

Dementia Friendly Community: Concept to Implementation

Dementia is one of the major noncommunicable diseases that now poses a global challenge for health care systems around the world. It is estimated that the number of people with dementia would increase from 57.4 million cases globally in 2019 to 152.8 million cases in 2050.^[1]

India is going through a major epidemiological transition with a tremendous increase in noncommunicable diseases, which in turn are the major preventable risk factors of dementia. Dementia usually involves a long course and great direct and indirect costs. A rough estimate of the total societal cost of dementia for India is likely to be INR 147 billion, which is huge for a resource-limited setting like India.^[2]

Dementia-friendly community is a novel concept that has been the talk of the day for dementia caregivers globally.

DEMENTIA-FRIENDLY COMMUNITY: ELABORATION OF KEY AREAS

Dementia-friendly community (DFC) has been defined as “A community in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.”^[3]

DFC recognizes and embraces the challenges that the condition presents to both persons with dementia and their caregivers, enabling them to live life to its full potential. Implementing an ideal DFC not merely involves physical environment but also proper holistic design taking into account the health issues, coping problems, and social issues of persons with dementia. A DFC should align with the societal and cultural norms in that part of the country. In a country like India where there is great socio-cultural diversity, this should be taken into account while in the design stage.

Different people experience the environment differently due to social and cultural as well as cognitive and physical reasons. In the UK, the neighborhood has long been a focus for policy and regenerations, especially in efforts to tackle deprivations and socio-economic inequalities as well as for DFC development.^[4] Neighborhoods that cause stress and disable people should be understood to be denying the personhood of people with dementia and thus are not friendly to the persons with dementia.^[5]

As found by Keady *et al.*,^[4] consideration of dementia-friendly environment not only involves the environment and experiences there but also how the social, physical, and organizational aspects interrelate with their experiences. Keady *et al.*^[4] drew attention to the importance of social networks, interacting with physical spaces, and the changing nature of the local environment experienced by people with dementia over

time. Involvement of various stakeholders (both government and non-government), civic bodies, policy planners, elected representatives of people, and caregivers of persons with dementia is crucial for designing a successful DFC.

Dementia-friendly neighborhoods and communities should be “welcoming, safe, easy, and enjoyable for people with dementia and others to visit, access, use, and find their way around.” Such neighborhoods should provide good housing facilities with both specific and general housing that facilitate home-based health and social care services to support people with dementia to lead independent lives.^[6-8]

Beyond housing, Mitchell *et al.*^[6,8] suggested that there are six key principles to designing dementia-friendly neighborhoods, which are as follows:

- Familiarity of surroundings to assist the recognition of the surroundings
- Legibility so that people can identify where they are and where they need to go
- Comfort so that people can be at ease with the surroundings
- Accessibility to allow people to be able to reach and enter places where they want to be
- Distinctiveness of different areas to assist with orientation
- Safety to allow people to move around the neighborhood without fear of harm

In the Indian setting, these principles have to be coupled with local values and culture. In traditional Indian families, children live with their parents; thus, there is less shortage of caregivers. However, with decreasing number of joint families and children settling out of their homes due to jobs, persons with dementia are facing problems in India as well. Care at home is very important for a person with dementia. Care should be taken so that the person with dementia adheres to a particular treatment regimen.^[9]

DFC: DESIGN AND FACILITIES

Marshall's^[10] recommendations for dementia-specific facilities are still regularly cited as the benchmark for good design. People with dementia should have single rooms, where they are able to have their own belongings; this is important for both the functionality of the room and people's sense of identity as well as encouraging reminiscence work.

The DFC would need a hospital with dementia-friendly wards. The points to be considered for a dementia-friendly ward are as follows: to have healthcare providers trained in dementia care along with empathy for persons with dementia, care should be taken for a proper diagnosis with the etiology for persons with dementia. Dementia being a long-standing state of disorder, while taking care of the person with dementia, proper counseling of the caregiver's needs should also be done.

Assistive technology (AT) is a term commonly used for assistive, adaptive, and rehabilitative devices for those who need it, and it has a big role in persons with dementia too.^[11] Nygard and Starkhammar^[12] in a qualitative ethnographic study explored the types of difficulties people with mild to moderate dementia might experience when they use everyday technology and stressed on the need for assisted technology in a DFC designed in a specific way for persons with dementia staying there.

Gesler^[13] opined that certain landscapes might have healing power, which he defined as therapeutic landscapes. This concept talks about the combination of physical (location, design, and layout), social (interactions and conduct), and symbolic (objectives, artifacts, language) organization of spaces themselves.

Traditionally, it was thought by many that it is better to keep people with dementia indoors most of the time, but now the concept is changing. There has been the emergence of a rights-based approach to dementia and framing of the status of a person with dementia according to a model of social citizenship.^[14] In this approach, we do not feel that people with dementia should be kept forcefully indoors, in their homes, and care centers; instead, they should be given greater freedom and administrative recognition.

Recent studies are showing the benefits of the non-pharmacological treatment regimen of dementia, especially to counter the over-prescription of psychotropic drugs. The benefits of outdoor and physical activities, including gardening, are now under investigation for their potential to play a preventive role in helping people with dementia remain at home, and further linked to this public health agenda are nutrition, dietetic, and behavioral change communication interventions.^[9,15] Belleville^[16] showed that cognitive training is an area that shows promise in terms of supporting communication and language skills in persons with dementia.

It has been found in various studies that going outdoors immensely benefits persons with dementia. In their research on sensory gardens, Gonzalez and Kirkevold found that having access to the outside world can bring benefits in terms of health and wellbeing in persons with dementia.^[17] Another research in this area reveals that having access to the outdoors can be greatly beneficial to people with dementia in providing further opportunities for physical activity, a reduction in cognitive decline, improved sleep patterns and circadian rhythm, and increased appetite. The same research also reports that going outdoor in people with dementia also reduces the number of falls and dose of antipsychotic medication.^[18]

Transport and travel are major challenges for people with dementia to venture outdoors. According to Alzheimer's Society,^[3] suggestions for a DFC transport and travel has been documented as one of the ten key areas of intervention to make the community dementia-friendly. A major concern in this regard is the issue of self-driving. Research shows that in people with dementia who continue to drive, there is an

increased risk of getting involved in a car accident.^[19] In people with dementia, there is increased risk associated with age also, whereby there is reduced reaction time, difficulty in decision making, and reduced ability to drive for a longer duration.^[20] Adding to this is deteriorating visual acuity with age. In India and across the globe, cab services are reducing the problem of self-driving. Cab services with proper sensitization of the drivers are required in DFC. A group of cab drivers trained in pertinent aspects of dementia care may be involved in the DFC for travel help for persons with dementia.

Walking as a part of healthy aging is important in people with dementia as found in the research by Hunter *et al.*^[21] He also found that the return journey is more difficult in people with dementia. Going to shops is also a challenge for people with dementia as found by Brorsson *et al.*^[22] Burton and Mitchell's study^[23] focuses on the issues of getting lost, chance of injury, and decreased safety in people with dementia venturing outdoors. They suggested the "streets for life" model for walking outdoors for people with dementia. In a model DFC, special stress should be given in this regard so that the shops and the important locations be properly labeled.

In a DFC, there should be a provision of specialized police force trained in the needs of the persons with dementia who along with providing security and help when needed will also provide empathy to the persons with dementia.

IMPORTANCE OF AWARENESS IN DFC

Accepting dementia—its symptoms and its progression to the end stage—is important not only for the caregivers of the persons with dementia but also the community surrounding the person with dementia. Intergenerational bonding may be helpful for persons with dementia in the community. Use of all media of health education, such as pamphlets, banners, mass media, and lecturing, may be done to ensure awareness regarding dementia.

ALIGNING DFC WITH THE HEALTH PROGRAMS IN INDIA

In India, dementia is broadly covered under two health programs: the National Mental Health Program and the National Program for the Healthcare of the Elderly. The issue of DFC should be approached by both health programs. Ayushman Bharat has envisioned the plan of health and wellness centers across India. The DFC concept and awareness can be spread from these health and wellness centers. The geriatric care part of Ayushman Bharat can focus on DFCs.

INTEGRATION OF DFC AND OTHER GERIATRIC HEALTH ISSUES INTO COMMUNITY MEDICINE CURRICULUM

Under the competency-based undergraduate curriculum for the Indian medical graduate formulated by the Medical Council of India,^[24] geriatric research has been included in the topics CM 12.1, 12.2, 12.3, and 12.4, that is, to define and describe the concept of geriatric services, describe health problems of aged population, describe the prevention of health problems of aged

population, and describe the National Program for Healthcare of the Elderly. All these are aimed for the vertical integration into the General Medicine curriculum of the undergraduate medical students. DFC can be taught under the heads of CM 12.2, CM 12.3, and CM 12.4. It is important for an undergraduate student of Community Medicine to have an idea of a futuristic better-living society for persons with dementia. In the post-graduate courses of Community Medicine (MD and DPH), Psychiatry (MD and DPM), Medicine (MD), and superspecialty courses such as DM (Neurology), the concept and multi-dimensional aspects of DFC should be dealt with great stress and importance.

CONCLUSION

As an emergent concept, DFC is unique in the way that it takes us from a vision of a mere physical environment for a person with dementia to a dynamic interactive environment for a person with dementia with proper social, material, and spatial qualities. Early diagnosis and proper behavior change communication activities regarding dementia are very important for a DFC. Involvement of various stakeholders (both governmental and nongovernmental) is key to the success of implementation of DFC. Its integration with the public health programs of India as well as in the implementation sector is the need of the hour. To sensitize the future medical workforce regarding DFC it is also important for us to integrate this concept into the new competency-based Community Medicine curriculum.

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