

Live networks in care production with the user at the center of the treatment for multidrug-resistant tuberculosis

As redes vivas na produção do cuidado com o usuário na centralidade do tratamento para tuberculose multidroga resistente (resumo: p. 15)

Las redes vivas en la producción del cuidado con el usuario en la centralidad del tratamiento para la tuberculosis multidroga resistente (resumen: p. 15)

Janaina Aparecida de Medeiros Leung^(a)

<janainaleung@hucff.ufrj.br> 

Fátima Teresinha Scarparo Cunha^(b)

<fatima.scarparo@gmail.com> 

Emerson Elias Merhy^(c)

<emerhy@gmail.com> 

Afranio Lineu Kritski^(d)

<kritskia@gmail.com> 

^(a) Pós-graduando do Programa de Pós-Graduação em Clínica Médica(doutorado), Faculdade de Medicina (FM), Universidade Federal do Rio de Janeiro (UFRJ). Rua Professor Rodolpho Paulo Rocco, 255, 1º andar, sala 01D 58/60. Rio de Janeiro, RJ, Brasil. 21941-913.

^(b) Departamento de Enfermagem de Saúde Pública, Escola de Enfermagem Alfredo Pinto, UFRJ. Rio de Janeiro, RJ, Brasil.

^(c) Departamento de Saúde Coletiva, Mental e da Família, Instituto de Ciências Médicas, Centro Multidisciplinar, UFRJ. Macaé, RJ, Brasil.

^(d) Programa Acadêmico de Tuberculose, FM, UFRJ. Rio de Janeiro, RJ, Brasil.

We followed the trajectory of a guiding user undergoing treatment for multidrug-resistant tuberculosis (MDR-TB). The narratives of Live Networks in care production showed: 1) Caring in the act of living: Overcoming stigmas and cultivating bonds that help overcome discourses fostered by fear, prejudice, exclusion and invisibility of subjects; 2) Live Networks of care: The in-betweens of the norm; and 3) Interfaces of user-health worker care: How can we demystify the judgment of health workers who, subordinated to limiting protocols, often stigmatize the user as someone who “abandons the treatment”? The guiding user perceived that caring means deterritorializing oneself, expressing one’s desires as power for transformation, and leaving the modus operandi towards creativity, with the user at the center of the process.

Keywords: Tuberculosis. Multidrug-resistant tuberculosis. Patient-centered care. Life-changing events. Community-based networks.



Introduction

In 2014, the World Health Organization (WHO) approved the End TB Strategy - Global Plan to End Tuberculosis by 2035, grounded on three pillars: 1) Integrated, patient-centered care and prevention; 2) Bold policies and supportive systems; and 3) Intensified research and innovation. The first pillar was the point of departure for this study, as patient-centered care means that the subject is the central agent in their comprehensive treatment, in their needs, and in the world where they live¹.

Care is the effect of action on the discovery made with the other, on a flow of continuous movement and experimentations, on the plurality of life, and on encounters between various actors that are part of the subject's trajectory. This process, together with the actors' perceptions and perspective of the health-disease process beyond what is formal and instituted, constitute live networks of care. These networks are innovations deriving from Pillar 3 and rupture structured thought, regimes of truths, and biopower, which establishes what health is. The regime of power over lives determines a universal form of living to the population, with economically active and politically docile bodies, and places the subject into restrictive taxonomies like dropout, disinterested, rebellious, uncommitted to life, when they do not comply with the established rules^{2,3}.

Informed by biomedicine, health actions are imposed on the subject's body by scientific and epidemiological discourses, related to the hegemonic technique, control and norms, by means of secondary data (information systems). This apparatus limits the assistance provided for the other, as it has "established truths" that meet the interest of other subjects, while health professionals transmit their biomedical and reductionist knowledge in the form of a vertical axiom. Fighting against the attempt to shape the subject based on a reality constructed through protocols that result in restrictions and obligations, this subject responds in an active way and produces tension in the instituted power devices^{4,5}.

In this context, the Brazilian National Health System (SUS) assists the subject diagnosed with tuberculosis (TB) in the primary, secondary, and specialized levels of care, integrated by Healthcare Networks (RAS), which recognize the population's needs and plan health actions. However, the discourses that circulate about TB still disregard experiences in the user-territory-health professional relationship⁶. Studies argue that subjects are citizens who belong to the same world; thus, establishing a relationship means being attentive to the other, recognizing the importance of hearing and respecting the multiplicity of life. The user is active in their care process in order to transform the way of acting in the area of health^{7,8}.

This article derives from a doctoral dissertation that analyzed Live Networks of Care for Users with Multidrug-Resistant Tuberculosis (MDR-TB). The dissertation aimed to monitor a guiding user, listening to narratives generated by live networks and analyzing discourses produced in encounters among the subjects involved in care production.

Method

This is a qualitative study guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ), and grounded on the theoretical framework of the French school of Discourse Analysis⁹⁻¹¹.

The research was carried out in Live Networks in intersection with Healthcare Networks (RAS), in the context of Primary Healthcare (PHC) and Specialized Ambulatory Care (Professor Newton Bethlem Phthysiology Outpatient Clinic of the Hospital Complex formed by the Institute of Thorax Diseases and the Clementino Fraga Filho University Hospital (IDT/HUCFF) of the Federal University of Rio de Janeiro, all of them located in the municipality of Rio de Janeiro, Brazil).

The diagnosis of drug-resistant (DR) TB (resistance to first-line drugs: rifampicin-RIF (RR-TB) and rifampicin and isoniazid-INH (MDR-TB); resistance to RIF and INH associated with second-line drugs (fluoroquinolone and amikacin; XDR-TB)) is made in the primary care unit and the subject is referred to the specialized care unit via electronic mail, according to the user's geographical location. The appointment is scheduled within seven days. In the city of Rio de Janeiro, users come from four Planning Areas (PA 1.0, PA 2.1, PA 2.2, PA 3.1) and from cities in the Metropolitan Region: Nova Iguaçu and Duque de Caxias.

The methodological path was that of the guiding user: a subject-centered movement in which the investigator assumes the user's perspective and is conducted by them in the live networks of care, placing themselves in the world and learning that it is not possible to separate the physical body from the social, emotional, and psychological dimensions^{12,13}.

The selection of the guiding user was a collective construction. Conversation circles were conducted with the participation of nine professionals who work at the specialized unit, after all of them had signed the consent form. The encounters took place between September and November 2020¹⁴. Zoe was chosen due to the complexity of her story and because of her bond with the nurse-researcher^{6,15}.

The development of the study involved 14 subjects who form the live networks that provide care for Zoe. During the encounters with the family and health workers, we presented the study and perspectives to proceed together with the participants. In addition, we promised to present the study to them again at the end of the research process.

Interviews were conducted from May to July 2021 respecting the participants' availability, on the dates, times and at the places established by them, and after the consent form had been signed. Physical distancing was adopted due to Covid-19, and there was no need to repeat the interviews. The interviews lasted fifty minutes on average. They were audio-recorded, transcribed, and submitted to an individual validation process. Fictitious names and alphanumeric identification were used.

The triggering question was the experience of care lived with Zoe during the period of her treatment for MDR-TB. Some sources of secondary data were also used, like the Special Tuberculosis Treatments Information System (SITE-TB), the patient's medical



record, and the file of the health unit. It is important to mention that this research is a development of a study carried out by the researcher with the qualitative methodology that validated the initial argument¹⁶.

In the French school of Discourse Analysis proposed by Michel Pêcheux, discourse produces meaning effects in a relationship between language and historicity. Therefore, we did not use the saturation criterion in the analysis so that we could reach the completeness of discourse, as it is not closed in itself nor does it have concrete and limited definitions. The researchers analyzed the interviews by repeatedly reading the material as it is, passing from the linguistic surface called de-superficialization to linguistic materiality: what is said, who says it, and in what position. Discursive Sequences (DSs) and Discursive Formations (DFs) outline the meanings that circulate in the excerpts under analysis. The discursive process itself consists of the analysis of DSs focusing on discourse production conditions, ideological formation and its materialization¹⁷⁻¹⁹.

The study complied with resolutions about research in Brazil. It was appraised and approved by the Ethics Committee for Research with Human Beings - Opinion no. 3.950.288, of April 2, 2020. To ensure anonymity, subjects were identified by their professional category. Proper names are fictitious.

Results

Zoe's and the Gomes family's life history and trajectory are described here according to the narratives of the subjects who compose the live networks of care. Zoe is now 38 years old and was born in Rio de Janeiro. She lives with her mother, Pilar, and her three children at the Borel community, located in the North Zone of the city of Rio de Janeiro²⁰.

In February 2016, Zoe went to the specialized-care outpatient clinic to undergo the second treatment for MDR-TB, due to discontinuation of the first treatment in 2015.

After the medical appointment, a complementary exam was performed and she received medication that would last fifteen days, up to the date of the next appointment. A chest radiography and laboratory tests were requested. In the 18 subsequent months, medication was sent via Planning Area Coordination (PAC 2.2), her catchment area.

In the next appointment, Zoe was tearful and irritated with the family health team. She reported that she felt disrespected, as the professionals were distant and intolerant, but she was following up with the unit's psychologist. She mentioned that she was having difficulties in adhering to the treatment due to the Regulation System's delay in scheduling exams, the journey between health units, the professionals' difficulty in reaching her house, which is located in the high part of the community, and the high prevalence of violence in the area.

In view of this, the nurse who worked at the specialized unit contacted professionals of the primary care units to understand the dynamics of care in the territory. This encounter innovated the care process and created a bond between user and health workers.



Care was shared between the primary and specialized care teams. From 2016 onwards, Zoe restarted and discontinued her treatment a number of times, with oscillations of her emotional state, crying, aggressiveness, and irritability, sometimes towards her mother and family, sometimes towards the family clinic team. In the meantime, Pilar, Zoe's mother, and Valentina, Zoe's sister, started and completed treatment for MDR-TB, and Zoe's children were examined in the specialized care sector of the pediatrics service. They did not proceed with the follow-up due to difficulties in going to the unit.

Just before suspending follow-up with the primary care psychologist, Zoe asked her to accompany her to the specialized unit - an innovation in the care process. Support was sought from the Psychosocial Care Center (CAPS), but the process was interrupted due to difficulties in getting there and issues like tiredness and financial cost. The PAC asked the municipal government to provide transportation so that Zoe could attend the medical appointments. Unfortunately, it was denied due to the Covid-19 pandemic. The specialized unit offered a vehicle for such transportation, but this was cancelled due to the financial cost. The health system refers the user to specialized units for MDR-TB treatment, but although users receive a transportation card, going to the units is considered an obstacle because of long journeys, tiredness and the financial cost¹⁸.

Due to the irregular follow-up, Zoe started to present pre-XDR TB (*M. tuberculosis* isolates resistant to second-line drugs). As her clinical condition worsened, she had to be hospitalized three times, but the bonds with the professionals from both units (primary and specialized care) were maintained by means of visits. On the first time she was discharged from hospital, in April 2020, it was established that, to reduce the number of journeys between health units, follow-up would be provided by the PHC doctor with the support of the specialized care doctor, in partnership with the State and Municipality Health Departments (SES-RJ and SMS-RJ) and the Family Health Support Center (NASF).

In March 2021, a Community Health Agent met Zoe on the street. Her clinical state had worsened and she needed to be hospitalized. The teams and PAC 2.2 paid her regular visits, which enabled her to have contact with her family through video calls, as there were Covid-19 restrictions and her mother could not visit her because she (the mother) had started treatment for XDR-TB¹⁵. Zoe reported having problems with the hospital team. Due to this, her trajectory was explained to the professionals and, on the initiative of the SMS-RJ social worker, a workgroup was created to facilitate communication between all the professionals involved in Zoe's care²¹.

The user-professional relationship is essential to the therapeutic project. The professionals' aloofness ruptures trust and breaks the bond, as the subject cannot participate in the decision-making process related to care provision and to the way in which they will conduct life concurrently with their treatment. This causes distancing and strengthens stigma, prejudice, and even their perception of humiliation⁸. Zoe, in accordance with the pseudonym that was chosen to her, which means "life", "full of life", proceeded with the care shared with her live



networks. Thus, for the analysis of discourses, the discursive sequences were divided into three analytical categories:

- 1) Caring in the act of living: Overcoming stigmas and cultivating bonds;
- 2) Live networks of care: The in-betweens of the norm;
- 3) Interfaces of user-health worker care: Are there subjects on both sides of the equation? How can the professional provide care?

In the first DS, the participants highlighted the experienced prejudice, marked and felt in the bodies. In TB, distancing generates fear and anguish. The violence suffered by the subject is twofold: lack of effective actions on the part of the government (referrer to the authorities who governed the country/state/municipality) and the illness itself, but the subject overcomes it with their own strength and with the help of the bonds constructed in the live support networks.

Discursive Sequence no. 1:

It's a disease that is rarely mentioned, right? You don't see... hardly anyone talks about it. (P-1)

[...] A very stigmatized disease, right?... because people are scared of it... people from the community... they are excluded from everything. (P-2)

Most people walked away from me... were afraid of me, of catching the disease... I got used to it, you know? Fear is the worst! Look, P-3 never judged me... (Fam-1)

We, as health agents, manage to have this broader view, 'cos we're there all day, almost everyday, with the family, the neighbors... we witness many violent situations... (P-3)

In the second DS, care is beyond the instituted, and is expressed in practices grounded on structured concepts. The step is to rediscover that care lies in the multiplicity of the subject interacting with live networks of care.

The professional must see... I mean: they must go beyond the diagnosis, right? So... when you see this user... as a complex being, you must understand their needs, the obstacles, the user's perception in relation to having multidrug-resistant tuberculosis. And, from this, you outline a plan. And this plan is related to a network. You must articulate both inside and outside the health sector. And I think that's what makes a network be alive, right? It's a long treatment... a sacrifice to the person due to the journeys to and from the health unit... we need to have a network perspective. (P-1)



[...] receive this patient in a way that they feel included. And not excluded from society... excluded from the health services, right? Due to these patients' difficulties, they are stigmatized as someone who... you don't want close to you, right? We must see the other in a clear way and leave aside this... these pre-fabricated things [laughs], you know? I think that, sometimes, health professionals put themselves in a situation of omnipotence. They know everything, they have the solution for your life... And the other person can only... (P-2)

A very positive thing Zoe brought to us as a Program, and to me as a professional, was the creation of the workgroup. When we're challenged by a user who doesn't follow rules, who doesn't want to do what we tell them to... who doesn't answer what we want, we distance ourselves from them, we get angry, we hold a grudge against them. We suggested doing an individual therapeutic project... for users who have more issues... And we have to involve the Network, we have to involve the others, we have to involve the territory, we have to involve the PAC. (G-1)

There was a car, and when there was another patient, we always arranged for the two of them to go together to the appointment, on the day the car was available. Then the descent... The stairs, it's very difficult to go down these stairs here, and he always took her in his arms. And she used to move very slowly on the highway. She had to wake up much earlier, you know? (P-3)

I went there driving my car once. But I also went there by bus with her. Anyway... A vehicle would fix this... Zoe, or it could have been anyone... she was so debilitated and she went there by bus. Go down the Borel Hill... get a bus... Dedicate myself more to these few... But if I assume a posture of accusation, if I think they are guilty for being in that situation... then it's difficult. The patient that abandons the treatment, who abandons it and comes back... who abandons it... It's pure disbelief! (P-4)

In the third DS, the professionals mentioned tiredness and lack of motivation. In 2017, Professor Emerson Merhy, who was a member of the board that appraised the project from which this study derived, asked the following questions: "Is there a subject of care in TB? Is there a subject who receives care and is there a subject who gives care?" These workers, immersed in their health practices, are absorbed by the intervention of biopower in the control of their lives, which is felt in the need to meet goals and provide the expected number of assistances, and in their discomfort and exhaustion with care provision.



Concerning treatment: I went six times to Zoe's house to perform DOT, because I couldn't find her there and I had to perform it. And you have to stay there. For hours... because I need to see the person taking the medication... This is not the strategy! It's not what I want to do!, but sometimes the order comes from above or there's a protocol that insists on making us do that. You see? No, let's create a strategy! Sometimes I want to create a strategy, but I can't because an order came from above telling me it has to be like that... I'm the one who knows how it should be! The patient is the one who should tell me how it is... (P-3)

What is done beyond the medical record is not seen. Because the paper is not all, guys! Some things don't appear on the paper. They are beyond the medical record, beyond bureaucracy, beyond the technical terms, beyond the administrative role of the paper... beyond all of this, there's an entire situation that doesn't show up. But what is the return? In terms of quality, for us too? Of instruction, for us too? Of evaluation, for us too? (P-5)

This really gets into our daily routine... The support network has to be very big... We have to receive care, right? 'Cos we also get ill; besides our physical part, our mental part also gets very, very ill!, really ill!, and we don't... Sometimes, our mental side is already worn out, right? ... it's not as if we lubricate it with oil and it gets fine. We're not robots, we're flesh and blood, right? How about giving care to the person who gives care? What about the health of the person who creates the patient's care strategy? This person is also important and sometimes they are not included in the care strategy. The person who gives care to the patient doesn't receive care, right? I don't mean just physically, but also mentally... (P-6)

Discussion

The study's corpus of analysis was composed of DSs extracted from interviews with the subjects of the live networks about experiences related to the care they provide for Zoe. The subject who is ill due to MDR-TB is marked by prejudice, stigmas, and is socially excluded. The discourses produce the meaning that society does not want the subject because they represent a threat. The social bond is not created due to fear of catching the bacillus that causes the disease. In addition, practices that are disease-oriented and epidemiological indicators that are a hegemonic power with an exclusion force marginalize the subject and promote their isolation.



Discursive materiality in DS1 promotes the meaning of discourses circulating in TB, such as fear, revolt, exclusion, and invisibility due to lack of recognition in society. The disease is marked by advertising campaigns in which ideas like fight, combat, war against disease circulate. The health campaigns launched by the Brazilian government follow marketing principles that view health as a consumer good, with materialization of an ideological formation that is founded on biopolitics in the production of effects of truth. Those who produce their own biopower, in the subject position they occupy when they manage disease and health, and when they control and repress the maladjusted body so that it adjusts to what is healthy and acceptable, disregarding discourses related to the subjects' life in their daily routine²². But what about the subjects? A study carried out in the United Kingdom states that treatment cannot be simplified as regular use of medication and attendance of medical appointments. Deep transformations in the user's life while they undergo treatment can rupture the dynamics of this life²³.

The experiences that the specialized care professionals lived with Zoe enabled them to expand their thought beyond what is instituted, so that they could feel the life in the territory. Zoe described, in the appointments, the difficulties she faced in her daily routine, related to her family, the territory, and the health professionals. Follow-up in the specialized unit was distant from the events of Zoe's life.

These aspects reiterate the silencing of discussions and the obliteration of the government's responsibility, as it particularizes the subject and considers them guilty for their actions, grounded on biopower and using a positivistic argument that guides the management of life in docile behaviors and bodies, but stiffens the governability of the self^{24,25}.

The exclusion of the user from the therapeutic project brings tension to the encounters in the state's health facilities. On the one hand, the user is marked by judgement and indifference in the dropout interdiscourse; on the other hand, the health worker is in the subject position, as someone who seeks the results proposed by the Tuberculosis Control Program (TBCP). In DS1, P-3's discourse promotes contradictions, marked by an interdiscourse with the ideological interpellation of biomedicine, and also by the experience lived in the territory, where the professional shifts from the position of TBCP health agent to that of an ally who faces daily situations together with the user. The bond potentializes care. It means being available to the user and experiencing the journey with them, with their family and community, hearing them and promoting reciprocity in the encounters. With this, innovations emerge as gradual ruptures of structures, characterized by an intertwining between health practices and what the persons involved experience, supported by the ethical values of mutual respect and responsibility^{15,26}.

The SUS is constituted of Healthcare Networks that should be integrated with the user's live networks. Zoe and her family disrupted the implemented structure, which made the professionals think and go beyond what is established. They stimulated innovations, the use of soft tools, which are the relational tools of the encounter, of hearing, of the attention given to the subject, and performed creative actions in



the provision of care. In DS2, the workgroup initiative surpasses the determinism of John Calvin Maxwell, who argued that the team meeting is a structural device for the resolution of a specific problem or for the pragmatic execution of processes with speedy achievement of goals, objectives, and indicators^{24,27}.

The workgroup terminology promotes a rigid and operational meaning, but the meetings and conversations that were started in the family clinic and, due to the pandemic, were subsequently conducted in the virtual space, overcome the austerity in the performance of health activities. The intertwining between primary care workers, specialized care workers, and managers escaped from the established norms due to the interaction with Zoe, and constituted encounters that expanded the possibilities of care based on the triad user, family, and health workers.

The professionals revealed their anguishes, frustrations, difficulties, fragilities, limitations, and the pressure they suffer as subjects of a care that is provided in accordance with the TBCP. The discussions in the workgroup constituted possibilities of care and rearranged the daily routine with the use of relational tools that are distant from norms and pragmatic actions. The meetings strengthened the professionals' joint participation in the visits to Zoe at the hospitalization unit and at her home, and this was incorporated into the dynamics of the user's life. Such connections modify the instituted network, which is organized and governed by norms controlling users' entry into and exit from care stations, and make it become a Live Network, with the emergence of new dynamics in the disorder of usual and technical actions, but in the logic of dialog²¹.

With Zoe, it was possible to think of intersections between user and professional, health and life, and be affected by the daily routine of the world of care. It was possible to amplify the way of thinking and de-territorialize concepts grounded on tough narratives of the hospital-centric, dichotomized interdiscourse.

User care and professional care cannot be separated in the world of health work in act, for the subjects are involved in all moments of the encounter. Although the field of Collective Health focuses on a horizontal work process, with discussions and movements of transformation in the daily routine, it is possible to notice, in the discursive sequences, an imprisonment in the established models, as well as compliance with the orders given to the professionals²⁸.

In DS3, interdiscourse marks the subject position of the health professional and the performance of health practices as the execution of techniques and compliance with protocols. Health management excludes and exercises power over users and professionals, with actions to control their lives, as language in health practices is aligned with the utilitarian concept of disease and recommends the performance of epidemiological surveillance of the bodies of subjects undergoing treatment for TB. Reconstructing the care path means promoting discussions among the agents of live networks and advancing interaction between user, family, community and health worker in a collective way, as regimes of ideological values erase life and silence their voices²⁹.

Provision of care for the subject in their territory and taking into account the multiplicity of their life can be potentialized, enhancing creativity and autonomy, investing in self-government, recognizing the health professionals' work, providing



alternative care, and respecting knowledge and experiences lived together with the user, based on actions and strategies in a horizontal and democratic model. The discourse of the TBCP, still in force, focuses on elimination of disease and control of subjects, in accordance with Law no. 7286 of March 31, 2022, which institutes the Municipal Policy for Tuberculosis Control and Elimination in the City of Rio de Janeiro. Its article 3, item V sets forth that professionals who work in tuberculosis control and prevention must be qualified and supervised. According to Discourse Analysis, this text expresses the meaning that, in the plans outlined in TB policies, the professional is under the control of the government³⁰.

The study had limitations due to the lack of a pilot project that could support its future conduction and due to the Covid-19 pandemic, which hindered the monitoring of the guiding user in the territory and in her live networks. Its strength lies in the premise of SUS: a national system that promotes access to health stations and integrates every citizen – user, family, professionals and managers - into the collective construction of care in live networks.

Final remarks

The study approaches care provided for the subject undergoing treatment for MDR-TB in the intersection between Pillars 1 and 3 of the Global Plan to End TB by 2035: integrated, patient-centered care and prevention, and intensified research and innovation, in order to give care to the user with TB, in act. In this sense, it argues that the centrality of the subject in the care process enables the continuous movement of health workers, who, in their daily practices, are questioned by the effects of biopower, which limit them in their health actions but do not prevent them from creating and maintaining bonds with the user, overcoming the meaning of pragmatic assistance to embrace care provided for the subject.

Experiencing live networks in the care provided for the user extrapolates what has been pre-determined and promotes a transformative reflection on other possibilities of the world of health work, going beyond protocols towards the art of “how to care” and “with whom to care”.

We highlight that technical-scientific learning is inherent in the education of health professionals, and intertwining it with relational technology, characterized by hearing the other and paying attention to their needs, provides the basis for care and puts the subject at the center of the process, respecting their knowledge and their life trajectory. Thus, individual therapeutic projects are constructed in this relationship.



Authors' contribution

All authors actively participated in all stages of preparing the manuscript.

Conflict of interest

The authors have no conflict of interest to declare.

Copyright

This article is distributed under the terms of the Creative Commons Attribution 4.0 International License, BY type (<https://creativecommons.org/licenses/by/4.0/deed.en>).



Editor

Denise Martin Coviello

Associated editor

José Roque Junges

Translator

Carolina Siqueira Muniz Ventura

Submitted on

04/19/23

Approved on

08/11/23

References

1. World Health Organization. Global tuberculosis report 2021 [Internet]. Geneva: WHO; 2021 [citado 26 Dez 2022]. Disponível em: <https://apps.who.int/iris/bitstream/handle/10665/346387/9789240037021-eng.pdf?sequence=1>
2. Kachenski IC. Foucault e o controle dos corpos pela linguagem: os caminhos da biopolítica contemporânea no saber-poder médico. *Kínesis*. 2022; 14(36):198-216. doi: 10.36311/1984-8900.2022.v14n36.p198-216.
3. Feuerwerker LCM, Bertussi DC, Merhy EE. Avaliação compartilhada do cuidado em saúde: surpreendendo o instituído nas redes [Internet]. Rio de Janeiro: Hexis; 2016 [citado 26 Dez 2022]. Disponível em: https://edisciplinas.usp.br/pluginfile.php/5798651/mod_resource/content/1/Avaliacao%20compartilhada%20do%20cuidado%20em%20saude%20vol2.pdf



4. Zago PTN, Maffaccioli R, Riquinho DL, Kruse MHL, Rocha CMF. Adesão terapêutica sob o olhar foucaultiano: saberes/poderes nos manuais de controle da tuberculose no Brasil. *Rev Gaucha Enferm.* 2022; 43:e20210075. doi: 10.1590/1983-1447.2022.20210075.en.
5. Oliveira Junior JB, Grisotti M, Manske GS, Moretti-Pires RO. As práticas corporais como dispositivos da biopolítica e do biopoder na atenção primária à saúde. *Saude Debate.* 2021; 45(128):42-53. doi: 10.1590/0103-1104202112803.
6. Oliveira KS, Grandi AL, Bortoletto MSS, Lima JVC, Baduy RS, Melchior R. O usuário e a sua busca pelo cuidado nas redes formais e redes vivas: uma produção cartográfica. *New Trends Quali Res.* 2020; 3:542-54. doi: 10.36367/ntqr.3.2020.542-554.
7. Furin J, Loveday M, Hlangu S, Dickson-Hall L, le Roux S, Nicol M, et al. "A very humiliating illness": a qualitative study of patient-centered care for rifampicin-resistant tuberculosis in South Africa. *BMC Public Health.* 2020; 20(1):76. doi: 10.1186/s12889-019-8035-z.
8. Law S, Daftary A, Mitnick CD, Dheda K, Menzies D. Disrupting a cycle of mistrust: a constructivist grounded theory study on patient-provider trust in TB care. *Soc Sci Med.* 2019; 240:112578. doi: 10.1016/j.socscimed.2019.112578.
9. Fernandes C, Vinhas LI. Da maquinaria ao dispositivo teórico-analítico: a problemática dos procedimentos metodológicos da análise do discurso. *Ling (Dis)curso.* 2019; 19(1):133-51. doi: 10.1590/1982-4017-190101-DO0119.
10. Aspers P, Corte U. What is qualitative in qualitative research. *Qual Sociol.* 2019; 42(2):139-60. doi: 10.1007/s11133-019-9413-7.
11. Booth A, Hannes K, Harden A, Noyes JP, Harris J, Jaure A. COREQ (consolidated criteria for reporting qualitative studies). In: Moher D, Altman DG, Schulz KF, Simera I, Wager E, organizadores. *Guidelines for reporting health research: a user's manual.* Oxford: John Wiley & Sons; 2014. p. 214-26. doi: 10.1002/9781118715598.ch21.
12. Freire MP, Louvison M, Feuerwerker LCM, Chioro A, Bertussi D. Regulação do cuidado em redes de atenção: importância de novos arranjos tecnológicos. *Saude Soc.* 2020; 29(3):e190682. doi: 10.1590/S0104-12902020190682.
13. Abrahão AL, Merhy EE, Gomes MPC, Tallemberg C, Chagas MS, Rocha M, et al. O pesquisador in-mundo e o processo de produção de outras formas de investigação em saúde. *Lugar Comum.* 2012; 39:133-44.
14. Sampaio J, Santos GC, Agostini M, Salvador AS. Limites e potencialidades das rodas de conversa no cuidado em saúde: uma experiência com jovens no sertão pernambucano. *Interface (Botucatu).* 2014; 18 Suppl 2:1299-311. doi: 10.1590/1807-57622013.0264.
15. Seixas CT, Baduy RS, Cruz KT, Bortoletto MSS, Slomp Junior H, Merhy EE. O vínculo como potência para a produção do cuidado em saúde: o que usuários-guia nos ensinam. *Interface (Botucatu).* 2019; 23:e170627. doi: 10.1590/Interface.170627.
16. Leung J, Cunha F, Kritski AL. Na tuberculose, como cuidar? *Entremeios (Pouso Alegre).* 2019; 19:63-78. doi: 10.20337/ISSN2179-3514revistaENTREMEIOSvol19pagina63a78.
17. Pavan PD, Galvão AN. Da produtividade do conceito de pré-construído e seus diferentes modos de funcionamento: uma abordagem teórico-analítica. *Ling (Dis)curso.* 2019; 19(1):173-91. doi: 10.1590/1982-4017-190103-DO0319.



18. Santos FL, Souza LLL, Bruce ATI, Crispim JA, Arroyo LH, Ramos ACV, et al. Patients' perceptions regarding multidrug-resistant tuberculosis and barriers to seeking care in a priority city in Brazil during Covid-19 pandemic: a qualitative study. *PLoS One*. 2021; 16(4):e0249822. doi: 10.1371/journal.pone.0249822.
19. Marques W, Pereira OJ. Sujeito e identidade na análise do discurso. *Res Soc Dev*. 2020; 9(9):e6059911716.
20. Dicionário de Favelas Marielle Franco. Favela do Borel [Internet]. 2021 [citado 26 Dez 2022]. Disponível em: https://wikifavelas.com.br/index.php/Favela_do_Borel
21. Maximino VS, Liberman F, Frutuoso MF, Mendes R. Profissionais como produtores de redes: tramas e conexões no cuidado em saúde. *Saude Soc*. 2017; 26(2):435-47. doi: 10.1590/S0104-12902017170017.
22. Melo e Costa SL, Alves W. Evaluating resistances to health promotion campaigns with Discourse Analysis. *Rev Esp Comun Salud*. 2019; Suppl 2:9-19. doi: 10.20318/recs.2019.4424.
23. Karat AS, Jones ASK, Abubakar I, Campbell CNJ, Clarke AL, Clarke CS, et al. "You have to change your whole life": a qualitative study of the dynamics of treatment adherence among adults with tuberculosis in the United Kingdom. *J Clin Tuberc Mycobact Dis*. 2021; 23:100233. doi: 10.1016/j.jctube.2021.100233.
24. Jaramillo J, Yadav R, Herrera R. Why every word counts: towards patient- and people-centered tuberculosis care. *Int J Tuberc Lung Dis*. 2019; 23(5):547-51. doi: 10.5588/ijtld.18.0490.
25. Souza KMJ, Sá LD, Assolini FEP, Queiroga RPF, Surniche CA, Palha PF. Discursos sobre a tuberculose: estigmas e consequências para o sujeito adoecido. *Rev Enferm UERJ*. 2015; 23(4):475-80. doi: 10.12957/reuerj.2015.16106.
26. Merhy EE, Baduy RS, Seixas CT, Almeida DES, Júnior HS. Avaliação compartilhada do cuidado em saúde: surpreendendo o instituído nas redes. Rio de Janeiro: Hexis; 2016.
27. Muna AN. Examining the importance of leadership skills in today's life. *Int J Soc Serv Res*. 2022; 2(10):977-82. doi: 10.46799/ijssr.v2i10.185.
28. Aciole GG, Pedro MJ. Sobre a saúde de quem trabalha em saúde: revendo afinidades entre a psicodinâmica do trabalho e a saúde coletiva. *Saude Debate*. 2019; 43(120):194-206. doi: 10.1590/0103-1104201912015.
29. Albino NM, Liporoni AARC. O desmonte da política de saúde sob a gestão das organizações sociais. *Rev Fam Ciclos Vida Saúde Contexto Soc*. 2020; 8 Suppl 3:1099-106. doi: 10.18554/refacs.v8i0.5029.
30. Rio de Janeiro. Câmara Municipal do Rio de Janeiro. Lei nº 7.286 de 31 de março de 2022. Institui a Política Municipal de Controle e Eliminação da Tuberculose no Município [Internet]. Rio de Janeiro: Câmara Municipal; 2022 [citado 27 Dez 2022]. Disponível em: <http://aplicnt.camara.rj.gov.br/APL/Legislativos/contlei.nsf/7cb7d306c2b748cb0325796000610ad8/85e76e859172cdd003258816004dd55b?OpenDocument>



Vivenciamos a trajetória de uma usuária-guia no tratamento para tuberculose multidroga resistente (TB-MDR). As narrativas das redes vivas na produção de cuidado apontam para os seguintes itens: 1) cuidar no ato de viver: suplantar os estigmas e cultivar vínculos que ajudem a superar os discursos fomentados pelo medo, preconceitos, exclusão e invisibilidade dos sujeitos; 2) redes vivas de cuidado: os entremeios da norma; e 3) as interfaces de atenção usuário-trabalhador da saúde: como desmistificar o julgamento dos trabalhadores da saúde, que, subordinados a protocolos limitantes, muitas vezes estigmatizam o usuário como “abandonador de tratamento”? A usuária-guia vislumbrou que cuidar é se desterritorializar, é colocar os desejos como potência para transformação, saindo do *modus operandi* rumo à criatividade, tendo o usuário no centro do processo.

Palavras-chave: Tuberculose. Tuberculose multidroga resistente. Cuidado centrado no paciente. Acontecimentos que mudam a vida. Redes comunitárias.

Presenciamos la trayectoria de una usuaria-guía en el tratamiento para tuberculosis multidrogo resistente (TB-MDR). Las narrativas de las Redes Vivas en la producción de cuidado señalan: 1) cuidar en el acto de vivir: suplantar los estigmas y cultivar vínculos que ayuden a superar los discursos fomentados por el miedo, prejuicios, exclusión e invisibilidad de los sujetos. 2) Redes Vivas de cuidado: los entresijos de la norma y 3) las interfaces de atención usuario-trabajador de la salud: ¿cómo desmistificar el juicio de los trabajadores de la salud quienes, subordinados a protocolos limitantes, muchas veces estigmatizan al usuario como “abandonador de tratamiento”? La usuaria-guía vislumbró que cuidar es desterritorializarse, es colocar los deseos como potencia para transformación, saliendo del *modus operandi* rumbo a la creatividad, colocando al usuario en el centro del proceso.

Palabras clave: Tuberculosis. Tuberculosis multidrogo resistente. Cuidado centrado en el paciente. Acontecimientos que cambian la vida. Redes comunitarias.