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Communication and palliative care in dementia: a 5-year review

Comunicação e cuidados paliativos em demência: revisão de 5 anos

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ABSTRACT: Dementia is an increasingly prevalent disease in the world's population. We reviewed the last 5-years articles in communication and palliative care in patients with dementia, their families and their caregivers. Our objective was to summarize the main strategies of communication in this specific population, in order to understand their desires and needs.

Keywords: Dementia, end-of-life care, palliative care, communication.

RESUMO: Demência é uma condição de prevalência crescente na população mundial, de grande correlação com o envelhecimento. Nós revisamos artigos sobre comunicação e cuidados paliativos em pacientes com demência, seus familiares e cuidadores publicados nos últimos 5 anos. Objetivamos sintetizar as principais estratégias de comunicação nessa população específica, de modo a entender melhor seus desejos e necessidades.

Palavras-chave: Demência, cuidados de fim de vida, cuidados paliativos, comunicação.

INTRODUCTION

Dementia is a clinical syndrome caused by degenerative lesions of the central nervous system and characterized by inexorably progressive deterioration in cognitive ability and capacity for independent living¹. It is caused mainly by Alzheimer's disease (AD) and Vascular Dementia (VaD) with many intersections between both (known as Mixed Dementia)². Its prevalence is very high worldwide, between 5% and 7¹, similar to the data obtained in Brazilian studies³. It was estimated that 35.6 million people lived with dementia in

2010, and it is expected to almost double every 20 years (65.7 in 2030 and 115.4 in 2050)¹. This high prevalence, together with the high costs demanded by these patients' care, makes dementia a health priority to governments of all countries³.

In spite of huge investments on research, the pathophysiology of Alzheimer, the most common cause of dementia, is not completely known⁴. However, it is certain that it is multifactorial and has genetical, lifestyle-related and environmental factors⁵. The most important

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known factor, however, is increasing age. Prevalence of dementia increased exponentially with age in every country, doubling with every 5.5-year increment in age in individuals from North and Latin America^{1,3}.

Symptoms of dementia may vary widely, from mild memory impairment until complete loss of contact with the environment⁶. Based on these symptoms, patients with dementia can be classified in three groups, depending on their clinical presentation. Symptoms of the early/mild stage include forgetfulness, losing track of time and becoming lost in familiar places. Patients at the middle/moderate stage present forgetful of recent events and people's names, becoming lost at home and having increasing difficulty with communication. Finally, symptoms of the late/severe stage include becoming unaware of the time and place, having difficulty recognizing relatives and friends and having an increasing need for assisted self-care⁷.

In this scenario, Palliative Care is a theme of major relevance, as the lack of available treatment for the diseases causing dementia, notably Alzheimer disease, associated with its high mortality and morbidity, qualifies patients with dementia to be referred to palliative, or end-of-life care⁸.

Palliative Care is defined as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual⁷.

Considering that the course of advanced dementia is often erratic, but almost always progressive and that no specific treatment is available, it is consensual that these patients need an end-of-life care approach⁹. In order to succeed in this task, it is indispensable for the health team to take charge of these patients to develop a good communication¹⁰. Telling these patients about their diagnosis or discuss their preferences regarding their end-of-life care becomes a major problem, since they present a marked impairment in their understanding capacity, particularly, when they are at advanced stages.

Even at earlier stages of the disease, talking about the diagnosis and prognosis of the disease are interpreted by the patients and families as an embarrassment. In an interesting study, 83% of family members of Alzheimer's patients would not tell their relatives that they have the

diagnosis of Alzheimer's disease. Paradoxically, from the same pool of relatives, 71 % wanted themselves to be told the diagnosis, should they develop AD¹¹. Although many authors consider important to tell the patient his diagnosis, each case must be evaluated individually. The patient's cognitive ability, psychiatric manifestations and family relationship must be carefully evaluated, before considering discussing the diagnosis with the patient. Besides that, the patient has the right to not be told about his diagnosis, if he does not want to know it¹².

At this point it is clear that end-of-life care in patients with advanced dementia is a complex issue. In one hand, it necessary to consider the patients' impaired ability to understand verbal communication; on the other side, the family, caregivers and general staff have the obligation of respecting these patients as individuals, with proper desires and expectations, in spite of their difficulties. Moreover, no other desire is more important than the decisions regarding each one's end of life.

Therefore, our main objective was to summarize our knowledge about whether it is possible to discuss about end-of-life care with patients in moderate or late stages of dementia. Moreover, we investigated how to communicate with these patients, their families and caregivers, in order to understand the necessities and desires of these patients - regarding their end of life care.

METHODS

We performed a systematic computerized literature search in PubMed (to December 2014). Exposure search terms, used were "(dementia OR Alzheimer OR neurological impairment [tiab]) AND (communication OR relationship OR advance directive [tiab]) AND (patient OR caregiver)" restricted by: Clinical Trial, Randomized Controlled Trial, published in the last 5 years, Humans, English or Spanish. From this search, 221 papers were obtained.

Then, two independent reviewers (Peixoto and Koyama) revised these studies' title and abstract for inclusion or exclusion, by using the following criteria: original article, and related – in its theme – with dementia, communication and palliative care. Of the 221 papers, 18 fulfilled the eligibility criteria. Diverging decisions on exclusion of articles were resolved by discussion between the authors.

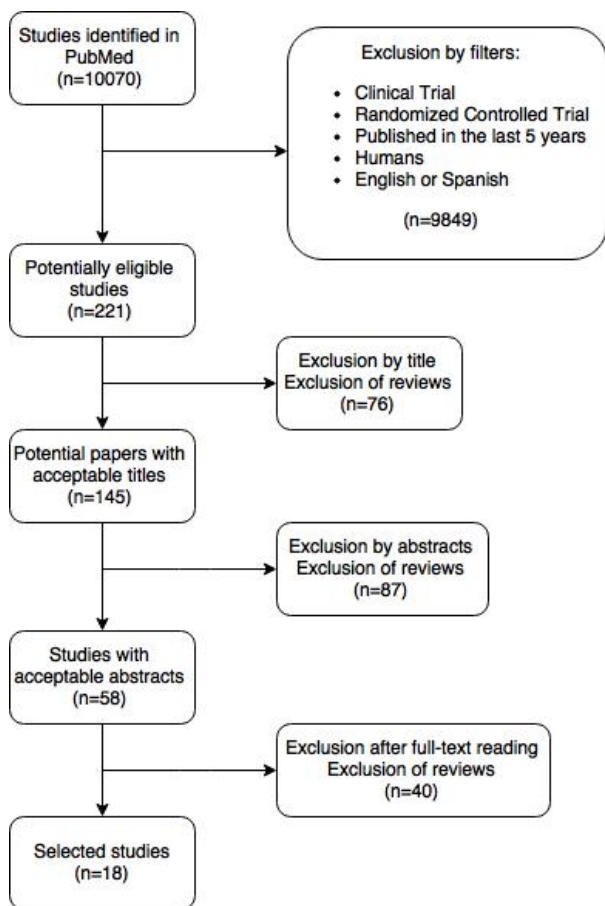


Figure 1. Fluxogram of the articles' selection

RESULTS AND DISCUSSION

Considering that the essence of the palliative care is to mitigate undesirable symptoms as well as keeping the respect to the patients' needs and desires, the main objective of this review was to answer the question of how to discuss end-of-life care with patients suffering from moderate or advanced dementia. In other words, how to identify and treat discomfort and how to understand what these patients want at the end of their lives.

Unfortunately, we could not find any published paper addressing precisely the subject we had proposed, even after a thorough search of the literature.

Therefore, we took a step back and tried to understand the obstacles to communicate with the patients with dementia. According to the World Health Organization (WHO)¹³, most of the people with dementia - in non-Western countries, almost all of them - live at home with the help of spouses, children, or others. In this same paper, WHO stresses the importance of the caregivers, since they are responsible for creating bonds with the patients and identifying their needs.

Therefore, we focused our review in three main

points. The difficulties that the caregivers have to evaluate the needs of patients with dementia, the ways in which the caregiver's talks can be improved by training and the alternative pathways to communicate with patients with dementia.

How difficult it is to evaluate discomfort symptoms in patients with advanced dementia

One of the pillars of palliative care is the recognition and treatment of discomfort symptoms, like pain. Since the verbal communications in patients with advanced dementia is largely impaired and they are dependent for routine tasks, symptoms recognition and treatment depend upon the relationship between the patient and the caregiver.

The importance of a good communication between the caregiver and the Alzheimer's patient was highlighted by a recent study by Savundranayagam et al.¹⁴. Evaluating video-taped conversations, they were able to identify multiple mismatches along the dialogues, prompting them to indicate the need for communication, education and training among caregivers, in order to establish empirically derived evidence-based communication strategies over the clinical course of dementia.

More importantly, in the palliative care scope, is the ability of the caregivers to identify symptoms that could be relieved or, at least, eased. Pain is the most under recognized and undermanaged symptom in older adults with dementia. These patients have a diminished capacity to communicate discomfort and pain is often expressed in the form of behavioral or psychiatric symptoms¹⁵. Again, the authors suggest that the response for this issue is a better training of the caregivers.

Other authors suggest that the use of validated tools to complement assessment of pain may assure that no pain goes undetected by the medical staff¹⁶. These tools, however, are not available to caregivers and should be applied by the interdisciplinary units.

Other disturbing symptoms that affect dementia patients are the ones related to behavioral changes. Isolating the potential causes and triggers of the symptoms is a gruesome task, due to these patients' poor communication. The best option to manage this kind of trouble is always to assume an individual approach, helping the caregivers to identify the source of the behavioral changes, excluding medical causes (through medical evaluation) and using interventions like telephone contacts to support them¹⁷. A similar intervention was successfully used to improve caregivers' emotional adjustments¹⁸.

As observed above, caregivers of dementia patients usually experience stressful conditions. According

to WHO¹³, caregivers not only develop feelings of burden but also show higher levels of psychiatric symptoms, depressive and anxiety disorders, poorer immune function, and even a higher death risk compared to non-caregivers or the general population^{19,20}.

Actually, most of the studies addressing the rapport between caregivers and dementia patients emphasize the necessity of educating adequately the former, in order to improve patients' care as well as to keep the caregivers' health.

Improving the care of the patient with advanced dementia: training and caring for the caregiver

In recent years, a growing body of literature indicates that communication barriers between patients with dementia and their caregivers have a significant negative impact in the quality of life, the quality of care received and the relationships experienced¹³.

However, there is evidence of insufficient communication abilities by medical specialists as well as of the limited retentive capacities of patients with Alzheimer disease (AD) and their caregivers. One major cause of this complication is that these patients usually use nonverbal communication to express symptoms as pain and dyspnea²¹. To understand these needs, an effective communication – verbal and nonverbal – is necessary^{14,22}. Moreover, it is particularly important for staff working with patients with dementia to train and be educated in communication approaches²³.

Several clinical trials have been designed to improve not only the training but also the quality of life of caregivers, what leads to a better attention to the patients with dementia.

In Northern Ohio, the project ANSWERS used six 90-min curriculum-guided sessions between a Masters-level intervention specialist and the primary family caregiver and patient with dementia. In these interventions, it was combined educational skills (traditionally used with caregivers) and cognitive rehabilitation skills training (traditionally used with individuals with dementia) into a single protocol. After 6 weeks, it was observed a marked decrease care-related strain in caregivers, characterized by lower emotional health strain, higher caregiving mastery and fewer symptoms of depression and anxiety. These improvements implicated a better care for patients with dementia under their attention²⁴.

In the United Kingdom, a strategy of educating caregivers through a manual and audio instructions have also been proved to be effective in reducing affective symptoms and case level depression in carers of family members with dementia. The carers' quality of life also

improved²⁵. Actually, technology has been an ally for patients with dementia and their caregivers. Devices for monitoring personal movements, medication use, environmental conditions have been used by caregivers in a multicenter international survey, with consequent improvement in communication and home-based rehabilitation with patients with dementia²⁶.

Interestingly, the use of more advanced technological devices seems to provoke less impact than the training for communicating with patients with dementia. Although both approaches have not been compared directly, training to improve personal relationship and communication skills in the patient with dementia proved to be very effective in reducing depressive symptoms in the caregivers and disruptive behaviors from the patients²⁷.

Training should also be given to the medical staff. Nursing aides from a community college based in a midsize city in the Rocky Mountain region were trained by teachers with large experience in treating patients with dementia. A control group did not receive the same training. The training module relied upon a learner-centered philosophy of education in which students reflect their own reactions to the material taught. Using this approach, teachers consider students to be coparticipants in the learning process and seek to empower them through knowledge. The results indicated the training was effective regarding nurse aides' understanding of residual cognitive abilities and need for meaningful contact among patients with advanced dementia. This study concluded that incorporating this training into nurse aide education has the potential to increase quality of life for people with dementia²⁸.

Other interesting study conducted in three European countries compared the clinical information provided by doctors about the care of patients with Alzheimer's disease and that perceived by caregivers. The authors concluded that many areas of information showed large differences in perception between physicians and caregivers of patients with dementia. They highlight the need of improving the communication process between doctors and caregivers, in order to achieve higher quality. No specific training for doctors or caregivers, however, was proposed²⁹.

From the data obtained in our research, it seems that it is more important to train the caregivers in identifying the verbal and nonverbal components of the communication of the patient with dementia, regardless the method used for the training itself. In a recent meta-analysis, authors assessed seven randomized controlled trials and concluded that educational programmes have a beneficial effect on caregiver burden and a small effect on depression³⁰.

Altogether, from the studies above, we can conclude that the patient with dementia and his caregiver must be considered as a dyad¹³. Whatever impacts positively one will also have a beneficial effect on the other.

Alternative paths to Communicate with PwD

As there is no definitive communication method for Patients with Dementia, many authors have been experimenting new approaches for this question. Methods as watching live music performances, debating using art images as a subject, visiting art galleries and performing in theatre based exercises have been successful in different levels of dementia, allowing a possible improvement in quality of life.

Ingeberg et al.³¹ proposed to improve dialogue between patients from a mental health care unit and staff members by the allocation of unexpected visual art ceramic stones and ceramic images. The patients were stimulated to establish both visual and tactile contact with the pieces of art. While the patient was exposed, the staff member would encourage him to combine earlier memories and experiences with the new impressions from the object. After the conversation with some patients, the staff members were invited to focus groups interviews with the mediation of one of the researchers. The allocation of the objects led the patients to reflexions and stimulated the dialogue with the staff member as a “door-opener” to communication. Quantitative methods were not employed.

Camic et al.³² performed a study that involved visits to two different art galleries, where people with mild to moderate dementia and their carers participated of two activities: view and the patient produced art, during an eight-week program in which each activity lasted 2 hours. On quantitative analysis, no significant pre-post difference was identified. However, thematic analysis – that was composed by reports of people with dementia and their carers – revealed improvement of quality of life, increase of cognitive capacities and other positive aspects, involving feeling more socially included and enhancing social engagement. Another important item suggested in this study was that art programs could stimulate the inclusion of the individual with dementia, improving attention and concentration. This intervention could represent a potential approach to the improvement of the capacity of people with dementia to make contact, once their personhood is supported and many aspects of communication are stimulated.

Another kind of approach which has been seen as effective into the improvement of communication is

intimate live music. Van der Vleuten et al.³³ studied live music performances presented by professional singers’ effect in patients with mild and severe dementia in nursing homes. This approach had the aim to establish an intimate contact with the resident, but in a non-invasive way. The study suggested that music can improve the ability to communicate and is important for mental well-being, as people may be able to express their emotions better. Besides that, the contribution of music to the person’s ability to establish contact had been significantly improved. Despite individuals with severe dementia could not concentrate their attention on the presentation, this group and that composed by people with mild dementia had experienced positive effects on mental well-being. These results suggest that intimate live music performances could enhance the ability of people with dementia – especially those with mild dementia – to communicate.

Another article, by van Dijk et al.³⁴ proposed a theatre based intervention to improve communication with the PwD. The researchers made 3 groups. One of the groups had a theatre based intervention with professional actors, another group had a similar intervention with trained caregivers and the third group had no different intervention at all. Although there were important biases (they have lost more than 20% of their original cases and the intervention with professional actors was 30% longer), there was a significant difference in some aspects of the patient’s mood, cooperation, memory’s recalling, attention and in the relationship with the caregiver and with other people.

Although the results seem promising, this 5-year revision found some biases in these studies. Most of them (except by the van Dijk’s³⁴) showed positive results based in a qualitative analysis, besides a non-significant analysis performed which showed no difference between the groups. Another inconsistency in the studies was the intervention itself. All the interventions showed, except by Camic’s³², were punctual – none of them was continuous, which make the results more likely to be related to other factors as a bad relationship with the original caregiver, a empathic relationship with the responsible for the intervention, a curiosity about the intervention or merely by chance.

Besides that, all of the studies had some issues that should be discussed. Ingeberg’s³¹ intervention with art communication was analyzed focusing in the staff members, not in the patient, which led us to question if the staff’s members point of view wasn’t biased. Although Camic’s³² intervention was not punctual, its number of participants was low (n = 26), which could facilitate a favorable result just by chance. The van der Vleuten study³³ recognizes itself its low number of participants (n

= 46), which could lead to the same issue as Camici's³² one.

Although these studies have important issues, we believe that their conclusions were consistent and have a great potential in the treatment of people with dementia. Besides that, we believe that more studies should be performed to confirm or deny the presented results.

CONCLUSION

We can conclude that although it is not possible to discuss end-of-life care with patients with advanced dementia, due to their cognitive impairment, it is still possible to provide them with effective and compassionate palliative care. In order to achieve this purpose, the caregivers and medical staff should be trained in

identifying and treating discomfort symptoms, using not only the verbal and nonverbal communications, but also alternative methods, like arts and music.

Although difficult in itself, the task of caring for a patient with dementia could also be very gratifying. Using a qualitative approach, Habermann et al.³⁵ interviewed 34 adult children who cared for their parents with dementia. The vast majority (86%) had a positive feeling about that experience. They cite the opportunity of spending and enjoying time together, appreciating each other and becoming closer, and returning and giving back care as constructive emotions during this period³⁵.

Therefore, as a final conclusion, we may affirm that providing adequate end-of-life care for the patients with advanced dementia is a difficult but rewarding task and efforts should be made to deliver it the best possible way.

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