

Chapter 12

A Critique of Autonomy and Patient Responsibility

If a desire, or choice, is not based on a rational evaluation then it is not autonomous. [2]

Abstract Autonomy for patients is respect for the rational decision-making, without coercion, of a patient regarding his or her medical care. Autonomy involves the view that the patient has the capacity: 1. to create ideas and goals for life, 2. for moral insight, self-legislation, privacy, 3. for political involvement and personal responsibility. Self-determination, care and responsibility go together, their separation weakens each of them. Unquestioned autonomy is challenged by criticisms of the principle of autonomy: Autonomy can be a way to avoid decision-making, it can be a way for physicians to transfer responsibility such as leaving patients to their autonomy as a form of defensive medicine. From autonomy follows responsibility. Challenging a severely limited autonomy concept we need rational, informed, critical decision making and a consequentialistic, naturalistic theory of ethics.

Keywords Autonomy · criticisms of the principle of autonomy · paternalism · consent · rational choice · self-determination · responsibility · transfer of responsibility · patient code of ethics · patient duties

12.1 Introduction

Autonomy is one of the four principles often given in the literature on bioethics [1–3]. Arras wrote, “Bioethics as a field has tended to enshrine the value of autonomy, it places individual rights above communal well-being” [4]. Daniel Callahan, on retiring as Director of Hastings Center confessed, “Nothing has exasperated me so much as the deference given in bioethics to the principle of autonomy” [5]. Autonomy is often seen as autocracy, which is the centrality of the patient’s interests to the exclusion of all else [6]. “The capacity for and exercise of self-determination can be . . . the fundamental ideal of the person [patient] within medical ethics” [7]. According to the principle of autonomy the patient has the ability and the right to determine his or her own treatment. Some say the ability to be autonomous is the characteristic of

being a person, i.e., of having the rational and psychological abilities, behavior and knowledge of one's own wishes, values and social abilities [8].

What we may call the "word-field" of autonomy can include many things such as the following:

1. The freedom to choose,
2. A total or partial authority,
3. A selfish decision-making,
4. An uninformed to totally wrong decision,
5. An absolutistic, non-holistic, non-consequentialistic decision,
6. A preference rather than an ethical decision because one has not studied ethics,
7. A decision, which disregards all interests of others.
8. Autonomy could be moral, unmoral, immoral, ethical, or unethical.
9. Autonomy could be a form of appeal to authority, even one's own questionable authority. One can suggest an "appeal to autonomy fallacy" just as we have an "appeal to authority fallacy." If one appeals to a physician as an expert, but evaluates the advice given, it is not appeal to authority. To appeal unquestioningly to someone having absolute knowledge, is an appeal to authority. One could appeal to patient autonomy.
10. Autonomy can include personal liberty,
11. Can allow the individual not to be governed by societal or religious dogmas or dictates.
12. Autonomy can mean to exercise individual rights,
13. To consent to suggestions (e.g., therapy, examinations),
14. To reject paternalistic/maternalistic decision-making.
15. Autonomy might also aim at independent decision-making.

Autonomy for patients is respect for the rational decision-making, without coercion, of a patient regarding his or her medical care [This would be the opposite of absolutist positions]. Autonomy involves the view that the patient has the capacity:

1. To create ideas and goals for life,
2. For moral insight, self-legislation, privacy,
3. For political involvement and personal responsibility.

12.2 Criticisms of the Principle of Autonomy

1. The problem of anti-inquiry. People are usually against critical thinking (speaking) as a challenge of what they are enculturated into and with what they feel comfortable and are deliberately anti-inquiry. As argued earlier, most have little interest or education in inquiry, ethical theory and practice, emotions, philosophy, etc. One may be said to have autonomy to the extent that one is qualified to have it. The informed, not the uninformed, patient is necessary for successful medical treatment. "The comprehension by patients of medical information is not outstanding" [9].

We must consider a person's disability to judge (*Unvermögen zu urteilen*) just as we consider the patient's medical disability. Anti-inquiry is anti-medicine. The so-called "autonomy of the patient" means respect for the patient as a rational agent acting freely and not under constraint. Without a background in critical thinking (speaking) and ethics, full autonomy of patients may be put in question.

2. Autonomy can be a way to avoid decision-making, or to give up on decision-making. It is a way for physicians to transfer responsibility [10]. Leaving patients to their autonomy can also be merely a form of defensive medicine on the part of the physician [11].

3. The execution of irrational autonomy can subject the patient and society to harm. Thus, medical drugs and food are regulated by the government to protect people from their own bad choices. One can consent to one's own demise.

4. The patient is often not interested in information and makes decisions without it and irrationally. "*Independent people may be self-centered, selfish, lacking in fellow-feeling or solidarity with others*" [12]. O'Neill says that autonomy can undermine trust, mutual obligation and recommends "principled autonomy," along Kantian lines, in place of "individual autonomy." It may be merely an adversarial claim. It may lead to failure to treat the mentally ill as they have autonomy to refuse treatment. O'Neill argues on a Kantian position that autonomy should be based on principles, which could apply to us all. This is almost what the word "principle" means. But how or whether this principle is one of reason is not clarified. This helps little if one would will that others also act as selfishly as most do. But what it does is to point out some major problems with mere autonomy and suggests that additional rational and ethical considerations must be involved in decision-making. Kilner, similar to O'Neill, holds the view that autonomy is often problematic because of patient's lack of information, lack of understanding, coercion, mental capacity, selfishness, and irresponsibility [13].

In a democratic society all may have an equal vote, but many vote irrationally. Allowing the uncritical and uninformed to have authority and autonomy, where they cannot have it in terms of their qualifications, is actually not to respect them, not to care about them because of disrespect for their welfare. Autonomy undermines the utilitarian view, and can undermine the benefit of other autonomous people as well as society. 14% of adults in the U.S have a below basic reading level (National Assessment of Adult Literacy). In some nations most of the people are illiterate. What value would autonomy have in such a context? Voting also requires an educated populace. A democracy based on an indoctrinated, uncritical and ethically and emotionally uneducated populace cannot yield a humanistic or enlightened government.

According to the Royal College of Obstetricians and Gynecologists the following guidelines should be followed by physicians: "Obstetricians must respect the woman's legal liability to ignore or reject professional advice, even to her own detriment or that of her fetus." "A competent woman, who has the capacity to decide, [may do so] for religious reasons, . . .irrational reasons, or for no reason at all. . .even though the consequence may be death or the serious handicap of the child she bears, or her own death" [14]. In the U.K., and the U.S., a woman may reject

treatment for any, rational or irrational, reason regardless of the consequences, e.g., the death of herself or her child [14]. Patients often make irrational decisions. One needs to deal here as well with emotional and dialogic patient-physician interaction [15]. “If a desire, or choice, is not based on a rational evaluation then it is not autonomous” [16].

Case Example – Autonomy: A pregnant woman in the 35th week of gestation was admitted to the obstetrical ward. She was in much pain especially in the right lower abdomen and so sought help. She was to stay as an in-patient. This was bad news for her and her husband as they had planned the delivery at home when the time was due. Her husband was very nervous and domineering. The routine examinations were performed: vaginal, blood, ultrasound, and cardiotocogram (monitoring of fetal heart beat before birth). An additional ultrasound exam of the kidneys of the pregnant woman was given as well as a urine analysis check for infection. The cause for the pain was not yet determined, but the cardiogram for the fetus indicated that a cesarean section was urgently and immediately necessary to save the life of the child. A conflict arose when the couple would not give consent. In her vulnerable and fearful situation a pregnant woman can be suggestible and find decision-making difficult. This was the case here, as her husband who was fixed on having a natural childbirth at home and also mistrusted the medical system convinced her to refuse the life-saving cesarean. Time to save the fetus had almost run out. The cardiogram results became even more critical. I, her obstetrician, could no longer wait for the fetus to die and at the very last moment convinced her to have the cesarean. As we prepared for the operation the husband aggressively attempted to stop us before the operating theatre by scolding me, and the nurses present. The operation was nevertheless successfully performed. Later the neonatologist on duty informed us that we had saved the child in the very last moment. He also specifically and emphatically stated that to the father. The child was admitted to the neonatal intensive care unit for further treatment, stayed there for about 10 days, and was released in a completely healthy state. I was extremely pleased to have saved the child from their parents’ judgments and their negative emotions. I prepared myself for a discussion about autonomy with the parents for the following day. I also recommended that they seek psychological support because of their negative attitudes, which endangered the child, and because of their partnership difficulties, which became apparent. It had taken much effort on my part to convince the mother-to-be about the urgently needed cesarean section against the incompetent counteractions of her husband. Later the couple returned to thank me for not having given up on them and for having the courage to oppose their autonomous choices thereby saving the child. They had both realized now that they were about to make wrong and fatal decisions.

They deliberately chose me as their obstetrician for their next pregnancy. The second birth also required a cesarean, and a healthy girl was born, but not, here again, without protest. The husband again fell back on prejudices against physicians and the medical system. The choice of me as the obstetrician by the woman seemed due to her idea, that she needed protection from herself and fatal decision-making. She even said so. She in effect held, “You are the expert and really care for us, so it is proper that you overrode our fatal demands.” With every further appointment

with me they also brought the boy who had been narrowly saved and who was now quite intelligent and adventurous.

“Autonomy” is an open-context term, which is situation dependent. There are times when the physician must have the authority and courage to aggressively enter in. It may be noted that it is sometimes necessary for the physician to educate the patients or refer them to therapy or for education. “Competent patients have the right to refuse treatment, even when the refusal will result in disability or death” [17]. Thus, physicians encourage patients to make bad decisions. On the other hand, they also give the qualification that autonomy must be reasoned autonomy [18]. It is important therefore for self-protection for the physician to have patients sign consent forms and attest that they understood the information given them. As a physician one has, also as a part of preventative medicine, to help the patient develop his or her capacity for autonomy [19]. Exercising one’s autonomy may mean a bad decision for all involved [20].

5. Suppose a patient refuses treatment or tells the physician that he or she does not wish to know what the ailment or appropriate treatment is.

6. Autonomy has no a priori standing, it is an atomistic myth that one is self-contained, self-sufficient, self-determined instead of living cooperatively [21].

7. The court conspires in supporting bad medical treatment (See also causation in the law, and “legal causality” in the [Chapter 3](#)). The court protects a so-called intrinsic value of autonomy even if the consequences and the actual interests of the individual are worsened or neglected. Court interests are in that sense against individual interests. The court stresses a fictional ideal autonomy.

Case Example – Autonomy and the Law: As a physician, one always has to wonder if one could have done something differently or better. Only such an attitude makes one into a physician critical about oneself and his/her actions and offers the chance to life-long learning. If a complication develops the physician tends to blame him/herself even if the complication could not have been anticipated. This is an unfair evaluation after the fact. In lawsuits it seems to be presupposed that there is a perfect principle of autonomy according to which there is a rational, fully informed patient who is able to select perfectly the best and least risky among the different options of therapy. The claim and realization of autonomy of a woman in the pain of labor is problematic. She is potentially misinformed, anxious, vulnerable, and suggestible. It would be difficult for her to make a genuinely autonomous decision. Even the law in specific cases accepts birth giving as an extraordinary and extreme situation. The patient’s information in his/her particular situation is always weak, and incomplete and informed consent often only fictionally given. Every anxiety driven decision cannot be considered autonomous or complete. In our experience, the patient at best accepts the physician’s advice, or rejects it, without having a critical assessment of the options. The alternative is the inhumane challenge of explaining all the possible risks in detail. At Salzburg’s Women’s hospital a free information course about birth giving is available once a week. The information about that course is made widely available for all pregnant women planning to deliver their babies at the hospital. They receive the written invitation at their appointments to check before delivery. Almost no one attends the session. This

indicates that they do not bother to obtain adequate information upon which to make autonomous decisions. They also seem not to wish to have such important information before giving birth. One would think that this would disqualify from making such decisions. But after difficulties arise people concerned can claim that they would have made a different decision if they only would have known about the difficulties now encountered and tend to blame the physician if anything goes wrong. Also, it may be noted that there is no risk-free option in obstetrics, in medicine, or elsewhere in our lives.

A physician has sometimes the dilemma of choosing between respecting a patient's unwise or even fatal autonomous choices and giving sound, effective and professional medical treatment. This is especially problematic when the patient lacks genuine autonomy of judgment. By definition, genuinely critical choices cannot be autonomous because they must involve inquiry, discussion, expertise, etc. It would not be fair then, if one had not fulfilled these requirements to complain about the decisions made by the physician afterwards or to claim that they did not receive such information, yet some do so. Physicians in such cases should not be blamed for complications during labor or birth. Should uninformed autonomy result in unfair complaint, the physician may be forced to offer fewer choices, for example, offer only cesarean sections and no more vaginal births, which is often the practice. The physician cannot give all possible consequences. If my car dealer does not give me all possible information about car accidents, I could even legally accuse the dealer of my driving on thin ice and falling through [22].

Insurance does not protect the physician if it is imagined that insufficient or incomplete information is given the patient. Lawyers even talk about such approaches as: We cannot get the physician for malpractice, but we can try to get him or her on grounds of giving incomplete information to the patient. Unfortunately anything may be construed as being incomplete. At what point is information complete? The patients even after signing a paper saying they have read and understood the information can in the court claim that they did not. The patients can claim they did not get the information they clearly got and disobey the instructions of the physician and still win a law suit. The legal system is conclusive, irrefutable, beyond question, yet not based on the actual facts of medical practice, and often in disregard of the medical facts. In Austria, the children of the physician may also inherit the lawsuit, consequences and costs. The result is that the physician is required to be extremely defensive also to the detriment of patients and the distancing of the physician from the patient. It blocks caring treatment.

8. Falsely conceived autonomy forces un-professionalism. It would often be ethically and medically unprofessional to accept without question the "autonomy" of the patient or spokesperson regarding the type and availability of medical care. The physician is usually bound by the patient's decision to operate or not. Must the physician have the possibility to give needed treatment even when a patient does not wish or allow it, just as we educate students even if they do not want it, for the benefit of the student and society? Psychiatric patients also often do not want much-needed treatment. "If a patient be under orders, he will not stray; left to himself, he will give up the struggle and depart this life...so [the physician must] take

the patient in hand” [23]. The patient is not on the same level in knowledge as the physician or nurse.

Autonomy of the expert can be contrasted with paternalism. “There are situations in which paternalistic behavior is ethically justified” [24]. Also, Loewy states, that unthinkingly and unfeelingly abandoning persons to their autonomy is the flip-side of paternalism. [25] Experts have knowledge others do not have and it is not paternalism to actively use such knowledge and guide the patient or those seeking such advice. It makes sense to: a. present the patient with all reasonable options, b. ensure that s/he understands the outcome, c. deal with negative emotions, e.g., fears. One cannot adequately communicate to the patient all of the reasonable options unless the patient can understand. There are serious problems with the principle of autonomy. Patient Centered Therapy is a form of autonomy. The principle that the therapist cannot help those who do not want to be helped is a rationalization. Not wanting to be helped is part of the disorder. The therapist must find ways around the resistance. But how?

9. Autonomy leading to extreme harmful outcomes of the patient must sometimes be severely limited although this is to be argued carefully in each case. Beauchamp and Walters wrote that rational autonomy must be based on informed choice and should sometimes be restricted on grounds of irrationality and harmful outcomes [26].

10. Unreliability of consent. Patients as well as their families are often not competent to decide about such matters. Such family members in Germany can only make treatment decisions if they have been previously authorized to do so by the family member or court [27].

Similarly, family members, who lack the needed ethical and critical ability background, especially if they are in addition to inherit, cannot be depended upon to make objective ethical and informed decisions about a patient. In these respects, it could be ethically and medically unprofessional to accept the “autonomy” of the patient’s spokesperson, but not the one based on a physician’s expertise. Family members may be selfish or have antagonistic relations with other family members. It cannot be assumed that because they are family that they support each other’s best interest. Therefore, only the patients themselves should be the ones to authorize decision-making for them on the part of a family member or other person. The patient should explicitly in advance authorize decision-making authority of a family member or friend, otherwise friendship or surrogate has to be carefully established.

Some physicians exclude anti-social preferences, unlikely preferences, and restricted actual desires [28]. To give an example, often women desire and even insist on undergoing even the most extreme, invasive reproductive measures to have a child even if they have virtually no chance to have one [29]. They feel they cannot live unless they have a child, yet they do not consider adoption. Some feel they are not really women unless they have a child. They think that somehow the genes must be their own ones among the millions of possible fertilizing sperm. A license is needed to drive a car, but not to have a child. Griffin wrote of an “informed desire” approach [30]. But even informed consent and preferences may not suffice. If each has a right to determine what is to be done with their own body by the principle of

autonomy, it would let the addict continue with the addiction, and let people die of easily curable diseases.

11. Autonomy involves unearned respect. It is an ethical fallacy to have respect-as-such for whatever is desired, asked for, demanded, and unquestioningly fulfilled not considering consequences. It is also a fallacy of the argument from authority, in which the patient is falsely regarded as the authority for his or her life or the quality of their lives unless they qualify as authorities. “Respect” is an open-context value term and must be given a meaning to be intelligible. When a meaning is given it will be seen that respect is not innate, but rather has to be earned. One has respect for someone typically because of what they have studied and learned to do, e.g., respect for a surgeon. Autonomy must be earned.

12. Autonomy may be only one self-serving factor and involve the disregard of the interests of others. This is like deciding for oneself without regard for other’s interests. Such kind of “autonomous” decision can neither be called ethical nor autonomous in terms of the requirements for autonomy. Autonomy may involve selfishness, concern mainly with one’s own desires, but altruism should not exclude one’s own interests. The good of the patient, the quality of life of those involved, including the physician who is often overworked and bears extreme liability, in addition to the other factors should not be excluded.

The uninformed cannot be said to give “consent.” It is often disallowed for minors, yet allowed for those even less rational and less informed adults. “Consent” presupposes that one can make informed choices. One form of autonomy is consent.

13. Autonomy is relativistic. There is relativism in the concept of each person having free judgment, or autonomy. Self-determination requires expertise and the help of others just as one may need medical advice from others. The assumption is also made in Rogerian therapy and Socratic oriented views of Philosophical Counseling, that the patient can solve his or her own problems and that the therapist need not actively guide and challenge the patient. In opposition to this view, the patients should not be regarded as experts in decision-making in medicine, however they should be encouraged to participate as much as possible in learning about all of the relevant factors.

Jopling opposes the anti-therapeutic, anti-realistic, relativistic approaches of Lahav, Achenbach and others in the area of philosophical counseling. He wrote, “The price of respect for the client’s autonomy may be the flourishing of the self-deception and self-illusion” [31].

Case Example – Alternative Medicine: A 44-year-old woman came to the walk-in of the Women’s Hospital accompanied by her family physician, a general practitioner of “alternative medicine.” The patient told me as a physician that she had abdominal pain on and off, and she mentioned anemia, because of what she imagined was a supposed “self regeneration” of her body. The general practitioner wanted only the alleged anemia to be treated. I asked for the permission to do a full gynecological examination and to order reports from previous hospital stays. From the report as well as from bimanual palpation and ultrasound examination, I learned that she had ovarian cancer (Stage IIIc), was operated on, but refused the much-needed chemotherapy. She was convinced that “self regeneration” had cured her,

and the “alternative medicine” physician had reassured her about that, whereas in fact the abdominal tumor she had was more than 12 centimeters in diameter. Thus, sound treatment or at least realistic chances for life were defeated by the patient’s fatal, unwise decision not to have chemotherapy a year earlier. I asked also about the role that the general practitioner had played. She said that she as a physician herself would not undergo chemotherapy no matter what chances would be there for life, and that it is too toxic for one’s body. Perhaps in this case irrational decision-making on the part of both the patient and the general practitioner were themselves toxic.

A criticism of this account is that autonomy can be a form of relativism according to which one can make an uninformed decision. Active guidance is needed in place of passive minimalism. On a higher level, Jopling states, “Philosophical counselors shoulder a significant burden of responsibility in helping their clients achieve an accurate, defensible, action-guiding and truth-oriented self-understanding” [31].

The more the patients know about their condition and participate in the treatment, the better. Some patients have even found minor and major medical information and cures not available to medical workers. Also, those patients who are experts in a relevant profession, for example, biologists, chemists, physicists, philosophical practitioners, etc., critical thinkers knowledgeable about ethics, etc. can in return offer guidance to the physician who may not be as well-informed in these areas. One surgeon learned about anti-scar salves from a patient who researched it on the internet and the physician revised his treatment procedure. The physician also depends on the patient to report the effectiveness of the treatment given, e.g., reactions to medications and drugs.

It is maintained that the physician or counselor and patient or client must be on an equal basis. If this were true, how could they claim to have expertise or anything to offer to the patient or client? An expert is not on an equal basis with the uninformed, not for information, not for the adequate treatment. Furthermore, the claim that they are equal is undermined by the claim that each person is unique. Our development is guided by competent others, we cannot be on top of everything and have to acknowledge that, but we can aim at finding out as much as we are capable of by the help of physicians, nurses, counselors.

14. Autonomy is neither an ethical theory, nor a theory of ethics. Unquestioned autonomy is not an ethically maintainable position.

15. Autonomy of the person or self requires a definition of these terms. A person for Harris is “a creature capable of valuing its own existence” [32]. On this view, also the patient would need to know about ethics in order to value. What definition of the self is to be given here?

16. Priority of scarce resources should not be based primarily on autonomy. If patients oppose the goals of medicine by their actions, requests (autonomy of patient), and belief systems, the physician may or must withdraw or withhold treatment [33].

17. Autonomy might be based on the supernatural. There is a problem with “ascertaining that the patient’s reasons for the choice [is one] that can – in terms of the patient’s and not the health professional’s value system – be logically defended. Thus, patients are entitled to make decisions, which a majority of us might consider

foolish – refuse transfusions, for example, because their particular faith prohibits it” [34]. Failure of the patient to understand because of “staunchly though unreflectively held opinions may stand in the way of functional understanding. . . (and be) a form of superstition that may be cultural, religious or idiosyncratic” [35]. There is no genuine autonomy if one’s views are dictated by religion. The “Church of Truth” rejects medical treatment of all illnesses in favor of spiritual healing. Their members refused an infant needing medical treatment. The courts tend to favor medical treatment over religious restraints for children, e.g., Jehovah’s Witness prohibition of blood transfusion [36].

18. The principle of autonomy is not consistently used in areas other than medicine. Should it apply to all areas of one’s life as well as medicine? (See Chapter 8)

19. Patient autonomy and consent blocks some lawsuits in that the decision is made by the patient rather than the healthcare worker, but promotes other lawsuits based on subjective authority. A patient’s consent is needed even when taking the pulse. [37] Courts recognize implied consent so doctor need not ask for consent. But the patient may always sue. Coming to a hospital or doctors office does not imply consent to being touched. Even touching without consent may constitute battery.

20. Autonomy is important in the area of abortion and even late abortion or fetocide as it allows the individual to make choices for their future quality of life. It is interesting that in such cases the autonomy of women is often especially put in question.

21. From autonomy follows the patient’s future quality of life with or without the required responsibility for his/her health. If patients are to have autonomy it is required that they be capable of and fully responsible for their decisions. Responsibility for oneself and others must be based on a sound ethics. It is almost identical with ethics, for example, on a naturalistic ethics whereby to be responsible is based on doing so because it is rational to bring about one’s holistic and informed wants and likes. An adequate naturalistic ethics leads to pragmatism and humanism. Also, Lenk and Maring have defined moral responsibility as a relationship between people [38]. Responsibility is the result of self-obligation, which corresponds to all people [39]. Self-obligation and social ascription are then overlapping [40].

“Self-determination, care and responsibility go together, their separation weakens each of them” [41]. The person who has the freedom for self-determination, has to take over the responsibility for such decisions. Autonomy is self-determination (*Selbstbestimmung*). Autonomy presupposes competence in decision making and acting. Autonomy without responsibility is half hearted, nothing, empty. It is valueless value.

22. Even with regard to a patient’s autonomy, physicians must have a possible professional discretion and action (*Handlungsspielraum*) due to their high degree of responsibility and the possible courses of complications of medical treatment, and their foresight because of experience. Good and open communication between patient and health care worker must be maintained before, during and after the treatment. This must be a central ingredient to patient care and especially so for

patient autonomy to be meaningful. Another word relevant to this whole structure is trust [40].

23. Autonomy may also be seen as autocracy: absolute power, dictatorship, and unlimited power over one's own decisions including the impact on others. This may be as true of the patient as well as of the healthcare worker, but is selfish and not ethical.

24. Autonomy is often clouded by bias, negative emotions such as, anger, fear, envy, revenge, thought-feelings of inferiority or superiority, burn-out, pain, etc. Frequently female patients ask for a male physician to do the operation, without realizing they could thereby be choosing the least experienced surgeon assistant instead of the experienced senior female physician.

25. Psychiatric patient autonomy. Mitterauer, Maier, and Griebnitz argue that informed consent in the case of psychiatric patients is not to be determined merely because of the psychiatric diagnosis or classification alone, but preferably on a case by case basis for understanding of consequences of the medical intervention for the body, quality and happiness of life [42]. Note that the assessment is holistic involving the positive emotions and happiness of one's life. Such patients may have diminished capacity for: (a) autonomous evaluation (e.g., delusions) (b) understanding facts and causal procedures, (c) resolving a conflict because of their personal evaluation, e.g., due to a psychotic state [43]. Criteria for determining the ability to understand (become informed) involve the following factors: cognitive, emotional, communicative, and behavioral. The actual capability of consent must also be assessed [44]. The above criteria and diminished capacities regarding autonomy apply to the non-psychiatric patient as well, but in lesser degree. They may have prejudices and dogmatic views, which prevent them from understanding information and arguments or drawing sound conclusions. Another problem is that a patient may deceive a physician or therapist by giving (e.g., DSM IV or learning) symptoms of a certain disease and pretending to have them.

In sum, challenging a severely limited autonomy concept we need rational, informed, critical decision making and a consequentialistic, naturalistic theory of ethics and education about emotions.

12.3 Patient Responsibility and a Patient Code of Ethics

Medical ethics is one-sided. It dwells on the ethical obligations of doctors to the exclusion of those of patients [45].

There is no patient autonomy without patient responsibility.

The physician's Hippocratic oath may be applied to everyone, rather than remain the exclusive domain of the healthcare worker alone. Everyone is or might (and will) become a patient in his/her life.

The American Medical Association states, *As a member of this profession, a physician must recognize responsibility to patients first and foremost* [46].

All of the burden is put on the physician. One could also state, *As a benefiting recipient of medical care, a patient must recognize a responsibility and gratefulness to healthcareers first and foremost.*

According to David Resnik patients have an obligation to be responsible enough to follow physician's orders and physician-patient contracts should be considered [47]. Although patient's rights have been extensively defended, "Surprisingly, the bioethics literature also [as with AMA and AHA publications] has very little to say about the ethical basis of the patient's duties" [48].

Draper and Sorell argued for the development of patient's responsibilities in medical ethics. "Duties fall mainly on doctors and only exceptionally on patients. . . [and] exempt patients from obligations" [49]. Patients also have responsibilities to doctors. It is as if patients can do no wrong. "Autonomy must go hand and hand with taking responsibility for what is chosen" [50]. "Autonomy without responsibility is not autonomy." [51] If things go badly the physician may be blamed for the autonomous patient's decision. Patients are often negligent, contributing to or causing their bad health, often opposing medical research for theological or other reasons, not supporting funding for medical services, failing to obey physician's directions, failing to show up for appointments, not telling the truth to physicians, refusing to contribute organs after death, being not grateful for their care, being difficult or non-cooperative. "Competent patients have a responsibility to look after their own health" [52]. In England as well as America patients have the right to refuse treatment for irrational reasons or no reason at all [53]. Patients actual as well as future also have a civil obligation to promote health care for all as well as for themselves. If and to what extent they do so may well be questioned. Patients have an obligation not to misuse or overuse medical resources or expect others to pay for their poor lifestyle [54].

The National Health Service (NHS) in Great Britain is dropping patients from healthcare lists if they frequently do not show up for appointments [55]. Proposals are also made to charge patients who do not show up. "Delivering the NHS Plan," stresses patient responsibility so as to use health resources fairly and appropriately.

The National Patient Safety Foundation [56] suggests ways patients may help prevent medical error. NPSF suggests these steps: become a more informed health care consumer, seek information about illnesses or conditions that affect you, research options and possible treatment plans; choose a doctor, clinic, pharmacy, and hospital experienced in the type of care you require; ask questions of your doctor, nurse, pharmacist, or benefits plan coordinator; seek more than one opinion, write down your medical history including any medical conditions you have, illnesses, immunizations, allergies, hospitalizations, all medications you're taking, and any reactions or sensitivities you've experienced; write down the names and phone numbers of your doctors, clinics, and pharmacies for quick and easy reference. Work with your doctor and other health care professionals as a team, make sure you understand the care and treatment you'll be receiving. Take medications exactly as prescribed. Buetow and Elwyn hold that, "Patients appear to be morally responsible for the avoidable errors they make, contribute to or can influence" [57]. Patients are also responsible to conserve resources.

The American Medical Association's Code of Medical Ethics [58] regarding patient responsibilities states that it is the responsibility of patients to:

1. Be truthful and express their concerns clearly to their physicians.
2. Provide as complete a medical history as possible.
3. Request information or clarification when they do not fully understand their health status or treatment.
4. Cooperate with agreed-upon treatment plans and appointments.
5. Take personal responsibility, when they are able, to prevent the development of disease.
6. Consider participating in medical education by accepting care from medical students, residents, and others.

Thus, the patient is expected to maintain "health-enhancing behavior." They should help prevent disease and consider adverse effects on others [59].

12.4 Patients Duties

Each of the following is a responsibility and duty of the patient [60]:

Check Diagnosis. Critically evaluate the diagnosis and treatment of the health-care worker.

Communication. Communicate fully and well with the healthcare workers.

Communication. Express your medical goals and desires clearly to the health-care worker.

Dependability. Show up promptly for appointments.

Designate Representative. Designate which, if, any family member you wish to medically represent you if you are not able to represent yourself.

Ethics Committee. In problematic cases seek the advice of an ethics committee.

Harm. Do no harm to oneself or the healthcare worker.

Healthy Lifestyle. Live a healthy lifestyle. Patients should tell the healthcare worker their idea of what a healthful lifestyle is and whether or not they have been living one. Such a lifestyle may help, but cannot be expected to protect one from all illness and disease.

Honesty and Comprehensiveness. Honestly and completely inform the health-care worker about one's condition to be treated.

Humanism and Altruism. Be humanistic and altruistic. Physicians are supposed to act for the society and humanity as a whole as well as for the individual [61]. Presumably, patients should do so as well. If the patient acts against humanity or society the physician is also defeated in fairly treating the patient.

Misuse of the Law. Do not use the legal system merely for financial gain in malpractice suits. Do not engage in unfair and unnecessary litigation.

Negative Emotions. Express no negative emotions against the healthcare worker, do not hold your illness as the physician's fault.

Nutritive Responsibility. Patients should be informed about nutrition and follow a healthful nutritional plan.

Obey Instructions. Follow the medical and treatment instructions given by the healthcare worker precisely and in a timely fashion.

Obtain Information. Obtain as much information as reasonably possible about one's own condition and treatment. Autonomy is not autonomy to refuse to obtain information.

Organ Donation. Sign to offer to contribute organs upon death.

Prevention. Preventative overall health measures should be taken at all times.

Question Decisions. Patient should question decisions at every step. If needed they may obtain an advocate [62].

Rationality. Make medical decisions on an ethical and rational basis. Autonomy is not autonomy to make bad decisions.

Reproductive Responsibility. Fertile women who have any chance of becoming pregnant should refrain from smoking, take folic acid, and live a healthy lifestyle. After conception they should immediately follow the obstetrician's plan of care. In certain countries if the doctor is negligent thereby producing a damaged child the doctor can be sued. The mother, however, may be completely negligent as to the damage of the fetus [63].

Required Information. Whatever the healthcare worker is required to offer, the patient must make an informed and rational decision about. For example, as doctors are by law required to offer prenatal diagnosis the patients should also avail themselves of prenatal diagnosis as well.

Respectfulness. Show respect and gratefulness to the caregivers. Try to especially reward them for their care.

Responsibility to Advance Medicine. Financially and politically support medical research and treatment institutions. Leave some of your will to such causes. It is also a duty not to undermine or block medical research and treatment, e.g., stem cell research, national and international healthcare systems, physicians without borders who volunteer to help people in the most dangerous areas of the world, etc.

Responsibility to be Informed. Attend relevant health information sessions offered.

Responsible Lifestyle. Avoid having others to pay or provide treatment for one's own risky or poor lifestyle.

Risks. Avoid risk taking which might endanger yourself or others. This includes risky sports and extra driving (See [Chapter 16](#)).

Second Opinion. Seek a second opinion if there is doubt about the treatment to be given.

Self-Care. Patients should actively participate in their own care (participatory treatment).

Sexual Responsibility. Use preventative measures to prevention of AIDS and other sexually transmitted diseases.

- Unnecessary Treatment. Do not misuse or overuse medical resources by risk-taking, poor lifestyle, demanding unneeded care.
- Will. Make a “living will” so that if in a coma, etc. the healthcare worker will know how to proceed.
- World Healthcare Responsibility. Support medicine financially and by acting and voting to promote national and world healthcare systems.

12.5 Case Report: Patient and Legal Irresponsibility

A Salzburg gynecologist examined a pregnant woman and determined that further examination of her fetus was required. He referred the woman to the center of prenatal medicine in the hospital. The woman did not follow the instructions. After additional urging from the physician the woman went for the hospital examination only 2 months later. It was found then that the baby would be a child with Down-Syndrome, severely disabled, and too late now for an abortion. The woman, though she failed to follow the physician’s instructions, sued the physician for the support of the child. The physician is thereby effectively made bankrupt for his lifetime though he has worked all of his life successfully. The lower courts ruled in favor of the physician, but the high court said the physician’s referral was not sufficient in terms of parent information. The high court also powered to make judgment. The experts in Prenatal Care determined that the physician had made no error in judgment or treatment, but in fact had been especially perceptive to ask for the referral, which others might have missed. The legal case shows that patients need not be responsible and that they do not accept the consequences of their own actions. If things go wrong they have the power to sue physicians and ruin their careers and lives [64]. The *Ärztammer* for Salzburg had to distribute special notices and display posters in July 2006 telling patients that they must follow physician’s orders and be responsible enough to obtain and understand the information given them, otherwise ask for further explanation. This notice came as a result of a suit by a patient who did not follow the physician’s instructions, but the high court on appeal in 2006 injudiciously supported the patient.

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