

RESPECT FOR HUMAN DIGNITY IN REHABILITATION MEDICINE*

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Summary

Dignity of the human being is a concept that provides a basis for human rights and is a cornerstone of our civilisation. The special value of human life is another basic concept that underlies medicine since the times of Hippocrates. Both of the two concepts continue to enjoy high reputation and have been used as the foundation principles for important international legal and ethical instruments, such as the Universal declaration on human rights of the United Nations (1948) and the Convention on human rights and biomedicine of the Council of Europe (1997). Unfortunately, these two concepts have recently been seriously challenged. According to some practical ethicists, human dignity as a reason for protection should only be accorded to conscious human persons capable of judgement. Similarly, the notion of special value and sanctity of human life should be abandoned. Medicine, and perhaps particularly rehabilitation medicine could undergo great changes if these, presently controversial views of utilitarian ethicists become widely accepted in the society. Chronically ill and disabled persons would be first to feel the adverse changes in public perception of the traditional values. Healthy people would follow.

Povzetek

Dostojanstvo človeškega bitja je koncept, ki predstavlja temelj človekovih pravic in je osnovni gradnik naše civilizacije. Posebna vrednost človeškega življenja je drugi temeljni koncept, ki je podlaga medicini od časov Hipokrata naprej. Oba koncepta imata še vedno velik ugled in sta bila izhodišči za pomembne mednarodne pravne in etične instrumente, kot sta Univerzalna deklaracija o človekovih pravicah Združenih narodov iz leta 1948 in Konvencija o človekovih pravicah v zvezi z biomedicino Sveta Evrope (1997). Žal sta bila oba koncepta v zadnjih časih ostro kritizirana. Po mnenju nekaterih praktičnih etikov bi smeli priznati dostojanstvo kot razlog za varstvo samo zavedajočim se, razsojanja sposobnim ljudem. Podobno bi morali opustiti mnenje o posebni vrednosti in svetosti človeškega življenja. Če bodo ti, zasedaj še sporni pogledi utilitarnih etikov v družbi splošno sprejeti, bo to verjetno hudo spremenilo medicino in posebno rehabilitacijo. Kronični bolniki in invalidi bodo prvi občutili neugodno spremenjeno javno dojemanje tradicionalnih vrednot. Sledili jim bodo zdravi ljudje.

INTRODUCTION

The title of this symposium may evoke optimistic expectations. Indeed, we have heard about promises of new medical technologies that may radically improve the outlook for many patients for whom there is presently little meaningful treatment or rehabilitation available. However, when such hopes become a reality, there may be problems of affordability, seriously limiting patients' access to the new modalities. Furthermore, some expectations may be quite unrealistic. Public attitude towards health as a value has changed. For many, health has become a goal in itself, while illness or disability has somehow acquired a connotation of a result of the sufferer's own carelessness and personal irresponsibility. Naturally this may have damaging effects upon popular perception of chronically ill and disabled people, as well as their right to societal support.

VALUE OF HUMAN LIFE

Questions about value of human life have repeatedly emerged in the discussions on ethical acceptability of euthanasia and in the heat of increasing public demand for its legalisation. During the last two decades, the discussions periodically flared up, triggered by individual tragic cases or by changes in domestic law of certain countries. The most recent examples include the cases of Giorgio Welby and Eluana Englaro¹, as well the introduction of act on euthanasia in Luxembourg.² Great Britain rejected two attempts at legalisation of euthanasia or physician assisted suicide. On both occasions, the final decision followed an extensive public debate which brought to light many important arguments (Lord Walton of

¹ Giorgio Welby, suffering from advanced ALS, requested stopping his ventilatory support. Eluana Englaro, a patient in persistent vegetative state, had her artificial feeding and hydration discontinued upon the request of her father. Neither of the two cases can be considered euthanasia.

² In March 2009, after a veto to the law by the Duke of Luxembourg was overruled by a change in Constitution.

* Rehabilitation in future: vision and dreams. Symposium, Ljubljana, April 4, 2009

Detchant, 1995). The Select Committee on Medical Ethics of the House of Lords received many pieces of evidence, some of which concerned different aspects of value of human life. The British Medical Association said that »...doctors are more conscious than most of the enrichment brought to society by people who experience disability or suffering... Life should be cherished and no individual should be seen as any less valuable because of physical or mental impairment« (quoted by Lord Walton of Detchant, 1995).

RESPECT FOR HUMAN DIGNITY

The concept of human rights is based on the inherent awareness of human dignity, a fundamental moral value. The respect of this value is basic to our civilisation. The present discussion concerns the inborn dignity of the human being as an intrinsic quality, which is independent of the special value attributed to a person by his or her immediate family or broader society - owing to his or her achievements, services and merits in the past, and those expected from him or her in the future. This inborn or intrinsic dignity is independent of any utility measure, and even of the moral standards that the particular individual exercises in his own life. It stands behind the "equal and inalienable rights of all members of the human family" enshrined in the Universal Declaration on Human Rights of the United Nations (1948).

Through the ages of history, the intrinsic dignity of human beings has been differently perceived and has been accorded different degrees of protection. The most recent decades have seen unprecedented universal efforts to increase respect for human rights, enshrine them in legislation and exercise them, without discrimination, in everyday life. Parts of our Western societies have indeed enjoyed this encouraging development and have greatly benefited from it. On the other hand, many unfortunate nations have been and still are suffering as much humiliation, injustice and massive violence as ever experienced by members of the humanity throughout its history. When such a sad statement can be made about a large part of the world's present population, the shadow of shame extends over the humankind as a whole.

It is not surprising that the attitude towards respect for human dignity is reflected in all walks of life. Medicine, although rather special due to its long-standing strong Hippocratic tradition, is no exception. Yet, some ethicists claim that the traditional paternalistic doctor to patient relationship does not conform to the full respect of human dignity.

THE CONCEPT OF DIGNITY IS CHALLENGED

The concept of human dignity, taken for granted by generations of philosophers, ethicists and lawyers, and undisputed over many decades of ethical debates, was recently chal-

lenged by some British philosophers. "Human dignity," they say, "is increasingly used as blanket justification for regulatory restraint. This use of human dignity marks a significant departure from the traditional human-rights informed view of human dignity that has dominated bioethics debates for decades. In addition, it stands as dubious justification for policies that are aimed at constraining controversial biotechnologies" (Caulfield and Brownsword, 2006). Furthermore, a contemptuous expression "dignitarian alliance" has been coined, to mark those who "inappropriately" base their ethical arguments on the concept of dignity, in order to more easily manipulate ethical opinion. The dignitarian alliance has presented a range of (problematic) views, among them the principle of sanctity of human life (interpreted broadly so that inter alia, it protects human embryonic and foetal life), the principle that human life should not be commodified (which is interpreted as precluding sex selection, reproductive cloning, saviour siblings and the like), and the principle that the human body should not be commercialised (precluding the sale of human bodies or body parts, prostitution, surrogate motherhood, patenting of normal gene sequences and so on). These principles might be presented by dignitarians as universal. Since the underlying values are not shared by all, in a pluralistic society they should not be used for a regulatory policy (Caulfield and Brownsword, 2006).

When the proposition of ban on human cloning and embryonic stem cell research was discussed in 2002, another commentator asserted that "dignity is a useless concept in medical ethics and can be eliminated without any loss of content" (Maklin, 2003).

Indeed, some ethicists went as far as to suggest that human dignity as a reason for protection should only be accorded to conscious human persons capable of judgement. If this view is accepted it would certainly make some scientists happy and comfortable while working on embryos, cloning human beings, etc. In medical practice, it would allow raising children as tissue and perhaps organ donors, trading in human body parts, physicians performing euthanasia on comatose or minimally conscious patients, etc. In neurology and rehabilitation medicine, it would relax ethical constraints when dealing with mentally handicapped patients.

Julian Savulescu, director of the Oxford Centre for Practical Ethics, while arguing against the exercise of conscientious objection in medicine, insisted that "doctor's conscience has little place in the delivery of modern medical care". Similarly he believes that "value driven medicine" is a door to "Pandora's box of idiosyncratic, intolerant, discriminatory medicine" (Savulescu, 2006). The law and the guidelines should take place of conscience and values. This rather extreme view was published in the British Medical Journal, and it was good to see that it was fiercely opposed in a flood of letters to the editor. Even in Slovenia, a philosopher has recently argued that ethical decisions should be taken out of the hands of the medical profession and entrusted to philosophers (Pribac, 2009).

DIGNITY AS THE BASIS OF THE MORAL STATUS OF THE HUMAN BEING

To many of us, such deliberations are unacceptable. Dignity of the human beings is recognised as moral basis of the status of human life as a value and is actually the basis of human rights. This is stated in the European Convention on human rights (1950) and is reiterated in the Convention of the Council of Europe on human rights and biomedicine, a central ethical instrument in the wider Europe with a power of law (Convention on human rights and dignity of the human being with regard to the application of biology and medicine, the Oviedo Convention, 1997). In other words, it is a fundamental concept which cannot be abandoned without seriously affecting human rights in general and particularly in relation to the practice and research in medicine.

German delegation to the Steering committee on bioethics of the Council of Europe (CDBI) made many quite essential contributions to the Convention on human rights and biomedicine during the drafting stage. Nevertheless, Germany was the only country to abstain in the final voting. Until today, Germany remains one of the few Member States that have not, so far, signed the Convention, and have not even made their first step towards the accession or ratification. Societies of disabled people who oppose research on persons unable to consent seem to present the main obstacles. This unfortunate opposition misses the point. For example, prohibiting the research on children with leukaemia would harm precisely the interests of the children. With such prohibition in place during the last decades, still all children with this disease would die; nowadays, over 80% can be cured. Similarly, progress in treatment of dementia cannot be imagined without research on demented patients. Prohibiting the inclusion of such persons in medical research would mean depriving them, as a group, of potentially significant benefits, possibly even harming the interests of the same persons as individuals.

Yet, it must be acknowledged that societies of disabled people have made some extremely valuable contributions to the societal debate on ethical views upon human life. Among other things, they are opposed to legalisation of euthanasia, one of the tragic errors of our time.

Some so-called practical ethicists suggest that we should abandon the principle of sanctity of life. If this view is widely accepted, it can be expected to affect public perception of seriously ill and disabled persons. – It is not surprising that the same philosophers call for legalisation of euthanasia.

CONCLUSION

To chronically ill and disabled persons, feelings of self-worth, self-esteem and dignity are even more vital than they are to

those in excellent health. For some, this need is closely related to values such as independence, autonomy and privacy. These are values that are in high esteem among the general population of our time. Disease and disability can take much of those values away. To be sure, the immanent dignity of the human being can never be taken away. If this seems to happen, the dignity is actually just disrespected. As mentioned above, the right to dignity has been denied to some categories of mentally handicapped patients by renowned philosophers. According to the controversial utilitarian ethicist Peter Singer the right to dignity should only be accorded to conscious human beings, capable of making choices.

In rehabilitation medicine, acknowledgement of, and respect for the dignity of human being, as well as recognition of the special value of human life will stay at the heart of the profession. It will not always be easy to exercise, especially in the view of the limited human and material resources and the justified requirement for such distribution thereof that will produce maximum benefit. However, abandoning these values would ultimately destroy the humanitarian nature of this noble vocation.

References:

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