

Subjective and objective burden of schizophrenic individuals on primary caregivers: From a Sri Lankan perspective

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Abstract

This study aimed to examine lived experience of six primary caregivers of schizophrenic individuals to determine the nature of subjective and objective burden experienced by the caregivers. Self-selected sample of caregivers belonged to two categories of schizophrenics; cared for at home and cared for in an institute. Qualitative approach was adopted and verbatim transcripts were analyzed using interpretative phenomenological analysis (IPA). Eleven themes emerged from the analysis for subjective burden and they were examined under two super ordinate themes; fifteen themes emerged for objective burden and they were examined under four super ordinate themes. The analysis identified causal factors and nature of subjective and objective burden. Findings suggest that schizophrenic individuals cause high subjective and objective burden on primary caregivers and caregivers of home living schizophrenic category experience high objective burden than the institutionalized category.

Key Words: Schizophrenia, Subjective & Objective Burden, Primary Caregiver, Home-living, Institutionalized.

Introduction

‘Burden of care of schizophrenic individuals is defined more by its impacts and consequences on caregivers. In addition to the emotional, psychological, physical and economic impact, the concept of burden of care involves subtle but distressing notions such as shame, embarrassment, feelings of guilt and self-blame. The early conceptualization of burden of care into two distinct components (objective and subjective) has guided research efforts until the present time’ (Adwad & Voruganti 2008). Subjective burden refers to the extent to which caregivers perceive the burden of care whereas objective burden indicates the effects on the household. The current study attempts to investigate this particular impact placed on primary caregivers of schizophrenic individuals in Sri Lanka.

Schizophrenia is one of the devastating heterogeneous entities, associated with a number of complications. This particular disorder poses positive, negative, and cognitive symptoms accompanied by serious limitations in normal living of the affected individual (Lefley 1989). Almost all the patients have a tendency of having treatment for their entire life span. Novel pharmacological treatments and other community based interventions have significantly helped to reduce the impact caused to affected individuals, but many have a number of deficits in areas of functioning (Kumar 2009). Although, despite medical and psychosocial interventions during the past 50 years, schizophrenia remains one of the top causes of disability in the world (Murray & Lope 1996) placing a heavy impact on the affected individuals, family and the community at large.

Schizophrenia fits into the definition of catastrophic stress which has been defined by Figley and McCubbin (1983) as stress as sudden, unexpected, frightening experiences that are often accompanied by a sense of helplessness, disruption, destruction and loss. Historically, it has been proved that any severe mental disorder becomes a catastrophic event to the family and caregivers (Marsh & Dickens 1997; Terkelsen 1987). This becomes calamitous and whole family is victimized with the repercussions accompanied by the disorder. These repercussions are associate with frequent crises with finance, health, social status, family and social commitments, emergency services, hospitals, rehabilitation centers, police, and jails and so on.

According to Jablensky (1986), worldwide, 7.0 to 9.0 of a 1000 population are affected by schizophrenia. But The American Psychiatric Association (1994) reflects somewhat higher rates ranging from 10 to 20 of a 1000 population. Recent studies reveal that men are one and half times more likely to develop schizophrenia than women (Iacono & Beiser, 1992a, 1992b). As indicated by some extrapolated statistics, 2,375,154 in USA; 487,483 in UK; 10,505,385 in China; 1,029,899 in Japan; 8,614,541 in India; 1,287,617 in Pakistan; suffer from schizophrenia (Statistics by country for schizophrenia 2014).

In Sri Lanka, there are no available statistics to quantify exact number of schizophrenic individuals. As indicated by same extrapolated statistics (Statistics by country for schizophrenia 2014) the number of patients has been estimated to be 160,997 out of the population of 19,905,165 in the country. As per the demographic profile, 2013 The Sri Lankan population is higher (21,675,648) than the above indication. According to present the present population and compared to worldwide rates of schizophrenia (10 to 20 per 1000 of a population) reflected by American Psychiatric Association (1994), Sri Lanka's ratio could be

higher than 160, 997 and it would exceed even 200,000 with undiagnosed and misdiagnosed categories of affected individuals in the country.

Many researches witness the gravity of relapse in schizophrenia. According to Almond et al. (2004), relapse in schizophrenia is a major facet causing high hospitalization rates and financial costs. Compared to other costly outpatient services and medication costs, relapse of schizophrenia has substantial direct mental health costs (Ascher-Svanum et al. 2010). These costs essentially could impose an enormous impact on caregivers' individual, family, and social life. Financial and social burden caused by the illness remains high elsewhere. In the United States, it has been estimated that 10 to 13 percent of homeless people are schizophrenic and estimate cost of the illness is greater than that of cancer (Alloy, Acocella, & Bootzin 1996).

One of the major challenges in the care of schizophrenia is globally assumed to be relapse prevention. Obviously, there are number of factors that lie behind this challenge. Complicated etiology makes dilemmas in treatments among the professionals and at the same time caregivers' lack of knowledge in factors influencing the relapse makes the situation worse. Hence caregivers are compelled to take precautions to avoid possible damages; they seek help from emergency services and hospital care, spend more time to look after and care for the patient (Almond et al. 2004). All these commitments of the caregivers finally can result with short-term as well as long-term economic setbacks. In Sri Lanka, limitations, such as minimum psychiatric in-patient facilities, lack of knowledge in the disorder and training in handling the affected individuals, scarcity of adequate mental health professionals and community based interventions make the situation more difficult for caregivers.

The nature of recovery and life-long impact of Schizophrenia, remain complicated to that of other severe mental disorders. As indicated by Shah & Shah (2000) according to an international pilot study conducted by WHO statistically of the effected individuals 27% is favorable, with relatively short episodes with full remission without relapse or social impairment; 12% complete remission with at least one relapse; 17% partial remission but no relapse; 18% partial remission with at least one relapse; 18% remained psychotic and severely handicapped. More than 50% of schizophrenic individuals are not receiving appropriate care and 90% of individuals with untreated schizophrenia are in developing countries (WHO 2014).

Burden on caregivers

Burden of care of schizophrenia is defined as ‘presence of problems, difficulties or adverse events which affect the lives of caregivers’ (Kheng 2005:7). Objective burden is defined as the concrete and observable costs to the family that result from the illness (Jungbaur 2004). Subjective burden is defined as the individual’s own assessment of his or her impairments and the extent to which he or she perceives the situation as burdensome (Jungbaur 2004).

The caregivers’ burden involves emotional, psychological, physical and economic impact as well as distressing notions such as shame, embarrassment, feelings of guilt and self-blame. These characteristics make the concept of caregivers’ burden popular amongst researchers and they use numerous instruments and methodologies to investigate this particular phenomenon (Fenton, Tessier and Struening 1979; Tessler, Killian, and Gubman 1987).

With de-institutionalization movement occurring all over the world, many schizophrenic individuals were sent to their families. During 1955 and 1991, The United States reduced the number of beds for the mentally ill from 560,000 to 100,000 and from 155,000 to 59,000 in the United Kingdom (Muijen& Hadley 1995). A recent study by Roick et al. highlighted prevailing in-patient facilities for schizophrenia individuals to be 6.3 beds per 10,000 inhabitants in London whereas 14.7 beds in Leipzig (2007). According to Goldman (1982), in the United States 65% of psychiatric patients had been transferred to their families from the hospitals. A survey conducted by National Alliance for the Mentally Ill in 1992 revealed that 41.7% of severe and persistent mentally disordered individuals live with their families (Skinner, Steinwack, and Kasper 1992). MacMillan et al. (1986) revealed that 60% of schizophrenic individuals return home whereas 60% of first episode individuals live with the family members. Further, as indicated by Hughes et al. (1996) 60% of long term schizophrenic individuals live with some specific caregivers. According to Kumar (2009: 12) ‘the proportion of persons with schizophrenia living with their relatives ranges between 40% in the west to more than 90% in the east’. Therefore, subjective and objective burden of schizophrenia on caregivers is an important topic in examining their particular experiences.

Though Sri Lankan picture is different from the developed world, in the last decade The National Institute of Mental Health has taken several steps to reduce the number of long-stay individuals in mental hospitals by sending them to the families. Unlike other countries,

our hospital facilities for severely mentally ill are very minimum; total number of beds in mental hospitals and psychiatric wards are less than 5,000 in the country (NIMH 2014). This fact indicates that majority of affected individuals live with their families even under severe conditions where they need institutionalized treatments.

The impact placed by schizophrenia could affect both psychological and physiological wellbeing of the caregivers. According to Kumar (2009) there are numerous factors likely to influence this impact such as patients' characteristics and caregiver characteristics, family type and size, economic and educational status, role expectations, and illness related beliefs. Miller et al. (1990) emphasize that families experience feelings of loss and grief; it is a 'loss of a loving relative'. This "loss" can place a high degree of psychologically traumatic sense in the family members (Engel 1961). 'They may confront with uncertainty, emotions of shame, guilt and anger; they are vulnerable to be humiliated and isolated through stigmatization; their lives may be disrupted' (Kheng 2005).

Many families experience unpredictable and weird behaviors of their schizophrenic individuals. Further, emotional distresses such as stigmatization, guilt and loneliness, isolation, interfamily conflicts, and exhaustion in the care process are common among the caregivers (Chian et al. 2004). Studies witness that majority of families fails to have sufficient interactions with their affected individuals being unaware of the disorder. Further, they have no proper coping strategies and became excessively critical and protective of their affected individuals (Miura et al. 2004, Harrison, et al. 1998).

This situation induces a great deal of anxiety amongst the caregivers. Anxiety and depressive behaviors could become more chronic in these caregivers inducing distress feelings (Boye et al. 2001). This anxiety can be usually exacerbated by the events that are unpredictable. Some spend sleepless nights with paranoid and harmful patients and these caregivers tend to develop insomnia in the long run. Due to long-lasting and life-long nature of schizophrenia this anxiety can affect caregiver's physical health in number of ways. Kheng (2005) emphasizes that lack of adequate rest and recreation for the caregivers lead to their inability to go about their daily functioning. It is not a rarity for these caregivers to suffer various physical ailments. Some may even succumb to depression, a common psychiatric morbidity for these caregivers.

In many cases of schizophrenia the entire family becomes the caregivers whereas the parents, siblings, and spouses take the responsibility in other cases. 'Some authors discuss

who becomes a caregiver and adopt the position that caregiver burden is not shared equally within the family (Platt 1985, Perring et al. 1990) but Martin (1995) disputes this. A range of authors such as Thompson and Doll 1982, Crotty and Kulys 1986, Aldridge and Becker 1993, Howe 1995 have noted that caregivers are more often female' (Harrison 2008: 148).

The nature of impact of course has different forms depending on the relationship of caregivers to the affected individuals. An early study indicated that majority of families reported severe burden and hardship; their perceived distress was severity of the individual's symptoms and long duration of the disorder (Grad & Sainsbury 1963). Having tense relationships in the household, physical and emotional problems are common among the family members of the affected individuals. As a result, primary caregivers experience disruption of the lives; their work performance is disturbed and decreased (Provencher 1996).

At the same time, parents experience similar as well as different kinds of problems. Their main concern is continuous worry about the future of their ill son or daughter. Mothers are more worried and vulnerable to have mental health problems in their old age whereas fathers become more stressful over the financial dependency of the patient. A study conducted with 2010 a majority was mothers who are caregivers revealed that 82% of the caregivers did not have a plan for the future for the affected child. Further, researchers found that intense anxiety about the future of the patient and inability to arrange financial resources required for their future were major obstacles of this planning (Hatfield and Lefley 2000). 'The care giving experience of spouses of persons with psychiatric disability was surveyed by Mannion, 1993. It was found that the experience of care giving was associated with both burden and resilience....financial problems, marital disruption, and mood symptoms such as grief, sorrow, and guilt were the problems faced' (Kumar 2009: 11).

Aim and Objectives

In the absence of specific data and related studies in Sri Lanka, industry practitioners believe that many schizophrenic individuals live with their family members whereas others are institutionalized, homeless, neglected and living on their own. Impact of these patients on their caregivers and family members could have many implications that have not been studied so far in the country. The aim of current study is to investigate the subjective and objective burden placed on primary caregivers of schizophrenic individuals in Sri Lanka.

Since being focused on caregivers, the study would specify the sample with two categories of caregivers, on the basis of patients living with caregivers and living in an institute. This specification is made to avoid complexities related to other categories of caregivers, such as finding the caregivers of neglected and homeless patients and getting their consent and cooperation for this study within a short period. The current study has two objectives:

- (1) To investigate the nature of subjective and objective burden caused by schizophrenic individuals on their primary caregivers in Sri Lanka.
- (2) To compare the nature of burden amongst two categories of caregivers to highlight peculiarities on schizophrenics living with caregivers and on living in an institute.

Thus this study seeks to uncover the essence, interpret, and describe the meaning of this particular situation in the country

In Sri Lanka, some schizophrenic individuals live in government hospitals, residential homes, and community based centers under short and long term basis. Nature of subjective and objective burden of these institutionalized individuals on their primary caregivers could have similar as well as different implications to that of the burden caused by individuals who live with the caregivers. The second objective of current study is to differentiate this impact among the two categories of caregivers.

Method

Purpose of this study was to gain an understanding of subjective and objective burden of schizophrenic patients on their primary caregivers. Interpretative Phenomenology was used to explore this particular impact. The Researcher sought to uncover the essence, interpret, and describe the meaning of this impact and identify its similar and different implications on two groups of caregivers.

Source of data is based on a community based center which has residential facilities for 60 mentally ill individuals located in Gampaha district, in Sri Lanka. Study sample consists of 06 caregivers. Schizophrenic individuals of 03 caregivers live in the institute and others those who come for out-patient psychiatric clinic of the center live with caregivers. Sample is a selective one and restricted to two categories of caregivers especially considering the involvement in caring of the patients.

Presently the center holds 25 schizophrenic individuals. Their diagnosis had been determined by a psychiatrist according to DSM-IV or ICD-10. Current study sample represents 06 schizophrenics who have been cared for continuously by the sample caregivers at least for last

six months. Out of the sample, three schizophrenics are cared for at home and others are residential.

Study sample represents three socioeconomic classes (upper middle, middle, and lower middle). Two categories of patients and caregivers of this sample would equally represent these socioeconomic classes. Caregivers' demographics would be noted under age, gender, relationship to the patient, civil status, educational and occupational background, monthly income, total duration of caring, training of caring, family support, etc.

Inclusion criteria for caregivers:

1. Having a schizophrenia patient for a minimum for two years diagnosed according to DSMIV or ICD-10
2. Parents, spouse, brother or sister with whom affected individual lived or was cared for the last six month period on regular basis
3. Willingness to give consent to participate in the study
4. Ability to cope with the interview

Procedure

This study gained ethical approval from Ethics Committee of Colombo Institute of Research and Psychology. Initial consent of the participants was obtained through the particular institute. As the center directly involves in facilitating the study, written approval from its board of directors was obtained. All the interviews were conducted on one to one basis and were arranged to take place at a mutually convenient time, in a confidential room at the institute. Participants were given the opportunity to re-read the information sheets and thereafter the written informed consent was obtained. After having completed the demographic sheet interviews were commenced. Each interview lasted between 30 and 60 minutes and audio recorded. All interview recordings were transcribed on a password

protected computer and participants' identity was protected using pseudonyms. The recordings of raw data were destroyed to protect some information such as names of medical practitioners, family members, friends, and institutes relating to caregivers and their schizophrenic individuals.

Analysis

IPA encouraged researcher to use smaller samples to go for detailed analysis of specific cases (Sheehan & Sullivan 2010). Further it is flexible as opposed to prescriptive in its approach (Storey 2007). Based on the approach, interview transcripts were read several occasions to gain a holistic overview of participants' phenomenological experience. Each interview was transcribed verbatim using the guidelines by Smith (2003).

Thus, transcripts were analyzed in accordance with IPA recommendations. Analysis involved reading and re-reading the transcripts and identifying emerging themes. Fifteen themes emerged from all the transcripts pertaining to subjective burden. They were examined under four categories; (1) financial distress (2) household disruptions (3) social interactions (4) personal limitations. Eleven themes emerged pertaining to objective burden and they were examined under two categories; (1) cognitive representation (2) affective representation. Finally, themes were integrated across six transcripts to identify the shared themes which provide the essence of caregivers' subjective and objective burden.

Results

Six primary caregivers of schizophrenic individuals are represented by the study sample. There were 2 females and 4 males. Their age ranged from 34 to 76 for this group. Table-I shows caregivers' demographics and it indicates the minimum and maximum duration of care which was between 05 and 26 years.

Table-I Demographics of Caregivers

Caregiver	Age	Gender	Religion	Education	Occupation	Duration of care	Relationship to patient	Social class	Training in care giving
Ramya	71	F	BU	G.C.E. A/L	former secretary	26Y	mother	LMC	N
Nancy	76	F	BU	B.A.	retired teacher	20Y	mother	MC	N
Gamini	66	M	BU	G.C.E. A/L	retired bank manager	10Y	farther	UMC	N
Nafish	34	M	MU	G.C.E. A/L	production manager	12Y	brother	MC	N
Saliya	53	M	BU	M.Sc	research assistant	08Y	farther	UMC	N
Perera	48	M	BU	G.C.E.O/L	businessman	05Y	father	LMC	N

M= male, F= female, BU= Buddhist, MU= Muslim, Y= years, LMC= lower middle class, MC= middle class, UMC= upper middle class, N= nil

Objective Burden

Themes emerged from each transcript pertaining to objective burden appeared to suggest similarities as well as peculiarities to some transcripts. Table-II shows all the themes captured from the transcripts.

Financial Distress

Increased cost: All the participants reported increased financial cost with their schizophrenic individuals. Four factors were found from the transcripts for this increased cost; (1) cost of medications (2) hospitalization (3) institutionalization (4) some destructive and abusive behaviors of the affected individual. Ramya has reported this several times.

“Every month I have to take her to the doctor and her medicines are costly—because She is on Flunexol injection which is quiet expensive...Most of the time she refuses home foods then I have get it for her from outside” (51-54).

Taking the patient for various treatments is also prominent with most of the participants. The complicated and long-lasting nature of the disorder has been one of the main reasons for caregivers to seek help and try local treatments, astrological help, religious help, and even going for number of psychiatrists from time to time.

“I took her to a place....for Aurvedic treatments. She was there for six months and there was some improvement...I was doing lots of religious activities, Bodhi Pujas [a religious act] going to astrologists—none of them helped. For last twenty five years, I think I have taken her to more than ten psychiatrists” (Rmaya 59-63).

“Actually I have tried every possible treatment..... (Nancy 41)

“I went to a Buddhist monk who knows astrology...he recommended twenty one Bodhi Pujas” (Perera 46-48).

Nancy has reported that her son’s excessive smoking habit which started with the disorder has badly affected her financial status. She says “for a day he smokes nearly three packets....this is the most difficult thing.....it costs me a lot” (67-69).

Hospitalization and institutionalization also has had a negative impact on caregivers’ financial cost. Long stays in hospitals, paying monthly institutional fees etc.; Nancy reported her monthly expenditure “could be forty to fifty thousand. When he is hospitalized, it exceeds one hundred thousand” (78-79).

Nafish reported how institutionalization increased his sister’s monthly expenditure. It is three times more than that of the amount he spent when she was cared for at home. He mentioned that institutional cost “is around about thirty thousand” (58) and the cost prior to that as “sometimes I had to spend more than this amount when she was hospitalized. But generally it was less than ten thousand including everything” (60-61).

Table-II Themes- Objective Burden

Financial Distress	Household disruptions	Social Interactions	Personal Limitations
Increased cost	Interruption in daily tasks	Limiting opportunity	Loss of entertainments
Dependency	Negative interactions	Disruption	Lack of rest and sleep
Decreased income	Unpleasant circumstances	Purposive avoidance	Deterioration of health
Future security			Missing responsibilities
Decreased savings			

Decreased income: Three participants reported a drop in income and two out of them reported the negative impact caused on their jobs. Basically, Ramya, as a widow who was looking after the daughter alone, could not manage to continue her job with daughter's troublesome behavior and insecure situation caused by the disorder.

Perera had been a government servant working at Ceylon Transport Board as a time keeper. He resigned at the age of 43, twelve years prior to his retirement since his wife and other two daughters were unable to cop up with the situation. This made him loose his steady income and depended on a small business. Perera reported difficulties even continuing the business with his daughter's condition.

“I had to resign from my job...At that time my other daughters were working and I had to depend on them for some time” (77-79).

Decreased savings: Four participants reported a decrease in their savings due to the schizophrenic individuals. Two out of four has mentioned the reason for this decrease was the loss of their job whereas other two reported retirement and decrease of regular income.

“I had some money in a fixed deposit—actually it was kept for daughters' weddings—I

withdrew it since I was unable to manage with my new income” (Perera 79-80).

“At that time he became ill very often....sometimes I had to admit him a few times a month....my pension was not enough to cover all the expenses...I had to depend on my savings” (Gamini 65-68).

Household Disruptions

Interruption in daily tasks: Three participants reported interruptions in daily tasks such as cooking, marketing, washing, arranging house, doing house hold chores. All three have revealed their inability of completing these tasks with the troublesome, lethargic, and non-supportive nature of the schizophrenic individual. Ramya and Nancy reported more troubles in their daily tasks since they manage alone with their daughter and son. According to participants, sometimes their daily tasks are rapidly interrupted for days and weeks when the schizophrenic is so paranoid, boisterous, or hospitalized. “She used to telephone me

every hour...asking me to come home...I was doing a responsible job—when she calls me every time it was very difficult me to concentrate on work” (Ramya 17-18, 21-22). “When he is hospitalized I have to visit him...I go every day in the morning and evening” (Gamini 57).

As indicated by Nancy, her son’s negative symptoms have affected her by giving her more duties at home and that has interrupted her daily religious activities, visiting other children, cooking etc. She says “ He is very lethargic—not helping me at all.....doesn’t do even his own things like arranging the room, washing his cloths...even to buy his cigarettes, I have to go” (27-29).

Social Interactions

Limiting opportunity: Three participants reported limiting opportunity for social interactions. Four factors were identified from the transcripts for limiting opportunity for social interactions; (1) participants’ involvement in full time caring, (2) fear of unpleasant circumstances created by the schizophrenic individual (3) positive symptoms of the disorder such persecutory delusions, (4) dependency of schizophrenic individual. As a result, participants have become house-bound with their schizophrenic individual.

“I don’t have time like those days...my daughter is in Colombo...I can’t keep Indika with my mother because she cannot monitor his drugs...actually I had to give up many social activities...I didn’t go for the senior citizens meeting of the bank for the last two years” (Gamini 81-85).

“She won’t allow me to go anywhere...never goes for functions—sometimes she gets ready and changes her mind at the last moment—I missed few important weddings of my sisters’ children and very good friends” (Ramya 30-33).

“He can’t manage without me....if I am not to be seen he becomes restless. This has been my life for past twenty years” (Nancy 29-30).

Purposive avoidance: All the participants reported purposive avoidance of social interactions. Two factors were found from their transcripts for this avoidance; (1) unpredictability and the troublesome nature of the behavior of the schizophrenic individuals (2) feeling of guilt attributing to be immoral. All the participants revealed their dislike to be humiliated and embarrassed in front of others; they didn’t want the situation to be unpleasant

Household disruptions

Interruption in daily tasks	+	+	+	0	0	0
Negative interactions	+	+	+	0	0	0
Unpleasant circumstances	+	+	+	0	0	0

Social Interactions

Limiting opportunity	+	+	+	0	0	0
Disruptions	+	+	+	0	0	0
Purposive avoidance	+	+	+	+	+	+

Personal Limitations

Loss of entertainments	+	+	+	0	0	+
Lack of rest and sleep	+	+	+	0	0	+
Deterioration of health	+	+	0	0	0	+
Missing responsibilities	+	+	0	0	0	+

+ = Applicable 0 = Not applicable

Lack of rest and sleep: Four participants reported lack of rest and sleep. Three factors were found from their transcripts for this limitation; (1) Dependency of schizophrenic individual (2) Positive or negative symptoms of the disorder (3) Unexpected stressful circumstances created by schizophrenic individual. Some schizophrenic individuals have become totally dependents on their caregivers. Ramya has reported this as “She is very lethargic...I have to do everything for her even arranging her room, washing clothes, even washing her cup” (39-40) , “I mean I had to think of everything...every day I had to struggle” (44-45). Nancy reported some behaviors of her son occurs in the nights; “His sleep is very poor even with the pills. When he cannot sleep, I have to prepare tea for him—sometimes it is four five times a night—he drinks tea and smokes cigarettes...when he is unable to sleep, he baths few times in the night. So, I also have no sleep” (21-24); sometimes I have no sleep for a single minute throughout the night...I can’t sleep when he is up” (112-113).

Deterioration of health: Three participants reported deterioration of health. These participants have been caring their schizophrenic individuals for longer periods under stressful circumstances; Ramya for 20 years, Nancy for 26 years, and Perera for 5 years. Root causes of the health problems witnessed by the participants are more psychological.

Therefore it can be assumed that their health deterioration is a result of their long-term stress. Ramya has developed depression and presently managing with antidepressants. Her first episode clearly shows the impact of her daughter's disorder; "I remember—she was so paranoid of me and accused me very badly saying I have a plan to kill her. Those days she used to scold me throughout the day—even I was afraid to look at her face because she was so hostile—she didn't eat what I cooked and used to buy the foods from outside. This was a very bad time for me—I couldn't sleep and gradually couldn't do any work" (82-86). Also Ramya reported diabetes and hypertension (79-80); Nancy reported Diabetes and cholesterol (102-103); Perera reported hypertension and a severe headache (111-112).

Subjective Burden

Themes emerged from each transcript pertaining to subjective burden appeared to suggest similarities as well as peculiarities to some transcripts. Table-III shows all the themes captured from the transcripts.

Cognitive Representation

Preoccupation: All the participants reported preoccupation. They are preoccupied with thinking of their schizophrenic individual. Getting such illness and its long-lasting detrimental impact has been the main reason for this preoccupation; it has become a continuous agony in their life. Saliya reveals this as "I know that my other two have come up in their lives...I have nothing to worry of them at all...day and night, this is my only worry—sometimes I can't sleep when I think of his future" (81-84). Future uncertainty of caring of their schizophrenic individual also has become a continuous worry to the participants; Ramya says "that is my biggest worry. Now I am old—I can't ask my sisters' children to look after her" (72-73).

Dissatisfaction of life: Three participants reported dissatisfaction of their life. Continuous suffering for longer periods, lack of social interactions, personal limitations such as loss of relaxation and entertainment and lack of rest caused by their schizophrenic individuals were found to be prominent causes of this dissatisfaction.

“I didn’t have life—how can I say I enjoyed my life? It was just suffering one after another incident—even today I am worried about rest of her life” (Ramya 90-91).

“So what to do... these is my bad Karma... I can’t say I have a happy good life...I am do not think about it” (Gamini 77-79).

Table-IV Themes- Subjective Burden

Cognitive Representation	Affective Representation
Preoccupation	Worry
Dissatisfaction of life	Shame
Stigma	Guilt
Uncertainty of future security	Grief & loss
	Fear
	Frustration
	Anger & resentment

Uncertainty of future security: All the participants reported uncertainty of the future security of the schizophrenic individuals. Three factors were found from the transcripts for this uncertainty; (1) unavailability of a future caregiver (2) absence of a future plan (3) present financial situation of the participant (4) dependency of schizophrenic individual. Nancy has another two children who are married and living separately. According to her they are not in a position to take the responsibly of their brother with their other commitments.

“They are doing jobs and very busy with their children’s work...how can I trouble them?. I refrain from thinking about his life after me....it is so hard when I think of it” (32-33, 62-63).

Five participants did not have a proper plan for the schizophrenic individual. Financial burden caused by the disorder has indirectly affected thinking of a steady future.

“I don’t know whether she will be able to marry with this problem.... I can’t ask my other daughters to look after her because it can be a problem for their family life.....she secure as long as I am there” (Perera 92-95)

Guilt: Four participants reported guilt. Three factors were found from the transcripts for their feeling of guilt; (1) perceiving the disorder as their own fault (2) absence of a future plan (3) inability of giving a satisfactory life for the affected individual. Two participants think that they are responsible for the problem of their children. Gamini reveals family problems previously he had with his wife. Also he admits that he was very strict on his children; “we had many arguments in front of our children...those days I used to get angry for slightest thing...I know now it’s too late” (46-48). Ramya has reported her own negligence during her daughter’s childhood; “mostly she grew up in day care centers and at my sisters in her childhood. I know she was really neglected” (68-69). Although participants have looked after the affected individual from the beginning of his/her problem, they have guilt feelings that they couldn’t do better for the affected individual. Ramya says “I couldn’t give her a good life” (76). Nancy also reported the same thing as “I must care for him—because I couldn’t give him what I have given my other two” (117-118).

Fear: Three participants reported fear. Two factors were found from the transcripts for their fear; (1) Aggressive and violent behaviors of the schizophrenic individual (1) Paranoid ideas of the schizophrenic individual. Participants reported continuous fear. Having a history of unpredictable and unexpected aggressive and violent behaviors with schizophrenic individuals has a high impact in maintaining their continuous fear. All three participants reported their schizophrenic individual to be aggressive, violent, and paranoid.

“She used to scold me very often—actually threatening. Also she was paranoid about neighbors. Sometimes she won’t talk to me for days—won’t allow me to go anywhere”, She was so paranoid on me and accused very badly saying that I have a plan to kill her...I was afraid to look at her face because she was so hostile” (Ramya29-30, 82-84).

“Those days he had delusions and hallucinations very badly. When he is fully delusional, starts to hit me and shout...difficult to keep him at home” (Nancy 47-49).

Frustration: Five participants reported frustration. Three factors were found from the transcripts for their frustration; (1) troublesome behaviors of the schizophrenic individual (2) long-term caring (3) absence of support. Continuous troubles of the affected individual such as accusing and scolding, being so lethargic, demanding, being hostile, having relapses and hospitalization were found to be events for that frustrated the participants most. Ramya

reported her frustration as “most of the time I cry to relieve my self—her words are unbearable. Once she chased me out—I was so depressed many times....there was a time I couldn’t sleep at all...I have tried to commit suicide six times” (35-37). Nancy reported “It is very hard and stressful to me at my age” “You Know, we are suffering for twenty years” (108-109, 92-93). Gamini has reported his frustration due to absence of support at home; “my wife can’t understand the difficulties I am having with Indika...if she is supportive it gives me a relief...I have to avoid troubles at home—give his medicines properly— take him to the doctor...this is a never ending problem” (52-55).

Findings among two categories

Study sample consisted of two categories of caregivers on the basis of schizophrenic individuals living with caregivers and living in an institute. Ramya, Nancy, and Gamini are living with their schizophrenic individuals and Saliya, Nafish, and Perera have institutionalized their schizophrenic individuals. Findings indicate similar as well as different implications of subjective and objective burden for these two categories.

All three participants living with schizophrenic individuals at home reported high financial distress, household disruptions, problems of social interactions, and personal limitations whereas one participant of institutionalized schizophrenic individuals reported only high financial distress and personal limitations; other two participants reported only low financial distress and less interruption in their social interactions (Table- III). These findings indicate high objective burden amongst the caregivers those who care for schizophrenic individual at home to that of the caregivers those who care for schizophrenic individual in an institute.

As findings indicate both categories of participants reported preoccupation and uncertainty of future security of the schizophrenic individual. Two participants of home living category and one participant of institutionalized category reported dissatisfaction of life and one participant of institutionalized category reported stigma. All the participants reported worry. Equally from both categories four participants reported shame. Three participants of home living category reported frustration, grief & loss whereas two participants of institutionalized category reported the same. Three participants of home living category reported fear and guilt whereas one participant of other category reported only guilt. Two participants of home living category reported anger & resentment (Table-V). These

findings indicate fairly similar implications of subjective burden amongst both categories of caregivers. Considerable significance of two categories in subjective burden is the stigma reported by institutionalized category and the fear, anger & resentment reported by the home living category.

Discussion

The current study examined the nature of subjective and objective burden of primary caregivers of schizophrenic individuals. Findings indicate the presence of both subjective and objective burden in different levels among the caregivers. Majority of caregivers reported subjective burden whereas caregivers of home living category reported high objective burden.

As findings of the current study indicated, caregivers experience high objective burden due to financial distress, household disruptions, social and personal limitations caused by the schizophrenic individual. These findings are in line with those of Thompson and Doll (1982), Provencher (1996), Salley (1994), Nasr & Kausar (2009) who reported empirical evidence of objective burden. But two specific factors relating to financial distress and personal limitations were found in the current study; (1) taking for various treatments (2) avoiding social events purposely. Caregivers have spent lots of money for traditional treatments, astrological help, and religious activities for a long period while the schizophrenic individual is undergoing on western psychiatric treatments. Also they do not like to have any leisure activities and avoiding them purposely thinking that is unfair and immoral. There could be a cultural and religious influence behind these two factors.

Findings of current study suggest the high objective burden among caregivers of home living category to that of caregivers of the institutionalized category. Some caregivers reported loss of jobs due to the troubles they have at home with the schizophrenic individuals and that has in turn caused a high financial distress that has affected the entire family of the caregiver. Institutionalization has helped the caregivers to have a peaceful environment at home and concentrate on their day to day work, job, and other responsibilities. Many studies (Jackson, Smith and McGorry 1990, Magliano et al. 1999, Beach et al. 2000) have reported high objective burden caused by schizophrenic individuals when they live with their caregivers. The finding of the current study would be useful in further studies researches to look at the usefulness of institutionalization in reducing caregivers' objective burden.

Current finding implications of subjective burden reflect some common features related to the study literature and some specificity to the current study. As reported by many studies, (Gibbons et al. 1984, Kuipers and Bebbington 1988, Adams 1994, Wheelar 1994) worry, shame, guilt, frustration, grief & loss, fear, dissatisfaction of life, and uncertainty of schizophrenics' future were found to be the subjective burden in the current study. Schizophrenics' Positive and negative symptoms, dependency, and long term troublesome behaviors, are causing and maintaining subjective burden of caregivers. Caregivers of current study sample show a greater contact with their schizophrenic individuals and they have been primary caregivers from the beginning of problem of the schizophrenic individual. This could be one major reason for caregivers to experience a high objective burden. As indicated by Roick et al. (2007) caregivers in greater contact with schizophrenics experience greater burden. Also, all the caregivers of current study do not have a steady future plan for the schizophrenic individual; there is no one to be a caregiver after the present caregiver. This situation also has an impact in increasing caregivers' subjective burden.

Stigma associated with schizophrenia has become as subjective burden for only one caregiver of the sample. Others do not perceive schizophrenia as a stigma and they see it only as an illness. But as indicated by western and some regional studies, caregivers report stigma experiencing high objective burden. Ryder, Bean, & Dion (2000) reported that Chinese caregivers were more likely to keep mental illness a secret from others. They found high stigma associated with schizophrenia among Chinese caregivers experiencing high subjective burden. Some limitations of current study sample could be the reason for this different finding and further research would help to get more reliable findings on stigma associated with the disorder in Sri Lanka.

The current study has reported fairly similar implications for subjective burden amongst two categories of caregivers, except, fear, anger & resentment, both categories of caregivers reported similar implications of themes emerged for subjective burden. Fear, anger & resentment were present amongst the caregivers of the home living category. Caregivers reported to be helpless when their schizophrenic individual exhibits behaviors such as aggressiveness, demanding and manipulation, paranoid ideas towards the caregiver and surroundings. Therefore, it can be assumed that institutionalization has helped to alleviate fear, anger and resentment amongst caregivers.

Overall findings indicate high subjective and objective burden in female caregivers than in males, in old caregivers than in young, in parents than in siblings; longer duration is

likely to induce high burden. Similar findings were reported by Lowyck et al. (2004), Roick et al. (2007) There was no significance of burden with social class and educational level of caregivers in the current study.

Limitations

The aim of current investigation was to examine subjective and objective burden of primary caregivers of schizophrenic individuals. The study sample had few limitations. Sample consisted of small number of participants therefore the results cannot be generalized to the entire population in the country. Also the sample does not represent all the categories of caregivers of schizophrenic individuals in the country. Some schizophrenics are homeless and neglected. Caregivers' burden of these categories could have different implications. The sample has limitations with participants' educational and social background, age, and representation of all kind of primary caregivers such as parents, brothers, sisters, and relatives. Therefore considering these limitations suggest further studies would help to have more reliable findings on caregivers' subjective and objective burden in the country.

Conclusion

From the findings of current study, it can be concluded that subjective and objective burden exists among the primary caregivers of schizophrenic individuals in Sri Lanka. Caregivers experience particular burden with financial distress, household disruptions, social and personal limitations and psychological distress caused by the schizophrenic individual. Caregivers' objective burden is high when schizophrenic individual is cared for at home. Institutionalized schizophrenic individuals cause less objective burden on their primary caregivers. Both home living and institutionalized schizophrenic individuals cause subjective burden on their primary caregivers. There is no considerable significance in subjective burden on primary caregivers when the schizophrenic individual is cared for at home or in an institute. Above conclusion is based on the findings of a small sample with few limitations. Hence I would like to recommend further larger

studies with more diverse sample of caregivers of schizophrenic individuals to investigate the particular burden in Sri Lanka.

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