

## ORIGINAL ARTICLE

### Caregivers' Experiences in Caring for the Elderly

Pabitra Gautam<sup>1\*</sup>, B Venkatesan<sup>2</sup>, Naresh Kumar<sup>3</sup>, Bhima Uma Maheswari<sup>4</sup>

<sup>1</sup>Nagarik College of Health Sciences, Nepal.

<sup>2</sup>Department of Medical Surgical Nursing, Padmashree Institute of Nursing, Bengaluru, India.

<sup>3</sup>JIPMER, Puducherry, India.

<sup>4</sup>Department of Paediatric Nursing, Padmashree Institute of Nursing, Bengaluru, India.

**\*Corresponding author:**

Pabitra Gautam, Lecturer (MSN), Nagarik College of Health Sciences, Nepal.

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#### Abstract

**Background:** Caring for the elderly is one of the most important aspects of primary health care, very few studies have been done on the experiences of caregivers in India.

**Aim of the study:** To explore the subjective experiences of the caregivers in caring for the elderly population.

**Methods:** This research study adopted qualitative research methods, and the design was phenomenology. The study used non-random sampling techniques, particularly, purposive sampling technique was applied to select a sample size of ten. Till data saturation, in-depth interview was conducted using open ended questions. The audio taped interviews were transcribed, meanings were formulated and emerging themes were identified. Content analysis was used for analysing the data.

**Results:** Six themes that emerged revealed the physical, psychological, social, economical, vocational and spiritual effects on caregivers of elderly.

**Conclusion:** The research finding of this study indicated that even though the task of caring for the elderly is rewarding and positive, there are challenges in the caregiving task that did not stand out as positive experiences. The study also revealed that with the increase in the age of the elderly, the strain and challenges in the caregiving also increased.

**Keywords:** Caregivers' experiences, Elderly population

#### Introduction

Aging is an inevitable developmental phenomenon bringing along a number of changes in the physical, psychological, hormonal and social conditions.<sup>1</sup> Some problems related to geriatric population are - cataract and visual impairment (88%), arthritis and locomotion disorder (40%), cardiovascular disease (CVD) and hypertension (HT) (18%), and neurological problems (18%). Respiratory problems including chronic

bronchitis (16%), Gastro intestinal problems (9%), loss of hearing (8%) are also reported.<sup>2</sup>

In India, according to the 2011 census, 8% of the total population belonged to the age group of 60 years and above. About 10.7% of the total population belonged to age group 65 years and above. In rural areas of Karnataka, 8.95% of the total population belonged to the age group of 60 years and above.<sup>3</sup>

The job of caregiving is not an easy one; the duties of caregivers can include helping with activities of daily living (ADL) and/or instrumental activities of daily living (IADL). As a result, the caregivers themselves become prone to physical and emotional strains and stressors due to the amount of burden exerted on them.<sup>4</sup>

Under its eleventh five-year plan, the Indian government has made many strides similar to that of Nepal. Article 41 of the Indian Constitution states that elderly citizens will be guaranteed social security and support for health care and welfare. A section of the 1973 Criminal Procedure Code, alluding to its traditional background, mandates that children support their parents if they no longer can support themselves.<sup>5</sup>

Caregivers report having difficulty finding time for one's self (35%), managing emotional and physical stress (29%), and balancing work and family responsibilities (29%) (NAC, 2004). About 73% of the surveyed caregivers said praying helps them cope with caregiving stress, 61% said that they talk with or seek advice from friends or relatives, and 44% read about caregiving in books or other materials (NAC, 2004), and unpaid caregivers provide an estimated 90% of the long-term care (IOM, 2008).<sup>6</sup>

## Objective

- 1) To explore the caregivers' experiences in caring the elderly
- 2) To explore the various dimensions of caregivers' experiences in caring the elderly

## Methodology

The research approach adopted was qualitative and design was phenomenology. Purposive sampling technique was used to select the subjects. The inclusion criteria included both male and female caregivers taking care of elderly within the duration of one year and above, who can speak English, Hindi or Kannada. The exclusion criteria included caregivers with speech difficulty and hearing problems and the caregivers who were not willing to participate. The sample size was 10 till the data saturation. Formal permission was obtained from the MO, PHC of Sulikere, Bengaluru. The purpose of the study was explained and informed consent was obtained from the participants to audio tape the conversation. After filling the demographic proforma, an in-depth interview was conducted with open ended questions. Semi structured and unstructured questions were directed towards their reaction, thoughts, emotions with their experiences in caring for the elderly. The

audio-taped interviews were transcribed into verbatim and coding was done and emerging themes were identified.

## Results and Discussions

Modified Colizzi's Analysis Framework was used. All the interviews were transcribed into verbatim and read to get an understanding of the verbatim. Significant selected phrases pertaining to the experience of patient under investigation were extracted. Meaning was formulated from these significant statements and statements were organized into cluster of themes. The themes and subthemes which emerged from the data are as follows:

### Theme 1: Lived Time

#### Subtheme 1: Denial of the responsibility of caregiving to elderly

*"It's a greater honour to take care of your parents but if the pressure is more, it is really difficult."*

*"I feel like going to some other place leaving everyone"*

*"My brothers too could take care of him; why I only have to take care of him."*

*"I wish she would go to her other sons houses also, but she cannot survive even for 2 days if she goes to her other son's houses."*

*"I feel like committing suicide."*

*"Sometimes I feel like I don't want to work and I don't want to take care of anyone."*

*"Sometimes my heart tells I don't need anyone, I don't need anything, I will leave everything and go somewhere."*

#### Subtheme 2: Acceptance of the caregiving responsibilities

*"I will take care of him until I have strength."*

*"When people say that you are serving God by serving your dad, I feel glad. This encourages me and motivates me in my service."*

*"I have offered my life for others."*

*"I manage. I am habituated of it."*

*"It's my responsibility; so I'll take care."*

*"He is very old than me, I think he goes through more difficulty than me and try to help him even by sacrificing my own health and desire."*

#### Subtheme 3: Uncertainty regarding future

*"Sometimes I wish I lived in this world not more than 60"*

*years and I pray to God for this.”*

*“Seeing my mother in-law, I feel like I don’t want to live longer because even though we love a person, sometimes it’s very difficult to take care of them. I don’t want to become a burden to my daughters when I get older.”*

*“I feel tense and get afraid about the future. Sometimes I used to have breathing difficulty. Once I went for check-up, then doctor told me that was because I take so much tension.”*

*“I ask God and pray from now only to be with me in my future also.”*

## **Theme 2: Lived Body**

### **Subtheme 1: Life changes: physical symptoms**

*“I feel strain sometime. I get tired and exhausted.”*

*“Sometimes I skip my breakfast.”*

*“Not just my back, but even my body pains sometimes.”*

*“I have gastric problem because my eating pattern is disturbed and other than that I get back pain, headache and body strain and lots of tension”*

*“My sleep won’t be complete sometimes.”*

*“Neither does she sleep nor does she let me sleep.”*

### **Subtheme 2: Life changes: change in daily activities**

*“My daily activities get affected because my dad cannot even go to toilet without support.”*

*“Honestly I don’t get time for myself.”*

*“Sometimes I don’t comb my hair for whole day.”*

*“I don’t think about my health.”*

## **Theme 3: Lived Relationship**

### **Subtheme 1: Relationship with spouse: supportive plus disturbed**

*“I keep the tensions with myself; but if it is unbearable, I tend to get angry and scold my wife or children and sometimes I share it with my wife, then she supports me emotionally.”*

*“My wife cared for me when I am unable to care for myself.”*

*“My wife knows he is very old now and if she has any complaints, she tells me rather than shouting at him.”*

*“I fight with my mother in-law sometimes but my husband tells me she has grown old and don’t get upset by her words. This helps me to calm down.”*

*“My husband’s support is there all the time.”*

*“Sometimes he passes urine in bed only. Sometimes even stool also. I am the only son here and my wife will no way clean all that.”*

*“No, there is no support, neither from father; nor from brother and not even from my husband. No help from anyone!”*

### **Subtheme 2: Relationship with elderly: disturbed**

*“Conflicts happen when separate food has to be prepared for him. If my wife has more works to finish, she gets irritated and also when my dad passes stool or urine in his pants itself, there occurs a hot discussion at home.”*

*“Even my dad scolds us sometimes and complains about food and room.”*

*“Sometimes she asks for tea and sometimes she wants to go to toilet or she keeps on talking to herself without any sense. At these times if I concentrate on her, then my work is affected.”*

*“Sometimes at midnight she complains of stomachache. Then I have to prepare tea and give her tea and biscuit. Neither does she sleep nor does she let me sleep.”*

*“No matter how much you work hard, old people will not be satisfied.”*

*“She tells that I don’t take good care of her.”*

*“The change of food pattern, timing of having food and medication differs; this disturbs our family life.”*

*“I feel like sleeping or taking rest, but I fear that my in-laws will scold me or talk on my back.”*

*“If we tell good things, then also they feel bad.”*

### **Subtheme 3: Relationship with children: disturbed**

*“My children want me to spend time with them, but I come home so tired and after coming home also most of my time is spent with dad only. Even Sunday also I have to use for him giving him a bath.”*

*“While taking care of my dad, I sometimes don’t get time to look after my children.”*

*“I get unhappy and I get irritated and I beat my children.”*

*“When I can’t meet the demand of my children, they often shout at me.”*

*“My sons are not bothered about what is happening here with us.”*

### **Subtheme 4: Societal relationship: supportive**

*“My neighbors are good and the villagers appreciate me. I feel happy because I have them. I have good friends*

*in my neighborhood. I feel light after I talk to them”*

*“We borrow money from family and neighbors and we move on.”*

*“I share my feelings with neighbors and spend some time with them.”*

#### **Subtheme 5: Relatives support: unsupportive**

*“I have my elder brothers, but they live in Mathura only. They don't help us but sometimes come to visit dad.”*

*“I have my husband's brothers and their wives who keep talking on my back.”*

*“They don't come to even visit her for so many months. If sometimes they came and gave her a bath, combed her hair or trimmed her nails that would be a big favor for me but what they will do, they just know how to gossip.”*

#### **Subtheme 6: Confined role in the society: avoiding social gatherings**

*“I attend all the gatherings except in the situation that she doesn't feel well.”*

*“No, we don't go for any social functions. We tell the people that our father is sick so we can't attend.”*

*“I never go to any social gathering, because I don't have so much of time.”*

*“If it's very urgent to go, I leave my children at home to take care of my mom and go and come back early.”*

#### **Theme 4: Lived Economical**

##### **Subtheme1: Economical difficulties: risk of loss of job and salary**

*“One year back, he had to go to Mathura for some paper work regarding our property. Three weeks of office leave. Actually, I had taken only two weeks of leave but he didn't want to come early, he acted like a kid, then we had to extend our stay. My pay was reduced because of this and thank God I was not thrown out of job.”*

*“10 to 5 is my time for office. I make sure that the issues at home will not affect my work. But sometimes when my dad needs to be fed or his bedding has to be kept in the sun, I get late for office.”*

*“If he is sick, I cannot concentrate on my job.”*

##### **Subtheme 2: Increased expenditure: difficulties in meeting financial needs**

*“We had to admit daddy to hospital some months back. He fell down when he was trying to go to toilet. That time I had to borrow some money which I have not returned till now.”*

*“His medicine, fruits, dates are additional expenses. For a medium class family, it is simply difficult to cope up with.”*

*“We get pension that will only help us to move on but sometimes if she falls sick, then it will be very difficult. I borrow from others and return it later.”*

*“The old people fall sick more frequently and of course more money need to be spent on their treatment.”*

#### **Subtheme 3: Family members had to work: to manage financial difficulties**

*“I wash dishes in others functions sometimes and I make some money with that.”*

*“My salary is not enough sometimes to carry household work. My wife does some tailoring work but she is not a professional.”*

*“We have sold our land and have been living life from that money.”*

*“My one son is studying B.Com final year, still he is earning for family.”*

#### **Subtheme 4: Reactions on the expenses on the elderly: negative**

*“My in-laws don't give a single rupee. When they come, they bring something for her to eat and that's all.”*

*“Our family members don't help financially. If we are in need, we borrow money from someone and after some days we return back the money.”*

*“My father in-law was a worker in the Indian Railways. So he is a pensioner. My co-sisters had a very big eye upon the pension amount we got from him. But my mother in-law gives it to me to handle. People talk about it but I don't care because I am the only caretaker of her.”*

*“My wife nags sometimes if I bring him something he likes. As a precaution, I give it hiding from her.”*

#### **Theme 5: Lived Vocational**

##### **Subtheme 1: Changes in performance: low standard of performance**

*“I reach my office late and feel ashamed of myself to see that all my colleagues are already there.”*

*“If he is sick, I cannot concentrate on my job.”*

*“Sometimes she falls sick. That time I can't go to collect grass for cows. I can't concentrate in anything else. I can't do my work properly.”*

*“Five days in a week I have to stand outside for being*

late for 10-15 minutes or half an hour. My boss gives me warning or cuts off my payment. Rs 30 for 1 hour will be deducted.”

### **Subtheme 2: Ability of time management due to caregiving task: decreased**

“Monday again my daily work starts; wake up, prepare breakfast, prepare lunch, heat the water, take bath, shout at him, shout at her, take care of mom, full of tension, combing of hair also sometimes I do in bus only. Breakfast I eat in bus only every day. I don't have time to eat breakfast at home.”

“Sometimes I skip my breakfast.”

“I wish I could give time to my family as well.”

“I don't have time for myself.”

“I cannot balance between my work and my caregiving responsibilities.”

## **Theme 6: Lived Spiritual**

### **Subtheme 1: Change in spiritual belief: unchange belief towards God**

“Sometimes in distress, I question God why all these tensions hover me around.”

“No complaints to God. This is my fate.”

“I don't blame God.”

“I trust God, and I don't complain anything till now. God has been good to me and my family.”

“I am not stressed spiritually on taking care of elderly”

### **Subtheme 2: Spiritual relation: belief towards God**

All of the clients had belief in God.

“When people say that you are serving God by serving your dad, I feel glad. This encourages me and motivates me in my service.”

“When I get tense, I question God why I had to come to this world. Why you brought me to this world? Sometimes if I sit alone and relax, I think like I might have done some sin in my previous life, so this is the result of that only.”

“I thank God I got the opportunity to be with my parents in their old age.”

“I really thank God that being a daughter, I have got to care for my parents. I feel blessed.”

### **Subtheme 3: Alternative methods to satisfy spiritual need**

“Once in a while, we conduct grand pooja in our house if my dad desires.”

“Sometimes I ask forgiveness from God for being rude to her.”

“I do say all my problems to God.”

“I do pooja and worship.”

The findings of this study are in agreement with a study “Caregiving as a risk factor for mortality: the caregiver health effects study”<sup>7</sup> with a conclusion that being a caregiver who is experiencing mental or emotional strain is an independent risk factor for mortality among elderly spousal caregivers. Caregivers who report strain associated with caregiving are more likely to die than non-caregiving controls.

Similarly, a study conducted in South Africa investigated the experiences of caregivers in caring for the elderly among eight samples. The general findings of the study indicated that more caregivers did not experience problems in caregiving, while a small number of caregivers did experience problems, which included depression and other serious psychological problems in the caregiving to elderly. The results obtained from this study about caregivers at La gratitude also indicated the rewarding and positive outcomes of the caregiving experience, although references were also made to some challenges about their work and job.<sup>5</sup>

## **Conclusion**

Caring for the elderly brings lot of challenges and frustration to the caregivers. This study concluded that caring for the elderly affects the caregivers physically, psychologically, socially, economically, vocationally and spiritually. Caregivers experience problems such as body strain, back pain, headache, gastritis, depression, frustration, stress due to caregiving task. The study also revealed that the challenges of the caregivers in caring for the elderly increases with the increase in the age of the elderly and that the financial constraints, vocational disturbances, decrease in job performance and spiritual distress faced by the caregivers were yet other reasons for sufferings caused by task of caregiving to the elderly. As the study investigated this phenomenon in rural settings in India, it enables appropriate interventions in all areas of the country.

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### Conflict of interest

Author have no conflict of interest.

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