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Do alcoholic liver transplantation candidates merit lower medical priority than non-alcoholic candidates?

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Abstract Alcoholic patients are frequently regarded as responsible for their alcoholism and alcohol-related diseases, such as liver damage. These patients run the risk of receiving lower medical priority for liver transplantation than patients who are considered as not responsible for their liver damage. However, hardly any scientific research findings support this supposed responsibility of the alcoholic patient for his addiction and the related diseases. Many alcoholic patients have comorbid psychiatric disorders such as antisocial personality disorder, schizophrenia and social phobia,

and these comorbid diseases are often linked specifically and also in a neurobiological way to alcohol abuse. Furthermore, concepts such as responsibility and health have multiple dimensions, which can be contrasted against each other. Useful and fair criteria are presented for the assessment of responsibility for our health.

Keywords Medical ethics · Alcohol abuse disorder · Comorbid mental disorders · Liver transplantation · Medical decision making · Patient selection

Introduction

Following the success and acceptance of transplantation in the treatment of end stage liver disease, there has been a progressive increase in the number of patients seeking a limited supply of donor organs. Because of the limited supply of these organs, the introduction of psychosocial selection criteria for patients who need liver transplantation is an issue of discussion, particularly in the last decade. One important question is whether organ transplant candidates who are likely to damage their organ should have lower priority for organ transplantation than patients not displaying such unacceptably risky behaviour. Should, for example, an alcoholic patient with liver damage receive the same priority in organ allotment as a person with a more healthy life-style? Some people believe that alcoholics merit lower priority for liver transplantation because of their supposed responsibility for their liver damage, while others suggest that all pa-

tients with the same medical urgency should have equal medical priority.

Because of the complicated nature of alcoholism, a precise and reliable assessment of the degree of responsibility is in most of the cases not easy and very labour-intensive. Furthermore, it is questionable if such an assessment, which has consequences for medical priority, is ethically desirable. Until now, there exist no adequate and fair criteria for the reliable assessment of a patient's responsibility for his disease or organ damage.

Diagnostic features

The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) [1] describes alcohol abuse as follows: School and job performance may suffer from either the after-effects of drinking or from the actual intoxication; child care or household responsibilities may be neglected; and alcohol-related absences

es may occur from school or job. The person may use alcohol in physically hazardous circumstances, legal difficulties may result from alcohol use. Finally, people with alcohol abuse may continue to consume alcohol despite the knowledge that continued consumption poses significant social or interpersonal problems for them. A number of mental disorders, such as antisocial personality disorders, schizophrenia, and social phobia, which are often related to alcoholism, will be discussed later. Their diagnostic criteria are relevant.

The DSM-IV describes antisocial personality disorder as follows: People with an antisocial personality disorder frequently lack empathy and tend to be callous, cynical, and contemptuous of the feelings, rights and sufferings of others. They may have an inflated and arrogant self-appraisal and may be excessively opinionated, self-assured, or cocky. They may display a glib, superficial charm and can be quite voluble and verbally facile.

According to the DSM-IV criteria, schizophrenia is characterised by:

- A Two or more of the following symptoms: (1) delusions; (2) hallucinations; (3) disorganised speech; (4) grossly disorganised or catatonic behaviour (5); negative symptoms, i.e. affective flattening, alogia, or avolition
- B Social occupational dysfunctions

The DSM-IV describes the diagnostic features of social phobia as follows: The essential feature of social phobia is a marked and persistent fear of social or performance situations in which embarrassment may occur. Exposure to the social or performance situation almost invariably provokes an immediate anxiety response. This response may take the form of a situationally bound or a situationally predisposed panic attack. Although adolescents and adults with this disorder recognise that their fear is excessive or unreasonable, this may not be the case in children. Most often, the situation is avoided, sometimes, however, it is endured with dread. The diagnosis is appropriate only if the avoidance, fear, or anxious anticipation interferes significantly with the person's daily routine, occupational functioning, or social life, or if the person is markedly distressed about having the phobia.

Are alcoholic patients always responsible for their damaged liver?

When we study the cases of alcoholic patients with liver damage, we frequently find a relationship between alcohol abuse and liver damage. Superficially, we can assume that these people are responsible for their health problems, but a closer look shows that matters are

somewhat different. Glannon [7], nevertheless, argues that the etiology of alcoholism may allow enough control for the alcoholic to be responsible for his condition and accordingly have a weaker claim to a new liver than someone who acquires the disease through no fault of his own. Glannon employs a somewhat narrow concept of etiology. He obviously does not know that neurological and biochemical factors play a role in the etiology of alcoholism and, as a consequence, he did not consider these important aspects. Furthermore, most alcoholics suffer from further comorbid severe mental disorders, which is not discussed by Glannon, in spite of its importance. Despite his substantial lack of medical knowledge and the absence of a discussion of the implications of these relevant psychiatric, neurological and genetic aspects, Glannon draws some incorrect and dangerous conclusions, which can have very harmful consequences for the alcoholic patients.

In the DSM-IV and the ICD-10 Classification of Mental and Behavioural Disorders of the World Health Organization [27], this alcohol use disorder (DSM-IV), or chronic alcoholism (ICD-10), is considered as a mental disorder. Consequently, the difficult question arises: Is a patient responsible for his own mental disorder? Some psychiatrists believe that patients sometimes choose their mental disorders, but many do not share this opinion. I believe that no patient chooses to suffer from a mental disorder on his or her own free will. In the etiology of some patients with a mental disorder there may perhaps be a few moments in which he or she had some power to fight the disorder, and, in fact, practically every patient does fight. In none of the handbooks, such as the DSM-IV or ICD-10, is it mentioned that patients choose, in any way, their mental disorder. Many alcoholics begin to drink in a period of deep sorrow, grief, anxiety, mental or physical pain, or unbearable stress, chaos, loneliness, rejection, humiliation, or loss of self-esteem. The life of these alcoholics was 'out of control' and they were 'out of character' when they developed an alcohol abuse disorder.

Alcoholics often show comorbid disorders such as personality disorders [20], schizophrenia [2, 5, 19], and social phobia [10]. Sallmen et al. [17] showed that 78% of the investigated alcoholics suffered from a comorbid psychiatric disorder. Indeed, many alcoholics have two or more mental disorders. It would be very difficult to assess the degree of responsibility of these patients for their comorbid mental disorders, because the relationship between these disorders and alcoholism frequently has a neurological and biochemical basis [4, 21, 25]. Nedopil et al. and Knop et al. [9, 16, 25] have found that alcohol abuse significantly correlated with behavioural characteristics of persons with antisocial personality disorder and conduct disorders. In schizophrenic patients, anxiety, psychosis, delusions and hallucinations [3] can be related to alcohol abuse, while neurological

dysfunction can be the foundation of the link between schizophrenia and alcoholism [19]. Alcohol problems develop secondarily to social phobia, with patients reporting that they find alcohol helpful in coping with symptoms of anxiety [10].

However, there do seem to be people who have the 'luxury' to choose their alcoholism, for example, as a result of boredom or apathy. These people are likely to be considered as responsible for their risk-taking behaviour, because they were not 'forced' to drinking by negative circumstances or experiences. Nevertheless, we must be very careful in the judgement of this group of alcoholics because it is not probable that all these persons choose their risky behaviour and the consequences of their alcoholism. Moreover, a mentally sane person would hardly choose to suffer from psychological conditions such as boredom and apathy, which are the reason for alcohol abuse, on his own free will. One might think that many of them could have overcome these negative mental conditions if they had made serious attempts to do so, but boredom and apathy are frequently diagnostic features of comorbid mental disorders. They are expressions of cortical under-arousal in persons with an antisocial personality disorder [3, 12, 13, 18]. According to the DSM-IV, alcohol abuse and alcohol dependence often have a familial pattern, and at least some of the transmission can be traced in genetic factors. The risk of alcohol dependence is three to four times higher for the close relatives of people with alcohol dependence [1]. As a result, these people can hardly be regarded as responsible for the genetic, biochemical, neurological or familial impact on their alcoholism.

Glannon [7] suggests that the etiology of alcoholism may involve enough control for the alcoholic to be responsible for his condition. I disagree with Glannon, because most alcoholics demonstrate a striking lack of control, which is interwoven with their whole life and behavioural patterns. Alcohol abuse and dependence have a variable course that is frequently characterised by periods of remission and relapse. A decision to stop drinking, often in response to a crisis, is likely to be followed by weeks or more of abstinence, which is often followed by limited periods of controlled or non-problematic drinking. It is, however, highly likely that alcohol consumption rapidly escalates thereafter and that the severe problems will again develop [1]. In a population of forensic alcoholic psychiatric patients, Martens [12] observed that these periods of remission, during which decisions to stop drinking are made, are characterised by positive and happy events, such as a new relationship, friendship, or professional help after an episode of social isolation. By means of these contacts and their social support, these alcoholics are capable of some superficial control, but serious alcoholics show a severe incapacity for long-lasting abstinence and adequate coping behaviour, despite their good will and seri-

ous effort to overcome their problem [12]. Nevertheless, some of these serious alcoholics can be helped by very intensive and professional care by social support groups, such as Alcoholics Anonymous, and with the help of long-lasting therapies. In these cases, the lack of internal control is compensated with a strong impact of well-aimed and supportive external control.

Is it ethically wise to link the degree of responsibility to medical priority?

In my opinion, it is not wise to link medical priority to the supposed degree of a patient's responsibility for his disease or disorder. If we adapt medical priority to an assumed degree of someone's health responsibility, we can hardly avoid unfair discrimination between persons, because we often cannot assess validly the extent to which a patient is responsible for his suffering. Some responsibilities are visible, while others are not. Alcoholic patients can hardly hide their alcohol problem, but many patients with poor health [14], neurobiological disorders [23, 26], and HIV [11] can hide their negative mental attitude during medical examination. Some patients seem responsible without being so, while others do not seem responsible, but are.

As opposed to alcoholic patients with liver damage, heart patients are held in some degree responsible for their health problems, but they are not blamed for it. A large number of studies show that there is a strong relationship between Type A behaviour and coronary heart disease [6, 8, 15, 22, 28]. The Type A behaviour pattern is an action-emotion complex that can be observed in any person who is aggressively involved in a chronic, incessant struggle to achieve more and more in less and less time, even, if required to do so, against the opposition of circumstances or people. It is a socially acceptable – indeed often praised – form of conflict [6]. Because their risk-taking behaviour is socially acceptable, these patients are rarely blamed for their heart failure, although they are in fact responsible for it. Compared with the medical treatment of this type of heart patient, who is responsible for his disease, the treatment of the alcoholic patient who is not responsible for his disease is frequently less pleasant and more biased and denouncing, even if they receive the same medical priority. In many hospitals there is an unjustified bias against alcoholic patients because of their supposed responsibility for their alcohol abuse and related health problems, and this is, of course, not tolerable.

If the degree of responsibility of the patients suffering from an alcohol-related disease were to be determined, it would only be fair to do so in all diseases. It would be a very intensive and time-consuming job to determine the real measure of responsibility for a patient's disease. After that, one would have to decide on the de-

gree of responsibility for one's disease to justify higher or lower medical priority. For example, whether someone who broke his leg during risky sport activities such as football or rugby is to be regarded as responsible for his injury. However, some risk-taking behaviour is required to maintain a level of emotional and psychological well-being. Many persons need a certain level of risk-taking behaviour to keep their attitude positive enough for daily routine.

I believe that even persons who can be considered as responsible for their disease and disorder should have the same medical priority as patients who are not. If a person harms himself it is his own choice and right to do so, even to the point of committing suicide. It is a matter of privacy and personal integrity that these aspects of an individual's life should play no role in the decision making with respect to medical priority. Furthermore, there are categories of health 'irresponsibilities' that are incomparable with each other. For instance, the poor alcoholic with low education and bad circumstances is totally different from the well-educated, rich alcoholic in favourable circumstances. Responsibility can thus not be determined adequately without considering other relevant factors. I believe it is impossible to compare in an adequate, useful, and just manner the responsibilities of different persons with distinctive backgrounds, capacities, education, opportunities, coping styles, social status, social support, and luck. How should the distinctions for the determination of medical priority be made in a reliable and just manner? Moreover, an otherwise very responsible and ethically wise individual may have only one reckless trait, such as a specific health irresponsibility. Should he be punished for that one irresponsibility? I think medical priority should be granted on the basis of medical facts and other objective and relevant information. Perhaps, we must first try to answer the basic question in this context: What do we mean by responsibility for our own health?

Responsibility for our own health

Most people think that we behave responsibly with regard to our physical and mental health when we avoid, as much as possible, any risk of health problems. But, is such stringently risk-avoiding behaviour always healthy for everyone? Such risk-avoiding conduct can easily become rigid and may also be paired with fear and anxiety, which, in turn, can indeed cause a mentally unhealthy condition. As a result of a fixation, the person in question can become over-aware of all the dangers that potentially threaten our physical or mental health, such as pollution or stress. Avoiding each and every risk in life could be fatal, as, in my opinion, not all dangers can or should be avoided since they are essential for the devel-

opment of character, personality and for the growth of emotional, ethical and moral capacities. For example, leading a wild life with the purpose of finding out the facts of life can lead to valuable insights and mental and emotional maturity, despite health-threatening dangers like alcohol abuse, smoking and unsafe sex. Some people need such an experience and this type of exploration in order to grow up. If such risky behaviour is necessary for the development of a person, it can be regarded as mentally healthy for that person. It is obvious that conduct beneficial to mental health can include a physically unhealthy dimension, and vice versa. There are evidently different dimensions of health and responsibility, and what may be unhealthy and irresponsible in one aspect, can be healthy and responsible in another. Furthermore, some things can be healthy for one person and unhealthy for another, such as low-cholesterol diets. The Trial Research Group [24] investigated the effect of low-cholesterol diets in a large population of heart patients. As a result, the patients demonstrated a significantly decreased risk of heart attack, but their risks of violent death by suicide or due to car accidents, for example, was significantly increased. For some patients the low-cholesterol diets had a perfect impact on their health, while for others this diet was fatal. Low-cholesterol diets caused, in some patients, neurobiological abnormalities that were linked to violent death.

For normal people alcohol abuse is unhealthy, but for many alcoholics drinking is a way of dealing with and enduring a life which would perhaps be unbearable otherwise. For many of them, not drinking can be healthier in some respects than drinking because of the extreme anxiety (e.g. in social phobia patients), mental suffering and mental abnormalities (such as in the case with schizophrenics), and restlessness that are related to a condition of non-alcohol use. Undoubtedly, all the described symptoms of mental disorders associated with alcoholism are not provoked by alcohol consumption and do not diminish during abstinence.

There are also attitudes and restrictions which can benefit the mental health of some persons but not of others, such as some ascetic, religious, and New Age activities. I have observed that many people cannot endure an excessively safe life, with its many restrictions, which would be for the benefit of their physical or mental health. They become distressed and very bored. They need compensation for their over-organised life with its numerous obligations. Responsibility for our own health is, in my opinion, always a balance between following our intense needs and passions, and following the rational and wise guidelines for a healthy life. This balance is different for every human being, and it varies continuously during one's lifetime. For some people who live under physically and mentally unhealthy conditions, such as in certain parts of big cities, and have stressful or dangerous jobs, it is very difficult to find

the right balance. It is often impossible for them to keep aware of or to pay attention to this balance. There are many circumstances in which people are hardly responsible for their unhealthy behaviour. Many studies demonstrate a relationship between stress and unhealthy habits such as alcohol use and smoking [23,26]. This unhealthy behaviour is perhaps a form of compensation for the endurance of too much mental pressure. Many people who demonstrate an unhealthy life-style have valid excuses.

In every society there are general agreements on the different forms of responsibility, including health responsibility. But they do not necessarily correspond with everybody's opinions and ethical judgements. Sometimes, it is very difficult to determine which attitude is most realistic and right, the ruling or the deviant one. Deviant behaviour and conception of responsibility can have equal value as, or be of higher value than, the conventional view, and it would be very unjust to condemn someone just for showing a different type of responsibility that is considered by others as irresponsible. There exists, however, not one unique and universally true conception of responsibility. It varies from culture to culture and from family to family. From my point of view, there are no guidelines for healthy conduct with the same value and benefit for everyone. As a consequence of the considerable differences in value and benefit, I think, it is not reasonable to found any form of conduct on uniform guidelines of responsibility. Responsibility is linked to concepts such as free-will, social consciousness, ethical and moral capacities, mental and emotional maturity. Each of these related abilities should be considered, if an assessment of health responsibility is required.

Criteria for health responsibility

Although the assessment of responsibility for health and disease is not easy, there are some useful and fair criteria for it. However, there are also exceptions in which a patient can not be held completely responsible for his or her health-damaging behaviour, such as:

- The existence of comorbid mental, neurological and physical disorders, which can have a negative impact on the free will and behaviour.
- Adverse environment and circumstances, which can influence the patient's free-will or behaviour, such as those who live in the slums
- Poor mental condition, as a result of long-lasting stress, sorrow, grief, desperation, or indoctrination
- Lack of the intellectual, ethical, moral, and emotional capacities required for following the guidelines of physical and mental health and understanding their benefits

- Social isolation and the absence of social support
- Rejections of former requests for professional help with referral to unhealthy behaviour in the past
- Deviant opinions, traditions and attitudes attributed to national, cultural, or familial backgrounds, related to poor health behaviour
- Former serious initiatives to stop consuming alcohol and a serious incapacity to continue abstinence

Discussion

An increasing number of theoreticians grant certain categories of patients, such as alcoholic patients with liver damage, lower medical priority, or even exclude them from medical care altogether because of their supposed responsibility for their disease. This is scientifically unfounded, and indeed, research suggests that many alcoholic patients are not, or to a lower degree, responsible for their alcoholism and related liver damage than non-alcoholic patients. Future medical decisions regarding medical priority should be based on the studies of independent research teams that include professionals of various medical disciplines related to the issue. The research for the responsibility of alcoholic patients with liver damage should be carried out by a multidisciplinary team of psychiatrists, psychopathologists, psychologists, medical ethicists, medical sociologists, medical epidemiologists, legal philosophers and addiction professionals.

Exclusion from medical care or decisions granting lower medical priority of certain patients are ethically undesirable. But, if health services were nevertheless forced to do so, at least specific, official guidelines and scientifically screened criteria that are as fair as possible should be employed. These guidelines should be inspired and drawn up under conditions of multidisciplinary research. It is furthermore important to update these guidelines and criteria continuously with new and relevant study results.

Only a powerful supervisory committee including members of an independent multidisciplinary research team could prevent an undesirable impact of agencies, such as medical insurance companies, or authorities serving economic interests, as these companies and authorities are likely to employ inadequate and scientifically underpinned criteria advocating less medical care or lower medical priority because they tend to favour certain categories of patients, for example, the affluent.

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