

The Perception of Stress by Indian Caregivers: A Thematic Analysis

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Caregiving may mean direct care of all types also including work done by paid workers such as nurses, social workers, and counsellors. But in this paper the focus is not on professional caregivers, but on family caregivers. Family caregivers are emotionally involved in the process of caregiving, although they may undertake caregiving as a responsibility with compassion still, they may perceive a threat to their physical and psychological being. Thus, caregiving being associated with emotional, financial and social turmoil forms a ground for research in itself. Indian caregivers, accept their caregiving roles, as reciprocity of duty and love, but still, they tend to perceive the engrained stress in caregiving tasks. The present study, thus, tends to identify such perceived caregiving stress in caregivers of patients suffering from physical chronic diseases such as diabetes, cancer, heart diseases. The sample of the study consisted of 120 caregivers of chronically ill patients; 110 female and 10 males, drawn from some private hospitals in the city of Gorakhpur and Ayodhya. The qualitative data was obtained in the form of narratives using semi-structured open interview methods and observations, thereafter, thematic analysis of the interview transcripts using manual coding techniques was done

Keywords: caregiving, chronic illness, caregiving stress, thematic analysis

Introduction

Caregiving may mean direct care of all types also including work done by paid workers such as nurses, social workers, and counsellors. But the focus of present piece of work is not on professional caregivers, but on family caregivers. Caregiving affects caregivers financially, socially, emotionally and even with regard to important life choices like work, career decisions, whether to have another child and relocating to another city or town. Being thrown into the responsibility of caregiving unexpectedly brings along intricate situations that are unavoidable. Such situations lead to conflict, stress, anxiety, depression and other deteriorating issues that are associated with the illness. Severity of psychiatric symptoms, behavioural disturbances and patient quality of life have a stronger association with caregiver experienced burden (Mohamed, et. al., 2010).

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In India, caregiving has a different meaning. Finke (2014) alleged that caregiving is a critical issue for the Indian Health system. Indian caregivers are taken for granted because in a collectivistic society, it is culturally expected that the family will look after the chronically ill patients, regardless of what changes and challenges it means. Caregiving in India is considered a continuation of an ancient custom of extended family and lifelong care for family. But that tradition may now be colliding with new realities as now people have more chronic health problems such as diabetes and obesity, and are less connected with traditions and supports, as well as the global migration for particularly educational and economic reasons make it difficult for offspring to take care of their ailment parents.

Caregiving maintains all the features of a chronic stressor (Juster & Marin, 2011) as it involves psychological and physical strain over long periods of time having the capacity to spill over into various areas of life (Wan, 2011). Equating it as a stressor, caregiving has been distinguished into primary and secondary stressor (Aneshensel, Pearlin & Schuler, 1993). The direct act of caring, i.e., the duties related to the care of patient, forms the primary stressor. The secondary stressors related to caregiving are the

varicoloured problems emerging as a consequence of caregiving. In a review article, Hunt (2008) proposed that caregiving literature suggest both negative and positive concepts related to caregiving. The negative concepts incorporate caregiver burden, hassles, strain and stress.

The present piece of work attempted to fill this knowledge gap by capturing different shades of caregiving experiences of family members who were engaged in caregiving for their chronically ill family members or relatives. Most of the studies on caregiving indulge in caregivers of mentally ill and not the physically chronically ill. Hence, this study intended to comprehend how family caregivers are involved in caregiving, whether they perceive it as a stress; if stress then what kind of stress. In chronic illness perspective, the findings of the study have implications for caring role in the Indian setup, where mostly family members play the role of caregivers at the time of chronic illness.

Objective of the study

Indian caregivers, although, have a tendency to find themselves dealing with anger, resentment, guilt, depression, financial difficulties, isolation, and conflicts with family and work. However, they are less likely to voice their difficulties possibly because caregiving is seen as part of family life and not as a “burden”, which has roots in collectivistic traditional norms.

While caregiving is an increasingly common family responsibility but this role does not fall equally on all the family members, particularly the gender and type of generational relationship determine which family member will assume the role of caregiver for elderly or chronically ill. The present paper focuses on drawing an arena of caregiving stress as perceived by the Indian caregivers.

Method

Sample: The sample consisted of both, male and female caregivers who took care of people who are afflicted with any chronic disease (i.e., on bed for more than a month and are dependent on others for their daily chores and self-hygiene). Total sample for present research comprises of 120 caregivers of chronically ill patients; 110 female and 10 male caregivers were drawn from some private hospitals in the city of Gorakhpur and Faizabad districts of state of Uttar Pradesh, India, where the patients of heart diseases, cancer, diabetes and other chronic illness are treated and admitted. Most of the caregivers were females including daughter-in-law caring for their mother-in-law, and then wives caring for their husbands, and also

daughters caring for their mothers. Mostly diabetic, cancer and heart disease patients were the part of the sample, as these diseases are prevalent in the region. All the caregivers have Hindi as their mother tongue, and they had given an interview in the same language.

Data Collection Method: The qualitative data was obtained in the form of narratives using semi-structured open-ended interview methods and observations. The semi-structured interview was concerned with few relevant questions related to caregiver’s stress: the experience of caregivers since the diagnosis of illness, the dependency of patients on caregivers, the major changes perceived since the diagnosis of illness. The narratives about the caregiving experiences from the caregivers has been thus obtained.

Data Analysis: To gain an in-depth understanding of the narratives, thematic analysis of the interview transcripts using manual coding techniques was done. Firstly, key direct quotes were identified, and common ideas were interpreted. Next, related patterns were combined into themes.

Results

Seven main themes on the caregivers’ stress from providing care as well as their own perspectives and comprehension of the illness had emerged from the thematic analysis. These themes are reflections of the emotions that caregivers have for the duty of providing care.

Table 1
Major themes emerged from Thematic analysis

Sl.No.	Major Themes
1	Seriousness of responsibility
2	Degree of dependence
3	Transitions in life
4	Urgency and responsibility
5	Emotional Roller Coaster
6	Positive feelings during caregiving
7	Negative feelings during caregiving

The detailed description of themes, subthemes and their exemplars are presented in tabular form

Table 2

The subthemes and exemplars of the major theme 'Seriousness of responsibility'

Major Theme	Subthemes	Exemplars in English with Hindi Transcript	f
Seriousness of illness	Too serious	This disease is too serious (<i>bahut hi gambhir bimari hai</i>) Nothing could be more dangerous than this illness (<i>is bimari se khatarnak to kuchho hi nahi sakta</i>)	92
	Life threatening	It is threat to their life (<i>unki jaan ka bhi khatra hai</i>)	42
	Prolonged	The treatment is ongoing since long (<i>itne lambe samay se ilaaj chal rha</i>)	40
	Indefiniteness	The future is always indefinite (<i>har waqt dar rehna hai ki pata nahi aage kya hoga</i>)	28
	Bed-sore	It's a punishment to be on bed all day long (<i>pure din bistar pe rehna bhi saza hai</i>)	12
	Weakness in patient	Weakness leads to inability to do any work (<i>kamjor hone se apna koi kaam nahi kar sakte</i>)	10
	Too much pain for patient	Cries out of pain (<i>dard se chilate hai</i>) Feel dying is better than living with the disease (<i>unko lagta hai marna thik hai is bimari me in dard sehne se</i>)	10
	Incurability	The disease is serious as there is no cure of it (<i>gambhir toh hai hi kyunki iska koi ilaaj nahi hai</i>) There is no way but to live with the illness (<i>rehna toh is bimari ke saath zindagi bhar hai</i>)	09
	Burden for family	The lives of all family members is disturbed because of the illness (<i>pure parivar ka jeevan inke bimari se hi ast-vyast hai</i>)	08

Table 2 clearly shows that the caregivers emphasized on the seriousness of the illness. They perceived the illness for which they are devoting their time in caregiving as serious and nine subthemes have been identified which are emphasizing the seriousness of illnesses, like diabetes, cancer, heart disease, etc.

The subthemes are: Too serious, life threatening, prolonged, indefiniteness, getting bed-sore, weakness in patient, too much pain for patient, incurability, and burden for family. Most of the caregivers stressed that their respective patients are facing too serious illness.

Table 3

The subthemes and exemplars of the major theme 'Degree of Dependence'

Major Theme	Subthemes	Exemplars in English with Hindi Transcript	f
Degree of dependence	Financial dependence	Needs to visit the doctor every month, which requires lot of money (<i>har mahine doctor ke paas leke jana hota hai, aane jane mein bahut kharch hota hai</i>) Half of the earning is invested in medicines (<i>aadhikam aitohdawameinjati hai</i>)	112
	Medical dependence	The regular medicines and injections are too costly and sometimes not easily available (<i>dawa bahut mehngi hai aur injection ozlagta hai jo bahut mehnga hai, kai baar milta bhi nahi hai</i>)	110
	Food intake	The family eats according to the patient (<i>parhez ka khana alag banta hai, humara khana -peena bhi inke hissab se ho gaya hai</i>)	86
	Personal Hygiene	Most of the time is spent in maintaining hygiene, else there is fear of infection (<i>roz subah ke sare kaam karo, aadha din usme hi chala jata hai, safai nahi rakho toh infection ka dar hai</i>)	68
	Physical and mobility dependence	Calls again and again for washroom (<i>bathroom le jana padta hai baarawazlagate hai</i>)	64

Table 3 depicts how the caregivers responded when inquired about the dependence of patients on them. It has been found in the narratives that patients are not only financially dependent in terms of purchasing medicines and other medical and pathological screening, etc., and consultation fee but also on commuting to hospitals and doctors. Most of the patients are financially dependent on caregivers while the other dependences included: intake of medicines, food intake, maintain personal hygiene and dependence of mobility. The patients are dependent on the caregivers for the timing and dosage of their medicines and the caregivers consider it extremely important task as it decides the

future progression of the illness. When facing physical chronic illness, the real bodily capacities are at decline leading to restrictions in intake of food items, the caregivers have to spend extra time and effort for managing it alongside managing their own diet. Chronic illness imposes the patient to be on bed from few to many days, this leads to problems in maintaining personal hygiene, the caregivers does have an additional task of brushing teeth, bathing, adhering to toilet demands and cleaning the place all around the patient. Such extreme dependency of patients on caregivers confines them to their home, caring for the patient, with less or no mobility.

Table 4
The subthemes and exemplars of the major theme 'Transitions in life'

Major Theme	Subthemes	Exemplars in English with Hindi Transcript	f
Transitions in life	Chaos in life	There is too much of hectic schedule (<i>bhaag-daud bahut hoti hai</i>), Everytime mind is diverted (<i>har waqt dimaag btarehta hai</i>)	44
	Changes in daily routine	The work never ends since early morning (<i>subah jaldi utho toh bhi kaam khatam nahi hota</i>)	40
	Eating habits changed	Our eating habits have changed accordingly (<i>humarakhana-peena bhi inke hissab se ho gaya hai</i>)	30
	Responsibility	An additional responsibility has been added (<i>ek nayizimmedaribadhgayihai</i>)	28
	No time for personal work (hobbies, interests)	No time for personal work, no leisure time (<i>apnekisikaamkeliye time nahimilta, khalisamay hi kaha hotahai</i>)	24
	More expenditure	New expenses have been added (<i>nayekharchebadhgayehai</i>)	24
	New challenge in life	It's too difficult to manage everything (<i>sab kuch manage karna bahut mushkillagtahai</i>)	22
	Immobility	Can't leave the patient alone so can't go anywhere (<i>kahin jane ki nahisochsakte, sathlekejanahisakte aur kiskebharosechodkejayein</i>)	22
	Less time for others Fear	The visits and interactions with others are very rare (<i>sab se milnajulna bahut kamhogyahai</i>)	20
	Tiredness/ restlessness	Fear of death is constant (<i>dimaagmeinhar pal ek darbanarehtahai, lagtahaikahin humepatanahichale aur kuchhojaye</i>)	14
	Anguish	Feel depressed, doesn't feel like doing anything (<i>man neerassahogyahai, kiskaam ko karnemeinthakanlagtithai</i>)	14
	Over-protectiveness towards patient	Life is full of sorrows (<i>zindagimeinkasht hi kashthai</i>) The patient should always remain in someone's observation (<i>unpeharwaqtkisinakisi ki nazartohhoni hi chahiye</i>)	10 09
	Rendering full life	Life is being controlled by the illness and not ourselves (<i>life bimaarikhissab se chalrhi, humarehissab se nahi</i>)	08
	Constant Negative thoughts	The mind is always perturbed with negative feelings (<i>galatbatein man meinaatihai, kahinjaye aur der hotoh man ghabratahai</i>)	08

Major Theme	Subthemes	Exemplars in English with Hindi Transcript	f
	Alertness	Even a little mistake would alter the course of the medicine	06
	Feeling patient's pain	<i>(agar dhyannadijayetohdawa ka course galathojayega)</i> The pain of chemo is intolerable <i>(chemo ka dard hum aapnahisamjhpayenge, bahut takatchahiye use sehnekeliye)</i>	04
	Pride in caring	It feels by caring for the patient we could return a part of whatever he has done for us <i>(lagta haizindagimein jo kuch inhone hamarelia kia haiuskebadlemeinkuchmahatvpoornakar pa rahe)</i>	02
	Receiving the possession of House	We got new home <i>(ghar mil gyahume naya)</i>	02

Caregiving is a task with continual demand of physical, emotional, mental and financial expenses. With such enormous responsibility, caregiving brings along varied changes in the life of the caregiver. Table 4 depicts the changes or transitions in lives of the caregivers as perceived by them during the task of caregiving. Such changes may be behavioural (eating habits), cognitive (constant fear of death, slow prognosis) or affective (losing one's family member, pain). Some of the major changes perceived were a

daily chaos in life and changes in daily routine. While the other diverse changes were: eating habits changed, increase in responsibility, no time for personal work (hobbies, interests), more expenditure, new challenge in life, immobility, less time for others, fear, tiredness/restlessness, anguish, over-protectiveness towards patient, rendering full life, constant negative thoughts, alertness, feeling patient's pain, pride in caring, and receiving the possession of house.

Table 5
The subthemes and exemplars of the major theme 'Urgency and responsibility'

Major Theme	Subthemes	Exemplars in English with Hindi Transcript	f
Urgency and responsibility	First priority	Care is above every duty, every work <i>(sabhizimmaraiyon se uparhai, harkaam se pehlezarurihai)</i>	76
	Righteousness/ Obligation	This is not our responsibility but our duty <i>(yeh zimmedarihamarakartavyahai, dharmtohyahihai ki hum puri seva karein)</i>	48
	Moral responsibility	The conscience doesn't allow to not care <i>(agar dekhbhalnakaretoh man kostahai)</i>	40
	Life of patient	What could be bigger than someone's life <i>(kisi ki zindagi se badikyazimaadarihogi)</i>	28
	Dependence	It's our responsibility no one else's <i>(hamarijawabdehихaiunkeprati, aur kisi kinahi)</i>	16
	Caring in return	They have done so much it's our time to return <i>(bachpan se sab kuch kia haihamareliye, ab hamaribarihahi, bahut madat ki haihumaritohsaathnahichodsakte)</i>	14
	Increase in self-importance / Pride	Feel pride that I could motivate someone to live <i>(garvmehsushotahai ki hum kisi ko jine ki prerna de rhe)</i>	14
	Good Luck to get this opportunity	We are lucky to have the chance to perform these duties <i>(hum bhagya wale hai ki hume yeh kartvya ka palankarne ka avsamila)</i>	12

Major Theme	Subthemes	Exemplars in English with Hindi Transcript	f
	Profoundness towards patient	If we don't consider it a task it would not be difficult (<i>seriously isekaamnasamjhkekareintoh koi mushkilnahogi</i>)	12
	Unexpected	Everything was spontaneous, happened all of a sudden (<i>achanak se hi sab hoga, ab jab ho hi gyahaitohkarna hi hai</i>)	08
	Effect on health	Little up and downs in own health doesn't matter much (<i>apnitabiyat ki chotimotibatein bahut mayanenahirakhti</i>)	08
	Role of companion is important	It is a companionship of seven births, be it joy or sorrow (<i>saatjanam ka saathhaitohdukhmeinbhitohhai</i>)	04

Medical conditions demand immediate gratification of the tasks. Chronic illness continues for months and years, with unexpected outbreaks during the illness. Thus, the caregivers need to be prepared for any sudden duty to be attached to their responsibility. The caregivers have no choice but to keep the caregiving responsibility as first priority. Family caregivers adopt the caregiving task as an obligation to show reciprocity

towards the loved ones. Some other subthemes that explain the imperativeness associated with responsibility of caregiving were: moral responsibility, life of patient, dependence, caring in return, increase in self-importance, good luck to get this opportunity, profoundness towards patient, no expectancy, effect on health, and importance of role of companion (Table 5).

Table 6
The subthemes and exemplars of the major theme 'Emotional roller coaster'

Major Theme	Subthemes	Exemplars in English with Hindi Transcript	f
Emotional Roller Coaster	Fear	In starting we could find no way out (<i>shurumeintoh koi rasta nazarnahiaatatha</i>)	41
	Sad/distress	Complete family was in distress after the diagnosis of the disease (<i>bahut taklifmeintha pura parivarbimarikebaaremeinjanke</i>)	36
	Better condition of patient	Even a little progress gives happiness (<i>jab thoda progress dikhtahaitohaachalagtahai</i>)	30
	Hope	Hope he recovers soon (<i>umeedkartehaijaldi theek hojaye</i>)	28
	Faith in God	With God's grace recovery would be fast (<i>bhagwansathdegatohsahihoga, sabki dua hai ki aajpehle se bahut thikhai</i>)	26
	Importance of life of patient	She managed the whole home, still many responsibilities are left upon (<i>ghar pura sambhaltithi, zindagimeinabhiinako bahut kuchkarnahai, kuchhogyatohanarthhojavega</i> (<i>cries</i>))	26
	Getting too much emotional	Whenever the situation gets worse, we lose hope (<i>jab halatbigadtihaiumeed tut jatihai</i>)	22
	Belongingness/love to patient	Cares a lot, it's important that he recovers (<i>bahut manateyhai, theek nahihuye to...</i> (<i>cries</i>))	20
	Habit developed	Now it is a part of daily life (<i>ab toh daily life ka hissaho chukka hai</i>)	14

Major Theme	Subthemes	Exemplars in English with Hindi Transcript	f
	My illness	Since his illness, even I don't feel well (<i>jabse yeh bimaarpadeapnihalatbhi theek nahirehti</i>)	14
	Irritation	Sometimes it is boring (<i>kabhi man ubjatahai</i>)	12
	Pray that no one should get this illness	Wish that no one gets prey to this illness (<i>kabhi yeh bimaarikisi aur ko naho</i>)	08
	A mix of positive & negative experiences	In starting it was difficult but slowly it was easy (<i>shurumein bhut taklifhuyiphirdhirethikhogya sab kuch</i>)	04
	Not just a patient but my mother	I don't consider her a patient, but my mother (<i>sirf ek mareejkejaisenahiapni maa kejaisesarjhtihun</i>)	02

Caring for their loved one or a family member is a different kind of experience for the caregivers in the Indian setting, long with an emotional roller coaster being faced by them, as depicted in table. The experiences of caregiving may vary from the diagnosis of the illness, adjusting with the new responsibility and then undertaking it as a customary responsibility. Sharing their experiences since the time of knowledge

of the illness, the caregivers fixated on fear related to the illness, feelings of distress and better condition of patient. They also shared the experiences with regard to hope, faith in God, importance of life of patient, getting too emotional, belongingness or love towards the patient, development of a habit, their own declining health, irritation, thoughts that no one should get this illness, and feeling that the person is not just a patient (Table 6).

Table 7

The subthemes and exemplars of the major theme 'Positive feelings during caregiving'

Major Theme	Subthemes	Exemplars in English with Hindi Transcript	f
Positive feelings during caregiving	Satisfaction	There is a satisfaction that I am doing something good (<i>ek satisfaction hai ki kuchacchakarrhe, aatma ko santushtirehtihaijtnathikhotejatehai</i>)	44
	Progress in condition of patient	The best part is he is recovering (<i>sabseacchibaat yeh hai ki sahihorahe din pe din</i>)	44
	Happiness while caring	Emotional attachment has increased that leads to happiness in caring (<i>Emotionallyitna attach hogyihun ki khushihotihaisabhikaamkarke, khushimehsushotiapnokeliyekuchkarnemein</i>)	42
	Caring for patient	The best feeling is that we are caring (<i>sabseacchi feeling tohyahihai ki dekhbhaalkarrahe</i>)	40
	Faith in God	The recovery builds faith in God (<i>sudharjaisehua use man meinasthabadhgayihai</i>)	33
	Spending time with patient	Caring gives chance to spend time with patient (<i>hameshaghar se dur rahe, ab kam se kam bahut sibateinkarne ko miltahai</i>)	24
	No positive feeling	What could be positive about illness (<i>bimaarimeinacchakyahoga</i>)	16
	Desire to eradicate the illness	I feel like eradicating the disease from world (<i>dilkartahaijahan se is bimari ko mitadein</i>)	16
	Fighting spirit of patientcare for me the same way	Even after pain, is always smiling (<i>itnedardkebaadbhi hasta huyachehra</i>)	12

Major Theme	Subthemes	Exemplars in English with Hindi Transcript	f
	Ability to manage various responsibilities	Now able to perform various tasks at the same time (<i>ab bahut se kaam ek saath manage hojatehai</i>)	10
	Knowledge of medicine	Got to know much about illness and medicine (<i>dawa aur bimarikebaaremein bhut sibateinpatachali</i>)	04
	Expectation in future someone else would	If I care for my parents today, it would be a lesson to my children (<i>aaj hum apne parents ki care karnegetoh hi tohumarebacchebhisikhenge</i>)	04

While many complications might be encountered by the caregivers during caring, but still they usually attach positive feelings in their experiences; the reason may be the reciprocity and “dharma” being attached to the caregiving task. Sharing their experiences the caregivers also attached positive feelings to the caregiving task, all associated for the good of the

patient. Some of them were: satisfaction, progress in condition of patient, happiness while caring, caring for patient, faith in God, spending time with patient, no positive feeling, desire to eradicate the illness, fighting spirit of patient, ability to manage various responsibilities, gaining knowledge of medicine, and future expectations of receiving care for themselves from others (Table 7)

Table 8

The subthemes and exemplars of the major theme ‘Negative feelings during caregiving’

Major Theme	Subthemes	Exemplars in English with Hindi Transcript	f
Negative feelings during caregiving		There is nothing bad in my mind, everything is fine (<i>kuchburanahihai man mein, sab theek hi tohhai</i>)	64
		There is no progress, medicine doesn't seem to work (<i>dawalagtahai koi asar hi nhikar rah, bahut time se koi progress nahihai</i>)	36
		Nothing negative, but a little tension related to money (<i>nakaratomaknahihai par ek dimagmein tension hotihaipaison ki</i>)	36
		Sometimes there is no hope (<i>kabhiumeed khatam sihojatihai</i>)	24
		The most negative part of illness is death (<i>bimarikesaathsabse buri cheezhaimaut</i>)	20
		Sometimes I feel bad while cleaning (<i>saafsaafaikarnemein man kharabhojatahai kai baar</i>)	18
		The biggest negativity is facing the fear at all times (<i>harwaqt ka dar hi sabsebadinakaratomakhai</i>)	14
		There is so much work that it is very difficult to remember anything (<i>itnekaamhotehai ki kuchbhiyaadrakhnemein bahut mushkilhotihai</i>)	08
		It seems that we too may not be like this in old age (<i>aisalagta ki hum bhibudhapemeinkahinaise hi nahojayein</i>)	08
		The negative is that the disease might occur in children (<i>yeh negative hai ki kahinbachonmein yeh bimarinaho</i>)	04
		It would have been better that he dies instead of calling again and again (<i>baarbulane se acchatoh mar jate</i>)	04
	Can't sit nearby whole day but still keeps on calling (<i>pure din paasmein baith nahisakte, par phirbhibulaterehtehai</i>)	04	

Major Theme	Subthemes	Exemplars in English with Hindi Transcript	f
	Uncontrollability of patient	Loses temper (<i>aaape se bahar hona</i>)	04
	Use of abusive words by patient	Upset by abuse (<i>gaaligalauj se khinhotihai</i>)	04
	Repetition of sentences	Asks the same thing again and again (<i>ek hi baatko baar-baarpuchte</i>)	02

The Indian caregivers consider caregiving as a shared responsibility, where one expects care in future in return of the care provided by them now. Thus, the caregivers in the present sample reported mostly no negative feelings attached with the task. Although, caregiving task is accompanied with intricate situations that are unavoidable, such as financial burden, social restrictions, emotional breakouts, career decisions. These situations instil negative experiences in the caregivers leading to conflict, stress, anxiety, depression and other worsening issues that are associated with the illness. So, caregiving, being a threatening task, certain negative feelings were also experienced. The negative feelings perceived were: Slow pace of treatment, financial burden, hopelessness, death, maintaining hygiene, fear, forgetfulness, negative thoughts of one’s own future, passing on of illness to next generation, calling without reason, uncontrollability of patient, use of abusive words by patient, and repetition of sentences (Table 8).

The stories derived from the data collected for this study show the pattern of stress experienced by caregivers, which revolves around physical stress (fatigue, ill health, etc.); psychological stress (anxiety, frustration); social stress (lack of social support, mobility restrictions); and financial stress (medical bills, doctor visits, etc.).

Discussion

The primary aim of the current study was to look into the stress patterns exhibited by the caregivers. The narratives derived from qualitative analysis were analyzed and discussed for the same.

The Canvas of Caregivers Stress

The burdens of caregiving stress affect all aspects of the caregivers’ lives, including their physical, social, psychological, and financial well-being. As an

interweaving web of complications, caregiving responsibilities generate physical exhaustion, social isolation, anxiety, financial deprivation, and family strife, among others. The stigma associated with caregiving is that of the “forgotten patient” (Levine, 2003), due to the significant stress that caregivers experience. Furthermore, Pinquart and Sorenson (2003) establish a correlation between caregiving tasks and psychological distress in their research. It has been demonstrated that mental symptoms are substantially correlated with the distress of caregivers (D’Amelio et al., 2009).

The following are descriptions of seven main themes that emerged from the accounts of the caregivers of chronically ill patients:

Major Theme 1: Seriousness of illness

The principal source of caregiver stress is conveyed through narratives that emphasize the gravity of the illness. The narrative states that the caregivers regard the ailment of their loved ones as a subject of profound concern, to the degree that they consider the gravity of the situation to be inconsequential. This malady is more perilous than anything else. **Chronic** illness holds little to no significant progress, and thus developing a threat to the life of the patient. Even such threat places a stress on the caregivers, in their words.

Major Theme 2: Degree of Dependence

Chronic illness necessitates a protracted state of health that places caregivers in a complex and extended reliance. The patients depend on their caregivers for everything from impeccable care to daily tasks, which include financial, social, medical, and physical necessities.

This degree of reliance also creates a web of tension for the caregivers, as evidenced by the exemplars.: ‘*Calls again and again for washroom; most of the*

time is spent in maintaining hygiene; needs to visit the doctor every month, which requires lot of money'. Financial dependence in lower social economic status has been found to move to a state of complete or partial loss of the savings of the seriously ill patients (Covinsky, Goldman, Cook, et.al., 1994), as narrated half of the earning is invested in medicines. Moreover, the financial cost associated with family caregiving, is a significant factor in caregiving burden, both for male and female caregivers (Mishra, Mishra & Lajjar, 2016).

Major Theme 3: Transitions in life

Stress in caregiving has many forms tracing almost every aspect of the life of the caregiver. Being a daily twenty-four seven job, the caregiving task demands from the caregiver changes at different points in their life. The caregivers voice the transitions in their life as there is too much of hectic schedule; every time mind is diverted; our eating habits have changed accordingly; can't leave the patient alone so can't go anywhere.

Caregivers also feel changes in their thought-process as they face a stage of constant fear: Fear of death is constant, continuous negative thoughts in the mind, the mind is always perturbed with negative feelings, empathetic feelings of pain, the pain of chemo is intolerable and grief, life is full of sorrows.

Major Theme 4: Urgency and responsibility

Uncertainty regarding one's ailment, according to Koocher (1989), constitutes the most significant psychological stressor. The present study also reveals that the caregivers perceive the indefinite nature of the patients' illnesses as a source of stress. Over follow-up periods of up to two years, stress is a strong predictor of entry, and physical distress and financial hardship are significant predictors of high levels of caregiver stress. As described in a narrative, *'the symptoms of an illness are unpredictable, the future is always indefinite, the unexpected prognosis, all lead to stress'*.

Major Theme 5: Emotional roller coaster

Caregivers endure hours, days, and even months of anxiety in order to provide their ailing companions with the necessary care. Thus, caregiving is a lifelong endeavour that requires the caregiver's undivided attention and concern. Caregivers express a range of emotions, both positive and negative, when recounting this experience. Despite this, a number of aspects of caregiving stress are acknowledged; nonetheless, caregivers perform the responsibility of caregiving despite differences in cultural norms and values.

Caregivers are able to recognize even the most favourable aspects of the caregiving process due to these cultural sentiments (Cohen, Colantonio & Vernich, 2002; Kramer, 1997). As stated in the narration, caregivers' compassion for patients enables them to perform their duties with positive emotions of reciprocity and obligation. According to Cassell (2012), compassion is an essential emotion for establishing connections with others through identification and for offering motivation and solace in times of distress. As stated by Batson et al. (2009), members of a collectivist culture develop a propensity for prosocial behaviour through exposure to compassion. In the context of India, a collectivist culture, family members were cared for out of compassion by the caregivers. This resulted in a positive perception of the caregiving task and consequently decreased the caregivers' stress levels.

Although both positive and negative experiences are associated with the caregiving role, the caregivers discuss their faith in God extensively. It is stated that: *The recovery builds faith in God. The faith in God is so strong that sometimes they believe more in prayers than in the medical treatments for recovery: with God's grace recovery would be fast; medicine doesn't seem to work.*

Major Theme 6: Positive feelings during caregiving

Positive experiences that were hindered despite the stress of caregiving included an improved prognosis for the patient, a sense of belonging with the patient, satisfaction and pleasure in the act of caring, quality time spent with the patient, the patient's fighting spirit, and an increase in medical knowledge. The positive sentiments expressed by the caregivers are conveyed in the following statements, which they have taken in their entirety: *'Cares a lot, it's important that he recovers (cries), the best feeling is that we are caring, caring give's chance to spend time with patient'*.

Major Theme 7: Negative feelings during caregiving

Despite the numerous positive attributes associated with it, caregiving is generally regarded as a burden in discourse. It is believed that the responsibility of providing care imposes a burden, whether physical, mental, social, or pecuniary. Additionally, caregiving restricts social engagement, family participation, personal objectives, and health. However, a substantial body of literature on caregiving establishes a connection between providing care and experiencing psychological

distress (Pinquart & Sorensen, 2003b). The caregivers, through their narratives, recount feelings of melancholy and anguish that they encountered while providing care for the care-recipient: Complete family was in distress after the diagnosis of the disease; In starting we could find no way out. Being a daily job, caregiving leads to irritability and hopelessness in the caregivers. The caregivers report of their own irritating behaviours: Sometimes I feel bored; it would have been better that he dies instead of calling again and again. The slow recovery process and prolonged illness leads to hopelessness in the patient, as reported in the following verbatim of the caregivers: Sometimes there is no hope; medicine doesn't seem to work. While negative experiences have been reported by the caregivers, but the majority in the present caregiver population do report of no negative feelings being associated with the caregiving experience, they clearly state: There is nothing bad in my mind; everything is fine.

Conclusion

Caregiving stress involves toll on the complete life of the caregivers, be it physical, social, psychological or financial. Caregiving task in itself acts as a stressor leading to physical fatigue, social isolation, stress, anxiety, financial scarcity, family conflicts and numerous other interwoven glitches. The amount of stress that the caregivers face lead to the connotation of caregivers as "forgotten patient" (Levine, 2003). Pinquart and Sorenson (2003) indicate in their study too that caregiving task is linked to psychological distress.

In Indian context, caregiving for a loved one is an emotional empathetic task aiming at betterment of the patient. As a consequence, the prognosis of the illness is a major concern for both the patient and the caregiver. The slow progress of recovery from illness

and or management of treatment regimen, etc. as reported by the caregivers, is a cause of unremitting stress to them.

According to Bhagat and Unisa (2006), caregiving in India is a result of expectations, duty, love, and a positive attitude in general. Also, as mentioned by Gupta and Pillai (2002), both parents and children do cultivate the idea of reciprocity as a familial responsibility. As such, the responsibility of caregiving is culturally attached to the individuals in India. The notion of reciprocity lying within caregiving tends to attach positive feelings to the task, as presented in the narratives: They have done so much it's our time to return and we are lucky to have the chance to perform these duties. Even then, an array of stress in Indian caregiving is found, this could be probably because of the urgency of tasks that has been reported during caregiving. The caregivers consider that the caregiving responsibility is the first priority in their life, as they state 'Care is above every duty, every work' and this is so because of obligation towards their loved one, as quoted 'This is completely our responsibility'.

In a nutshell, it could be inferred from the narratives of the caregivers that they do adopt the caregiving role due to the responsibility and obligation existing in the tradition, but with time the caregivers perceive stress, i.e., physical, psychological, social and financial stress, during the caregiving task. However, the narratives also revealed that the pattern of stress in the caregivers is such that they overpower such stress with their reasons of reciprocity and duty towards the family member. Lin, Rong and Lee (2013) similarly established in their study the positive facets of caregiving found in their study too that obligation is considered as a cultural caregiving motive which reduces subjective burden of caregiving.

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