

Decision Making and Ethical Issues in Dementia

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Received date: November 16, 2016; Accepted date: November 23, 2016; Published date: November 30, 2016

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Citation: Pajk B (2016) Decision Making and Ethical Issues in Dementia. J Comm Pub Health Nurs 2: e116. doi:10.4172/2471-9846.1000e116

Introduction

Few days ago I came across a really interesting media release from Alzheimer Europe on ethical issues in dementia [1], which made me contemplate about this issue.

When I look back, I believe that in the past we didn't think about ethical issues in dementia care so much. We just did what we thought is best for our patient. I remember we were often quite astonished when we got the patient with dementia with a broken hip back from the surgery without being operated, because he wasn't able to sign the informed consent for the procedure. Or further more we didn't discussed a lot when we prolonged patient's life in the terminal stage of dementia, administrating infusions, antibiotics, feeding tubes, and not to mention giving CPR. Everything to save a life, because this is what health care workers do, and most of relatives want to hear: "We did everything possible to save him". But what would that certain individual with dementia want? Well he/she could no longer tell.

Research and clinical ethics in dementia are challenging because of the nature of the disease [2]. Usually the treatment, care, and the research are based on an informed consent between professionals and rational and autonomous participants/patients. However when dealing with patients with dementia things get much more complicated, therefore special considerations are needed.

Alzheimer Europe launched two new publications at the European Parliament, wishing to promote a human rights-based approach to dementia, as well as policy makers interested in reforming their legal systems to better promote the rights of people living with dementia. Some of the new legal approaches move away from public protection as the main priority, towards an approach that safeguards and promotes the rights and dignity of the person, but also highlights the need to balance care and protection, against empowerment and rights. In line with this and following the requirements of the UN Convention on the Rights of Persons with Disabilities (UN CRPD), some of the most recent legislation has moved away from proxy to supported decision-making approaches [1].

I believe the hardest and most devaluating thing for the individual is not being able to make even the smallest decisions about his own life anymore like, where I am going to live, who will take care of me, what

am I going to eat, what I am going to wear today, and so on. In the end the more I am thinking about the decision making in dementia, the more I realize that we don't really involve patients that much. Patients in the hospital or nursing homes have to get when we wake them up, have a breakfast when we give them breakfast, and what we give them. I remember a book I read recently about old men with dementia who's biggest wish was to eat an apple, like big, red, whole apple, not a mashed one. But he never got one, because it supposed to be too dangerous for him.

That is why I strongly support initiatives about ethical issues in dementia care, treatment, and research, and most importantly early diagnostics of dementia.

Like Alzheimer Europe Executive Director Jean Georges said: "Everyone should have the right to decide how he/she wants to lead his/her life and a diagnosis of dementia should not change that. Whilst the wellbeing of the person should always be safeguarded, the emphasis should be on empowering rather than on simply protecting the individual" [1].

Among others I believe that we must make a shift from a medical to psychosocial approach when dealing with dementia patients. The person must be the main concern of our care not the disease. To establish an individual approach we must see the person behind the dementia, get to know him, his life, his wishes. And to be able to do that, an early diagnostics is essential, so that the person would be able to speak clearly about his wishes, needs, and priorities considering dementia care.

The growing number of individuals affected by dementia will intensify the ethical issues that emerge in clinical practice and research [3]. So dementia will continue to challenge us in many years to come.

References

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