



MODIFIED MENTAL HEALTH GAP MODULE'S IMPACT ON THE BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS OF COMMUNITY-DWELLING DEMENTIA PATIENTS

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ABSTRACT

BACKGROUND:

Dementia is a growing public health problem among the elderly in developing countries, where the aging population is increasing rapidly. Dementia is a disease marked by progressive cognitive impairment in clear consciousness. Worldwide, around 50 million people have dementia, with nearly 60% of them living in underdeveloped or developing countries. It is estimated that by the year 2020, approximately 70% of the world's elderly population will be living in developing countries, with 14.2% of them in India. There is no treatment currently available to cure dementia though there are medications to slow down the progress. Behavioral and psychological symptoms in dementia (BPSD) and the caregiver's burden are the two main concerns of health workers which severely affect the outcome of treatment. Non-pharmacological measures were found to be effective and gained attention in recent years in managing behavioral and psychological symptoms.

AIM: A Study to Evaluate the Effect of a Modified Mental Health Gap Module on Caregiver's Burden and Behavioral Psychological Symptoms of Dementia among Patients Living in a Rural Community.

MATERIAL AND METHOD:

This study was conducted in the Department of Medicine to estimate the BPSD and caregiver burden among patients with dementia and evaluate the effects of the modified mhGAP module on BPSD and caregiver burden among community-dwelling elderly with dementia. The evaluative approach was used to find the effectiveness of the modified mhGAP module on BPSD and caregiver burden on patients with dementia.

RESULTS:

BPSD was common among 85% of patients with dementia. Apathy, delusion, and agitation were the most common BPSD experienced by the patients. The symptoms that produced increased distress for the caregivers were apathy, delusion irritability, and agitation. 30.5% of the caregivers experienced mild to moderate burden and 25% of them experienced moderate to severe burden. The severity of BPSD symptoms showed a reduction after the implementation of the mhGAP module which was found to be statistically significant except for motor disturbances. The distress of caregivers due to the BPSD of patients also showed a decrease which was statistically significant. There was a significant reduction in the caregiver burden after the mhGAP module intervention.

CONCLUSION:

The results show that the mhGAP module was effective in reducing BPSD and caregiver burden. This study proved that training health workers are effective in managing patients with dementia at home in a developing country like India. This module can be used in community mental health settings to train health workers so that the morbidity and burden can be effectively controlled.

KEYWORDS: Dementia, BPSD, caregiver burden, elderly, community-dwelling, Behavioral and Psychological Symptoms of Dementia.

INTRODUCTION:

The number of older adults in the population is increasing worldwide. People aged 60 years and more will expand from 8.5% today to more than 21% of the total population in 2050.¹ Dementia is a

neurodegenerative disease usually affecting older adults marked by progressive cognitive impairment in clear consciousness. Dementia is one of the major causes of disability and dependency among older persons. Dementia is a growing public health

problem in developing countries, where the aging population is increasing sharply. Dementia is a collective term used to describe a group of symptoms associated with a decline in memory and other cognitive skills which is enough to reduce a person's ability to perform everyday activities. Around 60 to 80 percent of all dementia cases are caused by Alzheimer's disease.²

Worldwide currently, around 50 million people have dementia, out of which nearly 60% live in underdeveloped and developing countries. It is estimated that in every 20 years, the number of people around the world with dementia will be doubled.³ Around 10 million new dementia cases are being diagnosed every year, which means in every 3 seconds, one new case is diagnosed.⁴ It was the seventh leading cause of global death in 2019⁵ and 65% of deaths from dementia were women.⁶ Much of this increase will be visible in underdeveloped and developing countries. It is estimated that by the year 2020, approximately 70% of the world's older adult population will be living in developing countries, with 14.2% of them in India.⁷

Risk factors are broadly divided into modifiable and non-modifiable risk factors. Modifiable factors include cerebrovascular injury or stroke, severe head trauma or traumatic brain injury cardiovascular diseases, cerebral hypo perfusion, hypertension, diabetes, dyslipidemia, nutritional deficiency, metabolic syndrome, smoking, alcohol, obesity, physical inactivity, and unhealthy diet. Non-modifiable factors include age, family history, Apolipoprotein-34 (APOE) allele carriers,⁸ female sex, mutation on chromosome numbers 1,14, and 21, cerebral amyloidosis, and Down's syndrome.⁹

Symptoms of dementia comprise two major groups which can be divided into cognitive symptoms and non-cognitive symptoms. Cognitive symptoms focus on impairment of memory, especially on learning new material, and short-term memory which is a key early symptom. Non-cognitive symptoms constitute of neuropsychiatric symptoms, also known as Behavioral and Psychological Symptoms of Dementia (BPSD). The term has been used to describe a group of symptoms that arise in the course of dementia and are distressing and difficult to manage, both for caregivers and health professionals.¹⁰ Depression in early dementia is characterized by somatic symptoms and can be identified by the presence of sadness, depressive thoughts, and early-morning awakening. In later phases, symptoms of depression would include

sleep-wake cycle reversal, aggressive behavior, and agitation. Regardless of the stage of dementia, depression would accelerate its course.¹¹

Care of people with dementia is one of the areas in which people are unaware as it might be considered as a normal aging problem. Primary level health workers need¹² to be aware of dementia so that they can identify the cases early, and can train the family members how to deal with major symptoms at home especially BPSD and caregiver strain which will be highly effective than specialized care facility interventions. Though studies were conducted in developing and underdeveloped countries like Ethiopia, Pakistan, and Sri Lanka¹³ regarding the effectiveness of the mhGAP module on patients and health workers, not many Indian studies were found as researchers selected this topic.

MATERIAL AND METHODS

This study was conducted in the Department of Medicine to estimate the BPSD and caregiver burden among patients with dementia and evaluate the effects of the modified mhGAP module on BPSD and caregiver burden among community-dwelling elderly with dementia. The evaluative approach was used to find the effectiveness of the modified mhGAP module on BPSD and caregiver burden on patients with dementia. The sample is a subset of the population that is selected for a particular study and the members of a sample are the subjects. For this study, we have selected a patient and caregiver dyad. The sample of this study comprised 50 elderly patients with dementia. Data collection is a systematic process of collecting information for finding answers to the research question.

Research design: Quasi-experimental one-group pretest-posttest design.

Selection of the instrument

In this study, the researcher has developed Socio personal questionnaire to collect the socio-personal variables of the patient and caregiver. After searching the literature of dementia studies and discussing with a guide and other experts, Brief Community Screening Instrument for Dementia (CSID-BRIEF) for screening the elderly for dementia, Neuropsychiatric Inventory Questionnaire (NPI-Q) for assessing the Behavioral and psychological symptoms (BPSD) and Zarit Burden Interview (ZBI) for assessing the caregiver burden were selected for the study.

Inclusion criteria

The criteria for inclusion of the subjects in the study were Dementia patients

- with a CSID-BRIEF score of 6 or less.
- with age above 60 yrs.
- whose caregivers can comprehend the local language.
 - living with a primary caregiver who was caring patient for a minimum of 1 year

Exclusion criteria

The criteria for exclusion of the subjects in the study were Patients or caregivers who

- were diagnosed with vascular dementia.
- are not willing to participate in the study.
- had severe co-morbid medical/psychiatric illness.
- were on any medications for dementia.

Knowledge questionnaire: This was a 20-item self-report tool developed by the researcher after consultation with the guide and co-guide and after an extensive review of the literature. It includes age, gender, educational status, marital status, family monthly income, type of family, type of house, caregivers’ relationship with the patient, number of family members, duration of dementia, total duration of caregiving, level of dependence, source of income, any other dementia services available and any assistance in caregiving available. The tool took 3 to 5 minutes to complete.

Data collection: Data collection is a systematic process of collecting information for finding answers to the research questions. After taking permission, the first phase of the study was conducted at a trust in India. After taking consent, seven community health workers were randomly selected using the lottery method, and a pretest

was conducted with a knowledge questionnaire. A modified mhGAP module training session was conducted for the community health workers and all doubts were clarified.

Sample: The sample is a subset of the population that is selected for a particular study and the members of a sample are the subjects. For this study, we have selected a patient and caregiver dyad. Sample of this study comprised 50 elderly patients with dementia

Sampling technique: The sampling technique used in this study was the purposive sampling technique. The researcher collected the list of 300 suspected cases of cognitive impairment already available with Vikas trust from earlier dementia screening camps. The health workers of trust helped to shortlist the suspected cases.

Statistical analysis: Data were coded and entered in to excel sheet and cross-checked for any missing values after each entry. Data analysis was conducted with SPSS 16 statistical package and used descriptive statistics frequency, percentage, mean, median, and standard deviation. Kolmogorov-Smirnov test of normality done on pretest data revealed a non-normal distribution, so the non-parametric repeated measure test Friedman’s ANOVA was used to evaluate the effect of mhGAP module on BPSD and caregiver’s burden.

RESULT: -

This study was conducted among 50 older adults with dementia to identify behavioral and psychological symptoms (BPSD) and caregiver burden and to evaluate the effect of the modified mhGAP module on BPSD and caregiver burden. The collected data were analyzed by using both descriptive and inferential statistics.

Table 1: Comparison of BPSD total severity scores before and after the implementation of the modified mhGAP module.

	Mean + SD	IQR
Pretest	14.21 + 5.82	08.3 to 12
6 weeks	13.72 + 6.11	06.3 to 11
3 months	08.21 + 4.77	4 to 14
12 months	6.44 + 4.26	3 to 12

The effect of mhGAP module on BPSD total severity scores. There was a statistically significant difference in BPSD total severity scores before and after the implementation of the modified mhGAP module

Table 2: Comparison of delusion severity scores before and after the implementation of the modified mhGAP module

	Mean + SD	IQR
Pretest	1.13 + 1.16	1 to 2
6 weeks	1.41 + 1.21	0 to 2
3 months	0.88 + 1.10	0 to 1
12 months	0.94 + 1.12	0 to 1

The effect of mhGAP module on delusion severity. There was a statistically significant difference in delusion severity before and after the implementation of the modified mhGAP module

Table 2: Comparison of delusion distress scores before and after the implementation of modified mhGAP module

	Mean + SD	IQR
Pretest	2.31 + 1.18	0 to 3
6 weeks	1.02+ 0.99	0 to 2
3 months	0.82 + 0.60	0 to 2
12 months	0.78 + 0.33	0 to 1

The effect of mhGAP module on delusion distress. There was a statistically significant difference in delusion distress before and after the implementation of the modified mhGAP module

DISCUSSION

Dementia is being researched widely after the world's elderly population started to grow. After recognizing that there is no specific pharmacological treatment for dementia, the focus of interest was shifted to nonpharmacological methods. Many studies were conducted worldwide to test the effect of non-pharmacological interventions on BPSD and caregiver burden and were found equally effective on both parameters and have fewer side effects compared to pharmacological interventions. Many published studies like **Carnahana RM¹⁴ et al 2017**, **Aguilar 2017¹⁵**, or **Chen X 2019¹⁶** have used a quasi-experimental design to assess the effect of non-pharmacological interventions on BPSD.

Brief Community Screening Instrument for Dementia (CSID-BRIEF) is one of the most reliable and valid instruments for identifying the elderly with dementia. One of the biggest advantages is that it can be used by health workers of all levels in a community setting in a developing country.¹⁷ The

same tool was used by other studies in the same setting¹⁸ and found good diagnostic accuracy and also used in another major prevalence study conducted in India.¹⁹

Dan Qiu 2019²⁰ stated that the acceptability of non-pharmacological interventions was high in terms of participation, adherence to treatment, and customer satisfaction. Most of the caregivers feel they got benefitted from non-pharmacological interventions. So the researcher, being a psychiatric nurse, was inspired to develop a non-pharmacological intervention for managing BPSD and caregiver burden for dementia patients living in the community

World health organization found that in developing and underdeveloped countries the mental health services needed for patients were concentrated in urban areas. So, there is a mental health gap exists between patients in rural areas and mental health services. The treatment gap in south India was recently estimated to be as high as 90%,²¹ mhGAP intervention guide is an evidence-based module developed for this purpose and the researcher found this guide is useful in developing a module for health workers and testing the effect of these interventions on BPSD and caregiver burden.

Interventions based on principles of other non-pharmacological interventions were also added in the modified mhGAP module. Mahoney M suggested that an increase in the frequency of contact with family is useful.²²

In a study done by **Hamanna LB 2014**,²³ in which the mean age of patients was 80.47+ 5.62 years, 73% were females and the mean duration of dementia was 38.70 months. Since the dementia risk increases in every decade after 60 years, most of the studies found samples of mean age 75 years to 85 years which is also reconfirmed by the present study. In the study by **Kim H 2012** and others²⁴ where the mean age was 47.06 + 15.38 years and 57% of caregivers were women, with average education was up to high school, 6% of them were spouses similar to 16.9% in the present study. Studies found as the mean duration of dementia was 18 months²⁵ and the mean duration of caregiving was 33 months.²⁶

Many studies pointed out that BPSD is a major issue in patients suffering from dementia which worsens cognition, increases caregiver burden in family members, increases falls, fractures, emergency room admissions, and institutionalization in patients with dementia which causes higher costs for treatment and caregiving.²⁷ Many systematic reviews reported that Non-Pharmacological Interventions are effective because of the lack of side effects and better outcomes hence non-pharmacological interventions should be used as a first-line treatment.²⁸

According to **Smith et al 2004**,²⁹ motor disturbances increase due to reduced stress threshold and losing of coping abilities, and perceiving their environment as more stressful. Most of the samples might have been in their mild to moderate stages which can also be a reason for the increase in BPSD. There was a significant weak positive between caregiver burden and duration of caregiving. Hence it is interpreted that the caregiver burden tends to increase slightly with the duration of dementia. It adds to the current knowledge that the caregiver burden increases with the time of caregiving. It can be explained in view of physical and mental exhaustion along with decreased support and an increase in financial burden for the caregiver as time progress. It emphasizes the need for special support for caregivers who were taking care of dementia patients for a long period of time. But there were studies that say that the caregiver burden remains stable over time.³⁰

Allegri et al 2006³¹ argued that the caregiver burden was found to be higher in lower education levels. No association was found with marital status. Caregiver burden remains similar in a married and unmarried or widowed caregiver which explains that burden is universal irrespective of marital status. But some studies pointed out that caregiver burdens were higher in married caregivers.¹⁹

Studies by **Song JA 2018**²⁸ and **Wang 2015**³⁰ also confirmed that the availability of assistance doesn't change the burden. This makes us aware of the need for training caregivers in caring for dementia along with giving manpower assistance. Those who are properly trained can manage the burden well even without much assistance.

Attrition analysis was found to be coinciding with the socio-demographic characteristics of the total subjects in terms of age, gender, education, marital status, type of family, and type of house. So we can assume that attrition wouldn't have affected the total results of the study. But the attrition rate was 14% which was more than the expected 10% in the elderly population. Still, we were able to complete the data collection with 98% of the sample size which was sufficient to do the analysis.

CONCLUSION:

The participants were cooperative and willingly participated in the study. The community health worker-based mhGAP interventions are found to be feasible and effective in managing BPSD and caregiver burden in an individualized manner for patients with dementia. The experience gained during the study has influenced and motivated the investigator to take up more research in the future. Hopefully, this research will help other researchers to conduct studies in areas that will be beneficial for the elderly people with dementia in our community.

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