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A qualitative exploration of dementia care in Nepal

Jene Shrestha^{1#}, Sabitri Sapkota¹, Rekha Khatri¹, Srijana Shrestha ^{1,2*}

¹ Possible; ² Wheaton College

#presenter, *senior author

Background

- Approximately 57 million people worldwide are living with dementia, with projections indicating an increase to 152 million by 2050 (The Lancet, 2019)
- Limited resources and underdeveloped healthcare systems hinder effective dementia care in LMICs (World Alzheimer Report, 2021)
- Healthcare professionals report critical gaps in dementia care, including weak healthcare infrastructure, limited trained professionals, and a lack of awareness (Sapkota et al, 2023)



Objectives

General Objectives

- To understand personal, institutional and systemic factors that impact dementia care in healthcare and community settings.

Specific Objectives:

- To examine the attitudes and knowledge of family caregivers, Community health workers (CHWs) , health care and geriatric care providers, and a policymaker about memory loss and dementia care.
- To document recommendations from stakeholders from the spectrum of community and health care providers on how to improve care for seniors with memory problems living in the community.

Methodology

- **Study Site:** Four municipalities in Dolakha [Kalinchowk, Bhimeshwor, Baiteshwor and Tamakoshi]
- **Sampling:** Purposive
- **Study participants:** CHWs, health care and geriatric care providers, and a policymaker
- **Timeline:** August to July, 2023 (NHRC Ref no:304)
- **Data Analysis:** Thematically analyzed.

Participants

S.N.	Participants	Data collection methods	No. of Participants	Study site
1	Community health workers	Focus discussion: 3 groups	25	Dolakha
2.	Caregivers of individuals with memory loss and dementia	In-depth interview	7	Dolakha
3	Health care providers	Key informant interview	4	Dolakha
4	Geriatric care providers, and a policymaker	Key informant interview	2	Kathmandu

Themes identified

- Perception on memory loss or dementia
 - Misconceptions among community people
 - Lack of awareness and incomplete information
- Health services seeking behavior of caregiver and individuals with memory loss and dementia ,
 - Limited access to healthcare services
 - Delay in seeking help
- Challenges faced by caregivers
 - Lack of support from family members
 - Caregiver Burnout
- Healthcare System Preparedness on Geriatric Care
 - Insufficient Staffing and Resources
 - Difficulty Diagnosing Dementia in district level
 - Lack of motivation and support for health care workers
 - Policy level implications

Perception on Dementia

1. Misconceptions among community people

- Memory loss as a natural part of aging
- There is a general lack of awareness about memory loss as a medical condition;

“I’m not sure if it is a disease or not. It’s her mind. Maybe her brain is not working because of her old age.”

Caregiver 01, Female

“In our village, we don’t call it a disease. It’s just old age.”

CHW, FGD 2

“It is common of forgetting things in old age.”

CHW, FGD 3

Perception on Dementia

2. Lack of awareness and incomplete information

- Many assume that forgetfulness, even in daily life, is a normal experience, reinforcing the belief that cognitive decline is an inevitable part of growing old.

“We don’t need to. We know her. It is what it is. She has lost her mind. So, she shouts, then keeps quiet, then sleeps, then wakes up. It’s her usual stuff.”

Caregiver 1, Daughter in law

“Of course, the patients (family members) say it is due to old age. When they ask “doctor, what’s wrong with my patient?”, we say that it is dementia, that it is age-related and progressive. When they ask if it is curable, we say that it is not. After that, they also think that this condition cannot be helped much; they stop trying. So, from either side, I think it is difficult to really help the patient.”

Health Care Provider 3, Hospital

“What is the reason behind such problem? It is more in old age. I want to know what is the reason that it occurs in old age.”

CHW, FGD 3

Health services seeking behavior

1. Limited access to healthcare services

- Families often do not know where to care for such conditions.
- Limited access to healthcare services and dementia-related information.

“What to say about medicine... We didn’t know where to take for treatment so have not done any treatments.”

Caregiver 3

“Even the health care workers view neurodegenerative disorders as something that is not going to be cured, and as a progressive disorder which deteriorates with time, a condition for which nothing much can be done.”

Healthcare Provider 04, Hospital



Health services seeking behavior

2. Delay in seeking help

- Families seek help only after the condition worsens.
- Some awareness among the government and healthcare workers, but the level of preparation and support remains low.

“People usually present late. Ideally, patients with dementia should land up in OPD but here, we mostly meet them in the emergency. People only present when their condition deteriorates.”

Health Care Provider 03, Hospital

Challenges in caregiving

1. Lack of support from family members

- Women as a primary care givers
- Women are expected to take on caregiving duties regardless of their personal circumstances.
- Financial struggles and lack of awareness about treatment options hinder access to medical help.

“Even if both husband and wife work outside, the woman has to take care of the house and the elders.”

CHW FGD 1

My husband says he is tired from work, but what about me? I work too.”

Caregiver 3, Daughter in law

“She got old too, we have issues of expenses too. If we take her to hospital we have to stay there looking after her. Big reason for not taking hospital is expenses.”

Caregiver2 , Daughter-in-law

Challenges in Caregiving

1. Lack of support from family members

- Families are left without proper support, and the absence of such centers complicates the care of patients with dementia, especially when there is no younger family member to provide care due to migration.

“Patients usually come here without an accompanying family member. Even if they accompany them, they usually have come during their holidays to meet their parents so they don’t know what has happened during their absence.”

Health Care provider 03, Hospital

Challenges in caregiving

"I get tired myself and have no energy. For sometimes if someone... (not clear) I can't even cook dinner. I get tired and have no energy. Few days back, was not even able to raise these knees to walk. Have to walk dragging the knees. Just walking few steps, I would be so tired and feel like sitting in road."

Caregiver 3, Daughter in law

"Sometimes we don't get enough time We have not been able to give time properly as I need to take care of children and also take care of everyone."

Caregiver 5, Daughter in Law

2. Caregiver Burnout

- Joint families do not necessarily make caregiving easier.
- Unrecognized and unaddressed physical, and mental exhaustion

Healthcare System Preparedness on Geriatric Care

1. Insufficient Staffing and Resources

- Limited resources and staffing shortages in hospitals at local level hinder geriatric care, highlighting the urgent need for improved healthcare infrastructure and investment.

“We don’t have the infrastructure, talking about our hospital ward, we have 17-18 beds, including the 12 beds on this side. But there are only 2 nurses on duty at a time.”

Health Care Provider 04, Hospital

The number of geriatricians can be counted in the hand till now.”

Policymaker, Stakeholder

Healthcare System Preparedness on Geriatric Care

2. Difficulty Diagnosing Dementia in district level

- Lack of screening tools
- Importance of referrals
- Challenges inpatient care at community level
- Economic status also hinders referrals

"We don't have anything to screen dementia; but dementia is a wide term. It is very difficult to diagnose dementia in a peripheral setup like this because we need to exclude everything else first."

Health Care Provider 04, Hospital

"Referral became an important thing. And while referring, there is also another challenge if we can provide the service at his nearest referral point."

Policymaker , Stakeholder

"I remember 1-2 patients whom we suspected dementia who we thought needed further evaluation during follow-up, but we lost track of them. They did not come for a follow-up."

Health Care Provider 3

Healthcare System Preparedness on Geriatric Care

3. Lack of motivation and support for health care workers

- Lack of Geriatric Training and Career Opportunities in Nepal for health care providers
- Dementia care is demanding and requires patience, communication, and strong clinical judgment.

“But this job (care for dementia patients) is painstaking. You should have patience, you should have good communication and interpersonal skills. Also, you should have good assessment and clinical judgment. Because of these factors, this field has not attracted many health care workers. And the government has not invested in this area much. For someone going into this painstaking job, there is no guarantee of any reward or incentive from the government. They have introduced the concept of geriatric ward and geriatric department but they have not incentivized it.”

Health Care provider 3, Hospital

Healthcare System Preparedness on Geriatric Care

3. Lack of motivation and support for health care workers

- Lack of incentives and government support discourages healthcare workers from entering the field.
- Challenges in Attracting Healthcare Workers to Dementia Care

“Until now, this opportunity was lacking in Nepal (in this field). Even if we do a geriatric fellowship, we don’t have many opportunities (for work). There are other geriatric (professions) as well. There are geriatric nurse practitioners in Europe and America. We don’t have that concept here. Now in Dhulikhel, you may have heard of it, Barbara is leading a plan to start geriatric nursing fellowship. If there are geriatric fellowships, further geriatric training, short trainings, conferences then there is some hope. Lack of these opportunities is also causing problems in geriatric care.”

Health Care Provider 3, Hospital

Healthcare System Preparedness on Geriatric Care

4. Policy level implications

Government Focus on Aging Population:

- The government has acknowledged the demographic shift, with Nepal having a 10.2% geriatric population
- Efforts are being made to prioritize dementia care in health policies, including addressing it in the government's yearly action plan for dementia.
- Geriatric Friendly hospital mostly tertiary level hospitals
- Regulation of Geriatric care homes

Take home message

“Dementia is not just a normal part of aging. There is a lot to do in this domain in the community, health care facilities and policy level- early awareness, timely diagnosis, and community support can transform care and improve lives.”



WHAT NEXT?

We have plans to build and test an intervention that empowers and support caregivers and CHWs to better support the individuals with memory loss and dementia.



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Thank you!



An early-career researcher has been working in sexual and reproductive health (SRH) and mental health, particularly among vulnerable populations. Through qualitative methods, the research explores the lived experiences of individuals, ensuring culturally relevant solutions.



Jene Shrestha

Jene@possiblehealth.org