



Ministry of Social Security, National Solidarity and
Reforms Institutions

OBSERVATORY ON AGEING
REPORT

Thematic Area Health

Management of Dementia and Alzheimer's Disease
in Subsidised Care Homes

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Managers of Subsidised Care Homes

TABLE of CONTENTS

	Page No.
CHAPTER 1	
Introduction	9
1.0 Background	9
1.1 Aims and Objectives	13
1.2 - Methodology	13
1.3 Time Frame	13
1.4 Sample Size	14
1.5 Data Collection	16
1.6 Constraints and Difficulties in data collection	16
CHAPTER 2	
Literature Review	17
CHAPTER 3	
3.1 Ethical Considerations	30
3.2 Data Entry	30
CHAPTER 4	
Results, and Discussion	
4.1 Results	32
4.2 Discussion	43
CHAPTER 5	
Conclusion and Recommendations	46

List of Tables

1. *Table 1- Name of Home & Address*
2. *Table 2- Difficulty when dealing with residents with AD*
3. *Table3-Measures to improve the QoL of residents with dementia*

List of Charts

1. *Gender*
2. *Age group*
3. *Reason/s for admission*
4. *Stage of dementia*
5. *Living situation prior to admission*
6. *Level of dependency*
7. *Participation in activities*
8. *Doctors visits to resident*
9. *Carer training and experience*
10. *Difficulty when dealing with residents with AD*
11. *Measures to improve the QoL of residents with dementia*

Executive Summary

The Ministry of Social Security, National Solidarity and Reform Institutions has set up an “**Observatory on Ageing**” with the main objective of action oriented research analysis which will help to formulate appropriate policies to meet the needs of an ageing population.

There is ample evidence that the world population is ageing, along with increase life expectancy. As improvement in health care continues, there will be further increase in the longevity of people. People of advanced age have a heightened risk of age related disorders, and one of such disorder is the dementia syndrome. However dementia does not only affect people with this syndrome, but also affects their families, caregivers, including the economic, social and health conditions of nations.

One of the key areas identified by the Observatory on Ageing is Health Care among the elderly. Mauritius, as the world over, is facing an ageing population, with increased pressure on health care and social services and this has resulted in an increased burden of Non Communicable Diseases like dementia. Our study will in the first instance focus on Management of Dementia and Alzheimer’s disease (AD) identified as a new emerging disease. As we do not have any study done on Dementia and AD in Mauritius, this will give us a base line to engage stakeholders and to start thinking more on our strategies for medical and social care for Dementia and AD.

The health team of the Observatory on Ageing has chosen the theme” *Management of Dementia and Alzheimer’s Disease in Subsidized Care Homes* “ , as its first study concerning health care of the elderly, after discussing with the different members of the team and with the Ministry’s high officials.

In Mauritius, Dementia and Alzheimer’s Disease, are still unknown to many health and other professionals and also to the public at large. Mauritius being a demographic challenge, with the elderly, age 65 and above, representing 13% of the total population (approximately 172, 000). In addition,“ rapid ageing population is a main challenge for the health and social care delivery system in terms of provision of geriatric care and support”. The proportion of those aged 65 years and over has been on the rise over the past two decades, with the proportion of females growing faster than men, and this will be a challenge, specially when we consider that dementia and AD tend to affect more women than men , and also the roles of women in caring and being cared for.

The World health Organisation (WHO) and Alzheimer’s Disease International (ADI), an international federation of world-wide Alzheimer Associations, jointly developed a report, *Dementia: a public healthy priority* (2012). The purpose of the report was to raise awareness of dementia as a public health priority, to articulate a public health approach and to advocate for action at international and national levels based on the principles of

evidence, inclusion and integration. The report aims to encourage country preparedness by strengthening or developing policy and implementing it through plans and programmes which enhance dementia care in order to improve the social wellbeing and quality of life of those living with dementia and their caregivers. It was estimated in the World Alzheimer Report of 2009 that Mauritius could have between 4,000 to 7,000 persons with Alzheimer Disease.

The aim of the study is to find out what is the quality of care given to persons with dementia and AD in subsidized care homes, so as to improve long term care for persons with these conditions.

The objectives of the study are:

1. To understand the quality of life of persons with dementia and AD
2. To find out what are the services provided by care homes to residents suffering from dementia and AD
3. To find out what kind of support are given to caregivers looking after persons with dementia and AD.

The first phase of the research is a study on the persons with dementia and AD in subsidized care homes. For the purpose, a questionnaire has been designed, consisting of three sections; A-demographic details; diagnosis of dementia and AD ; B-Situation of the residents ,prior to admission, activities of daily living in the care homes, the stages of his/her disease and treatment Other medical problems and treatment; and C- Particulars on caregivers; training, aptitude, relationship with resident and support.

Officers of the health team visited the care homes and filled the questionnaires with information on the residents from their personal files, after approval of the managers of the care homes. The questionnaires were filled also by interviewing the carers and nurses looking after the residents with dementia and AD. Data entry was done using the SPSS tool and answers were grouped to facilitate entry and collection

This survey was carried in the 20 subsidised care homes and the numbers of residents with dementia and AD were 94, representing 12 % of the residents population in these care homes.

The three objectives were met as we could analyse from the data collected that:

- 1) In the subsidized care homes, residents were well looked after in terms of general care, board and lodging; but as regards dementia and AD; they did not receive a client- centred approach treatment adapted to their conditions;
- 2) There was in general, a lack of specialized services, except in the two homes which catered for severely disabled elderly persons;

- 3) Activities were not specific to residents with dementia and AD;
- 4) Awareness of dementia and AD was limited and most of the managers and carers did not know and understand that it was a chronic brain disease;
- 5) Support to carers was not provided;
- 6) There was no interaction between the health professionals and management and also between them and the carers;
- 7) Families were not involved in the care plan.

More information will be available from this study, when the second phase is done in the Private care homes, as we will be able to compare data and make relevant conclusions. In the third phase of the study collection of data will be done by administering a different questionnaire, to the public through health institutions, Ngo's, private and public health specialists, people in the community, Forces vives, and SCA's, to find out about their general knowledge , understanding and care of Dementia and AD.

Recommendations at this first stage of the study will be in general:

- 1) Dementia and AD being still unknown by many working in care homes, we will need to develop a strategy of awareness to professionals and the public in general;
- 2) Diagnosis of dementia and AD with staging of the disease is most important for the person and families and will help to prepare a dementia care plan adapted to the person and his family;
- 3) Managers of care homes should have personal files for each resident with medical and social reports, and also in it an individual care plan, so as to manage the dementia problems, like communication, mobility, challenging behaviors, feeding problems and last stage of the disease;
- 4) Families should be encouraged to visit and be involved in leisure and reminiscence activities;
- 5) Health and paramedical professionals must be trained in dementia and AD care, in fact, a dementia workforce to be made available to cope with increasing numbers of persons with dementia and AD;
- 6) Activities in care homes need to be improved and standardized, even made compulsory, as residents with dementia and AD, need to have specific activities, to help slow down the progress of the disease and make their quality of life (QoL) better;
- 7) Each care home should have a dementia policy, work with the health and social departments to make sure that residents with dementia and AD get the best possible care and management ;
- 8) Professional and public attitudes to and understanding of dementia and AD need to improve;
- 9) To invest in health and social systems to improve care and services for people with dementia and AD and their caregivers.

10) To start a national discussion on long-term care and management of dementia and AD and to prepare a National Strategy Plan for Dementia and AD for Mauritius.

CHAPTER 1 INTRODUCTION

1.0 Background

The Ministry of Social Security, National Solidarity and Reform Institutions has set up an “**Observatory on Ageing**” with the main objective of action oriented research analysis which will help to formulate appropriate policies to meet the needs of an ageing population.

There is ample evidence that the world population is ageing, along with increase life expectancy. As improvement in health care continues, there will be further increase in the longevity of people. People of advanced age have a heightened risk of age related disorders, and one of such disorder is the dementia syndrome. However, dementia does not only affect people with this syndrome, but also affects their families, caregivers, including the economic, social and health conditions of nations.

One of the key areas identified by the Observatory on Ageing is Health Care among the elderly. Mauritius, as the world over, is facing an ageing population, with increased pressure on health care and social services and this has resulted in an increased burden of Non Communicable Diseases like dementia. Our study will in the first instance focus on Management of Dementia and Alzheimer’s disease (AD), identified as a new emerging disease. As we do not have any study done on Dementia and AD in Mauritius, this will give us a base line to start thinking more on our strategies for medical and social care for Dementia and AD.

Mauritius being a demographic challenge, with the elderly, age 65 and above, representing 13% of the total population (approximately 172, 000).In addition, “ rapid ageing population is a main challenge for the health and social care delivery system in terms of provision of geriatric care and support”. The proportion of those aged 65 years and over has been on the rise over the past two decades, with the proportion of females growing faster than men, will be a challenge, specially when we consider the roles of women in caring and being cared for.

The World health Organisation (WHO) and Alzheimer’s Disease International(ADI), an international federation of Alzheimer’s Associations, jointly developed a report, *Dementia: a public healthy priority* (2012). The purpose of the report was to raise awareness of dementia as a public health priority, to articulate a public health approach and to advocate for action at international and national levels based on the principles of evidence, inclusion and integration. The report aims to encourage country preparedness by strengthening or developing policy and implementing it through plans and programmes which enhance dementia care in order to improve the social wellbeing and quality of life of those living with dementia and their caregivers.

At the 1st ADI Regional African meeting in Mauritius, in September 2012, the Mauritian participants decided to commit firmly to have a country report for dementia and AD, in the initial form of a situation analysis of dementia in Mauritius. Additionally, a strategic plan is expected to be developed in “line with the implementation of health and social programs”.

The report on “Situation analysis of Dementia and AD in Mauritius”, made by Dr J. Hilary Dennis, WHO Collaborator, in December 2013, recommends among important issues like promotion, awareness, prevention, diagnosis, treatment and care of people with dementia, that a prevalence study on Dementia and AD be undertaken.

Improvements in health care in the past century have contributed to people living longer and healthier lives. However, this has also resulted in an increase in the number of people with non-communicable diseases, including dementia. Current estimates indicate 35.6 million people worldwide are living with dementia. This number will double by 2030 and more than triple by 2050. Dementia is a costly condition in its social, economic, and health dimensions. Nearly 60 percent of the burden of dementia is concentrated in low- and middle-income countries and this is likely to increase in coming years. The need for long-term care for people with dementia strains health and social systems, and budgets. Dementia is overwhelming not only for the people who have it, but also for their caregivers and families. It is one of the major causes of disability and dependency among older people worldwide. There is lack of awareness and understanding of dementia, at some level, in most countries, resulting in stigmatization, barriers to diagnosis and care, and impacting caregivers, families and societies physically, psychologically and economically. Dementia can no longer be neglected but should be considered a part of the public health agenda in all countries.

Dementia mainly affects individuals aged 65 years and over, although early onset of the disease is not uncommon. A global estimate of the prevalence of dementia in “older” age groups in 2010 is approximately 1% in persons aged 65- 69 years, increasing to approximately 20% for 80 years and over , and approximately 40% in persons aged 90 years and over (ADI , 2010)

What is dementia?

Dementia is a syndrome due to disease of the brain – usually of a chronic or progressive nature –in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in a large number of conditions primarily or secondarily affecting the brain.

Alzheimer’s disease is the most common form of dementia and possibly contributes to 60–70% of cases. Other major contributors include vascular dementia, dementia with

Lewy bodies, and a group of diseases that contribute to front temporal dementia. The boundaries between subtypes are indistinct and mixed forms often co-exist.

Common symptoms experienced by people with dementia syndrome

Dementia affects each person in a different way, depending upon the impact of the disease and the person's pre-morbid personality. The problems linked to dementia can be understood in three stages:

- Early stage – first year or two;
- middle stage – second to fourth or fifth years;
- Late stage – fifth year and after.

These periods are given as an approximate guideline only –sometimes people may deteriorate more quickly, sometimes more slowly. It should be noted that not all persons with dementia will display all the symptoms.

The early stage is often overlooked. Relatives and friends (and sometimes professionals as well) see it as “old age”, just a normal part of ageing process. Because the onset of the disease is gradual, it is difficult to be sure exactly when it begins.

- Become forgetful, especially regarding things that just happened
- May have some difficulty with communication, such as difficulty in finding words
- Become lost in familiar places
- Lose track of the time, including time of day, month, year, and season
- Have difficulty making decisions and handling personal finances
- Have difficulty carrying out complex household tasks
- Mood and behaviour:
 - may become less active and motivated and lose interest in activities and hobbies
 - may show mood changes, including depression or anxiety
 - may react unusually angrily or aggressively on occasion

Family members become aware of changes and may prompt the person to seek assessment (in pre-diagnostic phase) Caregivers become aware of their caregiving role (often as a result of diagnosis)

- Provide emotional support following diagnosis and when the person is depressed or anxious
- Prompt and remind the person about events, tasks and other things to help them maintain involvement and independence
- Provide assistance with instrumental activities (e.g. personal finances, shopping).

Middle stage

As the disease progresses, limitations become clearer and more restricting.

- Become very forgetful, especially of recent events and people's names
- Have difficulty comprehending time, date, place and events; may become lost at home as well as in the community
- Have increasing difficulty with communication (speech and comprehension)
- Need help with personal care (i.e. toileting, washing, dressing)

- Unable to successfully prepare food, cook, clean or shop
- Unable to live alone safely without considerable support
- Behaviour changes may include wandering, repeated questioning, calling out, clinging, disturbed sleeping, hallucinations (seeing or hearing things which are not there)
- May display inappropriate behaviour in the home or in the community (e.g. disinhibition, aggression)

Caregivers become aware of their supervisory role

- Use communication strategies to aid understanding
- Provide help with carrying out personal care
- Provide help with other activities of daily living such as food preparation, dressing appropriately
- Respond to and manage behavioural disturbance and inappropriate behaviour.

Late stage

The last stage is one of nearly total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious.

- Usually unaware of time and place
- Have difficulty understanding what is happening around them
- Unable to recognize relatives, friends and familiar objects
- Unable to eat without assistance, may have difficulty in swallowing
- Increasing need for assisted self-care (bathing and toileting)
- May have bladder and bowel incontinence
- Change in mobility, may be unable to walk or be confined to a wheelchair or bed
- Behaviour changes may escalate and include aggression towards carer, nonverbal agitation (kicking, hitting, screaming or moaning)
- Unable to find his or her way around in the Home

Significant demands on caregivers as the care recipient becomes fully dependent and loses the ability to communicate needs and wishes

- Provide care, support and supervision around the clock
- Provide full assistance with eating and drinking
- Provide full physical care (bathing, toileting, dressing, mobilizing)
- Manage behavioural problems.

Support for informal care and caregivers

Dementia has an immense impact on the lives of the family, and particularly the person who takes the primary role in providing care. Most care is provided by family and other informal support systems in the community and most caregivers are women. However, changing population demographics may reduce the availability of informal caregivers in the future. The provision of care to a person with dementia can result in significant strain for those who provide most of that care. The stressors are physical, emotional and economic. A range of programmes and services have been developed in high-income countries to assist family caregivers and to reduce strain. The beneficial effects of

caregiver interventions in decreasing the institutionalization of the care recipient have been clearly demonstrated.

The Ministry developed a *Carer's Strategy in 2010*, with specific objectives, among which are :

- 1) To create a pool of formally trained caregivers to respond to the demand of paid carers by families needing support at home;
- 2) To provide basic training to informal caregivers to enable them to provide better quality care to older members of their families;

Numbers of formal carers trained since 2011 is 200 and the numbers of informal carers trained in different regions of Mauritius since 2013 is 500.

The continuous training and support to families coping with Dementia and AD is also one of the objectives of the Association Alzheimer in Mauritius. It runs a Day Care Centre where patients are cared for during the day so that their families can have respite. Also it provides all information and different types of support to the parents so that they can cope at home with their elders with dementia and AD. There is also a parent support group which meets and provides exchange and knowledge to each other. This aims to alleviate their burden of care or strain, that families can experience when having to look after someone with dementia and AD daily over a long period

Existing Services

Other institutions providing services to dementia and Alzheimer's patients:

- I. The Ministry of Health and Quality of Life focuses on treatment in General hospitals and has Outpatients facilities where patients gets a diagnosis and treatment with medications. The Brown Sequard Mental Health Centre, a specialized psychiatric facility, is used for admission of acute elderly with challenging behaviours and mental illnesses;
- II. The Welfare and Elderly Persons Protection Unit of the Ministry of Social Security, National Solidarity and Reform Institutions. Officers posted at the Welfare Unit ensure that Provisions of the Residential Care Home Act, 2003 and Provisions of the Residential Care Home Regulations, 2005 are being respected. They are also posted in Elderly Day Care Centres where they organize activities and support elderly people;
- III. The Medical Unit of the Ministry of Social Security, National Solidarity and Reform Institutions organizes Domiciliary visits and Mental Health assessments in various Homes. It also provides prevention and awareness programmes on health issues in Social Welfare Centres and Health Clubs.
- IV. '*Association Alzheimer*' of Mauritius is the only NGO looking after people with Dementia and AD. Its main objectives are informing and educating the public, raising awareness, providing support to patients and their families, running a Day Care Centre, training of health professionals, and participating in research work.

V. Private care in Mauritius offers a range of services in diagnosis, treatment, psychosocial support and residential facilities for persons with Dementia and AD.

VI F.I.A.P.A (Federation International des Associations des Personnes Agees) carries out training of managers and carers of Homes and Institutions on care for elderly in collaboration with MobiQual (France).

1.1 AIMS and OBJECTIVES

Aim:

To find out what is the quality of care given to persons with dementia and AD in subsidized care homes, so as to improve long term care of dementia and AD.

The objectives of the study are:

1. To understand the quality of life of persons with dementia and AD
2. To find out what are the services provided by care homes to residents suffering from dementia and AD
3. To find out what kind of support are given to caregivers looking after persons with dementia and AD.

1.2 - METHODOLOGY

The study started with this first phase, which has been carried out in 20 subsidized care homes, where elderly residents with dementia and AD are living. The managers of the care homes were contacted by phone and explained the project, an appointment was taken by a member of the health team to go to the care home for the survey.

This is a Qualitative study, where we gathered maximum information on the questionnaires of the residents with dementia and AD, and we analysed these, to look at their quality of life, QoL; the services offered in care homes and what are the difficulties carers have when looking after the residents with dementia and AD.

A desk review of personal files of residents with dementia in 20 care homes to gather relevant information and also filling of questionnaires by interviewing the carers and managers of the care homes

For the purpose of the survey a questionnaire has been designed .It consists of three sections:

1. Section A : residents demographic details; diagnosis of dementia and AD
2. Section B : situation of the residents ,prior to admission, activities of daily living in the care homes, the stages of his/her disease and treatment Other medical problems and treatment
3. Section C: particulars on caregivers; training, aptitude, relationship with resident and support

Data has been collected by retrieving information from personal files of residents with dementia and AD and by interviewing the cares and nurses looking after these residents

The structured interviews were carried with close and open ended questions

Interviews were done by an officer of the health team, questions were asked in English as on the questionnaire, but translated in creole language, whenever there was difficulty understanding. Maximum details were gathered and noted.

1.3 Time Frame

Discussions on the health team topics were done as from March 2013 and subject was decided and approved at the Ministry in May 2013.

Design and preparation of questionnaire were finalized after the health team was satisfied and then submitted for approval in April 2013

Testing the questionnaire was done by the officers of the health team among their colleagues and agreement given in July 2013.

The advisory committee on “Observatory on Ageing” agreed to launch the study in August 2013.

Collection of information done from September to November 2013

Data cleaning and input done from November to December 2013

1.4 Sample Size

The 20 care homes (Charitable Institutions) which are subsidized and having elderly residents were chosen for this study. Only residents with dementia and AD were chosen to be in the study. A total of 94 residents with Dementia and Alzheimer Disease were accounted for from the questionnaires filled.

Table 1.

S.N	Name of Home & Address	Total no of residents		Alzheimer patients	%
		M	F		
1	Bon et Perpetuel Secours Home (Belle-Rose)		62	4	6%
2	Rosie le Meme & Marcel Catherine Homes Quatre-Bornes	19	25	3	6%
3	Krishnanand Shiva Ashram & Lady Sarojini Jugnauth Women's Homes Callebasses	104	43	4	2%
4	Meenatchee Home Nicolay	9	24	2	6%
5	St-Hugues Home Rose-Hill	75		18	24%
6	Gandhi Breedh Home Petit Raffray	34		2	5%
7	Maharana Pratap Ashram	19	6	2	8%
8	Dr Chiranju Bhardwaj Ashram	1	15	1	3%
9	Mere Augustine Home		35	9	25%
10	Leonard Creshire Home-Tamarin & Pierrefonds	52		7	13%
11	Foyer Trochetia	30		14	43%
12	Foolbassea Babooram Ashram	15		4	26%
13	Shradanand Infirmary	69		4	5%
14	St Jean De Dieu Home-Pamplemousses	43		2	4%
15	Currimjee Jeewanjee Infirmary-Male & Female	67		4	5%
16	Ballgobeen Ashram	45		6	13%

1.5 Data Collection

There were three officers of the health team who carried out the collection of data on the questionnaires in different care homes, under the supervision of a team leader. The managers and carers were interviewed. Questionnaires were filled on site.

The data were processed at the Observatory 's office in Rose Hill by the intern under supervision of team leader and the consultant.

1.6 Constraints and Difficulties in data collection

The health team was at its first research project for the Observatory on Ageing. There was a lot of primary work which needed to be done to get the team going. There were changes in their work routine and some time management to be applied.

Although some training was done, there was a need for more practice before going to visit the care homes and collecting the data.

Medical reports with diagnosis were not always available in personal files in care homes, these were assumed to be present for each resident at the start of the study.

All residents did not have a diagnosis of dementia or AD made by their visiting medical practitioners/specialists or by the visiting Mental Assessment Team.

The nursing and paramedical staff were not aware of their residents medical diagnosis, though they could observe signs and symptoms of dementia. They had difficulties understanding the behaviours and communication patterns of residents with dementia.

Some managers of care homes did not even have residents files available for review and data collection.

Lack of understanding and knowledge on dementia and AD by carers and nurses was observed, as they were not conversant with terms used and they informed us that they were not all trained staff in elderly care and dementia care.

CHAPTER 2

Literature Review

The global dementia burden is estimated to be 35.6 million people with 4.6 million new cases occurring annually. However as population ageing is occurring more rapidly in the developing countries and an increasing number of people are living to an advanced age in those regions, the prevalence of dementia will be disproportionately greater in Less Developed Countries (LDCs). At present an estimated 60% of people with dementia live in LDCs, and this is projected to increase to 71% by 2050.

Increases in the prevalence of dementia in Low and Middle Income Countries, and indeed in all regions, will lead to substantial public health burden for the countries. In addition, an accelerated urbanization trend in LDCs is contributing to an increase in diseases of lifestyle, such as diabetes and hypertension- especially in Africa, which are risk factors for dementia.

A lack of primary knowledge about the disease in these countries detracts from an awareness of and policy responses to dementia, as well as management of the clinical and care of burden that arises.

Although an insidious and disabling disease, the diagnosis and management of dementia, predominantly prevalent in the older population, is not a priority for LDC's health care systems.

With an aim to redress the gap in knowledge and lack of response to dementia in LDCs, the *10/66 Dementia Research Group* has established itself as the forefront of dementia inquiries and policy interventions in developing regions. The group contends that although 66 per cent of dementia worldwide occurs in LDCs, only 10 per cent research on the disease and its effects is conducted in the regions. The group has conducted population based surveys (2003-2007) of dementia prevalence and its impact in 14 catchment areas in ten low to middle income countries: Argentina, Brazil, China, Cuba, Dominican Republic, India, Mexico, Nigeria, Peru and Venezuela. New studies have been done in Puerto Rico and South Africa. In addition to establishing prevalence rates, the studies have documented care arrangements for people with dementia and the impact of the disease on caregivers.

What had been established in these studies are:1) A need for increased awareness of dementia; 2) the important role that family plays in the care of persons with dementia;3) a need for increased community support for people with dementia; 4) the lack of healthcare and long term care services for these people; 5) how onerous the burden of dementia related disability is; and 6) how poor or inadequate or indeed non-existent , are responses from government in these countries.

Lack of awareness

An early lack of awareness of dementia prompted ADI, headquartered in the UK, to identify awareness raising in the public among health workers as a global priority (Graham & Brodaty, 1997). A common lack of awareness of the disease has been demonstrated in studies in India, (Patel & Prince, 2001), and showed that while typical features of dementia may be recognized, these features are frequently attributed to explanations such as “childishness” and “weak brain”. None of the studies found any awareness, in the settings in which they were conducted, of dementia being an organic brain syndrome and indeed a medical condition. Rather symptoms of the disease were perceived as a normal or anticipated part of ageing. On occasions, it is remarked that as the terms of AD and dementia are associated with stigma, use of these terms is best avoided, particularly if a person diagnosed with dementia is typically refused admission to an old aged home.

A study in a township around Cape Town, found very little, if any awareness or understanding of dementia as a medical condition or illness. People interviewed described signs and symptoms typical of the disease, but lacked knowledge that the signs represent a clinical condition. Many ascribed them to old age and perceived nothing could be done about them. Others attributed the symptoms to witchcraft (Ferreira & Makoni, 2002).

In Africa, medical doctors, largely at the primary care level lack awareness of and training in treating dementia, and are found disinclined to investigate symptoms of dementia- or to refer patients with the symptoms for investigation. They too, simply ascribe the symptoms to old age. Nurses who screen such patients at the primary level do the same, and inform patients that no medications are available for their ailment.

A general lack of awareness of dementia and potential responses, in LDCs leads to the following situations: 1) few families with an afflicted elder seek help from orthodox health care services; 2) no structured training is available or offered to health practitioners on recognition and management of dementia; 3) lack of advocacy to government and policy makers to provide responsive dementia care services; 4) families receive little or no support or understanding from other individuals or agencies, resulting in stigma, neglect and abuse; 5) older people with dementia are often not accepted for residential care and are denied admission to hospital facilities for fear of bed blocking; 6) disturbed behavior in demented individuals, which is common, is poorly understood, and leads to stigma, blame and distress for caregivers.

In parts of Africa, persons with signs and symptoms of dementia, specially elderly women who live alone and have certain physical characteristics, are branded as witches.

In MDCs awareness of dementia is growing rapidly, with the media playing an important role in spreading the information. In South Africa, media coverage of dementia remains poor, and is mainly linked to a single day in the year-World Alzheimer's Day (September 21). Here too, media intermittently reports on what Association Alzheimer does, specially during the Alzheimer month in September.

What do we mean by dependence (needs for care)?

Dependence (sometimes referred to as needs for care) is defined as "*the need for frequent human help or care beyond that habitually required by a healthy adult*". The nature of the help or care has been further defined as: "*beyond that would be expected by virtue of family or social ties*". There is naturally a close relationship between dependence (needing help and care) and caregiving (the provision of that help and care). Caregiving has been defined by Schulz as:

"...the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting".

Dependence arises from disability, but disability represents only a limitation in the performance of activities of daily living (for example cooking, shopping, laundry, household finances, washing, dressing, toileting and eating. Thus disability may be experienced without dependence, but dependence always implies some degree of disability, usually of a more advanced and severe form. Dependence also requires the presence of one or more health conditions to account for the underlying disability.

What people can do, or in fact habitually do is modified by cultural expectations, and gender, and changes with age. This can complicate the definition and assessment of dependence, and its comparison across countries and cultures. Dependence may get worse, remain stable or get better over time. The outcome depends to a large extent on the nature of the health condition/s that are contributing to the underlying disability and their prognosis. For people with dementia, the onset of needs for care and caring is hard to define; it emerges naturally from support customarily given and received before the onset of dementia and may precede or post date a formal diagnosis. Needs to care typically escalate over time, from support for instrumental activities of daily living (IADL), to personal care (core ADL), to what may almost be constant supervision and surveillance.

The natural course of needs for care for people with dementia is a marked progression over time, compared to no progression, and indeed recovery of independence among those with other health conditions.

Dementia and cognitive impairment are the leading chronic disease contributors to disability and particularly, dependence among older people worldwide. While older people can often cope well and remain reasonably independent even with marked physical disability, the onset of cognitive impairment quickly compromises their ability to carry out complex but essential tasks and then even to meet their basic personal care needs. The need for support from a caregiver often starts early in the dementia journey, intensifies as the illness progresses over time, and continues until death.

Caregiving by family members

Multi-generational residence is the norm in LDCs, and in most cases family members are the primary care givers to elderly relatives with dementia. A study in South Africa found that 79 per cent of a memory clinic's clients were being cared by family members (Kalula, 2010). In countries in South East Asia, adults children or children –in-law are the most common caregivers to a demented relative. In Mauritius, people with dementia /neurologic disorders are cared for family caregivers in their personal homes, followed by residential care homes and then in hospitals or private clinics.

Caregiving may be a source of enormous strain on a caregiver- particularly when little or no formal help is available, as in LDCs, they are ill-prepared and ill-equipped for caregiving tasks, and are unsupported. Caregiving to persons with dementia without support is also more onerous than caregiving to persons with other health conditions. Behavioural problems manifested by demented elders are a main contribution to the burden of care (Ferri et al, 2004).

The availability of family members in LDCs to help with caregiving has been on a decrease due to internal and international migration of employable members, declines in fertility, and women's increased participation in the workforce (Prince et al, 2007).

The majority of LAMICs, particularly low income countries, have no social pension system, neither do they provide any financial help for persons with dementia or their caregivers, financial help from family members was the main source of income. In Mauritius, all elder persons receive a non contributory basic retirement pension and those with dementia can also receive a carer's allowance, which can help them financially, but are often denied due to lack of training of health and social professionals on needs of elders with dementia. And often a caregiver has to forego paid employment to care for a demented elder, as well as increased expenditure on the elder's care needs, this put a particularly strain on affected house-holds in low income countries. In South Africa, although a small caregiver allowance (grant-in-aid) is payable to an older person with dementia to be used by the caregiver, few are aware of and access this grant.

Community Support

Although the prevalence of dementia is increasing rapidly in LDCs, the awareness of dementia as a clinical condition that merits special attention from health and social care providers is severely lacking among the public and the professionals. Care for dementia patients in these countries is mainly informal, with family members, wherever available, doing the largest part as caregivers, unsupported by formal structures. There is little or infrequent respite care for caregivers.

Given a lack of formal, or government driven responses to the support needs of carers of persons with dementia in the majority of LDCs, the non-government sector (ie NGOs) plays a critical role in making available community based care and support to these persons (WHO, 2005). Such services are largely organized and offered by Alzheimer's Associations and their agents, which function broadly under the umbrella of Alzheimer's Disease International (ADI) and its associations in 79 countries. Since 1984, ADI has progressively built and strengthened these associations, and enhanced their capacity to meet the needs of people with dementia and their families. National associations provide a platform for engagement between clinicians, researchers, caregivers and people with dementia. They raise funds, disseminate information, and act as a powerful advocate to the government, policy makers and the media. Association Alzheimer in Mauritius since 2008, is engaged in formal and informal training and education of carers, towards the achievement of a better understanding of and improvement of care for persons with dementia. It operates a Day Care Centre for persons with dementia, where diagnosis and management is done and also supports family caregivers by giving short respite. However, the centre is centrally situated in an urban area and the need for support groups and day care facilities are increasing in rural areas.

Healthcare and Long-term care services

In large number of LDCs, primary healthcare services often fail to meet the healthcare needs of older persons in general and persons with dementia in particular (Prince et al , 2007). Healthcare services tend to be clinic based, and focus on acute and "treatable" conditions- hence exclude dementia. Even the basic curriculum in training of health professionals in the diagnosis and management of dementia is underdeveloped.

Centralised hospitalized based services provide limited care to a small number of patients with serious mental illness, for the rest the burden of care falls on the family, the community and traditional healers. Transport difficulty, long journey and long waiting at a clinic are barriers to help seeking for demented older persons. Even if the clients are able to come to a primary healthcare clinic, the assessment and treatment they receive is likely to be oriented towards acute rather than chronic conditions. At time a diagnosis of dementia may be made specifically to exclude an older patient from receiving care.

The role of medical specialists in responses to dementia within the healthcare system also needs consideration and planning. Most LAMICs have an insufficient number of specialists (psychiatrists, neurologists, eldercare physicians) dedicated to dementia care. In Mauritius, in the public healthcare service, there are 30 Psychiatrists, 2 Neurologists, 35 Psychologists, 1,200 general practitioners, 31 psychiatric nurses, 2,900 general nurses, 3 Social workers and 7 Occupational therapists, who are involved in mental health care and care of people with dementia.

General nurses in the private sector have not received refresher training courses in dementia. Twenty doctors of the Medical Unit were trained 3 years ago in diagnosis and management of dementia and AD (Ministry Social Security, 2010)

There is no specific dementia facility in Mauritius and no Geriatrician available in the public healthcare service. There are five regional hospitals with psychiatric outpatients and liaison services on the island, where people with dementia are seen and referred to, but there is only one regional hospital in Flacq, which has psychiatric beds which may admit patients with dementia. Also elderly persons with challenging behaviors are sometimes admitted at the Brown Sequad Mental Health Care Centre.

Coordination of dementia healthcare and diagnostic gap is evident as there are: 1) little or inadequate interaction between psychiatrists and general practitioners; 2) inadequate interaction between psychiatrists and general nurses; 3) inadequate interaction between psychiatrists and caregivers; 4) people with dementia are diagnosed between middle and late stages; 5) psychiatrists and neurologists are the most likely to make the diagnosis of dementia.

Even when specialist assessment of such persons is conducted, the provision of drug therapy for dementia is a challenge in most LDCs. Dementia drugs that are used to improve cognitive function and treat underlying depression and /or behavioural disorders, are exorbitantly expensive in LDCs, and beyond the reach of the majority who might benefit from them. In Mauritius, drugs that modify cognitive function are neither on essential drugs lists for public healthcare facilities, nor supported by all private health insurance companies. In any case, the majority of Mauritians, have no health insurance cover, let alone persons with dementia, to access drugs through health insurance.

Burden of dementia related disability

The incidence of disability is typically higher in the older population, with multiple physical, mental and cognitive disorders and co-morbidity. Demographic ageing and the health transition has led to an increase in the number of persons who will live longer and be at risk of dementia-itself a disability. An adequate response to these trends calls for policies to:1) prevent disability and thus dementia through the control of chronic

diseases;2) limit disability through more active community based rehabilitation; and 3) manage disability through universal access to long term care (Sousa et al, 2009).

A study in Goa, India, showed that old age homes in that country, as a rule do not admit people with a permanent disability and specifically exclude persons with dementia. Ostensibly, they claim, they do not have the facilities or manpower to care for high dependency individuals. In South Africa, long term care facilities are sparse and unevenly distributed between urban and rural areas, with most facilities in urban areas, thus excluding people from rural areas. The growing number of persons with dementia and the diminishing availability of family caregivers will translate into a heightened demand for residential care.

The policy on ageing in Mauritius promotes active ageing and encourages family caregivers for elders with chronic conditions. Domiciliary visits are provided monthly to all those over 90 years old and to those above 75 years old who are bed ridden. Residential Care Homes (some 50 registered) are legislated under a Residential Care Homes Act 2005, to provide a quality long term care for the elders with chronic conditions and dementia.

The majority of people with dementia are living at home and even if they are well cared for by family caregivers, they are at high risk of abuse and neglect- an increasing trend (WHO, report on health and violence,2002). All the more, if a demented person lives alone, it is a clear signal for his/her relocation to long term care.

The WHO report on Dementia "*a public health priority*" (2012), in its chapter on caregiving and caregivers summarises the following points:

- Most care to people with dementia is provided by informal, unpaid caregivers who include spouses, adult children, daughters and sons in law and friends. Women are far more likely to be the caregivers in all countries. However, changing population demographics may reduce the availability of informal caregivers.
- The provision of care to a person with dementia can result in significant strain for those who provide most of the care. Support is needed and includes information to aid understanding, skills to assist in caring, respite to enable engagement in other activities and financial support.
- A range of programs and services have been developed in high income countries to assist family caregivers and to reduce strain. There is an urgent need to develop and implement an array of low cost or no cost government supported services within an accessible infrastructure, so that even those with significant barriers to accessing services will be able to do so if motivated.

- Information and education campaigns for the public –including people with dementia, their caregivers and families – aimed at raising awareness, improving understanding and decreasing stigmatizing attitudes should help accessing and using services.

Long-term care services and dementia

What is long-term care?

Long-term care has been defined by WHO as “ the system of activities undertaken by informal caregivers and/or professionals to ensure that a person who is not fully capable of self care can maintain the highest possible quality of life, according to her/his individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfillment and human dignity.

Within the concept of long-term care, it is implicit that the physical, mental or cognitive problems of the person that lead to loss of independence are such that the care is likely to be required for an extended period of time, although what exactly constitutes long-term is generally not explicitly defined. Therefore the types, levels and duration of support required may be difficult to predict and will need to be reassessed regularly. There is no unitary long-term care system; different agencies will be involved in providing, supporting, organizing and financing care. The family will always have the central role, supported to a greater or lesser extent by formal professional or paraprofessional care services. Care can be provided at home, in the community, or to a resident of a care home.

The impact of care giving in dementia can be practical (between 14 hours of ADL alone and 43 hours of ADL, IADL, and supervision weekly); psychological (caregivers physical health and psychological well being); and economic (cutting back or giving up on work to care).

Home care or care in a care home

Care homes for people with dementia typically comprise residential care homes, nursing homes and dementia special care units. These are often referred to in the literature as institutional care. In high income OECD countries, more than one half of all care recipients aged 80 years or over receive care at home in most countries, and only one third of all long term care users receive care in care homes. People with dementia are over-represented among care home residents. The mean proportion estimated to live in care homes was 34% in high income countries, but only 6% in low and middle income countries (ADI report 2010).

Reasons for moving into a care home

Several empirical studies have been conducted to identify factors that predict transition into a care home. Other than the obvious, that transition into a care home is associated with cognitive impairment and functional incapacity, is more likely to occur, when the care recipient and caregiver are older, when the caregiver experiences psychological distress or strain, and has expressed a wish for the care recipient to move to a care home.(ADI report 2011). In UK, most common reasons given by caregivers for recipient admission to care home, were :1) inability to cope with increasing care demand; 2) could no longer live independently, needed 24hr care;3) safety issues; 4)advised by health and social care services; 5) challenging behavior(aggressive, abusive);6) caregiver had issues of their own(failing health); and 7) personal care or hygiene issues(incontinence).

Care homes have an important part to play in the long term care system, and should not necessarily be seen as a last resort, to be avoided wherever possible. The relevance of care homes is not limited to high income countries. The provision and use of care homes in low and middle income countries is currently very limited, but growing, particularly in urban settings in middle income countries. In many parts of the world, the alternatives to family care are charitable or state provided homes, where care is highly institutionalized. However, care homes, previously reserved for the “three no’s” (no children, no income, no relatives) are now less stigmatized, open to all, and proliferating rapidly in cities, particularly in the private sector.

There are other important long term care services in the continuum of dementia care; 1) respite care is the temporary provision of care for a person with dementia at home, or in a care home by people other than the primary informal caregiver; the rationale is to give the primary caregiver a break from the caregiving responsibilities; 2) end-of-life care(palliative care) is provided in only 9% of people with dementia at the end of life on acute medical wards; dementia is not often thought of as a terminal illness that requires specialist care; the lack of specific dementia training for staff working in end of life facilities could play a role in this;

All the various components of the long-term care system for people with dementia; informal family caregivers, formal home care, respite care, residential care, nursing homecare, dementia specialist care units, and end of life care should form part of a seamless continuum of provision across the course of the illness, from the time of first help-seeking and diagnosis, to the death of the person with dementia, and beyond.

However, there are many barriers to achieving this objective including;1)late stage or no diagnosis of dementia is made, with consequent missed opportunities for effective intervention in the early stages of the illness and advanced care planning; 2) the lack of continuity of care post diagnosis, meaning the families have to struggle to re-establish

contact with services when problems begin to arise; 3) the lack of coordination and integration of services, particularly between health and social care service providers, and often bewildering range of agencies with whom people with dementia and caregivers must interact; 4) the limited opportunities for people with dementia to express their preferences for how they would like to be supported and cared for; and 5) insufficiently person centred packages of care, meeting the individual and particular needs of people with dementia and their caregivers. However, cost containment is likely to be a fundamental driver of long term care policy at least in high income countries.

Quality of care

In 2009, the Department of Health in England, enunciated a bold vision for the future of care services for people with dementia, in its National Dementia Strategy, "Living well with dementia". The agenda was subsequently formalized by the National Institute for Health and Care Excellence into a series of ten quality standards for supporting people to live well with dementia. (NICE 2013). Many, mainly high income countries are beginning to make significant progress towards realization of these goals. In other settings, awareness is much lower, and dementia is yet to be recognized as a leading priority for health and social care; available resources are few and service development in its infancy.

Four priority areas from evidence based interventions and practices are highlighted for action towards quality of care: 1) Measure and monitor the quality of care; 2) promote autonomy and choice (with four subsections; planning ahead, making information available to consumers, incorporate service users values and preferences into care, make care person-centred); 3) coordinate and integrate care for people with dementia; 4) value and develop the dementia workforce.

Quality of life (QoL)(encompassing different domains; emotional, physical, mental and environmental; as a potential indicator of quality of care) is considered nowadays to be a crucial outcome measure for health service research. Several scales have been developed to assess QoL in dementia. The DEMQOL, quality of life scale, is one example of such a scale, its items reflecting those areas that British people with dementia considered important to their QoL. The self reported QoL of people with dementia does not seem to change with the passage of time or clinical progression of dementia. This is, in many ways, a remarkable finding, since clinical outcomes (cognition, functional ability and neuropsychiatric symptoms) tend to show progressive deterioration. Caregiver assessments of the quality of life of the person with dementia do seem to show progressive deterioration, associated with cognitive and functional decline, suggesting that their ratings may be influenced by perceptions of clinical decline.

Currently very little is understood about the factors that influence self reported QoL in dementia. More attention has been given recently to the understanding of how the characteristics of care homes may influence the QoL of individual residents. QoL was assessed according to residents sense of comfort, autonomy, privacy, dignity, meaningful activity, relationships, food enjoyment, security, functional competence and spiritual well being. For residents with cognitive impairment, homes could mostly be distinguished in terms of their residents perceptions of QoL relating to functional competence, dignity, security and meaningful activity. The average number of hours of certified nursing assistant and activity personnel staff time per resident per day had a strong positive relationship with resident QoL. Nursing assistants provide the majority of hands-on resident care in nursing homes, including tasks that are deeply personal and strongly connected to individual dignity, such as bathing, toileting, dressing and feeding. Features that might increase resident QoL, include specialized staff training, reduction in environment stressors, frequent use of private rooms, smaller unit sizes, the increased availability of natural light and flexible resident routines.

What is dementia workforce?

People with dementia certainly need informed understanding and support from all the health, welfare and social care agencies that they come into contact with, not only from a specialist dementia service.

Therefore, basic curricula for undergraduate professional qualifications, and continuing professional development for doctors, nurses, therapists, other relevant health service staff and social care staff should all contain modules on dementia care. A lack of knowledge and skills in the direct care workforce can lead to harmful, neglectful or abusive care practices that add rather than alleviate the problems experienced by the person with dementia and their family caregivers. Providing adequate training and support is likely to have wider benefits beyond improvements in the quality of care delivered; staff morale should be improved, and recruitment and retention problems eased. Developing a stable team of staff, with the right attributes and skills, and keeping them motivated should be core objectives for the managers of care services. However, reports from both sides of the Atlantic underline the parlous state of training and preparation for direct care workers. A review published in 2000, reported that the minimum training provided to direct care workers had very little focus on issues specific to dementia care. Direct care workers in nursing homes were unlikely to receive adequate dementia training due to insufficient administrative support; however evidence suggests that staff training programs to improve quality of dementia care in nursing homes are effective. The five areas that were most commonly mentioned as deficiencies were: responding to challenging behaviours, use of anti psychotics, and alternatives; recognizing pain in people with dementia; suspected abuse of people with dementia, and emergency first aid.

Professionalism will come about, in part when training and acquisition of skills is seen as a continuing process of career development, and a striving for excellence rather than merely a question of meeting minimum regulatory standards. It should be noted that concerns have been expressed that by “professionalizing” a still rather easy sector to get in, rigidity may be introduced into jobs that are currently attractive because of their flexibility, hence harming recruitment. The Netherlands and Japan, which have put emphasis on professionalizing the sector, have been successful at creating a large workforce.

In an effort to drive up quality care, expectations placed upon direct care workers are rising, including that they should be trained and qualified to a higher level. Despite this, these have been low wage jobs. With remuneration close to minimum legal wage levels, pay is often not sufficient to support an adequate standard of living. There is now ample evidence that the chronic undervaluation of social care has important adverse consequences to those working in the sector, service providers, and their clients.

In low and middle income countries information on the paid workforce for long-term care is for the most part lacking. It is often said that family caregivers are the cornerstone of the long-term care system for people with dementia. All caregivers, paid or unpaid should be valued and recognized by society for the essential, difficult and demanding work that they carry out, and recompensed appropriately. Incentives need to be built into the system to encourage family caregivers to continue to provide quality care at home, and to promote retention, skills development and career progression among paid care workers.

Financing long-term care for dementia

In the 2010 World Alzheimer report, Alzheimer’s Disease International estimated the annual societal costs of dementia worldwide were \$ 604 billion. The costs of dementia included three components: the direct costs of medical care, the direct costs of social care, and the indirect costs of informal care provided by unpaid family caregivers. Dementia has an enormous impact on socio economic conditions worldwide. The total cost as a proportion of GDP varied from around 0.2% in low income countries to 1.2% in high income countries. The distribution of total costs between sectors was also different in countries with different income levels. In low and middle countries direct social costs are small and informal care costs predominate. In the ADI world wide survey of care home utilization conducted for the 2010 World Alzheimer report, the proportion of people living in care homes was significantly higher in high income countries than in low and middle income countries.

Future trends in the cost of dementia are notoriously difficult to predict and largely speculative. Most studies that have attempted this have simply factored in projected increases in the numbers of people with dementia, assuming that age specific prevalence,

patterns of service utilization, and unit costs remain constant. Thus ADI in its 2010 report predicted an 85% increase in worldwide societal costs from US\$604 billion to US\$1,117 billion by 2030.

The looming crisis in long-term care funding

In most low and middle income countries, long-term care policy is premised on the questionable assumption that informal provision will suffice. Standard & Poor's now considers global ageing to be the dominant threat to global economic stability, predicting that without sweeping changes to age-related public spending on health and social care, sovereign debt in developed economies will soon become unsustainable. How affordable and sustainable are the current levels of provision for long term care given the large projected increases in the numbers of older people with needs for care, coupled with decrease in the size of the working population?

How can the challenge be met?

In the last chapter of the World Alzheimer Report 2013 "*Journey of caring* ", suggestions are made, so that we can start reflecting upon: 1) By bolstering social protection for all older people in low and middle income countries; 2) by generating a second demographic dividend; 3) by pooling risk; 4) by ensuring that long-term care schemes are 'fully funded'; 5) by rationing (targeting) of public spending on care; 6) by supporting and incentivizing informal care by family members.

WHO proposes a national discussion using the document "*Towards an International consensus on Policy for long-term care of the Ageing*" (2000), which describes principles to inform policies for sustainable programs in long-term care that are consistent with the priorities of countries at different levels of development.

CHAPTER 3

3.1 ETHICAL CONSIDERATIONS

As residents were not interviewed directly, there was no need to get consent from the residents or their relatives and also we did not need to get approval from an Ethics Committee for this type of study.

Prior to visiting the care homes, appointment was taken by the officer with the manager and the study explained, so as to get access to the personal files of residents.

Carers were interviewed in the care homes, taking into consideration their availability and time constraint.

3.2 DATA ENTRY

The package used to make data entry is the SPSS

There were 31 variables identified

Questions were mainly open ended and grouping was done for these as follows:

Sections A-Particulars of residents

Which age group, gender, name of care home, reasons for admission

How many residents in care homes with dementia and AD

When the diagnosis of dementia or AD was made and at what stage of dementia the resident was at according to the medical records.

Section B –Situation of the resident prior to admission

What was the resident living situation prior to admission and did he/she have family caregivers?

The level of education and occupation of the resident

Participation in daily activities and level of dependency of the resident in the care home

Types of activities available in the care home

Section C- particulars of the carer

The training and the length of experience of the carer

Is the carer looking after residents with dementia only or after others also; The relationship with the resident is to find out about satisfaction in job; The resident's aggressivity level and possible causes of aggression in that particular resident, how they are coping; The difficulties the carer can encounter when dealing with any dementia resident in the care home; The measures to be implemented in the care home to improve the quality of life of residents

Some open ended questions have been worked out so as to get a common answer, as there were many different answers. The grouping of common answers have been done as such:

Can you identify possible causes of aggression?

ANS 1: personal hygiene can comprise of either bathing, changing of diapers and changing of clothes

Ans 2 : intake of food, do you want to eat, do you want to be fed, do not want to take medicines.

Ans 3 : signs of nervousity, do not want to listen , is authoritative, non acceptance of illness.

What in your opinion is most difficult when dealing with residents with dementia and AD?

Ans 1 : communication problem can comprise of don't want to listen to carers, tend to forget everything and unable to understand things.

Ans 2 : Movements, some have restricted movements and carers have difficulty in changing their clothes, others move a lot, some try to run away from the home, they want to walk away and forget how to come back

Ans 3 : personal hygiene

Can you suggest any measure that could improve the quality of life of residents with dementia and AD?

Ans 1: awareness and training of carers on dementia and AD

Ans 2: specialized services with specialists in geronto-psychiatrists and gerontology

Ans 3: More leisure activities for residents, outings , meeting family and friends

CHAPTER 4

RESULTS and DISCUSSION

4.1 RESULTS

Numbers of residents with dementia and AD

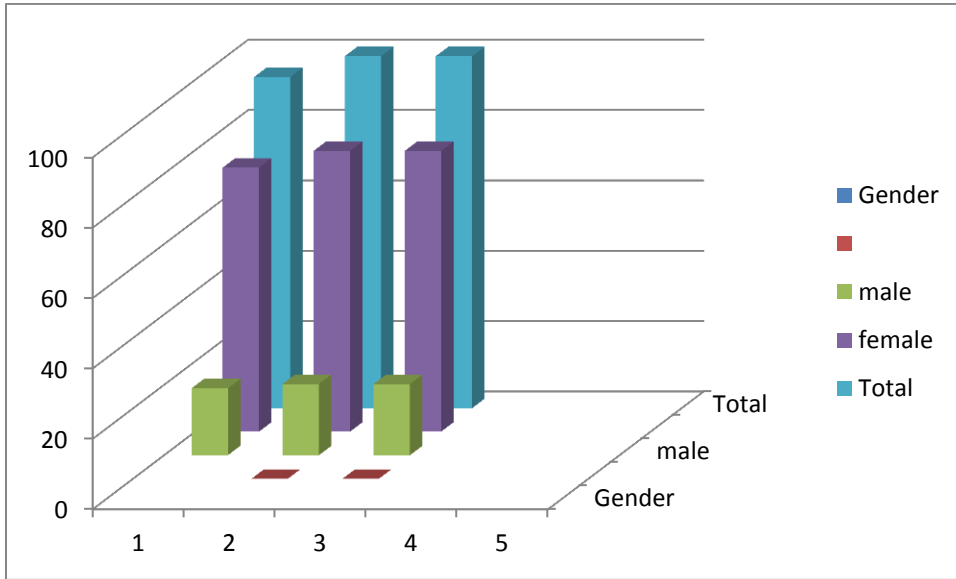
There are 94 residents with dementia and AD in the 20 care homes visited for this study. There were a total 792 residents in these 20 care homes. This represents about 12% of the total population of these care homes having dementia and AD. The percentage of residents with dementia and AD, ranges from 2% in Calebasses care homes(a residential care home) to 43% in Foyer Trochetia (a specialized unit for severely disabled elderly persons) care home. There are 3 care homes, namely St Hughes, Mere Augustine and Foolbassea Babooram Ashram, which have 24%, 25% and 26% respectively. One care home, Ballgobeen Ashram has 13% of residents with dementia and AD and the remaining nine care homes having 3% to 8% of residents with dementia and AD. Our figures are similar to what has been found in LAMICs and higher to what is seen in African countries.

Majority of persons with dementia and AD are being cared in their personal homes. In general, in residential subsidized care homes, there are fewer persons with dementia and AD; whereas, in residential subsidized care homes with specialized services, there are more persons with dementia and AD. This can be explained to the fact that persons with dementia and AD are not generally admitted in residential care homes and in fact, at the early and middle stage of the disease, it is not a reason for admission. But later when they are more incapacitated, the family caregivers cannot cope and will admit them in a specialized care home.

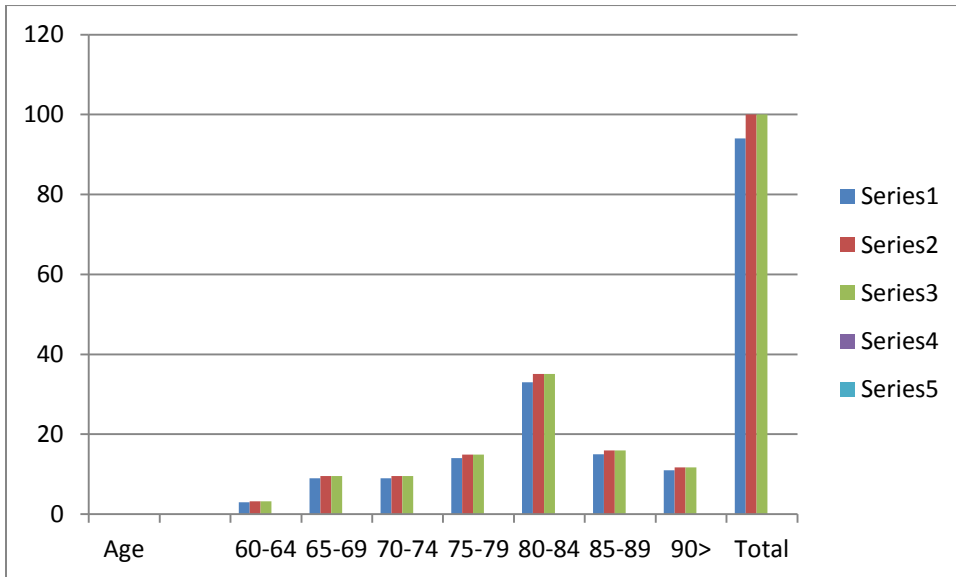
The importance of understanding that dementia and AD are conditions that are progressive and will demand more support in later stages. Numbers of persons with dementia and AD will increase as our population is ageing, and this percentage of 12 % with dementia and AD in subsidized care homes will probably double in the next 15 years by 2030. Though education and training of carers, both informal and formal, will be a must for the health and social sectors to invest into, there is an urgent need for policy makers to start the national discussion on dementia and AD, so as Mauritius will have a National Strategy and Plan for dementia and AD.

Gender

There are 20 male and 74 female residents with dementia and AD in these 20 care homes. This reflects that more women are getting older and when they cannot continue to cope at home they will be admitted in a care home. Also dementia and AD has been found to be more common in females, the ratio being 4:1 for female to male.



Age group



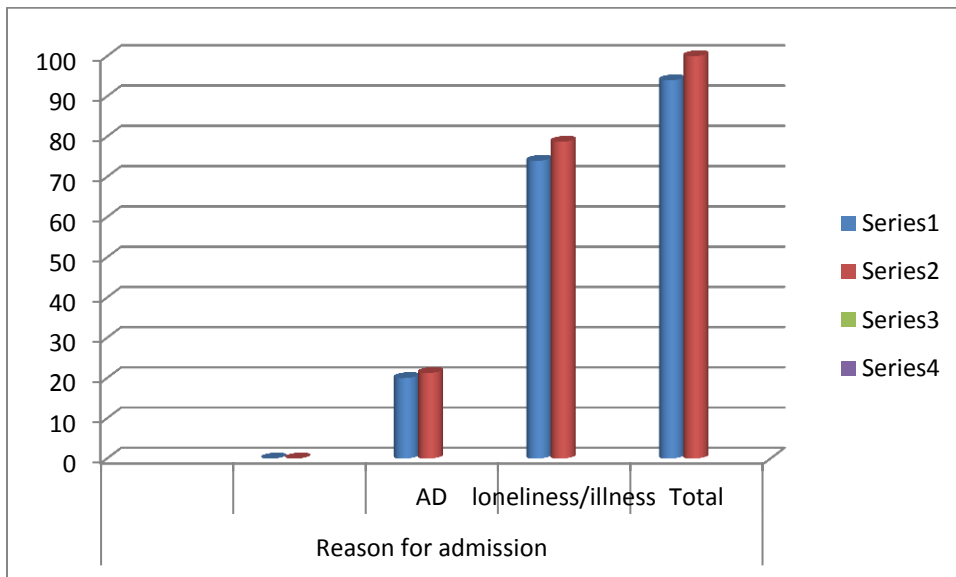
Majority of the residents are in the age-group 80-84 yrs and 85-89 yrs old. Again confirming that as one gets older the risk of having dementia and AD is higher.

Marital status

Two thirds are either single, widow or widower and one third are married. It is important to note even when married, someone with middle or late stage dementia and AD will be admitted, confirming that dementia and AD is a chronic, debilitating disease, that has lots of demands on caregivers, and when one cannot be cared for at their own house, there will be a need to have an admission into a residential care home.

Reason/s for admission

The first reason for admission in the subsidized care homes was loneliness; secondly, if someone was suffering from an illness related to old age, including dementia and AD. Being alone and having dementia and AD is the worst scenario, as research has shown that progression of the disease will be rapid and condition will worsen with a severe disability that will require constant care .

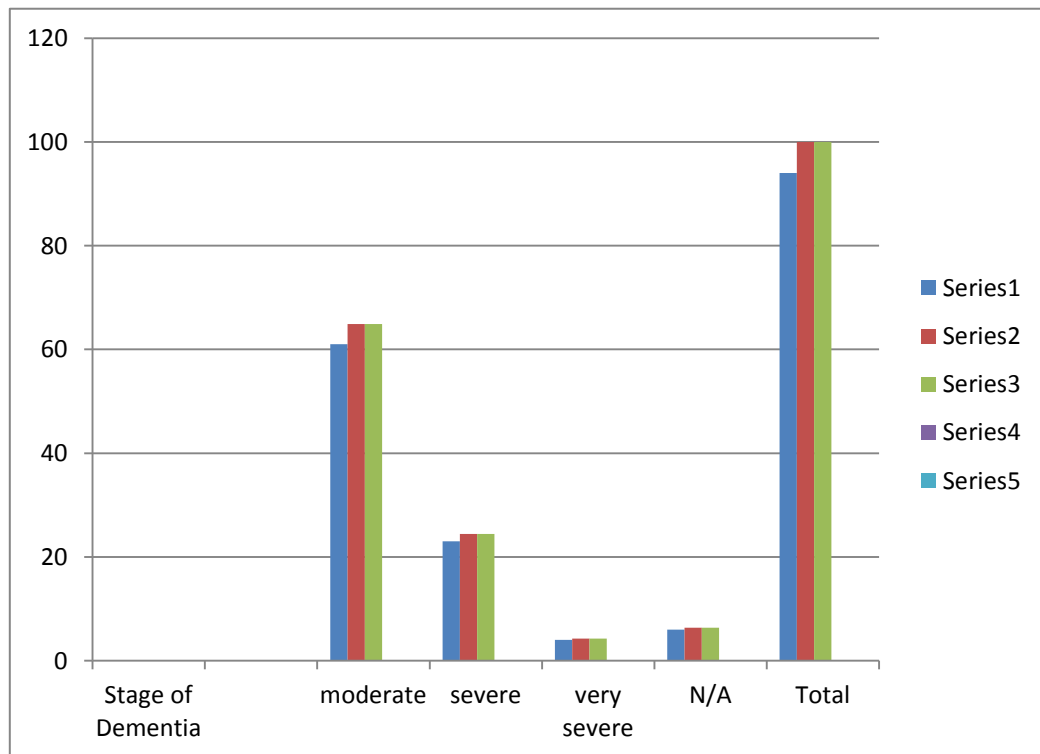


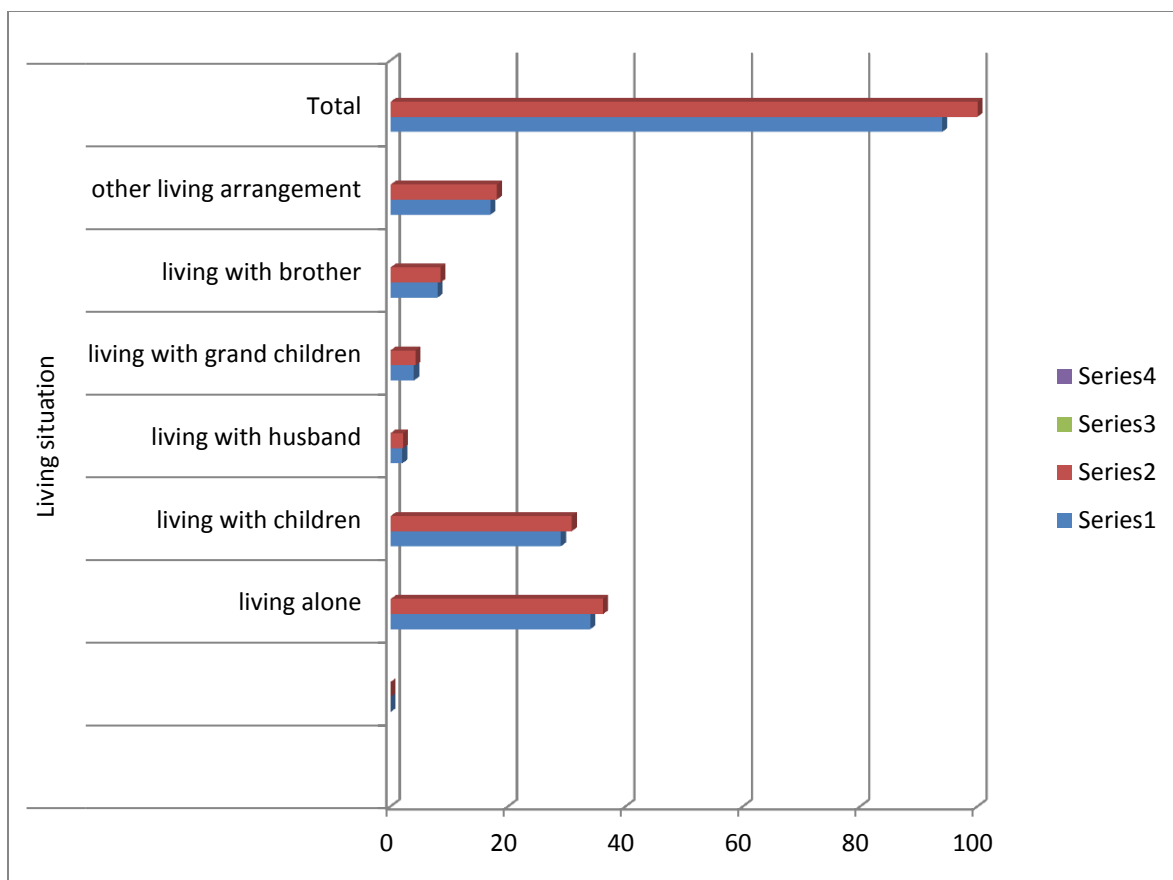
Diagnosis of dementia and AD and stage of dementia

About two thirds of the residents with dementia and AD, had a diagnosis report by a medical practitioner in their files, whilst the rest did not have a diagnosis. Two residents had been diagnosed more than 10 years ago with dementia and AD. Most were diagnosed in the last 2-3 years.

The carer or the nurse rated the stage of the disease from what she perceived as either 1st stage with no impairment to moderate, 2nd stage as severe and 3rd stage as very severe. There was one resident in 3rd stage, but most were in 1st and 2nd stages of dementia and AD.

Stage of dementia





Living situation prior to admission

The living situation prior to admission of a third of the residents was living alone and a third of the residents was with children, which both correlate with reasons for admission.

Family visits

There were 25 residents who never received visits from family members. The majority of residents had visits, even if nearly half of them had visits rarely. Keeping the family ties are important and also this can bring memories and good souvenirs.

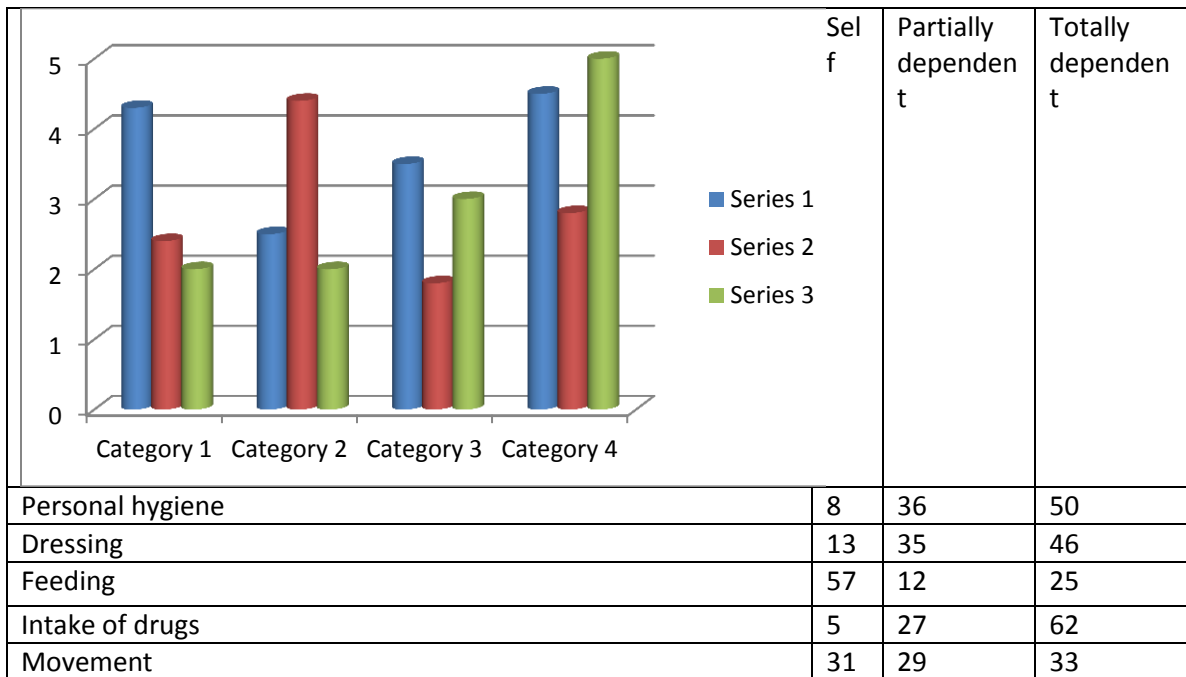
Education level and employment prior admission

There were only two residents who had done up to secondary level education. Most achieved up to primary school level and some did not go to school.

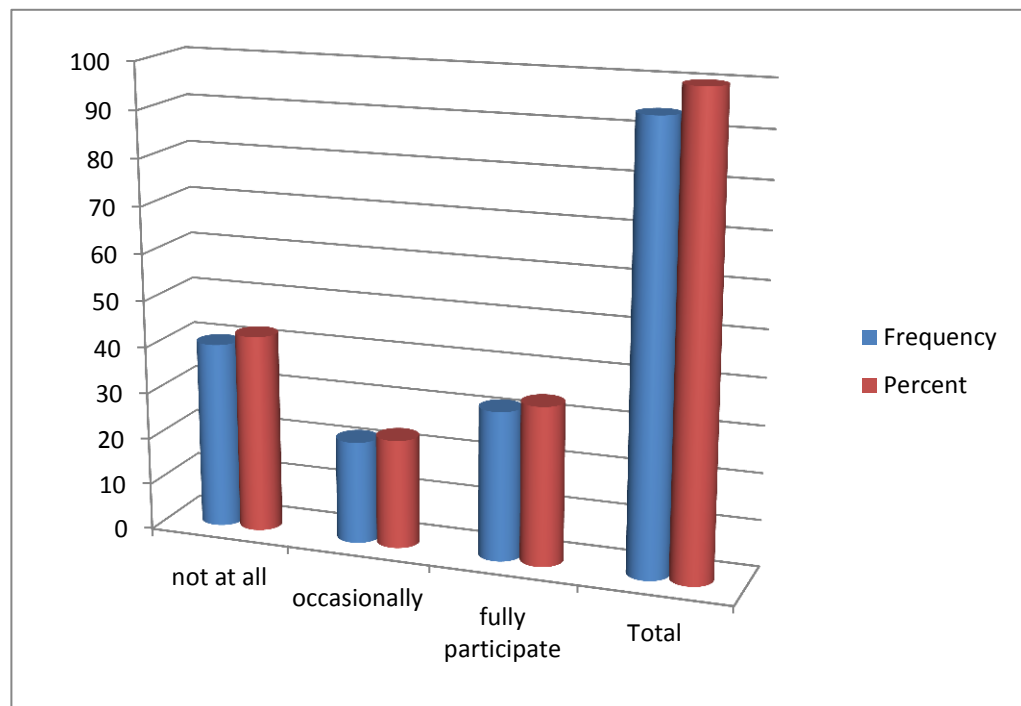
The female residents were mostly housewives and were never employed.

One of the risk factor for AD is low level of education and that may be seen here.

Level of dependency



Participation in activities

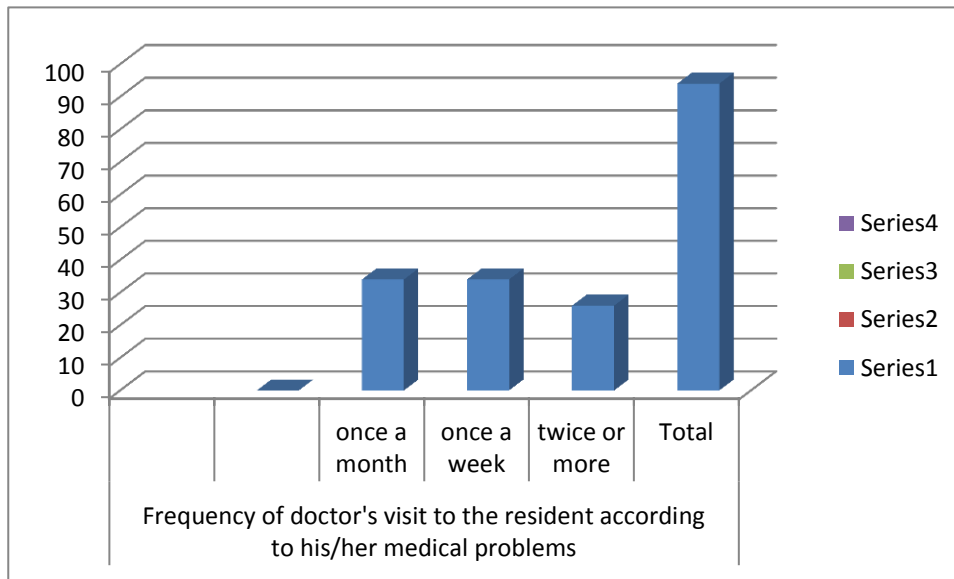


More than 50 % of residents would participate in activities, and 40% participating fully. The remaining half would never participate in activities. The quality of life (QoL) of residents participating in activities is better than those not participating. Also we can cross tabulate with dependency and probably find some interesting links here.

List of activities available in the 20 subsidized care homes

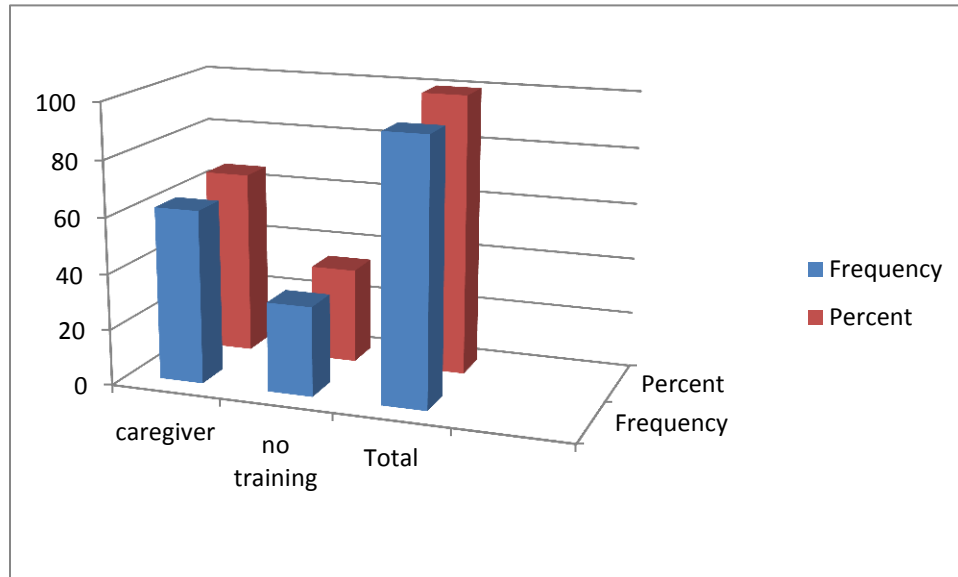
1. Physiotherapy
2. Indoor games (Domino, carom)
3. Watching television
4. Gardening
5. Music and Dance
6. Reading
7. Physical exercises
8. Occupational therapy

Doctors visits to resident



Doctors were visiting the residents from once a week to once a month.

Carer training and experience



About 60% of carers had been trained as general caregiver and 30% of carers received no training at all in elderly care and in dementia or AD.

Aggressivity of resident

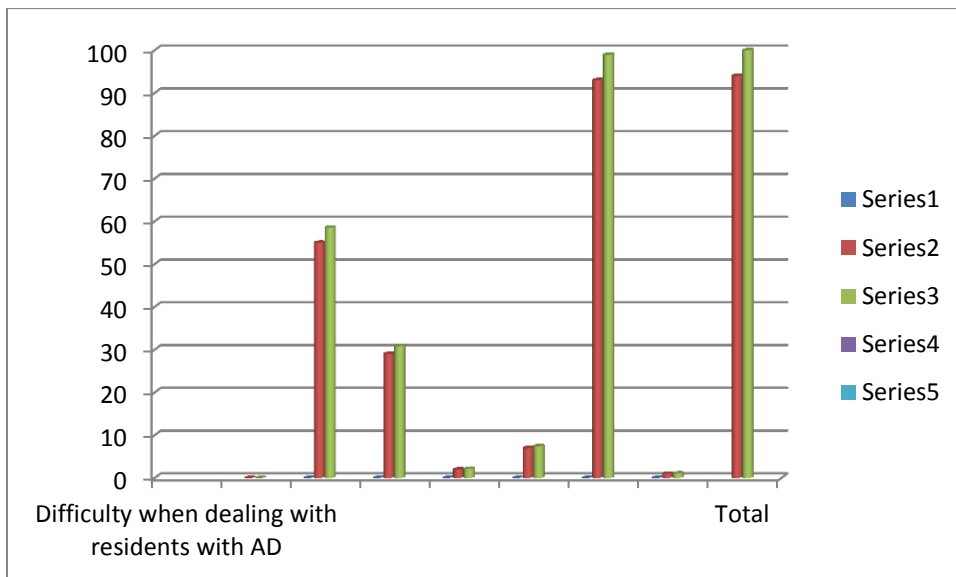
There were 29 residents who were aggressive mainly physically and verbally abusive when it concerned their personal hygiene. Some 10 of them were also showing signs of depression and nervousness.

Difficulties when dealing with residents with dementia

The main difficulty was communicating with a resident with dementia and AD. It was also difficult to get them to bathe, going to toilet and feeding.

Difficulty when dealing with residents with AD

		Frequency	Percent
Total	N/A	55	58.5
	communication	29	30.9
	problem	2	2.1
	movements	7	7.4
	personal		
	hygiene		
	Total	93	98.9
System	1	1.1	
		94	100.0

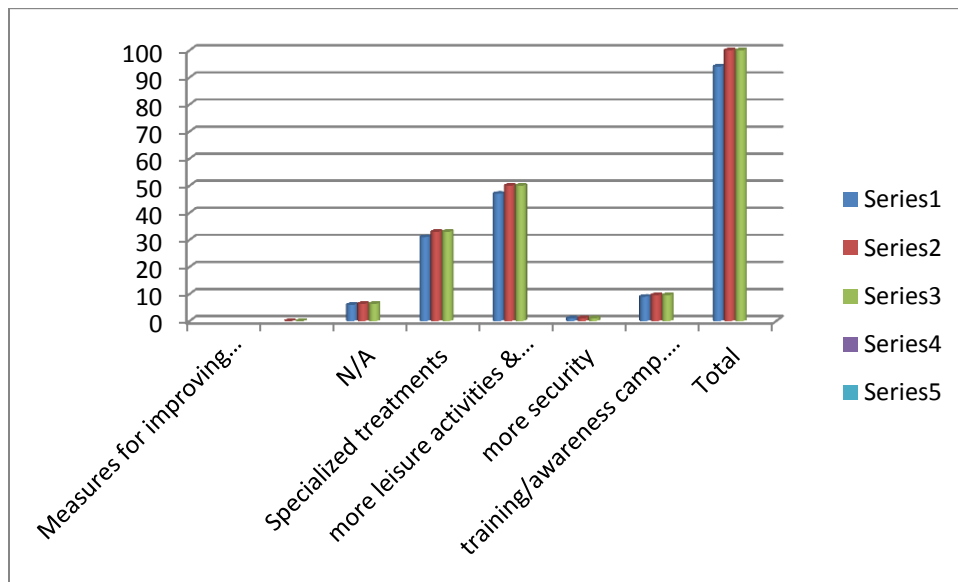


Relationship with residents

All of the carers were having good to excellent relationships with the residents, as they have been working with them for a long period of time. This explains that they also had job satisfaction and were not having too much strain whilst caring for them.

Measures to improve the QoL of residents with dementia

	Frequency	Percent
N/A	6	6.4
Specialized treatments	31	33.0
more leisure activities & Exercises	47	50.0
more security	1	1.1
training/awareness camp. for carers	9	9.6
Total	94	100.0



The most important measures would be to have more leisure activities and outings. Having specialized services to help them to manage the residents with dementia and AD would be helpful and would diminish the strain on them as carers.

4.2 DISCUSSION

As we started this first phase of the study with the three well defined objectives in mind; we were using it as our pilot project, and also to fine tune on what will be the important issues about carrying such a qualitative research.

The three important objectives of the study were to find out:

1. The quality of life (QoL) of residents with dementia and AD in subsidized care homes;
2. The services provided to residents in subsidized care homes to residents with dementia and AD
3. The support given to carers in subsidized care homes

As the results above have shown, in the answers given in the questionnaires, some qualitative understanding of the situation of the 94 residents with dementia and AD are living, can be appreciated.

First, it is important to state that the numbers of residents with dementia and AD that we found in the study, that is 94, is significant and that it represents 12% of the population of residents in these 20 subsidised care homes. It is higher than in most LAMICs where it is 6%. But it should be noted that in specialized homes the percentage reached 43% and this is comparable to developed countries figures. The reasons for admitting someone with dementia and AD are because one cannot cope on his own and also when the condition progresses, the need for care increases.

Quality of life (QoL) of residents with dementia and AD

The residents of the subsidized care homes with dementia and AD were older persons and they were admitted because there were no one to look after them in their own house or because they were too ill that the family was not able to care for them.

Their expectations were that they would have a better QoL in the subsidized care homes. They were given a safe and secure place to live in, and they were provided with the basic needs of daily life.

Their daily living activities or routine was organized but how participatory were they? From what we found it was satisfactory from the carer's point of view, and as we did not carry a self assessment of the residents QoL, we cannot confirm the residents satisfaction.

The activities were minimal and not totally adapted for persons with dementia and AD. Leisure activities were carried out in groups, which is not suited for residents with dementia and AD, who usually need individual attention.

We can say that they were given bed, lodging and laundry facilities, but their autonomy and independence were affected. The progression of dementia and AD depends to a large extent on what kind of stimulation and interaction are given.

Although the residents had good relationships with the carers and so, this would make them satisfied with QoL, they were not given opportunity to participate in activities that would cognitively stimulate them and also lift their moods.

Some of them had family visits and that definitely would improve the QoL; also families keeping the ties are so important to help in reminiscence therapy, where the person with dementia is allowed to live in the past, bring good memories and enjoying moments.

Services provided at the subsidized care homes

The range of activities we saw is minimal and again not specific to dementia and AD. Leisure activities and outings were not available, so the residents were kept indoors most of the time. There is probably more concern about safety issues, than giving personal satisfaction, the need for client centred services has not been thought of. Also may be the lack of more personel and animateurs, would prevent them doing more activities.

Doctors visits weekly or monthly are services to assure the good physical condition of residents are maintained. There are no proper mental health assessment and evaluation of the stage of dementia of the residents, here too the services are general not specific to dementia and AD.

There are communication problems with residents with dementia and AD, but there was none or rare service of speech or occupational therapists. Dementia and AD affects learning, language, comprehension and vocabulary; there is a need to develop other means of communication with residents with dementia and AD.

Even the service of a physiotherapist is important for a dementia person, but this was not available in the majority of subsidized care homes. Coordination and movements help the person to be mobile and prevent muscle wastage.

Services are needed to be given to residents to promote their well being and QoL. This was found to be very minimal and not dementia or AD specific.

Support to carers in subsidised care homes

The carers were all females and they were trained in general caring, with few of them trained in elderly care or dementia and AD.

They were satisfied with their work in general and had good relationships with the residents. This tells us that they could cope with the work load and though we did not ask specifically if they were stressed or overburden, they expressed the need for support, in

the form of continuous training and refresher course. Also there was no forum available for them to speak about issues that would worry them.

Doctors visiting the residents were not supportive to them and managers were not aware of their needs for support. They were not aware that dementia and AD are brain diseases that require lot of understanding and specific care. They were not even aware of the residents diagnosis and conditions.

The carers would benefit from focus groups discussion and would be able to speak on issues that are difficult, like communication with residents with dementia and AD, or dealing with challenging behaviours.

It appears from our study that residents in subsidized care homes were all treated same, that a diagnosis was not important, as there were no individual plans of care in their personal case files. Awareness of dementia and AD was lacking and it did not appear to be important for the managers, doctors and carers.

There was a lack of cognitive stimulation for the residents with dementia and AD.

The demand for specialised services and training in dementia care is totally justified.

CHAPTER 5

CONCLUSION and RECOMMENDATIONS

The first phase of the study has been done in the 20 subsidised care homes, where 94 residents with dementia and AD were found.

The numbers of residents with dementia and AD representing 12% of the population in these subsidized care homes which is a significant number. This number could be higher if proper diagnosis was made prior to admission or even during their stay at the subsidized care homes.

The three objectives of the study have been met, as we could evaluate from the results obtained ;

1. That the quality of life (QoL) of the residents with dementia and AD were difficult at their personal home prior to admission; that in the subsidized care homes they were well looked after in terms of general care, board and lodging; but when it concerned dementia and AD; they did not receive a client- centred approach treatment adapted to their conditions;
2. The services provided were basic and in general satisfactory, both for the residents and the carers; there was a lack of specialized services except in the two homes which catered for severely disabled elderly persons;
 3. Activities were minimal and offered to those who could participate, but not specific to residents with dementia and AD; important activities like speech therapy ,outdoor activities , leisure activities and reminiscence therapy were not available;
4. Awareness of dementia and AD was limited and most of the managers and carers did not understand that it was a chronic brain disease and that it required training and understanding to be able to cope with it;
5. Support to carers was not provided and not even seemed to matter, although, there was expressed wish from carers; respite for them was when they were off work, but no focus groups discussion and problem solving meetings were practiced in the care homes;
6. Although there were health professional visiting the care homes for visits and assessments, there was no interaction between them and management and also between them and the carers.
7. Families were not involved in the care plan neither at admission nor during the period of stay of the residents with dementia and AD in the care home.

More information will be available from this study when the second phase is done in the private care homes, using the same methodology and data collection, as we will be able to compare subsidized and private care homes and make relevant conclusions.

The third stage of the study will be a qualitative research on the knowledge , attitude and care of dementia and AD of the general population.

The important point here in doing a first stage , has been to pilot the study and get the officers of the health team to learn the process and to put their knowledge into practice.

Recommendations at this first stage of the study, will be in general:

- 1) It is very important to have been able to have done a study on residents with dementia and AD in subsidized care homes, as this study will then be done in private care homes, we have had a good opportunity to practice the questionnaire and got an interesting collection of data;
- 2) Dementia and AD being still unknown by many persons working in care homes, we will be able to develop a strategy of awareness to professionals and the public in general;
- 3) Early diagnosis of dementia and AD with staging of the disease is most important for the person and families and can help to prepare a dementia care plan adapted to the person and his family;
- 4) Managers of care homes should have personal files for each resident with medical and social reports, and also in it an individual care plan, so as to manage the dementia problems, like communication, mobility, challenging behaviors, feeding problems and late stage of the condition;
- 5) Families should be encouraged to visit and to keep contact with the person and be involved in leisure and reminiscence activities;
- 6) Health and paramedical professionals must be trained in dementia and AD care, in fact a dementia workforce to be made available to cope with increasing numbers of persons with dementia and AD in years to come;
- 7) Activities in care homes need to be improved and standardized, even made compulsory, as residents with dementia and AD, need to have specific activities, that will stimulate their cognition, to help slow down the progress of the disease and make their quality of life (QoL) better;
- 8) Each care home should have a dementia policy, work with the health and social departments to make sure that residents with dementia and AD get the best possible care and management ;
- 9) Professional and public attitudes to and understanding of dementia and AD need to improve;

- 10) A need to invest in health and social systems, to improve care and services for people with dementia and AD and their caregivers.

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APPENDICES

1. QUESTIONNAIRE USED

Form A01

Ministry of Social Security, National Solidarity and Reform Institutions

Observatory on Ageing

Study on Health (Dementia / Alzheimer's' Disease in Residential Care Homes)

Reference No:.....

SECTION A: Particulars of Resident

GENDER: M F

AGE: 60-64 65-69 70-74 75-79 80-84 85-89

≥90

MARITAL STATUS

Single Married Widow/er Divorced Separated

Name of
institution:.....

....

Address:.....
.....

Tel. No:.....

Date of admission:.....

Reason for admission/ Event leading to admission:

.....
.....
.....

If reason is other than AD, then since when has resident been diagnosed as AD patient?.....

Stage of Dementia/AD according to medical records:

No impairment Moderate Severe Very severe

Address prior to admission:.....

SECTION B: Situation prior to admission

Living Situation: living alone Living with children Living with grand children

Living with brothers Living with sisters other living arrangement (please specify).....

Frequency of visits by family members: regularly rarely never

Level of education: Primary Secondary Tertiary Other

Never been to school

Past occupation:.....
.....

Activities	Self	Partially dependant	Totally dependant	Remarks
Personal hygiene				
Dressing				
Feeding				
Movement				
Intake of drugs				
Leisure Activities				
Cognitive stimulation				

In what other activities does the resident participate?

Activities available	*Participation

*Participation: Not at all -1 Occasionally – 2 Fully - 3

Other medical problems, if any:

.....
.....
.....
.....

Frequency of doctor's visit to the resident according to his/her medical problems

Once a month once a week Others Please
specify.....

SECTION C: Particulars of Caregiver

Training of the caregiver in the past 5 years:

In AD As caregiver (general) In gerontology

Length of experience

- a) As caregiver in general:
- b) As caregiver with AD patient:

Do you look after

- i. Same resident every day?: yes/No
- ii. Other AD patient? Yes No If yes how many?
- iii. Other residents? Yes No If yes how many?

Relationship of caregiver/patient:

Excellent Good Bad Very bad

Is the resident aggressive? Yes No

If yes please rate the resident's level of aggressivity:

Physical

Verbal

High Mild Weak

High Mild Weak

Can you identify possible cause/s of aggressivity?

.....
.....
.....
.....
.....
.....

What in your opinion is most difficult when dealing with residents with AD?

.....
.....
.....
.....
.....

Can you suggest any measures that could improve the quality of life of residents with AD?

.....
.....
.....
.....

For office use:	
Name of officer:	Checked by:
Signature of officer:	Date checked:
Date:	Data input by:
	Signature:
	Date: