

Advanced Dementia and Social Engagement: Field Notes from Rural India

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Abstract

Dementia as an irreversible progressive disease having little effective treatment has been a great cause of concern in the fields of psychiatry, medicine and social work. The issue has become increasingly critical over the decades owing to the fact that while at present, globally, over 36 million people suffer from dementia, it is estimated that this number will possibly be doubled by 2030 and more than three-times by 2050.

Recent findings suggest that a rich social network may decrease the risk of developing dementia. Post-modern societies, with their excessive individuation and inward-looking characteristic lifestyles, have posed a greater risk to their present and future generations in this regard. As industrialization reaches its pinnacles, Poor social connections, infrequent participation in social activities and social disengagements predict the risk of cognitive decline in individuals especially after middle ages.

Keeping this broad spectrum of risks and threats the issue of dementia needs to be understood in a wider context cutting across disciplinary boundaries. The present paper aims at examining the influence of social networks and social engagements on cognitive decline of the elderly population. The basic objective of this research attempt is to study whether low levels of social engagements in middle and late life were associated with the risk of incident of dementia. The researcher hypothesized that active social engagements during midlife stages of the individual, having other life-chances similar, have a protective effect from the onset of dementia. Regular, frequent and positive social interaction and intellectual stimulation keep dementia away to a considerable extent.

The study starts from the 'end-point' of the cases of advanced dementia by adopting a cross-sectional, comparative sample study method. A study sample of 200 elderly individuals from rural Karnataka, South India, (N = 200 with experimental n = 100 and normal n = 100) selected through a stratified sampling technique (matched with five vital variables) was used to arrive at conclusions on the basis of data analysis and interpretation simple statistical techniques. The study was conducted between January-June 2018.

Analysis of data re-establish and re-confirm the conclusion that regular (daily/weekly/frequent) engagement of the elderly in mental, social or productive activities was inversely related to dementia incidence. Low social engagement in late life is associated with risk of dementia.

Keywords: *Dementia; Social Engagement; Alzheimer's; Indian Elderly*

Introduction

Demographers have repeatedly confirmed the rise in the aging population all over the world. People in the age group of 60+ have been swelling continuously in numbers, a major reason being the entrance of baby boomers to this population cluster. Needless to point out that this group is normally associated with psychosomatic health issues such as inconsistencies in blood pressure (both low and high BP),

cardio-vascular ailments and problems related to mental health. A major disorder concerning this cerebral dysfunction is slowing of brain functions as often shown up in memory lapse and symptoms such as delusions and hallucinations. However, the attribution of memory lapse to old age, which is accepted as a common aging symptom in many cultures, often masks the onset of a serious health ailment called dementia, Alzheimer's Disease (AD) being a major contributor to this suffering.

Recent findings suggest that a rich social network may decrease the risk of developing dementia. Post-modern societies, with their excessive individuation and inward-looking characteristic lifestyles, have posed a greater risk to their present and future generations in this regard. As industrialization reaches its pinnacles, Poor social connections, infrequent participation in social activities and social disengagements predict the risk of cognitive decline in individuals especially after middle ages.

While latest statistical inquiries have come out with unlike figures, the fact remains that dementia and Alzheimer's are rated as chief providers of agony and sufferings to the elderly in the world. Globally, Alzheimer's disease (AD) and related dementias affected 35.6 million individuals in 2010 and it is expected to grow to 115.4 million by 2050. The prevalence of dementia will increase as longevity increases and future family caregivers are likely to be predominantly spouses. This makes it chiefly as a problem of the family with domestic issues involved.

India, like most other societies, is also going through the time of swift population aging. As a result, the number of people with dementia and other late life mental health problems have been increasing significantly since the last few decades. It is being felt increasingly in the academia and medical practice that research and dissemination of research findings are critically important at this juncture. Alarming enough to the policy makers of India, the country is estimated to house the second largest number of dementia sufferers in the world today. While the number of individuals distressed from dementia in India varies between an estimated 4 million and 5.5 million people, 'Dementia India' report published by the Alzheimer's and Related Disorders Society of India puts the number at 4.1 million. What is even more worrisome than the mere number is the research finding that this number is expected to double by 2035. In fact, the big States of Maharashtra in the West and Uttar Pradesh in the North are estimated to have more than 500,000 patients together by 2026.

Keeping this broad spectrum of risks and threats, the issue of dementia needs to be understood in a broader framework cutting across disciplinary boundaries. The present paper aims at exploring the influence of social networks and social engagements on cognitive decline of the elderly population in India. The basic objective of this research attempt is to study whether low levels of social engagements in middle and late life were associated with the risk of incident of dementia. The researcher hypothesized that active social engagements during midlife stages of the individual, having other life-chances similar, have a protective effect from the onset of dementia. Plain premise here is regular, frequent and positive social interaction and intellectual stimulation keep dementia away to a considerable extent.

Understanding the term dementia

What is Dementia? While the general denotation of this term has not changed much over the years in common grasp for quite some time, the medical fraternity has changed the meaning, symptoms and characteristics of Dementia through years of research and application. Common understanding of Dementia as taught in text books of general psychology is that Dementia is a syndrome, not a disease as such. It is understood as a group of symptoms that affect mental cognitive tasks such as memory and reasoning. Dementia is an umbrella term with a wide variety of cognitive malfunctioning including Alzheimer's disease. It can occur due to a variety of individual conditions.

Psycho-medical understanding of dementia goes deeper into the issue of cognitive imbalance. Dementia, in this circle, is considered as a malady and an ailment. The trademark pointer to Alzheimer's is the trouble in recollecting stored new information. As Alzheimer's progresses, memory loss interrupts daily routine (for instance, the person may be lost even in his own farm or local market, may forget names of his own family members). The patient also starts experiencing deep decline in cognitive ability (finding it difficult to make choices

and judgments, solve common problems, or think logically), and may undergo significant changes in mood and personality. Often we find such persons as irritable, hostile to suggestions, or indifferent even to friends and family. Alzheimer's is severely incapacitating, and death usually occurs in ten years if not earlier.

Social engagement: "He who is unable to live in society or who has no need for it because he is sufficient for himself is either a beast or God" said Aristotle announcing a profound social fact which has been established since then. We know that man is a social animal and hence society is, and has been, possible for millennia. Because humans adopt a culture and take principal share of their personality from the community, their engagement with other humans becomes vital for their cognitive wellbeing. This engagement with society - with diverse social roles and responsibilities bound by values, norms, mores and folkways of the prevailing customs and traditions - is what we generally call 'social engagement'. This generic and descriptive word, however, needs to be spelt out in quantifiable terms if we have to engage in research associated with this concept. Let me try to lay it in determinate position. This is important because a large number of studies in the area of dementia indicated that level of social participation is a vital factor in dementia and a low level of social engagement is a critical risk factor. In other words, it is found that high level of social engagement can reduce the risk of dementia. Number of social contacts the individual has, with their depth, intensity and frequency, are considered to significantly influence the possibility of the onset of dementia.

It is extensively acknowledged that social engagement is associated with various helpful effects among the elderly. While some of them are general in their conclusions, they certainly point to the significance of stronger community engagement in cognitive health. Individuals with resilient social bonds have been found to live longer (see reviews by Antonucci, 2001; Bowling and Grundy, 1998), to have better health (see Berkman, 1985; Vaillant, Meyer, Mukamal, and Soldz, 1998), and to be less depressed (Antonucci, Fuhrer, and Dartiques, 1997). Many researchers now believe that social interaction is key to maintaining good mental health and warding off cognitive limitations such as dementia and Alzheimer's. Although researchers are not certain about what happens in the brain to produce the positive effects seen among the more socially engaged, it seems clear that close relationships and large social networks have a beneficial impact on memory and cognitive function as people age.

An interesting and important study on social engagement vis-à-vis dementia in the Indian context has been carried out by Mathuranatha, *et al* from which the present paper borrows considerably on its methodological ideas concerning research design. This study demonstrated that there are positive effects of social interaction in cases of dementia. While more evidences authenticated by solid research methodology and sound data analysis are needed, this is a clear pointer to the importance of social engagement in dementia and Alzheimer's [1-19].

Objectives of the Study

In the present study I intend to examine whether mid- and late-life social engagement, defined as maintained social connections and participation in social activities, was associated with the risk of incident dementia in a community-based cohort of elderly individuals in the State of Karnataka, India.

Methodology and Results

Study area

The Study was conducted in three Districts in the State of Karnataka, South India. The Districts of Uttara Kannada (Representing the Coastal Belt of the State), Shivamogga (representing the hilly terrain of the State) and the District of Bellary (representing the planes of the State) were chosen for selecting the study sample. Nine villages (three villages in each of the three districts) were chosen on the basis of general observations to bar any unusual or uncharacteristic demographic traits in the general population. The selection was done with the help of local revenue and panchayat (local governance) officials who were contacted in early January 2018. Data collection was done by 12 students trained in data collection methods as a part of their Bachelor of Social Work (BSW), Psychology and Sociology Bachelors courses.

Research tool

Social engagement

Five indicators of social engagement similar to measures employed in the study mentioned earlier were used: marital status (0 = unmarried, 1 = married); living arrangement (0 = living alone or with spouse only, 1 = living with joint/extended family); participation in social, political, or community groups (0 = less than weekly, 1 = weekly or more frequently); participation in social events with community fellows (0 = less than weekly, 1 = weekly or more frequently); and the existence of an intimate relationship (brother/sister/friend) (0 = no, 1 = yes).

An interview schedule was designed with 23 items to collect quantitative information in terms of social engagement of both groups. Questions directly relevant to (a) Midlife Social Engagement (b) Mid-late life Social Engagement (c) Late life Social Engagement as three stages were carefully decided and included. 12 graduate students of BSW-Psychology-Sociology departments of the local University were trained in the technique of interview and selection of the sample respondents as per the criteria. Interviewers were asked to record their observations as a qualitative support to interview data. Families were identified by village informants in social networking.

Sample: N = 200

Experimental Group (n1 = 100) [Uttara Kannada District = 29 (15 + 14), Shimoga District = 40 (20 + 20), Bellary District = 31 (15 + 16)]

Controlled Group (n2 = 100) [Uttara Kannada District = 29 (15 + 14), Shimoga District = 40 (20 + 20), Bellary District = 31 (15 + 16)]

Study variables: Matched between n1 and n2:

Gender (M = 100 [50+50] F = 100 [50+50])

Marital Status Married = 100 Single = 100

Education Less than primary education = 100. Beyond primary education = 100

Class - All 200 respondents are from middle-class and lower middleclass background

Previous Employment Status. No one had any formal government jobs. Many came from agrarian background and a few were from petty jobs like plumbing, fitting, electrician, etc.

Time frame of the Study: January to July 2018.

Data presentation through simple data tables: An attempt was made to compare sample characteristics by level of social engagement in mid- and late life. The tables are given below. It is desirable to employ analysis of variance for continuous variables and chi-squared tests for categorical variables. However, due to limitations in the project funding, that part is awaited for future spell. Information from the observation sheets was utilized as qualitative support to the quantitative data from the interview schedule in the field.

Discussion

Data analysis and interpretation of the data were done on the basis of prevalent socio-cultural and other relevant variables

The findings showed that (1) those who married were more than 30 per cent less likely to suffer from the condition than those who remain single. (2) It is also found distinctly that those who were actively engaged in social relationships with other members in the neighborhood and family were less affected by this ailment. (3) Engagement in social activities Of individual choice and chance also has revealed a positive influence in lessening the possibility of dementia. The reason behind these outcomes is simple and vibrant: Interaction

of a loving and positive relationship as well as engagement in loving activities help keep the brain active and reduce the risk by some considerable extent. This conclusion is similar to the findings of a larger study led by Andrew Sommerlad, Professor at the University College, London.

Dementia is still considered a “taboo” subject in India. General awareness about this issue is also thin. While people had a broad awareness of the condition and some of the better-known symptoms, they knew little about the causes of the condition, its impact on people’s lives and how the disease progresses. This combination of good general awareness of the existence of dementia but poor detailed understanding of its causes, progression and implications tends to lead to inaccurate assumptions about the lives and experiences of people with dementia.

Conclusions, Recommendations and Future Research Avenues

In this study, I examined the association of social engagement, defined as maintained social connections and participation in social activities, with the risk of dementia in older Indian men and women. We found increasing risk with decreasing social engagement in late life but no evidence to establish a correlation association between midlife social engagement and late-life dementia. Persons whose level of social engagement declined from midlife to late life had the highest risk of dementia, which suggests that low social engagement in late life may be a prodromal symptom of dementia.

These findings have implications for the design of future cognitive and social clinical intervention trials attempting to reduce the risk of dementia in older adults. On the basis of these results, it is important to consider both midlife and late-life social engagement when designing intervention trials. Previous work on the influence of leisure activity on Alzheimer’s disease risk has suggested that interventions designed to enhance life experiences and activity in later life may reduce the risk of dementia. Findings of the present study suggest that researchers implementing social- engagement interventions in late life need to consider the possibility that the dementing process may have already modified social engagement. Considering mid- to late-life trajectories of social engagement may provide insight about persons with low levels of social engagement in late life and may highlight those who are at greatest risk of dementia.

People, by their nature, are not isolated individuals but rather are embedded in a network of social and family relationships. The ability to create and develop relationships with others is crucial to our well-being, although personal circumstances will clearly vary enormously as to whether those relationships extend very widely or are limited to a small number of close family or friends.

Biological and psychosocial factors could contribute to the development of depression in late life. It is possible to modify many of these factors at least to some considerable extent. Vascular risk factor reduction and adoption of lifestyle changes may help to delay the onset of late life depression and dementia. The usefulness of simple community-based psychosocial interventions for conditions like depression in older people needs to be addressed by future studies.

Development of services for older people with mental health problems will remain a huge public health challenge. Service development in resource-limited settings is not an easy task. Voluntary organisations and non-governmental agencies in rural India can play a vital role in this respect due to their personalized approach to issues and social proximity to the community.

Caregiver support is important in the management of late life mental health problems. Management of disabled older people with behavioral disturbance can be very stressful for the families. Many studies from India had highlighted the importance of identifying and managing behavioral symptoms of dementia. Packages for care for dementia in low and middle income countries had been proposed and management of behavioral symptoms and the provision for caregiver support are given importance in this. Care can be delivered by trained primary care teams, with a paradigm shift towards chronic continuing care and community outreach. Care delivery will be more

efficient when integrated with that of other chronic diseases, and more broadly based community support programs for the elderly and disabled. To be successful, all efforts in psychogeriatric service development need to be supported by a clearly spelt out policy on long-term care and political commitment.

Limitations of the Study

The study has the following limitations:

This is only a pilot study and needs to be done on a larger sample basis after receiving feedback.

The conclusions of this pilot research attempt need to be verified with further methodological rigour in terms of applying other field techniques coupled with interview and general observation methods.

Relevant statistical techniques need to be applied on the basis of which the conclusions can be made more accurate and reliable.

The present study has drawn sample from rural India and does not authenticate on urban Indian situation concerning dementia.

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