Advance Directives in patients with Dementia

Advance Directives are the that tools enable informed adult patients to demand a certain plan of action regarding their treatment in case they lose the medical decision-making ability. One question concerning the usage of the advance directions is the case where a person who is going through some psychological change is regarded as a distinct entity from the one who signed the directive. If that is so, then the authority of the directive – which is supposed to be limited to the person who has completed it and not to his new identity – is decision-making rationale since these guidelines are regarded as an appropriate continuation of the competent patients' decision-making ability (Albert et al., 2011). The latter has the freedom to agree to an informed choice or to deny any health insurance given to them. This means the right to make an informed and voluntary decision. In regular cases, the patient is capable at both the times i.e., when approving the medical treatment and while receiving the meical treatment (or sometimes before receiving it, as in the case of surgery needing general anesthesia). However, case reports of advance directives vary from situation to situation and ailment to ailment. A skilled patient finishes a directive that guides them to apply only when they are incompetent in future times (Nys, 2013).

Appreciation for patient independence is established from a moment in time to a future where there is no more competence. (The authority to design advance directives may be more specifically conceptualized, but it does not have to be enumerated for our purposes). Several questions about advance guidelines mean that their jurisdiction should be limited and that they should often be disregarded. One such question is that the conditions in which the directive is applicable are sometimes not well understood so that the current decision related right to be questioned. This is known as the dilemma of being someone else (Nys, 2013). The Advance Directives on behalf of once competent patients are widely recognized as a clinical to these conditions is not well-informed. Suppose a 50-years old finishes a directive that allows the preservation of life if he gets demented, a choice centered on the expectation he has that he will despise such a life. 10 years later after being moderately demented, he is optimistic at times and does not want to die. The current directive is deprived of the meager capacity of the 50 years old person to know what being demented would mean (Dubois et al., 2007). Another problem with the application of advance directives includes significant changes in the principles and priorities of the agent between both the time a directive is

completed and the date of application. In general, an existing directive may be repealed and another that best expresses the current objectives can be issued.

Though, people may fail to do so because of timescales, delays, clumsiness, or lack of motivation. Suppose someone intellectual finalizes a directive for life support for dementia to be withheld, for it considers the life to be degrading. But shortly thereafter his wife passes away and in the grief, he draws first reassurance and solace from religion first time in life. His global vision varies considerably and, regardless of its academic content, he appreciates all human lives. He's mildly demented a few years back. His advance care directive seems to conflict with the most recent value system he had (or still retains, insofar as someone in his state may be considered to also have a system of values (Porteri, 2018). An advance care directive obliges the agent to design its principles under different potential future conditions.

Two main forms that the prediction may be insufficient demonstrate the questions which have just been described: The life of an individual will alter or change such that he cannot expect or understand it entirely. However, the next issue is a much more drastic transition. The "issue of being someone else" is generally raised in conjunction with dementia, (DeGrazia, 2005) so a short explanation of the condition will be useful.

Dementia

Dementia is a common term that refers to certain symptoms of cognitive decline. Alzheimer's disease is the most prevalent form of dementia. Today, there are over 46 million dementia sufferers around the world. It is expected that by 2050 this figure will rise to 131.5 million (Prince et al., 2019). Alzheimer's disease (AD) is a degenerative neurological, chronic, and extremely disabled disease and currently does not have adequate medications. The world's population is expected to grow exponentially by about 50 million individuals now afflicted by AD and other types of dementia as the lifetime expectations of the population increases with age-related disorders (Prince et al., 2013). Dementia is among the main reasons for disability and dependence for elderly persons globally. It causes immense pain in the demented individual and his family, and it is believed to become an enormous burden on their carers and communities, and the whole of society. Through publishing new Alzheimer's diagnosis criteria, which are centered on biomarker information (Albert et al., 2011) the opportunity to make a mild cognitive impairment (MCI) or pre-dementia/prodromal diagnosis is becoming real, while biomarkers in people who are asymptomatic or with mild symptoms are not yet verified, they can only be used in research environments. This calls for more treatment for the already daunting job(Gauthier, Leuzy, Racine, & RosaNeto,2013). Clear and loyal contact to the client about the testing nature of the exams and the diagnostic

confusion is of great importance. In addition to the communication of the extent and type and nature of the additional value of the testing which refers towards the possible rise in diagnostic accuracy and to the possible benefits of the results received. In context with prodromal AD, these advantages could be greater if people themselves can take the appropriate decisions and prepare for their future that when the mental decline takes place (Prince et al., 2013). In contrast, a considerable amount of individuals are still undiagnosed with dementia and are also in the advanced disease phase before diagnosis occurs. A large group of individuals is therefore not considered competent to complete the advance directives at the initial referral to specialist services (Fazel, Hope, & Jacoby, 1999).

Experiments on advanced interventions or other preventive measures are currently in progress or are in the planning stages (Carrillo et al., 2013). Furthermore, according to the findings of recent research, a multi-dimensional intervention could preserve cognitive functioning and decrease cognitive loss in older people with an increased likelihood of developing disorder, in the general populace (Ngandu et al., 2015). This indicates positive findings on the prospect of prevention against cognitive disability that need to be tested further (Porteri, 2018). However, currently, there are no suitable therapies for Alzheimer's disease or other forms of dementia. Hence, in this sense, one of the key benefits of early detection of the disorder is the ability to prepare for the future (Mattsson, Brax, & Zetterberg, 2010). Therefore, this needs to be a real option for the patients who receive the diagnosis and are still willing to engage in decision-making practices; clinicians should promptly address the problem after the diagnostic results have been declared (Burlá, Rego, & Nunes, 2014). The legislative framework and implementation status of advance directives varies from country to country and is determined by the socio-cultural background of the community, which at times makes it difficult to pass legislation. Nevertheless, advance directives are widely regarded as a useful method for coordinating medical treatment in cases in which the subjects become mentally incapacitated. It is, however, an issue of debate in academia, and multiple scholars have challenged the importance of advance directives in context to dementia patients, and have raised arguments like personal identity, autonomy, and the shifting desires of an individual before and after the development of disease. (Porteri, 2018)

The issue of personal identity

Scholars who respond to the statement of individual identity (Dresser, 1990) challenged the importance of advance care directives during dementia. Self-identity claim

suggests that as people with dementia become inept, they will be a separate person because the previous person (the person who they were) no longer exists. In this case, for the simple explanation, one individual is not morally authorized to make a care decision for another person, hence the earlier orders cannot apply to the person that he/she is becoming. As Derek Parfit (1984) believes, psychological consistency will, with time, be a required necessity for individual identification. Patients with dementia will experience such serious and irreversible harm that they are not the same individual anymore (Parfit,1984). The vivid analysis of the personal identity of serious dementia patients demonstrates how theoretically interesting this viewpoint is. It seems, though, that there is no real ground, where, on the opposite, it will have rather dangerous implications

In reality, people fear learning that they are about to die much more than being diagnosed with dementia, and they are concerned about their potential future in advanced stages of the disease, rather than of the future of a new individual. Expected alteration in personality, beliefs, and preferences as a result of the disorder are feared precisely because people assume that this shift will affect them, rather than giving rise to a completely different individual. Friends and families of the patients are also in the same boat. The statement that "Dad is no more dad" is merely a tragic metaphor for how difficult it is for a family to cope with the adverse symptoms of the disorder. Individual with dementia is still a parent, a companion, a sibling, a child, or a friend to someone, regardless of his/her stage of the disorder or the level of disease progression. Friends and family members believe they owe them and try to fulfill their responsibilities and commitments towards them not due to the societal pressures, but also because they look at the patient the same way they used to, before the onset of the disorder. Another evidence in support of the continuity of personal identity is that the patients' creativity and artistic skills are preserved until the onset of late stages of the disorder, despite the development of cognitive deficits (Crutch & Rossor, 2006). Aside from not aligning with patients' and families' daily lives, the discontinuity viewpoint will have some intriguing practical implications. According to Robert Olick (2001), the acceptance of this approach, would necessitate a massive change in significant social, religious, and cultural norms, traditions, and principles. He furthers his discussion on the subject, by bringing the identity argument to its logical conclusion: if the earlier individual is no longer alive when serious dementia strikes, he/she should be considered newly deceased (dead). This separates the death of the individual from the "death of the body", raising questions about what kind of bereavement is appropriate in this situation, how legislative framework regarding family law

should be re-structured to state clearly that the deceased person's family is not the same as the new person's family, and how insurance policies concerning both, health and life should be modified to adhere to the new explanation of death. When compared to any psychological continuity norm, bodily identity or the presumption that the continuity of body is sufficient for the identity of the person has a lot of benefits as a standard for same-person identity (Porteri, 2018). This suggests that the bodily continuity is better aligned with an individual's real-life and has numerous practical socio-political implications. Furthermore, considering the bodily continuity of the patient, and thereby considering the individual with dementia being the same individual, better ensures that the individual's interests and welfare are respected both before and after he is regarded as incompetent. Most importantly, it protects the incompetent individual's biographical rights (even if the person is at a stage where he/she is unable to acknowledge it), substantive relations (whose underpinnings can be traced back to the past experiences and are still recognized by friends and family), and social inclusion (which is preserved by loved ones), and personal interests (Nys, 2013).

The issue of Conflicting Interests

Presenting the perspective that an individual with dementia is not a different person does not resolve the problem of the conflicting interests of the patient before and after the onset of later stages of dementia. To elaborate this, the well-known case study of Mrs. Margo as mentioned by Firlik can be used. She is content with her life and appears to live a normal life despite severe dementia (Firlik, 1991). Now according to Dworkin's point of view (Dworkin, 2011)., Margo, when completely healthy, signed a written agreement stating that if she develops Alzheimer's disease, she would not be treated and can even be killed if she contracts any other severe disease. Under such a situation of competing interests, one might reasonably wonder whether the current interests of the patient should take precedence over the prior agreement, and advance directives that she signed should be ignored. Dresser (1995) advocates the standard for the best interest of the patient at present; it requires a comprehensive evaluation of the overall current interests of the incompetent patient: in her opinion, it makes no sense to assert which issues like body integrity and privacy, (all of which are the core components for the wellness of the normal competent individual) may impact the prosperity of the patient suffering from advanced mental disabilities. This implies that upholding the previous health and treatment directives can cause substantial harm to the incompetent patient (Porteri, 2018).

Margo's current and previous concerns, on the other hand, are defined by Dworkin (2011) as experiential rather than critical. Critical interests, as per his opinion, are the ones that give our lives direction and meaning; these are second-order interests and hold much more significance for an individual as compared to the experiential ones. Thus, according to this viewpoint, Advance Directives that safeguard a person's vital interests should be respected. Although the argument that people want to enjoy a cohesive life and be compliant with their principles and beliefs before they die has been called into question (Dresser,1995), Porteri (2018) asserts that the fulfillment of an advance directive is evidence that this claim is valid for an individual who wrote it. Although there can be some justifications for prioritizing experiential interests during the lack of a patient's explicit indication, the individual's preference for vital interests specified in an advance directive must be respected.

Revocation of the Directive

According to a study by Schmidhuber and his colleagues (2017), patients and their carers who used the advance directives highlighted three major reasons for it, self-determination at time of making decision, avoiding miserable treatments during advanced stages of the disease,and a sense of preserving self-determination till the time of death. While those patients who didn't use the instrument reported that they never considered it as an option, in fact, never gave it a thought (Schmidhuber et al., 2017). While the patients and carers are well aware that advance directives are legally binding, only a small proportion is aware of the fact that the patients have the right to revoke the document (Schmidhuber et al., 2017). However, there are numerous issues related to the application of revocation, for instance, till when the demented patient's revocation is acceptable, who else has the right to claim revocation, which expressions of the patient are enough, and is the patient autonomous enough to revoke the directive, etc. The literature lacks clear answers to these questions. Sometimes, patients with dementia do experience clear cognitive moments. If they repeatedly express the need for revocation during these moments, it should be considered. However, scholars argue if verbal revocation is necessary or gestures and expressions can also be taken into consideration (Coggon, 2018). Mostly, at later stages only gestures are possible. Where some scholars assert that the expressions are equally acceptable (Dabrock, 2007). others argue that non-verbal expressions are a symbol of lack of autonomy and are merely “vegetative life signs” (Ethics Council, 2012). Thus, it is crucial to decide on a case-to-case

basis, and all the key stakeholders (clinicians, family, and caregivers) should collectively make the decision. If situation is completely vague, an “when in doubt, favor life” approach should be adopted (Schmidhuber et al., 2017). However, this does not means that the directive should not be implemented, in fact, it suggest a careful examination of the situation before disregarding the patient’s desires. Moreover, this necessitates clear policy guidelines to make advance directives known and efficient, specifically in regards to the increased likelihood of an early diagnosis of dementia combined with the lack of treatment options. While various states have devised their own set of rules, the family practitioner should play an important role in urging people to use this tool at an early stage of the disorder, advising and raising awareness among people on how to properly execute a directive, and ensuring its consistent revision and accessibility at any stage and in any form of treatment (Spoelhof & Elliott, 2012).

Issues of Implementation

The undeniable moral significance of these directives for demented patients, as well as their right to have their orders implemented, does not resolve all the differences of opinion on the matter. The gradual deterioration of the patient's illness over a spectrum ranging from no to mild, followed by severe symptoms makes it hard to determine the appropriate time to enforce the directive to prevent either a too late or a too early implementation. The proponents of the "new person" concept will also consider honoring the directive in the situation where a patient bodily functioning is maintained but he is no longer conscious since there is no "new person" with "real interests" to contend with the previous person in this condition. However, implementing the patient's directive at this point of the illness will almost certainly be too late to honor his/her wishes (Porteri, 2018). From a legal perspective, determining an individual's competence is a matter of establishing a balance between two competing rights. It is necessary to establish a reasonable balance between the right of autonomy and the right to safety to inhibit a rash decision due to potential incompetence. Since determining an individual's incompetence is not a simple task, various aspects of incompetency should be taken into account through careful consideration. Competence should not be confused with complete rationality. Everyone has the freedom to take an irrational or bizarre decision. Thus, the various methods used for assessing competence are just tools to aid in understanding the ability of the individual in question. The evaluation is a

clinical decision. This implies that competence evaluations should only be done by people who have specialized knowledge in this field (Nys, 2013).

In conclusion, to efficiently address the issue of individual autonomy, we must begin to address how to manage the desires of patients in advanced stages of dementia, despite the legal and moral complexities of the problem. The tool of "advance directives" makes the tacit presumption that anticipating one's treatment desires under various ailments in the far future is possible (precedent autonomy). However, individual attitudes in this regard may not possibly be the best; they may be founded on incomplete knowledge and biased, particularly when social prejudices are prevalent (like in dementia). Thus, for patients with dementia, Advance directives should be focused on circumstances that realistically portray the patient's viewpoint, along with the likelihood of having positive feelings during the condition. Promoting and honoring advance directives in demented patients neither contradict their complete dignity nor the social and personal responsibilities towards others. On the other hand, denying patients the ability to implement an advance directive or failing to honor the directive would be an inappropriate form of discrimination against demented individuals.

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