

Memory clinics- a model for dementia care

Babu Varghese¹, Mathew Abraham², CT Sudhir Kumar^{3,*}

¹Volunteer, Alzheimer's Australia Vic. Australia, ²Senior Consultant Neurologist, Dept. of Neurology, Aster Medcity Hospital, Cochin, Kerala, ³Honorary Consultant Psychiatrist, Alzheimer's and Related Disorders Society of India (ARDSI), Cochin, Kerala, India

***Corresponding Author:**

Email: sudhirkumarct@hotmail.com

Abstract

Alzheimer's Disease International estimates there are around 4.1 million people in India with dementia. Services available in India are inadequate to meet the needs of people with dementia and their families. Memory clinics are multidisciplinary teams led by specialist doctors with inputs from other professionals like nurses and social workers. This paper will explore the predominant themes emerging from a qualitative study assessing the core principles of memory clinics. The procedural details and the basic characteristics of attendees to one of the earliest memory clinics in the region would be described. Parson centred nature of care, rationalising medications, psychosocial support, multidisciplinary approach and family support were the emerging themes the experts identified as the functions and core principles. In addition to medical treatment, memory clinics can play a major role in appropriately guiding the patients with dementia and their families to address various challenges associated with the condition thus reducing caregiver stress. Memory clinics can also contribute to training, education and research and can play a major role in creating dementia friendly communities. There should be a collaborative approach in establishing appropriate dementia care between various agencies including governmental and non-governmental agencies.

Keywords: Memory clinic, Dementia, Alzheimer's, ARDSI.

Introduction

According to current estimates by Alzheimer's Disease International, there are around 4.1 million people in India who have dementia.¹ While the numbers are expected to double by 2030, costs of care would increase three times. Dementia already has a serious impact on the society and this will grow larger in future. The emotional toll is enormous for patients and their families. Lack of awareness and understanding of dementia results in stigmatization, barriers to diagnosis and care, and impacts caregivers, families and societies physically, psychologically and economically.² Services available in the country are grossly inadequate to meet the needs of patients and their families.³ Most people still do not understand dementia as a medical condition. People tend to see it as memory loss associated with normal ageing, changed behaviour of the elderly or as other stigmatising conditions. Early identification and treatment helps to delay the progression of illness. Understanding of dementia as a neuropsychiatric condition which results in cognitive impairment, behavioural and psychological symptoms and personality changes is essential to create a positive family attitude of caring towards the affected. Lack of awareness on the manifestation of the disease and lack of knowledge on how to care for these patients lead to inappropriate care. Misunderstanding of the symptoms as deliberate can lead to maltreatment and abuse by the family and the community. Dementia receives poor attention not only among the public but also among the health professionals. Even when affected patients are taken to health professionals, many do not receive a proper diagnosis and appropriate care plan.

There is no curative medical treatment available for dementia so far and hence a pure biomedical approach is not helpful. In addition to medical treatment, the essential components of managing dementia include creating awareness in the society, early identification, and education of family members regarding various strategies to deal with symptoms of dementia.^{4,5} With such wide targets, it is clear a multidisciplinary approach is essential in provide appropriate care for people with dementia. Memory clinics play a central role in providing such care in many parts of the world. A memory clinic/service is defined as a multidisciplinary team that assesses and diagnoses dementia, and may provide psychosocial interventions for dementia.⁶ Though a universal definition is not available, it is widely agreed memory clinics consist of a multidisciplinary team of professionals. In addition to specialist doctors the teams may include nurses, social workers, psychologists, care workers etc. Early diagnosis plays a key role in improving the quality of life of those affected and their families and there should be an emphasis to reduce caregiver burden, which are the main functions of such clinics.

This paper will explore the predominant themes emerging from a qualitative study assessing the core principles of memory clinics. We will narrate the procedural details and our experience of closely working with a memory clinic. We will also describe the basic characteristics of attendees to this memory clinic.

Materials and Methods

Qualitative Study: Twenty experts with significant experience in the field of dementia were contacted as

part of ongoing work by Alzheimer's and Related Disorders Society of India (ARDSI) which is a non-profit non-governmental organisation working in the field of dementia care. They included psychiatrists, psychologists, neurologists, social workers and carers to explore what they considered the major functions and core principles of a memory clinic service were. A thematic analysis was done to identify the predominant themes.

Description of the Service: Memory clinic at Cochin, was started in 1999, which probably was the first of its kind in the country. This was a joint venture of Indira Gandhi Co-operative Hospital and Alzheimer's and Related Disorders Society of India (ARDSI). Assessing people with suspected memory impairment with a view to arrive at a diagnosis and formulating a management plan was the primary function of the memory clinic. A comprehensive history, cognitive assessment and physical examination will help in delineating 'true' cognitive impairment from other conditions such as depression, stress or anxiety, sensory impairment, which may need to be referred to appropriate services. Once cognitive impairment is established, the nature of the underlying condition needs to be investigated. Memory clinics play a major role in identifying reversible/ treatable causes of cognitive impairment such as general medical conditions (eg. anaemia, endocrinological problems like thyroid diseases, vitamin deficiencies), delirium, medication side effects, head injury etc and treating them. Once the progressive, neurodegenerative nature of the cognitive impairment is established the assessment and investigations aim to identify the sub type of dementia which will help in specific management of the condition and other associated/contributing factors. In complex presentations specialised investigations may be necessary before arriving at a probable diagnosis.

A multidisciplinary team functioned as a part of the neurology out patients department which had inputs from a social worker who focused on the psychosocial care of the families and with close inputs from ARDSI and was also able to play a sign-posting and supportive role. The major functions of the clinic were early identification and management of dementia, treating co morbid conditions, counselling and support for patients and their caregivers. Though the memory clinics are envisaged as outpatient clinics, this particular service encouraged an inpatient stay of three days for easy facilitation of assessment and investigations. This inpatient stay was subsidised in agreement with the hospital management. The clinic also took initiative in training health care professionals and organizing awareness campaigns to promote public awareness regarding dementia.

Results

I. Qualitative study

A. Emerging themes

The following themes emerged from the responses of the experts regarding the functions of memory clinics.

Nature of Care: The memory clinics should offer a person centred care and the three groups of patients who would benefit from the service are the following:

- i. Patients with memory problems who have been seen elsewhere. Their families usually have some knowledge about dementia and are mostly on medications. What they would usually require is clarification of history, confirmation of diagnosis, reviewing treatment so far, rationalising medications and further management.
- ii. Patients with memory problems and not assessed elsewhere, would require a comprehensive work up including necessary investigations; and after a diagnosis is made, appropriate treatment to be provided.
- iii. Patients who already have a diagnosis of dementia arriving with new onset problems which may or may not have been consulted elsewhere arriving for appropriate management of symptoms most often behavioural, psychological or psychotic in nature.
- iv. Patients who have memory problems who worry about brain diseases including dementia but do not have dementia, who may require assessment and appropriate referrals.

Rationalising Medications: Optimising medications often involve stopping inappropriate medications and reducing dosages due to side effects or inadequate response. This often results in patients having fewer medications on a reduced dosage.

Psychosocial Support: Sign posting; the memory clinic usually have a wealth of information regarding local services available and is often possible for information to be provided about the services families require. Eg day hospitals, self-help groups. The social worker attached to the clinic is able to attend their future calls and give advice on emergencies or further needs. This is especially helpful as the social worker already knows the person and would be able to give person specific advice.

B. Key words: On asking to identify the core principles or roles of memory clinics the predominant responses were

Multidisciplinary: The variety of skills brought by the team of professionals from various backgrounds is quite rich. Moreover, the time and attention the families receive from the higher number of professionals is much more than a routine hospital clinic.

Medication Treatment: The memory clinics provide expert care and monitoring of medications prescribed for dementia. The expertise helps not only in initiating medications but stopping them timely as well.

Family Support: It is often said families find it harder to manage the behavioural problems than cognitive impairment. They become significantly stressed when behavioural problems emerge as they do not have the skills to manage them. Memory clinics play a

supportive role in imparting the necessary skills to the families by way of counselling and education. These clinics are thus able to provide a person specific care.

II. Procedural details and Characteristics of the Memory Clinic Attendees:

The main source of referrals included general practitioners, specialist doctors, relatives and friends of the patients, social service agencies, dementia helpline and memory screening camps. The service followed a three day assessment with the patient getting admitted to the hospital for a comprehensive multidisciplinary diagnostic approach. An experienced Social Worker took a comprehensive history of the patient from the relatives and collateral sources on a chronological basis and performed a cognitive assessment. Following this, the neurologist undertook a detailed examination and organised necessary referrals, radiological and laboratory workups. Once the evaluation was completed, diagnosis was made, treatment options planned and discussed with the patient and their family. The behavioural and psychiatric manifestations associated with dementia were managed by psychiatrist. The social worker coordinated the caregiver intervention, counselling, psycho education and follow ups. To support the family members, monthly support group meetings were held and the families were linked to other ARDSI services including dementia helpline.

730 people (384 males and 346 females) were assessed by the memory service in a period of 13 years. Majority of attendees (24.22%) were between the age of 71 and 75. 9.24% of the people were below the age of 45. 28% had Alzheimer's disease, 20.99% had various psychiatric conditions and 13.38% had a diagnosis of vascular dementia. The following general observations were made by the staff associated with the service. Even when the families have been to many health professionals they still did not have adequate information about dementia and strategies to cope and communicate with patients. Most patients were cared at their own homes by family members. It was quite evident behavioural problems associated with cognitive impairment contributed to the majority of stress among caregivers.

The service arranged pre and post-diagnostic sessions for the caregivers and family members focusing on information and education about dementia. As part of caregiver education and training, relatives were encouraged to spend time with residents at the ARDSI care facilities to observe how situations arising out of communication problems and behavioural difficulties were managed by experienced staff and clarify their questions regarding care. There were opportunities to meet and discuss with other family carers. They were also connected with national dementia helpline operating from Cochin to gather information and assistance after discharge from the hospital. When patients were unable to come for follow

up visits, the caregivers were encouraged to attend the clinic so that they received the necessary support from the clinic. This usually helps the families to cope with difficulties during late and advanced stage of dementia, when patients were not usually brought to the clinic. We observed an increasing number of calls from families who utilised this service, via the national dementia helpline.

Additional services for the memory clinic patients which ARDSI provide included monthly support group meetings each lasting for around two hours. The session starts with a presentation by an expert followed by discussion and information sharing. Dementia support group included family members, friends, neighbours, senior citizens, volunteers and anyone who are directly or indirectly involved in the care of a person with dementia. It gave an opportunity to meet with others in a similar situation to share experiences, learn new ideas and skills for living with people who have dementia and engaging in mutual problem solving strategies. The clinic also conducted dementia awareness programmes in the community and provided dementia training for undergraduate and postgraduate students of nursing.

Discussion

Memory clinics have been promoted as opportunities for improving dementia diagnosis and care.⁷ They are now found worldwide and as the movement has matured, clinical and research interest groups or networks have developed. This serves to disseminate best practice or argue the case for sustained growth, even where finance is limited.⁸ These clinics are not to be confused with various establishments which promise memory enhancement or memory boosting among the general population. Memory clinics are services led by specialist medical professionals (psychiatrists, neurologists, geriatricians) for assessment and management of cognitive impairment predominantly dementia. In India, the number of memory clinics run by government hospitals is quite small and it is estimated that there are only around one hundred memory clinics functioning all over the country and thus the vast majority of the population do not receive the intended benefits.³ They can be an effective, successful, and sustaining means of delivering specialized health care services for people with dementia⁹ and clear cut goals will help in improving the quality of services provided.¹⁰

Following the experience in Cochin and extensive work they do with families of those with dementia ARDSI has established a memory clinic in Kunnampulam near Thrissur in September 2014 which runs on a monthly basis and led by a psychiatrist. Other members of the clinic include nurses and a social worker experienced in dementia care. This is based on an outpatient model. Involvement of allied health professional is found to improve the health related quality of life of attendees of memory clinics in other

settings.¹¹ ARDSI has been in the forefront in guiding and assisting various key partners and recently brought out guidelines for establishing memory clinics relevant across various settings, resource intense or scarce; government or private; rural or urban.¹² Opportunities should be explored to see whether existing health and social care systems can implement this service models with keeping any additional expenses minimum. This model especially based on outpatient services can be incorporated into the existing infrastructure of many health care settings. Quality indicators for memory clinics have been identified¹³ and there should be collaborative networks forged among existing memory clinics so that better models can be adapted, useful information exchanged and databases can be created. Peer support has been identified as a major determinant of satisfaction of the services provided,¹⁴ however we do not have any information about the attitude and perception of people who use the memory clinics in India about the services they receive. It would be useful to evaluate whether it matches the expectations of the service users and culturally appropriate. This information can guide us in providing an effective service especially when expanding or setting up a new service. Memory clinics can also play a major role in training health and social care professionals and coordinate caregiver intervention programmes and develop as a nodal centre for appropriately trained personnel.

Conclusion

In addition to medical treatment, memory clinics can play a major role in appropriately guiding the patients with dementia and their families to address various challenges associated with the condition thus reducing caregiver stress. This service may also contribute to training, education and research and definitely can play a major role in creating dementia friendly communities.

References

1. Prince, M, Wimo, A, Guerchet, M, Ali, GC, Wu, Y, and Prina, AM. World Alzheimer Report 2015: The global impact of dementia. An analysis of prevalence, incidence, costs and trends. Alzheimer's Disease International, London;2015.
2. WHO and Alzheimer's Disease International. Dementia: a public health priority. World Health Organization, Geneva;2012 (http://www.who.int/mental_health/publications/dementia_report_2012/en/. accessed Feb 12, 2018).
3. Shaji KS, Jotheeswaran AT, Girish N, Bharath S, Dias A, Pattabiraman M, Varghese M, (Eds). Dementia India Report 2010: prevalence, impact, costs and services for Dementia. Alzheimer's & Related Disorders Society of India. New Delhi: ARDSI; 2010.
4. Gurukartick J, Dongre Amol R, Shah Dharav. Social Determinants of Dementia and Caregivers' Perspectives in the Field Practice Villages of Rural Health Training Centre, Thiruvannainallur. *Indian J Palliat Care* 2016;22(1):25-32.
5. Srivastava G, Tripathi RK, Tiwari SC, Singh B, Tripathi SM. Caregiver Burden and Quality of Life of Key Caregivers of Patients with Dementia. *Indian J Psychol Med.* 2016;38(2):133-6.
6. Royal College of Psychiatrists. National Audit of Memory Clinics 2014. <http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/memoryclinicsaudit.aspx> (accessed Feb 12, 2018).
7. Lee L, Hillier LM, Stolee P, Heckman G, Gagnon M, McAiney CA, Harvey D. Enhancing dementia care: A Primary care based memory clinic. *Journal of the American Geriatric Society* 2010; 58 (11): 2197-2204.
8. Jolley D, Moniz-Cook E. Memory clinics in context. *Indian J Psychiatry.* 2009;51 Suppl 1:S70-6.
9. Nair G, Van Dyk K, Shah U, et al. Characterizing cognitive deficits and dementia in an aging urban population in India. *Int J Alzheimers Dis.* 2012; Article ID 673849.
10. Cahill S, Pierce M, Moore V. A National Survey of Memory Clinics in the Republic of Ireland. *International Journal of Psychogeriatrics* 2014;26: 605–13.
11. Park MH, Black N, Ritchie CW, Hendriks AAJ, Smith SC. Is the effectiveness of memory assessment services associated with their structural and process characteristics? *Int J Geriatr Psychiatry.* 2018 Jan;33(1):75-84.
12. Sudhir Kumar .C.T., ARDSI guidelines for establishing Memory clinics, ardsi.org/downloads/Memory_Clinic_guidelines-18-8-2015.pdf (accessed Feb 12, 2018).
13. Willis Rosalind, Chan Jeni, Murray Joanna, Matthews David, Banerjee Sube. People with dementia and their family carers' satisfaction with a memory service: A qualitative evaluation generating quality indicators for dementia care. *Journal of Mental Health* 2009;18 (1):26-37.
14. Drasković I, Vernooij-Dassen M, Verhey F, Scheltens P, Rikkert MO. Development of quality indicators for memory clinics. *Int J Geriatr Psychiatry* 2008; 23(2):119-28.