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The difficult longitudinal care of a female patient in a severe chronic situation: analysis of an emblematic case

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Ethical problems faced by professionals of primary care are complex, due to their emergence in unique situations, caused by the multiple dimension of care. The followup of patients resistant to treatment, which are difficult to care are cases that demand a differentiated handling. The article reports the analysis of a case of tough follow-up by a primary care team. The case emerged in a qualitative research about ethical problems, which took place in a municipality of the metropolitan region of Porto Alegre. The data collected by focus discussions regarding ethical problems and its possible ways of solution. To overcome the difficulties of the therapeutic relation between users and practitioners, the results pointed out to the need to enlarge the understanding of the health needs, recognizing the relational context of the application of clinic proceeds and the significance of the subjective experience of illness.

Keywords: Primary health care service. Health services needs and demands. Delivery of health care. Communication barriers. Bioethics.

Introduction

In general, the tertiary hospital level of healthcare is defined as complex due to its gradual technification. However, those who assume an amplified view of the health-disease process argue that the complexity is present predominantly in the primary level, as it is there that the psychological, social and cultural determinants of a continued attention emerge. Technological resources are more implicated in tertiary care, configuring ethical problems related to patient care. In primary care, assistance is configured by the human and sociocultural delimitations of the user who is longitudinally followed up in his/her existential path. Due to this, the ethical problems faced by primary care professionals are more complex, as they involve the incidence of diversified human determinants interwoven with each other and connected with the person's life. They cause the emergence of unique and stimulating situations as regards the provision of care.

One of these challenging situations for healthcare professionals are patients who resist assistance and are difficult to handle. Because of their reactions and behaviors, they require a differentiated assistance. Due to this, the primary longitudinal follow-up of difficult patients has its own complexity, as it involves comprehensiveness in patient embracement and temporality in the provision of care, that is, considering the singularity of the patient's case and ensuring continued attention to the temporal course of this situation.

The issue of difficult patients has been approached in the literature. The discussion generally focuses on the cause of the difficulty, identified through the association of the disease with psychiatric and psychopathological states[1-5]. According

to these authors, the problem lies in patients' behaviors that stress the professionals' assistance. However, they do not ask themselves why the patient reacts negatively to what is proposed to him/her as a benefit.

Due to this, the emphasis has shifted, in recent times, to relationships between patients and professionals that are difficult. A cohort study has shown that the problem in the interaction is caused by patients' expectations and level of satisfaction concerning the professional's action. Generally, these patients have diverse severe symptoms, a deteriorated functional status, and high utilization of clinical services associated with mental disorders. On the other hand, in these difficult encounters, the professionals have inadequate psychosocial attitudes and little experience of treating patients with a difficult therapeutic condition[6].

In view of this change in perspective, recent articles propose strategies to overcome difficulties and improve the encounters. For example, the professional can reflect on how the singular elements of this case can affect the relationship negatively, how he/she feels about treating this patient and how this assistance is included in his/her agenda of the day. Becoming aware, in advance, of the patient's singularity can create the conditions for an encounter that produces better results[7]. It is about shifting from a defensive to a collaborative attitude towards difficult patients, sharing the responsibility for their care and using coping strategies. To achieve this, the professional must collect information to understand the wholeness of the ill person within his/her family and sociocultural context, reflecting on the way of conducting the consultation, facilitating the patient's coping based on these data, and avoiding stress in the encounter[8].

Fiester[9] argues that placing the problem on the patient's physical and mental pathologies is an explanation that is not only insufficient, but also ethically irresponsible, as it does not explore deeper causal dynamics. That is why he defends that it is necessary to completely rethink the way of understanding and treating difficult patients, focusing on relationships and considering their fracture and difficulty as an ethical question. Although the doctor had the best intentions, if the patient does

not feel he/she has been well treated and hampers the relationship, this generates the ethical duty for the professional to remedy and amend this sensation. This obligation has nothing to do with whether the damage is real or not; it depends on how it is perceived. If the professional's behavior is reactive in relation to the patient, the solution is to change the perception about him/her to be able to improve the encounter's atmosphere and the patient's conduct in the relationship. Therefore, if the problem lies in difficult relationships, it poses an ethical question to professionals[9].

If this analysis applies to any clinical relationship, even more so when it happens at a primary care service, because there is a closer follow-up included in the patient's experiential context, and care is provided over the person's life course. In this context of health monitoring, difficult relationships are more frequent than in any other service, and it is fundamental to analyze these situations to help professionals perceive what elements are interfering in the quality of the encounter and improve the atmosphere of the clinical relationship. That is why it is important to evaluate primary care in the perspective of user embracement, bond-accountability and quality of care, as putting these concepts into practice may influence the construction of comprehensiveness[10].

Based on the theoretical framework, we will discuss here a case of difficult follow-up involving a user with a severe condition of chronic disease. The case emerged in a study about ethical problems in the primary care service of a city located in the metropolitan region of Porto Alegre (Southern Brazil). This case was reported during the focus discussion for the data collection of a qualitative study involving seven family health teams, with the aim of recognizing the ethical problems that the professionals faced in their practice and the solutions for them. One of the teams provided a long report that described, in detail, the clinical condition, the assistance practice and the difficulties related to the follow-up of a user who had multiple complaints and created a high level of stress in the professionals. We decided that it was worth taking this report as an emblematic case of longitudinal assistance in primary care to be analyzed and discussed. The project was approved by the

university's Research Ethics Committee through Resolution 031/2013 and all the professionals signed the consent document.

Case report

The lengthy description delivered by the team was summarized in the report below, in which we attempted to provide basic and important elements to explain the case of the user who we fictitiously call Rosa.

Rosa is 67 years old, illiterate, does not have children, and used to be a sex professional. Today she lives with a partner who is always absent because he works all day. Therefore, she is alone most of the time, working at a bar. She takes advantage of the fact that she lives in front of a cemetery and sells flowers. Rosa needs a wheelchair for mobility as a result of an anterior lower limb amputation. She presents serious injuries in the fingers, caused by vascular problems, diabetes, and hypertension. In addition, she is a heavy smoker and has great difficulty in adhering to the treatment and changing her lifestyle.

During the process of care, she has multiple complaints and requests, and calls the healthcare unit many times. She addresses the professionals using vulgar language and offends them verbally, but, on the other hand, she becomes intimate with the team by giving them flowers. Without the team's approval, she requests the help of a neighbor who is a manicurist to apply dressings to the wounds, and this person even extracts nails and necrotic tissues using nail cutters. Guided by this initiative, Rosa suggests that the nurse should dress the wounds in the same way that the neighbor does, and tries to direct the way in which the professional should perform the procedure. The team dresses the wounds three times per week. On the other days, this is performed by the neighbor, without following the medical and nursing orientations.

The complexity of Rosa's case demands of the team a non-traditional approach based on equity, as care is provided at her home and requires a permanent and differentiated assistance. However, the team itself wonders whether such assistance is

characterized by equity, as the user exceeds the limits of the relationship by requesting domestic actions that are not part of the care and by trying to direct the form in which the team must act in the clinical procedures. Furthermore, any success the user has in relation to her wounds is a result, according to her, of the neighbor's work, and she declares this verbally. Rosa's independence and disorganization regarding medications and her lack of adherence to the treatment, with the consequent worsening of her clinical condition, create serious difficulties for the care that is provided for her. These difficulties generate, in the professionals, feelings of frustration, impotence, discouragement, exhaustion, and impatience. Due to these difficulties, the team automatizes the assistance and the professionals take turns at providing care for Rosa.

Case discussion

In Rosa's case, one cannot simply blame the user for the difficulties in the follow-up; rather, one should ask oneself which elements and circumstances interfere in the relationship and make the encounter become difficult to the professionals. On the other hand, it is necessary to question the way in which the professionals see the user, as this may produce defensive attitudes in them that may be the origin of Rosa's stressful behaviors. This means assuming an ethical perspective to analyze the case, in which it is necessary to highlight the relationship, especially the two subjects of this relationship: the user and the professionals. Both must perceive the threads that weave the relationship and how these threads influence the quality of the encounter. However, the initiative of treading the awareness-raising path must be taken by the professionals, as Rosa's dissatisfaction becomes, to them, an ethical responsibility. They will have to reflect on, become aware of and react to this difficulty, improving, as much as possible, the quality of the clinical relationship. This means replacing the defensive reaction by a propositional attitude.

Three issues deserve to be analyzed in Rosa's case, as they seem to influence the quality of the therapeutic encounter: 1) Has the follow-up established, with the user, her real health needs or does it just take her demands into account? 2) Is the professionals' assistance based on the relationship or has it been reduced to a mere automatization of clinical procedures? 3) Is the model of clinic applied to the case able to take the user's subjectivity into consideration or does it respond to purely biomedical parameters? It is possible to notice that the three elements are intimately connected and involved in any clinical assistance at the primary care level: health needs, therapeutic relationship and attention to subjectivity.

User's health needs

Generally, the search for a health professional's assistance is caused by the experience of a lack, and the professional's intervention is understood as the consumption of some input or procedure that has a cost and is characterized as a demand. The result of this intervention and the intervention itself are recognized as needs and the services are organized to meet such demands. To rationalize these demands, three levels of care have been organized: primary, secondary and tertiary. This stratification responds to the consumption of a diversity of technological interventions that meet needs that are known and naturalized as demands, but it is possible to ask whether there would be other needs that have not been named and are beyond these established interventions.

In the case studied here, the professionals attempt to meet Rosa's demands in the best possible way. Her demands are understood as procedures that can improve her health status. However, they are disappointed because she does not adhere to the treatment; on the contrary, she prefers the measures taken by her manicurist neighbor concerning the serious wounds in her fingers. This attitude stresses the professionals, but they do not ask themselves if Rosa would have other health needs that are not solved by strictly clinical procedures. They neither ask for nor encourage Rosa's

narratives about her happiness projects[11]. The fact that she trusts the manicurist more than the team is not an alternative to their clinical procedure; rather, it is a sign that there is another health need that the professionals do not meet, connected to personal esthetics and her former profession and which points to a happiness project. Instead of being stressed by her apparent rebellious nature, they could ask themselves what need is targeted by this attitude that is not satisfied by them. However, to achieve this, it is necessary to let these hidden needs emerge and be recognized.

Due to this, Schraiber and Mendes-Gonçalves[12] have proposed the creation of spaces for the emergence of needs in the organization of healthcare services that are not dominated by professionals. Such needs regard daily-life lacks related to illness and recovery that are not assumed by traditional science and are not included in assistance processes. This means recovering and introducing other values that have been denied by scientific rationality and excluded from social organization because they are identified with subjectivity. This is certainly Rosa's case, and it is necessary to create, in the organization of the service, a space for the recognition of needs that have not been met.

This means, according to Schraiber and Mendes-Gonçalves[12] (p. 34):

"1) Avoiding the reduction of health needs to physiopathological processes in the conceptions of healthcare services, as such a reduction has prevented us from understanding the difference that exists between the scientific complexity of pathologies and the technological complexity of health work... 2) Revaluing the search for progressively holistic assistances of the produced care, instead of the sum of specialized acts... 3) Instituting the subjective dimension of health practices as part of technological innovation, revaluing, a practice whose interpersonal relations also protect the human meaning of health professions".

In the case report, it is possible to notice the professionals' strong concern for health needs connected to physiopathological processes, revealed by their uneasiness towards the wounds in the hands. This prevents the provision of holistic care and does not consider the interpersonal subjective dimension in the use of health technologies.

Cecílio[13] (p. 114-115) emphasizes the importance of a taxonomy of health needs that encompasses enjoying "good living conditions", both functional and environmental; being able to access and consume health technologies of all types when they are necessary to recover and improve health; establishing a bond with a team and/or professional as a reference and trust for receiving care; and, finally, reaching gradual levels of autonomy to be able to deal with health and live life.

Rosa wants good living conditions, which are expressed in health needs understood in a broad and comprehensive sense. Many times, clinical procedures do not meet these needs. Due to this, she takes initiatives to promote her wellbeing within her happiness project, and requests technologies to improve her status. To achieve this, she wants to establish a bond with the team, calling them frequently to perform actions in her favor, but she also demonstrates autonomy when she asks her manicurist neighbor to help her meet some needs that are not satisfied by the professionals.

Therapeutic encounter between user and professionals

The dynamics developed in the therapeutic encounter depends on the way of organizing the working processes in a healthcare service and this organicity depends on the elements that configure the micropolitics of health work. Here, it is necessary to introduce two distinctions proposed by Merhy[14] among hard, hard/soft and soft technologies, and between dead work and live work in action, essential to analyze this micropolitics. The close connection of different technologies in the working processes is fundamental to understand the quality of the therapeutic encounter. Rosa's therapeutic encounter with the team is difficult and this difficulty may be related to the role of technologies in the working processes, which is determinant to the service's organization. This fact points to the second element that influences the difficult relationship: the work dynamics.

The three types of technology that intervene in the work dynamics are: hard technologies, which are the different technical inputs and instruments used in the assistance; hard/soft technologies, which is the necessary knowledge to define the diagnosis and therapeutics; and soft technologies, which configure the relationship, trust and bond that are established in the encounter between professional and user[14]. The three types of technology are present in Rosa's clinical relationship with the team: instruments and inputs to improve her status, knowledge to understand the case and establish therapeutic measures and, finally, the central technology in this case: relationship, user embracement, bonding and care. The question is whether the use of techniques and knowledge happens in a relational context of care.

Depending on the presence and implication of these diverse technologies in the therapeutic intervention, it is possible to speak of live work in action or dead work. The first emphasizes the bonding relationship that is established between the professional and the user. The use of the other technologies depends on this relational focus that serves as the context for their intervention. In this sense, it is a live work because it remains open, due to the ongoing relationship. A dead work, in turn, would be work that emphasizes the performance of a procedure, because it ends and dies in its execution and in its expected result. Nothing remains of the encounter, of the product that was achieved, at least formally, as the procedure was applied[14].

The dynamics of the therapeutic work performed by the professionals does not produce the expected results in Rosa, and this makes the relationship become difficult and stressful, because the care ends in the applied procedures, characterizing the work as dead. This is so much so that the professionals established a rotation scheme to go to Rosa's house and dress the wounds. They want to escape from the encounter and, thus, they automatize care itself. However, it is not possible to provide care, in this case, without a relationship of embracement and bonding, which are hindered by obstacles in the relational dynamics. In this sense, the professionals are more concerned about technical success, that is, the instrumental dimension of their action, which can be verified by the measurable clinical results of their procedures, instead of

being concerned about practical success, which is the value dimension, revealed by the symbolic, relational and material implications of their therapeutic actions in Rosa's daily life[15].

Clinical model of the user's care

The attention to Rosa's health needs and the presence of the relational dynamics in the therapeutic encounter with the team depend on the model of clinic present in the service's working processes. In many cases, this model is naturalized and automatized to such an extent that the professionals and the team do not realize how it functions. This is what happens in the present case report. Being aware of the functioning of this model is the basis for an ethical accountability of the professionals.

In the traditional model, the clinic is based on instrumental rationality, expressed in a set formed by knowledge, artifacts and interventions to prevent, diagnose and treat diseases with the objective of reversing or controlling injuries that hinder body functioning. This clinic focuses neither on the subject who suffers nor on the consequences of this suffering to the person's biography, as what matters is to detect the problem, to establish the clinical action and to wait for a predictable and quantifiable product. The insufficiencies of the traditional clinic have led to the proposal of an alternative model[16]. The therapeutic failure in Rosa's case is caused by the team's lack of awareness of the assistance model that is being employed in the user's clinical follow-up. The solution would be for the professionals to perceive this inadequate path and search for an alternative one.

This alternative path would be the proposal of the subject's clinic[16], which overcomes fragmentations and biological reductionisms and affirms the subject's active role in the clinical relationship through the axis of bonding. Such axis helps professionals to recognize the real needs of the person who is receiving care. The professionals are failing to give an active role to Rosa in the recognition of her health needs and in the establishment of her clinical itineraries. The alternative path would

transform the therapeutic encounter into a conversation practice that enables the patient to narrate life and suffering, feeling embraced[18]. This might mean bringing the manicurist to the conversation, as she has become the bond of trust to Rosa, although she is the bone of contention to the professionals.

This amplified subject's clinic is the basis for care, understood as "healthcare interested in the existential meaning of the experience of becoming physically and mentally ill and, consequently, also in the practices of health promotion, protection or recovery"[11] (p. 22). Are the professionals open to Rosa's narrative about the meanings of her existential experience of becoming ill? This knowledge is fundamental to the team as the therapeutic context to the applicability and adaptation of different health technologies to the particularity of Rosa's case. Otherwise, noises occur in the clinical relationship, hampering the encounter and the provision of care due to the professional's lack of capacity: 1) to listen to and accept the user's demand, 2) to articulate general and specific knowledge to understand the problem, and 3) to include health technologies in the user's individualized therapeutic project[19]. These three noises are present in Rosa's therapeutic follow-up due to lack of attentive listening to the cultural context of her process of becoming ill.

However, it is also necessary to bear in mind that the provision of care happens in a web and depends on a care network that is beyond the professionals and local team[20]. Certainly, Rosa's case needs the advice of other professionals, like psychologists and social workers, contacted within the network, which does not happen in this case. Nevertheless, to enable this access to the network, the professionals need to understand themselves as networked actors. The macropolitical view of the Healthcare Networks depends on the presence of networks in the micropolitics of the health work processes, as the planning of organizational arrangements cannot be tied to a normative matrix with a purely structural concern. Rather, this planning must recognize that the presence and formation of micronetworks inside the organization conducts therapeutic projects efficiently, for the network's good functioning and communication at the system's macro level depends

on networked dialog and relations at the service's micro level[21]. The professionals have difficulties in understanding themselves as micronetwork actors at their own healthcare unit, as they take turns to provide care for Rosa as a way of escaping from the stress of meeting her. Due to this, they automatize assistance without self-management, and there is not a self-analysis in group to potentialize the presence of her subjectivity and to create new therapeutic paths in the practice of Rosa's care.

Final remarks

Rosa's case is emblematic to analyze the "knots" and noises that hamper a clinical relationship. The problem is not in Rosa's personality; rather, it lies in the relationship that is established between her and the professionals. It is easier to label the patient as "difficult" than to investigate what elements are interfering in the encounter and making it be neither beneficial to the patient nor pleasant to the professional. This questioning about the quality of the relationship must be made by the professional, as he/she has the ethical responsibility for the patient's care. Three issues were discussed in the case analysis. They reveal the cause of noises in the relationship: health needs, working processes and the model of clinic.

The results may contribute to the practice of primary care professionals who deal with chronic users whose follow-up is difficult. Before anything else, it is necessary that they talk as a team about these cases to agree on paths to overcome the difficult relationship, without labelling the user as difficult. To achieve this, it is important not to reduce the discussion of the case to purely clinical aspects; rather, the professionals must bring to the conversation the aspects that stress the relationship and ask if the patient has other needs that they are failing to meet, bearing a broader range of health needs in mind. So that these specific needs emerge, the performance of therapeutic procedures must occur in a relational context that facilitates dialog and communication. The aim is that the user is able to express the

subjective experience of his/her disease, reporting on how the chronic disease affects his/her way of living life and his/her happiness projects.

Collaborators

José Roque Junges participated actively in the discussion of the results and in the proposal, writing, review and final approval of the article; Raquel Brondísia Panizzi Fernandes participated actively in the discussion of the results and in the proposal of the article; Noéli Daiam Raymundo Herbert, Francine Tomasini, Leonice Werle, Cátia Pereira and Andressa Wagner Moretti participated in data collection, discussion, and in the search for references.

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