PALLIATIVE CARE IN ALZHEIMER'S DISEASE

CUIDADOS PALIATIVOS NA DOENÇA DE ALZHEIMER

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ABSTRACT

Palliative care has generally been a neglected area of medicine as it is commonly associated with terminal cancer. Palliative care itself should start as soon as the patient and the doctor become aware of any incurable, progressive and degenerative disease, such as Alzheimer's. The adequate care of a patient with Alzheimer's disease will allow not only him/her, but also his/her family, to go through the stages of this disease comfortably and respectfully so as to end his life as a loved and cared for individual, and with as little discomfort as possible. In this article we will discuss what is necessary for that.

Key-words: hospice care, neurodegenerative diseases, Alzheimer disease.

RESUMO

Cuidados paliativos é uma área geralmente negligenciada da medicina, já que é comumente associada ao câncer em estágio terminal. Por outro lado, ele começa assim que o paciente e o médico se tornam cientes de uma doença incurável, progressiva e degenerativa, como a doença de Alzheimer. O cuidado adequado de um paciente com esta doença irá permitir que não somente ele, mas também a sua família, caminhe confortável e respeitavelmente através dos degraus desta doença e termine a sua vida como um ser humano amado e cuidado, com tão pouco desconforto quanto possível. Neste artigo vamos discutir o que é necessário para tal.

Descritores: cuidados paliativos, doenças neurodegenerativas, doença de Alzheimer.

INTRODUCTION

The growing ageing of the population has been increasing the prevalence of all degenerative diseases. Therefore, having elderly with progressive incapacitating diseases taken care for in long-stay institutions is becoming more and more common.

Among these incapacitating diseases, neurodegenerative disorders are the ones that require more attention even though most part of the palliative care has been, up until now, directed to cancer. Parkinson's disease, for instance, has a developing course that causes severe debilitation to the patient, who usually ends his/her days lying on a bed, incapable of moving and with severe respiratory problems.

Alzheimer's disease, however, only leads to motor disabilities at its most developed stages. During the years or even decades before that, the person can move around without much difficulty and is considerably active though very confused, what makes him/her a burden to the family. Therefore, it is not at all uncommon for the families to have their beloved ones in an institution. Mostly, they cannot supply the required care for the person and, on behalf of the family's well-being, they decide it might be better if someone else becomes responsible for the sick one. Nevertheless, it is also not uncommon for the Alzheimer's diseased person to become progressively less and less visited by the family, as the disease progresses;[1] for, why would anyone visit someone who does not remember him/her anymore?

It is important to mention that palliative care does not start at the moment you realize the patient is going to die, but it starts at the moment the diagnosis of an incurable disease is found out. From then on goals and care are to be decided regarding the progression of the disease, and mainly the patient's well-being and dignity.

To promote dignity is to maintain the person's social status and confirm him/her his/her social role, even when mental or physical deterioration occurs; to encourage choices and decisions; to know the person always when it is possible before starting his/her care, and ask for his/her approval for the procedures to be performed.[2] And how can we maintain the dignity of a patient who no longer can take care of his/her basic needs alone and no longer recognizes his/her family?

Chochinov[3] defines four principles to maintain a patient's dignity. With those principles even these patients, who so many times seem to be deprived of their dignity, may be respectfully and palliativelly taken care of.

A. Attitude: having human attitudes to the patient, respecting his/her single freedom, without stereotypes or prejudice;
B. Behavior: being kind and respectful forwards the patient;
C. Compassion: showing compassion and understanding of the problem, not only from the professional point of view, but also from the human one; and
D. Dialog: based on the knowledge of the patient, using psychotherapeutic approaches.

Taking these basic and extremely important concepts as a foundation for the palliative care, the other details of the care will flow naturally.

Hygiene and Comfort[4]

The level of assistance necessary for the personal hygiene varies in Alzheimer's disease according to its severity. Individuals who are capable of taking a shower, brushing their teeth and changing their clothes by themselves should be stimulated to do so. If it is necessary, they may be helped throughout these functions, up until a point when they are not capable at all of taking care of their own hygiene. That is when the caretakers should do it for them. A bath on the bed, if possible, must be restricted to those patients who are too weak and cannot get out of bed even on a wheelchair.

Even at this moment, basic hygiene must not be neglected.

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Comfort for a patient in palliative care is very important. Although in the first stages of the disease the patient is not seated all the time, as the disease progresses (and also as a side effect of medication) it will be natural for him to stay seated in the same position for long periods of time. Therefore, it is important to stimulate the patient to change position when possible or to change it passively, so as to avoid pressure ulcers. Comfort must be evaluated and aimed for, for there is no use if in order to avoid an ulcer the patient must stay in a painful position for a long time.

Feeding[5]

As often as possible the patient should be stimulated to feed him/herself, or if it is not possible, to be fed orally by a caretaker no matter how long it takes. Patients with neurodegenerative diseases generally present some kind of swallowing difficulty, so it is natural that they take longer to be fed. As a result, diet must be adequate, being prepared in such a way it is easy to be swallowed (in the form of a cream or liquid, when necessary).

Feeding is the first stage in the human being's development and is an essential part of his/her psychic constitution. To be deprived of this pleasure is practically the same as being deprived of his/her own humanity, even for a patient who is not lucid enough to communicate. Feeding through nasogastric tube or even parenteral nutrition must be, thus, restricted to when there is no other option.

In these cases when the patient is in an Intensive Care Unit, for instance, the time he/she is going to spend there must be taken into account. It is recommended that if he/she is expected to stay longer than two weeks, a colostomy be made, instead of a nasogastric tube, in order to avoid lesions and/or stenosis of the esophagus and subsequent incapacity of oral nutrition.

Patients with Alzheimer's disease in its final stage presenting secondary parkinsonism will mandatorily need a bigger intake of calories and proteins than normal. Nevertheless these patients are usually fed even less than normal due to the difficulties related to this condition. It is essential that attention be paid to this difficulty and that it be avoided at all cost. These patients, when lucid, may claim that they are hungry all the time; when they do not, it is possible to perceive so their constant loss of weight, in spite of being fed.

Medication[6]

Patients with Alzheimer's disease usually take anticholinesterasic medication. It is known that such drugs cause cholinergic symptoms and may predispose to dry mouth, constipation and delusions. Some special care must be taken:

- Constant hydration, especially because the elderly are more prone to developdehydration as they tend to feel less thirsty;
- Measures to stimulate defecation such as laxatives that increase the volume of feces (fibers) or that facilitate their movement (surfactants, such as sodium docusate; lubricating laxatives must be avoided in patients with swallowing difficulties, due to the possibility of aspiration); colonic mucosa stimulants (bisacodil), which are particularly useful in constipation due to opioids; and, finally, rectal laxatives when all other measures have proved ineffective or cannot be used or there is feces impaction. It is important to note that, in case of fecaloma, using oral laxatives may cause severe pain and lead to no result at all. Then an intestinal cleanser or manual removal of the feces is needed; and
- In case of delusions the cause must be identified (alterations of the medication dosage, medications interaction, dehydration or organic diseases, psychiatric commorbidities or delirium) and the correct treatment must be made.

Delirium[7]

Delirium is the alteration of the conscience level, quantitatively (when there is lowering of the level) and/or qualitatively (changes of the conscience and its clearness). It is often characterized by time and space disorientation, delusions and/or hallucinations, and fluctuating course during the day, being worse at sundown (sundown effect). It may be hyperactive, hypoactive (when it causes more lethargy and drowsiness) or both.

The main causes of delirium are organic and must be thus looked for: dehydration, constipation, urinary retention and infections in general, being urinary the most prevalent. Drug induced causes cannot be overlooked; besides, it is possible that an elderly embedded in a room without stimuli or with excessive stimuli comes to develop delirium without any causal factor in a matter of hours.

The treatment must firstly be directed to the cause in order to stop it; secondly, in case it is not enough neuroleptic and/or benzodiazepines may be used to control the crisis. Always remember to use those with shorter half-life, which cause fewer side-effects.

It is possible to prevent it by preventing the above related causal factors and keeping the patient with adequate stimuli and information, such as day, hour and sunlight, apart from the constant contact with the caretakers.

Spirituality[8]

The spirituality of patients in palliative care must be always taken into account. What is important for the patient in the process of sickness and death? It may be a hastening question when we think of a patient at the beginning of the disease; however, when we think that the natural course of this disease results in a progressive cognitive deterioration it is important for the Alzheimer's patient, to have a course of action laid out bearing in mind since the beginning what is important for him/her.

Does he/she have any religious belief? Any ritual? How important is religion to him/her? Would it be benefitial to take him/her to church? Or to make a religious reunion in the long-stay institution?

Besides, as soon as it is necessary and preferably before the patient becomes irreversibly demented, it is important to know what he/she wishes for his death: to be buried or cremated? How will his/her funeral be? Who should be present at the moment of his/her death? Does he/she want any religious leader to be called?

During the progression of a terminal disease, it is quite visible that the patient becomes gradually more aware of his/her terminality, thus making it important for the caretaking team to help the patient then. The Alzheimer's patient, however, may somehow seem spared of it, since in the final stages he/she may be so little lucid that seem unable to understand what is happening.

In these cases it is up to the caretaking team, which probably has known the patient for several years by then, to evaluate how he/she is feeling; if he/she is spiritually comfortable and if all his/her wishes, previously determined, have been answered, before the moment of death comes.

The Namaste Care Program[9]

Created by Joyce Simard approximately five years ago, this program aims to honour the innern spirit above all as the word itself Namaste says.

It involves the creation of a room specifically for that by using nature sounds, aromas, stuffed animals, touchable and stimulating surfaces, and furniture for the patient's comfort.

During the morning and/or in the afternoon these patients are served by one or more specific caretakers depending on the demand, and receive corporeal care, such as shaving or creaming the face, legs and feet, everything very slowly and always accompanied by smooth conversation aiming mainly at the process itself, rather than the results.

Through this type of care, the demented patients become calm and accommodated, receiving what they need more: human attention and warmth. Their relatives, when they come to visit, may be invited to help with the tasks or feed them tasteful creamy foods such as puddings, for instance and as a result, they feel very grateful for the fact that their beloved ones are being well taken care of.

Moreover, through this type of caring we can achieve the motto of palliative care: to preserve the patient's dignity.

CONCLUSION

The most important part in the palliative care is preserving the dignity of the patient and bringing him comfort and well being, no matter how severe the disease is. Through simple and small things, such as basic hygiene, adequate nurturing, comfortable furniture, adequate and smooth stimuli and most important of all human attention and care it is possible for us, health professionals as a group, to promote a comfortable and honored care for those who are so loved by their families. We cannot forget that, eventually, we might be the ones on the other side in need of the same care.

REFERENCES

1. Simard J. Silent and invisible; nursing home residents with advanced dementia. J Nutr Health Ageing. 2007; 11(6):484-8.
2. Holmerová I, Jusaková B, Kalvach Z, Rohanová E, Rokosová M, Vanková H. Dignitiy and palliative care in dementia. J Nutr Health Aging. 2007; 11(6):489-94.
3. Chochinov HM. Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. BMJ. 2007; 335:184-7.
4. Pereira I, Sera CTM, Caromano FA. Higiene e conforto. In: Oliveira RA, coordenador. Cuidado paliativo. São Paulo: Conselho Regional de Medicina do Estado de São Paulo; 2008. p. 195-219.
5. Carvalho RT, Taquemori LY. Nutrição e hidratação. In: Oliveira RA, coordenador. Cuidado paliativo. São Paulo: Conselho Regional de Medicina do Estado de São Paulo; 2008. p. 221-57.
6. Hatanaka VMA. Constipação e diarréia. In: Oliveira RA, coordenador. Cuidado paliativo. São Paulo: Conselho Regional de Medicina do Estado de São Paulo; 2008. p. 427-44.
7. Figueiredo MGMCA. Delirium. In: Oliveira RA, coordenador. Cuidado paliativo. São Paulo: Conselho Regional de Medicina do Estado de São Paulo; 2008. p. 513-8.
8. Saporetti LA, Aitken EVP, Kovács MJ, Franco MHP. Espiritualidade, morte e luto. In: Oliveira RA, coordenador. Cuidado paliativo. São Paulo: Conselho Regional de Medicina do Estado de São Paulo; 2008. p. 519-70.
9. Volicer L. Goals of care in advanced dementia: quality of life, dignity and comfort. J Nutr Health Aging. 2007; 11(6):481.

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