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The impact of cultural practice and policy on dementia care in Nepal

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Abstract

Background People's wider culture plays a vital role in both dementia care and policy. This study aims to explore the cultural practice and policy influence around caring for People Living with Dementia (PLWD) in Nepal.

Methods An exploratory qualitative study was designed to investigate dementia care in Nepal. The study comprised four in-depth interviews and four focus group discussions with 29 participants, including family members, health care professionals, and other stakeholders. Data were analysed using thematic analysis.

Result Four major themes (each with several sub-themes) were identified: (1) Cultural practice in dementia care; (2) Impact of policy on the dementia care; (3) Service provision; and (4) Education and training.

Conclusion There is a need for community-based awareness raising on dementia and its care, to sensitise all relevant stakeholders to meet the needs of PLWD. In addition, capacity building of health workforce is needed to enhance their knowledge of and skills in providing culturally appropriate dementia care.

Keywords Dementia, Nepal, Alzheimer's, Aging, Older people, Culture, Policy, Service Provision

Background

Dementia is a growing public health challenge and needs urgent attention. Globally people are living longer with more ending up living with dementia. Worldwide, more than 55 million people have dementia and over 60% of them live in Low- and Middle-Income Countries (LMICs), which is estimated to increase to 72% by 2050 [1, 2]. Population ageing is the main driver for the increase in People Living with Dementia (PLWD) [3], as

age is one of the risk factors. The population is also ageing in Nepal [4, 5], where it is estimated that over 50% of population over age of 60 years have some form of memory-related problems [6]. A recent study in old-age care homes has found that nearly 75% of older adults have dementia symptoms [7]. Similarly, research in a psychiatric clinic revealed that 11.4% of older people with memory problems had dementia [8]. Lack of awareness of dementia among health workers has created a significant gap in dementia care particularly in LMICs [9]. Similarly, many nurses in Nepal's nursing homes lack dementia knowledge [10].

The growth in older PLWD brings with it numerous challenges including rising cost in health and social care and challenges for policy makers to allocate appropriate resources and services. Dementia also increase the dependency on family and carers. It is tradition of family to take care of elderly people at home in Nepal (i.e. informal care), but there is very limited preparedness around

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dementia care and support in the community. With the expected rise in PLWD, the responsibility of care of older parents with dementia falls to family members [11]. Dementia often carries with its stigma, which is complicated by cultural beliefs and lack of awareness within society. A recent review suggested that within Nepalese cultures there are several stigmas related to mental health disorders, such as prestige, difficulty of accepting individual level stigma as well as structural challenges like the lack of policies, programme planning and resources to address these problems [12]. Moreover, there are demographic changes taking place in Nepal with an increase of people living in nuclear families, due to internal and international migration. Currently, 2.1 million youths from Nepal are abroad for employment and education [4], and hence living away from their parents. Consequently, more older people are living alone in Nepal and suffering from loneliness, depression, and poorer health outcomes, or older people, who in the past were looked after by extended family now need carers or are forced to move to care homes. Recently the number of older people opting to go to such homes has increased [13, 14].

Though number of PLWD is increasing in Nepal, awareness of dementia is still poor in the general public, family and health workers, including nurses [15–17] and policy makers. Consequently, PLWD are not getting appropriate care even in care homes [18]. Dementia is not yet included in national health policy [19]. There is very limited research in Nepal on how cultural practice and policy affect dementia care. Moreover, most focuses on health workers in hospital settings. Therefore, this study explores cultural practices and policy influences related to dementia care which might be useful to raise awareness, and reduce stigma, among family members, caregivers and other stakeholders.

The objectives were to:

- explore perceptions of dementia in Nepal.
- assess dementia care and cultural practices and its barriers in the community.
- identify the available resource and support mechanism on dementia care in Nepal.

Table 1 Background of participants

Participants Focus Group Discussion	N=
Paid caregivers	14
Unpaid family member caregiver	5
Other stakeholders	3
Health workers (Staff Nurse)	3
Participants In-Depth Interview	
Unpaid Family member caregiver	1
Health professionals (Doctor)	2
Specialist Mental Health Nursing Academic	1

Methods

Study design

The exploratory qualitative design was chosen to gather comprehensive understanding around dementia care in Nepal. In-depth interviews and focus group discussions (FGDs) were used to understand the influence of cultural practices and policy on dementia care.

Study setting and sampling

The participants from Kathmandu, Lalitpur and Bhaktapur districts were purposively recruited with support from Ageing Nepal. Caregivers from different care homes and those giving care at home were approached. All interviews were conducted virtually due to the COVID-19 pandemic lockdown in the country in 2021.

Altogether, four in-depth interviews: one with a young family member caregiver who was caring for his mother at home and three senior health care professionals with long-standing experiences in geriatric care and mental health were interviewed. In addition, four FGDs were conducted, three comprising a mixture of paid caregivers and unpaid family member caregivers from different socio-economic backgrounds and one with other stakeholders including junior staff with different professional backgrounds and very experienced health care professionals in dementia care (Table 1). There were five to seven participants in each FGD. The FGDs lasted between 60 and 90 min and in-depth interviews 30 to 45 min.

Data collection

Altogether 29 participants, representing all relevant stakeholders, took part in this study. The FGDs were conducted with paid caregivers and unpaid family members together to understand the caring responsibilities, challenges and cultural practices, and available support system. Whilst FGD with stakeholders explored available support and policy in dementia care in Nepal. An example of a FGD question is: “Tell us your experience of providing care and services to people living with dementia”; “What kind of policies and practices are in place to support people living with dementia?” The FGD started in a very informal way to build rapport including welcoming participants, explain the interview process, use of probing to get detailed information and ensure that the discussion stays focused on the research objectives. The in-depth interviews with family caregiver explored the individual challenges and awareness on available policy to supporting dementia care, whereas in-depth interviews with senior health professional explored the challenges related dementia care in health facilities and health care institutions for caregivers, health care professionals and PLWD.

We considered the information power during data collection [20] to capture the relevant information to fulfil our objectives and reach data saturation, i.e. no new information emerged from the participants [21]. Therefore, the information from these 29 participants was rich and comprehensive and helped to explain how cultural practice and policy in dementia care is impacting PLWD in Nepal.

Data analysis

The data were analysed considering six steps of thematic analysis [22]. The interviews and FGDs were conducted in Nepali language and recorded to transcribed and then translated into English by a bilingual researcher (BS and STM). The transcripts were thematically analysed using following six steps; Step 1: Become familiar with the data, Step 2: Generate initial codes, Step 3: Search for themes, Step 4: Review themes, Step 5: Define themes, Step 6: Write-up [22] by STM, PS and BS. PS and STM coded all transcripts independently and compared their findings. An inductive coding approach was utilised to describe the experiences shared in the interviews. Intercoder reliability was maintained to ensure that the coding process was consistent and reliable [23] and any discrepancies were resolved through discussion and consensus among the researchers. Trustworthiness of the findings was strengthened through careful selection of the keywords, identifying themes or patterns during coding and interpreting data for meaningful findings. During the interview, any doubts were often cleared and clarified, where necessary to ensure credibility and trustworthiness. Also, as the themes were discussed and evaluated by three authors (BS, STM and PS) to ensure the four general criteria [24] of credibility, transferability, dependability and confirmability were kept in mind.

Ethical considerations

The ethical approval was obtained from Nepal Health Research Council (Ref: 2873) and Bournemouth

University. Potential participants were provided with a participant information sheet, participation was voluntary, and written consent was obtained before data collection. Participants were assured that their answers would be confidential and anonymised during analysis. Given the study’s nature, attention was given to psychological distress among participants, especially caregivers during interviews. They were also informed that they could leave the interviews if they found it difficult to share their experiences. Participants experiencing distress while sharing their caregiving experiences were signposted to appropriate support services as required. The study obeyed the ethical standards defined in the Declaration of Helsinki.

Results

The thematic analysis resulted in four major themes (Table 2): (1) Cultural practice in dementia care; (2) Impact of policy on the dementia care; (3) Service provision; and (4) Education and training.

Cultural practice in dementia care

Cultural practice in dementia care covers different issues including perceptions, attitudes, misconceptions, beliefs and stigma (Table 2).

Perceptions and attitudes towards dementia

Most participants reported that people in Nepal know very little about dementia, but that awareness levels are increasing particularly in urban settings. Some families started to accept the situation of their older parents. The shift in mindset is attributed to the increase in dementia prevalence.

Five to ten years ago Alzheimer disease itself was a new disease in Nepal... the situation has changed in urban settings. In rural setting, people still take memory impairment or cognitive impairment as age related issues. They now tell my father is suffering from this disease and we provide care to them accordingly. In the past, there was stigma. People used to take PLWD as insane.(FGD 3, Paid caregivers and family members caregiver).

A son who provided care for his father with dementia over a decade shared:

Now, there are some people. But when I started caring for my father living with dementia, I was helpless. I felt like living in an island. No doctors said anything.(FGD 1, Paid caregivers and family members caregiver).

Misconceptions about dementia

Some interviewees noted misunderstandings around dementia and late diagnoses are major problems. As a result, most PLWD are diagnosed very late when people start showing challenging behavioural symptoms that are

Table 2 Key themes and associated sub-themes dementia Nepal

Main theme	Sub-themes
Cultural practice in dementia care	<ul style="list-style-type: none"> · Perceptions and attitudes towards dementia · Misconceptions about dementia · Traditional beliefs · Stigma
Impact of policy on dementia care	<ul style="list-style-type: none"> · Government priorities and policy · Dementia guidelines and protocol
Service provision	<ul style="list-style-type: none"> · Dementia care practice and support · Lack of care facilities · Family priority regarding health needs
Education and training	<ul style="list-style-type: none"> · Lack of professional training · Paucity of education

hard to manage at home by the family. An experienced healthcare provider narrated that:

I have never seen any family members, relatives and friends bringing their parents saying they have forgetting problem. They bring them here when they have behavioural problem or when delusion is established, when they start running away from home, when they start to shout or when they start to do toilet everywhere and when they start showing psychological symptoms. (Interview 1, Health professional)

This cultural misunderstanding around dementia and the associated problem of people seeking help for family members late meant any dementia treatment started late, as highlighted by a geriatrician who argued that delayed diagnosis is a cause of untimely management of comorbidities, which can lead to premature death PLWD.

If early diagnosis is done, we can use medicine to slow the rate of progression of Alzheimer from moderate to mild. And we can timely address other comorbidities. (Interview 3, Health professional)

Traditional beliefs

Family members shared how religious faith and traditional spiritual beliefs influenced them when caring for their parents, for example, some mentioned witchcraft:

I went to show her horoscope (Chinanaa) thinking someone might have done black magic on her. (Interview 2, Family member caregiver)

A son caring for his mother living with dementia showed strong traditional beliefs:

I am a spiritual person. ...we all should listen to our mother, father and teacher and take their advice. Especially, I have found that reading such religious verse to mother and father with dementia is good for them. (FGD 3, Paid caregivers and family members caregiver).

Stigma

There is a social stigma towards placing parents in old age care homes in Nepal. The concept of care home has negative connotations. Due to social stigma, people reject the idea of putting PLWD in care homes, even if they struggle to manage at home. Some participants expressed how they could not actively care for their family members living with dementia because they anticipated some level of stigma from the community. Consequently, this social stigma towards care homes have increased other health risk and untimely death of PLWD, one professional recalled:

One of the Alzheimer patients. What his son used to do is, due to the fear of society and his friend circle, he used to turn on the light of his father's room though he had already placed his father in care home. It was very tough for him to look after his father at home by hiring caregiver. But due to fear of the society, he hidden it for 3–4

months. (FGD 1, Paid caregivers and family members caregiver).

According to some key informants, PLWD are viewed as insane due to their psychotic symptoms. As a result, to avoid the stigma associated with family members being known as 'insane' people and to hide, family keep the PLWD away from the wider society. This perception is seen across the society, but perhaps more common in higher status families. Suggesting that often the behavioural change (s) in dementia is often misunderstood as psychiatric symptoms and the associated stigma is much greater.

When patient start showing behavioural psychotic symptoms then people say that person has gone insane. Then they think it as a mental illness and take patient to psychiatric wards. If a person who had reputation and of high class, starts to show behavioural psychotic symptoms; there is high stigma. They don't want to go out from home, they don't want to talk to other. (Interview 3, Health professional).

A care worker shared that family members from higher social status hesitates to place older parents in care home due to the social expectations. It has led to instances where older parents are deprived of proper care and suffer pain.

People with good background can't take their father and mother into care home due to social barrier. Because of this we found many conditions where many father and mother are in pain. (FGD 3, Paid caregivers and family members caregiver).

One of the caregivers, who also had experience of caring for PLWD in Israel, shared that people see as its cause sins committed in previous life or as the result of bad deeds.

Multiple stigmas related to dementia still exist ma'am. People relate it with sin they did in previous life, "paap dhuribata karauchha" or relate it to the result of bad deed done by son and daughter-in-law of the patient. (FGD 4, Caregivers).

Impact of policy on dementia care

Currently there is no overarching dementia policy and the health of older people is not a priority for the Government of Nepal (GoN), which is a major barrier in dementia care, although there is a policy around small amount of financial support specific to the Alzheimer and Parkinson medication and treatment.

Government priorities and policy

Most participants shared their experiences of the GoN's lack of attention towards PLWD and older people's health. According to a geriatrician, the GoN can provide one lakh (about 750 USD) equivalent free service/treatment to older people if their diagnosis is Alzheimer and

Parkinson. Most of these free services for older people are limited to very few hospitals and centralised mainly in the capital and urban areas, nor are these clearly advertised.

At present Nepal government only provides support equivalent to one lakh (about 750 USD) to the Alzheimer diagnosed patient only if they are from poor family background. In Nepal, only 8/9 hospitals are selected for this support. And those are also around Kathmandu Valley.(Interview 3, Health professional).

The stakeholders' FGD mentioned that due to financial constraint they are unable to undertake programmes outside Kathmandu.

We couldn't take any programmes related to caring PLWD out of Kathmandu Valley due to financial constraints.(FGD 2, Health workers and stakeholders).

However, one doctor and owner of a private care home stated that the Ministry of Health has formulated some policies or directives to support the well-being of older people, and some ad hoc services had started in two hospitals in the capital:

The Ministry of Health and Population has started prioritising dementia issues. Department of Health Service has directed one Nursing Society to address those issues. In some government hospitals memory clinics are started to look after PLWD. At first, memory clinic was opened in Patan hospital and now, it is also opened in Bir Hospital. But it has not been regulated. If people with Alzheimer's disease... are referred by psychiatric doctor, they get free treatment equivalent to 1 lakh (about 750 USD). But it is very difficult to get that. I think no more than 2% people have received government services.(FGD 2, Health workers and stakeholders).

A doctor working with older people and PLWD mentioned that there is lack of clarity in government policy. The people diagnosed with Alzheimer's and Parkinson disease are the only ones eligible for free government services.

Either we should write Alzheimer or Parkinson. Let's say they have vascular dementia, and they need to get that service and facility. We must write mix dementia, Alzheimer plus vascular. Hopefully, one day government will make correction on that.(Interview 1, Health professional).

Dementia guidelines and protocol

There is no specific dementia protocol or policy. However, it is recently included under National Mental Health Strategy which is yet to be implemented. Some health-care providers interviewed had made efforts to draft a guideline for dementia care and presented it to the GoN.

No, we don't have policy for dementia and Alzheimer's. For that we have drafted a National Dementia Care Plan and given to government. We also met Health

Minister and shared our view with him.(Interview 1, Health professional).

Another mentioned having been able to add an element of dementia care into a different strategy which focused on mental health:

I was able to put one component under mental health strategy on National Mental Health Strategy which is one of the big health policies in Nepal. Once the component strategy will come into implementation then it will be processed to make the protocol guideline, everything. (FGD 2, Health workers and stakeholders)

Lack of information is another problem in dementia care, as there is no specific government body or non-government organisation (NGO) for providing information for PLWD. Some were concerned about the lack of information:

If someone suffer from dementia, then exactly where to go....., When someone's family is suffering, or father and mothers are suffering whom shall they contact for this there is no exact guideline from the government.(FGD 2, Health workers and stakeholders).

Moreover, a nurse/owner of care home shared how they are working without government protocol, guidelines and policy in their care home.

Though, we do not have national protocol for caring PLWD, I have developed a protocol for my care home as per the need of patient living there. In the protocol, I have included how we can do counselling with a dementia patient, what kind of food is needed for them, how we can involve them in walking and going out, how we can reserve their back memory and how they can still remember things.(FGD 2, Health workers and stakeholders).

Service provision

There are very few services for older people and even fewer, i.e. barely any for PLWD.

Dementia care practice and support

Some private care homes for older people had started primarily in the capital. Although there is social stigma towards the keeping parent in such care homes, as mentioned above, some saw changes beginning to occur in young people's perception. Now, children who cannot provide proper care at home prefer to keep their parents in care home.

In past there was a thinking that care home means leaving parents in "bridha aashram" (old age home) when they had no family members. But at present there is a thinking that mother/father should be taken to care home for better care. Changes is seen. People think that they must go to office, and they can't provide care at home.(FGD 2, Health workers and stakeholders).

An independent campaigner on mental health and Alzheimer's disease reported that their NGO developed

an intervention to support family members and PLWD although it did not last long due to the lack of time (resources).

We developed an intervention. That is community-based, volunteers are from neighbourhoods. For example, there are 10 houses and among those 10 houses one house has dementia patient. After that we provide and share technical knowledge to other nine household members. Then what we expect from them is to go and look after that dementia patient for at least one to two hours a day from each household. So that family members of that dementia patient can get break. We launched this type of programme in [one district]. It was successful in some extent. (FGD 2, Health workers and stakeholders).

Lack of care facilities

A health worker raised the issues of lack of care facilities for dementia, particularly outside the capital. Lack of the day care facilities forces the working children to look after their parents with dementia, forcing them to leave their job. This can spark conflict in families.

At Kathmandu we have some good Day Care Centres. Children takes their parents living with dementia in Day Care Centre and bring them back home when they return from work. But outside Kathmandu we don't have that facility and that creates dispute among son and daughter-in-law. Because either they must leave job or must leave parents. (Interview 1, Health professional).

The lack of dementia specialised care facilities is an additional problem. Whilst a few government hospitals have created geriatric wards, they do not provide dementia specific medical services.

The Nepal government has separated geriatric wards for senior citizens in only a very few hospitals...I don't think the Nepal government has separated any area that is dedicated to dementia patients, and which are focused on dementia services and supports. (Interview 4, Health worker).

Family priority regarding health needs

Generally, the health need of older people competes with childcare need, especially in extended families. Poor people may have to choose between the wellbeing of their children and that of their parents, often compromising the latter.

If I have to say from service recipients' point of view, there is awareness plus priority issue. A person with a limited purchase capacity must do out-of-pocket payment. In that case people think who they shall put into priority. Whether to put his child's health into priority or to put his grandfather or father's health into priority. (Interview 3, Health professional).

Education and training

There is problem on health workers' understanding of dementia care, due to a lack of education. Academic and professional training (on the job training) should be developed to increase the knowledge and skills of the health workforce in dementia.

Lack of professional training

There are still gaps human resources, especially people who can diagnose dementia and provide treatment and care to PLWD, as one doctor explained:

There are three to four doctors who have done geriatric medicine. But the good part is, neurologist and psychiatric also look after them. Because it is in their course curriculum as well. And every year, there are eight to ten doctors who pass out as MD specialist in neurologist and psychiatric... In big cities, Zonal hospital and medical college are there and there is no problem. (Interview 1, Health professional).

The poor education and training on the disease was highlighted by a geriatrician, who found that health workers often confuse with dementia and Alzheimer, and then provide the wrong medicines.

We can say that there is little more knowledge and awareness on dementia among geriatricians, [general] physicians, psychiatrics, neurologists who are sub-specialists. I should say very frankly on this matter. The thing is dementia doesn't mean Alzheimer. There are types of dementias which can be reversible. But I have seen so many cases where that has been levelled as Alzheimer and prescribed donepezil. Like, in some cases infection related delirium is labelled as dementia and medicine is prescribed. (Interview 3, Health professional).

However, one organisation ARDS (Alzheimer's and Related Dementia Society Nepal) has started post-registration/professional training starting but there are no organisations yet to provide training to current health workers and carers on how to care for PLWD.

ARDS provides training to medical officer, internist and psychiatrics particularly. The training is related to how to deal with dementia and how to diagnose it. (Interview 1, Health professional).

Although there is limited, but expensive, training available from the private sector. One caregiver described the financial challenge to get some training.

If we see the average income of Nepali individual person and compare it then I think the training is not affordable. (FGD 4, Caregivers).

Paucity of education

There is need for developing the healthcare curriculum to meet the need of PLWD. It is expressed that there is insufficient course content about dementia in health curricula. According to one health worker, there is less

than a 15-minutes class on Alzheimer's in undergraduate medicine.

In Nepal, at premium medical institute in MBBS level there is nothing about Alzheimer's. I did my MBBS from B.P. Koirala Institute of Health Science. But there was not even 15 min class on Alzheimer's.(Interview 3, Health professional).

Similarly, a graduated nurse shared:

Most of the staff don't have knowledge about dementia. As a nurse, I have to say that we don't have many dementia courses. There are one to two classes after doing bachelor's in nursing. So, don't know properly on how to care for dementia patient.(FGD 2, Health workers and stakeholders).

Discussion

This qualitative study explored issues around dementia care in Nepal. The thematic analysis generated four overlapping themes: (1) culture; (2) policy; (3) service provision; and (4) education and training.

Culture covers largely the negative aspects of dementia care, i.e. those linked to stigma, fear, superstition and traditional beliefs. Stigma and stereotyping around dementia have been widely reported, not just in low-income countries such as Nepal [25]. Studies in South Asia attribute this finding to traditional perspectives of associating the symptoms of dementia with old age in general [26]. This is echoed in Tanzania where some PLWD, carers, and traditional and religious healers were unsure of the exact nature of dementia [27, 28]. This limited awareness of dementia can lead to a delay in healthcare seeking for older PLWD. Moreover, in India it was noted that stigma and discrimination can also come from health workers who can be dismissive of PLWD [29]. Our findings revealed several cultural factors that may affect both family carers (paid and unpaid) and healthcare providers in the care they offer. Cultural barriers have also been observed elsewhere in South Asia, including in India [29], Pakistan [30, 31], and Sri Lanka [32] also relies heavily on informal care for PLWD.

People are ashamed of taking their parents to care homes as they are often judged as not fulfilling their familial responsibilities. This is partly linked to South Asian culture, as Herat-Gunaratne and colleagues [33] in the UK observed, namely that expectation that family, especially the oldest son, is responsible for the care of parent in their home even if they live in high-income countries where formal health and social care systems are well established. Moreover, this societal stigma may discourage individuals from seeking early diagnosis and treatment for dementia or lead to exclusion from everyday life. According to Willis et al. [30], PLWDs in Pakistan are unable to participate in religious activities due to their memory impairment. A study with dementia

care experts from 19 LMICs also reported that cultural beliefs and stigma are strong influences and symptoms of dementia are being associated with witchcraft [9] again like Nepal where family visited traditional healers and traditional horoscope readers.

Our findings suggest a paucity of both education and training on dementia and other aspects of ageing in Nepal. This finding recognised the need for adequate dementia care content and its management in both medical and nursing curriculum to meet the need of PLWDs in Nepal. A recent study in Nepal also highlighted the need for educational support to improve nurses' knowledge and confidence to provide effective dementia care and management [10]. This finding is consistent with research in the USA that found significant gaps in the training and education of dementia workforce [34]. Our research further identifies the need for post-registration training and CPD (Continuous Professional Development) to prepare health professionals to recognise signs and symptoms and provide dementia friendly care. The lack of dementia care training in Nepal is a key challenge to provide quality dementia care [18]. The inadequate pre-registration and post registration education in dementia care in Nepal has led inadequate knowledge and skill to provide appropriate care to PLWDs. In Malaysia, the workforce also had limited knowledge of dementia or could use dementia care guidelines [35]. The health workers in our study acknowledged that there is lack of availability of training and institutions to care for PLWDs. It indicates that there is need for culturally appropriate learning materials and training on dementia tailored to Nepal's health system. Research in the UK also suggests that dementia training is complex and there is a need for developing appropriate learning materials, length of training, delivery method and condition for learning to be effective [36]. Another study in Nepal described similar findings of having an adequate knowledge is very important for understanding the causes and provide quality of care [18]. Whilst insufficient training reduced health professionals' confidence in managing PLWDs in Malaysia [37]. Therefore, dementia care training should be offered as an important step in promoting dementia-friendly services in Nepal.

At the time of this study there was a beginning discussion around a draft dementia strategy for the country. Recently, the Ministry of Health and Population, Nursing Division conducted a consultation for drafting the National Policy for Dementia, and one of the authors (STM) contributed to this discussion. The current five-year National Mental Health Plan (2020-25) has planned to conduct programmes on diagnosis and management of PLWD, training around caring and increasing social protection as good start in dementia care in Nepal [38]. Participant of this study recognised that Nepal needs better policies and guidelines to help PLWDs. It also found

that there are very limited interventions to support families, although the GoN provides some financial support for medical treatment of Parkinson and Alzheimer's disease in poor people. However, participants didn't get supported if the diagnosis stated other types of dementia [39] and it does not support for other social care. Similarly, there is no guideline for health workers to follow screening and diagnosis and referral for dementia at community level and causing difficulty in dementia care even though the WHO Dementia Plan mentioned that 75% of countries will have national policies, strategies, plans or frameworks for dementia by 2025 [40]. Our study has identified the need for appropriate policy to improve the dementia care in Nepal which is in line with the research where lack of policy recognized as a significant barrier for dementia care [9].

This research unveiled a notable gap in availability of services for older PLWD although the Constitution of Nepal confirmed the right to basic care and extended its geriatric health care services to larger hospitals with more than 100 beds [41]. However, this care is still not functioning in government facilities. Prince et al. (2015) also revealed the poor quality of health care services for PLWD in Nepal. Katiwada et al., [15] also noted that the GoN has not allocated specific hospitals for free dementia diagnosis. This study indicated the increasing numbers of private care homes providing dementia care and the changing attitudes of some young family members to keep their parents in care homes but still a prevalent social taboo in Nepalese society causing distress [42]. This study also raises the issue of how poor families are forced to choose between the well-being of their children and that of their older parents. Research conducted with the experts of different regions of the world [9], has also revealed that competing health systems prioritize the health of younger people and pregnant women.

This is first qualitative study of its kind in Nepal, but it has limitations, as it covered a small number of participants in selected districts only. Moreover, the study had to be conducted online during the COVID-19 pandemic, potentially affecting participants' views and opinions.

Conclusions

This study found that cultural practices and dementia-related policy gaps in existing service provision in Nepal. The findings indicate that stigma, misconceptions, social taboos, and limited awareness of dementia hinder early diagnosis of dementia and the care for people living with dementia. The study findings highlighted the lack of national dementia policy and guidelines for dementia services causing confusion in implementing local policies and limiting access to available services. The study recognises insufficient professional knowledge and skills among healthcare professionals to provide dementia

care. Therefore, capacity building of health workforce is needed to enhance the knowledge and skill around dementia care. The community base awareness on dementia issue can alert people to understand the need of PLWD. Community awareness on dementia is essential to mitigate stigma, misunderstanding and social barriers to promote early recognition of sign and symptoms of dementia. It also suggests formulating appropriate policies, guidelines and intervention programmes are needed to support PLWD. Moreover, dementia care should be given a greater priority in pre-registration healthcare curricula and post-registration training and CPD to address the scarcity of trained carers for PLWD.

Abbreviations

ARDS	Alzheimer's and Related Dementia Society Nepal
BS	Bibha Simkhada
CPD	Continuous Professional Development
EvT	Edwin van Teijlingen
FGD	Focus Group Discussion
GoN	Government of Nepal
LMIC	Low- and Middle-Income Countries
MD	Doctor of Medicine
NGO	Non-government Organisation
PLWD	People Living with Dementia
PS	Pallavi Simkhada
SF	Shanti Farrington
STM	Sanju Thapa Magar
UK	United Kingdom

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Author contributions

BS developed the idea and led the work, involve in data analysis with PS and STM and BS drafted first draft, EvT was involved from the idea generation and played an important role in shaping the methodology. STM contributed to transcribing and data analysis. PS contributed to coding and drafting result section and EvT ensured the consistency in data analysis and proofreading the manuscript. SF was involved from the project development and contributed to tools development and ethics application.

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Data availability

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participant

The ethical approval was obtained from Nepal Health Research Council (Ref: 2873) and Research Ethics Committee, Bournemouth University, UK. Potential participants were provided with a participant information sheet and informed that their participation was voluntary. Written informed consent was obtained from all participants before participating in interviews or FGDs. The study obeyed the ethical standards defined in the Declaration of Helsinki.

Competing interests

The authors declare no competing interests.

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