

A SERVICE MODEL FOR HOME-BASED CARE IN LATE STAGE DEMENTIA: SCOPE, SCALE AND POLICY IMPLICATIONS

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ABSTRACT

Dementia care as it exists today in India is threadbare. Quality of life of dementia sufferers needs much improvement. Considering the resource constraints, care models for chronic conditions like dementia will be sustainable only if they are cost effective. Community-based care, preferably at home with a health worker providing domiciliary support, would be ideal, and evidence in support of such care is accumulating. However, implementing such care in real world settings is a challenge even for the well-resourced health systems of high income countries, and most of the responsibilities will have to be entrusted to a low cost workforce with multidisciplinary skills. The author describes a putative model for home-based dementia care that horizontally integrates two programs which already function in Kerala — District Mental Health Program and Palliative Care Program.

Keywords: Dementia care, home-based care, DMHP, palliative care

INTRODUCTION

Provision of affordable and comprehensive care for dementia remains a formidable challenge even in high-income countries, and the situation in low-income and middle-income countries, where 62% of people with dementia live, may prove intractable.¹ Dementia care as it exists today in India is threadbare, and the quality of life of dementia sufferers needs much improvement. Much of the care is left to family members, without provision for any sort of support. Care of patients with

dementia is both physically and mentally exhausting. Strain of the caregiving role is often shouldered by the unaffected spouse, often a woman. Health professionals, besides caring for the patient, have to also consider providing mechanisms of support, skill building and respite for the family caregivers. Health delivery systems in low and middle income countries, despite their fragilities, will be called upon to address such emerging challenges in geriatric care, and care delivery machinery for late-life degenerative conditions like dementia will have to adopt the chronic illness

Please cite this article as: Ramkumar GS. A service model for home-based care in late stage dementia: scope, scale and policy implications. Kerala Journal of Psychiatry 2015; 28(1):78-81.

management model.² Given the resource constraints, such care will be sustainable only if cost effective models are adopted. Sufficient coordination between different sectors like health sector, social and disability sector, etc. will be essential. Community-based care, preferably at home with a health worker providing domiciliary support, would be ideal, and evidence for such care is emerging.^{3,4} However, implementing such care in real world settings will be a challenge even for the health systems of high income countries. Creating a new cadre would be financially unviable, especially in under-resourced health systems. (In India, cost-cutting measures like collapsing various centrally sponsored schemes that have overlapping mandates, like the public health programs for cancer, geriatrics, non-communicable diseases and mental health, have already started.⁵) Hence, the responsibility of caring for conditions like dementia will have to be entrusted to a low cost workforce with multidisciplinary skills. In case of dementia, behavioral symptoms are an important disease-related factor which might pose additional challenges for a home-based management by a less skilled workforce.

I hereby describe a putative model for dementia care by horizontally integrating two programs that are already functional in Kerala — the District Mental Health Program (DMHP) for decentralized mental health care and the Palliative Care Program (PCP) for homebound debilitated patients (mostly cancer).

DECENTRALIZED HEALTH CARE: KERALA SITUATION IN MENTAL HEALTH AND PALLIATIVE MEDICINE

DMHP, the flagship program for decentralized mental health care, is

functional in all fourteen districts of Kerala. It has been functioning for at least 1-2 years even in those districts where it started late. I work at DMHP of Kottayam district which started functioning in mid-2012. DMHP functions in Kerala by providing outpatient mental health clinics at 15-20 peripheral centers, usually a Community Health Center. Monthly clinics are conducted at each of these centers by a multidisciplinary team comprising a Psychiatrist, a Clinical Psychologist, a Psychiatric Social Worker and a Psychiatric Nurse. The program has provisions for a vehicle to carry the team around, and for psychotropic medications that are distributed for free.

Despite the multidisciplinary team, DMHP is constrained and is able to provide only once in a month outpatient services at 15-20 locations in a district. Such services may prove inadequate if we are to follow a chronic disease management model — especially so in conditions like dementia. We at DMHP Kottayam noted that once in a month outpatient visits was inadequate to provide comprehensive care for dementia patients. Most follow-up visits were by the relatives, without the patient. A refill of the psychotropic medications for control of behavioral symptoms and providing certificates to avail government benefits were the only practically possible interventions. (We proactively facilitated disability certification for dementia patients so that they can avail disability pension. Caretakers belonging to the Below Poverty Line category were also provided certificates to avail caretaker allowances for bedridden patients as per Ashwasakiranam scheme.)

A review of our database, after about a year of commencement of the program, revealed that we had 14 patients with dementia. (270 of the total 725 patients registered till then

were included in the database.) Similar findings are reported from DMHP clinics at Palakkad district too.⁶ Also, more number of older patients are reported to utilize peripheral DMHP clinics than central tertiary facilities.⁷

Being in familiar surroundings helps people with memory problems, and hence domiciliary care is an appropriate, cost-effective option for people with late-stage dementia. But DMHP, with a team of four for a district, is not in a position to do that. At this juncture, we thought of the possibility of utilizing a readily available home-service cadre — the PCP.

PCP too is existent in most districts of Kerala. It is more rooted in the community as it is directly supported by the local self government.⁶ Its working model involves home visits by a cadre of community health nurses and field workers in a vehicle provided through local self government funding. Kottayam district has about 150 community nurses working in the PCP, and they are supported by seven doctors from the health department. Both DMHP and PCP in Kottayam district receive funding towards vehicle expenses, salary of staff, and provisioning of medicines and equipment from the NRHM.

NEEDS ASSESSMENT SURVEY AMONG PALLIATIVE CARE NURSES

Though it primarily serves cancer patients, PCP also provides home-based care for functionally impaired patients with chronic neurological problems, severe mental retardation, and even dementia.⁶ This was evident from the referrals we received — a pathways to care analysis revealed that 28 (10.6%) of the total 270 patients in our database were referred by field staff that included palliative care staff. A needs

assessment survey (Table 1) was done among palliative care nurses when they assembled at the district level for their monthly meeting. Responses from 70 nurses were summarized, and it was found that 69% of them have not received any formal training in home-based dementia care. They also anticipated many difficulties in taking up this new responsibility. According to them, the major challenges were difficulties in communicating with dementia patients, difficulties the patients experience in cooperating with their family caregivers, and the patients' refusal to take medicines. We decided to address these issues through a training program.

TRAINING PROGRAM IN HOME- BASED DEMENTIA CARE

A half-day training workshop was organized to sensitize the district's palliative care team about dementia and its care. Main topics addressed were providing support to caregivers, environmental modifications at home, and referring patients with behavioral symptoms to DMHP clinics. A few months after the training, informal feedback about the initiation of home-based care was gathered from some family caregivers of dementia patients during their routine follow-up visits at our clinics. All of them were happy that some care was being made available at home. However, it was noted that, though the nurses visited the patients' homes once or twice after receiving the training, the caretakers continued to have limited capabilities in dealing with the care challenges. Therefore, there might be a need for continued training on a one-to-one basis, with a collaborative care plan on a case by case basis. Continuous handholding and adequate hardship incentives may be necessary to make this model sustainable.

Needs Assessment Questions	Yes	No
Do you see people with mental health problems as a part of your routine work?	90%	10%
Are home-bound patients with severe mental illness included in your home care program?	90%	10%
Have you ever received any training in the care of home-bound patients with severe dementia?	31%	69%
Do you anticipate any difficulties or challenges in the care of such patients?	50%	50%
What are those difficulties?	See text	
Have you received any training in counseling for caretakers in distress?	50%	50%
Have you heard of DMHP?	50%	50%
Have you referred any patients to DMHP clinics so far?	18.5%	81.5%

Table 1: Responses from the needs assessment survey done among the palliative care nurses (n=70)

IMPLICATIONS OF THE MODEL

Implications with respect to scope: It might be possible to render home-based comprehensive care for dementia, without additional staff requirements for DMHP, by training palliative care nurses who have direct access to homes of patients in the community.

Implications with respect to scale: DMHP, with its multidisciplinary team, is now functional in all our districts. Likewise, PCP is vibrant at panchayat level all over the state. The model is thus scalable across the length and breadth of our state.

Implications with respect to policy for decentralized care: As the national strategy for the vertical programs for geriatrics, cancer care, etc. is converging, bottom-up models like the one described, which crosstalk with the existing vertical care infrastructure, can claim more meaning and value. At the program (meso) level, pooling of funding from vertical programs can be specifically earmarked to support such hybrid models of care. At the macro policy

level, priority can be given to such hybrid models which can produce comprehensive, cost-effective and sustainable care.

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Source of support: None Conflict of interest: None declared