QUALITY OF LIFE & QUALITY OF CARE AMONG POST STROKE DYSPHAGIA

By

Mahfuja Zaman Milva

4th year, B.Sc. in Speech & Language Therapy Dept.

Session: 2014-2015

University Of Dhaka

Bachelor of Science in Speech & Language Therapy

Bangladesh Health Professions Institute (BHPI)

(*The academic institute of CRP*)

Faculty of Medicine, Affiliated by

University of Dhaka

[February, 2019]

QUALITY OF LIFE & QUALITY OF CARE AMONG POST STROKE DYSPHAGIA

A Research presented to the
Bachelor of Science in Speech & Language Therapy
Bangladesh Health Professions Institute
(*The academic institute of CRP*)
University of Dhaka

By

Mahfuja Zaman Milva
milvaslt30@gmail.com

Supervisor
Nahid Parvez
Lecturer
Department of Speech and Language Therapy
Bangladesh Health Professions Institute (BHPI)

In partial fulfillment of the requirements for the degree of
B. Sc in Speech and Language Therapy

[**February, 2019]**

APPROVAL

We the under signed certify that we have the carefully read and recommended to the Faculty of Medicine, University of Dhaka, for the acceptance of this dissertation entitled- **‘‘ Quality of Life & Quality of Care among Post Stroke Dysphagia”**

By

Mahfuja Zaman Milva

4th year B.Sc in Speech and Language Therapy

Approved by

Signature of Supervisor

…………………………………………………….

Nahid Parvez

Lecturer

Department of Speech and Language Therapy

BHPI, CRP, Chapain, Savar, Dhaka-1343

Signature of Head of Department **……………………………..**

Md. Sazzad Hossain

Lecture & Head (Acting)

Department of Speech and Language Therapy

CRP, Chapain, Savar, Dhaka-1343, Bangladesh

DECLARATION

I am Mahfuja Zaman Milva, want to confirm that any single discussion of my research project will not be harmful to other. All the sources used in this study have been cited correctly.

All errors or inaccuracies are my own.

Signature & Date

……………………………………………………..

Mahfuja Zaman Milva

4th year, B.Sc in Speech & Language Therapy Department

Bangladesh Health Professions Institute (BHPI)

CRP, Savar, Dhaka

Bangladesh

DEDICATION

Dedicated to ……………………………………………………

……… My Beloved Parents and siblings

TABLE OF CONTENTS

List of figure

List of table

List of Annexure

List of Acronym

Abbreviation	Elaboration
BHPI	Bangladesh Health Professions Institute
BOM	Because of My
CRP	Centre for the Rehabilitation of the Paralyzed
SLT	Speech and Language therapy
SC	Swallowing Clinician
SLT	Speech & Language Therapist
SP	Swallowing Problem
SPSS	Social Package for the Social Science
QOC	Quality of Care
QOL	Quality of Life
SWAL- CARE	Swallowing related Care
SWAL-QOL	Swallowing related Quality of Life
WHO	World Health Organization

ACKNOWLEDGEMENT

At first I want to express my gratitude to the Almighty Allah who has given me enough ability, patience and intelligence for completion of this study successfully in time. I am grateful to my family members for supporting and encouraging me in crucial time of the study. I would like to thank my honorable and praiseworthy supervisor Nahid Parvez, Lecturer of Speech & Language Therapy (SLT) Department, CRP for his excellent guidance throughout the whole research project and for being such an excellent supervisor. Without his guidance and persistent help, the dissertation would not have been possible. I would also like acknowledge the name of my honorable teacher Md. Sazzad Hossain, Shohidul Islam Mridha, Jannatul Ferdous, Nure Naznin and clinical Speech & Language Therapist Sharmin Hasnat, Geetasree Das and Nurvin Jahan Asha to help me by providing valuable guidelines.

I am very much thankful to all of my classmates specially Sotota, Fatema, Sharif, Shuvra, Antara for their inspiration and direct help in my study. I would like to very much thankful to my friend Ashiq who help me to translate the questionnaire from English to Bangla.

Finally, I would like to be grateful to all of the participants of the study who made my research successful.

EXECUTIVE SUMMARY

Stroke is a health problem, it is major cause of mortality and morbidity in the developed and developing world and also one of the main cause of adult acquired complications including Dysphagia. But, still there is no study in Bangladesh about the QOL among dysphagic patients after stroke. This study represents the QOL & QOC among post stroke dysphagia which aim is to determine the Dysphagia related QOL & QOC after stroke. This is a quantitative type of cross sectional survey study where 69 samples were assigned purposively from 2 setting in CRP. The SWAL-QOL & SWAL-CARE questionnaire was used for the study. Data was analyzed by using descriptive statistical analysis (SPSS= Statistics package for social science) method. Among the 69 participants majority of participants were male. The majority of the age of the participants 36.2% were in the age range of 51-60 years. Majority of participants 71% took longer time at the time of eating. 69.6% patients showed cough when they eat and 62.3% chocked at the time of drinking liquids. 71% participants faced difficulty to understand meaning and 87% don not go out to eat because of SP. In QOC 100% participants were satisfied with the Therapists care. All participants declared that SLT gave them all advice which they needed and SLT discussed about their treatment strategies with the participants. SLT gave them advice on the food/ liquids and the techniques to help get food down & help avoid chocking.

This study might create a new field for Speech and language therapist to work with stroke patient who suffered from swallowing difficulties. By knowing the quality of life & quality of care among dysphagia related stroke patients then find out the difficulties among their lifestyle and impact on it. This will help to improve treatment procedure and patient can take treatment in different aspects which are really needed for develop patient condition.

Key words: Dysphagia, QOL, QOC, Stroke

Chapter- 1 Introduction

1.1 Introduction

Stroke is the second leading cause of death and the leading neurological cause of disability (Kim et al., 2015). It affects as many as 5% of the population over 65 years old, and this number is growing annually due to the aging population (Altman et al., 2007). Globally, 70% of strokes and 87% of both stroke-related deaths occur in low- and middle-income countries and the stroke incidence is more than doubled in over the last four decades (World Health Organization, 2016).

Stroke is an especially serious problem in Asia, which has more than 60% of the world's population for "developing" economies (Venketasubramanian, Yoon, Pandian, & Navarrod, 2017). South Asian countries (India, Pakistan, Bangladesh and Sri Lanka) constitute 22% of world's population and 40% of the developing world, and are the most affected regions probably accounting for more than 40% of global stroke deaths (Mehndiratta, Khan, Mehndiratta, & Wasay, 2014).

Stroke is caused by the interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue. It is also a leading cause of dementia and depression (World Health Organization, 2016). A higher burden of risk factor and lack of preventive measures are the main cause of higher risk of death and disability. Hypertension, antihypertensive treatment, alcohol intake previous stroke are the most commonly known risk factors for stroke (Robinson, & Jorge, 2016). Others risk factor are smoking, diabetes, previous coronary heart disease (CHD), electrocardiogram (ECG), excessive alcohol intake, and family history of Stroke. The most common symptom of a stroke is sudden weakness or numbness of the face, arm or leg, most often on one side of the body. Other symptoms include: confusion, difficulty speaking or understanding speech. The effects of a stroke depend on which part of the brain is injured and how severely it is affected. (World Health Organization, 2016). Because of stroke swallowing, speech- Language difficulties, voice problem are occurred.

Dysphagia, derived from the Greek Phagein, meaning "to eat", which is a common disabling issue after acute stroke. Dysphagia affects more than 50% of stroke survivors. Within 7 days the majority of these patients recover swallowing function and only 11-13% remain dysphagia after 6 months. (Fernandez, Ottenstein, Atanelov, & Asare, 2013). A significant portion of stroke patients that initially survive are faced with the risk of aspiration as well as quality-of-life issues relating to impaired communication. Dehydration and malnutrition are also common in dysphagic patients especially those who receive thickened liquids or modified diets (Pontes, Amaral, Rego, Azevedo, & Silva, 2016). One study reported that 49% of stroke survivors admitted to a rehabilitation unit were malnourished, and that malnutrition was associated with dysphagia. Approximately 58% of acute stroke survivors with dysphagia had signs of dehydration (Fernandez, Ottenstein, Atanelov, & Asare, 2013).

Dysphagia not only increases morbidity and mortality after stroke but also significantly affects quality of life when it is not possible to share meals with family and friends. Patients with dysphagia did not find eating enjoyable and experience anxiety or panic during mealtimes. More than 1/3 of patients avoid eating with others because of dysphagia (Pontes, Amaral, Rego, Azevedo, & Silva, 2016). According to Davis (2007), quality of life related to multiple issues including “physical, spiritual, emotional, nutritional and social” aspects of life, which contribute to a patients overall quality of life perception. It was found that many post stroke patients have difficulty chewing, fear of choking and coughing, and are at risk for aspiration. Many patients prefer to eat alone, creating a social isolation. Many patients felt discomfort while eating, or never felt fully satisfied after a meal (Kim et al., 2015).

In order to manage this anxiety, many health professionals attempt to modify the client’s diet. Usually, diets are reduced to softened foods due to the risk for choking or difficulty chewing, and liquids are thickened because of coughing or risk of aspiration (Logemann, 1998). Even with dietary modifications, many potential complications can arise when a patient has dysphagia including- aspiration, malnutrition, dehydration, and psychological stress or anxiety over eating. Not only the patients but also their caregivers need professional attention and support in order to maintain their own physical and emotional health and well–being. Stroke is one of the area where Speech & Language Therapist can work. As literature suggest that Dysphagia is one of the complication of stroke patient but there is no any available data in Bangladesh about the quality of life and patient’s satisfaction among post stroke dysphagic patients.

1.2 Literature Review

Fernandez, Ottenstein, Atanelov, & Asare, (2013) conducted a study on Dysphagia after stroke where they found that the maximum dysphagic patients recover their swallowing function during 7 days after stroke. But 11–13 % cannot recover their swallowing function even after 6 months. Dysphagia can adversely impact on quality of life. Dehydration and malnutrition are frequent in dysphagic patients who take modified diets. 45% of patients with dysphagia eat with enjoyment and 41% of patients with dysphagia experience anxiety or panic during the time to eat. More than 1/3 of patients avoid eating with others because of remaining dysphagia.

Finding of the study of Martino, Martin, & Black, (2012) showed that Patient with stroke who admitted in hospital 55% of them suffered in dysphagia. Early identification of Dysphagia is needed because the consequences of untreated dysphagia could be serious. Dysphagia patient with stroke who had pneumonia they are more likely to stay in extended time in hospital and they had the greater possibility of having death. Early identification is helpful to minimize the pneumonia and manage the symptom of dysphagia. Appropriate management is required for patient with dysphagia. We can use some compensatory procedure to reduce the complication of dysphagia such as dietary modifications, posturing for feeding, advice on safe eating, and oral hygiene, as well as behavioral maneuvers and effortful swallowing.

Bahceci, Umay, Gundogdu, Gurcay, Ozturk, & Alicura, (2017) conducted a research with 72 stroke patients who are mostly diagnosed dysphagia within 30 days after stroke and aged between 50-75 years where 58.3% (42) took modified food (semi solid). Complications of dysphagia involve with pneumonia, aspiration and malnutrition as well as the psychological and social complication also. Dysphagic patient generally did not enjoy eating and they cannot cope up with other environment so that they feel insecurity and isolation. They also showed the different studies report in their study which represent that they feel anxiety and fear at the time of eating. Findings of the study of Chen, Golub, Hapner, & Johns (2009) demonstrated that impaired swallowing cause aspiration, which may lead to severe level of pneumonia and increased mortality, failure to thrive, upper airway obstruction and numerous eating difficulties which may result as social withdrawal. It often results in considerable morbidity and mortality and clinical problem. Difficulty in chewing, fear of choking and coughing, and are at risk for aspiration are common after stroke. Many patients like to eat lonely which creates a social isolation. Many of them felt discomfort during eating, or never felt fully satisfied after taking a meal. They require extended time and effort to move food or liquid from mouth to stomach.

Bays (2001) conducted a study on stroke where he stated that dysphagia needs to be detected early and managed effectively because the consequences of untreated could be serious. To manage this anxiety, many health professionals attempt to modify their client's diet. Usually, diets are modified into softened foods due to the risk for choking or difficulty chewing, and liquids are thickened because of coughing or risk of aspiration. The concept of quality of life is complex and varied. In a review of the research on quality of life in stroke survivors, it was suggested that a screening utilizing quality of life instruments should evaluate social, mental, and physical functioning to achieve the most holistic assessment of quality of life. The study found that many patients measure their quality of life on the basis of only to mental, and not including physical, health.

Findings of the study of Vieira, & Antunes (2017) showed that dysphagia not only increases morbidity and mortality after stroke but also significantly affects their quality of life because it causes limitations or restrictions on activity and participation. It leads to functional limitations and major complications and interfere with QOL in several aspects such as emotional, physical and sociocultural, spiritual, emotional, nutritional and social of life. Davis, (2007) also conducted a research which suggested that in order to obtain the highest possible level of quality of life, patients should achieve the maximal degree of independence and functionality for activities of daily living. Dysphagia, likely a chronic state, has the potential to significantly impact quality of life in post-stroke patients with dysphagia. It can impact their diet, social activities, level of independence, and emotional well-being.

Quality of life & Quality of care can be used as a prognostic tool to help predict a patient's mortality. Abnormal quality of life scores can be used to identify physical or mental markers for clinically significant abnormalities in pathophysiological and psychological function, allowing understanding of patient's stability. Through this study investigator will try to find out the quality of life & quality of care among post dysphagia.

1.3 Significance of the study

Dysphagia is the result of the stroke which affects various aspects of life such as functional, physical, emotional, and communicational which can significantly disrupt their quality of life. Speech therapist are allowed to work on this area. This study will inform health professionals to know the health related quality of life. The purpose of this study will be to identify the quality of life and quality of care among post stroke dysphagia. It will help to speech and language therapist to expand their field and get clean and clear idea about their roles, to increase their knowledge and in making speech and language therapist awareness about the quality of life & quality of care among post stroke patients. Speech and language therapists can use this information in their practice and this study will be useful to develop their treatment protocol for post stroke patient. Speech and language therapists work in multi-disciplinary team and they can use the information in their collaborative team work. This study will present transparent evidence about their quality of life and quality of care among post stroke dysphagia. It would be also helpful for different professionals or organizations who are working or interested to work with dysphagia patients of stroke. This study will help the professional to identify the impact of swallowing patients on their quality of life. It will also help the other professionals so that they prepared their treatment plan according to impact. The study will make a future prospect of Speech & Language Therapy profession in Bangladesh. This study will be helpful to cultivate a new field for Speech and language therapist to work with stroke patient who are suffering in swallowing difficulties. Lastly this research will provide a stepping stone for all further research in the field.

1.4 Research Question

What is the impact on Quality of life & Quality of care among post stroke dysphagia?

1.5 Objectives-

1.5.1 General objective

To explore the impact of dysphagia on Quality of life & Quality of care among post stroke patients.

1.5.2 Specific objectives

- To explore the socio- demographic status of post stroke dysphagic patients.
- To identify the effect on communication & social interaction among post stroke dysphagia.
- To identify the effect on mental health among post stroke dysphagia.
- To address the patients satisfaction on SLT care.

1.6 Operational definition

Key words-

Quality of life, Quality of care, Stroke, Dysphagia

1.6.1 Quality of life

Quality of life refers to a subjective and multidimensional concept that encapsulates the standard of living of a person: their physical wellbeing, psychological wellbeing, happiness, desire to attain a goal of their life, wishes and overall expectations of life, personal thoughts, religious beliefs and relationship with others around him. In this study investigator tried to find out the quality of life (physical health, psychological state, personal beliefs, and social relationships) in stroke people with dysphagia.

1.6.2 Quality of care

Quality care is ensuring safe, affordable, perfect treatment and overall improvement in the health and heath care to all the people in the community or society so that everyone gets the opportunity to have equal treatment and health related facilities. Technical component is the first component of quality care that includes using high quality of technical components, machines and the one stands for providing equal treatment procedure or therapy across all racial, cultural issues and gender barriers.

1.6.3 Stroke

Stroke is a syndrome characteristic by the sudden acute onset of a neurologic deficit that persists for at least 24 hours and effects the central nervous system. It is the result of a disturbance of a sudden loss of blood supply to the brain, which leads to permanent damage to the brain tissue, caused by thrombotic, embolic, or hemorrhagic events. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue. Common symptom of a stroke are swallowing difficulties, sudden weakness or numbness of the face, arm or leg, most often on one side of the body (Robinson, & Jorge, 2016).

1.6.4 Dysphagia

Dysphagia is a medical term used to describe a swallowing disorders. It is characterized by difficulty moving food from mouth to stomach through all stage of swallowing. It also include behavioral and physiological aspects of the process which may occur in patients of any age and may be caused by a variety of structural or physiological abnormalities. It is the inability to conduct safe and efficient swallows. It may result in weight loss, malnutrition and aspiration and its related complications. (Logemann, 1998)

Chapter- 2 Methodology

2.1 Study Design

In this study the quantitative type of cross sectional survey design was used to identify the quality of life & quality of care among post stroke Dysphagia patients. Because quantitative research is used to establish facts (Bailey, 1997) and cross-sectional studies examine a phenomenon at one point of time (DePoy, 1998). Stein and Cutler, (2000) & Frankel and Wallen, (2000) said that the main function of the survey research is to obtain precise objective descriptions from a specific universe of people or entities by face to face interview about a particular topic or issue. It was prospective studies because here information was collected directly from the people studied. Besides these cross sectional survey design is simple to operate, cheaper and relatively quicker to carry out (Hicks, 2000). So it was suggested that survey method was the most applicable method to conduct the study, for these reason the investigator was used cross-sectional prospective survey method.

2.2 Study Place

This study was conducted in the clinical department of Speech and Language Therapy at Centre for the Rehabilitation of the Paralyzed (CRP) in Savar & Mirpur.

2.3 Study Population

The people who were diagnosed as stroke with dysphagia was selected as study population for this study.

2.4 Sample Size

A sample is a group of subjects that will be selected from the population, who will be used in pieces of research. Though a larger sample is more likely to be representative of the population in a survey study. But in many situations, it is not possible for the researcher both for practical and financial reasons (Hicks, 2000). So the investigator was used a sampling equation to determine the sample size. The equation is according to sample size –

$$n = \frac{z^2 \times p(1-p)}{d^2}$$

$$= \frac{1.96^2 \times 0.5 \times (1-0.5)}{(.05^2)}$$

$$= 384.16$$

Where,

Percentage of population, P= 0.5

Prevalence, q= 1-P= 1-0.5 = 0.5

Confidence level, Z= 1.96 at 95% (Standard value)

Degree of accuracy, d = 0.05

Required sample size, n=?

From this calculation total sample size was 384 but the investigator had found 69 samples from the 2 places which was Savar & Mirpur, CRP within 2 months. So, the sample size was 69.

2.5 Sampling Procedure

In this study the sample was selected through purposive sampling procedure to accomplish the aim and objective. Here purposive sampling was used because the investigator could not find out whoever was available, but could use judgment or inclusion and exclusion criteria to select a sample (Frankel & Wallen, 2000). Another reason for using purposive sampling was that it would be the easiest, cheapest and quicker method of sample selection (Bailey, 1997).

2.6.1 Inclusion Criteria

- The patient who had diagnosed as stroke
- History of swallowing problem after stroke.
- Both male and female patients.

2.6.2 Exclusion Criteria

- Patients with associate neurological deficits except Stroke.
- History of dysphagia before stroke.

2.7 Data Collection Tools

The SWAL- QOL & SWAL-CARE questionnaire was used as a data collection instrument which was developed by McHorney et al. It is a 59-item tool where the SWAL-QOL, 44 item tool that asses ten quality of life concepts and the SWAL-CARE, 15-item tool that asses quality of care and patient satisfaction. Several studies have confirmed the reliability and validity of this tools. Each response is rated by the patient from 0 to 4 on a Likert scale, with 0 described as "never" and 4 described as "Always" and the advice is rated as "yes/ no". All Scores are calculated separately for each domain. Higher scores for the scales and subscales indicate better quality of life & quality of care. The English questionnaire was converted into Bangla & asked the participants during the interview (McHorney et al., 2002).

2.8 Data Collection Procedure

Investigator was collected data from the participants through face to face interview and was clarified to all participants about the aim of the study. Investigator took permission from each volunteer participant by using a written consent form. Investigator requested to the caregiver of illiterate participants to sign in consent form and other side literate participants filled up the form by themselves. For the illiterate participants, investigator read the questionnaire and filled it up according to their response which aimed to elicit information relevant to the research topic (Hicks, 2000). Data was collected by using SWAL- QOL & SWAL- CARE questionnaire. Pen, papers, clipboard & stamp pad were also be used for collecting data.

2.9 Pilot Study

The investigator had accomplished the pilot study with six participants before starting the collection of data. The investigator had informed the participant about the aim and objectives of the study during the interview session. It was important to carry out a field test before collecting the final data because it helped the investigator to refine the data collection plan.

2.10 Data Analysis

Descriptive statistics is described, organize and summarize data (Bailey, 1997) and are commonly used for describing the survey data (Hicks, 2000). So investigator was used descriptive analysis to analyze the findings of this study as it was a survey. A computer program-“Statistical Package for the Social Sciences, version-22 (SPSS-22)” was used as a data analysis tool. In another study of Johansson and Kerstin (2013), here all statistical analysis was performed in Excel and in SPSS. The variables were labeled in a list and the investigator established a computer-based data definition record file that consists of a list of variables of order. The investigator put the name of the variables in the variable view of SPSS and defined the types, values, decimal, label alignment and measurement level of data. The next step was cleaning new data files to check the inputted data set to ensure that all data had been accurately transcribed from the questionnaire sheet to the SPSS data view. Then the raw data was ready for analysis in SPSS. Data was analyzed by descriptive statistics and calculated as percentages and presented by using a table, bar graph, and pie charts. At last, the result of this survey consisted of quantitative data.

2.11 Ethical Consideration

Voluntary participation from the participant’s was considered. Participants were provided with a written consent form. The Investigator was collected written permission to conduct the research from the participants. Participators were informed verbally about the aims and objectives of the study and investigators role as well. Participants also assured that the study would have no harm to the participants physically or mentally because it was a survey study and was not involved any experiments. Confidentiality was maintained by the investigator by keeping the name, address and personal information of the client confidential and as data was not shared with others except the supervisor of the investigator. Participants were also being informed that they had full rights to withdraw themselves or refuse to answer any question any time during the study.

Data were analyzed by descriptive statistics and calculated as a percentages and presented by using bar grapes, pie charts and tables.

3.1 Demographic information of the participants

3.1.1 Gender

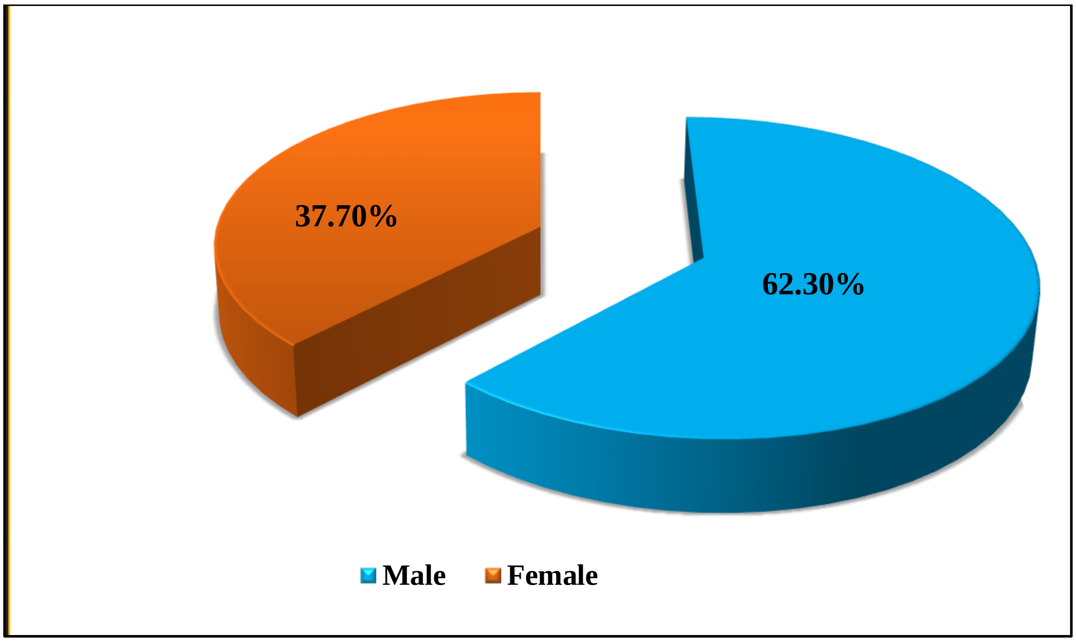


Figure 3.1.1: Gender of the Participants

The pie chart showed that the majority of participants 62.3% (43) were male and other Participants 37.7 % (26) were female.

3.1.2 Age

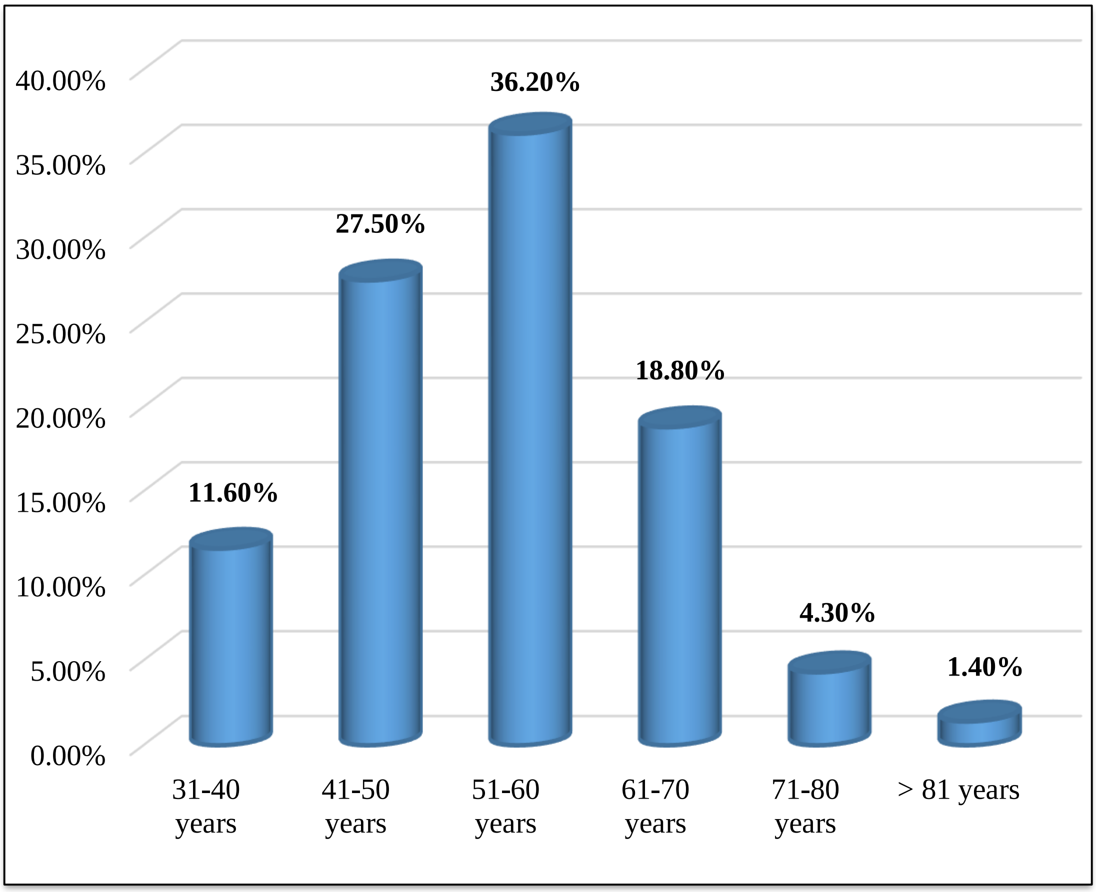


Figure 3.1.2: Age of the Participants

In this bar graph, the maximum number of participants, 36.2 % (25) were in the age of 51-60 years. It was found that 11.6% (8) participants those were in the age between 31-40 years. Also, 27.5% (19) participants found in the age between 41-50 years and 18.8% (13) participants found in the age between 61-70 % years. Limited parentages of participants 4.3% (03) were in the age between 71-80 years. Only 1.4% (01) participant was in the age range equal or greater than 81 years.

3.1.3: Educational Status

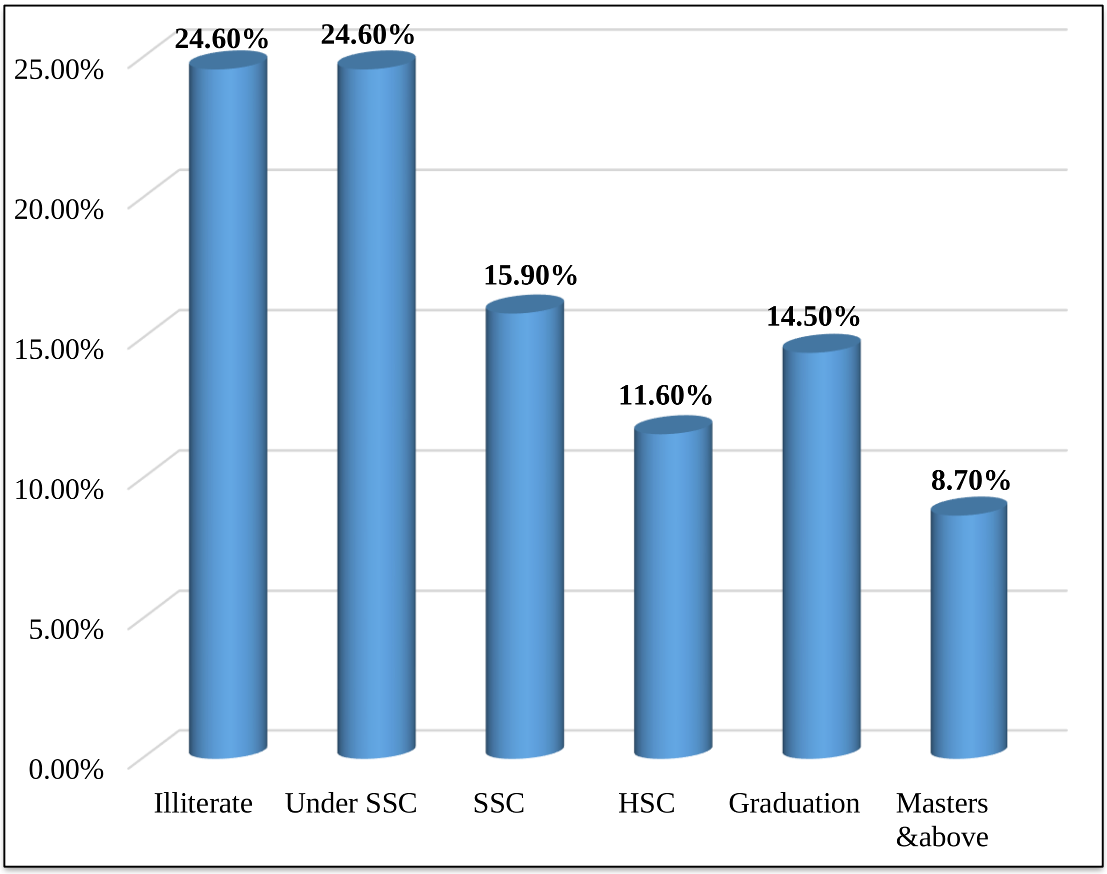


Figure 3.1.3: Educational Status of Participants

The bar graph shows that the majority numbers of participants 24.6 % which were equal in illiterate (17) & under SSC (17). Among the participants 15.9% (11) were in SSC level, 11.6% (8) were in HSC level, 14.5 % (10) were found completed the graduation and 8.7% (6) were masters and above.

3.1.4: Occupational Status

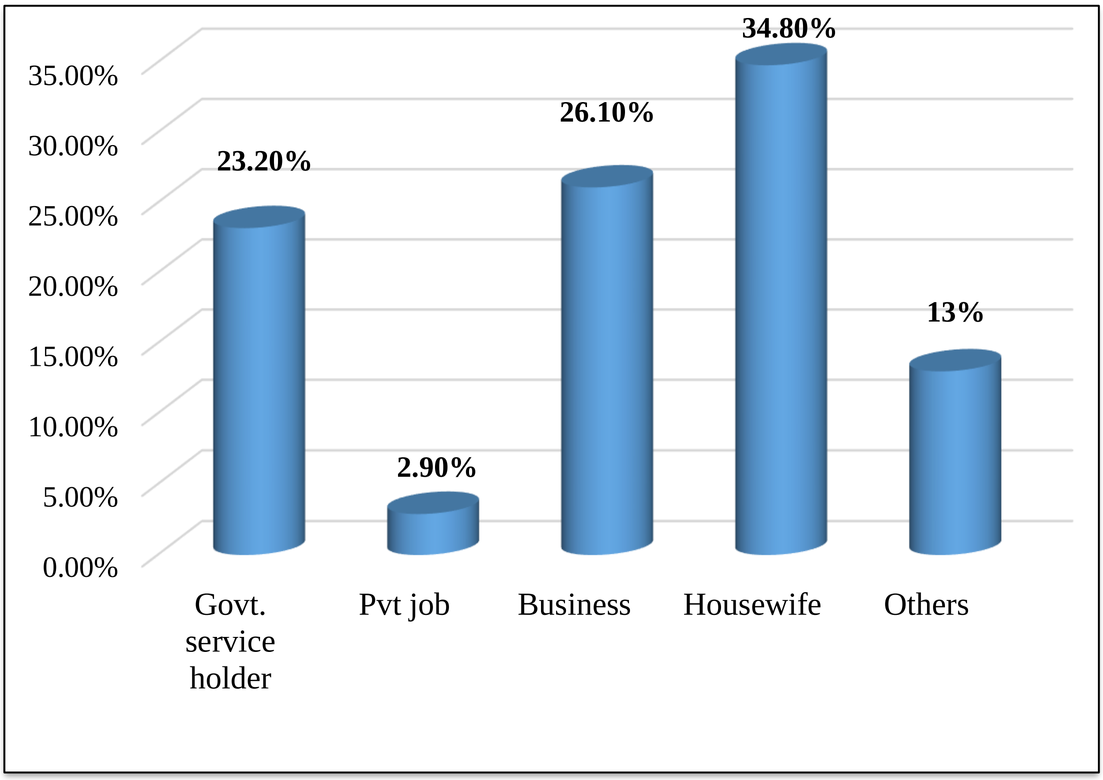


Figure 3.1.4: Occupational Status of Participants

This bar graph shows that among the participants, a highest number of respondents 34.8% (24) were found as house-wife. Besides that 26.1% (18) participants were business man. Above bar chart tells that 23.2% (16) were Government Service Holder along with 2.9% (2) were private service holder. Among all respondents 13% (9) were from other professionals.

3.1.5: Living Status

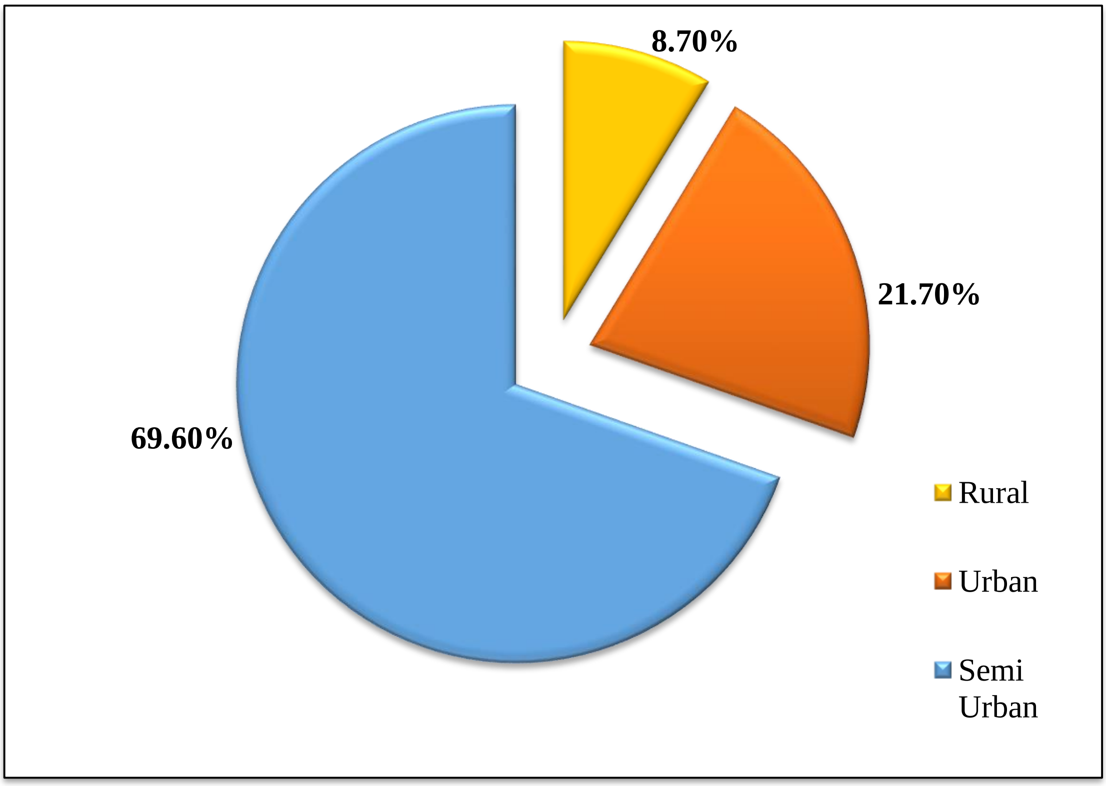


Figure 3.1.5: Living Status of Participants

The pie chart indicates that majority of participants 69.60% (48) were in semi urban areas. It was found that 21.70% (15) participants were in urban areas and 8.70% (6) were in rural areas.

3.1.6 Onset of Stroke

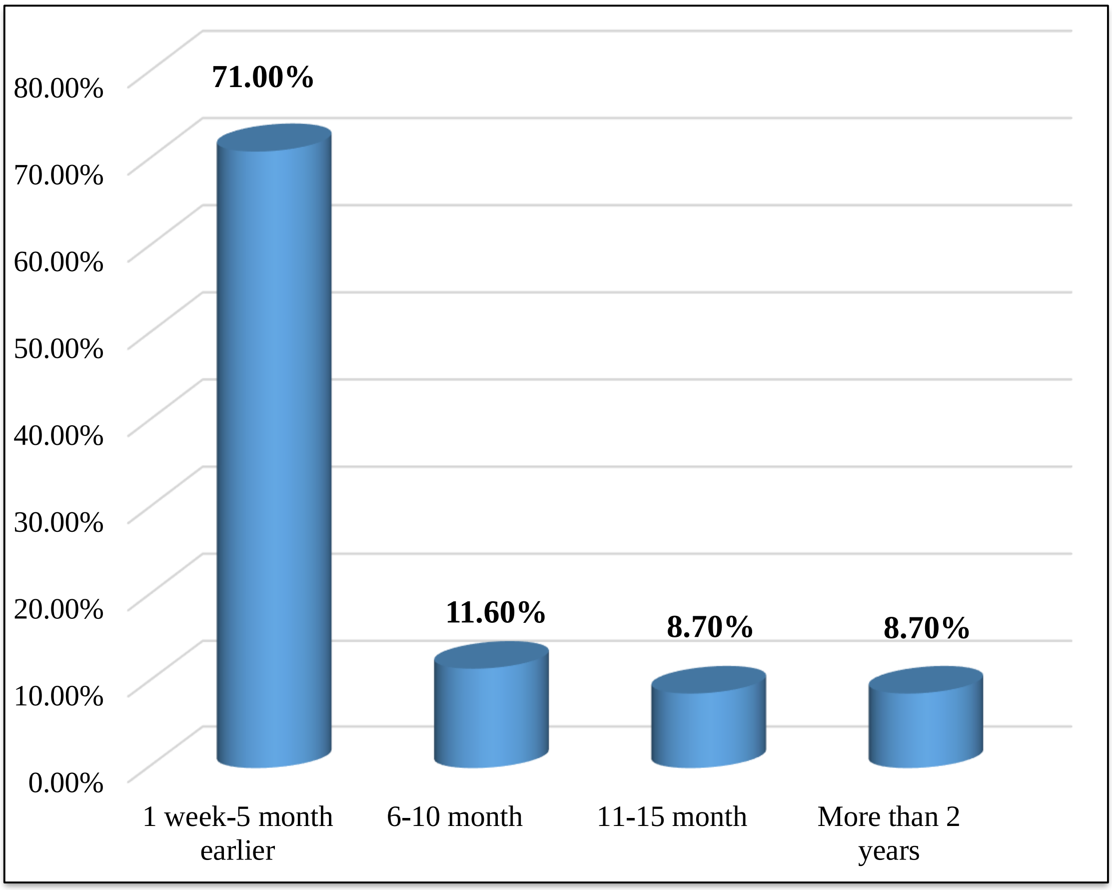


Figure 3.1.6: Participants Onset of Stroke

In this bar graph, it shows that among all the participants 71% (49) had stroke in 1 week to 5 months earlier. It was found that 11.6% (8) people had stroke in 6-10 month. In this graph it also found that 8.7% (6) had onset of stroke in both 11-15 month & more than 2 years.

3.1.7 Recurrent of Stroke

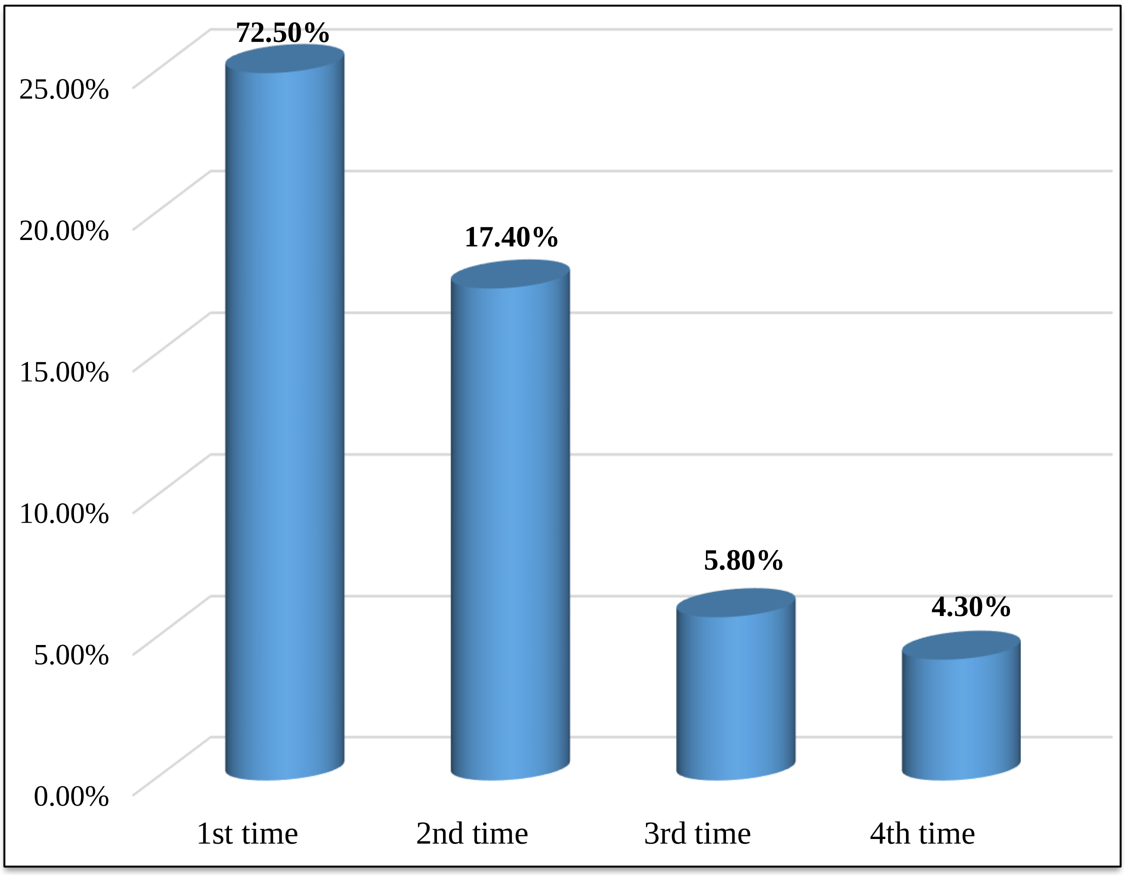


Figure 3.1.7: Participants Recurrent of Stroke

In this bar graph it shows that from the 69 participants majority of them 72.50% (50) had stroke at first time, 17.40% (12) participants had stroke at second time, 5.80% (4) participants had stroke at third time and 4.30% (3) participants had stroke at 4 times.

3.1.8 Texture of Current Eating Behavior:

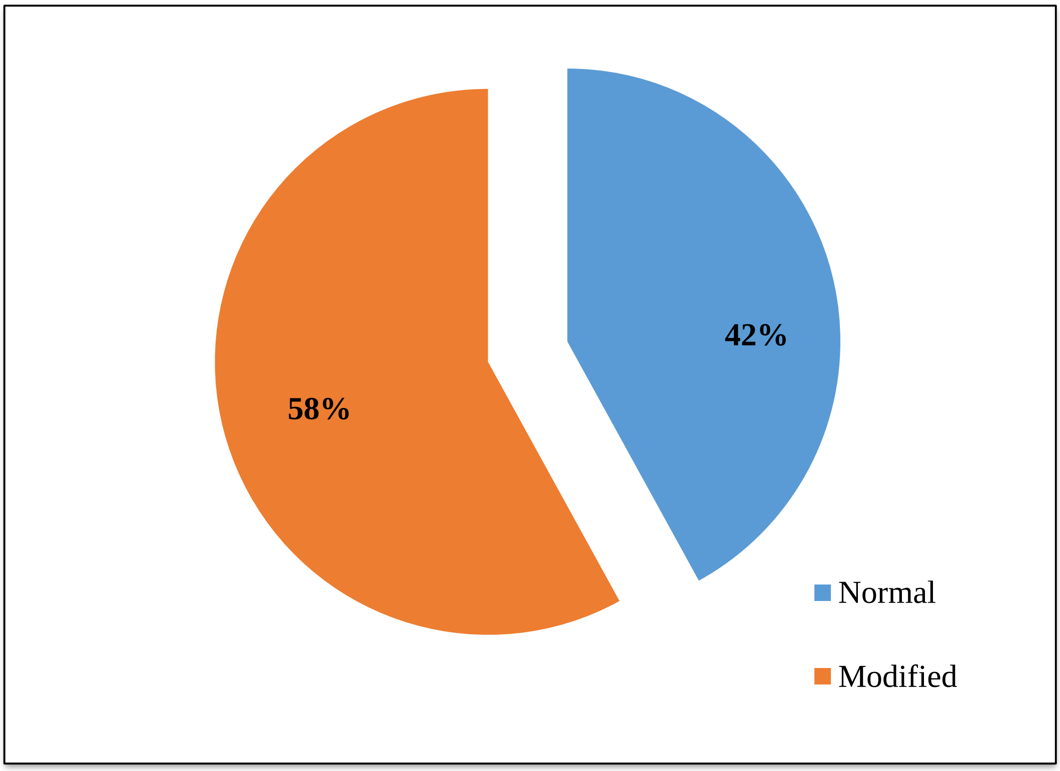


Figure 3.1.8: Texture of Current Eating Behavior

The pie chart shows that majority of 58% (40) participants types of foods were modified and other 42% (29) participants types of foods were normal.

3.1.9 Taking SLT Service

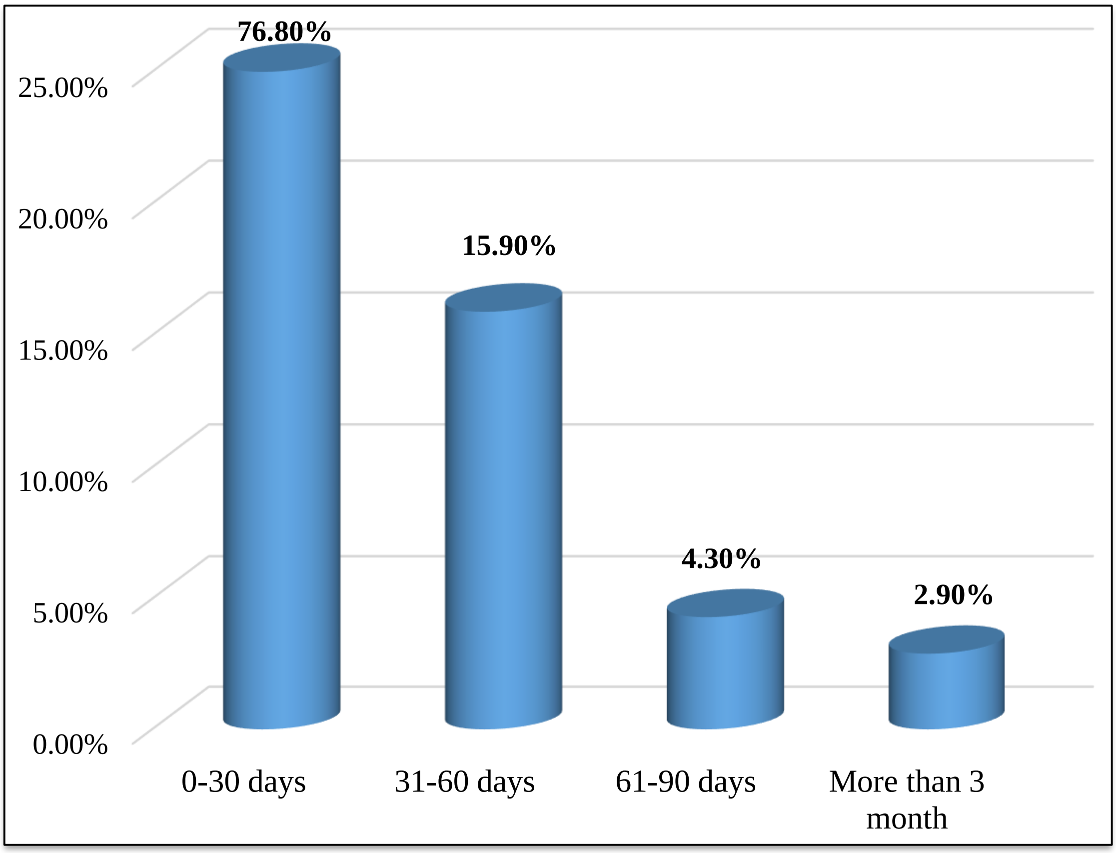


Figure 3.1.9: Taking SLT Service of Participants

The bar graph shows that the majority of 76.80% (53) participants taking SLT service in 0-30 days. 15.90% (11) participants were taking SLT service in 31-60 days, 4.3% (3) participants taking SLT service in 61-90 days and 2.9% (2) participants taking SLT service for more than 3 months.

3.2 Level of Quality of Life & Quality of Care

3.2.1 Level of Burden

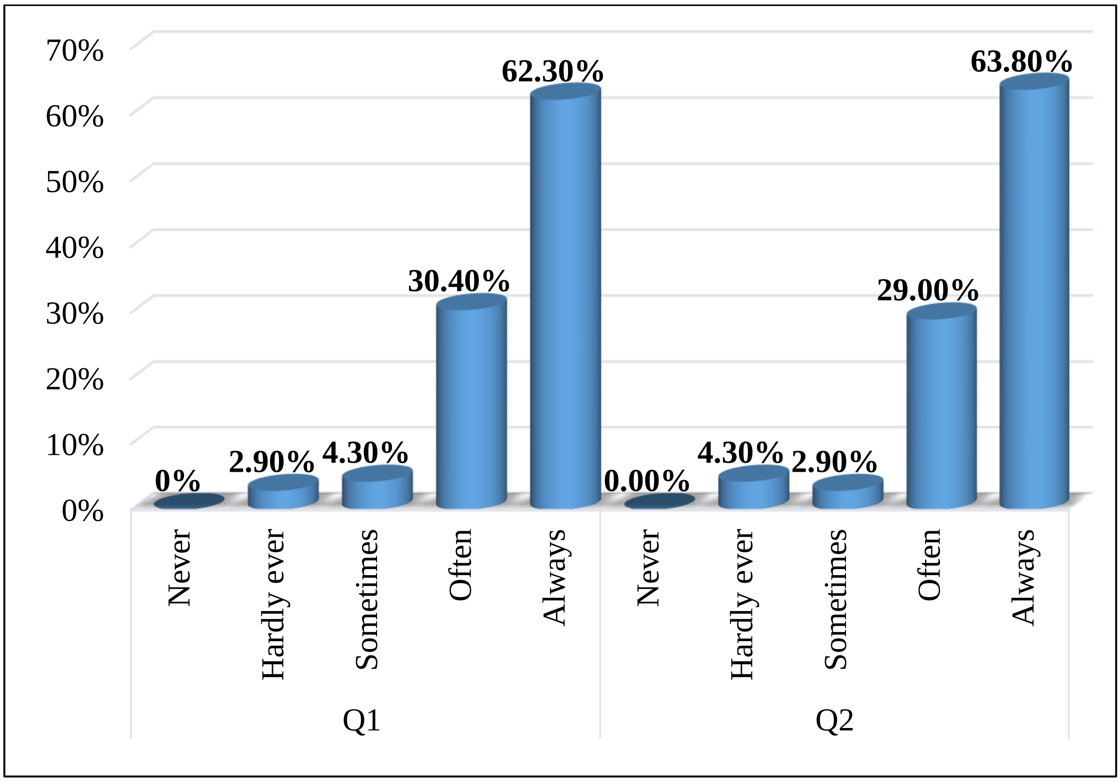


Figure 3.2.1: Participants Level of Burden

The graph shows, majority of the participants 62.3% (43) respond that always dealing with SP is very difficult to them. Many of the participants 30.4% (21) answered that they had often feel difficulty, other 4.3% (3) participants said as sometimes and 2.9% (2) participants said that hardly ever faced difficulty when they deal with their SP. The highest 63.8% (44) participants answered that always SP is a major distraction in their life. Many of the participants were answered 29% (20) as often, 2.9% (2) said sometimes and 4.3% (3) participants declared, hardly ever SP is a major distraction in their life.

3.2.2 Eating Duration

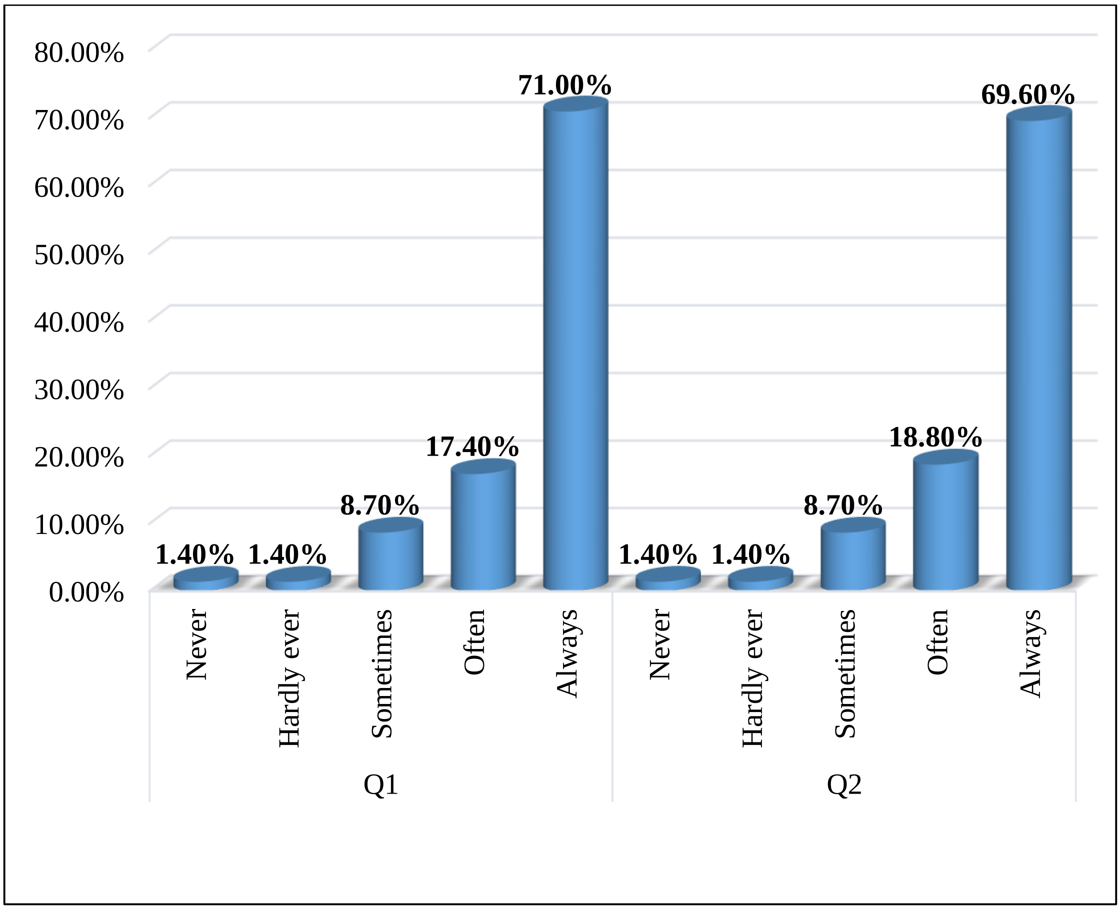


Figure 3.2.2: Eating Duration of Participants

The graph demonstrates that the majority of participants 71% (49) were always took longer time to eat rather than other people. Among them 17.4% (12) participants said it as often, other 8.7% (6) participants said it as sometimes, and another 1.4% (1) participants declared that they did not take longer time to eat than other people. The highest 69.6% (48) participants declared always they took forever to eat a meal. 18.8% (13) declared it as often, 8.7% (6) said it as sometimes, 1.4% (1) said it as hardly ever and 1.4% (1) said as never he took forever to eat a meal.

3.2.3 Eating Desire

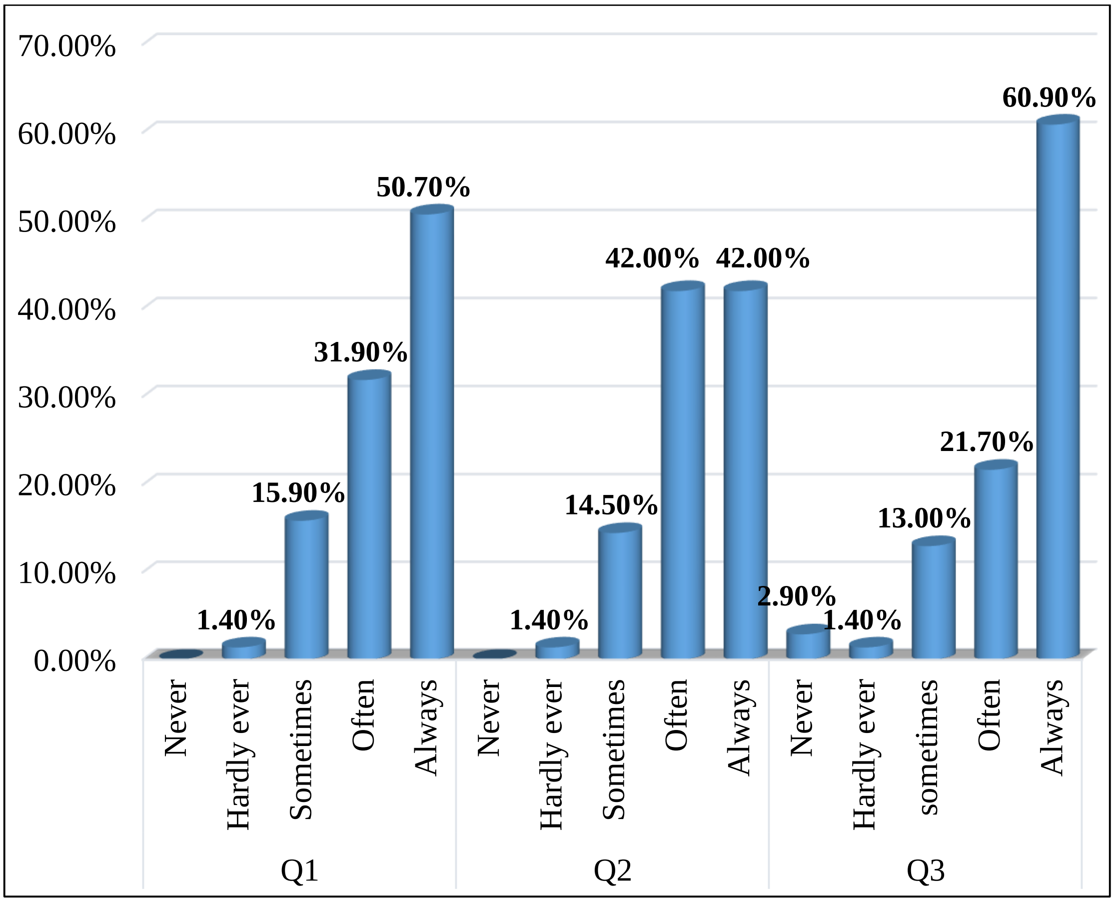


Figure 3.2.3: Participants Eating Desire

In this bar graph, it shows that 50.7% (35) participants always don't care if they eat or not, 31.9% (22) often don't care about their eating, 15.9% (11) participants sometimes don't care and 1.4% (1) participants hardly ever don't care if he/ she eat or not. The equal number of participants 42% (29) was responds both always and often they did not enjoy eating anymore. The least 14.5% (10) participants answered as sometimes they did not enjoy eating and another 1.4% (1) said he/ she enjoyed the food what he ate. The majority of participants 60.9% (42) declared as always they were rarely hungry anymore. Many of them 21.7% (15) participants answered it as often, other 13% (9) participants declared that sometimes they feel hungry.

3.2.4. Table 1: Symptom Frequency

Symptom Frequency	**Patients response**				
	Never	**Hardly ever**	**Sometimes**	**Often**	**Always**
Coughing	1.4%	2.9%	1.4%	24.6%	69.6%
Choking when you eat food	4.3%	4.3%	17.4%	18.8%	55.1%
Chocking When you take liquid	4.3%	1.4%	10.1%	21.7%	62.3%
Having thick saliva or phlegm	20.3%	5.8%	13%	14.5%	46.4%
Gagging	30.4%	7.2%	17.4%	14.5%	30.4%
Having excess Saliva or phlegm	24.6%	5.8%	13%	8.7%	47.8%
Having to clear your throat	20.3%	8.7%	21.7%	10.1%	39.1%
Drooling	30.4%	7.2%	13.0%	5.8%	43.5%
Problems chewing	4.3%	4.3%	10.1%	23.2%	58.0%
Food sticking in your throat	1.4%	7.2%	15.9%	27.5%	47.8%
Food sticking in your mouth	1.4%	8.7%	14.5%	29.0%	46.4%
Food/liquid dribbling out your mouth	8.7%	2.9%	7.2%	14.5%	66.7%
Food/liquid coming out your nose	94.2%	2.9%	2.9%	0%	0%
Coughing food/liquid out your mouth when stuck	2.9%	2.9%	10.1%	26.1%	58.0%

Table 1: Symptom frequencies of Participants

This table shows that the majority of 69.6% (48) participants had always coughing as a symptom frequency, 24.6% (17) participants answered coughing as often. The highest participants 55.1% (38) answered as always chocking at the time of eating food, 18.8% (13) answered it as often and 17.4% (12) participants reported as sometimes chocking occurred at the time of eating food. The highest 62.3% (43)

participants declared that they always chocked when they drink liquid, 21.7% (15) participants declared they had often chocked when they drink liquid. The majority 46.4% (32) participants respond as always having thick saliva or phlegm, many of them 14.5% (10) participants respond as often and 13% (9) participants respond as sometimes having thick saliva or phlegm. Here 30.4% participants declared always having gag reflex. The 47.8% (33) participants said they always had excess saliva, 13% said as sometimes and 24.6% declared they had never excess saliva. The majority of 39.1% (27) declared as always having to clear their throat. The other 21.7% (15) participants declared as sometimes and 20.3% (14) participants declared as never they have the tendency to clear their throat. The majority of participants 43.5% (30) answered they had always drooling as symptom and other 30.4% (21) participants answered they did not have drooling as symptom. The highest participants 58% (40) declared always food sticking in their throat, other 27.5% (19) participants declared as often and 15.9% (11) declared as sometimes. The majority of 46.4% (32) participants respond as always food sticking in their mouth, 29% (20) respond it as often, 14.5% (10) participants respond sometimes food sticking in their mouth. 66.7% (46) participants declared as always food / liquid dribbling out from their mouth, other 14.5% (10) participants declared as often of this symptom. The majority participants 94.2% (65) declared that food /liquid never come through nose, the equal number of participants 2.9% declared as hardly ever (2) and sometimes (2) food/ liquid come through nose. The 58% (40) respond as always coughing when food /liquid stuck in mouth, 26.1 % (18) declared as often and 10.1% (7) declared the symptom as sometimes.

3.2.5 Selection of Food

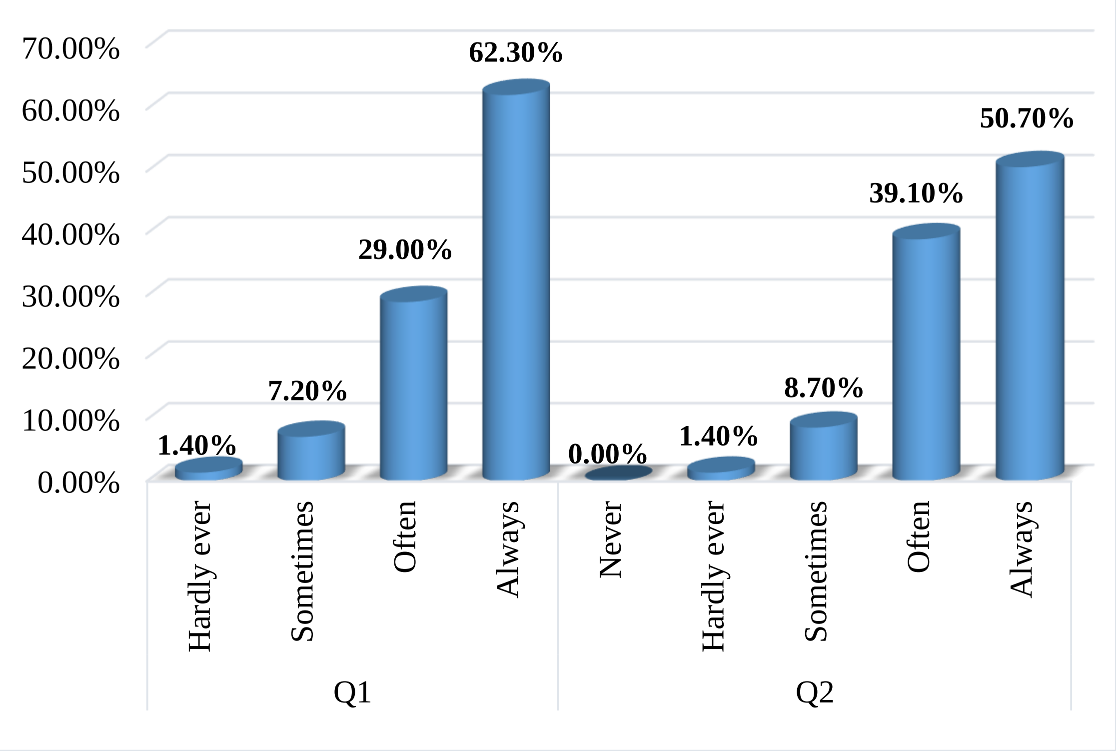


Figure 3.2.5: Participants Selection of Food

From the bar graph, the majority of participants 62.3% (43) respond as always figuring out what they can eat is a problem for them. The 29% (20) participants declared it as often, other 7.2% (5) declared it as sometimes and 1.4% (1) declared hardly ever figuring out is a problem what they eat. The highest participants 50.7% (35) declared as always difficult to find foods both like and can eat. The 39.1% (27) participants declared it as often, other 8.7% (6) declared as sometimes and 1.4% (1) declared as hardly ever difficult to find foods both like and can eat.

3.2.6 Communication

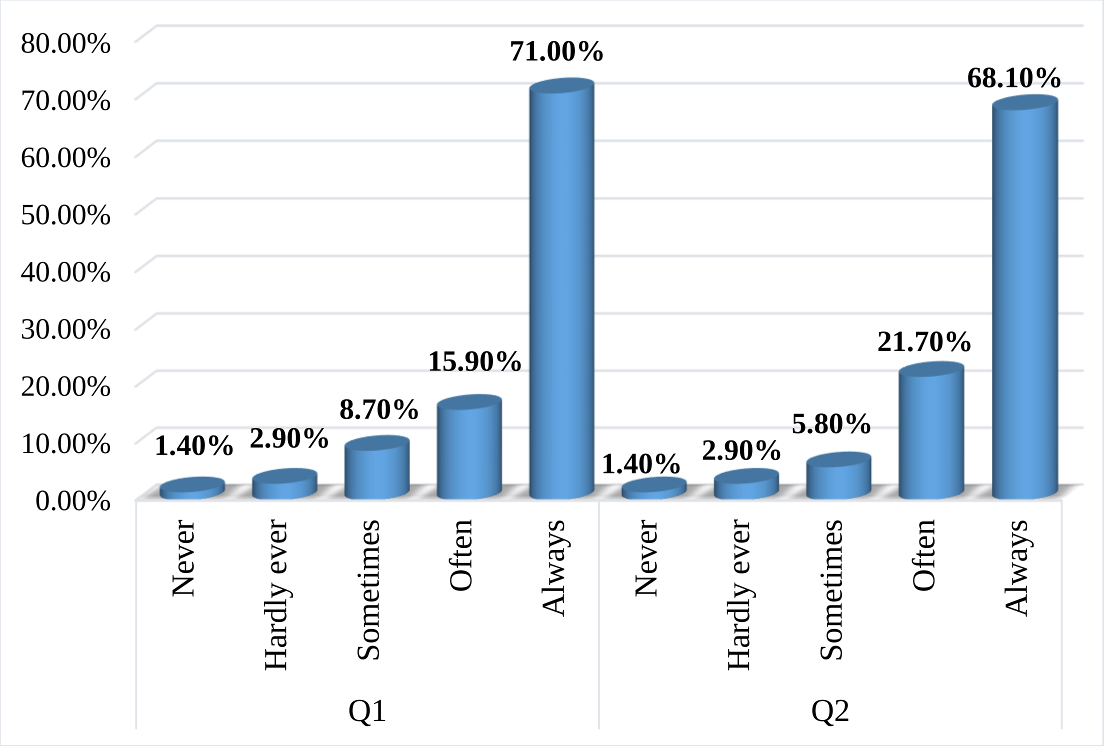


Figure 3.2.6: Participants Level of Communication

This bar graph shows that the majority of participants 71% (49) declared as always people faced difficulty to understand their meaning. The other 15.90% (11) participants declared it as often, 8.7% (6) declared it as sometimes, 2.90% (2) declared it as hardly ever and another 1.4% (1) declared as never faced difficulty to understand meaning. The highest respondent 68.1% (47) said that always they felt difficult to speak clearly. The other 21.7% (15) respondent said it as often, 5.8% (4) declared it as sometimes, 2.9% (2) declared as hardly ever and 1.4% (1) declared as never felt difficulty to speak clearly.

3.2.7 Fear

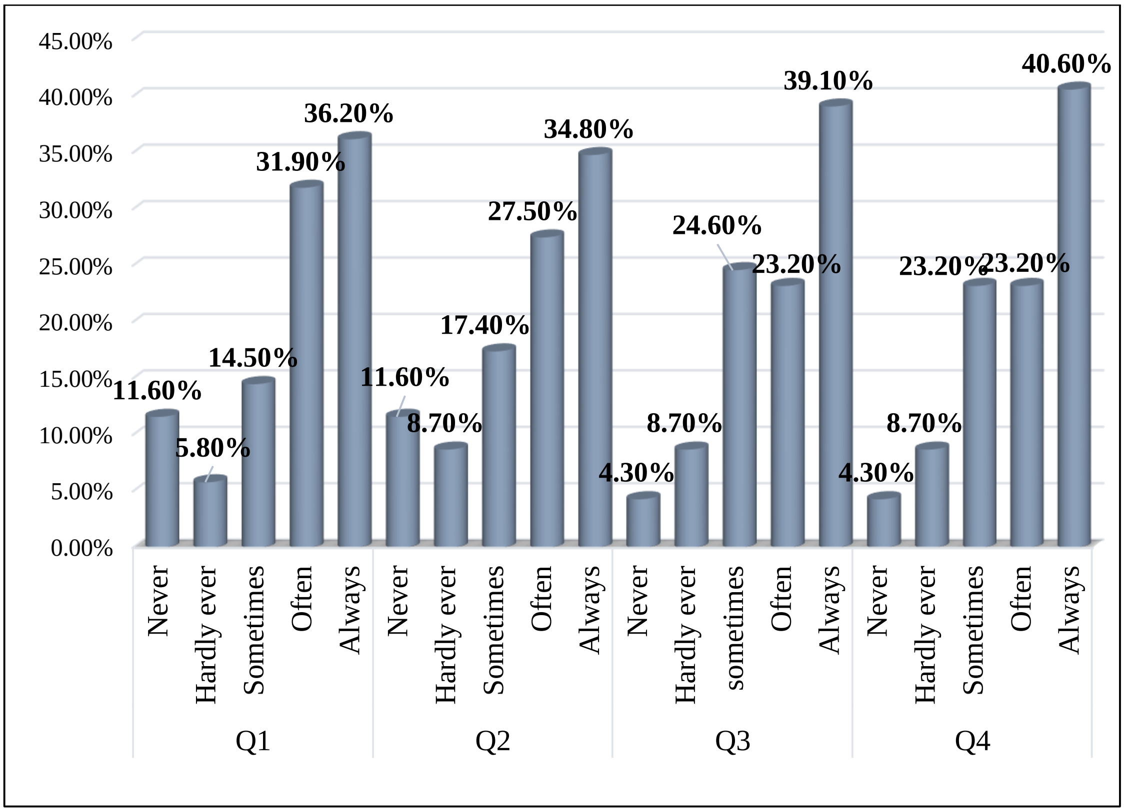


Figure 3.2.7: Participants Level of Fear

The bar graph shows that the 36.2 % (25) participants always fear of chocking when they eat food, another 31.9% (22) participants answered it as often, 14.5% (10) answered it as sometimes, 5.8% (4) answered as hardly ever and 11.6% (8) answered that they did not fear of chocking when they eat food. The highest participants 34.8% (24) always feared about getting pneumonia, 27.5% (19) 0ften fear about this, 17.4% (12) sometimes fear, 8.7% (6) participants hardly ever fear and other 11.6% (8) participants answered they never fear to get pneumonia at the time of eating. The next majority of participants 39.1% (27) always afraid of chocking when drink liquids, the 24.6% (17) participants sometimes afraid of it and other 23.2% (16) participants often afraid of chocking when they drink liquids. The 40.6% (28) participants declared that always they never know when they were going to chock, the equal number of participants 23.2% (16) declared that sometimes and often they never know when they were going to chock.

3.2.8 Mental Health

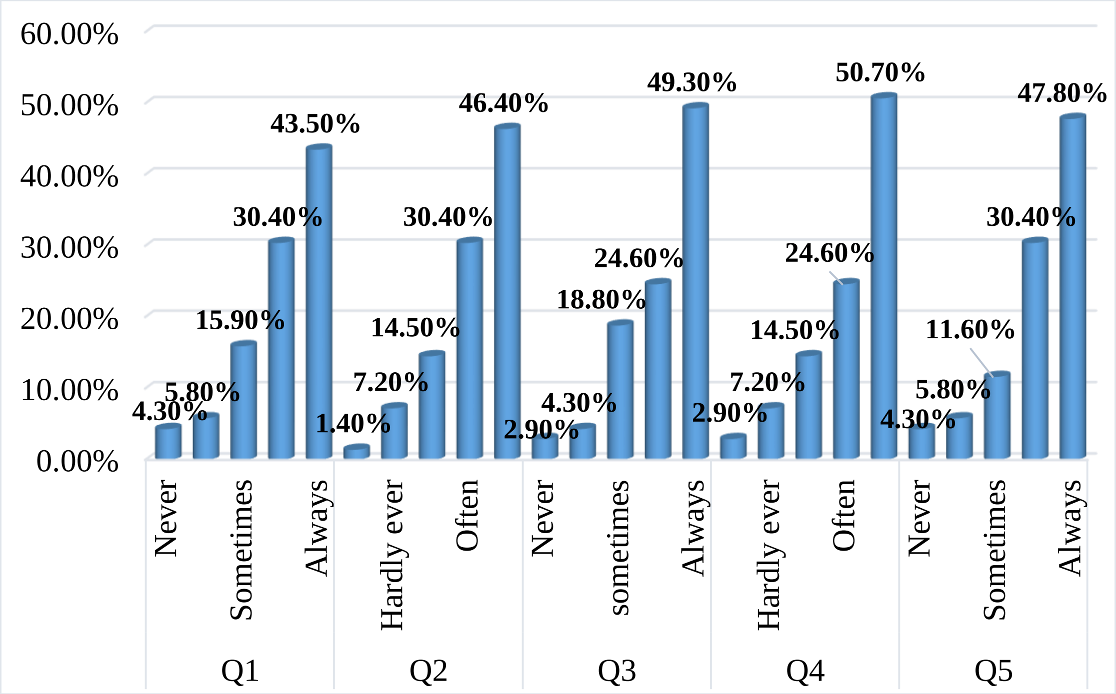


Figure 3.2.8: Participants Mental Health

The bar graph shows that the majority participants 43.5% (30) declared always SP depressed them. Many of them 30.4% (21) participants declared it as often, 15.9% (11) participants declared it as sometimes, 5.8% (4) declared it as hardly ever and other 4.3% (3) declared they never depressed because of their SP. The highest 46.4% (32) participants declared always they get impatient with SP and 30.4% (21) participants declared it as often. 18.8% (13) participants declared it as sometimes and other 2.9% (2) declared they never get impatient with SP. The 49.3% (34) participants respond that being so careful at the time of eating or drinking that annoyed them always, 24.6% (17) participants respond it as often, 14.50% participants declared as sometimes. The highest participants 50.7% (35) said always SP frustrates them and 24.6% (17) participants said often they frustrates with their SP. The 47.8% (33) participants declared they had been discouraged always by SP. The 30.4% (21) participants declared it as often and 11.6% (8) participants declared it as sometimes and 4.3% () declared they never been discourage by SP.

3.2.9 Social

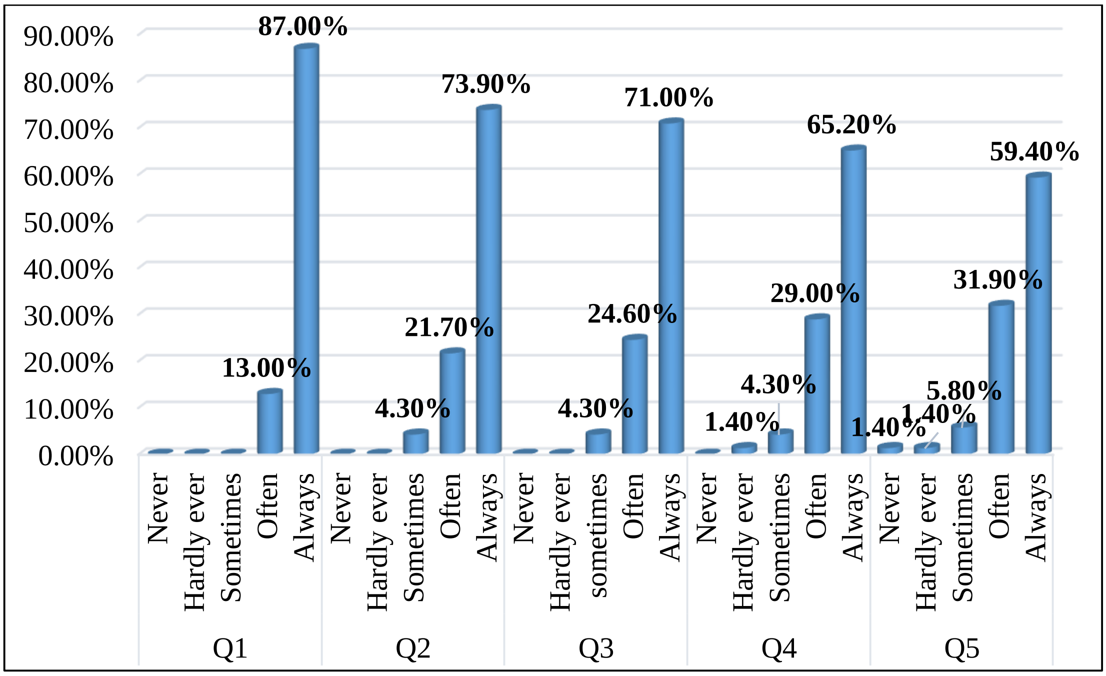


Figure 3.2.9: Participants Social Interaction

The bar graph shows that the highest participants 87% (60) declared they do not go out to eat because of their SP, other 13% declared it as often. The 73.9% (51) participants declared that their social life was so hard because of their SP, the 21.7% (15) participants declared it as often and another 4.3% (3) participants declared sometimes their social life was so hard. The 71% (49) participants declared always their usual activity had changed for SP, the lowest 24.6% (17) participants declared it as often and 4.3% (3) declared as sometimes their usual activity had changed. The 65.2% (45) participants said that they did not enjoy social gathering and 29% (20) participants declared it as often. The 59.4% (41) participants declared that their role in the family had been changed in every step, 31.9% (22) participants said that it occurred often and another 1.4% (1) participant said his role never changed in his family.

3.2.10 Fatigue

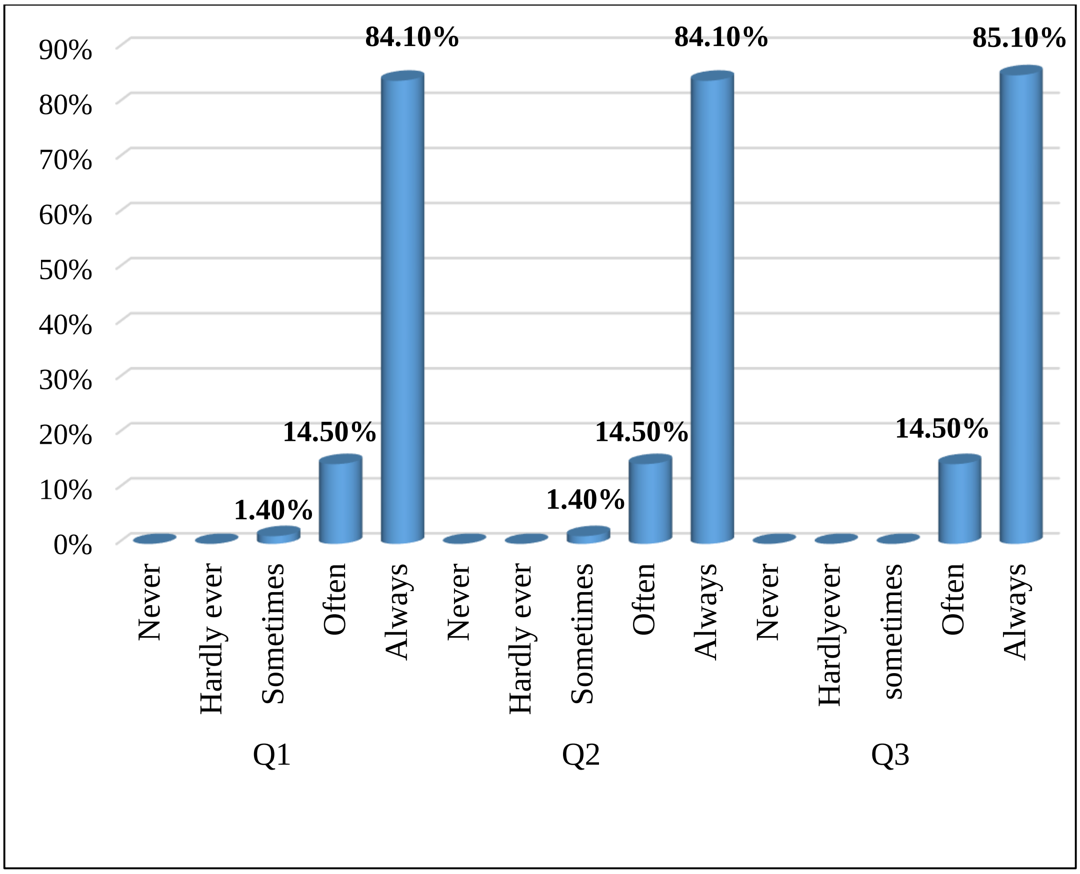


Figure 3.2.10: Fatigue

The equal number of participants 84.1% (58) declared that always they felt exhausted. Other 14.5% (10) declared they felt exhausted as often and 1.4% (1) declared sometimes they felt exhausted. The equal number of participants 84.1% (58) declared that always they felt weak. Other 14.5% (10) declared they felt weak as often and 1.4% (1) declared sometimes they felt weak. The percentage was same for feeling exhausted and weak. The highest number of participants 85.1% (59) responded that they always felt tired and other 14.5% (10) participants respond as sometimes they felt tired.

3.2.11 Sleeping

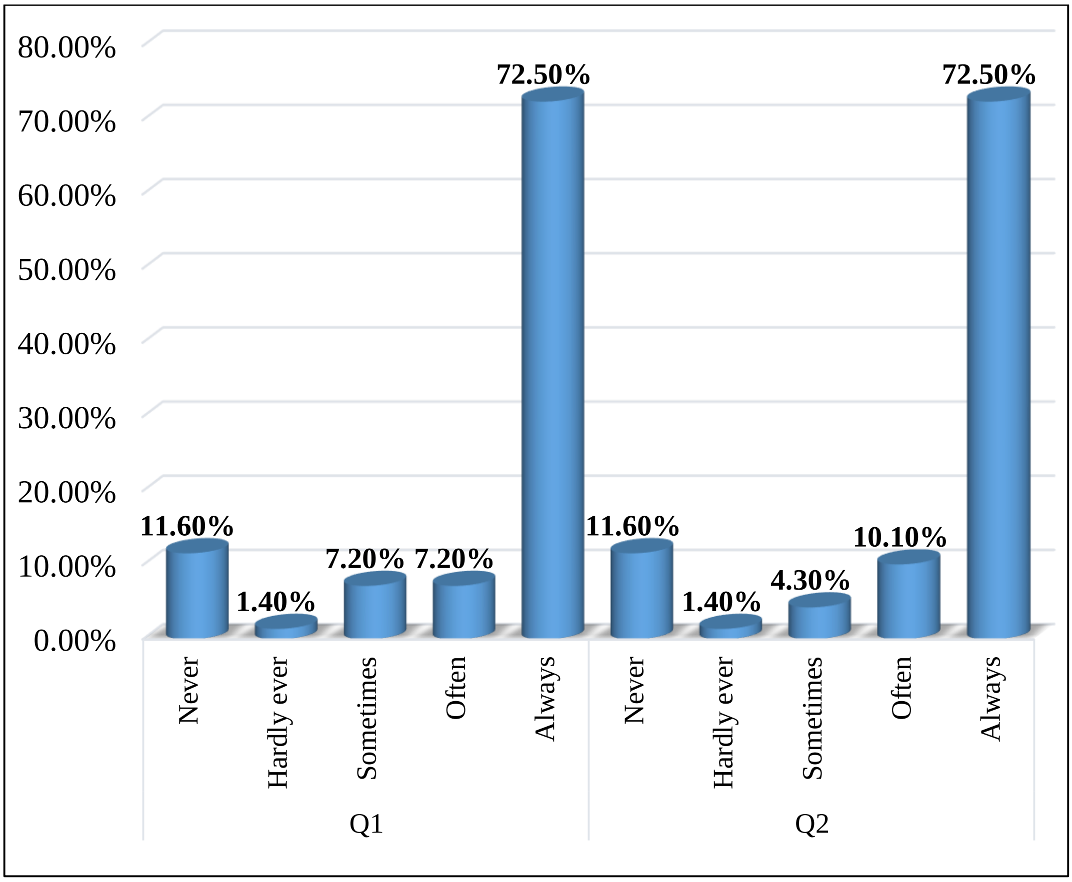


Figure 3.2.11: Sleeping

The bar graph shows that the highest participants 72.5% (50) declared, they always had trouble falling asleep. Many of them 7.2% (5) participants declared that sometimes or often they had trouble to fall asleep, other 11.6% (8) declared as they never fall trouble falling asleep. The major participants 72.50% (50) declared that always had trouble staying asleep, other 10.1% (7) participants declared as often and 11.6% (8) participants declared they had never trouble staying asleep.

3.3.1 Table 2: Advice (SWAL-CARE)

Advice	Patients Response	
	Yes	**No**
Food I should eat	100%	0%
Foods I should avoid	100%	0%
Liquids I should drink	100%	0%
Liquids I should avoid	100%	0%
Techniques to help get food down	100%	0%
Techniques to help me avoid choking	100%	0%
When I should contact a swallowing clinician	100%	0%
My treatment options	100%	0%
What to do if I start to choke	100%	0%
Signs that I am not getting enough to eat or drink	100%	0%
Goals of the treatment for my SP	100%	0%

Table 2: Advice (SWAL-CARE)

In the category of therapist's advice, we can see from the bar graph the 100% (69) participants respond positively for the advice of food they should eat & avoid. The 100% (69) participants answered "yes" for the advice of liquids they should eat & avoid. The 100% (69) participants respond positively for the advice of techniques to help get food down & help avoid chocking. The 100% (69) participants respond positively for the advice of when they should contact a swallowing clinician. All participants 100% (69) answered positively about the therapist's advice for their treatment options and what to do if they start to choke. All participants 100% (69) respond positively for the advice of the signs that are not getting enough to eat or drink. The 100 % (69) participants respond as yes for the therapists' advice on the treatment for their SP.

3.3.2 Patient Satisfaction (SWAL-CARE)

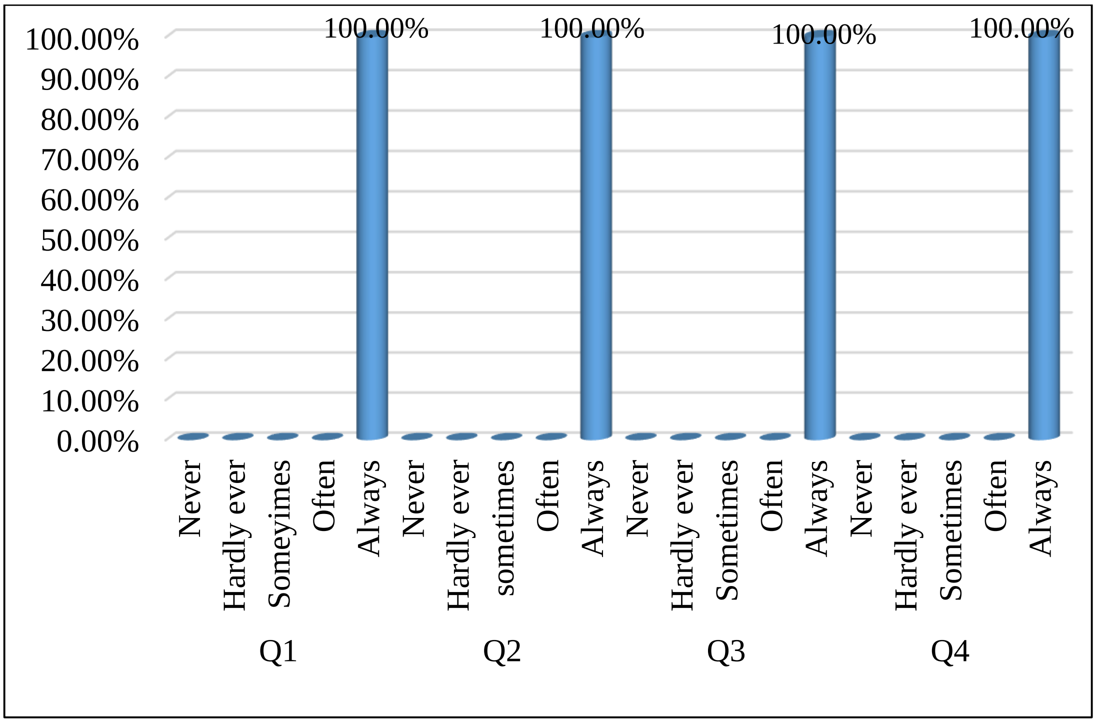


Figure 3.3.2: Patient Satisfaction (SWAL-CARE)

The bar graph shows that the 100% (69) participants answered, always they had confidence in their swallowing clinicians. The 100% (69) participants declared that their clinicians always explained treatment to them. All participants 100% (69) said that swallowing clinicians (SC) always spent enough time with them. The 100% (69) participants declared that the SC always put the participants need first.

Among 69 patients who had stroke, the majority of participants 62.3% (43) were male between the age ranges 51-60 years. On the hand, Hiraga, (2017) conducted a study and found that males have the greater possibility to get stroke with increase of the age. The result of current study demonstrated that the aged male individuals had greater possibility of having stroke with dysphagia.

In this study, the result of educational level showed that the major group of participants (24.60 %) were equal in both illiterate & under SSC. Pontes, Amaral, Rego, Azevedo, & Silva, (2016) also found in their study that less educated people had the greater possibility to get stroke. So it can be said that the incidence of dysphagia after stroke is higher among those who were less educated. In this study, maximum number of respondents 34.8% were House-wife and the majority of participants 69.60% were from semi urban areas.

Among total participants 71.00% had stroke in 1 week to 5 months earlier. Bahceci, Umay, Gundogdu, Gurcay, Ozturk, & Alicura, (2017) showed in their study that they evaluated 72 patients for a mean period of 16.51 ± 8.32 days after stroke and they found dysphagia in oral phase 95.8%. These patients also represented the whole spectrum of mild to very severe dysphagia. So, the interpretation of the current study demonstrated that during early period of getting stroke, there is the greater chances to get dysphagia.

In this study the investigator found that the majority of the participants 72.50% had stroke at first time. Yeoh et al. (2018), also revealed in a study that maximum participants 81.3% were having first time of stroke and others were having recurrent stroke. So, it was a clear indication that Dysphagia occurred in 1st time stroke patients more than recurrent.

Findings of the current study showed that the majority of participants 58% were taking modified food. Bahceci, Umay, Gundogdu, Gurcay, Ozturk, & Alicura, (2017) described that 95.8% participants had oral phase dysphagia that means they took modified food. So most of the patients who had dysphagia took modified food. The highest number of respondents 76.80% were taking SLT service within 0-30 days.

In this study found that 62.3% participants faced difficulty in dealing with SP and 63.8% had major distraction in their life. Leow, Huckabee, Anderson, & Beckert, (2010) described in their study that young people (100%) and aged people (98.4%) who had Dysphagia declared that SP as a burden in their life. So in this study, it is indicated that SP is a burden for post stroke patients.

The result in the study demonstrated that 71% participants took longer time to eat food and 60.9% were rarely hungry anymore. Kraus, Romme, Stoll, Oettinger, Voge, & Synofzik, (2018) interpreted in their study that the maximum patients took longer duration for eating and the desire of eating is poor than other people. So this study found that people with dysphagia’s eating duration is longer than other people and the desire of eating is comparatively less than others.

The result showed that in case of symptom frequencies, coughing 69.6%, chocking when drink liquid 62.3%, excess saliva 47.8%, food sticking in throat 58%, food / liquid dribbling out through mouth 66.7%, coughing when food /liquid stuck in mouth 58%. But 94.2% participants declared never food/liquid coming out their nose. Leow, Huckabee, Anderson, & Beckert, (2010) also revealed same symptom frequencies in their study. So the study demonstrated that people with SP shows some symptom such as coughing, chocking, drooling, excess saliva, food dribbling through the nose.

In this research, 62.3% figuring out what they can eat is a problem for them and 50.7% faced difficult to find foods both like and can eat. Kraus, Romme, Stoll, Oettinger, Voge, & Synofzik, (2018) interpreted in their study that the maximum patients were not able to select their food with the context of like & eat. So the study found that people with dysphagia faces difficulty at the time of food selection.

The study result found that 36.2 % participants fear of chocking when they eat food, 39.1% afraid of chocking when drink liquids. McHorney, Robbins, Lomax, Rosenbek, Chignell, Kramer, & Bricker, (2002) also found that maximum participants who had SP also fear at the time of eating. So in this study demonstrated that people were getting fear of choking & pneumonia at the time of eating/ drinking.

The study result showed that 43.5% participants depressed & 50.7% frustrates with their SP. 49.3% being so careful at the time of eating or drinking that annoyed them and 47.8% had been discouraged always by SP. Pontes, Amaral, Rego, Azevedo, & Silva (2016) described in their study that the majority of stroke patients had found mental health problem. So also in this study I found that the majority of participants had shown mental health problem.

The study result demonstrated that 87% participants do not go out to eat because of their SP. The 65.2% did not enjoy social gathering and 71% faced difficulty to understand their meaning. 68.1% felt difficult to speak clearly. Sarkar, Halder, Saha, & Biswas, (2016) also found that the Dysphagia after stroke patients have communication and social functioning difficulties. In this study demonstrated that social interaction & communication were difficult because of their SP.

The study result showed that 84.1% participants felt exhausted & weak, 85.1% felt tired and 72.5% had always trouble in falling and/ or staying asleep. But 11.6% had never trouble in falling/ or staying asleep. Leow, Huckabee, Anderson, & Beckert, (2010) described that Feelings of weakness, tiredness, and exhaustion with trouble falling and/or staying asleep were also significantly increased in neurological subjects. So the study showed that people with SP have feelings of weakness, tiredness, and exhaustion with trouble falling and/or staying asleep.

The study result showed that all participants 100% declared SLT gave them all advice which they need and SLT discussed about their treatment strategies with the participants. SLT gave them advice on the food/ liquids and the techniques to help get food down & help avoid chocking. There is no negative answered from the participants about the advice from SLT of CRP. The 100% participants declared, they had confidence in their SLT. SLT always spent enough time with them and always put the participants need first. So, there was no negative review about the SWAL-CARE of Speech & Language Therapist and patients were satisfied with their SLT care.

Chapter- 5 Policy Implications

- This study will help Speech and Language therapy service providers to start new practice of Dysphagia management and assessment for the patient with Dysphagia after stroke.

- This study can be implicated during teaching students that stroke patient may have Dysphagia and the percentage of dysphagia among them.

- In future, this study will influence the policy makers to make policy to refer the Stroke patients with Dysphagia to SLTs for Dysphagia management.

6.1 Limitation

There were some situational limitation and barriers while considering the results of study in different aspects. Those are following below-

- 69 participants were selected to conduct the whole study for short period of time. It was a small number of participants to conduct a survey to find out the QOL & QOC among post stroke Dysphagia.

- The investigator only questioned a small number of subject that was small to generalize the results.

- Due to lack of number of participants, the external validity of the study reduced.

- Some recently stroke patients were the participants of the study, for this reason the caregiver were not generalized the questions about patient difficulties.

- Time was limited that have a great deal of impact of the study.

6.2 Recommendation

This is the first primary study on the QOL & QOC among post stroke dysphagia in Bangladesh. So there were some limitations and barriers during conducting the study. These are-

- The study was done within a short period of time and only 69 participants were selected to conduct the whole study. It was a small number of participants conduct a survey to explore the QOL & QOC among Post Stroke Dysphagia due to lack of number of the participants. So the external validity of the study decreased and further study can be conducted with a wide range and large participant size.

- Purposive sampling was used to select participants and study place. So further study can be conducted by simple random sampling.

- Including Speech therapy services in different organization where working in this area for their program for delivering Dysphagia management services, also include the SLT service as health care service delivery system in Bangladesh.

Chapter- 7 **Conclusion**

Swallowing difficulty is a life-threatening problems including physical, functional, emotional and overall quality of life that can be happened after Stroke. The investigator explored to determine the presence of dysphagia on QOL & QOC among post stroke patients. In this study, the total respondents were 69 whereas 62.3% (43) were male and other 37.7 % (26) were female.

The result showed that the highest number of participants 36.2 % were in the age of 51-60 years. The education level of the participants found that the equal number 49.2 % were illiterate & under SSC. Among the participants a highest number of respondents 34.8% were found as house-wife. It showed that living status of 69.60% people were in semi urban areas. Among all the participants 71% had stroke in 1 week to 5 months earlier. In the study first time stroke patient were more than others. Majority of participants 71% took longer time at the time of eating. 69.6% patients showed cough when they eat and 62.3% chocked at the time of drinking liquids. 71% participants faced difficulty to understand meaning and 87% don not go out to eat because of SP. In QOC 100% participants are satisfied with the Therapists care. All participants declared that SLT gave them all advice which they need and SLT discussed about their treatment strategies with the participants. SLT gave them advice on the food/ liquids and the techniques to help get food down & help avoid chocking.

Thus, professionals (Doctors, physiotherapists, occupational therapists) working with stroke patients need to remain alert to the presence of Swallowing and refer to SLTs for diagnosis and treatment of swallowing difficulties; which will increase the quality of life and quality of care of people with Stroke and will also decrease morbidity. It will also help the SLT professionals to manage the specific diagnosis and treatment for Post Stroke Dysphagia patient.

Altman, K. W., Schaefer, S.D., Gou-Pei., Hertegard, S., Lundy, D., Blumin, J. H. (2007). The voice and laryngeal dysfunction in stroke: A report from the Neurolaryngology Subcommittee of the American Academy of Otolaryngology–Head and Neck Surgery. *Otolaryngology–Head and Neck Surgery,* 136, 873-881.doi: 0.1016/j.otohns.2007.02.032

Amionff, M. J. (Eds.). (1993). *Clinical Neurology* (3rd ed.). The UNITED State America: Appleton & Lange.

Bahceci, k., Umay, E., Gundogdu, I., Gurcay, E., Ozturk, E., & Alicura, S. (2017). The effect of swallowing rehabilitation on quality of life of the dysphagic patients with cortical ischemic strokes. *The Iranian Journal of Neurology*, 16, 178-84. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/29736223

Bailey, M. D. (1997). *Research for the Health Professional.* Philadelphia: F. A. Davis.

Bays, C. (2001). Quality of life of stroke survivors: a research synthesis. *The Journal of Neuroscience Nursing: journal of the American Association of Neuroscience Nurses, 33,* 310-6.Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/11776713

Brook, R. H., Mcglynn, E.A, & Shekelle, P.G. (2000). Defining and Measuring quality of care: A perspective from US Researchers. *International journal for Quality in Health care, 12,* 281-295. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/10985266

Chen, P., Golub, J., Hapner, E., & Johns, M. (2009). Prevalence of perceived dysphagia and quality-of-life impairment in a geriatric population. *Dysphagia*, *24*, 1-6. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/18368451

Davis, L. (2007). Quality of life issues related to dysphagia. *Topics in Geriatric Rehabilitation, 23*, 352-365. Retrieved from https://kb.osu.edu/bitstream/handle/1811/52061/1/Blake_Robinson_Thesis

DePoy, E., & Gitlin, L. N. (1998). *Introduction to research- Understanding and applying multiple strategies.* USA: Mosby.

Fernandez, M.G., Ottenstein, L., Atanelov, L. & Asare, B. (2013). Dyphagia after stroke: An Overview. *Current Physical Medicine and Rehabilitation Reports*, *1,* 187–196, DOI 10.1007/s40141-013-0017-y

Frankel, J., & Wallen, N., (2000). *How to Design and Evaluate Research in Education.* USA: McGraw-Hill.

Han, B., & Haley, W. E. (1999). Family care giving for patients with stroke: review and analysis. *Journal of the American Heart Association, 30,* 1478-85. Retrieved from http://www.ncbi.nlm.nih.gov/m/pubmed/10390326/

Hicks, C. M. (2000). *Research Methods for clinical Therapists*. Edinburgh: Churchill Livingstone.

Hiraga, A. (2017). Gender Differences and Stroke Outcomes. *Neuroepidemiology,* 48, 61–62. doi: 10.1159/000475451

Johansson, K., & Kerstin. (2013). Speech and voice characteristics in multiple sclerosis and cervical spinal cord injury: descriptive studies and effects of respiratory training. *Karolinska Institute,* Retrieved from https://openarchive.ki.se/xmlui/bitstream/handle/10616/41746/Kappa%20Kerstin%20Johansson%20131025.pdf?sequence=2&isAllowed=y

Kim, K.J., Heo, M., Chun, I., Jun, H., Lee, J., Jegal, H., & Yang, Y. (2015). The Relationship between stroke and quality of life in Korean Adults:based on the 2010 Korean community health survey. *Journal of Physical Therapy Science,* 27, 309-312, doi: 10.1589/jpts.27.309

Kraus, E. M., Romme, N., Stoll, L. H., Oettinger, A., Voge, A. P., & Synofzik, M. (2018). Validation and Psychometric Properties of the German Version of the SWAL-QOL. *Dysphagia, 33,* 431-440. Retrieved from https://link.springer.com/article/10.1007%2Fs00455-017-9872-5

Landau, S., & Everitt, B. S. (2004). *A Handbook of Statistical Analyses using SPSS.* London: Chapman & Hall.

Leow, L. P, Huckabee, M, Anderson, T & Beckert, L. (2010). The Impact of Dysphagia on Quality of Life in Ageing and Parkinson's Disease as Measured by the Swallowing Quality of Life (SWAL-QOL) Questionnaire. *Dysphagia, 2*5, 216–220; DOI 10.1007/s00455-009-9245-9

Logemann, J. (Ed.). (1998). *Evaulation and Treatment of Swallowing Disorders (*2nd ed.). Austin, Tex: Pro-Ed.

Martino, R., Martin, R.E., & Black, S. (2012). Dysphagia after stroke and its management. *Journal of Canadian Medical Association,* 184, 1127-1128; DOI: https://doi.org/10.1503/cmaj.101659

McHorney, C.A., Bricker, D.E., Robbins, J., Kramer, A.E., Rosenbek, J.C., Chignell, K.A. (2000). The SWAL-QOL outcomes tool for oropharyngeal dysphagia in adults: II. Item reduction and preliminary scaling. *Dysphagia,* 15, 122-33. Retrieved from https://link.springer.com/article/10.1007%2Fs004550010013

McHorney, C.A., Robbins, J., Lomax, K., Rosenbek, J. C., Chignell, K., Kramer, A. E., & Bricker, D. E. (2002). The SWAL-QOL and SWAL-CARE outcomes tool for oropharyngeal dysphagia in adults: III. Documentation of reliability and validity. *Dysphagia,* 17, 97-114. Retrieved from https://doi.org/10.1007/s00455-001-0109-1

Pontes, E. S., Amaral, F. J., Rego, F.L.S., Azevedo, E.H.M., & Silva, P. O. C. (2016). Quality of life in swallowing of the elderly patients affected by stroke. *Arquevos de Gastroenterologia, 54, 27-32. Retrieved from http://dx.doi.org/10.1590/s0004-2803.2017v54n1-05*

Robinson, R.G., & Jorge, R.E. (2016). Post Stroke Depression: A Review. *American Journal of Psychiatry, 173,* 221-231, doi: 10.1176/appi.ajp.2015.15030363

Roth, F. P., & Worthington, C. K. (Eds.). (2011). *Treatment resource manual: for speech and language pathology (4th ed.).* USA: Delmar.

Sarkar, D., Halder, S., Saha, B. K., & Biswas, P. (2016). A study of stroke patients

with respect to their clinical and demographic profile and outcome. *International Journal of Research in Medical Sciences*, 4(9), 4061-4066. doi: http://dx.doi.org/10.18203/2320-6012.ijrms20162934e

Shaughnessy, J. J, Zechmeister, E. B., & Zechmeister, J. S., (2003). *Research methods in psychology.* USA: McGraw-Hill.

Stein, F. & Cutler, S. (Eds.). (2000). *Clinical Research in Occupational Therapy (4th ed.)*. Singular Publishing Group: California.

Vieira, D., & Antunes, E. B. (2017). Clinical Characteristics of Dysphagia related quality of life questionnaires. *Journals of Latin America and the Caribbean, Spain and Portugal, 2,* 157-188. Retrieved from https://revistas.ucm.es/index.php/RLOG/article/download/58193/52371

Yeoh et al. (2018). Can acute clinical Can acute clinical outcomes predict health related quality of life after stroke: a one year prospective study of stroke survivors. *Health and quality of life outcomes*, 16, 221. Retrieved from https://hqlo.biomedcentral.com/articles/10.1186/s12955-018-1043-3

World Health Organization. (2018). Measuring quality of life. Retrieved October, 2018, from http://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/index1.html

World Health Organization. (2018). What is Quality of care and why is it impotant? Retrieved October, 2018, from http://www.who.int/maternal_child_adolescent/topics/quality-of-care/definition/en/

Annexure-1 (A)

DEMOGRAPHIC INFORMATION

Code no:	Date:
Patient’s name:	
Age:	Sex:
Educational level:	Occupation:
Living Status:	Mobile no.:
Medical Diagnosis:	SLT Diagnosis:
Onset date of stroke:	Recurrent Stroke:
Types of food/liquid:	Duration of taking SLT service:

Instructions: These are statements that many people have used to describe their dysphagia related QOL & QOC on their lives. Circle the response that indicates how frequently you have the same experience.

0= Never, 1= Hardly ever, 2= Sometimes, 3= Often, 4= Always

Burden (QOL)

Dealing with my SP is very difficult.	0	1	2	3	4
SP is a major distraction in my life.	0	1	2	3	4

Eating Duration

It takes me longer to eat than other people.	0	1	2	3	4
It takes me forever to eat a meal.	0	1	2	3	4

Eating Desire

Most days, I don’t care if I eat or not.	0	1	2	3	4
I don’t enjoy eating anymore.	0	1	2	3	4
I am rarely hungry anymore.	0	1	2	3	4

Symptom Frequency

Coughing	0	1	2	3	4
Choking when you eat food	0	1	2	3	4
Chocking When you take liquid.	0	1	2	3	4
Having thick saliva or phlegm	0	1	2	3	4
Gagging	0	1	2	3	4
Having excess Saliva or phlegm	0	1	2	3	4
Having to clear your throat	0	1	2	3	4
Drooling	0	1	2	3	4
Problems chewing	0	1	2	3	4
Food sticking in your throat	0	1	2	3	4
Food sticking in your mouth	0	1	2	3	4
Food/liquid dribbling out your mouth	0	1	2	3	4

Food/liquid coming out your nose	0	1	2	3	4
Coughing food/liquid out your mouth when stuck	0	1	2	3	4

Food selection

Figuring out what I can eat is a problem for me	0	1	2	3	4
It is difficult to find foods I both like and can eat	0	1	2	3	4

Communication

People have a hard time understanding me	0	1	2	3	4
It has been difficult for me to speak clearly	0	1	2	3	4

Fear

I fear I may start chocking when I eat food	0	1	2	3	4
I worry about getting pneumonia	0	1	2	3	4
I am afraid of choking when I drink liquids	0	1	2	3	4
I never know when I am going to choke	0	1	2	3	4

Mental Health

My Swallowing Problem depresses me	0	1	2	3	4
I get impatient dealing with my SP	0	1	2	3	4
Being so careful when I eat or drink annoys me	0	1	2	3	4

My swallowing problem frustrates me	0	1	2	3	4
I have been discouraged by my SP	0	1	2	3	4

Social

I do not go out to eat because of my SP	0	1	2	3	4
My SP makes it hard to have a social life	0	1	2	3	4
My usual activities have changed BOM SP	0	1	2	3	4
Social gatherings aren’t enjoyable BOM my SP	0	1	2	3	4
My role with family/ friends has changed BOM my SP	0	1	2	3	4

Fatigue

Feel Exhausted	0	1	2	3	4
Feel weak	0	1	2	3	4
Feel tired	0	1	2	3	4

Sleep

Have trouble falling asleep	0	1	2	3	4
Have trouble staying asleep	0	1	2	3	4

Advice (SWAL-CARE)

Food I should eat	Yes	No
Foods I should avoid	Yes	No
Liquids I should drink	Yes	No
Liquids I should avoid	Yes	No
Techniques to help get food down	Yes	No
Techniques to help me avoid choking	Yes	No
When I should contact a swallowing clinician	Yes	No
My treatment options	Yes	No
What to do if I start to choke	Yes	No
Signs that I am not getting enough to eat or drink	Yes	No
Goals of the treatment for my SP	Yes	No

Patient Satisfaction (SWAL-CARE)

Had confidence in your swallowing clinicians	0	1	2	3	4
Swallowing clinicians explained treatment to you	0	1	2	3	4
Swallowing clinicians spent enough time with you	0	1	2	3	4
Swallowing clinicians put your needs first	0	1	2	3	4

Annexure-1 (B)

ডেমোগ্রাফিক তথ্য

কোড নং :	তারিখ :
রোগীর নাম :	
বয়স :	লিঙ্গ :
শিক্ষাগত যোগ্যতা :	পেশা :
জীবন যাত্রার মান:	ফোন নং :
মেডিকেল ডায়াগনোসিস :	এস এল টি ডায়াগনোসিস :
কখন স্ট্রোক হয়েছিল :	পুনরায় স্ট্রোক :
কঠিন/ তরল খাবারের ধরন :	কত দিন ধরে এস এল টি সেবা নিচ্ছেন :

নির্দেশনাঃ গলধঃকরণের সমস্যার জন্যে আপনার জীবন যাত্রার মান ও সেবা নেওয়ার ধরন কেমন তা নিচের মান অনুসারে প্রকাশ করুণ-

০ = না,   ১ = কখনওই না,   ২ = মাঝে মাঝে,   ৩ = প্রায়ই,   ৪ = সবসময়

SWAL-QOL

বোঝা

আমার গলধ:করনের সমস্যার সাথে টিকে থাকা খুবই কষ্টসাধ্য।	০	১	২	৩	৪
গলধ:করনের সমস্যা আমার জীবনের একটি প্রধান বিভ্রান্তি।	০	১	২	৩	৪

খাদ্যগ্রহনের সময়

অন্যদের তুলনায় আমার খাওয়া দাওয়া করতে বেশি সময় লাগে।	০	১	২	৩	৪

একটা খাবার খেতে আমার দীর্ঘ সময়ের প্রয়োজন হয়।	০	১	২	৩	৪

খাদ্যাভাসের ইচ্ছা

বেশিরভাগ সময়ই আমি খাচ্ছি কি খাচ্ছি না তা আমি গুরুত্ব দেই না।	০	১	২	৩	৪
আমি খাওয়াটা উপভোগ করি না।	০	১	২	৩	৪
আমি খুব কম সময়ই ক্ষুধার্ত থাকি।	০	১	২	৩	৪

লক্ষণের ধরন সমূহ

কাশি হয়?	০	১	২	৩	৪
যখন খাবার খাই তখন কি বিষম হয়?	০	১	২	৩	৪
পানি বা তরল খাবার গ্রহনের সময় কি বিষম হয়?	০	১	২	৩	৪
মুখে আঠালো যুক্ত লালা বা কফ জমে?	০	১	২	৩	৪
ওয়াক আসে?	০	১	২	৩	৪
আঠালো লালা বা কফ কি অনেক বেশি হয়?	০	১	২	৩	৪
গলা কি পরিষ্কার করতে হয়?	০	১	২	৩	৪
মুখ দিয়ে কি লালা বের হয়?	০	১	২	৩	৪
চিবিয়ে খেতে সমস্যা হয়?	০	১	২	৩	৪
খাবার কি গলায় আটকে যায়?	০	১	২	৩	৪

খাবার কি মুখে আটকে যায়?	০	১	২	৩	৪
খাবার বা পানি কি মুখ থেকে পড়ে যায়?	০	১	২	৩	৪
কঠিন / তরল খাবার কি নাক দিয়ে বের হয়ে আসে?	০	১	২	৩	৪
যখন কঠিন বা তরল জাতীয় খাবার মুখে আটকে যায় তখন কি কাশি হয়?	০	১	২	৩	৪

খাদ্যাভাস নির্বাচন

কোন খাবার খেতে পারব সেটা খুঁজে বের করা কষ্টসাধ্য।	০	১	২	৩	৪
কোন খাবার আমি খেতে পছন্দ করি ও খেতে পারি তা খুঁজে বের করা কঠিন হয়ে যায়।	০	১	২	৩	৪

যোগাযোগ

মানুষের আমার কথা বুঝতে খুব সমস্যা হয়।	০	১	২	৩	৪
স্পষ্টভাবে কথা বলা আমার জন্যে খুব কষ্টসাধ্য।	০	১	২	৩	৪

ভয়

আমার ভয় হয় হয়তো আমি খাবার খাওয়ার সময় বিষম খাবো।	০	১	২	৩	৪
আমি নিউমোনিয়াতে আক্রান্ত হওয়ার ভয়ে থাকি।	০	১	২	৩	৪
তরল খাবার খাওয়ার সময় ভয়ে থাকি আমি কি বিষম খাব।	০	১	২	৩	৪

আমি কখনও জানি না কখন বিষম খাবো।	০	১	২	৩	৪

মানসিক অবস্থা

আমার এই গলঃধকরন সমস্যা আমাকে বিষন্ন করে।	০	১	২	৩	৪
আমি আমার গলঃধকরন সমস্যা নিয়ে অধৈর্য হয়ে পড়েছি।	০	১	২	৩	৪
কঠিন / তরল খাবার খাওয়ার সময় আমাকে সর্বদা সতর্ক থাকতে হয় যেটা খুবই বিরক্তিকর।	০	১	২	৩	৪
আমি গলঃধকরন সমস্যা নিয়ে হতাশাগ্রস্ত।	০	১	২	৩	৪
গলঃধকরন সমস্যা আমাকে নিরুৎসাহিত করে।	০	১	২	৩	৪

সামাজিক

আমার খাবার গলধঃকরনের সমস্যার জন্য আমি বাহিরে কোথাও খেতে যেতে পারি না।	০	১	২	৩	৪
আমার এই সমস্যা আমার সামাজিক জীবন খুব কঠিন করে তুলেছে।	০	১	২	৩	৪
আমার নিত্য কার্যকলাপ এই সমস্যার জন্য অনেক পরিবর্তন হয়ে গিয়েছে।	০	১	২	৩	৪
এই সমস্যার জন্য লোকসমাগম উপভোগ করতে পারি না।	০	১	২	৩	৪
এই সমস্যার জন্য পরিবার এবং বন্ধুদের মধ্যে আমার অবস্থানের পরিবর্তন হয়েছে ।	০	১	২	৩	৪

অবসাদ

ক্লান্তিবোধ হয়?	০	১	২	৩	৪
দূর্বলতা অনুভব হয়?	০	১	২	৩	৪
পরিশ্রান্তবোধ হয়?	০	১	২	৩	৪

ঘুম

ঘুম আসা কষ্টকর ?	০	১	২	৩	৪
ঘুমিয়ে থাকা কষ্টকর ?	০	১	২	৩	৪

উপদেশ (SWAL-CARE)

যে খাবার আমার খাওয়া উচিত।	হ্যাঁ	না
যে খাবার আমার পরিত্যাগ করা উচিত।	হ্যাঁ	না
তরল খাবার যেটা খাওয়া উচিত।	হ্যাঁ	না
তরল খাবার যেটা পরিত্যাগ করা উচিত।	হ্যাঁ	না
কৌশল , যা আমাকে খাবার গিলতে সাহায্য করে।	হ্যাঁ	না
বিষম খাওয়া থেকে পরিত্রানের কৌশল।	হ্যাঁ	না
কখন আমাকে একজন গলঃধকরণের বিশেষজ্ঞের কাছে যাওয়া উচিৎ ।	হ্যাঁ	না
আমার চিকিৎসার ধরণসমূহ ।	হ্যাঁ	না
বিষম খাওয়া আরম্ভ হলে কি করতে হবে?	হ্যাঁ	না
লক্ষণ যেগুলো দেখলে আমি বুঝতে পারব আমার খাওয়া / পান করা সম্পূর্ণ হচ্ছে না ।	হ্যাঁ	না

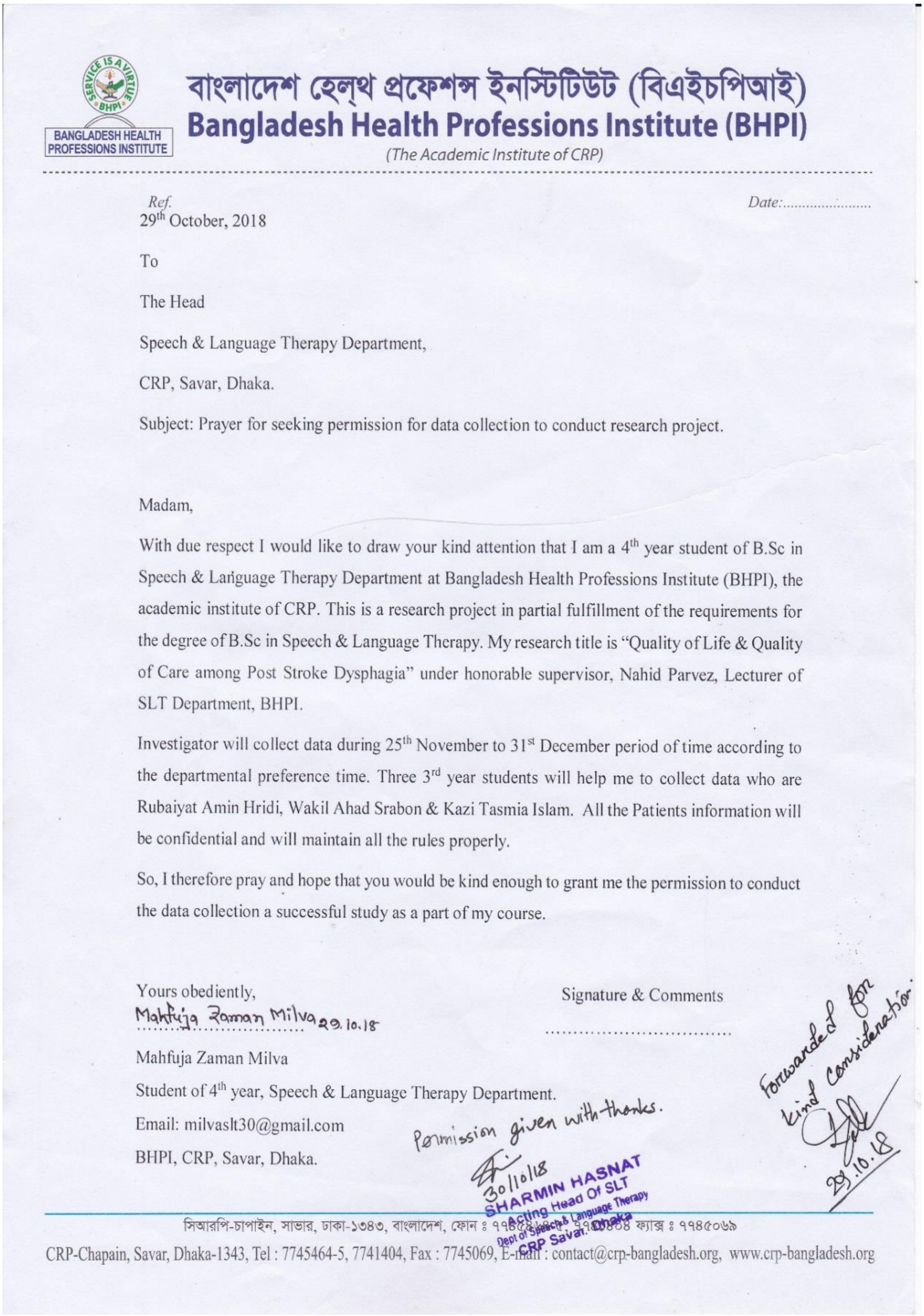
আমার এই সমস্যার চিকিৎসা ব্যবস্থার উদ্দেশ্য কি?	হ্যাঁ	না

রোগীর সন্তুষ্টি (SWAL-CARE)

আপনার থেরাপিস্ট এর উপর কি আপনার আস্থা আছে?	০	১	২	৩	৪
চিকিৎসকরা কি ভালোভাবে চিকিৎসার পদ্ধতি বুঝিয়ে বলেন?	০	১	২	৩	৪
চিকিৎসকেরা কি আপনাকে যথেষ্ট সময় দিচ্ছে ও পরিচর্যা করছে?	০	১	২	৩	৪
চিকিৎসকরা কি আপনার প্রয়োজনগুলোকে গুরুত্ব দিচ্ছে?	০	১	২	৩	৪

Annexure-2 (A)

Permission letter



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

Ref. 29th October, 2018 *Date:.........................*

To

The Head

Speech & Language Therapy Department,

CRP, Savar, Dhaka.

Subject: Prayer for seeking permission for data collection to conduct research project.

Madam,

With due respect I would like to draw your kind attention that I am a 4th year student of B.Sc in Speech & Language Therapy Department at Bangladesh Health Professions Institute (BHPI), the academic institute of CRP. This is a research project in partial fulfillment of the requirements for the degree of B.Sc in Speech & Language Therapy. My research title is "Quality of Life & Quality of Care among Post Stroke Dysphagia" under honorable supervisor, Nahid Parvez, Lecturer of SLT Department, BHPI.

Investigator will collect data during 25th November to 31st December period of time according to the departmental preference time. Three 3rd year students will help me to collect data who are Rubaiyat Amin Hridi, Wakil Ahad Srabon & Kazi Tasmia Islam. All the Patients information will be confidential and will maintain all the rules properly.

So, I therefore pray and hope that you would be kind enough to grant me the permission to conduct the data collection a successful study as a part of my course.

Yours obediently,

Mahfuja Zaman Milva 29.10.18
....

Mahfuja Zaman Milva
Student of 4th year, Speech & Language Therapy Department.
Email: milvaslt30@gmail.com
BHPI, CRP, Savar, Dhaka.

Signature & Comments

....

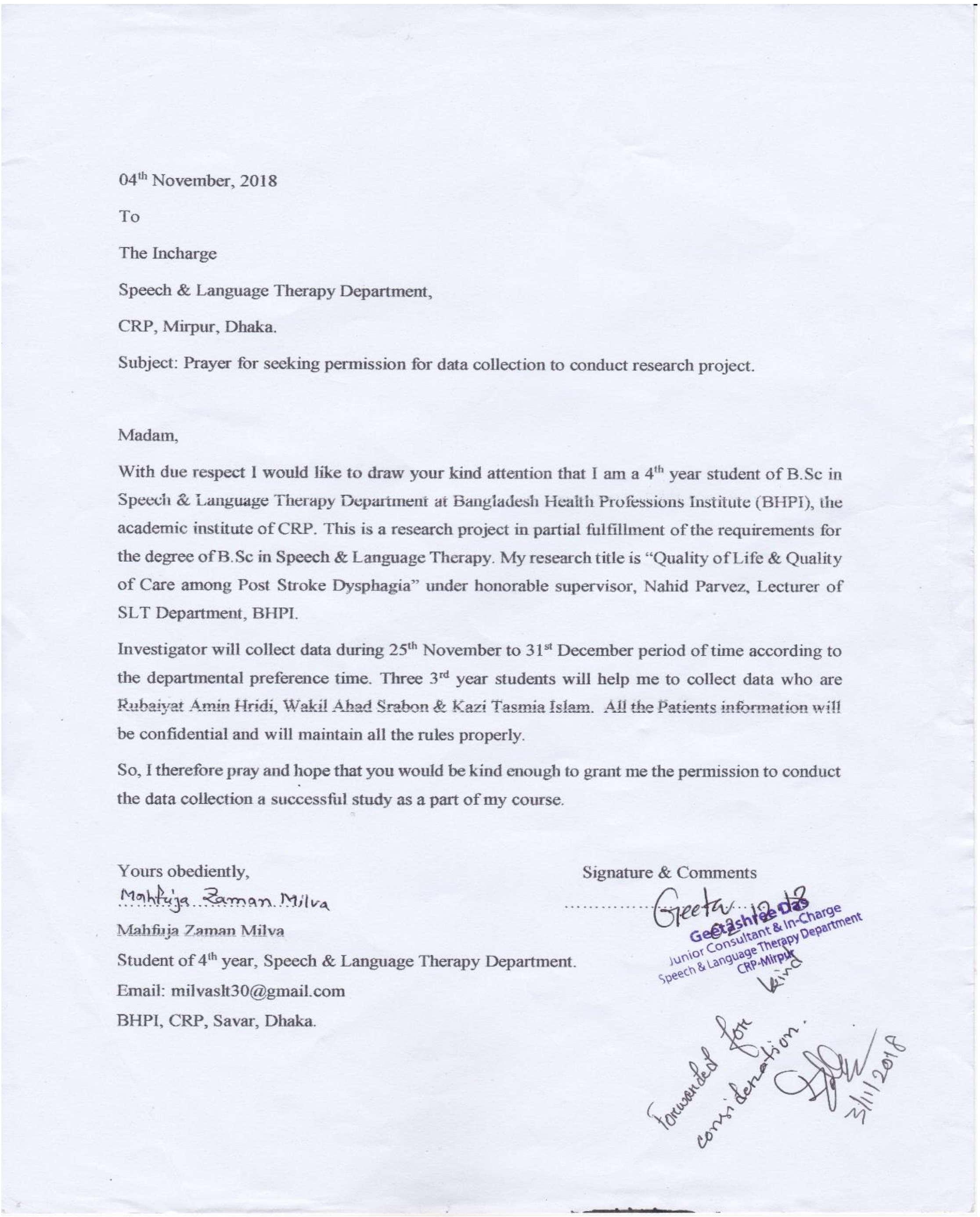
Forwarded for kind consideration.
29.10.18

Permission given with thanks.
30/10/18

SHARMIN HASNAT
Acting Head Of SLT
Dept of Speech & Language Therapy
CRP Savar, Dhaka

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ, ফোন ঃ ৭৭৪৫৪৬৪-৫, ৭৭৪১৪০৪ ফ্যাক্স ঃ ৭৭৪৫০৬৯
CRP-Chapain, Savar, Dhaka-1343, Tel : 7745464-5, 7741404, Fax : 7745069, E-mail : contact@crp-bangladesh.org, www.crp-bangladesh.org

Annexure- 2 (B)
Permission Letter



04th November, 2018

To

The Incharge

Speech & Language Therapy Department,

CRP, Mirpur, Dhaka.

Subject: Prayer for seeking permission for data collection to conduct research project.

Madam,

With due respect I would like to draw your kind attention that I am a 4th year student of B.Sc in Speech & Language Therapy Department at Bangladesh Health Professions Institute (BHPI), the academic institute of CRP. This is a research project in partial fulfillment of the requirements for the degree of B.Sc in Speech & Language Therapy. My research title is "Quality of Life & Quality of Care among Post Stroke Dysphagia" under honorable supervisor, Nahid Parvez, Lecturer of SLT Department, BHPI.

Investigator will collect data during 25th November to 31st December period of time according to the departmental preference time. Three 3rd year students will help me to collect data who are Rubaiyat Amin Hridi, Wakil Ahad Srabon & Kazi Tasmia Islam. All the Patients information will be confidential and will maintain all the rules properly.

So, I therefore pray and hope that you would be kind enough to grant me the permission to conduct the data collection a successful study as a part of my course.

Yours obediently,

Mahfuja Zaman Milva

Mahfuja Zaman Milva

Student of 4th year, Speech & Language Therapy Department.

Email: milvaslt30@gmail.com

BHPI, CRP, Savar, Dhaka.

Signature & Comments

Geeta 12.18

Geetashree Das
Junior Consultant & In-Charge
Speech & Language Therapy Department
CRP-Mirpur

kind

Forwarded for consideration.

3/11/2018

Annexure-3 (A)

Consent form

This research is a part of Speech & Language Therapy course and the name of the researcher is Mahfuja Zaman Milva. She is a 4th year student of B. Sc in Speech & Language Therapy in Bangladesh Health Professions Institute (BHPI). The study will entitle as “**QUALITY OF LIFE & QUALITY OF CARE AMONG POST STROKE DYSPHAGIA.”**

In this study I am …....…………………………………………......................... a participant and I have been clearly informed about the purpose of the study. I am willingly participating in this study. I will have the right to withdraw from this study at any stage and I will not be bounded to answer to anybody. I understand that there will be no impact receiving treatment at present or in the future by participating in this study.

I am also informed that, all the information will collect from the interview that use in the study will be kept safe and maintain confidentiality. Only the researcher will be eligible to access in the information for his publication of the research result. My name and address will not published anywhere in this study. I can consult with the researcher and the research supervisor about the research process or get answers to any questions regarding the research project. I have been informed about the above-mentioned information and I am willing to participate in the study with consent.

Signature of the study Participate:	Date:
Signature of the Researcher:	Date:
Signature of the Witness :	Date:

Annexure-3 (B)

সম্মতি পত্র

এই গবেষণা স্পীচ এন্ড ল্যাঙ্গুয়েজ থেরাপি বিভাগের অধ্যয়নের একটি অংশ এবং গবেষকের নাম মাহফুজা জামান মিলভা। তিনি বাংলাদেশ হেলথ প্রফেশনস ইন্সটিটিউটের বি এস সি ইন স্পীচ এন্ড ল্যাঙ্গুয়েজ থেরাপি বিভাগের ৪র্থ বর্ষের অধ্যয়নরত একজন ছাত্রী এবং তার গবেষণার বিষয় “Quality of Life & Quality of Care among Post Stroke Dysphagia.”

এই গবেষণার আমি -- একজন অংশগ্রহণকারী এবং আমি এই গবেষণার উদ্দেশ্য পরিষ্কার ভাবে জানতে পেরেছি। আমি যে কোন সময় এবং গবেষণার যে কোন পর্যায়ে আমার অংশ গ্রহণ প্রত্যাহার করতে পারি। এই জন্য আমি কারো কাছে জবাব দিহি করতে বাধ্য থাকব না। আমি অবগত হয়েছি যে, এই গবেষণায় অংশ গ্রহণ করার ফলে বর্তমান ও ভবিষ্যতে তা আমার ও অংশ গ্রহণ কারীদের কোন প্রকার প্রভাব ফেলবে না।

এই গবেষনার সাক্ষাতকারের সকল তথ্য যেগুলো গবেষণার কাজে ব্যবহৃত হবে,সেগুলো সম্পুর্ণভাবে গোপনীয় থাকবে। শুধুমাত্র গবেষক এ তথ্য সমূহের প্রবেশাধিকার পাবে। গবেষকের নাম, পরিচয় ছাপা হবে না।

আমি গবেষণার পদ্ধতি এবং জটিলতা অথবা সুফলের ব্যপারে বা গবেষণা সংক্রান্ত যেকোনো প্রশ্নের উত্তর দানের জন্য এ গবেষনার তত্ত্বাবধায়কের সহিত আলোচনা করতে পারব।

আমি উপরোক্ত সকল তথ্য গুলো সম্পর্কে জানি এবং আমি এই গবেষণায় অংশ গ্রহণে সম্মতি জ্ঞাপন করছি।

অংশ গ্রহণকারীর স্বাক্ষর/ টিপসই:	তারিখ:
গবেষকের স্বাক্ষর:	তারিখ:

স্বাক্ষীর স্বাক্ষর:	তারিখ: