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Bachelor of Science in Occupational Therapy



Bangladesh Health Professions Institute (BHPI)

Faculty of Medicine
UNIVERSITY OF DHAKA

**Perceived Understanding of Barriers Related to Quality of Daily Life
among Cancer Caregivers**



**By
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Except where is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis presented by me for any other degree or seminar.

No others person's work has been used without due acknowledgement in the main text of the thesis.

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

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

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TABLE OF CONTENT

Points	Page
Title page	i
Board of Examiners	ii
Statement of Authorship	iii
Acknowledgement	iv
Table of content	v
List of table and figure	vi
List of abbreviation	vii
Abstract	
CHAPTER 1: INTRODUCTION	2-5
1.1 Background	2-3
1.2 Justification of the study	3-4
1.3 Operational Definition	4-5
CHAPTER 2: LITERATURE REVIEW	6-9
CHAPTER 3: METHODOLOGY	10-17
3.1 Research question	10
3.2 Study aim and Specific objectives	10
3.3 Conceptual framework	11
3.4 Study design	12
3.5 Study population	12
3.6 Study setting	13
3.7 Study period	13
3.8 Inclusion criteria	13
3.9 Sampling techniques	14
3.10 Data collection tools	14
3.11 Data collection method	15
3.12 Data analysis	15-16
3.13 Quality control & quality assurance	16
3.14 Ethical consideration	17
CHAPTER 4: RESULT & DISCUSSION	19-30
CHAPTER 5: LIMITATION & RECOMMENDATION	31
CHAPTER 6: CONCLUSION	32
LIST OF REFERENCE	33-37

List of table

Table	Topic	Page
Table- 1	Problem are face by the person with cancer	21
Table- 2	Difficulties in performing daily living activities	22
Table- 3	Impact on caregivers leisure activities	24
Table- 4	Different types of problem are faced by the caregivers of cancer patient	25
Table- 5	After cancer diagnosis the caregiver faces different types of social and mental problem	26
Table- 6	Negative impact on relationship with the patients and relatives for caring the patient	28
Table- 7	Caregiver and family members faces financial difficulties during their treatment	29

List of Appendix

Appendices	Topic	Page No.
Appendix- 1	Permission letter for conducting study	I
Appendix- 2	Permission letter for data collection	Ii
Appendix- 3	Informed consent form in English	iii- vi
Appendix- 4	Informed consent form in Bengali	viii- ix
Appendix- 5	Questionnaire in English	X
Appendix- 6	Questionnaire in Bengali	Xi

List of Abbreviations

ADL: Activities of daily living

BHPI: Bangladesh Health Professions Institute

CRP: Center for the Rehabilitation of the Paralysed

IRB: Institutional Review Board

OT: Occupational Therapy

QCA: Qualitative content analysis

QDL: Quality of daily life

WHO: World Health Organization

Abstract

Background: Cancer is a devastating disease that affects a person's quality of life, create hopelessness and reduce self-esteem and overall it causes death. It is a harmful effect on individual and their family member and also affect in economical aspect. After diagnosis the cancer patient they have faced many difficulties and barrier in their daily living activities. They cannot participate those activities that are reduce their quality of life. At the time they survive their life is very critically and need to support from their family member. The objectives of the study is to explore the understanding of barriers related to daily living performance among cancer caregivers and to explore the physical, mental, interpersonal and financial problem enacted with daily living performance among cancer caregivers in general hospital.

Methods & Materials: The study was a phenomenological qualitative research design to collect in-depth information of the participant's perception. Purposive sampling was used and twelve participants who met the inclusion criteria were selected. Semi-structured, face to face interviews were conducted to collect the data.

Result and Discussion: Most of the cancer patients need to proper support for their daily activities. From finding the research, it was seen the caregiver understanding about the barriers to their quality of daily life. On the other hand the family members and caregivers play an important role for handling the patient. At the time they face lot of problem to support. They face different physical problem, psychosocial problem, problem of interpersonal relationship and financial problem and also faces many barriers to their daily activities. They cannot perform their daily living activities according to previous routine.

Conclusion: caregivers of cancer patient have lots of barriers on their daily living activities. They have also faced problem on relationship with patient, family members and relative as well.

Key Words: Cancer, Caregivers, Quality of daily life.

1.1 Background

Cancer is a major public health problem in all over the world. It is the second leading cause of disability, morbidity and mortality (Torre et al., 2015). Cancer statistics describe that it was happen a large group of people and at the time it's provide a picture of the burden of cancer patient's caregiver on family. According to statistical (2016) data the cancer in general and it is available for most developing countries and also Bangladesh is particular (Rahib et al., 2014)

According to World Health Organization (WHO), estimated that the cancer rate, incidence and mortality was approximately 200000, 800000 respectively for the 130 million people of Bangladesh. In the other words the new cases of cancer in Bangladesh was appraised at 167 per 1, 00,000 population (Jemal et al., 2011). Before the diagnosis of cancer it has not only a major effect on the affected people but also their family members and it may causes emotional responses of shock, doubt , anxiety and depression (Smith et al., 2009). The cancer rapidly developing into a continuous care problem because of increasing incidence rates, survivor time and a trend toward outpatient treatment, providing support and managing care has placed added responsibilities on caregiver (Ullah et al., 2016& Hossain et al., 2014).

In this time they survive their life is very critically that time need to proper support from their family members. Caregiver understandings has been defined by a broad range of varying concepts, largely expressed as an overall measure for example burden, stress, or role overload. The mental health of the caregiver also has been defined differently, e.g., psychological distress, well-being, psychological and physical symptoms, depression, life satisfaction, and self-reported health (Hudson, Ph, Aranda, & Ph, 2004).

In addition, Nijboer et al (2001) observed that the caregiver account for over 50% of cancer patient's care needs throughout their illness. So that the cancer affect not only the quality of life of patient with cancer but also their family member and friends. It impact on various aspects of the family caregivers and quality of life is important during the

route of the illness. Family caregiver reported that various problems from their caregiving experience including conflict among their social roles, restricted of their daily activities, strain in marital and family relationship, psychological distress and reduced their physical health. The family caregivers have great communication responsibilities tied to caregiving such as sharing the patients' medical history, relaying diagnosis to other family members and also making decision about care with the patient, try to give proper support for reducing mental stress, frustration etc. (Grunfeld et al.,2004).

Others related research shows that greater objective burden or care intensity (i.e., providing a high number of hours of care and assistance with a higher number of functional deficits) as well as main stress or burden (i.e., the perception of caregiving as straining) are linked with higher levels of caregiver anxiety, depressive symptoms, and emotional stress (Palos et al., 2011) Further, caregiver characteristics, such as poor self-rated health, and residence in the same household activity, and some barriers of their daily living performance, have also shown to be associated with greater caregiver emotional stress (Etters et al., 2008).

So the caregiver of cancer patient has a higher risk to fall in stress, depression, burden and anxiety and also impact on their quality of daily life because the caregiver faces difficulty to manage those problems and fell stress. For this reason the investigator wants to know the barriers related to quality of daily life among cancer caregiver.

1.2 Justification of the study

The caregivers are working as the co-therapist. Caregivers take care of their patient with restricting diseases. Generally they are parents, wives, sibling, sons, daughters, close relatives, friends and neighbors. They assist patients in managing medication, therapy and medical emergencies, provide supervision, emotional support, and assist in personal care, mobility and other ADL's. The various study show that maximum cancer patient are need assistance in performing their important ADL's such as eating, dressing, personal hygiene, mobility and provide their emotional support and physical care. Generally the cancer patient (according to their stage) depend on their caregivers. The caregivers as well as partners take part to handle the client.

The investigator explained broadly about the barriers to quality of daily life among cancer caregivers. This study also identified common challenges of caregiver for their daily caregiving. It may be physical, social, psychosocial (emotional, mental) and financial. It is very difficult of caregiver to manage the family member, relatives and care of cancer patient. On the other hand the caregiver get insufficient support from the family member or relatives. It makes the caregiver emotionally distress. So that this study will be helpful to find out the barriers of daily living performance and also identify the physical, mental, interpersonal and financial problem that are impact on the caregiver's daily living performance. It became more burden for caregiver and other side the caregiver burden is a complex issue that includes regular hospitalizations and the need for long-term psychosocial and economic support, as well as life-time lost productivity.

For these reason the occupational therapist can work with both patient and caregiver. If there are no smooth relationship among patients and their caregiver it will hamper provision of intervention. An occupational therapist can provide advice to the patient and caregiver by understand the problem on their caregiver, by know the impacts or challenges of daily living performance of caregiver, an OTs can provide advice to the caregiver. Similarly, the caregivers will be benefited by getting Occupational Therapy (OT) management. Through these study the investigator have identify specific barriers of cancer caregivers. As an OT has taken this specific barriers they can work better and after completing this study, an Occupational Therapist are used this study by evidence based document and will be able to enrich their knowledge and resource by using this study in Bangladesh. An Occupational Therapist will also establish in different management strategies for the caregiver of cancer patient.

1.3 Operational definition

Caregiver of cancer patient

Caregiver refers to any relative, partner, friend or neighbor who has an established different personal relationship and provides a wide range of assistance for an older person or an adult with a different types of chronic or disabling condition. These caregiver may be primary or secondary. In many studies describe the definition of 'caregiver' as the

person who always helps the person with cancer and it is not paid to give the care for the patient. Most of the caregiver of the person with cancer they have many roles and responsibilities. In this role depends on the patient's needs, change during and after taking cancer treatment. As a caregiver they try to give proper support on the patient's psychosocial factor such as emotional and mental support and always try to working closely with the patients. The caregivers of cancer patient they can help the patient contract with these challenges and get through any problems that come up and also help to improving their quality of life (Waldron et al., 2013).

Quality of life

WHO definition to Quality of daily life as "individual' perception of the caregiver's position in life and the context of the culture and value system. Which they live to their goals, expectation, standard and concern. The quality of life is a broad concept that are affects in a complex way by the person's physical health, psychosocial factor, level of individuality, social relationships and personal beliefs (Oort, 2005).

Bangladesh is the most populous country in the world, here lives in 142 million people. There are 13 to 15 lakh cancer patient in Bangladesh (Torre et al., 2015). Every each year in those two lakh patient newly diagnosed with cancer. Cancer is a chronic disease that causes patient lose their control for living long time and it affect many people directly or indirectly. On the other hand it has an adverse impact on their social activities, work, and family/marital life and also reduce their health status and quality of life (Ryan, Figueroa-Moseley, Jean-Pierre & Morrow, 2007)

According to (Hofman et al., 2007), the cancer can worsen the caregiver's health, impair social life, increase stress, and cause depression. After diagnosing of cancer it's a major impact not only on patient, but also on their family member and caregivers. So cancer has a large impact on both patients and their families. Family members and caregivers play an important role for cancer patient. Generally it become a lots of burden and frustration for caregiver. On the other hand it hamper on their quality of daily life that are creates different type of barrier (Graven, 2007).

The cancer statistics in 2012 show that, it arise more or less 14 million new cases. The amount of recent cases is predicted to rise by 70% over the next two decades and it also depend on cancer symptoms, risk factor, early detection and treatment (Hanahan & Weinber., 2015). In 2017 there are increase new 1688780 cancer cases and 600920 people with cancer are death. According to United States, cancer is a second leading causes of death. Globally 1 in 6 death is because of cancer (Lowy & Schiller., 2012). Approximately 70% of deaths from cancer occur in low and middle income countries and the biggest problem for the cancer patient is economical problem. It increasingly day by day. The overall annual economic cost of cancer in 2010 was estimated at more or less 1.16 trillion. Only 1 in 5 low and middle income countries have the necessary information to drive cancer policy (Hawlder et al., 2015).

National Center for Health Statistics (2014- 2018) estimated that there are 1,735,350 new cancer cases diagnosed and 609,640 cancer are deaths in those year (Rebecca et al., 2018). According to World Health Organization estimated that cancer is currently one amongst the leading cause of death in Bangladesh. Incidence rate in 200,000 and mortality rate in 1, 50,000 people every year and overall cancer load is around 12, 00,000 with the number expected to increase several fold by 2030 and on the other hand it expected that there will be 23.6 million new cancer cases worldwide this is 68 more cases than in 2012, with slightly larger and growth in low and medium human development countries than in high and very high countries (Siegal et al., 2018). After cancer diagnosis it impact on work and income for patients and family member and change in financial gain on family budgets. Most of the cancer patient can not able to continue work during their illness (Parkin et al., 2005). Cancer treatment may cause financial stress for pediatric oncology patient and their families and the cancer caregiver perceived financial burden associated with socioeconomic factors and some health care uses factor for example of unexpected hospitalizations (Peter et al., 2004).

According to Oxford Advanced Learner's Dictionary (2014) "*Caregiver is a person who takes care of a sick or old person at home*". On the other hand caregiver is a person who is trained to assume responsibilities for the physical and emotional needs for another who is capable of self-care. There may be relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for an older person or an adult with a chronic or disabling condition (Grant et al., 2013), 40% to 70% of family caregivers have clinically significant symptoms of depression for their caregiving. Caregiving is an occupation that can encompass 24 hours a day, 7 days a week, with no sick family, and caregiving responsibilities simultaneously. These challenges put caregivers at risk for experiencing caregiver burden (Naguwa, 2010).The terms family caregiver and informal caregiver refer to an unpaid family member, friend, or neighbor who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding and ventilator care (Reinhard et al., 2014). Family caregivers those who are closely related (Husband, wife, parents, children or siblings) to cancer

patients. While cancer caregiving is a meaningful experience, it is also associated with deteriorating quality of life (QOL) greater psychiatric sequelae and increased risk of mortality for the caregiver (Luppana & Cohen, 2006). The families and caregiver are the most valuable or vulnerable resource for the cancer or disabled patients. The family members play a major role in supporting their impaired relative (Lasebikan & Ayandi., 2013). Caregiving responsibilities can make a burden or interpersonal stress on caregivers' daily lives, physical health, and emotional well-being. High levels of caregiver burden can have considerable consequences for patients and wider society as a whole as well as for caregivers themselves. For instance, the impact on the caregiver becomes too great. In addition, caregiving has a significant impact on informal caregivers' own physical and psychological health (Gater, 2014).

Caregiver burden has been widely researched and is defined as *“a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience”*. Many studies have found that caregiving is related to physical and psychosocial issues, such as depression, illness, and decreased quality of life (Naguwa, 2010). The economic burden related need to support the patient and the loss of productivity of the family unit, emotional reactions to the patient's illness, such as guilt, a feeling of loss and fear, The stress of coping with disturbed behavior, Disruption of household routine, Problems of coping with social withdrawal or awkward interpersonal behavior, limitation of social activities (Bektas & Ozer, 2009). Each family divides up the tasks of caregiving differently. The majority of families, parents and step-parents are primary caregivers. 90% of caregivers express concern about what their death would mean for the cancer patient in their care. 63% of caregivers report not having time for them, and 55% don't have time to perform their daily living activities (Berkman & Sampson, 1993; Gordon et al., 2007). Their mental factor is also affected, including an increased likelihood of depression, insomnia, and anxiety. In Bangladesh caregiver is the most important for patient because of social stigma, social isolation. Sometimes many patient and caregiver are stigmatized in their society. On the other hand, when caregiver giving support of the cancer patient that time they face in many difficulties and barriers that are impact their daily life also their personal life. They cannot maintain their daily

activities such as rest and sleep, education, work, play, leisure and social participation. At the time giving care the caregiver feel depressed and emotional problem (Talwar and Matheiken, 2010).

Occupational therapists work with health care and other professionals in a variety of places, such as long term care facilities, community support services, family health teams, hospitals and clients' homes (Player et al., 2014). Occupational therapy services should be an integral part of cancer or palliative care. Occupational therapists work with people in a wide variety of settings, including; community health, aged care, community rehabilitation, outpatient clinics, acute care, tertiary rehabilitation centers, day hospice, hospice and inpatient palliative care units (Kealey & McIntyre, 2005). Occupational therapy in palliative care aims to enable the individual's participation in valued and essential everyday activities (occupations). Optimizing participation and function is achieved through the prescription of assistive equipment, task analysis, adaptation and energy conservation, symptom management e.g., relaxation, positioning, home modifications, and education of patients, psychological support on patient, caregivers and family members (Coope, 2013). Interventions must be person-centered and decision making of patients and caregivers can be informed by Occupational Therapy knowledge (Piersol & Otr, 2015). On the other hand Occupational Therapist can work with both patients and caregivers. If there are no smooth relationship among patients and their caregiver it will hamper provision of intervention. Education about the condition can help motivate the caregiver to stick to the treatment plan. An Occupational Therapist can provide advice to the patient and caregiver by understand the problem on their daily living performance and also can provide advice to the caregiver. Similarly, the caregivers will be benefited by getting occupational therapy management.

3.1 Research Question

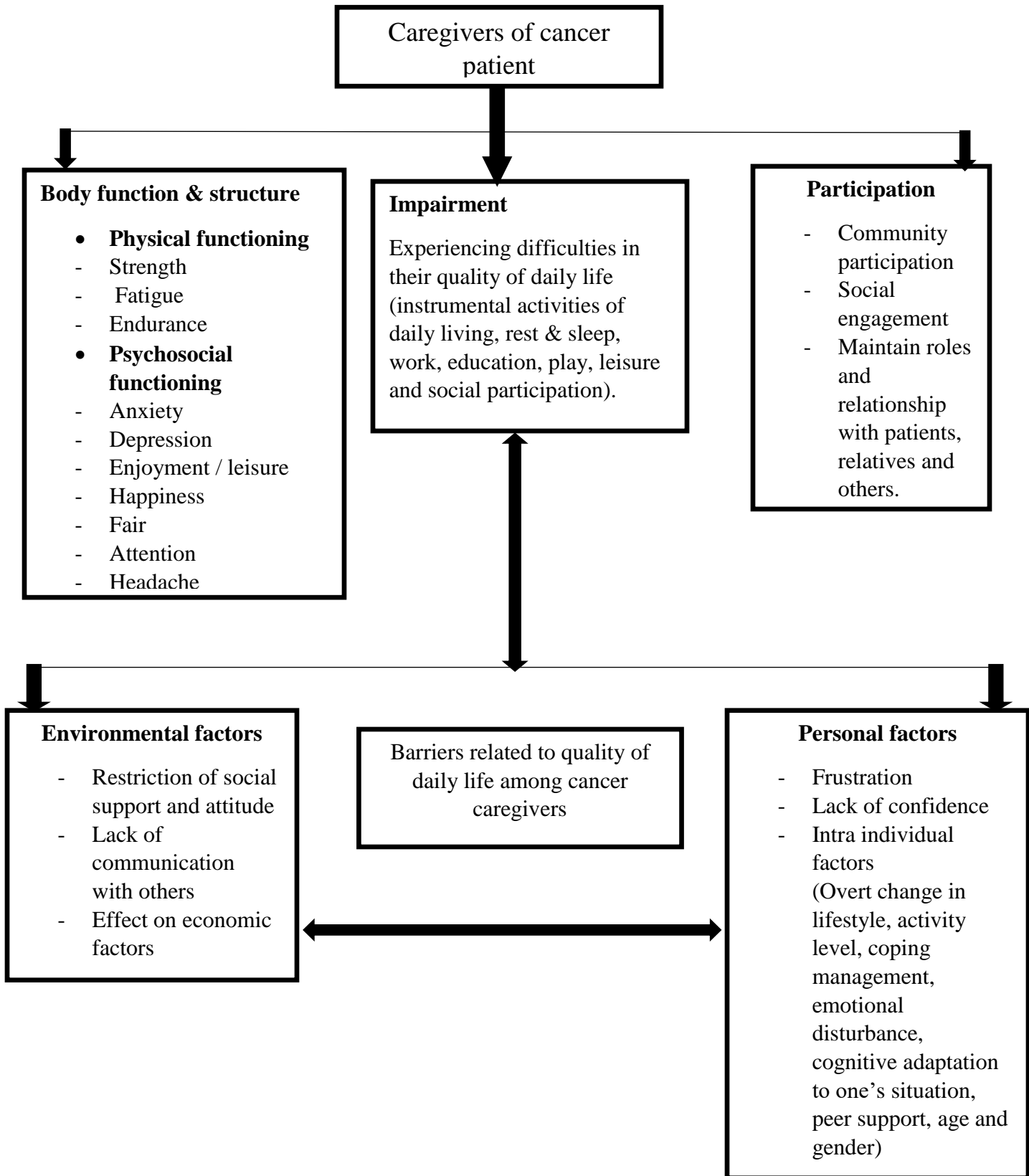
How is the perceived understanding of barriers related to quality of daily life among cancer caregivers?

3.2 Study aim and objective***3.2.1 General objective***

To explore the perceived barriers related to quality of daily life among cancer caregivers in general hospital.

3.2.3 Specific Objective

- To understand the barriers related to daily living performance among cancer caregivers in general hospital.
- To explore the physical, mental, interpersonal and financial problem enacted with daily living performance among cancer caregivers in general hospital.



3.1 Figure: Conceptual framework

3.4 Study design

The investigator used phenomenological qualitative research design in this study because this method helps to explore the in depth information on the perception of the participants (Hissong et al., 2014). On the other hand, this phenomenological research design can be used to knowing the living experience at the present time and also experienced to their barriers related to quality of daily life. For this reason the investigator was selected this method for doing this study because of the investigator to know the qualitative methods help to explore the experience of participants and also it focus on the experience of people as they engage in their everyday work. Again it helps to identify the beliefs people hold and the perception of them from different perspectives. The investigator thought that the design was appropriate for this study because the caregiver of cancer patient are a specific group of people in our society and the study aim is to explore the perceived barriers related to quality of daily life among cancer caregivers, who are stayed at hospital. The investigator collected the information of participant's opinions because each participant's opinion is unique. So the investigator used phenomenological approach of qualitative research design.

3.5 Study population

Non-paid caregiver of cancer patient who were living with patient at hospital were the study population in this study.

3.6 Study Participants

The caregivers of patient with cancer who were admitted at Oncology Department of Dhaka Medical College & Hospital were study participant among them 12 participant were selected purposively.

3.7 Study setting

The study was conducted in the Indoor and Outdoor unit of the Oncology department at Dhaka Medical College & Hospital in Bangladesh. This institute was established in 1946 with the aim of providing quality care to people with cancer in Bangladesh.

3.8 Study Period

The study has been done as the part of the academic education of the B. Sc in Occupational Therapy. The period of this study was from October 2017 to March 2018. In particular data collection was conducted from December 2017 to February 2018.

3.9 Inclusion and exclusion criteria

3.9.1 Inclusion criteria

- The caregiver of cancer patient who are interested to become a participant of the study.
- The participant who cares the cancer patients regularly.
- The caregiver who are closely related to cancer patients (family members- person who provide the most assistance like spouse, children, parents and siblings).
- The participant's age range is 18-60 years.

3.9.2 Exclusion criteria

- Paid caregivers of cancer patient.
- Caregivers of cancer patient who have hearing and cognitive impairment.
- Those caregivers who did not stayed at hospital with the patient.

3.10 Sampling Techniques

The investigator was interested to obtain experience of the participants. For this reason the investigator were selected by using purposive sampling because they explain some feature that are relevant to the research. Therefore the investigator used purposive sampling and chooses participants who can offer the fullest and most relevant information about the topics under the study. The study was a qualitative type of study and this Subjects were collected by using purposive sampling from the population who met the all inclusion criterions. This method was also used to find out lived experience of a specific population. Samples were selected from caregiver of cancer patient. Participants were selected by using purposive sampling to conduct the study.

Aim of the study was to identify the barriers related to quality of daily life among cancer caregivers. As there were many caregiver of cancer patient with male and female, the investigator selected the study participant by purposive sampling method. It is the most common type of non-probability sampling to complete the study within the fixed time period. Purposive sampling method is based on the knowledge of a population and the purpose of the study. Investigator took approximately about 12 caregiver of cancer patient by data saturation. If the investigator does not attain data saturation any resulting theory may be unbalanced, incomplete. In this study investigator used data saturation to achieve appropriate results.

3.11 Data collection tools

- Semi-structured questioners was developed to collect data and it was used in interview session (semi-structured questionnaire both Bangla and English).
- Information sheet and consent form was used to take permission from the participants for data collection.
- Stationary items (pen, paper and clipboard) were used to take notes and write down observations, general information of the participants.
- Recorder was uses to record the data of the participants during data collection session.

3.12 Data collection procedure

To collect the data, the investigator has used the semi structure and face to face interview system that was easier to guide the interview without fixed format of question. On the other hand the semi structure question participant get much freedom to explain their feeling in their own word. The approval of the study was taken from the Institutional Review Board (IRB) of the Bangladesh Health Professions Institute (BHPI). Investigator to get the permission from the Head of the Occupational Therapy Department for data collection. After that Dhaka medical college granted the data collection in the hospital. At first investigator addressed the subjects and informed them of the study. Then investigator took the opinions of subjects who were interested and confirmed time and date of the interview. At first the investigator took consent from the participant. Then, investigator spent some time to build rapport with the participant. The interviewer

explained the title and aim of the study to gain the trust of the participants. Trust is a very important element during an interview, because if the participants feel uneasy to discuss sensitive issues then they may hide the truth. The questionnaire was based on to explore the perception of the caregiver of cancer patient about their barriers related to quality of daily life. Interview was conducted in Bengali so that participants would be able to understand easily. The answers were recorded by a tape recorder. The investigator also wrote the important notes. Time range was approximately 1 hour for each interview.

3.13 Data analysis

Data analysis is the most complex and most vital aspect of qualitative research. In qualitative research, it was suggested to analyze the collected data to organize the information according to different codes, categories and theme (Bowling, 1997). Data analysis allowed the investigator to establish the study aims according to collected information from the participant. The appropriate analysis would give an accurate finding for the data. So the investigator selected Qualitative Content Analysis (QCA) method for analysis the data. At first, the investigator would organize the interviews and transcribe the entire interview in Bengali from the audio tape recorder. Each of the transcripts were translated into English by 3 different individuals, one was the investigator and another 2 were such people who are not involved in the study. Then the investigator verified the accuracy of the data. Data analysis had started with reading all data repeatedly word by word to derive the code. Codes are derived from participants' answers. Data had been organized according to the categories. Investigator had found some question categories, all the information had been coded from participants' interviews. The coding was different from each participant and after finishing the coding; some important codes had been detected that reflected the themes of the study findings. Therefore, the data had been analyzed in 3 stages:

Coding \longrightarrow Categorizing \longrightarrow Generating themes

3.14 Quality control & quality assurance

Before beginning the final data collection, it is necessary to carry out a field test which will help to refine the data collection plan. It gave a practical knowledge about the application of questionnaires for the study population and gave opportunities to rearrange

the study questionnaires again. Also the investigator accomplished the field test with four participants. Investigator informed the participant about the aim and objectives of the study during interview session. Carrying out field test is a preparation of starting final data collection. It helped to make a plan that how the data collection procedure can be carried out, sorting out the difficulties during questioning, making a basic plan of questioning and if there is needed any modification of the questionnaire. The collected data by the field test firstly transcribed from the audio tape recording. Then the transcription copy was translated into English. The field test helps the investigator to make the plan on how the ways can be for collecting data, how a question can be asked on different ways and what can be the probing question to find out the participant's actual response on the event. The questionnaire was both in English and Bengali Questionnaire is fulfilling the purpose of the study or not. The questionnaire will not be sensitive and it will be culturally appropriate.

3.15 Ethical consideration

The research had to maintain ethical consideration in all aspect of the study. This study research following issues should be considered:

- The investigator obtained permission to conduct research from the Institutional Review Board (IRB) of Bangladesh Health Professions Institute (BHPI).
- Investigator had taken approval from supervisor and head of the Department of occupational therapy of Bangladesh Health Professions Institute (BHPI) an academic institute of CRP.
- Investigator was taken permission for data collection from the authority of Oncology Department at Dhaka Medical College & Hospital in Bangladesh.
- Investigator was maintained confidentiality about service information of those institutes.
- Informed consent form was collected from the participants.
- All participants were informed about the aim and objectives of the study by the investigator.

- The investigator had promised to the participants that all information provided will be kept confidential and will not expose their identity.
- Subjects or sample had full rights to withdraw themselves from the study without any hesitation.
- The Investigator also ensured that their participation would not cause any harm but would benefit them but in future.

Summary of data analysis and result

Objectives	Question	Categories	Themes
<p>1. To understand the barriers related to daily living performance among cancer caregivers in general hospital.</p>	<p>1, 6</p>	<p>1. Problem of the patient due to cancer.</p>	<p>1. Cancer patients have faced many difficulties due to their illness.</p>
		<p>2. Difficulties in performing daily living activities.</p>	<p>2. Caregivers faces many difficulties in performing daily living activities as well as leisure activities for regular handling the patient.</p>
		<p>3. Impact on their (caregivers) leisure activities.</p>	
<p>2. To explore the physical, mental, interpersonal and financial problem enacted with daily living performance among cancer caregivers in general hospital.</p>	<p>2, 3, 4, 5, 7, 8</p>	<p>4. Different types of physical problem faces by caregiver for looking after the cancer patient.</p>	<p>4. Caregiver of cancer patient faces various types of physical problem for handling and maintaining the caregiver roll.</p>
		<p>5. Social and mental problem of the caregiver.</p>	<p>5. After cancer diagnosis the caregiver faces social and mental problem.</p>
		<p>6. Impact on relationship with the patients and relatives for caring the patient.</p>	<p>6. Cancer have negatives impact on their relationship between the patient and relatives.</p>
		<p>7. Caregiver and family member faces financial difficulties.</p>	<p>7. After the cancer diagnosis and taking treatment from the hospital, the caregiver and family member faces financial problem.</p>

Discussion section is a very important part where the investigator can add her explanations to the work. It has presented the result of the research study and finding. According to Shuttleworth (2009), during this important a part of the analysis paper, the investigators begin the method of explaining any links and correlate those with findings of the study. The findings and discussion have been presented together with the necessary literature support. Result part of this section has describe as completely so that is possible to judge the finding of the study.

The aim of the study was to explore the understanding of barriers related to quality of daily life among cancer caregivers. There were two objectives of the study. The first objectives was to understand the barriers related to quality of daily living performance among cancer caregiver in general hospital. The question number 1, 6 were used for this objectives and developed three categories.

Category 1: Problem of the patient due to cancer.

Under this category one theme was emerged as follows-

Theme 1: Cancer patients have faced many difficulties due to their illness.

Category 2: Difficulties in performing daily living activities.

Category 3: Impact on their (caregivers) leisure activities.

Under this two category one theme was emerged as follows-

Theme 2: Caregivers faces many difficulties in performing daily living activities as well as leisure activities for regular handling the patient.

Second objectives was to explore the physical, mental, interpersonal and financial problem enacted with daily living performance among cancer caregivers in general hospital. Under this objectives question number 2, 3, 4, 5, 7, 8 was used and following four categories was emerged.

Category 1: Different types of physical problem faces by caregiver for looking after the cancer patient.

Under this category one theme was emerged as follows-

Theme 1: Caregiver of cancer patient faces various types of physical problem for handling and maintaining the caregiver role.

Category 2: Social and psychological problem of the caregiver.

Under this category one theme emerged as follows-

Theme 2: After cancer diagnosis the caregiver faces social and mental problem.

Category 3: Negative impact on relationship with the patients and relatives for caring the patient.

Under this category one theme was emerged as follows-

Theme 3: Cancer have negative impact on relationship between the patient and relatives.

Category 4: Caregiver and family member faces financial difficulties

Under this category one theme was emerged as follows-

Theme 4: After the cancer diagnosis and taking treatment from the hospital, the caregiver and family member faces financial problem.

In this section coding were selected on the basis of participant's views and opinions by which the theme was selected. The finding were describe by using the table and also highlighted their interview is a coding basis. Each of the tables below presented the collected data. The tick was given only for those columns where caregivers spoke about those issues. Here 'P' was used for participant. According to categories and coding it has given the description of theme at below.

Category 1: Problem of the patient due to cancer.

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Having pain in the body parts	√	-	√	√	-	-	-	√	-	√	-	√
Face difficulties in performing eating activity	√	√	-	√	-	-	-	-	√	√	-	√
Face difficulties in walking	√	√	√	√	√	√	√	√	√	√	√	√
Encounter difficulties activities in daily living performance	√	√	√	√	√	√	√	√	√	√	√	√
Impaired bowel and bladder control	√	-	-	√	-	√	-	√	-	-	-	-

Table 1: Problem are face by the person with cancer

Most of the participant said that,

“After cancer diagnosis their patient faces many difficulties but most of the important problem are they cannot participant activity of daily living performance such as walking, eating, self-care, productivity. Around half of the participant said that patient faces difficulty in walking that’s why they can’t engage their daily living performance.”

One of the participant said that,

“Yes, after cancer diagnosis my patient faces difficulties, sometimes they feel severe pain in whole body and difficulty to move body parts that’s why they can’t participant in daily living activities”.

There are thirteen to fifteen hundred thousand cancer patients in Bangladesh, with concerning 2 hundred thousand patients newly diagnosed with cancer each every year. Cancer is a chronic disease that causes patients to lose control over their lives, has an adverse impact on their social activities, work, family/marital life, daily living performance and reduce their health status and quality of life. Cancer affects many people directly or indirectly (Hofman, Ryan, Figueroa-Moseley, Jean-Pierre, & Morrow, 2007).

Few participant are said that,

“Impaired patients bowel and bladder control, most of the time patient cannot control it so that its impact on the patients’ health function.”

So after cancer diagnosis, the patients faces many difficulties and its running. Cancer is a chronic disease that cause patient to loss their functional capacity, loss their health status, strength, endurance, and also impact on their QOL, balance that’s why they do not perform in their previous work (self-care, productivity and leisure) and on the other side it impact on their social and emotional factor that are create a big problem.

At the time the patient do not participant in activity of daily living that are hampered their quality of life and they became fully dependent on their caregivers.

Category 2: Difficulties in performing daily living activities.

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Can’t maintain self-care activities	√	√	√	√	√	√	√	√	√	√	√	√
Difficulties to maintain daily routine	√	√	√	√	√	√	√	√	√	√	√	√
Always have to take care of patient	√	√	√	√	-	√	-	√	√	√	√	√
The patient has to do all the work	-	√	√	-	-	√	-	-	-	√	-	-
Purchase medicine for the patient and timely taking to chemotherapy	√	-	-	√	√	√	-	√	-	√	√	-
Have to work faster than before	√	√	√	-	√	√	-	√	√	√	-	√
Not enough time for taking rest and sleep	√	√	√	√	√	√	√	-	√	√	√	-

Table 2: Difficulties in performing daily living activities.

All participant answered from their own perspective about their ADL's and leisure. They did explain different problem due to their patient's illness. They always face difficulties in managing ADL's such as eating, bathing, sleeping, taking rest and maintaining others rolls and responsibility as well as participation in leisure.

Most of the participant said that-

“I cannot do anything timely. Now I am all-time busy with the patient. That's why I can't able to maintain daily routine, self-care activities, maintain rolls and responsibility with others (family members, friends, relatives etc.). I did not sleep properly because there are always many kind of thought inside the head and sometimes not get enough time for taking rest. For these reason I have to stay beside him. As a result difficulties to performing daily living activities and maintaining daily routine.”

Few participant said that,

“I cannot perform my activities appropriately. I am always busy with the patient and maintain every work to me but sometimes my family members support me for handling the patient and patients related work. I cannot eat properly.”

Another participant explained her own point of view as-

“Problems must occur. I cannot do perform anything'. I cannot do timely.”

Caregivers who engage themselves in caregiving of their patients, sometimes try to make balance among their activities. Often they find it difficult to focus on positive aspect if negative reactions are seen. The caregivers have responsibility is take care of their patients and to maintain their patients ADL's. They have to perform their own activities and patient's activities together.

From the perceptions of the investigator, most of the Bangladeshi caregivers try to engage themselves in patient care. They dedicate their life for the patient, children and family. They forget about their own need of eating, bathing, grooming etc. From the perceptions of the participants the investigator found that caregiver of cancer patient they

have many problems. These are – most of the caregiver can't manage their ADL's after taking care of their patients, some cannot perform according to routine, some have to complete tasks as quickly than before (Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004).

According to (Hossain et al 2014), Cancer caregivers perform a range of tasks and responsibilities that are labor intensive including administering medications, providing transportation, assisting with activities of daily life, providing emotional support, coordinating finances, and advocating for health care. So the investigator wants to carry out this study to explore the challenges or barriers to quality of life of caregiver among cancer patients.

Category 3: Impact on their (caregivers) leisure activities.

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Perform as like before	-	√	-	-	√	-	-	-	-	√	-	-
Difficulty in performing leisure activity	√	√	-	√	√	√	√	-	√	√	√	√
Does not maintain time for leisure	√	√	√	-	√	-	-	√	-	√	√	-

Table 3: Impact on the caregivers leisure activities.

Most of the participants said that-

“They do not get time to pass their leisure because they always busy with the patient. As a caregiver they always every time treat the patient like as a nurse.”

Another participant expressed her opinion as-

“I cannot do anything during leisure period. Always stay beside patient. I have to stay with patient during leisure. I cannot do my own activities. I cannot do any activity as like before.”

According to (Stenberg et al, 2010), the caregivers who are always busy with taking care of their patient (may be parents, husband, wife, son/daughter, relatives etc.). They cannot pass their leisure activities. They have to be concerned about their patient that when her patient needs help for doing anything. They are also anxious about the situation. The caregiver does not get enough time to enjoy recreational activities due to look after their patient.

Category 4: Different types of physical problem faces by caregiver for looking after the cancer patient.

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Low back pain	-	√	-	√	-	√	-	-	√	√	-	√
Pain in whole body	-	-	√	-	-	-	-	√	-	√	-	√
Feel so much lethargy and liege for whole day	√	√	√	√	√	√	√	√	√	√	√	√
Feel tension	√	√	√	√	√	√	√	√	√	√	√	√
High blood pressure	-	-	√	-	-	√	-	√	-	-	√	-
Headache	√	√	√	√	√	-	√	√	√	√	-	√
Sleep disturbance	√	√	√	√	√	√	√	√	√	√	√	√

Table 4: Different types of problem are faced by the caregiver of cancer patient

Most of the participant said that.

“They have faced many problem after diagnosis the cancer. Most of the time they can’t sleep at night, feel severe headache, feel so much lethargy and liege for whole day life, low back pain and every time they feel tensed for their patient condition.”

Few participant complained that-

“Sometimes I feel sick and some problem are faces in everyday life such as high blood pressure, feel pain in whole body that are mainly hamper our health status”.

Another participant said that-

“There is various problem. Some problem are faces very critically such as sleep disturbance, feel tension (not only the patient related tension but also the family and others tension), high pressure, feel pain in the whole body and sometimes so much lethargy for whole day.”

The caregiver and families are the most valuable and the most vulnerable resource for the cancer or disabled patient. The caregiver play a major role in supporting their impaired problem (Kim et al., 2008). Caregiving responsibilities can make a burden or inter personal stress on caregivers’ daily lives, physical health, and emotional well-being.

The duration of caregiving negatively affect the physical function. The duty of caring for a patient with a chronic disease can increase one’s levels of fatigue and result in a lower QOL. The pressure of the burden can impact the physical health of the caregivers. It causes problems like mechanical back pain and knee osteoarthritis, headache, pain in the whole body as well as having a lower general health condition. These problems can cause limitations for the caregivers. It can be concluded that most of the caregivers face various types of physical problems (Hawlder et al., 2014).

Category 5: Social and mental problem of the caregiver

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Feel prolong frustration	√	√	√	√	√	√	√	√	√	√	√	√
Depression	√	√	√	√	√	√	√	√	√	√	√	√
Feel so much tensed	√	√	√	√		√	√	√	√	√	√	√
Worries about how to maintain family and others	√	√	√	-	-	√	√	√	√	√	√	√
Experiencing in stigma	-	√	-	√	-	-	√		√		√	-
Sympathetic towards caregiver and family members	√	-	√	√	√	√	-		√	√	√	√
Lack of social support	-	√	-	-	-	-	√	√	-	-	√	-

Table 5: After cancer diagnosis the caregiver faces different types of social and mental problem.

Most of the participants explained that-

“They feel so much depressed after the cancer diagnosis, at the time most of the patient are fully detached in their daily activities and they fully depend on the caregiver. The caregiver take care of the patient that time they faces difficulty such as they feel prolong frustration for patient illness, worries about how to maintain family and others. Sometimes it create the caregivers mental problem that are impact on their quality of daily life”.

Few participant said that,

“Sometimes they have faced social problem like stigmatized. Neighbors are not enough sympatric towards the caregiver talked about various types of negatives such as this disease is not good it’s bad too much. They think it is contagious disease.”

Another participant stated that-

“People always tell. Different people say many things. Allah did it. People said different things. I have worriedness. My children stay at home. I stay with my caregivers. For these reason it is tension, worriedness. It obviously comes, if I don’t want.”

In a study of Yun et al., (2005) there is a considerable impact of caring on psychosocial and social adjustment. This study reported that the majority of caregiver understanding high levels of stress as a result of caring. Feelings of helplessness were stated in this study by many caregivers, as were depression, loss of independence, frustration, guilt over neglecting other family members and physical strain. While caregiver try to improve the QOL of their patients with cancer through intensive care, their own quality of life may deteriorate and they have faces barrier of their quality of daily life.

As psychological issues play an important role in this situation. Frequency of depression and anxiety has effects on the caregiver. They reported that caregiving can have a negative effect on the mental health of these persons and depression and anxiety are

highly prevalent among them. The caregiver have a lower QOL and experience greater psychological stress (Kim et al., 2006).

Category 6: Negative impact on relationship between the patients and relatives for caring the patient.

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Impact fall on relationship with the patient.	√	-	√	-	√	√	√	√	√	√	√	√
Impact fall on relationship with the relatives.	√	-	√	-	-	√	-	-	-	√	-	√
Maximum time patient rude behave with the caregiver	√	-	√	-	√	√	√	√	√	√	-	-
Lack of communication.	√	-	-	-	-	√	-	-	-	√	-	-
Sometimes maintain communication	√	√	√	-	√	-	√	√	-	-	√	√
Does not get help financially	√	-	√	-	√	√	-	-	-	√	-	-
Relatives gives blame	√	-	-	-	√	√	-	-	-	√	-	-
Pressurize to money return	-	√	-	-	√		√	-	-	√	-	-

Table 6: Negative impact on relationship between the patients and relatives for caring the patient.

Most of the participant said that,

“Yes there is some problem between me and patient. Sometimes the patient become angry with me. Even he show bad behave with me if there is a little change in his daily activities like delay in feeding or taking to washroom.”

Another participant said that,

“There is some problem between patient and relatives with me. Some relatives blame to me for their illness and do not care much about us. They can’t help with money even they have no capability for help and neighbors do not help any more. Sometimes many

relatives do not contract with us and also do not come here and also sometimes family members are angry with me. This related problem are the big problem for me.”

Few participant are explain that,

“There is a lots of problem. My relatives are not give any kind of help. Sometimes they pressurized to return money and do not have communicate with us”.

In many study give the definition of ‘caregiver’ as the person who always helps the person with cancer and it is not paid to give the care for the patient. In the other hand Professional care providers are paid to give care of the patient. Most of the caregiver are the lifeline of the person with cancer and they have some many roles. In this roles change as the patient’s needs, change during and after taking cancer treatment. The caregiver is part of a cancer care team that are made up of the patient, other family, relatives, friends, and the medical staff. As a caregiver they give proper support on the parent’s psychosocial factor such as emotional and mental support and always try to working closely with the patient. Sometimes they faces many problem with the relatives. Some relatives are showing bad response with the caregivers (Van Ryn, 2011).

Category 7: Caregiver and family member faces financial difficulties.

Coding	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Worries about money management	√	√	√	√	√	√	√	√	√	√	√	√
Not sufficient amount of money from the family members	√	√	-	-	√	√	√	-	√	-	√	√
Sometimes feel tensed about how manage the money for treatment	√	√	√	√	-	√	√	√	-	√	√	√
sometimes relative gives financial support	√	√	-	-	√	-	-	-	√	-	√	-

Table 7: Caregiver and family member faces financial difficulties during their treatment.

Most of the participant explain her opinion that,

“Yes I have economic problem. When the patient treated to many doctors for few years, for this reason a sufficient amount of money has been finished and not sufficient amount of money from the family members. Sometimes feel tensed about how manage the money for manage the treatment.”

Another participant are said that,

“It is the big problem. Nobody give the helping hand to me but sometimes any critical situation some relatives are giving financial support. Now managing money has become the biggest problem”.

Most of the cancer patient and their family members are claimed that almost all families confronted with a diagnosis of cancer have financial issues or economic losses. Cancer patients are more likely to report financial difficulties than persons without cancer. In several small studies (Mohantti, 2011) conducted in diverse locations, between 11% and 16% of patients considered themselves to have major financial difficulties due to a cancer diagnosis. The impact of a cancer diagnosis on work and income for patients and family members; and the impact of both changes in income on family budgets. Most cancer patients are not able to continue to work during their illness and need to take some sick leave (Boone-Heinonen et al, 2011).

5.1 Limitation

There are many studies in the world about caregiver but in the Bangladeshi context there have very few. The investigator had to use many secondary sources assessed by the internet. It was difficult to discuss the finding in the Bangladeshi context. The investigator always tried to consider the limitation during the period of study. These are given below:

- The investigator were collected data only from Dhaka Medical College & Hospital (Oncology Department).
- There have not enough literature about information of caregiver among cancer patient in Bangladeshi context or south Asian context.

5.2 Recommendation

- For further study, the investigator used in thematically analysis than it will be get in deep information and a good finding.
- For further study, the investigator could collect data from another cancer hospital.

Cancer is a life threatening disease that causes the patient lose their control for living long life. After diagnosis the cancer patient they have faced many difficulties and barriers such as difficulties in their daily living activities (self-care, productivity, leisure). They cannot participate those activities that are reduce their quality of life. Than need to support for cancer patient that can give a caregiver. In Bangladesh perspective caregiving have to maintain major care-giving responsibilities of their patient and also have to manage their household responsibilities. As caring a cancer patient is very challenges for caregivers. It often impact the caregiver's daily life and quality of life. The study has been conducted to explore the perceived understanding of barriers related to quality of daily life among cancer caregivers.

The study would be helpful to identify specific barriers and challenges of caregivers to provide appropriate emotional support and education to increase their self-esteem and coping skill. From the result of the study it has found that caregiver have faced many difficulties in performing their daily living activities. They usually don't get enough time to perform their ADL's properly due to high care-giving burden. Moreover they also faced different physical, psychosocial, family and social problem after having a cancer patient and thus their daily life and quality of life is greatly decline and also faced different barriers of their daily life.

This study is important for Occupational therapist as they can work with caregivers and other side they can give motivation and education to the caregivers to increase their mental stability and coping skill. The Occupational Therapist has an important role to understand the caregiver's situation and promote a better social and psychosocial support for quality of life of caregivers.

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