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Will User-Friendly, Nonpharmacological Graded Intervention Toolkit for Dementia Help in Better Domiciliary Care: An Implementation Study in Select Areas of Northern Part of West Bengal.

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Statement of problem:

Dementia is an oftly neglected aptly repeated issue that looms large not only in textbooks of mental health but in the community at large. It remains a grey zone where no defined rules and codes exist and when a family gets diagnosed with a demented member amidst them, they are at a loss as to how to cope and tide over, creating more mayhem in the process. The financial burden combined with the fact that it runs a downhill course further increases the mayhem.

Caregivers also bear the brunt of caring for such patients and are often suffering from clinical or latent depression. They need patience and most importantly training. It takes its toll on their health if they are not equipped enough for domiciliary management and aware of warning signals. The downhill disease progression plays a contributory role. Moreover, few cases may remain undetected and hence uncared given the taboo, stigma, and ignorance attached to mental health issues in India. Rural India stands as the worst sufferer[1].

Hence equipping caregivers with culturally sensitive aids, and decisions that are operationally feasible along with forming a graded domiciliary dementia management module may prove beneficial. The very tenets of community psychiatry lie in reaching the doorstep of every household so that in a nation where doctor doctor-population ratio is severely deranged, common people do not have to bear the brunt and get the primary level of essential health care designed and designated for them.

Hence with the objective of

The objectives of the project were early identification of dementia patients based on warning signs at a community level and severity grading them by qualified practitioners by FAST staging. Assessing the status of dementia patients before, during, and aftercare by practitioners using CGI (Clinical Global Improvement Scale) and Assessing the Quality of Life of caregivers and patients using the QOL scale was done. Finally formulating a graded domiciliary nonpharmacological intervention of dementia based on FAST staging and Capacity building of caregivers according to the structured module for uniformity in care at community level was the vision.

- Study design, setting, duration: Community-based qualitative study in hilly areas of Darjeeling district catering to North Bengal Medical College was done with one year of data collection in a year study period.
- Study participants, sampling, and study subjects - Eligible willing caregivers of demented patients chosen out of the select households under DMHP. All eligible willing study participants were enrolled for study purposes. Complete enumeration was followed
- Data collection tool, technique, and Data collection - Pretested designed interview guide, records, and In-depth Interview (IDI), record review was done and feasibility and usability of the module were asked.
- The module was inserted (It was translated, back-translated, data compiled, collated after necessary alterations, and validated before applying. DMHP implemented it and it was accepted by Sangath Goa in the ESSENCE Fellowship Category for the year 2020-21). It will be shared with all stakeholders

A structured module will be formed which will consist of -

1. Screening questions: To identify high-risk cases of dementia in the community

a. Any history of personality change
b. Any history of recent mood change
c. Any history of recent forgetfulness

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d. Any history of recent aggression
e. Any history of any recent tendency to fall
Anyone will be diagnostic

2. To get assessed by the local medical officer on a FAST staging if screened positive and be graded as Mild (1-3), Moderate (4-5), Severe (6-8) and get an MRI done to corroborate
3. Those diagnosed withMild dementia -
Usually have a lesser tendency to fall or forgetfulness
a. Can wear an Identity Band at wrist
b. Can take walking support or tripod stand-repeated tendency to fall if
c. Infection control and pneumococcal vaccine administration
d. Socially engage the person
e. Providing writing and reading support
f. Help to do Basic activities of living

Those diagnosed withModerate dementia -
a. All the steps of mild dementia and
b. To control apraxia – help to dress up
c. Help to feed patient – a semisolid bland diet, a small portion every 2-3 hours, 8meals/ 24 hours, and increased protein-rich diet
d. Functional clarity decreases so daily activities by self should be encouraged
e. Self-care encouraged and helps

Those diagnosed withSevere dementia -
a. Bowel bladder incontinence will develop or retention
b. Illness or diarrhea- Water and food intake and ORS need to be increased to prevent hyponatremia. Protein and Vitamin A-rich food needs to be given
c. Patient needs to be shifted sides to avoid bed sores. Water bed may be tried
d. Pneumococcal, influenza vaccine, and immune-compromised state to be taken care of
e. Preventing abuse of elderly
A few salient strategies for caregivers -
a. Having an emergency contact number and knowing warning signs
b. Having a peer support group
c. Be careful and self-screen if the genetic stock of the patient and caregiver is the same for signs of constant sadness, constant irritability
d. Proper nutrition, lifestyle changes, and medications
e. Having breaks and catharsis techniques
f. Capacity building by trained counselors. Medics and psychologists

- Ethical issues

Ethical clearance and voluntary consent will be obtained. Permission for conducting the study by all higher authorities will be taken. Eligible caregivers at the hospital will be enrolled for study purposes. Sensitization will be done and the intent, benefit, and purpose of the study explained. Queries will be addressed. Anonymity ensured. Data will be used for academic purposes only.

- Data collection plan - Capacity building of the caregivers regarding the module was done and asked to implement it in their home settings. Feedback was taken after two days. The module was restructured and modified based on inputs received, translated, back-translated, and then made final before implementation. Satisfaction and usability status of the module were elicited from study subjects after a fortnight. Challenges and barriers were addressed and further modifications started.
- Data Analysis Plans: Collected data was cleaned, collated, compiled, and then entered for data analysis. Atlas Ti Software will be used for data interpretation and diagrammatic representation as and where required. Qualitative data was analyzed using the verbatim method, identifying nodes making a chapati diagram, and ranking in preference in descending order the most preferred interventions. Pile sorting and other Nominal field techniques and Grounded theory were applied.
- Result – It was seen that the module helped caregivers in developing the confidence to treat. The demarcated sections gave an insight and understanding of the work and even recruits / changed caregivers faced fewer problems. The majority of them were satisfied because of the structured directions given and the grading of the patients. In rural remote places where staff shortage and transits are difficult, they found it to be a ready reckoner. However Pharmacological Interventions are to continue alongside was stressed to them repeatedly. They insisted on hands-on training and a further expansion for the same.
- Discussion and conclusion –Caregiver modules are not much in use though from Goa such an initiative has been taken and has been accepted positively by many. The research concluded such graded domiciliary care nonpharmacological intervention modules can help perform caregivers better and more structured and a Uniformity will be established. Reinforcements, updating the

module, and customized care can be areas of further improvisation. However, a larger study with a more representative sample is warranted in similar terrains

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