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Asymmetries of Patient Autonomy and Paternalism

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It has been questioned whether it is morally acceptable for a husband or son [the closest family members] to be permitted to convince a terminally ill patient, an 83-year-old woman, contrary to her initial will, to continue to receive intensive but “futile” therapy. This implies another question: whether by this act of persuasion, the patient’s autonomy is being seriously violated. We think that reviving the motivation to continue to live is not necessarily violating a person’s autonomy, even if the objective quality of life would be unsatisfactory and that such an act also cannot be characterized as a restriction of a person’s autonomy. Here it is maintained that there is an important asymmetry in the meaning of the principle of autonomy and of paternalism: while being quite permissive, when applied in cases of an eventual decision in favour of life, they are quite limited when applied as principles of conduct for decisions concerning the termination of life. The emotional concerns of some other actors in the patients close emotional circle [family members], could also be important for such decisions, if they had played an important role in the development of the patient’s ethical and moral motives and attitudes during his/her lifetime. It would be similarly appropriate for psychologists and social psychiatrists to devote intensive attention to this question. If the latter failed to reach a rational decision, then it must be accepted that the “pro vita” decision cannot be refuted and that probably some forms of encouragement to accept advanced forms of life maintenance should be offered to the patients by those who are within her/his close emotional circle.

Keywords: Terminal care; End-of-life; Futile care; Palliative care; Elderly; Paternalism; Autonomy

Background

In a short “perspectives” paper entitled “Fighting on,” Dr. Drazen and colleagues ask whether it is morally acceptable that the husband and son [the closest family members] convince a terminally ill patient, an 83-year-old woman, to continue to receive intensive, but “futile,” therapy against her initial will [1]. This implies another question: whether by this act of persuasion, the patient’s autonomy is being seriously violated? We think that reviving the motivation to live is not necessarily violating a person’s autonomy, even if the objective quality of life would be unsatisfactory and that such an act cannot be characterised as restricting a person’s autonomy. Indeed, it is sometimes extremely difficult to recognise moral motives essential for accurately applying the principle of autonomy and the principle of paternalism [2].

In the case cited above, the decision not to stop futile therapy was influenced by the family of the patient and it may appear that the patient’s autonomy was not “respected”. The patient, after previously declaring that she had wanted to stop her therapy, succumbed to the insistence of her son to continue with apparently futile therapy, to live for another 3 months. We believe that the authors [1] considered the issue with sufficient depth and that their uncertainty concerning whether they were mistaken in their handling of this difficult case, is inherent to this very complex situation involving a difficult moral decision.

To explain the dilemma of the authors, let us start from a simplified example and pose a quite common sense question: Do mothers not often say, and very often really mean, that they live only for their children? Why should the decision of a mother to live a couple of days or months longer because her son wanted to have her alive for as long as possible, not be autonomous? Pure autonomous actions [3-6] and actions free from external influences are probably merely automatic, non-intentional actions and therefore would not qualify as autonomous, conscious actions anyway. It may be that the patient’s decision had been influenced by the son’s egotistical desire that was obviously contrary to

his mother’s wishes and may even be against her interests. We could, if we want, blame the son for not complying with his mother’s desires. Although, the fact that the mother accepted to change her decision may demonstrate that such a decision created new values of life [for a relatively short period], which would have not existed, had the decision to continue therapy and live longer, not been taken.

On the one hand, the mother had the pleasure of living for her son, on the other the son had not only the pleasure of having prolonged his mother’s life, but also to have brought the pleasure to his mother of continuing to live for her son. I believe that the son, had he been asked may have offered a similar explanation. From the point of view of principlism [7,8], such an action on the part of the patient’s son, is justified and the decision of the mother could be approved for similar deontological reasons. A utilitarian would probably also say that such a decision increased the amount of good and that it was justified. The apparent dilemma that ICU physicians may have with such decisions could stem from the quite sophisticated nature of the two essential moral principles that I mentioned in the beginning. The first is the principle of paternalism, the second the principle of autonomy.

Paternalism versus autonomy

The most general definition of paternalism is probably given in the Merriam-Webster dictionary: “a system under which an authority undertakes to supply needs or regulate conduct of those under its control in matters affecting them as individuals as well as in their relations

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to authority and to each other" [9]. Yet, the most frequently used description of paternalism was provided by Dworkin: "Paternalism is the interference of a state or an individual with another person, against their will, and justified by a claim that the person interfered with will be better off or protected from harm" [10]. Indeed, opposition to the patients' will may not always be involved, but rather only an absence of the patients' or persons' consent: "Paternalism" comes from the Latin "pater", meaning to act like a father or to treat another person like a child. ["Parentalism" is a gender-neutral anagram of "paternalism".] In modern philosophy and jurisprudence, it is to act for the good of another person without that person's consent, as parents do for children [11]. The essential feature, irrespective of the definition, is that the paternalistic act is "aimed at" the interests of the protégée.

On the other hand, autonomy seems less controversial. The online Merriam-Webster Dictionary gives again the simpler definition: "the quality or state of being self-governing; especially: the right of self-government" [12]. Yet, autonomy may have many facets and a definition that involves moral concerns may be as follows: Individual autonomy is an idea that is generally understood to refer to the capacity of being one's own person, living one's own life according to reasons and motives taken by oneself and not the product of manipulative or distorting external forces [13]. It seems as though autonomy may often, but not always, be "aimed at" the patient's interests. Both principles leave the interests, toward which they are oriented, undefined.

Asymmetries

It is commonly assumed that the arguments based on autonomy are stronger than those based on paternalism and this is related to our understanding - some aspect of the concept dating back to ancient times - that everyone is a master of her/his own life. There is, however, an important asymmetry of the meaning of autonomy and paternalism: while being quite permissive in regards to their application for eventual decisions in favor of life prolongation, their powers to influence decisions are quite limited, when applied as rules of conduct pointing towards termination of life, for example, in some permissible forms of euthanasia [14]. This common aspect of these rules is often misunderstood.

The most prominent asymmetry will be, when an argument based on autonomy would point to death, while at the same time, an argument based on paternalism would point to life. When a patient has lost all will to continue to live, in spite of a good chance that s/he will profit from therapy, the argument based on paternalism, in spite of being weaker, will still most often obtain. In the example of Drazen et al., we have an exactly contrary argument, where the opinion of the experts was paternalistically pointing to death [and intention to withhold the therapy], but the patient decided [under influence of the relatives] to continue to "fight" and maintain apparently futile therapy, i.e. decided "for life". The fact that the decision was based on autonomy and that it pointed to life, doubled the strength of the argument. The objection was raised as to whether this decision of the patient had been fully autonomous. A powerful counter argument would be needed to prove this to be the case, because the proof would theoretically be in opposition to the expressed desire of the patient and would point to a death decision. In such circumstances, at least theoretically, very strong evidence of violent coercion and very obvious and forceful limitations of the patient's autonomy would have to be presented. Certainly, this could not be demonstrated. We maintain however, that in addition, a number of other motives must also be considered. These would be primarily based on emotions and feelings of obligations towards other close persons, and based in principle on various concerns that the

patient has and which had constituted and are still present in her life. This will be briefly considered below.

We think, therefore, that there is little doubt that when there is explicit and reliable expression of a patient's desire to continue measures prolonging life, even if the quality of life would be judged unsatisfactory, in these cases, we would have to follow the course of therapy, sometimes in spite of the absence of rational medical justifications for such a therapy. Let us turn now to some specific concerns of a patient.

Autonomy: concerns and emotions

It seems that the given situation is not very different from general situations, where we govern our intentions by the motives which are defined by our concerns, which, in turn, could be dynamically dependent upon our interaction with our entourage. Whether life is worth living and how much pleasure we have, depends very much on these relations and cannot be objectively measured. We believe that the concerns of a patient's close relatives who may not even be in a position to express his/her own intentions and unable to be consulted, are also to be respected, at least theoretically. As we argued elsewhere [15], the emotional concerns of some other actors, who may be defined as the close emotional circle of the patient [family members, but possibly not limited to close relatives], are important for such decisions, if, and since, they certainly played an important role in developing the patient's ethical and moral motives and attitudes during his/her lifetime.

People are often motivated by their concerns for their entourage and in particular for their close family. Professor Roger Scruton states: "Life becomes worthwhile through relations with others, in which mutual affection and esteem lift our actions from the realm of appetite and endow them with significance - significance for the others, who observe them and acknowledge them as worthy" [16]. For a mother, it is certainly a valid incentive to continue to "live" if her son expressed such a desire, since the interests of a son would present her with a primary concern sufficient for taking such a decision. Her physicians, no doubt, had informed her of the certainty of an imminent end of life - while obvious "external" influence that interfered with her autonomy in a quite determined way, was already in progress. As a consequence, the initial decision to decline futile therapy contributed to the patient losing all intentional aspects of her mental life, finding herself deprived of all concerns. The expression of the concerns of her son obviously led to the renewal of her essential concerns for members of her family [and her caring about their concerns] and permitting a re-establishment of the previously lost intentional aspects of her mental life, thereby rendering her life worth living.

We could pose the same question again, for the sake of argument and with the scope to bring more clarity: was it morally wrong to persuade that patient to continue futile therapy? Let us imagine an inverted situation, where one mother insisted on futile therapy while her son persuaded her [successfully] to give up therapy. Would the patient's autonomy be respected if this were to happen? I presume that a number of practicing physicians would respond negatively, illustrating the asymmetry of the application of the principle of autonomy and of paternalism with respect to the possible outcomes.

It appears that we tend to judge the acceptability of the influence of the patient's entourage according to what we consider desirable, neglecting thereby the importance of their emotional circles [17-19]. This could be seen in situations where someone wants to continue to live when "we" judge life not worth living, or when someone desires to die, when "we" believe that it would be rational to continue to live. We often try to objectively determine other people's value of life,

and this is probably wrong. Yet, whether we could know what would be “objective” in such circumstances is far from being clear and has been challenged [20,21]. Indeed the recent study [22] is explicit. The subjective experienced quality of life of heavily handicapped people, suffering from amyotrophic lateral sclerosis, is comparable to that of healthy people. As stated in the editorial in the same issue [23], the life shortening measures for patients with similar presumed sufferings, should no longer be rationalized as a “relief from suffering”. The will to live is a valuable target that obtains and is not to be suppressed by the pressure from economic interests of the society. A patient may be compliant to such demands and such a choice may not be the expression of her/his autonomy. These examples further demonstrate the higher degree of permissiveness in favour of exercising autonomy and greater reserve, in cases of applying paternalism in situations, where it could be more plausible to promote decisions aimed at life termination.

Therefore, the most important and easy to remember would be that the principle of autonomy and paternalism, in addition to how they are commonly understood [2,3,8,24], contain important asymmetries and are both more useful when opposing the tendencies toward terminating life, than when they are applied, maybe quite exceptionally, when opposing some tendencies toward prolonging life. The flagrant example is the Italian case that caused a bitter reaction from the Italian President [25]. These situations need intensive attention of psychologists and social psychiatrists. If the latter fail to reach a rational decision other than to recommend life maintenance, then it must be accepted that the “pro vita” decision cannot be refuted by rational argument.

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