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DEVELOPING A DEMENTIA FRIENDLY ECOSYSTEM THROUGH A DEMENTIA FRIENDLY COMMUNITY WITH HEALTH BENEFITS OF NON-PHARMACOLOGICAL INTERVENTIONS' USAGE IN DEMENTIA CARE: OPPORTUNITIES AND CHALLENGES

Community Medicine

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ABSTRACT

Developing a model dementia friendly community in a developing nation is a biggest challenge. With limited resources and funding, it is of utmost importance to device changes in the existing infrastructure, considering the sociocultural norms of the place where we want to develop a dementia friendly community. The place where we want to develop this model is urban area of Bagalkot city, Karnataka, as the density of the senior citizens is higher in this area. The plan of this assignment is to create our own design model which includes the role of four principle based, dementia friendly community. This assignment helped us identify the shortcomings currently faced by the senior residents of Bagalkot city and gives a detailed plan of how to make a community dementia friendly. Own definition of a dementia friendly community includes development of age friendly environment modifications, access to better living conditions using assisted technologies, assisted Instrumental Activities of Daily Living (IADL)1and caregiver support, keeping in mind the cultural considerations of the study area. The four principles include: cultural considerations specific for the area of the study, nature therapy, use of technology, and caregiver role in caretaking. With the assistance from the Bagalkot Town Development Authority, Natural spaces like gardens, walking pathways in the gardens could be doubled, from what we currently have. Community gardening sessions for improvement of functional status of the small group of muscles of the hand could be arranged for the senior citizens. Laughter therapy session for senior citizens and caregivers, training and education sessions, could be done frequently to manage caregiver stress and burnout. Stake holders involved are Governmental and non-governmental agencies who could fund for fulfilling the four-principle model within a specified time frame of five years. Applying for financial grants could be an important way of procuring the funds which could be useful to bring about changes in the environment. Conclusion: developing Dementia friendly communities like these, could be useful for the senior citizens to help them age gracefully. Urban areas(SNMC Campus) in Bagalkot can be made dementia friendly by adopting the four-principle based model suggested in this document. This could be done by writing proposal for providing financial grants to fulfil the requirements of this project to the government officials concerned with the national program of the health care of the senior citizens. Limitations which need to be addressed include training of large manpower and modifications within the existing infrastructure. Recommendations include road safety measures, environmental modifications and providing new technologies to assist senior citizens living with dementia.

KEYWORDS

INTRODUCTION

It is a fundamental right of every individual in the society to live independently. In majority of the developing nations, there is lack of awareness regarding the changes due to dementia and people consider it as a normal ageing phenomenon. Dementia poses a big challenge both as a social and health issue which we cannot ignore. Despite the magnitude, there is gross ignorance, neglect and scarce services for people with dementia and their families (Dementia India report 2010)2 In India, urbanization, change of family structure from joint families to nuclear families and economic migration has changed the social structure of the country. It is estimated that the cost of taking care of a person with dementia is about rupees 43,000 annually; much of which is met by the families. The financial burden will only increase in the coming years.

Developing a Dementia Friendly Community for the people living with dementia amidst the limited resource settings of developing nations is a challenge by itself. The principles in establishing a Dementia Friendly community should be considering the sociocultural aspects where the senior citizens dwell. An own model based on the four domains of Cultural considerations, environmental modifications, caregiver training and support and use of assistive technology has been devised to address the need for developing a Dementia Friendly Community. Under the National Program for the health care of the elderly (NPHCE) in India, financial aid could be procured to bring about changes in the community to make it Dementia friendly. Active Involvement of stakeholders which include Government and Non-Governmental Organizations, Voluntary Health agencies and international organizations could together, bring about small changes at the community level, thus creating suitable environment for senior citizens to help them age gracefully.

Dementia friendly communities: Indian scenario

What has been done in India so far for the people living with dementia (ARDSI 2015):

***Awareness programs*:**

Kerala state in India is doing extensive work for the people living with dementia. Kerala is the most literate state in India, with lots of awareness about all the health issues each age group would face during their lifetime. Kerala state of India has taken a lead role in dementia awareness programs.

In 2011-2012,1941 persons were trained in Cochin in 104 training programs, which included school children, old age home staff members and volunteers.

A dementia friend campaign "I am a Dementia Friend" campaign, was launched in 2015, with a 10-day vehicle rally during which, all 14 districts in Kerala were visited. Citizens, schools and colleges students, and senior associations, pledged to be a Dementia Friend in the awareness-raising events and training sessions.

***Dementia guides**:* People from various walks of life belonging to various professions were trained and a new cadre of trained dementia Guides was formed, who could guide people about care and diagnosis of symptoms of dementia. A brief but intensive training was held to train 2260 persons through 39 training programs. An option was given to volunteers of Cochin city to come forward and play a lead role in making Cochin a dementia friendly city. The Dementia Friendly Community project comprises of equipping social and health care personnel in dementia care, establishing Memory Clinics in Government Medical hospitals for early diagnosis and intervention, Model Dementia Day Care and Fulltime Care Centres in the urban areas of the city.

Criteria in Defining a Dementia Friendly Community:

We need to frame our "Age-friendly" communities, based on the World Health Organization (WHO) definition that an age-friendly community, in which "policies, services, settings and structures, support and enable people to age actively" (WHO, 2007, p. 5)3.

Currently, there is no universally accepted definition of what constitutes an "age-friendly" (or elder-friendly) community (Lui, Everingham et. al. 2009)4. One has to consider the physical environment factors and socio-cultural aspects which shape in developing the dementia friendly community. For example, the Advant-Age Initiative launched in the late 1990s defines an elder-friendly community as one that satisfies four objectives: (a) addresses basics needs (e.g., housing, safety, and information about services); (b) promotes social and civic engagement; (c) optimizes physical and mental health and well-being; and (d) maximizes independence for frail and disabled individuals.

Consistent with previous definitions (Alley et al., 2007; Feldman &

Oberlink, 2003)5, a range of domains are considered important. These include outdoor spaces and buildings, housing, transportation, respect and inclusion, social participation, civic participation and employment, communication and information, and community supports and health services (WHO, 2007).

Own definition of Dementia Friendly Community:
A community which supports, assists and empowers the senior citizens to perform their ADL, IADL to optimum, through assisted caregiver and technological support. The definition uses these four domains, which help in setting up a dementia friendly community.

What we wish to do for the people living with dementia in our area:
We wish to bring about some modifications in the existing areas which could be converted into an age friendly environment. The modifications include environmental changes, where the people living with dementia are made to spend time amidst nature (nature-therapy) where community gardening is also included. Conducting laughter therapy sessions to destress and reduce agitation and aggressive symptoms of Dementia, assistive technology to aid the changes due to ageing process. And conductive caregiver training sessions to minimize caregiver stress, strain and burnout.

How to achieve a Dementia Friendly Community

- We have conducted surveys and pilot-studies through a predesigned, pretested tool like The Place Standard Assessment Tool devised by NHS Scotland, Environment audit tool2 Dementia friendly environment checklist3 and adapting them to the locality to assess the felt needs of the people living with dementia.
- We used the place standard assessment tool (NHS Scotland)6 as a pilot study to validate the tool for our study setting. We interviewed 50 senior citizens living with dementia along with their caregivers. Caregivers were present along with the senior citizens and assisted in interpreting the questions, to get a complete detail about the place through the perspective of the senior citizens themselves. The interview was held on 21/12/2018 where we had a get together in the community hall of the Urban area in the city of Bagalkot.
- The tool helped us to identify the shortcomings which were from the senior citizens' and caregiver's perspective.

a) Public transport: only school buses ply by the locality, and the other citizens have to travel a distance of 800-1000 metre to get on a local bus,

b) Traffic and parking: More number of cars ply by the roads than the number of pedestrians. Unregulated speeding vehicles, plying by the streets of the locality are troublesome for the pedestrians. Traffic calming measures need to be implemented which include: No Horn zones, Zebra crossings, exemption of usage of roads by heavy vehicles. These measures could be implemented to reduce the stress associated to dwell in the city.

c) Facilities and amenities: Far off shops to procure the amenities, make it difficult for the senior citizens to manage their day to day activities.

d) Safety: Low lit lamp posts in the evening, slippery roads in monsoon, make it unsafe for senior citizens.

- Identified resources that are pre-existing which include natural spaces like gardens and parks which can be modified to suit the senior citizens with dementia. Providing community gardening spaces which could be useful to strengthen the small muscles of the hand and could also help in improvising the reflexes. It would also provide a sense of content to see the same flowers bloom, which they seen in their yester years.
- Empowered the people living with dementia and their caregivers through health education sessions in the community level. Health education sessions were given after the above survey that we conducted, on accepting changes due to the ageing process, addressing caregivers' issues related to managing stress associated with caretaking.

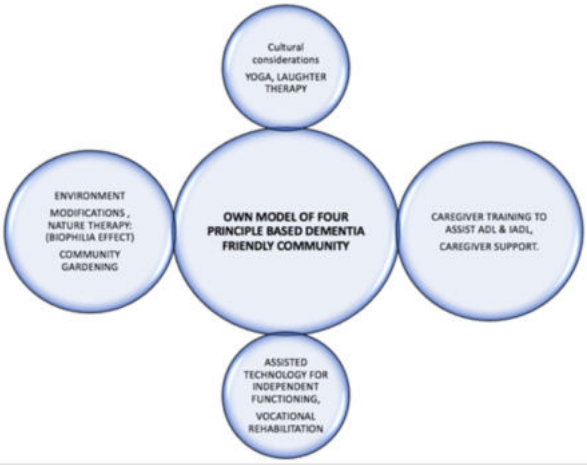
Providing an improvised physical environment in our setting, that will be convenient to dwell.
The city is divided into sectors where each block is uniformly designed and has a community hall, where health professionals, create awareness about various health issues and educate the relatives. The health professionals, are a cadre of Government employees, who are working under the National program for the health care of the elderly (NPHCE)4 and the staff employed at a medical college in the same urban area of the city.

Bagalkot is a city which has two subdivisions as per the Bagalkot Town Development Authority (BTDA**):**
a) Navanagar (urban area of the city) is an area where we have a town that is divided into sectors, which are well planned and well-connected roadways, have access to health care facilities, and have better environment and sanitation. It is divides into sector plots with lots of green spaces and has a very detailed planning in the sectors.

b) Old Bagalkot (rural area of the city): the city has predominantly a little away from the backwaters of Almatti water reservoir.

We intend to develop the dementia friendly community in the urban area i.e. Navanagar which has abundant natural canopies and green spaces, with transportation facilities and community halls for conduction caregiver training sessions.

SNMC Campus Residential area:
Action plan: Own Model of four principle-based Dementia Friendly Community.



Involving all the four principles for the people living with dementia could have a better health and involving these four principles in the daily routine.

Practicing yoga, meditation and laughter therapy for at least four days a week, being amidst nature and experiencing the beneficial effects of nature therapy, could be an integral part of development of a dementia friendly community.

The city of Bagalkot has four large nature patches in the urban area, where one could practice nature therapy. Yoga, meditation and laughter therapy can be practiced at the community gathering halls for at least four days a week to experience the beneficial health effects.

1)Cultural considerations:
The first principle of use of cultural considerations which are unique to India are Yoga, laughter therapy which have proven health benefits to reduce aggressive and agitation symptoms and improve the quality of life among people living with dementia. Interviewing caregivers for considering the socio-cultural background and its determinants is a priority before developing a dementia friendly community.

Role of yoga7 (One of the philosophical traditions of India): Yoga and meditation provide a strong feeling of well-being that are beneficial for people living with dementia. Practicing meditation and yoga would increase the state of mindfulness and can make difficult situations easier to bear. Music therapy along with meditation could stimulate imagination and improve memory. Sessions of yoga could be organized in the community gathering halls for physical and mental wellbeing.

Festival gatherings, mythological plays, bhajans and kirtans8,

which are open and free for all, help the people living with dementia increase their wellness quotient. Participating the above-mentioned social events could revive their cherished memories and also gives them an opportunity to experience these events as a music therapy.

Use of Non-Pharmacological interventions in Elderly Care (Laughter therapy9 for the people living with Dementia)

Every locality should have a laughter club. 'Laugh for no reason' is an exercise routine developed by an Indian physician Madan Katari, which has proven medical benefits on individual's mood and cardiovascular health. Laughter has a unique position in Complementary and alternative medicine (CAM). The benefits of laughter as stated by Bertrand Russell, 'Laughter is the most inexpensive and wonder drug. Laughter is a universal medicine'. A study done by Oxford university found that pain thresholds become significantly higher after laughter therapy. The study suggests that laughter produces an 'endorphin mediated opiate effect', which is crucial in social bonding.

Community clubs where local schools encourage young children to interact with elder persons. This helps in nurturing the wisdom from the experienced senior citizens to the young children.

2)**Concept of nature therapy**: The second principle of environmental modifications include nature therapy, community gardening which have proven health benefits. The Environment has natural canopies providing shade, gardens and four large patches of thickly planted trees within the urban area.

Nature therapy:

These are a set of practices aimed at exposure of natural stimuli that render a state of physiological relaxation. With a stressed state an individual is unable to perform his activities optimally. The restorative effects of nature therapy involving forests, flowers bring about a physiological relaxation, improvement and immune function recovery. There is an increase in parasympathetic tone and a heightened awareness that leads to a state of relaxation. For example: Shinrin Yoku10 (forest bathing) and nature therapy practiced in Japan and China help in boosting physiological, psychosocial, immunological and sensory domains proved to be beneficial for longevity and graceful ageing. Nature therapy, a health promotion measure acts as a destressor in the modern technological era.

Various hypothesis like the Kaplan's attention restorative hypothesis11, Ulrich's stress reduction hypothesis11 Kellert and Wilson's Biophilia hypothesis11 provide support and are proved by the Shinrin Yoku forest bathing nature therapy.

Kaplan's attention restorative hypothesis:

explains the benefit of nature and green spaces on mental fatigue. According to Kaplan (1993), nature therapy i.e. being amidst trees can serve a restorative function for people suffering from mental fatigue. Thus Shinrin-yoku can be considered to be effective tool for recovery from agitation and stress among people living with dementia.

Ulrich's stress reduction hypothesis:

how a natural environment can reduce stress and averse emotions. Ulrich in 1981 observed that when a person is amidst nature there are many physiological variations, which include reduction of muscle tone physiology, lowering of blood pressure and higher amplitudes of Alpha waves which are beneficial effects of nature on a stressed individual.

Kellert and Wilson's Biophilia hypothesis:

It derives its hypothesis from evolutionary theory. Humans have affinity for nature like patterns and stimuli and life like processes as we were primarily exposed to nature during our evolution. According to Park BJ et. al. (2007)11 walking and watching the forest area could bring about calmness. The salivary level of cortisol (a stress hormone) were significantly lower among those who were supposed to experience Shinrin Yoku compared to those who were supposed to travel in a traffic congested city.

Community Gardening12

Horticulture and gardening offer benefits to the people with dementia irrespective of the stage of physical mobility and mental acuity. Gardening activity assist in reduction of the persons frustrations and help in gaining self-esteem, self-confidence and both sensory and motor improvements. According to Alzhiemer's society practical guide to make a Dementia friendly gardening centre, community gardening, plants and gardens are a tool for reminiscence, to recall the plants, flowers the people living with dementia liked before. They could also help them recall all the memories that are associated with the gardening, thus helping them recall and reconnect to their old memories. There is also a multisensory stimulation of smelling the flowers, touch, visual, auditory sounds of the hustle of the leaves, bees humming etc. There are a variety of health benefits of gardening to the people living with dementia which are: small muscle exercise during gardening, improving balance, stamina, strength and coordination among antagonist group of muscles. There would also be opportunities to increase Vitamin D production due to natural exposure to sunlight, which is important in maintaining the circadian rhythm and better sleep quality.

According to (Thompson Coon et al 2011, Pallister 2001, Lee and Kim 2007)13,14,15, community gardening has shown that there are benefits of sleep quality, better energy levels through the day and reduction in agitation, confusion and confusion among people living with dementia.

According to (Cobley 2003)21, gardening could bring about reminiscence opportunities to talk about their past lives, group activity could also help in expression of emotions which could encourage interactions among people living with dementia.

3)Caregiver support:

The third principle of caregiver support, and training of caregivers is included because there has been a significant level of caregiver burden among caregivers of people living with dementia. As per the study done by Desai et.al16. the prevalence of caregiver burden among people living with dementia in urban area of North Karnataka, India, the average burden was 69% of caregivers experienced moderate to severe burden (Zarit caregiver Burden Inventory (ZBI) score 41-66), 29% experienced mild burden (ZBI score 21-40) and 2% experienced severe burden (ZBI score 61-88). People living with dementia are usually under strain. Their relatives are at even more strain because they are worried about caregiving. A positive emotion and laughter, will help in coping up with the illness, strengthen immune system, increase pain threshold and increase their ability to cope with stress better. There would be benefits to the caregivers as well as they can handle caregiving better with a relaxed mind.

4)Technologies and interventional approaches for Independent ADL and assisted IADL in devising a Dementia Friendly Community:

The fourth principle includes use of assistive technology: this field is yet to be explored as the details about their use in India is limited and requires a pilot project to validate their functioning and role for the people living with dementia. Appropriate technology could be used to make the community a safe place to dwell and improve the quality of life**.** Biomedical engineering measures could be useful in designing rehabilitation equipment that would aid people living with dementia. (Instruments like robots, wheelchairs etc. could be devised as per the type and physical and anthropometric requirements of the senior citizens). The criteria for appropriate technology in setting up a Dementia friendly community should be

1.Safe and tailor made to cater the needs of the senior citizens.
2.Help in managing comorbidities
3.Should help in betterment of quality of life
4.Should be useful in daily routine
5.Should assist the senior citizens and also to the caregivers.
6.Easily understandable.
7.There should be no dependence on this tool.

Technology used can be classified as

1.Health Related Quality of life enhancing technology
2.Technology providing safety.

Health related technological tools,17 **which enhance the quality of life**

Safer walking technologies, medication dispensers i.e. the drug boxes and alarms and sensors for independence.

Medication Dispensers

Drug box is a novel strategic tool to prevent forgetfulness and help in better compliance.

Drug boxes are equipped with alarms, self-dispensing compartments and have help prevent a double dosage or skipping a pill.

Technology providing safety: Alarms and sensors for independence.

Property exit sensors which could beep at the time when the doors are opened, and prevent the persons living with dementia from wandering away. Telehealth services which monitor the health through wrist-bands with global positioning enabled systems could help track emergencies among senior citizens.

Surveillance cameras should be installed on the roads and outside the house to monitor the activity and prevent senior citizens with dementia from wandering away from home.

Issues related to appropriate use of technology

- Quality assurance and usefulness that the equipment is safe to use.
- Periodic monitoring and servicing of the gadgets.
- Service and equipment standards to be provides as per the norms prescribed by the certifying authorities.
- Timely repair in case of any malfunction.

Scale of the project:

The pilot study model conducted could be validated by the officials from the state and national governments concerned with the national program for health care of the elderly under the Ministry of Social Justice and Welfare.

Phase wise upgradation of the model could be implemented in the study area and in collaboration with the Public Private Partnership we could involve NGO's, Government officials and private organisations to implement the model after successful validation in three districts representing North Karnataka region of India. Based on this validation report we could write recommendations to the Government of India to implement this model throughout India.

Timeframe:

The time frame that we choose to develop the dementia friendly community over a period of five years include:

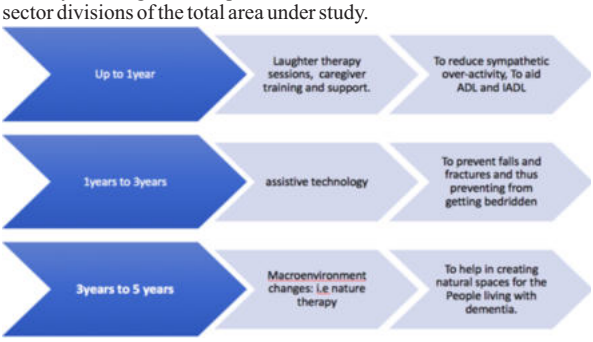
Up to one year: in the first year, we would like to address the caregivers and people living with dementia separately in sessions in the community gathering hall located in the urban area of our city.

We would conduct laughter therapy sessions for the senior citizens with dementia in the first year and would gradually reduce the sympathetic over activity of the autonomic nervous system and this could calm down the aggressive and agitation symptoms in dementia. We would also conduct separate sessions for caregivers of the people living with dementia to train them to help aid in activities of daily living and assist in instrumental activities of daily living.

Issues related to caregiver stress management and how to manage caregiver burnout could be addressed in the sessions conducted by Geriatricians and trained Government officials under the National program for the health care of the elderly.

We would conduct pilot studies for testing assistive technology for people living with dementia. The funding for providing the assistive technology tools could be procured by writing a funding proposal to the Government of Karnataka, India for procuring the instruments required for the functional assistance.

For the next five years the macro-environment modifications could be done by creating natural spaces in the urban area in each of the ten-sector divisions of the total area under study.



Planned Output:

To develop a model community for the senior citizens with dementia and help them navigate through the community free from any challenges related to the environment or the changes due to ageing process.

Stakeholders involved would be the following:

1.Spouse, relatives, neighbours and friends who aid in assisting ADL & IADL1 i.e. caregivers to the people living with dementia**.**

2.NGO's includes the team from the NGO Help Age India,

3.Business organizations: who would manufacture the instruments (assistive technology) for the senior citizens by public private partnerships where the government of Karnataka would provide the funds and the business organizations could manufacture the assistive technology equipment.

4.Local governments, ministers, which could contribute in framing legislations and policies through inputs from pilot projects conducted by the trained researchers from the medical college which will be favouring the people living with dementia.

5. Doctors and staff from the national program(NPHCE) for the health care of the elderly in India could address the medical issues through mobile health delivery units.

Monitoring The Stakeholders Through Regulatory Bodies:

The Ministry of Social Justice and Welfare and Ministry of Health and Family Welfare would be monitoring the stakeholders involved in forming the dementia friendly community.

Social Issues Arising In The Community

Social issues like senior citizen abuse, senior citizen violence by the children and social deprivation need to addressed through helpline numbers to the Ministry of social justice.

Legal issues also to be addressed by the court.

CONCLUSION:

To conclude, the four-principle model is an effective tool and can be implemented in Karnataka. There are proven benefits of nature therapy, role of community gardening and laughter therapy which can be the core aspects of the model.

Developing the model on a large scale would have benefits to the people living with dementia and their caregivers.

Recommendations:

1)Environment modifications Required to make it Dementia Friendly:

Accessible supermarkets to procure groceries and commodities within the vicinity of their residence, setting up of sign boards, marking separate pathways for senior citizens to walk through the city, implementing no horn zones, marking zebra crossings as the streets are crowded, setting up of telephone booths and toll-free helpline services, is a mandatory inclusion-criteria to fulfil the needs of a dementia friendly community.

2)Issues to be addressed for caregivers:

During caregiving, what caregivers experience, is caregiver burnout. This could be minimised by sharing the responsibility of caregiving.

3)Legal issues:

Legal support and assistance to empower people living with dementia: issues like senior citizen abuse, violence against senior citizens and social isolation could be addressed through legal approaches.

4) Addressing Issues related to the senior citizens and caregivers:

- Setting up suggestions' boxes in the places where senior citizens get together.
- Regular feedback from senior citizens about the issues they are facing from their own perspective.
- Regular meetings to be held at a community hall where all senior citizens can get together and discuss their concerned issues.
- Grievance addressal through a grievance addressal cell setup at the community level by the residents' association and periodic surveillance by higher authorities.
- Senior citizen helpline toll free contact number connected to the grievance cell working 24 hours a day x 7 days a week.
- Issuing Identity cards for senior citizens with all details about them could be useful in case of an emergency situation.

- Creating social opportunities for people living with dementia.
- Creating opportunities for intergenerational activities24 to assist young people to know what it means to live with dementia. This would also create a possibility of increase in wellness and happiness quotient of the people living with dementia.

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