. In India, the primary social unit is society, family and community might have an influence on illness perception, due to which the patients might perform healthy behaviour and keep away from unhealthy behaviour (Kelly et al., 2016). Another factor influencing might be the positive bond between the doctor and the patient that might facilitate the patient to be aware of the symptoms’ after the diagnosis of the illness. These might help them build understanding about the illness that helped them change their health behaviour (Cai et al., 2013).

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In the findings, it is observed that there is an effect of a subtype of type D personality on health behaviour. It is observed that Type D personality patients have negative thoughts regarding their illness (Denollet, 2005). Negative affectivity negatively predicts health changes, which is supported by earlier studies (Nefs et al., 2015; Williams et al., 2011; Li et al., 2017). Cancer patients higher on negative affectivity are less likely to take medications, which might lead to adverse outcomes. They are found to perform fewer health enhancing behaviours such as eating a good diet, regular exercise and taking regular medicine (Williams et al., 2011; Lee & Kim, 2006). They might experience negative feelings towards self and others that hinders the pathway for any positive change leading to more destructive behaviours among them.

Therefore, the hypotheses 2a “Selected dimensions of Perceived illness, self-blame, and type D personality would be a significant predictor of psychosocial adjustment and positive health changes among the cancer in-patients” and 2b “The hierarchical model would predict selected dimensions of psychosocial adjustment and positive health changes among the cancer in-patients” is partially accepted.

Section VI: *Gender differences on dimensions of psychosocial adjustment and positive health changes among the early stage cancer in-patients*

Hypothesis 3 (a): There would be a significant gender difference between selected dimensions of psychosocial adjustment and positive health changes among the cancer in-patients.

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Table 5.8: Mean, SD and t-value among early stage male and female cancer patients

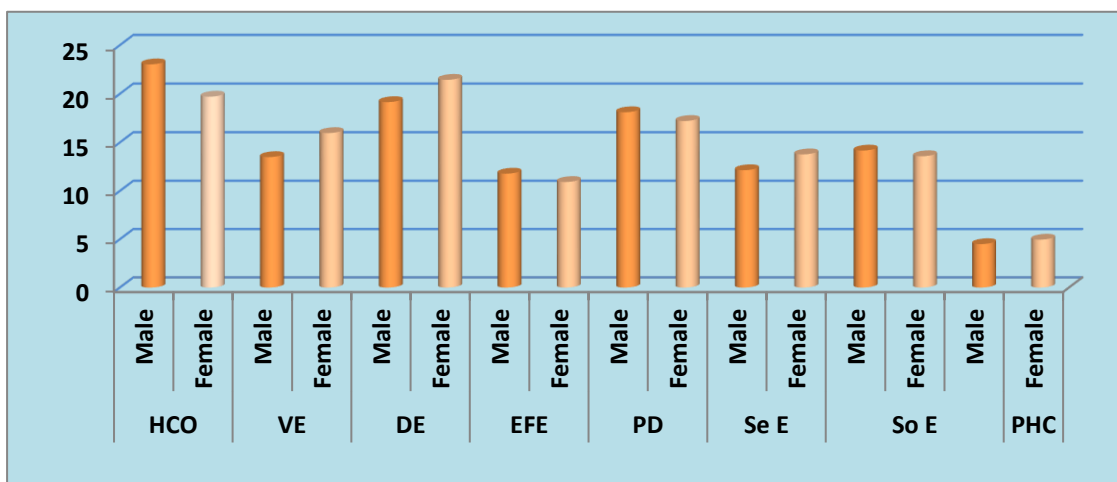
(N=66)

Dimensions		N	Mean	SD	t-value	Sig
HCO	Male	34	23.03	4.56	4.03	.000(sig)
	Female	32	19.71	3.72		
VE	Male	34	13.50	1.61	5.95	.000 (sig)
	Female	32	15.97	2.03		
DE	Male	34	19.15	2.61	3.03	.004(sig)
	Female	32	21.44	3.24		
EFE	Male	34	11.79	1.90	1.75	.08
	Female	32	10.93	2.25		
PD	Male	34	18.11	1.35	2.72	.008 (sig)
	Female	32	17.21	1.48		
SE E	Male	34	12.15	3.18	.31	.75
	Female	32	13.78	2.17		
SO E	Male	34	14.17	2.69	-.65	.51
	Female	32	13.59	4.34		
	Male	34	4.50	1.33	1.45	.15
PHC	Female	32	4.96	1.28		

***p<.05; **p<.01**

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Fig 5.1 (Bar diagram): Mean value of male and female early stage cancer in-patients on different dimensions of psychosocial adjustment and positive health changes among the (N=66)



The t-test in the Table 5.8 portrayed a significant gender difference on psychosocial and physical adjustment. Differences were found to be significant on Dimensions such as health care orientation problems ($p < .001$) and psychological distress problems ($p < .01$) with males higher on the problems than females respectively. However, significant differences were found among the dimension such as vocational environment problems ($p < .001$) and domestic environment ($p < .001$) with females higher on the problems than males respectively. Dimensions such as extended family relationship, sexual relationship and social relationship with PHC were found to have no significant difference.

Patients, health related behaviours such as how people seek, obtain, evaluate and use the information related to health is useful to perform health care behaviours that might reduce problems related to health care orientation. HCO dimension addresses the nature of the patient's attitude to health and if the attitude helps promote adjustment to

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the illness. Findings reported that males had greater problems related to health care orientation than female. Previous studies have shown that women used health care services more than men and are also found to frequently visit the care centers and doctors higher than male (Bertakis et al., 2000; Weir et al., 1996). The findings can be explained by previous studies which showed that women who perceived themselves to be worthy of care might utilize more health care treatments and seek assistance (Currie & Weisenberg, 2003). Another study showed greater dysfunction in health care orientation among female. No matter women might suffer more than men, but they have started valuing their health rather than being selfless helpers by taking a rest, getting support from spouse and children that promotes better adjustment in HCO.

This can be explained with the help of Curie’s model of women’s health care seeking behaviour. The first phase of the model is related to gathering of knowledge about how to protect them from the illness where patients might believe they need to make their own health care decisions. The second phase is related to health seeking behaviour, where the women find themselves to be an important part in their culture, family and society. They need to take care of themselves in order to take care of the family. The third phase is where they view if the health care system would meet their needs. If the needs are fulfilled, there is an adjustment in perception of health.

Moreover, studies showed that the female is more concerned with body image than male. This might encourage them for better health care needs and services (Cash & Grasso, 2005).

Findings indicated that women face more difficulty adjusting to domestic and vocational environment. Cinnamon and Rich (2005) reported that women give

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importance equally to their family, workplace playing the role of a wife, mother and working women. They need to invest efforts in both the environment which is quite different from the other. No matter, females might have started investing in their health quality, but due to the biological traits such as being compassionate, nurturer and caretaker they cannot ignore providing selfless help to their family members. Therefore, a sick woman is expected to take care of self as well as the family and needed to perform family duties (Soos, 1992; Blanch et al., 2004) leading to more emotional distress and more conflict. This might lower their adjustment by increasing problems at home and work place with symptoms of illness playing a mediating role between them. Moreover, family members and colleagues of the patients might not have accepted their illness which makes the patients challenging to adjust. After the diagnosis and treatment, they might not be taken proper care not to perform any duties.

Although studies have reported females higher on psychological distress, depressive symptoms than men (Bultz & Carlson, 2006; Katz et al., 2004; Oren et al., 2003; Stommel et al., 2004) regarding higher appearance related distress and more family related responsibilities. In the present study, male patients are found to have more psychological problems than female which is supported by other studies (Gill et al., 2009; Susan et al., 2005). This can be explained through social constructionist studies of masculinity. Cancer might create a threat to the traditional masculinity identity as it demands for lack of control over one's body. The patients might hold a strong belief of confidence, masculinity and control that might elevate the psychological distress among them (John, 2006).

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Since no difference was found regarding sexual relationships. This might be because both male and female patients might suffer from sexual problems. However, problems in sexuality with women is found in other studies (Heinonen et al., 2001). It might be because of loss of body image, decrease strength due to immunotherapy and fear of relapse (Choidi et al., 2000). Additionally, women don't like to expose the surgical scars (Blanch et al., 2004). On the other hand, males were found to have psychosexual problems. Another study conducted by Bethany et al. (2019) showed that both male and female patients experienced sexual problems related to desire, frequency and other related sexual problems. Moreover, when the patients undergo treatments such as chemo/radiotherapy and surgery, there was less sexual interest reported by both male and female patients. Studies have shown that old age, difficulty in social contact, weight loss, fatigue, pain, loss of appetite and constipation might affect sexual functioning among both the gender (Smith, 2018).

Peleg-Oden et al. (2003) conducted a study to examine the gender differences in the social and psychological adjustment among cancer patients with chemotherapy and radiation. Men undergo many difficulties in social adjustment than women. Reports from various countries revealed no gender differences among social adjustment (Vickberg et al., 2001) which supports the recent findings. However, various side effects of the treatments such as change in speech, disfigurement, loss of hair, loss of teeth, scars in the visible part, speech impairment and eating problems might be similar to both male and female. These physical alterations might increase the social isolation among both male and female. However, spending time with the family members, communicating with the friends, neighbours, relatives are very important components for adjustment of a person suffering from any illness.

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The findings have highlighted that there are significant differences among male and female regarding psychosocial adjustment even though they have gone through a similar kind of illness and related outcomes. The bar diagram (5.1) also shows the same trend.

Therefore, the hypothesis 3a “There would be a significant gender difference between selected dimensions of psychosocial adjustment and positive health changes among the cancer in-patients” is partially accepted.

SECTION VII: *Age-wise differences on dimensions of psychosocial adjustment and positive health changes among the early stage cancer patients*

Hypothesis 3(b): There would be a significant gender difference between selected dimensions of psychosocial adjustment and positive health changes among the cancer in-patients.

Table 5.9: *Mean, SD and t-value among early stage cancer patients below and above 45 yrs. (N=66)*

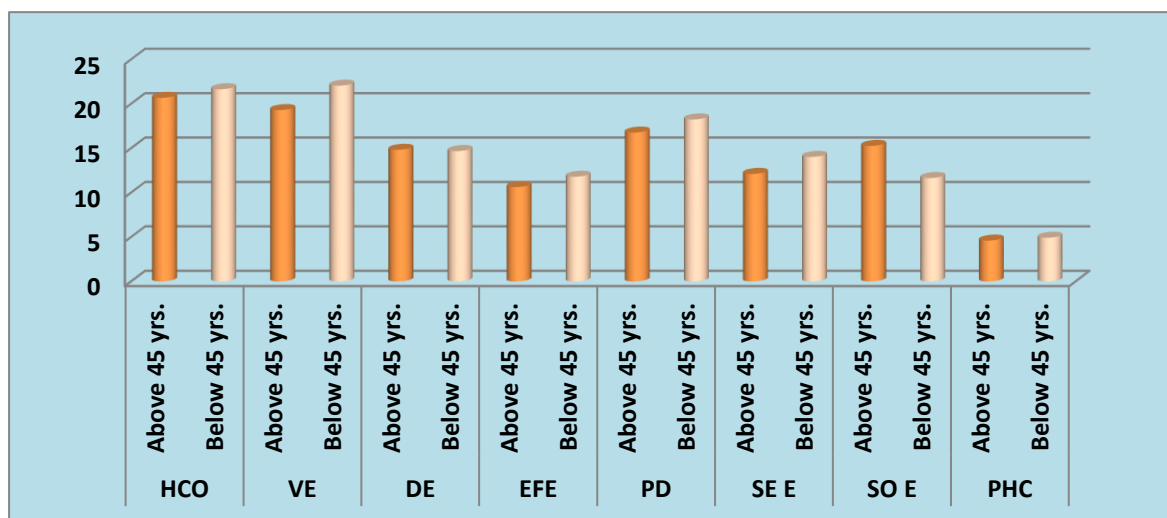
Dimensions	N	Mean	SD	t-value	Sig	
HCO	Above 45 yrs.	39	20.67	4.82	1.27	0.20
	Below 45 yrs.	27	21.64	4.02		
VE	Above 45 yrs.	39	19.29	2.24	3.63	.001(sig)
	Below 45 yrs.	27	22.04	1.81		
DE	Above 45 yrs.	39	14.82	2.92	.28	.78
	Below 45 yrs.	27	14.68	3.06		
EFE	Above 45 yrs.	39	10.63	1.59	1.68	.09
	Below 45 yrs.	27	11.79	2.08		
PD	Above 45 yrs.	39	16.76	.73	4.82	.000 (sig)

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	Below 45 yrs.	27	18.24	1.73		
SE E	Above 45 yrs.	39	12.11	3.18	4.32	0.000 (sig)
	Below 45 yrs.	27	14.02	3.02		
SO E	Above 45 yrs.	39	15.26	2.31	.68	.50
	Below 45 yrs.	27	11.64	2.54		
PHC	Above 45 yrs.	39	4.60	1.33	.92	.35
	Below 45 yrs.	27	4.92	1.28		

* $p < .05$; ** $p < .01$

Fig 5.2 (Bar diagram): Comparison between early stage cancer in-patients below and above 45 yrs. on different dimensions of psychosocial adjustment and positive health changes ($N=66$)



The t-test in the Table 5.9 portrayed a significant age difference on psychosocial and physical adjustment. Differences were found to be significant on Dimensions such as social environment ($p < .001$) with patients above 45 yrs. higher on the problems than below 45 yrs. However, significant differences were found among the dimension such as psychological distress ($p < .001$), sexual problems ($p < .001$) and vocational

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environment ($p < .001$) with patients below 45yrs. higher on the problems than above 45 yrs. respectively. Dimensions such as health care orientation, domestic environment, extended family relationship, and PHC were found to have no significant difference.

Although health related problems, well-being, age related changes results in diminished psychological and physical functioning, older adults with chronic disease such as cancer are likely to have increased functional impairment leading to more amount to psychological distress and social isolation (Hewitt, Rowland, & Yancik, 2003; Greimel et al., 1997). However, in addition to the damaged caused by the cancer, the side effects of therapies, surgery and other treatments might lead to permanent impairment in the organs, resulting more pain, anxiety and depression (Oeffinger et al., 2004).

However, the present study indicated higher psychological distress among younger cancer patients. This is supported by the findings of many previous studies (such as Watanabe, 2001; Zabora et al., 2001). This might be because the diagnosis of cancer might become unexpected for them facing difficulty to accept the nature of the cancer (Almigbal et al., 2019) with the fear of recurrence of cancer in the future. Moreover, they might be overflowing with guilt for not being able to take care of their family, for not performing the duties and responsibilities as young adults have a greater demand in the field of parenting as well as work. This might make them more stressful. Cancer might be a traumatic event for them (Erin et al., 2009). However, older cancer patients face lower distress as they might have developed skills and resilience to recover and handle the psychological distress (Egan et al., 2015).

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Concerning adjustment in the vocational environment domain, maladjustment was found to be higher among the younger patients. Elder cancer patients might have already been retired or left their jobs. Therefore, the importance of occupation might be less essential to them than the younger cancer patients (Nishigaki et al., 2007).

On the domestic environment, no differences were found among both the age groups. However, earlier studies showed younger patients might have a more psychological burden than older patients (Mor et al., 1994) as they have more domestic roles such as child-rearing and supporting the family. This may lead to fear regarding the recurrence of the illness or consequences of death. In older patients, presence of physical symptoms might lead to maladjustment in the domestic environment. They might fear of becoming a burden upon the family due to the illness (Valliant & Milofsky, 1980).

Regarding sexual relationship, maladjustment was found to be higher among the patients under 45 yrs. although studies have shown sexual problems reported frequently by older patients due to low desire, sexually inactive and lack of interest shown by mostly older female spouses (Lindau et al., 2007) and erectile dysfunction due to various illnesses among the older male patients than younger patients (Gareri et al., 2014). In the younger patient’s sexual role may be more important than older patients; however they get ignorance from their partners due to the illness, symptoms and consequences experiencing poor adjustment the sexual activity (Masakazu et al., 2007).

Social environment problems were also found to have no significant difference between the two age groups. However, as individuals grow older their social group might shrink leaving behind the family members by their side. Moreover, their

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physical activity, social gatherings and social activity might decrease, leading to maladjustment in the social environment. This might be applicable for both the groups. However, peer involvement and social support may provide a chance for the younger patients to cope with social situations (You & Lu, 2014). Patients in both the groups might also be involved with cancer organizations and society that facilitates them for better social adjustment.

In both the Tables 5.8 and 5.9, no difference was found regarding PHC regarding gender and age. Men and women with both the age groups suffering from cancer stage I and stage II basically have comparable outcomes, which might facilitate them to take similar steps for self-care management in order to live a healthy life. This might be the reason that no gender differences were found related to PHC in the present study. It is important for overall cancer patients to identify the symptoms, cause of the symptoms and to explore the various ways to alter their unhealthy behaviour.

These findings can be explained with the help of the Fogg Behavioral Model (Fogg, 2009). This model provides insight to many domains in behaviour-change, from health to education. The FBM has three principle factors: motivation (people have to be motivated to change their behaviour), ability (they must have the ability to perform the behaviour) and trigger (something must prompt them to do the behaviour). The patients might be motivated by the extreme pain, fear of death or hope to live a better life and social acceptance or rejection. The abilities among the patients might be mental effort, physical effort, time and a routine to maintain. The third factor is an effective trigger or reminder that is essential to prompt the action among the patients

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might be the increase in symptoms, heavy intake of medicine/therapies, physical impairments. The bar diagram (fig 5.2) is also showing the same trend.

Therefore the hypothesis 3b “There would be a significant gender difference between selected dimensions of psychosocial adjustment and positive health changes among the cancer in-patients” is partially accepted.

CHAPTER VI**SUMMARY, CONCLUSION AND RECOMMENDATION FOR
FURTHER RESEARCH**

Living under the influence of physical and psychological distress after the diagnosis of cancer, the patients need certain strategies to regain a sense of balance which might otherwise affect the psychosocial adjustment in different domains of life. Adjustment to cancer is similar to adjustment to any stressful events. However, adjusting to the cancer illness depends on a series of factors such as belief the patient holds on the illness, blaming their specific behaviours or characters, personality and the different demographic variables.

Problems related with the disease include nausea, vomiting, pain, constant fatigue, loss of appetite as well as libido, anemia and structural and physical changes. Along with it the patients suffer from alopecia, mastectomy and amputation. Furthermore, even though patients do not develop any clinical symptoms they may experience worries, fears that might make psychological distress common among them.

An estimation of about 21 million is considered to be a burden of cancer across worldwide. However, the worldwide burden is expected to increase to 21.4 million of new cancer cases and 13.2 million cases of cancer deaths by 2030. Worldwide cancer deaths are anticipated to increase by 60% from 2012 to 2030. These might be due to the increase in size of the population as well as acceptance of western lifestyle such as smoking, poor diet, physical inactivity and reproductive factors.

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Approximately 30 -40% of all cancers are HNC in India, accounting for 23% of all cancers in males and 6% in females, highest among the northeast states of Assam, Manipur, Mizoram, Tripura and Nagaland with an incidence rate of 54.48%.

Some consequences of chronic illness such as HNC cancer are rapid and unexpected while others are gradual. Decline in day-to-day activities, vitality, relationships may lead to an irregular course of life. These variations may present actual challenges among people to adjust to the disease. This led to the growing focus in psycho-oncology research during all stages of treatment and recovery.

After reviewing the relevant literature, the psychological and physical adjustment to HNC patients was found to be unexplored. Therefore, it is essential to understand the various factors contributing to better as well as poor psycho-physical adjustment among the patients.

Justification of the study

- The northeast region is turning to be the stock house of cancer due to different kind of food habits like the tradition of chewing betel nut and addiction to other sources of tobacco.
- Hence, there is a requirement of enthusiastic help to provide an opportunity for the patients to understand the cause of the illness and create cognitive and emotional representations about their illness. This will help them make sense to manage the illness and provide a better environment for adaptation.
- After the diagnosis of the illness among the patients, it is reasonable to wonder how they experience the life-limiting chronic conditions. Therefore, this is an

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important area of research as there is involvement of researchers making the patients realize the cause of the cancer and comprehend the necessities of adjustment to the illness at an early stage of cancer will help them better adapt and increase the longevity of the patients.

- Thus, focusing on the early stage of cancer (stage I and stage II) might facilitate in improving the health and for better adjustment and increase the longevity of the patients.
- It is understandable that cancer sufferers encounter mental, social and physical problems. However, till date, most of the researchers are trying to emphasize the factors that hinder the physical as well as mental health and leads to a distressed life.
- As, people have a tendency to study something that troubles the well-being of life Therefore, it is vital for the researchers to shift their focus towards features that helps them adapt to the illness through internal as well as the external environment.
- Some consequences of chronic illness such as cancer are rapid and unexpected while others are gradual. These variations may present actual challenges among people to adjust to the disease. This led to a growing focus on psycho-oncology research.

Objectives

The present study has the following objectives:

1. To explore the relationship between self-blame, type D personality, perceived illness, psychosocial adjustment and positive health changes among the cancer in-patients.

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2. To determine the significant predictors of self-blame, personality trait, perceived illness and other selected demographic variables on adjustment and positive health changes among cancer in-patients.
3. To make a gender-wise and age-wise comparison of variables of psychosocial adjustment and positive health changes among cancer in-patients.

Hypotheses

H1: Selected dimensions of Self-blame, type D personality and perceived illness would significantly relate to psychosocial adjustment and positive health changes among the head and neck cancer in-patients.

H2a: Selected dimensions of Perceived illness, self-blame, and type D personality would be a significant predictor of psychosocial adjustment and positive health changes among the cancer in-patients.

H2b: The hierarchical model would predict selected dimensions of psychosocial adjustment and positive health changes among the cancer in-patients.

H3a: There would be a significant gender difference between selected dimensions of psychosocial adjustment and positive health changes among the cancer in-patients.

H3b: There would be a significant age difference between selected dimensions of psychosocial adjustment and positive health changes among the cancer in-patients.

Methodology

Representativeness of the sample, inclusion/exclusion criteria, tools and statistical investigations are exhibited as follows:

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Sample

The sample for the present study comprised of 66 HNC patients were purposively selected (34 male and 32 female) from 3 different hospitals from Kamrup district, Assam (Guwahati, North-East Cancer Hospital, Guwahati Medical College Cancer Hospital, Guwahati and Night angle hospital, Guwahati) and one hospital of Sonitpur district, Assam (Tezpur Civil hospital). Age of the participants was grouped accordingly < 45yrs and >45yrs

Participant Inclusion Criteria

- ❖ Patients with stage I and II
- ❖ Patients suffering from head and neck cancer
- ❖ Both male and female
- ❖ Permission was taken from the directors of all the cancer hospitals
- ❖ Residence of Assam

Participant Exclusion Criteria

- ❖ No prior /present history of psychiatric illness
- ❖ Patients who didn't give their consent

Ethical Considerations

- ❖ Permission was taken from the institution/hospital for data collection
- ❖ Informed consent of the participants as well as the caregivers were taken
- ❖ Confidentiality: Ensuring privacy and confidentiality of personal information
- ❖ Non-inclusion of subject's personal information in data files

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Tools Used

1. *Socio-demographic Datasheet (Self, 2019)*: Socio-demographic data sheet consists of the personal record of the participants like age, sex and intake of substances like drinking, smoking, chewing tobacco, or any other substance.
2. *Brief Illness Perception Questionnaire*: Brief illness perception questionnaire was developed by Broadbent et al. (2005). The questions assess 9 dimensions: consequences, timeline, personal control, treatment control, identity, concern, understanding, emotional response and causes. Reliability of the items ranges from 0.42 to 0.73.
3. *Self-blame Questionnaire: Behavioural and Characterological self-blame* was accessed via two questions used during individual structured interviews. Portion of this interview were based on prior research on the psychological adjustment of cancer patients (Compas et al., 1994; Taylor et al., 1984). Embedded in the structured interview had questions about both behavioural and Characterological self-blame.
4. *Type D personality: Dutch 14-item Type D Personality Scale (DS14)* developed by Broadbent et al. (2006). It consists of 2 dimensions with 14 items: Negative affectivity, Social inhibition. The reliability of the scale is 0.88.
5. *Positive Health Changes*: Positive health changes (Lebel et. al., 2012; Mullens et al., 2004; Rabin & Pinto, 2006) measures were measured using a 2-item indicator. Reliability of the items is 0.86.
6. *Psychosocial Adjustment to Illness Scale*- Self report developed by Derogatis and Derogatis (1990) has 7 dimensions: Health care orientation, vocational environment, domestic environment, extended family relation, social environment, sexual

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relationship and psychological distress with 48 items. Reliability of the items ranges from 0.47 to 0.85.

Procedure for Data Collection

The concerned authorities in the various hospitals were contacted for permission to collect data from the respondents. After the consent was taken from the respondents, the purpose of the study was explained and the instructions were given in details for completing the questionnaire. After the participants were assured that the responses would be kept confidential data was collected individually by the questionnaires along with the social-demographic data.

Statistical Techniques Used

Keeping in view of the objectives and hypothesis, different statistical techniques were used for analyzing the data. The quantitative data were analyzed using SPSS version 23. For the descriptive statistics techniques like mean, SD, frequency was used. For the inferential statistical techniques like correlation, t-test and regression was used to measure the significant relationship, significant differences and significant prediction among the variables and groups.

MAJOR FINDINGS

- Among the 66 participants, 51.5 percent were male and 48.5 percent were female.
- Out of 66 HNC patients, 62 percent were above the age group of 45 yrs. and 38 percent were below the age group of 45 yrs.
- In the substance use category, it can be observed that 37.0 percent among all the participants were involved in chewing betel-nut, 30.3 percent were involved in

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chewing/smoking tobacco, 15.2 percent involved in multiple use and 16.6 percent were engaged in consuming none of the substance.

Findings on Causal attribution of Illness

Regarding the open-ended question of the IPQ-brief questionnaire, various cancer causal attributes have been extracted from the answers.

a) Environmental exposure, such as the use of plastic, chemicals in the food, harmful inhalation of smoke, b) bad habits such as intake of harmful substances (tobacco, gutka, betel-nut), wrong food habits, poor hygiene, lack of physical exercise, poor life style leading to weight gain/ loss, c) physical injury/accidents/infections, d) religious cause such as karma, punished by the God, e) luck or fate and f) don't know.

For the purpose of the analyzing the causes in the study, the patient's first three answers were considered to be the most important causes.

Findings on Positive Health Changes

Some of the positive health changes identified by the patients: Healthy food habits, Regular physical activity, Cessation or decrease of tobacco/betel-nut/smoking/alcohol intake, Meditation and Therapy, maintaining a proper hygiene, Better sleep quality, Getting rest and Active participation in social activities/groups.

Findings on Psychosocial Adjustment

The psychosocial adjustment was found to be higher among few of the domains such as Health care orientation, Domestic environment and Extended family environment while lower among Vocational environment, social environment, sexual relationship, and psychological distress.

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Findings on relationships between different Variables

- Consequences of illness was significant correlated with the health care orientation, vocational environment, psychological distress and positive health changes among the patients
- Timeline of illness was significantly correlated with the health care orientation, vocational environment and psychological distress among the patients
- Personal control was significantly correlated with the health care orientation, domestic environment, social environment, psychological distress and positive health changes among the patients
- Treatment control was significantly correlated with vocational environment, domestic environment, social environment and positive health changes among the patients
- Identity was significantly correlated with the health care orientation and vocational environment among the patients
- Concern was significantly correlated with the health care orientation, vocational environment, domestic environment, social environment and psychological distress among the patients
- Understanding was significantly correlated with the health care orientation, vocational environment and domestic environment among the patients
- Emotional responses were significantly correlated with the vocational environment, social environment and psychological environment among the patients
- Social inhibition was significantly correlated with the social environment and positive health changes among the patients

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- Negative affectivity was significantly correlated with the health care orientation, social environment, sexual environment and psychological distress among the patients
- Characterological self-blame was significantly correlated with social environment, and psychological distress among the patients
- Behavioural self-blame was significantly correlated with the health care orientation, psychological distress and positive health changes among the patients
- Gender, timeline, personal control and identity significantly predicted psychosocial adjustment among the patients.
- Identity and negative affectivity significantly predicted positive health changes.

Findings on Gender and Age Wise Difference

- Health care orientation, vocational environment, domestic environment and psychological distress were found have a significant difference between male and female patients.
- Vocational environment, sexual environment and psychological distress were found to have a significant difference between patients above 45 yrs. and below 45 yrs.

6.2 Interventions based on Findings

The head and neck cancer patients have considerable challenges to overcome.

Although patients cope surprisingly well, there is a sizeable amount experiencing psychological and physical effects, including uncertainty of recurrence of cancer, disruption of daily life, diminished self, attempts to understand the changes and cause and finding a plan to move forward. Treatment recovery may be inhibited by mood, belief system and physical immobility. Therefore, physical and psychological

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managements should be highlighted in the course of the treatment among the head and neck cancer patients as the focus should not only be to eradicate cancer but also restore and improve their well-being, interpersonal relationship and quality of life.

Nurse counselling and after intervention (NUCAI) is an educational intervention that helps patients manage their physical, psychological and social consequences. Patients receive advice, emotional support, educational information on diagnosis, treatment, and coping strategies as well as behavioural training. Such kind of sessions is problem-focused and patient-driven delivered by the trained nurses at the hospital.

The patients receive sessions every 2 month over a period of 1 year. It consists of 6 domains: 1) Discussing current problem (e.g. Pain, fatigue, eating and speech impairment) 2) Discussing life domain (e.g. Home situation, leisure activities, mood, and relationship), 3) providing the AFTER intervention: Adjustment to fear, Threat or expectation of recurrence (e.g. Fear of recurrence, identifying belief, evaluating self-examination and relaxation) 4) Providing general medical assistance and advice (eg. Provide medical/behavioural treatment) 5) Referring patient to psychological aftercare (e.g. Social workers, support group, rehabilitation centers). Such kind of intervention programs is found to be effective among HNC patients (Meulen et al., 2014).

Therefore, it should be held mandatory for implementing in daily clinical practice for effective improvement in several domains of the patient’s life.

Nutritional intervention: Head and neck cancer patients go through serious malnutrition. Treatments such as surgery, chemo/radiotherapy or a combination of both results in worse oral symptoms, decrease food intake, reduce weight loss leading to decreased quality of life as well as poor prognosis (Van et al., 1999). Moreover, when a disease is stable, the nutritional status may lead to recurrence of cancer. Well-

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being of the patient might also be influenced by the dietary habits. Therefore, doctors should go through a nutritional assessment to get an impression of the overall nutritional status. However, medical organization should take care of the early nutritional intervention that is crucial to stabilize the nutritional status thereby increasing nutritional intake. Individual Nutritional counselling or oral nutritional supplements should be provided to the patients’ dietary intake. However, a study revealed that patients maintaining nutritional counselling with regular food rather than supplements were found to have reduced symptoms of vomiting, nausea, anorexia and xerostomia (Bossola, 2015).

Behavioural interventions: patients with head and neck cancer undergo negative physical experiences such as speech problems, swallowing problems or lack of mobility/physical activity. Several behavioural interventions might be used by the patients to modify the behaviour for better physical outcomes.

Behavioural Wheel Change (BMW): the model aims to design and evaluate behavioural interventions. Initially, it is important to evaluate the behavior that is to be changed through Capacity, Opportunity and Motivation (COM-B model).

Followed by BWM model that describes 9 intervention functions: education (providing proper knowledge and understanding of the illness, symptoms, consequences), persuasion (using communication to induce positive/negative feelings or actions), incentivization (reward), training (imparting skills), coercion (creating expectation of cost) restriction (to increase the target healthy behaviour rules are implemented to reduce the opportunity to get engaged in the previous unhealthy behaviour), environmental restructuring (changing the physical or social situation), modelling (providing an example of people benefiting by altering the behaviour),

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enablement (increase means and reduce barriers to increase their skills and motivations) (Sinnott et al., 2015). Studies have shown to have an effective outcome regarding swallowing and physical activity (Finne et al., 2018; Govender et al., 2015).

Cognitive Behaviour Therapy (CBT) emphasises to reduce the distorted thoughts. It focuses to replace the negative thoughts with adaptive thoughts. CBT encourages coping and adapting with the illness. It might mostly be effective for reduction of anxiety and fear among the HNC patients with facial disfigurement, social isolation and negative belief about the illness and self. Exposure to feared situation, especially for the social environment may help them adapt with the scars and disfigurements and other disturbances with body image with development in the social skills (Newell & Clarke, 2000).

Among the patients with cancer related cognitive distortion impaired verbal memory, impaired working memory and impaired attention might be caused due to chemo/radiotherapy. Cognitive retraining methods might be used to enhance the behavioural and cognitive changes such as verbal rehearsal methods recording numbers from a computer to written form that would enhance working memory, learning how to apply smart phones calendar with alerts for important task (Kucherer & Ferguson, 2017).

Adjuvant psychological therapy is a cognitive behavioural therapy program developed especially for cancer patients. The therapy is conducted with both the patient and their spouses. The therapy focuses on the personal meaning adhered to cancer and the ways people think and use strategies to reduce the threat created by cancer. It encourages identifying the strength to raise their self-esteem, reduce helplessness, promote

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fighting spirit and encourages carrying out activities to gain control over their lives (Greer et al., 1992).

Smoking cessation intervention can be used among the patients smoking/chewing tobacco and betel-nut. It helps to quit smoking and chewing tobacco. Nicotine replacement therapy can be used among the patients. It consists of smoking cessation aids and CBT. Smoking cessation aids have 3 categories of antismoking strategies: nicotine replacement treatment (replacing nicotine induced substance with gum, sublingual tablets, etc.), tobacco-free cigarettes and medications (bupropion). CBT is used to support people (who smoke) change and behaviour by restricting their thought pattern. The low intensity interventions are used among the cancer patients. They are provided with self-help materials such as booklets, brochures, video clips and paper-based materials (Lucchiari et al., 2016).

Decrease in health changes and lack of adjustment to cancer may give rise to other psychological issues, including negative emotions, suicidal tendencies and other health related issues. Affected patients can be encouraged for professional help through proper counselling, necessary therapies and by providing coping skills. Psychotherapeutic techniques can be provided which will help the patients increase the positive emotions and as such become more aware, have better coping skills, positive adjustment with self/others and good physical quality. Hospitals can adopt certain strategies to focus on the improvement of positive emotions. Positive emotion will overall transform the individual into a new fashion. Besides family plays an important role in the adolescent’s life so they should be informed and involved in the process of the counselling. In addition, counsellors, teachers and families can work together to make the life of the patients enjoyable and happy to have a good health.

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6.3 Strength and Limitations of the Study

Some strength and limitation of the study has been addresses. To my knowledge, no study has been carried out to combine illness perception, self-blame, type D personality, psychosocial adjustment and positive health changes among the head and neck cancer patients. The study adds a new sight to the existing literature on how belief about the illness Characterological self-blame and negative affectivity contributed to adjustment. Therefore, the study not only has theoretical but also practical value. Understanding how Characterological self-blame and illness belief predicted health changing behaviour might have clinical implication as well. This information might help in identifying the individuals vulnerable to physical problems and develop some intervention programs. The study has enlightened how different domains of adjustment such as domestic, vocational, social, psychological, sexual, extended family and health care environment might be related to the belief the patients have about the illness, blaming their self for the illness and personality. Furthermore, strength of the study is that the questionnaires have facilitated to identify the causes of the illness and the various positive health changes adopted by the patients.

It is essential to mention some limitations as well. Due to the limited time, very few samples were considered for the study. As such no proper conclusion was drawn regarding the physical health changes and self-blame. However, a longitudinal study with larger samples would lead to better insight and gain better relationships among the constructs. As the current study provides a preliminary result in a bidirectional relationship, further study should be emphasized to test the meditation or moderation model in a longitudinal perspective. Moreover, the predicting effect of behavioural

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self-blame with adjustment and PHC was not found, which was one of the crucial parts of the study.

The findings of the present study were limited as the focus was on the overall HNC patients. Future studies should aim to segregate the various categories of HNC such as esophageal cancer, oral cancer, pharyngeal cancer, nasal cancer and salivary gland cancer as patients with different cancer might experience dissimilar symptoms. As such their needs and behaviours might differ accordingly. Moreover, there were patients with chemo/radio therapies, surgery, both or none. This might have affected the result of the study. Future studies should consider the patients on the basis of the above-mentioned categories.

The findings of the study could not be generalized to the other cancer groups with HNC as they might vary regarding disease severity, stage of the illness, prognosis and recovery of the symptoms. Stage III and stage IV cancer patients might differ as they were not taken into consideration.

The demographic variables studied further limits the research as most of the variables were not taken into consideration such as treatment type, time since diagnosis, duration of cancer education, income, type of HNC and family time which might add to the interpretation and understanding of the findings.

6.4 Conclusion

The study adds to the existing and growing literature that portrays some complexities as well as compositions in determining the psycho-physical adjustment outcomes among the patients with HNC.

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In addition, the findings highlighted the differences among the HNC patients of Assam in terms of causes of illness, gender, age and substance use. However, the findings suggest that factors such as illness perceptions, Characterological self-blame and negative affectivity among the patients elucidate adjustment and positive health changes among the HNC patients. As such, patients ‘negative belief of illness should be modified along with the perspective of blaming their character, which happens to be a barrier for better adjustment in several life domains and changing cancer-related health behaviour. Type D personality was found to be vulnerable factor that inhibits social, psychological, sexual adjustment along with deterioration of health behaviour. Further investigations could be done to understand if interventions would increase adjustment among patients with Type-D personality.

The experience of cancer characterized both positive and negative feelings, thoughts and behaviours among the patients. However, some might report benefits and adjusted while others may feel guilt, depressed and ashamed. Thereby, it is clear that patients undergo a wide range of experiences with cancer. Therefore, it is essential to recognize the patients with poor mental and physical health to provide them a better life. Finally, the results guided us to wonder that patients who are young as well as old, who attributed the causes of cancer to smoking, chewing tobacco and betel-nut and the one who attributed to other causes were likely to be in need of interventions and counselling to promote health.

Therefore, the result provided a direction to the caretakers, doctors and counsellors to provide better cancer management opportunities for the patients, providing proper guidance for options related to the belief system, blame factor that will help them

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change their behaviours. Thus, counselling should be started at an early stage of cancer accompanied by other psychological therapies.

6.5 Suggestions for Further Research

Various problems such as perceived illness, Characterological self-blame, behavioural self-blame, negative affectivity, social inhibition, and psycho-social adjustment and health changes are a few of the major areas among the cancer patients. The present study however revealed few interesting results. There are some suggestions for future research: a) the study needs to be conducted in a larger sample, b) patients suffering from different kinds of cancer such as lung cancer, stomach cancer, breast cancer can be included in the future research as highest number of cases are reported among the above mentioned three types of cancer, c) qualitative approach can be used to understand the challenges and well-being among the patients, d) a comparison among patients from rural and urban area can be done, e) patients with/without chemo/radiotherapy or surgery can be taken into consideration, f) this type of research can be extended to other districts of Assam such as Barpeta, Dibrugarh and Cacharas well as north-east states such as Manipur, Nagaland, and Tripura where the cancer prevalence is found to be higher g) interventions programme can be developed for reduction and control of the negative beliefs about the cancer and selves.

Thus, research studies in the present area demonstrate good scope in the area of cancer and will add to make a significant and sensible contribution in the future.

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From

I am hereby willing to participate in the study initiated by Kinnari Kashyap on “ Role of Perceived Illness, Self-Blame and Type D Personality on Physical and Psychosocial Adjustment among the Cancer, ‘In-Patients’, Assam” . Ms. Kinnari Kahyap has explained in details the procedural aspects of the study well in advanced. I agree to be a part of the study in my wish and not by force. I have not been paid any amount for the purpose of proving information.

Signature

SOCIO-DEMOGRAPHIC DATA SHEET

1	Name				
2	Gender	Male	Female		
3	Age				
4	Substance use	Smoking cigarette /tobacco	Chewing betel-nut	Mix of both	None

Appendix A. The Brief Illness Perception Questionnaire

For the following questions, please circle the number that best corresponds to your views:

How much does your illness affect your life? 0 no affect at all	1	2	3	4	5	6	7	8	9	10 severely affects my life
How long do you think your illness will continue? 0 a very short time	1	2	3	4	5	6	7	8	9	10 forever
How much control do you feel you have over your illness? 0 absolutely no control	1	2	3	4	5	6	7	8	9	10 extreme amount of control
How much do you think your treatment can help your illness? 0 not at all	1	2	3	4	5	6	7	8	9	10 extremely helpful
How much do you experience symptoms from your illness? 0 no symptoms at all	1	2	3	4	5	6	7	8	9	10 many severe symptoms
How concerned are you about your illness? 0 not at all concerned	1	2	3	4	5	6	7	8	9	10 extremely concerned
How well do you feel you understand your illness? 0 don't understand at all	1	2	3	4	5	6	7	8	9	10 understand very clearly
How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?) 0 not at all affected emotionally	1	2	3	4	5	6	7	8	9	10 extremely affected emotionally

Please list in rank-order the three most important factors that you believe caused your illness.

The most important causes for me:-

1. _____
2. _____
3. _____

Self-blame Questionnaire

(1) *How much do you blame yourself for the kinds of things you did, that is, for any behaviours that led to your cancer?*

1=not at all, 2=somewhat, 3= very much, 4=completely

(2) *How much do you blame yourself for the kind of person that you are (that is, for being the kind of person that has things like cancer happen to them)?"*

1=not at all, 2=somewhat, 3= very much, 4=completely

Positive Health Changes Questions

(a) 'I take better care of my health'

(b) 'I have made some PHCs'

The types of positive health changes that I have made are:

1.

2.

3.

Appendix 1 DS14 questionnaire

DS 14 Name: Today's date:

Below are a number of statements that people often use to describe themselves. Please read each statement and then circle the appropriate number next to that statement to indicate your answer. There are no right or wrong answers: your own impression is the only thing that matters.

0=false 1=rather false 2=neutral 3=rather true 4=true

1. I make contact easily when I meet people	0	1	2	3	4
2. I often make a fuss about unimportant things	0	1	2	3	4
3. I often talk to strangers	0	1	2	3	4
4. I often feel unhappy	0	1	2	3	4
5. I am often irritated	0	1	2	3	4
6. I often feel inhibited in social interactions	0	1	2	3	4
7. I take a gloomy view of things	0	1	2	3	4
8. I find it hard to start a conversation	0	1	2	3	4
9. I am often in a bad mood	0	1	2	3	4
10. I am a closed kind of person	0	1	2	3	4
11. I would rather keep other people at a distance	0	1	2	3	4
12. I often find myself worrying about something	0	1	2	3	4
13. I am often down in the dumps	0	1	2	3	4
14. When socializing, I don't find the right things to talk about	0	1	2	3	4

Scoring of the DS14.

Scoring of Negative Affectivity and Social Inhibition scales can be used as continuous variables to assess each of these two personality traits in their own right. Scores on both scales range from 0-28, and can be calculated as follows.

Negative Affectivity = sum of scores on items 2 + 4 + 5 + 7 + 9 + 12 + 13.

Social Inhibition = sum of scores on items 1 (reversed) + 3 (reversed) + 6 + 8 + 10 + 11 + 14.

SECTION I

(1) Which of the following statements best describes your usual attitude about taking care of your health?

- a) I am very concerned and pay close attention to my personal health.
- b) Most of the time I pay attention to my health care needs.
- c) Usually, I try to take care of health matters but sometimes I just don't get around to it.
- d) Health care is something that I just don't worry too much about.

(2) Your present illness probably requires some special attention and care on your part. Would you please select the statement below that best describes your reaction.

- a) I do things pretty much the way I always have done them and I don't worry or take any special considerations for my illness.
- b) I try to do all the things I am supposed to do to take care of myself, but lots of times I forget or I am too tired or busy.
- c) I do a pretty good job taking care of my present illness.
- d) I pay close attention to all the needs of my present illness and do everything I can to take care of myself.

(3) In general, how do you feel about the quality of medical care available today and the doctors who provide it?

- a) Medical care has never been better, and the doctors who give it are doing an excellent job.
- b) The quality of medical care available is very good, but there are some areas that could stand improvement.
- c) Medical care and doctors are just not of the same quality they once were.
- d) I don't have much faith in doctors and medical care today.

(4) During your present illness you have received treatment from both doctors and medical staff. How do you feel about them and the treatment you have received from them?

- a) I am very unhappy with the treatment I have received and don't think the staff has done all they could have for me.
- b) I have not been impressed with the treatment I have received, but I think it is probably the best they can do.
- c) The treatment has been pretty good on the whole, although there have been a few problems.
- d) The treatment and the treatment staff have been excellent.

(5) When they are ill, different people expect different things about their illness, and have different attitudes about being ill. Could you please check the statement below which comes closest to describing your feelings.

- a) I am sure that I am going to overcome the illness and its problems quickly and get back to being my old self.
- b) My illness has caused some problems for me, but I feel I will overcome them fairly soon, and get back to the way I was before.
- c) My illness has really put a great strain on me, both physically and mentally, but I am trying very hard to overcome it, and feel sure that I will be back to my old self one of these days.
- d) I feel worn out and very weak from my illness, and there are times when I don't know if I am really ever going to be able to overcome it.

(6) Being ill can be a confusing experience, and some patients feel that they do not receive enough information and detail from their doctors and the medical staff about their illness. Please select a statement below which best describes your feelings about this matter.

- a) My doctor and the medical staff have told me very little about my illness even though I have asked more than once.
- b) I do have some information about my illness but I feel I would like to know more.
- c) I have a pretty fair understanding about my illness and feel that if I want to know more I can always get the information.
- d) I have been given a very complete picture of my illness, and my doctor and the medical staff have given me all the details I wish to have.

(7) In an illness such as yours, people have different ideas about their treatment and what to expect from it. Please select one of the statements below which best describes what you expect about your treatment.

- a) I believe my doctors and medical staff are quite able to direct my treatment and feel it is the best treatment I could receive.
- b) I have trust in my doctor's direction of my treatment; however, sometimes I have doubts about it.
- c) I don't like certain parts of my treatment which are very unpleasant, but my doctors tell me I should go through it anyway.
- d) In many ways I think my treatment is worse than the illness, and I am not sure it is worth going through it.

(8) In an illness such as yours, patients are given different amounts of information about their treatment. Please select a statement from those below which best describes information you have been given about your treatment.

- a) I have been told almost nothing about my treatment and feel left out about it.
- b) I have some information about my treatment, but not as much as I would like to have.
- c) My information concerning treatment is pretty complete, but there are one or two things I still want to know.
- d) I feel my information concerning treatment is very complete and up-to-date.

SECTION II

(1) Has your illness interfered with your ability to do your job (schoolwork)?

- a) No problems with my job
- b) Some problems, but only minor ones
- c) Some serious problems
- d) Illness has totally prevented me from doing my job

(2) How well do you physically perform your job (studies) now?

- a) Poorly
- b) Not too well
- c) Adequately
- d) Very well

(3) During the past 30 days, have you lost any time at work (school) due to your illness?

- a) 3 days or less
- b) 1 week
- c) 2 weeks
- d) More than 2 weeks

(4) Is your job (school) as important to you now as it was before your illness?

- a) Little or no importance to me now
- b) A lot less important
- c) Slightly less important
- d) Equal or greater importance than before

(5) Have you had to change your goals concerning your job (education) as a result of your illness?

- a) My goals are unchanged
- b) There has been a slight change in my goals
- c) My goals have changed quite a bit
- d) I have changed my goals completely

(8) An illness such as yours can sometimes cause a drain on the family's finances; are you having any difficulties meeting the financial demands of your illness?

- a) Severe financial hardship
- b) Moderate financial problems
- c) A slight financial drain
- d) No money problems

SECTION IV

(1) Sometimes having an illness can cause problems in a relationship. Has your illness led to any problems with your husband or wife (partner, if not married)?

- a) There has been no change in our relationship
- b) We are a little less close since my illness
- c) We are definitely less close since my illness
- d) We have had serious problems or a break in our relationship since my illness

(2) Sometimes when people are ill they report a loss of interest in sexual activities. Have you experienced less sexual interest since your illness?

- a) Absolutely no sexual interest since illness
- b) A marked loss of sexual interest
- c) A slight loss of sexual interest
- d) No loss of sexual interest

(3) Illness sometimes causes a decrease in sexual activity. Have you experienced any decrease in the frequency of your sexual activities?

- a) No decrease in sexual activities
- b) Slight decrease in sexual activities
- c) Marked decrease in sexual activities
- d) Sexual activities have stopped

(4) Has there been any change in the pleasure or satisfaction you normally experience from sex?

- a) Sexual pleasure and satisfaction have stopped
- b) A marked loss of sexual pleasure or satisfaction
- c) A slight loss of sexual pleasure or satisfaction
- d) No change in sexual satisfaction

(5) Sometimes an illness will cause interference in a person's ability to perform sexual activities even though the person is still interested in sex. Has this happened to you, and if so, to what degree?

- a) No change in my ability to have sex
- b) Slight problems with my sexual performance
- c) Constant sexual performance problems
- d) Totally unable to perform sexually

(6) Sometimes an illness will interfere with a couple's normal sexual relationship and cause arguments or problems between them. Have you and your partner had any arguments like this, and if so, to what degree?

- a) Constant arguments
- b) Frequent arguments
- c) Some arguments
- d) No arguments

SECTION V

(1) Have you had as much contact as usual (either personally or by telephone) with members of your family outside your household since your illness?

- a) Contact is the same or greater since illness
- b) Contact is slightly less
- c) Contact is markedly less
- d) No contact since illness

(2) Have you remained as interested in getting together with these members of your family since your illness?

- a) Little or no interest in getting together with them
- b) Interest is a lot less than before
- c) Interest is slightly less
- d) Interest is the same or greater since illness

(3) Sometimes, when people are ill, they are forced to depend on members of the family outside their household for physical help. Do you need physical help from them, and do they supply the help you need?

- a) I need no help, or they give me all the help I need
- b) Their help is enough, except for some minor things
- c) They give me some help but not enough
- d) They give me little or no help even though I need a great deal

(4) Some people socialize a great deal with members of their family outside their immediate household. Do you do much socializing with these family members, and has your illness reduced such socializing?

- a) Socializing with them has been pretty much eliminated
- b) Socializing with them has been reduced significantly
- c) Socializing with them has been reduced somewhat
- d) Socializing with them has been pretty much unaffected, or (I have never done much socializing of this kind)

(5) In general, how have you been getting along with these members of your family recently?

- a) Good
- b) Fair
- c) Poor
- d) Very poor

SECTION VI

(1) Are you still as interested in your leisure time activities and hobbies as you were prior to your illness?

- a) Same level of interest as previously
- b) Slightly less interest than before
- c) Significantly less interest than before
- d) Little or no interest remaining

(2) How about actual participation? Are you still actively involved in doing those activities?

- a) Little or no participation at present
- b) Participation reduced significantly
- c) Participation reduced slightly
- d) Participation remains unchanged

Please continue on the following page ►

(3) Are you as interested in leisure time activities with your family (i.e., playing cards & games, taking trips, going swimming, etc.) as you were prior to your illness?

- a) Same level of interest as previously
- b) Slightly less interest than before
- c) Significantly less interest than before
- d) Little or no interest remaining

(4) Do you still participate in those activities to the same degree you once did?

- a) Little or no participation at present
- b) Participation reduced significantly
- c) Participation reduced slightly
- d) Participation remains unchanged

(5) Have you maintained your interest in social activities since your illness (e.g., social clubs, church groups, going to the movies, etc.)?

- a) Same level of interest as previously
- b) Slightly less interest than before
- c) Significantly less interest than before
- d) Little or no interest remaining

(6) How about participation? Do you still go out with your friends and do those things?

- a) Little or no participation at present
- b) Participation reduced significantly
- c) Participation reduced slightly
- d) Participation remains unchanged

SECTION VII

(1) Recently, have you felt afraid, tense, nervous, or anxious?

- a) Not at all
- b) A little bit
- c) Quite a bit
- d) Extremely

(2) Recently, have you felt sad, depressed, lost interest in things, or felt hopeless?

- a) Extremely
- b) Quite a bit
- c) A little bit
- d) Not at all

(3) Recently, have you felt angry, irritable, or had difficulty controlling your temper?

- a) Not at all
- b) A little bit
- c) Quite a bit
- d) Extremely

(4) Recently, have you blamed yourself for things, felt guilty, or felt like you have let people down?

- a) Extremely
- b) Quite a bit
- c) A little bit
- d) Not at all

(5) Recently, have you worried much about your illness or other matters?

- a) Not at all
- b) A little bit
- c) Quite a bit
- d) Extremely

(6) Recently, have you been feeling down on yourself or less valuable as a person?

- a) Extremely
- b) Quite a bit
- c) A little bit
- d) Not at all

(7) Recently, have you been concerned that your illness has caused changes in the way you look that make you less attractive?

- a) Not at all
- b) A little bit
- c) Quite a bit
- d) Extremely