



ALZHEIMER'S DISEASE IN NEPAL

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Submitted by:

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Abstract

Nepal is a developing country in South Asia. The demographic and epidemiological transition have increased the prevalence of the non-communicable diseases of the elder population. The number of patients with Alzheimer's disease, which causes gradual and progressive memory loss in old age has been increasing in Nepal.

This was a fundamental research. The objective of the study was to estimate the burden of Alzheimer's disease in Nepal, identify its importance as a social and public health problem and make appropriate recommendations to the different stakeholders responsible for tackling the problem. A descriptive study was done by interviewing different key persons from the responsible government bodies and the organizations working for the welfare of patients with Alzheimer's disease. Additional information was taken from the literature available in the internet.

The number of patients with Alzheimer's disease in Nepal was estimated to be 78,000 in 2015 and estimated to double every 20 years. There isn't enough priority and fund allocated to the disease by the government and there are only a few organizations working for the disease. A lot of work need to be done to make the lives of the patients living with Alzheimer's disease and their caretakers easier.

Declaration

The report was prepared for the HelpAge International, Nepal. I declare that this report is a property of The HelpAge International, Nepal and the author. Both of them shall have the right to disseminate this report in print/ electronic format. The contents in the report can be freely used for academic and research purpose as long as the HelpAge International, Nepal and the author are properly acknowledged.

Sharad Koirala

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Acronym

AD:	Alzheimer's disease
ADI:	Alzheimer's disease International
ARDS, Nepal:	Alzheimer's and Related Dementia Society, Nepal
CBS:	Central Bureau of Statistics
DHO:	District Health Office
DOHS:	Department of Health Services
DPHO:	District Public Health Office
KMCTH:	Kathmandu Medical College Teaching Hospital
MOHP:	Ministry of Health and Population
MOWCSW:	Ministry of Women, Children and Social Welfare
NASCIF:	National Senior Citizens' Federation
NGO:	Non-governmental organization
NRs:	Nepali Rupees
US:	United States

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Chapter 1

Introduction

Nepal is a developing country in South Asia with a population of over 27 million (CBS). The proportion of elderly people 60 years of age and above has been gradually increasing and was 8.13% in 2011 compared to 5.88% in 1971 (CBS, 2014).

According to the Merriam Webster dictionary, Alzheimer's disease is a disease of the brain that causes people to slowly lose their memory and mental abilities as they grow old. It is a relatively new term for Nepalese people who take forgetfulness to be a common part of ageing. With the focus of the mainstream public health in nutrition, hygiene and infectious diseases in children and mothers, mental health has received a very small attention. Alzheimer's disease being a mental condition of elders, is even a back runner among the little space given to the mental health.

The term Alzheimer's disease was first coined by a German physician, Alois Alzheimer in 1915. It is a disease of unknown cause usually starting in the late middle age or old age. It can be defined as a degenerative disease of the brain resulting in progressive memory loss, impaired thinking, disorientation and changes in personality and mood and histologically marked by the degeneration of neurons in cerebral cortex and presence of neurofibrillary tangle and plaques containing beta-amyloid (Fauci, 2008).

The government of Nepal has recently included Alzheimer's disease to the list of diseases whose patients are provided a financial help for medical management in case of recommendation from the District Health Office (DHO) or the District Public Health Office (DPHO) (MOHP, 2014). This facility by the government marks a recognition of Alzheimer's disease as a public health condition in the country though the amount given by the government is very small in comparison to the expense that occurs after the disease.

Another important aspect of Alzheimer's disease is that there is a requirement of special centres equipped with enough skilled and semi-skilled manpower to take care of the persons with the disease.

Objectives:

There is very minimal work done and literature published about Alzheimer's disease in Nepal. This study intends to compile all the information available about the works on the disease in Nepal and provide a picture where Nepal stands in terms of policies made, works done and achievements made towards helping the patients with Alzheimer's disease. The objectives of the study can be listed as:

- To show the national and global magnitude of the Alzheimer's disease and identify its importance as a public health and social problem
- To give a picture of the organizations working for Alzheimer's disease in Nepal
- To make recommendations regarding improving the facilities and services to the patients with Alzheimer's disease to different stakeholders in Nepal

Methodology:

The study was done for and the report submitted to the HelpAge International, Nepal. This was a descriptive study which took a duration of 3 months from June, 2016 to August, 2016. The techniques used for the study were literature review, visit to government offices directly involved in planning and making policies about Alzheimer's disease, visit to non-government organizations (NGOS) working for elderly people and Alzheimer's disease, visit to a hospital where a memory clinic was proposed, visit to an elderly home where patients with dementia were served and in-depth interviews with key persons who were involved with the organizations. The visits and the interviews were done during June-July, 2016. The report was written in August, 2016.

Chapter 2

Alzheimer's disease - International scenario

The population pyramid of most countries of the world shows that the elder population is gradually increasing in proportion to the young population. This has increased the importance of the diseases that are seen in this population. Additionally the disease trends in the world show that the communicable diseases are gradually decreasing and the non-communicable diseases are taking over. Alzheimer's disease (AD) being a non-communicable disease of old age has become an important social and public health problem.

The data presented in this chapter is based on the World Alzheimer's Report, 2015 published by the Alzheimer's Disease International. The worldwide population of people 60 years and over was about 900 million in 2015. The population is estimated to increase by 56% in the high income countries, 138% in upper-middle income countries, 185% in lower-middle income countries and 235% in lower income countries by 2050.

According to the Alzheimer's disease International (ADI), there were about 46.8 million people living with AD in the world in 2015 which is estimated to double every 20 years. This will increase the population of the people with AD to 74.7 million in 2030 and 131.5 million in 2050. With this trend in the increase in proportion of persons with AD, it is estimated that the current proportion of 58% of the patients being from the middle and lower income countries will increase to 63% by 2030 and 68% by 2050. These estimates show there are about 9.9 million new cases every year, with a new case occurring every 3.2 seconds.

The elderly population is growing fast in China, India and their neighboring countries with the improvement in overall nutrition and healthcare in the region. The prevalence of dementia, which is usually seen in persons above 60 years, has increased the most in this region.

The total global expense for dementia in 2015 was estimated to be around 818 billion US dollars, an increase of about 35% from the expense in 2010, representing 1.09% of global GDP. This included the cost of informal care (about 40%, provided by family and others), direct cost of community care (about 40%, provided by community care professionals and residential care

settings) and the direct medical cost of treating dementia (about 20%). The informal care cost is higher in African region while lower in the Western Europe, North and South America while the social sector costs are just the reverse in those regions. Important thing to be noticed is that though the expenses have increased in all the regions of the world, relatively higher increases are seen in the African and the East-Asian regions owing to the higher prevalence of the disease in those regions.

Research have shown that most of the people living with dementia haven't received a formal diagnosis. Only 20-50% cases have been diagnosed in the developed and high income countries, while much less patients have received a diagnosis in the lower income countries. A study in India had shown that over 90% patients with dementia are left undiagnosed. If these statistics are extrapolated to all the countries of the world, it suggests that approximately 3/4th of the patients with dementia are left undiagnosed worldwide and thus away from treatment.

Chapter 3

Alzheimer's disease - Nepal scenario

Alzheimer's disease (AD) is relatively a new term in Nepali society. Though elderly people had been suffering from dementia, it was taken to be a normal part of ageing. The Nepali literature does not have a term for Alzheimer's disease even till date.

The society has its own norm for the normal forgetfulness of the elderlies. When the dementia exceeds the "so-called" level, rather than recognizing it as a disease related to memory the person is thought to have "lost the mind" and taken as a serious psychiatric patient. The society is still to be taught about the presence of an ailment called "Alzheimer's disease", its symptoms, the progressive development of the disease and the measures to be taken to make the lives easier for the patients.

There is a stigma about mental disorders in the Nepali society. Families with a mental disorder in one of the members is taken differently by the society. They face a risk of being eluded from the regular social functions. People do not like having any forms of relation, social, professional or nuptial, with the members of the family. This has helped in the development of a tendency of unrevealing the mental disorders in a family. AD is also taken to be a serious mental illness, so the unwillingness of the family members to reveal it has hampered in getting the actual data about the prevalence of the disease in the country. The ADI has done a trend analysis of the disease in countries with similar social and economic structure and estimated that there were about 78,000 patients with AD in Nepal in 2015 and this number is bound to double every 20 years reaching 134,000 in 2030 and 285,000 in 2050. Recently, a study done by ARDS, Nepal for the MOWCSW has shown that the prevalence of AD among the persons living in different elderly homes in Kathmandu valley is 11.01% among males and 10.64% in females (Lamichhane, unpublished).

The importance of Alzheimer's disease has also increased due to change in the age-wise composition of the population in the country. When the trends of the population in Nepal is observed from 1971 to 2011 (as shown in the table below) it is seen that the population aged 60 years and above is exponentially increasing, firstly by the increase in population and secondly by

the increase in share in the total population, thus increasing the chances of diseases of the age-group.

Population of Nepal by Census

Census Year	Total Population	%population >=60 years
1971	11,555,983	5.88
1981	15,022,839	-
1991	18,491,097	-
2001	23,151,423	7.46
2011	26,494,504	8.13

Source (CBS, 2014)

Patients of dementia who try to come under medical attention are also not able to get a proper care due to lack of proper manpower and health centres. There are very few doctors trained in memory and dementia. A few nursing staffs and care takers trained to provide services to persons with dementia and almost no centres established to give daily services to patients with dementia. The little services that are available are from the non-governmental and private sectors. There is no place for the management of patients with AD funded by the government, though the need of the time is an institute that could train the manpower required for the management of the disease, including the clinicians, nurses, counselors and the caretakers, and rehabilitation centres throughout the country to provide the daily services to the patients.

In addition to the lack of manpower and facilities, the lack of awareness among the public about AD has made it very difficult for the proper mitigation of the problem in the country. The knowledge about the disease, the knowledge that the dementia is gradually progressive and irreversible and the knowledge that the patient will be requiring supportive care throughout life is lacking even in the family members of the patients. The expectation that the condition will revert after the treatment makes the condition even worse when the expectations are not met.

An important part on the management of Alzheimer's disease is the availability of caretakers, nursing personnel and the rehabilitation homes where the patients can be well taken care-of. This would systematize the caretaking of the patients and also help the family members in not losing their productivity. However, in Nepal there is unavailability of these types of services. The

scarce resources are also present only in the capital city. This has caused a difficulty in part of the family members of the persons with AD. They have to give-up their employments to take care of their near ones. It affects the person in two ways: firstly the loss of employment brings an economic crisis in the family and secondly, though the person tries his/her best in taking care of the patient, absence of professional knowledge hinders a lot during the process. There is another problem in this regard in the cities and towns. The family members cannot give-up their employment due to the ever-increasing demands of the lives in those areas and are forced to send their elders to elderly-homes in the city. This leads to the patient not getting a proper care and support in those areas which are not well equipped to handle these patients.

There are a few proficient and semi proficient centres to take care of AD in the Kathmandu valley, but they are also not enough for the patients in the valley. Taking 78,000 as the number of patients in the country, the prevalence of the disease comes to be about 0.3%. This prevalence signifies the presence of about 12,000 patients in the valley with a population of about 400,000 whereas the proficient and semi-proficient centres in the valley aren't equipped to give service to even a thousand patients. So, the patients of AD are forced to live in the care of their emotional and untrained family members or the care of the untrained caretakers in one of the elderly homes.

When a family member or a friend notices something unusual about the memory of an elderly person, he/she first thinks of getting a medical help for the person. This is a common culture of most societies. In Nepal, if the person thinks of getting such help, he will have to face a big problem. This will happen due to the absence of proper healthcare centres and clinics for this condition. There are only a few specialized centres and medical personnel trained in memory pathologies and getting in touch with them is a difficult task. There are only a few memory clinics in the country where persons with memory disorders could go for proper counselling, diagnosis and management. With the increasing elderly population and an increasing prevalence of AD it is the need of the hour to train more health personnel in memory pathologies and establish memory clinics throughout the country.

Note: The chapter is based on the talks with Dr. Gaurishankar Lal Das (NASCIIF and ARDS, Nepal), Mr. Shridhar Lamichhane (NASCIIF and ARDS, Nepal), Mr. Krishna M. Gautam (Ageing Nepal) and Ms. Pramila Bajracharya Thapa (Hope Hermitage)

Chapter 4

Programs in Nepal

Alzheimer's disease (AD) was taken as a social and public health problem only after the advent of the twenty-first century in Nepal. It started from very small corners of the society with the inputs from very little people. The condition was considered a stigma and revealing about the presence of the condition in a family was almost impossible due to the social fears. There were no government programs and policies mentioning the disease and there were no organizations in the civil society to advocate for the disease. The families of the persons with AD were the sole stakeholders to think about the disease and face its consequences.

The Nepal Government has only recently recognized AD as an emerging public health problem and included it in the list of diseases whose patients are eligible to a financial help for medical management. The patients of AD are provided a free service and medicines worth NRs. 100,000 (one hundred thousands) from certain enlisted hospitals on the diagnosis of the disease and a recommendation from the DHO or the DPHO (MOHP, 2014). This aid is given by the Department of Health Services (DOHS) through 4 enlisted hospitals in the country (National Academy of Medical Sciences, Tribhuvan University Teaching Hospital and Patan Academy of Health Sciences in Kathmandu Valley and BP Koirala Institute of Health Sciences in Dharan). Though it is a small amount compared to the expenses that occur in the management of the disease after its diagnosis, it can be taken as a positive step towards the recognition of the disease as a public health problem. This has made way for inclusion of the disease in the health policies and programs of the government in the future. According to the records in the DOHS, it is noteworthy that there have been only 9 patients with AD receiving the government facilities in the last 3 fiscal years (2013/14, 2014/15 and 2015/16).

Another government agency that has started working for Alzheimer's disease since a year is the Ministry of Women, Child and Social Welfare (MOWCSW). The ministry is the focal institution for all the works related to Senior Citizens in the government. It has helped in conduction of a training for caretakers of the patients through a non-governmental organization. It has also conducted a study on the prevalence of AD in the elderly homes in the Kathmandu valley through ARDS, Nepal.

There are a few non-governmental organizations (NGOs) working on the subject of AD and a few others working on the subjects of elderly population and making AD as a part of their work in Nepal. The organizations like Ageing Nepal, Alzheimer's and Related Dementia Society Nepal (ARDS Nepal) and the Hope Hermitage are directly working on AD and dementia. The organization like National Senior Citizens' Federation (NASCIF) makes AD a part of its work while advocating for the welfare of senior citizens. The organizations have been working both singly and in collaboration with each other for the cause of increasing the awareness and knowledge about AD in the public. The organizations come together to celebrate the World Alzheimer's Month in September and the World Alzheimer's Day on the 21st of September.

The movement on AD in Nepal was informally started by Asmi- a group for empowered age in 2006. It mainly worked to increase the awareness about AD in school children by conducting programs in different schools.

The Aging Nepal was established in 2011 and has been working to increase the awareness about AD and dementia in the society through different media. It has been publishing a bimonthly newspaper, a monthly e-newsletter and running a weekly radio program. It has also been conducting regular workshops and seminars about different problems of the elderly and talking about AD and dementia in all available forums.

The ARDS Nepal was established in 2012 with an aim to raise the public awareness about dementia, support persons with dementia and their caretakers and provide trainings to health and social care professionals. It has been working in partnership with the NASCIF in its programs on AD and dementia. It has been working by conducting regular workshops and trainings for the different stakeholders like the family members of the patients, caretakers, social organizations and other dignitaries in the society from different international and national experts. It is also connected to the operation of two memory clinics outside the Kathmandu valley (Dharan and Pokhara) and has been trying to facilitate the establishment of three memory clinics in the valley. It has also been operating a 24-hour Alzheimer's helpline dedicated to people seeking information about AD since the day of its establishment. The ARDS Nepal is also a member of ADI since 2014 and has been taking part in the world conferences and sharing experiences about the disease in different parts of the world. It also has a twinning partnership with Alzheimer's Australia, Victoria and has been exchanging different technical knowledge with them.

The Hope Hermitage was established in 2014 to advocate for the welfare of persons with AD and dementia. It has been working to raise the awareness about AD and dementia in the public through the radio and television. It has also been conducting workshops and trainings for the caretakers of the persons with dementia with aids from different national and international agencies.

In addition to the governmental and non-governmental organizations working for the welfare of persons with AD and dementia, there are a few elderly homes providing services to the persons with the disease. The organizations like Pashupati Briddhashram, Siddhi Shaligrame Briddhashram, Hope Hermitage, Orchid Home, Amaghar, Nisahaya sewa sadan, Tapasthali Briddhashram and Matatirtha Briddh ashram have been providing their skilled and semiskilled services to persons with AD and dementia.

In short, the government has just started taking notice of the disease and there are a few organizations and people working for the disease. The limited resource is also concentrated in the Kathmandu valley except for a few memory clinics. The lack of proper co-ordination is hampering in getting the proper results from the few works being done. The organizations become more active towards the month of September (World Alzheimer's Month) and all of them do similar works to the same target population in the valley. There is a need of decentralization of the minimal work being done.

Note: The chapter is based on the talks with Dr. Baburam Marasini (DOHS), Mr. Daya Krishna Panta (DOHS), Mr. Daya Ram Neupane (DOHS), Mr. Shankar Pathak (MOWCSW), Ms. Mira Sherchan (MOWCSW), Mr. Shridhar Lamichhane (NASCIF and ARDS, Nepal), Mr. Krishna M. Gautam (Ageing Nepal), Ms. Pramila Bajracharya Thapa (Hope Hermitage) and Dr. Rachana Sharma (KMCTH).

Chapter 5

Conclusion and Recommendations

Conclusion

The importance of Alzheimer's disease as a public health problem has increased with the epidemiological transition from the communicable diseases to the non-communicable diseases and the increase in the elderly population above 60 years of age. The global trends of the disease show that the number of patients with AD is exponentially increasing and Nepal can't be separate from those trends. Moreover, it has been predicted that the elderly population will drastically increase in the low and middle income countries like Nepal causing a sudden increase in the number of patients with AD and dementia.

This will be requiring a huge fund, infrastructure, manpower and a positive thought in all the stakeholders who will be involved. However, taking the present scenario, the level of awareness among all the stakeholders including the public, civil society and the governmental institutions is below par and has to be uplifted a lot. This would include educating all about the disease, the impending epidemic and the awareness about ones responsibility in tackling the impending problem.

There are only a few organizations in the civil society working on the subject. They are concentrated within the Kathmandu valley and no one is aware of what is happening in the peripheral parts of the country.

Recommendations

The study is a small step in an effort to know about the level of different stakeholders that are directly involved in tackling the impending epidemic of Alzheimer's disease in Nepal. We are in the initial stages of knowing about AD and formulating plans and policies to face the problem. The recommendations are thus directed towards development in both the highest policy-making level of government and the grassroot level where the actual works are done to make the lives of the persons suffering with the disease and their care takers easier.

Recommendations to the government:

- It is time for a new health policy which must include different sections for diseases like Alzheimer's disease which will be creating a menace in the near future.
- There should be a proper co-ordination between the Ministry of Health and Population which is the government institution responsible towards a good health of the citizens and the Ministry of Women, Children and Social Welfare which is the focal government institution for matters related to Senior citizens in the subject of Alzheimer's disease so that a proper plan could be developed in mobilizing different stakeholders and helping the persons affected by the disease.
- Rehabilitation centres for the persons suffering from AD and other dementia should be established at the central and federal levels so that the patients could get the facility when needed. The rehabilitation centres should gradually be extended to district and local levels for a better service. The civil society could be mobilized for this purpose.
- The development of the manpower that would be required to serve the increasing number of patients with AD and dementia, including the doctors, nurses, caretakers and the administrative staff should be included in the policy and acted upon well in advance to be able to handle the impending crisis.
- The financial aid that is granted to the patients with AD should be increased substantially after study and recommendation by a team of experts so that the treatment and management of the patients becomes easier. The process of getting the financial aid should also be simplified so that the grant reaches the homes of the patients instead of them and their families moving around for the aid.
- Enough funds should be allocated for the programs on AD and dementia well in advance so that all the preparatory measures that are needed for handling the impending epidemic are done in time.

Recommendations to the Civil Society:

- The foremost thing is a lot of organizations working for the cause of Alzheimer's disease and dementia must be started in all the areas of the country.
- There should be a proper co-ordination between different organizations working for the same cause so that programs could be taken on a larger scale and to a bigger population. The

organizations should also have a coordination with the government bodies. This would make it easier to include proper programs in the government policies.

- The programs should also be taken to the peripheral parts of the country so that the people living outside the valley also become educated about AD and dementia.
- The organizations working in the area should include the family members of the patients while planning a program so that programs are designed according to the need of the target population.
- The civil society must encourage the formation of self-help groups among the persons and families affected by the disease. This would create a platform for experience sharing and helping each other.
- The civil society must encourage the culture of talking about ones problems and getting out of the stigma of Alzheimer's disease in the public by the use of different media like the newspaper, radio and television.

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Annex-I: Case study on Mr. NPG

(Narrated by his eldest son)

Mr. NPG was a healthy and physically active person in his adult days. He was in India for employment and came back to Nepal after his retirement at the age of 65 years. He enjoyed a peaceful family life till the age of 72 years when his wife died.

The family members noticed some strange behavior a year after this tragedy. He started taking a long time in the bathroom, taking a long time to finish his food, losing his belongings like keys and excessively being attached to his praying rituals. The family members took this to be due to the tragedy and thought it will be fine as time passes. But the strange behavior persisted and became even more distinct. He was taken to the nearby Kathmandu Medical College Teaching Hospital for a checkup at about 74 years of age for an episode of fever. The routine examinations and investigations were normal. The physician referred him to the Department of Psychiatry after hearing about his strange behavior. The psychiatrist diagnosed him of having "dementia" and prescribed some medicines.

This could not help him and the symptoms got even worse with time. His eldest son had to leave his job and sit back at home to take care of his father. Meanwhile the symptoms got even worse like wearing strange combinations of dresses, just sitting in front of the mirror for a shave without doing anything and just sitting in front of the food without taking in anything. He slowly started to not recognize the people with whom he was familiar, his sons were the only persons whom he could recognize. He was even irritated with other persons, especially women. He had to be given a company round the clock for he would go out into wayward walks and just go on roaming. Later he had to be fed his food. He had to be helped in all his daily routines like cleaning and bathing. He was even unaware about his bladder and bowel movements. The condition got even worse when he suffered a pneumonia at about 80 years of age after which he was bound to a wheelchair.

The family continuously tried their best with both the Allopathic medicines and the eastern methods like the yoga without any success. At the age of 84 years, he forgot how to swallow his food. He died after about 5 months of starvation.

May the heavenly soul rest in peace.

Annex-II: Suggestions to caretakers of patients with AD

(As narrated by Mr. Krishna M. Gautam, a former caretaker)

- Inform your relatives, friends and neighbors about dementia and its symptoms so that they could be useful to you. For example, they may bring back home the person if they find him or her wandering alone away from home.
- Read literature about “caring for dementia patients” and update yourself on good practices for caring the patient. Make friends in virtual (social media like facebook) and real world for sharing experiences with people who are also taking care of persons suffering from dementia.
- Find families facing the same problem as yours and exchange the experiences of caring the patient.
- Do not get overwhelmed with the problem faced in caring the patient so much as to ignore your own personal health and wellbeing. Find time for recreation, exercise, and other important things for your own wellbeing. Find some time to get out of the house and go where you feel yourself free and comfortable to do things you love doing.
- This is the best time for you as a care-giver to focus on to excel in your hobby such as creative writing, playing music, singing, body building, or anything that you can do being nearby the patient. If you do not have a hobby that you can do inside your home, find and start one.
- Remind yourself at least once a day that you can give best care to the patient only if you are at the best of your physical and mental health.
- Weigh pros and cons of admitting the patient in “care homes” and take time to decide ensuring that you will not have to repent for the decision taken.

Note: Mr. Krishna M. Gautam is the chairperson of "Ageing Nepal"