Quality of Life and its Predictors in Person with Dementia: Search for Possible Research Arenas

Abhik Sinha

Abstract

Dementia is a public health problem of today. Dementia is characterized by a loss of or decline in memory and other cognitive abilities, and it reduces the lifespan of affected people. It is estimated that 24.3 million worldwide and 1.8 million people in India were affected with dementia. Quality of life in recent years has evolved as a very useful indicator in assessing the present overall wellbeing of an individual. Thus evaluating the quality of life in persons with dementia and finding its predictors is important. The literature review was done to form a document about the possible research scopes and policy direction in this regard. It was found that male gender, poor socioeconomic status, illiteracy, diabetes, hypertension, the presence of stigma were significant predictors of quality of life in dementia. It was also found that the presence of good caregivers and proper family support were also significant predictors for quality of life in dementia. Thus community-based studies in this regard should be conducted. Establishment of dementia-specific care centres, more awareness generation camps to reduce the stigma of dementia should be considered. Revamping the public healthcare delivery system to make it dementia friendly is an essential area for thought. Specialized health programmes on dementia are the urgent need of the country.

Key words: Dementia, Quality of Life, Dementia Research

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Introduction

Dementia is characterized by loss of or decline in memory and other cognitive abilities, and it reduces the lifespan of affected people. It is estimated that 24.3 million worldwide and 1.8 million people in India were affected with dementia. In India, the number of people with Alzheimer's Disease and other dementias is increasing every year because of the steady growth in the older population and stable increment in life expectancy, and it is expected to increase two-fold by 2030 and three-fold by 2050.¹ By 2050 the number of people in the Asia Pacific Region suffering from dementia will rise to 71 million from 23 million in 2015, with India coming second only to China with over 12 million likely victims of dementia.²

Dementia is often associated with the physical, mental and financial burden and evidence suggest that elderly people with dementia in developing countries do not usually utilise health care services, and when they do, the health care system is often ill-prepared to provide quality services for dementia.³ Around 10-37% of the elderly population with dementia in developing countries are classified as having potentially vulnerable living circumstances requiring long-term and specialised care.⁴

Quality of life is defined as a composite measure of physical, mental and social well-being as perceived by each individual or by group of individuals that is to say, happiness, satisfaction
and gratification as it is experienced in such life concerns as health, marriage, family work, financial situation, educational opportunities, self-esteem, creativity, belongingness, and trust in others. Thus it can be said that the distinction between ‘level of living’ and ‘quality of life’ lies in the fact that level of living is an objective criterion while quality of life comprises of the individual’s own subjective evaluation of these. Quality of life is a very important outcome measure for treatment efficacy in dementia.\(^5\)

Dementia still now doesn't have a definitive curative treatment. The management of dementia involves long-term treatment. The outcome measures in dementia treatment are multifactorial. Quality of life is an important measure to understand the treatment effectiveness and disease progression. Knowledge of the predictors of quality of life in persons with dementia helps to find out interventions for its betterment. Thus assessing the quality of life in persons with dementia (PWD) and finding its predictors is important. The literature review was done to form a document to get the possible research scopes in this field.

The search pattern and methodology

Articles and journals pertaining to this subject were were searched in the following search engines: Google, Google Scholar, Pubmed, Embase, and Cochrane database.

For Indian studies, the search was done on the site of National Medical Library, India. Apart from this search was done in the institute library too.

Search terms used for the literature review, in this case, were Dementia, Quality of life (QOL), Predictors of QOL in dementia.

The selection of the articles for review was done from peer-reviewed journal articles, abstracts available, full text available and only English language articles were reviewed.

The studies which did not match with the objective to predict quality of life in dementia were not included in study.

Global scenario

Woods et al (2014) suggested in their study that male gender, the severity of irritability shown by the person with dementia, self-concept of quality of relationship (rated by the person with dementia) were significant predictors of quality of life in persons with dementia.\(^6\) They also suggested that the awareness of memory function, knowledge of functional abilities were the significant predictors of quality of life in persons with dementia.

Buckley et al (2012) opined that increased depressive symptoms and poor caregiver support were associated with poor quality of life (QOL) in persons with dementia (PWD).\(^7\) The study supported the associations between lower QOL scores and the presence of neuropsychiatric symptoms.

Maria Jesus et al (2003) suggested associations between lower QOL scores and presence of overall poor health.\(^8\) Heyworth et al., (2009) proposed associations between lower QOL scores and the presence of lower education in persons with dementia.\(^9\)

Smoking and alcohol use were found to be significant predictors of quality of life in persons with dementia in the study by Buckley et al. (2012).\(^7\) Quality of relationship with his/her relative was also found to be an important predictor of quality of life in persons with dementia in a study by Woods et al. 2014.\(^6\)

A study by Sands L et al. (2004) revealed that awareness scores in the areas of memory function and functional abilities showed a small to medium correlation with QOL-AD, but the Global Interview Ratings of awareness and awareness scores related to socio-emotional functioning and memory performance were not found to be significantly associated with QOL-AD.\(^10\)

Indian scenario

Das et al (2012) in their study from India suggested that predictors of quality of life in dementia were illiteracy, addiction, hypertension, diabetics, poor socioeconomic status, familial or genetic factors and nutritional factors.\(^11\)

Saldanha et al., (2010) in a study from west India documented poor literacy level, low socioeconomic status, and positive family history as the predictors of poor quality of life in dementia.\(^12\) On the other hand, marriage was found to be associated with better quality of life in the same study. Marriage was possibly linked to health and economic benefit. Married individuals tend to have better physical health and psychological well-being thus having the better quality of life the researchers have opined.\(^12\)

Chandra et al. (1998) speculated based on their study of from North India, that the predictors for quality of life in persons with dementia were the history of head injury or seizure disorders.\(^13\)

A study from South India by Shahji et al. (1996) has documented family history of dementia, smoking and hypertension as predictors of quality of life in dementia.\(^14\)
From East India, a community study by Das et al. 2008 has shown that the risk factors for Mild Cognitive Impairment which includes hypertension, diabetes mellitus, smoking, previous recurrent attacks of stroke are significant predictors of quality of life in persons with dementia. HIV is an important cause of cognitive dysfunction among young and middle-aged persons. One study from South India by Shahji S et al. in 1996 documented cognitive dysfunction in about 60.5% of HIV subjects. Prevalence of AIDS-related dementia is, however, lower among Indian (approx. 2%) is much lower than Americans (15-30%). This has been related to "TAT" protein which is stable in Indian variants of HIV C type virus than in western countries. This also indicates the existence of a protective factor in the Indian environment and probably needs to be probed further. Studies by Longston in 2002 and Lucas in 2012 have suggested dementia in persons with HIV/AIDS were having a lower quality of life than non-HIV persons with dementia.

Srivastava et al. (2016) in their study revealed that a negative correlation was found between the amount of burden for the caregiver assessed by Zarit's caregiver burden scale and QOL in person with dementia. Mougias AA et al. (2011) suggested that professional help and supportive psychotherapy can be provided to the key caregivers of dementia patients to reduce their burden, strengthen their coping skill. This will, in turn, lead to the betterment of QOL in the person with dementia.

Possible research areas

Among the predictors of poor quality of life in a person with dementia there are many factors which can be acted upon. Thus by working on these factors, there is the scope of the betterment of quality of life in a person with dementia.

a. Research focus

One of the neglected areas of research is the role of social support and health care services over the quality of life of persons with dementia. In India, there is the transition from the joint family to nuclear family. Thus with the dissolution of the traditional Indian families, getting a proper caregiver for a person with dementia is now a major issue. More research in this area is required especially in Indian context.

While evaluating for cognition, we should obtain patient's self-report and subjective impressions regarding changes in memory and cognitive functioning. It is equally important to obtain an assessment from caregiver, relatives or peer. Depression and other psychological factors often lead to over-reporting of cognitive disturbances. Brief mental status examinations and screening instruments are not adequate for diagnosis in most cases, and a comprehensive neuropsychological evaluation is needed. Thus research can also be done on the methodological issues on dementia assessment in the persons with dementia.

Quality of life in persons with dementia can be assessed with a locally validated version of Cornell Brown Scale of dementia. As the presence of neuropsychiatric symptoms, the presence of depressive symptoms was found to be associated with poor QOL in PWD. Thus proper assessment of these conditions and management is necessary for PWD to better their QOL.

PWD are mostly elderly population. In India, social security and financial security in this age group is scarce. Role of these two factors as predictors of QOL in PWD needs to be explored extensively.

One interesting research by S Mishra (2008) suggested that a yellow curry paste (turmeric) which is almost consumed universally by Indians which has antioxidant and anti-inflammatory effects and decreases amyloid protein synthesis may be a protective factor in the lower prevalence of dementia among Indians. Researches to find out these type of dietary interventions which can have a role in the betterment of quality of life in persons with dementia can be carried out.

A study by Jha and Patel (2004) suggested that stigmatisation leads to poor quality of life in persons with dementia. Thus this also an important area which can be an important area of intervention.

b. Future scope of research to face this public health challenge

This review article deals with the various facets of people with dementia. Dementia problem is increasing in India. Thus integrated research is needed to develop a comprehensive public health model in this regard. Developing a national public health policy in this regard is also essential. Therefore multidisciplinary research including operational research in this field is required.

i) Kerala Model: Lessons to learn

Kerala, an advanced state in terms of literacy and human development index, has undergone rapid urbanisation and modernisation in the 80s and 90s of the last century. As a result, there is an
exodus of earning member for an economic reason. Traditionally in Indian culture, the elderly persons are taken care of by the next generation family members. Urbanisation leads to disruption of the joint family due to migration and older people are left in rural communities with meagre or absence of family support in many cases. Thus, demographic changes characterised by increasing elderly population and modernization has led to the negative influence of people with dementia. In such a situation, non-governmental organisations have come in the forefront. They are attempting to arrange awareness program and daycare and homecare centres for the patients as well as for the caregivers. In this state, many institutions have been set up to take care of patients with dementia. All these interventions have proven to better the quality of life in persons with dementia.  

Conclusion  

Male gender, poor socioeconomic status, illiteracy, diabetes, hypertension, the presence of stigma were significant predictors of quality of life in dementia. The presence of good caregivers and proper family support were also important predictors for quality of life in dementia.

Extensive community-based studies are required to assess the relevance of the risk factors already found in the local geopolitical and social context and to search for newer predictive factors if any. Community-based interventions to reduce the modifiable predictors of poor quality of life in persons with dementia should be taken care of.

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