

Dementia, Living Will And Autonomy

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Abstract

The following is how the situation is to be judged when patients with dementia have a living will. An important issue for both medical and legal practice is how to deal with the previously expressed wishes of the patient, after he has become dementia. Fundamental fears of dementia exist in society, with the loss of autonomy and a change of essence. Many of those affected are also afraid of being a burden on relatives and society. Because of this, ethical conflicts are often to be inevitable, especially where decisions have to be made that relate to central values of modern western society, such as independence, productivity and rationality. In medical ethics, time does not allow for moral-philosophical basic problems to be solved. To find a consensus, it recommends using the principles of biomedical ethics used by Beauchamp and Childress from 1979. It is recommended because these principles are on a medium level, they are well suited for consensus. Furthermore, the author supports these principles because only the clear identification of the ethical problem contributes to a first step in conflict resolution

Index Terms – Ethics, Autonomy, Living will & Health Care.

I. INTRODUCTION

According to estimates by the World Health Organization (WHO), about 50 million people worldwide suffer from dementia. Due to demographic trends, an estimated 10 million new cases of dementia are reported annually (WHO, 2017). The Alzheimer Association Switzerland (ALZ) currently estimates that around 148,000 people in Switzerland suffer from dementia. According to projections, this figure will double by 2040 (ALZ, 2018). Among the most relevant neurodegenerative pathogenesis include dementia, organically induced personality changes and Korsakoff's syndrome. Such disorders are usually irreparable (Höwler, p. 94, 2016).

II. OBJECTIVE

The aim of this article is to make a contribution in this seemingly hopeless situation to all those affected (patients, relatives and specialists). Because of the challenges described above, the author decided to analyze the following question: **Under which conditions must a living will be strictly adhered to in case of dementia?**

III. DEMENTIA

Dementia is a syndrome usually chronic or progressive in which cognitive function (that is, the ability to process thoughts) goes beyond what might be expected from physiological aging. It influences memory, thinking, orientation, understanding, calculation, learning ability, language and judgment. The consciousness is not affected. Impairment of cognitive function is usually accompanied and sometimes preceded by a deterioration in emotional control, social behavior or motivation. Dementia results from a variety

of diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer's or stroke. Dementia is a major cause of disability and dependence in the elderly worldwide. The impact of dementia on caregivers, family and society can be physical, psychological, social and economic (WHO, 2017).

People with dementia are often denied basic rights and freedoms available to others. In many countries, physical and chemical restrictions are often used in nursing homes for the elderly and in acute care, even if there are provisions guaranteeing people's rights to liberty and freedom of choice. An adequate and supportive legislative environment based on internationally recognized human rights standards is needed to ensure the best possible quality of services for people with dementia and their caregivers (WHO, 2017).

IV. LIVING WILL

Living wills are experiencing a boom. According to surveys in Germany, the number of living wills has multiplied in recent years. Investigations are based on the assumption that living wills often have little or no effect in practice because they cannot be found or allow too much scope for interpretation by experts (Jox, Ach & Schöne-Seifert, 2014).

The SAMS (Swiss Academy of Medical Sciences) sees the patient living will as an instrument of self-determination. A person capable of judgment can specify which medical measures he agrees to in the event of his or her lack of judgment. The person thus anticipates a situation of judgment inability. Furthermore, the person can determine who decides their representation in the case of medical treatment. A living will can make statements on topics such as Transplantation, autopsy or organizational instructions, etc. Many organizations offer divorce declarations of varying quality.

Some only have to be signed, some texts can be added or options can be selected. These patient orders are simple. Individual patient appointments focused on the individual are more complex and offer professional support (SAMW, 2018).

It should be noted that a living will reflects the current will of the affected person. As long as there is no doubt that patients have changed their mind, the living will should be followed. The difficulty with dementia is defined by the SAMS as follows: "If the nonverbal behavior of the patient (e.g. in dementia patients) or other clues give reason to believe that the living will no longer corresponds to the current will, they must do so with the help of the patient's caregivers (relatives, GP) etc.) should be carefully clarified." (SAMW, 2018).

If people with dementia lose their ability to judge and are no longer able to make certain decisions themselves, their wishes and values are still central to the treatment team and relatives. If patients have a living will, it will guide the treatment team (SAMW, 2017).

The term action guiding can be interpreted differently. Is there a duty here to follow this instruction? Or does the term leave room for interpretation for the treatment team? It may be right, in case of doubts about a patient's appointment, not to comply with it or to check and analyze. However, it seems that some medical professionals are just looking for this room for interpretation because they themselves are overwhelmed by the situation.

Bimbacher (2016) notes that patient orders are often made that were not accompanied by a knowledgeable advisor or consultant. Furthermore, individual experiences, strokes of fate and prejudices against the so-called "apparative medicine" raise doubts about the validity of living wills (Bimbacher 2016).

Monteverde (2010) describes this problem as follows: "In the major social discourses on health, illness and addiction, including patient dispositions, there is an astonishingly unspecific and undifferentiated terminology regarding dementia: terms such as 'vegetating,' Brain Degrading Process or mental disintegration reveal a judgmental, fearful and stigmatized metaphor that does not allow a possible meaning dimension in dementia." (Monteverde, 2010)

According to Bimbacher (2016), among other things, the following prerequisites must be met in order for a living will to be obeyed in any case:

- That they meet the legal requirements for living wills, they must relate to medical treatment: "so only the break or the non-inclusion of certain medical treatments, but not their implementation require

(Bimbacher, 2016). "

- It must be clear that the living will was not created under pressure or coercion. Furthermore, a knowledge and consent is a prerequisite.

V. AUTONOMY AND SELF-DETERMINATION

The term autonomy comes from the Greek words "autos" and "nomos" and literally means "self-legislation" (Bobbert & Werner, 2014, p. 105).

The terms autonomy and self-determination are equated in the debate. This presents a challenge. Especially in such aspects, it is very important that the same language is spoken. Wunder (2008) describes this as follows: "In its etymological meaning of self-legislation, the concept of autonomy negates man's dependence on his nature, his social involvement, and ultimately his dependence on God (Wunder, 2008)."

In German-speaking countries, the notion of autonomy of Kant is strongly influenced and represents a realization of the morality of man. "The concept of self-determination, on the other hand, is more modest and always incorporates relativity: I determine for myself what lies with the self, what it constitutes, what it surveys, what it can determine. Self-determination is the opposite of the fact that others are dividing into my self-domain and making me strange" (Wunder, 2008).

"Individual autonomy is generally understood as the ability of individuals to determine their own lives, to lead their own lives based on reasons, considerations, motives, desires that are their own and not others - personal or spiritual political reasons - be imposed. That is why autonomy is responsible and demands respect from others. Since the Enlightenment, autonomy has been one of the central guiding concepts in both ethics and political philosophy. " (Rössler, 2011, p. 93)

Autonomy is often differentiated from negative and positive freedom. This means that the negative freedom, the freedom from external interference (freedom from) is. Positive freedom is freedom to act in harmony with one's own will (free). Furthermore, autonomy is differentiated into individual and collective autonomy. These relate primarily to groups or organizations (Rössler, 2011).

Kruse, Becker, Schröder and Seidl (2015) warn that people with dementia no longer understand anything, act unreasonably or are no longer able to interact. In their 2005 research, they conclude that those affected, even at an advanced stage, are able to respond in a differentiated manner. Furthermore, they conclude that the abilities to experience positive emotions and to express oneself non-verbally are still present (Kruse, Becker, Schröder & Seidl, 2015).

The German Reference Center for Ethics (2018) describes that medical professionals fear that the declared will in the living wills can change. Aspects that were important to a person when making a living will can change over time. This has an impact when these people are sick. This will can be influenced by illnesses. It is also described that people with dementia can lose their personal identity (German Reference Center for Ethics, 2018).

The Swiss National Ethics Committee in the field of human medicine (2011) concludes that the continuity of a person, even in dementia, is present. Accordingly, the validity of a living will cannot be fundamentally called into question. Especially not under the argument that there may be a loss of personal identity in dementia (NEK-CNE, 2011).

The ethical principle of respect for the autonomy of the patient / subject has become increasingly important in modern medicine. The emphasis on the autonomy of patients and subjects in all recent international declarations unequivocally expresses this tendency (Wiesemann, 2012).

VI. BEAUCHAMP AND CHILDRESS

Tom L. Beauchamp and James F. Childress published *Principles of Biomedical Ethics* in 1979. The approach of *Biomedical Principles* characterizes the debate in medical ethics. This is also reflected in the fact that her book has been revised several times. The central contents are the four ethical principles, which are:

Respect for Autonomy

Respect for Autonomy after Beauchamp and Childress *Principles of biomedical ethics* are based on resistance to medical paternalism and critical ambiguity in their primary principle of autonomy (Beauchamp and Childress, 1979). First, Beauchamp and Childress cite Kant's autonomy to explain the power of their autonomy principle. On the other hand, they see their principle of autonomy as respecting what Kant calls heteronomous decisions, as immoral decisions. For Beauchamp and Childress, because of their heteronomous individuality, physicians must respect the decisions of patients, even when decisions are made based on bias, rather than rational decisions. Their respect for heteronomous, autonomous decisions puts their principle of autonomy into tension with the principles of charity, non-harm, and justice, which affect the patient's best interests that are not focused on freedom. Beauchamp and Childress urge health professionals to respect the decisions of patients who are determined by their inclinations, and also urge them to respect the decisions of patients and patients that the duties of patients are themselves hurt yourself to save their lives and health (Hinkley, 2012).

Hinkley (2012) describes this as follows: "The concept of autonomy in Beauchamp and Childress bioethical principlism is not merely unclear; it contains within itself two distinct understandings of what actually constitutes autonomy that are fundamentally contradictory. A critical examination of this tension places much of what would be termed medical paternalism by Beauchamp and Childress in quite a different and, perhaps, positive light (Hinkley, 2012, S. 86). "

The first principle of biomedical ethics for Beauchamp and Childress is that medical professionals respect the autonomy of patients (Beauchamp and Childress, 2009, p. 103). Healthcare professionals should then give patients the right to have their own views and to determine the health services they receive based on their beliefs, values, and beliefs (Hinkley, 2012).

Such respect includes respectful action, not just respectful demeanor. It requires more than just non-interference in the personal affairs of others. In some contexts, this involves building or sustaining the ability of others to make autonomous decisions, and helping to dispel fears and other conditions that destroy or disrupt autonomous action (Beauchamp and Childress, 2009, p. 103).

This respect for patients' autonomy therefore requires more than just impairment of decision-making ability or ability. Respecting the autonomy of others for Beauchamp and Childress requires positive action from healthcare professionals to help those affected make their own choices based on their own views, values, and beliefs (Hinkley, 2012).

Respect in this context means recognizing the person's value and decision-making powers and enabling them to act autonomously, while non-observance of autonomy includes attitudes and actions that ignore, insult, disparage or misappropriate others' rights to autonomous action (Beauchamp and Childress, 2009, p. 103).

For bioethics, respecting autonomy means supporting patients in their decisions based on their own criteria, even if those criteria are wrong. This requires that medical professionals do not make any attitudes and actions that affect the ability of Patients are hampered by making their own decisions about the medical treatment they receive, even if the medical profession believes that patients are against their will (Hinkley, 2012).

The principle of autonomy gives every person the right to have their own views, to make their own decisions and to carry out events that correspond to their own moral concepts. For medical personnel, this means that they should provide information to and / or support the patient in this process. In

this context, informed consent is relevant. All diagnostic and / or therapeutic interventions need the explicit consent of the patient. This means that patients must be sufficiently informed. This consent must be voluntary so that they can be approved by medical and / or therapeutic measures (Marckmann, 200). By obtaining consent, respect for autonomy is valid (Maio, 2012).

VII. DECISION ASSISTANCE

People with dementia should be protected in the exercise of their self-determination and support as much as possible. The protection and support of self-determination becomes especially relevant when dementia progresses and those affected continuously lose cognitive abilities. Participation in the exercise of self-determination should be made possible here (SAMW, 2017).

In this respect, the German Ethics Council (2012) becomes a little clearer, not to say more “moral”: “Ethical commitment follows from the mutual dependence of people and from social solidarity, and to the best of one's fellow man to help everyone claim for themselves ... Therefore, it is ethically not enough to insist only on the legally required respect for the freedom of everyone and not to hinder him in the exercise of his self-determination. Rather, it is ethically necessary to strive for the self-determination of peers (Deutscher Ethikrat, 2012). “

Bimbacher (2016) describes the decision assistance as follows: “Decision support is clearly to be distinguished from a decision substitution in which a person other than the person affected decides based on his or her own judgments. In the decision-making assistant, the patient decides on his own, either alone or, for example in the sense of shared decision making, he makes a significant contribution to the decision. In contrast to the internationally accepted term of supported decision making, decision-making assistance is more closely understood here as an aid to the patient's own decision-making and expression, and not as the interpretation of the current or presumed will by a third party (Bimbacher, 2016)). “

VIII. ADVANCED CARE PLANNING

“Advance Care Planning is generally understood as a patient-oriented, professionally supervised discussion, documentation and implementation process (Karzig, Otto, Loupatatzis, Krones, 2016).”

Advance Care Planning (ACP) is a continuous, dynamic process of early reflection and dialogue between a sick person and the healthcare professional concerned about the person's preferences and values for future treatment and care, including on-care end of life. Upon request, the content of these discussions may be recorded in the form of a preliminary ruling and an authorized person for the power of attorney may be

appointed or a permanent power of attorney may be issued pending further deterioration.

Care planning is defined as a process of formal decision-making designed to help patients make decisions about future care that will take effect if they lose their capacity for judgment. Prevention planning differs from general care planning in that it is usually used with progressive disease and expected deterioration. This has an impact on patient acceptance. If those affected lose discernment, healthcare professionals should use the information they have received from the plan for care planning to help them make informed decisions when needed (Coors, Jox, & in Schmitt, 2015).

“Advance planning for treatment and care takes place in a process in which patients and their relatives, together with the health professionals involved, discuss strategies and treatment goals for anticipated situations, determine them and adapt them to the specific course of the disease over and over again (SAMW, 2017). “

The University Hospital Zurich and the University of Zurich (under the direction of Tanja Krones) have examined the decisions at the end of their life in the double-blinded, randomized controlled study of the ACP for capable and incapacitated patients with their authorized representatives. Here are just a few results of this study. The authors conclude:

- Six months after an ACP counseling process, the treatment needs of patients are significantly better known to medical professionals as well as relatives than before.
- Affected as well as their relatives describe significantly fewer decision-making conflicts after six months than before (Krones, Loupatatzis, Otto, Karzig-Rudner, Budilivski, 2017).

Piers et al. (2018) conducted a systematic literature review aimed at developing evidence-based clinical recommendations that medical professionals can use in the practical application of ACP in dementia treatment.

Based on 67 publications and validations by ten experts, 51 end-users and two peer review groups (24 participants), 32 recommendations (see Annex) were developed for eight areas: initiation of ACP, assessment of mental performance, Carrying out ACP discussions, the role and meaning of the relatives of those affected: ACP with people who are difficult or even unable to communicate orally, documentation of wishes and preferences, including information transfer, decision making at the end of life and conditions for optimal treatment Implementation of ACP. Nearly all recommendations were graded, with evidence of low to very low quality. They conclude that there are no high-quality guidelines for ACP for

the treatment of dementia (Piers et al. 2018).

IX. CONCLUSION

The author concludes that many factors are relevant to answering this question. In his view, above all, the intentionality / information and understanding / insight and judgment / absence of controlling influences and authenticity are important. These factors are all based on Simon's (2015).

Another factor is the respect for the autonomy of those affected. It may well be that medical professionals from an altruistic position do not want to comply with living wills. This is mainly because they have a conflict on a personal level. Under no circumstances should this moral stress, which has always been more prevalent in medicine and nursing, be borne at the expense of patients. Under no circumstances may medical professionals, based on their responsibility, pass on the will of those affected to their expertise. If those affected cannot express their will or are not ready yet, then they need support to recognize and manifest that will. If all the factors mentioned are transparent and clear, then a living will have to be respected.

Due to the fact that living wills are experiencing a boom and the numbers of dementia diagnoses are on the rise, there must be a change of perspective in the treatment and care of people with dementia. At the societal level, the issue of dementia must be even more present. Medical professionals need to be aware that patients are reluctant to speak of a living will in a hospital or nursing home. This means that this issue needs to be addressed by medical professionals. The lack of validity, which has been mentioned again and again, can be solved or mitigated with the help of decision assistance and ACP. This is especially relevant since it is known that individuals have anosognosia at the onset of dementia. This is a big challenge for all involved.

The benefits of Decision Assistance and ACP are given. This was demonstrated by the studies of the University Hospital Zurich and various other institutions. A clear advantage in the whole debate is that dementia usually progresses slowly and all those involved have time - especially those people affected - to think about their will.

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