

Challenges of anorexia nervosa in adolescence: ethnography in a public health service of Rio de Janeiro, Brazil

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Abstract *Through anthropological, ethnographic research, this paper seeks to reflect on the dynamics of the daily functioning of a public health service specialized in the treatment of eating disorders, as well as on the process of illness experienced by adolescents who publicly face anorexia nervosa. The Eating Disorders Program observed in Rio de Janeiro provides both outpatient care and hospitalization. Fieldwork provided the knowledge about care provided to adolescents and their families, as well as the difficulties experienced by the multi-professional team. The closer coexistence of the researcher and health services facilitated the identification of the many challenges that permeate the health professional-user relationship, professional lack of motivation in the face of the complex disease, lack of qualification to treat adolescents, and other obstacles. We seek to stress the importance of this theme for the Brazilian Public Health, with the development of guidelines to orient health services, as well as public health policies that promote the establishment of programs, actions and activities aimed to give visibility and ensure rights for people with eating disorders in the country.*

Key words *Anorexia nervosa, Eating disorders, Adolescence, Health policies, Ethnography*

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Introduction

Eating Disorders (ED) are serious diseases. They are described as psychiatric conditions that affect mainly adolescents and young female adults and can have biological and psychological consequences with high morbidity and mortality^{1,2}. These are chronic course diseases that are difficult to treat, with consequences for individual nutritional status and may favor both malnutrition and obesity³. They are significantly more common in women (90%) than in men (10%), as pointed out in by Teixeira et al.⁴ in their paper review of national and international studies, and relate to the way subjects experience their body and (re) organize their bodily image⁵.

Among the main EDs are anorexia nervosa (AN) and bulimia nervosa (BN), where the latter is more frequent than the former, although the former shows higher morbimortality⁶. AN is characterized by the individuals' refusal to maintain adequate weight for their height, intense fear of gaining weight, refusal to feed associated with distortion of the bodily image, and denial of their pathological condition².

As has been conceived in the scientific literature since its identification, it has become usual to associate women with the occurrence and propensity to the disease and minimize its expression in men⁷, which should be considered with caution. Because it is uncommon in boys, health professionals should be alert when they identify severe malnutrition with no apparent cause, since the rapid onset of treatment is essential for a good prognosis⁸.

The studies^{9,10} that dedicate themselves to adolescence as a generational segment most affected by ED seek to attribute illness to the characteristics of age, such as the importance given to peer evaluation and the need for social acceptance, as predisposing aspects to develop such pathologies.

Some Brazilian and foreign authors have pointed to the lack of ED-focused ethnographic data in health institutions¹¹⁻¹⁴. Krauth et al.¹² state that although they are rare, when compared to other pathologies, AN and BN should be of great social interest due to the high financial costs to health systems and the health impact on the population, especially among young people.

However, in Brazil, only a few, rare studies measure the problem in the population at risk¹³, as well as public ED-related health services^{13,15}. International studies point to the scarce information available to guide professionals in AN treatment¹⁶. Works that are geared to patients' view-

points shows that, for these patients, AN does not only mean a concern with food and weight, but is a way of addressing the complex social relationships, and it is surprising that treatments still invest in an individualistic perspective of care.¹⁴

In addition, a gap is found in the curriculum of undergraduate health courses, since in many cases content is not considered to enable health professionals and teams to address the problematic aspect of the issue¹³.

The scenario found indicates the relevance of the theme to Public Health, especially for Brazilian adolescent health¹⁷. The research was developed in a public health service in the city of Rio de Janeiro, evidencing a dramatic institutional care context, with secondary care provided to adolescents with ED and their families. It is crucial to think about the organization of health policies and the provision of programs and services that can fully serve the adolescent population with ED.

This study aimed to understand, from the socio-anthropological point of view, the dynamics of the daily functioning of a public health service that specializes in attending ED, as well as the process of illness experienced by adolescents who publicly face AN. In this work, priority was given to addressing the challenges inherent in the care of adolescents, setting their subjective experience of illness aside for later review.

Methodological and ethical aspects

This is a socio-anthropological study that used the ethnographic method¹⁸ to understand the operational dynamics of the Eating Disorders Program (EDP) geared to adolescent care, located in a public hospital in Rio de Janeiro, with fieldwork conducted between November 2011 and September 2013. The name of the institution was kept confidential for ethical reasons.

The theoretical approach of the research problem considered its sociological realms¹⁹, highlighting its chronic course^{20,21} and the possible appropriation of the disease process by the suffering subject as a way of self-constitution or, in other words, individualization²². The fertile ethnographic perspective²³ in health services allows the monitoring of social interactions among adolescents, their relatives, and health professionals, to capture the meanings and conflicts involved in the negotiations and decisions for the treatment, as well knowledge of the different ways of understanding the disease and its coping.

The research proposal included, initially, observing the meetings of the team of professionals of the Program, the medical and nutrition consultations and the waiting room, where adolescents and their families await care, in order to capture the operational dynamics or, according to Malinowski²⁴, “the imponderable things of real life”. Subsequently, we sought to interview users under treatment in the Program to ensure a specific moment of listening and dialogue with adolescents in follow-up outside the routine of care.

Thus, observation of daily care was recorded in a field diary, for a period of 22 months, with weekly visits by the same researcher on the day the outpatient clinic was operational. Later, 11 adolescents aged 12-18 years were interviewed, ten females and one male, reflecting the unequal distribution of ED between men and women, since there were only two male adolescents in regular care in the EDP. The criterion for inclusion in the study was to be in follow-up at the service, and all who met this requirement were invited to the interview. The names used are fictitious, to preserve participants’ anonymity.

The interviews were held at the end of the care shifts when the offices were empty. Thus, there was no risk of interfering with the routine of appointments or interrupting the interview. The analysis of data gathered the field diary, coming from participant observation, and transcription of the interviews, and were organized through the axes of interpretation: the adolescents’ subjective experience of illness; the care of adolescents and their families and the experience of hospitalization²⁵.

With an interdisciplinary approach, the EDP has been serving adolescents of both genders suffering from AN and BN. It was created in 2005, with an outpatient clinic that operates weekly and has a team of psychologists, general practitioners, psychiatrist and nutritionist, as well as residents of these specialties. We highlight the relevance of this space within a service exclusively aimed at adolescent health, an audience admittedly more affected by the ED. In the program, most adolescents are under 16 years of age and recognized as “vulnerable” subjects by legislation regarding human research ethics²⁶. Considering that the adolescents attended the consultations accompanied by their guardians, who ended up taking the place of the children in the interaction with the health professionals, the reproduction of such mediation was avoided in the contact of the researcher with the adolescents, regarding the written authorization for interview. Thus, the

researcher’s contact with those responsible was usually performed in the waiting room, accompanied by their children, when they were invited to participate in the research, with the knowledge of their parents. We evaluated at the time that waiving the Informed Consent Form (ICF) of those responsible would be essential in the construction of the link between researcher and adolescents in this specific context in which the decision-making power of adolescents was already significantly reduced by the presence of the disease. A reasonable proportion of those receiving care does not do so voluntarily but constrained by their guardians. The inclusion of adolescents in a research without their interest in participating would undoubtedly compromise the data obtained in the interviews.

Thus, the Research Ethics Committee of the Institute of Collective Health Studies of the Federal University of Rio de Janeiro approved the suppression of the parents’ or legal guardians’ ICF (CAAE: 04846312.6.0000.5286), and the request for formal authorization (ICF) and link of the researcher established directly with the adolescents, a realm that was crucial for the approximation, interaction and immersion in the social universe of these users.

Difficulties and challenges in addressing adolescents with eating disorders and their families

From the definition of a precise diagnosis, the management of family conflicts that arise from the illness of an adolescent child, the many occasions in which patients abandon treatment with relapses and new hospitalizations, to the dramatic confrontation of suicide attempts, there are many challenges facing health professionals who receive adolescents with ED.

Delicate relationships: intermittence, mistrust and (dis) agreements

The relationship between the health team and adolescents attended at the EDP was mediated by family members, and it was common for them to enter the clinic with their daughters (during the survey, most adolescents attended were women, so it was decided to address them as females), although this did not occur with all professionals. It is recognized that evaluation of children’s health is often based on parental responses²⁷. Because they were accustomed to pediatrics services, where they were always present, or

even because they did not trust that their daughters would be able to establish a doctor-patient relationship autonomously, those responsible did not approve of the professional attitude of being heard at a different time from care. Many felt the need to tell the team what was happening, believing they had in-depth knowledge about what was going on and sometimes leaving little room for teenagers.

In the presence of those in charge, adolescents often did not express themselves, even when the issues were addressed to them in particular. They seemed to avoid contact with the world around them, although their silence did say more about their condition than if they tried to answer the questions of health professionals²⁸. Introspection of adolescents with AN is a recognized trait of its carriers and consistently established in the scientific literature^{29,30}. Instead, those in charge used to be very engaging, providing intimate details of teenage life that might be slow to reveal. The challenge of the team is to consider both adolescent-child and responsible as a complementing dyad, without neglecting the account and the bond with who is sick and requiring treatment. Many of the advances in AN treatment were based on agreements between health professionals and adolescents. Strauss et al.³¹ emphasize that the negotiation process of patients with health professionals is a significant aspect to understand the hospital's organization. However, we still have professionals' negotiations with users and their families. Each week small changes were harshly negotiated, and however small, users announced that they would be unable to meet them, revealing the degree of suffering involved in coping with the disease and the attitudes required to recover it.

Faced with the difficulties of adherence to treatment, professionals deal differently, which evidences unpreparedness to address specific behaviors proper to this life stage. Some health professionals felt powerless, conniving with the worsening of a situation that could last for weeks, due to the adolescents' refusal or inability to change their diet, routine, and medication intake. Other professionals, perhaps out of despair or distress before what they could not change, would abandon the patient right in those crucial moments. In fact, "hard nut" patients impose enormous challenges and impasses in the health professional-user relationship. It is necessary to consider whether these obstacles are not due, in part, to the difficulties of the professional to establish links or are unable to address adolescent

patients, since not all of them receive specific training to do so.

There were also disagreements between the team's demands and the social conditions of the adolescent and her family to comply with them. One of the adolescent girls was never able to attend the scheduled appointments and routinely arrived when health professionals were about to complete them. She was late, missing a lot, disappeared from the service, but in the midst of the whirlwind of adolescent personal issues, her family lost all it had, facing severe financial constraints. However, the team did not consider the efforts of her father and the adolescent herself to keep attending as much as possible.

The comment of one of the health team members about adolescents' "leaves", that is, not showing up at the service, reveals how much back-and-forth in the treatment process are frequent, expected, and are part of ED routine daily care. The team tasked with making healing possible are at a loss vis-à-vis such "dropouts" and setbacks. The view that adolescents get "tired" of the treatment is shared by all staff and highlights the intricate nature of the problem, which also corroborates the understanding of relapses and temporary treatment abandonment.

There were cases in which the parents' relationship with the health professional was so intense that at one point it would wear out and the adolescent would be forced to change professionals or spend time without that care. Family conflicts, always present at consultations, permeating the relationship between parents and children and between families and staff emotionally strain health professionals. One has to be very skilled at unique listening at different times or together when the consultation requires the presence of both. Demanding serenity, maturity, and emotional balance of families in the face of the severity of daughters' illness can also be far beyond what they can provide. Such an equation makes the challenge of treating them more painful for those who are at the frontline, concerned with dietary routines, weight gain, body balance, without being able to change the family dynamics that they witness.

The users developed differentiated relationships with the team's professionals. As the routine of care requires circulating among all professionals (psychology, medical clinic, nutrition, psychiatry), they ended up saying what they wanted to a professional and in the subsequent consultation, they expressed not wanting to say again what had already been said. They told some professionals

that they were not taking the medication, but they asked the rest of the staff and the family to keep it a secret. That is, they selected what to say, to whom, and when.

Some users tried to manipulate the professionals, using the opinion of other team members. They assumed that they were often “taken for a ride” by their daughters. The sincerity of those responsible was rewarded with the credibility of the team, which started to give full support to the “responsible-victim”, leaving the teenager in the background. On the other hand, the teenager was seen with suspicion, even without necessarily having done something to deserve it, hindering the establishment of a bond with the team. The power of manipulation of individuals with ED is consensual among health professionals, although families sometimes morally condone such an attitude. It is up to the health team to point out that this adolescent posture is not a moral flaw, one of character, but one of the symptoms of the ED³².

Care in adolescence

It is sometimes difficult for health professionals to understand the conflicts inherent in adolescence, which ultimately compromises their relationship. By seeking autonomy, accepting adult assistance can be understood by the adolescent as an inability to solve their problems alone. It also happens that adults often identify a problem in the adolescent's life that is not necessarily a nuisance to the teen. On the contrary, adolescent complaints can be conceived by adults as secondary, subjective, irrelevant and the result of a “difficult stage” of the life cycle³³.

In health services, in addition to the unpreparedness to treat adolescents, the team also expresses a value judgment towards this group, considered as “rude” and “permissive” among their peers, increasing the difficulties of relationship and the establishment of links³⁴. Regardless of personal stance or inability to listen and respect adolescents, it is necessary to reinforce the need to maintain an ethical position as a health professional³⁵.

In the field, it was possible to follow cases of EDs that were difficult to treat in which attempts at suicide and cuts/mutilations were frequent. Sometimes these situations were identified as ways for adolescents to draw the attention of adults, and were trivialized: “deep down, it's just about drawing attention”. Such understanding reveals how hard it is for a team that was not necessarily “trained” to attend ED and may not have

the desire or ability to work with the adolescent population, having to do so. Because it is a public service, professionals have a limited capacity to refuse to take care of this or that case, even if they are not sure to do so.

The Adolescent Healthcare Manual³⁶ of the Health Secretariat of São Paulo brings as its theme the “Characteristics of the professional and the doctor-adolescent relationship”, providing the following recommendations, which can be extended to all health professionals:

Attending teens requires interest, time and professional experience. A good doctor/adolescent relationship is fundamental to obtain a fruitful consultation and is only possible if the doctor LIKES to work with young people since they have a keen sensitivity and soon perceive lack of interest or empathy. The professional must show competence, firmness, and authority without, however, seeming authoritarian. Doctors should listen more than talk and not judge or give clues. However, they must clarify and inform where necessary, always with rectitude, honesty, and truthfulness, which is different from a warning. [...] Adolescents should identify themselves as clients, but, on the other hand, parents or guardians cannot remain on the sidelines of the service, because they can benefit from information and clarification³⁶.

Due to the amount of “rules” and “details” advocated for proper care of the adolescent, it is not uncommon for members of a health team to be insecure about attending them. In this regard, it is worth emphasizing that definitions within the health service should be taken collectively by the team. With the uncertainties surrounding moral, legal and ethical issues, insecurity intensifies if the health professional is forced to shoulder such decisions alone³⁵.

Different documents³⁵⁻³⁷ aimed at health professionals attending adolescents have the same recommendation: group activities, aiming to provide a space for the exchange of experiences, where the teenager feels safe. In a group, each participant becomes less fragile, less solitary and others can value their ideas, issues, feelings, and experiences³⁶.

Besides, activities in a program for adolescents should show a broad focus, shifting the attention from technical and biological aspects, also involving psychosocial, social, cultural, and political issues, noting that the health professional should feel apt to deal with this complexity of knowledge³⁸.

Coupled with the difficulties of some professionals to address unusual aspects of adolescent

care, there is an enormous challenge of treating and seeking the recovery of a person affected by ED. Individuals with this disorder are described as resistant to interventions, contributing to one of the highest rates of refusal and early withdrawal from treatment³⁹.

One reason for resistance to treatment is the fact that many people with AN deny their illness because they consider that they are seeking weight loss on their own. On the other hand, at a certain point in their illness, they may be able to identify the negative implications for their health, their lives, and close people's lives, causing feelings of loss of control⁴⁰.

Patients with AN seldom seek treatment on their own. They have little motivation to change, and treatment outcome is generally below that expected by the health team⁴¹. Moreover, it is common for patients to see health professionals as an enemy who wants to make them gain weight⁴², which does not always mean that they do not wish to be treated.

The challenge faced by health professionals includes recognizing the differences among adolescents, always respecting the meanings they assign to their illness. To do this, they need to understand that the experiences and perspectives of adolescents about illness and treatment may be radically different from the viewpoint that the health team feels comfortable to act⁴³.

Due to the difficulties evidenced, it is possible to think that every relationship is a "two-way street". The routine of the Program's health team is a lot of dedication and effort without, however, receiving a positive stimulus for their work. The patient who recovers from a disease shows gratitude to the team that attended it, but in the case of ED, recovery involves adolescents gaining weight and this ends up discouraging them and further distancing them from the health team, who needs to be continuously stimulated, even with such adverse reality.

Adolescent's voice

Despite the observed program being inserted in a broader adolescent health service, the way in which care was organized was not always shaped by its needs and aspirations. When asked in the interview, most adolescents evaluated the program thoroughly. Among the reasons for the positive evaluation of the care received was the fact that it helped them to realize that what they did was detrimental to their health and the conditions of care, gathering physical space, health

professionals, and available tests. The only adolescent who said she thought it was "boring" to go to the clinic was because she had to "talk". In fact, his complaint lay in the fact that she had to repeat three or four times the same thing in the same morning in each of the sessions she attended, which made that flow exhausting. Thus, besides being repetitive, queries become demotivating.

The medical questioning *Can't you think of a more adult way to solve this?* illustrates how difficult it is to be a teenager. On the one hand, they are in the health service, taken by relatives and often attended in their presence, wholly guarded, without a voice, and at all times are required to submit and obey the institution's rules. On the other hand, they want them to behave like adults, to face the typical problems of this stage of life as adults, and they are usually treated as children.

The above question arose when a teenage girl arrived for treatment with injuries from the cuts she had inflicted on her body. It takes much sensitivity to address such cases, and the family is not often prepared, it is not something simple to understand and face. The family members are lost and do not find this support in the program since there is an activity planned to receive parents and guide them on this issue.

When asked to qualify the "good care" received, the adolescents emphasized the amount of information provided, showing that they value well-trained health professionals or the simple fact that they had been *concerned, tried to help, done something*. Expressing what they feel is valued by them: *It's very cool here... because they talk here... they care about what we think... what we're feeling...* Having the autonomy to speak what one wants in a service aimed at teenagers (and not adults!) was something that surprised them positively, when in fact it should be the norm.

In addition to the repetitive questions, they also assessed as harmful in the care received the fact that health professionals are constantly condemning adolescents' attitudes and not "listening properly", not giving a voice to patients and not basing their care on what is being reported by them. More than one teenager signaled that enduring "too much pressure" has been the worst thing for the treatment. Natasha, 16, explains clearly how she assesses this situation:

(taking a deep breath) *I think when you start to want to force "you have to!", it's bad! Put pressure... Because we already feel pressure, because we know it's terrible! [...] then, there is pressure from people, society and being pressured to improve*

something that we do not control is more difficult. It's much pressure!

When asking the interviewed adolescents for tips on how to organize a program to attend to ED, suggesting group/joint activities among the patients that promote sociability among adolescents suffering from EDs was almost unanimous.

I think it's cool when you put people who have gone through it... Because I remember at my first session [...] you're already scared, then you see a person who has improved! There's hope, you know? You see that it's not just you suffering from it... (Natasha, 16)

It would be nice to have some girls who have gone through this and healed, they are fine, getting on with life, without worrying about the appearance. [...] For us to see that it is possible! (Silvia, 16 years old)

I saw a girl here once, that girl looked like a real skeleton! So I have a problem, but maybe I'll help her... (Ester, 13)

I think what would work was not to make the treatment a sort of punishment [...] if they came here and it's a series of questions, a serious thing, a hostile environment, it will not work! (Yasmin, 17 years old)

When reflecting on some recommendations to improve the health care provided to adolescents with EDs, support groups would be a welcome strategy, both for the relatives who voiced how much they were lost and for the adolescents who sought to share their experience of illness with others going through the same situation. However, it is important to emphasize that the desire to participate in joint activities was not unanimous, so, besides being consulted about participation in these group activities, they cannot be implemented in standard fashion, since there is immense diversity in the ways of experiencing adolescence.

The proposal for a more stimulating activity that promotes integration in a life stage where the development of social relationships is central is what they aim for. A program aimed at this audience cannot minimize the establishment of links between its users and their parents^{27,44} as a way of providing mutual help networks, therapeutic support groups to stimulate and attract the interest of adolescents in keeping with treatment sessions.

Final considerations

In order to gather some proposals of the adolescents interviewed, it would be interesting to integrate new goals to the treatment, coupled with the promotion of sociability between them, withdraw the focus from restating body weight, calories, fats and to give importance to what they emphasize as necessary: building a good therapeutic relationship, attention to their emotional and psychosocial aspects, gradual shift of attention to other daily life activities, related to studies, fun, leisure... They demand more and more responsibilities that enable them to exercise different levels of autonomy. It would be important for the health service to seek a balance between the hardships and strengths of each adolescent, as well as worry about intermittent dropouts, making them genuinely aware that recovery is important for the health team⁴⁵.

Another possible proposal for the resolution of the adolescents' complaint about the need to repeat the same information in three or four consecutive consultations in the same morning would be the collective attendance by the health team. Thus, a welcoming environment could be created so that adolescents would feel encouraged to speak out and be heard by the team as a whole, avoiding attrition for all parties.

Taking into account the national reality of ED care, the aspects raised in this research may inspire new proposals that consider the training/qualification of health professionals to provide adequate care for adolescents; adequate financial remuneration of the health team, usually consisting of professionals who work on a voluntary basis, motivated by interest in teaching and research in this area of knowledge, which increases the difficulties in structuring a stable and competent interdisciplinary team¹¹.

Most ED-related health services are assigned to public universities whose budget distribution often makes it impossible to hire specialized professionals only to work in these spaces. Besides difficulties of maintaining available services and creating new treatment centers are the lack of any guidelines or public policy aimed at ED care¹¹, as well as any effort on the part of the State to determine the prevalence of these disorders in the country⁴⁶.

It is important to emphasize the importance of inserting the TA in the agenda of discussions on adolescent health care and definition of a future action plan, considering the investment in the training of specialized personnel. It is necessary to

expand the early debate in the country on the definition of public health policies that focus on ensuring the access of ED patients to a health service geared to their needs, with an adequate physical structure and trained health professionals.

We have to value the work that has been carried out, with all the difficulties pointed out, which are common in other public health services, and characteristic marks of the national context of ED care. However, much more needs

to be done. Since seeking space for research, the reality of ED care has turned out to be dramatic. The reconstruction of the therapeutic course of these adolescents was an impossible task to fulfill, due to the scarce and poor initiatives that do not dialogue with each other. The alternative of ethnographic research was especially fruitful to give visibility to such problematic and assign centrality to those adolescents who often are not heard, remaining silent even having much to say.

Collaborations

PS Castro worked on the design, outline, data analysis and interpretation and paper drafting. ER Brandão worked on the design, critical review and approval of the version to be published.

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