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Review Article

Inclusive practice, personhood and co-production to promote person centred care for people living with dementia: A review on approaches of two countries regarding care of people living with dementia

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ABSTRACT

This article attempts to describe a case study of a person living with dementia, a senior citizen, who is staying with her children at home, who are her caregivers. We will critically evaluate and analyse the strengths and weaknesses of the services that have been provided to her by the Health Care Providers and will highlight the topic of Person-centred Care provided to her by her caregivers. We will be highlighting her case scenario wherein we will enlist and elaborate the details, about dementia care from the moment of receiving the diagnosis to challenges faced both by the people living with dementia (PLWD) and their caregivers, in providing care. In this article, we will compare the details about the various studies and findings in discussion and compare the caregiving practices in India and the UK.

1. Introduction

A person steps into the phase of dependence, from the time of receiving the diagnosis of dementia. Receiving the support of the caregivers and providing person centred care, has been described in this article with an example of a case study. This article highlights the details of a case study of Mrs A and her caregivers and how the support from them helped her to cope up with the changes associated with dementia. It also describes the critical evaluation of the services in India to the PLWD and their caregivers in comparison with the services provided to them in the United Kingdom.[1]

2. Objective of the study

This study aims to critically evaluate the services provided by the Alzheimer's and related disorders society of India and support provided to people living with dementia and their caregivers living together at home. We will be discussing and comparing the research conducted pan India by the Alzheimer's and related disorders society of India with the services in the UK. We will compare the cultural differences, urban and rural care and special initiatives related to dementia care in India.[2]

2.1. Case study

The article highlights details of a senior citizen, Mrs A, a person who lived with dementia (PLWD) and her caregivers Mr. B and Mrs. B (son and daughter-in-law of Mrs A).

2.2. Seeking a diagnosis

Mrs A was an 88-year-old PLWD, now deceased a year ago, and I am writing this article recalling the experiences that I have seen, residing with her, at home, since my childhood days. Mrs A, on a morning realized she was forgetting to

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turn off the water heater and the water had been boiling. This happened for many days and Mr. B realized she needed to see a doctor. She was interviewed by our family physician and found out that she had mild cognitive impairment after screening with Mini Mental State Examination scale.[3] Mrs A had mixed feelings. She was assured that the doctor would visit her regularly, and she would be taken to the memory clinic regularly, but at the same time anxious about many questions which were unanswered. She discussed with everyone during our routine tea time get-together about how anxious she was, about her issue of forgetting things and was worried about who would assist her and pondered if, she would be excluded from discussions about issues related to household matters. Mrs. A thought that the changes in her were normal due to the 'ageing process', and it was ok to forget, but once she was diagnosed of having dementia, she began feeling worried, once she came to know about the clinical changes associated with dementia.[4] She was not comfortable to accommodate the diagnosis of dementia. She was still in the stage of denial, to accept the fact that she was clinically manifesting with symptoms and signs of Alzheimer's disease.[5]

2.3. Experiencing a diagnosis

At first, Mrs. A was diagnosed of dementia initially, there was limited access to a memory clinic. When the family physician began assessing her at home without being told about the purpose of assessing, she began interpreting and developing her own meaning to assessment, as a normal ageing phenomenon.[6]

2.4. Disclosing the diagnosis

As narrated by Mr B and Mrs B were in an initial stage of denial to accept the fact that Mrs A was forgetting essential things and needed to be addressed. Hence, they were in a dilemma whether or not to disclose to her the details of the morbidity, due to associated emotional distress and stigma.

2.5. Responding to the diagnosis

Initially it was a very difficult task for Mrs. A to accommodate the diagnosis into her identity, What, was just forgetfulness before is now perceived as pathological, thus socially it was a kind of being demoted in the social circle. The word itself, was perceived in a negative frame of mind initially. Once explained about the changes Mrs. A was undergoing, she was alright with the morbidity and accepted dementia. Fortunately, it was acceptable, culturally and Mrs. A was received adequate assurance about the support she would receive throughout the clinical spectrum.[7]

2.6. Support and information following a diagnosis

Post diagnosis the proactive support from the relatives, caregivers were immense and helped Mrs. A to cope up with early stage dementia. Mr B had an extensive literature review to make himself aware about what symptoms Mrs. A was going through.

2.7. Early intervention

Once diagnosed, information sharing, education and advice regarding coping up with dementia symptoms and regular monitoring of progression was done by the family doctor. Non-Pharmacological interventions in the form of music and nature therapy became a part of Mrs. A routine. Intentional increase in social gatherings helped Mrs. A to experience happiness and met relatives often, to stay happy.[8]

2.8. Living 'at home'

A home is something that is more than a shelter, a place, providing warmth and comfort (Kelly 2011). In this case study, as Mrs. A grew older, the changes in the home, had to be done to adapt to the needs of the ageing elderly. Physical changes, and social aspects changed at home which included elderly friendly equipment and fittings and more friends and family members began visiting Mrs A. This helped Mrs A keep up her physical and mental wellbeing, being at home. This finding was identical to the concept described by Lansley (2007).

2.9. Day care services

The day care services offered domestic and practical help, social development leisure and personal care. In Scotland, it was provided by local authorities and voluntary agencies. These services were limited to the urban areas in India, not present in the place where Mrs. A was residing.[8]

2.10. Services and support

Following the diagnosis of dementia, social engagement and supporting the identity are important aspects of post diagnostic support received by PLWD in Scotland (Gorska et al. 2013). These aspects of post diagnostic support have also been featured in the review study by Bunn et. al. (2012) The review found three themes within the research:

First is the pathways through diagnosis including its importance on identity, roles and relationships. Second is resolving conflicts to accommodate a diagnosis, including the acceptability of support focussing on the present or the future and the use or avoidance of knowledge and third are the strategies to minimise the impact of dementia.[9] The findings were very similar to the case study that we have included in this article, wherein there was extensive post diagnostic support to Mrs. A, by her caregivers. The caregivers were very knowledgeable which helped them understand the symptoms and clinical progression very well. This finding from the case study was very similar to Stoke et al. who highlights the importance of carers, having adequate knowledge about the clinical changes of behaviour to adjust to the impact of the illness. There was a memory clinic in a tertiary care hospital was easily accessible which was contradictory to the findings from Kelly and Szymczynska (2012) where-in they discuss the challenges faced by caregivers of PLWD.[10]

2.11. Post diagnostic support

According to Fortinsky (2008), the main aim is to address the anticipatory feeling of isolation and uncertainties in adjustment and financial planning.[11–15] As regard to our case study the caregiver support and bonding was so strong, that Mrs. A was never left unattended and isolated. She was always under the caregiver support and affection of Mr. B

2.12. Early intervention following a diagnosis

The communication domain which includes providing information, educating them about the changes and bring about a behavioural change to adopt to the changes of dementia has been provided through the memory clinics in the UK in the 1990's which is very similar to the services provided to the case study of Mrs. A.

2.13. Inclusive practice, personhood and person-centred care approach:

Person centred care is equivalent to high standards of care, promoting decision making and user engagement in health care planning (Kitwood 1997). Person Centred Approach as devised by Dr. Carl Rogers (1992) in health and social care settings, in which an individual is the heart of the care planning process.[16] The framework has been designed to provide care according to the individual's physical and psychological needs, spiritual beliefs, culture, likes and dislikes, family and friends. This inturn promotes the active participation, making the PLWD a contributor for his own care than being a passive recipient. Mr and Mrs. B played a role of a very supportive caregiver to Mrs. A. Mrs A was equally contributed for her wellbeing along with receiving care.

2.14. Co-production to promote person centred care

It is one method followed in Scotland where practitioners integrate with all stakeholders to provide an integrated care and support to the PLWD. Co-production and integrated approach is a requirement to be met for optimum care of PLWD in India.

2.15. Adopting a family oriented approach to dementia care practice

In this case study, the caregivers Mr B and Mrs B shared the responsibilities of caregiving, equally. They balanced the caregiving responsibilities well and assured a person centered care to Mrs. A.

Mr and Mrs B used to patiently listen patiently and be accommodative to the imaginative stories that Mrs A used to create when she would be alone at home, when Mr and Mrs B went to work. Sometimes slipping back in time, recalling all her remote events.[17–19] She would also have imaginations of thefts at home, sitting alone, thinking all by herself which were addressed by her caregivers, that they were not true and resolved the issue. In the absence of the caregivers the grandson of Mrs. A spent time with her and used to patiently listen to her.

2.16. Families and meal times

The families are reminded to engage mealtime experience to support and provide companionship and connectedness to the PLWD (Keller et al., P. 437)**.** This support system was present in the family of the case study. Everybody birthday in the house was celebrated as Mrs. A's birthday and this made her happy and used to delight her very much. Having a meal together with all the family members, enjoying the connectedness and time together was an experience very similar to the one described above (Keller et al.).

2.17. Stigma towards a PLWD

Results when there is labelling, social distancing, stereotyping, with an emotional reaction towards the PLWD. Labelling and stigmatization can be frustrating for the PLWD, threatening their independence and autonomy. (Mac Rae 2011). In a study done in the United states (Burgener et al. 2015 p.609) showed that social rejection can lead to behavioural symptoms and anxiety. In the above-mentioned case study of Mrs. A, there was no stigma associated with Dementia, and is very well accepted gently as a part of growing old.

2.18. Challenges faced

There were few challenges faced by the caregiver's and health care providers when the PLWD had to experience a diagnosis and it was such a challenge to accept the diagnosis, as it is associated with stigma and required a lot of support to accept a PLWD in the family. The other noteworthy challenges faced in our setting were providing the Person-centred care and setting up Co-production by all the stakeholders in meeting the person-centred care. Challenging the negative attitudes towards the PLWD, needs to be addressed (Harris and Caporella (2014). Lack of specific policies in the past have made it a current challenge to frame new guidelines on dementia care.

2.19. Discussion on cultural aspects of providing care and comparison between UK and India, regarding providing care: A critical evaluation of the services provided to the PLWD and the caregivers in urban and rural areas in India and the UK

Promoting Authentic partnership for dementia care in a country like India has significant differences in urban and rural areas: In rural areas, as per the levels of citizen participation (Arstein, 1969), the people living with dementia, most of them are unaware of the changes related to dementia. Here they think it's a normal process related to ageing. They are also unaware about receiving care and support from caregivers and hence non-participatory approach is seen in rural areas. But a significant point to be noted is that they have the joint family system prevalent in most of the families and hence they are always interacting with other members of the family and grandchildren which being an important social determinant which probably is a reason for slow progression of dementia. This prevented stigma associated with dementia and was an important determinant for wellbeing of the PLWD, in the family with respect to the other members in the family. This was the exact case scenario in the case of Mrs. A, where in living in a joint family acted as an excellent support system socially, culturally and emotional attachment with the family members helped her cope up with the changes associated with dementia and helped her age gracefully. In rural and semi urban India most elderly sit down and socialize under banyan trees all throughout the days and it serves as an unofficial get-together meeting and helps greatly in wellbeing.

A person-cantered approach (Arstein,1969), would be relevant through qualitative structured interview. With respect to the ethical issues in taking their consent needs is a challenge, especially considering their approval for an interview and for authentic partnership.[20–23]

As regards to dementia care in the urban areas, there are predominant nuclear families, among which majority of the family members are working population and the senior citizens have to stay at home all by themselves, with limited care giving support by other family members. The higher standards of living in urban areas compels them to work and hence their role as caregivers is very limited. Considering their level of participation in the dementia care, there is an opportunity, as a member of the district commissioners' panel for senior citizens in implementing the policies for senior citizens. The people living with dementia get an opportunity to participate in the meetings, provided they are in the early stages of dementia. In the two day-care centres, they also get an opportunity to discuss their experiences with the people who are in the early 50-60years of age. Level of citizen participation is informing, which is a one-way channel of communication.

There would not be much difficulty with ethical issues as they are well-educated and understand the importance of dementia care. We could further enhance the degrees of tokenism through health education and awareness sessions.

Service improvement could be done by involving the People Living with Dementia (PLWD) for peer health education awareness programs, we could bring diverse voices with diverse issues addressing the views of other peers, family members and professionals regarding the methods to address issues related to dementia, caregiving and policy making, respectively, for the PLWD.

Barriers for hindrance of the work include addressing the low level of literacy and lack of awareness about the morbidity. Ethical issues and informed consent would also have to be taken into consideration. An existence of medical model of dementia care, suggests only care but no involve their participation which limits autonomy and focuses only on providing medical care which needs to be changed to comprehensive dementia care.

2.20. Challenges in authentic partnerships approach

Implementing the authentic partnership approach in our setting in India would take significant time to implement as it would require multidisciplinary efforts in implementing especially in rural areas due to all the sociodemographic features mentioned above.

2.21. Provision of post diagnostic support

A Scottish Government initiative (Alzheimer Scotland 2011) to everyone diagnosed with dementia, receives one year of specialist dementia advisor or dementia link worker's support. The five-pillar dementia support model sets out five key elements of this approach. The five-pillar support model has been established to shape local services by the five-point approach. They have also developed a third sector partners to give personal advice about dementia.

2.22. Dementia day care centres

Trained staff will look after the people living with dementia for a couple of hours, where the caregivers get couple of hours break from caregiving. There are active ageing centres or elder enrichment centres as well, where a PLWD spends time with his peers engaging in social, mental and physical activities.

2.23. Respite care

They are short term care facilities, with caregivers and trained staff to assist PLWD 24x7 to handle care for some time, when the caregivers need to attend some other activities for a short duration run by the ARDSI Bangalore.

‘ Dementia Friends’ scheme should be an excellent initiative which will address stigma in the community. It has been put forward and initiated in Karnataka state by the ARDSI Bangalore chapter, on 19thSeptember 2019 along with Nightingale’s medical trust in India.

The Dementia Friends network is an Indian wing of the global movement towards creating awareness and reducing stigma associated with dementia. Guidelines have also been set up by the ARDSI to establish memory clinics which aid in diagnosis, helps and supports the People Living with Dementia (PLWD) and their family from the time of comprehensive diagnosis to the advancement of dementia symptoms. The memory clinic offers assessment of memory problems, multidisciplinary approach by trained qualified specialists. Thus, addressing key issues related with early diagnosis and continued care.

2.24. Facilitators and barriers to developing this scheme in India

Facilitators would definitely be medical interns, nursing staff and relative caregivers who could be providing care during working hours and a helpline which has been established, who will be addressing the health issues twenty-four hours a day, seven days a week.

2.25. Reservations or criticisms

There are no criticisms for this initiative, however there are certain barriers being, lack of ignorance and awareness about Dementia, detection of early onset of symptoms and awareness generation to the whole population, which can be addressed through establishing memory clinics, throughout, to reach large number of PLWD.

2.26. Benefit of this scheme contribute to better hospital care for people with dementia

Schemes like these, would provide Health education session, creating awareness and providing strategies to the caregivers for better management of PLWD and their symptoms.

2.26.1. An initiative to address stigma at workplace

Establishing dementia friendly communities, coordinating between the medical colleges and government and promoting the planned dementia friend and dementia champion campaign.

2.27. Dementia diaries and benefits of having online dementia diaries

2.27.1. Strengths

The diaries are unique by themselves and an excellent initiative to keep interacting and sharing their experiences, with every PLWD, the changes happening to them, and the various ways in which each PLWD is coping up with it. However, it is not a fixed pattern in which the changes occur, but a prototype of symptoms, that such type clinical manifestations can occur as the transit to severe stages. The themes like a strong positive attitude, that the PLWD, have, towards the declining memory and finding ways to cope up with, shows the ‘never give up’ attitude is an inspiration to the other PLWD worldwide. The personal reflections described in the dementia diaries are valuable and definitely have an impact on changing understanding of Dementia. It would be an archive for the newly diagnosed to know about the progression and interact with other PLWD.

2.27.2. Weaknesses

It would be a prototype of symptoms but cannot be taken as a standard, as the PLWD would experience it differently.

2.28. Dementia diaries could improve practice at workplace in India

These diaries, however can be a way to connect, share and interact with the numerous PLWD with various different clinical spectrum of Dementia. It would be a prototype of dementia progression for PLWD. It could be a database or a registry to the newly diagnosed, how to adapt to such similar situations by connecting with other PLWD. The care and assistance by the professionals should be monitored, timely and quick, whenever required by the PLWD. Follow up, about the progression, and the ways they are coping up should be guided, for ageing gracefully, with dementia.

2.29. Current policies, approaches, interventions, and services for the PLWD in India

The dementia India strategic plan is a plan devised by ARDSI India in 2018 to address the increasing number of senior citizens with dementia in India. This plan addresses to various issues related to the PLWD and their caregivers through the following strategies:

1. Strategy 1: To make dementia a national health and social care priority
2. Strategy 2: Develop sustainable awareness programs for the PLWD and caregivers
3. Strategy 3: Risk reduction by decreasing salt, alcohol and tobacco consumption and thus prevention of dementia progression.
4. Strategy 4: Improved access to medical care and treatment options in distant areas of India
5. Strategy 5: Adequate social support activities for the PLWD and the caregivers
6. Strategy 6: Conducting adequate research related to dementia care
7. Strategy 7: Strengthen the dementia disease surveillance systems in India

The various Central Government Initiatives in India for dementia support in India include:

2.30. The ministry of social justice and empowerment

has a scheme of Integrated Programme for Older Persons (IPOP) to improve the quality of life of the Older Persons, where financial assistance is provided under it to State Governments for running and maintenance of old age homes, day care centres, mobile units, helplines and counselling centres, etc.

Day care, helpline, counseling, and old age homes for persons with dementia fall under the purview of this scheme.

The Ministry of Health and Family Welfare, has a National Programme for the Health Care for the Elderly (NPHCE). This scheme includes setting up community-based primary centres and better district centres, as well as dedicated facilities and special beds for the elderly. Initiatives to train healthcare professionals for dementia, setting aside beds for persons with dementia.. The income tax department has a support for elder health care in the form of tax reliefs under various categories like 80DDB or other sections that recognize expenses related to dementia care.

3. Conclusion

Providing person centred care for the clinical changes associated with dementia is an excellent approach to help the PLWD age gracefully. Acceptance of the clinical changes associated with dementia and avoiding stigma can help them respond to a diagnosis of dementia better. The positive home environment, caregiver support and having a good post diagnostic support system can immensely help the PLWD.

4. Recommandations

4.1. Creating awareness

It's essential to create awareness and knowledge among the PLWD and the caregivers to address dementia as a morbidity and not as a normal ageing phenomenon. Addressing issues related to anxiety, lack of awareness about dementia and stigma associated with dementia through extensive awareness programmes is mandatory recommendation for the semi-urban and rural population of India.

4.2. Promoting positive personhood through dignity in care

Person centred care could be addressed through the following domains: The behaviour of the carer should be considerate, valued throughout the duration of the care keeping in consideration the following domains to maintain dignity in person centred care. Carer should maintain eye contact, with adequate standards of behaviour with the PLWD, and be considerate, not because he has been made a diagnosed of dementia, but as a human being.

4.3. Participation

The PLWD need to participate in decision-making for health and social care.

Recognition and respect for both the caregiver and the PLWD: with the severity of the disease the PLWD and the caregivers have to be treated with respect and needs to be valued.

Whenever applicable one needs to take help from other valuable agencies like those outside the home. Recognition of the role of the carer for the PLWD.

4.4. Environment

Proving familiar environment enhances optimum care for the PLWD.

Personal space / dyadic space: Providing the layout and an environment very similar to that at home could be of benefit to both.

4.5. Relationship and communication

The care plan should be explained to the PLWD and their careers, by including them to be a part of the conversation. Booklets with images, flip charts should be given in an accessible format. For the excessive information that has to be conveyed, multiple time planned visits have to be undertaken. Autonomy should be promoted for the PLWD by providing navigation equipment, calendar clocks, which will provide independence. Educating the public through mass media and involving self-help groups, communities and families in policy making. Training of primary health providers, doctors and geriatricians to create a network of health care professionals for dementia care. Linking dementia care awareness programs in schools, workplace and Non-Governmental organizations for dementia care.

Promoting Authentic partnerships and Co-production could help in assisting dementia care by leaps and bounds in India.

4.6. Dementia care mapping

Setting up this established method of person-centred care for PLWD in urban and rural areas of India, for the PLWD at home which will help monitor the quality of life of these individuals. This mapping would help trained healthcare professionals to develop an evidence- based person-centred care practice and address chances in providing health care based on periodic scrutiny of care provided to the PLWD. This would help in maintaining quality of healthcare and would definitely act as a supervisory framework for the caregivers of PLWD at home.

5. Source of Funding

None.

6. Conflict of Interest

None.

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