

**LEVEL OF CAREGIVER BURDEN: A STUDY ON CAREGIVERS
OF STROKE SURVIVORS AT CRP IN BANGLADESH**

By

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Statement of Authorship

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

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

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

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DEDICATION

*.....To my honorable and
Beloved parents
Whose instruction always my inspiration*

Key Abbreviations

CG- Caregiver

CB Scale- Caregiver Burden Scale

HS- Hemorrhagic Stroke

IS- Ischemic Stroke

TIA- Transient Ischemic Attack

AVMs- Arteriovenous Malformations

ADLs- Activities of daily living

BHPI- Bangladesh Health Professions Institute

CRP- Centre for the Rehabilitation of the Paralyzed

WHO- World Health Organization

SPSS- Statistical Package of Social Science

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Abstract

Aim/Objectives of the study: The study identified the level of burden among caregivers of stroke survivors at CRP in Bangladesh. Beside it also found the level of burden of caregiver of stroke survivor about general strain, isolation, disappointment, emotional involvement and environment and also found out the association in between level of caregiver burden and caregiver's age, sex, occupation, relationship with stroke survivors & stroke survivor's onset of stroke and caregiving duration.

Method: The study conducted through Cross-sectional design among 151 participants who were selected from occupational therapy outdoor and stroke rehab unit, CRP (Savar & Mirpur) by a structure questionnaire with face to face interview.

Main Outcome Measure: Caregiver Burden Scale

Results: Most of the caregivers (78.8%) of stroke survivors faced with moderate level of burden and in terms of domain most of the caregiver faced with moderate burden about general strain (58.9%), isolation (63.6%) where faced higher burden about disappointment (60.3%) and lower burden about emotional involvement (59.6%) and environment (78.8%). Caregiver burden level was significantly associated to caregiver characteristics: age ($P=0.006$), sex ($P=0.002$), occupation ($p=0.04$), relationship with stroke survivors ($P=0.02$), caregiving duration ($P=0.000$), and caregiving hours ($P=0.009$), and onset of stroke ($P=0.000$) of stroke survivors. Female caregivers who were housewives, wife and daughter in relationship with stroke survivors giving long duration of care exhibit higher burden.

Conclusion: The result will help the occupational therapists to know the situation of caregiving of stroke survivors in Bangladeshi content and in future caregiver will be benefited to reduce stress and a significant advice about maintaining their family role and occupational therapists have an important role to promote a better social and psychological support for quality life of caregiver and stroke survivors.

Key Words: Stroke/stroke survivor, Caregiver, Burden.

Content

Points	Page Number
Title page	I
Approval page	II
Statement of the Authorship	III
Dedication	IV
List of Abbreviation	V
Acknowledgement	VI
Abstract	VII
Chapter-1: Introduction	1-4
1.1. Introduction	1-2
1.2. Background	2-3
1.3. Significance	3-4
1.4. Aim of the study	4
1.5. Objectives of the study	4
Chapter-2: Literature Review	5-13
2.1. Stroke	5-6
2.1.1. Type of stroke	6-7
2.2. Stroke survivor	7
2.3. Consequences of stroke	7-9
2.4. Recovery after stroke	9
2.5. Caregiver	9-10
2.6. Role/Responsibilities of caregiver	10-11
2.7. Burden	11
2.8. Caregiver burden	11-12
2.9. CRP (Occupational Therapy outpatient and stroke rehab Unit)	12-13

Chapter-3: Methodology	14-20
3.1. Study Design	14
3.2. Study Area	14-15
3.3. Study Participants	
3.3.1. Study population	15
3.3.2. Inclusion Criteria	15
3.3.3. Exclusion Criteria	15
3.3.4. Sample size estimation	16
3.3.5. Sampling procedure	16
3.4. Field Test	16
3.5. Data Collection	
3.5.1. Data collection technique	16
3.5.2. Data collection procedure	17
3.5.3. Data collection Instrument	17-18
3.6. Data Analysis	18-19
3.7. Ethical Consideration	19-20
3.8. Reliability and Validity	20
3.9. Dissemination of the Result	20
Chapter-4: Result	21-30
Socio-demographic characteristics of the caregiver	21-22
Socio-demographic characteristics of the stroke survivor	22-24
Caregiver burden	24-25
Overall Burden	24-25
General Strain	25
Isolation	25
Disappointment	25-26
Emotional Involvement	26
Environment	26

Association between level of burden and Caregiver's & Stroke survivor's socio-demographic characteristics	27-30
Chapter-5: Discussion	31-42
5.1. Socio-demographic characteristics of the caregiver	31-33
5.2. Socio-demographic characteristics of the stroke survivor	33-34
5.3. Level of burden of caregiver of stroke survivor	34-35
5.3.1. General strain	35
5.3.2. Isolation	36
5.3.3. Disappointment	36
5.3.4. Emotional Involvement	36-37
5.3.5. Environment	37-38
5.4. Association between level of burden and Caregiver's & Stroke survivor's socio-demographic characteristics	38-42
5.5. Limitation of the study	42
Chapter-6: Conclusion and Recommendation	43-44
6.1. Conclusion	43
6.2. Recommendation	43-44
Reference List	45-51
Appendix	i-xx

List of Table

S.N.	List of Table and Figures	Page No.
01.	Table-1: Characteristics by Socio-demographic factors and care information of the Caregivers (n=151) and stroke survivors at CRP, Bangladesh.	23-24
02.	Table-2: Prevalence of overall burden and different domains of caregiver burden by level of burden among caregivers of stroke survivors at CRP- Savar and CRP- Mirpur, Bangladesh.	26
03.	Figure-1: Level of total burden of caregiver of stroke survivor (Chart).	25
04.	Figure-2: Level of burden among caregiver of stroke survivors in five domains (Chart).	27
05.	Table-3: Association between caregiver's socio-demographic factors and level of caregiver burden among caregivers of stroke survivors at CRP, Bangladesh.	29
06.	Table-4: Association between level of caregiver burden and stroke survivor's demographic factor & caregiving duration among caregivers of stroke survivors at CRP, Bangladesh.	30

List of Appendix

S.N.	List of Appendixes	Page No.
01.	Permission for conduct Research	i
02.	Permission to use 'Caregiver Burden Scale'	ii
03.	Permission for Data Collection-A	iii
04.	Permission for Data Collection-B	iv
05.	Information Sheet (English)	v
06.	Consent Form (English)	vi
07	Information Sheet (Bangla)	vii
08	Consent Form (Bangla)	viii
09	Socio-demographic Questionnaire (English)	ix-x
10	Caregiver Burden Scale (English)	xi-xv
11	Socio-demographic Questionnaire (Bangla)	xvi-xvii
12	Caregiver Burden Scale (Bangla)	xviii-xx

1.1 Introduction

Bangladesh is a developing country located in South Asia, is home to approximately 160 million people living in an area of 147,570 sq. km (Situation of Bangladesh, n.d.). Estimates indicate that 10% of the population i.e. 16 million peoples are living with a disability that need assistance from a caregiver or family member and stroke is one of the common cause of this disability (WHO 2011).

Bangladesh Bureau of Statistics (2004) and Islam et al. (2012, p.211) revealed that stroke was the third leading cause of death in Bangladesh and accounting for 2.55% of the total number of disabilities. Also Islam et al. (2012, p.211) stated that the World Health Organization (WHO) ranks Bangladesh's mortality rate due to stroke as number 84th in the world. The high number of disability-adjusted life-years lost due to stroke (485 per 10 000 people) shows that stroke severely impacts Bangladesh's economy. Knipmann (2012, p.208) also stated that stroke is a leading cause of serious long-term disability worldwide, with a dramatic impact on the survivor but also their families.

Stroke does not just affect the survivor; it also affects their family or caregiver. Han & Haley (1999, p.1478) stated that most of stroke survivors and caregivers suffer from depression and Xie et al. (2000, p334-335) stated this is because survivors require help from family members or close friends who become a valuable resource for the patient. Anderson et al. (1995, p.847) stated that most stroke survivors return to their own home with caregiver assistance, after a period of inpatient care and rehabilitation. As stroke causes serious and long term disability, impacting their ability to perform activities of daily living independently thus they are dependent on their family members which are known as caregivers. Family members already have a lot of responsibilities in the family, but when a family member acts as a caregiver role, they have to take on additional responsibilities of the stroke survivor besides other responsibilities of family. So, these additional responsibilities seem unbearable or a burden for them. On the part of the family caregivers, the adjustment to the new challenges poses the necessity of learning to cope with various potentially stressful problems in everyday life. Gaugler (2010, p.109) mentioned that many caregivers

report considerable burdens and display poor mental and physical health than the general population during the months or years following the onset of their family member's stroke. The extensive literature on caregivers, Bugge et al. (1999, p.1520) found that many caregivers have high levels of burden and strong needs for emotional support, information, knowledge and skills about stroke care and available resources. Chow et al. (2006, p.140) found that stroke caregivers experience higher level of anxiety and depression indicates the need for nurses in neurological units to provide enhanced discharge planning for this group of patients. Therefore, families need assistance in learning how to maintain their own health whilst dealing with a new and difficult life situation. This is particularly relevant for older caregivers and for caregivers who are less educated. A well designed discharge plan with continuity of care may benefit both patients and caregivers in the long term caregiving process.

1.2 Background

Rigby et al. (2009, p.152) stated that caregiver burden is a multi-dimensional concept that encompasses the psychological, health, social and economic impacts of caregiving.

Whilst Reimer et al. (1998, p.1606) states majority of patients need professional care but most care is provided by their relatives and primarily their partners in the community. An increasing amount of demands is made on them while the caregivers themselves have to cope with the devastating effects that stroke had on their partner or relatives and caregivers had unmet personal needs that were disrupted by the stroke. They have to provide more emotional support and assist the patient in activities of daily living and subsequently caregivers may experience unacceptably high levels of burden which leads to isolation, exhaustion and relational deprivation if the care recipient was the primary source of this type of support and the deficits incurred by the stroke impaired their role in the relationship according to Greveson et al. & Schulz et al. (cited in Grant et al. 2004b, p803-804). Kniepmann (2012, p.209-214) stated, several studies have shown that family caregivers report problems in managing ADLs, maintaining their own physical health, citing fatigue, tiredness and inadequate rest loss of independence and inadequate time to manage multiple roles and responsibilities because of stroke survivor functional losses. Beside it is also challenging for caregivers to make adjustment with new experience life. Many

caregivers experienced considerable strain from the early post stroke period and after 5 years stroke in some case. Berg et al. (2005, p.639) found in previous studies, 11% to 42% of caregivers showed signs of depression due to their spouse's limitation in functional activities in Finland. Bhattacharjee et al. (1999, p.118) stated that caregivers of stroke survivors face a significant amount of stress at all times in India. In another study in Netherland Reimer et al. (1998, p.1607) has shown that partners of stroke survivors express feelings of heavy responsibility, ambiguity about patients' care needs, constant worries, restraints in social life, and feelings that patients rely on only their care.

When the researcher worked with stroke clients and their caregiver, she observed that managing stroke survivors put a greater burden and risk of injury on the caregiver and also caregivers shared about their difficulties and unmet needs to researcher. From that time researcher had a hidden interest to do something about caregiver and wanted to know how much burden they feel. Now when she has got opportunity to conduct a research study, she is focusing to fulfill her hidden interest about caregiver burden. Also caregiver burden can be different in different culture, society where caregivers live and Bangladeshi culture is different from other countries in the world and here Institutionalize care is limited in comparative to western countries. So the caregiver burden may differ from other countries. Within the world several studies have been conducted about caregiver burden and level of burden but there have not available study in Bangladeshi content. So, researcher emphasizes her concentration more on this topic. Also the researcher has found many literatures to support the background of this topic.

Recently research on family caregiving has expanded rapidly and several studies have showed greater burden and stress among family members caring for chronically disabled relatives who have stroke and dementia disorders even after institutional placement according to Zarit & Townsend (cited in Elmastahl et al. 1996, p177).

1.3 Significance

In occupational therapy treatment process a caregiver acts as a co-therapist. Also in a home environment they provide continuous care to stroke survivor who actually needs help and care. During providing care to their loved one or stroke survivor, caregivers have to face many problems which are burden for them. Also, caregiver may have

serious health consequences and it may impede on the rehabilitation program of stroke survivor. So, it is very important to know how much burden they face to reduce their burden. Kniepman (2012, p.209) stated that traditionally, the health care system focuses on the diagnosed person. Research emphasizes the valuable contributions of family caregivers and the potential benefits or hazards that they experience. This has important implications for occupational therapy practice. A family-centered approach with individuals following a stroke could be guided through knowledge of activity changes and their effects on younger family caregivers. A better understanding of family caregiver's experiences could enable occupational therapists to develop strategies that reduce caregiver burden, promote social participation and enhance health for the caregiver and the entire family by awareness, management, occupational training, counseling and education etc. If caregivers are maintaining their own health, they are more likely to continue assisting family members who survive strokes. As well as Occupational therapists can ensure a successful rehabilitation program.

1.4 Aim of the study

To identify the level of burden among caregivers of stroke survivors at CRP in Bangladesh.

1.5 Objectives of the study

1. To find out the level of burden of caregiver of stroke survivor about general strain, isolation, disappointment, emotional involvement and environment.
2. To find out the association in between level of burden among caregivers and onset of stroke of survivors & duration of caregiving.
3. To find out the association in between level of burden among caregivers and caregiver's age, sex, occupation and caregiver's relationship with stroke survivors.

Stroke is a common phenomenon over the world. It is also comparatively high in Bangladesh. In this literature review the researcher has defined key terms of the title. The key terms are stroke, stroke survivors, Caregiver burden, CRP-Bangladesh. The literature shows that the caregiver feels burden to their stroke patients. The study has conducted due to there have still scarcity of information and findings in Bangladeshi context.

2.1 Stroke

Rosamond et al. (2008, p.27) Stated stroke is one of the major causes of long-term disability.

Stroke as defined by the World Health Organization is “a *rapidly developed clinical signs of focal or global disturbance of cerebral function, lasting for more than 24 hours or until death, with no apparent non-vascular cause. 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*” (World Health Report 2007).

According to WHO estimation every year about 15 million of world population suffers from stroke where around 33% (5 million) people die and 33% become permanently disabled. Globally a life is taken by stroke every 10 seconds and an incident of stroke occurs every ½ second. Although high blood pressure is the major risk factor in stroke which causes more than 80% of stroke cases (12.7 million) worldwide. Other risk factors of stroke are smoking, atrial fibrillation, heart failure and heart attack as stated Rosamond et al. (2008, p.29). In terms of disability as per the Lancet 28 November 2009 issue, stroke is found to be the leading cause worldwide and in developing countries beside it is the second leading causes of disability (Qamar 2011, p.2). In Pakistan prevalence of stroke has been observed in much younger age in some studies comparison with the west. Mohammed et al. (2011, p.640) found that in Bangladesh a community study has been estimated the prevalence of stroke involving 15,627 participants aged 40 years and older and stroke prevalence were reported as 0.20% for the age groups 40-49 years, 0.30% for 50-59 years, 0.20% for 60-69 years, 1.00% for 70-79 years, and 1.00% for 80 years and

above, respectively and Islam et al. (2012, p.211) stated that the overall prevalence of stroke was 0.30%, and the ratio of male: female patients was 3.44: 2.41 in Bangladesh.

Stroke has a serious impact on stroke survivor as well as family member or caregiver. Das et al. (2010, p.2965) stated that stroke causes physical, cognitive, and behavioral dysfunction of stroke survivor necessitating caregiver support for rehabilitation and general care. When a caregiver provide these continuous care they face subsequent problems include pain, distress and lots of physical, emotional, social and financial problems which may affect their quality of life.

2.1.1. Types of stroke

There are 2 classifications of stroke: Ischemic and Hemorrhagic stroke-

Ischemic stroke:

Qamar (2011, p.2) stated that Ischemic stroke is caused by obstruction in a blood vessel supplying blood to brain. This blockage in blood vessel could be caused due to blood clot in the vessel or due to hardening of blood vessel supplying blood to the brain because of accumulation of fat in vessel walls.

These fatty deposits can cause two types of obstruction: Cerebral thrombosis refers to a thrombus (blood clot) that develops at the clogged part of the vessel. Cerebral embolism refers generally to a blood clot that forms at another location in the circulatory system, usually the heart and large arteries of the upper chest and neck (American Heart Association 2013). Hossain et al. (2011, p.19) stated that around four fifth (> 80%) of stroke cases are caused by ischemic brain infarction.

Hemorrhagic stroke:

Hemorrhagic stroke accounts for about one fifth (13 %) of stroke cases, which is less frequent and occur due to rupture or burst of a blood vessel which leads to the bleeding. Accumulation of blood compresses surrounding brain tissues causing deprivation of oxygen and nutrients to the surrounding tissues. This type carries higher risk of death according to Siddique et al. (2009, p.88).

The two types of hemorrhagic strokes are intracerebral (within the brain) hemorrhage or subarachnoid hemorrhage and two types of weakened blood vessels usually cause hemorrhagic stroke: aneurysms and arteriovenous malformations (AVMs) (American Heart Association 2013).

These two types of stroke produce different types of paralysis, causing functional dependency on the stroke survivor's caregiver, which can create lots of burden.

2.2. Stroke survivor

Generally stroke survivor means who lives through affliction of stroke. Morrison et al. (1999, p.265-66) stated that a significant proportion of stroke survivors suffer from some form of chronic residual physical disability and some form of communicative disorder. Many stroke survivors experience long-term physical, psychosocial, cognitive and functional impairments that are terrible challenges to family caregivers according to Sit et al. & Van et al. (cited in Haley et al. 2009, p.2129). Carek et al. (2010, p.91) stated that stroke survivors can experience a range of ongoing problems including weakness or paralysis, problems with balance and coordination, problems with speech and language (e.g. aphasia), difficulty swallowing and mood swings. Cramer (2008, p.272-273) stated that major recovery occurs within first three months after stroke but long term disability often remains for a longer period of time. Also Qamar (2012, p.3) mentioned that stroke has major long term durations of effects on quality of life of its survivors and of their caregivers requiring more appropriate rehabilitation to avoid further complications in terms of depression and other allied disabilities. Morrison (1999, p.265-66) stated that survivors are increasingly likely to be cared for in the community and many have relatives as their primary caregivers.

2.3. Consequences of stroke

Stroke affects the person's whole life, the change depends on location of the obstruction and the extent of brain tissue affected. Stroke affects a person's motor, sensation, cognitive, behavior and perception sometimes language as stated Larish et al. & Adams (cited in Rugg and Clark, 2005, p.165). As impairment depends on location of brain obstruction so caregiver burden may also vary according location and impairment.

If specifically analyzed the impairments due to the location of the stroke can include the following:

2.3.1. Common problem:

Stroke survivors affected by either right brain disorder or left brain disorder may have some common problems. Such as-

Motor Dysfunction:

Stroke affects a person contra laterally. So usually hemiplegia is common. Person's coordination and rhythm of movement is decreases due to upper motor neuron lesion and affects a person's normal postural mechanism, normal righting, equilibrium and protective reactions are lost on the affected side (Pedretti, Smith & Pendleton, 1996, p.787). All of this interfere a person's functional performance.

Sensory Disturbance:

Sensory system is generally affected after stroke. Pulaski (2003, p.774) stated that in case of stroke patient, tactile, vision, pain, temperature, proprioception and kinesthesia is affected.

2.3.2. Right Brain disorder:

The person having stroke affected by right brain disorder may have lots of impairments such as-

Cognitive Deficits:

Long and short term memory loss, orientation, problem solving, logical thinking; concentration and attention can be affected by stroke (Jackson 1996, P.443). 10-55% of stroke patient's has memory disorders. And 27% cases at least three impaired cognitive functions are seen three months after stroke Pohjasvaara et al. (cited in Pulaski 2003, p.774).

Behavior and Emotion Change:

Many people become emotionally labile after the stroke that exhibiting uncharacteristic emotion. Depression is the most common emotional change after stroke. Other psychological changes can be frustration and aggression. This mood change affects person's motivation and performance. Additionally they may become anxious and apathetic after stroke. All of this has direct impact on person's functional ability (Jackson 1996, p.442-443; American Stroke Association 2013).

Perceptual Deficits:

After stroke perceptual deficits is more common. According to Jackson (1996, pp.444-445) perceptual dysfunction occurs when sensory and organ is intact but the cortex area is damaged, a person is unable to interpret the external stimuli. The common perceptual problem is the inability to recognized familiar objects called agnosia, other more common problem is less ability to perform precise movements called apraxia, body image disorder and spatial relation disorder is more common.

2.3.3. Left Brain Disorder:

Speech and Language Disorder:

Stroke may result in mild to severe speech and language disorder. Facial muscles movement is affected after stroke caused dysarthria. That affects the precision of speech sounds quality and loudness of the voice, and the ability to speak normally. It also affects language center and causes dysphasia. As a result, individuals speaking, reading, listening and writing and their ability become more limited (American Stroke Association 2013).

Due to damage in the brain the person may experience people various body functions, emotion and perception are changed. As a result the person's normal function is disrupted. So, ultimately person's all occupational performance will be hampered and requires full time care from caregiver which can be stressful.

2.4. Recovery after stroke

Recovery after stroke depends on the severity of the stroke and the extension of brain area involve. Pitkanen (2000, p.4) stated that the majority of case spontaneous recovery of function occurs during the first month after stroke. In case of stroke arm function loss is most common. Most of the improvement occurred during the first 16 weeks after stroke. About 20% of patients die within a month, and among survivors at one year about one-third are dependent on others for activities of daily living (ADLs). Any type of disability can affect a person's occupational performance. As the outcomes of a stroke are incurable, disablement in activities of daily living is usually common which is related with caregiver burden.

2.5. Caregiver

A person who is responsible for attending to the needs of a child or dependent adult. A caregiver can provide a wide range of service, depending on the degree of disability, economic situation and living environment of the older person. A caregiver is defined as the unpaid person closely involved in physical (feeding, bathing, toileting, walking) and emotional care (empathic listening, encouragement and motivation to adhere to treatment); they were commonly a family member living with the patient (Das et al. 2010, p.2965). Also caregiver can be formal and informal.

The caregiver is vulnerable to stress and strain developing as a result of nursing/attending to a patient over a prolonged period of time. Although the physical, psychological, emotional, and social consequences of care giving and its economic benefit to society are well recognized (Low et al. 1999, p.713), care givers needs are often given low priority in the management of stroke (Karr & Smith 2001, p.434). Advances in stroke rehabilitation have successfully reduced severe disability and institutionalization, which has increased the number of disabled patients living at home and being supported by caregivers, who feel inadequately trained, poorly informed, and dissatisfied with the extent of support available after discharge (Simon et al. 2001, p.295-7).

2.6. Role/Responsibilities of caregiver

Stroke survivors often have multiple needs. So the responsibility of a caregiver is not fixed it depends on person's needs and level of dependency. A caregiver has no control over these needs. Moreover there is no fixed working schedule; usually a caregiver of a stroke patient assists the patient in all types of activities. The crucial role of caregivers in prevention, early intervention, treatment and recovery will be acknowledged, respected and provided with appropriate support to enable them to fulfill their role. In the treatment area, the role of caregiver is very important for the client's improvement.

Hudson (2004, p.4) stated the following responsibilities of a caregiver in his study, these are;

- Personal care- Such as hygiene, feeding.
- Domestic care- Such as cleaning, meal preparation.
- Auxiliary care- Such as shopping, Transportation.
- Social care- Such as counseling, emotional support conversing.
- Nursing care- Such as administering medication.
- Planning care- Such as establishing and coordinating support for the patient.

Cohn et al. (2003, p.546) stated that caregivers have a lot of responsibilities. If the client stays in the traction bed, the caregivers have to do everything. In case of stroke patient, the caregiver has a big role. If the caregiver cannot take proper care of the

stroke survivor, many complication may arise which affect the recovery of stroke survivors.

Being a caregiver can result in significant emotional, social and economic burden. Caregivers have their own needs, and are known to be at risk of experiencing depression, anxiety and stress. Caregivers need must be recognized and their health and wellbeing safeguarded. This should occur through access to information, resources and support programs and where necessary, to crisis assistance and respite care services.

2.7. Burden

When the responsibility seems unbearable, uncomfortable and difficult to maintain for a person then it may be called a burden. A caregiver may feel burden when he/she has to provide continuous care. The burden of caring can cause serious disruption to caregiver's lives (Bugge et al. 1999, p.1519).

2.8. Caregiver burden

When a caregiver faces strain and feels uncomfortable providing care and when caring to loved one is unbearable for a caregiver. Stroke has a great impact on caregiver and creates lots of perceived burden of caregiver. Caregiver burden or stress is a multidimensional concept as it entails the physical, social, psychological and financial factors. Caregiver burden as described by Zarit *et al.* (cited in Bhattacharjee et al. 2012, p.114): *“the state resulting from necessary caring tasks or restrictions that cause discomfort for the caregiver.”* Caregiver burden can be: (i) objective means costs related to caregiving, how much physical assistance and intervention is needed to assist in Activities of Daily Living (ADLs) due to increased physical disability, cognitive impairments and housekeeping tasks, (ii) Subjective burden: The positive or negative feelings and perceptions of the caregiver associated with providing caregiving functions. Reported contributors to caregiver stress include financial strain, being confined to the home, changes in the relationship with the care recipient, noncompliance of the stroke survivor, the demands of caregiving and having little time for oneself (Saban & Hogan 2012, p.10). One study in Turkey showed that caregiver burden is an important factor on stroke prognosis and these factors are significantly affected by both individual and local factors in the same country (Ozge et al. 2009, p.139). The burden of informal caregiving often lies with

women where 59–75% of informal caregivers being female (Family Caregiving Alliance 2003). Studies demonstrate that stroke caregivers who report high levels of burden are at elevated risk of developing poor mental health including depressive symptoms (Perrin et al. 2009, p.145). Higher levels of burden was related to large amount of care provided, partners unmet demands for psychosocial care and their emotional distress (Reimer et al. 1998, p1607). A population based assessment study in Australia showed that almost all caregivers reported adverse effects on their emotional health, social activities, and leisure time, and more than half reported adverse effects on family relationships (Anderson et al. 1995, p.847).

One study in India showed that caregivers of stroke survivors face a significant amount of strain at all times which was their first time experience. Stroke caregivers have experienced financial, emotional, physical and mental anxiety and have influence of family bonding and social customs. 80% of caregivers were women and majority of the patients were cared for by immediate family members for example a spouse, son/daughter, son-in-law, daughter-in-law, siblings etc (Das et al. 2010, p.1967). Also the family members had to adjust their work schedule while many had to give up their jobs. Younger caregivers and daughter-in-laws faced major stress but comparatively spouse caregivers had relatively mild stress. Overall the caregivers are faced a lot of burden for their stroke survivors where it is very prominent with younger caregivers and ultimate result severe depression (Bhattacharjee et al. 2012, p.115; Han & Haley 1999, p.1478).

2.9. CRP (Occupational Therapy outpatient unit & stroke rehab unit)

The Centre for the Rehabilitation of the Paralyzed, commonly known as CRP, was founded in 1979 by a small group of Bangladeshis and a British physiotherapist, Valerie Taylor which is situated in Savar but it has many branches over the Bangladesh such as Mirpur, Gonokbari, Chittagong, Sylhet, Rajshahi, and Barisal. Beside this CRP have outdoor facilities for person with disabilities like- pediatric unit, neuromusculoskeletal unit, stroke rehabilitation unit, sports injury unit and hand therapy unit etc.

The Occupational Therapy Outpatient Unit and Stroke Rehab unit in both Savar and Mirpur has been providing service to stroke survivors for many years. In CRP-Savar, every year large number among total patients is stroke survivors who come to have

rehabilitation from Occupational Therapy outpatient unit. Also in CRP-Mirpur many stroke survivors come to the outpatient unit and some are admitted to stroke rehab unit (Inpatient service). However in CRP-Savar stroke rehab unit provide service as outpatient service. Different types of individual therapy and group therapy are provided in these units. In stroke rehab unit Physiotherapists and Speech & language therapists work together with Occupational Therapists. There is also an academic side to CRP 'Bangladesh Health Professions Institute (BHPI)' affiliated by Dhaka University where three departments: Occupational Therapy, Physiotherapy and Speech & language Therapy are run.

Methodology of the study is usually discussed about the following aspects: study design, setting, participants & sampling procedure, measuring instruments, field test of Caregiver Burden Scale, data collection procedure & technique, variable, data analysis, ethical issues, reliability and validity, dissemination of the result.

3.1. Study Design

Cross sectional study design was used for this study. Cross-sectional studies are carried out at one time point or over a short period. Data can also be collected on individual characteristics including exposure to risk factors, along with information about the outcome. In this way cross-sectional studies provide a ‘snapshot’ of the outcome and the characteristics associated with it, at a specific point in time. The purpose of the study is descriptive. Usually there is no hypothesis as such, but the aim is to describe a population or a subgroup within the population with respect to an outcome and a set of risk factors (Levin 2006, p.24).

The purpose of this study is to find out the level of burden of caregivers of stroke survivors at present. Data has been collected from caregivers within three months which was collected at one time. In this present study the researcher has also to investigate associations between level of burden and demographic factors of the respondents and stroke survivor. Cross sectional studies are useful to identify associations that can then be more rigorously studied using a cohort study or randomized controlled study (Mann 2003, p.57).

For this reason the researcher found the cross-sectional study design is best suitable for her study.

3.2. Study Area

The Centre for the Rehabilitation of the Paralyzed (CRP) was established in 1979 by a group of therapists. CRP is a non-government organization (NGO) which treats and rehabilitates people with disabilities regardless of their socio-economic means and aims to improve the quality of life of people with disability in Bangladesh. CRP has many branches over the Bangladesh. In CRP-Savar and CRP-Mirpur there has an Occupational Therapy outpatient unit and stroke rehabilitation unit which provide

services to stroke survivors and other neurological condition's patient. In CRP-Mirpur there has a residential program in stroke rehab unit whereas in CRP-Savar stroke rehab unit serves outpatient service. The study was conducted in occupational therapy outpatient unit and stroke rehab unit of CRP-Savar and CRP-Mirpur. Because CRP is working for rehabilitation of people with disabilities and in CRP stroke survivor come to take treatment from different division and area of Bangladesh. So, they may be the representative of whole Bangladesh.

3.3. Participants

3.3.1. Study population

The study population was Bangladeshi caregivers of stroke survivors who have at least 1 month experience of taking care of the client and who were come to CRP within 3.5 months (Mid-August, 2013- November, 2013), who had no communication problem or other chronic diseases.

3.3.2. Inclusion criteria

- Caregivers who provided care to the stroke survivors at least for 1 month after stroke and who were continuing providing care at home and at CRP.

Because different studies found that caregivers face no burden in the first few weeks of providing care and in this time they feel more comfortable to care their relatives but when they continue providing this care for a month long then this responsibilities seem unbearable for the caregiver and feel burden to continue this caring. When the duration of caregiving is increased the caregivers are faced with more burdens stated Grant et al. (2004, p.109-110).

- Caregiver who had no difficulties in communication. If caregiver has communication problems like speech and language disorder, then they may not be able to provide appropriate information.

3.3.3. Exclusion criteria

Caregivers who were suffering from severe/chronic illnesses. It may act as a confounding factor to identify the caregiver burden if the caregivers already have any severe illnesses and they have possibility to feel more burdens in comparison with caregivers without any illnesses.

3.3.4. Sample size estimation

The researcher purposefully selected 151 caregivers and sample had been included as 2:1 ratio from CRP-Savar and CRP-Mirpur.

3.3.5. Sampling procedure

The sample was selected through purposive comprehensive sampling. The procedure was to include all of caregivers of stroke survivor actually who met the inclusion and exclusion criteria. The researcher has explained to every participant about the research aim, objectives. The researcher has included a sample of those who have willingly participated in this research. The researcher has selected participants in the purposive way for her study purpose.

3.4. Field Test of Caregiver Burden Scale

Before starting the collection of data the researcher accomplished the field test with the participants. The questionnaire was adapted from the Solve Elmstahl (1996) which is originally developed by Oremark for assessing the level of caregiver burden of caregiver of disabled people. To make the questionnaire feasible researcher has translated the main questionnaires in Bengali by five different people. The researcher has informed the participants about the aim and objectives of the study. Then the researcher has performed field testing with four to five caregivers of stroke survivors. It has been conducted to check the appropriateness of wording as well as easiness of understanding.

3.5. Data collection

3.5.1. Data collection technique

Researcher has been conducted face to face interview through a structured questionnaire to collect information from the caregivers about their level of burden. Through the face to face interview the researcher developed rapport with the caregiver which can help to collect accurate or appropriate data/information. According to Baily (1997, p.96) *“Interview conducted face to face are more innovative allowing the interviewer to interact directly and develop rapport with the interviewee”*.

3.5.2. Data collection procedure

At first the researcher took permission from the Head of the Occupational Therapy Clinical department of both Savar-CRP & Mirpur-CRP to collect data from Occupational Therapy unit and Stroke Rehab Unit. After that the researcher collected the patient schedule of stroke patients from the unit In-charge and then made a daily potential participant list to check the inclusion criteria. Before collecting data the participant were given information sheets and consent forms which was explained by the researcher. Participant had opportunity to ask questions and they signed the consent form after being satisfied. Then the researcher collected the demographic information from the participants. Once it had been completed the researcher completed the 'Caregiver Burden Scale' questionnaire through face to face interview. Through this face to face interview the interviewer had a chance to understand the nonverbal cues given by the interviewee who may indicate confusion or lack of understanding. The interviewer helped the interviewee to understand the questions by changing some words with the same meaning as stated Bailey (1997, p.96). The entire interview was conducted in Bengali whereas questionnaire was translated into Bengali following WHO guidelines for translation. The researcher explained the question into local language that was helpful to the participant.

3.5.3. Data collection Instruments/Tools

- A self-demonstrated demographic questionnaire was used to collect data from the participant. Caregiver's Age, Sex, Occupation, Marital status, Relationship with stroke survivor, caregiving hours & duration and also stroke survivor's Age, Sex, Occupation, Marital status, onset of stroke were included in demographic questionnaire to show association with level of caregiver burden.
- A Standardized questionnaire/tool named "Caregiver Burden Scale" was also used to collect information about caregiver burden from the participants. Data was collected through this Novel Caregiver Burden Scale which was adapted from Solve Elmstahl (1996). To make a feasible questionnaire the researcher has translated the main questionnaires in Bengali by five different persons following by WHO guideline for translation then made a standard one by cross checking then it was checked by a linguistic expert. The Caregiver Burden Scale was used to assess subjective burden. The scale was modified from a scale designed by Oremark for assessment of caregivers of chronically ill

persons. The scale has 22 items and all scored from 1 to 4 (Not At All, Seldom, Sometimes, Often) covering areas like the caregiver's health, feeling of psychological well-being, relations, social network, physical workload, and environmental aspects that might be important. The scale was divided into five indices-general strain, isolation, disappointment, emotional involvement, and environment (Solve et al. 1996, p.178). Higher scores represent greater burden; lower scores represent minimal burden.

- Pen and Paper were used to write down the information/data.

3.6. Data analysis

The data were initially analyzed using Statistical Package of Social Science (SPSS) software version 17.0 and Microsoft excel spreadsheet, at a descriptive level. Caregiver Burden Scale and Demographic questionnaire were analyzed. Demographic factors were discussed such as age, sex, occupation, marital status, relationship, onset of stroke, caregiving duration and caregiving hours etc.

Caregiver Burden Scale discussed about the level of general burden and level of burden in five indices such as general strain, isolation, disappointment, emotional involvement and environment. Caregiver Burden Scale comprised of this five indices where general strain comprised of questions no. 1, 3, 4, 5, 7, 10, 14 and 19; Isolation comprised of question 8, 12, 22; Disappointment (question 2, 13, 18, 20, 21); Emotional Involvement (6, 11, 16) and environment comprised of question no. 9,15,17. Total Caregiver Burden Scale questionnaire score is 88 ranges from 22-88 and in case of five domain/indices the minimum general strain score is 8 and maximum is 32, isolation ranges from 3-12, disappointment 5-20, emotional Involvement 3-12 and environment 3-12 but numerical average for the specific domain and overall burden has been used to interpret data or analysis. Total Caregiver Burden Score has been divided by three categories low burden (mean score 1.00-1.99), Moderate burden (mean score 2.00-2.99) and High burden (mean score 3.00-4.00). After collecting data the researcher categorized the questionnaire into these domains; general strain, Isolation, disappointment, emotional involvement and environment.

Researcher categorized the age into seven groups such as 18-24 years, 25-30 years, 31-35 years, 36-40 years, 41-45 years, 46-50 years and 50+ years among both the caregiver and stroke survivor. Marital status categorized by married and others.

Occupation of caregiver and stroke survivor was categorized by housewife, teacher, service holder, businessman, student and others and relationship was categorized by wife, mother, daughter, sister, husband, son, brother, father, paid caregiver and others.

Caregiving duration and onset of stroke was categorized by 1-5 months, 6-11 months, 12-36 months, 37-72 months and 73-120+ months. Also caregiving hours was categorized by 4-6 hours, 7-9 hours, 10-12 hours, 13-15 hours, and 16-19≤ hours in per day.

A Pearson Chi-square test was done to show association between level of caregiver burden and both caregiver's & stroke survivor's age, sex, occupation; caregiver relationship with stroke survivor, onset of stroke, caregiving duration. A significant association has been regarded when probability value was less than 0.05 ($P < 0.05$). Study also showed level of burden of caregiver in general strain, isolation, disappointment, emotional involvement and environment. Firstly the researcher found the results by SPSS software then result was presented through the pie chart, bar chart, column etc. Descriptive data are presented as proportions, means as appropriate. Results were also discussed and presented through figures and tables as applicable.

3.7. Ethical consideration

The researcher took permission from the ethical committee of Bangladesh Health Professions institute (BHPI) an academic institute of Centre for the Rehabilitation of the Paralyzed (CRP) to do the study and also took approval from supervisor and head of the department, Department of Occupational therapy, BHPI. Researcher also took permission from Solve Elmstahl for using 'Caregiver Burden Scale' and used the translated version for this study. Then permission took from the Head of the Department of Occupational therapy service in both CRP-Savar and CRP-Mirpur for data collection from the caregiver. A written consent form had been signed by each participant who was interested to participate in the study and informed verbally about the topic and purpose of study. The researcher assured them that their personal identity will be kept confidential and all the documents were kept in a safe place

where only the researcher will have access. The researcher maintained ethical consideration in all aspect of the study. The researcher ensured that the service of patient will not be hampered by participants in this study. Subjects had full right to withdraw themselves from the study at any time without hesitation. All rights of the participant would be reserved and researcher is accountable to the participant to answer any type of study related question. Researcher also ensured that would not cause any harm or benefited to them but in future caregiver of stroke survivor may benefit from the study.

3.8. Reliability and Validity

- The ‘Caregiver Burden Scale’ is valid and reliable instrument to assess caregiver burden (Solve et al. 1996, p.177).
- The ‘Caregiver Burden Scale’ was individually discussed with each participant and full time for questions were given to them prior to complete the questionnaire.
- Caregiver Burden Scale requires only 10-15 minutes time to complete.
- ‘Caregiver Burden Scale’ is perfect for assessing burden of caregiver of stroke survivor (Solve et al. 1996, p.178).

3.9. Dissemination of result

This is academic research which was done to complete the degree of B. Sc. in Occupational Therapy. The research will be published in the Library of the Academic Institute named BHPI Library and a copy will go to occupational therapy department in both Savar-CRP & Mirpur-CRP.

Socio-demographic Characteristics of the Caregiver:

Demographic data of caregiver and stroke survivor are listed in Table-1. The Table shows that among 151 participants, most of the participants were (66.9%) female (n=101) and 33.1% were male (n=50) where 74.8% (n=113) were married, 23.2% (n=35) were unmarried or single, 1.3% (n=2) were widow and only one participant was divorcee.

In case of caregiver age most of the caregiver's age ranges were from 18-24 years and mean age was 36.41 years and the Table-1 describes 19.9% (n=30) were of 18-24 years, 17.2% (n=26) were of 25-30 years, 13.2% (n=20) were of 31-35 years, 13.2% (n=20) participants age were of 36-40 years, 13.2% (n=20) were 41-45 years, 16.6% (n=25) were of 46-50 years and 50+ years of participants were 6.6% (n=10).

Regarding their relationship with stroke survivor, most of the caregivers were wife (36.4%, n=55), 13.9% (n=21) were daughter, 10.6% (n=16) were son, 8.6% (n=13) were paid caregiver, 7.9% (n=12) were husband, 5.3% (n=8) were mother, 6.6% (n=10) were brother, 2.6% (n=4) were sister and 7.9% (n=12) had other relationship such as nephew (n=3), daughter-in-law (n=5), grand-child (n=2), sister-in-law(n=1), brother-in-law (n=1) with stroke survivor (Table-1).

Among all the participants (n=151), 58.9% (n=89) were housewife, 11.3% (n=17) were student, 8.6% (n=13) were businessman, 2.6% (n=4) were teacher, service holder were 4.6%(n=7) and 13.8% (n=21) had other occupation such as farmer 2.6%, driver 1.3%, day laborer also 1.3%, only one participant was lawyer & unemployed 9.9% (Table-1).

Most of the participants 60.9% (n=92) were providing care about 1-5 months, 19.2% (n=29) were providing care about 6-11 months, 13.9% (n=21) 12-36 months, 2.6% (n=4) 37-72 months, 3.3% (n=5) 73-120 months and mean duration was 11.28 months (Table-1).

Table-1 also shows that most of the caregivers (41.7%, n=63) provided 16-19 hours and more care to their relative/stroke survivor per day where mean hours was 13.74 hours, 21.9% (n=33) provided total 10-12 hours of care per day, 21.2% (n=32) provided 13-15 hours of total care, 13.2% (n=20) provided care about 7-9 hours in a day and 2% (n=3) provided care about 4-6 hours in every day.

Socio-demographic Characteristics of the stroke survivor:

Among 151 stroke survivor, most were male than female and Table-1 shows 100 stroke survivors (66.2%) were male where female were 51 (33.8%). Most of the stroke survivor were married, few were widow both female & male and very few survivors were single and the Table-1 presented 76.8% (n=116) were married, 3.3% (n=5) were single, 10.6% (n=16) were widow (female) and 9.3% (n=14) survivors were divorcee.

Regarding to survivors age, most of survivor's age were above 50 years (43%, n=65), 3.3% (n=5) survivor was of 18-24 years, 25-30 years of were 2% (n=3), 31-35 years of were 7.9% (n=12), 36-40 years of were 6.6% (n=10), 41-45 years of were 9.3% (n=14) and 46-50 years of survivors were 27% (n=42) and mean age was 51.97 years.

In respect with stroke survivor's occupation, 31.1% (n=47) survivors were housewife where 20.5% (n=31) were businessman, 17.9% (n=27) were service holder, 5.3% (n=8) were teacher, 1.3% (n=2) were student and 23.8% (n=36) survivors had some other occupation such as farmer, day laborer, driver, retired person (Table-1).

In terms of duration of having stroke, 49.7% (n=75) survivors had been affected by stroke for 1-5 months whereas 24.5% (n=37) were for 6-11 months, 19.9% (n=30) were for 12-36 months, 2.6% (n=4) were for 37-72 months and 3.3% (n=5) had been affected for 73-120 months and mean duration was 12.29 months (Table-1).

Table-1 Characteristics by Socio-demographic factors and care information of the Caregivers (n=151) and stroke survivors at CRP, Bangladesh.

Parameters	Caregivers n=151, %	Stroke Survivors n=151, %
Age		
18-24 years	30(19.9%)	5(3.3%)
25-30 years	26(17.2%)	3(2%)
31-35 years	20(13.2%)	12(7.9%)
36-40 years	20(13.2%)	10(6.6%)
41-45 years	20(13.2%)	14(9.3%)
46-50 years	25(16.6%)	42(27.8%)
50+ years	10(6.6%)	65(43%)
Mean Age(\pm SD*)	36.41 \pm 11.56	51.97 \pm 11.84
Sex		
Female	101(66.9%)	50(33.8%)
Male	50(33.1%)	100(66.2%)
Occupation		
Housewife	89(58.9%)	47(31.1%)
Teacher	4(2.6%)	8(5.3%)
Service Holder	7(4.6%)	27(17.9%)
Businessman	13(8.6%)	31(20.5%)
Student	17(11.3%)	2(1.3%)
Others	21(13.8%)	36(23.8%)
Marital Status		
Married	113(74.8%)	116(76.8%)
Others	38(25.2%)	35(23.3%)
Relationship		
Wife	55(36.4%)	----
Mother	8(5.3%)	----
Daughter	21(13.9%)	----
Sister	4(2.6%)	----
Husband	12(7.9%)	----
Son	16(10.6%)	----
Brother	10(6.6%)	----
Paid Caregiver	13(8.6%)	----
Others	12(7.9%)	----
Caregiving Duration		
1-5 months	92(60.9%)	----
6-11 months	29(19.2%)	----
12-36 months	21(13.9%)	----
37-72 months	4(2.6%)	----

73-120+ months	5(3.3%)	----
Mean \pm SD	11.28 \pm 17.95	
Daily Caregiving Hours		
4-6 hours	3(2%)	----
7-9 hours	20(13.2%)	----
10-12 hours	33(21.9%)	----
13-15 hours	32(21.2%)	----
16-19 & more hours	63(41.7%)	----
Mean \pm SD	13.74 \pm 4.31	
Onset of stroke		
1-5 months	----	75(49.7%)
6-11 months	----	37(24.5%)
12-36 months	----	30(19.9%)
37-72 months	----	4(2.6%)
73-120+ months	----	5(3.3%)
Mean \pm SD		12.29 \pm 18.4

Caregiving burden:

The study examined the caregiver burden using Caregiver Burden scale which consist five domains. This scale analyzed the total caregiving burden as well as its five domains- general strain, isolation, disappointment, emotional involvement and environment.

Overall caregiver burden:

Analyzing Caregiver Burden scale the researcher found out the overall burden. Table-2 shows that most (78.8%, n=119) of the caregivers of stroke survivor have moderate burden, where as a significantly small percentage (12.6%, n=19) of caregivers have higher burden and only 8.6% caregivers have low burden respectively (Figure-1)

Figure-1: Level of caregiver burden

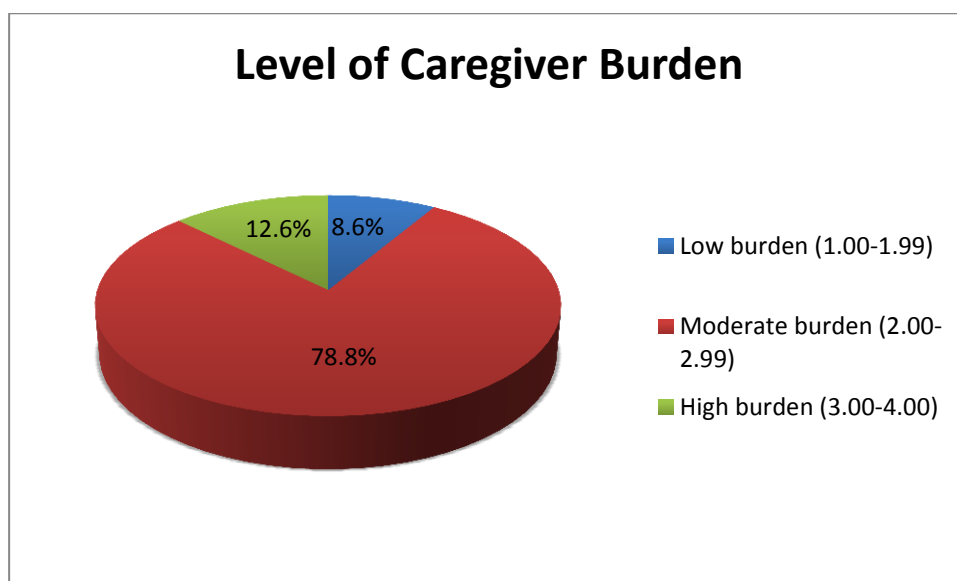


Figure-1: Level of caregiver burden

General strain:

Respectively half of the caregiver mentioned moderate burden in case of general strain where one third of the caregiver were reported higher burden in this domain and only small proportion of the caregiver reported low burden. Table-2 shows that 58.9% (n=89) were faced moderate burden in case of general strain, 37.7% (n=57) were faced higher burden and 3.3% (n=5) were faced low burden in general strain (Figure-2).

Isolation:

Table-2 shows more than half of caregivers (63.65%, n=96) felt moderate burden of being isolated, at least one third (27.2%, n=47) felt high burden of being isolated and a small number (9.3%, n=14) of caregiver thought low burden of being isolated (Figure-2).

Disappointment:

Respectively a difference had been observed in disappointment. More than half (60.3%, n=91) of caregiver reported higher disappointment where a significantly little number (2%, n=3) of caregivers were in low level of disappointment and the rest of them (37.7%, n=57) were in moderate level of disappointment (Figure-2).

Emotional involvement:

Table-2 presents that 59.6% (90 caregivers) were faced low emotional burden regarding to the care for their stroke survivors, 30.5% (46 caregivers) were faced moderate emotional burden and 9.9% (15 caregivers) were faced higher emotional burden during caring for their relatives (Figure-2).

Environment:

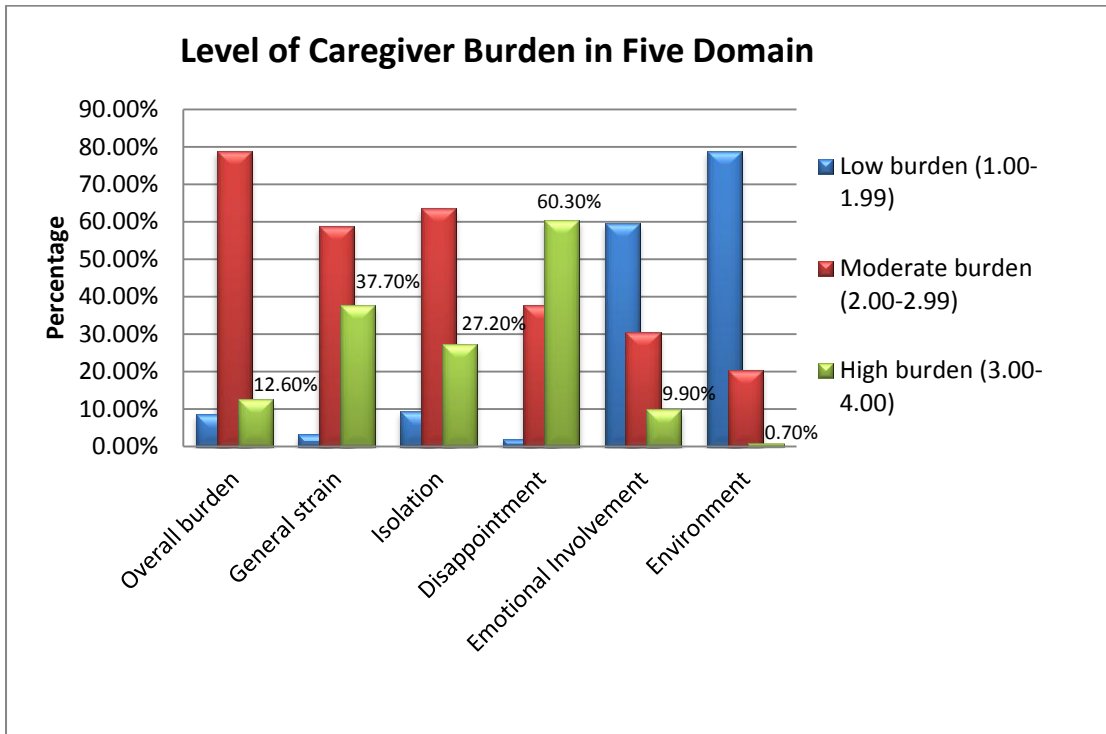
A large number of caregivers faced low burden regarding the environment when caring for their relatives. Table-2 shows 78.8% (n=119) caregivers faced low environmental burden, 20.5% (n=31) faced moderate burden from environment and only one caregiver (0.7%) was faced high environmental burden during providing care for his/her near ones (Figure-2).

Table-2: Prevalence of overall burden and different domains of caregiver burden by level of burden among caregivers of stroke survivors at CRP-Savar and CRP- Mirpur, Bangladesh.

Component	Low	Moderate	High
	Burden(1.00 - 1.99)	Burden(2.00 - 2.99)	Burden(3.00 - 4.00)
	N=151 (%)	N=151 (%)	N=151 (%)
Overall burden(2.04±0.460)*	13(8.6%)	119(78.8%)	19(12.6%)
General strain(2.34±0.542)	5(3.3%)	89(58.9%)	57(37.7%)
Isolation(2.19±0.593)	14(9.3%)	96(63.6%)	47(27.2%)
Disappointment(2.58±0.534)	3(2%)	57(37.7%)	91(60.3%)
Emotional Involvement(1.5±0.672)	90(59.6%)	46(30.5%)	15(9.9%)
Environment(1.22±0.43)	119(78.8%)	31(20.5%)	1(0.7%)

*(Mean ± SD)

Figure-2: Level of burden among caregiver of stroke survivors in five domains



Association between level of burden and Caregiver’s & stroke survivor’s socio-demographic characteristics:

In the following Table-3 shows the association between level of burden and demographic characteristics of the caregiver & stroke survivor. A Pearson Chi-square test was performed to show association between these variables. Regarding to caregiver age, $X^2 (12, N=151) = 27.872, P = 0.006$, there was significant association between caregiver age and level of burden and burden increases with the increases of caregiver age. Table-3 shows from 18-24 years only 5.3% (1 caregiver) were faced higher burden which gradually increased with caregiver age and from 50+ years 26.3% (n=5) caregivers of total 19 caregivers were faced higher burden.

Also there was strong association between caregiver sex and level of burden, $X^2 (2, N=151) = 12.42, p= 0.002$ and female were faced more burden than male (Table-3).

Also caregiver occupation was significantly associated with the level of caregiver burden, $X^2 (10, N=151) = 18.982, p= 0.04$ where housewives were faced higher burden than others. Regarding to the relationship with stroke survivor there was

significant association with caregiver burden, $X^2 (16, N=151) = 28.696, p= 0.026$ that means burden were increased according to nature of relationship among caregiver and stroke survivor and closer relatives were faced less burden

In case of total caregiving hours in a day, $X^2 (8, N=151) = 20.439, p= 0.009$ that means there was a significant association between caregiving hours and caregiver burden which was increased with time as shown in Table-3.

In case of stroke survivors characteristics, there is no significant association between survivors age, $\{X^2 (12, N=151) = 12.789, p= 0.385\}$, sex $\{X^2 (2, N=151) = 0.732, p= 0.625\}$ but have a strong association with duration of having stroke and burden was increased with stroke duration $\{X^2 (8, N=151) = 39.297, p= 0.000\}$. Also a strong association has been found between caregiving duration and level of caregiver burden, $X^2 (8, N=151) = 38.199, p= 0.000$ (Table-4).

Table-3: Association between caregiver's socio-demographic factors and level of caregiver burden among caregivers of stroke survivors at CRP, Bangladesh.

Parameters	Level of caregiver burden			Total	X ² Value	P-value
	Low Burden n=13,	Moderate Burden n=119,	High Burden n=19,			
Caregiver age						
18-24 years	2	27	1	30	27.872	0.006
25-30 years	5	19	2	26		
31-35 years	3	17	0	20		
36-40 years	1	15	4	20		
41-45 years	0	18	2	20		
46-50 years	2	18	5	26		
50+ years	0	5	5	10		
Caregiver sex						
Female	6	76	19	101	12.420	0.002
Male	7	43	0	50		
Caregiver Occupation						
Housewife	5	66	18	89	18.982	0.040
Teacher	0	4	0	4		
Service Holder	2	5	0	7		
Businessman	1	12	0	13		
Student	1	16	0	17		
Others	4	16	1	21		
Relationship with stroke survivors						
Wife	1	41	13	55	28.696	0.026
Mother	0	6	2	8		
Daughter	3	17	1	21		
Sister	1	3	0	4		
Husband	0	12	0	12		
Son	2	14	0	16		
Brother	2	8	0	10		
Paid caregiver	1	9	3	13		
Others	3	9	0	12		
Caregiving hours/day						
4-6 hours	2	1	0	3	20.439	0.009
7-9 hours	3	16	1	20		
10-12 hours	4	23	6	33		
13-15 hours	1	25	6	32		
16-19≤ hours	3	54	6	63		

Table-4: Association between level of caregiver burden and stroke survivor's demographic factor & caregiving duration among caregivers of stroke survivors at CRP, Bangladesh.

Parameters	Level of caregiver burden			Total	X ² Value	P-value
	Low Burden n=13	Moderate Burden n=119	High Burden n=19			
Stroke survivors age						
18-24 years	0	5	0	5	12.789	0.385
25-30 years	0	3	0	3		
31-35 years	3	7	2	12		
36-40 years	0	9	1	10		
41-45 years	0	14	0	14		
46-50 years	5	31	6	42		
50+ years	5	50	10	65		
Survivors sex						
Female	5	41	5	51	0.625	0.732
Male	8	78	14	100		
Onset of stroke						
1-5 months	13	59	3	75	39.297	0.000
6-11 months	0	31	6	37		
12-36 months	0	25	5	30		
37-72 months	0	3	1	4		
73-120+months	0	1	4	5		
Caregiving Duration						
1-5 months	12	76	4	92	38.199	0.000
6-11 months	1	21	7	29		
12-36 months	0	19	2	21		
37-72 months	0	1	3	4		
73-120+ months	0	2	3	5		

5.1. Socio-demographic characteristics of the caregiver:

Socio-demographic characteristics are a strong predictor of perceived caregiver burden and sex is an important factor of socio-demographic characteristics. Regarding the socio-demographic status this study findings is similar to other study findings. This study finding revealed that 66.9% (n=101) caregivers were female and 33.1% (50 caregivers) were male. Several studies have been done on stroke caregiver and they found similar findings as Reimer et al. (1998, p.1607) reported in their study that 77% caregiver were female and Das et al. (2010, p.2976) reported caregiver were younger and more commonly women (86%) in their study. Also Chow et al. (2007, p.137) reported 59.1% caregivers were female while Anderson et al. (1995, p.847) reported 82% of their study were female caregivers. Females are more commonly devoted for managing household works and for caring family members thus most of the caregivers were female in comparison with male.

In this study, it was also found that the most of the caregivers were middle aged (mean age 36.41 years) and majority (19.9%) of the caregivers were of 18-24 years. Also most of the caregiver's age group was similar to other group. Previous studies had been said different things. As one study finding revealed that the vast majority of family caregivers are female and middle aged according to National Alliance for Caregiving and the American Association for Retired Persons, 1997 (cited in Bookwala & Schulz 2000, p.607) and also Das et al. (2010, p.2967) found in their study in India that mean age of caregiver was 42.5 years where Anderson et al. (1995) found that caregiver ages ranged from 30 to 80 years (mean, 58 years) and Suh et al. (2004, p.614) found caregivers mean age was 44.61years. Also Chumbler et Al. (2004, p.948) stated caregivers mean age was 59.9 years. In Bangladesh caregivers are any member of the family or outside of the family rather than spouse only in comparison with other country where commonly spouses are main caregiver. Thus caregiver age differed from other study.

Marital status is another important component of socio-demographic factor. By this study total 74.8% (n=113) were married and rest of the caregiver were never married,

widow and divorcee. Study on stroke caregiver revealed similar findings as Rigby et al. (2009, p.154) reported 88.4% caregiver were married, 11.6% were not married. Huges et al. (1999, p.538) reported majority (72.9%) of the caregiver were married and Suh et al. (2004, p.614) mentioned 77.8% caregiver were married.

In regard to caregiver occupation, most of the caregivers (58.9%) in this study were housewives. In this study most of the caregivers were female and in Bangladesh usually female are less engaged with any outside occupation, they usually are housewives. Das et al. (2010, p.2967) reported similar things on their study that 71% of the caregivers were housewife, 24% of were in services and rest of them were retired & unemployed.

The caregiver relationship with stroke survivor is also an important factor for determining burden. In this study most of the caregivers were wife (36.4%), daughter (13.9%), son (10.6%), and paid caregiver (8.6%) respectively. Pervious findings revealed similar things as Rigby et al. (2009, p.154) reported regarding relationship 44.6% were wife, 18.9% husband, 25.7% daughter. Also Huges et al. (1999, p.538) reported majority of the caregiver (55.3%) were spouses, 17.9% were child and 15.1% other relative. Mackenzie et al. (2007, p.114) reported that the majorities of caregiver were spouses (57%) and other caregiver relationships were daughters (19%), sons (5%), mothers (5%) and daughter in law (12%) and Chow et al. (2007, p.137) reported approximately half of the caregivers were the spouses who accounted for 54.5% for their study. In Bangladesh family bonding is strong than western country and the entire family member are eager to provide care though they have or have not spouses.

Caregiving duration also is an important predictor of burden. Current study finding revealed most of the (60.9%, n=92) caregivers were providing care for 1-5 months (mean 11.29 months). A study of Kamel et al. (2012, p.149) on stroke caregiver revealed that the median duration of caregiving was 12 months, ranging from 3 to 96 months (8 years) on their study. Also long term caregiving is a dynamic process, burden changes over time. During 1st months caregiver may not feel significant burden, it can change overtime.

Another important component of socio-demographic factor is caregiving hours in a day which predicts caregiver burden. Current study findings stated that vast majority

of the caregivers (41.7%) provided at least 16-19 hours care and more in a day to their stroke survivors where only 2% spent 4-6 hours for care and rest of the caregivers were spent similar hour for care between in these hours group and mean caregiving hours was 13.74 hours. This finding were similar to another study as Choi-Kwon et al. (2005, p.1044) stated that in South Korea, caregivers spent more than 15 hours of caregiving a day to their survivors. Current findings which differed from some other study as Elmastahl et al. (1996, p.179) reported the mean weekly time of caregiver assistance was less than 10 hours for half of the caregivers and spouse caregivers were spent more time than other caregivers and their relatives. Also Kamel et al. (2012, p.149) mentioned that caregivers reported that they spent 4.15 hours each day assisting stroke survivors in their ADLs. In Bangladesh, culturally a person is dependent on their family member for care and when they get ill. Also caregivers of that ill family member always stand for the survivors when they need help which supposed to greater hours.

5.2. Socio-demographic characteristics of the stroke survivor:

The present study exposed that majority of the stroke survivors were male (66.2%) and this finding is similar to previous study findings as Reimer et al. (1998, p.1607) reported in their study that most patients were male (77%) and Huges et al. (1999, p.538) reported half of the stroke survivors were men. Kao & McHugh (2004, p.125) reported 51 % of those care recipient were male and 49% female.

Regarding stroke survivor's age in this study, it was found that most of the stroke survivor's age was 50+ years where mean age was 51.97 years. In similar with this finding Suh et al. (2004, p.614) reported that patient mean age 56, ranged from 36 to 82 years and nearly 70% of the patients were over 50 years of age on their study. Huges et al. (1999, p.538) reported survivors mean age 70.8 years and McCullagh et al. (2005, p.2183) reported the mean age of patients was 74 years. Kamel et al. (2012, p.149) reported that the 116 stroke survivors ranged from 38 to 100 years of age, with a mean age of 68 years. In Bangladesh person's average life expectancy is 66.8 years (BBS, 2011) and they get ill from early age may be due to lack of awareness about healthy lifestyle and illiteracy of people so that mean age of stroke survivors vary from other country.

Although the stroke survivor's marital status was not related to burden but it is an important factor of socio-demographic characteristics and this study found that most of the survivors (76.8%) were married and rest were widow and single. Traditionally Bangladeshi people care to their family member whether they are spouse or not due to strong family bonding. Another study on stroke caregivers exposed similar things that Suh et al. (2004, p.614) reported that a large majority of the stroke survivors were married (77.8%). Kamel et al. (2012, p.149) reported that majority of stroke survivor either married (56%) or widowed (40.5%).

The present study also found that most of the stroke survivors (31.1%) were housewife and in case of male survivor most of were businessman (20.5%), service holder (17.9%) and others (23.3%) were retired person, farmer, day laborer. Several studies revealed similar findings. Suh et al. (2004, p.614) reported that majority of stroke survivor (76.0%) of their study were not working. Das et al. (2010, p.2967) reported on their study that 50% were housewife, service holder 19%, retired 26% and unemployed 5%.

Stroke survivor's onset of stroke is also a powerful predictor of perceived burden. This study finding revealed that a most of the stroke survivors (49.7%) were having stroke for 1-5 months and rest of the survivors were for 6-11 months and 12-36 months where mean duration of stroke attack was 12.29 months. In similar to this finding Suh et al. (2004, p.614) reported that the mean duration of first stroke attack was 11.8 months but Das et al. (2010, p.2967) reported on their study the mean duration of stroke attack was 46.57 months.

5.3. Level of burden of caregiver of stroke survivor:

Data on caregiver burden assessed by the Caregiver Burden Scale (CBS) indicate there is a wide variation in the five main domains among caregivers of stroke survivor.

The findings from this study showed that the results indicated level of burden about general strain, isolation, disappointment, emotional involvement, environment and socio demographic data. The Caregiver burden scale indicated that a higher score means a higher burden and lower scores means less burden. In this situation the researcher found the result in the five main aspects such as general strain, isolation,

disappointment, emotional involvement and environment are different in level of burden. In this research total level of higher burden rate is only 12.6%, moderate burden rate is 78.8% and lower burden rate is 8.6%. So, from this study researcher could be said that most of the caregivers faced moderate level of burden. However, few studies have been observed higher level of burden among caregiver of stroke survivor. King & Semik (2006, p.41) stated in their studies that caregivers of stroke survivors report high levels of stress and burden. Han & Haley (1999, p.1478) stated that family caregiver of the stroke survivors have potentially high burden and Greveson et al. (1991, p.340) stated that caregiver experiences higher level of burden. Also Reimer et al. (1998, p.375) found that relatively high mean burden among stroke caregivers where McGullah et al. (2005, p.2183) estimated moderate burden among stroke caregiver. Culturally Bangladeshi people feel emotional and they are eager to take care of their relatives. So they don't ever see it as a burden. Also in Bangladesh sometimes an ill person is cared for by multiple caregiver or family members rather than a single person so it may seem to lessen the burden level. Most of the caregivers of this study were provided care to their relatives for 1-5 months which supposed to create fewer burden because caregiving burden are increased over time.

5.3.1. General strain:

The caregivers of stroke survivors who care for their relatives have moderate caregiver burden score. Half of the caregivers (58.9%, n=89) have moderate burden regarding general strain and 37.7% (n=57) percent have higher level of general strain where only 3.3% (n=5) have low level of general burden. This finding is slightly different from another study (Haley et al. 2009, p.2131) which found overall levels of strain, 44% of caregivers reported no strain, 41.33% reported some strain, and 14.67% reported a lot of strain. Where Ory et al. (1999, p.180) stated in terms of physical strain, overall, caregivers reported a moderate degree of strain. Bangladeshi people cordially accept an ill family member and due to having a strong family relationship stroke survivors are cared by not only a single person. All members of the family are devoted to take care of the survivor in need and generally exhibit fewer burdens which are expected. Also there is an important aspect to consider that burden is also dependent on caregiving duration. This study discover most caregiver of stroke survivor explicit moderate level of general strain but also a remarkable number of caregiver have higher level of strain in general where most of were female, housewife

and have spousal relationship. Elmastahl et al. (1996, p.179) mentioned in their study that type of relationship was correlated with greater level of general strain. It is also a breaking point that caregiver who has moderate strain are at risk to have higher in general strain over longer period of time.

5.3.2. Isolation:

Isolation is also an important domain of caregiving burden. When a member within the family becomes ill other members have to give attention to him/her even though they have already so much family responsibility. When a caregiver tries to balance both responsibilities they have to be deprived from other responsibilities and time from own self thus it leading so much isolation. This study identified that 63.6% (n=96) caregivers were moderate level of isolation and about 27.2% (n=47) caregivers were higher isolated where age of the caregiver were have similar distribution in all age groups. It is also found that female, in relationship who were wife, daughter and paid caregiver exhibit greater isolation than male caregiver and Elmastahl et al. (1996, p.179) stated that spouses were experienced greater isolation than other caregiver. Schulze et al. (1988, p.140) stated that caregivers experience unacceptably high levels of burden, leading to isolation and exhaustion. Also caregiver isolation leads to poor quality of life of stroke survivor. Elmastahl et al. (1996, p.179) mentioned in their study that poor quality of life among patients was positively correlated to caregivers burdens for isolation and emotional involvement.

5.3.3. Disappointment:

Disappointment also is an important factor of caregiver burden. In this research surprising result was found about disappointment. More than half of the caregivers (60%, n=91) have higher level of disappointment who were female (housewife) and their relationship was wife, daughter and husband. That means caregivers who have closer relationship with stroke survivor exhibit greater disappointment. This finding was similar as in the study of Elmastahl et al. (1996, p.179) and there he mentioned that caregiver relationship was correlated with caregiver disappointment and spouses are experienced higher level of disappointment than other caregivers. In this study it was revealed that among the five domains of Caregiver Burden Scale, participants are highly disappointed than other domain. This may be due to most of the caregiver in

Bangladesh was family member and family members always worry for their ill family member. This leads to disappointment of that family member.

5.3.4. Emotional Involvement:

In this study, it was showed a different picture regarding emotional burden than other domain. This study found that more than half of the caregivers (60%, n=90) were faced with lower emotional burden where only 9.9% (n=15) caregiver faced higher emotional burden and rest of them have moderate burden regarding emotional involvement. But Ory et al. (1999, p.180) stated in terms of emotional strain caregivers reported a moderate degree of strain. Also Reimer et al. (1998, p.1608) found among 115 caregivers, 66 caregivers emotional status was very good where 34 caregivers have moderate emotional status and only 15 have very poor emotional status. But Anderson et al. (1995, p.843) found that caregiver of stroke survivor have higher degree emotional distress suggest that caregiver may have unmet needs. This study also revealed those only females who were housewives, wife in relationship and provided long periods of care explicit high emotional burden where in this study no male caregiver faced any emotional burden. Other research found that women caregivers to report more symptoms of emotional disorders than men caregivers (Vincent et al. 2009, p. 660; Bakas et al. 2006, p. 38; Tiegs et al. 2006, p.59; Berg et al. 2005, p.640; White et al. 2003, p.186; Dennis et al. 1998, p.1867). Reimer et al. (1998, p.1608) stated that caregiver unmet demands for psychosocial care and their emotional distress were related especially to higher levels of burden. Also caregiver emotional distress also may relate if the stroke survivors were depressed and become functionally dependent on caregiver. Dennis et al. (1998, p.1897) mentioned caregivers suffered more emotional distress if the patients had been dependent before their strokes and emotionally depressed themselves. In Bangladesh initially caregiver were not so emotionally depressed because in this time they become adjust with caregiving but when time elapses they become more emotionally depressed if there is no improvement of survivor's functional status.

5.3.5. Environment:

In comparison to the environment, the score was much lower, thus less important. This study findings shown that more than two-third of caregivers (78.8%) were have lower environmental burden where only one caregiver had higher environmental

burden and rest of them had moderate burden. Those who have moderate environmental burden were female (housewife), wife as relationship and provided long term care to the survivors. The researcher could say that the environment did not create so many burdens for caregiver. It may depend on several factors, may be the environment was more supportive for the caregiver or as there was not a fixed caregiver for the stroke survivors thus it may didn't create significant burden for caregiver. Also Bangladeshi people are so much hospitable and there also have a good relationship with neighbors and they always eager to help the caregiver and stroke survivors and this may decrease the caregiving burden regarding environment. Also Elmastahl et al. (1996, p.179) found caregivers to patients with an extrovert personality showed less burden, general strain, and influence of environment. So the researcher can say that caregivers of stroke survivors greater disappointed, moderately isolated from society and having strain in general where environment didn't create so burden for them and their emotional status during care was good when divided the burden into different domain. A better support system can minimize this breaking point.

5.4. Association between caregiver & stroke survivor's characteristics and caregiving burden:

This study set out to also show association in between level of burden and caregiver characteristics (age, sex, occupation, relationship with stroke survivor, caregiving duration, caregiving hours) and stroke survivor characteristics (age, sex, onset of stroke).

In respect with caregiver's age, this study showed that there was an association ($P=0.006$) between caregiver age and caregiver burden and it increases with increased age that means older caregiver experienced higher burden. But other research finding was reverse to this as Fitting & Rabins (cited in Huges et al. 1999, p.534) found that younger caregivers experience greater burden than older caregiver. Also Morrison (1999, p.266) stated caregiver burden at six months was predicted by caregiver age as older caregiver were less burdened. But Huges et al. (1999, p.539) stated that increased caregiver age was significantly related to decreased caregiver physical and emotional role functioning and McCullah et al. (2005, p.2183) mentioned that there was a negative correlation between caregiver age and increased caregiver burden.

This was happened because caregiver burden may differ from different society, cultures, familism and individualism according to Morimoto et al. (2003, p.222). In western country older people have their own caregiver rather than they were being a caregivers for ill person and they are facilitate from old care centre and Goldstein et al. (1981, p.27) suggested that in greater old age, roles may be less disturbed because there are fewer obligations to other family members in western country. But in Bangladesh both young and old are caregiver of their relatives and older caregivers also have to take care of own-self where patients also are totally dependent on caregiver. Older caregiver are physically less fit than younger caregivers and when older caregivers must care for their-self and stroke survivors, there is a higher burden for them.

Also caregiver sex is a strong predictor of caregiver burden as this study found strong association ($P = .002$) between caregiver sex and perceived burden where female exhibit higher burden than male caregiver. Several studies also discover similar findings. Ory et al. (1999, p.180) revealed women reported more physical and emotional strain than did men. Kao & McHugh (2004, p.124) stated that female caregivers had significantly higher scores on all five caregiver burden subscales than did male caregivers but Wu, Hu & Yao (cited in Kao & McHugh 2004, p.124) found no significant relationship between caregiver sex and caregiver burden. However, Wu et al. (cited in Kao & McHugh 2004, p.124) found that women explicit significantly higher scores on caregiver burden than men. Chiou (cited in Kao & McHugh 2004, p.124) also found that female caregivers experienced greater physical burden than male caregivers though the differences in emotional, social, and financial burden were not significant. All over the countries most of the caregivers were female and have higher burden may be due to female are more unstable physically, mentally/emotionally which push them into greater burden as other studies said, Bookwala & Schulz (2000, p.613) stated that male caregivers may be more physically able to assist their functionally disabled wife with the labor-intensive activities of heavy housework and using the toilet than are female caregivers to assist their husband. Skaff & Pearlin's (1992, p.662) found that female caregivers report experiencing a greater loss of self than male caregivers.

Regarding the caregiver occupation, this study showed significant association ($p = 0.04$) between burden level and caregiver occupation. Similar to this findings

Knipmann (2012, p.213) stated in his study that occupational loss is associated with higher levels of burden and lower mental health among caregivers. This is because burden can differ depending on different occupation and as caregivers have to attend certain responsibilities require by the occupation in daily basis, so if they also have to take responsibilities of ill family members creates a lots of burden for them.

But Wenger (1990, p.217) stated different thing that caregiver may see caring as an extension of the marital relationship and not experienced as burdensome. This may happen in cases of housewives, because they cannot consider house holding activities and home management as an occupation. When they have to play caregiver role as an extension of their role, may be consider this role as a mandatory family responsibilities. That's why it may not become a burden for them.

In respect with caregiver relationship with stroke survivor, the existing study found out that there is a significant association ($P= .026$) between caregiver relationship with survivors and caregiving burden level. This study revealed caregivers who were wives, daughters and paid caregiver explicit higher burden. This finding is consistent with other study. Esdorfer, Mui & Rankin et al. (cited in Hughes et al. 1999, p.553) stated that with respect to relationship studies have found that wives and daughters exhibit greater burden than husbands and sons and caregiver relationship was significantly related to burden but he also stated that spousal caregiver had lower burden scores than nonrelated caregivers. Also Morimoto et al. (2003, p.219) also found that caregiver who were wives reported significantly higher burden than other caregivers. From this study and different literature review it is found that most of the caregivers were wives and daughter and as female are less stable than male so they felt greater burden. Also it is estimated that closer relationship has greater burden may be due to they were continuously worry about their nearest one and they spent more time for caring than other. Cantor (1983, p.601) found that the closer relationship (i.e. comparing spouse, child, other relative, friend), the greater the reported strain. In case of a formal/paid caregiver, they were bound to provide continuous care to the survivors which put them under greater strain.

The existing study also found a strong association ($P= 0.000$) between caregiving duration and caregiver burden level. Results showed increased duration of providing

care is associated to increased caregiving burden. Several studies Anderson et al. (1995, p.843) observed long-term consequences of informal caregiving and Reimer et al. (1998, p.1605) observed caregiver burden increases over time. Initially caregivers are more comfortable with caregiving responsibilities when caregiving duration increases they feel more burden. Grant et al. (2004, p.110) found that during first month caregivers became comfortable with the caregiving routine and viewed caregiving problems and their associated feelings more objectively. Feelings are very intense during this time and family members starting to feel more confident in the third to fourth week of caregiving.

Also this study showed a significant association between caregiving hours in a day and level of caregiver burden. Study revealed that increased caregiving time exhibit increased burden. Similarly Morimoto et al. (2003, p.219) found that increased caregiving hours significantly related to increased burden and caregivers who provided more hours of care had the greatest burden. The National Alliance for Caregiving 1997 (cited in Bookwala & Schulz 2000, p.607) found in their survey of caregiving that caregivers who spent the most time in care provision and assisted with the most difficult self-care tasks, 31% experiencing a mental and physical health issue. Also Choi-Kwon et al. (2005, p.1044) found that patient's daughter-in-law have faced higher level of burden giving more than 15 hours of caregiving a day. So the caregivers who spend more time caring for their stroke survivors have a higher burden.

In case of stroke survivor's age, present study found no association between stroke survivor's age ($P= .385$), sex ($P= .732$) and level of perceived burden. That means caregiver burden is not dependent on stroke survivor age and either they are male or female. Similarly McCullagh et al. (2005, p.2185) found that patient age was not significant with caregiver burden and quality of life. Also Bhattacharjee et al. (2012, p.116) found that patient age was not related to increased burden but patient being a female was related to increased burden. But Rigby et al. (2009, p.155) mentioned that patient demographic variables (older age and male sex) were significantly correlated with higher levels of caregiver burden. In Bangladesh ill people are much more dependent on their caregivers and there is no difference in burden level if the patient is young or older, male or female.

Regarding stroke survivor's onset of stroke, current study found a strong association ($P = .000$) with perceived caregiving burden. It was revealed that increased duration of having stroke produce increased caregiver burden. McCullagh et al. (2005, p.2183) found that caregiver burden score was decreased significantly between 3 months and 1 year post stroke. When the duration increased caregiver burden score also increased. Because caregivers of this survivors were more comfortable with caregiving during initial stage of stroke as Grant et al. (2004, p.110) found that stroke survivors ADLs related to functional deficits and cognitive, behavioral and emotional changes during the first month but when onset increased caregivers were exposed to feel burden as they have undertaken long duration of care. A stroke survivor is more functionally able with the time elapses which supposed to less burden but a caregiver provided care to the survivors from initial stage to long duration so they exhibit higher burden and there have an influence of caregiving duration on onset of stroke to become a predictor for increased burden.

5.5. Limitation of the study:

Some issues regarding the study which impacted negatively on the validity, reliability and usefulness of findings were identified. These include:

- Enough literature regarding caregiver burden in South Asian culture was not available.
- The sample was selected purposive convenient way rather than randomly.

6.1. Conclusion:

This study extends knowledge about the level of burden experienced by the caregivers of stroke survivors in terms of general strain, isolation, disappointment, emotional involvement and environment. The study findings revealed that most of the caregivers faced moderate burden where they were highly disappointed rather than isolated or emotionally upset. The environment did not create any burden for them, possibly due to the Bangladeshi culture where country people are more hospitable. Caregivers think that caring for their near ones is their responsibility and they take this responsibility enthusiastically rather than feel burden. Through this study it was also found that the degree of burden depends on several aspects, such as caregiver's social and demographic characteristics: age, sex, relationship, caregiving duration & time and onset of stroke of survivors. The study also discovered that there is a possibility to have higher burden or caregiver in respectively large proportion in the future. This study suggests the health professional to focus on the caregiving situation to provide a better support to them and also Choi-Kwon et al. (2005, p.1047) suggested that it will be advisable to provide equivalent services for caregivers and their families as provided to the stroke survivors. Reimer et al. (1998, p.1610) also suggested that appropriate advice and support may preserve caregiving which eventually enables the survivors to live a longer and more fulfilling life in the community. So the occupational therapists have an important role to understand the caregiver's situation and promote a better social and psychological support for quality life of caregiver and stroke survivors.

6.2. Recommendation of the study:

- The researcher recommends that future similar research will conduct in the broader area and large scale of sample size.
- Serial follow-up studies are required to understand the changing pattern of caregiver burden and also to investigate the caregiver needs.

- A further research in this area can contribute to further refinement in understanding the characteristics of vulnerable caregivers and the factors or predictors that increasing caregiver burden and caregiving situation.
- A better understanding of this mechanism and implementation of psychological and social support for the caregiver can minimize the burden.
- The current study also recommends that health professionals can contribute to minimize the caregiver vulnerable situation by providing proper education, patient handling training, occupational training, counseling, maintaining own health and promoting social participation of the target caregiver.

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Appendixes

Permission for conduct Research

Date: 1st July 2013

To

The Head of the Department & Research Supervisor
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP, Chapain, Savar, Dhaka-1343

Subject: Prayer for seeking permission to conduct the research project.

Madam,

With due respect and humble submission beg most respectfully to state that I am a student of 4th year of B.Sc. in occupational Therapy of Bangladesh Health Professions Institute, the academic institute of Centre for the Rehabilitation of the Paralyzed(CRP). I am sincerely seeking permission to conduct my research project as the partly fulfillment of the requirements of degree of B.Sc. in Occupational Therapy. The title of my research is- "*Level of caregiver burden: A study on Caregivers of stroke survivors at CRP in Bangladesh*". The aim of the study is- 'To identify the level of burden among caregivers of stroke survivors at CRP in Bangladesh'.

So, I therefore pray and hope that you would be kind enough to grant me the permission of conducting the research and will help me to complete a successful study as a part of my course.

Your most obedient pupil,

Salma Begum

Salma Begum

4th year, B.Sc in occupational Therapy,

Bangladesh Health Professions Institute (BHPI)
CRP-Chapain, Savar, Dhaka-1343

<i>Approved by</i>	<i>Signature</i>
<p>Head of Department & Research Supervisor Nazmun Nahar Assistant professor and Head of Department Department of Occupational Therapy Bangladesh Health Professions Institute (BHPI) CRP-Chapain, Savar, Dhaka-1343</p>	<p><i>It may allow to conduct her study. Best of luck.</i></p> <p><i>Nahar</i> 06.07.13</p>

Permission to use Caregiver Burden Scale

salma_begum48 - Yahoo! Mail

file:///j:/Copy of permission.htm

Home Mail News Sports Finance Weather Games Groups Answers Flickr More

Search Mail Search Web Salm

INBOX CONTACTS CALENDAR Re: Looking forward of ...

Compose Delete Move Spam Actions

Inbox
Drafts (2)
Sent
Spam
Trash
FOLDERS
MESSENGER
APPLICATIONS

Re: Looking forward of your emergency response, from Bangladesh

Dear Salma Begum, you are free to use my caregiver burden scale for your intended disserta
Yours sincerely Solve Elmståhl, professor in Geriatric Medicine

Skickat från min Sony Ericsson Xperia arc

Salma Begum <salma_begum48@yahoo.com> skrev:

Dear solve,
I am a final year student of B.Sc. in Occupational Therapy from Bangladesh. The
name of my institution is Bangladesh Health Professions Institute (BHPI). I am
interested to conduct a dissertation in my graduate program under a supervisor.
My title is:
"Level of Caregiver burden among caregiver of stroke survivor in Bangladesh".
My aim and objectives are-

- To find out the level of physical, emotional, mental, financial, social burden
of caregivers of stroke survivor.
- To find out association in between level of burden among caregivers and
functional level of stroke survivors.
- To find out association in between level of burden among caregivers and
caregiver's age, gender, occupation and caregiver's relationship with stroke
survivors.

I am interested to use your caregiver burden scale for my study. Can I get your
permission, sir? I am looking to your permission. You know that Bangladesh is a
developing country and a very limited research has conducted in our country. If
you give me permission to use it then I will conduct my study. I promise that
never do any plagiarism of your scale and obviously will acknowledge you in my
study. I have got your scale in website but there has no interpretation of total
score. Can you help me about it, sir?

I have some limited time to conduct my study and my study is depend on your
permission. So, If you reply me early it will very helpful for me.
Hope so, you will reply me as early as possible, please.

Your Sincerely,
Salma Begum
4th year, B.Sc. in Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
Centre for the Rehabilitation of the Paralysed (CRP)
CRP-Chapain, Savar, Dhaka- 1343.
Bangladesh.
•Contact no. [+8801736552231](tel:+8801736552231)

3/17/2014 10:20 AM

Permission for Data Collection-A

Date: 20.08.2013

To

The Head of the Department

Occupational Therapy Department

CRP, Savar, Dhaka

Subject: Prayer for seeking permission to collect data from Out-patient and Stroke Rehab unit, CRP.

Sir,

I beg most respectfully to state that, I am a student of 4th year occupational therapy department of Bangladesh Health Professions Institute. I am interested to conduct a quantitative study on occupational therapy outpatient unit and stroke rehab unit. My research title is- "Level of caregiver burden: A study on Caregivers of stroke survivors at CRP in Bangladesh". The aim of the study is 'To identify the level of burden among caregivers of stroke survivors at CRP in Bangladesh'. Caregivers of stroke survivors are the participants of my research project. Now I am looking for your kind approval to start my data collection and I would like to assure that anything of my research period will not harmful for the participants. Informed consent will fill up by the caregiver for their ethical consideration.

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

I remain Sir,

Salma Begum

Salma Begum

4th year, B Sc in Occupational Therapy

BHPI, CRP-Chapain, Savar, Dhaka-1343.

Permitted to
collect data
20.08.13
Md. Julker Nayan
Assist. Professor & Head of OT
Occupational Therapy Department
CRP, Savar, Dhaka-1343

Permission for Data Collection-B

Date: 21.9.13

To

The Head of the Department

Occupational Therapy Department

CRP, Mirpur-14, Dhaka

Subject: Prayer for seeking permission to collect data from Out-patient and Stroke Rehab unit, CRP.

Madam,

I beg most respectfully to state that, I am a student of 4th year occupational therapy department of Bangladesh Health Professions Institute. I am interested to conduct a quantitative study on occupational therapy outpatient unit and stroke rehab unit. My research title is- "*Level of caregiver burden: A study on Caregivers of stroke survivors at CRP in Bangladesh*". The aim of the study is 'To identify the level of burden among caregivers of stroke survivors at CRP in Bangladesh'. Caregivers of stroke survivors are the participants of my research project. Now I am looking for your kind approval to start my data collection and I would like to assure that anything of my research period will not harmful for the participants. Informed consent will fill up by the caregiver for their ethical consideration.

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

I remain Madam,

Salma Begum

Salma Begum

4th year, B Sc in Occupational Therapy

BHPI, CRP-Chapain, Savar, Dhaka-1343.

Give permission to
Anima to collect data
21/09/13
Anima Das Nupur
Occupational Therapist & in charge
CRP Mirpur

Information Sheet

I am the researcher Salma Begum, 4th year B. Sc. in Occupational therapy student of Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralyzed (CRP). To complete my course I have to conduct a research study.

In this regard, I would like to invite you to take part in the research study, titled “**Level of Caregiver Burden: A study on Caregivers of stroke survivors at CRP in Bangladesh**”. The aim of the study is to identify the level of burden among caregivers of stroke survivors at CRP in Bangladesh.

In this study your participation is voluntary. If you do not agree to participate at all you can withdraw from the study.

Your answer will be recorded in this questionnaire named “Caregiver Burden Scale” which will take approximately 10 minutes and will be kept highly confidential and private. You will not be paid for your participation. Participation in this study might not benefit you directly. This study will not the cause any risk or harm to you. Confidentiality of all documents will be highly maintained. Collected data will never be used in such a way that you could be identified in any presentation or publication without your permission.

If you have any question now or later regarding the study, please feel free to ask the person stated below.

Salma Begum

B.Sc. in Occupational Therapy

4th Year, Session: 2009-2010

Occupational Therapy Department

Bangladesh Health Professions Institute (BHPI)

CRP-Chapain, Savar, Dhaka-1343

Cell Phone: 01736552231

Consent Form

In this study I am _____ a participant and I have read or have been explained to me the information sheet and I am informed about the topic of the research and aim of the research study. I will have the right to refuse in taking part any time at any stage of the study. For that reason I will not be bound to answer any body. This study will not have any impacts on me or my relatives.

I am informing that, the entire information collected from the interview that will use in the study will be safety enough and maintained confidentiality. Here only the researcher and supervisor eligible to access in the information. The researcher will be available to answer any study related question or inquiry to the participant.

I have been informed about the above all mentioned and agree to participate in the study willingly.

I agree to take part in this study.

Participant's signature.....Date:.....

Data collector's signature.....Date:.....

Witness' signature.....Date:.....

কোড নং:

তথ্য বিবরণী

আমি সালমা বেগম, সি.আর.পি'র শিক্ষা প্রতিষ্ঠান বাংলাদেশ হেল্থ প্রফেশনস ইন্সটিটিউটের বি.এস.সি ইন অকুপেশনাল থেরাপি বিভাগের ৪র্থ বর্ষের অধ্যয়নরত একজন নিয়মিত ছাত্রী। আমার কোর্সটা সম্পন্ন করার জন্য আমাকে একটা গবেষণা সম্পন্ন করতে হবে।

এই সুবাদে আমি আপনাকে আমার গবেষণায় অংশগ্রহন করার আমন্ত্রন জানাচ্ছি, আমার গবেষণার বিষয় –“ সাহায্যকারীদের বোঝার মাত্রাঃ বাংলাদেশের সি.আর.পি'র স্ট্রোক রোগীদের সাহায্যকারীদের নিয়ে একটি গবেষণা ”। আমার গবেষণার লক্ষ্য হল বাংলাদেশের সি.আর.পি'র স্ট্রোক রোগীদের সাহায্যকারীরা তাদের আত্মীয়দেরকে সাহায্য করতে গিয়ে কতটুকু বোঝা অনুভব করে বা সম্মুখীন হয় তা নির্ণয় করা।

এই গবেষণায় আপনার অংশগ্রহন একান্তই আপনার ইচ্ছায় এবং যদি আপনি রাজি না থাকেন তাহলে আপনি আপনার অংশগ্রহন প্রত্যাহার করতে পারবেন।

“সাহায্যকারীদের বোঝা নির্ণয়ক স্কেল” নামক একটি স্কেল দিয়ে আপনার উত্তর নেয়া হবে যেটা ১০ থেকে ১৫ মিনিট সময় নিবে এবং আপনার উত্তর সম্পূর্ণ গোপন এবং ব্যক্তিগতভাবে রাখা হবে। আপনার অংশগ্রহনের জন্য কোন আর্থিক সহায়তা পাবেন না। এই গবেষণায় অংশগ্রহনের জন্য আপনি সরাসরি কোন লাভবান হবেন না এবং এই গবেষণার কারণে আপনার কোন ক্ষতি বা বিপদ হবে না কিন্তু এই গবেষণার ফলাফলে যদি দেখা যায় যে আপনারা অথবা সাহায্যকারীরা অনেক বোঝার সম্মুখীন হচ্ছেন তাহলে ভবিষ্যতে সাহায্যকারীদের জন্য প্রতিকারমূলক ব্যবস্থা নেওয়া যাবে। সব তথ্যের সম্পূর্ণ গোপনীয়তা মানা হবে। আপনার অনুমতি ছাড়া সংগৃহীত তথ্য গুলো এমনভাবে ব্যবহার করা হবে না যাতে আপনার নাম জনসম্মুখে প্রকাশ পায়।

যদি এই গবেষণা সম্পর্কে আপনার এখন অথবা পরে কোন জিজ্ঞাসা থাকে তাহলে নিম্নলিখিত ব্যক্তিকে দ্বিধাহীন ভাবে জিজ্ঞেস করতে পারেন-

সালমা বেগম

বি.এস.সি ইন অকুপেশনাল থেরাপি

৪র্থ বর্ষ, সেশনঃ ২০০৯-২০১০

অকুপেশনাল থেরাপি বিভাগ

বাংলাদেশ হেল্থ প্রফেশনস ইন্সটিটিউট

সি.আর.পি-চাপাইন, সাভার, ঢাকা-১৩৪৩

ফোনঃ ০১৭৩৬৫৫২২৩১

কোড নং:

সম্মতিপত্র

এই গবেষণায় আমি----- একজন অংশগ্রহণকারী এবং আমি এই গবেষণার উদ্দেশ্য পরিষ্কারভাবে জানতে পেরেছি। আমি যে কোন সময় এবং গবেষণার যে কোন পর্যায়ে আমার অংশগ্রহণ প্রত্যাহার করতে পারি। এ জন্য আমি কারো কাছে জবাবদিহি ও ক্ষতিপূরণ দিতে বাধ্য নই। এই গবেষণায় অংশগ্রহণ করলে আমার আত্মীয়ের চিকিৎসার অথবা আমার কোন ব্যাঘাত ঘটবে না সাক্ষাৎকারের সকল তথ্য যেগুলো গবেষণার কাজে ব্যবহৃত হবে, সেগুলো গোপনীয়তার সাথে নিরাপদ স্থানে রাখা হবে। শুধুমাত্র গবেষক এ তথ্যগুলোর প্রবেশাধিকার পাবে এবং কারও নাম কোথাও না ছাপিয়ে এ তথ্যগুলো গবেষণা পত্রে প্রকাশিত হবে।

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

অংশগ্রহণকারীর টিপসই অথবা সাক্ষরঃ----- তারিখঃ-----

গবেষকের সাক্ষরঃ----- তারিখঃ-----

সাক্ষীর সাক্ষর অথবা টিপসইঃ----- তারিখঃ-----

Socio-demographic questionnaire

Code:

Caregiver's Information

Name:

Age: 1) 18-24 years 2) 25-30 years 3) 31-35 years 4) 36-40 years
 5) 41-45 years 6) 46-50 years

Sex: 1) Female 2) Male

Occupation: 1) Housewife 2) Teacher 3) Service Holder 4) Businessman
 5) Student 6) Others.....

Marital Status: 1) Married 2) Others.....

Relationship with Patient: 1) Wife 2) Mother 3) Daughter 4) Sister
 5) Husband 6) Son 7) Brother 8) Father
 9) Paid caregiver 10) others.....

Caregiving duration: 1) 1-5 months 2) 6-11 months 3) 12-36 months
 4) 37-72 months 5) 73-120+ months

Caregiving hours in a day: 1) 4-6 hours 2) 7-9 hours 3) 10-12 hours
 4) 13-15 hours 5) 16-19≤ hours

Permanent Address:

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Stroke survivors Information

Name:

Age: 1) 18-24 years 2) 25-30 years 3) 31-35 years 4) 36-40 years
5) 41-45 years 6) 46-50 years

Sex: 1) Female 2) Male

Occupation: 1) Housewife 2) Teacher 3) Service Holder 4) Businessman
5) Student 6) Others.....

Marital Status: 1) Married 2) Others.....

Onset of stroke: 1) 1-5 months 2) 6-11 months 3) 12-36 months 4) 37-7
5) 73-120+ months

Caregiver Burden Scale

Questions

Please, place a tick in the appropriate box.

No 1. Do you feel tired and worn out?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 2. Do you feel lonely and isolated because of your relative's problem?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 3. Do you think you have to shoulder too much responsibility for your relative's welfare?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 4. Do you sometimes feel as if you would like to run away from the entire situation you find yourself in?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 5. Do you find yourself facing purley practical problems in the care of your relative that you think are difficult to solve?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 6. Do you ever feel offended and angry with your relative?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 7. Do you think your own health has suffered because you have been taking care of your relative?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 8. Has your social life, eg with family and friends, been lessened?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 9. Does the physical environment make it troublesome for you taking care of your relative?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 10. Do you feel tied down by your relative's problem?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 11. Do you feel embarrassed by your relative's behavior?

- Not at all1
- Seldom2
- Sometimes3

No 12. Has your relative's problem prevented you from doing what you had planned to do in this phase of your life?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 13. Do you find it physically trying to take care of your relative?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 14. Do you think you spend so much time with your relative that the time for yourself is insufficient?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 15. Do you worry about not taken care of your relative in the proper way?

- Not at all1
- Seldom2

- Sometimes3
- Often4

No 16. Are you sometimes ashamed of your relative's behavior?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 17. Is there anything in the neighborhood of your relative's home making it troublesome for you to take care of your relative?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 18. Have you experienced economic sacrifice because you have been taking care of your relative?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 19. Do you find it mentally trying to take care of your relative?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 20. Have you a feeling that life has treated you unfairly?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 21. Had you expected that life would be different than it is at your age?

- Not at all1
- Seldom2
- Sometimes3
- Often4

No 22. Do you avoid inviting friends and acquaintances home because of your relative's problem?

- Not at all1
- Seldom2
- Sometimes3
- Often4

Total Score:

Score Interpretation (mean score):

Low burden: 1.00-1.99

Moderate burden: 2.00-2.99

High burden: 3.00-4.00

জনসংখ্যাতাত্ত্বিক তথ্যাবলী

কোড নং:

সাহায্যকারী/সেবায়ত্তকারী সম্পর্কিত তথ্যাবলীঃ

নাম-

বয়স- ১। ১৮- ২৪ বছর ২। ২৫ – ৩০ বছর ৩। ৩১ – ৩৫ বছর ৪। ৩৬- ৪০ বছর

৫। ৪১ - ৪৫ বছর ৬। ৪৬ – ৫০ বছর ৭। ৫০+ বছর

লিঙ্গ- ১। মহিলা ২। পুরুষ

পেশা- ১। গৃহিণী ২। শিক্ষক ৩। চাকরিজীবী ৪। ব্যবসায় ৫। ছাত্র / ছাত্রী

৬। অন্যান্য (.....)

বৈবাহিক অবস্থা- ১। বিবাহিত ২। অন্যান্য (.....)

রোগীর সাথে সম্পর্ক- ১। স্ত্রী ২। মা ৩। মেয়ে ৪। বোন ৫। স্বামী ৬। ছেলে ৭। ভাই
৮। বাবা ৯। বেতনভুক্ত সাহায্যকারী ১০। অন্যান্য (.....)

সাহায্য প্রদানের সময়সীমাঃ ১। ১-৫ মাস ২। ৬- ১১ মাস ৩। ১২ – ৩৬ মাস ৪। ৩৭- ৭২ মাস

৫। ৭৩-১২০+ মাস

দৈনিক সাহায্যপ্রদানের সময়ঃ ১। ৪ - ৬ ঘণ্টা ২। ৭ – ৯ ঘণ্টা ৩। ১০ – ১২ ঘণ্টা

৪। ১৩- ১৫ ঘণ্টা ৫। ১৬-১৯ ≤ ঘণ্টা

স্থায়ী ঠিকানাঃ

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স্ট্রোক রোগী সম্পর্কিত তথ্যাবলীঃ

নাম-

বয়স- ১। ১৮- ২৪ বছর ২। ২৫ – ৩০ বছর ৩। ৩১ – ৩৫ বছর ৪। ৩৬- ৪০ বছর

৫। ৪১-৪৫ বছর ৬। ৪৬ – ৫০ বছর ৭। ৫০+ বছর

লিঙ্গ- ১। মহিলা ২। পুরুষ

পেশা- ১। গৃহিণী ২। শিক্ষক ৩। চাকরিজীবী ৪। ব্যবসায়ী ৫। ছাত্র / ছাত্রী

৬। অন্যান্য (.....)

বৈবাহিক অবস্থা- ১। বিবাহিত ২। অন্যান্য (.....)

স্ট্রোকে আক্রান্ত হওয়ার সময়সীমাঃ ১। ১-৫ মাস ২। ৬- ১১ মাস ৩। ১২- ৩৬ মাস

৪। ৩৭ – ৭২ মাস ৫। ৭৩-১২০+মাস

সাহায্যকারীদের বোঝা নির্নয়ক স্কেল

দয়া করে সঠিক বাক্সে টিক(√) চিহ্ন দিন-

১। আপনি কি ক্লান্ত এবং জীর্ন অনুভব করেন ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

২। আপনি কি আপনার *আত্মীয়ের অসুস্থতার/সমস্যার জন্য নিজেকে একাকী এবং নিঃসঙ্গ অনুভব করেন ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

৩। আপনি কি মনে করেন আপনার আত্মীয়ের মঙ্গলের জন্য আপনার কাছে অনেক বেশী দায়িত্ব রয়েছে ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

৪। আপনি কি কখনও মনে করেন যে, যদি আপনি সবকিছু থেকে পালিয়ে যেতে পারতেন তাহলে আপনি স্বস্তি পেতেন?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

৫। আপনি কি আপনার আত্মীয়ের যত্ন নেওয়ার সময় এমন কোন বাস্তবিক সমস্যার সম্মুখীন হন যেটা আপনার কাছে সমাধান করা কষ্টকর বলে মনে হয় ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

৬। আপনি কি আপনার আত্মীয়ের উপর কখনো অসন্তুষ্ট বা রাগান্বিত হয়েছেন ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

৭। আপনি কি মনে করেন আপনার আত্মীয়ের যত্ন নিতে গিয়ে আপনার নিজের স্বাস্থ্য ক্ষতিগ্রস্ত হচ্ছে ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

৮। আপনার আত্মীয়ের কারণে আপনার কি সামাজিক জীবন যেমন আপনার পরিবার এবং বন্ধুর সাথে সম্পর্ক কমে গিয়েছে?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

৯। আপনার আত্মীয়ের সেবায়ত্ত করার সময় কি আপনি আপনার চারপাশের পরিবেশ দ্বারা সমস্যার সম্মুখীন হচ্ছেন ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

১০। আপনি কি আপনার আত্মীয়ের সমস্যা দ্বারা নিজেকে আবদ্ধ মনে করেন ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

১১। আপনি কি আপনার আত্মীয়ের ব্যবহারে বিব্রত বোধ করেন ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

১২। আপনি আপনার জীবনের এ ধাপে যে পরিকল্পনা করেছিলেন তা কি আপনার আত্মীয়ের সমস্যার কারণে বাধাগ্রস্ত হয়েছে ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

১৩। আপনার আত্মীয়ের সেবায়ত্ত করার জন্য কি আপনি শারীরিকভাবে সাহায্য করছেন ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

১৪। আপনি কি মনে করেন আপনার আত্মীয়ের সাথে বেশী সময় কাটানোর জন্য আপনার নিজের জন্য সময় অনেক কমে গেছে?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

১৫। আপনি কি আপনার আত্মীয়ের যত্ন সঠিকভাবে নিতে পারছেন না বলে চিন্তিত ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

১৬। আপনি কি আপনার আত্মীয়ের ব্যবহারে কখনও লজ্জিত হন ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

১৭। আপনার আত্মীয়ের প্রতিবেশীদের কোন কারণে কি আপনার আত্মীয়ের যত্ন নিতে সমস্যা হচ্ছে ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

১৮। আপনার আত্মীয়ের যত্ন নেওয়ার জন্য কি আপনাকে আর্থিকভাবে কোন ত্যাগ স্বীকার করতে হয়েছে ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

১৯। আপনি কি অনুভব করেন যে, আপনি মানসিকভাবে আপনার আত্মীয়ের সেবায়ত্নের চেষ্টা করছেন ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

২০। আপনি কি নিজেকে হতভাগা মনে করেন ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

২১। আপনি কি আশা করেছিলেন যে, এই বয়সে আপনার জীবনটা এখনকার চেয়ে অন্যরকম হতে পারতো ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

২২। আপনার আত্মীয়ের অসুস্থতা/সমস্যার কারণে কি আপনি বন্ধুদের দাওয়াত এবং বাড়িতে আলাপ করা পরিহার করছেন ?

- মোটেই না^১ কদাচিৎ/ খুবই অল্প সময়^২ মাঝে মাঝে^৩ প্রায়ই^৪

(*আত্মীয়ের ক্ষেত্রে সম্পর্ক অনুযায়ী সন্মোদন করা হবে)

মোট মানঃ