



## LIVED EXPERIENCE OF CAREGIVERS OF ELDERLY WITH COGNITIVE IMPAIRMENT LIVING IN A SOUTH INDIAN URBAN COMMUNITY

### Nursing

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### ABSTRACT

**INTRODUCTION :** Cognitive impairment is a major issue in old age characterized by a progressive and devastating reduction in cognitive abilities, functional independence and social relationships.

**OBJECTIVE:** This qualitative study explored the lived experience of primary caregivers of elderly with cognitive impairment

**METHODS:** Elderly people with cognitive impairment were purposively recruited and their primary caregivers were included in the study. Participants were asked open ended questions about their caregiving experience. Interviews were audio recorded and transcribed to major and minor themes.

**RESULTS:** Major themes identified firstly relationship changes with subthemes were role reversal and support and secondly life changes with subthemes behavior changes, time management and changes in freedom. The findings revealed the need of support and counseling for caregivers focused on themes identified.

### KEYWORDS

Qualitative, Phenomenology, Lived Experience, Cognitive Impairment, Caregiver

### INTRODUCTION

Ageing is a process that begins with birth and continuous throughout life. The current elderly population is large and growing due to advancement in health care. About 92% of elderly population has at least one chronic disease and 77% have at least two.<sup>1</sup> Cognitive impairment is a condition in which one has minor problems with their mental abilities such as thinking, learning and remembering. Symptoms of cognitive impairment are often vague and include forgetfulness, language difficulties and attention problems. They also will have troubles with memory, speaking or understanding things, and recognizing people, places or others.<sup>2</sup>

Prevalence of Cognitive impairment is increasing with age. From 60 years to 90 years of age, the prevalence is will increase from 10 % to 25%.<sup>3</sup> Almost half of the people with cognitive impairment will be diagnosed with dementia in 3 to 5 years.<sup>4</sup> It also contributes to decreased quality of life, increased neuropsychiatric symptoms, increased disability and increased health care costs<sup>4</sup>. At any given time, 80% of elderly with cognitive impairment are living at home and cared by family members primarily by spouses or children and they experience emotional stress in assuming these responsibilities. Worldwide, 15.2 million unpaid caregivers taking care of people with cognitive impairment in an average of 17.4 billion hours of non-professional care. Out of them 32% of caregivers are doing it more than 5 years.<sup>5</sup> Caregiver burden is a likely outcome of the caregiving experience. But this experience is difficult to comprehend and measure through quantitative studies. Moreover, caregiving experiences vary with cultural pattern. Hence a phenomenological approach is used to understand the caregiving experience of the primary caregivers.

### Ethical consideration

The study protocol was approved and monitored by Institutional Research Committee and Institutional Ethical Committee of Government College of nursing Thrissur.

### Methodology

A qualitative approach was used with a phenomenological study design. The study was conducted in an urban area of Thrissur Corporation at Kerala, India. We have included primary caregivers of elderly with cognitive impairment with purposive sampling who were caring for a minimum of one year and were willing to participate in the study. A pilot study was conducted on two subjects to check the feasibility of the study.

### Study procedure

After obtaining permission from the authorities, home visits were made with community health workers of the area to increase the acceptance. We screened the elderly with standardized tool PMIS (Picture Memory Impairment Screening Tool) and those who scored less than 4 were included and their primary caregivers are selected. The place of interview was participant's home to minimize distractions. In the initial sessions, participants were made comfortable and their cooperation was gained by the researcher. Multiple in depth interviews were conducted with open ended semi structured interview method in the subsequent sessions. There were one broad question and 2 lead questions. All sessions were audio recorded. A field diary was maintained to record the nonverbal communications. After analyzing each day's data, follow up interviews were conducted until data saturation occurs. Data saturation was achieved after interviewing 6 participants, which was fixed as sample size. The collected data was translated to English and transcribed to common themes.

### RESULTS

#### Demographic details

All participants were females, out of it, two were spouses, 2 were daughters, one was daughter in law and one was niece. All were married and education varied from primary to higher secondary level of education. Five participants were home makers and one was retired. Two of them were in caregiving for more than six years, three of them for three to six years and one for past one year.

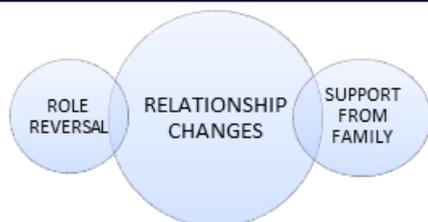
#### Data generation and analysis

Three to five sessions completed with each participant resulted in 23 interview sessions in total. Each session lasted one to three hours. After establishing rapport, participants were asked the broad question "how do you feel about caring the elderly at your home?" In order to clarify the concepts, lead questions were asked in a conversation mode. We translated the recordings after listening to audiotapes many times and transcripts were made. Transcripts were read many times and coded to different themes. The essence of caregiving experiences were classified in to two major and five sub themes as seen in figure 1 and 2

### MAJOR THEMES

#### 1. RELATIONSHIP CHANGES

Many caregivers expressed that the relationship with the elderly became one sided and elderly feels that they became a burden to the caregiver. There were two subthemes identified, role reversal and support from family.



**Figure 1 Relationship changes**

### A. Role reversal

Participants feel that the role of the caregiver was changed from a home maker to head of family or from an earning member to a home maker.

*"I was the earning member of the family but now I don't go for job because of caregiving. She took care of me in my childhood and after my child birth (thankful). She (elderly) is not married and I don't have my father and mother with me, so I care her in the place of a daughter (confident smile)"*

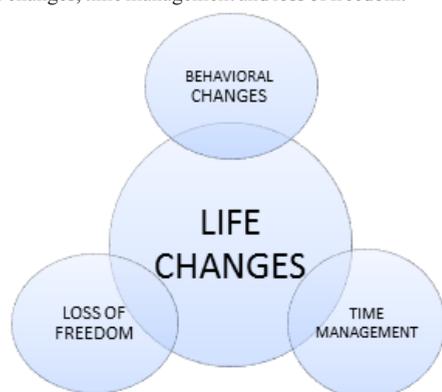
### B. Support from family

Almost all participants expressed that they are getting adequate support from other members of the family.

*"My husband is very supportive and the kids too. All are in a healthy relation (Feels relieved). All people in the neighborhood are supportive."*

## 2. LIFE CHANGES

Many caregivers expressed that their life has changed after the onset of cognitive impairment in d elderly. The subthemes identified were behavior changes, time management and loss of freedom.



**Figure 2 Life changes**

### A. Behavioural changes

Participants expressed that they become anxious easily, losing their temper some of them learned to control themselves over the period.

*"At times I lose my temper and I shout at my mother (regretful smile). Sometimes the arguments are so intense that she asks me to leave home (annoyed). I know it is annoying"*

*"I used to get mad easily. But now I became more patient. Older people get angry easily, so we have to be patient. (Smiles) I became active and bold now."*

### B. Time management

Many of the participants expressed that the time for their personal matters have decreased as more time is spent in caregiving. They give less priority to self because they feel that elderly need more care and become used to it.

*"I don't eat anything in the morning before bath. Now I could take bath only after attending to the needs of my mom. As I am having diabetes, I used to have some rusk or biscuits in the morning. But now it's more like I skip my breakfast every day (wistful smile)... I used to pray twice daily after taking bath and lighting the lamp before dinner but now I hardly get time for that (worried). Morning I will just have a black coffee and start the work... Even my bond with my son has tampered*

*due to this. We used to have telephonic conversation for hours, but now it is interrupted as my mother calls for assistance. When he hears that through phone, say that he will call me later and disconnect (disappointed)."*

### C. Loss of freedom

Most of the participants stated that their lives became restricted. Some of them believe their own illness could be a reason.

*"I have not gone to my home for past three years. My brothers come here. They know that I can't leave him (elderly) and go.. After marrying him I didn't go anywhere alone. By the time I return, he becomes angry (disappointed). So I don't go anywhere (wistful)."*

## DISCUSSION

Relationship changes found as a theme in a qualitative study done by Plank et al<sup>6</sup> in which the theme identified was the newly acquired role which is similar to role reversal in the current study.

In many studies, participants described life changes as lack of time and not having adequate rest or sleep<sup>78</sup> and current study also confirming the same by experiencing lack of time and lack of freedom.

Current study revealed that participant's negative behaviors made caregiver frustrated which is similar to study findings by Trossman<sup>7</sup> in which caregivers were upset and frustrated by care recipient's negative behavior.

According to a study by Kenneth M Langa<sup>10</sup> et al, cognitively impaired dementia patients received up to 17.4 hours of care per day which correlates with the current study findings that participants have no time for personal matters because of increased caregiving hours.

Current study found loss of freedom as a theme which is confirmatory to the finding of a phenomenological study by Molly EWassman<sup>11</sup> among cognitively impaired dementia patients which describes that caregiver's life became more restricted to travel and things they used to do.

## CONCLUSION

The themes identified from thus study was helpful in understanding the experience of caregivers which could be effectively utilized for developing guidelines for cognitively impaired elderly home care and managing caregivers distress.

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