

Are Physicians best Decision makers for Unrepresented Patients?

One of the moral principles that is important in bioethics and end of life decisions is the principle of autonomy. This principle implies the right of a patient to choose his own treatment and this right is not lost even when the patient is unable to make decisions for himself. Because of this, there are legal instruments devised to help in making these decisions when one is incapacitated to make them. Respect for patient's rights made it necessary to consider the values and best interest of every individual concerning the person's medical treatment. It is therefore very important for individuals to make end of life decisions, which entails having an advance directive or Physician Orders for Life Sustaining Treatments (POLST) where one outlines in clear terms what one would like to happen at this critical period of his life. In advance directives, the patient puts in writing his wishes about medical treatment that he would want to be provided at the end of life. Nevertheless, where this is not the case, what happens? When there is no advance directive or POLST, the necessity of having a surrogate decision maker arises. In some states in the U.S, surrogate decision makers have been designated in this order, first the spouse, followed by adult children, parents, siblings, and often other relatives and friends (Pope, 2013). However, there are circumstances in which these steps are not taken and no surrogate decision maker is appointed, no family to share his preferences, and the patient is incapacitated to make any decision for himself or herself; the question is; what happens in this situation? Who makes the decision for medical treatment for this group of people?

It has been observed that health care professionals encounter difficulty in making treatment decisions for this group of people called the "unrepresented patients" These patients have sometimes been identified as 'unbefriended', or for older individuals called 'elder

orphans'(Kinlaw, 2017) 'patients alone', 'solo citizens', patient without surrogate decision makers, patients without proxies(Pope, 2013). These terms seem to stigmatize unnecessarily these individuals. I prefer to use the term 'Unrepresented' in this paper because I think it sounds more dignifying than the other terms.

In the paper, I will argue against the position that the clinicians are better decision makers for the unrepresented patients. Despite the fact that clinicians may be close to the patient, many factors militate against their competency in knowing the patient's preferences and best interest and therefore cannot be best decision makers. I will point out some of these factors and examine critically why they cannot carry out this role as required, suggesting other alternative mechanisms, such as guardians and ethics committees that can act as decision makers. I will also point out the inadequacies of these mechanisms, favoring ethics committees as a better mechanism that can effectively make decisions than the treating physician or clinician. In the usage of terms, I will use both clinicians and physicians interchangeably.

Who are the Unrepresented?

These unrepresented persons include the elderly, homeless, mentally disabled, or socially alienated and those for whom potential decision makers are remote (Pope, 2013). "These patients have lost the capacity to make their own decisions and no longer have anyone to make decisions for them. There is no existence of family members or next of kin and no one else recognized by the state law as having the right to represent the patient's preferences. Generally, these individuals have no advance directives, and if at all it exists, it does not provide information that is specific and clear enough to guide medical teams treating the patient"(Kinlaw, 2017). These people are vulnerable and their number seems to be increasing (Pope, 2013). They are often alone, and estranged from family, neglected and abused, and are at risk of receiving

inappropriate medical treatment. They may be subject to overtreatment, under treatment or treatment that does not reflect their values or address their well-being (Karp & Wood, 2003). “Experts estimate that 3 to 4% of the 1.3 million people living in U.S. nursing homes and 5% of the 500,000 per year who die in intensive care units are unrepresented”(Pope,2013). Demographic data show trends that have escalated the urgency of the problem. The elderly population is increasing, the number of individuals with dementia is growing, and a high percentage of nursing home residents have some degree of cognitive impairment. There is a substantial number of incapacitated individuals, who have no willing and available relatives or friends, and are in need of guardians and other surrogate decision makers (Karp & Wood, 2003).

Some guidelines to follow in making decisions for these patients rely initially on “exhausting all efforts to discover surrogates, identifying friends or community members who could provide information on the patient’s life before hospitalization. It could also involve reviewing any prior contacts with the medical community during which the patient may have discussed preferences regarding medical intervention” (Courtwright & Rubin, 2016). However, many times no solution is found, and no matter how much effort is spent, it does not yield result, which leads back to seeking for a surrogate. Therefore, the problem of who can consent to treatment and make decisions on behalf of these unrepresented patients continues to endure.

Are Physicians better Decision Makers?

Many ethicists have made various suggestions on who is best to be a surrogate decision maker for these unrepresented patients. Many, such as Courtwright and Rubin, have proposed that the treating physicians are in the best position to make treatment decisions for the unrepresented patients. (Courtwright & Rubin, 2016) They argued that physicians know the patient well, as well as know what is in the patient’s best interest. Physicians will better appreciate “the risks,

benefits and alternative of various treatment options. They can also make quick decisions” (Pope, 2013). For these people the clinicians understand “disease, therapies, and their expected outcomes of treatment. All these are essential to sound medical treatment. The clinicians are held in high esteem by society, and they have strong professional obligation to act for the benefit of the patient. They can also make decisions in a timely fashion” (Pope, 2013).

The over-riding principle that protects medical decisions on behalf of the unrepresented patients is the best interest standard. The implication of this principle is that whoever is making a decision for the unrepresented must have the aim of doing what is best for the patient. As already noted above, many people are of the view that physicians or clinicians know the best interest of the patient and therefore are best to make medical decisions for the unrepresented. This seems to be the norm; “although numerous approaches to decision making for unrepresented patients have been proposed during the last 2 decades- including ethics committee oversight, appointment of a hospital based advocate as surrogate, or use of a lay member of ethics committee – the dominant approach remains the “clinician as decision maker” model (White et al, 2012).

Even though this seems to be accepted, we are going to point out the challenges posed by allowing the physician as the decision maker for the unrepresented; as Pope explained, “Their responsiveness and expertise notwithstanding, physicians often do not make good surrogates”(Pope, 2013)

Arguments against Clinicians as the best decision makers: One of the arguments why Clinicians are not regarded as best in making decision for the unrepresented is that they may sometimes have conflict of interest and competing obligations(White et al, 2012) This happens when the clinician has 2 or more valid professional responsibilities that conflict. Clinicians have ethical commitments to the patients and to the society to manage resources in a cost conscious

manner. The clinician has to give the patient the best treatment as well as manage the resources of the state. The clinician is spared of this conflict when a family member of the patient makes the decision. However, the unrepresented has no family member and therefore the problem persists. The physician will have a hard time of satisfying two masters and there are occasions when this may not be possible. (White et. al, 2012)

The clinician as a surrogate for the unrepresented will bring conflicts of interest and biases related to disability, race, religion and culture. The clinician may have the problem of acting against his religion or culture. There is a possibility of trying to pay more attention or acting favorably to people of similar culture with him and acting with bias towards people of other cultures or race. This can lead to overtreatment or under treatment. Robert Veatch suggests, “Physicians may have systematic biases inclining them toward certain decisions that may be contrary to the patient’s real interest” (Veatch, 2003). A conflict may arise if for example, a clinician may have a personal religious belief that is against withdrawal of life-sustaining treatment. Some circumstances may arise in which, it is necessary to withdraw life-sustaining treatment regardless of the patient’s preferences. In this case, these conflicts will arise and he may be unable to manage them well.

A good working environment ensures much success and having a good working relationship enhances this success. The staff of the Intensive Care Unit tries to maintain good working relationship. End of life decisions sometimes causes conflicts among staff but the physician will make effort to maintain this cordial relationship with other members of the staff. His decision will tend towards making peace in ICU. He will then have the conflict of making peace and making a decision that will be of best interest to the patient (White et. at, 2012).

Making a decision to either continue treatment or withdraw it for the unrepresented is a complex and difficult process, which involves social, ethical, legal as well as medical considerations. The clinician cannot possess the expertise in these fields and therefore may not be able to make sound decision in such a situation. Decisions to cease life-sustaining treatment for a patient is value based, rather than biomedical ones (White et.al, 2012). Buchanan and Brock point out that physician acting as a principal decision maker for the incompetent patient is an overestimation of the knowledge that physicians usually have of their patient's interests and values. There is also the confusion between medical judgements, which the physician special training qualifies him to make and moral decisions for which he possesses no special credentials to make (Buchanan & Brock, 1990). Explaining further, "the judgement that an individual in the advanced stages of Alzheimer's disease is in a persistent vegetative state is a medical judgement expressing a prognosis. The judgement that a patient who is in a vegetative state may be allowed to die is not a medical but a rather a moral judgement" (Buchanan & Brock 1990). In the same way, Robert Veatch criticized this tendency to view physicians as experts on complex value based judgements simply because of their scientific training. He argued that there is no relationship between physician's expertise on scientific questions and their expertise on social and ethical questions. (Veatch, 1973)

Many unrepresented patients are homeless and are mostly on the margins of society. They are also vulnerable members of the public. Because of this situation, the physician may not consider so much about the patient's value and preferences. In addition, as White et al. point out, given the circumstances, the decisions of the physician may no longer be trusted, and there are doubts about the transparency of such a decisions (White et. al, 2012). There is lack of confidence in the physician's ability to give effective decisions.

Following the arguments of Pope and White, et al, that the physician will have not only bias but also conflict of interest, the physician also has the tendency to give different treatments according his personal characteristics than preference of the patient. (White et al, 2013)

I am of the view, that physicians cannot be the best to make decision for the unrepresented, but they can be involved as part of other effective mechanisms that can make unbiased decisions for the unrepresented. We have to examine other mechanisms and see their merits in providing effective and better decisions than the physicians.

A look at other Mechanisms: Guardians:

When all other avenues for resolving the need for surrogate decision making fail, the unrepresented patient may be referred to a legally appointed guardian who will make decisions on his behalf (Pope, 2013). Cohen et al, share this same view when they explain, “For some incapacitated person, health care decisions are made by a *guardian*, or conservator of persons – a surrogate decision maker appointed by a judge”(Cohen et al, 2015). In many instances, the guardian is an organization or a paid official with no knowledge of the patient prior to the appointment (Cohen et al, 2015). Using guardians as decision makers for the unrepresented patients is filled with many challenges and criticisms. There have been criticisms that “the judicial process is too slow and cumbersome relative to the need of treatment decisions, it is expensive, and guardians often lack time, given the heavy caseload, to learn about the patient. The judicial process is hampered by inadequate budgets and the guardians are widely considered unsuitable for timely health care decisions” (Pope, 2013). Because they have no prior relationship with the individual they represent, it will be difficult for a professional guardian to make a treatment decision that will reflect a patient’s value and preferences (Cohen et al, 2015).

The guardians, because they are not trained in medical field may also find it difficult to make effective decisions on medical intervention of the unrepresented patient.

Studies have shown that there is variety of ideas about what guardians should do and should not do in many states. Because of this it is very difficult for physicians to work effectively with guardians to ensure that high quality end of life decisions are made. Therefore, we can argue that considering the relationship between guardian and physician, standard of treatment cannot be left solely on legislative or judicial process (Cohen et al, 2015).

To mitigate this problem encountered in using guardian as a surrogate decision maker, a non-profit legal advocacy group in the state of Indiana now trains volunteers made up of social workers, lawyers, retired nurses, medical and law students to serve as guardians who make health care decisions for the unrepresented. These volunteers follow the patients for some time trying to learn more about their values and preferences. They have now taken many cases but the demand for their services is outpacing the ability to recruit and train them (Bandy et al, 2014, Span, 2015). What this means is that the need for them is enormous. They have their hands full and that is why making decisions for the unrepresented by the guardians take so long.

We have seen that this approach of making decisions through guardians cannot guarantee a better alternative to physicians even when they work together. It has many limitations and more challenges. Therefore I will examine another alternative which I argue in this paper should be better than the first two mechanisms and this alternative is the ethics committee.

Consideration for Ethics Committees: Some hospitals and nursing homes have ethics committee. Drawing from the argument of Pope he says, “We must strike an appropriate balance

between a decision maker who is responsive and can make timely decisions and a decision maker who is independent from the treating clinicians. Occupying this middle ground I would argue is the ethics committee” (Pope, 2013). This paper therefore follows Pope in arguing in favor of ethics committees in different institutions serving as a better alternative to the other mechanisms as outlined above. I will examine the ethics committee, see what challenges, and shortfalls it has in being a better alternative in making decisions for the unrepresented.

In the practice of modern medicine, many problematic issues continue to arise from medical, legal, and ethical directions. Therefore, physicians and healthcare professionals make effort in solving these issues. Because of the importance and sensitivity of health care, as well as the pluralistic nature of our modern society, they face many contrary opinions expressed by patients and their families. The healthcare providers and physician have expertise in the medical field but sometimes do not have the vast knowledge to tackle ethical and legal issues. Because of the complexity of these issues, there is need for having some knowledge in ethical and legal matters, therefore the need for ethics committee.

The highly publicized cases of Karen Quinlan (1976) the baby Doe (1980) and Nancy Cruzan (1990) gave rise to the development of ethics committee in the United States (Ausilio & Arnold, 2008). Mclean says “Hospitals ethics committee and ethics consultants feature in many US hospitals and perform variety of roles” (Mclean, 2007). Pope highlights the composition of ethics committee as “at least a physician, a nurse, a social worker, a bioethicist and a community member” (Pope, 2013). The ethics committees therefore help in taking care of the ethical issues in health institutions. “Ethics committees can be helpful to clinicians in addressing value conflict or uncertainty as it arises in their practices primarily through a threefold function of ethics education, policy formation and review, and ethics consultations”(Ausilio & Arnold, 2008). The

ethics committee is in the best position to clear ethical conflicts arising from treatment options for the unrepresented patients as well as making suggesting of the best way to go. “The interdisciplinary, collaborative, and deliberative nature of a facility ethics committee provides a setting where physicians can engage with other professionals and involved persons to best make an assessment of the trajectory of decline” (White Paper, 2004). Having ethics committee seems to consider the patient’s interest than all other mechanisms we have treated. Being a committee made up of many people most probably from different cultures as well as backgrounds, limits the issue of bias and conflict of interest. The members of ethics committee also take confidentiality oaths, which instills trust to their decisions. The composition of the ethics committee gives it more solidity such that the basic Christian principles of charity and love of neighbor becomes a guide in their decisions.

The nature of ethics committee makes it look abstract and idealistic that it seems to make irrelevant the patient physician relationship that is, highly valued in medical practice. Also having ethics committee do not allow imputing responsibility to a case, it looks as if everybody is in charge where nobody is in charge whereas in the case of a physician, someone is responsible for such a decision. However, these objections are still minimal.

Conclusion:

Kathy Kinlaw observes that “among the complex ethical decisions that clinical team face are treatment decisions for unrepresented patients” (Kinlaw, 2017), and this is because there is nothing to help in knowing the patient’s preferences or values. Many have tried to proffer solution to this complex and problematic issue and I have tried to look at these solutions arguing that physician or clinician taking sole decision for the unrepresented does not represent a good solution. With the many criticism of guardianship, we cannot rely on such solution concerning

giving adequate health care. However, I have favored ethics committee, which many hospitals in the United States employ presently to solve these end of life ethical issues. It is more encompassing, holistic, and seems to be more objective in dealing with unrepresented patients. The physicians should also be involved by accepting recommendations. As Pope recommends, “clearly, we need a decision making process that is not only accessible, quick, convenient, and cost effective but also provides the important safeguards of expertise, neutrality, and careful deliberation”(Pope, 2013). I think ethics committee fits this bill.

Even though all these mechanisms have been outlined and have been in use in health institutions in many states, they do not guarantee a satisfactory and effective decision making process that seems to take care of the unrepresented patient. Therefore, more need to be done to prevent people from falling into the group of ‘unrepresented’. It is better to manage the cause than the effects, to heal from the root. There is need for advance care planning, seeking for family members or friends who may know the patient before he becomes incapable of making his own decision. More efforts should be made in eradicating the social ills like the excessive use of alcohol and drugs, employers paying just wages, government and agencies providing good housing opportunities such as low cost buildings to eradicate the problem of homelessness.

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