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Taking anorexia nervosa as an object of socio-anthropological study: approach with the research subjects

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Abstract

Anorexia nervosa is an eating disorder that mainly affects adolescents and young women. Although the disease is always associated with body and food when it is addressed, because it is conceived as a psychiatric disorder, the way it is understood is often limited to the field of mental health. The objectve of this ethnographic study with adolescents in treatment for anorexia nervosa in a benchmark public health service in the city of Rio de Janeiro is to describe the daily operations of the institution and demonstrate how knowledge of the disease can be broadened by other disciplinary viewpoints and by adolescents themselves. This paper presents a first approach to the field and adolescents surveyed. It also deals with the construction of the field of research and the "conversion" of the nutritionist into an anthropologist. Such a conversion was needed, among other reasons, to identify the tension within the seelcted health service among health professionals, families and adolescents.

Keywords: Adolescent. Adolescent Health Services. Social Sciences. Public Health. Ethnography. Anthropology Cultural.

Introduction

Eating disorders (ED) are serious diseases and they are sometimes described as psychiatric conditions that affect mainly adolescents and young adult females. They can lead to organic and psychic consequences with high morbidity and mortality.[1,2] They are chronic diseases whose treatment is difficult, with implications for a person's nutritional status, such as malnutrition and obesity.[3] Significantly more common in women (90%) than in men (10%),[4] they are associated with the way people experience their body and (re)organize their body image.[5]

Although it is not totally known how these factors will trigger EDs, they have multiple origins, comprised of psychological, biological, sociocultural, genetic and familial aspects.[1,3,6]

In recent years, there has been a significant growth in both the prevalence and incidence of these disorders in Latin America, with figures greater than those found in the U.S.[7] In Brazil, there are still few population-based studies that address the problem in the population at risk. The few scientific data available come from clinical trials whose characteristics do not allow epidemiological analyses that can help understand the determinants and provide comparisons with other social contexts, so that interventions can be properly guided.[7]

One of the main eating disorders is anorexia nervosa (AN), which has the highest mortality rate among all psychiatric disorders in the world, around 0.56% per year in the population. This value is about 12 times higher than the mortality of young women in the general population.[8]

Anorexia nervosa (AN) is characterized by a person's refusal to maintain a healthy weight for their height, intense fear of weight gain, feed refusal associated with a distorted body image and pathological denial of the condition itself. There is also a relentless pursuit of thinness and amenorrhea.[1,9]

Body image distortion may increase to such an extent that people may feel "fat" even when they are very thin.[10] Often, their family only becomes aware of the problem when weight loss is severe, because dieting is highly valued in many situations.[11]

However, symptoms indicative of EDs and dissatisfaction with one's body image may be important risk factors for the onset of AN. Moreover, partial EDs can become twice as prevalent as full syndromes, with intense suffering for the people affected and their family.[12]

Nervous anorexia nervosa at present

Worship of body image and beauty is not exclusive of the postmodern world, as it has always been common in different periods of history and in different cultures, distinguishing social classes, eating habits, clothing as well as body care and health care.[13] After the second half of the nineteenth century, when NA started to be diagnosed, thinness was defined as a sign of prestige and social status, while fat and heavy bodies were disqualified and represented vulgarity.[14]

Beauty varies by ethnicity, age, social status, societies, cultures and also with individual "taste". However, a beautiful body is currently associated with an aesthetic standard disseminated by the media, which place symbolic value on the slim body.[15] In this context, it hould be noted that food diets, exercise and plastic surgery are largely encouraged by different media, which determine which body type is socially acceptable, which clothes should be worn on each body type, what to do to be someone fashionable and, thus, be successful and admired by everyone.[16]

At present, the standard body and beauty serve as a benchmark for health and quality of life, creating the belief that a beautiful body also comes with personal achievement.[15] The sight of skinny or muscular bodies on a daily basis, conveyed by the media, makes it difficult for people to acknowldge beauty in its uniqueness and diversity, without clinging to unattainable aesthetic standards.[17] Thus, "feeling fat" is very frequent among women, regardless of whether or not hey have an ED, because with a body pattern so difficult to achieve, there is an increasing number of women dissatisfied with their own body image.[18]

Nowadays, the body is the focus of power, which submits such body to the internal discipline of self-control, producing "docile bodies". This docile body can be subjected, used, transformed and manipulated.[19] Because of all the changes potentially made to the body, Rodrigues[20] compares it to modeling clay where society imprints different shapes and patterns according to its will.

According to Le Breton,[21] one can no longer accept the body they have, they need to complete it and turn it into what they want it to be. However, the adaptations to the demands of the modern world can become an impossible task, which requires constant work on the body, as an endless journey.

As regards all the pressure placed on individuals, it should be stressed that the media often play a role within the cultural context of promotion of EDs.[22] In addition, there is a growing market that survives on the appreciation and maintenance of good appearance, with a multitude of products and strategies that transform the body into a "moving business card".[23] People seek to improve their own identity by achieving what is culturally valued, and the time and work invested reproduce the value of these assets.[24]

The pursuit of this ideal, unattainable for many, has led women, in particular, to adopt deviant eating behaviors and inappropriate weight control practices.[17] For Le Breton,[23] the disproportionate attention devoted to the body is not spontaneous whatsoever, but rather a response to social imperatives, as the body currently takes a privileged position in social discourse.

EDs are also relevant because of their degree of association with sociocultural factors.[25] Beliefs relative to AN may differ between cultures and people suffering from AN can explain their self-starvation consciously, through different cultural norms and belief systems.[26] In addition, AN may no longer be restricted to white, middle/ upper class women, because there is an increase of reported cases among black women,[27] in different socioeconomic classes and ethnic groups, as well as in men in Western societies.[28]

However, one cannot deny the influence of the media, including the internet,[27] and its association with the occurrence of AN with motivations similar to those in other Western cultures (with fat phobia, desire to achieve an ideal of thinness/ beauty), which used to be protected by their cultural beliefs.[25]

Lee[29] emphasizes that the role of the media towards EDs should be studied together with the rapid socioeconomic changes that shape young people's daily life and concerns. In Brazil, Gonzaga & Weinberg[28] found an increasing number of patients with ED in the low-income population, who use the ideals of beauty of the higher classes as a source of inspiration. For Weinberg,[30] this finding illustrates the Brazilian reality and shows that the profile of AN is changing, contrary to classic positions that it is directly associated with wealth and abundance.

Men and women are bombarded daily by appeals from different media. However, each gender responds to such appeals in different ways, although a greater number of information is targeted to a female audience. Women, in general, are more vulnerable to the acceptance of social, economic and cultural pressure associated with aesthetic standards.[31]

However, men are also concerned about body image.[32] In general, however, men perceive their bodies with less distortion. Some studies have shown the extreme concern of young people with physical fitness and body mass, rather than weight itself.[33] Nevertheless, some groups of men are more likely to develop an ED, especially those whose professions are associated with an exaggerated preoccupation with weight or body shape, as well as homosexuals. Andersen[34] stresses that thinness, body shape and worked muscles are highly valued by homosexuals, who may be more susceptible to this disorder, as a result.

One of the aspects that contextualize AN as a modern phenomenon is pro-anorexia or the pro-ana movement (ana is the nickname given to AN in online communities). Giles[35] stresses that the pro-ana community is a unique social phenomenon of the Internet age; it could not exist without the Internet, and has no offline equivalent.

Pro-anorexia websites are a place for disseminating information on EDs (where people can learn techniques for weight loss, learn how to hide the disorder from parents and health professionals, and support other people on deprivation diets), especially NA. The goal of these websites is to create a community where the sense of community is built precisely by means of the body.[36] These sites offer support to individuals, thus allowing the perpetuation of EDs in the absence of supervision and treatment.[37]

For the participatants in the "pro-ana" groups, the anorexic condition is a form of stability and control, and a state to be maintained.[38] It is a lifestyle that anyone can adopt, intentionally led as part of an identity and as a way to overcome resistance to medical and social theories about the disease.[37]

The participants in this movement often experience domestic conflicts with their families about their eating habits, which results in low levels of social support at home; Thus, they begin to seek support in online communities.[39] It should be noted that members of pro-ana website visitors describe their identity positively and are more resistant to recovery; visiting such sites also correlates with a delay in seeking treatment.[37]

Much remains to be clarified and the results found in different studies in different cultures may seem confusing, but it is enough to ask whether AN is a disease of the Western world, of modern times, or due to a single factor.[30]

Anorexia nervosa and adolescence: vulnerability and autonomy

Although the profile of people who develop AN is increasingly heterogeneous, with diagnoses being made in pre-adolescents, people in lower economic levels, in developing countries and in different social groups[1,3], adolescents continue to outnumber the cases.

According to the World Health Organization[40] (WHO, accessed in 2012), adolescence is the stage of life between 10 and 19 years of age. The definition of a particular stage of human development, delimited by bio-physiological, psychological and social changes, is a social and historical construction that consolidated during the twentieth century.[41] Adolescence is recognized as the transition period between childhood and adulthood.[16]

The literature indicates that AN mainly affects adolescent girls and young women.[1,6] According to Appolinário & Claudino[6] and Schmidt & Mata,[9] the most common form of AN is expected to occur mainly in young people aged between 14 and 17, although it can appear either earlier (at age 10 or 11) or later.

Adolescence is a time of great physical, emotional and intellectual changes as well as changes in social roles, relationships and expectations, which are often confusing for adolescents and their families alike. The rapid physical changes that occur at this time can lead to preoccupation with body image, resulting in a high level of dissatisfaction and unhappiness about their body.[42] Thus, adolescence is a period which requires readjustments to body image, accompanied by transformations and concerns with the new form and weight of the body.[5]. During this period, high prevalence of dissatisfaction with body image is common, and there is also an increase in the number of cases of AN and BN.[43]

Adolescence is the most vulnerable age group also because it is more influenced by the prevailing body aesthetic standards.[43] Adolescents dissatisfied with their bodies often adopt deviant eating behaviors and inappropriate weight control practices, and they are exposed to a higher risk of developing an ED when compared to adolescents satisfied with their body image.[44]

According to Taquette and colleagues,[45] adolescence is seen to be longer nowadays, which can be evidenced by the early onset of puberty, a longer period of schooling and the delayed entry into the labor market. The authors claim that adolescents seeking health services are socially distinct and require specific actions that can generate bioethical, legal and ethical conflicts.

It is acknowledged that individuals with AN usually do not seek treatment, [46] but when it comes down to a disease that particularly affects adolescents, this issue has other implications. Adolescents, as an age group, are notorious for not taking professional resources into account when asking for help.[47] Os adolescentes formulam um modelo explicativo que entende as aflições como produtos do mundo social. Adolescents formulate an explanatory model that considers afflictions as products of the social world. Thus, if the causes of discomfort are the result of social interactions, welfare should be restablished upon these same relationships and regardless of the adult world.

According to a study by Martínez-Hernáez & Muñoz[47], adolescents perceived that the aspects considered by adults as problematic in their lives necessarily corresponded to the concerns of adults themselves (parents, teachers / professionals), without consideration of the issues and concerns of adolescents per se. Likewise, the discourse of doctors in the hospital does not necessarily define the constructs of adolescents about themselves, about AN, the treatment or their relationships with the healthcare team. In the hospital, the medical discourse is dominant. Thus, the strategies used by adolescents include following the treatment correctly in order to be released and then resume the practices of anorexia; or resisting help and the dominant discourse, trying to reassert their anorexic actions. The recognition of individual differences between patients, and respect for the meanings they attach to their condition, is central to the therapeutic alliance in the treatment of AN.[48]

Health care provided to adolescents has controversial issues, and there is not enough evidence of clinically effective treatments. People living with EDs have been recognized as representative of a group of health care consumers whose level of dissatisfaction tends to be high, and such level may be exacerbated by the attitude of the user towards the disease, because there is usually ambivalence between wishing treatment or not, which can kead to objection to treatment. It is generally reported, however, that parents are more satisfied with the treatment received than their teenage daughters, even when the results are good.[46]

The most difficult aspect of AN management is likely to be the commitment of the person in treatment. This is because the person does not accept that something is wrong, as opposed to the concerns of people nearby,[49] and also because they are reluctant as a result of the positive aspects they receive from the disease.[50] On the one hand, anorexia is seen as a way to achieve the desired results and, on the other hand, as a disease that adversely affects the health and life of the person and their family. Thus, people with anorexia often feel ambivalent about whether to keep anorexia or recover from it.[50]

EDs are usually understood by the layman and sometimes by public health professionals as a weight loss diet that crossed the line for the sake of vanity.[49] It is surprising that individuals who accept the treatment often feel misunderstood by health professionals who treat them, and seek support and comfort of the only people who they believe can understand them, i.e., those with AN.[51]

The treatment of AN through hospitalization is sometimes unsuccessful, with many patients abandoning the treatment or having repeated admissions. Such schemes are seen as being reductionist because they focus largely on weight gain, without considering other aspects of the disease.[48] Often, people with AN do not seek treatment only becacause they fear being forced to gain weight or have their sense of self-control removed.

Hospitalization is the primary mode of treatment for AN when the individual is medically compromised, and the feedback is viewed as the initial and essential step in this process. But often, young people lose the weight they gained in the hospital soon after release.[48] In this sense, nutritionists play a central role, because food is sometimes presented in a reductive way in the hospital. Hospitalized individuals are deprived of all conditions that make people hungry: the smell of good food, its attractive appearance, good company and physical activity to increase appetite.

The contradiction of hospital meals is that they prevent, precisely, the ultimate goal that the treatment seeks to achieve: making patients with anorexia have a “normal” eating behavior. Boughtwood & Halse[48] admit that some girls are physically compromised upon entering the hospital and that a strict new diet is perhaps the first step of such treatment; they point out, however, that it is not desirable that this strategy should continue indefinitely, which is often the case.

When providing health care to adolescent patients, clinical history, dietary habits, personality traits and body image perception should serve as a warning to the healthcare team. Early intervention can reverse the disease process, because, contrary to popular belief, most children and adolescents with AN recover, even those who are considered chronically ill.[52]

Anorexia nervosa in adolescence and the socio-antropological approach

There are still many gaps as for study of EDs, particularly AN, in the fields of social sciences and public health in Brazil. The increased incidence of AN all over the world[53] highlights its importance as a public health problem and, to date, public health policies in the country do not realize its severity and scope of occurrence within the Brazilian population.[7]

The diversity and severity of symptoms, the absence of preventive interventions and the lack of specialized services have important impact on health care services, e.g. unnecessary expenses, often ineffective actions and isolated treatments which neglect symbolic elements and the social environment. To address this issue, an analysis os required to articulate biomedical assumptions with social ones.[7]

Few efforts have been made to empirically establish the meanings that people with AN associate with their behavior, [54] As well as the social processes of circulation and reception of body patterns, and how the latter are involved in the development and maintenance of AN[55]. It is noteworthy, also, that there are few ethnographic studies on the different aspects of AN.[56]

The objectve of the present study is to reveal the meanings that people assign to such an intriguing and sometimes frightening experience, as AN. This is a contribution towards increasing knowledge about this disorder in the field of social sciences in health care in Brazil. The theme of this research is anorexia among adolescents, and it is an ethnographic study conducted with a public health service focused on health care provision for EDs in the city of Rio de Janeiro. It is the first approach to the study object. This paper discusses some aspects of the approach to the field, from an ethnographic perspective.

It is considered that a benchmark public health service is the legitimized, visible surface, where EDs earn official recognition, treatment and care, and the patients, a social identity as such. Immersion into the world of anorexic people implies addressing the reality of suffering and distress, while an important dimension of the disease, which has been overlooked.[57]

This research aims to clarify, from a socio-anthropological view, the dynamics of everyday operations of a public service providing health care for patients with eating disorders, as well as the disease process experienced by adolescents publicly facing anorexia nervosa. It is a socio-anthropological study that includes an ethnographic look into a health institution, which requires long-run monitoring of this service, through participant observation.[58,59] This includes participation in daily activities of assistance to adolescents, as authorized for the study.

According to this approach, human behavior can only be understood and explained if the social context where they operate is taken as a reference.. It is up to the researcher to examine different aspects of the social life of the group studied, through intensive field work, aided by direct observations, so that their knowledge is based on the confrontation between their hypotheses and observations.[59]

This methodology allows the researcher to understand the cultural practices within a broader social context, establishing links between specific phenomena of a given worldview.[59] For Malinowski, anthropologist founder of the ethnographic method, it was necessary to live with the people being studied and participate in their lives as much as possible. In this method, the permanence in the field was essential for the ethnographer to be fully acquainted with the local way of life.[60] In contact with the users within the health service, the usual procedures comprising an ethnographic study were used: informal discussions, participant observation, health records, among other documents.[58,59]

The observation in the research includes “examination” of a person or group of people within a specific context, with the aim of describing them. It differs from any other observation because it is focused on the description of a previously defined problem, which requires specific training [59]. Participant observation is considered to be the primary tool of ethnographic research, which seeks to record respondents’ perspective.[60]

The importance of observation in the field work lies in the fact that a considerable number of elements could not be understood solely by means of oral records or written documents; they must be observed in their full realization.[61]

This study was approved (CAAE: 04846312.6.0000.5286) by the Research Ethics Committee of the Institute of Public Health Research at the Federal University of Rio de Janeiro (CEP/IESC/UFRJ), and it is being developed with adolescents aged between 12 and 20 years, both male and female, contacted by a public health institution in the city of Rio de Janeiro. A second stage of this investigation consisted in approaching some of the adolescents contacted in the health service, in order to conduct interviews. Adolescents were selected as the target based on the fact that they are the most vulnerable age group, where the incidence of AN is increasing.[28,53]

During the contact with adolescents, they are formally interviewed by means of a semi-structured script, in a private room in the health service facility, away from the area of staff circulation and without the presence of parents or guardians, to maintain privacy and appropriate conditions to a good interview. In an ethnographic study, interviews cannot be considered in isolation, outside the context of the research; it must be clear that they should always be analyzed together with participant observation and written documentation. They are long, detailed and recorded with the consent of respondents.[58]

In general, adolescents attend the health facility where the study takes place accompanied by their relatives, parents or guardians. However, they show great embarrassment and keep silent before health professionals who serve them in the presence of their parents. In adolescence, there is a significant incidence of conflict situations, whereby the standards set are insufficient to respond clearly to ethical questions. All research to be carried out with minors under 18 years old needs written consent from one of their parents. This requirement is often hampered by the absence of parents or because young people do not feel comfortable or simply do not want to disclose confidential information.[45]

Thus, it was ephasized that the interview with individuals with AN patients should be conducted without the presence of their parents, with relative autonomy of research subjects, and that should not depend on the consent of the parents, who could intervene in the research context unfavorably by hampering the spontaneous expression of their children. It should be noted that, after a long debate between the researchers and CEP, it was agreed that the Informed Consent Form should be signed by the adolescents, rather than by their parents. This favored the bond between the researcher and the research subject, who contacted, requested authorization and interviewed the adolescents personally and directly.

The adolescents were selected directly in the waiting room while waiting for assistance, away from the health staff, whose absence avoided embarrassment in case the adolescent had no interest in participating in the research. If the adolescent agreed to participate in the research, he or she was interviewed on the same day, after provision of health care by the team, or next time they came to the health facility. The interviews were conducted in a private room, where only the researcher and the respondent can talk.

The interview took place as a conversation, and although there is a list of questions, they are not fixed, so that the adolescents are free to talk about what is important to them and are not be worried about giving “correct answers”. For profiling purposes, the first questions addressed socio-demographic characteristics such as level of schooling, family composition and income, self-reported skin color, place of residence and religion.

When the conversation started, adolescents were free to talk about themselves, what they like to do, how they came to the health service facility, among other questions aimed at trying clarifying how they understand what has happened to their body and their health and how it relates to the diagnosis received from their admission and treatment in a facility that is a benchmark in eating disorders. The script also includes questions about the adolescents' relationships at school, in the family, with affective-sexual partners and other social networks that they appreciated.

Researcher in the field

Conducting this ethnographic research has been a strenuous exercise, because it was necessary to reconcile two identities: the researcher - which begins in the anthropological method - and the nutritionist. The researcher's routine at the clinic was defined at the meeting of the health team early in the morning (when the cases of the day are discussed) and, subsequently, by alternating between observations in the waiting room and observations of the appointments with doctors and nutritionists.

Observation of health care provision is not well understood to date. Sometimes, health professionals went up to the researcher in the waiting room and asked what she was doing there. She explained that she was taking notes of details of the routine, observing the interactions between people, and the answer was always well accepted.

As the observations of the waiting room started later, the researcher already knew many of the adolescents and their parents from the appointments and also from the account of health professionals, through team meetings. Thus, the waiting room has become an essential complement to the observations and notes previously recorded by the researcher in her field diary.

One issue that worried the researcher at first was being identified as a nutritionist. Even though she had highlighted the importance of being referred to as a researcher, the health professionals never introduced her to the adolescents as such. Nutrition training can often be interpreted negatively, since the relationship between the users of the health service and nutritionists is not always friendly, with cases of patients avoiding the appointment, crying so as not to enter the room or making their acceptance of the treatment conditional on the lack of need to have an appointment with a nutritionist. At the same time, the researcher admitted that she had difficulty not playing that role. Both at the meetings and in the appoinments, it is difficult to modify the type of listening that must be done or identify what should be observed[62], especially on nutrition appointments.

The interaction of the researcher with the health team from the ED clinic is friendly, although their relationship is usually limited to meetings and appointments, as there are not many opportunities for informal conversations with professionals during health care provision hours. All of them are aware of the researcher's professional training and the fact that she is a doctoral student doing research with adolescents suffering from AN. Overall, they did not ask her many questions, although some team members were curious.

Field work and contact with adolescents in this investigation have been happening for over a year and a half, in order to consolidate the bond built on interaction in the health service. The "success" of ethnographic fieldwork is closely associated with the social relationship that researchers establish with their informants, and the quality of data obtained is very dependent on this relationship. Therefore, researchers should seek to establish a close relationship based on trust and ethical principles with their subjects.[59]

It is believed that while interacting during fieldwork, researchers can gradually approach healthcare professionals and users, and get familiar with the dynamics of service of the institution, its rules, and then learn how the phenomenon of AN is handled and recreated in that space[63,64] In fact, as activities in the field and the research take place over time, the relationship between researcher and subjects is being built and strengthened. Time on the field is also helping the researcher to gain experience in conducting an ethnographic study. Thus, through questions that are answered, relationships that are built and a constant reflection, the researcher can get to the core of the issue: capture the worldview of their "natives".

As regards the risks and benefits of the participation of adolescents as subjects in this research, it should be noted that these subjects are an important part of the public that suffers from EDs, and it is crucial to gather knowledge of their disease process, as well as reconstruct the route taken by the subjects towards the clinic for treatment. In Brazil, to our knowledge, there are no studies that have investigated, in the anthropological theoretical-methodological perspective, the dynamics of the operations of a public service that provides health care for EDs, in order to understand how AN and the treatment provided by health staff interfere in the lives of adoelscents that face the problem publicly.

Interpersonal relations: health team x family x adolescents

In general, the relationship between the health team and the users is mediated by their legal guardians. They often get into the room together with theor children, although this does not occur with all professionals. For example, the first appointment takes place between the coordinator psychologist, the adolescents and their guardians. In nutrition appointments, adolescents are asked whether or not their parents can stay in the room, but to date there was no occurrence of refusal. In the clinical appoitment this is variable: some patients enter the room alone and, after the appointment, the doctor talks to the parents; and there are also adolescents who enter the room with their parents or guardians. In psychology appointments, the adolescent enters alone. The parents do not always enter the room, or they just come in later. But in the first appointment of the program, the adolescent is usually accompanied by their parents.

In the waiting room, mothers commonly complain about not being able to accompany their daughters in the appointments with thepsychologist, as they know that the adolescents would not speak “the whole truth” but rather hide “things”. In the presence of their parents or guardians, adolescents often keep quiet. Instead, their parents or guardians often participate a great deal, giving intimate details from the early life of their children, which the latter might reveal only much later. Mothers, especially, speak of the reasons for the girls to stop eating, although the adolescents do not always agree, or do not address the issue. Parents or guardians usually ask more questions than the children and give a great deal of opinions on the treatment. The more passive adolescents hear and speak nothing, nor contradict their parents. But there are cases of adolescents who scream and overreact in an attempt to be heard and to have the recognition of their autonomy in matters relative to their body and health.

The health professionals do not react well to this kind of attitude, which generates negative feedback at staff meetings. The professionals have already reacted in different ways: asking parents to leave the room so that only the adolescent continues with the appointment; asking everyone to leave the room and return only after they have resolved the conflict; or leaving the room themselves and stating that the appointment should continue “normally” upon their return.

Some features suggest that adolescents are treated and seen as children, both by their parents or guardians and by the health staff that host them. This can be observed in the field on a daily basis: the TV set in the waiting room only shows children’s cartoons; the waiting room was remodeled and was enlarged for a “recreational” space furbished with four chairs and a table in children’s size, where markers and coloring pencils can be seen. The bookshelf located in the same space has not only textbooks (English, biology, geography, etc..), encyclopedias and educational material on health issues (such as oral health, healthy eating, hygiene), but also children’s comic books. During appointments, although adolescents are users of the service, they have little or no chance of participation. On this issue, Leite[41] says there is a permanent tension between autonomy and protection as part of discussions of attention to adolescence. On the one hand, adolescents are reassured as having rights. On the other hand, their real capacity to anwer questions is challenged on the verge of giving them autonomy.

Many of the advances made in the treatment of AN are based on agreements made between health professionals and adolescents. Strauss et al.[65] pointed out that the process of patient negotiation is a significant contribution to understanding hospital organization. But there are also negotiations between professionals and users and their families. Thus, the hospital can be viewed as a place where numerous contracts are continuously terminated or forgotten, but also created, updated, revised or revoked.

On a weekly basis, as adolescents are escorted by their parents a small change is negotiated. However small such changes are, users say that they will not be able to fulfill them. Given the difficulties of adherence to treatment, the professionals deal with the situation in different ways. Some feel powerless, colluded with the worsening of a situation that can go on for weeks, given the refusal or inability of adolescents to change their diet, change their routine and take medication. Other professionals stop seeing the patient precisely at these moments. Given the fact that the adolescent does not take medication or comply with their prescriptions, the professionals state that they do not want to assist them anymore. In fact, "difficult" patients pose challenges and dilemmas in the relationship between health professionals and users. It does not reflect whether these barriers are due, in part, to the inability to establish professional ties, or even to the inability to deal with adolescents.

Negotiations are successful when the adolescent wishes to resume leisure time alongside friends or do a physical activity that they used to do before the disease. In such cases, users accept the agreement proposed by the health team. In the course of treatment and disease stabilization, the adolescents are now scheduled every five or six months, just for follow-up. However, adolescents in serious condition usually disappear for months, and return later even more sickened.

There are also cases where the parents' relationship with the professional is so intense that at one point it wears away and the adolescent is forced to see another professional because the mother, father or both do not get along with that professional anymore. Family conflicts, always present in the appointments, permeating the relationship between parents and children and between families and staff, stress health professionals out emotionally. Sometimes, the conflicts between parents, with mutual accusations and disputes over custody of the adolescent, interfere in the management of the disease and treatment; sometimes the anxiety and concern of those responsible for the adolescent in the pursuit of further knowledge about the health of their children ruins the professional's attempt to build a bond with the patient with an ED.

The periods of hospitalization are difficult for users and their parents or guardians. The team points out that hospitalized adolescents are very weak, but they quickly eat everything and do not vomit so that they can be sent home. They all reported that the period in the ward (exclusive for adolescents) was very bad. News of the admission or readmission is usually accompanied by crying, pleading on the part of the adolescent, who requests to stay home or have one more chance. Those who violate the agreements made with the healthcare team for many weeks started to be "threatened" with admission, where they will be constantly monitored and lose their freedom. In such cases, hospitalization is adopted as a way to punish them.[19]

Some parents or guardians cannot seem to exert their authority on their children, laughing without realizing the gravity of what is happening, or mistaking their child's behavior for prank. Admission of their child comes as a shock to the family, which often cannot withstand the drama of the situation. The mother of one adolescent who comes to the appointments with her father and grandmother fell sick with depression, given the severity of her daughter's illness. Her father, who is taking care of the house, the other children and his wife, said his daughter is absent from care after hospitalization because he thought she was better and decided to prioritize the care of his wife.

Users develop different relationships with the professional team. As the routine requires them to see all professionals, they say what they wish to say to a particular professional and in the following appointment they do not want to speak again to another professional what they had previously said. Sometimes, they tell a professional that they are not taking medication but ask them to keep it secret from the rest of the team and the family. Some users try to manipulate the professionals who treat them, using the opinion of other staff members. The team do not have a strategy for combined clinical, psychology and nutrition assistance to avoid the adolescent's exhausting set of subsequent appoitments with all the health professionals in the same morning.

Some parents warn the team about their "manipulative" children, "who do whaterver they can not to eat." Parents themselves admit that they are often tricked by their children. Parents' honesty is awarded with the trust of the team, which shall give full support to the victim-responsible, leaving the adolescent - the target of care - in the background.

Final remarks

During the time of observation of everyday operations in the health service, it was possible to understand, in practical terms, what was described in the scientific literature, and to compare the information obtained from third parties on the facts observed on a weekly basis. Feeling the sadness, joy, dejection, excitement and a whole lot of emotions that only contact with the field and with the group that the researcher wants to study can provide, is priceless.

It is recognized that participant observation involves the interaction between the researcher and the research participants. Thus, the information that researchers collect at the end of their work will depend on their behavior and the relationships they develop with the group they observed. In the case of this research, meeting this basic requirement has been a challenge, since the degree of interaction with the health care team and the parents or legal guardians is sometimes higher than with adolescents themselves.

The fact that they are adolescents and their autonomy is not recognized, coupled with the severity of the disease, which makes them even more guarded, has a decisive influence on the observed silence and lack of interest in interacting and having their say on the issues that arise. This fact cannot be ignored or taken as failure; on the contrary, it is perceived as important data.

In the field, this researcher had to learn to control the urge to intervene, to help, to express her views, and allow the emergence of someone who is there with a clear interest in researching, observing and learning from other people. To grasp a social reality, it is not enough to be there; one has to remember their goals, while keeping an eye out for what the field has to reveal and being open to changes which will definitely occur along the route. This task is difficult, but possible, as well as enriching personally and professionally.

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