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Learning to live with dementia - supporting people to live at home with dementia

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Abstract

This paper has focused on the experiences of people with dementia and their carers living at home. Home can be a very important place for people with dementia as it offers a familiar and comfortable environment. People may very much comfortable with their home due to the familiar atmosphere and comfortable cares. As a country like India, a place given for family centred care has positive and negative aspects of the care for person with dementia. This paper considers the role of care givers, family members and other systems in the quality care of person with dementia. Also analyses the effectiveness of these systems in the care of person with dementia.

Keywords: Dementia, learning to live

Introduction

A home is somewhere that provides much more than shelter (Kelly, 2001). Homely atmosphere may stand for a place of healing and ventilating of emotions and stress. The facts that more people with dementia live at home than in institutional settings. It is also important to understand the culture where they live and their socio economic factors regarding the care settings.

Dementia journey

Dementia Journey is a tool for people with dementia, their families, caregivers and service providers. It focuses on the experience of dementia, from pre-diagnosis, through mild, moderate and severe stages, and presents it through stories that reflect the journey with dementia.

It also provides links to available resources. This will enable people with dementia and their families and caregivers to become informed and active participants in their own management and care.

There are different stages of dementia journey should face by the person with dementia and their cares. These are awareness of difficulties, assessment and diagnosis, living with dementia including support for person with dementia and support for cares and end of care.

Awareness

A person may begin to notice problems, for example, forgetting things. Other people might notice the person not managing their life in the usual way. It is too complex to identify what is going on the person and how to handle it in a manageable way. Clare *et al* (2005) ^[3] suggest that expression of awareness interacts with coping style, illustrating the need to consider both factors in combination in order to better understand individual expressions of awareness of change. Getting awareness is process and it is important to handle it in a positive way.

Assessment / diagnosis

A person may start to struggle with everyday living, needing prompts and reminders. As it becomes more obvious that the person is having difficulties this leads to assessment and a diagnosis. Keady *et al.* (2002s) ^[13] also note that what was important for people with dementia and their families was the role that professionals took on (sharing diagnosis, supporting, giving information, mediating, advocating and counselling) rather than on the

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professional undertaking that role. Getting a diagnosis can be difficult and it is estimated that currently only a third of people get a diagnosis (Source: Alzheimer's Society). A person's General Practitioner, and local memory assessment services should ensure people are screened, assessed and diagnosed. Fisk *et al.* (2007)^[8] argue that a diagnosis is not a one off event but should start when the cognitive impairment is first suspected and should then continue over time as more information is gathered.

Living with dementia

Living with dementia – a person will need increasing ongoing support in a number of areas around everyday living. But focussing on a person's strengths and wellbeing is important throughout the course of the illness to help them live well. Downs, *et al.* (2008)^[6] indicated that people with dementia represent one of the most marginalised groups of older people. Research in the United Kingdom (Boise in Downs *et al* 2008)^[6] points out that ethnicity and cultural beliefs play an important role in how people experience dementia, how families respond to it and how they approach support services.

It is also essential to provide support, guidance and education about dementia to the carers who are living with the person. Hellstrom, I., *et al.* (2005)^[11] presents a case study of an elderly married couple living with dementia and explores how their relationship has continued to flourish. In drawing on their story we highlight ways in which both partners seek to 'maintain involvement' of the person with dementia (Keady, 1999), and consider the various types of 'work' that is required. We suggest that whilst the 'personhood' of the PWD as an individual has received much recent attention, a consideration of 'couplehood' is also essential to a full understanding of how spouses live with and respond to the impact of dementia.

End of life care

In India end of life care mainly based on family care and family members are the carer to look after the person. Keeping a person comfortable and pain free is the focus of care at end of life. Making decisions about the care and treatment for the person with dementia needs to take into account the person's best interests in consultation with the carers/family. Where a person has completed any form of advance care planning this can help decision-making. Using pain assessment tools can be helpful in determining appropriate pain management.

Indian scene – Prevalence of dementia

Demographic projections indicate that India's old-age population would increase at a rate of about 4 percent per annum in the next three decades due to the decline in mortality and fertility levels. Current demographic trends for the elderly population predict a steady increase in the number of people suffering from dementia and other age related neuropsychiatric disorders.

Prevalence is the proportion of the existing cases of the disease in a population at a given point or over a brief period in time. It is estimated through cross sectional study (server) design, examining all personal (or a random sample of persons) in a community. Prevalence of dementia in a population depends on the age structure and life expectancy of the population and differential survival rate with disease. Since prevalence is dependent on the duration of disease, factors such as health care that might influence survival can

also influence prevalence. Incidence itself may be different in different populations if they have different levels of risk factors for the disease or protective factors against the disease. (Ganguli & Pandav 2012). This increasing rate of the prevalence indicate that the importance of the quality of home care in India.

Supporting person with dementia during Living with dementia in home.

Personal relationships

Previous studies (e.g. Bowers, *et al.*, 2009)^[2] in confirming the importance of meaningful relationships to older people with high support needs. The personal circumstances and family histories of the people we spoke to were very diverse, as were their current living arrangements and levels of mobility.

Support/good relationships with carers

Given the social benefits of receiving paid practical care, people told us that it was particularly important for carers to be friendly as well as effective and dependable. Beyond this, a number said they had closer friendships with certain care workers Self-determination (involvement in decision making) Under this heading, we also cover the related ideas of independence, autonomy, involvement in decision making and control. These concepts had slightly different meanings for participants. For many, remaining in control of key aspects of their lives was central to their self-esteem. Awareness – a person may begin to notice problems, for example, forgetting things. Other people might notice the person not managing their life in the usual way. Self-determination (involvement in decision-making)

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Social interaction

This is very important for the quality living of person with dementia living at home. The person-centred practice in service delivery in the 21st century shifts power from the service providers to those who use the services. It describes the process of asking people what they want, planning the support they need and showing them how they can get it (Morley *et al* 2010)^[15]. Sometimes social interaction may minimise due to the physical and mental constrains. But it is good to maintain effective social interactions. With the advent of the NHS and Community Care Act (1990) there was a vision of a shift from hospital-based care to community care; however, in reality this has meant a shift to care homes, which have become the major provider of long-term care for older people. Clare, L., (2008 b)^[4] explains one important element in the process of dementia is the way in which people with dementia band together to help themselves and one another, and influence social attitudes, through mutual support and collaborative advocacy. At any stage of life, making a contribution that is valued is important in order to maintain self-esteem and a sense of connection with others.

Good living environment

Another aspect of quality life to discuss is the embodied relationship with physical space. All persons took a great deal of pleasure and pride in their location, with much of the

‘warm up’ and ‘hand on door’ interview interaction taking place around admiring the views, the landscape and the spectacular journey that was often undertaken to reach the person at their home. This focus on the physical location was specifically linked to their experience of living with dementia. The relationship with space and place appears to be related to the progress of the condition.

Supporting with Care givers and their role

Much of the long-term care is still family based. This is more so when it comes to providing care to elderly persons suffering from dementia. The physical and social implications of care giving have never been estimated. Given the cognitive, behavioral and affective losses in AD cases, caregiving is considered to be a burden. There is an increasing demand on the family given the larger numbers of older people simultaneously; the crude birth rate is failing. This implies smaller families with fewer young people to shoulder the burden of caring. Even today, in spite of small families and women working outside home, caregiving is largely a family issue. Beattie, A., *et al.* (2004)^[1] arguing that the challenge for health and social care professionals is to engage with and consult such individuals about their experiences and what they want from dementia care services.

There is no reason to believe that family caregiving will not be available in the near future. Recent innovations in cognitive function enhancing drugs and residential facilities may reduce the burden to some extent. Gallant & Connell (1998)^[9] claims that structural factors in the caregiving situation, such as lack of time to sleep and physically draining caregiving tasks (for example, lifting and bathing), may contribute to the poorer health found among older caregivers.

Caregiving may be due to several motives individuals may be motivated to provide care either for social approval, for fulfilling social expectations and norms, to avoid social censure, because of genuine attachment and concern, financial compensation, and so on. The pattern of caregiving depends on the condition of the person requiring care, medical problems and characteristics of the care provider. The pressure and burden of care may isolate the caregiver and may result in neglect or even abuse of the care recipient. Considering all these factors, it becomes necessary to provide assistance to caregivers.

Role of caregiver for quality living

1. Caregivers should be educated about the nature of the disease and its progression. They should have a clear understanding of the symptoms. Very often family members may think that the person with dementia is deliberately being difficult, vulgar or faking problems.
2. Caregiving should be carefully planned. Considering the intensity and duration of the caregiving, the entire family should be involved. It is better to have family counseling to educate the family to support all the members involved in providing care.
3. Caregivers need respite from care frequently. Respite from care should be planned so that the caregiver does not get stressed and face burn-out. The possibility of internalization, partial or full, also has to be discussed. At times, the family may not be able to carry out its function adequately.

4. Caregivers should be counseled to handle negative emotions and feeling. Caregiving is not always easy. Knowing the possibility of experiencing guilt, anxiety or depression helps cope with such feelings better.
5. Caregivers should be encouraged to join support groups. Self- help and support groups provided both social- emotional and instrumental support to caregivers.
6. Families could also consider financial compensation to caregivers who may have to give up employment to be primary carers. They will be at a disadvantage later on when they grow old. Many people give up their social activities as the caregiving demand is high. It is unfair to them if they face an economic crisis at a later stage due to this.
7. Caregivers need to be alert to signs and symptoms of stress and burn-out. Often carers neglect themselves till they end up with a diagnosed disorder. Teaching them to listen to their own bodies, respond to their own needs and maintain a regular regime of self-care is essential.
8. Carers should also examine their own motivation for providing care. Some feel that are the only persons who are capable or destined to provide care. This prevents them from seeking help from others. Carers should be encouraged to caregiving has to be a collaborative effort. Family, neighborhood, health services, non-governmental agencies could work together to make quality care available to people who need it.

Assuring a dignified existence to people suffering from AD is not easy. It requires planning and coordinating services. One has to keep in mind the health of the family, especially of the primary caregiver, while planning care. This requires professional counseling of the families concerned.

Personal health of the carer

A good quality care depends on the physical and mental health of the carer. The available research in the developed world has identified some emotional disturbance 97% of the carers surveyed. We believe even in the developing world the problem will be similar. As such, it is necessary for the professionals to enquire into this issue and help and advise the carer to cope with his or her own emotional problems. In cases of clinical depression, we recommend the use of antidepressants. Structural factors in the caregiving situation, such as lack of time to sleep and physically draining caregiving tasks (for example, lifting and bathing), may contribute to the poorer health found among older caregivers (Gallant & Connell, 1998)^[10].

Some of the closest relatives of the sufferers might go through a grief process – a shock state, where they may be in a state of emotional numbness, later a phase of denial, where they do not accept the problem and then a period of bargaining (Why me?) Where they may try to intellectualize the suffering until adjustment may remain angry and discontented which could lead to abusing the dementia sufferer physically or mentally. This only can escalate the problems of caring.

Literature in the developed world also indicates that the carers have problems tolerating reduced social life, embarrassment, anxiety or depression, dressing, washing, urinary incontinence, but are able to cope with it, with varying degrees of tolerance. Carers poorly tolerate physical aggression, verbal abuse, wandering, inappropriate urination, sleep disturbance and restlessness by day.

This finding of research work done in the developed world cannot be directly extrapolated to carers in the developing world. As the culture in the developing world is to respect the elderly person in the family and try and continue to care for the person whatever the difficulties are. Recognizing one's own physical, emotional and social problems will prompt the carer to seek help or deal with it. It is a common experience that the carer feels less understood by others or even criticized. Carers groups may help for mutual support and learning methods of coping.

Further, the lack of adequate residential facilities which could care for a demented patient, as well as the lack of financial resources to be able to pay for such care in a residential home, necessitates the carers having to cope with the problems presented by a dementia sufferer in the family. However, the problem is somewhat lessened by the availability of extended family members who would join in the process of caring for the elderly dementia sufferer.

Having said that, similar to the western world, the major challenges of care falls on the shoulders of female carers such as spouses, daughters or daughter in laws. Similar to the developed world are entering the employment market and it results in added strain for them to be able to cope with the dementia sufferer and their own personal and family life. We recommend that voluntary organizations can help the carers by offering them relief by way of arranging for carers to meet in small groups and to be sharing their problems.

Voluntary organizations can also lobby the government for better resources to be made available and also raise charity money which could help provide better resources.

We are aware of the practice in some cities in India where one young resourceful couple became guardians of care of one demented elderly, visiting the individual and helping the care once a week in different ways. We feel this practice which can make a great change in the lives of people anywhere in the world.

How effective support? Support by care givers

Caregivers face numerous issues, including accepting the diagnosis, coping with increased stress, managing conflict within the family, and planning for the future. These issues become even more challenging when the spouse is the caregiver, because the very person with whom the caregiver would discuss important decisions is no longer able to participate in such a discussion. Caregivers may feel isolated, guilty, embarrassed, grief-stricken, helpless, angry, and depressed. It is important to discuss coping mechanisms with the caregivers, who often feel guilty about ventilating their frustrations and problems in the presence of the patient. Caregivers themselves are at risk for a number of disorders. As dementias progress, patients inevitable lose functions in the various Activities of Daily Living (ADL). There is a direct relationship between loss of these ADLs and caregiver burden. Increased stress levels can lead to physical illness, depression, weight loss, insomnia, alcohol abuse and increased use of psychotropic drugs in the caregiver, and verbal and physical abuse of the patient. Marital relationships often suffer due to social withdrawal, isolation and financial distress. Several studies have demonstrated much higher rates of psychological morbidity and/or depression in most caregivers. Caregivers of patients with Alzheimer's disease (AD) are much more likely to be affected than those caring for patients with other chronic diseases. For example, blood pressure has been shown to

rise in individuals with existing hypertension while they are delivering care.

Monitoring the health of the caregiver is essential, but often overlooked. Clinicians should encourage caregivers themselves to obtain adequate health care, good nutrition, sufficient sleep, and moderate use of alcohol and caffeine. It should be emphasized to them that unless they take care of themselves and their own health, they will not be able to take care of their loved ones with Alzheimer's disease.

How effective support? Education of Caregivers

Emmatty, L., *et al.* (2006) ^[7] explains the need to create awareness about the illness among different sections of the general population and interventions suited to the Indian caregivers are discussed. Physicians and other health care providers should be prepared to spend time and effort educating caregivers about the nature of Alzheimer's disease and practical aspect of caregiving. Information should be provided in simple, lay terminology, preferably as part of an oral discussion as well as in printed form. The following section is an example of the type of information that can be useful to caregivers. Parker, J. (2005) ^[16], indicates the need for training at a deep and reflective level in which the new culture of person-centred dementia care becomes part of daily practice rather than a distant ideal.

How effective support? With other systems

Day care centers

Hellstrom, I., *et al.* (2005) ^[12] conducted a study in Sweden and conclusions may be drawn from the findings: (1) that offering day care services to persons with dementia who also show signs of behavioral problems is questionable; or (2) that the planning of day care in Sweden should be adjusted to also meet the needs of persons with behavioral problems, such as depression. In its current form, day care in Sweden seems only partially to fulfill its goals. Reilly, S., *et al.* (2006a) argued that day centers and day hospitals appeared to perform two distinct, but complementary functions. These results provide key material for shaping the provision of day care for older people with dementia, especially given the absence of national standards in this area. The other main services are respite care centers, care support by home nurse, and are support by family members.

Conclusion

Learning to live with dementia is a process and it needs lot of supportive systems. This assignment discussed about the support during the person with dementia live at home and about the effective systems for them. Care givers support and family support discussed more the other system because the Indian care system is mainly based on family care.

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