

Caregiver Burden, Coping strategies and Quality of life of Family
Caregivers of Patients with Alzheimers and Dementia



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Supervisor

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Dedicated to

My Parents and brothers for being my constant support, encouraged me and prayed for me throughout the time of my research.

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List of abbreviation

CB	Caregiver burden
QOL	Quality of Life
AD	Alzheimers Disease
WHO	World Health Organization
DQOL	Dementia Quality of Life
NPSs	Neuropsychiatric symptoms
PHF	Physical functioning
PSF	Psychological functioning
SOF	Social functioning
ENF	Environmental functioning
BCS	Brief cope scale
AAC	Active Avoidance coping
PFC	Problem focused coping
PC	Positive coping
RDC	Religious/denial coping

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Abstract

The aim of conducting present study was to examine the relationship between caregiver burden, coping strategies and Quality of life of family caregiver of patients with Alzheimers and Dementia. Moreover, relationships of different demographics variables i.e age, gender, disease, relationship with the patient, marital status, employment status, income and education level were also studied with study variables. Instruments used in the thesis are 'Burden scale for Family Caregivers' (BSFCs) developed by Grassel (2013). 'Quality of life' (WHOQOL BREF) is developed by WHO (1996) and to measure the coping style, 'Brief COPE' scale was used which is developed by Carver (1997). The sample of study consisted of 60 caregivers of diagnosed patients with Alzheimers and Dementia. Age of participants ranged from 17-57 years. The non-probability purposive sampling technique was used for the selection of the sample which means sample is selected based on some specific characteristics. Here, in this study only the caregivers of diagnosed patients of Alzheimers and Dementia is addressed. The sample was approached from different hospitals (include private and government) of Rawalpindi and Islamabad. The criteria to select the sample was the caregivers of patients with Alzheimers and Dementia. The findings of the study showed that there is a significant inverse relationship between the two study variables i.e caregiver burden and Quality of life. Furthermore, results revealed non-significant age difference on the coping strategies i.e the caregivers falling in the category of late adulthood showed good coping than the early adulthood individuals. Moreover, there is non-significant gender differences on the subscale of quality of life. i.e Social functioning which reveals that quality of life of male caregivers is better than that of female caregivers. The caregivers living with the patients showed greater non-significant results of caregiver burden, poor quality of life and poor coping strategies than the caregivers who does not live with the patients. The current study will provide the relationship among the study variables that what extent of caregiving would start effecting the quality of life of the caregiver. Results of the study have important implications for the caregivers to improve coping strategies which would lessen their burden.

INTRODUCTION

Introduction

The human body, like all natural organisms, is very fragile and is subject to a wide variety of malfunctions resulting in what we call *illnesses*. These illnesses can happen either due to the interaction of foreign organisms like bacteria or viruses, or due to genetic predispositions coded into the individual's DNA. Whatever the cause or type of the ailment, they all have one thing in common: they bring pain to the individual and disrupt their normal way of life. Chronic ailments are illnesses that last a long time and due to their nature effect the lifestyle of the patient and their family in a profound way. A patient suffering from renal failure, for example, may have to go for regular sessions of dialysis twice a week for their entire life; and someone afflicted with cancer or an auto-immune disorder may need constant care and attention from their close relatives. Similarly, psychological conditions such as Dementia, Alzheimer's and even Addiction can be termed as chronic ailments as their effects force fundamental, sometimes permanent, changes in the patient's lifestyle. All these chronic ailments are associated with many physical and psychological challenges that affect not only the patient, but the caregivers of the patient as well by putting them in an abnormally stressful environment. This tremendous psychological burden is not easily recognized by an observer despite causing acutely affecting the caregivers. The present study aims to identify and investigate what part coping plays by identifying better coping strategies which would lessen the caregiver burden and to check how the family life is affected by it.

Caregiver

An individual who helps with the physical care and helping in dealing with the disease is known as caregiver. The literature has provided with many definitions of caregiver burden. Caregiver burden could be stated as the cost (either observable or perceived) to the caregiver and the negative effect caused by providing assistance and help to the care recipient (Hunt, 2003).

Similarly, informal caregiving is defined as the care or assistance provided to the individuals merely relative or loved ones who are unable to perform anything on their own (Pearlin, 1990).

Types of Caregivers

Primary caregivers. A caregiver performs activities that help to the member of the family who needs care that involves the financial help, respond to them quickly, devote themselves for the care recipient. The members of the family usually provide care and time to the recipient of care without getting paid. The caregivers might provide the extra care with reference to the severity of the disease by helping the care recipient in the daily functioning of life that includes: eating, toilet habits, bathing and medical processes of their daily life to manage their disease.

Secondary caregivers. They might help the patients with the medical checkups and work. They do not visit often for days. They usually provide help to the primary caregivers. They are depended upon by the caregivers of family because of the hope of getting help in daily chores.

Working caregivers. They work outside the home to provide financial help as well as they provide the patients with the physical care involving bathing, dressing etc.

Long distance caregivers. They live far from the patient and arrange schedule to visit the care recipient. Although, they do not live with them but they provide a complete support.

Community caregivers. They help the primary caregivers in doing the daily chores by sometimes providing help in cleaning etc.

Future caregivers. The plans are made by the caregivers to seek medical and professional help if the disease proceeds or the level of severity increases. They are majorly responsible to focus on the plans that facilitate the patient.

Theoretical Background of Caregiver Burden

Roy adaptation theory. The burden or stress that is experienced by the caregivers in providing help and assistance to the patients with chronic illness was explained by the theories that were derived from the Roy Adaptation Model.

The main focus of the theory is that to extract and organize the events of life of the caregivers that leads to the stress from the characteristics of caregivers. The stress that is faced while providing care.

This theory consists of four basic postulates includes that: the response of the caregiver when there is an environmental quickly, the response of the caregiver to the stimuli is determined by the caregiver's perception and in the end, the better caregiving because of the caregiver satisfaction and self-esteem (Olbrish, Bendict, Ashe, & Levinson, 2002).

Double ABCX model of family stress. The stressor event (A) interacts with the family's crisis- meeting resources (B) with which the interaction of the family interception of the event (C) produces the crises (X). It was designed to discriminate between the family components (balanced or imbalanced) faced with the chronic illness. Double ABCX model portrays the coping of family with the problem and how the stressors are faced by the family.

The double ABCX model describes the adjustment and coping of the family with the changes that occur and depicts how the changing demands are met and managed. The family adapted various ways to provide help and support to the patients and how the crisis are managed by the families by showing resilience or flexibility.

Caregiver Burden

The condition of the caregiver resulting from necessary caring tasks or restrictions that cause discomfort for the caregiver. It could be described as the type of stressor or crises that is experienced by the caregivers associated with the problems and challenges they face as a result of the condition of the care recipient is known as caregiver burden (Zarit, Reever, & Bach-Peterson, 1980) or the experience of the caregiver that is probably subjective and is negative (Chwalisz, 1996).

Braithwaite (1996) described caregiver burden as the level which conflicts between the needs of the caregiver that are basic and fulfilling the demands of the caregiving. It could be further defined as the threat or demand (external) that has been assessed as a stressor (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989).

The caregiver burden is a term which indicates the responses that are particularly emotional in nature which resulted because of providing the care to the patients merely elder. The activities that are performed by the caregivers in providing assistance to the patients with illness cause the feeling of burden or fatigue. Caregiving is therefore, an activity that involves a great deal of effort to provide support and care to the members of the family or relatives that needs care wither physical or spiritual. The excess of strain or stress that is borne by the individual who provides care for a patient with disease (disability, chronically ill) or a family member that could not do work on his own merely elderly. Caregiver burden can be stated as a response that is multidimensional in nature that includes the stressors either physical or psychological, emotional or social, and even financial stressors that are linked with the experience of caregiving (Stucki & Mulvey, 2000).

Caregiver burden differs from caregiving as it involves the psychological distress which comes along the experience in providing help and assistance to those who are in need of the care (Pearlin, Mullan, Semple, & Skaff, 1990).

Caregiver Burden is derived from the perception of the caregivers and is affected by many psychosocial factors including: kinship, environment, and culture of activities and stressors. Furthermore, Caregiver burden includes all the hurdles that come along the way while providing care in the life of the caregiver which negatively affect the health (psychological or physical) of the caregiver. Caregiver burden is a vast term that describes the negative impact on the health and quality of life of caregiver in providing care (Jones, 1996).

Protective factors. There are protective factors that lessen the caregiver burden which includes support from other family members, and to use problem focused coping strategies, provision of help from the society. It is noticeable that dementia is a significant disease that negatively effects the families and individuals themselves. Providing care to the demented individuals is of great responsibility and burden and therefore, caregivers face much more problems and difficulties than the individual himself.

Risk factors. Caregiver burden is enhanced by a number of factors that includes the social isolation, lack of knowledge about the problem of the patient, limited resources and interpersonal skills. Moreover, maladaptive coping strategies, relationship issues (after condition started) and the feelings of regret (e.g. over a decision to institutionalize the person) plays a vital role in increasing the caregiver burden.

Types of caregiver burden.

Objective burden. It is the burden on the caregiver that can be observed with the naked eye which is caused by providing care to the recipient (Jones, 1996).

Subjective burden. It is the cost perceived such as the degree to which the caregiver takes the difficulty while performing the activities or the positive or negative feelings involved in taking care of the recipient

The feelings either positive or negative experienced while providing care is known as subjective burden (Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999).

Subjective burden can be defined as the act of an individual in assessing the situation (Maurin & Boyd, 1990).

It is reported by the researches that increase in subjective burden in the caregiver often lead to the higher risk of negative impact on health such as depression. It plays a vital role in predicting the health of the caregiver (Hunt, 2003)

Informal caregiving. Informal caregiving can be defined as performing tasks to help in the physical needs and are mainly conceptualized as the psychosocial support than the professional care (Kane, Kane, & Newcomer, 2005).

The study of Bower showed five categories of informal caregiving that are overlapping but conceptually unique. The five categories of caregiving (anticipatory caregiving, preventive in nature, supervisory caregiving, instrumental and protective). Among these five categories of informal caregiving, only instrumental caregiving is considered as informal caregiving. The remaining four types does not include in the general conceptualization of informal caregiving. In spite of that, the informal

caregivers reported that instrumental caregiving is even more important than the other four types of caregiving in providing care.

Literature on Caregiver burden

The lower quality of life and higher risk of depression have a relationship with the level of perceived burden for caregivers of patients with Multiple Sclerosis (MS) (Aronson, 1997).

The members of the family taking care of the patients with dementia at home report that experience as frustrating and long lasting stress, the term used to describe this experience or phenomenon is known as caregiver burden (CB) (Butcher, Holkup, & Buckwalter, 2001).

Caregiver burden can also be defined as a multifaceted feedback to the stressors that can be: physical, psychological, emotional, social or financial, that are associated with the experience of providing care. The burden that is perceived by the caregiver other than any other family member dispose the effect on the individual's life. The research has reported that more than 80% of the caregivers of patients with Alzheimers disease (AD) stated that they often undergo high levels of stress and almost half reported that they experience depression (Kasuya, Polgar-Bailey, & Takeuchi, 2000).

The negative health effects including poor quality of life, depression and illness are strongly linked with the caregiver burden (Etters, Goodall, & Harrison, 2008).

The poor health conditions of the caregivers are strongly associated with the informal caregivers. The caregivers, specifically spouses of old age stated that their physical health is badly affected by the caregiving. Caregiver burden is also strongly linked with the caregiver's physical health. The research has reported the caregivers who experience caregiver burden had 63% higher mortality risk. In spite of this, those caregivers who do not experience caregiver burden have decreased mortality rates (Schulz & Beach, 1999).

The studies showed that the caregiver burden is influenced by the relationship of the caregiver and the recipient. They reported that the spouse caregivers are



considered to experience high levels of burden (Papastavrou, Kalokerinou, Papacostas, Tasangari, & Sourtzi, 2007).

However, some research reported that the children or children in-law caregivers are more effected by the caregiver burden as compared to the spouse caregivers. It is also suggested by the studies that nursing home admission is related to the caregiver burden (Cho, 2007).

The caregiver burden was investigated in varied caregiving relationships. It is found out that distant relatives showed greater caregiver burden than family members. Hence, the literature has provided with varied results in terms of caregiver burden and the relationship with the patient (Chumbler, Grimm, Cody, & Beck, 2003).

The literature also studied the patients with dementia and their caregivers and it was found out that the nursing home placement is predicted by the characteristics of the caregivers rather than the level of impairment of the patient either cognitive or medical (Hope, Keene, Gedling, Fairburn, & Jacoby, 1998).

A worldwide demographic shift to an aging population resulted in the individuals with dementia. Approximately 5.1 million American are diagnosed with Alzheimers Disease (AD), and it is assumed that 63 million number of people suffers from all kinds of Dementia (Etters et al., 2008).

Major responsibility of the caregiving is on the family caregivers including the spouse or other members of the family such as siblings, children are likely to be responsible or assume the role. The increase in the seriousness of dementia influences the amount of time required for caregiving (Langa et al., 2001).

The primary nurse practitioners confront a prevailing problem, known as caregiver burden. They work on to construction and appliance of multicomponent interventions to the caregivers of patients with dementia as the health of the caregivers is poorly affected by the caregiver experience. The improvements in the caregiver burden scores including the lessen depression, use of effective coping skills and delayed institutionalization of patients are seen after targeting the caregivers with the multicomponent interventions. The Caregiver burden can be addressed by the nurse practitioners by early noticing and prevention. The caregivers must be screen out every 6 months to detect and identify those who are at risk of caregiver burden.

After the identification of caregiver burden, the active participation of the caregiver in the interventions showed remarkable improvement. Interventions that are provided includes the information about dementia, involving the family members, helping them to understand the benefits they would receive from caregiving, assessing the in-home environment and educating the caregivers about the safety issues. The increase in severity of the dementia demands more attention from the caregivers and skill-based training to support the daily functioning of patients with dementia (Pinquart & Sorensen, 2006).

The constant stress that the caregiver is subjected to effect the psychological and physical well-being of the caregiver, thereby effecting their quality of life. The caregiver may even develop neuroses and illnesses due to self-neglect, et cetera. These effects can be mitigated by developing appropriate coping mechanisms.

Coping Strategy

Thousands of studies on coping of individuals with impairment or illness are published by the researchers in social medicine, medical psychology and health psychology including the topics of pain, anxiety and caring which showed the growing interest in coping. Coping could be stated as a procedure that includes at least two stages of appraisal (primary or secondary). Primary appraisal includes the importance of an event on one's life e.g is this something to worry about? Whereas, the assessment of one's ability to cope with situation is known as secondary appraisal (What one can do in a situation). Furthermore, coping can be seen as helping among the two functions of coping namely, Problem focused and emotion focused coping (Lazarus, 1993).

Coping can be defined as both the state or trait i.e it could be change with the change in circumstances as well as the characteristics of a person that are stable over a period of time. Secondly, coping can also be defined as the management of external or internal demands that are seen as crossing one's resources or taxing. The late importance on coping was quite approachable in helping to solve a problem, more rational, and lastly it is more concerned with the regulation of emotional reaction i.e controlling a situation, venting or ignoring (Andresson, 2003).

Hasting's types of coping. Hasting et al. (2005) had identified the four types of coping strategies when they conducted a study on the caregivers of autistic children that were mainly parents. The four distinct categories of the coping strategies are; Active avoidance coping, Problem-focused coping, Positive coping, and Religious/denial coping.

Active avoidance coping. This type of coping includes the avoidance behavior that gave the individual a short term relief which negatively effects in a longer run. The examples of such behavior mainly involves the detachment of oneself from the situation either physically or mentally, escaping, drug abuse or blaming oneself negatively of the situation. A person distracts himself from the situation physically to reduce the effect of stressor, this type of coping is known as behavioral disengagement (Akhtar, 2005).

A coping strategy in which the individual cope up by focusing on the stressor that is experienced and ventilate those feelings. This response might be effective sometimes. Moreover, the focus on distress experienced by the individual removes his attention from active coping (Ismail & Mehmood, 1997).

An individual divert his attention to stop himself thinking about a stressful situation is known as mental disengagement. An individual can distract himself from a stressful situation by indulging himself in activities, which divert him from thinking about the stressor (Riaz, 2002).

Problem-focused coping. It is an active form of coping that helps the individual to plan about the future to overcome the situation. He might use support either instrumental or emotional. The active coping includes the mental exercise of an individual. He take steps that are valid and could reduce the negative effect produced by the stressor. This type of coping is done in a proper organize manner that includes the execution of plan stepwise.

The other form in this type of coping is planning which helps the individual to make a mind map to fight against the stressors effectively. The new actions are kept in mind to deal with the problem and which actions would be the best option to pursue. The problem focused coping is somewhat related to it but they differ in a sense to perform any action that focuses problem (Riaz, 2002).

Positive coping. It includes the humor style and positive restructuring of the stressors by using support (emotional or instrumental). It is another form of coping strategy. In this coping strategy, the stressors are dealt effectively by keeping in view the positive side of the event that cause distress. To accept the situation is another way of coping that comes with a basic concept that what is done cannot be undone. It is more like the coping which is adaptive in nature which compensate the stressor and the consequences could be changed (Riaz, 2002).

Religious/denial coping. This form of coping includes the activities that are involved in performing religious act such as offering prayer. As well as it also includes the coping that is denial in nature. With the help of praying, one feels himself as being blessed and interpret the situation positively by taking the stressor as God's will but sometime it enhances the emotional stress on an individual (Riaz, 2002). Whereas, a coping in which the individual does not admit that whatever happened, has happened is denial coping. This type of coping might provide a short term relief but turns out to be more disastrous in a longer run (Baron, 1989).

Coping strategies are the actions or mental set of schemas that aid us in dealing with the stressful situation. Health status could be directly affected by the coping strategies that probably reduce stress directly or indirectly i.e by the alcohol use or by using the social support. It is not the coping itself that is considered as adaptive but the use of coping strategy is regarded as adaptive or maladaptive for example the use of specific coping strategy as in problem solving or avoidance strategies with stress. The differences in adaption could not be depicted by this simple picture as it does not consider the role of process or time.

The coping strategies are considered as beneficial, but the maladaptive coping strategy such as avoidant coping could provide short term relief in terms of avoiding being in a stressful situation but produce poorer outcome in the long run. The priority or resources of individual and the external demands influence the choice of coping strategy (Suls & Fletcher, 1985).

The past decade showed remarkable interest in the processes of the coping of people with stress. Coping is described as a procedure to manage one's demands that are seen as crossing the limit of an individual. The two forms of coping used are Problem focused coping that is when the situation is under control of an individual

and the problem or the source of problem is manageable. The other form of coping is the emotional focused coping in which the reaction of the individual that is emotional in nature is controlled, as compare to the problem itself. The better coping strategies enables the individual to return to a stable condition after coping with the problem or stressor effectively which result in the lessen negative effect of the stress on the individuals' health whereas the negative consequences of stress are potentially increased by the maladaptive coping strategies (Gamal, Alhosain, & Alsunaye, 2018).

Lazarus and Folkman described (as cited in schaffer, 1992) the three stages from which an individual goes through whenever any challenge is faced. The stages include; Primary appraisal, Secondary appraisal and Coping.

Primary appraisal. It is the first stage of facing any stressor or cluster of stressors. An individual, upon facing a stressful situation, sit back, relax and think about the problem in a rational way that whether it is a danger to him or not and if the stressor or threat is not affecting him, the process of coping will end. If the stressor is meaningful then the process of coping is continued (as cited in Schafer, 1992).

Secondary appraisal. In this stage, the individual upon hitting by a stressor gathers information about the resources he might be needed to deal with the stressor. Holryod and Lazarus (as cited in Schafer, 1992) stated that this stage is strongly influenced by the prior experiences in the situations that are somewhat like this in nature. This appraisal deals with the control of an individual which he had on himself and the environment. The greater the control, the lesser the distress will be caused by the stressor.

Coping. This stage deals with the appropriate action of an individual to the stressor (Schafer, 1992).

Individual Differences in Coping

A major issue that is to be consider concerns with the individual differences and the role played in the coping processes. The coping might be influenced by the individual differences which could be considered as two ways. Firstly, most significant and obvious, that when people confront a stressful situation, the stable coping styles and temperament comes automatically. Keeping in view this concept, the coping strategies remains relatively stable across time and circumstances, the

individual bear a preferred set of coping strategies rather than approaching each coping context again and again. This idea of the existence of such stable coping styles is somewhat controversial. Folkman and Lazarus repeatedly highlighted that coping should be considered as a vital and active process that changes its nature according to the stage of a stressful transaction. This view proposed that one must be free and flexible in one's changing responses according to the changing situation, the development of such coping style could be counterproductive as they restricts the person to opt only one type of response. The second likelihood is step ahead. Particularly, the argument that the more traditional personality dimensions are derived from the ways of coping that is preferred. Thus, individuals tend to cope in particular ways whenever they encounter a stressful situation which perhaps predispose that there are certain personality characteristics which leads them to do so (Folkman & Lazarus, 1980).

Therefore, there were doubts on the part of Folkman and Lazarus and the test of a valid position raised such issue related to the role of temperament or nature of an individual more generally. Specifically, Cohen and Lazarus were unable to find any support for the hypothesis that sensitization versus the personality dimension. The results which were concluded from the findings were that the personality dispositions were not probably the beneficial predictors of coping.

However, it is not acceptable by the population that there is no role of individual differences in deciding that to which extent the involvement of a given coping strategy is at any point of transaction. This is not acceptable to compensate the overall probability of the relationship exist between specifically personality disposition and the sequences or patterns or the changes that exist in coping with the passage of time.

The certainty that in the past, the poor predictors including the trait measures does not tell about the individual differences in general whereas the predictive value of a particular personality different was predicted.

People often do things to avoid the harm caused by the stressors of life, such act is known as coping. The very major concept is the important assumption that the individual actively react to the stimuli that cause a negative effect on them. As it could be clearly seen that many of the forces that negatively affects one's life are

social in their origins, the effect of the societies which is exerted on the members can only be understood after the understanding of coping.

As the less relativity of the temperament or nature and substance of individual's coping priorities and the effectiveness of different ways of coping are even more less relative.

As Lazarus stated that the psychological dispositions has been given greater emphasis by the previous literature rather than the particular responses with reference to the situational conditions. Usually, coping ability has been judged merely on the basis of the personality characteristics possessed by the people which they use for safety from the external threats. The personality characteristics which enables the individual to deal efficiently with the problems of life are considered as the right personality characteristics, wherever the problems might come up or whatever the nature of the problem is. Individual develop modal styles to effectively deal with the life stressors or strains, that surpass the role or the limits of the situation. However, in contrast to it, the specificity to which it is attempted to identify what particular response an individual show to life strains in particular role areas.

Coping can be stated as the changing efforts of an individual either cognitive or behavioral to manage the demands (external or internal) that are appraised as crossing the limits of the resources of an individual or taxing. The two major functions of the coping are widely recognized as changing the bothered or disturbed relation of the individual causing distress (problem focused coping) or regulating stressful emotions i.e emotion focused coping. The literature has provided strong empirical evidence that coping includes both the functions of emotion focused coping as well as the problem focused coping. The literature has reported that the both forms of coping were represented by the middle aged men and women whenever they confront a stressful situation over 98% and the coping of college students with a stressful examination. (Lazarus & Folkman, 1984)

The responsiveness to stress involves operational multiple response systems that includes the changes in thought processes, emotional, physical and physiological levels that results in the negative consequences on number of disease or disorders. (Campbell & Ehlert, 2012). The attention has been paid to study the individual difference in the response of stress win the past decades, because of the increase in the

disorders related to stressful experience with the different prevalence among men and women. The activation of hypothalamus-pituitary- adrenal (HPA) is related to the disorders, which showed the sex difference, which resulted in the consideration of the difference responses of stress in men and women (Kajantie & Phillips, 2006).

Furthermore, the previous studies on sex difference in response to the stressors that are psychosocial in nature, using the trier social stress test, reported that the responses either psychological or physiological are different in men and women to acute stress, that are assessed predominantly by the parameters that is anxiety, mood and cortisol. In most cases, the higher cortisol level is shown by men than women (Villada, Hidalgo, Almela, & Salvador, 2016).

The literature suggests that people develop the ways to reduce the pain, tolerate or lessen the effect who experience pain. The patients made effort to reduce or to deal with the pain effectively is known as coping strategies. The acute and chronic patients were interviewed and it was found out that the cognitive and behavioral coping strategies were developed by most of the patients to deal with their pain. The cognitive coping strategies involves the distracting features of environment, counting numbers or praying whereas the activities such as communication with other individuals and physical exercise is involved in the behavioral coping strategies (Rosenstie & Keefe, 1983).

It was reported that during a dental procedure, the amount of distress reported by the patients were clearly related to the coping mechanism used by the patients to deal with pain. The coping strategies were used by the individual to deal with clinical pain and the evidence was provided by the previous literature or studies. It could be an important acknowledgement that coping strategies might play an important role in determining how the patients adjust to pain i.e chronic in nature (Keefe, 1982).

The increase in age-related disorders are strongly associated with the growing rate of aged people in the Western countries. Alzheimers disease, including in the disorders related to age carries with it the greater epidemiological, economic and social impact and is therefore considered as the most serious disease. For instance, in Italy, providing daily assistance and help to the people with dementia is the core responsibility of the families. The data provided by the report of Italian Statistical Institute stated that the majority of patients with dementia lives at home. The informal

caregivers that includes the unpaid or unprofessional individuals whose burden and stress becomes heavier with the severity of disease are female caregivers.

The caregivers are overburdened psychologically, financially or physically because of the challenges they face in providing the care to the recipient. The clinically significant anxiety and depression are associated with the caregivers. The physical health status of the caregivers is worsening by the contribution of chronic distress, which reduces their life expectancy and made them more vulnerable to develop disease. The study of a large sample of US caregivers confirmed the findings that reported the increase prevalence of hypertension with is linked with an increased risk of cardiovascular disease among caregivers (Iavarone, Ziello, Pastore, Fasanaro, & Poderico, 2014).

A paradigm of the general adaptation is seen by the caregiver's condition. According to this view, stress can be seen as a nonspecific biological and general response of the whole body. The request when exceed the subject's resources from the environment, this response is appeared. In this view, major focus has been given to the study of coping strategies used by the subject to deal with a distressing situation (Cooper, Katona, Orrell & Livingston, 2008).

The coping varies from family to family for a number of reasons. The coping has been emphasized as a basic concept. In the developed countries for the adaptation and study of mental health (Doornbos,1996).

Moreover, the recovery or rehabilitation of persons with mental illness and the effects of age, duration of disease or illness, living arrangements or other contextual factors on the coping style are considered to be the important factors (Doherty, 2008).

The patient's characteristics and behavior must be understand and learned by the family caregivers. Coping with the symptoms that includes: hallucinations, delusions, violence and inappropriate behaviors might involve the negotiations that are complex, lengthy and distressing in nature. The caregivers who are overburdened and use less effective coping strategies report the frequent health problems either physical or mental (Perlick et al., 2008).

The neuropsychiatric symptoms (NPSs) at some point during the illness have higher rates in the patients with Alzheimers disease. The existence of the symptoms of

neuropsychiatry increases the risk of caregiver burden, long term institutionalization and greater cost to care. The presence of the NPSs has adverse effects on both the quality of life of caregivers and the patients with Alzheimers disease because of the loss of freedom. The literature has given importance to the significance of a complex and unique interaction of psychological, social and neurobiological factors that includes the neuropathological, genetic or neurochemical change in one's body, but the pathogenesis of NPSs has not been clearly defined (Tatsumi et al., 2009).

The predictors of the NPSs have been investigated by many studies which focus on the characteristics of the caregiver or the patient with disease. The characteristics of the caregiver includes: age, education, hours spent caring, relationship with the patient, whether living with patient or economic status. Whereas, the characteristics of the patient includes the demographics, severity of the disease, impairment (cognitive and functional). Furthermore, the role of caregiver burden in the presence of neuropsychiatric symptoms is investigated in very few studies. The hypothesis that the caregiver burden is caused by the neuropsychiatric symptoms. However, the presence of NPSs undoubtedly contribute to the caregiver burden, their exist a bidirectional relationship between both the presence of NPSs symptoms and caregiver burden. The patient's increasing reduced capacity to deal with stress or the un met needs of the patient because of the presence of the NPS might result in the interpersonal interaction of caregiver and patient, the coping strategies used by the caregiver also get influenced by it (Alberca et al., 2014).

The process of coping consists of responses either behavioral or cognitive which is used by the individual to deal with the demands (external or internal) that can be stated as when it cross the limit of the normal and is given much importance because it has a great significance on mental and physical health problems related to stress and for the intervention potential. The coping is conceptualized as a dynamic process, which is consisted of the responses that are reciprocal in nature in which the environment and individual interacts and influences one another. It consists of a series of actions that are intentionally performed either cognitively or behaviorally and their main aim is to lessen the adverse effect of the stressful situation or event (Lazarus, 2006).

It is difficult, however, to identify the effects of these coping mechanisms on the quality of life of the caregiver for an external observer thereby making it difficult to observe their effectiveness. In the following section, the scope of the caregiver's Quality of Life is discussed and elaborated upon.

Quality of Life

Quality of life is an incomprehensible approach that varies and cannot be generalized by the assessment of community or societal wellbeing or by the individual perception and evaluation of the situation. The variations are reflected by the conceptualization. The wellbeing of populations at average was sketched by the broad social indicators. To reflect the individual welfare, the social and psychological indicators were developed. It can also be stated as the fulfillment of individual's values, ambitions and desires through the realization of their abilities (Felce & Perry, 1995).

Wellness could also be defined as quality of life. An individual who has a good quality of life efficiently performs all his duties towards his social life and himself. A community that is supportive in nature is needed to enhance the quality of life (Corbin, Welk, Corbin & Welk, 2006).

The operational definitions of the quality of life are versatile, the diversity is not only in terms of the perspectives either societal or individualistic but also by the variety of theoretic models. The diversity of the quality of life was addressed in many writings. It was stated that the definitions of quality of life are different in view of people studying this aspect, the individuals who were lacking in agreement to operationalize the concept was highlighted by this remark (Baker and Intagliata, 1982).

Quality of life is defined as the happiness that comes from personal experience. The subjectivity of QOL is to be recognized which would help in the better understanding of the concept. QOL explains the disparity between present experience and hopes and expectations of an individual. Humans adjustment is that life expectations are adapted within the possible perception of individual. Therefore, it is helpful in maintaining a reasonable quality of life even in their hard times (WHO, 2012).

According to World Health Organization (WHO), Quality of life is defined as the perception of individual about their life with reference to their culture and value systems in relation to their ambitions, standards, aspiration and concerns. It is a vast concept that is affected by the environment and its relationship with the individual's health either physical or psychological, the level of freedom, social relationships or schemas (WHO, 2010).

Definitions of Dimensions of Quality of Life

Physical functioning. A decreased level of disease which enables the individual to perform one's duties effectively.

Psychological functioning. A sound condition of one's mind that enables him to deal efficiently by good reasoning and thought processes.

Social Dimension. The social support provided by the surrounding of an individual to perform his/her daily activities effectively.

Environment. The environmental factors that influence and enhance the individual's perception of the quality of life. It includes culture, work status, resources of an individual, health service etc (WHO, 2012).

Conceptual models of quality of life

The conceptual model was made to illustrate the approach of Quality of life. The judgment of the objective situation by the individuals in different aspects of life in accordance to the comparison standards that are based on personal values and needs, expectations, reference group comparisons, justice and aspirations. The evaluation of the judgment is their achievement in that domain. The general sense of wellbeing is produced by the domain satisfaction. The mental health or individuals with disability are addressed in this model involving the individuals acting as mediator between satisfaction with life and experience of life. The bio-psycho component of their model refer to the distinguish elements: levels of need, set of attitudes and beliefs. (Baker & Intagliata, 1982). The elements within the self is listed as beliefs, rituals, ambitions and aspirations of his model (Parmenter, 1988).

The quality of life has been presented by the dimensions as: quality of one's life condition, satisfaction of one's with his life and a combination of both one's life

condition and satisfaction. The other is more significant than the former one as the quality of life in this dimension is depicted as a mixture of one's life conditions and satisfaction in accordance with the expectations, aspirations and personal values. The definition of the construct showed that quality of life and satisfaction with life are two separate phenomena. The one possible model could be the sum total range of objectively measurable experience of an individuals' life conditions including the physical health, living condition of one's life, social relationship, daily functional activities and broader in terms of economic and societal effects. The domain of personal satisfaction with life is a subjective response to such condition. The model could be interpreted from the argument that every citizen had the right to equality of opportunity and life rather than the right to satisfaction with life. The potential relationships and the subjective appraisals does not affect the personal satisfaction whereas it could be influenced by the life conditions. The population is assessed by the diversity of conditions of life to establish the general indicators of life. Thus, the quality of life of an individual would be noticed by considering the position of the individual on the total population distribution (Duffy, 1992).

The quality of life should consist of both objective and subjective assessment and it must be considered while to produce an overall appraisal by combining subjective assessment of individual across different life domains should be in accordance with the importance of individuals' position on particular aspect. The objective assessment could be done by same concept. The importance of objective life condition must consider an individual's set of values. The three-factor model was thus formulated in which the quality of life is determined by the interaction of personal values, life conditions and life satisfaction (Cummins, 1992).

The importance of an individual's place on a particular life domain elucidate the significance of the objective or subjective assessment. For example, an individual's quality of life whose values are non-materialistic would be highly effected by the satisfaction with income (i.e enough to meet personal needs) rather than the size of income (the objective measure).

The vast health status and the definitions of health related QoL overlap with one another including the role of functioning either physical or psychological and health perceptions. (Ware & Sherbourne, 1992).

The QoL is a multifaceted approach, vast than the health related or disease specific QoL. Therefore, it is significant in evaluating a whole person, proposing interventions or the conditions which can affect the individual's whole life which might involve the long term illnesses either mental or physical, specifically in older age. Thus, it can be stated that QoL includes more than health (Bowling, 2015).

The literature on social science on the wellbeing and satisfaction with life greatly influenced the vast models of QoL (Andrews & Withey, 2012).

The investigators use broader health status scales of Health- Related Quality of Life (HRQoL) as proxy measures due to the lack in agreement on optimal measurement instrument. Sometimes, the measures: symptoms: functioning either mental or physical, generic or disease specific QoL and wellbeing combine with the type of measures. In acceptance of the variety and the diverse range of measures used resulted in the new term i.e patient reported outcome measures PROMS (Fitzpatrick, Davey, Buxton & Jones, 1998) .

With the increase in caregiver burden, the worsen effect of Quality of life can be managed by the coping strategies. Coping plays a vital role in maintaining good quality of life and enables the caregiver to cope effectively with the stress.

Literature Review

The relationship between the Quality of life and Caregiver burden and can also be observed by the research by Jeong, Jeong, Kim and Kim, (2015) in which they found that the health status of the caregiver, their income, spouses of patients caring for them, and duration of hospitalization are the determinants of the Quality of life of the caregivers and the burden that is caused to them. The study suggested that a rehabilitation program must be organized that should be family-centered specifically for the spouses would lessen the effect of their burden. Furthermore, the caregivers must be provided with the support they are in need of whether financial or health related which would enhance their psychological well -being.

Another study shows that the QOL is effected by the caregiver burden. Hayes, Hawthorne, Farhall, O'Hanlon, & Harvey, (2015) showed that the caregivers isolate themselves and completely cut themselves from the social life, their distress increases with the passage of time and their QOL affected adversely. They reported that the caregiver burden is increased because of the stressors they face in their daily life.

Parekh et al. (2017) conducted a study in which they proved that involvement in religious activities improves the quality of life and reduces caregiver burden. The study was done on a the caregivers of the patients with Inflammatory Bowel Disease (IBD). The study reported that high level of caregiver burden and decrease in QOL existed in the caregivers. The severity of the disease influences the QOL of the caregivers. The female caregivers are more prone and vulnerable to experience caregiver burden. It was reported that the religious activities plays vital role in improving QoL. It was suggested by the study that caregiver's must be assist and helped to cope with the challenges of life they face every day by providing health care professionals either mental or physical.

The better coping strategies and interventions are necessary to reduce the caregiver burden which is proved in the study recently conducted. Stanley, Balakrishnan and Ilangovan (2017) indicates the need for intervention for family caregivers to enable them cope more effectively with the demands of care giving.

The caregiver burden is lessen by the good coping strategy and improves the quality of life. Chronister et al. (2016) in their research stated that elevated levels of burden, stress, and depression are faced by the caregivers of persons with traumatic brain injury frequently. The adverse impact of caregiver burden on QOL of the caregiver could be lessen by the positive personal and environmental support, particularly social support, professional/community supports, and mastery.

Cullagh, Brigstocke, Donaldson and Kalra (2005) conducted a study on Caregiver burden in determining the Quality of life in caregivers of the patients of stroke. They reported in their research that poor family support, advancing age and anxiety in caregivers and patients and high dependency identify caregivers at risk of adverse outcomes, which may be reduced by providing training to the caregivers.

They suggested that caregivers of the patients with severe disability and cognitive impairments should be included.

The study to find out the relationship between caregiver burden and Quality of life among the caregivers, and the characteristics of the caregiving situation which increase their risk of caregiver burden of stroke patients in Japan was conducted by Morimoto, Schreiner and Asano (2003). They reported that worsening health-related quality of life increase the risk of caregiver burden, specially mental health is affected by it.

The relationship between caregiver perceived burden and QOL with the mediating effect of the personal and environmental factors was studied by Chronister et al. (2016). The increased level of burden, depression and stress was reported by the caregivers of patients with traumatic brain injury was reported. They stated that the support both the personal or environmental support could reduce the negative effect on the QOL by the caregiver burden. It is suggested that the different types of social support must be investigated that are related to caregiver stressors.

Buono, Corallo, Bramanti and Marino (2015) in their research proved that the patients who adopted assimilative coping showed decreased QOL as compared to the patients who prefer accommodative or active coping after stroke. They suggested that the condition of caregivers can be improved by providing them the support either psychologically or by counseling.

Litzelman, Kent and Rowland (2018) conducted a study in which the relationship between coping strategies and caregiver burden is explored. They reported that the coping strategies and health related behaviors have a mutual relationship with the informal caregivers of patients with cancer. It is suggested that the understanding of the mechanisms linking the coping and health behaviors and organized into interventions that can influence the health of the caregivers and their families.

A research was conducted on the factors that are associated with caregiver burden by Sultan, Fatima, Kanwal and Khurram (2017). The role of the various coping styles of caregivers was affirmed to deal with the burden faced by the

caregivers in providing the necessary care. They also reported that the effects of the characteristics of caregivers are moderated by the coping strategies.

Raggi, Tasca, Panerai, Neri and Ferri (2015) conducted a research on the burden of distress and related coping strategy on the family caregivers of the patients with Alzheimers disease. They reported that the severity of the impairment (cognitive, psychological, behavioral or motor) of the patients with Alzheimer's disease strongly influence the distress level or burden of the caregivers.

A research was conducted on the gender, coping and psychological wellbeing in the spouses of the caregivers by Borden and Berlin (1990). It was reported in the research that women are more likely to experience distress than men in the context of illness.

Kramer and Kipnis (1995) conducted a study on the gender differences in caregiving tasks and the burden they produced. It was reported that the assistance with care provision task are related with the females and they experience higher level of caregiver burden than men.

The determinants in family members of terminally ill cancer patients and the gender differences in caregiver burden were studied. In which, it was reported that the caregiver burden in females is significantly higher (Schrank et al., 2016).

Iavarone et al., (2014) conducted a research which addresses the burden on the caregivers of patients with the diseases either Dementia or Alzheimer's. It reported that the caregiver burden will be higher in the caregivers of patients with dementia. It also stated that the level of severity of the disease i.e dementia influence the burden on the caregivers.



Rationale of the Study

Caregiver burden is a huge issue which affects the Quality of life of the caregiver. There are factors that provide help to decrease the possibility of the burden perceived by the caregivers. These include the help from other family members, the ability to use problem-focused coping strategies and Availability of support from the community. Pakistan is a state with a collectivistic culture. The scenarios are quite complex. The patient lives with the family and is cared by the family members which increases their responsibility. Along with providing care to the patient, they also suffer from financial burden, tiresome. In Pakistan there is lack of published work on Quality of life and Caregiver burden because caregiver burden is ignored and the only focus remains on the patient himself.

Caregiver burden and Quality of life is studied worldwide, and in Pakistan also but not with the protective factor of coping strategies. Therefore present study is needed to explore the relationship between caregiver burden, coping strategies and Quality of life of caregivers of diagnosed patients with Alzheimers and Dementia. All these constructs are really important and need to be studied. Moreover, study aim at exploring the differences across different demographics and study variables.

Imran et al. (2010) conducted a study on the Quality of life, mental health and family burden of the caregivers of patients with mental illnesses in which they proved that the caregivers of such patients suffers from impaired QOL. The caregivers should be screen out by the health care professionals for early interventions.

This research has significant value, as it will provide information regarding different aspects of caregiver burden, coping strategies and quality of life in Pakistani cultural context. The issues like caregiver burden are at least discussed by the researchers and layperson in our society that may cause them to be insensitive in understanding and dealing with the caregivers and the problems related to this aspect. This study may prove to be an initiative towards raising awareness among the families with the patient of chronic ailment and to provide psychological help to the caregivers to lessen their caregiver burden and improve quality of life by adopting good coping strategies.

Method

Objectives of the study

To study the relationships between caregiver burden, coping strategies and Quality of life among the caregivers of patients with Alzheimers and Dementia.

1. To investigate the relationship between caregiver burden, coping strategies and Quality of life.
2. To investigate the role of various demographics (age, gender, SES) in relation to study variables.

Hypotheses

1. Caregiver burden will be negatively associated with Quality of life.
2. Coping strategies will be positively associated with quality of life.
3. Caregiver burden will be negatively associated with coping strategies.
4. Caregiver burden will be higher in female caregivers of patients with Alzheimers and Dementia.
5. Caregiver burden will be higher in the caregivers of patients with Dementia than Alzheimers.
6. Quality of life of male caregivers will be better than the female caregivers.
7. Coping strategies will improve in the late adulthood.

Operational definitions

Caregiver burden. An unpleasant condition of the caregiver i.e restlessness and tiresome that resulted after providing necessary care is known as caregiver burden (Zarit et al., 1980). The greater caregiver burden is indicated by high scores (Graessel, Berth, Lichte & Grau, 2013).

Coping strategies. A specific set of positive or negative actions or thoughts that is triggered by the endangered situation or stressors is termed as coping. (Compass, Smith, Saltzman, Thomsen, & Wadsworth, 2001). The use of the specific

coping strategy is indicated by the high score on that particular coping strategy (Hastings et al., 2005).

Quality of life. Quality of life is defined as the realization of the abilities or lifestyle as the satisfaction of human values, goals and desires (Emerson, 1985). High scores indicate higher quality of life in that particular domain.

Sample

For the study, a sample of 60 caregivers (26 men and 34 women) of patients with Alzheimers and Dementia patients were addressed. Age of participants ranged from 17-57 years. The non probability purposive sampling technique was used that means the sample with specific characteristics was addressed. In the present study, the caregivers of diagnosed patients with Alzheimers and Dementia were catered. The frequency of participants in each demographics category is presented in the following table.

Table 1

Demographic Characteristics of the Sample (N = 60).

Demographics	<i>f</i>	%
<i>Information about caregiver</i>		
Age		
17-37 (young adulthood)	44	73.3
38-57 (middle adulthood)	16	26.6
Gender		
Men	26	43.3
Women	34	56.7
Relationship with the patient		
Spouse or partner	8	13.3
Adult child	26	43.3
Other family member/ friend	26	43.3
Lives with patient		
Yes	56	6.7
No	4	93.3
No. of years providing care		
Less than 2 years	17	28.3
2-5 years	16	26.7
More than 5 years	27	45.0
General health of caregiver		
Good	42	70.0

Excellent	7	11.7
Fair/poor	11	18.3
Marriage		
Single	25	41.7
Married	35	58.3
Widow/er	0	0
Divorced	0	0
Employment		
Full time	14	23.3
Part time	15	25.0
Not working	31	51.7
Income		
Less than 25,000	15	25.0
25,000-50,000	22	36.7
More than 50,000	23	38.3
Education level		
Secondary (Matric, Inter)	23	38.3
Higher (bachelors & above)	37	61.7
<u>Individual with Dementia/</u>		
<u>Alzheimer</u>		
Disease		
Alzheimers	32	53.3
Dementia	28	46.7
Comorbidity		
Yes	37	61.7
No	23	38.3
Hospitalization time duration		
Nil	28	46.7
1-6 months	18	29.9
1-3 years	12	20.1

Table 1 shows the allocation of whole sample on the bases of the characteristics of caregiver and the information related to the patient with Alzheimer or Dementia. Characteristics of the caregiver includes Age, gender, relationship with the patient, living with the patient, no. of years providing care, general health, marital status, employment status, income and education level. Ages of the participants range from (15-60). Educational levels of the participants were range from secondary (Matric and intermediate) to high (Bachelors and above). The details regarding the patient includes the disease, co morbid condition and hospitalization time duration. The total sample was consisted of 60 caregivers.

Instruments

Caregiver Burden on Family Caregivers (BSFC). Graessel et al. (2003) developed the short version (BSFCs) of the Burden Scale for Family Caregivers. The scale consisted of 10 items. It is a scale of 4 point rating with ranges of scores from “strongly agree” to “strongly disagree”. Overall score range is (0-30) scores. There is no subscale or reverse item. The alpha reliability of the scale is 0.92 (Bortz and Doring, 2006). (Appendix C)

Quality of life Questionnaire (WHO-QOL-BREF). The questionnaire was developed on WHO-Quality of life by Power (2003). The Urdu version of the scale was translated by Khan, Akhtar, Ayub, Alam and Leghari, in 2003. It was translated in Urdu by. It is a scale with 5 point ratings. Scoring categories range from (strongly disagree) to (strongly agree). No cut off scores exist in the scale, it is indicated therefore that high quality of life is indicated by high scores. The questionnaire consists of 26 items and comprise of four subscales. item numbers (3,4,10,15,16,17 and 18) measures the Physical functioning. Item numbers (5,6,7,11,19 and 26) measures the Psychological health. Social relationship is measured by item numbers (20,21 and 22). item number (8,9,12,13,14,23,24 and 25) measures the Environmental functioning. Item No. 3,4 and 26 are reverse score items. The alpha reliabilities of the subscales are Physical functioning (.80), psychological health (.76), social relationship (.66) and environmental functioning is (.80) (WHOQOL User Manual, 1998). (Appendix D)

Brief COPE. Carver (1989) originally developed the scale of brief COPE to measure the coping strategies. Akhtar (2005) translated the scale into Urdu version. It consists of 28 items, that are arranged in a 4 point Likert type scale (1= Never, 2= very less, 3 = sometimes and 4= a lot). Factor structure of Hastings et al. (2005) for Brief COPE is used in the present research. Reported four scales namely: Problem focused coping, Active avoidance coping, Religious denial coping and positive coping. Problem focused coping include items from original brief COPE scale subscales planning active coping, seeking instrumental social support and one item from seeking emotional support scale (Item no 2,5,7,10,14,23 and 25). Active

avoidance coping include all items from original brief COPE scale subscales for substance use , behavioral disengagement, self-blame, venting of emotions and one item from the distraction scale (item no 1,4,6,9,11,13,16,19,21 and 26). Religious denial coping in the mixed factor that included all the brief cope item for religious denial (item no 3,8,22 and 27). Positive coping includes items from the subscales of Brief COPE for the use of humor and positive reframing and one item each from the acceptance and emotional support scale (item no 12,15,17,18,20,24 and 28). Low scores on each subscale indicate less use of that coping strategy and high score indicate the more use of that coping strategy (Carver, 1997). (Appendix E)

Procedure

For the present study, data was collected from Benazir Bhutto Hospital, Armed forces of Institute for Rehabilitation Medicine (AFIRM), Armed Forces Institute of Mental Health (AFIMH) and Pakistan Institute of Medical Sciences (PIMS) of Rawalpindi and Islamabad. Firstly, executive director was informed about the purpose of research. After taking the official permission from respective hospitals, caregivers of the diagnosed patients with Alzheimers and Dementia were approach individually. They were informed about the aim of the study and their willingness was required and assured about the confidentiality of obtained information. They were also instructed that their participation is voluntarily, if they feel uncomfortable, they can quit at any time.

After their agreement of participants in study they were given booklet containing the questionnaires with some demographic information and guided in case of having some issues in understanding of the questionnaire. Participants were requested to fill the questionnaire honestly and accurately. However, there was no time restriction for completion of the questionnaire, but respondents took 20-25 minute approximately to fill the questionnaire.

Results

The present study was carried out to compare the caregiver burden, Quality of life and coping strategies of caregivers of patients with Alzheimers and Dementia, To check internal consistency of the scales, Cronbach Alpha reliability coefficient was computed. In order to test the hypotheses of the study, *t*-test was applied.

Table 2

Descriptive Statistics and Alpha Reliability Coefficients of Scales (N = 60).

Scale	Items	<i>M</i>	<i>SD</i>	<i>a</i>	Range		Skewness	Kurtosis
					Actual	Potential		
CGB	10	19.15	4.53	.85	6-27	0-30	-.66	.85
QOL	26	74.10	13.56	.90	50-101	26-130	.63	-.79
PHF	7	21.32	3.72	.73	11-30	7-35	-.04	1.18
PSF	6	14.70	1.65	.49	10-18	6-30	-.69	.66
SOF	3	8.63	2.53	.54	3-13	3-15	-.18	-.95
ENF	8	15.82	4.59	.87	10-26	8-40	.99	-.05
BCT	28	74.03	8.93	.78	50-89	28-112	-.50	.74
AAC	10	24	2.93	.28	15-28	10-40	-.70	.40
PFC	7	20.50	4.03	.75	10-26	7-28	-.56	-.06
PCS	7	18.88	3.14	.57	14-25	7-28	.20	-1.02
RDC	4	10.65	1.98	.46	5-14	4-16	-.52	.70

Note. CGB = Caregiver burden, QOL = Quality of Life, PHF= Physical functioning, PSF= psychological functioning, SOF= Social functioning, ENF= Environmental functioning, BC = Brief coping, AA = Active avoidance coping, PF= Problem focused coping, PC = Positive coping and RD= Religious/ Denial coping.

Table 2 showed the alpha reliability, mean, standard deviation, range, skewness and Kurtosis of scales. Reliabilities of Caregiver burden scale, Quality of life and coping strategies were found to be in acceptable range. The skewness and kurtosis of scales were found in desired range of -2 to +2.

Table 3*Correlation Matrix for Study Variables Caregiver burden, Quality of life and coping strategies(N = 60).*

Variables	1	2	3	4	5	6	7	8	9	10	11
1 CGB	-	-.53**	-.72**	.45**	-.17	-.61**	-.23	-.09	-.14	-.38**	-.03
2 QOL		-	.78**	-.08	.63**	.80**	.24	.24	.10	.36**	-.05
3 PHF			-	-.02	.44**	.65**	.26*	.18	.15	.34**	.07
4 PSF				-	.13	-.43**	-.02	.08	.00	-.17	.02
5 SOF					-	.50**	.25*	.35**	.07	.32*	-.01
6 ENF						-	.22	.11	.05	.39**	.11
7 BCT							-	.73**	.80**	.79**	.51**
8 AAC								-	.44**	.39**	.31*
9 PFC									-	.51**	.13
10 PCS										-	.37**
11 RDC											-

Note. CB = Caregiver burden, QOL = Quality of Life, PHF= Physical functioning, PSF= psychological functioning, SOF= Social functioning, ENF= Environmental functioning, BC = Brief coping, AA = Active avoidance coping, PF= Problem focused coping, PC = Positive coping and RD= Religious/ Denial coping.

Table 3 revealed inter-correlation of all the variables which determine the direction and strength of relationships across all the study variables. It showed the significant negative relationship between Caregiver burden and Quality of Life. It is found that increase in Caregiver burden results in the decrease in the Quality of life. Furthermore, table shows that the decrease in caregiver burden will enhance the physical functioning and decreases the environmental functioning. Moreover, Increase in caregiver burden lessen the use of positive coping. Quality of life shows positive significant relationship with the Coping strategies i.e increase in positive coping will result in the better Quality of life.

Table 4

Linear Regression Analysis for Study Variable (Caregiver Burden) Predicting Quality of Life (N=60)

Variables	<i>B</i>	<i>S.E</i>	β	QOL	
				95 % CI	
				<i>LL</i>	<i>UL</i>
Constant	99.03			87.02	111.04
CB	-1.28	.29	-.49	-1.87	-.68
R ²	0.24				
F	18.47				

Note. CB = Caregiver burden scale and QOL=Quality of Life.

Table 4 indicates the role of caregiver burden for predicting overall quality of life. A linear regression was run to get the prediction of Quality of life from caregiver burden. It is indicated by the results that 24% variance in Quality of life is ascribed by the predictor (i.e Caregiver burden).

Table 5

Linear Regression Analysis for the Study Variable (Brief cope) predicting Quality of life (N=60).

Variables	B	S.E	β	QOL	
				95 % CI	
				LL	UL
Constant	46.98			18.12	75.84
BC	.36	.19	-.49	-.02	.75
R ²	0.58		.52		
F	3.58		-.72		

Note.BC= Brief COPE and QOL= Quality of Life.

Table 5 indicates role of Brief cope scale for the predicting overall Quality of life. Results indicated that 58% variance in Quality of life is ascribed by the predictor i.e Brief Cope.

Table 6

Mean, Standard deviation and t- values of Study Variables along Participant's age (N=60)

Variables	Young adulthood		Middle adulthood		<i>t</i>	<i>p</i>	95 % CI	
	17-37		37-57				<i>LL</i>	<i>UL</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>				
CGB	19.61	3.79	17.88	6.08	1.32	.19	-.89	4.37
QOL	73.82	13.29	74.88	14.69	-.26	.79	-9.04	6.93
PHF	21.20	2.76	21.63	5.70	-.38	.70	-2.61	1.77
PSF	14.82	1.66	14.38	1.62	.91	.36	-.52	1.40
SOF	8.50	2.70	9.00	2.00	-.67	.50	-1.98	.98
ENF	15.70	4.36	16.13	5.30	-.31	.75	-3.12	2.28
BCS	72.18	8.31	79.13	8.86	-2.8	.00	-11.88	-2.00
AAC	23.55	3.12	25.25	1.91	-2.04	.04	-3.37	-.03
PFC	19.64	3.90	22.88	3.48	-2.92	.00	-5.45	-1.02
PCS	18.43	2.84	20.13	3.66	-1.88	.06	-3.49	.10
RDC	10.57	1.98	10.88	2.02	-.57	.60	-1.47	.85

Note. CGB = Caregiver burden, QOL = Quality of Life, PHF= Physical functioning, PSF= psychological functioning, SOF= Social functioning, ENF= Environmental functioning, BC = Brief coping, AA = Active avoidance coping, PF= Problem focused coping, PC = Positive coping and RD= Religious/ Denial coping

Table 6 shows *t*-test was computed to look across the age of the caregiver (Young and Late adulthood) among the study variables that are Caregiver burden scale, Quality of life and brief cope scale. Result shows that mean of Coping is more effected in young adulthood (M=72.18, SD=8.31) which is greater in late adulthood (M=79.13, SD=8.86). Active avoidance coping and the Problem focused is most used in the caregivers in young adulthood.

Table 7

Mean, Standard deviation and t- values of Study variables along Participant's gender (N=60)

Variables	male (n=26)		female (n=34)		<i>t</i>	<i>p</i>	95 % CI	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			<i>LL</i>	<i>UL</i>
CBT	18.46	5.57	19.68	3.54	-1.02	.30	-3.57	1.14
QOL	76.92	14.91	71.94	12.22	1.42	.16	-2.03	11.99
PHF	22.35	3.74	20.53	3.57	1.91	.06	-.08	3.71
PSF	14.85	1.93	14.59	1.41	.59	.55	-.60	1.12
SOF	9.46	2.24	8.00	2.58	2.29	.02	.18	2.73
ENF	16.19	4.30	15.53	4.83	.55	.58	-1.74	3.07
BCT	74.92	9.94	73.35	8.17	-.67	.50	-3.11	6.25
AAC	24.73	3.10	23.44	2.71	1.71	.09	-.21	2.79
PFC	20.19	4.19	20.74	3.94	-.51	.60	-2.65	1.57
PCS	18.88	3.64	18.88	2.76	.00	.99	-1.65	1.65
RDC	11.12	1.86	10.29	2.02	1.61	.11	-.19	1.84

Note. CGB = Caregiver burden, QOL = Quality of Life, PHF= Physical functioning, PSF= psychological functioning, SOF= Social functioning, ENF= Environmental functioning, BC = Brief coping, AA = Active avoidance coping, PF= Problem focused coping, PC = Positive coping and RD= Religious/ Denial coping

Table 7 shows that *t*-test was computed to look across the gender of the caregiver (male and female) among the study variables that are Caregiver burden scale, Quality of life and brief cope scale. Result shows that mean of Caregiver burden is low in males i.e (M=18.46, SD=5.57) and higher in females i.e (M=19.68, SD=3.54). Quality of life in males (M=76.92, SD=14.91) is better than females (M=71.94, SD=12.22) and the results of Brief cope scale in males shows that coping in males (M=74.92, SD=9.94) is better than females (M=73.35, SD=8.17)

Table 8

Mean, Standard deviation and t- values of Study variables along Participant's disease (N=60)

Variables	Alzheimers		Dementia		<i>t</i>	<i>p</i>	95% CI	
	(n=32)		(n=28)				<i>LL</i>	<i>UL</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>				
CGB	19.53	4.33	18.71	4.79	.69	.49	-1.54	3.17
QOL	73.38	11.96	74.93	15.37	-.44	.66	-8.62	5.52
PHF	21.28	2.60	21.36	4.74	-.07	.93	-2.02	1.87
PSF	15.00	1.48	14.36	1.78	1.52	.13	-.20	1.48
SOF	8.50	2.74	8.79	2.29	-.43	.66	-1.60	1.03
ENF	15.25	3.84	16.46	5.31	-1.02	.31	-3.59	1.16
BCT	71.53	8.69	76.89	8.47	-2.41	.01	-9.81	-.90
AAC	23.22	3.37	24.89	2.04	-2.28	.02	-3.14	-.20
PFC	19.09	3.58	22.11	3.96	-3.09	.00	-4.96	-1.06
PCS	18.78	3.12	19.00	3.22	-2.67	.79	-1.86	1.42
RDC	10.44	2.07	10.89	1.87	-.88	.37	-1.48	.57

Note. CGB = Caregiver burden, QOL = Quality of Life, PHF= Physical functioning, PSF= psychological functioning, SOF= Social functioning, ENF= Environmental functioning, BC = Brief coping, AA = Active avoidance coping, PF= Problem focused coping, PC = Positive coping and RD= Religious/ Denial coping

T-test was computed to look across the disease of the patients (i.e Alzheimer or Dementia) among the study variables that are Caregiver burden scale, Quality of life and brief cope scale. Result shows that mean of Caregiver burden is comparatively higher in Alzheimer i.e (M=19.53) than the patients with dementia i.e (M=18.71). Quality of life in caregivers of patients with alzheimers is lower (M=73.38) than patients with dementia (M=74.93) and the results of Brief cope scale in caregivers of Azheiners shows that coping is comparatively poor (i.e M=71.53) than the caregivers of patients with dementia (M=76.89).

Table 9

Mean, Standard deviation and t- values of Study variables along Participant's disease Comorbidity (N=60)

Variables	Without comorbidity		With comorbidity		<i>t</i>	<i>p</i>	95% CI	
	(n=23)		(n=37)				<i>LL</i>	<i>UL</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>				
CBT	19.61	3.75	18.86	4.99	.61	.54	-1.68	3.16
QOL	72.83	11.25	74.89	14.91	-.57	.57	-9.31	5.18
PHF	21.52	2.33	21.19	4.40	.33	.74	-1.66	2.32
PSF	15.00	1.00	14.51	1.93	1.11	.27	-.38	1.36
SOF	8.17	2.65	8.92	2.44	-1.11	.27	-2.08	.59
ENF	15.26	4.16	16.16	4.85	-.73	.46	-3.35	1.54
BCT	71.91	5.75	75.35	10.29	-1.46	.14	-8.14	1.26
AAC	22.57	2.88	24.89	2.62	-3.21	.00	-3.37	-.87
PFC	20.61	2.99	20.43	4.59	.16	.87	-1.98	2.33
PCS	18.52	2.52	19.11	3.49	-.69	.48	-2.26	1.09
RDC	10.22	1.67	10.92	2.12	-1.34	.18	-1.74	.34

Note. CGB = Caregiver burden, QOL = Quality of Life, PHF= Physical functioning, PSF= psychological functioning, SOF= Social functioning, ENF= Environmental functioning, BC = Brief coping, AA = Active avoidance coping, PF= Problem focused coping, PC = Positive coping and RD= Religious/ Denial coping.

T-test was computed to look the comorbidity (i.e with or without comorbidity) among the study variables that are Caregiver burden scale, Quality of life and brief cope scale. Result shows that mean of Caregiver burden is comparatively higher with patients without comorbidity i.e (M=19.61) than the patients with comorbidity i.e (M=18.86). Quality of life in caregivers of patients without comorbidity i.e (M=72.83) is less than patients with comorbidity (M=74.89) and the results of Brief cope scale shows that coping is good with the patients without comorbidity (M =71.91) and not much good with patients with comorbidity (M=75.35)

Table 10

Mean, Standard deviation and t- values Of Study variables along the Caregiver's Living Status with Patient (N=60)

Variables	Lives with the patient (n=56)		Does not live with the patient (n=4)		T	p	95% CI	
	M	SD	M	SD			LL	UL
CGB	19.84	3.73	9.50	4.04	5.33	.00	6.45	14.22
QOLT	73.04	13.02	89.00	13.85	-2.36	.02	-29.50	-2.42
PHF	20.91	3.42	27.00	3.46	-3.43	.00	-9.63	-2.54
PSF	14.86	1.54	12.50	1.73	2.93	.00	.74	3.96
SOF	8.54	2.59	10.00	.00	-1.12	.26	-4.08	1.15
ENF	15.38	4.29	22.00	4.61	-2.96	.00	-11.09	-2.15
BCT	73.11	8.52	87.00	.00	-3.23	.00	-22.48	-5.29
AA	23.86	2.98	26.00	.00	-1.42	.16	-5.15	.87
PF	20.11	3.88	26.00	.00	-3.01	.00	-9.81	-1.97
PC	18.59	3.05	23.00	.00	-2.87	.00	-7.48	-1.33
RD	10.55	2.01	12.00	.00	-1.42	.16	-3.48	.58

Note. CGB = Caregiver burden, QOL = Quality of Life, PHF= Physical functioning, PSF= psychological functioning, SOF= Social functioning, ENF= Environmental functioning, BC = Brief coping, AA = Active avoidance coping, PF= Problem focused coping, PC = Positive coping and RD= Religious/ Denial coping.

T-test was computed to look the status of living with the patient (i.e lives with the patient or not) among the study variables that are Caregiver burden scale, Quality of life and brief cope scale. Result shows that mean of Caregiver burden is greater of the caregivers living with the patients than the caregivers not living with the patients. Quality of life of the caregivers living with the patients is more negatively affected than the caregivers who does not lives with the patient and the results of Brief cope scale shows that coping is poor of the caregivers living with the patient than the caregivers living far from the patients.

Discussion

The present study was aimed at exploring the relationship between Caregiver burden, coping and Quality of life of family caregivers of patients with Alzheimers and Dementia. The study further investigates the differences among age, gender, disease, comorbid conditions, relationship with the patient, number of years providing care, general health of caregiver, marital status, employment status, income, education level and hospitalization time duration.

The first hypothesis of this study was that caregiver burden will negatively correlate with the Quality of life of the caregiver. Inter-correlation of all the variables and then dimension of correlation matrix is generated to determine the direction and strength of relationships across all the study variables. It is found that Caregiver burden scale is significantly negatively correlated with Quality of life. (See Table 2). According to a previous research it was found out that Caregiver QOL had a significant inverse correlation with caregiver burden (Mc Cullagh, Brigstocke, Donaldson, & Kalra, 2005). Another research stated that caregiver burden is significantly related to the health related quality of life. (Morimoto, Schreiner and Asano, 2003). The results of the present study give support to the earlier researches. The overburdened caregiver would suffer a poor quality of life as he would be too occupied in giving care to the patient and would have less time for his own self. The whole life of the individual would surround with the patient, his health, both psychological and physical would be effected.

The second hypothesis was that the coping strategies are positively associated with the quality of life. Correlation was computed for the caregiver burden, quality of life and scores on coping strategies. Results showed that coping is inversely correlated with caregiver burden and positively correlated with quality of life. (See Table 2). A research was also conducted which stated that caregiver burden is lessen by the good coping strategy and improves the quality of life. (Chronister et al., 2016). Researches showed that coping strategies such that active or accommodative were used by patients enhances their quality of life in relationship to the assimilative coping. (Buono et al., 2015). The earlier researches explored the relationship between



caregiver burden and coping strategies as it stated that health behaviors and coping strategies were interrelated among informal cancer caregivers. (Litzelman, Kent & Rowland, 2018). So the result of present study is in line to the earlier researches. In my view, when the individual is good at coping, the burden would less effect his QOL because he would be able to cope with good coping strategies whereas, if the maladaptive coping strategies or denial would result in the poor QOL.

The third hypothesis was that caregiver burden is negatively associated with coping strategies. The results showed significant negative correlation between caregiver burden and Positive coping (i.e $-.38^{**}$).The present findings added to the literature by affirming the role of caregivers coping ways in dealing with their burden. (Sultan, Fatima, Kanwal & Khurram, 2017). Caregiver burden is directly affected by the coping styles, consistent with existing literature. The severity of caregiver distress was correlated with specific coping strategies, such as seeking for social support, using avoidance behaviors and focusing on problems. (Raggi, Tasca, Panerai, Neri & Ferri, 2015).The coping styles play an important role to increase or decrease burden. The overburdened caregiver with good coping styles would definitely find a way to deal with the stressor effectively without making the stressor effect his functioning. Whereas, the individual with maladaptive coping styles would never lessen the burden in long term that is why caregiver burden is negatively associated with the coping strategies.

Fourth hypothesis states that females are more likely to be burdened by the caregiving. According to a previous research depression and levels of burden are higher in the females (Borden & Berlin, 1990). According to previous researches, females are more likely to experience higher levels caregiver burden than males (Kramer & Kipnis, 1995). Another research reported that burden was significantly higher in females. (Schrank et al., 2015). Females are overburdened with the household chores as well as providing care to the patient all day long without any rest leaves her all alone and restless. She does not have time for herself which makes her quality of life miserable.

The fifth hypothesis was that caregiver burden will be higher in the caregivers of the patients with dementia. According to a previous research, the burden was highly influenced by the severity of dementia (Iavarone et al., 2014).

Lastly, hypothesis states that coping improves in the late adulthood. The previous study suggested that defenses grew more adaptive from midlife to late life. (Joy et al., 2017). In my view, coping improves with the passage of time, experience of life enables the individual to see things from different perspective and to adapt optimistic approach. They are more practical in life and are comparatively in a better condition to deal with the stressors.

The present study was aimed to study the relationship between Caregiver burden, coping and Quality of life of family caregivers of patients with Alzheimers and Dementia. The results showed that the coping in caregivers of Azheimers is significantly poorthan the caregivers of patients with dementia. The results showed no significant difference between mean scores of Alzheimers and Dementia on caregivers burden scale and Quality of life.

One objective is to investigate the role of various demographics in relation of study variables. Results were computed to look across the age of the caregiver (young adulthood and middle adulthood) among the study variables that are Caregiver burden scale, Quality of life and brief cope scale. Results of the study shows that there is significantly less coping in young adulthood and is greater in late adulthood. The subscales of coping i.e active avoidance coping, problem focused coping and positive coping also showed significant results with the differences in age.

Results were computed to look across the gender of the caregiver (male and female) among the study variables that are Caregiver burden scale, Quality of life and brief cope scale. Results showed significant good Quality of life of men on the two subscales of QOL i.e Physical functioning and social functioning. Results were computed to look the comorbidity condition (i.e with or without comorbidity) among the study variables that are Caregiver burden scale, Quality of life and brief cope scale. Results of the study showed significant results with the subscale of brief COPE i.e active avoidance coping and states that active avoidance coping is good in the caregivers of patients without the comorbidity.

Results were computed to look the status of living with the patient (i.e lives with the patient or not) among the study variables that are Caregiver burden scale, Quality of life and brief cope scale. Many significant results were reported. Caregiver

burden in the caregivers living with the patient showed significant higher results than the caregivers living far from the patients. Research reported that informal caregivers living with the patients had greater burden than the relatives who live far away (Chumblor, Grimm, Cody & Beck, 2003). Similarly, results of the study reported that quality of life living far from the patients is significantly better than the caregivers living with the patient. The subscales of quality of life also show significant results. i.e physical, psychological and environmental functioning. The caregivers of patients living far from the patients also shows significantly good coping rather than the caregivers living with the patients.

After analyzing the results one can arrive a conclusion that quality of life and caregiver burden showed a strong relationship and coping strategies plays a mediating role. This study was mainly carried out to check the caregiver burden, coping styles and Quality of life of the family caregivers of patients with Alzheimers and Dementia. It gives us the concrete evidence that caregiver burden and coping strategies are correlated that effects the quality of life of the caregivers.

Implications and Limitations

- 1- Health care professionals should screen out the caregivers of patients with mental illnesses.
- 2- Educating caregivers about the disease and teaching caregiver about the effective coping strategies that would provide benefit to them in a longer run.
- 3- The results cannot be generalized on the wider population because the investigation includes the caregivers of patients with Alzheimers and Dementia only of Rawalpindi and Islamabad.
- 4- The data collected from the caregivers were merely quantitative, the interview or qualitative technique might be helpful in providing the accurate information of the condition of the caregivers and their stressors.

Suggestions for further research

- 1- Studies on caregiver burden in Pakistan should further explore the role of physical/biological and cultural factors.
- 2- More qualitative data are also needed to elaborate caregiver's experiences and coping mechanisms.
- 3- Constructs related to caregiver burden should be observed within nomological frameworks of well-established theories where multiple variables operate together in naturally occurring settings.

References

- Al Gamal, E., Alhosain, A., & Alsunaye, K. (2018). Stress and coping strategies among Saudi nursing students during clinical education. *Perspectives in psychiatric care, 54*(2), 198-205.
- Akhtar, M. (2005). *Coping strategies and relationship with stress and time demands among university students*. Unpublished master's thesis. National institute of Psychology, Quaid-i-Azam University.
- Alliance, F. C. (2006). *Caregiver assessment: principles, guidelines and strategies for change: Report from a National Consensus Development Conference*. Family Caregiver Alliance.
- Andersson, G., & Willebrand, M. (2003). What is coping? A critical review of the construct and its application in audiology. *International journal of audiology, 42*(sup1), 97-103.
- Andrews, F. M., & Withey, S. B. (2012). Social indicators of well-being: Americans' perceptions of life quality. Springer Science & Business Media.
- Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in nursing & health, 13*(6), 375-384.
- Aronson, K. J. (1997). Quality of life among persons with multiple sclerosis and their caregivers. *Neurology, 48*(1), 74-80.
- Baker, F., & Intagliata, J. (1982). Quality of life in the evaluation of community support systems. *Evaluation and program planning, 5*(1), 69-79.
- Borden, W., & Berlin, S. (1990). Gender, coping, and psychological well-being in spouses of older adults with chronic dementia. *American Journal of Orthopsychiatry, 60*(4), 603-610.
- Borthwick-Duffy, S. A. (1992). Quality of life and quality of care in mental retardation. In *Mental retardation in the year 2000*(pp. 52-66). Springer, New York, NY.

- Bowers, B. J. (1987). Intergenerational caregiving: adult caregivers and their aging parents. *ANS. Advances in nursing science*, 9(2), 20-31.
- Bowling, A., Rowe, G., Adams, S., Sands, P., Samsi, K., Crane, M., ...&Manthorpe, J. (2015). Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales. *Aging & mental health*, 19(1), 13-31.
- Braithwaite, V. (1996). Understanding stress in informal caregiving: Is burden a problem of the individual or of society?. *Research on Aging*, 18(2), 139-174.
- Brod, M., Stewart, A. L., Sands, L., & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: the dementia quality of life instrument (DQoL). *The Gerontologist*, 39(1), 25-36.
- Brookmeyer, R., Johnson, E., Ziegler-Graham, K., &Arrighi, H. M. (2007).Forecasting the global burden of Alzheimer's disease. *Alzheimer's & dementia: the journal of the Alzheimer's Association*, 3(3), 186-191.
- Butcher, H. K., Holkup, P. A., &Buckwalter, K. C. (2001).The experience of caring for a family member with Alzheimer's disease. *Western Journal of Nursing Research*, 23(1), 33-55.
- Campbell, J., & Ehlert, U. (2012). Acute psychosocial stress: does the emotional stress response correspond with physiological responses?. *Psychoneuroendocrinology*, 37(8), 1111-1134.
- Carver, C. S. (1997). You want to measure coping but your protocol'too long: Consider the brief cope. *International journal of behavioral medicine*, 4(1), 92.
- Carver, C. S., Scheier, M. F., &Weintraub, J. K. (1989).Assessing coping strategies: a theoretically based approach. *Journal of personality and social psychology*, 56(2), 267.
- Cho, E. (2007). A proposed theoretical framework addressing the effects of informal caregivers on health-related outcomes of elderly recipients in home health care. *Asian nursing research*, 1(1), 23-34.

- Chronister, J., Johnson, E. T., Chan, F., Tu, W. M., Chung, Y. C., & Lee, G. K. (2016). Positive person–environment factors as mediators of the relationship between perceived burden and quality of life of caregivers for individuals with traumatic brain injuries. *Rehabilitation Counseling Bulletin*, 59(4), 235-246.
- Chumbler, N. R., Grimm, J. W., Cody, M., & Beck, C. (2003). Gender, kinship and caregiver burden: the case of community-dwelling memory impaired seniors. *International journal of geriatric psychiatry*, 18(8), 722-732.
- Chwalisz, K. (1996). The Perceived Stress Model of Caregiver Burden: Evidence from spouses of persons with brain injuries. *Rehabilitation Psychology*, 41(2), 91.
- Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry: A journal of the psychiatry of late life and allied sciences*, 23(9), 929-936.
- Corallo, F., Bonanno, L., De Salvo, S., Giorgio, A., Rifichi, C., Buono, V. L., ... & Marino, S. (2015). Effects of counseling on psychological measures in caregivers of patients with disorders of consciousness. *American journal of health behavior*, 39(6), 772-778.
- Corbin, C.B., Welk, G.J., Corbin, W.R., Welk, K.A. (2006). *Health, wellness, fitness, and healthy lifestyles: An introduction, concept of fitness and wellness* (6th ed). New York: McGraw-Hil.
- Cronin, J., Arnstein, P., & Flanagan, J. (2015). Family members' perceptions of most helpful interventions during end-of-life care. *Journal of Hospice & Palliative Nursing*, 17(3), 223-228.
- Doornbos, M. M. (1996). The strengths of families coping with serious mental illness. *Archives of Psychiatric Nursing*, 10(4), 214-220.
- Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of the American Association of Nurse Practitioners*, 20(8), 423-428.

- Felce, D., & Perry, J. (1995). Quality of life: Its definition and measurement. *Research in developmental disabilities, 16*(1), 51-74.
- Fitzpatrick, R., Davey, C., Buxton, M. J., & Jones, D. R. (1998). Evaluating patient-based outcome measures for use in clinical trials.
- Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. J. (1986). Dynamics of a stressful encounter: cognitive appraisal, coping, and encounter outcomes. *Journal of personality and social psychology, 50*(5), 992.
- García-Alberca, J. M., Lara, J. P., Garrido, V., Gris, E., Gonzalez-Herero, V., & Lara, A. (2014). Neuropsychiatric symptoms in patients with Alzheimer's disease: the role of caregiver burden and coping strategies. *American Journal of Alzheimer's Disease & Other Dementias, 29*(4), 354-361.
- Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005). The longitudinal effects of early behavior problems in the dementia caregiving career. *Psychology and Aging, 20*(1), 100.
- Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism, 9*(4), 377-391.
- Hayes, L., Hawthorne, G., Farhall, J., O'Hanlon, B., & Harvey, C. (2015). Quality of life and social isolation among caregivers of adults with schizophrenia: Policy and outcomes. *Community mental health journal, 51*(5), 591-597.
- Hope, T., Keene, J., Gedling, K., Fairburn, C. G., & Jacoby, R. (1998). Predictors of institutionalization for people with dementia living at home with a carer. *International journal of geriatric psychiatry, 13*(10), 682-690.
- Hunt, C. K. (2003). Concepts in caregiver research. *Journal of nursing scholarship, 35*(1), 27-32.
- Iavarone, A., Ziello, A. R., Pastore, F., Fasanaro, A. M., & Poderico, C. (2014). Caregiver burden and coping strategies in caregivers of patients with Alzheimer's disease. *Neuropsychiatric disease and treatment, 10*, 1407.

- Imran, N., Bhatti, M. R., Haider, I. I., Azhar, L., Omar, A., & Sattar, A. (2010). Caring for the caregivers: Mental health, family burden and quality of life of caregivers of patients with mental illness. *Journal of Pakistan Psychiatric Society*, 7(1), 23.
- Iseleso, M. K., Kajula, L., & Yahya-Malima, K. I. (2016). The psychosocial problems of families caring for relatives with mental illnesses and their coping strategies: a qualitative urban based study in Dar es Salaam, Tanzania. *BMC psychiatry*, 16(1), 146.
- Ismail, Z., & Mehmood, M. (1997). Situational coping and coping disruptions of Pakistan, Students in stressful transactions. *Pakistan Journal of Psychology*, 38, 3-25.
- Jeong, Y. G., Jeong, Y. J., Kim, W. C., & Kim, J. S. (2015). The mediating effect of caregiver burden on the caregivers' quality of life. *Journal of physical therapy science*, 27(5), 1543-1547.
- Jones, S. L. (1996). The association between objective and subjective caregiver burden. *Archives of Psychiatric Nursing*, 10(2), 77-84.
- Kajantie, E., & Phillips, D. I. (2006). The effects of sex and hormonal status on the physiological response to acute psychosocial stress. *Psychoneuroendocrinology*, 31(2), 151-178.
- Kartalova-O'Doherty, Y., & Doherty, D. T. (2008). Coping strategies and styles of family carers of persons with enduring mental illness: a mixed methods analysis. *Scandinavian journal of caring sciences*, 22(1), 19-28.
- Kasuya, R. T., Polgar-Bailey, M. P., & MPH Robbyn Takeuchi, M. S. W. (2000). Caregiver burden and burnout a guide for primary care physicians. *Postgraduate Medicine*, 108(7), 119.
- Keefe, F. J. (1982). Behavioral assessment and treatment of chronic pain: current status and future directions. *Journal of Consulting and Clinical Psychology*, 50(6), 896.

- Kramer, B. J., & Kipnis, S. (1995). Eldercare and work-role conflict: Toward an understanding of gender differences in caregiver burden. *The Gerontologist*, 35(3), 340-348.
- Landesman, S. (1986). Quality of life and personal life satisfaction: Definition and measurement issues. *Mental retardation*.
- Langa, K. M., Chernew, M. E., Kabeto, M. U., Regula Herzog, A., Beth Ofstedal, M., Willis, R. J., ...& Fendrick, A. M. (2001). National estimates of the quantity and cost of informal caregiving for the elderly with dementia. *Journal of general internal medicine*, 16(11), 770-778.
- Lawton, M. P., Kleban, M. H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology*, 44(3), P61-P71.
- Lazarus, R. S. (2006). *Stress and emotion: A new synthesis*. Springer Publishing Company.
- Lazarus, R.S. (1993), Coping theory and research: past, present and future, *Psychosomatic medicine*, 55, 234-247.
- Litzelman, K., Kent, E. E., & Rowland, J. H. (2018). Interrelationships Between Health Behaviors and Coping Strategies Among Informal Caregivers of Cancer Survivors. *Health Education & Behavior*, 45(1), 90-100.
- Martin-Joy, J. S., Malone, J. C., Cui, X. J., Johansen, P. Ø., Hill, K. P., Rahman, M. O., ... & Vaillant, G. E. (2017). Development of adaptive coping from mid to late life: a 70-year longitudinal study of defense maturity and its psychosocial correlates. *The Journal of nervous and mental disease*, 205(9), 685-691.
- Maurin, J. T., & Boyd, C. B. (1990). Burden of mental illness on the family: A critical review. *Archives of Psychiatric Nursing*, 4(2), 99-107.
- McCullagh, E., Brigstocke, G., Donaldson, N., & Kalra, L. (2005). Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke*, 36(10), 2181-2186.

- Morimoto, T., Schreiner, A. S., & Asano, H. (2003). Caregiver burden and health-related quality of life among Japanese stroke caregivers. *Age and Ageing, 32*(2), 218-223.
- Nijboer, C., Triemstra, M., Tempelaar, R., Sanderman, R., & van den Bos, G. A. (1999). Measuring both negative and positive reactions to giving care to cancer patients: psychometric qualities of the Caregiver Reaction Assessment (CRA). *Social science & medicine, 48*(9), 1259-1269.
- Olbrisch, M. E., Benedict, S. M., Ashe, K., & Levenson, J. L. (2002). Psychological assessment and care of organ transplant patients. *Journal of Consulting and Clinical Psychology, 70*(3), 771.
- Ong, H. C., Ibrahim, N., & Wahab, S. (2016). Psychological distress, perceived stigma, and coping among caregivers of patients with schizophrenia. *Psychology research and behavior management, 9*, 211.
- Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H., & Sourtzi, P. (2007). Caring for a relative with dementia: family caregiver burden. *Journal of advanced nursing, 58*(5), 446-457.
- Parekh, N. K., Shah, S., McMaster, K., Speziale, A., Yun, L., Nguyen, D. L., ...& Kane, S. (2017). Effects of caregiver burden on quality of life and coping strategies utilized by caregivers of adult patients with inflammatory bowel disease. *Annals of Gastroenterology: Quarterly Publication of the Hellenic Society of Gastroenterology, 30*(1), 89.
- Parmenter, T. R. (1988). An analysis of the dimensions of quality of life for people with physical disabilities. *Quality of life for handicapped people, 7-36*.
- Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of health and social behavior, 2-21*.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The gerontologist, 30*(5), 583-594.

- Perlick, D. A., Rosenheck, R. A., Miklowitz, D. J., Kaczynski, R., Link, B., Ketter, T., ... & STEP-BD Family Experience Collaborative Study Group. (2008). Caregiver burden and health in bipolar disorder: a cluster analytic approach. *The Journal of nervous and mental disease*, 196(6), 484.
- Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects?. *International Psychogeriatrics*, 18(4), 577-595.
- Raggi, A., Tasca, D., Panerai, S., Neri, W., & Ferri, R. (2015). The burden of distress and related coping processes in family caregivers of patients with Alzheimer's disease living in the community. *Journal of the neurological sciences*, 358(1-2), 77-81.
- Riaz, A. (2002). *The relationship of coping strategies with family relations among adolescent*. Unpublished master's thesis. National Institute of Psychology, Quaid-i-Azam University.
- Rosenstiel, A. K., & Keefe, F. J. (1983). The use of coping strategies in chronic low back pain patients: relationship to patient characteristics and current adjustment. *Pain*, 17(1), 33-44.
- Schrank, B., Ebert-Vogel, A., Amering, M., Masel, E. K., Neubauer, M., Watzke, H., ... & Schur, S. (2016). Gender differences in caregiver burden and its determinants in family members of terminally ill cancer patients. *Psycho-Oncology*, 25(7), 808-814.
- Schölzel-Dorenbos, C. J. M., Krabbe, P. F. M., & Rikkert, M. O. (2010). Quality of life in dementia patients and their proxies: a narrative review of the concept and measurement scales. In *Handbook of Disease Burdens and Quality of Life Measures*(pp. 3671-3689). Springer New York.
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *Jama*, 282(23), 2215-2219.
- Schulz, R., Boerner, K., Shear, K., Zhang, S., & Gitlin, L. N. (2006). Predictors of complicated grief among dementia caregivers: a prospective study of bereavement. *The American journal of geriatric psychiatry*, 14(8), 650-658.

- Stanley, S., Balakrishnan, S., & Ilangovan, S. (2017). Psychological distress, perceived burden and quality of life in caregivers of persons with schizophrenia. *Journal of Mental Health, 26*(2), 134-141.
- Stucki, B. R., & Mulvey, J. (2000). *Can Aging Baby Boomers Avoid the Nursing Home: Long-term Care Insurance for "aging in Place"*. American Council of Life Insurers.
- Sultan, S., Fatima, S., Kanwal, F., & Khurram, S. (2017). FACTORS ASSOCIATED WITH CAREGIVERS BURDEN: DO COPING STRATEGIES MAKE ANY DIFFERENCE?. *Pakistan Heart Journal, 50*(1).
- Suls, J., & Fletcher, B. (1985). The relative efficacy of avoidant and nonavoidant coping strategies: a meta-analysis. *Health psychology, 4*(3), 249.
- Tatsumi, H., Nakaaki, S., Torii, K., Shinagawa, Y., Watanabe, N., Murata, Y., ... & Furukawa, T. A. (2009). Neuropsychiatric symptoms predict change in quality of life of Alzheimer disease patients: A two-year follow-up study. *Psychiatry and Clinical Neurosciences, 63*(3), 374-384.
- Villada, C., Hidalgo, V., Almela, M., & Salvador, A. (2016). Individual differences in the psychobiological response to psychosocial stress (Trier Social Stress Test): the relevance of trait anxiety and coping styles. *Stress and Health, 32*(2), 90-99.
- Ware Jr, J. E., & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical care, 473-483*.
- Weaver, R. H., & Roberto, K. A. (2015). Home and community-based service use by vulnerable older adults. *The Gerontologist, 57*(3), 540-551.
- World Health Organization. (2012). 2008-2013. *Action plan for the global strategy for the prevention and control of non-communicable diseases*. Retrieved from http://www.WHO.int/nmh/publications/ncd_action_plan_en.pdf
- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The gerontologist, 20*(6), 649-655.

Zautra, A., & Goodhart, D. (1979). Quality of life indicators: A review of the literature. *Community Mental Health Review*, 4(1), 1-14.

Informed Consent

I am Maryam Naeem, research student of 4th semester at National Institute of Psychology, Quaid-i-Azam University, Islamabad. The partial fulfillment of my degree requires conducting a research thesis. For this purpose, I request you to give your honest opinions on the questionnaire attached along. Information provided by you will be kept confidential and anonymity will be ensured. Moreover, the provided information will be used for academic purpose only. You have a right to quit at any time if you want to. However, your participation will be highly appreciated.

Thank you.

SIGNATURE

Maryam Naeem

Marryamnaem@gmail.com

Demographic sheet

Age of the caregiver _____

Gender Male Female

Disease _____

Co-morbidity (any other disease) Yes No

If yes, specify. _____

Relationship with the patient

Spouse or partner Adult child Other family member/friend Lives with patient. Yes No

Hours of care providing per week

20 hours 21-40 hours 40 above hours

No of years providing care

Less than 2 years 2-5years more than 5 years

General health of caregiver

Good Excellent Fair/ Poor

Marriage

Single Married Widow/er Divorced

Employment

Full time Part time Not working

Income

Less than 25,000 25,000-50,000 More than 50,000

Education level

Matric Intermediate Bachelors Masters

Hospitalization time duration _____

Caregiver Burden Scale on Family Caregivers (BSFCs)

APPENDIX C

We are asking you for information about your present situation. The present situation comprises your caregiving deduced from the illness of your family member (or friend).

The following statements often refer to the type of your assistance. This may be any kind of support up to nursing care.

		Strongly agree	Agree	Disagree	Strongly Disagree
1.	My life satisfaction has suffered because of the care.				
2.	I often feel physically exhausted.				
3.	From time to time I wish I could 'run away' from the situation I am in.				
4.	Sometimes I don't really feel like 'myself' as before.				
5.	Since I have been a caregiver my financial situation has decreased.				
6.	My health is affected by the care situation.				
7.	The care takes a lot of my own strength.				
8.	I feel torn between the demands of my environment (such as family) and the demands of the care.				
9.	I am worried about my future because of the care I give.				
10.	My relationships with other family members, relatives, friends and acquaintances are suffering as a result of the care.				

ہدایات: درج ذیل بیانات ان تمام طریقوں کے متعلق ہیں جو آپ اپنی زندگی میں ذہنی دباؤ سے نمٹنے کے لیے استعمال کر رہے ہیں۔ ہر بیان ذہنی دباؤ سے نمٹنے کے ایک خاص طریقے کی نشان دہی کرتا ہے۔ میں یہ جاننا چاہتی ہوں کہ ہر بیان جس طریقے کی نشاندہی کرتا ہے آپ اس کو کس حد تک استعمال کرتے رہے ہیں (کتنا زیادہ یا کتنی دفعہ)۔ اس بنیاد پر جواب نہ دیں کہ طریقہ مفید ہے کہ نہیں۔ صرف اس بنیاد پر جواب دیں کہ آپ نے وہ طریقہ اختیار کیا یا نہیں۔ ہر بیان کے سامنے متبادل جوابی صورتوں میں سے کسی ایک کا انتخاب کریں۔

نمبر شمار	بیانات	کبھی نہیں	بہت کم	کبھی کبھی	بہت زیادہ
1	میں اپنے ذہن سے کچھ چیزوں کو نکلانے کے لیے دوسرے کاموں یا مشاغل کی طرف متوجہ ہو جاتا/ جاتی رہی ہوں۔				
2	میں جس صورتحال میں ہوں اس سے نکلنے کے لیے میں اپنی تمام کوششیں صرف کرتا/ کرتی رہی ہوں۔				
3	میں اپنے آپ سے کہتا/ کہتی رہی ہوں کہ یہ حقیقت نہیں ہے۔				
4	میں بہتر محسوس کرنے کے لیے سکون آور نشہ آور ادویات استعمال کرتا/ کرتی رہی ہوں۔				
5	مجھے دوسروں سے جذباتی سہارا ملتا رہا ہے۔				
6	میں اس صورتحال کو بہتر بنانے کی کوشش میں اقدامات کرتا/ کرتی رہی ہوں۔				
7	میں صورتحال سے نمٹنے کے کوششیں ترک کر دیتا/ دیتی رہی ہوں۔				
8	میں یہ یقین کرنے سے انکار کرتا/ کرتی رہی ہوں کہ ایسا ہو چکا ہے۔				
9	میں ایسی باتیں کہتا/ کہتی رہی ہوں جن سے میرے ناخوشگوار واقعات جذبات میں کمی آسکے۔				
10	میں دوسروں سے مشورہ/ مدد حاصل کرتا/ کرتی رہی ہوں۔				
11	میں اس صورتحال سے نمٹنے کے لیے سکون آور ادویات استعمال کرتا/ کرتی رہی ہوں۔				
12	میں اس صورتحال کو مختلف پہلوؤں سے دیکھنے کی کوشش کرتا/ کرتی رہی ہوں تاکہ یہ زیادہ مثبت نظر آئے۔				
13	میں اپنے آپ پر تنقید کرتا/ کرتی رہی ہوں۔				
14	میں صورتحال کے بارے میں کچھ کرنے کے لیے ایک حکمت عملی تلاش کرنے کی کوشش کرتا/ کرتی رہی ہوں۔				
15	میں کسی دوسرے سے آرام اور ہم خیالی حاصل کرتا/ کرتی رہی ہوں۔				
16	میں اس صورتحال پر قابو پانے کی کوشش ترک کرتا/ کرتی رہی ہوں۔				
17	جو کچھ ہو رہا ہے میں اس میں بہت کچھ بہتر پہلو دیکھنے کی کوشش کرتا/ کرتی رہی ہوں۔				
18	میں اس صورتحال کے بارے میں مزاح پیدا کرتا/ کرتی رہی ہوں۔				
19	میں اس صورتحال کے بارے میں کم سوچنے کے لیے کچھ نہ کچھ کرتا/ کرتی رہی ہوں جیسے فلم کے لیے جانا، ٹی وی دیکھنا، پڑھنا، دن میں خواب دیکھنا، سونا یا خریداری کرتا۔				

نمبر شمار	بیانات	کبھی نہیں	بہت کم	کبھی کبھی	بہت زیادہ
20	میں اپنے منفی جذبات کا ظہار کرتا/کرتی رہی ہوں۔				
21	میں اپنے مذہب یا روحانی عقائد میں سکون تلاش کرنے کی کوشش کرتا/کرتی رہی ہوں۔				
22	صورتحال کے متعلق کچھ کرنے کے لیے میں دوسرے لوگوں سے مدد اور مشورہ لینے کی کوشش کرتا/کرتی رہی ہوں۔				
23	میں اس صورتحال کے ساتھ گزارہ کرنا سیکھتا/سیکھتی رہے ہوں۔				
24	میں اس بارے میں بہت غور کرتا/کرتی رہی ہوں کہ کیا اقدامات لوں۔				
25	جو کچھ ہوا اس کے لیے میں اپنے آپ کو قصور وار ٹھہراتا/ٹھہراتی رہی ہوں۔				
26	میں عبادے اور دعا کرتا/کرتی رہی ہوں۔				
27	میں حالات کو مذاق میں اڑاتا/اڑاتی رہی ہوں۔				
28	میں اس حقیقت کو تسلیم کرتا/کرتی رہی ہوں کہ ایسا رونما ہو چکا ہے۔				

WHOQOL-BREF

ہدایات:

اس سوالنامے میں آپ کی زندگی کے معیار، صحت اور زندگی کے دیگر پہلوؤں کے بارے میں پوچھا جائے گا۔ برائے مہربانی آپ تمام سوالات کے جواب دیں۔ اگر آپ کسی سوال کے جواب کے بارے میں یقینی طور پر کچھ نہیں کہہ سکتے تو سب سے مناسب جواب کا چناؤ کریں۔ عموماً یہ وہ جواب ہو سکتا ہے جو کہ آپ کے ذہن میں سب سے پہلے آئے۔ آپ سے گزارش ہے کہ اپنے ذاتی معیار، اُمیدیں، خوشیاں اور خدشات ذہن میں رکھیں، سوالات دیتے وقت پچھلے دو ہفتوں کی زندگی کو ذہن میں رکھیں۔

مثلاً:

کیا آپ کو دوسروں کی ایسی مدد حاصل ہے جو آپ چاہتے ہوں؟

بالکل نہیں	تھوڑی بہت	درمیانی حد تک	بہت زیادہ	بہت ہی زیادہ
1	2	3	4	5

اگر پچھلے دو ہفتوں سے اگر آپ کو دوسروں کی بہت زیادہ مدد حاصل رہی ہے تو آپ نمبر 4 پر دائرہ لگا سکتے ہیں۔

کیا آپ کو دوسروں کی ایسی مدد حاصل ہے جو آپ چاہتے ہوں؟

بالکل نہیں	تھوڑی بہت	درمیانی حد تک	بہت زیادہ	بہت ہی زیادہ
1	2	3	4	5

لیکن اگر پچھلے دو ہفتوں میں آپ کو دوسروں کی مدد بالکل بھی نہیں ملی تو نمبر 1 پر دائرہ لگا سکتے ہیں۔
آپ کے تعاون کا شکریہ

آپ سے گزارش ہے کہ ہر سوال کو فوراً سے پڑھیں اور اپنے احساسات کا جائزہ لیں اور پھر اُس نمبر پر دائرہ لگائیں جو آپ کے احساسات کو بہتر طور پر ظاہر کرتا ہو۔

1	آپ اپنے معیار زندگی کو کس درجہ کا محسوس کرتے ہیں۔	بہت بُرا	بُرا	نہ اچھا نہ بُرا	اچھا	بہت اچھا
		1	2	3	4	5
2	آپ اپنی صحت سے کس حد تک مطمئن ہیں۔	بہت غیر مطمئن	غیر مطمئن	نہ مطمئن نہ غیر مطمئن	مطمئن	بہت مطمئن
		1	2	3	4	5

مندرجہ ذیل سوالات میں آپ کچھ مخصوص چیزوں کے بارے میں پوچھا جائے گا کہ ان سے آپ کا پچھلے دو ہفتوں میں کس حد تک تجربہ ہوا ہے۔

3	آپ کس حد تک محسوس کرتے ہیں کہ جسمانی درد آپ کے لیے وہ کام کرنے میں رکاوٹ بنتی ہے جس کا کرنا آپ کے لیے ضروری ہوتا ہے۔	بالکل نہیں	تھوڑا بہت	درمیانی حد تک	بہت زیادہ	بہت ہی زیادہ
4	روزمرہ کاموں کی ادائیگی کے لیے آپ کس حد تک طبی علاج کی ضرورت پڑتی ہے۔	1	2	3	4	5
5	آپ کس حد تک اپنی روزمرہ زندگی سے لطف اندوز ہوتے ہیں۔	1	2	3	4	5
6	آپ کس حد تک اپنی روزمرہ زندگی کو بے معنی محسوس کرتے ہیں۔	1	2	3	4	5
7	آپ کس حد تک اپنے آپ کو توجہ مرکوز کرنے کے قابل سمجھتے ہیں۔	1	2	3	4	5
8	آپ روزمرہ زندگی میں اپنے آپ کو کس حد تک محفوظ کرتے ہیں۔	1	2	3	4	5
9	آپ کے ارد گرد کا ماحول کس حد تک صحت مندانہ ہے۔	1	2	3	4	5
10	کیا آپ روزمرہ زندگی کے لیے مناسب توانائی محسوس کرتے ہیں۔	1	2	3	4	5
11	کیا آپ کے لیے اپنی ظاہری جسمانی شکل و صورت قابل قبول ہے۔	1	2	3	4	5
12	کیا آپ کے پاس اپنی ضروریات پوری کرنے کے لیے مناسب پیشہ موجود ہے۔	1	2	3	4	5
13	آپ کو روزمرہ زندگی گزارنے سے متعلق کتنی ضروری معلومات دستیاب ہیں۔	1	2	3	4	5
14	آپ کو سیر و تفریح کے مواقع کس حد تک میسر ہیں۔	1	2	3	4	5
15	آپ ارد گرد جسمانی طور پر کس حد تک چلنے پھرنے کے قابل ہیں	1	2	3	4	5

مندرجہ ذیل سوالات میں آپ سے پوچھا گیا ہے کہ پچھلے ہفتوں سے آپ نے اپنی زندگی کے مختلف پہلوؤں کے حوالے سے کس قدر اچھا یا مطمئن محسوس کیا۔

16	آپ اپنی نیند سے کس حد تک مطمئن ہیں۔	انتہائی غیر مطمئن	غیر مطمئن	بہت مطمئن نہ	مطمئن	انتہائی مطمئن
17	آپ اپنی روزمرہ کام سرانجام دینے کی صلاحیت سے کس حد تک مطمئن ہیں۔	1	2	3	4	5
18	آپ اپنی کام کرنے کی صلاحیت سے کس حد تک مطمئن ہیں۔	1	2	3	4	5
19	آپ اپنی ذات سے کس حد تک مطمئن ہیں۔	1	2	3	4	5
20	آپ اپنے تعلقات سے کس حد تک مطمئن ہیں۔	1	2	3	4	5
21	آپ اپنی جنسی زندگی سے کس حد تک مطمئن ہیں۔	1	2	3	4	5
22	آپ اپنے دوستوں سے ملنے والی مدد سے کس حد تک مطمئن ہیں۔	1	2	3	4	5
23	آپ اپنی رہائش کی جگہ کے حالات سے کس حد تک مطمئن ہیں۔	1	2	3	4	5
24	آپ طبی سہولتوں تک اپنی رسائی سے کس حد تک مطمئن ہیں۔	1	2	3	4	5
25	آپ اپنے ذریعے آمد و رفت سے کس حد تک مطمئن ہیں۔	1	2	3	4	5
26	آپ کس حد تک منفی احساسات کا شکار رہتے ہیں مثلاً اُداسی، مایوسی، پریشانی، افسردگی وغیرہ۔	کبھی نہیں	بعض اوقات	کبھی کبھار	بہت زیادہ	ہمیشہ
		1	2	3	4	5

Automatic reply: Permission for QOL

Inbox

whoqol <whoqol@who.int>

May 7, 2018, 10:13 AM

to me

Thank you for your interest in the WHOQOL questionnaires.

If you would like to obtain a free copy of a WHOQOL/WHOQOL-BREF/WHOQOL-OLD questionnaire, please fill in the user-agreement form which can be downloaded from the website below and return a signed copy of the form to whoqol@who.int:

http://www.who.int/entity/mental_health/publications/whoqolbref_user_agreement.pdf

We will send you the questionnaire as soon possible. Please note that the questionnaire exists in over 20 languages.

Please note that if the questionnaire is for clinical use (not for research), just fill in the form accordingly.

If you are writing from the U.S., please click on the link below for information on how to obtain a copy of the U.S. version of the questionnaire:

<http://depts.washington.edu/seaqol/WHOQOL-BREF>

Finally:

Link for the SRPB and HIV versions of the WHOQOL-BREF:

http://www.who.int/mental_health/publications/whoqol/en/

Thank you and best regards.

whoqol <whoqol@who.int>

May 9, 2018, 5:22 PM

o me

Dear Maryam,

Thank you for the form. Please find attached the English version of the questionnaire (I can also send you the Urdu version of you like), along with related materials.

Best regards,

Sibel

Sibel Volkan (Mrs)

WHOQOL

Information, Evidence and Research (IER) Department

The World Health Organization

20 Avenue Appia

CH-1211 Geneva 27

Switzerland

From: Maryam Naeem [mailto:marryamnaem@gmail.com]

Sent: 08 May 2018 09:26

To: whoqol

Subject: Re: Automatic reply: Permission for QOL