



School of Social Sciences, Humanities and Arts

Department of Educational & Social Policy

## **Dementia among health workers: Knowledge, Practice and Obstacles**

Krishna Prasad Pathak

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**Committee Chair:** Dr. Anthony Montgomery, Associate Professor, Department of Educational and Social Policy, University of Macedonia, Thessaloniki, Greece

**Committee Member:** Dr. Alexis Benos, Professor, Laboratory of Hygiene, School of Medicine, Faculty of Health Sciences, University of Aristotle, Thessaloniki, Greece

**Committee Member:** Dr. Efharis Panagopoulou, Assistant Professor, Laboratory of Hygiene, School of Medicine, Faculty of Health Sciences, University of Aristotle, Thessaloniki, Greece

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### **Committee members**

**Committee member 1:** Dr. Hariklia Proios Assistant professor of Neurocognitive disorder and rehabilitation of the department of education and social policy, University of Macedonia, Thessaloniki, Greece.

**Committee member 2:** Dr. Elvira Masoura, Assistant Professor, Department of Psychology, University of Aristotle, Thessaloniki, Greece

**Committee member 3:** Dr. Despina Moraitou, Lecturer, Department of Psychology, University of Aristotle, Thessaloniki, Greece

**Committee member 4:** Dr. Siriopoulou-Delli Christina, Lecturer Department of Educational and Social, Policy, University of Macedonia, Thessaloniki, Greece.

## **Abstract**

This thesis explores the knowledge, practices and obstacles to appropriately diagnose and manage dementia in Nepal. Dementia is a progressive deterioration of a largely irreversible clinical syndrome in cognitive function- the ability to process thought. It is significant global burden due to under detection, diagnostic misconceptions, the ambiguous nature of its symptoms and sub-optimal management in primary care. Dementia is difficult to pre-diagnose in the early stages for health professionals (HPs) and thus a substantial percentage of patients with cognitive signs and symptoms are missed. However, HPs have a crucial role in the diagnosis and management of dementia, to evaluate the severity of the problem, in providing quality primary care in terms of the identification, assessment, provision of information, referral and ongoing management. There is a gap in the literature as to what represents best practice with regard to educating HPs improving dementia detection practices and management. This gap, which exists in developed countries, is quite substantial in Nepal. This thesis reports on the experiences of Nepalese HPs, but the conclusions have policy and practice implications for other developing countries.

This thesis is structured in 7 chapters which includes three empirical studies and one systematic review. The overall aim is to identify the key obstacles and barriers to the successful diagnosis and management of dementia. The three empirical cross-sectional studies examine the problem from different perspectives.

The first study identified general practitioners' (GPs) knowledge, practices, and obstacles with regard to the diagnosis and management of dementia. The study used standardized questionnaires covering knowledge, practices, and obstacles were distributed among a purposive sample of GPs in Kathmandu, Nepal. The study found that the knowledge

of practitioners' with regard to the diagnosis and management of dementia was unsatisfactory. Moreover, the following diagnosis and management barriers were identified: are communicating the diagnosis, negative views of dementia, difficulty diagnosing early stage dementia, acceptability of specialists, responsibility for extra issues, knowledge of dementia and aging, less awareness of declining abilities, diminished resources to handle care, lack of specific guidelines, and poor awareness of epidemiology. The majority diagnostic tools were referred to: ask about past mental illness, ask carer about behavioral or personality changes, test for depression, check glucose, arrange a chest X-ray, check FBC, check TSH, arrange an ECG, check calcium, check renal function, test for cognitive function, check for functional loss, check BP, test urine for infection.

The second study concerns the diagnosis practices, confidence, management practices and difficulties of multi-specialist doctors concerning dementia. Results indicated that they diagnosed more as false- positive and false-negative on average of new cases of dementia and the majority showed a desire to take dementia specialist training to improve their performance.

The third study concerns the knowledge, practices and barriers of nurses concerning dementia care. This study involved a purposive sampling approach with 44 nurses using structured multiple choice questionnaires covering demographic questions, knowledge about dementia, management of dementia and barriers to care. The results indicated that the knowledge of Nurses' with regard to the diagnosis, management and care of dementia was unsatisfactory. The care and management of patients with dementia in hospital settings is a challenge for Nurses in Nepal. Educational programs and health-care policies are needed to increase awareness of dementia in nursing practice with regard to management and care.

The fourth study reports on a realist review of interventions aimed at improving knowledge, detection practices and management of dementia among health professionals. Healthcare professionals (HPs) play a key role in the detection and management of dementia.

However, there is a gap in the literature as to what represents best practice with regard to educating HPs improving the dementia detection practices and management. Thus, the objective of this study was to synthesize the aggregated studies aimed at improving health care knowledge, detection practices and management of dementia among HPs. The relevant medical and social science databases were searched and 25 intervention studies were identified. The results indicated that collaborative programs of practice based workshops with community and multi-faced educational program were the most effective. The early diagnosis, management and care of dementia patients can be improved by; combined (between the HPs) intervention programmes, theory based programmes, better computer training, skills based training, self-directed learning and electronic based interventions and multiple visits to suspected dementia patients.

The overall conclusion of the thesis is that HPs should be supported to improve their knowledge, tackle behavioural problems associated with dementia, be made aware of services and be enabled to engage in more early diagnosis in primary care. Future intervention programs should train HPs with bespoke programmes that are sensitive to the context.

## **Abstract in Greek**

Άνοια είναι η προοδευτική επιδείνωση ενός μη αναστρέψιμου κλινικού συνδρόμου στη γνωστική λειτουργία- την ικανότητα να επεξεργάζεται τη σκέψη. Η άνοια αποτελεί ένα σημαντικό ζήτημα σε όλο τον κόσμο κατά τον 21ο αιώνα καθώς βρίσκεται υπό ανίχνευση και υπό προσπάθεια διαχείρισης από τους επαγγελματίες υγείας. Ένα σημαντικό ποσοστό των ασθενών με γνωστικά σημάδια και συμπτώματα δεν εντοπίζεται από τους επαγγελματίες υγείας.

Η εργασία αυτή στοχεύει στον προσδιορισμό των βασικών εμποδίων και των φραγμών στην επιτυχή διάγνωση και την αντιμετώπιση της άνοιας. Η εργασία αποτελείται από τέσσερις συγχρονικές μελέτες που εξετάζουν το πρόβλημα από διαφορετικές οπτικές γωνίες.

Η πρώτη μελέτη που διεξήχθη εντόπισε τις γενικές γνώσεις των γενικών ιατρών, τις πρακτικές και τα εμπόδια όσον αφορά τη διάγνωση και την αντιμετώπιση της άνοιας. Η μελέτη χρησιμοποίησε τυποποιημένα ερωτηματολόγια που καλύπτουν τις γνώσεις, τις πρακτικές και τα εμπόδια, τα οποία διανεμήθηκαν σε ένα σκόπιμα επιλεγμένο δείγμα γενικών παθολόγων στο Κατμαντού του Νεπάλ. Η μελέτη αυτή διαπίστωσε ότι η γνώση των επαγγελματιών όσον αφορά τη διάγνωση και την αντιμετώπιση της άνοιας δεν ήταν ικανοποιητική. Επιπρόσθετα, εντοπίστηκαν τα ακόλουθα εμπόδια στη διάγνωση και την αντιμετώπιση: ανακοίνωση της διάγνωσης, αρνητικές απόψεις για την άνοια, δυσκολία στην διάγνωση της άνοιας σε αρχικό στάδιο, αποδοχή των ειδικών, ευθύνη για επιπλέον θέματα, γνώση της άνοιας και της γήρανσης, λιγότερη επίγνωση της μείωσης των ικανοτήτων, μειωμένοι πόροι για το χειρισμό της φροντίδας, έλλειψη ειδικών κατευθυντήριων γραμμών, και περιορισμένη γνώση της επιδημιολογίας.

Η δεύτερη μελέτη αφορά τις πρακτικές διάγνωσης, την εμπιστοσύνη, τις πρακτικές διαχείρισης και τις δυσκολίες των πολλών ειδικευμένων ιατρών σχετικά με την άνοια. Τα αποτελέσματα έδειξαν ότι διέγνωσαν περισσότερα ψευδή θετικά και ψευδή αρνητικά αποτελέσματα κατά μέσο όρο των νέων περιπτώσεων άνοιας και η πλειοψηφία εξέφρασε την επιθυμία να λάβει ειδική εκπαίδευση στην άνοια για να βελτιώσουν τις επιδόσεις τους.

Η τρίτη μελέτη αφορά τις γνώσεις, τις πρακτικές και τα εμπόδια των νοσηλευτών σχετικά με τη φροντίδα της άνοιας. Η μελέτη αυτή αφορούσε μια σκόπιμη δειγματοληψία με 44 εγγεγραμμένους νοσηλευτές χρησιμοποιώντας δομημένα ερωτηματολόγια πολλαπλής επιλογής που κάλυπταν δημογραφικές ερωτήσεις, γνώσεις σχετικά με την άνοια, διαχείριση της άνοιας και εμπόδια στην παροχή φροντίδας. Τα αποτελέσματα έδειξαν ότι η γνώση των νοσηλευτών όσον αφορά τη διάγνωση, τη διαχείριση και τη φροντίδα της άνοιας δεν ήταν ικανοποιητική. Η φροντίδα και η διαχείριση των ασθενών με άνοια στο νοσοκομείο είναι μια πρόκληση για τους νοσηλευτές στο Νεπάλ. Τα εκπαιδευτικά προγράμματα και πολιτικές φροντίδας υγείας απαιτούνται για την αύξηση της επίγνωσης της άνοιας στη νοσηλευτική πρακτική όσον αφορά τη διαχείριση και τη φροντίδα.

Η τέταρτη μελέτη αναφέρεται σε μια ανασκόπηση των παρεμβάσεων που αποσκοπούν στη βελτίωση της γνώσης, στον εντοπισμό των πρακτικών και στη διαχείριση της άνοιας ανάμεσα στους επαγγελματίες υγείας. Οι επαγγελματίες υγείας διαδραματίζουν ένα βασικό ρόλο στην ανίχνευση και τη διαχείριση της άνοιας. Ωστόσο, υπάρχει ένα κενό στη βιβλιογραφία ως προς το τι αντιπροσωπεύει τη βέλτιστη πρακτική όσον αφορά την εκπαίδευση των επαγγελματιών υγείας στη βελτίωση των πρακτικών ανίχνευσης της άνοιας και της διαχείρισης της. Έτσι, ο στόχος της παρούσας μελέτης ήταν να συνθέσει τις συγκεντρωτικές μελέτες που αποσκοπούν στη βελτίωση της γνώσης της φροντίδας υγείας, στον εντοπισμό των

πρακτικών και στη διαχείριση της άνοιας ανάμεσα στους επαγγελματίες υγείας. Οι σχετικές βάσεις δεδομένων των ιατρικών και κοινωνικών επιστημών ερευνήθηκαν και 25 μελέτες παρέμβασης εντοπίστηκαν. Τα αποτελέσματα έδειξαν ότι προγράμματα συνεργασίας που βασίζονται σε πρακτικά σεμινάρια στην κοινότητα και πολυδιάστατα εκπαιδευτικά προγράμματα ήταν.

τα πιο αποτελεσματικά. Η πρόωμη διάγνωση, διαχείριση και φροντίδα των ασθενών με άνοια μπορεί να βελτιωθεί με: συνδυασμό (μεταξύ των επαγγελματιών υγείας) προγραμμάτων παρέμβασης, προγραμμάτων με βάση τη θεωρία, καλύτερη κατάρτιση στην πληροφορική, εκπαίδευση δεξιοτήτων, αυτο-κατευθυνόμενη μάθηση και ηλεκτρονικές παρεμβάσεις και πολλαπλές επισκέψεις σε πιθανούς ασθενείς με άνοια.

Το γενικό συμπέρασμα της διδακτορικής διατριβής είναι ότι επαγγελματίες υγείας πρέπει να υποστηρίζονται για να βελτιώσουν τις γνώσεις τους, για να αντιμετωπίζουν συμπεριφορικά προβλήματα που σχετίζονται με την άνοια, να ενημερώνονται για τις υπηρεσίες και να έχουν τη δυνατότητα να συμμετάσχουν σε πιο έγκαιρη διάγνωση στην πρωτοβάθμια φροντίδα υγείας. Μελλοντικά προγράμματα παρέμβασης θα πρέπει να εκπαιδεύουν τους επαγγελματίες υγείας με εξειδικευμένα προγράμματα που είναι καταρτισμένα ως προς το περιεχόμενο.

## **Abbreviations**

<b>AD</b>	Alzheimer disease
<b>PD</b>	Parkinson disease
<b>LBD</b>	Lew-body dementia
<b>MMSE</b>	Mini- mental state exam
<b>VaD</b>	Vascular dementia
<b>WHO</b>	World Health Organization
<b>GPs</b>	General practitioners
<b>HPs</b>	Health professionals

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I dedicate my PhD degree to the victims of Nepal Earth Quacke, April, 2015 and who are struggling with early onset dementia.

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## **Chapter -I**

### **1.1 Introduction**

Dementia is the progressive deterioration of a largely irreversible clinical syndrome in cognitive function- the ability to process thought. Dementia is a significant burden issue all over the world in the 21st century due to its under detection and sub-optimal management in by healthcare professionals (HPs). Patients have a life expectancy of 7 to 10 years (van der Flier & Scheltens, 2005) after the onset of symptoms.

Differential diagnosis and longer time to identification can be an issue in dementia diagnosis as when taking the medical history or during physical examination. It can be confused with other conditions that share similar signs and symptoms. More than 50% of cases are not diagnosed by the GPs in their practice (Boustani, Peterson & Hanson, 2003). In 2021, over half a million people will be living with dementia that has gone undiagnosed. Even in higher income countries, only 20-50% of dementia cases are recognized and documented in primary care (World Alzheimer report, 2013). Approximately 28 million of the 36 million people with dementia have not received a diagnosis. Furthermore, it is projected that up to 90,000 patients are living without diagnosed dementia in the UK (Alzheimer society UK. 2014). The global challenge of dementia is compounded by the fact that it is under diagnosed and under treated in primary care across the under developing countries of the world (Cahill, Clark, Walsh, O'Connell & Lawlor, 2006).

It is significant issue for HPs (Santacruz and Swagerty, 2001) family members and caregivers (Iliffe & Manthorpe, 2002) to effectively distinguish between aging and dementia. The misdiagnosis rate is increasing. Therefore, it is far better to test early which can significantly aid in the diagnosis and management process. It is estimated that around a quarter

of hospital beds are occupied by dementia patient in UK (Alzheimer society UK, 2009). At the end of their life older people with dementia (two thirds) spend their final years in a hospital (McCarty, Addington-Hall & Altman, 1997). All the aforementioned is exacerbated by the fact that dementia can be present, but being less concerned area.

In society, people with dementia and those who care for them are the most vulnerable, disadvantaged and powerless. Intrinsicly, dementia patients require special diagnosis, management and care in both hospital and society to ensure that their voices, rights and their interests are protected. In Nepal, dementia is not considered a priority area. Thus, the present thesis will add much needed research on the experiences of HPs in Nepal. Such research is particularly important when we consider the increasing burden that dementia places on families, caregivers, HPs and health and care systems.

## **1.2 The situation in Nepal**

Nepal is a small and land located south-Asian country with the population of about 30 million of which over 2.2 million (8.3% of the population) are over the age of 65 years, and this population is estimated to double in next ten years (Central Bureau of Statistics, 2010). (The study place has given in appendix E) The number of older population rate is growing faster than the total population. In Nepal, the number of doctors was 15,052 in 2014. Among of them, 5633 doctors are involved in Kathmandu city and nearly 1000 specialized doctors in different sectors (Nepal Medical Association, 2014).

Nepal's mental health policy was formulated in 1996. In Nepal, both government and private health care services are provided but it does not cover the WHO standards. According to the (WHO- 2010) data the average living 65.8 years and Nepal's rank is in 139<sup>th</sup> in life expectancy. Other than south country, especially in remote area disease prevalence rate is high including diarrhoea, goitre intestinal parasites tuberculosis, gastrointestinal disorders,

leprosy, HIV, maternal-child- health in the figure. Still the government is not capable to address even a common communicable disease due to the less infrastructure, equipment and less access of health services.

In terms of mental health financing, less than 1% of health care expenditures by the government are directed towards mental health. The majority of users are treated in outpatient facilities. Both physician based primary health care centres (PHC) and non-physician based PHC clinics provide primary health care (negligible mental health services) services in the country. In terms of training for primary health care staff, 2% of the training for medical doctors is devoted to mental health, and the same percentage is provided for nurses. Except some districts, community mental health services are not available, as mental health service is not yet integrated in the general health service system. The total number of human resources working in mental health facilities or private practice per 100,000 population is 0.59. The breakdown according to profession is as follows: 0.13 psychiatrists, 0.06 other medical doctors, 0.27 nurses, 0.02 psychologists (WHO, 2012 and WHO- AIMS 2006). In Nepal, no community based psychiatric inpatient units as such (Jha & Sapkota, 2013).

To date, no scientific data has been announced. However, WHO (2012) estimated that about 135,000 people would be suffering from some kind of dementia in Nepal. This figure is likely to double every 20 years. No formal arrangements for diagnosis, treatment care support and caregivers are available. Likewise, no national survey has started (beyond this study) to examine the health professionals' knowledge/attitudes, practices and obstacles to diagnose, management and care in Nepalese medical community. Although dementia did exist in the past, it seems to have gotten worse in recent years due to the increasing of old age population with better life standards and health facilities, the disintegration of the joint family, depression at the end age of life, vitamin deficiency, memory loss, brain tumour, mental pressure on the elderly. Furthermore, there is virtually no more attention of dementia problem amongst public,

professionals, policy makers and no formal arrangements for diagnosis, treatment, care support, and caregivers are available.

On the other hand, the government is not capable to address for the common communicable disease like diarrhoea and others epidemic disease, yet. So for this dementia disease has given less prioritised health issues in Nepalese hospital and in community. As well as due to lack of expertism and less access of health services of people is helping to increase dementia rapidly in Nepalese community. Basically the psychiatric or mental health services based hospitals are standing as practical spot with the dementia patients due to the lack of expertism.

Likewise, the majority of Nepalese HPs find that it is difficult to diagnose on primary care because health workers feel less confident, poor knowledge (Pathak & Montgomery, 2014), misinterpretations of dementia characteristics and its longevity for define, less access of health care services and poor caregiver support. The communication difficulty is a vital issue for primary care practitioners with the patients. Likewise, other difficulties pointed out that talking with patients about the diagnosis responding to behaviours problems, coordinating support services, lack of time and social services support. Furthermore, the major obstacles to good quality care is unfamiliarity with current management practices or with local resources (Pathak & Montgomery, 2014; Knopman, et al. 2001). HPs should be encouraged and aided in developing local collaborative models that maximize available professional and agency resources.

The care of older age people with dementia is bound to increase in Nepali society for the same reasons stated above-increased longevity and disintegration of joint families etc. In Nepal, some programs for elderly people are being set up at present by the government; unfortunately, these tend to be politically motivated. It is the time that stakeholders should consider the integration of mental health services designed for the elderly, besides merely

handing out old age allowances. There is the emerging evidence that the dementia problem is gradually expanding as a future crisis and a national challenge in Nepal.

Hospitals in Nepal (either public or private) are not adequately prepared to provide dementia care services. None of the hospitals offers dementia friendly facilities. In public hospitals some effective dementia care is offered by psychiatric and psychology clinics. The mental based hospitals are handling the dementia-related issues without any dementia expertise. Hence, doctors and nurses might have less contact/practice/experiences with people suffering from dementia when compared to developed countries. As mentioned before, nurses and doctors in Nepal have not received well information and training regarding managing dementia in the hospital. All the mental issues covered by a team of psychiatrists. At the same time the limited mental health team is overburdened with large amounts of patients. This situation lowers the quality of care and management of dementia.

Nepalese health professionals need more knowledge towards the diagnosis of dementia and obstacles to the caring process need to be minimized. HPs should be encouraged and aided in developing local collaborative models that maximize available professional and agency resources. The need for educational programs and health-care policies that help to increase awareness of dementia in Nepalese nursing practice, management and care thereby improve the care provided to Nepalese people. Demographic changes mean that dementia will represent a significant problem to manage in the hospital for a nurse in the future. Therefore, there is a need for ongoing education to the nurses and doctors in dementia diagnose, manage and care. Thus, the unnecessary conflicts regarding knowledge, practices and management of dementia may be reduced.

The Nepalese Ministry of Health has announced its intention to address the issue of dementia formally but significant gaps in the service offered persist. Unfortunately, the government is not able to provide the specific dementia friendly services in the hospitals, with

the adequate level of education, training and the amount of interventions for health professionals (a team of doctors, nurses). The post diagnostic care (follow-up care, promoting independent mobility, intervention for carers, psychosocial intervention for cognitive symptoms, regular orientation through the means of media, post and current assessment etc.) is also need to be examined (Jha et al., 2013; WHO, 2012).

Furthermore, still there is unanswered question who has the most pivotal role with the dementia diagnosis, managenet and care eg, neurologist, psychologist, psychiatrist, and Geriatricianlike-psychiatric nurses/admiral nurses, dentist, optometrist, audiologist, physiotherapist, occupational therapist, dieticians, clinical psychologist, speech and language therapist, caregivers and social care staff, optometrists etc).

All the above-mentioned facts and figures of HPs in dementia brought the considerable attention to conduct this study as dementia is a known worldwide burden for families, health institutions, GPs and nurses, in terms of difficulties in diagnosing, managing and caring in Nepal. This study adds new information to the development of clinical practice and management in dementia and dementia related issues in Nepal. Therefore, the proposed research will be one of the first in Nepal to systematically evaluated diagnostic and practices knowledge and obstacles to manage and care in dementia.

### **1.3 Purpose of the Study**

The aim of this thesis is to explore the knowledge, practices, and obstacles to diagnosis, management and care of dementia that challenge health workers in Nepal. More specifically, the thesis has been guided by the following research questions:

1. How do health workers diagnose, manage and care for dementia and what are the critical issues and concerns associated with dementia in Nepal?

2. What are the specific gaps in knowledge for HPs in Nepal?
3. With regard to dementia, is the situation improving or deteriorating in Nepal?
4. What is the optimum way to improve services directed at dementia in Nepal?

#### **1.4 Significance of study**

This thesis aims to provide an insight into the real situation of HPs with regard to dementia. However, the current study did not identify the prevalence of dementia in the Nepalese population. So, prevalence data in this study is unavailable. Therefore, this study is relevant as it contributes by increasing the body of knowledge on the Nepalese practice of HPs and health care services provided to older adults with dementia. The thesis represents the first attempt to assess the state-of-play among HPs in Nepal. Thus, it is an important resource for Nepalese policy makers and health planners. Moreover, there is relatively little data on the diagnosis and management of dementia in developing countries, and the present thesis fills an important gap in the literature.

#### **1.5. Study overview**

This dissertation consists of seven sections. The second chapter provides an overview of dementia with a focus on the challenges for HPs in the diagnosis and management of dementia. The aim of this chapter is to set the scene and provide a state-of-the-art review of the important trends in the area. Chapters' three to five cover the main work of this thesis and report in detail on four studies among Nepealse HPs concerning their diagnosis and management of dementia.

Chapter three reports on a study to assess general practitioners' (GPs) knowledge, practices, and obstacles with regard to the diagnosis and management of dementia. The study

used standardized questionnaires covering knowledge, practices, and obstacles were distributed among a purposive sample of GPs in Kathmandu, Nepal. The study found that the knowledge of practitioners' with regard to the diagnosis and management of dementia was unsatisfactory. Moreover, the following diagnosis and management barriers were identified: are communicating the diagnosis, negative views of dementia, difficulty diagnosing early stage dementia, acceptability of specialists, responsibility for extra issues, knowledge of dementia and aging, less awareness of declining abilities, diminished resources to handle care, lack of specific guidelines, and poor awareness of epidemiology.

Chapter four reports on the experiences of specialists regarding dementia. The chapter concerns the diagnosis practices, confidence, management practices and difficulties of multi-specialist doctors concerning dementia. Results indicated that they diagnosed more as false-positive and false-negative on average of new cases of dementia and the majority showed a desire to take dementia specialist training to improve their performance.

Chapter five reports in the experiences of nurses concerning dementia. The chapter examines the knowledge, practices and barriers of nurses concerning dementia care. This study involved a purposive sampling approach with 44 - nurses using structured multiple choice questionnaires covering demographic questions, knowledge about dementia, management of dementia and barriers to care. The results indicated that the knowledge of Nurses' with regard to the diagnosis, management and care of dementia was unsatisfactory. The care and management of patients with dementia in hospital settings is a challenge for Nurses in Nepal. Educational programs and health-care policies are needed to increase awareness of dementia in nursing practice with regard to management and care.

The above chapters asked more questions than it answered. Therefore, we conducted an initial review of the literature indicated that an exhaustive review of strategies to help HPs did not exist. Therefore, it was appropriate to conduct a systematic review of the area. The

heterogenous nature of the identified literature indicated that a realist review would be the most effective way to identify what works and for whom. Chapter four reports on a realist review of interventions aimed at improving knowledge, detection practices and management of dementia among health professionals. Healthcare professionals (HPs) play a key role in the detection and management of dementia. However, there is a gap in the literature as to what represents best practice with regard to educating HPs improving the dementia detection practices and management. Thus, the objective of this study was to synthesize the aggregated studies aimed at improving health care knowledge, detection practices and management of dementia among HPs. The relevant medical and social science databases were searched and 25 intervention studies were identified. The results indicated that collaborative programs of practice based workshops with community and multi-faced educational program were the most effective. The early diagnosis, management and care of dementia patients can be improved by; combined (between the HPs) intervention programmes, theory based programmes, better computer training, skills based training, self-directed learning and electronic based interventions and multiple visits to suspected dementia patients.

Finally, chapter seven is the conclusion part of this thesis. This part summarizes the implications, limitations and future directions for researchers in the field. .

## **2. Review of the literature**

In the following chapter, we will review health professionals' (primary care doctors', multi-expert professionals, nurses') knowledge, practices and obstacles with regard to the diagnosis and management of dementia.

### **2.1 Meaning of dementia**

The word dementia comes from the Latin *de* meaning "apart" and *mens* from the genitive *mentis* meaning "mind". Dementia is the progressive deterioration in cognitive function - the ability to process thought (intelligence). The Oxford Dictionary defines dementia as a serious mental disorder caused by brain disease or injury that affects the ability to think, remember and behave normally.

Dementia starts from the foetus and it ends with human life. Also, in every language of world it has recognised as a destruction of brain. In different languages the word has a different conceptual meaning; in Greek, *άνοια*(anoia); in Nepali-पागलपन (Pagalpan), madness, mental illness; in Hindi-जड़बुद्धिता (Jadabudhita) insanity, craziness); in Chinese- 癡呆 (craziness); In Japanese- 認知症 (Ninshishō), madness, crazy; in Irish-néaltrú; in Germany –Demenz, idiocy, mental deficiency; in Africa-dementia; in Arabic- خبل , insanity, craziness, madness etc. All these definitions refer to a broad category of brain disease that is chronic and gradual, resulting in a decrease in the ability to think, remember and an increase in daily life disturbances.

### **2.2 History of Dementia**

In Ancient times (2000 BC) in Egypt, it was believed that the main health problems were concerned with the mind, heart and diaphragm, which determined the pathogenesis of the body and from which came the major problems associated with memory disorder (Breasted, 1930).

Additionally, Horatius, Plato thought that this was synonymous with senile dementia. In Roman and Greek history it was described as bizarre and atypical behaviour of the person (Freeman, 1927). Galen and Hippocrates also described it as cerebral impairment and thought disturbances. Particularly, Hellenistic writers (Aulus Amentia Celsus first century AD), Galen (130- 201) and Aretheus of Cappadocia explained about organic mental disorder and acute psychiatric and neurological disorders (end second century AD) wrote about the dementia (Freeman, 1927). During these days it was recognized with the different names like; Anoea, foolishness, idocy, insanity, alienation, fatuitas, senile psychosis, lethargy, phrenesis etc. Philippe Pinel (1745-1826), a founder of psychiatry described dementia in detail. In the modern era after the description of Aloysius “Alois Alzheimers” (1864-1915) a German psychiatrist and neurologist identified that as "Presenile dementia” was a related disorder in the brain (Boller & Forbes, 1998).

### **2.3 Dementia scenario**

Dementia is the gradual decline of mental functions and overall personality including cognitive problems. People with dementia gradually lose their previous skills, as well as other executive mental functioning like planning, judgment, abstract thinking and psychiatric disorders such as agitation, delusions and depression are very common in patients with dementia (Hendrie, 1997). Dementia is a pathological process in the brain that reduces the quality of life and it caused by a number of different illnesses. As part of the normal aging process people may become more forgetful but it does not affect their daily living activities. Dementia is therefore quite separate from the symptoms of normal aging. However, it can affect people at any age of life (Alzheimer's Association, 2006).

The World Alzheimer report, (2012) suggests that dementia overlaps with Alzheimer disease as it covers all most 70% sign and symptoms. It is significantly more common among

elderly people. According to Chopra, Cavalieri & Libon, (2007) the prevalence of dementia increases with age and affects approximately 5-8 percent of individuals over age 65, 15-25 percent of individuals over age 75 percent and approximately 15-50 percent of individuals over age 85. It is important to note that it is not a normal part of aging.

Yet, most researchers claim that there is not specific cause to dementia per se and it has been most commonly associated with: Alzheimer's disease, drugs and other substances alcohol, brain tumor, neurological disorders like- Parkinson's disease, Huntington's disease and head injury, malnutrition, endocrine abnormalities, infection of the brain, vascular dementia due to stroke, over excessive alcohol, Creutzfeldt-Jakob disease, nutritional deficiencies like- vitamin B-12 and folate deficiency, certain types of hydrocephalus, Porphyria etc (Dementia Today, 2013).

There are three main categories of dementia; 1) early stage (mild stage) 20-24 out of 30 points MMSE score, 2), Middle stage (moderate dementia) 13-20 out of 30 points MMSE score and, 3) Later stage (severe dementia) 12 out of 30 MMSE score. Dementia can show ambiguous characteristics with longer periods and it will progressively make the person more disabled (Alzheimer's society UK, 2004; Ruitenber, Ott, Swieten, Hofman & Breteler, 2001). Research reveals that the dementia is a significant public health problem that should be considered as a public priority (Wortmann, 2012). It is under-recognized in primary care settings and the rate of under diagnosed dementia is 65 percent by physicians in the community. Furthermore, physicians miss opportunities for the application of available treatments, participation in research advances, care planning and the support of caregivers (Chopra, et al, 2007). Pucci, et al., (2003) found that primary care physicians fail to recognize & properly manage of suspected dementia. Both dementia, and Alzheimer disease pose a significant public health issue. It is estimated that about 5 percent of people (fewer than 65 years) suffer from dementia all over the world. Out of all types of dementia, more than half are due to Alzheimer's

disease, a condition in which the brain produces insufficient amounts of a neurotransmitter called acetylcholine. Dementia is problematic because it takes more time to diagnose due to its vague signs and symptoms and slowly it is going to be a future crisis. It is estimated that the number of people with dementia will double every 20 years to 81.1 million by 2040 (Alzheimer's society, 2003).

Likewise, Alzheimer disease international and Alzheimer's Australia (2014) estimates that the rate of dementia will double every year such that by 2050, more than 100 million people or nearly 1 in 85 persons will be affected worldwide. In another study, Harvey et al (2003) claims that dementia is not exclusively a disease of older age and there are over 18000 people under the age of 65 living with dementia in UK (Harvey, Rabinson & Rosser, 2003). The number of older people as a proportion of the population has been rapidly increasing between the 1964-1982 years. Thus, the number of older people (over 65) doubled while the population under 14 grew by only 20 percent (Ikels, 1998). In Canada and Australia accordingly 26 percent and 39 percent of physicians are regularly screening for dementia (Henry & Louisa, 2006).

Iliffe, Mitchley, Gould & Haine, (1994) recommend the use of the mini-mental state examination to screen for dementia. Generally in the clinical practice the mini-mental test (folstein ME, Folstein SE) clock drawing test (verbal), 1-4 minute, GPCOG (verbal 4-5) minute & minute screen (verbal-7 minute) memory impairment screen (verbal minute), mini cog (verbal 2-4-5 minute) (Harvan, & cotter, 2006) are frequently using to assess for dementia. However the screening skills may be influence on the basis of practice opportunity, education, proper guidelines (Brodaty, Kemp & Low, 2004). The majority of GPs are hampered by a lack of competence, lack of training, less performance to referral towards specialist inappropriate time, and differences in medication for prescribing in diagnosis of dementia. (Cahil et al, 2008). There fore it is highlight to test early for the patients with the GPs. Gps can play a vital role with effectivlyat the first visit in the primary care and ca do the refer in right time as well as

right professionals for further detection. But the concern has been raised as to the adequacy with which they can fulfil this role (Downs, Cook, Rae & Collins, 2000).

## **2.4 Types of dementia**

It is known that dementia is a progressive neurodegenerative disease so over the coming decades, it has become a set of the world's largest socio-economic healthcare burden issues. The most common type of dementia is Alzheimers disease that accounts 60%-70% with the elderly. Followed by vascular dementia (17%), mixed (AD and vascular) dementia (10%), dementia with Lewy bodies (4%), fronto-temporal dementia (2%) and Parkinson's dementia (2%) (Ashraf, Mehta, & Edison, 2013, Alzheimer Society UK, 2012. According to the Alzheimer's society and Alzheimer association (2013); Gupta, et al., (2009); Alzheimer Europe (2002); WHO (2003); Alzheimer's Association, UK, (2012, 2013); Knopman, (1998); Ganzer, (2007); Alzheimer's Association, 2013; Christensen & White, (2007) the types of dementias are given in two forms. The first type is called major types of dementia these are: Alzheimer disease, vascular disease, frontotemporal disease, dementia with low body And the second type of dementia is called rare and unusual types of dementia eg. Huntingtons disease, parkinsons disease, wernicke-Korsakoff disease, pure hippocampal sclerosis, human prion disease, niemann – pick disease disease type C, corticobasal degeneration, whipple's disease. Here, the most common types of dementias Alzheimer Disease is described a bit more other types of dementias.

### **2.1.1 Alzheimer Disease (AD)**

This disease was found by a German psychiatrist (a patients with 51- year-old woman Auguste Duter) after her death by brain autopsy while it was called senile dementia. After identifying in 1907 by "Alois Alzheimer", Alzheimer disease is considered as a global health issue over the coming decades that shows a progressive cognitive and functional decline in the

patients. Alzheimer disease is an escalating epidemic. It is a chronic progressive neurodegenerative illness which clooacps of the cholinergic system and regulates acetylcholine in the brain (Ganzer, 2007). AD has two forms- one is early onset that may appear in ages 30's, 40's, 50's and second is late onset. In general, AD develops after age 65. Research into its symptoms, causes, risk factors, and treatment has gained momentum during the past 30 years, even though it was investigating more than 100 years before.

This is the most common type of disease and its 70% -80% characteristics appears with dementia (Chapman, Williams, Strine, Anda, Moore, 2006). Apathy, depression, difficulty remembering names and recent events week judgment, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking are the symptoms of AD. In the later stage impaired judgment, disorientation, confusion, behaviour changes, and difficulty, speaking, swallowing, and walking complication appears. The evidence of nerve cell in the brain may damage and death. Also, the hallmark of brain abnormalities are deposits of the protein amyloid beta (plaques) and twisted strands of the protein tau (tangles). The three- Amyloid plaques, neurofibrillary tangles and loss of connection between neurons are the main hallmarks in the brain that is related with the AD.

It afflicts mostly elderly people with cognitive impairment that double every five years with the over 60 years (Comings, et al., 2002). If we talk about only U.S. population, has been estimated 5.2 million Americans of all ages have Alzheimer's disease in 2013 and is listed as six leading cause of death and fifth leading cause of death for those age 65 and over in U.S.(Alzheimer association USA, 2015).

Patients with AD- Agitation, depression (Drye, et al, 2012) and language deficit (Nakamura, Kitamura, Homma, Shiosakai, & Matsui, 2014) are common (Olin, Katz, Meyers, Schneider, Lebowitz, 2002 b), (Porsteinsson, 2014) for elderly and depression is associated serious disorder (Blazer, Hughes, & George, 1987). Depressive symptoms in elderly

age or patients appear as ranges 7%-42% (Bruce, Seeman, Merrill, & Blazer, 1994). Especially disorder and own by dementia is strongly associated with the increase of cognitive dysfunction (Castaneda, Tuulio-Henriksson, Marttunen, Suvisaari & Lonnqvist, 2008). A next study (Lyketsos, et al, 2000) found 20% persons are suffered by dysphoria and the same 20% were suffered by irritability and many kinds of depression. Researches from UK and USA showed that depression is one of the most and high rates in the population. Also, it is not short term illness requiring psychopharmacological treatment over short periods of time. Therefore, treatments need to be reliable and efficacy, but in an illness requiring long-term medication, acceptability to patients must also be addressed (Montgomery & Djärv, 1996). Likewise, agitation is another most important neuropsychiatric symptom with AD patients which has particularly shown emotional activities, aggressive behavior, irritability and psychomotor activity. Nearly 42% people developed agitation in one study, after 5 year follow up (Steinberg, et al, 2006). In the earlier stages of AD, oxidative stress is an important cause in pathogenesis. So to reduce the stress the trial of vitamin E supplementation was in use with moderate to severe AD. Even though there is also controversial of using E and its reliability as general antioxidant therapies. The multiple contributing factors that develops the clinical manifestations of AD should be considered while designing anti-oxidative stress therapy (Lee, H.P et al., 2010).

Many risk factors can cause the AD. Among of them, the greatest risk factors is advancing age. However, younger than 65 of age can get the AD so age is not only part of risk factors for aging. Family history- genetics; APOE e4 gene-it is blue print of protein that can carry cholesterol in the bloodstream and 40-65 % can cause the AD; Traumatic brain injury- destruction of normal brain function by blow to the head; Mild cognitive impairment- mild and measurable changes in thinking; cardiovascular disease-smoking, obesity, diabetics Mellitus, high cholesterol, hypertension; education- higher level of education can connect neurons in the

brain and reserve cognitive power but low level of education does not; social and cognitive engagement- socially and mentally active may support for healthy brain- are the main leading factors that can cause AD to the people (Alzheimer association report 2013, P.214).

## 2.5 Differences between normal aging and dementia

Is dementia, more than old age or something else? Or does the difference beyond the normal aging? What exactly are dementia and normal aging? Is memory loss not necessary to say dementia? What is actually confusing fact about dementia, that is not a dementia disease. All of these questions help to highlight the differences between aging and dementia. Nearly 40 percent has some form of memory loss in the elderly over the age of 65. So memory problem is the vital agenda of dementia .So it can be projected that if some has not any other medical malfunction with the memory loss is called a part of a normal aging process(Alzheimer Societty canda, 2015).

The American Medical Association (1999), Alzheimer Society of Canada (2015), APA (2010) and John Hopkins Medicine (2009) have clearly defined the clinical criteria between the normal aging and dementia as below table. Most physicians make the diagnosis under the following criteria.

**Table 1. Differences of normal aging and dementia**

<b>Normal aging</b>	<b>Dementia</b>
Slightly independency in daily tasks.	The person may need dependency from others with the simply work
Memory loss problem may be appearing but can provide considerable detail regarding incidents of forgetfulness.	If someone complains of memory problems and asks frequently about the recall problem is considerable notice of memory loss.

The individual is more concerned about alleged forgetfulness than close family members are	Close family members are much more concerned about incidents of memory loss than the individual
Recent memory for important events, affairs, and conversations is not impaired	Patients cannot remember even the recent memory of events and ability to converse are both remarkably impaired.
word-finding difficulties may appear occasionally	Frequently word-finding difficulties and substitutions may appear.
With the familiar territory, person does not get the problem but may have to pause momentarily to remember way.	Consequently, Person gets lost in very familiar territory while driving, at working office, on walking and supermarket as well as may take hours to return home too.
Individual operates common appliances even if unwilling to learn how to operate new devices	A person cannot learn even simple and new words and their application.
Does not seem no decline in interpersonal social skills	Person may show socially inappropriate behaviors like; less interest in social activities.
Due to the individual's culture and education the normal performance on mental status examinations may be differences	Mental status examinations may appear below-normal performance even though there are not any influencing factors like; education and cultural phenomena.

**Source:** American Medical Association, 1999; Galvin & Sadowsky (2012); (John Hopkins Medicine, 2009, pages 1-2). Alzheimer Society Canada, 2015.

In daily clinical practice, physicians confront older patients who suffer from some kind of dementia. Many physicians are used to defining cancer, neurological disorders, congestive heart failure, diabetics and chronic obstructive pulmonary disease and most do not diagnose dementia in the similar way. Therefore, the AMA has recommended that as above mentioned criteria determining the differences between dementia and normal aging for evaluation process (AMA, 1999).

Furthermore, older patients are at a higher risk for the cognitive disorders, mood disorders, depression and chronological mental disorders at the end age of life. For the

physician to distinguish between depression, delirium and dementia is difficult due to difficulties with comorbidities and frequently changing characteristics of older persons. According to Insell, Badger (2002); Rivelli (2008); (Jane P Gagliardi, 2008); Bridges-Webb, C., & Wolk, J. (2003); (NSW Department of Health, 2006, Pages-32) they showed the some criteria/differences to define between depression, delirium and dementia for the physicians. See the below table.

**Table 2. Differences between depression, delirium dementia**

<b>Features</b>	<b>Dementia</b>	<b>Delirium</b>	<b>Depression</b>
<b>Mood</b>	Unstable	Fluctuates	Apathetic
<b>Course, motion, movement</b>	Chronic, with deterioration over time	Acute; responds to treatment	Chronic to treatment.
<b>Inception /incubation</b>	1 months to years (up to 10 years)	Some hours to days	Weeks to months
<b>Memory/ cognition</b>	Impaired latest memory, As the phase of disease progresses, long term memory may affected, Other cognitive deficits like word finding, judgement and abstract thinking	Instant memory impaired, Attention and concentration Impaired.	Currentent memory impaired, Long-term memory generally entire, sporadic memory loss, Poor consideration
<b>Vigilance</b>	Usually normal	Fluctuates-lethargic or hypervigilant	Normal way
<b>Activities of daily living behaviors</b>	May be unimpaired early rising behaviors, disability as disease progresses	May be intact or impaired	Negligence basic self-care
<b>Commencement</b>	Usually gradual, over several years and sneaky incharacteristics.	Acute or subacute (hours or days)	Typically over days or weeksmay concur with life changes
<b>Activities of daily living</b>	As the disease progresses phase ADLs may be intact early, impaired before.	May be intact or impaired	Might be impaired early sign.

<b>Duration</b>	It may take some months or over a years and progressive degeneration	Many hours to days (Although it can take a month too)	It ay takes from two weeks to several months to years.
<b>Self-conscious</b>	Apparently unaware of cognitive crunch.	It seems slightly aware of changes in cognition and rocky.	Likely to be concerned about memory impairment.
<b>Thoughts</b>	Repetitiveness of thought decreased interests, difficulty for logic or formal argument. Slow brain and lazy actions, delay response.	Weird and vivid thinking scary thoughts and ideas, Paranoid schizophrenia symptoms.	Often slowed thought processes may be preoccupied by sadness and hopelessness, negative thoughts about self-reduced interest.
<b>Sleep or rest</b>	Often a disturbed 24 hour clock mechanism (later in the disease process).	Confusion disturbs sleep(reverse sleep-wake cycle), Night confusion, Vivid and disturbing nightmares	Early morning waking or intermittent sleeping patterns (in atypical cases, too much sleep)
<b>Course</b>	May be variable depending on type of dementia.	Fluctuates- usually worse at night in the dark, Coherent periods.	Commonly worse in the morning with improvement as the day continues.
<b>Orientations</b>	Increasingly impaired sense of time and place.	Flicker impairment of sense of place, person, date, time and seasons.	Usually normal.
<b>Spontaneous</b>	May be able to conceal or compensate for deficits (early), frustration, helplessness, impatience, negative, hostile, impulsive, anger, instructions, break down tasks step-by-step and answer repetitive questions.	May occur as a consequence of a drug interaction or reaction, physical disease, psychological issue or environmental changes.	Often disguised and may have past history with the patients.

## 2.6 Proposed Dementia treatments in the current practice

Worldwide dementia is rapidly being recognized as one of the most significant medical issues in older people (Yiannopoulou and. Papageorgiou 2013). There is a variety of medicines used to prescribe at different times for people with dementia according to types of disease such

as Alzheimer disease, dementia with lewy bodies, mix dementias and other rare types of dementias. A wide range of herbal remedies, medical foods, and dietary supplements are prescribed to promote memory issues or to prevent Alzheimer and related dementias. The established treatments are only able to relieve the symptomatic nature in the patients. Most medications used for Alzheimer related dementia in the clinical practice because Alzheimer's disease accounts for up to 80 percent of all dementia cases. Knowing the crucial characteristics and pathology of each dementia can help in the accurate diagnosis of patients, so they can receive the proper treatment and services for their highest possible quality of life. Among of them, three cholinesterase inhibitors are prescribed for the treatment of first stage of dementia disease. These drugs work by blocking the enzyme (acetylcholinesterase) which destroys neurotransmitters for memory, called acetylcholine. These drugs commonly show improving result within the six months of treatment periods (Alzheimer Society UK, 2014; Kavirajan and Schneider, 2007). However, the questions are how dementias can be treated?-If the almost dementias are incurable except some exceptions (vitamin and thyroid hormone deficiencies dementia can be treated with the supplements). As well as, brain tumours, hydrocephalus or head injury can be treated by surgically. Also behavioral disorder type of dementia and neurodegenerative type of dementia can be treated such as: high blood pressure and over cholesterol. A wide range of medications have been showing for mild, moderate and severe type of dementia issue can be treated. However not for everybody these prescribed drugs will be benefited. More than 50-60 conditions can cause the symptoms of dementia.” and “dementia-related disorder (can only be) distinguished from other dementias at autopsy. Most of the medications have now emerged as a baseline of major cause of mitochondrial damage, which may explain many adverse effects. The current medications are not able to cure dementia however such medicines may help to minimize without side effects and can help to improve temporarily slow down symptoms and their progression (Alzheimer

Association USA, 2014; Alzheimer society UK, 2014). The causes of unable to treat the dementias are that- it shows a dozens of causes of behavioral, neurological and psychological signs and symptoms (depression, agitation, aphasia, gout, pain, hallucinations, ideas of persecution, anxiety, sleeplessness, misidentification of relatives or places and aggressive behavior with psychological characteristics) that can be misdiagnose or over diagnose therefore the treatment may not be accurate without the combination of specialist such as; neurologist, geriatrician, psychogeriatrician, neuropsychiatrist, psychologist.

## **2.7 Who is responsible for the diagnosis, management and care of dementia?**

It is already known that a key person is the GP for dementia diagnose- GP is a first focal point of contact-usually begins with a GP. General practitioners (GPs) and the primary care team are uniquely situated to play a central role both in the diagnosis and ongoing care of dementia. GPs face several challenges in fulfilling this role owns (Downs, 1996).

The GP can refer a person to a Psychiatrist of Later Life or a Geriatrician to obtain specialist support during the course of the condition. Where a person is under 65, a neurologist may be the consultant referred to geriatrician. A GP diagnose the type of dementia, cognitive impairment, changes that emerge and how you can manage symptoms and medication, blood pressure, cholesterol and general health. However this issue has raising in UK regarding with the fee of GPs. GPs will be paid 55 pound for each patients and every time to declare dementia. GPs need to visit more time of the diagnosis and treatment of dementia within primary care. People with dementia who need to go five-six- even-eight or nine times, and then referrer to a memory clinic. There might be another false probability to be referred by GPs for memory clinics. With dementia there is factual reason why primary care can't give its right contribution on diagnosis and care on right time, that is why dementia diagnosis is being overburden to the

patients each time to visit the GPs- only 45% formal diagnosed (Alzheimer disease international, 2011; Alzheimer Society Ireland, 2015).

Nurses are crucial for the management and care of dementia. There are considerable gaps in the staff's knowledge (Furaker & Agneta, 2013) to provide effective knowledge. A health nurse works with people in their homes, in care centers and hospitals, to manage their health condition early identification of dementia and the formulation of management strategies for patients and their carers. By their wide range of skills and knowledge increase family and patients' awareness of the early identification and the negative impact on people with dementia and their carers (Bryans & Wilcock, 2001). The goals of nursing care person with dementia in hospital and community settings include: develop the dementia friendly relationship like empathy and trusty, supports for patients for self-care and their loved ones for effective communication, maintain the safe environment for patients, promote the persons' social engagement.

Therefore, those nursing staffs working close to the other staff and residents assess their observations that can prevent unsuitable elucidation and lack of information. Also, RN's companionship can find what the staffs are doing and RNs needs to be developed (Furaker, et al, 2013).

Dementia is complicated to diagnose. The referring process to the neuropsychiatric, geriatric and neurology in dementia might have an important element for the further assessment (Beck, Cody, Souder, Zhang, & Small, 2000). Not only medical doctors, any type of medical doctors can diagnose the problem of seniors complication like urinary tract infections and others primary care health.

A multi-expert team is necessary to diagnose dementia, not only by the GPs, psychiatrist, neurologist and geriatrician. In the sense of Occupational Therapists (OTs) care, they can

provide an especial care of the whole person and focus to be on activities of daily living like; dressing, eating and grooming, bathing, neat and cleaning etc. Its main goal is to restore and reduce the decline in the person's functional ability and to play in assessing suitability for assistive technology. Likewise, physiotherapists can have the aim to maximise the person's abilities regarding mobility to allow the greatest level of independence possible and to make a vital role in falls risk-assessment. Speech and Language Therapists (SALTs) can help on improving quality of life of patients by maximising communication ability and cognitive function. Also to assess swallow and advice regarding food and drink consistency with the dementia patients. A further, social workers can play a role in need of proper assessment, counselling in people with their service entitlement. As well as, in protecting the rights of people with dementia and safeguarding the health and welfare of primary caregivers (Folsey et al, 2014). A person with dementia needs a special care services by the speech and language therapist, ENT (ear, nose, teeth/throat). They can provide assistive technology- assistive, adaptive and reahabilitive devices and services to the patients.

## **2.8 Diagnostic Criteria of dementia.**

Doctors can apply/employ the verities of diagnostic criteria or strategies to the suspected person due to lacking of gold standard guideline. Therefore, dozens of trial based practices and maximum reliable of techniques have been used to assess the dementia with reasonable accuracy options. At present the DSM-IV-TR (APA, 2000) American psychiatric association is the most commonly used methods at globally. Most research studies (APA, 2010); Tolaki, et al, 2010; Chen, Lin & Che, 2009; Ruth, 2009; Hatfield, Dudas & Dening 2009, World Alzheimer report 2010, 2012, 2014, Alzheimer association UK, 2013, American Psychiatric Association (1994) have common agree with the following diagnostic criteria to define dementia patients. These are given below box.

Language (aphasia), Motor skills (Apraxia), Object recognition (Agnosia),
Head injury: Repeated concussions, loss of consciousness (e.g., football, boxing, risky sports, and occupations, wrestling),
Poor cardiovascular health (reduces blood flow and oxygen to the brain), strokes etc.
Age: the probability of dementia approaches over 60 ages
Diabetes: type of diabetics
Stroke (blocked blood supply in the brain)
High cholesterol: in arteries reduce oxygen level
High blood pressure, neurological examination, cognitive and neuropsychological tests, brain scan,
Obesity and lack of nutrition, Body mass index: Overweight and obesity
Lower educational level
Sleep apnea: it reduces oxygen to the brain and cognitive deficits
Impaired vision or hearing
Gait: "asymmetrical" and symmetrical" based on limb movement or a shuffling gait (like elephant walking symptoms)
Infections: longitudinally in body, wound.
History of family genetic –(5% of the incidents of dementia diagnoses)
Pressure, depression, delirium, all the psychological assessments, behavioral assessments, daily living activities,
Drugs: previous using drugs, current using drugs, and other chemical effects, poisons, side effects of drugs, benzodiazepines etc.
Alcohol consumption before and current time
Environmental factors: Lead, metal, iron, copper, jink
Assessments of between other types of dementia and overlapping characteristics and others disorders.
Comorbidity: hypertension and others blood level status

In the Nepalese medical context dementia screening and management, protocol has adapted from mhGAP- IG (World Health Organization mhGAP, 2010). These are as following domains: Ask the Medical History- Is there a clinical history of pathology dysfunction, previous medication consumption, and all the physical examinations- Goitre, any kind of pain, urinary infection, poor appetite, constipations, strain, dependency for caring, slow pulse, wandering, dry skin or hypothyroidism?, sexually transmitted infection or HIV?, cardiovascular risk factors?, hypertension, hyperlipidaemia, diabetes, smoking, obesity, heart disease, previous stroke or transient ischaemic attacks) Poor dietary intake, malnutrition, anaemia, alcoholism?, cognitive test – subjective memory impairment test, language test, activities of living, such as family member and their activities- smoking, early morning wakening, drinking, personal hygiene, mental state like- mood, depression, suicidal thoughts, hallucinations, delusions etc.

## **2.9 Dementia Treatment Gap**

Prince (2009) has reported that the dementia treatment gap of dementia is significantly high in even high income countries as well as in middle income and low income countries. Still the low level of dementia awareness, specialist care services, primary health care access and long term support care are not sufficient therefore the public awareness, care effectiveness, community health care services, interventions program of comorbidity, cognitive, mental and physical health, ageing, their access- affordable, accessible health care is essential worldwide for the health professionals, caregiver and patients since all of these can lead treatment gap. Alzheimer society UK in 2013, revealed a new figure of wide variation in people are receiving diagnosis. Diagnosis rates range from 31.6 per cent in East Riding of Yorkshire to 75.5 per cent in Belfast (Alzheimer Society UK, 2013).

Similarly, in 2021, over half a million people will be living with dementia that has gone undiagnosed. A new partnership between Tesco, Alzheimer's Society and Alzheimer Scotland have for the first time mapped the state of dementia and diagnosis levels in the UK and announced bold plans to help fight the disease (Alzheimer society Switzerland, 2011).

In high-income countries, only 20-50% of dementia cases are recognized and documented in primary care (Alzheimer disease international, 2013). This 'treatment gap' is certainly much greater in low and middle income countries, with one study in India revealed 90% remain unidentified (Dias & Patel 2009; Nair, 2009). Approximately 28 million of the 36 million people with dementia have not received a diagnosis. If we talk only about UK, It is projected up to 90,000 patients are living without diagnosed dementia (Alzheimer Society UK, 2013). Therefore do not have access to treatment, care and organized support that getting a formal diagnosis can provide (Alzheimer disease international, 2013).

## **2.10 Dementia misdiagnose and mismanagement by the health professionals. Why?**

Dementia consists of combination of 100 types of characteristics that is why diagnosis of dementia may be delayed or missed because early onset symptoms develop gradually and are often associated with the normal aging process. Also, symptoms of dementia can mimic as of a variety of disease conditions like; depression, delirium neurological disorder and other psychological disorders which can have all forms of dementia. In addition, a misdiagnosis and its mismanagement of the underlying cause of dementia is possible because there are many associated causes, among of them can be difficult to diagnosis and management due to their hidden causes. The journal of of the American Aedical Association (2012) highlighted the nurses six steps to manage dementia across all settings to help clinicians and effectively manage: 1)symptoms identify, 2) early behavioral systems screening, 3) delineate the triggers

and risk factors, 4) appropriate intervention at the care spot, 5) evaluate the intervention, and 6) follow the patients' improvement (Ford, 2012).

According to World Alzheimer Reports (2009, 2010, 2011) and Alzheimer Association USA, (2013, 2015) the following are common for misdiagnose and mismanagement with the suspected dementia patients by the health professionals: Alzheimer's disease over-diagnosed, Tremor, stiffness and shakiness need not be Parkinson, Dementia may be a drug interaction, Undiagnosed stroke may have to aphasia, MTBI misdiagnosed, Manic-depressive or Bipolar disorder conditions, Eating disorders under-diagnosed in men, Mild traumatic brain injury often remains confusing, Manic-depressive or Bipolar disorder conditions, ADHD under-diagnosed in adults, Normal brain pressure or hydrocephalus condition with as dementia, Undiagnosed Parkinson's disease and related disorder, Post-concussive brain injury often misdiagnosed, Children and migraine often misdiagnosed with children, Undiagnosed anxiety and depression, Undiagnosed depression in teenagers, Vitamin B12 deficiency under-diagnosed.

## **2.11 Obstacles to diagnose or contributing for timely diagnosis, effective management and care for dementia.**

Risk of dementia and AD begins in the Womb (Llibre, 2012). Dementia can be an unpleasant and social burden disease. Diagnosis and management barriers are presented with regard to primary care doctors' factors, patient factors and carer factors. These some issues are: time, communicating the diagnosis, negative views of dementia, difficulty diagnosing early stage dementia, acceptability of specialists and responsibility for extra issues, knowledge of dementia and ageing, less awareness of declining abilities and diminished resources to handle care, not specified guidelines, poor awareness of epidemiology and less confidence to advise

(Pathak et al., 2014; Alagiakrishnan, 2010; Bradford et al, 2009; Koch, Iliffe & for the EVIDEM-ED 2010; Murphy et al., 2014; Phillips, Pond; Goode, 2011.

On the other hand, the 20<sup>th</sup> international conference of ADI KYOTO declaration has suggested an action plan for dementia to minimize the problems. These following 10 overall recommendations may help to minimize the dementia problem. These are; a) Provide treatment in primary caregivers, b) Make appropriate treatments available, c) Give care in the community, d) Educate the public, e) Involve communities families and consumers, f) Establish national policies, programs and legislation, g) Develop human resources, h) Link with other sectors, i) Monitor community health, J) Support more research (Access Economics, 2006).

## **2.12 Early identification/diagnosis/ treatment for people with dementia**

In the dementia history the most common forms of AD was found in the age 50s of a patient's case study (Auguste D. in 1906) in Germany by a German Psychiatrists Alois Alzheimer. It means that was the landmark of early onset evidence, the dementias are not a part of normal aging or late onset forms only. However, no one consider the early onset disease can appear with the younger ager. The most common forms of dementia is AD and also, vascular demenot, korsakoff's syndrome, Alchohal related dementia, Parkin's disease, Huntingons disease, HIV-AIDS, people with down-syndrome and some learning disabilities, and multiple sclerosis may develop as early onset of the patients in their life(Alzheimer society of Ireland 2015). Also, the rare forms of dementias and genetics types can affects the 30s to 40s of ages.

There is universal belief that dementia is an ambiguous, nonspecific and unrecognized by the HPs in their practices because it is not expected with the younger age. In UK, nearly 60% people are struggling as dark for diagnosis (BBC News, 2014) that means younger people are not getting high perception of clinician for diagnose. The doctors may not aware when a person goes with the complaining the dementia symptoms at the first visit. Since, people with

EOD are in their 40s and 50s; they may physically fit, aware of their symptoms, able to working at the time of diagnosis, have a dependent for children/parents at home, have vital financial commitments (food, shelter, mortgage, children fees, etc.), find it hard to accept losing skills, difficult to get information, support and services adapted to younger people with dementia (Alzheimer society Canada, 2015). Some clinical person may not have diagnostic confident, as a result, getting a proper detection and management can be frustrating and long (Alzheimer Association Washington, D.C, 2006). Most research have shown a significant fact over 10 years, with early dementia diagnosis case are undiagnosed in the primary care (Valcour, Masaki, Curb & Blanchette, 2000). Despite this, the appropriate test tools are lacking there and people with dementia never get diagnosis in the primary care. It means that the demented person and his/her family always looking for effective treatment with stress (Beeston, 2013). Also, it has vague process, iatrogenic illness and diagnostic cost in the hospital (Harris & Keady, (2004) as well.

Therefore, there is the better solution to minimise the rate of diagnostic errors by improving the HPs skills toward the dementias. Earlier diagnosis is the first step to understand and manage the disease condition. It is appropriate, reliable, desirable effective for several causes that allow family, patients, clinician and health care institution to make more plan effectively for the future. Even though, there is not similar believe with early diagnostic benefits (Lepeleire, et al., 2008), in the past, there was argued of benefit of an early diagnosis since the people with YOD seems physically strong, healthy and they could reluctant to see themselves as aged-care clients and economically able to earn (Thomson, 2011). There is common believe, the early diagnosis helps to reduce the catastrophic events like accidents, save the nursing care cost and quality of life and others harmful incidents events (Laske, 2015). However, the wide range of research is required to expand it, aiming at what clinical diagnosis can show more effective for YOD.

The onset of dementia is often not possible to identify with easy diagnostic process when first symptoms appears. Alzheimer's Australia, (2005) has identified some indicators of early dementia that may offer for carers and professional for assessment. The person can show more apathetic with less sparkle, less desire hobbies or activities, unwillingness for new things, unable to adapt to changing societies and life style, poor judgement/poor decisions, slower response for complex ideas, blaming to others for 'stealing' things, materials, money items less concerned with emotions and feelings, selfishness, forgetful of details of recent events, repeating themselves or lose the thread of their conversation, irritable or upset with simple matters, have difficulty handling banking process like deposit/withdrawal money (Carlson, Abbey, Kocur, Palk, & Parker (2008).

Since the last decades the definition of dementia has been refined- professionally, socially and culturally formulated as the elderly disease. However, the prevalence and incidence rate of dementia are unknown globally, there are a number of 'pre assumption'. The preliminary consensus of Australia was announced about 10,000 (Thompson, 2011), In UK 15,034 in 2007 (Knapp, 2007) and in Japan 30,000, in 1995 (Asada, 2008) people had early onset dementia although, the Services for people with young onset dementia are completely ignored in the hospital setting and community. The early onset dementias do effects on families, their dependent young children, and the economic implications are particular challenges (Asada, 2008). In one study of Japan, the forms of dementias such as vascular dementia was found more common (42.5%) followed by Alzheimer disease (25.6%), head trauma (7.1%), dementia with Lewy body/Parkinson disease with dementia (6.2%), frontotemporal lobar degeneration (2.6%), and other (16.0%) with the young populations (Lkejjima, 2009). Likewise, a study from Sydney showed that the alcohol-related dementia with young age was most high (18.4%) among of 204 patients, followed by AD (17.7%), vascular

dementia (12.8%), and frontotemporal dementia (11.3%). This prevalence shows the higher rate than before from UK, and Japan. Withall, Draper, Seeher, & brodaty, (2014).

The literature of Thomson, (2011) focused the good practices of service model for early onset. These are: timely diagnosis with prompt referral services, sufficient information and deliver, differentiation between dementia, later life, and YOD, financial commitments, employments for caregiving and responsibility for dependent children, identification of crucial difficulties faced by younger and their caregivers, and multidisciplinary team, respite services with age appropriate(younger Onset Dementia Social Support and Respite care) etc.

In Aurelian states, YOD and their family careers are getting services from Alzheimer Australia. Similarly, the others countries have started as first step to develop targeting to YOD services and advocates in the UK- by Alzheimer society UK, In Ireland-by Alzheimer society of Ireland, Alzheimer Association of USA, 2006, Newzeland, Europe- COGKNOW, 2006, Netherland and Japan.

The main reason of YOD have vary, what disease occurs in life of the person. At age of 40s and 50s is quiet difficult than 60s to define ahead. Cox and Keady (1999: pp. 293-4); social care institute for excellence, (2013) listed a number of relevant factors that lead to have YOD. Among of them, the first factor is history of past and current concerns of person. Accordingly;

- The changing life style meaning,
- Continued mobility and physical strength,
- Financial capacity and responsibility to the dependency children,
- Genetic transmission,
- The expectation of family, friends,
- Society and society patterns, social network,
- Self-confidence and satisfactions with the goal of life,

- Issue of social settings status-like, social position, social relationships, economy status, independency with others,
- Down syndromes,
- Learning disabilities- aphasia, dyslexia, Intellectual impairment,
- All forms of dementias,
- Alcohol-10% (Royal College of Psychiatrists and Alzheimer's Society 2006),
- Drugs misuse,
- Other external environmental characteristics and
- Other physical dysfunctions (neurological, psychological, neuropsychological, anatomical and physiological issues).

All most all, screening tools are carried out with the huge experiment (population based) even though do not provide a diagnosis of dementia- only, they offer indicators for further clinical evaluation. Therefore, the screening should not be determine on the basis of “population-based” –(within a certain age group) because the dementias are vague and, complex process (Alzheimer Society of Canada, 2008). Rather, initial dementia assessment criteria (Alzheimer's association and national chronic care consortium 2003); Elsayy and Higgins, 2011) can be useful for every suspected patients. The initial interview should have with the family members and caregivers asking in details of:

- Individuals' history of past and present (current functioning, memory status, cognitive issues, safety activities, behavioural activities).
- Medication/ medical history- head trauma and some neurological functioning, poly pharmacy.
- Geriatric situation-constipations, vision, hearing, depression, vision, falls and fall related injuries, osteoporosis, sleep disorders, continence and others activities, chronic pain, balance, hypoxia, anaemia, postural hypotension,

physical appearance, gait, Katz index of independence in activities of daily living etc.

- Social engagement/participation.
- Preventive medicine- review of Immunizations, cancer types, diabetics, HIV.
- Family interview- asking a social attitudes (positive-negative), perceptions and relationship.
- Cognitive incapacity and problem behaviour.
- Laboratory test- CBC, TSH, drug level-digoxin/lanoxin, toxin, Glucose, BUN/creatinine, level of cholesterol, diabetics, cancer, liver functions, VDRL-screening test for Syphilis), Calcium, B12,b6, haemoglobin rate, vitamins-A-B-C, iron; zinc; and other trace minerals deficient etc.
- Therapeutic test-
- Lawton instrumental daily living activities scale.
- Genetic test-ceruloplasm, huntigton's disease, copper, wilson's disease.
- Brain imaging- Hydrocephalos, mass lesions, infarcts, and subcortical ischemic changes,
- And using the above mentioned tools.
- Lumber puncture test-(spinal cord, cerebrospinal cord, and other neurons.
- Anasthesia using, operations of tumors, kidney failure, hurt and lungs, kidney transplantation, chronic infections,
- Patients' nutrition- body weight, height and good looking body figure.

### **2.13 Prevalence of Dementia**

Already 62% of people with dementia live in developing countries, and by 2050 this will rise to 71%. Additionally, in another study it is estimated that developed and developing

countries 35.6 million (WHO, 2012; Alzheimer society, 2012) people lived with dementia worldwide in 2010, that numbers expected to almost double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050.

The estimated number of European dementia population will be per year about 4.1 million in the year 2050 and the working-age group will considerably decrease during the next 50 years. Nearly 7.1 million dementia cases faced 493 million persons in working-age in the year 2000. This equals a ratio of 69.4 persons in working per one demented person. Directly and indirectly the huge burden will be faced by the young populations (Wancata, Musalek, Alexandrowicz & Krautgrtners, 2003)

It is estimated that 6 % to 10% (Chapman, Williams, Strine, Anda & Moore, 2006) of individuals of aged 65 years older people are affected by dementia. Similarly, in another investigation, 40% of those aged 90 to 94 will suffer from dementia (Hendrie, 1998.) A majority of the US population is affected by dementia and related disorders and the cost of dementia care is high, annually, per older patient by \$4134, with 75% of these increased costs attributable to nursing facilities and hospitalization (Hill, et al., 2002).

In 2010, 58% of all people with dementia lived in countries with low or middle incomes, with this proportion anticipated to rise to 63% in 2030 and 71% in 2050 (Prince, et al., 2013). According to Ferri, *et al.*, (2005) the estimation of worldwide prevalence of dementia is 24 million and its ratio may reach 40 million by 2020 and 80 million by 2040. Mainly the Prevalence of dementia seems in high throughout developed countries than in low- and middle-income countries. However, Prience, et al., (2013) reveals that in 2010, 58% people with dementia will remain in low or middle income countries and this proportion will rise respectively up to 63% in 2030 and 71% in 2050.

The prevalence of diseases such as dementia is nearly 42 million in 2012, with approximately 4.6 million new cases a year. These figures are estimated to increase up to 300% by 2040, with an impact on expenditure of over US\$ 422 billion (Rodriguez, et al, 2013); (WHO, 2013). In Canada the number of cognitive impairment and related disorder of dementia is rising sharply (Alzheimer society Canada, 2015) and that figure stands at 747,000 and will two fold to 1.4 million by 2031. In Australia, 2007, it was projected that by 2050 there will be 220,000 people will be affected and by 2050 will reach 7300001(Woodward, et al., 2007). So if we could prevent or delay the risk of dementia it would major benefit of society.

#### **2.14 Cost of dementia worldwide**

According to Alzheimer's Disease International, (2013) "if dementia care would be country, it could be the world's 18th largest economy, ranking between Turkey and Indonesia. Likewise, if dementia care was a company, it would be the world's largest by annual revenue exceeding Wal-Mart (US\$414 billion) and Exxon Mobil (US\$311 billion). Furthermore, costs of informal care- unpaid care eg., families and others- and the direct costs of social care- care professionals and in residential home settings- contribute similar proportions (42%) of total costs worldwide, while direct medical care costs are much lower (16%).

In another study, WHO (2012, p.2) reported that the cost of dementia in 2010, around US \$604 billion in the world and in North American countries and European countries was about 70% of the costs occurred. Moreover, the direct cost and informal costs of social care and medical care contributes in high income countries which remains very high than in low and middle income countries. Not only in EU and American countries dementia is rapidly increasing in Asian region as a huge burden on a growing army of carers, who are mainly family members (Parry & Weiyuan, 2011). In south Asia, for fifty years, the family has been a crucial part of mental health care program.

Due to the increasing suffering number of dementia in the worldwide, the costs of care of dementia patients have a huge economic burden on social and health care system. It was estimated that the world wide cost of dementia care may have US\$156 billion for 27.7 million demented persons in 2003 (Wimoa, Winblad, & Jönsson. 2007).

In another study Wimoa & Winblad (2006) found that in 2003 the demented number was 27.7 million (38%) in developed countries, (47%) in middle income countries and 5.2 million only in China. And accordingly, worldwide its cost was estimated around \$156.2 billion (92%) but the highest country was USA (\$48.6 billion). Similarly, Japan (\$24.7% billion), 25-EU regions (60.5 billion) and china was 2.5 billion in 2003. When the dementia prevalence rate is increasing annually accordingly the cost of dementia care also increase automatically. The same researcher was conducted another study to measure the dementia cost in 2009 was found the dementia rate was also increasing and the cost rate also was multiplying nearly 2 fold. Around \$422 billion (direct cost and informal cost) societal costs was found in the world. Again the highest cost was appeared in developed countries like North America, EU, Japan and China. Accordingly the cost was in United States (\$97 billion in base option, and \$133 billion if the higher figure of informal care is considered), Japan (\$45 billion) and China (41 billion). Although China has around 6.4 billion demented populations, no national plan to cope with AD and dementia. Similarly, there is not also a national plan in India with dementia issue (Rosowa, et al, 2011). Even though, a study shows that the dementia cost in India, ranged between INR 45,600 to INR 2, 02,450 in urban and INR 20,300 to INR 66,025 in rural areas (Rao & Bharath, 2013).

So all of these above data strongly suggest that the growth of the dementia disease will put particularly over pressure on the budget management of large developing countries like China and India. Additionally, the annually the worldwide cost per case is estimated \$12,200 with low cost in Africa (\$4400) (Wimo, Winblad & Jonsson, 2010).

A projected future cost of England by the King's Fund was in 2008, from £14.8 billion in 2007 to £34.8 billion in 2026, a rise of 135 percent. Among of them, 36 % the dementia cost was informal care cost in UK and care cost would rise to £50 billion by 2038 (Alzheimer society UK, 2012). Likewise, Alzheimer's society Canada projected the 70 percent woman are affected by Alzheimer's dementia and by 2040, dementia cost will around \$293 billion a year through Canada (Alzheimer's society Canada, 2015; Wimo et al, 2013).

## **2.15 Management of dementia**

The management goals of dementia in primary care are: to maintain the quality of life, maximize the daily function activities, endorse safety environment, promote the involvement of social engagement, enhance cognitive and behavior, to empower them to make own decision, plan for best possible care, further clinical management, to keep balance of antipsychotics long-term use and management of psycho-behavioural symptoms, treating pain, understating medical conditions, and risk factors of Alzheimer disease, Lewybody disease, Frontotemporal disease, Vascular disease and Parkinsons disease (BMJ Learning and Alzheimer society (2012); Foley et al., 2014).

The health professionals' (doctors and nurses) roles are versatile in the hospital to manage the patients' better health, health care setting, early diagnosis and interventions, collaboration and co-ordination with the other health professionals. Also, the advance technology settings in new health issues and their settings need to be integrated and adjusted. The community participation, fosters a safe environment, promote social engagement, carers services and best communication on dementia for elderly people also can help to the dementia patients. During this couple of decades of period there are vary emerged pathological diagnosis and management innovations for dementia and its related disorders (Alzheimer Association, 2015). Doctors, nurses and caregivers' are important for the long-term care placements and reduction of caregivers' difficulties and patients' behaviour problems in the hospitals (Yaffee,

et al., 2002). Formal care and management will provide by the nurse, doctors and paid care workers in hospitals. However there is lack of diagnosing, managing and caring with HPs (Alzheimer Association 2015; Nolan, 2007). Of southern Taiwan nurses on dementia care knowledge was found 10.8 (SD=2.0) poor. Most nurses showed confusion between dementia and delirium. In comparisons RNs with more working experience had higher dementia care knowledge rate. But both age and working experience were negatively associated with a reality-oriented approach toward care (Lin, Hsieh & Lin, 2012).

Patients with dementia often need special care and management either by the caregiver from family or nursing homes. Particularly, the behavioural and psychological problems of management is burden to the caregivers. A study identified the three management strategies like; encouragement, active management and criticism were associated with three aspects. These were; family member's emotional adjustment, psychiatric disorders and willingness to institutionalize the dementia patients (Hinrichsen & Niederehe, 1994). The active management and criticism was associated to the caregiver burden and less desire to the institution of the patients. A study (Corcoran, 1992) showed that male caregivers were more task oriented approach and oriented with the activities, while female were more concern with the nurturing and nest activities. It mean that both sex is necessary for management strategies of the dementia patients. The caregiver can predict burden issues and behaviour of patients and implement the interventions programmes aimed at adequate management strategies (Vugt et al., 2004).

The Management and carer support strategies for persons with dementia should have focus on foundation of initial stage of management, long-term management, follow-up and referral (as necessary) (Bridges-Webb, Wolk, and NSW Faculty, 2003).

- Treatment of co-morbidities
- Maintenance of function
- Dementia and disability

- Legal issues/ Decision making capacity
- Abuse and neglect
- Financial assistance
- Health promotion and Prevention
- Interventions to support the carer
- Behavioural management
- Service provision
- Impact of caring on sexual relationships
- Respite care

## **2.16 Dementia education, training and intervention**

Insufficient skills can increase the workload and burnout among HPs (Morgan, Semchuk, Stewart, & D'Arcy, 2002). Many studies have shown the lower knowledge of dementia issues with the RNs and doctors. That is the main factors to have misdiagnose and increase the prevalence rate (discussed in the above chapter).

In southern Taiwan, a questionnaire survey was revealed that the total mean score for Nurses on dementia care knowledge was 10.8 (SD= 2.0). Most nurses showed confusion on dementia with delirium. In comparisons, RNs with more working experience had higher dementia care knowledge rate. But both age and working experience were negatively associated with a reality-oriented approach toward care (Lin, Hsieh & Lin, 2012).

Globally the older population rate is growing, thus we can expect an increase in the numbers of people with dementia in the hospital. The findings of Fessey (2007) shows the knowledge, understanding and implications for care of adult nurses working with patients who present with dementia in general hospital wards concerns care gaps.

The rapid increase in the number of older people who need dementia care and the critical need for skilled care providers prompted Florida legislators to enact legislation to improve the care of these residents. One component of the new legislation mandated dementia training for long-term care staff and led to the development of dementia care competencies that would guide a competency-based curriculum to meet the demand for training. The competencies, methods used for development, and information regarding how to access these newly developed resources are described in this article (Nolan, 2007).

Caring for people with dementia presents a significant challenge in an acute hospital setting. Nolan, (2007) explored nurses' experiences of caring for older people with dementia people structural inadequacies of the acute hospital as a dementia care environment and the resultant challenges and complexities of the care experience. Despite this nurses considered the specific needs of people with dementia and the environmental effects of the acute setting on their ability to meet identified needs. (Ballantyne, Cheek, O'Brien, Pincombe, 1998) & (Zhang, Luk, Arthur & Wong, 2001) focused the need for the development of competency criteria that will be effective on care providing in working with the older adults and nursing competencies of knowledge, skills, traits, motives and attitudes that are essential for effective performance in a wide range of nursing activities.

Training is the way of helping people and health professionals to contribute for effective health services and to do things that they could not do before they were trained. Training can achieve an optimal level of quality. Skilled health professional are the main component to cater quality health services to the people.

Over 65's can occupy up to a quarter of hospital beds (The Royal College of Nursing 2013). Normally dementia patients may stay longer than other patients due to the chronic procedure. In general, patients tend to stay longer in hospital than patients without dementia. Training can be helpful to meet the specific needs with the specific work so it may improve

within own work setting, to face challenging and to get feedback with the concerned issue. These training might be a workshop, conference, and seminar for the health professional and community members to cope dementia.

The Royal College of Nursing (2013) reports that around a quarter of hospital beds are occupied by dementia patients. At the end of life, many people with dementia (two-thirds) spend time in the hospital and die in hospital. Even though, institutionalization is not the end-point of caregiver interventions. Researchers have shown that demented patients dying during hospital admission compared to similar people without dementia (Bryans & Wilcock, 2004). Likewise, people with dementia receive less palliative care compared with similar individuals without dementia therefore HPs need to be more aware of palliative care frameworks.

In the care settings, behavioral and psychological symptoms are highly prevalent and problematic in care settings (Spector, Orrell & Goyder, 2013). Both, hospital settings and primary care healthcare professionals (HPs) play a key role in the diagnosis of dementia. There is a need for better interventions to detect, prevent and ameliorate the impact of dementia. Dementia creates problems for HPs all over the world (Iliffe & Manthorpe, 2002), and presents a particular challenge for primary care providers (Iliffe, Walters & Rait, 2004) who do not adequately diagnosis it in the earlier stages of its cognitive impairment (Ambigaa, *et al.*, 2011). GPs are often in the first position to observe patients (Van Hout, Vernooij-Dassen & Stalman, 2007) but are not effective in diagnosing dementia (Pucci, *et al.*, 2004]. More than 50% cases are not diagnosed by the GPs in their practice (Boustani, *et al.*, 2003). Moreover, the global challenge of dementia is compounded by the fact that it is under diagnosed and undertreated in primary care across the underdeveloped world (Iliffe, *et al.*, 2012).

Dementia shows the problems for hospital staff like; a team of doctors, nurses, other staff and administration. However, not yet, any kind of special training have been received by the HPs. For example, the Alzheimer's Society UK (1995, 2003) indicates that 71% have

insufficient training in dementia management and poor awareness of the support services available for dementia. Further, nurses have more opportunities to support patients and families relative to physicians. When a person with dementia is living at home, nurses are often more aware of the support networks available and the care services on offer than the patient's GP (Alzheimer's Society UK, 1995, 2003). They may also have an integral role to play in maintaining channels of communication with other professionals involved in the provision of care and treatment, such as community psychiatric nurses, social workers and voluntary agency staff. GP colleagues, nurses feel insufficiently prepared to provide dementia management service (Bryans & Wilcock, 2004). Overall, HPs consistently cite inadequate professional training and as the main influencing factors to their ability to provide an optimal service to demented patients in many researches (Alzheimer's Society UK, 1995, 2003). However, as of yet, it is unknown what method of training would most beneficial for HPs. All the aforementioned is exacerbated by the fact that dementia can be present, but untreated in hospitals.

Perry, et al (2006) shows the improving knowledge, detection practices and management of dementia among health professionals. The present review builds upon a systematic review of educational interventions in primary care (Sampson, Blanchard, Tookman & King, 2009). That review identified only six studies and concluded that educational interventions for primary care that require active participation to improve detection of dementia. They showed on their systematic review moderate positive results was improved with the skills of dementia and management. Five articles reported at least some effects of the interventions and small group workshop and a decision support system (DSS) increased dementia detection rates. Likewise, a 2-hour interactive seminar was risen GPs' suspicion of dementia. Adherence to dementia guidelines only improved when an educational intervention was combined with the appointment of dementia care managers. This combined intervention also improved patients'

and caregivers' quality of life. The effects on knowledge and attitudes were showed minor that educational interventions alone did not seem to increase adherence to dementia guidelines.

Pathak et al (2014) finds that combined educational intervention program can improve to detect, manage and care of dementia patients in the hospital settings. Newly developed dementia knowledge guidelines for GPs/physicians can be used in improving the skills. Moreover, registered nurse (RN) and physician practice based workshops with community services, certain level of dementia care training, and decision based support system are more effective in managing and to decrease the negative attitudes of dementia care. That helps to link between care providers, community, dementia clinicians and caregivers. A comprehensive dementia care management model resulted in few differences in providers' knowledge or attitude.

A good quality of evidence with GPs and nurses intervention education and their multiple visits can increases skill of earlier dementia diagnoses, management and caring in the dementia patients. That helps to minimize cost and time for detection and management to the health professionals. So all the intervention need to address the effects of intervention however our findings suggest good quality intervention are essential to test the effectiveness and cost effectiveness to increase dementia detection rate (Mukadam, *et al.* 2014). Stephen, et al., (2004) explores in his study- one third (UK) GPs were felt lacking the appropriate epidemiological knowledge, management and caring aspects, behaviors changes, support services and little chance or offer to have demented patients in clinical practice.

The finding of Vickrey, et al., (2006) provides evidence that can improve in quality of care for patients with complex, chronic condition of disease by dementia guideline-based disease management program that led to improvement in quality of care for patients with dementia and helps for systems change, including use of care managers for achieving meaningful. And also the intervention can modify for institutionalized patients and for those

without a usual source of care and stable insurance (Vickrey, et al., 2006). Even though, after taking the intervention program with GPs suspicion of dementia detection rate was two-fold higher. Probably it may increase with age of patients and decrease with education status. However, with the GPs the intervention could not increase the number of diagnosed rate of dementia, but increased the number of suspected cases of correctly detecting demented patients (Rondeau, et al., 2008).

The collaboration between physicians and occupational therapists may lead to appropriate referrals service to the patients to the community services (Döpp, *et al.*, 2013). Alzheimer society UK had started in partnership with BMJ Learning, GPs and RNs to raise awareness via online regarding with diagnosis practices/management procedure, carriers relevant services, information on managing medication across the UK in 2012. That study found that only 37 percent of GPs felt they had sufficient basic training on dementia. Also, 71 per cent said they wished to find out more online training, while 75 percent wanted to know more about to manage symptoms of behavioral of dementia (Alzheimer society UK, 2012).

### **2.17 Dementia knowledge, attitude and practices with the HPs**

Sufficient knowledge of dementia among health care staff is essential to the quality of care delivered to this dementia. Such a universal skills like; medicine science, diagnosis, treatment and caring aspects. Diagnosing knowledge/skills remains the vital role with the doctors to understand what is wrong with the patients inwardly. On the other hand, correct treatment, proper referral to another doctors, communication skills, patients and care knowledge are most important.

There is still unanswered questions as to what types of knowledge can help health professionals (nursing, medical, allied health, and support in hospitals) and, how and what dementia-specific education or training and experience can develop the dementia related

knowledge these improve the diagnosing, caring, and managing rate to the patients. From now on, varieties of dementia knowledge assessment tools have been used. Among of them the oldest tools of Alzheimer's Disease Knowledge Test (ADKT) (Spector, Orrell, Schepers & Shanahan, 2012) most widely used, reliable to show good psychometric properties. Originally only used by its developers, two recently published articles have confirmed the utility of the ADKS in this context (Nordhus, Sivertsen & Pallesen, 2012; Hudson, Pollux, Mistry & Hobson, 2012). Assessing the level of dementia knowledge among health professionals is important to explore the fact of knowledge gaps and the effectiveness of a dementia knowledge education program for the overall skills to diagnose and management of dementia in the hospitals (Millard, Kennedy, Baune, Spector & Orrell, 2011).

Dementia presents a particular challenge for primary care providers (Illife, Walters & Rait, 2004), who do not adequately diagnose it in the earlier stages of its cognitive impairment (Ambigaa, Suthahar, Ramli, Radiah & Marymol, 2011). GPs are often in the first position to observe patients (Van Hout, Vernooij-Dassen, Stalman, 2007) but are not effective in diagnosing dementia (Pucci *et al*, 2004). Then after nurses considered the substantial roles. More than 50% of cases are not diagnosed by the GPs in their practice (Boustani, *et al*, 2003). This 'treatment gap' is in India around 90% unidentified (Dias & Patel). Alzheimer society UK in 2013, revealed a new figure of wide variation in people are receiving diagnosis (Hughes, 2013). In 2021, over half a million people will be living with dementia that has gone undiagnosed. In high income countries, only 20-50% of dementia cases are recognized and documented in primary care (World Alzheimer report, 2013).

Often patients expects from their GPs/nurses know the dementia diagnosis and management for their better health but the expectation may not always true (Millard, 2008). Nursing acute care in geriatric ward is often lack of specialized education and do not have appropriate environment to care the dementia patients. Also, they do have high work load and

creates burnout situations and rise mismanagement (Eriksson & saveman, 2002). It is already known in primary care diagnosis of dementia, early diagnosis and management of patients is often delayed with dementia and to improve patient care. An online survey, older experience GP responded more confident in diagnosing and giving advice about dementia early diagnosis was beneficial. Also it was little positive to improve quality of life although GPs had not had neither basic nor post-qualifying training in dementia. Therefore their knowledge was low (Orrell, Iliffe & Gracie, 2010).

However, yet, there is doubt about the value of training and useful in dementia care in U.K. nursing homes. One UK study found within 158 nurses increased person-centered attitudes was associated with better recognition of cognitive impairment independent of training and experience. The espousal of restrictive practices was also associated with better recognition, but only when analysis included nurses reporting on only one impaired resident (Macdonald & Woods, 2005).

In Australia residential aged care facilities dementia is growing due to its older age population ratio (Robinson, et al, 2014). Another Australian survey (N=360) conducted to measure the Knowledge of Alzheimer's disease with the diverse group (health service district staff) through mail on the basis of demographic categories, professional groups, and professional's or personal experience with dementia. The result was find out moderate level on medically-oriented, 'risk factors' and 'course of the disease (Smyth, 2013).

The findings Smyth et al, (2013) shows from the diverse group of health district staff, a generally moderate level (average of 79% correct) of dementia knowledge. Those medical, nursing, and allied health workers were in direct contact with the patients, showed higher levels of knowledge than administrative, housekeeping, security and transport staff in the supportive roles (Smyth, 2013).

A cross-sectional study with 249 nurses never used the diagnostic tools for acute delirium 57.80%. Those nurse were (80% -81%) involved in interventions of managing patients' physical environment and 62% and 71% deal with managing communication. Given theoretical training in the use of tools for nurses was confusing and significantly associated with nurses' knowledge and practices (Sampaio & Sequira, 2014). But in one study of participant's dementia care knowledge was poor 10.8 (SD=2.0) in Taiwan hospital nurse. Most nurses were confusion on dementia and delirium. However, in comparisons the RNs with more working experience had higher dementia care knowledge scores (Lin, Hsieh & Lin, 2012).

Nurses' care practices (with in 265 nurses) in internal medicine and geriatric wards of Israel hospitals showed greater attention to these patients care nurses' care practices are more connected with organizational characteristics than other factors (Lecovich & Rabin, 2014). In Korea, there is not norm to care long term in hospitals and culturally- it is considered the shameful for parents. Korean nurses' attitudes towards older people with dementia in acute care moderately positive attitudes. Two-thirds (n= 65, 65.7%) who were working in medical wards demonstrated significantly more positive attitudes than those working in surgical wards (n=34, 34.3%). However the working environment, routine and technology may influence the negative attitude towards dementia. So, education is essential to the nurses in dementia care that may reduce the potential of such conflicts (Kang, Moyle & Venturato, 2011).

A rural practitioners' (aged 31-67, mean age 50.5) experiences to recognition in diagnosis and treatment of dementia showed several to 1 months, from the nineteen primary care providers' team. Further, they showed the limitation of consultants and limitation of non-existent community support and education. That was the major impediments to diagnosis and treatment, respectively. Also, family members were absent, unaccommodating, and creator extra challenges for providers in proper making and communicating diagnoses and in supporting institutional care. Therefore, the providers believed that education services are more

important caregivers, although had few excess to offer the families and carers, which constrained their ability to provide optimal care (Teel, 2004).

However, a study (regression analysis) showed diagnostic rates and treatment of dementia was significantly increased from 2006-2012 per previous year. There was a lower rate in between 2006-2008 compared with 2009. The skill of HPs' dementia diagnosis rate increased by an estimated 4% in 2010 and 12% in 2011 compared with 2009. With the GPs, the prescription of anti-dementia drugs has been increased dramatically since 2010. Although there was a downtick in cost in 2012, not in the prescription ratio (Mukadam, Livingston, Rantell, Rickman, 2014).

### **3. General practitioners' knowledge, practices and obstacles in the diagnosis and management of dementia.**

#### **3.1 Introduction**

Dementia is a significant issue in the twenty-first century due to under detection and sub-optimal management in primary care (O'Connor, Ollitt, Hyde, Reiss, & Roth, 1998). It afflicts up to 7.5% of those above 65 years of age and presents multiple challenges for primary care. The fact that it is difficult to diagnose in the early stages complicates the issues for general practitioners (GPs) (Turner et al., 2004; Zahinoor, Tarek, & Kenneth, 2009) as the primary care team has a crucial role in the diagnosis and management of dementia (Brodaty et al., 2002; Murphy et al., 2014). Typically, GPs have a pivotal role in both the diagnosis of dementia and evaluation of the severity of the problem. However, research suggests that a substantial percentage of patients with cognitive signs and symptoms are missed by GPs (Brodaty, Kemp, & Low, 2004), and thus dementia remains under-diagnosed among the older population (Zahinoor et al., 2009). There is clear evidence (Beattie, Daker-White, Gilliard, & Means, 2004) that the early diagnosis of dementia benefits both health care professionals and carers. Early diagnosis enables individuals to gain better access to information, resources, and support; demystify and destigmatize the condition; benefit from treatments; plan for the future; and prepare family, friends, and colleagues for the changes that can be expected. However, some doctors may not be confident in their diagnosis in the early-onset period (Millard & Baune, 2009). Normally it takes up to one year to diagnose and, therefore, it is a frustrating process for physicians, patients, and their relatives to diagnose and manage.

Moreover, undetected dementia in younger people may be associated with work disability and an individual being (incorrectly) released from their job. To lose one's job at a young age due to dementia problems is a significant financial problem for the affected person

and his/her family members (Maslow, Langa, Kabeto, & Weir, 2004). There remain many barriers to identifying dementia, for example, the assessment and management of symptoms, health systems, and lack of available time for GPs, caregivers, and bereavement (Iliffe, Edeen, Downs, & Rae, 1999; Iliffe et al., 2002; Philips, Pond, & Goode, 2011; Sachs, Shega, Joseph, & Cox-Hayley, 2004). In addition, the complexity of dementia creates delays in diagnosis and is exacerbated by the following: lack of awareness that there are memory problems, difficulty distinguishing between normal age-related memory changes and dementia, fear or loss of independence, lack of skills among GPs to detect dementia due to overlapping signs and symptoms of age and psychiatric patients, and no specialist services (Foster, 2001; Phillips, Pond, Goode, 2011).

Globally, dementia is a huge economic burden (The Global Voice on Dementia, 2012) and is the fourth commonest cause of death among older people. Moreover, dementia is still not widely recognized as a chronic condition that can impact every sector of society, and there is a commonly held belief that dementia is the disease of older people (Harris, Analyst, Ho, & Verne, 2010). In 2010, the estimated cost of dementia worldwide was US\$604 billion. In addition, in EU and North America, informal care accounts for the majority of total costs, whereas direct social care costs are negligible (Wimo, Jeonson, Bond, Prince, & Winblad, 2013).

Nepal is a small, multi-ethnic, and multi-lingual (more than 68 languages) country. It is a low-income south-Asian country with a population of about 30 million of which over 2.2 million (8.3% of the population) are over 65 years, and this population is estimated to double in next 10 years (CBS-Nepal report, 2068). The demographic picture is one where the percentage of older people is growing faster than the total population. Life expectancy is 60.2 for females and 59.9 for males (World Health Organization (WHO), 2004). According to the WHO (2004), there are 18.82 hospital beds/100,000 population (Department of Health Services

(DoH, 2006), the proportion of the health budget to the GDP is 5.3%, and there are 4.9 GPs per 100,000 population (WHO, 2001). In terms of primary care, there are 268 physician-based primary health care clinics in the country (e.g., district hospital, primary health center, and health centers) and 3179 non-physicians-based primary health care clinics (DoH, 2006; WHO, 2001). In 1996, the Nepalese mental health policy was established on a formal basis. However, less than 1% of all health expenditure is directed towards mental health, and there is little investment in training for inpatient psychiatric unit staff (<2% for nurses and 2% doctors) and no community-based psychiatric inpatient facilities are available. All psychiatric issues, such as schizophrenia, neurotic disorders, anti-psychotic, antidepressant, mood stabilizer, anxiolytic, and antiepileptic cases, are diagnosed in the outpatient rooms in hospitals or in one of the central mental hospitals a total of 0.20 beds per 100,000 population (DoH, 2006).

In Nepal, the total number of doctors was estimated to be 14,372 in 2013, as reported by the Nepal Medical Association. A majority of doctors are involved in the capital city of the country, and there are over 1000 specialized doctors in different sectors. In addition, there is a trend for Nepalese health care professionals to go abroad. For the government, common and communicable disease is the biggest priority, with dementia being a less-prioritized health issue in hospital settings. There is a shortage of health care infrastructure in Nepal, and there are no long-term care facilities for dementia patients. Also, there are relatively few dementia specialist doctors and no routine examination system is available. Access to care is also an issue for individuals outside urban centers. Dementia in Nepal is regularly misdiagnosed as depression, memory loss, urinary infection, vitamin deficiency, and brain tumors.

In Nepal, there is virtually no awareness of the dementia problem among the public, professionals, and policymakers. Even if it is not recognized as dementia, the illness places a heavy burden on both older people and their relatives. It is estimated that currently about 135,000 people can be classified as exhibiting dementia in Nepal (Jha et al., 2013). This figure

is likely to double every 20 years. No published data are available on the number of dementia patients in Nepal. To date, no national surveys have been conducted to understand the physicians' knowledge/attitudes, practices, and obstacles to diagnose/management and care in Nepal.

In the current situation of Nepal, nursing care via community psychiatric/mental health units is a potential practical solution. GPs should be encouraged and aided in developing local collaborative models that maximize available professional and agency resources. There is a need for educational programs and health care policies that help to increase awareness of dementia in Nepalese nursing practice, management, and care. Failure to diagnose is linked to increasing patient numbers, a general misunderstanding of dementia, reduced access to health care services, and less caregiver support. Gulland (2012) reported that around 58% of people with dementia live in low- and middle-income countries. It is estimated that, by 2050, China, India, and Latin America will have the highest number of older people with dementia. The majority of developing countries do not have welfare systems and have given low priority to mental health and neurological issues, which tends to give the message that dementia is not a normal part of aging (Gulland, 2012). Dementia is a devastating situation in the present and creates huge financial, emotional, and physical challenges for families, nations, and society (Alzheimer's Association, 2013). The objective of the present research is to identify GPs' knowledge, practices, and obstacles with regard to the diagnosis and management of dementia.

### **3.2 Methods**

Using a purposive sampling approach, 420 questionnaires were distributed to 12 public hospitals in Kathmandu. Three hundred and eighty GPs responded (response rate 89%) and completed the self-report questionnaires. The 12 hospitals selected represented all the public hospitals in the Kathmandu area. The final sample represents 6.9% of the total sample of GPs

in Kathmandu. General practice is at an early stage of development in Nepal and all GPs are presently located in the hospital. Questionnaires were distributed and collected between July and September 2012. Questionnaires were in three parts: Part A addressed demographic questions and current practices in dementia, part B was a knowledge quiz, and part C collected background information. Respondents needed 15-20 minutes to complete the questionnaires.

Part A of questionnaire addressed the following issues: awareness of local support, dementia care and attitudes, current practices of dementia, difficulties, current diagnostic tools, management and caring process, common signs and symptoms, diagnostic confidence, and problems concerning diagnosis. Of part B, the dementia quiz covered the following issues: diagnosis, medication, epidemiology, and management. Dementia knowledge was measured by 14 multiple-choice questions (epidemiology part Q. 1-4, diagnosis part Q. 5-11, management part Q. 12-14), and there was a 'do not know' option on each question. The quiz included questions concerning the anatomy and physiology of dementia. Knowledge According to GPs factor some obstacle to diagnose or contributing to timely diagnosis and effective management and care of dementia are as follows about dementia was measured by 14 multiple-choice questions. These were designed to reflect the content of current and future prevalence, risk factors, diagnosis (including differential diagnosis), medication, and management. The quiz was adapted from two US instruments: the AUB Alzheimer's Disease Knowledge Test (six questions; Barrett et al., (1997) and the ADK Test (seven questions; Dieckmann et al., (1998) and utilized a scoring system of correct, don't know and wrong. Part C included open questions aimed at assessing the views, perceptions, and GP experiences of IT, professional seminars/training, use of MRI/CT, and the collaboration of specialist clinical practice with dementia.

Parts A, B, and C were adapted from Turner et al., (2004). These questionnaires were adapted for use in Nepal, and, where necessary, were adapted to reflect cultural and language

differences. The questionnaire format was similar to the approach of Turner et al. (2004). The questions were coded according to the Statistical Package for the Social Sciences, SPSS version 20. Our data analyses utilized frequencies, percentages, means, and standard deviations. We content analysed open questions and the results were summarized in a descriptive format. Prior to the research, ethical approval was provided by the Nepalese Health Research Council.

### **3.3 Results**

The first part of this section will address demography, major signs and symptoms of dementia, testing tools of dementia in current practice, confidence in making diagnosis and advising, difficulty experiencing, awareness of local services, GPs' attitudes to dementia care, confidence in advising on management of common problems, perceived barriers to good practice, knowledge updating, and ratings of knowledge about dementia. The second part reports the results of dementia quiz for practitioners and the third part covers general information from practitioners. Details are provided in Appendixes and tables of ours published journal on Ageing and mental health.

#### **3.3.1 Related symptoms of dementia**

Practitioners were requested to identify the four most important signs and symptoms related to dementia. Overall, 20 separate signs and symptoms were identified, and the most common causes were: (1) forgetfulness (25%), (2) cognitive problems (15.8%), (3) disorientation (9.2%), (4) Alzheimer symptoms (12.2%), (5) psychiatric symptoms (3.2%), (6) difficulty to communicate (10.8%), (7) memory loss (7.9%), (8) phobia (7.1%), and (9) mental disorders (7.1%). Beyond this, respondents also mentioned depression, disturbance to do daily work, impairment, anxiety, anomia, amnesia, aphasia, agnosia, apraxia, loss of hearing, vision problems, irritability, lethargy, and phobia.

### **3.3.2 Dementia diagnosis methods in current practice**

The diagnostic methods are not goldstandard for the GPs yet, however, we asked some commonly accepted methods how and what methods you (GP) apply to define the dementia in their daily practice, the tools that practitioners used to diagnose dementia in hospitals. The respondents were presented with 14 tools and were requested to answer 'yes', 'no', or 'do not know' on each item. There were: Ask about past mental illness, Ask carer about behavioral or personality changes, Test for depression, Check glucose, Arrange a chest X-ray, Check FBC, Check TSH, Arrange an ECG, Check calcium, Check renal function, Test for cognitive function, Check for functional loss, Check BP, Test urine for infection. Results showed that the most frequently used methods were to check for depression (364 (95.8%)), social function loss (357 (93.9%)), and cognitive loss (357 (93.9%)).

### **3.3.3 GPs' confidence concerning diagnosis/management**

The confidence of GPs with regard to diagnosis/management and advising of dementia patients and their family members was very low. One hundred and seventy-eight (46.8%) practitioners noted themselves as being somewhat confident towards the diagnosis process and 176 (46.3%) practitioners were somewhat confident about the advice regarding the management of dementia. Accordingly, 138 (36.3%) practitioners were a little confident and 38 (10.0%) practitioners were not at all confident. Overall, nearly half of the respondents (45.8%) rated themselves as either a little confident or not confident at all, and the overall mean confidence score was 2.4 and SD D 0.76.

Respondents were asked 'why' they were not confident and the following answers were reported: no proper instruments available, overload from patients, not specific to their clinical ward, few follow-up services, low priority of care for older people, system problems, diagnostic skills, poor awareness of its epidemiology, limited confidence/ experience in this field, overlapping features with the others neurological and psychiatric conditions, limited time,

reduced communication time, negative views of dementia by the family and society, less concern of early diagnosis practices, less acceptability of specialist and responsibility for extra issues, and barriers in specific diagnosis instruments and management.

### **3.3.4 Awareness of dementia care services**

Awareness is an important element and is related to levels of KAP (knowledge, attitudes, and practices). More than half of the respondents (200 (52.6%)) reported that they were unaware of any services in their local area, and only 78 (20.5%) respondents noted that they knew of patients' support groups in their areas, while 102 (26.8%) respondents answered 'don't know'. In the second question, the respondents were asked about their awareness of 'carer support groups' in their area. They replied as follows: 24 (6.3%) yes, 238 (62.6%) no, and 117 (30.8%) do not know. Two further questions asked about day care services and memory clinic services in their area. Accordingly, the answers were 30 (7.9%) yes, 218 (57.4%) no, and 132 (34.8%) do not know. In all four questions, the most frequent answer was 'NO'. This reveals that local supportive services for dementia patients are lacking and insufficient. The questionnaire were asked on the following aspects: 1) Information about old-age psychiatric services, 2) Protocol for assessment and investigation of patients with possible dementia. 3) Brief screening instrument for early identification, 4) Nurses with mental health training working in association with the practice, 5) Information about benefits (attendances) allowance, invalid carer's allowance 6) Information about support services for carers, 7) Information about social support services for people with dementia.

### **3.3.5 Obstacles to diagnosis, effective management and care dementia for GP.**

The diagnosis of dementia is problematic due to the fact that it can have overlapping symptoms with other conditions. The overall mean difficulty rating was 3.6 (SD. 1.5). Other obstacles to diagnose dementia were identified and are summarized in below table.

**Table 3.Obstacles to diagnosis or effective management and care dementia.**

<b>Patient factors.</b>	<b>Primary care doctor factors.</b>	<b>Care givers factors.</b>
Residence in backward community.	Lack of knowledge/skills/training and guidelines.	Younger age of caregivers.
Overlapping characteristics of dementia.	Probability of misdiagnosis.	Lower level of education and Knowledge of dementia.
The nature of personal behaviors(Extrovert/talkative or introvert/ shyness).	Lack of time to consult.	Lack of cognitive changes and normal ageing.
Family status(Married, unmarried, widow, single, and class of society).	Medication confusing and delaying to referral.	Limited treatment options.
Personal alertness.	Especialist access.	Limited knowledge of dementia, psychiatric, normal ageing.
Refusing further assessment.	Prioritize treatment of physical health problems.	Misuse of medication and follow up.
Patient's lack of insight.	Early diagnosis is a hangout for family and patients.	Delay referral.
Miss-understanding of end age life character.	Negative view of dementia to diagnose.	Denial to know the diagnosis of dementia.
Perception of limited treatment options.	Less concern about possible burden issue.	Low insure, value of diagnosis and treatment in time.
Less concern of treatment.	Desirability of early diagnosis.	Hesitation or fear of risk.
Denial of assessment or treatment.	Less prioritize to discuss cognitive problems.	Emotional, financial or other burden of diagnosis on the patient's autonomy.
Unwillingness, less confident, fear negative perception.	Avoidance of pressure from patients and caregivers for intervention.	Insecure feeling to address the dementia.
Less priority for dementia diagnosis and cognitive impairment.	Perception of limited treatment options.	Uneasy feelings to communicate.

Multi-cultural and language barriers.	Lack of standardized validated screening protocols.	Lack of Interpretation to physicians.
Forgetting to mention cognitive symptoms.	Uneasy or not feasible of practice.	Lack of physicians.
Fully determination on physicians to make diagnose.	Discomfort administering assessment.	Social value and norms towards caregivers.
Education Status.	Not to have familiar with the existing guide lines.	Lack of experts caregivers.
Money, transportation.	Less access to MRI and CT.	Lack of health services knowledge.
Social access of patients.	Less communication between physicians, patients and caregivers.	
Lack of financial support.	Difficult to discuss with patients, family and their caregivers.	
Lack of prioritizing in public health.	Socio-cultural and language biases.	
Waiting list for appointment and missed appointments.	Discrimination in care and time.	

### 3.3.6 Diagnostic difficulties and care.

Primary care doctors perceived some difficulty in their delaying to providing diagnosis and care for people with dementia as well as with their carers. Details in below table no. 7. To diagnose dementia is insecure due to its insidious and its overlapping symptoms as well as other barriers with the patients. The overall mean difficult rating was 3.6(SD=1.5). These difficulties scores were means on a score of 1-7(1= not at all difficult- 7 very difficult) and the highest respondents participator was 375 out of 380.

**Table no. 4. Diagnostic difficulties and care**

No	Items	Mean	SD	N
1	Establishing a diagnosis.	3.1	1.1	368
2	Telling the patient the diagnosis.	3.3	1.3	375
3	Telling the family the diagnosis.	3.5	1.4	372
4	Responding to the family's concerns.	3.5	1.6	367
5	Responding to co-existing behavior problems.	3.6	1.5	372
6	Responding to any psychiatric problems	3.5	1.6	369
7	Coordinating support services for carers	3.5	1.5	361
8	Getting specialist assessment services	3.5	1.5	361
9	Getting information about anti-dementia (cognitive enhancing) medication	3.4	1.6	363
10	Getting information about support services for carers & people with dementia.	3.5	1.5	360

**3.3.7 Barriers to good practice in dementia care**

The dementia care practices barriers was measured on the following aspects to the GPs and summerised in the below table.

**Table 5. Barriers to good practice in dementia care (ranked) below.**

No	Items	Prevents	Does not	Canot say
1	Too busy/not enough time during surgery visits	149(39.2%)	184(48.4%)	379
2	Unfamiliar with advances in the management of dementia related symptoms	180(47.4%)	169(44.5%)	379
3	Unfamiliar with available services to help keep patients at home	211(55.5%)	139(36.6%)	376

4	Unsure how to refer patients to available services to help keep	232(61.1%)	126(33.2%)	380
5	Lack of team/staff in the practice	235(61.8%)	121(31.8%)	379
6	Lack of funding within the with the practice.	232(61.1%)	122(32.1%)	379
7	Lack of social service support available to practice	243(63.9%)	107(28.2%)	379

### 3.3.8 Attitudes of primary care doctors with the dementia care

This research reports, in Nepal, the Primary care Doctors' attitudes to care and management of dementia is in poor condition. Whilst majorities were agree to improve the life style of patients and carers' life. More than a third realized that diagnosis of dementia is long process so it more frustrating than rewarding in their practices. Responses varied considerably between items, with no evidence of a making set for a neutral answer, which ranged from 29.5% -38.7%. Which is shown in given in table in detail.

**Table 6. General practitioners' attitudes to dementia care (ranked by level of agreement)**

No	Item	Strongly agree	Agree	Neither agree nor disagree	Strongly disagree	Donot know
1	Providing diagnosis more helpful than harmful	53(13.9%)	151(39.7%)	129(33.9%)	24(6.3%)	7(1.8%)
2	Managing dementia is more often frustrating than rewarding	25(6.6%)	184(48.4%)	112(29.5%)	28(7.4%)	18(4.7%)
3	Much can be done to improve the quality of life carers of people with dementia	30(7.9%)	54(40.5%)	141(37.1%)	38(10%)	10(2.6%)
4	Dementia is best diagnosed by	35(9.2%)	137(36.1%)	139(36.6%)	43(11.3%)	15(3.9%)

	specialist services rather than primary care team					
5	It is better to talk in euphemistic terms when discussing the condition with someone with dementia with dementia	33(8.7%)	131(34.5%)	129(33.9%)	57(15.0%)	12(3.2%)
6	Families would rather be told about their relative's dementia as soon as possible	40(10.5%)	126(33.2%)	134(35.3%)	50(13.2%)	13(3.4%)
7	Patients with dementia can be a drain on resource with positive outcome.	31(8.2%)	117(30.8%)	137(36.1%)	54(14.2%)	17(4.5%)
8	There is little point in referring families to services as they do not want to use them	34(8.9%)	108(28.4%)	147(38.7%)	50(13.2%)	17(4.5%)
9	Much can be done to improve The quality of life carers of People with dementia	42(11.1%)	127(33.4%)	140(36.8%)	39(10.3%)	12(3.2%)
10.	The primary care team has a very limited role to play in the ongoing care of people with dementia	31(8.2%)	126(33.2%)	146(38.4%)	37(9.7%)	27(7.1%)

### 3.3.9 General information of dementia with the practitioners

The third part of the research assessed special issues for practitioners such as access to IT and the regulation of specialist clinical practice. GPs tended to obtain information from web pages, books, and textbooks. The lowest information source reported was from seminars and

professional bodies, e.g., Royal College of General Practitioners (RCGP) update. Both access to computers 157 (41.3%) and access in relation to specialist clinical service suggests that Nepalese GPs are not updating their knowledge in relation to dementia.

### **3.4 Discussion**

The study reveals that Nepalese GPs' knowledge, practices and obstacles about dementia diagnosis, management, and care are poor. To the knowledge of the authors, this is the first data on these issues from Nepal. The lack of knowledge of GPs means that future efforts to estimate the number of dementia patients in Nepal are seriously hampered. In addition, we have no information on the level of misdiagnosis. While dementia is an ongoing issue in Nepal, the situation has deteriorated in recent years due to following reasons: (1) a larger older population; (2) misdiagnosis and misunderstanding towards older people with regard to dementia; (3) disintegration of the family unit with younger family members migrating to foreign countries, which leads to increased pressure on older people to manage themselves. In Nepal, there are no specialized centers to diagnose dementia. Psychiatric/mental hospitals and nursing homes are the only practical solution available at present. It is time for stakeholders to invest resources in planning the integration of mental health services designed for older people. The results of the study suggest that the challenges for Nepal are still significant. This study reveals difficulties or obstacles in three key areas: GP-related factors, patients' experience, and carer support (Alzheimer's Association, 2013; Batsch and Mittelman, 2012; Iliffe, et al., 2004; Iliffe et al., 2002; Philips et al., 2011; Travers, Martin-khan, & Lie, 2009; Turner et al., 2004; World Alzheimer Report, 2012). Moreover, the data reveal that the management and care is rated as less important than diagnosis. In general, health professionals do not consider dementia to be an issue for younger patients, and thus the diagnosis is missed at an early point. This is a lost

opportunity as dementia can negatively impact on the professional life and working experience of individuals (Maslow et al., 2004).

Our study indicates that the overall knowledge of dementia among Nepalese GPs is poor. Our results are similar to research from the UK (Turner et al., 2004), where only one-third of GPs demonstrated confidence in their diagnostic skills, while two-thirds lacked confidence in the management of behavior and other problems in dementia. Van Hout (1999), in a review of seven studies regarding the ability of GPs to recognize dementia, found that they performed only moderately well in the management of different aspects. In addition, an Irish study (Cahill et al., 2008) revealed that more than one-third (35%) of practitioners identified late presentation as a key factor. Furthermore, they reported that other factors that contributed to delay were lack of time, confidence, lack of current education of dementia, lack of time with screening symptoms, lack of specific training, low concern for early diagnosis, confusing symptoms, embarrassment, and false-positive/false-negative problems. Moreover, medication efficacy is another important issue for GPs (Olafsdottir, Foldevi, & Marcusson, 2001). There is no gold standard regarding the best way to disclose the diagnosis of dementia, but groups such as the Alzheimer's Association encourage physicians to disclose the diagnosis directly to their patients, discuss the dilemmas that arise, and share successful strategies (Connell, Walter, Kunz, & Homless, 1999). People with dementias and related disorders need long-term care services, but neither the government nor any social welfare legislation in Nepal supports patients.

Our results suggest that educational interventions for clinicians, nurses, and health workers should focus particularly on KAP issues (Downs et al., 2006). Research indicates that GPs often confuse a diagnosis which contributes to false-positive and false-negative situations (Pucci et al., 2003). In our study, one-third of our sample believes that the diagnostic aspect of dementia should be the responsibility of a specialist. Overall, our results indicate that the

situation in Nepal can only be ameliorated by increased awareness at the community level, better training for health professionals, a greater emphasis on early detection, easier access to information, better access to care, and the development of community networks between health care professionals and families.

### **3.5 Limitations**

Our response rate was high, but we cannot generalize our findings outside of Nepal. Our research did not include observational research in clinical practice, which would have provided extra data on clinical practices. Our research focused on public hospitals, and the situation may be different in private hospitals. Finally, one of our reviewers suggested that, given the limited service infrastructure for supporting people with dementia, asking clinicians to complete questionnaires developed in the West raises a whole set of issues that it is entirely reasonable to say ‘no’ to. Therefore, a ‘no’ in Nepal may be a different context compared to UK or US samples.

### **3.6 Conclusions**

Nepalese primary care practitioners need to have specific dementia assessment tools/guidelines for better diagnosis and management. Primary care practitioners have a crucial part to play in diagnosing, monitoring and providing long term support for the dementia patients. In this regard, especially in Nepal, they need to work more closely with the caregivers, geriatricians, neurologists, social workers, NGO/INGOs; allied health teams the Alzheimer Association of Nepal and psychiatric hospital. Many of the aforementioned issues can be addressed via, their professional educational development. More priority needs to be focused towards; quality development, research and planning, active care, improving collaboration with professional doctors and medical follow up, understanding and responding to behavior changes, care and management with screening instruments.

Dementia is the future crisis of the world. However, to date, no clear treatment exists for dementia patients. Efforts in Nepal need to be directed towards improving financial support, community support, family support, establishing day care home services, memory clinic services with geriatric services, a separate department of dementia in the hospital and in the community. Improvements in dementia knowledge and self-confidence for using the guidelines should lead to an improvement in service delivery in Nepal.

### **3.7 Key points**

1- Educational support programs are needed to improve GPs knowledge and confidence with regard to the diagnosis and management.

2- There is an urgent need to develop a more systematic approach from GPs and a central register of residential and nursing home facilities.

3- GPs should be responding to dementia issues and be encouraged to engage in open communication with their patients. Existing home care, community care, and medical care programs may be the best option for early-onset individuals.

4- GPs need to collaborate more with geriatric specialists, psychologists, neurologists, and caregivers. The wider use of screening instruments is a good first step.

## **4. Medical Specialists and dementia: Clinical practice and difficulties in diagnosis, management and care**

### **4.1 Background**

Dementia is a progressive disease affecting various higher cortical functions that can result in physical dependency (Azermai *et al.*, 2013). Dementia can vary from single individual to another but over longer periods it makes the person more disabled (Alzheimer's Society, 2004; Ruitenberg *et al.*, 2001) and challenges for primary care to detect for both caregivers and general practitioner and multidisciplinary team in their practice. It is a rapidly increasing public health issue all over the world that is under recognized in primary care settings (Sagar *et al.*, 2006). The rate of under diagnosed dementia is 65 percent by the physicians in community. Furthermore, physicians do miss opportunities for the application of available treatments, participation in research advances, care planning and the support of caregivers (Chopra *et al.*, 2007). Therefore, dementia and related disorder, disease pose a substantial public health topic. Besides, it requires longer duration to diagnose due to its vague signs and symptoms and slowly it is starting to be a future crisis. It is calculated that the number of people with dementia will double every 20 years to 81.1 million by 2040 (Alzheimer's Society, 2003; Alzheimers Association, 2013).

In current practice, the final decision as to when dementia is present is the responsibility of the neurologist. The neurologist should collaborate with multidisciplinary team in primary care and ease the growth of multi-disciplinary teams for appropriate diagnosis (Waldemer *et al.*, 2000).

Iliffe *et al.*, (1994) finds that to screen the dementia the mini-mental state examination is important test due to its relatively good reliability and validity in comparison with other scales. Generally in the clinical practice the mini-mental test (Folstein, Folstein & Haugh, 1975) clock

drawing test (verbal) 1-4 minute, GPCOG (verbal 4-5) minute & minute screen (verbal-7 minute) memory impairment screen (verbal minute), mini cog (verbal 2-4-5 minute) are frequently using to assess the dementia (Brodaty, Low, Gibson & Burns, 2006). Still, the screening skills depend on HPs' confidence, experiences and knowledge (Brodaty, Low, Gobson & Burns, 2004).

Globally the prevalence rate of dementia is increasing in tandem with increasing age and moves approximately 5-8 percent of individuals over age 65, 15-25 percent of people over age 75 percent and about 15-50 percent of people over age 85 (Chopra, Cavalieri, and Lisbon, 2007). Likewise, in the Nepalese context the proportion of older people with dementia is increasing. The WHO (2012) has calculated that approximately 135,000 people would be aching from some variety of dementia in Nepal. It stands for that dementia rate is turning but the Nepalese medical community is not ready to tackle, however. The multidisciplinary team plays a substantial part in acute hospital, outpatient clinic, residential setting, home and the wider community) in the management and care of older people by extending support to patients, households and helping to adapt treatment plans, patients and family educations (pre and post hospital), delirium of end age life (Tanaka, 2003). Nevertheless, there are gaps between recommended current practices.

## **4.2 Methods**

### **4.2.1 Study site and sampling process**

This survey was conducted in united mission hospital, where 90 percent is working full-time. This hospital is oldest one that was first established before 50 years. Twenty nine were working (including trainees) and 10 mission appointees from six different countries, who work mostly as senior physicians in a teaching role, or in other support roles, at the movement. A purposive sampling approach identified 18 multidisciplinary medical specialists GP-2,

neurologist-2, paediatrics-2, cardiologist-2 gynaecologist-2, orthopaedic-2, dentist-2, otorhinolaryngologist-2, psychiatrist-2. Questionnaires were given a self-completed structured with multiple choice items in English version. Approximately 70% the patients who attend the hospital come from the surrounding nine districts, Western Nepal, and from nearby components of north India and total bed capacity is 165.

#### **4.2.2 Design**

A purposive sampling method was applied and it was taken after the seeking permission using self-filled out questionnaires (English edition). All these questions were both administered and picked up by the hospital manager and it was compiled after the information by the same manager

#### **4.2.3 Measurement**

The questionnaires covered demographic questions and a dementia quiz: diagnosis, medicine, epidemiology, and management. It was on multiple choice items for each question as easily as in the aspect of dementia quiz there was “do not know” option on the interrogations. In the first section of the questionnaire; awareness of local living, dementia care, trust and attitudes, current practices of dementia, difficulties, current diagnostic tools, management and caring process, common signs and symptoms, diagnostic confidence, diagnostic facing problems was assessed with 40 questions and in the second part: dementia knowledge was assessed with 21 inquiries. These questions included questions pertaining to the anatomy and physiology of dementia, medication effects and its efficacy, perceived difficulties and some remaining questions were open typed to measure their, perception and their experiences in the dementia.

#### **4.2.4 Data analysis**

The questionnaire format was similar with Turner's *et al.*, (2004). These questions were coded according to the Statistical Package for the Social Sciences, SPSS version 20. Our data information was used frequencies information with percentages, mean, and standard deviation and we summarized open type of answer manually in a descriptive manner and analyzed with other associated workplace.

### **4.3 Results**

#### **4.3.1 Demographic characteristics of subjects**

Overall 18 multidisciplinary doctors' data were collected on the basis of their response and analyzed. The practice confidence, management difficulties to diagnose, diagnostic place, covering instruments, sources of dementia updating knowledge and its treatment procedure was evaluated by the multidisciplinary doctors in the hospital. These respondents' minimum age was 28 and maximum 52 (mean age 39.10/ S.D.7.26). 50% of respondents were women. The majority experts (12) of specialists were educated outside of Nepal; European Union 2(11.1%), Asia 4(22.2%), Africa 1(5.6%), Nepal 6(33.3%), Australia 1(5.65), Russia 1(5.6%), China 2(11.1%), USA 1(5.65) and among of them 6 were foreigner specialist from UK, Australia, Africa, USA, Germany and China, who were working in that hospital continuously.

More than eighty percent were full time. At that place was no geriatric services or dementia specialist in the hospital settings even though they could handle up to 13 suspected patients in a specific month. The continuance of the detection of dementia was 1-3 months for the suspected dementia patients. Overall 18 specialist doctors' overall knowledge was really poor (Mean 12.83, SD= 2.8). It suggests that dementia is very poorly focused disease than other types of disease in the infirmaries.

### 4.3.2 Current diagnosis practices to the suspected dementia patients by the Multi-specialist doctors

The majority of the doctors 15 (83.3%) reported asking about the mental history at first around their clinical diagnosis process, then systemic illness: Cancer, Connective tissue 15 (83.3%), Trauma 12 (66.7%), Check renal function 13 (72.2%), Check glucose 12 (66.7%) See below table for detail.

**Table 7. Current diagnosis practices to the suspected dementia patients by the Multi-specialist doctors.**

Items	Yes	No
Check for functional loss	11(16.7%)	3(16.7%)
Ask about past mental illnesses	15(83.3%)	2(17.7%)
Arrange a chest X-ray	7(38.9%)	11(61.1%)
Check BP, B12 levels	10(55.6%)	27(38.9%)
Check liver function	5(27.8%)	11(61.1%)
Check endocrine gland.	7(38.9%)	9(50.0%)
Arrange an ECG	8(44.4%)	8(44.4%)
Check calcium	6(33.3%)	9(50%)
Check glucose	12(66.7%)	3(16.7%)
Check renal function	13(72.2%)	3(16.7%)
Check memory impairment	13(72.2%)	4(22.2%)
Depression test	10(55.6%)	4(22.2%)
Test urine infection	12(66.7%)	3(16.7%)
Ask behavioural/ personality changes with carer	14(77.8%)	2(11.1%)
Thyroid test	10(55.6%)	6(33.3%)
Screening syphilis	11(61.1%)	3(16.1%)
Psychiatric disease test	11(61.1%)	2(11.1%)
Trauma	12(66.7%)	3(16.7%)
Systemic illness: cancer, connective tissue	15(83.3%)	3(16.7%)

### **4.3.3 Awareness of local avails**

In respect to awareness of day care services in fifty percent knew there were day care services in the country, and with regard to memory clinics”13 (72.2%) stated “no knowledge similarly, 7 (38.9%) respondents said “no” carer support group of living area. They could call the local dementia support organizations like; day care services for elderly, but a few 6 (33.3%) were able to name of the places where that is situated to refer the patients. Besides, they were unsure as to the availability or access to dementia medicine medicine in the mart. This outcome reflects the dementia care is still in the shadows in hospital scenes.

### **4.3.4 Confidence in making diagnosis dementia**

Almost thirty-nine percent (38.9) were confident to prescribe medicine to suspected dementia patients themselves. Respondents were not convinced to recommend medication at the time of diagnosis (Wilkinson, Stave, Keohane & Vincenzino, 2008). The overall score reflects low confidence in the dementia diagnosis with the specialist professionals.

### **4.3.5 Aspects of the difficulties of dementia care**

Respondents difficulty with “creating a diagnosis” particularly in the early phases. They also reported difficulties with the following; establishing a diagnosis 13(72.2%), telling the patient the diagnosis 8(44.4%), telling the family the diagnosis 8 (44.4%), responding to the family's concerns 8(44.4%), getting information about anti-dementia (cognitive enhancing) medications 7(38.9%). The open question revealed other barriers; like not having clinical research, the complexity of biological and psychological disorders, the ethical nature of the condition, limited training, neglect of the diseases of older people etc (Faranak *et al.*, 2012; Greta, Kate, Illiffe, 1999). See below table.

**Table 8. Aspects of the difficulties of dementia care.**

<b>Items</b>	<b>Not at all difficult</b>	<b>Extremely difficult</b>	<b>Don't know</b>	<b>Mean/SD</b>
Establishing a diagnosis	13(72.2%)	1(5.6%)	4(22.2%)	2.6/2.9
Telling the patient the diagnosis	8(44.4%)	6(33.3%)	4(22.2%)	2.8/2.9
Telling the family the diagnosis	8 (44.4%)	6(33.3%)	4(22.2%)	2.8/2.8
Responding to the family's concerns	8 (44.4%)	8 (44.4%)	2(11.2%)	2.2/2.1
Responding to co-existing behaviour problems	6(33.3%)	8 (44.4%)	2(11.2%)	2.3/2.4
Responding to any psychiatric problems	5(27.8%)	8 (44.4%)	5(27.8 %)	3.3/2.9
Co-ordinating support services for carers and people with dementia	2(11.1%)	11(61.11%)	5(27.8%)	3.5/2.8
Getting specialist assessment services	1(5.6%)	13(72.2%)	3(16.7%)	3.0/2.3
Getting information about anti-dementia (Cognitive enhancing) medications	7(38.9%)	7(38.9%)	3(16.7%)	2.6/2.5
Getting information about support services for carers and people with dementia	2(11.1%)	10(55.6%)	6(33.35%)	4.2/3.0

#### **4.3.6 Attitudes to dementia care (ranked on scale of agreement)**

The data exposed the bulk of respondents thought that dementia diagnosis is more frustrating issue than rewarding and felt that a diagnostic issue is not just with the general practitioners. Respondents reported a five categories for each instruction. Eventually, all practitioners were required to rank their own ability with respect to dementia diagnosis and management on a scale of “strongly agree” to “Cannot say” option about their experience in caring for dementia patients. They strongly agree that the families can play an important part in early testing and the management of dementia. See below table for more detail.

**Table 9. Multi experts' attitudes to dementia care (ranked on scale of agreement).**

No	items	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Can not say
1	Providing a patient with a diagnosis is usually more helpful than harmful	10(55.6%)	6(33.3%)	.....	.....	.....	2(11.2%)
2	Managing dementia is more often frustrating than rewarding	5(27.8%)	3(16.7%)	4(22.2%)	2(11.1%)	2(11.1%)	2(11.1%)
3	Much can be done to improve the quality of life for people with dementia	9(50%)	8(44.4%)	.....	1(5.6%)	.....	.....
4	Dementia is best diagnosed by specialist services rather than by the	4(22.2%)	2(11.15)	.....	2(11.1%)	10(55.6%)	.....

	primary care team						
5	It's better to talk in euphemistic terms when discussing the condition with someone with dementia	4(22.2%)	.....	.....	9(50%)	4(22.2%)	1(5.6%)
6	Families would rather be told about their relative's dementia as early as possible	10((56.6%)	2(11.1%)	2(11.1%)	.....	.....	2(11.1%)
7	The primary care team has a very limited role to play in the ongoing care of people with dementia	2(11.1%)	2(11.1%)	.....	.....	7(38.9%)	7(38.9%)
8	Much can be done to improve the quality of life of carers of people	7(38.9%)	7(38.9%)	.....	1(5.6%)	.....	3(16.7%)

	with dementia						
9	Patients with dementia can be a drain on resources with little positive outcome.	2(11.1%)	5(27.8%)	7(38.9%)	1(5.6%)	.....	3(16.7%)
10	There is little point in referring families to services as they don't want to use them	3(16.7%)	1(5.6%),	4(22.2%)	5(27.8%)	5(27.8%)	5(27.8%)

*Note: the blank means in the table is unanswered.*

#### **4.3.7 Common sign and symptoms of dementia**

A bulk of respondents reported that dementia is an umbrella term, so there is no specific sign and symptom to determine that patients have definitely dementia problem. There was asked to choose between 18 symptoms of dementia. Nevertheless, the most usual signs and symptoms identified was forgetfulness. Followed by, memory loss, social skill loss and difficulty to acknowledge others and behavior disorder. The specialist professionals reported at least 10 warning symptoms which are the most basics characteristics to identify dementia ; loss of interest in daily activities 8(44.4%), loss of interest in social activities6(33.3), loss initiative 12(66.7%), memory loss 17 (94.4%), phobias 8(44.4%), Difficulty performing familiar task 7(38.9%), Recurring thoughts of death or suicide 18(0%), social skills loss 16(88.9%), change in appetite 6(33.3%), low self-esteem 8(44.4%), difficulty to recognize

others 13(72.2%), Conduct disorder 10(55.6%), forgetfulness 18(100%), fatigue 3(16.7%), problems with language 9(50%), disorientation with time and date 11(61.1%), poor or decreased judgment 5(27.8%), Depression anxiety 6(33.3%). Above mentioned warning signs help to recognize at first stage of dementia for doctors (National institute in ageing, 2014; Hyman *et al.*, 2012; Alzheimer Association 2013).

#### 4.3.8 Barriers to good practice in dementia for the doctors

Table 12 shows reports the barriers to good practice. Most barriers related to insecurity concerning the referral of patients, lack of team staff in the practice, unfamiliarity with available services to help keep them at home and lack of financing for further treatments. Others are given below in table in detail.

**Table 10. Barriers to good practice in dementia care.**

No	Items	Yes prevents	No doesnot	Donot know
1	Too busy: not enough time during surgery visit	11(61.1%)	5(27.8%)	2(11.15)
2	Unfamiliar with advances in the management of dementia-related symptoms	8(44.4%)	10(55.6%)	
3	Unfamiliar with available services to help keep them at home	12(66.7%)	1(5.6%)	5(27.8%)
4	Unsure how to refer patients to available services to help keep them at home	15(83.3%)	1(5.6%)	2(11.1%)
5	Lack of team staff in the practice	13(72.2%)	4(22.2%)	1(5.5%)
6	Lack of funding within the practice	10(55.6%)	7(38.9%)	1(5.6%)
7	Lack of Social Service support available to the practice	6(33.3%)	10(55.6%)	2(11.1%)

#### **4.3.9 Experiences on current practices regarding with dementia**

There was most common agreement with all specialist doctors that dementia diagnosis is a less prioritized problem in Nepal than other public health issues, and that no adequate facility for screening dementia is available in hospitals. Moreover, hospitals do not have dementia care centers, dementia specialists, or specialist nurses.

#### **4.3.10 Open ended responses**

The open question provided valuable comments/perceptions with regard to drug treatment (Donepezil, Glantamine, Memantamine, Rivastigmine etc), diagnosis process/guideline, perceptions of satisfaction, further recommendations, education issues (internet, web, journal) and general advice. One third of respondents reported that less access with the internet and MRI, CT to confirm dementia diagnoses. This result was similar with the Chew et al (2004) with (Chew et al., study. This figure is low compared to internet access in both North America 60-70% (Masters, 2004) and Norway 72% (Nylenna, 1999). The respondents reported a desire to be updated on neuro-degenerative disorders and dementia, a desire to cooperation and coordination with patients, caregivers and their loved one, multi-discipline working teams, further treatment and investigation and wanting to have access with CT/MRI as well. Our result and Iris, (2000) result was matching in regarding with the use of access CT/MRI. Efforts in Nepal need to be directed towards improving financial support, community support, family support, establishing day care home services, memory clinic services with geriatric services, a separate department of dementia in the hospital and in the community. Improvements in dementia knowledge and self-confidence for management and care should lead to an improvement in service delivery in Nepalese hospital and research is substantive.

#### 4.4 Discussion

The purpose of this survey was to evaluate the clinical practices, ongoing management and care difficulties of medical specialists with respect to dementia. Specialists diagnosed more as false-positives and false-negatives (on average) and the of respondents reported a desire to take dementia specialist training for better diagnoses respondents were get used in keeping the update of MRI/CT/SCAN services to diagnosis dementia. Among of them none get 4(22.2%) were non-user and 14(77.8%) were played with it. Further they noted that due to the less access of MRI/CT scan of brain in time, was taken long duration to determine dementia properly.

In the Nepalese context, dementia has been a less prioritized public health problem than others diseases. It is a complex disease and its management and care path is quite challenging for patients, family and society as like Monterial, Quebec (Gold, Reis, Markiewicz, Andres, 1995). The overall knowledge mean (12.83/SD 2.89) was poor with the 18 experts in the overall dementia quiz.

A European study revealed that there was not any systematic registration system of patients in the hospitals as should be the current practice (Myrra *et al.*, 2005). Yet, these states were more concerned to control the dementia issues and to launch a friendly dementia society in the hospitals than a Nepalese health care hospital. Typically, in Nepal dementia patients visit a primary care unit and the detection duration had up to 1-3 months for suspected patients. So, it means that dementia is not easy to detect in a short time and takes time for confirmation. Referral process and multi-discipline work in the diagnosis often depends on the health care system of that county policy (Illiffe *et al.*, 2005).

In terms of diagnosis confidence, most experts indicated that they were somewhat confident 7 (38.9%) to detect the dementia in their practice. Further we examined the

knowledge of anti-dementia drug's effects and its utility with the experts and drew that nearly 7(38.9%) know about it. It expresses that need of special training to the health professional to address the diagnosis and management and information about local services Irish research reveals (Cahill, et al, 2006) that only 19% often or always disclosed to the diagnosed patient and (90%) GPs had never undergone any specific dementia training.

Lepeleire *et al.*, (2008) suggest the diagnostic process should be early rather than late with the appropriate guidelines. This can help to identify the difficulties to diagnose and how one should manage patients (Turner *et al.*, 2006) . Such a finding is consistent with the results of our study. Also, we found, the general concept of dementia is not considered in a positive way. Interestingly, the bulk of medical experts is not concerned to conduct a cognitive assessment/ screening of their the patients (Murphy et al., 2014).Our limitations relate to our reliance on self-report as we conducted no observational research in clinical practice. Also, our results represents a relatively small sample of medical specialists.

#### **4.5 Conclusions**

Overall, the findings indicate the specialist group find dementia a challenging/complex disease due to its multiple variables, characteristics and the longevity of the diagnostic process. Second, early diagnosis, collaboration with multi specialist doctors (Azermi, 2013) appropriate referral pathways, diagnostic guideline and refined MMSE tools (Boustani, et al, 2003) would help to improve services. The burden impact of dementia prevalence has been underestimated in developing countries in African and Asian regions (Nepal) and the burden will shift more to poorer countries. Finally, dementia should be a public health priority.

#### **4.6 Key points**

1. The burden and impact of dementia has been underestimated in developing countries. The global burden will soon shift to the poorer countries of world.
2. GPs are the gatekeepers for the early signs of dementia, but they need to collaborate closely with multi-expert teams. In order to promote better management and care of dementia a national dementia plan in Nepal is needed.

#### **4.7 Limitations**

We have limited ability to generalize this findings to all the multidisciplinary doctors of Nepal. However, the first step could be to find out the dementia diagnosis, management and care in the hospital settings. Later on the research should be focused on treatment efficacy, other aspects of the clinical process and the management/care in the hospitals.

## **5. Dementia Care and Management in Hospitals: Knowledge, Barriers and Practices of Nurses**

### **5.1 Background of the Study**

Dementia creates a challenging event with respect to management and care due to its overlapping signs and symptoms and chronic mental health condition so it is a problematic topic for both caregivers and HPs in their exercise. It is a rapidly increasing as common public health issue (incurable, life-limiting illness, and death with dementia is increasingly common) all over the world that is under-recognized in primary care settings (Sagar, *et al.*, 2004). The idea of the world-wide prevalence of dementia is 24 million and its proportion may reach 40 million by 2020 and 80 million by 2040. Approximately 58% of people with dementia will remain in low or middle income states and this ratio will rise respectively up to 63% in 2030 and 71% in 2050. In the US, 5.2 million people have dementia related disorders (especially Alzheimer dementia), and it is known as the sixth leading cause of death among older people (Alzheimer Association USA, 2013).

Nursing care is a crucial component of the management of patients that can lead to a more serious outcome (Andersson, Cederfjäll, July, Nilsson, & Kalang, 2007). The Global cost of Alzheimer and its related dementias has been estimated at US \$600 billion (World Alzheimer's, report, 2010) on the base of the non-residential care and home care that it requires. If dementia specialist nurses were able to scale down even for one day of the hospital occupancy rate of older people, 11 million pounds sterling could be delivered in the UK (Royal College of Nursing, 2013). Likewise, the world Alzheimer report indicates that if dementia care was a country, it could be the world's 18th largest economy, ranking between Turkey and Indonesia.

Nursing care is a crucial part of the management of patients in terms of supporting carers and early identification. More can be done to improve care for people with dementia and their families. In the UK, the 2001 National Service Framework revealed that older people are the fundamental patient category in acute hospitals, accounting for 60% of hospital bed days (Department of Health, 2001). Nurses can also increase family and patients' knowledge, awareness and alertness of the early identification, impact of dementia and prepare care plans for patients and their families (Bryans & Wilcock, 2001). Nurses need multi competencies, which involves experience and evidence-based knowledge. To be competent in their consultative roles they need to know how to teach, lead, delegate, and supervise staff (Perry et al., 2003). This wide range of knowledge is all important for dealing with complex situations. Nannies must be capable to solve practical problems and distinguish the differences between nursing and social concern. However there are some factors- underestimation, frustration, making mistakes, moral distress that impede a nurses potential to conduct research or to develop their competence in health care (Karlsson, Ekman, & Fagerberg, 2009).

The Royal College of Nursing (2013) published five principles under the acronym of SPACE for supporting good dementia care: 1) Staff who are skilled and have time to care, 2) Partnership working with carers, 3) Assessment and early identification, 4) Care that is individualized, and 5) Environments that are dementia friendly for improving dementia care in hospital settings. Additionally, skilled staff with enough caring time, proper palliative care, sufficient nutrition supplements, individualized care plans, rehabilitation and person centered care can improve the dementia patients' quality of life. At the end of their life patients with dementia (two thirds) spend their final years in hospital (McCarthy et al., 1997). Sampson, Gould, Lee and Blanchard, (2006) testified that people with dementia receive less palliative care compared to similar individuals without dementia in UK hospitals. Guidelines have been enlisted to serve nursing homes to evolve policies and exercises in the end-of-life care for

residents with dementia (Cahill, Doran & Watson, 2010 a). UK research has shown that dementia patients die during curing time in hospital due to the extended continuance of the healing process (Sampson, Blanchard, Tookman, & King, 2009). As well, it increases the disability rate among the elderly and creates problems for both primary care providers and the individual suffering from dementia (Hsieh & Wang, 2011). Often in the later stages of dementia it creates more complications for the family members and carers as they need expert care from the specialized trained professionals. Usually the nursing staff finds varieties of practices in regards to the dementia management practices and drills with the medications in the hospital settings (Flaherty & Little, 2011), encourage to the patients, quality of communication, degree of trusting environment between the patients their families, holding staff and physical restraints (Laitinen, 1996).

The Nepalese older population is increasing rapidly and has already reached 8.2% of the total population (Chalise & Rai, 2013). However, relatively little attention is given the healthcare needs of this important group in Nepalese society. The concern of older age people with dementia is projected to increase in Nepalese society- due to the increased longevity and the disintegration of joint households. On that point is emerging evidence that the dementia problem is gradually spreading out as a future crisis and a national challenge (Jha et al., 2013) and will soon be graded by a substantial increase in its elderly population like Ireland (Cahill, O'Shea & Pierce, 2012b). Also, the ratio of mental health professional is low (psychiatrists 0.13, 0.27 nurses and psychological providers 0.19 in 100000 populations) relative to WHO standardization (Jha et al., 2013). This shortage trend of nurses exists in Nepal as global trend due to falling levels of job satisfactions with the geriatrics care issue and increasing degrees of burnout in the professions (Nantsupawat et al, 2011. This course is situated in the USA. The advocates of elderly warn nurses with basic competency in geriatric care is essential to meet

the especial skills that can be help on the path of looming nurse shortage (Robert wood Johnson Foundation, 2012).

In Nepal, there is virtually no awareness of dementia amongst the public, healthcare professionals (Pathak & Montgomery, 2014) and policy makers. On the other hand, on that point is a substantial shortfall of educated professionals and there is little awareness of dementia as a public health matter. The illness places a great onus on both older patients and their relatives.

There is a need for educational programs and health-care policies that help to increase awareness (Furaker & Agneta, 2013) of dementia in nursing practice, management and care thereby improving the care provided to people with dementia because nurses can help to make identification of dementia as soon as possible for person. It is important to explore the barriers to the successful management and care of patients with dementia, given that it tends to be undertreated and results in long-term hospital care.

The aim of the present work was to study the perceptual experiences of nursing staff regarding barriers to postoperative management in the hospital with dementia, their attitudes, knowledge, and management practices to surmount these roadblocks.

## **5.2 Methods**

### **5.2.1 Study Site and Sample**

This purposive sampling study was carried out in a sample of nurses in Kathmandu, who worked at two private hospitals in a metropolitan area (capital city). We picked out two newly established private hospitals to measure the nurses' management and attention skills in dementia. The selected hospitals were established with 50 beds. While hospitals of not more than 50 beds have a diversity of patients presenting to them for attention, they do not have on-

site specialist services (New South Wales Health, 2009). Furthermore, the choice of only two hospitals reflects the fact that the research was significantly restricted in terms of time and financial resources (Marshall & Rossman, 2011). The number of beds in the hospitals in the sample represents the most common hospital size in private hospitals of Nepal. Private hospitals of this size have a mix of acute services, and in a few cases, committed long-term aged care beds (New South Wales Health, 2009). There are numbers of small private hospitals in the metropolis, but in this study, we choose very currently established hospitals.

In this survey, only female nurses participated as in Nepal nursing is not however considered a profession for men. We identified 44 Registered Nurses (RN) from an initial sample of sixty-six nurses (response rate 66.66%). Five incomplete answers questions excluded from the 66 participants. Questionnaires were distributed and collected by the Head Nurses in each unit during a two months period. Twenty respondents were from one hospital and 24 from an adjacent hospital. Thirty-three percent nurses declined to participate. Altogether (86 nurses) were working full-time in different wards (in OPD ward-6, in ICU/OT ward-3, from emergency ward-4, from gynecological ward-4, orthopedic ward-5, pediatric ward-3, psychiatric ward- 5, from neurology ward-5, from ENT-4, dermatology, rheumatology-5). The barriers were the time limitation of nurses' norms, rules of hospital and nurses individual interest. Participation were fully voluntary and nurses responded to the questionnaire anonymously. Quantitative and qualitative data were collected. This study was chosen to give nurses the opportunity to reflect on and explore their practices on dementia and what competencies they have, they may require and wish to develop. The participants worked in the long term and short term care in different wards. They were from the starting phase (1 year) of the profession for 15 years.

### **5.2.2 Measurement**

For this study, we developed the structured questionnaire methods on the basis of Turner's et al., (2004) format. A pilot sample of the questionnaire was taken before 20 days prior to start of the main study with nursing staff that were not required in the primary work. Grounded on this fender, some details were altered and added to the main questionnaire. In the primary study, respondents answered multiple choice questions related to a dementia quiz: concerning diagnosis, epidemiology, medication and management of dementia difficulties. Each question also included a "do not know" option. In the first part 18 questions assessed current practices in dementia care and in the second part nurse were asked questions that covered different aspects of dementia (i.e., managerial, use of dementia screening tools, anatomy and physiology, diagnostic procedure, epidemiology, use of medicine and its side effects). In summer 2013, the researcher contacted head nurses to coordinate the data collection.

### **5.2.3 Data Analysis**

The data was analyzed using frequencies, percentages, means and standard deviations. Open-ended questions were analyzed thematically by the qualitative content analysis. The qualitative analysis provided a comprehensive description of perceived care and management practices, barriers, and the perspectives of nurses. The quantitative data were analyzed with the use of SPSS 20 for Windows.

## **5.3 Results**

This is the first work to examine the care and management knowledge, barriers and patterns of dementia among the nurses in Nepal. In the results section data are presented under the following subheadings: knowledge of dementia, diagnosis practice in hospital- the

experience of nurses, duration of dementia diagnosis and number of visited in a typical month, usually diagnosed dementia types and suggestions of nurses, awareness dementia services and location, awareness of dementia-related medicine, perceived barriers to the management and care dementia in the hospitals, perception of nurses' towards the dementia and their suggestions to patient. The effects of dementia quiz knowledge are summarized in Table for every query.

### 5.3.1 Knowledge of dementia

Nurses were evaluated with regard to: management and role of dementia screening tools, physical body and physiology, diagnostic procedure, epidemiology, and the role of medical specialty and its side effects. The total average score of participants' on their knowledge of dementia care and management was low (mean = 3.54, SD = 1.82). Responses to the knowledge quiz are indicated in below table. The below results indicates that nurses were unknown and not paying attention towards the dementia.

**Table 11. Dementia quiz answers giving by nurses (N=44)**

No.	Questions	Number of correct answers
1.	When was Alzheimer disease (AD) recognized as the most common cause of dementia? A. 1970s B. 1907s C. 1987s D. 1894s	6(13.6 %)
2.	Which of the following is not a risk factor of cardio-vascular disease? A. Hypertension B. Atrial fibrillation C. Ebixa disease D. coronary artery	30(68.2%)
3.	Which of the following one is correct that the most common type of Alzheimer dementia takes account for approximately? A. 50-70% B. 20-30% C. 30-50% D. None of them	19(43.2%)

4.	When a patient develops a sudden onset of confusion, disorientation, and inability to sustain attention, this presentation is most consistent with the diagnosis of: A. Alzheimer's disease                      B. Acute confusional state C. Major Depression                          D. Vascular dementia	4(9.1%)
5.	Which of the following clinical findings best differentiates vascular dementia from Alzheimer's? A. Word finding problem                      B. Short term (2 minute span) visual memory loss C. Stepwise disease course                      D. Presence of depression.	9(20.5%)
6.	The effect of anti-dementia drugs is to: A. Temporarily halt the disease in all cases.                      B. Temporarily halt the disease in some cases C. Temporarily halt the disease in some cases but often causing liver damage. D. Permanently halt the disease in some cases.	5(11.4%)
7.	Which of the following statements one is correct? A. Mild dementia shows-20- 24 out of 30 points MMSE score. B. Moderate dementia shows- 9-20 out of 30 points MMSE score. C. Severe dementia shows - 6 out of 30 points MMSE score. D. None of them.	4(9.1%)
8.a	Which of the following clinical findings best differentiates vascular dementia from Alzheimer's? A. word findings problems B. short term C. 2 minute visual memory loss test stepwise disease course D. presence of depressions	18(40.9%)
8.b	Vascular disease refers to multiple little strokes that have damaged particular areas of the brain. A) Yes.                      B) No.                      C) Do not know.	15(34.1%)
8.c	Is this true that people with lewoe body dementia often have delusions, stiffness, tremors, visual hallucinations? A) Yes.                      B) No.                      C) Do not know.	12(27.3%)
8.d	A progressive disorder of the central nervous symptoms is characterised by stiffness in the joints and limbs, tremors difficulty to movement, speech. A) Yes.                      B) No.                      C) Do not know.	25(56.8%)

9.	Rivastigmine tartrate (Exelon®) Oral; approved for: A. mild and moderate Alzheimer’s Disease only and severe Alzheimer’s Disease B. moderate, and severe Alzheimer’s Disease C. for mild cognitive impairment D. None of them	6(13.6%)
10.	The side effects of Memantine (Namenda®) are: A. Headache, Dizziness, Sedation, Agitation, Constipation B. Nausea, vomiting C. Nausea, vomiting, and diarrhoea D. None of them	8(18.2%)
<b>Correct answers:</b> 1 B; 2 C; 3 A; 4 C; 5 C; 6 B; 7 A; 8-a 1, 8-b 1, 8-c1, 8-d 1; 9 B; 10 A. All questions also included a ‘don’t know’ option.		

### 5.3.2 Diagnosis Practice in Hospital- The Experience of Nurses

Nurses were asked “who typically diagnosis the patient” to the suspected dementia patients in the hospitals? The result found that the most diagnostic practices are done by physicians 16 (36.4%) at the first clinic visit and afterwards by the neurologist 13 (29.5%) than by others specialist doctors of the dementia patients. Accordingly, the diagnostic role goes to the GP colleague 6(13.6%), old age psychiatric 5(11.4%), geriatrician 13(29.5%) on the basis of nurses response.

### 5.3.3 Duration of Dementia Diagnose and Number of Visited in a Typical Month

In the reaction of “How long is the continuance of your patients diagnosed with dementia”? The nurses reported that final diagnosis duration of dementia time was taken from one month to sixteen months by the doctors. In addition, thirty-four (77.3%) respondents reported “do not know” with regard to the time period of diagnosis in the clinical praxis. A further, 30 nurses (68.2%) reported that they were unable to say the exact number of dementia patients in a typical month.

### **5.3.4 Types of clinical diagnosis and suggestions of nurses.**

In the response of “which clinical diagnosis will you find frequently?” The nurses reported that 16 (36.4%) a behavioral problem was most diagnosed issue with the suspected patients. And then Parkinson, Alzheimer, and Huntington disease were diagnosed issue in the hospitals. Majority 24(54.5%) nurses were used to suggest to visit psychiatrist/psychologist, if the patients do comply with the memory problems with the family members at the very first beginning. Followed by 4(9.1%) nurses suggested to visit with the GPs 7(15.9%) to the neurologist, 6(13.6%) with geriatrician for further consult for the patients and his/her family. It means that nurses also confused to whom should visit at the very first beginning for the diagnosis dementia like; with the GP or neurologist, or psychiatrist. This proves that the nurses are innocent on this issue yet though their characters are significantly important for the proper identifications, manage and care of dementia.

### **5.3.5 Awareness of Dementia Services and Location**

Nurses were asked two questions concerning services: 1) Are there memory clinics services for dementia patients in the community? 2) Is there a local support group for people with dementia One third of nurses were unaware of these services. The majority 18 nurses (40.9%) were unknown in regarding of local support of dementia in community, but they were confirmed to say that there was no local support for the demented patients (40.9%). On the other hand, only 3(6.8%) nurses could able to name memory clinic and their location and 27 (61.4%) were able to say about the day care service for the elderly in the community. Thusly, these above-presented results indicate that the level of awareness is low with the nurses.

Barriers were reported in the following key areas: 1) misdiagnosis, 2) late referral by the physicians, 3) lack of knowledge with the family member, patients and health professionals about the dementia and, 4) no special services/ resources in the hospital for older people. Additionally, the open-ended questions revealed that nurses had problems with the discharge process, an inability to provide one-to-one care; wandering/keeping people on the ward and ensuring patient safety, including lack of access to additional support such as a physiotherapist,

managing difficult/unpredictable behaviour; communicating; not having enough time to spend with patients. The above picture that emerges from the responses to the open-ended questions is that dementia is the burdensome disease but still is not a public health priority.

### **5.3.6 Open Ended Response**

Most nurses felt insufficient preparation like training and specialization to provide dementia management and care. So primary health care nurses would benefit by the training in this area and that could lead to improved access to services for people with dementia and their carers (Michelle & Jane, 2001). Most nurses were not satisfied with the current practice services to the dementia patients in their hospitals.

## **5.4 Discussion**

This study explores nurses' dementia care and management knowledge, practice and barriers in hospitals. The outcomes of this study indicate poor awareness and poor practices regarding dementia. In our survey, nurses indicated that inadequate knowledge regarding dementia. Our results are similar with data from southern Taiwan nurses, where more than half nurses confused dementia and delirium (Lin, Hsieh, & Lin, 2012) It is possible that our results might have suffered from misinterpretation, connected to a fear and lack of information about how to answer the questions for the nurses. Additionally, they might have less informations of dementia and practices because none of them (both) hospitals were not providing dementia friendly services beyond the psychiatry clinical department. Only the psychiatry department were handling the dementia-related issues without any dementia expertise. Hence, in our study nurses were less confident than others developed countries nurses in the management and care. So, an attempt of this investigation of nurses' on dementia care and management knowledge would be extremely important to examine the dementia care, management and barriers among nurses

In an open-ended questions, nursing staff reported the present care trend is mainly the responsibility of relatives or spouse at home (Zarit, Gaugler, Jarrott, 1999; Hsieh Mei-Hui & Wang Hsiu-Hung, 2011). Understanding the social burden issue of dementia and its costs is a crucial issue for future health care and socioeconomic policymakers. Additionally, under detection should be addressed by developing strategies to increase the awareness and training of health professionals, public media and the community (World Alzheimer report, 2008 & 2013).

Nursing staff are important in the process of delivering dementia care and interventions, as well as a challenging and complicated for assisting and contributing towards an improvements of patients' better health (barker, 2007) because nurses are considered the disease experts by patients and caregivers. They can play a non-pharmacological and pharmacological role in the management and care of dementia (Azermai, *et al.*, 2013). However, globally, 71% have insufficient training in dementia management and poor awareness of the support services available with the dementia on the nurses (Alzheimer's Society UK, 1995).

In our study, Nurses felt insufficiently prepared to provide appropriate services and would take no action at suspected dementia. The management of patients with the dementia in hospital settings is a challenge for our current models of health care delivery (Boustani, Schubert, & Sennour, 2007). The study concluded that nurses would benefit from training and that could lead to improved access to services for people with dementia and their carrers. Nolan (2007) explored nurses' experiences of caring for older people with dementia, people structural inadequacies of the acute hospital as a dementia care environment and the resulted the challenges and complexities of the care experiences.

This report outlines the evidence of problems and solutions that Nepalese nurses' in the community need to embrace in order to trade effectively with diagnosis care and management.

Thus, there is a need for ongoing teaching of nurses in dementia care that may minimize the unnecessary barriers/conflicts regarding the management of dementia. We would wish to propose that the nurses should be paying more attention/updated by themselves to improve their skills on dementia. Likewise, hospital administration and nursing college/institutions should provide training, guidelines to make improve their competencies regarding dementia.

## **5.5 Conclusions and Recommendations**

Nepalese nurses need to have specific dementia assessment tools/guidelines for better care and management. Nurses have a crucial part to play for better diagnosis, monitoring and providing long-term support for individuals with dementia. In this regard, especially in Nepal, they need to work more closely with the caregivers, geriatricians, neurologists, social workers, NGO/INGOs; allied health teams and psychiatric the hospital. Many of the aforementioned issues can be addressed via their professional educational development. More priority needs to be focused towards: quality development, research and planning, active care, improving collaborations with multiple especilst doctors and medical follow-up, understanding and responding to behaviour changes, care and management with screening instruments. Efforts in Nepal need to be directed towards improving financial support, community support, family support, establishing day care home services, memory clinic services with geriatric services, a separate department of dementia in the hospital and in the community. Improvements in dementia knowledge and self-confidence for management and care should lead to an improvement in service delivery in Nepalese hospital with nurses.

## **5.6 Key Points**

1-Educational support programs and evidence base nursing practice are needed to improve nurses' knowledge and confidence with regard to the care and management.

2-There is an urgent need to develop a more systematic approach from nurses and a central register of residential, trained dementia nurses and hospital facilities.

3-The screening procedure is necessary for the early onset period in the community and should address the issue of negative attitudes to dementia care and management.

4-Nepalese nurses need to cooperate more with geriatric specialists and Neurologists, to contribute positively to the psychosocial needs of individuals with dementia and their primary care providers.

## **5.7 Limitations**

The outcomes of this research should be treated with caution given the relatively small sample size and the fact that our respondents worked in the private health care sector. That said, research on Nepalese nurses is rare and our open questions provided future hypotheses to examine.

## **6. A realist review of interventions aimed at improving knowledge, detection practices and management of dementia among health professionals.**

### **6.1 Introduction**

Dementia creates problems for health professionals (HPs) globally (Illiffe, et al., 2004) due to its worldwide dramatic increasing prevalence rate (World Alzheimer report, 2010, 2012, 2014). In both hospital settings and primary care, HPs play key role in the diagnosis of dementia. Dementia presents a particular challenge for primary care providers (Illiffe, et al, 2004), who do not adequately trained to diagnose it in the earlier stages of its cognitive impairment (Ambigaa. et al., 2011). GPs are often in the first position to observe patients (van Hout, et al., 2007), followed by nurses who have important role but are not effective in diagnosing dementia (Pucci, et al, 2004). Therefore there is a need for better interventions to detect, prevent and ameliorate the impact of dementia.

More than 50% of cases are not diagnosed by the GPs in their practice (Boustani, et al, 2003). In 2021, over half a million people will be living with dementia that has gone undiagnosed. Even in high income countries, only 20-50% of dementia cases are recognized and documented in primary care (World Alzheimer report, 2013).

Alzheimer society UK, (2014) reveals that approximately 28 million of the 36 million people with dementia have not received a diagnosis. Furthermore, it is projected that up to 90,000 patients are living without diagnosed dementia in UK (Alzheimer society U.K., 2014). The global challenge of dementia is compounded by the fact that it is under diagnosed and under treated in primary care across the under developing countries of the world (Cahill et al., 2006).

The barriers to the appropriate treatment and management of dementia are considerable. Factors such as time, lack of knowledge and skills, misunderstanding of symptoms in

diagnosing and treating dementia, fears associated with both false positives and false negatives, and fear of diagnostic errors can prevent HPs from starting an appropriate diagnostic work-up. Moreover, GP-related barriers include the absence of reliable screening tools, lack of time and financial reward, and limited access to neuropsychological consultations and neuro-imaging investigations (Turner S. et al, 2004).

Dementia presents significant problems for nurses also. For example, the Alzheimer's Society, 1995 (Alzheimer's Society 2009) indicates that 71% have insufficient training in dementia management and poor awareness of the support services available for dementia. When a person with dementia is living at home, nurses are often more aware of the support networks available and the care services on offer than the patient's GP. They also have an integral role to play in maintaining channels of communication with other professionals involved in the provision of care and treatment, such as community psychiatric nurses, social workers and voluntary agency staff. GPs and nurses feel insufficiently prepared to provide dementia management service (Bryans & Wilcock, 2004). Overall, HPs consistently cite inadequate professional training as the barrier to provide an optimal service to dementia patients (Alzheimer's Society 2009). For example, Cahill et al found only 47.6% of GPs had received sufficient training in the diagnosis and management of dementia and only 43.9% used specific protocols for diagnosis (Cahill, et al., 2008).

All the aforementioned is exacerbated by the fact that dementia can be present, but be untreated in hospitals. The Royal College of Nursing (2013) reports that around a quarter of hospital beds are occupied by dementia patients. At the end of their life older people with dementia (two thirds) spend their final years in hospital (McCarty, Addington-Hall & Altmann, 1997). Dementia patients have a higher mortality rate during hospital admission compared to similar people without dementia (Bryans & Wilcock, 2004). Likewise, people with dementia receive less palliative care compared with similar individuals without dementia (Sampson,

Gould, Lee & Blanchard, 2006). HPs need to be more aware of palliative care frameworks for patients' betterment (Alzheimer Association USA, 2009).

More than 13% of people require long term care and it is estimated that somewhere between the 101 to 277 million dementia patients will need care between 2010-2050 (World Alzheimer report, 2014). In the UK, if dementia specialist nurses could reduce even for one day the hospital occupancy rate of older people, the amount to be saved would be almost £11,000,000 nationally (Royal college of nursing, 2013). On the other hand, "if dementia care were a country, it would be the world's 18th largest economy (World Alzheimer report, 2013).

The present review builds upon a systematic review of educational interventions in primary care (Perry et al. 2011). This previous review identified six studies, and concluded that educational interventions for primary care required active participation by the HPs to improve their skills regarding the detection of dementia. Apart from the aforementioned review, two other reviews in this area have been published. The first, a narrative review, (Mukadam et al, 2014) included thirteen studies, and found that GP education was associated with better to detection. Also, the review indicated that memory clinics increased timely diagnosis.

The second review (Koch & Illiffe, 2011) identified fifteen studies, and found that guidelines were helpful in overcoming diagnostic and management barriers. Additionally, practice based dementia and decision support software was useful for the GPs. Facilitated sessions and decision-support software helped to improve diagnosis of dementia, and some of the case-management trials showed improved stakeholder satisfaction, decreased symptoms, and care that was more concordant with guidelines.

All the above mentioned facts and figures of HPs in dementia brought our considerable attention to conduct this systematic review again because we already knew that the intervention was moderately helpful. Also, GPs and nurses are facing difficulties in diagnosing,

management, care and need of interventional program. So that we need to find the relationship of intervention program and competency of HPs that could be effective for further strategies. And is there lack of knowledge and treatment gap on dementia and increasing the misdiagnosis rate/ prevalence rate?

## **6.2 Methods**

The search strategy used a broad brush approach using overarching terms/keywords. The use of overarching terms/ keywords ensured that all potentially relevant articles were included in the initial screening. We searched Google scholar, Scopus, Pub Med/ Medline, Embase, PsycInfo, Bibliographies, Cinahl for relevant articles without limitation. Abstracts of conferences and opinion papers were excluded. We used the following search terms; Dementia AND nurse AND intervention, Dementia AND physicians AND intervention, Dementia AND primary care doctors AND intervention, Dementia AND primary care doctors AND knowledge, dementia AND primary care physicians AND knowledge, dementia AND primary care, physicians AND dementia management, dementia AND knowledge and nurse, Dementia AND primary care physicians AND diagnosis. In all the databases, the search was restricted to articles where the keywords were the major focus of the article. A similar search strategy was used in the remaining databases. In addition, we reviewed the reference lists of previous reviews to identify potentially eligible studies. We applied the following inclusion criteria (1) intervention studies aimed at improving HPs practices concerning dementia care (2) we included only those studies that were conducted with health professionals (nurses and doctors) on the basis of detection practices and management and (3) peer-reviewed and written in English.

The search strategy is detailed in figure 1. Twenty five studies fit the inclusion criteria and these results are summarized in Table 7 and Table 8 for every program in order to quickly overview the results.

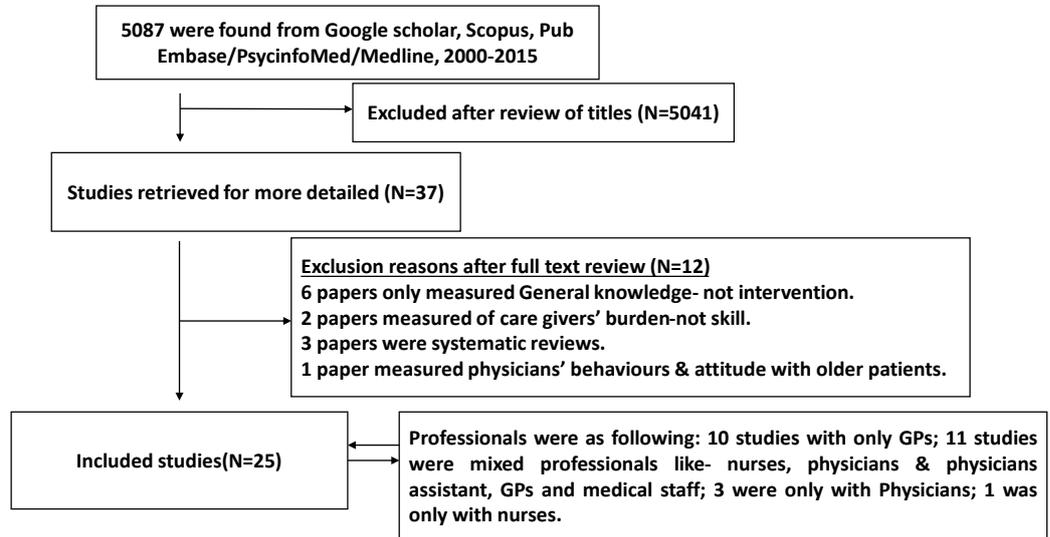


Figure 1. Searching Process

## 6.3 Results

### 6.3.1 Study characteristics

All the studies involved developed countries- 9 studies from UK, 2 from Denmark, 1 from France, 7 from the USA, 2 from Germany, 3 from the Netherlands and 1 from Australia. Thus, we have no information on the situation in developing countries. In total, the selected studies of the HPs population were as followings: 10 studies with only GPs; 11 studies were mixed professionals like- nurses, physicians & physicians assistant, GPs and medical staff; 3 were only with Physicians; 1 was only with nurses. Table 7 and 8 describe in detail of study characteristics and interventions programs.



**Table 12. Study characteristics**

<b>Author, year, location</b>	<b>Sample</b>	<b>Study design</b>	<b>Follow up duration</b>	<b>Intervention procedure/act</b>	<b>Outcomes</b>
Boisal <i>et al.</i> , 2010.US A[41]	11 family physicians, 1 internal medicine physician, 4 assit. Physician, 2 nurses practitioners and 26 medical assistants.	CBA	3-5 months	Intervention procedure was audio-video, hands out distribution, power presentation and web conference with the HPs.	Results included a substantial increase in screening for dementia, a modest increase in the proportion of patients who were diagnosed with dementia or mild cognitive impairment, and improved clinician confidence in diagnosing dementia.
Borson <i>et al.</i> , 2007, USA[43]	39 clinicians in two intervention and two control primary care clinics.	CT	3-9 months	Cognitive screening of all patients over 65 years with at least one appointment in trial period plus clinician education programme.	Results showed nearly 70%, 26 physicians screened cognitive to patients those patients were at least 1 clinic visit during the intervention period. Physician's actions occurred in only 17% of screen-positive patients. Among of them, most medical assistants were showed to the lowest Mini-Cog score screening level.
Bryans <i>et al.</i> , 2003. UK.[50]	78 nurses	RCT	NA	Intervention procedures were as following: Self	Results show no significance improve the knowledge of epidemiology and diagnosis quiz score were lower level after the intervention,

			<p>completion questionnaire before the educational interventions with the 78 nurses. Category of nurses were district nurse, practice nurses, community nurses. Each nurses participated in self completion questionnaire before and after interventions to measure the difficulties, attitudes and confidences in the dementia.</p>	<p>however, management strategies were slightly higher with nurses. Self-reported ratings of confidence were also low in identifying dementia and dealing with coexisting behavioral and mental health problems.</p>
<p>Chodosh <i>et al.</i>, 2006. USA.[37]</p>	<p>232 PCP</p>	<p>CLCR T 9 months</p>	<p>Multi faced intervention was 100 minutes small group workshop with interactive hands outs and web site, decision support system and tutorial on CD- Room, indirect learning with care managers' collaboration.</p>	<p>There were no differences in knowledge, attitudes, or care quality perceptions across intervention and usual-care providers. In primary care dementia management was difficult than usual care.</p>

Chan <i>et al.</i> , 2010. U K[42]	GPs	CBA	10 months	14 intervention and 7 control practices about memory to GP and community organization.	An important role in improving the quality of care and management was a community based program. Rate of recording of new cases wise rise by 29% in intervention and 64% in control locality. Referral data was more change with the GP contract to encourage the use of screening questionnaires.
Downs, <i>et al.</i> , 2006 UK.[51]	36 GP practices	RCT	9 months	3 educational intervention studies were applied: a workshop, a CD and specialized computer software and tested between the control and no-control group(received intervention and not received intervention group).	Result showed that no significant differences in mean concordance scores for diagnosis or management of dementia. CD-ROM able to increase the knowledge and ability to diagnose on dementia who were received the training.
Eccles <i>et al.</i> , 2009. UK[30].	644 Mental health team	Four-arm RCT	NA	One theory-based and two pragmatic interventions, postal questionnaire; evidence based communication; Interventions were delivered as pen and-paper exercises at the start of a second postal questionnaire that re-	Result showed that no more effect with the team of mental health team and no significant differences in terms of intention or simulated behaviour between the trial groups but theory based intervention positively increased rate for attitudes to (p=0.03) and perceived behavioural control (p=0.001) for the behaviour of “finding out.

				measured the same psychological variables. The outcome measures were intention and scenario-based behavioral simulation.	
Glavin <i>et al.</i> , 2012,US A[48]	146 HCP	CBA	7 years	Training, open ended questions, didactic, observational and skill-based teaching techniques.	HPs showed improvements in knowledge and confidence to diagnose and treat and increased use of dementia screening tools. Rural research participation in an urban Alzheimer Disease Research center increased 52% over the pre-CPP period.
Illife <i>et al.</i> , 2010 UK[33]	20 PCP	UCRC	3 years	Practice-based-face to face educational workshops and electronic Support material.	In improving rates of detecting dementia, a computer decision support system and practice-based educational workshops were effective although not in all changing clinical management with the primary care practices.
Illiffe <i>et al.</i> , 2013.UK [34]	23 GPs	CBA	60 months	Practices using electronic patient records—11 intervention, 12 control face to face workshop, NICE-SCEI Guideline. Each practice was followed up to 12 months; practice requirement was staggered so the	Case detection rates were unaffected. Estimated detection rate (1.03, p-value was 0.927 with 95% confidence interval 0.57–1.86) was from multi-level Poisson regression modelling.

whole project took 60 months.

Jansen <i>et al.</i> , 2011. Netherland[47]	99 pair of GP& Nurse.	RCT	6-12 months	12 months of case management by district nurses for both older adults and informal caregivers versus usual care.	Results showed no statistically significant but clinically relevant differences between the two groups. The process evaluation revealed that intervention fidelity could have been better. Meanwhile, informal caregivers' were satisfied with the quality of case management.
Lathren <i>et al.</i> , 2013. USA.[40]	Physicians 29 and affiliated staff 24.	RCT	6 months	One day training. Questionnaires before and 6 months after the training intervention.	Physicians' confidence rate was higher in their dementia care after 6 months. Majority did agree improvements ability to educate patients and caregivers about dementia and appropriate referrals to community care services. Physicians showed positive improvement to use of cognitive screening tools and community referral service.
Perry <i>et al.</i> , 2008. Netherland[30]	151 GPs	BRCT	6months	Home assessment,	The number of dementia diagnosis was increased in controlled group less than in intervention group. Additionally home assessment and managements was effective than primary care.

Perry <i>et al.</i> , 2008, Netherland[31]	100 duos of GPs and practice or district Nurses	assessor- BRCT	9 months	Workshops, self-registration forms and questionnaires	Educational intervention program showed highly effective modifying professional behaviour. Multifaceted interventions were viewed as more effective. In both groups (either the experimental or the control group) GPs and nurses are fully aware of their assignment.
Pond <i>et al.</i> , 2012. Australia [45]	114 GPs and nurses	cluster randomised study	12 months	Two educational sessions from a peer GP or nurse, and the GPCOG to consenting patients at baseline and 12 months. Distributed Guidelines by post to the GPs (waitlist Group).	Rates of GPs to identification of dementia compared to a more detailed in the patient's home; cognitive impairment and GP referral to specialists, Alzheimers' Australia and support services. A "case finding" and a "screening" group will be compared and the psychometrics of the GPCOG will be examined.
Rondeau <i>et al.</i> , 2008. France[27]	681 GPs	CLCC T	17 months	2 hour educational group meeting, no training	GPs from the intervention group had a higher probability rate of correctly detecting dementia. This showed information on dementia and application of simple psychometric tests could improve the precision of a GP's diagnosis without changing the efficacy of detection of dementia.
Smythe <i>et al.</i> , 2014. UK[49]	81 staff from three wards	Mixed study	NA	Mixed methods; questionnaires, interview and training	Result showed skills based training, problem solving and self-directed learning to the staff increased knowledge, confidence and to use clinical time as well as, organisation and the physical

environment. Additionally no differences between the participants who did and did not receive the intervention. Nearly one third ward were having positive trends to identify.

Smythel et al., 2015, UK [46]	70 Medical staff including care giver.	CBA	3-6 months	Focus group(14) with purposive sampling training and audio-recorded, anonymised and transcribed verbatim	Result showed the increasing the competency-based skills, beliefs, enablers and barriers and ways of learning. Though, some groups of staff found educational program is difficult to identify their skills and thus the idea of ‘magical touch’ emerged.
Turner, S., et al., 2004. UK [12].	20 GPs	RCT	9 months	Self-completion questionnaire using electronic medical records about knowledge, confidence and attitudes, for capture of clinical data, including diagnoses, investigations and referrals.	Result showed that one third of GPs reported limited confidence in diagnostic skills, whilst two-thirds reported lacking confidence in management of behavior and other issues in dementia
Vollmar et al., 2007. Germany [28]	137 GPs	CT	3-5 hours	Educational training based on the evidence-based guideline and questionnaire.	Result showed that 137 GPs rated the overall positive improvements of training. They gained the mean knowledge score 4.0+2.6 correctly answered questions (po0.001; CI 3.6 to 4.5) comparing pre-and post-test (n ¼ 132). In addition 45 GPs, in the group of training diagnosis rate showed (n ¼ 45).

The group with additional training on therapy (n ¼ 87) achieved a difference of 5.172.3 questions (po0:001).

Vollmer <i>et al.</i> 2010. Germany [32].	389 GPs.	CRCT	30-45 minutes	Questionnaire survey 2 times, face to face teaching, discussion, online modules.	Results showed that both study arm A and arm B approach of educational intervention was positively increased to gain knowledge between GPs.
Vickrey BG., <i>et al.</i> , 2006. USA[36] .	3 health care organizations, 3 community agencies.18PCC and 408 patients, 408 informal caregivers.	CLCR CT	12-28 months	Internet-based care management, co- ordination, seminars, software but not training.	Results showed the dementia based guideline helped to improvement in quality of care and disease management which was significantly higher in intervention group than usual care group. Participants were able to identify patient's health related overall quality of life and social assistance. Also, result showed the caregiver's health related quality of life did not differ between the groups.
Waldorff <i>et al.</i> , 2005. Denmark [35].	24 GP	CBA	6 months	Controlled study, three hours training, for a subgroup training for two hours oral presentations video and interactive elements.	Result showed that who(GPs) read the guideline, 88% found applicable in primary care. No increase in the adherence to guideline recommendations was observed regarding the use of laboratory tests or cognitive tests in the diagnostic evaluation of dementia in general practice.

Waldorff <i>et al.</i> , 2003. Denmark [25]	535 GPs with physicians	CBA	4-7 months	Assessment of guide line with multifaceted.	Result showed between the control and intervention group was not significantly difference in the diagnostic but GPs were able increased the skill of cognitive testing performance and use to guideline.
Wenger <i>et al.</i> , 2009. USA[39] .	1st group 30 physicians and 2nd group 100 physicians.	CT	13 months	Telephone call with patients, 3-h educational session, and data were completed from medical record and questionnaire.	Result showed that quality care cognitive impairment screening skills did not improve with the physicians team. However, practice based intervention, intensive intervention and embedding intervention, electronic based intervention was useful to improve the care skills in incontinence of dementia. The practice of clinicians physicians were shown able to adapt and review the prompts to suit their local services and personnel.

NA- not available, GP-general practitioners, RCT- randomised control trial; CBA- controlled before and after; CCRCT- clinic level cluster randomized controlled trial; CT- controlled trial; BRCT-Blinded randomized controlled traileid; CRCT- cluster randomized controlled trial, UCRC-un-blinded, cluster randomised controlled.

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In the below table the descriptions of the intervention context of each study has summerised.

**Table 13. Descriptions of the intervention context of each study.**

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**Author**      **Description of the each study context (RCT=randomized controlled trial), (GP= general practitioners), (CBA= controlled before and after)**

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Boisal <i>et al.</i> , 2010.US A	Intervention duration was 3-5 months. Intervention procedure were: Audio-video hands out materials, power presentation, conference, Clinicians and medical assistants were trained in dementia screening using the ROAM protocol via distance learning methods. Medical assistants screened patients aged 75 years of age and older. For patients who screened positive, the clinician was alerted to the need for a dementia work-up. Outcomes included change in the proportion of patients who were screened and diagnosed with dementia or mild cognitive impairment, clinician confidence in diagnosing and managing dementia, and response to the intervention.
Borson <i>et al.</i> , 2007, USA	Duration of intervention was 3 months (in one clinics)-9 months (in next clinics); intervention process was in 39 clinicians in two intervention and 2 control primary care clinics. The intervention assessed the cognitive screening with patients who were over 65 years and least one appointment in trial period plus clinician education program.
Bryans <i>et al.</i> , 2003. UK.	Intervention duration was not available with it however intervention procedure were as following: Self completion questionnaire before the educational interventions with the 78 nurses. Category of nurses were district nurse, practice nurses, community nurses. Each nurse participated in self completion questionnaire before and after interventions to measure the difficulties, attitudes and confidences in the dementia.
Chan <i>et al.</i> , 2010.UK	Intervention duration was 10 months and intervention procedure was in 14 intervention practices with leaflets about memory to GP and community organization. Also, anonymized routinely collected computer data were gathered pre and post the program.
Chodosh <i>et al.</i> , 2006. USA.	Duration of intervention was 9 months and intervention procedure were- Small group workshop, decision support system and tutorial on CD- Room. Intervention was in five session combined hands out and web site with 100 minutes interactive seminar. Intervention participants were offered five educational modules comprising a total of 100 minutes. They received a medical assessment, an overview of the dementia care and management program, role of managers, recognition of dementia related disorders like depression and delirium and questioned were on quality of resources and ability to coordinate and correspondence from other providers.
Downs, <i>et al.</i> , 2006. UK.	Duration of implemented intervention was 9 months. Intervention procedure had three parts. These were electronic tutorial, decision support software, practice based workshops and case analysis electronic book.
Eccles <i>et al.</i> , 2009. UK.	Duration-NA. One theory-based and two pragmatic interventions was send (to measure psychological variables) postal questionnaire to the clinical psychologist, community psychiatrist nurses and others HPs (old age mental health team); Participants were divided in to four groups: evidence based communication, patient-based intervention, scenario-based behavioural

simulation and pen and paper based exercise on the second phase postal questionnaire.

Illiffe et al., 2010 UK  
During the 3 years intervention procedure were combine based workshops, practice-based-face to face and electronic support material. Intervention was conducted with the 20 primary care practices to measure the proportion of patients with dementia those were received at least 2 dementia specific management per year and next was practice concordance with management guidelines and quality of life.

Illiffe et al., 2013 UK  
Intervention duration was 1year and procedure were practice-based-face to face educational workshops and electronic support material was the intervention procedure. In first phase interviews with 115 practitioners to measure the knowledge and expectations, new policy and changing process.

Jansen et al., 2011.Net herland  
The intervention duration was 6-12 months and detection procedure was divided in to three ways- 55 PCPs sent the informant questions on cognitive decline, 44 PCPs persons suspected of dementia among the persons. Nurses visited the home and assessed the caregiver's situation of capacity and burden issue through questions.

Glavin et al., 2012,US A  
Intervention duration was 7 years and following intervention activities were applied- Training, open ended questions, didactic, observational and skill-based teaching techniques. The CPP is a 3-day "mini-residency" of didactic, observational and skill-based teaching techniques. Participants completed pre- and post-tests evaluating dementia knowledge, confidence in providing care, and practice behaviors. Between May 2000 and January 2009, 146 individuals (48% physicians, 25% advance practice nurses and physician assistants, 23% psychologists, social workers, and other health professionals, 4% other) graduated from the CPP.

Lathren et al., 2013. USA.  
Intervention process were to the 29 physicians and 24 affiliated staff one day training program to the diagnosis and management using questionnaires before and 6 months after the training intervention. Questionnaires assessed about their dementia care skills and referral patterns and these questions were completed before and 6 months of the training.

Pond et al., 2012. Australia  
Duration of intervention was 1year with the 114 GPs and nurses; Intervention- Two educational sessions from a peer GP or nurse, and the GPCOG to consenting patients at baseline and 12 months. Distributed Guidelines by post to the GPs (waitlist Group).

Perry et al., 2008.Net herland  
Duration of intervention was 3- 6months; intervention procedure were to assess the patients' MMSE in home, hospitals by the multi disciplines with in the 3-6 months follow up. All the diagnostic guideline were coded by EASY guideline and measured daily activities and behavioral activities.

Perry et al., 2008, Netherlands.  
Intervention duration was 9 months. intervention procedure were workshops, coaching program, computerised support system with the 100 duos of GPs and nurses, self-registration forms and questionnaires were the procedure in the intervention. Nurses, geriatrician and physicians were frequently met the

patients to discuss on the subject matters at home for assessment. GPs, nurses and physicians were referred to study of patients and met regularly to discuss cases. Geriatric Specialist Nurse were visited patients at home for assessment with the EASY care instrument to measure daily living activities, mood and cognition. The nurse, primary care physician, and geriatrician met regularly to discuss cases.

Rondeau et al 2008. France Intervention was 2-hours group educational meetings on Alzheimer's disease and other forms of dementia but no training. Educational meeting was on cognitive screening tests with the patients.

Smythe et al., 2014. UK. Intervention duration was not mentioned. Intervention questionnaires, interview and training was the main procedure for the intervention. Learning and a mixed methods approach was adopted using self-administered standardized questionnaires and qualitative interviews.

Smythe et al., 2015. UK Intervention duration was 3-6 months and procedure was applied mixed methods including questionnaires, interview and training with the medical staff to assess the capacity and improve staff knowledge of dementia

Rondeau et al., 2008. France. The intervention duration- 17 months and intervention activities were: 2 hour educational group meeting but no training by the neurologist, psychiatrist and geriatrist on AD and other forms of dementia in the use of a battery of four neuropsychological tests.

Turner, S., et al., 2004. UK. Duration of intervention was 9 months. Intervention procedure was electronic medical records for capture of clinical data, investigations and referrals and including diagnoses. Every four study arm were asked to complete a postal questionnaire to the doctors and nurses regarding with practitioner dementia quiz knowledge, awareness of local services, confidence of diagnosis, communication and perceived difficulties with diagnose and management.

Vollmar et al., 2007. Germany. Intervention duration was 3-5 hours and intervention program were with the GPs practical action- evidence-based guideline, internet based learning materials and questionnaire to measure the potential effects of knowledge gain.

Vollmer et al. 2010. Germany. Intervention duration was 30-45 minutes slide presentation, on dementia-related training and case discussion was 45 minutes, Questionnaire survey 2 times, face to face teaching, discussion, online modules. Knowledge was evaluated with the participants in both groups by the process of test pre- and post-intervention, and at 6 months, as well as an evaluation form and knowledge test comprised 10 MCQs on diagnosis and 10 MCQs on management of dementia. To all participants distributed printed materials of the guidelines.

Vickery et al., 2006. US A. Intervention duration was 12-28 months and intervention procedures were; internet-based care management, co-ordination, seminars, software but not no training. Ninety minutes interactive seminar for 5 sessions for primary care physicians on the issue of depression, behaviors changing of patients was given. Twenty-three guidelines were used by a multidisciplinary group for

caring assessment. Also, social workers were trained, and carried out the assessments. Follow-up was arranged based on need but regular 6-monthly format assessments were carried out. Assessments were made, software assisted in providing a care plan, and recommendations to primary care physician were made. The software also facilitated multidisciplinary communication, and referrals to other agencies.

- Waldorff *et al.*, 2007. Denmark Intervention duration was 6 months and intervention program were-Controlled study, before and after study three hours training, for a subgroup training for two hours oral presentations video and interactive elements.
- Waldorff *et al.*, 2003. Denmark Duration of intervention was 4-7 months and procedure was assessment of multifaceted strategy, four seminar, outreach visit, and small group training with clinical practice guideline was the intervention process. Also, local GPs and specialists collaborated in the design of the multifaceted strategy and underwent a 5-hour symposium of training.
- Wenger *et al.*, 2009. USA. Period of intervention was 13 months and intervention procedure were-telephone call with patients to find the problem, 3-h educational session on care assessment and physicians' triggered a specific condition. Educational session for practitioners on the management and care for patients.
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Waldorff *et al.*, (2003) found the guideline based instruction/intervention with multifaceted professionals was helping to increase the diagnostic confidence. A further two studies found no significant differences in mean concordance scores for diagnosis or management of dementia with the GPs (Jansen *et al.*, 2011). Effects of 2 hour seminar (Rondeau, Allain & Bakchine, 2008) for the GPs was helped to detect correctly. (Vollmar, Butzlaff, Lefering, Rieger, 2007) made a comparison between the two groups of GPs that showed that those who were self-reported using online learning base program had showed a significant knowledge gain. Twelve studies (Waldorff *et al.*, 2011; Vollmar, *et al.*, 2007; Perry, Drasković, van Achterberg, 2008; Eccles, Francis, Foy, 2009; Illife, *et al.*, 2010; Wilcock *et al.*, 2013; Waldorff, Rishoi, Waldemar, 2005; Galvin, Meuser, John & Morris, 2012; Smythe *et al.*, 2014; Lathren, Sloane, Hoyle, Zimmerman, Kaufer, 2013) showed the gradual increase of the overall HPs' attitude, practices and dealing confidence. They improved cognitive screening skills, home

assessment and management to the patients' behavioural activities with effectively. In addition four studies lead to the increase in application of psychometric tests, to use the dementia based guidelines and disease management, care performance and confidence of the HPs (Rondeau, Allain, Bakchine, 2008; Perry et al., 2008; Vickrey et al, 2006). A further the guideline based intervention helped to find management difficulties (Vickrey, et al, 2006) and improve the care management (Vollmar, et al, 2010) of the patients for the PCPs after the intervention. Although in some intervention studies we found no significant combination in knowledge (Eccles, 2009; Bryans et al, 2003), attitudes, or care quality perceptions across intervention and usual-care providers (Bryans, et al., 2003) with their skills. It might have the less interest to learn the educational programs and implementation of instruction to the detection with the nurses, mental health team and GPs, not to be positive outcomes.

Two studies (including with physicians, GPs, Nurse and medical staffs) in primary care services and one geriatric liaison nurse assessment service (Perry, et al., 2008) were not sufficient to gain the knowledge. However, geriatric nurse were more able than others rest of the medical staff to manage dementia and also, physicians were capable to define the disease (Perry, et al, 2008; Lathren, Sloane, Hoyle, Zimmerman, Kaufer, 2013). The USA study (Smythe, et al., 2014), involving physicians, measured the increased detection rate of dementia or suspected dementia for people presenting with memory complaints, to make collaboration with local services and incontinence of dementia but they were less weakness in quality care and cognitive impairment screening skills.

Two studies revealed that dementia management is more difficult in primary care than usual-care providers (Vickrey, et al., 2006; Bryans, et al, 2003). A dementia guideline based disease management program led to substantial improvements in quality of care for patients with dementia (Vickrey, et al, 2006). Additionally, in another study nearly (87%) physicians used a cognitive screening test with confidence after the six months training (Lathren, Sloane,

Hoyle, Zimmerman & Kaufer, 2013) and increased the ability to educate patients and caregivers about the referrals and community services. Similarly, USA study found (nearly half) the improving skill to use cognitive screening practices with the patients after 3 months trial periods (Boise, et al, 2010). They compared the rates of those diagnosed with dementia or mild cognitive impairment before and after the intervention. A community based study (Chan, Van, Dhoul & De, 2010) revealed the impact of distributing leaflets about dementia to community centres and GP practices to improve the quality of care and management in the community. Another next, 39 clinical USA based study (involving geriatricians, family doctors or general internists and medical assistants) (Borson et al, 2007) showed the confident rate to define the dementia and dementia related cognitive disorders. Results showed nearly 70%, 26 physicians screened cognitive to patients those patients were at least 1 clinic visit during the intervention period. Physician's actions occurred in only 17% of screen-positive patients. Among of them most medical assistant were showed to the lowest Mini-Cog score screening level.

A Further, a study found district nurses (Perry et al., 2008) were satisfied and capable to measure the difficulties, attitudes and confidences in the dementia than practice and community nurses with the quality of dementia case management after the post intervention.

#### **6.4 Discussion**

Our review takes a broader view of the literature by assessing studies across HPs (nurses and doctors) and including studies that use a range of methodologies. We have summarized and evaluated interventions concerning HPs skills such as knowledge, attitudes, practice, diagnostic rate, management and confidence. Overall, attendance at educational programmes was associated with improved diagnosis in agreement with previous reviews (Perry, et al., 2011; Mukadam, Cooper, Kherani, Livingston, 2014; Koch & Illiffe, 2011). Our review indicates that a collaborative program of practice based workshops with community and multi-

faced (Chodosh, et al, 2006) educational program was the most effective. Moreover, even educational programmes for physicians improves diagnostic confidence (Lathren, Sloane, Hoyle, Zimmerman & Kaufer, 2013). Interventions helped to modify care strategy and dementia detection performance rate (two-fold higher) with HPs in usual care group (Vickrey, et al, 2006). Participants who received intervention programme was higher care quality performance on 21 of 23 guidelines and higher proportions received community agency assistance ( $P < \text{or} = 0.03$ ) than those who received usual care. That lead to substantial improvements in quality of care for patients i.e.; patient health-related quality of life, overall quality of patient care, caregiving quality, social support, and level of unmet caregiving assistance.

Our review showed peer education (Pond et al., 2012) training programs and guideline intervention are most effective than single intervention. It is not associate between the short and long duration of intervention but HPs active participant for learning attempt is required. Computer and practice based intervention, intensive intervention, theory based (Eccles, Francis & Foy, 2009), community based training (Borson, et al, 2007), and electronic based intervention was useful to improve the overall skills of dementia. But six studies (Waldorff, et al, 2003; Eccles, et al, 2009; Chodosh, et al., 2006; Wenger, et al., 2009) did not show the significant improvements in the cognitive screening, care confidence and management. Educational interventional has been largely tested to the HPs however, the cause of unsuccessful might have short term duration of intervention, less practice based opportunity, less clinical task and laboratory testing, personal dealing capacity, quick defining strategy and prescribing habits. Effects of intervention need to evaluate the perspective of patients, their caregivers and their development on skills (Koch & Illiffe, 2011).

We did not find none of the included intervention study was not focus to measure or relate the outcomes of intervention between the duration of intervention and its effects to

increase overall HPs' increasing competences, patients' quality of life, the cost of interventions and hospital's managerial aspects. Also, organizational factors were not measured that might be useful in the understanding of care and management issues to the HPs. All the studies conducted from developed country. So we are unknown how generalizable of this findings would be developing countries and multi ethnic groups.

Already carried out (Perry et al, 2011) study reflects only 3 of 5 possible outcomes levels in medical education research. Further to understand the changing patterns and mechanism of relevant of health care and educational intervention have to conduct in all five levels. They found moderately improved results. Especially, effects of intervention and micro group workshop and decision support system increased the rate of detection of dementia. Likewise, a short term interactive 2-hour seminar (Rondeau, Allain & Bakchine, 2008) raised GPs' confidence and to adhere the guideline. Accordingly, Koch & Illiffe, (2013) found detection and management change in primary care's professionals was difficult to change the diagnostic and management skills also none of the interventions program (seminar based) was success to show the improving outcomes accurately (Koch & Illiffe, 2011). Likewise, Mukandum et al, (2014a) revealed that GPs based memory clinics increased timely detection evidence rate. They added that studies across all clinical settings that might have a marked effect on dementia diagnosis figure, exactness or stage of diagnosis. However that is not the best evidence to make proof they can help to increase the competency with the HPs through the interventions. Further, they drawn (UK based observational study national data base) on the dementia diagnosis and treatment rates was lower rate in between 2006- 2008 compared with 2009; the skills of HPs on dementia diagnosis rate increased by an estimated 4% in 2010 and 12% in 2011 compared with 2009. But the rate was significantly increased from 2006-2012 per year. The prescription rate of anti-dementia drugs has been increased dramatically since 2010. Moreover, there was downtick in cost in 2012-not in the prescription ratio (Mukadam et al., 2014a).

However, our review cannot claim the intervention benefit in population screening for dementia that helped to rise the overall competencies or developing interventions is worthwhile because some interventions also are not able to bring out the differences in their practices. Thus we suggest to update the skills by personal effort and should be self-conscious about what strategies can help for timely diagnosis, proper management, and cost effectiveness of patients.

## **6.5 Conclusions**

In this review we found evidence of awareness of dementia is increasing but not sufficiently and there is a considerable misunderstanding with regard to dementia among the health professionals. In particular, educational interventions for health professionals are required to cope with the misdiagnosis and underestimation of dementia at the first visit/consultation. Overall, combined programs of practice based workshops with community and multi-faced educational program were the most effective. In addition, focus group discussion and person-centred care could be effective, as well as learning by doing can help to improve competency-based skills, confidence, and reduce the barriers (Bryans, et al, 2003).

## **6.6 Limitations**

In this review there is a risk of missing studies due to the file drawer problem that refers to the fact that important data has been missed due to it being unpublished. All the studies involved doctors and nurses from developed countries. The number of eligible studies was comparatively small and some studies had significant methodological limitations. The intervention components varied considerably, which makes the comparison across studies difficult. We could not conduct a meta-analysis due to its heterogeneous nature of outcomes evaluated.

## **6.7 Key points**

- There is evidence that combined GPs, nurses, physicians and community-based education intervention can improve the appropriately overall management and diagnosis of dementia, especially for early detection.
- Guideline based training are more effective.
- There are no gold standard educational interventions for the HPs to improve the skills.

## **7. General Discussion**

### **7.1 Introduction**

This thesis explores dementia knowledge, patterns and obstacles among Nepalese health workers. We applied the questionnaire methods to discover the findings from Nepalese healthworkers to examine health workers' understanding, practices, obstacles, management and care of dementia.

Equally we know dementia is an incurable disease and creates problems for health professionals (HPs) globally (Illiffe, et al., 2004) due to its worldwide dramatic increasing prevalence rate in both hospital settings and primary care. More than 50% of cases are not identified by the GPs in their practice (Boustani, et al, 2003). If the present trend continues over half a million people will be living with dementia that has gone undiagnosed. Even in high income countries, only 20-50% of dementia cases are identified and documented in primary care (World Alzheimer report, 2013). Additionally, the global challenge of dementia is compounded by the fact that it is under diagnosed and under treated in primary care across the developing countries of the world (Cahill et al., 2006). Also, at the final stage of their life older people with dementia (two thirds) spend their last years in hospital (McCarty, Addington-Hall & Altmann, 1997). Dementia is still misdiagnosed, mismanagemened and misunderstood by the health professionals globally. Hence, we resolved to conduct four studies on the basic research questions: to explore the knowledge, practices, and obstacles to diagnosis, management and care of dementia that challenge health workers in Nepal. This main aim of research questons was guided by these sub questions. A) How does health workers diagnose, manage and care for dementia and what are the critical issues and concerns associated with dementia in Nepal? B) What are the specific gaps in knowledge for HPs in Nepal? C) With

regard to dementia, is the situation improving or deteriorating in Nepal? D) What is the optimum way to improve services directed at dementia in Nepal?

The solutions address the next issues: obstacles of the diagnosis, views of dementia, difficulty diagnosing early stage dementia, acceptability of specialists, responsible for special issues, knowledge of dementia, awareness dementia services, medicinal drugs, and further process to the patients, poor awareness of epidemiology.

Moreover, combing the results of our three empirical studies and a realist review results the following diagnosis and management barriers were identified-communicating the diagnosis, negative views of dementia, difficulty diagnosing early stage dementia, acceptability of specialists, responsibility for extra issues, knowledge of dementia and aging, less awareness of declining abilities, diminished resources to handle care, lack of specific guidelines, and poor awareness of epidemiology.

Chapter four added more on the experiences of specialists regarding dementia concerning the diagnosis practices, confidence, management practices and difficulties of multi-specialist doctors. They indicated that they diagnosed more as false- positive and false-negative on average of new cases of dementia and the majority showed a desire to take dementia specialist training to improve their performance and chapter five reported in the experiences of nurses concerning dementia. This chapter examines the knowledge, practices and barriers of nurses concerning dementia care. The results indicated that the knowledge of nurses' with regard to the diagnosis, management and care of dementia was unsatisfactory. The care and management of patients with dementia in hospital settings is a challenge for Nurses in Nepal. Educational programs and healthcare policies are needed to increase awareness of dementia in nursing practice with respect to management and maintenance.

In special, educational interventions for wellness pros are needed to cope with the misdiagnosis and underestimation of dementia at the first visit/interview. Overall, combined programs of practice based workshops with community and multi-faced educational program were the most efficient. Therefore we recommend that HPs be updated on dementia diagnosis, management and care by.

Chapter six reviewed healthcare professionals (HPs) skills in the dementia identification and management role in the detection and management of dementia. Nevertheless, there is a gap in the literature as to what represents best practice with respect to educating HPs improving the dementia detection practices and management. The review suggested that collaborative programs of practice based workshops with community and multi-faced educational program were the most efficient. The early diagnosis, management and care of dementia patients can be improved by; combined (between the HPs) intervention programmes, theory based programmes, better computer training, skills based training, self-directed learning and electronic based interventions and multiple visits to suspected dementia patients.

The results of this thesis increase our understanding of dementia and its progressive features. We realized that the lack of dementia diagnosis and care is the leading factors to increase the prevalence rate in Nepalese community. Health professionals' reported there are a large number of barriers to the identifications and proper management of dementia. These are: insulting to be updated or to be aware of dementia and dementia related disorders, social isolation, limits the health workers of the evolving knowledge of senior people in the community, language barriers to communication for the covering, multi-ethnic community and its behavioral difficulties for assessing, lack of multi experts' coordination for the declaration of disease, early diagnosis complication or negligence or over diagnosis or misdiagnosis etc.

## 7.2 Implications

The overall objective of this work was to examine the dementia knowledge, diagnostic practices, and obstacles to diagnose, manage and care with the health workers in the Nepalese medical community. The outcome of our research explored that in the Nepalese medical community (GPs, nurse and medical especialsit) dementia and dementia care is a low priority plus the public concern does not accept dementia as a serious disease.

Therefore, there needs to be a national strategy to cope with dementia and a more proactive strategy in tandem with wellness care organizations. The leading causes of dementia like; life style factors, diabetics, hypertension, cancer, drug and drug addiction need to be addressed as factors. Training strategies, participation of local funding, educational programs (training, intervention, seminars, conferences, guideline developing) for the problems associated with dementia can help to bear out all health workers, the community and older people. In particular, increasing awareness, diagnostic confidence, better management and proper referral services can improve the impact of dementia. We can use telehealth for service consultations, especial mental health services, training, radio, TV and other news media's application and NGOs and INGOs empowerment, improve the care of dementia persons and skills of HPs in remote and urban fields. Moreover, there is a demand to extend the theoretical account of service design, policy and support in the hospital like geriatric services and specializations, admiral nurses, research exercises, memory clinic centers, and challenge negative concepts of getting on. Additionally, improving financial support, improved community and household funding, establishing day care home services, greater provision of geriatric clinic services, and separate units in the hospital dedicated to dementia can help. Improvements in dementia knowledge and self-confidence for using the guidelines would lead to an improvement in service delivery in Nepal. Nepalese HPs need to have specific dementia assessment tools/guidelines for better diagnosis and management.

### **7.3 Limitations and critique**

This thesis has integrated 4 separate research studies involving the health workers' knowledge, diagnosis practices, and obstacles to cope and worry with the dementia patients. Each survey offers a foundation of HPs' qualitative and quantitative results that offer further exploration into the care and clinical patterns of senior adults with dementia in Nepalese hospitals.

The strength of this thesis relates to the examination of knowledge, practices and obstacles for health workers (GPs, nurses, and medical especialistas) that have not been previously investigated. Our conclusions are limited by the small sample sizes and self-report methods, but this counterbalanced by the fact that we have conducted research on three different professional bodies in Nepal. We did not apply a multi research design to evaluate the health workers' skills in this subject that might be a strong criticism. The fields have the following research limitations;

1. The selected population is low and only from (urban) city-based hospitals where most of the facilities are set up.
2. The survey tool is a self-report questionnaire (self-made out regarding with dementia diagnosis, manage and care in the health professionals in their everyday exercise). As well, it is contrived with a multiple types of question, and respondents may have been affected by affectivity.
3. The three cross-sectional studies suffer from the limitations associated with accumulating data at one time full stop.

We trust the findings of our results provides a minimum contribution to knowledge, diagnostic exercises and proper management in the Nepalese medical community.

#### **7.4 Fututre Directions**

Up to now, we knew, the dementia is a burden for health workers and a complex condition to diagnose and manage also there is still no gold standard guidelines for HPs. Knowledge of GPs, nurses and medical especialities with regard to the diagnosis, management and care of dementia was unsatisfactory in our field. We could not discover a specific focus on the dementia with the health professionals. HPs are facing challenges in the maintenance and management of patients with dementia in hospital scenes. We have offered a clear identification of HPs' knowledges, diagnostic exercises and obstacles to manage and care of dementia however a rigorous study is however required.

We further advocate that future research should focus on dementia area with collaboration of health professionals with care givers, managerial staff from the hospitals, family caregivers, community care givers, social health workers and community health care organizations. Further research should address the health workers' skills, ethical debate between clinicians (who is dementia specialist), epidemic of dementia, cause, cure and management.

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## Appendixes

### Appendix A

#### **Dementia: Diagnosis & Management in Primary Care: A primary care based education/research project General Practitioner Questionnaire**

Thank you for agreeing to complete this questionnaire. Most responses only involve you circling a number, and we have avoided questions which might require you to refer to your records.

We would ask that when the questionnaires are completed that colleagues do not confer, or crosscheck textbooks for responses, because it is very important that we get an accurate picture of any change in knowledge as a consequence of the interventions. The responses will not be divulged to anyone.

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#### Part A: Current practice

Date..... Name..... Practice no.....

1. Gender: Male 1 Female 2 Date of Birth / / Year qualified....

2. Are you a: (please circle one)

Principle GP 1 GP Registrar 3 Other (specify)  
.....5  
Locum 2 Retainer 4

3. Are you: Full time 1 Part time 2

4. Post graduate training (please circle all that apply)

Elderly medicine 1  
Old Age Psychiatry 2  
General Psychiatry 3  
Other post graduate training (specify)...4  
None 5

5. Could you estimate the number of consultations with patients with dementia that you have in a typical month?

Enter number    Don't know 8

6. Please indicate where these contacts most commonly take place, using 1 = most common setting to 5 = least common

The surgery  Patient's home  Carer's home   
Residential Home  Other (specify).....

7. In a typical month, how many contacts with carers of people with dementia do you have?



12b. How confident are you about the advice you usually give about managing dementia-related symptoms?

Very confident 1 Somewhat confident 2 A little confident 3 Not at all confident 4 Other 5

Why is this?.....

13. From your experience, please rate the difficulty of these aspects of dementia care, from 1 (not at all difficult) to 7 (extremely difficult) by circling the appropriate number on the scale.

	Not at all Difficult			Extremely Difficult			DK	
	1	2	3	4	5	6	7	8
Establishing a diagnosis	1	2	3	4	5	6	7	8
Telling the patient the diagnosis	1	2	3	4	5	6	7	8
Telling the family the diagnosis	1	2	3	4	5	6	7	8
Responding to the family's concerns	1	2	3	4	5	6	7	8
Responding to co-existing behaviour problems	1	2	3	4	5	6	7	8
Responding to any psychiatric problems	1	2	3	4	5	6	7	8
Co-ordinating support services for carers and people with dementia	1	2	3	4	5	6	7	8
Getting specialist assessment services	1	2	3	4	5	6	7	8
Getting information about anti-dementia (cognitive enhancing) medications	1	2	3	4	5	6	7	8
Getting information about support services for carers and people with dementia	1	2	3	4	5	6	7	8

14. Do you have a local support group for people with dementia? Yes 1 No 2 DK 8  
If Yes.... Which organisation(s) provides this service?.....

15. Do you have a carer support group in your area? Yes 1 No 2 DK 8  
If Yes.... Which organisation(s) provides this service?.....

16. Do you have day care services in your area? Yes 1 No 2 DK 8  
If Yes.... Which organisation(s) provides this service?.....

17. Do you have a memory clinic in your area? Yes 1 No 2 DK 8  
If Yes.... Who provides this service?.....

18. How do you rate the following in regard to dementia care in your area?

Available and needed	Available but not satisfactory	Needed, but not satisfactory	Not available	Can't say
1	2	3	4	5

Information about old age psychiatry services	1	2	3	4	9
Protocol for assessment and investigation of a patient with possible dementia	1	2	3	4	9
Brief screening instrument for early identification	1	2	3	4	9
Nurse with mental health training working in association with the practice	1	2	3	4	9
Information about benefits (attendance allowance, Invalid Carer's allowance)	1	2	3	4	9
Information about support services for carers	1	2	3	4	9
Information about social support services for people with dementia	1	2	3	4	9

19. Please indicate on the scale below your responses to the following statements regarding dementia in primary care

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Can't Say
Providing a patient with a diagnosis is usually more helpful than harmful	1	2	3	4	5	9
Managing dementia is more often frustrating than rewarding	1	2	3	4	5	9
Much can be done to improve the quality of life for people with dementia	1	2	3	4	5	9
Dementia is best diagnosed by specialist services rather than by the primary care team	1	2	3	4	5	9
It's better to talk in euphemistic terms when discussing the condition with someone with dementia	1	2	3	4	5	9
Families would rather be told about their relative's dementia as early as possible	1	2	3	4	5	9
The primary care team has a very limited role to play in the ongoing care of people with dementia	1	2	3	4	5	9
Much can be done to improve the quality of life of carers of people with dementia	1	2	3	4	5	9

Patients with dementia can be a drain on resources with little positive outcome	1	2	3	4	5	9
There is little point in referring families to services as they don't want to use them	1	2	3	4	5	9

20. Which of these options would you prefer to utilise to provide ongoing management and support for people with dementia and their carers?

Refer them elsewhere for ongoing management and support	1
Personally share ongoing management and support with a service organisation in the area	-2
Have practice team members share ongoing management and support with a service organisation in the area	-3
Provide ongoing management and support myself or only with help from the practice team	-4
Don't know	-8

21. Which of the following prevent you from doing as much as you would like for people with dementia and their carers?

	YES PREVENTS	NO DOESN'T	DON'T KNOW
Too busy: not enough time during surgery visit	1	2	8
Unfamiliar with advances in the management of dementia-related symptoms	1	2	8
Unfamiliar with available services to help keep them at home	1	2	8
Unsure how to refer patients to available services to help keep them at home	1	2	8
Lack of team staff in the practice	1	2	8
Lack of funding within the practice	1	2	8
Lack of Social Service support available to the practice	1	2	8
Other (Please specify).....			

22. Given the demands on your time what priority would you give to updating your knowledge of dementia?

Low	1	Moderate	2	High	3	DK	8
-----	---	----------	---	------	---	----	---

How would you rate your own current knowledge, on a scale of 1–10, about diagnosis and care of people with dementia and their families?  
Rate please.....

## Part B. Pre-training knowledge quiz

Please answer the following questions from your current knowledge without consulting colleagues or reference materials. Indicate your answer to each question by circling only one of the responses.

1. A GP with a list of 1,500 – 2,000 patients can expect to have the following number of people with dementia on their list:

- |                 |   |
|-----------------|---|
| A. 1-6          | 1 |
| B. 7-11         | 2 |
| C. 12-20        | 3 |
| D. 21 or more   | 4 |
| E. I don't know | 5 |

2. By 2021, the prevalence of dementia in the general population in the UK is expected to:

- |                                  |   |
|----------------------------------|---|
| A. Decrease slightly             | 1 |
| B. Remain approximately the same | 2 |
| C. Increase slightly             | 3 |
| D. Nearly double                 | 4 |
| E. I don't know                  | 5 |

3. One of the risk factors for the development of Alzheimer's disease is:

- |                             |   |
|-----------------------------|---|
| A. Hardening of arteries    | 1 |
| B. Age                      | 2 |
| C. Nutritional deficiencies | 3 |
| D. Exposure to aluminium    | 4 |
| E. I don't know             | 5 |

4. All of the following are potentially treatable aetiologies of dementia except:

- |                                  |   |
|----------------------------------|---|
| A. Hypothyroidism                | 1 |
| B. Normal pressure hydrocephalus | 2 |
| C. Creutzfeldt-Jacob disease     | 3 |
| D. Vitamin B12 deficiency        | 4 |
| E. I don't know                  | 5 |

5. A patient suspected of having dementia should be evaluated as soon as possible as:

- |  |   |
|--|---|
| A. Prompt treatment of dementia may prevent worsening of symptoms    | 1 |
| B. Prompt treatment of dementia may reverse symptoms                 | 2 |
| C. It is important to rule out and treat reversible disorders        | 3 |
| D. It is best to institutionalise someone with dementia early in the |   |

- course of the disease 4
- E. I don't know 5
6. Which one of the following procedures is required to definitely confirm that symptoms are due to dementia?
- A. Mini-Mental State Exam 1
- B. Post mortem 2
- C. CAT scan of the brain 3
- D. Blood test 4
- E. I don't know 5
7. Which of the following is not a necessary part of the initial evaluation of someone with possible dementia?
- A. Thyroid function test 1
- B. Serum electrolytes 2
- C. Vitamin B and foliate levels 3
- D. Protein electrophoresis 4
- E. I don't know 5
8. Which of the following sometimes resembles dementia?
- A. Depression 1
- B. Acute confusional state 2
- C. Stroke 3
- D. All of the above 4
- E. I don't know 5
9. When a patient develops a sudden onset of confusion, disorientation, and inability to sustain attention, this presentation is most consistent with the diagnosis of:
- A. Alzheimer's disease 1
- B. Acute confusional state 2
- C. Major depression 3
- F. Vascular dementia 4
- E. I don't know 5
10. Which of the following is nearly always present in dementia?
- A. Loss of memory 1
- B. Loss of memory and incontinence 2
- Loss of memory, incontinence and hallucinations 3
- None of the above 4
- E. I don't know 5

11. Which of the following clinical findings best differentiates vascular dementia from Alzheimer's?

- |  |   |
|--|---|
| A. Word finding problems                         | 1 |
| B. Short term (2 minute span) visual memory loss | 2 |
| C. Stepwise disease course                       | 3 |
| D. Presence of depression                        | 4 |
| E. I don't know                                  | 5 |

12. The effect of anti-dementia drugs is to:

- |  |   |
|--|---|
| A. Temporarily halt the disease in all cases                                 | 1 |
| B. Temporarily halt the disease in some cases                                | 2 |
| C. Temporarily halt the disease in some cases but often causing liver damage | 3 |
| D. Permanently halt the disease in some cases                                | 4 |
| E. I don't know  | 5 |

13. Which statement is true concerning the treatment of people with dementia who are depressed?

- |  |   |
|--|---|
| A. It is usually useless to treat them for depression because feelings of sadness and inadequacy are part of the disease | 1 |
| B. Treatments of depression may be effective in alleviating depressive symptoms  | 2 |
| C. Anti-depressant medication should not be prescribed   | 3 |
| D. Proper medication may alleviate symptoms of depression and prevent further intellectual decline                       | 4 |
| E. I don't know  | 5 |

14. Which of the following best describes the functions of the Alzheimer's Society?

- |   |   |
|---|---|
| A. Central research, information and campaigning role   | 1 |
| B. Provision of local support and education to carers   | 2 |
| C. Providing day and home care for people with dementia | 3 |
| D. All of the above                                     | 4 |
| E. I don't know   | 5 |

**Part C. Background Information**

1. From where do you get information on dementia?

- |                                     |   |                    |   |
|-------------------------------------|---|--------------------|---|
| Journals eg BMJ, Pulse              | 1 | Internet, web page | 4 |
| Drug co. representatives            | 2 | Seminars           | 5 |
| Professional body e.g.; RCGP update | 3 | Others _____       | 6 |

2.Specialinterests .....

3. How would you assess yourself in relation to the use of computers in general?

Non user 1      Played with 2    Regular user 3    Expert 4. Don't know 8

4. How would you assess yourself in relation to the use of the Practice specialist clinical system?

Non user 1      Played with 2    Regular user 3    Expert 4    Don't know 8

Comments on questionnaire.....

**Thank you for completing this questionnaire**

## Appendix B

### Nursing practices in dementia management and care; Hospital based study.

Thank you for agreeing to complete this questionnaire. Please answer the questions by circling only one of the responses without consulting colleagues or reference materials because it is very important that we get an accurate picture. Your responses will not be divulged to anyone.

---

#### Part A: Current practice

Name (it is option)..... (NMC/NNC. No.).....

1. Age.....

2. Year qualified in the profession.....

3. Where did you receive your Nursing degree? Please indicate the country name below.

1. European country ..... 2. Asian country. .... 3. African country.....

4. Nepal (private / governmental college). .... 5. Others.....

4. Could you estimate the number of dementia patients that you have visited in a typical month?

Enter number \_ \_ \_ can't say..... 9

5. Over the last 5 years how many educational programmes / trainings have you taken regarding with dementia diagnose and management?

Not yet all 1 How often 2 frequently 3 very rarely 4 don't know 8

6. How long has it since one of your patients was diagnosed with dementia?

Enter number of months \_ \_ \_ Don't know 8

7. Who makes the diagnosis mostly?

Physicians 1 GP Colleague 2 Old Age Psychiatrist 3

Geriatrician 4 Neurologist 5 Other(specify)..... 6

8. Is there easy or available to get the medicine for those dementia patients in the market?

Yes 1 No 2 very difficult 3 Do not know 4 others.....5

9. Is there a local support group for people with dementia? Yes 1 No 2 Don't Know 8

IF YES;....

Which organisation(s) provides this service?.....

10. Is there memory clinic in your area?      Yes    1                  No        2                  Don't Know. 8

IF YES.... Who provides this service?.....

11. What is the best dementia screening instrument for general practitioners to diagnose dementia?

(Choose only one)

- A) AMT (Abbreviated mental test    D) MMSE (Mini-Mental status Examination)    G) Min-cog  
B) Time and change test                  E) Clock drawing test    H) Addenbrookers cognitive examination  
C) Seven minute Examination.        F) Do not know

12. In your practice, which clinical diagnosis will you find frequently?

1. Fronto –temporal dementia                  2. Behavioural assessment        3. (AD) Alzheimer disease (AD)  
4. Creutzfeldt-Jakob disease (CJD)    5. Huntington's disease        6 .Parkinson's disease  
7. Vascular dementia                          8. Donot know

13. Which types of diagnostic services (professional consult for diagnosis) would you suggest to the demented patients?

1. General practitioner    2. Neurologist    3. Psychologist    4. Geriatrician    5. Others.....

14. What types of problems are you facing to manage and care with the demented patients?

1. Disbelief        2. Misdiagnosis        3. Late referral        3. Lack of Knowledge  
4. High cost        5. I do not know.....8

WHY?.....

15. What do you think might be the advantages of the early diagnosis of dementia?

Yes    .....1                  No    ..... 2

(If yes; to whom.....people with dementia, carers, professionals).

16. Do you think dementia training will be useful to protect elderly people?

If yes, why?.....

If no, why not?.....

17. Is the dementia affecting your work? Please outline if yes, which areas .....

or no and why?.....

18. Have you had any training on dementia diagnose in your practice?

If yes, what in particular? .....

19. How do you feel about current practice regarding with the dementia?

1. Satisfied..... 2 Not satisfied                  8 Do not know.

**Part B. knowledge quiz**

1. When the Alzheimer disease (AD) recognized that is most common cause of dementia?

- |                 |   |          |   |
|-----------------|---|----------|---|
| A. 1907s        | 1 | B. 1907s | 2 |
| C. 1987s        | 3 | D. 1894s | 4 |
| E. I don't know | 5 |          |   |

2. Which is not the risk factor of cardio-vascular disease?

- |                  |   |                            |   |
|------------------|---|----------------------------|---|
| A. Hypertension  | 1 | B. Atrial fibrillation.    | 2 |
| C. Ebixa         | 3 | D. coronary artery disease | 4 |
| E. I donont know | 5 |                            |   |

3. The most common types of dementias of Alzheimer disease takes account for approximately:

- |                 |   |                 |   |
|-----------------|---|-----------------|---|
| A. 50-70%       | 1 | B. 20-30%       | 2 |
| C. 30-50%       | 3 | D. None of them | 4 |
| E .I donot know | 5 |                 |   |

4. All of the following are potentially treatable aetiologies of dementia except:

- |                              |   |                                  |   |
|------------------------------|---|----------------------------------|---|
| A. Hypothyroidism            | 1 | B. Normal pressure hydrocephalus | 2 |
| C. Creutzfeldt-Jacob disease | 3 | D. Vitamin B12 deficiency        | 4 |
| E. I don't know              | 5 |                                  |   |

5. Which one of the following procedures is required to definitely confirm that symptoms are due to dementia?

- |                           |   |                |   |
|---------------------------|---|----------------|---|
| A. Mini-Mental State Exam | 1 | B. Post mortem | 2 |
| C. CAT scan of the brain  | 3 | D. Blood test  | 4 |
| E. I don't know           | 5 |                |   |

6. Which of the following is not a necessary part of the initial evaluation of someone with possible dementia?

- |                                 |   |                            |   |
|---------------------------------|---|----------------------------|---|
| A. Thyroid function test        | 1 | B. Serum electrolytes      | 2 |
| C. Vitamin B and foliate levels | 3 | D. Protein electrophoresis | 4 |

- E. I don't know 5
7. When a patient develops a sudden onset of confusion, disorientation, and inability to sustain attention, this presentation is most consistent with the diagnosis of:
- A. Alzheimer's disease 1      B. Acute confusional state 2  
 C. Major depression 3      D. Vascular dementia 4  
 E. I don't know 5
8. Which of the following clinical findings best differentiates vascular dementia from Alzheimer's?
- A. Word finding problems 1      B. Short term (2 minute span) visual memory loss 2  
 C. Stepwise disease course 3      D. Presence of depression 4  
 E. I don't know 5
12. The effect of anti-dementia drugs is to:
- A. Temporarily halt the disease in all cases 1  
 B. Temporarily halt the disease in some cases 2  
 C. Temporarily halt the disease in some cases but often causing liver damage..... 3  
 D. Permanently halt the disease in some cases 4  
 E. I don't know 5
14. Which one is correct?
- A. Mild dementia shows-20- 24 out of 30 points MMSE score 1  
 B. Moderate dementia shows- 9-20 out of 30 points MMSE score 2  
 C. Severe dementia shows - 6 out of 30 points MMSE score 3  
 D. None of them 4  
 E. I donot know 5
16. (Please make a circle for each question)
- |  | Yes | No | DK |
|--|-----|----|----|
| A. A physical disease which causes brain cells to die, plaques disrupt message with in brain is called Alzheimer disease   | 1   | 2  | 8  |
| B. Multiple little strokes have damaged particular areas of the brain is called Vascular disease.  | 1   | 2  | 8  |
| C. Abnormal lumps called Lew Body Bodies develop inside nerve cells in the Brain. People with LBD often have delusions, stiffness, tremors, visual hallucinations is called LBD. | 1   | 2  | 8  |

D. A progressive disorder of the central nervous symptoms is characterised 1 2 8  
by stiffness in joints and limbs, tremors difficulty to movement, speech  
impairment is called Parkinson disease.

17. Which medicine is not use in dementia disease patients?

- |                  |   |               |   |
|------------------|---|---------------|---|
| A. Ginkgo Biloba | 1 | B. Glantamine | 2 |
| C. Rivastigmine  | 3 | D. Donepezil  | 4 |
| E. I donot know  | 5 |               |   |

19. Rivastigmine tartrate (Exelon®) Oral; approved for:

- |   |   |   |   |
|---|---|---|---|
| A. mild and moderate Alzheimer's Disease only | 1 | B. moderate, and severe Alzheimer's Disease | 2 |
| C. for mild cognitive impairment              | 3 | D. None of them                             | 4 |
| E. I donot know.                              | 5 |   |   |

20. Side effect of Memantine (Namenda®):

- |   |   |                     |   |
|---|---|---------------------|---|
| A. Headache, Dizziness, Sedation, Agitation, Constipation | 1 | B. Nausea, vomiting | 2 |
| C. Nausea, vomiting, and diarrhoea                        | 3 | D. None of them     | 4 |
| E. I donot know.  | 5 |                     |   |

20. Have you any predictions about the DEMENTIA prevalence? Please mention the number?

Have you had any training on dementia diagnose in your practice? If yes, what in particular?

22. How do you feel about current practice regarding with the dementia over all with Nepalese doctors?

- |                         |                  |                 |   |
|-------------------------|------------------|-----------------|---|
| A. In your country..... | B. In world..... | C. I donot know | 8 |
|-------------------------|------------------|-----------------|---|

21. Finally, According to your experience, what are the dementia diagnosis, management and care difficulties?

.....

**Thank you for your time!**

## Appendix C

### A Multi expert diagnose practice, management and care based research project 2013.

Thank you for agreeing to complete this questionnaire. Please answer the following questions from your current knowledge without consulting colleagues or reference materials because it is very important that we get an accurate picture. Indicate your answer to each question by circling only one of the responses. The responses will not be divulged to anyone.

---

#### Part A: Current practice

Name (it is option)..... Practice no (NMC/NNC. No.).....

1. Gender:    Male    1            Female    2            Age.....    Year qualified in the profession.....
2. Are you a:  
Gerontologist    1            Neurologist    2    General Psychiatry    3  
Retainer    4            Other (specify) .....    5
3. Special interests in your profession).....  
Why?.....
4. Working hour:            Full time    1            Part time    2
5. Where did you receive your medical degree? Please indicate the country name.  
1. European country .....    2. Asian country. ....    3. African country.....  
4. Nepal (private / governmental medical college). .....    5. Others.....
6. Did you have taken Post graduate training (please circle all that apply)  
Gerontologist    1            Neurologist    2            General Psychiatry    3  
Other post graduate training (specify)...    4            None...    5
7. Could you estimate the number of dementia patients that you have consulted in a typical month?  
Enter number    \_ \_ \_            can't say    9
8. Could you please indicate where these contacts most commonly take place to diagnose?  
Hospital (OPD)\_    1            Patient's home    2    Carer's home    3  
Private clinic/nursing home.....    4            Other (specify).....    5.....
9. What is the main source of information on dementia? (Please rate orderly 1-5 own your excess.)  
Internet, web    1            Journals    4

Colloquies 2 Seminars, training, conferences 5  
 Drug representatives 3 Others..... 6

10. Do you believe the instruction of dementia, you received in medical practice is adequate?

Low 1 Moderate 2 Not enough 3  
 Somewhat adequate 4 Satisfied 5 Others..... 6

11. About what percentages of your older patients come in your practice?

1. Enter number.....2. Do not know 8

12. Over the last 5 years how many educational programmes / trainings have you taken regarding with dementia diagnose and management?

Not yet all 1 How often 2 frequently 3 very rarely 4 don't know 8

13. How long has it since one of your patients was diagnosed with dementia?

Enter number of months \_ \_ \_ Don't know 8

14. Who makes the diagnosis mostly?

Myself 1 GP Colleague 2 Old Age Psychiatrist 3  
 Geriatrician 4 Neurologist 5 Other (specify)..... 6

15. Please make circle, up to 10 warning signs that you feel are indicative of the first stages of dementia.

1. Forgetfulness 2. Loss of interests in activities. 3. Loss of interest in activities 4. Loss initiative  
 5. Memory loss 6. Phobias 7. Difficulty performing familiar task 8. Recurring thoughts of death  
 or suicide 9. Social skills loss 10. Change in appetites 11. Depression anxiety 12. Low  
 self-stem 13. Difficulty to recognize 14. Conduct disorder. 15. Fatigue. 16. Problems  
 with language. 17. Disorientation to time and place 18. Poor or decreased judgement. 19. If  
 Any.....

16. Which of the following would you do for every patient where you suspected dementia, no matter how the condition is presented? (Please circle Yes, No or Don't know for each option)

	YES	NO	DK
1. Check for functional loss	1	2	8
2. Ask about past mental illnesses	1	2	8
3. Arrange a chest X-ray	1	2	8
4. Check BP, B12 levels	1	2	8
5. Check liver function	1	2	8

6. Check endocrine gland.	1	2	8
7. Arrange an ECG	1	2	8
8. Check calcium	1	2	8
9. Check glucose	1	2	8
10. Check renal function	1	2	8
11. Check memory impairment	1	2	8
12. Depression test	1	2	8
13. Test urine infection	1	2	8
14. Ask about behavioural or personality changes with carer	1	2	8
15. Thyroid test	1	2	8
16. Screening syphilis	1	2	8
17. Psychiatric disease test	1	2	8
18. Trauma	1	2	8
19. Systemic illness: cancer, connective tissue	1	2	8

17. How confident do you feel to reaching about diagnosis of dementia?

Very 1      Somewhat 2      A little 3      Not at all 4  
 Other 5 confident  
 confident      confident      confident  
 Why?.....

18. How confident are you about the medication you usually give to the dementia-related symptoms?

Very 1      Somewhat 2      A little 3      Not at all 4      Other 5 confident  
 confident      confident  
 Why ?.....

19 - Is there easy or available to get the medicine for those dementia patients in the market?

Yes 1      no 2      very difficult 3      don know 4      others.....5  
 Why?.....

20. Is there a local support group for people with dementia?      Yes 1      No 2      Don't Know 8

IF YES.... Which organisation(s) provides this service?.....

21. Is there a carer support group in your area?      Yes 1      No 2      Don't Know 8

IF YES.... Which organisation(s) provides this service?.....

22. Is there day care services in your area? Yes 1 No 2 Don't Know 8

IF YES.... Which organisation(s) provides this service?.....

23. Is there a memory clinic in your area? Yes 1 No 2 Don't Know 8

IF YES.... Who provides this service?.....

24. From your current knowledge, the difficulty of these aspects of dementia care, by circling the appropriate number on the scale.

	Not at all Difficult	Extremely Difficult	Don't know
Establishing a diagnosis	1	2	8
Telling the patient the diagnosis	1	2	8
Telling the family the diagnosis	1	2	8
Responding to the family's concerns	1	2	8
Responding to co-existing behaviour problems	1	2	8
Responding to any psychiatric problems	1	2	8
Co-ordinating support services for carers and people with dementia	1	2	8
Getting specialist assessment services	1	2	8
Getting information about anti-dementia (cognitive enhancing) medications	1	2	8
Getting information about support services for carers and people with dementia	1	2	8

25. How do you rate the following in regard to dementia care in your area?

	Available and satisfactory	Available but not satisfactory	Needed, but not available	Not needed	Can't say
Information about old age psychiatry services	1	2	3	4	9
Protocol for assessment and investigation of a patient with possible dementia	1	2	3	4	9
Brief screening instrument for early identification	1	2	3	4	9
Nurse with mental health training working in association with the practice	1	2	3	4	9

Information about benefits (attendance allowance, Invalid Carer's allowance)	1	2	3	4	9
Information about support services for carers	1	2	3	4	9
Information about social support services for people with dementia.	1	2	3	4	9

26. Please indicate on the scale below your responses to the following statements regarding dementia in primary care.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	Can't Say
Providing a patient with a diagnosis is usually more helpful than harmful	1	2	3	4	5	9
Managing dementia is more often frustrating than rewarding	1	2	3	4	5	9
Much can be done to improve the quality of life for people with dementia	1	2	3	4	5	9
Dementia is best diagnosed by specialist services rather than by the primary care team	1	2	3	4	5	9
It's better to talk in euphemistic terms when discussing the condition with someone with dementia	1	2	3	4	5	9
Families would rather be told about their relative's dementia as early as possible	1	2	3	4	5	9
The primary care team has a very limited role to play in the ongoing care of people with dementia	1	2	3	4	5	9
Much can be done to improve the quality of life of carers of people with dementia	1	2	3	4	5	9
Patients with dementia can be a drain on resources with little positive outcome	1	2	3	4	5	9
There is little point in referring families to services as they don't						



- B) Time and change test    E) Clock drawing test    H) Addenbrookers cognitive examination  
 C) Seven minute Examination.    F)    Donot know

32. What is the risk for assessment of dementia?

1. Education    2. Blood pressure    3. Body mass index    4. Age    5. Do not know.6. Others...

33. In your practice, which clinical diagnosis will you define frequently?

1. Fronto –temporal dementia    2. Behavioural assessment    3. (AD) Alzheimer disease (AD)  
 4. Creutzfeldt-Jakob disease (CJD)    5. Huntington’s disease    6 .Parkinson’s disease  
 7. Vascular dementia    8. Others.....

Why?.....

34. Which types of diagnostic services or professional consult for diagnosis would you suggest?

1. General practitioner    2. Neurologist    3. Psychologist    4. Geriatrician    5. Psycho geriatrician  
 6. Others.....

35. What types of problems are you facing to diagnose dementia?

1. Disbelief    2. Misdiagnosis    3. Late referral    3. Lack of Knowledge    4. High cost

WHY?.....

36. How do you feel about current practice regarding with the dementia?

- |  |                |       |           |          |                   |            |
|--|----------------|-------|-----------|----------|-------------------|------------|
| 1. I feel I have less knowledge with this.   | Strongly Agree | Agree | Neither   | Disagree | Strongly disagree | Can’t say. |
|  |                |       | Nor agree |          |                   |            |
| 2. We have adequate facility for screening dementia in the hospitals.                                      | 1              | 2     | 3         | 4        | 9                 |            |
| 3. My staff member does encourage diagnosing dementia in the practice.                                     | 1              | 2     | 3         | 4        | 9                 |            |
| 4. I think, in the movement, it has very less prioritized problem than other health issues in our country. | 1              | 2     | 3         | 4        | 9                 |            |

37. How would you assess yourself in relation to the use of MRI,CT /SCAN to diagnose dementia in general?

- Non user . . 1    Played with . . 2    Regular user . . 3    Expert . . 4    Don’t know    8

38. How would you assess yourself in relation to the use of the Practice specialist clinical system?

Non user. 1    Played with. 2    Regular user . 3    Expert . 4    Don't know 8

### Part B. knowledge quiz

Please answer the following questions from your current knowledge without consulting colleagues or reference materials. Indicate your answer to each question by circling only one of the responses

1. When the Alzheimer disease (AD) recognized that is most common cause of dementia?

A. 1907s	1	B. 1907s	2
C. 1987s	3	D. 1894s	4
E. I don't know	5		
  
2. Which is not the risk factor of cardio-vascular disease?

A. Hypertension	1	B. Atrial fibrillation.	2
C. Ebixa	3	D. coronary artery disease	4
E. I donont know	5		
  
3. The most common types of dementias of Alzheimer disease takes account for approximately:

A. 50-70%	1	B. 20-30%	2
C. 30-50%	3	D. None of them	4
E. I donot know	5		
  
4. All of the following are potentially treatable aetiologies of dementia except:

A. Hypothyroidism	1	B. Normal pressure hydrocephalus	2
C. Creutzfeldt-Jacob disease	3	D. Vitamin B12 deficiency	4
E. I don't know	5		
  
5. A patient suspected of having dementia should be evaluated as soon as possible as:

A. Prompt treatment of dementia may prevent worsening of symptoms	1
B. Prompt treatment of dementia may reverse symptoms	2
C. It is important to rule out and treat reversible disorders	3
D. It is best to institutionalize someone with dementia early in the course of the disease	4
E. I don't know	5
  
6. Which one of the following procedures is required to definitely confirm that symptoms are due to dementia?

A. Mini-Mental State Exam	1	B. Post mortem	2
C. CAT scan of the brain	3	D. Blood test	4
E. I don't know	5		
  
7. Which of the following is not a necessary part of the initial evaluation of someone with possible dementia?

- |                                 |   |                            |   |
|---------------------------------|---|----------------------------|---|
| A. Thyroid function test        | 1 | B. Serum electrolytes      | 2 |
| C. Vitamin B and foliate levels | 3 | D. Protein electrophoresis | 4 |
| E. I don't know                 | 5 |                            |   |
8. Which of the following sometimes resembles dementia?
- |                 |   |                            |   |
|-----------------|---|----------------------------|---|
| A. Depression   | 1 | B. Acute confusional state | 2 |
| C. Stroke       | 3 | D. All of the above        | 4 |
| E. I don't know | 5 |                            |   |
9. When a patient develops a sudden onset of confusion, disorientation, and inability to sustain attention, this presentation is most consistent with the diagnosis of:
- |                        |   |                            |   |
|------------------------|---|----------------------------|---|
| A. Alzheimer's disease | 1 | B. Acute confusional state | 2 |
| C. Major depression    | 3 | D. Vascular dementia       | 4 |
| E. I don't know        | 5 |                            |   |
10. Which of the following is nearly always present in dementia?
- |  |   |                                    |   |
|--|---|------------------------------------|---|
| A. Loss of memory                                  | 1 | B. Loss of memory and incontinence | 2 |
| C. Loss of memory, incontinence and hallucinations | 3 | D. None of the above               | 4 |
| E. I don't know                                    | 5 |                                    |   |
11. Which of the following clinical findings best differentiates vascular dementia from Alzheimer's?
- |                            |   |  |   |
|----------------------------|---|--|---|
| A. Word finding problems   | 1 | B. Short term (2 minute span) visual memory loss | 2 |
| C. Stepwise disease course | 3 | D. Presence of depression                        | 4 |
| E. I don't know            | 5 |  |   |
12. The effect of anti-dementia drugs is to:
- |  |   |
|--|---|
| A. Temporarily halt the disease in all cases                                 | 1 |
| B. Temporarily halt the disease in some cases                                | 2 |
| C. Temporarily halt the disease in some cases but often causing liver damage | 3 |
| D. Permanently halt the disease in some cases                                | 4 |
| E. I don't know  | 5 |
13. Which statement is true concerning the treatment of people with dementia who are depressed?
- |  |   |
|--|---|
| A. It is usually useless to treat them for depression because feelings of sadness and inadequacy are part of the disease | 1 |
| B. Treatments of depression may be effective in alleviating depressive symptoms  | 2 |

C. Anti-depressant medication should not be prescribed				3
D. Proper medication may alleviate symptoms of depression and prevent further intellectual decline				4
E. I don't know				5
14. Which of the following best describes the functions of the Alzheimer's Society?				
A. Central research, information and campaigning role				1
B. Provision of local support and education to carers				2
C. Providing day and home care for people with dementia				3
D. All of the above				4
E. I don't know				5
15. Which one is correct?				
A. Mild dementia- 20- 24 out of 30 points MMSE score				1
B. Moderate dementia – 9-20 out of 30 points MMSE score				2
C. Severe dementia – 6 out of 30 points MMSE score				3
D. None of them				4
E. I donot know				5
15. One of the risk factors for the development of Alzheimer's disease is:				
A. Hardening of arteries	1	B. Age		2
C. Nutritional deficiencies	3	D. Exposure to aluminium		4
E. I don't know				5
16. (Please make a circle for each question)				
		<b>Yes.</b>	<b>No.</b>	<b>DK</b>
A. A physical disease which causes brain cells to die, plaques disrupt message with in brain is called Alzheimer disease		1	2	8
B. Multiple little strokes have damaged particular areas of the brain is called Vascular disease.		1	2	8
C. Abnormal lumps called Lew Body Bodies develop inside nerve cells in the Brain. People with LBD often have delusions, stiffness, tremors, visual hallucinations is called LBD.		1	2	8
D. A progressive disorder of the central nervous symptoms is characterised by stiffness in joints and limbs, tremors difficulty to movement, speech		1	2	8

impairment is called Parkinson disease.

E. Excessive use of alcohol, low level of B1 is a cause to be Korkoffs disease...1 2 8

It affects the most valuable parts of the brain which are used for memory social skill and balance judgment and planning organizing.

F) Huntington's disease means the inherited, degenerative brain disease which affects 1 2 8 the mind and body.

17. Which of the following medication always not using in dementia disease?

- |                  |   |               |   |
|------------------|---|---------------|---|
| A. Ginkgo Biloba | 1 | B. Glantamine | 2 |
| C. Rivastigmine  | 3 | D. Donepezil  | 4 |
| E. I donot know  | 5 |               |   |

18. Which of the following behavioural features of fronto-temporal dementia not specified in diagnostic criteria?

- |                                  |   |                                     |   |
|----------------------------------|---|-------------------------------------|---|
| A. Tau-positive                  | 1 | B. Hyperorality and dietary changes | 2 |
| C. Akinesia, rigidity and tremor | 3 | D. Motism                           | 4 |
| E. Don't know.                   | 5 |                                     |   |

19. Rivastigmine tartrate (Exelon®) Oral; approved for:

- |   |   |   |   |
|---|---|---|---|
| A. mild and moderate Alzheimer's Disease only | 1 | B. moderate, and severe Alzheimer's Disease | 2 |
| C. for mild cognitive impairment              | 3 | D. None of them                             | 4 |
| E. I donot know.                              | 5 |   |   |

20. Side effect of Memantine (Namenda®):

- |   |   |                     |   |
|---|---|---------------------|---|
| A. Headache, Dizziness, Sedation, Agitation, Constipation | 1 | B. Nausea, vomiting | 2 |
| C. Nausea, vomiting, and diarrhoea                        | 3 | D. None of them     | 4 |
| E. I donot know.  | 5 |                     |   |

20. Have you any predictions about the DEMENTIA prevalence? Please mention the number?

- |                         |                  |                 |   |
|-------------------------|------------------|-----------------|---|
| A. In your country..... | B. in world..... | C. I donot know | 8 |
|-------------------------|------------------|-----------------|---|

According to your experience, what, where and how extra resources are needed for dementia diagnose management and care? .....

**Comments.....**

**Thank you for your time!**

## **Appendix-D**

### **Recruitment announcement and consent form**

You are invited to participate in a study entitled “Dementia diagnosis practices, management and care: knowledge, practices and obstacles with health professionals ” Please read this form carefully, and feel free to ask any questions you might have.

Researcher: Krishna Prasad Pathak

Doctoral Student

Macedonia University, Thessaloniki. Email: kaledai28@yahoo.com

Dissertation Supervisors: Dr. Anthony Montgomery, Macedonia University, Thessaloniki. Email- antmont@uom.gr

Address for correspondence: Prof. Dr. Anthony Montgomery, Macedonia University, Thessaloniki. Email: antmont@uom.gr, phone: +30 2310 891308.

### **Purpose and Procedure:**

The purpose of this study is to explore Dementia diagnosis practices, management and care: knowledge, practices and obstacles with health professionals in hospitals. The findings of this study can be useful for nurses and team of doctors by extending understanding of factors associated with the diagnosis, management and care of demented patients in Nepal and the practice of nursing and team of doctors in this unique setting. This study will involve participating in the self-completion of a brief aspects covering questionnaire. The questionnaires will take place at a location of your choice. The questions are in English and answers will be in English version too. The researcher may contact you in person or by telephone up to twice within the 6 months following the survey to further clarification, if needed.

Thank you for agreeing to complete this questionnaire. Most responses only involve you circling a number, and we have avoided questions which might require you to refer to your records. We would ask that when the questionnaires are completed that colleagues do not confer, or crosscheck textbooks for responses, because it is very important that we get an accurate picture of any change in knowledge as a consequence of the interventions. The responses will not be divulged to anyone.

**Potential Risks:**

There are no known anticipated risks to participating in this project. At any time during the interview you may chose not to answer questions. If this occurs, you have the option of withdrawing from this study.

**Potential Benefits:**

The potential advantages of this project include that can be valuable concern to the nurse and doctors diagnosis management and care knowledge and difficulties in the hospitals. Further this study will provide valuable figures in dementia practice settings

**Storage of questions Transcripts:**

The set of answer will be stored and locked in the office of university then after completion of projects years will be destroyed.

**Confidentiality:**

Your information will be for the writing doctoral thesis. Your personal information will be confidential. But your name will be only for researcher confidential and never expose on written work or any documentations.

**Right to Withdraw:**

Always we respect your right to participate or withdraw from the project and your contribution will be remain as volunteer.

**Questions:**

We ask your questions concerning about this study. Please feel free to contact, if you have questions or concerns about this study, please feel free to contact on this address.

Krishna Prasad Pathak- Macedonia University, Thessaloniki. Email: krishnapathak32@gmail.com and Dr. Anthony Montgomery-family name, Macedonia University, Thessaloniki. Email- antmont@uom.gr, phone: +30 2310 891308.

**Consent to Participate:**

I, \_\_\_\_\_, have chance to read the purpose of study and my contribution with the researcher. I have no doubt and agreed to ask questions and receive the answer regarding on my involvement in this study, Therefore this it is acceptable for me without any hesitation. I have read and understand all the norms that I can participate and withdraw at any time. I freely accept to attain in this project.

\_\_\_\_\_  
Participant's Signature Date

\_\_\_\_\_  
Researcher's signature Date

Krishna Prasad Pathak

PhD Candidate

# Appendix E

## Map of Study Area

