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Lived Experiences of Caregivers of Dementia Patients in Nepal

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The image features a large, stylized tree with a thick brown trunk and a wide, spreading canopy. The canopy is split horizontally: the top half is a vibrant red, and the bottom half is a lush green. A solid teal horizontal band cuts across the middle of the tree, serving as a background for the title. The tree is set against a sky with soft white clouds. Numerous red leaves are shown falling from the red canopy, drifting upwards and to the right. The ground is a flat, green field with some fallen red leaves scattered near the base of the tree.

Introduction

Background

- Dementia is a syndrome characterized by a decline in cognitive function, including memory, thinking, and behavior, that interferes significantly with a person's ability to perform daily activities. (1)
- A serious problem in low-resource countries like Nepal, where aging population and weak healthcare system makes it harder to manage.
- Caregivers, often family members face extreme financial, emotional, and physical hardship due to limited support.
- Services rely on personal resilience, community networks, and traditions.

Objective of the study

- Study aimed to understand the daily struggles, coping strategies, and support needs of dementia caregivers in Nepal, and fill the information gap to improve care and support systems.



Methodology

Methodology

Research Methods	Description
Study design	Qualitative phenomenological study design
Study Site	Selected urban and rural areas of Nepal were included, regardless of availability of home care services
Study Duration	1 year
Study population	Dementia caregivers
Sampling technique	Snowball sampling
Sample Size	27
Ethical approval	Reviewed and approved by the Nepal Health Research Council (ERB#462-2024)

Data Management

Data Collection Tool

In- depth
interview guides

Data Collection Technique

Face-to-face In-
depth Interviews
(Physical/Virtual)

Data Management and Analysis


Transcription and
translation of
interviews



Thematic
Analysis

Ethical considerations

As per ethical
guidelines by
NHRC



Results

Socio demographic information of the study participants

SN	Age/Sex Caregiver	Address	Rural/Urban	Education	Occupation	Relation with patient	Patient's age/sex	Other major diseases	Dementia duration
1	30/M	Kathmandu	Urban	Bachelors	MR (Service)	Grandson	62/F	No serious	3-4yr
2	52/M	Parbat	Rural	Master	Business	Father	90/M	Depression	8-10yr
3	51/M	Morang	Rural	Bachelor	grocery store	Son	83/F	Parkinson's	4yr
4	56/M	Morang	Urban	High school	Farmer	Son	78/F	RTI/Head injury (5-6yr ago)	6months
5	41/M	Gulmi	Rural	PhD	Business	Son	59/F	Pneumonia/COVID, Parkinson's	2-3yrs
6	68/F	Bhaktapur	Urban	MN	Ex-Nurse	Daughter	94/F	Shock due to the death of a sibling	11Yrs
7	28/M	Kalikot	Rural	SLC	Student	Son	55yrs	No serious diseases	10-11yrs
8	56/F	Jhapa	Rural	High school	Home-maker	Daughter	98/F	No serious diseases	6-7yr
9	45/F	Pokhara	Urban	Bachelor	Home-maker	Daughter-in law	88/F	No serious diseases	4yrs

Socio demographic information of the study participants

SN	Age/Sex Caregiver	Address	Rural/Urban	Education	Occupation	Relation with patient	Patient's age/sex	Other major diseases	Dementia duration
10	24/F	Myagdi	Rural	Bachelor	Student	Grand daughter	88/M	He was injured	4yrs
11	72/M	Tanahu	Urban	Bachelor	school teacher	Husband	71/F	Parkinson's	3yrs
12	76/M	Parbat	Rural	Master	Ex-Govt employ	Husband	76/F	Rumatic Arthritic	4yrs
13	48/F	Dhangadhi	Urban	High school	Home-maker	Daughter	78/F	No serious diseases	14-15yrs
14	36/M	Kathmandu	Urban	Bachelor	Business	Son	67/F	Diabetic	1.5yrs
15	54/M	Kathmandu	Urban	Bachelor	service	Son	71/F	No serious diseases	7yrs
16	61/M	Kathmandu	Urban	Master	Business	Son	82/F	No serious diseases	5yrs
17	49/M	Bardibaas	Rural	Bachelor	Health worker	Son	95/M	No serious diseases	5yrs
18	55/M	Rolpa	Rural	Bachelor	School teacher	Son	81/M	No serious diseases	5yrs

Socio demographic information of the study participants

SN	Age/Sex Caregiver	Address	Rural/ Urban	Education	Occupation	Relation with patient	Patient's age/sex	Other major diseases	Dementia duration
21	68/F	Chitwan	Urban	Literate	Housewife	Daughter	87/F	Under-treatment of uric acid & high blood pressure	2yrs
22	50/M	Kritipur	Urban	Master	Business	Son	82/M	No serious diseases -smoker	2yrs
23	58/F	Sindhuli	Rural	SLC	Housewife	Daughter	75/M	suicide of son	1.5yr
24	45/F	Butwal	Urban	SLC	Housewife	Daughter	74/M	RTA	3yrs
25	65/F	Baglung	Rural	SLC	Housewife	Wife	70/M	No serious diseases	4yr
26	68/M	Rautahat	Rural	Literate	Farmer	mother	98/F	No serious diseases	6yr
27	78/M	Parbat	Rural	Literate	Farmer	wife	76/F	No serious diseases	3yrs

Themes and Codes

Themes	Codes
Relation with the Dementia patients	History of Dementia
	Multi Responsibility as a care-giver
Home Based Care	Modification done by the care-givers
	Role as a health service provider
	Learning by doing
Challenges faced by the Caretakers	Challenges in daily life
	Physical challenges
	Emotional challenges

Themes and Codes

Themes	Codes
	Financial challenges
	Social challenges
Factors Impacting the quality of care	Physical factor
	Economic factor
	Emotional factor
	Socio cultural factors
	Technological factors
Recommendation	Recommendations to Family, Recommendations to Society
	Recommendations to Health Workers, Recommendation to Society

Relation with the Dementia patients

After the suicide of 22-year-old son, he began showing symptoms of dementia. It has been around five years, and for the past one and a half, his symptoms have worsened. He has started forgetting things, like leaving his sickle after cutting grass, misplacing his slippers, and sometimes going outside because he thinks someone has called him.

58yrs, Daughter, Sindhuli

I believe aging, stress, and loneliness might be contributing factors.

68/F, Bhaktapur

Currently, all my family members are out of the home, so I have been taking care of him alone not taking the support of my other family members.

52yrs, Son, Parbat

Home Based Care

I built a bathroom inside her room and arranged the kitchen and sitting area nearby so I can always be with her. I also installed a safety railing on the window.

48yrs, Daughter-in-law , Pokhara

Due to her age and limited mobility, we cannot take her to the hospital frequently. Instead, I visit the doctor myself to discuss her symptoms and receive guidance.

68yrs, Daughter, Bharatpur

I have not undergone any formal training, but I make an effort to educate myself by reading books and watching videos online. I also consult with doctors regularly to ensure I am following the best practices.

68yrs, Daughter, Bharatpur

Challenges faced by the Caregivers

I brought her to Kathmandu, but she couldn't enjoy her time here. It was very challenging for a middle-class family to create an enabling environment in urban setting, that's why I decided to take her back to the village.

41yrs, Son, Gulmi

Initially, basic care was manageable, but as my father's condition has deteriorated, the challenges have intensified both mentally and physically...My own struggle with chronic back pain makes it physically challenging to lift him.

55yrs, Son, Rolpa

Challenges faced by the Caregivers

One of the main challenges is her childish behavior. For instance, she sometimes accuses us of things she has done herself. For example, she hit her daughter-in-law and granddaughter inappropriately, and we have had to confine her to one area to manage her behavior.

51yrs, Son, Morang

Emotionally, it is difficult because she no longer recognizes me, though she remembers her mother's side of the family.

68yrs, Daughter , Bharatpur

Challenges faced by the Caregivers

From a social perspective, it seems people don't understand. Behind our back, some call her crazy or mad. They believe that all people should be the same, and they don't understand the situation.

31yrs, Grand son, Kathmandu

His medications are expensive, and he also requires physiotherapy, which adds to the financial burden..... Families with sufficient income can hire professional caregivers. However, for low-income families, managing care can be extremely challenging.

51yrs, Son, Morang

Recommendations

Families must take full responsibility for their elderly members. Proper care starts at home.

48yrs, Daughter-in-law, Pokhara

Counseling is required to manage long-term stress effectively.....Provide training to family members and caregivers to help them understand the disease and adopt appropriate caregiving methods.

40yrs, Daughter-in-law

Recommendations

Financial assistance would be very helpful. Additionally, if the government could provide home visit by skilled health workers, it would make caregiving easier.

28yrs, Son, Kalikot

Mental Health Counseling: Counseling is required to manage long-term stress effectively.....Provide training to family members and caregivers to help them understand the disease and adopt appropriate caregiving methods.

40yrs, Daughter-in-law



Conclusion

Conclusion

- Dementia is a growing issue in Nepal, with home caregivers essential yet challenged.
- Strengthening support through education, resources, and formal support systems for caregivers is crucial for improving quality of care.
- A government support system through financial provision to people taking care of severe dementia is necessary.
- The study identifies areas for improvement and offers recommendations to enhance dementia care services.
- Very little is known about this due to the limited researches.

Acknowledgement

I would like to acknowledge the respondents for sharing their lived experience related to caregiving to the dementia patients in their family.

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