Rev. Latino-Am. Enfermagem
2015 Nov.-Dec.;23(6):1165-72
DOI: 10.1590/0104-1169.0516.2662
www.eerp.usp.br/rlae

Original Article

Alcoholic patients' response to their disease: perspective of patients and family

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Objective: to know the perspective of alcoholic patients and their families about the behavioral characteristics of the disease, identifying the issues to modify the addictive behavior and seek rehabilitation. Method: ethnographic research using interpretative anthropology, via participant observation and a detailed interview with alcoholic patients and their families, members of Alcoholics Anonymous (AA) and Alanon in Spain. Results: development of disease behavior in alcoholism is complex due to the issues of interpreting the consumption model as a disease sign. Patients often remain long periods in the pre-contemplation stage, delaying the search for assistance, which often arrives without them accepting the role of patient. This constrains the recovery and is related to the social thought on alcoholism and self-stigma on alcoholics and their families, leading them to deny the disease, condition of the patient, and help. The efforts of self-help groups and the involvement of health professionals is essential for recovery. Conclusion: understanding how disease behavior develops, and the change process of addictive behavior, it may be useful for patients, families and health professionals, enabling them to act in a specific way at each stage.

Descriptors: Alcohol Drinking; Sick Role; Behavior, Addictive; Self-Help Groups.

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Introduction

Alcoholism is a public health problem worldwide, estimated to affect 10% of the population, causing 2.5 million deaths annually. Europe, with 23 million alcoholics, is the region with the highest consumption and accounts for 195,000 annual deaths[1-3]. Alcohol is the addictive substance with most negative consequences in terms of morbidity and mortality, and violence related to both homicide and motor vehicle fatalities[3-5].

However, alcohol is part of culture and social life, and in the lifestyles of Western countries there is an excessive permissiveness towards its consumption[2,5]. The socially moderate drinker is accepted, while the uncontrollable drinker is rejected, thinking that people can use alcohol properly and normally, regardless of the fact that alcohol can void their will and gradually lead to alcoholism. Thus the responsibility of alcoholism is placed on the alcoholic patient rather than on the effects of the alcohol, and we reject and marginalize the patient who is unable to control it[6-7]. Therefore, this is a disease that affects the somatic, psychological and social level, full of strong social disapproval, which influences how the person develops disease behavior, and makes it difficult to approach it therapeutically [8-10].

The term 'disease behavior' refers to the stable disposition of the individual to respond to a certain form of the disease as a result of the interaction between personal and social variables. It develops through the following steps: (1) initial, in which symptoms are perceived and interpreted, (2) assuming the role of patient after interpreting the symptoms as a disease, (3) seeking assistance to solve the problem, (4) assuming the role of patient and accepting the recommendations, and (5) recovery or acceptance of the disease, in the case of chronicity [11-12].

From another viewpoint, it is possible to identify a person's level of predisposition to change his addictive behavior[13]. Prochaska's Transtheoretical Model considers behavior change as a process that occurs in five stages: 1) pre-contemplation, in which the person does not try to act in the immediate period, 2) contemplation, in which the person considers changing within the next six months, 3) preparation, when the person is willing to take action within a month, 4) action, when changes have been made during the last six months; 5) maintenance, when the person is confident in the changes and is less likely to return to the unwanted behavior[14].

It is necessary to note that many factors influence the development of this behavior, highlighting the group's beliefs, expectations and opinions of the disease, because the overall experience of the disease is shaped by society and culture[10]. This is especially important in socially stigmatized diseases[2, 6] as in the case of alcoholism. This can lead to self-stigma by the patient and family, leading them to reduce their self-confidence and self-esteem, causing social isolation, a lack of interest in obtaining knowledge about the disease, and decreased hope for recovery[15]. It is common to have difficulties in identifying oneself as a patient and requesting therapeutic assistance.

Nurses are the professional group most involved in the care of patients addicted to substances such as alcohol, and their position allows them to help patients[7,16] to adopt the patient role earlier, and thus move them from precontemplation to the next steps in the process of behavior change. For that, it is essential to understand the behavior of this disease from the point of view of the patient and the family, due to the psychosocial connotations that this has. Based on the above, and given the small number of studies located on this, in order to increase the knowledge of the nursing discipline and to improve care for these patients, we have addressed the perspective of alcoholic patients and their families on the development of disease behavior. We also focus on identifying the main difficulties encountered, to modify addictive behavior and begin the recovery.

Method

A qualitative study was proposed, following the Consolidated criteria for reporting qualitative studies (COREQ) guide for the description of the methodology[17]. The studied population included alcoholics and their family members from Alcoholics Anonymous (AA) and Al-Anon Family Groups (Al-Anon) in the province of Seville (Spain), in scenarios in which they provide recovery processes[18]. The selection was made by deliberate sampling, looking for cases of alcoholic patients who were in the last stage of disease behavior and the addictive behavior change process, also counting their family members. Therefore, patients in recovery and their family members were included. In order to interpret the meanings of alcohol consumption, the development of illness behavior and addictive behavior change process, an ethnographic method to understand social and cultural aspects of groups that share characteristics was used. This allowed discovering meanings of the practices, motivations and conceptions, integrating them into the cultural context using interpretive anthropology based on hermeneutics[17].

The study is part of a line of research that is intended to describe the management of the disease, in the context of self-help groups. Previously, the research team contacted the heads of the AA and Al-anon groups, and the study objectives and reasons for it were explained.

The data collection techniques were participant observation and detailed interviews. Scripts for both types of techniques consistent with the objectives of the study were developed, agreed upon by members of the research team. As interviewers, two members of the research team, male and female, with anthropological training and a doctoral and master's degrees, respectively, participated.

Observation was performed through participation in fifty meetings in closed and open spaces in which the AA and Al-anon groups conducted their recovery programs; it ended in 2013. An average of 40 people attended these groups: 25 alcoholic patients and 15 family members. In AA, 80% of the participants were men, ages ranged between 25 - 65 years, with the largest group comprised of those between 40 - 60 years of age. In Al-Anon, 90% were women, aged between 30 - 65 years, and the largest group was between 35 - 50 years. Five face-to-face interviews with three patients (men of 43, 61, and 67 years of age), and two family members (women, aged 38 and 50 years) were also conducted at the home of respondents or work center of researchers. These lasted between 90 and 120 minutes; they were recorded and transcribed verbatim. The observations and interviews were conducted in the absence of other actors not involved in the research. The saturation of information was used to determine the end of data collection, to the extent that the information was repeated and did not produce new and relevant knowledge. Finally, the interviews and the survey results were provided to the participants for their comments or corrections.

During the data analysis, two members of the research team were involved. It occurred after an exhaustive reading of the interview transcripts, field notes collected of observations, and the testimony offered during participation in meetings. Given that the disease behavior results from the interaction between personal and social variables, the stages were considered as main themes of such behavior for data encoding, also considering the change process of addictive behavior, according to Prochaska's Transtheoretical Mode and other sociocultural factors influencing the experience of the disease. Cores, or units of meaning, were sought in which the similarities and differences offered by the participants, following the establishment of terms of hermeneutic interpretation[17] . The presentation of the results was made based on the testimonies (T) contained in the meetings, and what was said in interviews (I).

Informed consent was requested of the leaders of both associations, and of the participants. Anonymity, confidentiality and data protection was guaranteed. The study was approved by the Research Ethics Committee of the Universidad de Sevilla (Spain).

Results

Initial stage or perception and interpretation of the signs of disease

The alcoholic patient participants tended to start drinking at an early age, contributing to it was the fact that these people lived with other drinkers, or in an environment in which consuming alcohol was well accepted. In many cases it is seen that the wives of alcoholic patients had similar experiences. *I worked from a young age, "surrounded" by older men and during lunch time they would fill my glass with wine and I would drink it...* (T1). *My father was an alcoholic and when I got married, it turns out my husband is also an alcoholic, whose father is also an alcoholic* (E4).

During the early years, the alcohol consumption by these people was part of their fun, leisure, social relationships. This helped them overcome some personality problems, such as insecurity or shyness, or to improve their relationships with friends, people of the opposite gender, etc., which led them to find benefits in consumption. *Alcohol was like a medicine that helped me fix my personality problems, my shyness, my embarrassment, my fears* (T2). *At first, he would have a "couple" of drinks and he would get chatty, he would make jokes, he was more fun, I would like that about him* (E4). This pattern of consumption, although it was sometimes excessive, was considered normal by the consumer and his own family. *My husband would drink on the weekend and sometimes he would lose his documents. But, I'd always seen a lot of people like that, well I thought it was normal* (E5).

In this first stage of precontemplation, future alcoholic patients considered themselves social drinkers capable of taking control. This prevented them from perceiving or interpreting the model of alcohol consumption as a sign or symptom of disease, although most admitted that from the beginning, their consumption was different from

others. *I remember that other kids would drink maybe two cups, I would drink the whole bottle. I realized I was drinking more and stronger drinks* (E1) Thus consumption would increase progressively, leading them to the loss of control over it up until the crossed over what they termed as the "invisible line". This line separates the social drinker who is able to control it from the drinker whos is unable to do so. Crossing this line meant to lose the possibility of returning to controlled consumption and moving to the progressive development of the disease. *This invisible line is like using a staircase to cross over a very tall wall and, once you've crossed, you see that on the other side there is no staircase and you can't go back* (T3).

Once the person has lost the ability to control consumption, he begins to deny it. This denial also occurred in families that hid the existence of the problem and the patient. *They knew I drank but they thought I didn't drink that much, because my wife would also tend to hide the issue* (E1). These people would often normalize excessive consumption of alcohol and were unaware of the existence of the disease. *Since I was a kid, I was always surrounded by people who drank a lot of alcohol, my father, even my grandfather. The truth is that I didn't know my father was an alcoholic until I started going to Al-anon groups* (E4).

The progressive increase in consumption led the alcoholic patient to prioritize alcohol over other family, work, and social responsibilities, and was accompanied by a series of problems affecting the areas of their life and their family. *This disease is like a puddle of water, when you step on it you splash everyone around you* (T4). *His alcoholic behavior was increasing and I was getting even worse in my behavior and I would end up taking it out on the children, always yelling at them* (E5).

The lack of performance of marital or parental roles by the alcoholic patient was increasingly affecting the whole family unit. *Intercourse was a sacrifice. God knows that it was a sacrifice, the way a person that has that problem smells is indescribable* (E4). *When I came home, my children would hide, they would get out of the way* (T5). *He's not my husband anymore, he's not my children's father, and he doesn't act like it* (T6).

Troubles with the law, such as traffic violations, drunk driving, accidents involving injury to others that sometimes entailed imprisonment, labor problems and health problems resulting from consumption are common at this stage of the disease. *I had a very bad accident, that's when they gave me two years in jail, and then work and I kept drinking and even more* (E1). *It hurts your liver, your pancreas, the shaking, the sweating, and the nightmares. I needed sleeping pills* (E3).

However, it was common for patients participating to not relate these problems with alcohol but to blame them on their families, bosses, friends, etc., with whom relationships were breaking down, causing isolation. In addition, they used these issues to justify and continue drinking. *Everyone else was to blame for my drinking. If I came home and my wife would get angry because it was late, I would go back to the bar and drink some more* (E3). *And you end up alone, your friends, your family, everyone leaves you* (T7).

At this stage, the family became aware of the existence of the problem; they would try to get the patient to realize it as well, pressuring them to stop consuming or to decrease consumption. However, the patient would continue to deny it. *You wanted that person to see it and that person would not see it, and said no, you're crazy, it's not like that, and it's been two beers, and no…* (E5). Also, some patients would request assistance or would enter a rehabilitation center against their will and due to family pressures; once these diminished, they would resume consumption. *I was admitted into a rehabilitation center by force, and the first thing I did when I left was give myself "homage"* (T9).

Family pressures could lead the alcoholic patient to attempt quitting consumption, usually on his own and without seeking help for it, sometimes to the point of spending some time without consuming, but he would eventually relapse. *When he was in a good mood he would say he didn't drink anymore and that he wouldn't drink anymore, and he would spend maybe three months without drinking, but the three months were all bitter* (E4). *I have tried many times. I would stop drinking and after some time, I would start with non-alcoholic beer, and when I felt reassured, I would get them with alcohol, and a little after that I was "hooked" again* (T8). These testimonies helped with understanding that these individuals were caught between two divergent forces: on the one hand the benefits of consumption (as an aid to escape from their problems or prevent symptoms associated with abstinence) and secondly, the negative consequences (including, along with the problems already mentioned, the spiritual suffering characteristic of this stage). *I felt euphoric with alcohol, I forgot about my problems with work, with my family, it was like evasion* (T10). *I would get out of bed and everything would be spinning around, my hands were shaky, horribly fatigued and I would have two drinks and I*

was fine (T11). *It is suffering, after a binge, and pity, and repentance, but you feel so bad that right away you go back to drinking* (T12).

Awareness of the disease

Promptly after a binge, a hangover or accident, feelings of self-blame and regret would appear that made them take a slight awareness of their situation and develop a desire to stop consuming. Even up to the stage of contemplation and preparation, depending on the case. *It's a disease of the soul, it fills you with sorrow. When I was aware of what I had done, I felt pain and regret and I would swear to never drink again* (E3). *You want to stop drinking but you can't because alcohol has turned you into a slave* (T13). In many cases, the alcoholic patient ended by "hitting bottom" and accepting that his consumption pattern was the source of his problems. *You accept it when you don't care anymore, when you have nothing else to lose, when you "hit rock bottom"* (T14). For participants, hitting bottom was related to failing to perceive alcohol as an ally and starting to see it as a cause of one's problems, to stop making sense of an unruly life due to the disease and the problems that it caused. *And then you realize you're nobody in your house, you have no control, you know nothing, you're embarrassed to come home* (T15). *That night when I was coming back drunk to my house, my wife had changed the lock and I slept in the car for three days. I was about to lose my family, that's when I asked for help* (T16). In this way, the patient goes deeply into the preparation stage of the change process that will take him in search of assistance.

Searching for Assistance

In many cases, alcoholic patients looked for help without thinking of themselves as sick. *I would say: an alcoholic is the poor guy living under a bridge, with shaky hands and morning vomiting and goosebumps, that hasn't happened to me yet.* (E2). In many cases, they would not consider stopping their consumption of alcohol, but they would want to learn how to control it. *I never came to AA to stop drinking, I wanted to learn how to drink. Because I was not an alcoholic, an alcoholic was the one with the carton, or lying in the street drinking* (T17).

Accepting the Patient Role

The people who came for the first time to AA meetings, took time considering themselves as sick. The process of acceptance of this role began with a change in the image of what it means to be an alcoholic. *When I was going to my first meeting I thought I would find a bunch of alcoholics drinking and talking nonsense (T18).* The change occurred after observing many alcoholic patients in many meetings, whose images were quite different from what they had of an alcoholic. *I saw people who smiled, they were cheerful, while I had been a long time without smiling (T19).* After changing their preconceived image to that of a normal person with a disease, it provided for the beginning of a process of identification with those who attended the same meeting and, in their testimony, narrated experiences and problems similar to what they had. *You get to a place with many problems, with an emotional mess, sentimental, disordered, my whole body would shake. People who didn't know you, they'd never seen you in their lives, and it seemed like they had known me for years (E1). When I went to the first meetings, it felt like somebody had told them my story, I would see myself reflected in everything they were saying (T20).* Similarly, in the meetings, alcoholism was referred to as a chronic disease. *Alcoholism is a disease, chronic, progressive and fatal, recognized by the World Health Organization (T21).*

Attendees used to describe how they were when they went first to AA, reflecting a similar state as the newcomers also showed changes in their lives with recovery, showing newcomers that there was a solution for their problems, helping them to see alcoholism as a disease that has a recovery.

Recovery Stage

This stage forms the last stage of disease behavior, and must be preceded by the acceptance of the role as a patient. It is noted that the first step in the overall recovery was quitting. *Two bottles of whiskey don't hurt me, what hurts me is the first drink because then I can't stop, because one small dose of alcohol in your body immediately activates the disease process and makes it start, It's like a train, it starts the machine and it's running over all the coaches* (E2). The recovery process of the participants aimed to develop a system of life in abstinence and to prevent relapse. *To recover from alcoholism it is necessary to stop drinking and change actions and attitudes* (T22). *It's a life program, not something to stop drinking, that's clear. But to stay on it, you need to re-learn life, that's what it is all about* (E1). At this stage, the work of self-help groups is essential to keep the alcoholic patient in the action and maintenance stages of health behavior that have replaced the addictive behavior.

Discussion

It was observed that the profile of those studied who were attending meetings of the AA group was similar to other Spanish groups[19].

Since the behavior of the disease involved personal and social factors, the combination of a theoretical approach that provided the motivational change of Prochaska's Transtheoretical Model, with the ethnographic method, allowed us to capture the influence of these factors on the development of such conduct. Indeed, it was observed that the alcoholic patient may have some motivation for change, through the recognition of a pattern of different and higher consumption than most people around them. However, they find many barriers to change their patterns of consumption; highlighting the advantages associated with it in terms of fun, leisure and improvement in social relationships[20], and denial of the problem, based on the belief that this model of consumption is not problematic and that the patient is capable of controlling it. These barriers hinder the identification of the disease[21] and progress towards the next stages in the disease behavior and motivation for change[13-14], often staying in the precontemplation phase.

As mentioned, a central issue in the disease behavior of the alcoholic patient and his family is denial. This denial may be closely related to the social stigma associated with alcoholism, which leads them to hide their situation to avoid embarrassment, marginalization and social rejection[2,6,15]. The consequences are reflected in the difficulty to ask for information and help, even to reject it when it is offered, since it is contradictory to denial of the existence of a problem and in turn to seek help to resolve it. Hence, the importance of a social approach to alcohol in order to remove the stigma attached to patients and their relatives[18].

There is an "invisible line" that separates the social drinker from the alcoholic patient, which is associated with the ability to control consumption. It is the difference between being able to say, "I do not want to drink more" and continuting to drink so compulsively until the person loses count[20]. Binge drinking and loss of control are fundamental characteristics of this disease, because taking a single drink will activate the consumption model. Thus, abstinence programs are recommended for patient recovery versus controlled consumption alcohol programs[5].

Disorders due to alcohol generate an enormous burden on the family and cause large-scale interpersonal conflicts[2,21], since alcoholism is beyond the scope of the patient and settles in the family system. Occurrence of these conflicts is interpreted differently by the alcoholic and the family. The former does not relate them to consumption, remaining in denial and blaming others for his problems. Because of the conflict, the family begins to become aware of the existence of a problem in the consumption model and starts the search for solutions, usually by pressuring the alcoholic to abandon or decrease it. Due to family pressure, patients can accept seeking assistance, but the change will not be effective if they are still in the pre-contemplation stage. In other cases, such pressure is conducive to disease awareness and progress in recovery, demonstrating the importance of involving the family in the process[2].

However, relapses in consumption are common. This could be related to the lack of support or resources, health and social, necessary for recovery and for moving to the action and maintenance stages[13]. The support of health professionals (physicians, nurses, psychologists) is essential, or belonging to self-help groups to facilitate the recovery process [5,16,22]. Another cause of relapse could be the rejection of the patient role. Such acceptance is favored by the recognition that alcohol makes one vulnerable, it causes damage and then one can start coping[4]. Acceptance of the patient role comes by ceasing to consider alcohol as an ally and starting to identify it as the cause of one's problems, the fact of "bottoming out", and family work favoring calling for help and stepping into action[2,9,19,23].

The initial search for assistance is often accompanied by a lack of information about the disease of alcoholism, and the social image of the alcoholic that is difficult for those assuming the patient role and begining rehabilitation. This situation could be explained from the social consideration that alcoholism is not a disease but rather an illegitimate behavior, so that a person with alcoholism does not consider it to be a disease[2,4,6]. As a result, it is common when asking for help that these patients did not think about ceasing consumption but rather trying to learn to control it. This is inadequate in alcohol withdrawal programs[5]. Therefore, the process of accepting the patient role and of behavior change starts with a change in the image the individual has of the alcoholic. After watching other patients attend meetings, an identification process starts with those equals narrating, as part of the AA recovery program, their own experiences[24] that in many cases are similar to their own. To identify themselves as having a disease is a release because

the patient is not considered responsible for his illness. It is understood to be an event that occurs that is beyond his ability to control. For the alcoholic, to be considered a patient is a "beam of light" in the "tunnel" of doom and gloom, which frees him from the burden of guilt that accompanies it. From that moment he understands that he is not a vicious immoral person, but a patient. This promotes behavior change, asking for help, and assuming the role of patient[6,18].

Once the patient role is assumed, it is confirmed with every affirmation and testimony exposed daily in meetings. This is why self-help groups are very useful[22], where coping strategies and the search for appropriate solutions are shared in a therapeutic environment[25], and this eases the acceptance of the patient role. In this sense, the work of AA and Al-anon is highlighted because the challenge to quit using is very difficult if patients do not have the help of friends and family[2,22].

Limitations to this study are the fact that the results of this study may lack external validity, and although these groups are one of the main resources for recovering alcoholics and family internationally, observation units belong to the particular socio-cultural context of Sevilla (Southern Spain), so one should be cautious when extrapolating the findings to other, different socio-cultural realities.

Conclusions

Illness behavior in alcoholics has its own characteristics. Difficulties in the initial stage due to numerous sources of resistance are highlighted, and they become barriers to accepting the disease. This leads them to remain for long periods in the precontemplation stage of addictive behavior without advancing to change and, therefore, recovery. The progress of disease behavior is complex, because of the difficulty in assuming the patient role and reaching the preparation stage. It is common to seek help before assuming the patient role, and in these cases the behavior change is not effective. The importance of family, in a double sense, as a nursing resource that can promote alcohol rehabilitation, and as a group that needs help to tackle the problems of alcoholism of any of its members, is also highlighted. The work of self-help groups throughout the recovery process is essential.

This research has implications for practice and research. It is essential to deepen knowledge on disease behavior for alcoholism which, despite its serious consequences for society and public health, is often denied and presents difficulties in its therapeutic approach, mainly in the field of health institutions. In this sense, the findings are of interest to health professionals and nurses in particular, to improve the quality of the therapeutic process, because they can tailor their interventions, taking into account the characteristics of disease behavior, and motivations and difficulties associated with each stage.

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Received: Sept. 3rd 2014
Accepted: May 3rd 2015