

Dementia and Palliative Care: Sex Differences

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Abstract - Patients who need palliative care have complex physical and psychosocial needs during their illness. The results of previous studies show clear sex inequalities in the occurrence of various symptoms and the need for palliative care. Despite the undoubted sex differences in the creation of palliative care, sex is not a key determinant and is regularly neglected. According to the results of previous studies, women live longer than men, but they live more years with disabilities, especially with cognitive impairment. They end up in hospices much more often than men and die more often in institutions (21 % vs. 10 %). The biggest sex differences are present in the domain of caregivers. Most caregivers are women and according to the results of studies it is evident that more than 75 % of all caregivers are women and that women spend 50 % more time providing care than men. The time and effort that women put into caregiving is largely unrecognized and assumed to be a 'natural' role for women. In contrast, male caregivers are seen as heroes and numerous studies show that male caregivers receive more support than female caregivers. This is thought to be the reason why female carers have more physical and mental health problems, including anxiety and depression. Health professionals also play a role in the creation of this stereotype. A recent study showed that nurses felt that wives and daughters of patients needed less help than husbands and sons. Overall, all studies show that although women provide most of the care during life, they often lack a reciprocal level of care at the end of their lives. The policy of palliative care is focused on the approach that care at the end of life 'in the community' is desirable and achievable for everyone. Unfortunately, the fact that in this context care falls disproportionately on one person- who is most likely a woman- is ignored.

Key words: dementia; female; palliative care

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Introduction

Dementia is a progressive disease without known cure. The number of people suffering from dementia rises with the increase of older adult population, since they are most at risk of developing this progressive disease. Symptoms of dementia affect one's memory, cognition, and ability to function. Medication that exists to treat this disease merely decelerate the

progression of dementia, and each individual inevitably goes through early, middle and late stage of the disease, eventually dying from the disease. Affected persons have a diminished quality of life and, as the end of disease approaches, are becoming more dependent on full-time assistance. This trajectory should be better known and explained to families and caregivers in order to plan end-of-life care in advance and on time [1]. Aim of palliative care is to enhance quality of life for people suffering from this disease. Palliative care should be utilized throughout the patient's life, from communication and support in the time of di-

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agnosis, and providing care and support in last days of one's life.

Considering the nature of this disease, it is becoming more clear that palliative care should be implemented in treatment of patients with dementia and should become a public health priority [2]. Yet, studies show that the needs are not adequately met, palliative care staff knowledge and access to palliative service is low and many residents in nursing homes die in pain, with unrecognized and undertreated symptoms [3]. Hospice and palliative care was created for people suffering from cancer or other terminal diseases that usually have a predictable course, but health declines differently in each patient with dementia and is therefore harder to predict when palliative care would be necessary [4].

Discussion

Role and results of palliative care in dementia

While palliative care in patients with dementia is not completely utilized yet, it has proven to be beneficial, and its aim is to improve quality of life of patients and their families. Since dementia is a terminal disease and requires a multidisciplinary approach especially in advanced stage, palliative care is becoming more implemented in its treatment and has an increasing trend [5]. It helps families to make goals and plans regarding end-of-life care even when the patient is still in early stage of dementia. Palliative care consultation proved to be beneficial in various aspects such as discussing goal of care, symptom management, emergency room visits and prescribing behaviour. Patients and families benefit from advanced care planning, but they are reluctant to make such plans at the beginning of the disease. Evidence show that palliative care helps them make such plans and therefore, improve quality of life of both patients and their families. Also, palliative care implementation shows financial benefits due to deprescribing unnecessary medication. After consultation, medica-

tions are optimized in a way to treat symptoms better while at the same time reducing costs. palliative care consultations, when implemented, also reduce emergency room visits, making patients life easier and more comfortable while again reducing the costs. Palliative care intervention also manages patient's symptoms which are especially prominent at the end of life successfully. Moreover, it increases the number of discharges of hospitalized patients with dementia to a hospice which provides them adequate care [1].

How to use palliative care in dementia

Palliative care should be implemented in patient's treatment as soon as possible, starting with communication between clinicians, family, and the patient. Breaking bad news, discussing further course of the disease is the first and often the hardest one to take [6]. Since it is hard for the family to perceive the progressiveness of the disease, communication with the family about the progressive nature of dementia and providing insight in the inevitable is very important. It helps families and patients express their concerns and fear, get needed information from the clinicians and help them make advanced care plans. Also, they can talk about where and how the patient wants to spend their lives, when to provide placement for them and what each individual finds most important to improve their quality of life. Such topics should be brought up as soon as possible, in the earliest stages of the disease, when patients can still make decisions by and for themselves [7]. A pilot randomized trial showed that specialty palliative care that was triggered by acute hospitalization proved to be efficient and good for the patient and the family. Family was more prone to discuss end of life care, while patient's symptoms alleviated. Furthermore, because families organized and talked about assistance and care as the late stage was approaching, persons with dementia less likely to move constantly from the hospital to a nursing home, having constant care and support [8]. Patients with advanced dementia often suffer from dysphagia,

dyspnoea, agitation and skin breakdown, with the most common cause of death being aspiration pneumonia. Since cancer patients experience the same symptoms and receive palliative care which improves their quality of life, it should be standard for patients with advanced dementia to receive the same treatment [1]. It is important to recognize behavioural and psychologic symptoms (agitation, depression, delusions, anxiety), find the cause and properly treat them in order to improve patient's quality of life [9]. Behavioural and psychologic symptoms are common in patients with dementia and should be assessed on time, since they can affect not only the patient, but also the family and can predict their placement in a nursing home as well as higher mortality. That is why those symptoms should be taken and treated seriously, and further diagnostic procedures made to exclude secondary causes of such behaviour. Treatment should begin with non-pharmacological agents, and if the symptoms persist, medications should be started [7]. The important thing to remember is that people who are usually most included in patient's care is his closest family, and they should also be considered for psychosocial support since caring for the patient with dementia can be burdensome [6]. Contrary to popular beliefs, end-of-life care is usually not the biggest and most important part of palliative care, and it is harder to make the whole rest of patient's life more enjoyable than just few last days of his life when maintaining proper nutrition and hydration and pain relief should be in focus [6]. Since the course of dementia is hard to anticipate and even medical professionals are not completely aware of its terminal nature, they often do not receive needed amount of palliative care. Therefore, they undergo frequent hospitalizations and aggressive treatments for infections, falls, or delirium. Palliative care can help reduce number of hospitalizations and medications which would not only improve patient's quality of life, but also reduce utilization of medical services. Hence, it should be integrated in nursing homes for terminal dementia patients [5].

How to improve palliative care

Dementia inevitably progresses to a stage where patients experience symptoms like cachexia, functional decline, and other medical complications, which make dementia patients similar to cancer patients. Therefore, dementia should be approached more seriously and perceived not only as a memory loss disease, since these patients experience multiple other health complications [2].

Considering its beneficial role, palliative care should be implemented more often and sooner in treatment of patients with dementia, seeing as even patients with late-stage dementia have limited access to palliative care and many experience symptoms like shortness of breath, fatigue, pain, and neurological symptoms. One issue is that palliative care staff have little training on how to deal specifically with dementia. In order to make lives and outcomes for dementia patients better, both specialist and primary palliative care improvement is needed [8]. Families themselves also stated they would like to be provided with more information on dementia so they can have better understanding of the disease and plan end of life care in advance [10]. Training nursing home staff could improve palliative care since it has been noticed that they are not educated enough about patients suffering from advanced dementia, which unfortunately leads to worse outcomes (poor pain management, unnecessary transfers to hospitals etc.). There has been a study evaluating a training program Improving palliative care education and Training Using Simulation in Dementia (IMPETUS-D), a staff simulation training. It consisted of 11 different modules that included videos of realistic events or situations happening with patients suffering from advanced dementia that served for learning and practicing and could be accessed online. Unfortunately, this specific study did not show any changes due to low staff participation and the idea for future projects is to create a more simple version of IMPETUS-D, since there is no doubt that more staff education is needed in this area, especially with the increasing number of the aging population [11].

The palliative care for Older People (PACE) Steps to Success Program includes training the staff in nursing home to provide care and support to patient and family while following 6 steps. "The steps are (1) advance care planning with residents and family, (2) assessment, care planning, and review of needs and problems, (3) coordination of care via monthly multidisciplinary review meetings, (4) delivery of high-quality care focusing on pain and depression, (5) care in the last days of life, and (6) care after death." [3]. The PACE steps to success program improved the quality of dying and end-of-life care in nursing homes but was not proven useful in providing comfort in last days of life. There was no difference in improving the quality of dying between patients suffering from dementia and those not suffering from dementia [12].

Furthermore, healthcare professionals are torn between wanting to help every patient and focusing on individual one. They especially prioritize dying patients and, in order for them to have someone stay with them, new staff is often hired, and the rest of the staff relocated between the sheltered and the long-term wards. Such principles diminish the quality of care because of lack of continuity. Since the personnel is constantly changing, there is not enough time to get to know the patients better, which is especially important in advanced stages when they have hard time communicating. Patients with dementia need a stable surrounding as it helps reduce fear and confusion, whereas moving wards and having new staff only forces them and their relatives to adapt to new routines. In conclusion, the findings show that long term facilities should be better adapted for the needs of patients suffering with dementia, and also employees not moved from one ward to another [13].

Another issue is availability - rural and remote areas mostly consist of older population who have even greater difficulties receiving palliative care than those living in cities. One study showed that those who had high level of health literacy were 12 times more likely to choose comfort care compared to patients

who lived in rural areas with lower levels of health literacy. Potentially, technology could solve the problem of rural older adults having limited access to palliative care. In that way, there would be more opportunities to frequently see patients, talk to them and their families, reducing the likelihood of hospitalization while making sure they are getting proper care. Despite great advancements in technology, it is not often used in healthcare. This study further highlights three things that should be improved: general knowledge about dementia and the trajectory of the disease, making decisions about the end of life care at the beginning of the disease, having an individual approach [14]. Finally, it is important to provide a patient not only physical relief, but to take spiritual and psychosocial issues into consideration and help a patient maintain his dignity, which should be accentuated more in the future [6].

Sex-specific differences in palliative care for persons with dementia

It is estimated that two-thirds of patients diagnosed with end stage dementia are female [15]. To provide a broader perspective on palliative care for advanced dementia, it is useful to see how and whether it differs between male and female patients. One study showed substantial sex-specific differences in interventions and therapy at the end of life. Men had much higher rates of burdensome interventions such as physical restraint use, and higher chances of dying in acute care facility. Furthermore, men were more likely to be hospitalized and had higher odds to experience at least one end-of-life transition of care. These differences could have a sociocultural origin more than a biological one, seeing that women are generally more likely to discuss their condition with families, and also more prone to reject feeding tubes and other interventions [16].

Studies showed there was a greater number of female participants as hospice recipients and hospice decedents with advanced dementia, but the reason for that could be longer female life span. Males were mostly associated

with measures for prolonging life, and therefore more likely to get feeding tubes, while females were three times more likely to receive comfort care (symptom control and pain relief) [14,17,18]. Findings emphasize the need for additional future research for sex-specific differences in advanced dementia.

In the end, palliative care is gaining its popularity and importance when it comes to treating patients with dementia and is becoming more recognized, seeing that dementia is a progressive and irreversible disease [19]. It is however, still a relatively new area of care for patients with dementia and further research on how to use it in the most optimal way is needed [2]. Also, it is still not utilized enough compared to patients with other terminal diseases such as advanced cancer [5]. Palliative care could be improved by provid-

ing more training to palliative care staff on how to deal specifically with dementia and by increasing its availability. Considering a plethora of benefits patients and families, but also hospitals can gain from utilization of palliative care, it would be beneficial to implement it as standard practice, and not providing it could be detrimental [1].

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Conflict of interest

None to declare.

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