Activity limitations and participation restrictions among cancer survivors in National Institute of Cancer Research and Hospital, Bangladesh

By

Md. Azharul Islam

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Project Paper completed by:

Md. Azharul Islam
4th year, B.Sc. in Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralysed (CRP) ……
Savar, Dhaka- 1343 Signature

Study Supervisor's name, designation and signature:

Nayan Kumer Chanda
Lecturer
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralysed (CRP) …….
Savar, Dhaka- 1343 Signature

Head of department' name, designation and signature:

Sk. Moniruzzaman
Assistant Professor & Head
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralysed (CRP) …….
Savar, Dhaka- 1343 Signature

Statement of Authorship

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This thesis has not been submitted for the award of any other degree or diploma in any other tertiary institution.

The ethical issues of the study have been strictly considered and protected. In case of dissemination the finding of this project for future publication, research supervisor will highly concern and it will be duly acknowledged as undergraduate thesis.

Signature: _____ Date: _____

Md. Azharul Islam
4th Year, B.Sc. in Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralysed (CRP)
Savar, Dhaka- 1343

Board of Examiners

Nayan Kumer Chanda
Lecturer
Department of Occupational Therapy …….
Bangladesh Health Professions Institute (BHPI) Signature
Centre for the Rehabilitation of the Paralysed (CRP)
Savar, Dhaka- 1343

Md. Julker Nayan
Associate Professor
Department of Occupational Therapy …….
Bangladesh Health Professions Institute (BHPI) Signature
Centre for the Rehabilitation of the Paralysed (CRP)
Savar, Dhaka- 1343

Suman Kanti Chowdhury
Senior Research Investigator ……....
icddr,b Signature
Mohakhali, Dhaka -1212

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Dedication

I dedicate this project to Almighty Allah my creator, my strong pillar, my source of inspiration, wisdom, knowledge and understanding. To my parents and sister who have always loved me unconditionally and whose good examples have taught me to work hard for the things that I aspire to achieve.

Contents

List of Abbreviations

ADL – Activities of Daily Living

I-ADL- Instrumental Activities of Daily Living

ICF- International Classification of Functioning, Disability and Health

NICRH – National Institute of Cancer Research and Hospital

P-ADL – Personalized Activities of Daily Living

WHO- World Health Organisation

WHODAS 2.0 – World Health Organisation Disability Assessment Schedule

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Abstract

Cancer is major public health problem in the world and 6th leading cause of death in Bangladesh. Cancer survivors possibly have the treatment to eliminate the malignancy that have medical and psychosocial late effects. Activity limitations and participation restrictions have been noticed after cancer treatments and these create problems in everyday activities and hamper the involvement in activities. The aim of the study is to explore activity limitation and participation restriction of daily activities among cancer survivors in National Institute of Cancer Research and Hospital, Bangladesh.

A cross sectional study design was used in the study. 120 respondents were selected by purposive sampling based on inclusion criteria. Data was collected by World Health Orgranisation Disability Assessment Schedule 2.0 (WHODAS 2.0) scored 0–100; a high score indicates greater activity limitations and participation restrictions). Data was analyzed through SPSS, analyzing descriptive and bivariate analysis.

Among 120 respondents, 54.2% participants were hospitalized where 57.5% were male and 42.5% were female while keeping ratio of 1.5:1. 36.7% of the respondents were aged between 48-62 years. 31.7% were illiterate and 58.3% of the respondents were married. The majority of people were aged and they are unemployed because of aging factor. Age ($p < .001$) was the strongest significant contributing factor followed by educational status ($p = .000$) for activity limitations and participation restrictions among cancer survivors.

This study would indicate that age and educational status are the key contributions in limiting the activity and participation among cancer survivors.

Chapter I: Introduction

Chapter I Introduction

1.1. Background

Cancer is major public health problem in the world and 6th leading cause of death in Bangladesh (Are, 2017). According to International Agency for Research on Cancer (2012), the total population of the world was 7 billion and there were 14.1 million new cancer cases. 8.2 million deaths in cancer and 32.6 million were surviving people (within 5 years of diagnosis) worldwide in 2012.

In Bangladesh, the total population was 1.5 billion. There were 1.3 to 1.5 million cancer patients in Bangladesh, about 0.2 million patients were newly diagnosed (Hussain, 2013). Among all cancer types, cancers of respiratory tract have occupied the top position (21.9%). Gastrointestinal tract (19.2%) has occupied the second position and others are breast (12.6%), lip, oral cavity and pharynx (11.1%) and lymph node (10.4%) cancers. Lung cancer, lymphoma, oesophagus, stomach and liver cancer are mostly prevalent cancers in males. In females, breast, cervix, lymphoma, lung, gall bladder are mostly seen among all cancers (National Institute of Cancer Research and Hospital, 2014).

According to National Cancer Institute (2015), People with cancer not only have only one treatment but also most of the people have a combination of treatments such as surgery with chemotherapy and/or radiation therapy. In addition, people may have immunotherapy, targeted therapy or hormone therapy. The diagnosis and treatment of cancer are so advanced. As a result, two in three adults (diagnosed) are likely to survive more than 5 years approximately.

Cancer survivors possibly have the treatment to eliminate the malignancy that have medical and psychosocial late effects. Powerful chemotherapy, invasive surgery and high doses of therapeutic radiation are necessary to cure the cancer which result potential outcome in long-term impairments of organ system function. Those may limit physical performance and unable to carry out daily activities (Ness, Wall, Oakes, Robison, & Gurney, 2006). From the study of Ness, Wall, Oakes, Robison & Gurney (2006), above half of the cancer survivors informed at least one limitation in physical performance, and one third reported a participation restriction. The increasing number

of patients are living and surviving with cancer because of improvement of early detection and treatment. Surviving cancer patients may experience functional disabilities which have effect on health, quality of life and capacity to work. Physical illnesses may include fatigue, less muscle strength, cognitive dysfunction, paresthesia, nutrition problems and mental disorders may include anxiety, depression, fear of relapse or insomnia (Rick, Dauelsberg, & Kalusche-Bontemps, 2017). Cancer survivors have difficulties in participation across all areas of life as a consequence of the cancer and ensuing cancer treatments (Baxter, Newman, Longpre, & Polo, 2017). For those problems, they have many functional problems in daily activities. Functional status assessment is required for a specific part of the quality of life evaluation. Functional status has a significant role in determining the context of quality of life because it has important life skills that a person needs to do as daily activities (Garman & Cohen, 2002).

According to World Health Organization (2002), activity limitations are "difficulties an individual may have in executing activities" and participation restrictions are "problems an individual may experience in involvement in life situations."

Activity limitations and participation restrictions have been noticed after cancer treatments and these create problems in everyday activities and hamper the involvement in activities.

To identify the whole functioning and disability, ICF was developed. It is the 'WHO framework for measuring health and disability at both individual and population levels. World Health Organization (2002) stated that, ICF is a scientific international tool that is a unified biopsychosocial model of human functioning and disability. It has dimensions including "impairments at the body and body part level, person level activity limitations, and societal level restrictions of participation". It also offers "the conceptual model and classification required for instruments to assess the social and built environment". ICF is a standard concept of data concerning all aspects of human functioning and disability around the world. ICF is useful for persons with all types of disabilities, not only for detecting their health care and rehabilitative requirements, but also in detecting and determining the effect of the physical and social environment on the difficulties that experience in daily lives.

Impairments across all diseases that include mental, neurological and addictive disorders, WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) was developed through a collaborative international approach to develop a single general instrument for measuring health status and disability across diverse cultures and settings (WHO, 2017). Cancer survivors has so many functional limitations during the treatment and afterwards. Activity and participation limitations also contain employment or occupational life, education, finances, and social and family relationships. During treatments, health care professionals do not state psychological well-being and participation in meaningful occupations. So, it is necessary to identify activity limitations and participation restriction.

1.2.Justification of the study

Cancer survivors face many difficulties in daily life because of their treatments. They may have problem in self-care, cognition, locomotion, working area, social participation etc. Function has different aspects and it is valuable for a person. The significance of impairments and their impact on activities are frequent and constant.

Activity limitations and participation restrictions are prior problems because it has many complications from various types of interventions Not only that, cancer and cancer treatments can lead to some impairments that are long lasting and devastating. Moreover, it affects the person with many difficulties.

The study is focusing on the importance of activity limitation and participation restriction based on daily living activities among the cancer survivors at tertiary level hospital in Dhaka city. It is very much important to know the activity limitations and participation restrictions because the survivors find so much limitation while they are doing the activity in the hospital and home. For that they are unable to participate in the work or programs in their home and hospital settings.

The finding will be helpful for the both service providers (specially doctors and other health professionals) and service takers (specially patients) to understand to understand the activity limitation and participation restrictions of the Cancer survivors in Bangladesh (either treatment or demographics perspective). However, the participations restrictions are merely depending on the magnitude of the severity which should be scoring by using standardized tool to consider some major domains of human

being. Moreover, this result will enhance the sustainable Quality of Life (QoL) for the cancer survivors and also suggest the possible way to overcome the limitations.

1.3. Variables

1.3.1. Dependent variable:

WHODAS 2.0: WHO Disability Assessment Schedule 2.0

1.3.2. Independent Variable:

Living Situation: Present situation where the person lives

Sex: Gender either male, female or others

Age: The length of time that a person has lived

Education: The process of receiving or giving systematic instruction specially at school or university

Current Marital Status: A person's situation with regard to whether one is single, married, separated, divorced or widowed

Main Work Status: A person's employment status

Chapter II: Literature Review

Chapter II Literature Review

Cancer

According to World Health Organization (2018), Cancer is a 'generic term for a large group of diseases that can affect any part of the body. Other terms used are malignant tumours and neoplasms. One defining feature of cancer is the rapid creation of abnormal cells that grow beyond their usual boundaries, and which can then invade adjoining parts of the body and spread to other organs, the latter process is referred to as metastasizing. Metastases are a major cause of death from cancer'.

Cancer is not only single disease but also compound sequence of events. Cancers not only grow at a single site, but also consequence from malignant alteration within a single clone, or cluster, of cells. This multiplies and obtains different changes that give it a persistence chance over its neighbors. Cancer cells mature when they have defects in regulation that administrate normal cell proliferation and homeostasis as for example: they lose the ability to die and continue to multiply (Cooper, 2006).

World Health Organization (2018), stated the etiology of the cancer begins from the transformation of normal cells into tumor cells. It is a multistage development that usually progresses malignant tumor from a pre-cancerous lesion. These are the result of the interaction between an individual's genetic factors and 3 categories of external agents, including (1) physical carcinogens i.e. ultraviolet and ionizing radiation, (2) chemical carcinogens, i.e. asbestos, components of tobacco smoke, aflatoxin that is a food contaminant, and arsenic and (3) biological carcinogens i.e. infections from certain viruses, bacteria, or parasites.

Investigations

Screening: Well established screening are breast and cervical cancer screening; breast cancer screening is for only positive for females' elderly over 50 years. Cervical screening agendas are existing as often as resources allow. Trials have unsuccessful to display effectiveness for lung cancer screening, and testicular cancer has such a decent therapy rate that screening could only improve prognosis.

Staging: Staging classifies the stage that the disease has got and is one way of establishing the issues that are on the verge of influence prognosis in any individual. The TNM system assesses the tumor by size, lymph node spread and presence of distance metastases:

T – size of tumor, site and depth of the primary tumor's incursion dependent on the category of tumor, evaluated on a scale ranging from T1–T5

N – lymph node spreading, assessed on a scale ranging from N1–N5

M – the existence of distance metastases, assessed on a scale ranging from M1–M5

e.g. T3, N1, M0 laryngeal cancer recommends a primary tumor which are locally advanced to attach with the vocal cord and early lymph node invasion triggering a palpable swelling in the neck but no indication of metastatic spread.

Other Investigation: Individuals undergoes with many of the following investigations in order for diagnosing and treatment procedures to be established. They are x-ray, blood counts, enzymes, ultrasound, computed tomography (CT) scan, positron emission tomography (PET) scan, magnetic resonance imaging (MRI) scan, isotope scanning, surgery.

Stewart & Wild (2014) stated in a report that, ageing is an important factor for developing cancer. Major cancer risk factors for the cancer are tobacco use, alcohol use, unhealthy diet, and physical inactivity are worldwide. There are some chronic infections that are the risk factors for cancer which is relevance in low to middle income countries.

In 2012, approximately 15% of cancers are diagnosed with carcinogenic infections, including Helicobacter pylori, Human papillomavirus (HPV), Hepatitis B virus, Hepatitis C virus, and Epstein-Barr virus. Infection with HIV significantly increases the risk of cancer especially cervical cancer (Stewart & Wild, 2014).

According to American Cancer Society (2018), there are more than 100 types of cancer in the world. Cancer types are generally named by the organs or tissues where the cancers occur and may be described by the type of cell which formed them. There are some cancers which can begin in specific cells. They are (1) Carcinoma that is the most common type of cancer that is formed by epithelial cells; (2) Sarcomas form in bone

and soft tissues that include muscle, fat, blood vessels, lymph vessels, and fibrous tissue (tendons and ligaments); (3) Leukemia is the cancers of the bone marrow that begin in the blood-forming tissue are called leukemias; (4) Lymphoma begins in the lymphocytes (T cells or B cells). There are two main types of lymphoma: Hodgkin lymphoma –abnormal lymphocytes that are called Reed-Sternberg cells and Non-Hodgkin lymphoma – a large group of cancers that start in lymphocytes. The cancers can grow quickly or slowly and can form from B cells or T cells; (5) Multiple Myeloma are Melanoma & Brain and Spinal Cord Tumor.

Cancer Treatments and Following Consequences

According to National Cancer Institute (2017), There are so many treatments for cancers to improve the survival rate. The treatments depend on which type of cancer individual has and how it has been advanced. Some people have one treatments but most of the people have combination of the treatments. They are surgery, radiation therapy, chemotherapy, immunotherapy, targeted therapy (type of treatment which targets the changes in cancer cells that help them grow, divide, and spread), hormone therapy, stem cell transplant and precision medicine.

In recent days, cancer treatments are so advanced that the survivors have been increased. The survivors face participation restriction throughout the life as a result of cancer and following treatments. There are some impairments which have been present in cancer survivors that are seen for long and short time. The impairments are cognitive impairment, neurological systems, reduced stamina, loss of range of motion, and changes in sensation (Baxter et al., 2017).

Cancer Survivorship

According to GLOBOCAN (2012), 14.1 million new cancer cases that have been diagnosed, 8.2 million people had deaths from cancer and 32.6 million people are surviving with cancer (within 5 years of diagnosis) worldwide.

According to American Society of Cancer Oncology (2018), Cancer survivorship has 2 shared meanings, that are (1) no signs of having cancer after the treatment and (2) Living with cancer, through the cancer and beyond cancer. There are 3 phrases of cancer survivorship. They are described as the specific period a survivor that is going through Acute survivorship which start from the diagnosis to the end of early cancer treatment.

Extended survivorship starts at the end of initial cancer treatment and goes throughout the months. Permanent survivorship is called when years have passed since treatment ended and relapse seems to be less likely.

Functional Limitation following Activity Limitations and Participation Restrictions

Study from Sweeney et al. (2006) showed that, female cancer survivors (less than 2 years) reported the most functional limitations, but long-term (5 or more years) cancer survivors are more likely to state that they are unable to do heavy household work, unable to walk a half mile and unable to walk up and down stairs. Kärki, Simonen, Mälkiä, & Selfe (2005) stated that, the impairment was seen in lifting, carrying, reaching out the objects and sleeping. Those individual without cancer or other chronic sickness were significantly more likely to give statement of being in fair or poor health, psychological problems and to have one or more limitations in ADL or IADL. They are likely to have one or more functional limitations, and among those aged 65 and younger. They are incapable of work because of their poor health (Hewitt, Rowland, & Yancik, 2003). In a critical review by Garman & Cohen (2002), older patients were more likely to have ADL limitations. In older people, 40% of the people had ADL limitations with having cancer or without cancer, 48% of people with cancer had trouble with at least one ADL. Results for the IADL were similar to the results for the ADL questions. 40% of the elderly people (85 years old) in the study reporting difficulty with at least one IADL. IADL limitations are more likely to be seen in survivors of cancer with comorbidities rather than cancer survivors. Another study by Avis & Deimling (2008) stated that, older patient has psychological difficulties rather than physical problems. Comparison among individual with cancer and without history of cancer suggest that older cancer survivors have more physical and psychological deficits than noncancer comparison group.

Because of functional difficulties, the survivors reported participation restrictions with more functional deficits. Demographics including race, gender, age, cancer stage of diagnosis and cancer symptoms have indirect role in determining functional deficits that results in participation restrictions. The participation restrictions have impact on daily and social activities. On the other hand, other health problems have impact on participation restrictions that is indirectly occurred through functional difficulties.

Among the demographics, gender has subsidiary effect on functional deficits and participation restrictions through comorbid health problems. Female cancer survivors have more problems in functioning and activities rather than non-cancer male individuals. Race, and age have uncertain but substantial indirect effects on participation restrictions through functional difficulties (Deimling, Sterns, Bowman, & Kahana, 2007).

Ness et al. (2006) ,showed that physical performance limitations were seen over half of the cancer survivors and one third of them reported participation restrictions. Physical performance limitations were significantly and more likely to be seen among both recent (54.4%) and long-term cancer survivors (52.7%) while compared to those with no cancer history (21.2%). Participation restrictions was reported higher significance among recent (30.5%) and long-term survivors (31.3%) than the people with no cancer history (13.0%). In another study by Baker, Denniston, Smith, & West (2005) stated that about 1 year of diagnosing with cancer, 68.1% of patients were reported that their illness was returning, and more than half were worried with progression of a disease reappearance (59.8%) or had worries regarding the future (57.7%). These psychological problems focused on fear. Approximately two-thirds of patients were concerned about a physical health problem, fatigue, and loss of strength. Two-fifths individuals were reported sleep difficulties (47.9%) and sexual dysfunction (41.2%). Younger survivors (18-54 years old) women, nonwhites and unmarried people were reported more problems. The people who were taken treatment for cancer reported more problems on average and had a higher score that was compared with those who were not in treatment. Oh, Han, Byeon, Bae, & Choi (2015) reported in their study that people are reported approximately 29.4% activity limitations in daily activities, people experienced 14.6% lying in a sickbed, and in a month 4.3% experienced more than 15 days lying in a sickbed.

National Institute of Cancer Research and Hospital (NICRH)

NICRH is the only tertiary level center of the country engaged in multidisciplinary cancer patient management. In April 2015, the hospital officially inaugurated the 300-bed hospital with Department of Radiation Oncology, Medical Oncology, Surgical Oncology, Gynaecological Oncology, Cancer Epidemiology, Haematology, Pediatric Oncology, Radiology & Imaging, Histopathology, Cytopathology, Clinical Pathology,

Microbiology, Immunology & Molecular Biology, Blood Transfusion Medicine, ENT Oncology, Dental & Faciomaxillary Surgical Oncology, Plastic & Reconstructive Surgical Oncology, Orthopedic Surgical Oncology, Genito-urinary Surgical Oncology, Anaesthesiology, Physiotherapy, Psychotherapy and Emergency Oncology (NICRH, 2018).

Chapter III: Methodology

Chapter III Methodology

3.1.Research Question

How much activity limitations and participation restrictions are present among cancer survivors in National Institute of Cancer Research and Hospital, Bangladesh?

3.2. Study aim and Specific objectives

3.2.1. Aim

To explore activity limitation and participation restriction of daily activities among cancer survivors in National Institute of Cancer Research and Hospital, Bangladesh**.**

3.2.2. Specific Objective

- To describe demographic characteristics of the cancer survivors based on activity limitation and participation restriction in daily activities
- To know how disability could impact on demographic factors

3.3.Operational Definition

Activity Limitation: Activity Limitations are difficulties an individual may have in executing activities.

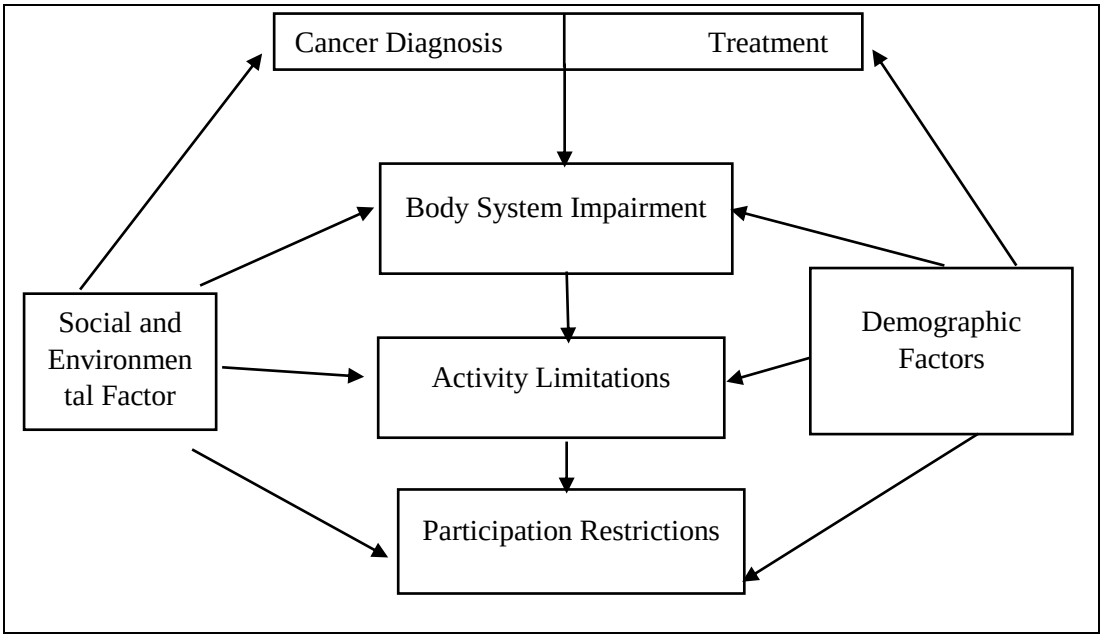
Participation Restriction: Participation Restrictions are problems an individual may experience in involvement in life situations.

Cancer: Cancer is the uncontrolled growth and spread of cells. It can affect almost any part of the body. The growths often invade surrounding tissue and can metastasize to distant sites.

Cancer Survivor: In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life.

NICRH: National Institute of Cancer Research and Hospital

3.4.Conceptual Framework



Conceptual Framework (adapted from Ness et. al., 2006)

3.5. Study Design

In this study, the investigator used a prospective cross-sectional survey of the quantitative research design. The investigator used this method to fulfill the aim and objectives of the study. The cross-sectional design is the best suited method for the presenting a situation over a short period of time. Using this study design, the investigator collected information about the cancer survivors who have activity limitations and participation restrictions at National Institute of Cancer Research and Hospital for treatment. The investigator had chosen this design as a means of using large number of participants and then collecting data accurately.

Data were collected from only once form each participant by using a structured questionnaire. Cross sectional study is useful for recognizing the association between the variables of the questionnaire (Mann, 2003). For that reason, the study had been done in this study design.

3.6. Study population

This study targeted all types of cancer survivors at NICRH those who are taking treatment from the hospital.

3.7. Study place

The investigator selected National Institute of Cancer Research & Hospital (NICRH). The hospital offers an energetic and dynamic environment and staffed by well trained professionals dedicated to cancer patient management, education and research.

3.8. Study period

The period of the study from October, 2017 to April 2018. However, the investigator got time to collect data from December 2017- February 2018.

3.9. Sample size

$$\mathbf{n}=\frac{z^2 \times pq}{d^2}$$

Here,

n = Sample Size

z = The standard normal deviate usually set at 1.96 which correspondents to 95%

p = 0.9859; positive finding similar to the proposed study (In a study by Hussain (2013), among 142 million of people in Bangladesh, 1.4 million people are diagnosed with cancer. From this study, prevalence of cancer survivors is 0.9859%)

q = (1-p) = 0.141; proportion in the target population not having the particular characteristics

d= 0.05; degree of accuracy required (level of significance/ margin of error)

Data were purposefully collected from 120 respondents to get significant findings.

3.10. Inclusion and exclusion criteria

3.10.1. Inclusion criteria

- Cancer survivor who had taken any local (surgery or radiotherapy), systemic treatments (Chemotherapy, hormone therapy and biological therapies) and adjuvant treatment (chemotherapy after surgery) in National Institute of Cancer Research & Hospital (NICRH) over 1 month
- Cancer survivor who had faced problems at activity limitation and participation restriction in daily activities

3.10.2. Exclusion criteria

- Cancer survivors those did not take treatment from the hospitals
- Cancer survivors with severe illness during the treatment at this hospital

3.11. Sampling Techniques

Investigator selected purposive sampling techniques to collect data. The investigator selected cancer survivors as sample of study purposively based on inclusion and exclusion criteria. Purposive sampling techniques were selected because it involves the deliberate selection of the individuals by the investigator based on pre-defined criteria and getting of those samples whose criteria were concerned with the study purpose. Here another factor is resource limitation to get the sample as bigger aspect as well as the limitation of time. The method contained some inclusion criteria to select the participant as to find out the actual snaps of the situation. Moreover, purposive sampling is non-representative subset of some larger population and is constructed to serve a very specific need or purpose (Oliver, 2013).

3.11. Data collection procedure

WHODAS 2.0 is a practical and generic assessment instrument which can measure health and disability at level of population or in clinical practice. WHODAS 2.0 captures the level of functioning and questionnaire contains the interviewer-administered 36-item version of WHODAS 2.0 containing six domains and that are

Domain 1: Cognition
D1.1. Concentrating on doing something for ten minutes?
D1.2. Remembering to do important things?
D 1.3. Analysing and finding solutions to problems in day-to-day life?
D 1.4. Learning a new task, for example, learning how to get to a new place?
D1.5. Generally understanding what people say?
D1.6. Starting and maintaining a conversation?

Domain 2: Mobility
D 2.1. Standing for long periods such as 30 minutes?
D 2.2. Standing up from sitting down?
D 2.3. Moving around inside your home?
D 2.4. Getting out of your home?
D 2.5. Walking a long distance such as a kilometer [or equivalent]?

Domain 3: Self-care
D 3.1. Washing your whole body?
D 3.2. Getting dressed?
D 3.3. Eating?
D 3.4. Staying by yourself for a few days?

Domain 4: Getting along
D 4.1. Dealing with people you do not know?
D 4.2. Maintaining a friendship?
D 4.3. Getting along with people who are close to you?
D 4.4. Making new friends?
D 4.5. Sexual activities?

Domain 5
D 5.1. Taking care of your household responsibilities?
D 5.2. Doing your most important household tasks well?
D 5.3. Getting all the household work done that you needed to do?

D 5.4. Getting your household work done as quickly as needed?
D 5.5. Your day-to-day work/school?
D 5.6. Doing your most important work/school tasks well?
D 5.7. Getting all the work done that you need to do?
D 5.8. Getting your work done as quickly as needed?
D 5.9. Have you had to work at a lower level because of a health condition?
D 5.10. Did you earn less money as the result of a health condition?

Domain 6: Participation
D 6.1. How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?
D 6.2. How much of a problem did you have because of barriers or hindrances in the world around you?
D 6.3. How much of a problem did you have living with dignity because of the attitudes and actions of others?
D 6.4. How much time did you spend on your health condition or its consequences?
D 6.5. How much have you been emotionally affected by your health condition?
D 6.6. How much has your health been a drain on the financial resources of you or your family?
D 6.7. How much of a problem did your family have because of your health problems?
D 6.8. How much of a problem did you have in doing things by yourself for relaxation or pleasure?

The investigator take face to face interview to collect data. In this study WHODAS 2.0 questionnaire was used as data collection tool.

The investigator will use simple scoring where the scores assigned to each of the items:

None	Mild	Moderate	Severe	Extreme
0	1	2	3	4

This method was referred to as simple scoring thus there was no weighting of individual items. This approach was practical to use as a hand-scoring approach and may be the method of choice in busy clinical settings or in paper–pencil interview situations.

Simple scoring of WHODAS was specific to the sample at hand. (Üstün, 2010). WHODAS 2.0 World Health Organization Disability Assessment Schedule 2.0 (0-100, higher = greater activity limitations and participation restrictions). Data was collected from hospitalized and outdoor patients.

3.10. Data management

By collecting data, the investigator selected the questionnaire carefully when there was any incomplete data or gap in any questions. And finally, all data are entered in SPSS for analysis

3.11. Data analysis plan

All data were analyzed using SPSS (Statistical Package for the Social Sciences) statistics version 23. Descriptive analysis was used to analyses quantitative data. Multiple regression analysis was used to find out the ability of some independent variables to predict the value of a dependent variable. Results were presented in frequency tables, bars and pie chart.

3.12. Quality control and quality assurance

Questionnaires were pretested. Bengali version of WHODAS 2.0 was provided by WHO WHODAS website. All the members as interviewee were trained and sensitized with the research before data collection. After each interview questionnaire were checked for possible error. Data was entered carefully first and then again checked by the investigator and were matched for possible error.

3.13. Ethical Consideration

- At first, the permission was taken from the research Institutional Review Board (IRB) of Bangladesh Health Professions Institute (BHPI).
- Then permission was first taken from National Institute of Cancer Research and Hospital (NICRH).
- Investigator built rapport with respondent before interview. Respondent were informed about several key things

- the study, its purpose, benefit and risk associated with the study and written inform consent was taken.
- Investigator informed respondent that they had full right to refusal at any of interview.
- Respondent were also assured that the study would not involve any physical, social, or psychological harm, discomfort, or invasion of their privacy.
- Responses were recorded anonymously and by identification number and confidentiality were maintained. Data and relevant documents have stored in a secured file.

Chapter IV: Result

Chapter IV Result

Findings of the Study

The following chapter details the findings of the activity limitations and participation restrictions among cancer survivors including socio-demographic characteristics. The valid response for each question had been used.

1. **Descriptive Analysis:** This analysis was used to describe the basic features of the data in a study. Simple summaries about the sample and the measures are done by this analysis. Here the descriptive analysis was used to describe Living situation at the time of interview, Age, Sex, Educational status, Marital status & Work status which were predictors or independent variables.

Table 1: Descriptive analysis of respondents

Variable	Frequency (n)	Percentage (%)
Living Situation at the Time of Interview		
Independent in the Community	20	16.7
Dependent	35	29.2
Hospitalized	65	54.2
Sex		
Male	51	42.5
Female	69	57.5
Age (Years)		
18-32	34	28.3
33-47	24	20.0
48-62	44	36.7
63-77	18	15.0
Educational Status		
Primary	36	30.0
Secondary	26	21.7
Higher Secondary	12	10.0
Undergraduate	3	2.5
Graduate	5	4.2
Illiterate	38	31.7
Marital Status		
Married	70	58.3
Separated	6	5.0
Never Married	17	14.2
Divorced	1	0.8
Widowed	26	21.7
Work Status		
Paid work	9	7.5
Self-employed, such as own your business or farming	7	5.8
Non-paid work, such as volunteer or charity	2	1.7
Student	16	13.3
Keeping house/ homemaker	28	23.3
Retired	40	33.3
Unemployed (health reasons)	16	13.3
Other	2	1.7

Table 1 showed that, most of the participants are hospitalized (54.2%) among 120 participants. The percentage of participants with assisted living was 29.2% and others are independent in the community (16.7%). Male respondents were 57.5% and female respondents were 42.5%.

Most respondents were aged between 48-62 years old (36.7%). Among 120 respondents, aged between 18-32-year people were 28.3%, aged between 33-47 years were 20% and aged between 63-77 years were 15%. Most respondents are illiterate (31.7%). Among 120 respondents, 30% respondents had primary education, 21.7% respondents had secondary education, 10% respondents had completed higher secondary degree, 4.2% respondents were graduate, and 2.5 % respondents had undergraduate degree. most respondents were married (58.3%). Among 120 respondents, widowed respondents were 21.7%, unmarried respondents were 14.2%, Separated respondents were 5% and other respondents were divorced 0.8%. Most respondents (33.3%) were retired.

2. **Bivariate Analysis:** It is the simultaneous analysis of two variables (characteristics). It explores the concept of relationship between two variables, whether there exists an association and the strength of this association, or whether there are differences between two variables and the significance of these differences. Living situation at the time of interview, Age, Sex, Educational status, Marital status & Work status which were predictors or independent variables whereas WHODAS 2.0 was dependent variable.

Table 2a: Activity Limitations and Participation Restrictions according to the Relation of Variables

Variable	Activity Limitations and Participation Restrictions (Mean Score)	P value
Living Situation at the Time of Interview		
Independent in the Community	40.00	.074
Assisted Living	57.79	
Hospitalized	54.79	
Sex		
Female	48.55	.079
Male	56.63	
Age (Years)		
18-32	41.07	**.001**
33-47	55.46	
48-62	56.69	
63-77	64.57	
Educational Status		
Primary	49.58	**.000**
Secondary	38.61	
Higher Secondary	56.76	
Graduate	51.50	
Illiterate	65.42	
Marital Status		
Unmarried	42.62	.618
Separated	71.54	
Divorced	71.69	
Widowed	64.47	
Married	49.74	

Table 2b: Activity Limitations and Participation Restrictions according to the Relation of Variables

Variable	Activity Limitations and Participation Restrictions (Mean Score)	P value
Work Status		
Paid Work	52.20	.134
Self- Employed	40.70	
Non- Paid Work	66.98	
Student	40.92	
Housewife	46.86	
Retired	65.31	
Unemployed	54.48	
Other	22.16	

Table 2a and 2b indicates that, age was the most significant factor ($p<.001$) related to activity limitations and participation restrictions. 63-77 years old have most (64.57%) activity limitations and participation restrictions. 48- 62 years old scored 56.69% activity limitations and participation restrictions followed by 33-47 years had 55.46% and 18-32% had 41.07% activity limitations and participation restrictions.

Education status had .000 significant factor where illiterate people had more activity limitations and participation restrictions (65.42%) followed by people who had higher secondary education had 56.76%, graduate people had 51.50% activity limitations and participation restrictions and who had primary educational status had 49.58% activity limitations and participation restrictions.

P value of living situation was .074 where people who need assistance had 57.79% activity limitations and participation restrictions subsequently hospitalized cancer survivors had 54.79% and independent in the community had 40% activity limitations and participation restrictions.

According to sex, male had 56.63% activity limitations and participation restrictions and female had 48.55% activity limitations and participation restrictions, and the P value of sex was .074

P value of work status was .134 in relation to activity limitations and participation restrictions where non-paid worker had 66.98% activity limitations and participation restrictions.

Retired survivors had 65.31% activity limitations and participation restrictions followed by unemployed people had 54.48%, paid workers had 52.20%, housewives had 46.86%, self- employed had 40.70% and other survivors had 22.16% activity limitations and participation restrictions.

Marital status of respondents had .618 P value where separated survivors had 71.54%, divorced had 71.69%, widowed had 64.47%, married had 42.62% and unmarried people had 42.62% activity limitations and participation restrictions.

This indicates that activity limitations and participation restrictions of cancer survivors have a significant effect on age and educational status.

WHODAS 2.0 Score indicates not only the overall disability score but also activity limitations and participation restrictions. The table shows that, there is a relationship between predictors or independent variable (living situation, age, sex, educational status, marital status and work status) and dependent variable (WHODAS 2.0 Score) where activity limitations and participation restrictions of the cancer survivors have impact on less education and aging.

Chapter V: Discussion & Conclusion

Chapter V Discussion & Conclusion

5.1. Discussion

This was the cross-sectional study to investigate the activity limitations and participation restrictions among cancer survivors who were attending National Institute of Cancer Research and Hospital in Bangladesh. The respondents were both from the community and those who were living in hospital. The study identifies demographic characteristics, relationship between demographic characteristics and activity limitation and participation restriction in daily activities.

Demographic Details of Respondents

Among 120 participants, 54.2% respondents are hospital bounded followed by assisted living (29.2%) and independent in the community (16.7). Ness et. al. (2006) studied the physical performance limitations from the people who were stayed in the hospital.

Cancer Registry Report (2014) showed that majorities (55.1%) of the patients were male and male female ratio was 1.2:1. Most respondents in this study were male (52.5) and others were female (42.5%) where the male, female ratio was 1.5:1.

Majority of the respondents of this study were aged between 48-62 years (36.7%) followed by aged between 18-32 years (28.3%), 33-47 years (20%) and 63- 77 years (15%). The mean age was 46.01 years (SD±16.54).

Most respondents of the study were illiterate (31.7%). According to Cancer Registry Report (2014), total population who were taking cancer treatment were illiterate (41.7%), but in male (22.4%) had primary education.

Among 120 respondents, most respondents were married in this study (58.3%). Followed by widowed (21.8%) and unmarried (14.2%). From the Cancer Registry Report (2014), the study in NICRH showed that 88.6% people were married whereas 5.7% were widowed and 5.5% were never married.

The registry report (Cancer Registry Report, 2014) showed that the housewife (41.9%) occupied the top position among all other occupations. But this was applicable for only females. 29.7% people were occupied with agricultural work, 8.8% people did service and 2.8 were retired. In this study, the investigator found that 33.3% survivors were retired because of age, 23.3% survivors were housekeeper, 13.3% were unemployed and students.

Activity limitations and participation restrictions among respondents

Educational status, age and living situation at the time of interview are the important factors describing activity limitations and participation restrictions among cancer survivors.

There was lack of information and published work about activity limitations and participation restrictions Bangladesh, or countries from the region. This study conquers the study from the United States and Norway.

From the analysis of 120 respondents, age ($p < .001$), educational status ($p = .000$) were more significant. 7% people had work disability associated with cancer. There was significant effect on work disability associated with cancer in occupational perspective(Short & Vasey, 2007). But in a study by Kwon, Hou, & Wang (2012) stated that, cancer survivors had a tendency to have higher education in United States of America. In other study by Dowling et al. (2013) reported that 51.4% cancer survivors had college degrees whereas 15.9% were illiterate. In a review article by Stein et al. (2008) stated that lower education level in females have an impact on specific deficits in cancer survivorship. A possible explanation could be that people with less education encounter greater physical challenges than those who have primary and higher degrees. Cancer survivors who were illiterate, had less awareness about cancer and its treatments. For this, whenever they were affected by neoplasms as well as cancer do not take participate in activity and do not participate in their work and social programs. They have been stigmatized by people around them not only from society but also from their family person. By getting stigmatized they do not take part in the work and social programs. Bangladesh was a developing country where many cancer patients came from rural place, there was presence of stigma. Cancer carries association with death. People often manifest the survivors with many unevidenced words. This decreases willingness of people to discuss and participation in society. This also affects the well-being of the survivors. Individuals with cancer faced the interpretation of potential threats that may occur in the workplace, social interactions and media as stigmatized or not to their identity (Knapp, Marziliano & Moyer, 2014).

This study adds to the body of evidence linking age to increased activity limitations and participation restrictions for cancer survivors. Cancer is disease for the elderly people.

In this study, 36.7% people were between 48-62 years and have significantly (p=.002) related to activity limitation and participation restrictions. From the study of Ness et. al. (2006), Age during interview was strongly associated with physical performance limitations. People with recent cancer diagnosis who were 40–49 years old had higher percentage of physical performance limitations (52.3%). In a review article Avis & Deimling (2008) stated that, greater than 60% of new cancers occur in people aged >65 years, and 60% of the current 10 million cancer survivors are aged more or equal to 65 years. Kwon et al. (2012) observed that middle-aged (40–64) cervical and endometrial cancer survivors informed less moderate-to-intensity physical activity equivalent than older people. They have less physical activity level and this can hamper activity limitation among cancer survivors. Cancer survivors are expected less likely to have participated regularly in physical activity before cancer diagnosis that is compared to non-cancer population. In that study, 40–49 years old with a recent cancer diagnosis had a much higher percentage (52.3%) of physical performance limitations when compared with no cancer history (14.8%) with 40–49 years old (14.7%). The maximum reported physical performance limitations had trouble in stooping, crouching or kneeling (46.8%), had problems in lifting or carrying 10 pounds (47.3%), had difficulty in reaching overhead and forward (40.5%), and had trouble in getting out of bed (35.1%). 24% of recent survivors reported a history of breast cancer, 17% reported they had history of prostate cancer, and 11% reported with the history of cervical cancer.

Again, Ness et. al. (2006) stated that both recent (30.5%) and long-time (31.3%) cancer survivors had reported more participation restrictions than those who had no cancer history (30.5%). Maximum prevalence of participation restrictions among cancer survivors had required constant levels of participation in both long-term survivors (16.5%) and 12.9% of recent survivors (12.9%). They reported that they had difficulty in leaving the house to participate in events e.g. shopping, movies or sporting events. Long-term survivors (13.3%) and recent survivors (15.0%) had reported that they had trouble in presence social events. Long-term cancer survivors (24.7%) and recent survivors (25.1%) said that they had difficulty in performing household chores. The association between participation restrictions and the person with cancer history persisted for both recent and long-term survivors even after adjusting for age at interview, sex, race/ethnicity, and income.

After adjusting for age at interview, sex, race/ethnicity, and income, long-term cancer survivors were 1.4 times and recent cancer survivors were 1.6 times more likely than those with no history of cancer to report any participation restriction.

Living situation at the time of interview was another factor that was found in this study. There were three categories in that question. They were independent in the community, dependent and hospitalized. Hospitalized cancer survivors reported more activity limitations and participation restrictions during the interview. There was limited facility in the hospital setting in NICRH. The responders were from the common ward and there were approximate 20 people in the ward. There was a little place to move around and no programs had been organized for the survivors. In that regard, they have faced limitations in activity of daily living (self-care, productivity and leisure). In this study we had found more activity limitations and participation restrictions (53.2%)
Ness et. al. (2006) reported that, they had found a higher percentage of participation restrictions (31.3% and 30.5%) than study from Hewitt et. al. (2003) which was 11.3%. Another study by Grov, Fosså, & Dahl (2010) reported that P-ADL problems were existing in 10% of the cancer survivors. Similarly, 38% of the cancer survivors had I-ADL problems.

5.2. Limitation

- In this study the investigator only took 6 independent variables, there should be more variables to find out demographic factors that had been linked to activity limitations and participation restrictions.
- This study is an academic research project and the investigator got only a couple of months to conduct the study so the sample was purposefully selected. This study had been conducted in NICRH which is a tertiary level hospital for cancer patients in Bangladesh. There were more hospitals in Bangladesh who are providing treatments for the cancer survivors. But time was so short that the investigator could not collect data from the other institutes
- More respondents could have been collected if more data collectors would be possible to assign. The patients' willingness to participate were less than prediction. There were so many brokers/ agents that were present in that hospital so that the patients were so much uncomfortable to be included in the study.

- Moreover, the study involved a considerable size of data and variables; as this was a part of investigator's learning process, statistical analysis and interpretation could have been more better.

5.3. Conclusion

In conclusion, age, educational status, situation at the time of interview and sex appeared as important factors associated with activity limitations and participation restrictions among cancer survivors. These demographics had more limitations in activity and participation restrictions among cancer survivors. The outcomes of this study may deliver some useful information for the development of evidence-based interventions. There is a great need to develop interventions based on hospitalized survivors according to age. Moreover, hospitalized survivors will be in focus while developing interventions to reduce activity limitations and participation restrictions among cancer survivors.

5.4. Recommendation

- Since this is the first study from Bangladesh to identify the demographic factors regarding activity limitations and participation restrictions among cancer survivors, the present findings need to be replicated in other population with cancer survivors in other hospitals and community in Bangladesh.
- Therefore, future research will benefit from more socio-demographic factors to understand how activity limitations and participation restrictions progress over time among cancer survivors.

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Appendices

Appendix A

National Institute of Cancer Research and Hospital
Mohakhali, Dhaka-1212.

Ref. no: NICRH/Ethics/2017/ 331 Date: 15/11/17

Certificate of Ethical Approval

Title: "Activity limitations and participation restrictions among cancer survivors at selected cancer hospitals in Dhaka city".

Investigator: Md. Azharul Islam, Sessain: 2013-14, B.Sc in Occupational Therapy, ID: 122130109
Bangladesh Health Professions Institute (BHPI), CRP, Saver, Dhaka-1343.

Recommendation: APPROVED/~~APPROVED AFTER CORRECTION~~/~~NOT APPROVED~~

Note: The research study to be carried out must comply with the national laws and regulations of the country and "WMA declaration of Helsinki-Ethical Principles for Medical Research Involving Human Subjects, amended, October 2008'

15/11/17

Prof (Dr.) Md. Moarraf Hossen
Chairperson
Ethics Committee
NICRH

Prof. (Dr.) Md. Mahbubur Rahman
Member Secretary
Ethics Committee
NICRH

BANGLADESH HEALTH PROFESSIONS INSTITUTE

বাংলাদেশ হেল্‌থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)
Bangladesh Health Professions Institute (BHPI)
(The Academic Institute of CRP)

Ref.

Date: 06/12/2017

CRP-BHPI/IRB/11/17/161

To
Md. Azharul Islam
B.Sc. in Occupational Therapy
Session: 2013-2014, Student ID: 122130109
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal "Activity limitation and participation restrictions among cancer survivors at selected cancer hospitals in Dhaka city" by ethics committee.

Dear Md. Azharul Islam,

Congratulations,

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application on 02/10/2017 to conduct the above mentioned dissertation with yourself, as the Principal investigator. The Following documents have been reviewed and approved:

Sr. No.	Name of the Documents
1	Dissertation Proposal
2	Questionnaire (English and Bengali version)
3	Information sheet & consent form.

Since the study involves the use of WHO Disability Assessment Schedule (WHODAS 2.0) questionnaire to collect data that will takes 10 to 15 minutes and have no likelihood of any harm to the participants. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 9:00 AM on October 08, 2017 at BHPI.

The institutional Ethics committee expects to be informed about the progress of the study, any changes occurring in the course of the study, any revision in the protocol and patient information or informed consent and ask to be provided a copy of the final report. This Ethics committee is working accordance to Nuremberg Code 1947, World Medical Association Declaration of Helsinki, 1964 - 2013 and other applicable regulation.

Best regards,

Muhammad Millat Hossain
Assistant Professor, Dept. of Rehabilitation Science
Member Secretary, Institutional Review Board (IRB)
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Appendix B

Consent Form

This research is part of Occupational Therapy course and the name of the researcher is Md. Azharul Islam. I am a student of 4th year B.Sc. in Occupational Therapy in Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP) which is affiliated to University of Dhaka. The study was entitled as **"Activity limitations and participations restrictions among cancer survivors in National Institute of Cancer Research & Hospital, Bangladesh"**.

In this study I am ……. a participant and I have been clearly informed about the purpose and aim of the study. I have the right to refuse in taking part any time at any stage of the study. I will not be bound to answer to anybody. There will be no impact on my treatment at present and in future.

I am also informed that, all the information collected from the interview will be only used for study purpose and would be kept safety and confidentiality will be maintained. My name and address will not be published anywhere. Only the researcher and supervisor will be eligible to access in the information to publish the research result. I have been informed about the above-mentioned information and I am willing to participate in their study.

Signature/Finger print of the Participant:	Date:
Signature of the Researcher:	Date:

সম্মতিপত্র

আমি মোঃ আজহারুল ইসলাম, বর্তমানে ঢাকা বিশ্ববিদ্যালয়ের চিকিৎসা অনুষদ অধিভুক্ত সিআরপির অধীনস্থ বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই) -এ বি.এস.সি ইন অকুপেশনাল থেরাপিতে চতুর্থ বর্ষে অধ্যয়নরত । আমার গবেষণার শিরোনাম- জাতীয় ক্যান্সার গবেষনা ইন্সটিটিউট ও হাসপাতালে টিকে থাকা ক্যান্সার আক্রান্ত ব্যক্তির কার্যক্ষেত্রে সীমাবদ্ধতা ও অংশগ্রহণে বাঁধা প্রসঙ্গে।

এই গবেষনাতে আমি .....একজন অংশগ্রহনকারী এবং পরিষ্কারভাবে এই গবেষনার উদ্দেশ্য সম্পর্কে অবগত । আমার যে কোন সময়ে এই গবেষনা থেকে নিজেকে প্রত্যাহার করার অধিকার আছে । এজন্য আমি প্রশ্নের উত্তর প্রদান করার জন্য করো কাছে দায়বদ্ধ না । এই গবেষনাটি বর্তমানে এবং ভবিষ্যতে আমার চিকিৎসাক্ষেত্রে কোন রকম প্রভাব ফেলবে না ।

আমি আরও অবগত আছি যে, এই কথোপকথন থেকে নেওয়া সমস্ত তথ্যাবলি নিরাপদে এবং গোপনীয়তার সাথে শুধু মাত্র গবেষনার কাজেই ব্যবহার করা হবে । আমার নাম এবং ঠিকানা কোথাও প্রকাশ হবে না । শুধু মাত্র গবেষণাকারীর এবং তার গবেষণার সমন্বয়কারীর সাথে এই গবেষণার পদ্ধতি সম্পর্কে অথবা যে কোন প্রশ্নের উত্তর জানার জন্য কথা বলতে পারবে । আমি উপরোক্ত তথ্যগুলো ভালোভাবে জেনে নিজ ইচ্ছায় এই গবেষনায় অংশগ্রহন করছি ।

অংশগ্রহনকারীর স্বাক্ষর/টিপসই	তারিখ:
গবেষকের স্বাক্ষর	তারিখ:

Appendix C: Questionnaires