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Review Article

Palliative care and end of life care for people with dementia

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ABSTRACT

Palliative care and end of life care are relatively new concepts in dementia care. The provision of end of life care and palliative care in the recent past has been emphasised for people with dementia rather than focusing only on cancer. There are now a huge number of strategies and policies that support and highlight the need for person cantered, high quality care for the people with dementia approaching towards the end of life. Despite this there are numerous challenges and hurdles in improving and providing palliative and end of life care. This is basically due to the fact that dementia is still not considered as terminal illness and also because of the fact that the practitioners and the carers are still not certain on when to initiate end of life care plan.

Physical, psychological, emotional, spiritual, nutritional, environmental, pain controls are the aspects to be supported in end of life care. Decision making in provision of care plan during the end of life is very much essential in order to provide a personhood care but in practice a little application is seen. Advanced care planning for end of life care for people with dementia is still not practiced.

Cultural diversity and beliefs towards the death are to be considered as important aspects in provision of end of life care. The practitioners should be adequately informed about the cultural beliefs. There is also a considerable lack of training among the care staff regarding the cultural belief and communication skills. Spiritual integrity is also important for provision of end of life care.

Promotion of palliative and end of life care along with changing the attitude towards looking at death is very essential for people with dementia.

1. Introduction

World Alzheimer Report 2015, estimated by Alzheimer's disease International's, states that there are 46.8 million people living with dementia worldwide in 2015.[1] This is going to double in every 20 years and reach 74.7 and 131.5 million in the year 2030 and 2050 respectively, which is 12-13% higher than the reported estimate in World Alzheimer Report 2009.[2] Much of the increase in the number of people living with dementia will be in developing countries. The projected increase of the older people is by 56% in higher income countries, 138% in upper middle income countries, and 185% in lower middle income countries and by 239% (a more than three-fold increase) in low income countries, between 2015–2050.[3,4]

According to World Health Organisation (2013), the projections for death due to Alzheimer's disease and other dementia are 685 thousands for the year 2015 and 966 thousands for the year 2030. Adding to this, long standing dementia as a cause of death is often omitted in the death certificates and also the undiagnosed dementia in the population is often excluded.[5] A prospective study where 4,197 elderly people were followed for 12.5 years, found that among 1,976 deaths 403 were due to dementia but even with the known cause of death as dementia, the death certificates did not mention dementia as the primary cause of death. It was concluded that the presence / absence of dementia in the death certificate were significantly associated with age at death, severity of dementia, aetiology of dementia. It was also concluded that the reporting

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of dementia is poor and suggests lack of awareness of importance of dementia as a terminal illness and a major cause of death are the reasons for this under reporting.[6] However dementia is usually reported as secondary illness because of the fact that the person with dementia will usually develop co-morbid conditions. But over the past decade there have been significant improvement in reporting of deaths due to dementia.[7,8]

With these alarming facts it could be suggested that the end of the life care provision for people with dementia should be a prime focus. Palliative care and end of life care are relatively new concepts in dementia care. The provision of end of life care and palliative care over the recent past has been emphasised for people with dementia rather than focusing only on cancer.

The prime role of Palliative care is to make the person comfortable and to meet their wishes and needs as the life approaches to the end. It is believed that still a lot can be done even when the cure of the disease is not possible.[9] Department of health, London (2001) calls for end of life care to be provided for every older people.[10] Maintaining and enhancing the personhood of people with dementia seems to be excluded as the death approaches and it is very much essential to relate the need trajectory of an individual with dementia as he / she approaches death in order to maintain the quality of life.[11] Department of health, London (2001, 2008) recognizes the growing need for end of life care to be provided irrespective of age, diagnosis, gender, ethnicity, religious belief, socio-economic status and disability and also that whenever a person needs care, be at home, in care home, a hospital, terminal care centre, he or she should be provided with high quality end of life care.[10,12]

Quality of life of people with dementia and eventual dying of people with dementia in the later stages of the disease is a neglected area in dementia care plan. This negligence is attributed to lack of understanding of dementia as a terminal illness,[13] despite the fact that there is no cure and that dementia is six to eight times more mortal than other conditions.[14] Only 18 percent of the people realise dementia as a terminal illness and very few people know that Alzheimer's is fatal.[15,16]

There are now a huge number of strategies and policies in developed countries like UK that support and highlight the need for person cantered, high quality care for the people with dementia approaching towards the end of life.

Environment, pain control, and emotional effects are the important points to be taken into consideration while planning for end of life care for the people with dementia.[17] It has also been argued that, due consideration should be given in understanding on what quality of life might the person require at the end of his life.[18] Hence personhood, relationships and their acknowledgement and involvement of the family members are keys factors for quality care. On critically comparing the trajectories of dementia and cancer it is concluded that dementia has prolonged dwindling along with progressive disability with time. This prolonged disability poses a challenge in providing appropriate and timely end of life care.[19] The mean length of survival of person with dementia from the time of diagnosis is eight years and the person experiences gradual decline.[20,21] It is also suggested that it is very difficult to predict when end of life is approaching.[22,23] Although now there are tools to indentify and predict when a person with dementia is likely to be in the end of life but the validation of these tools is still to be established.[24]

In the present article, author attempts to consider a large number of aspects of end of life care for the people with dementia. The discussion focuses on what kind of support people receive during end of life, how end of life care services fit with the experiences and views of people with dementia. The discussion will also focus on how the services provided during the end of life care meet the diverse needs of people with dementia. Case studies are provided to further support the discussion.

1.1. *Kind of support people receive during end of life*

Facilitating death through end of life care should be recognised as a basic clinical proficiency and technical expertise, ethical and humanistic inclinations are essential aspects to manage death.[25] Scottish Government, 2008, suggests that palliative care should be from an early stage in the disease process.[26] A changing understanding of palliative care has been illustrated as it was previously considered to be promoted when the cure of the disease is no longer possible, as to the current understanding of promoting/ suggesting palliative care right from the diagnosis till death. Hence palliative care is not just providing support during last hour of the disease rather ensuring quality of life of person with dementia and their carers from the diagnosis to every stage of the disease.[19] Thus it is important to look at palliative and end of life care as an integral part of care provided by any health / social care professionals.[27]

The two main issues which were found when palliative care was considered according to the old concept were- first - the consideration on providing palliative care when care staff was unready and second - relatives inclusion in the care was not considered as palliative and thus supportive relationships of the staff and relatives in care delivery was not moulded and also it is concluded to widen the focus of considering the palliative care throughout the duration of the disease rather being provided only during the end hours of life.[28]

1.2. Type of support

The type of support depends on the fact whether the person with dementia will stay at home, or in care home, in hospital of anywhere else. Palliative care should be active rather than being passive, that means practitioners need to be sensitive, realistic and flexible when matching the needs of the dying person and carers.[29] Positive interventions such as providing psychological, physical, social and spiritual support should be given rather that just viewing end of life as just waiting for death and a very little can be done to keep the person comfortable till he dies.[30]

1.3. Challenges

There are numerous challenges and hurdles in improving and providing palliative and end of life care.[31] The family members also do face challenges such as coping with loneliness, facing death, shock of witnessing the person's deterioration, difficulties in anticipating death and the work necessary to complete after death of the person etc.[32] There is a very limiting body of research to support the proven examples in provision of palliative care in dementia. However while investigating delivery of palliative and end of life care in care homes, highlights the factors such as insufficient staff training, poor inclusive planning and anticipatory care planning, lack of co-ordinated approach and inequitable access to NHS support were responsible for poor results in provision of end of life care.[33]

1.4. Generalist and specialist palliative care: How are they different

Generalist care is the care provided to anyone at the advanced stage of the disease by the people who are not specialists in palliative care. Usually generalist palliative care is provided by GP's, district nurses, nursing home staff, health and social care practitioners. Specialist end of life care is provided by specialist palliative teams.[34] According to House of Commons Select Committee, 2004, most palliative care is given by non- specialist staff.[35] But in such a case meaningful end to life and opportunities to relieve symptoms and pain may be miserably missed.[36] This means that even with requirement of specialist palliative care the people with dementia at the end of life would receive generalist care.

1.5. Case study- Patrick

Patrick was 89 years old and was diagnosed with Alzheimer's disease. Patrick was staying in a care home since 8 years and by then the care staff was very closely attached to him and were trying to do the best for him. They had a specialist nurse coming (occasionally/on demand) for assisting them as they had no training in end of life care. The care management suggested by the specialist nurse was varying with what care home staffs were trying to do for him. This was really disappointing the care home staff as they were feeling that they were not able to do much to help him to have a pain free and peaceful death and also expressing the need for specialist care for the people with dementia.

1.6. Services provided during the end of life care.

1.7. Artificial nutrition and hydration

An important area to be provided at the end of life is supporting in nutrition and hydration. Refusal and inability to eat in the later stages of dementia is a challenging issue for the carers and the family. People with dementia can suffer with swallowing difficulties at any stage of the disease but is more prominent at the end stage of dementia.[37] This means that serious care support and interventions are required.

There are controversies associated with providing artificial nutrition and hydration. The usefulness of artificial nutrition and hydration in persons with dementia is questionable.[38] However the use of these artificial feeding methods is prevalent in USA.[39] It is suggested that the pressure from the family members is the major reason for using these methods, as the family members may feel worried with withholding nutrition and hydration.[40] However it is noted that withholding nutrition and hydration did not increase the discomfort level but it is also not clear on the levels of discomfort associated with other influencing factors. And also since the recording of the discomfort was done by the care staff the validity of the recording is questionable.[41]

However in a position paper by the Alzheimer's Society (2010), it is advocated that one to one nursing, sitting with person and providing sips of water are more appropriate and effective interventions as compared to artificial nutrition and hydration.[42,43]

1.8. Recognising and controlling pain in end of life care

Identifying the distress related to pain is challenging in people who lack communication especially people who are at the terminal stage[44,45] Even if a care staff notices the distress, without properly articulating this feeling it so happens that the distress can remain unnoticed. Distress manifests as silence, reduction in activity, restlessness, aggression. Since these are often seen as common symptoms in people with dementia there is a high risk of the pain being ignored/ neglected.[46] This can have a profound impact on quality of life of the person.[47] This calls for a proper pain assessment tool for the people who do not communicate.

There are numerous pain assessment tools but none of the tools provide a holistic and comprehensive assessment and that pain assessment for the people with cognitive impairment is complex and very poorly understood. The tools developed to assess the pain were comprehensive in assessing with regards to certain criteria but an important part of pain assessment also lies in having the knowledge of how the person expresses his/her pain and the behaviours associated with pain and these cannot be measured/ quantified and it is very difficult to establish criteria's for behaviours.[48] Each person has his/ her own way of expressing the pain. Information from the family members is very essential in pain management. Tools to assess pain can be important resource but should not be used in isolation of subjective observations such as physical examination and information from close relatives.[49]

Improper recognition of pain among the care staff in the end of life care can be attributed to lack of training in pain identification among the care staff, fear of using opioids and belief that pain is a normal part of ageing. It can be concluded that there is a varying degree of complexity in effectively identifying and managing pain in the end of life care of the people with dementia but at the same time it is an important aspect of palliative care which can impact quality of life of people with dementia.[50]

1.9. Spiritual support and care

Spiritual and religious aspects of care acquire high importance for an individual approaching towards end of life/ death.[51] Spiritual well being can be truly ensued by person centred approach to care.[52] Spiritual care is not just allowing attending religious events. Well trained career and family member can provide spiritual care and support to the person with dementia approaching end of life which can improve the quality of life of people with dementia.[53]It is argued that the emotional and spiritual needs of the people with dementia are largely neglected.[26]

There is a limited research on the spiritual experiences and people with dementia, but it can be strongly suggested that people with dementia at the end of the life still do have the ability to connect spirituality and possess spiritual values.[54] It is concluded that people with dementia find comfort when they were engaged in spiritual practices when the carers used spiritual practices as coping support. It is also suggested that care plans should be reworked on for including, matching and accommodating spiritual needs.[55] Spiritual, emotional and psychological considerations should be given importance throughout the journey and not only during the terminal stage of dementia.[46] This can be possible if the professionals develop deeply human relationships with which they care and establish a clear commitment to the betterment of the vulnerable person.[56]

It is very important to have a spiritual connection up to the end of the life and such support should be the utmost responsibility of the carer. This kind of support need not only be by religious practices but also could be through the experiences triggered by colours, smells, music etc.[51]

1.10. Cultural diversity Cultural needs

Palliative care / end of life care support should understand and consider the cultural needs and diversity of the people with dementia. There are a vast number of cultural beliefs and values which are to be considered. This is of particular importance in societies which are multi-cultural and also in the families who observe rituals and customs. Cultural needs not only limit to the physical care practices but strongly associated with death itself. For instance Vietnamese people believe that those who die outside the house their souls will be wandering without a place to rest. Buddhist people believe that death with difficulty means punishment for the deeds in the former life. Hence one should have a clear knowledge of these beliefs in order to make decisions about end of life care plan. It is suggested that cultural and religious beliefs can limit the type of care provided.[57]

Different cultures do have different attitudes towards the aspects of palliative care. For example Muslims during Ramadan, will strictly refuse oral analgesia during the fasting period. This strongly impacts the food and pain control aspects of palliative care.

1.11. Case study-Mr Gupta

Gupta was diagnosed with dementia since 11 years. He was in a care home for his palliative care. The family members and the care team knew that Gupt a was approaching to end of life. When his family were informed about his condition Gupta was brought back to his residence as the family wanted him to breathe his last breath at home. Hindus strongly believe Ganges water is pure and holy water and putting Ganges water into the dying person's mouth will purify all the former sin of the person. Hindus also believe that the person dying will rest in peace if he dies at his own house or the place where he usually resides. This is how a meaningful end of life care with a strong inclination towards the cultural belief was designed for the person with dementia.

1.12. Decision making in the end of life

Often decisions for the person with dementia approaching to end of life are made on proxy basis usually by the professionals,[58] but it happens to be making decisions for the person whom the professionals may not even know. This is because of the fact that the person with dementia may not be in a position to actively decide regarding their care. It is also stated that the person diagnosed with dementia may not be able to make specific decisions but there are not incapable of making decisions.[59] But a person with dementia can meaningfully contribute in discussion and preparation of transition into a care home.[60] It is of utmost importance to note here that care professional must deduce a need for person centred care at all the stages of dementia, and to respect the freedom.

Department of Health, London (2008) suggests that the effective decision making at the end of life is through advance care plans (ACP).[12] However it is at most importance that the person with dementia should be actively involved in evolving care plan for the future and this should be done at the early stages of dementia. Planning for future in some cultures has a different attitude. For example in Cuban Americans, planning for future is of little importance as they believe that it will not make any difference how you plan for future because " it will happen anyway " is there attitude. They believe in present and do not plan for future.[61] In contrast it was found that people never bother about the relevance of advance plans for the future as they may change their wish and views over time. It might also happen that the family and the professional may not stick to the decisions / wishes.[62,63]

1.13. Case study- Helen

Helen was 80 years old and was in a hospice centre for her end of life care. As she was in her terminal stages of the illness and she had two children who were caring her a lot. Her condition deteriorated and she stopped identifying and communicating. She landed in another critical issue of deciding on her artificial nutrition as her swallowing capacities had come down. Helens children were now in a dilemma on deciding on putting her on artificial nutrition. Her elder son felt that there is nothing decided well before and he wanted to take opinion from the professional. Younger son felt that his mother would never want all of this but "how can we leave her to starve?" was his opinion. The doctor has to follow the decision of the family. In such situations decision on what care plan should be followed becomes really complex. The family is confronted with decision making regarding end of life care.

1.14. Experiences and views of people with dementia and the carers

There is a growing evidence which suffices the fact that experiences of the persons with dementia and their carers throughout their course of journey with dementia influences what sort of the support they feel they need towards there end of life. It is stated that the caregivers in a care home reported that people with dementia who are dying have special needs which are related to communication difficulties. It was also stated that they need one-on-one care, and need attention for most minute exp ressions associated with pain. It was reported that lack of emotional support for the caregivers after the person died had a major influence on their performance and this reflected on minimal attention to other residents. It was also reported that the lack of training on caring a dying person with dementia.[64] It is also reported the emotions of the care staff after the death of the person with dementia was not supported.[46] These findings conclude and draw our attention to the varied needs of the people with dementia, the care staff and other carers in the end of life care.

Research in England with residential care staff pointed out the fact that the care staff were not working in an integrated manner, and often used vague expressions when talking about death and dying. They also lacked understanding of different cultures. It can be concluded here that there is lack of cultural knowledge, training, and communication skills among the care staff.

1.15. Case study- Mr John

Mr John was diagnosed with vascular dementia and was staying at care home after his wife's death. His wife died to cancer and she was in hospice centre during her terminal illness. John was never willing to go to hospital as he felt that, his wife died due to improper care in a hospital set up. Though his cognitive ability was deteriorated still he used to feel and experience hospitals as not a proper set up for care.

2. Conclusion

Even though there is a strong evidence to promote palliative care the implementation of palliative care is not up to the mark in dementia care. The challenges for poor implementation are lack of awareness and knowledge about advanced care plans. The low level of implementation is also due to the fact that the carers and the professionals are uncertain about the benefits of palliative and end of life care.

The support provided towards the end of life should take into account all the essential needs of the person such as physical, psychological, spiritual, emotional, nutritional, environmental, pain control etc. in a way that the personhood of the person with dementia is maintained and enhanced. This will surely improve the quality of life of people dementia approaching end of life. Although there are numerous strategies and policies on pain management, nutrition and hydration, the delivery of these support services is complex for the people with dementia approaching end of life. It can also be concluded that there is a requirement for training of care practitioners and family caregivers. The author concludes that promotion along with change in the attitude at looking towards end of life care is essential. Lack of confidence and knowledge on proper/ right time to initiate the end of life care and palliative care also pose challenge in implementing effective end of life care. Cultural diversities and beliefs and attitude towards death should be considered with utmost importance and the care practitioners and care staff should be well informed about the cultural beliefs, values and attitude towards death. This helps the practitioners to plan appropriate support and care plan for people approaching death.

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4. Conflict of Interest

None.

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