

## Madness and work: comprehensiveness and network care in the SUS

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**Abstract** *This paper addresses a local the Unified Health System (SUS) management experience that managed to implement networked care and took work as a determinant of cross-sectional health through the integrated action between actors in PHC and the Psychosocial Care and Occupational Health Networks. We monitored one automotive industry worker, whose work activity led him to illness due to inhalation of chemical substances. The theoretical framework and the analysis method are based on the recognition of the user-guide as an investigation strategy. The user-guide biography uncovered distress from the concrete life of the working man. The organic aspects that trigger a mental disorder have been trivialized or neglected in various services, in the understanding of the illness process that originated in their work. According to current work-related mental health studies, the results confirm the need for a contextualized work clinic, integration between services, intersectoral interventions per SUS guidelines, and public Mental Health and Occupational Health policies.*

**Key words** *Occupational health, Mental health, Integrated health service networks, Organic psychosis, User-guide*

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## Introduction

Investigations that take as the object of study the situation experienced by a worker are not new to occupational health and studies that analyze work-related mental disorders<sup>1-3</sup>. The production of Laurel and Noriega<sup>4</sup> influenced the experiences developed in Brazil in occupational health before the structuring of the Unified Health System (SUS)<sup>5,6</sup>. They were supported by prevention and health promotion with the participation of workers, anchored in criticism of the occupational medicine model and centered on the social health-disease process<sup>7,8</sup>. The social determinants were incorporated into the explanation about the health-disease of the working class, and the production of health started to focus on work and worker wear. However, we are lacking investigations whose central object of analysis is the pilgrimage of workers in SUS care networks and the integration strategies between Occupational Health and other points of care in the network to provide comprehensive care to sick workers.

The favorable environment for the articulation of care in mental health and work is found in the health network, which goes back to the two program areas with common origins, Occupational Health and Mental Health, but disjointed and traditionally structured in specialized units<sup>9</sup>.

Care strategies and the setting for the circulation of knowledge occurred predominantly at the municipal level, with the locus of Health Care Networks (RAS), which aim to promote the integration of care and management and ensure the effectiveness and efficiency of services to users<sup>10</sup>. In this setting, the Psychosocial Care Network (RAPS) was articulated with the Comprehensive Occupational Health Care Network (RENAST), established in 2002, revised and expanded later<sup>11</sup>. RENAST hosted the existing Occupational Health Reference Centers (CEREST) and RAPS the Psychosocial Care Centers (CAPS). These two networks had peculiar characteristics of the public policies that established them, with mental health historically being based on psychiatric reform<sup>12</sup>, and occupational health in recognition of work as a determinant of the health-disease process<sup>13</sup>. A common feature is the distance between the two areas vis-à-vis PHC<sup>14,15</sup>.

The integrated action, articulating the different points of care in the health network, implies overcoming health actions merely guided by protocols, flows, and referral services. It is about creating new care devices that favor comprehensiveness, impossible to be offered and guaranteed

in just one service. Cecílio<sup>16</sup> points out that the epidemiological method and the perspective of the microsocioal universe of health needs favor equity and comprehensive health care.

The pilgrimage of users across health services described by care flows and protocols exposes the bureaucratic dimension and does not reveal the dynamism, agencies, and crossings in the path built in the care production. Agency refers to the permanent production of life collectively and the establishment of new movements<sup>17</sup>. As a result, “users are self-living networks; they are constantly producing movements, developing knowledge and building and sharing care”<sup>18</sup>, like nomads seeking care through service networks and robust leading figures of its production.

Aligned with these formulations, building on the monitoring of a working user with mental distress, this paper aims to identify the networks activated for his care and analyze an experience of local SUS management that assumed work as a cross-sectional determinant of health and sought to implement care in a network, through integrated action between stakeholders in PHC, specialized care, mental health, and Occupational Health surveillance. The use of the ‘work’ category is of strategic importance for studies targeting health care analysis<sup>4,19</sup> because, although it is central to people’s lives, it most often appears as an aspect neglected by health teams in public and private services<sup>9,20</sup>.

## Methods

This descriptive, qualitative paper was produced from the systematization of the experiences of its authors, taken as an object of investigation, which fall within the research: “*Public policies and current issues in the world of work: impacts to mental health and subjectivity*”. This work is related to monitoring a user-guide<sup>17,18</sup>, in which an automotive industry worker in the upholstery sector was selected. His activity resulted in illness and lay-off, and he was initially recognized as a mental health user.

This user was selected from the study on the production of access and mental health barriers<sup>21</sup>, which conducted an investigation route based on the users who mobilized the team, those considered “completely crazy”<sup>21</sup>, from their multiple pilgrimage routes across care networks and the construction of care.

Our user-guide was seen at a PHC unit in São Bernardo do Campo, municipality of the Grande

ABCD region, located in the metropolitan region of São Paulo, with more than 800 thousand inhabitants and an important industrial center in the country. He had a history marked by mental suffering and comorbidities, expressed in eight codes of the International Classification of Diseases (ICD) and ten medical reports; and his trajectory guided the health team. Questions about his situation mobilized the staff of this service to understand his situation and his care project better.

The methodological path consisted in the elaboration of reflections and analyses revisiting the records of meetings of the team and between professionals from different services, notes in field notebooks, and bibliographical productions<sup>22,23</sup>. A synthesis of the user's pilgrimage in the care networks and through the care process was built after reading each record, enabling the construction of analysis categories. The analysis recognized the practical situations, daily work, the complex work, health and education process, and the participation and autonomy of professionals<sup>17</sup>.

This paper is nested in a study approved by the Ethics Committee of the Pontifical Catholic University of São Paulo. The necessary ethical procedures were observed, obtaining the informed consent from the respondents.

The user-guide is 54 years old, brown, 1.85m tall, thin, married for about 20 years. He has a teenage son, low socioeconomic status, attended high school, and was born and resides in the suburbs. Meetings reconstructed his history to identify his pilgrimage searching for care, his nomad-like ways of moving around in his existence<sup>18,23</sup>. The user-guide's ordeal journey across public and private health networks lasted about five years. A significant milestone was the loss of the right to health insurance after his dismissal from the company. The user faced the lack of work, money, care through the health insurance without achieving INSS benefits.

In 2010, the user began to receive the attention of the team consisting of a family doctor, a nurse, a community health worker from PHC, and supporters of different professional groups: psychology, social work, physiotherapy, and pharmacy, who were in charge of articulating care, as described hereunder. The team discussions promoted in the articulation of mental health care were based on the socio-ecological understanding<sup>24</sup> of the health-disease process, which considers the biological factors and the social, economic, cultural, political, environmental, and subjective aspects in the production of

health. It is supported by the establishment of health-conducive environments, the promotion of individual and collective health, and the active role of subjects in the process of social transformation<sup>24</sup>. Anchored in the criticism of the asylum-based and hospital-centered model, the construction of care adopted the consolidation of health care networks on the bonds achieved through attentive listening, the shared responsibility between users, workers, and managers, and the respect for freedom.

## Results and discussion

The exercise experimented in this case required a qualified dialogue from the Primary Care teams and the different services, favoring the treatment, prevention, and health promotion of the user-guide. It facilitated the understanding that agency services from the user-guide can reveal when work goes crazy, recognize care production, and reflect on management policies and devices. In this context, categories of analysis of the care process were constructed, as described below.

### **User-guide: the worker identity supplanted by the experience of madness**

In mid-2010, a Basic Health Unit (UBS) in a neighborhood on the outskirts of São Bernardo do Campo had new demands arising from the restructuring of primary care, which incorporated the Family Health Strategy and support of multidisciplinary teams<sup>22,23</sup>. Also, the reorganization of work processes led to the implementation of reception as an organizational device targeting comprehensive and humanized care<sup>25</sup>.

The multidisciplinary support strategy chosen aims to enhance the listening of health teams, given the complexity of the cases and the articulation of care through the mobilization of different knowledge. The health supporter is trained in one of the professional health centers and travels through the various services in the network, brokering conversations to share care and contribute to realizing comprehensiveness<sup>26</sup>. The network dialogue is expanded through this device to support its implementation<sup>27</sup>.

In this context, a user sought care at the UBS because he needed an INSS benefit to support his family. The request of the distressed user reverberated in the records of this service and the information about the history of his illness, the diagnosis of schizophrenia.

The user was instructed to return a few days later to be seen by the supporters (social worker and psychologist) who received him, listening carefully to his pain and psychological distress: *I have an invisible disorder. It was because of the environment... there's a lot I can't understand.*

The user was placed on the radar of care at the UBS, resulting in structuring a unique therapeutic project (PTS). The first stage of the PTS – the diagnosis – recognized a psychiatric hospitalization in 2005 with a diagnosis of schizophrenia. *It was Christmas 2005 when everything got weird. Then I found myself in a hospital, tied up and being medicated with painful injections by people I never saw before...* After the hospitalization, he started having trouble remembering things. He started writing down everything in notebooks – dates of appointments, medications he had to take, the hardships endured in the services, and the injustice experienced. Two other diagnoses accompanied him: asthma and an accumulating behavior (Diogenes Syndrome).

The reconstruction of some routes reveals many moments of distress in the services, from being able to reach places (distant and in other municipalities and going on foot for not being able to stay in a bus or car) to waiting hours and being treated at the specialty clinic of a Faculty of Medicine (5 or 6 hours) in a classroom with more than 60 students. Difficulties in understanding his distress until getting the medication right, lack of listening, and lack of reception. The user mentioned negligence and that he was mistreated in the services he visited. The outbreak was expressed with many exaggerated laughs and cries. At the time, the pastor of the Baptist church he attends helped him get care at a private “open space” service. The doctor at that service gave him heavy medication, and he spent three months doped in bed. He didn't eat alone and just slept. Little by little, he got better, but a panic syndrome was triggered. The drugs were expensive; they could not afford them and maintain the care.

He sought the SUS before 2010, and the health unit referred him to a specialty outpatient clinic of a Faculty of Medicine. He was attended to in an auditorium. He referred to feeling like a “monkey in a zoo”. Then he was hospitalized for 28 days at a State Hospital to get the medication right, as he was “poisoned”. He says that he suffered a lot with the hospitalization, and he was not allowed to go to the INSS for medical examination. Therefore, he lost the service and did not get the benefit. He says that, in general,

professionals and people devalue his speech as if he were lying. He felt ignored, and this produced distress. He faced neglect and carelessness. He thought that the medicine collaborated, but it did not solve everything, as he needed to talk and be listened to.

Regarding his occupational history, he mentioned companies where he worked with under the Consolidated Labor Laws (CLT) regimen as a hydraulic and pneumatic electric mechanic. In the last company, he worked for about five years with chemical products in an automotive upholstery multinational firm. His wife said he has always been a hard worker and had a psychotic break after working for many hours consecutively. He had the social support of his wife and child, owned a house, and had been fired from work in 2005.

In 1999, the user worked informally in an environment with exposure to chemicals. The following year, in an admission exam to work in an automotive company, the sentence was “fit with restrictions: cannot work with foam”. In 2003, he began to have severe asthma attacks, and on one occasion, he suffered cardiac arrest and was resuscitated. In 2004, after the Pulmonary Function Test, he was diagnosed with “mild obstructive ventilatory disorder”. He started to show constant asthma attacks and antisocial behaviors that led to the diagnosis of schizophrenia. He was dismissed from work due to his state of health.

He was submitted to different treatments and countless professionals, collecting different types of disease classifications (ICDs). In 2008, he underwent a neuropsychological assessment that revealed “signs of cortical-subcortical volume reduction and cortical predominance”. The user's course revealed fragmented care, gaps, and much distress. Care problematization by the team triggered a process of reflection and analysis to reorganize care and offer comprehensive care. The user-guide<sup>17</sup>, which catalyzes the integration between services and provides for inter-institutional dialogue, emerged in this context.

The meetings between health workers from different services provided an understanding of the complex paths taken by the user and developed collective knowledge about the production of care. The narratives enabled the elaboration of several questions, the identification of gaps, and the establishment of different care strategies. The reports produced had the user as a reference. The first clues about the illness process experienced by the user emerged in the conversations of the health teams in the production of care.

### The interweaving of care networks enhanced by the health support strategy

The first network conversations involving teams from UBS, CEREST, and CAPS fitted the parts of the “puzzle” of the user-guide’s illness history. Care followed the investigation of asthma attacks. An inter-appointment was arranged with a pulmonologist and the supporter (physiotherapist) evaluation, noting intense pulmonary fibrosis, with no smoking history. The cranial tomography report showed frontal lobe lesions, which led to the hypothesis of organic psychosis.

The pre-employment occupational health exam carried out at the company identified healthy lungs. The second periodic examination found a small lung lesion, and the third regular examination revealed considerable deterioration of the lung injury. Soon after that, the employee was dismissed and developed a psychotic break.

The user handled substances that quickly solidified, forming vehicle upholstery foams. The chemical composition contained xylene, toluene, and even benzene<sup>28</sup>. The hypothesis of prolonged inhalation of chemical products was elaborated, which was viable due to his occupational exposure, ruling out the theory of schizophrenia.

During the appointments, he mentioned that many company workers filed lawsuits for health reasons during the same period. By reconstructing the work history, we could relate the period of deterioration of his respiratory problem with the dismissal. His wife assumed he had done something wrong on the job to motivate his lay-off.

The severe mental confusion, fragmented dialogue, and a long history of pilgrimage in different health network services, apparently without progress and without recovery of his social well-being, gained new contours. The clinical history articulated with the professional trajectory started to make sense, revealing an organic mental disorder resulting from exposure to chemical substances<sup>29</sup>.

According to the Manual of Work-Related Diseases<sup>30</sup>, unspecified organic or symptomatic mental disorder (ICD-10, F09) is part of the group of several disorders that also includes organic and symptomatic psychosis, and can be included in the Group I of Schilling’s Classification, in which work plays the role of necessary cause.

The user worked in an unhealthy place, and no causal relationship between the occupation and his respiratory disease and, later, between the mental disorder and his work activity had

been established<sup>31</sup>. The countless tests and medical reports issued by the private health network and the SUS, and the medical documentation, showed a tortuous and polyphonic process, expressed in eight different ICDs in the documents studied. From the qualified listening of the health care supporter<sup>25</sup> at a UBS, it was possible to connect life and work by paying attention to the user’s statement about his work.

The intertwining of RAPS and RENAST is infrequent in the experience of workers who become ill at work. While with a common origin in the Health Movement and SUS references, they remained disconnected from the care network<sup>9</sup>. The user-guide allowed us to recognize the gaps between these two program areas and regarding primary care<sup>20,32</sup>.

The care networks in the SUS are defined as structures that integrate to provide health actions and services, institutionalized by public policy in a given regional space built on collectively planned work and the deepening of interdependent relationships between the actors involved<sup>33</sup>. It is not enough to have health equipment distributed in a specific geographic area<sup>34</sup> to build a network.

The clinical practice that does not recognize the work category reveals a weakness in the understanding and treating several psychopathologies<sup>35</sup>. The user-guide’s work history has been neglected for a long time. The company did not comply with the restrictions established in the occupational exams. Consequently, his labor and social security rights were also denied. His distress was aggravated, with important repercussions on his family, but he accessed the SUS, and the attentive and qualified listening to his report, his complaints, and his worker’s identity enabled new agencies.

Another aggravating factor for his crises was the saga faced in the quarterly inspections at the Brazilian National Social Security Institute (INSS), the suspension of sick pay, and the official “return-to-work” opinion issued. That was the reason that encouraged him to ask the UBS for help: “*Help me with my benefit.*”

Workers excluded from work require psychological support due to distress, shame, and passivity<sup>36</sup>. Disaffiliation<sup>37</sup> marks the trajectory of social exclusion and the dissolution of social bonds. Deprivation is the central aspect of disaffiliation in unemployment, and disruptions in sociability contribute to the unemployed individual’s social isolation<sup>19</sup>.

### Weaving network care

The definition of a framework of organic psychosis resulting from labor exposure re-elaborated the PTS, as recognizing the causal link between work and illness gave rise to the review of social security and labor rights. CEREST completed the Work Accident Communication, echoing on the worker's face, which shone triumphantly.

In the following days, he began to show greater personal cleanliness and a greater willingness to proceed with the other actions coordinated by the PTS with the CAPS and UBS. The feeling of belonging and the construction of the narrative of life drive identity construction<sup>19</sup>.

From the intervention of the CAPS team, carried out by the social worker and the psychiatrist, who contacted and questioned the INSS expert about the case, the user-guide became better understood in the social security agency. CAPS and the INSS agency weaved intersectoral connections<sup>26,38</sup>. The benefit was restored and helped him stabilize, as he could provide for his family. A short time later, he was retired by the INSS due to disability, which gave him peace of mind, directly affecting his way of acting in the world<sup>21,23</sup> and enriching his professional know-how.

The user-guide began to take care of everything on his own: the house, the child, his health, and the rehabilitation of his wife, victim of a hemorrhagic stroke. He continued to participate in the meetings at CAPS and bonded with the professionals. In the past, the user had experienced a psychiatric hospitalization that left marks in his history. When incorporated into the CAPS, an efficient device in mental health care, he led the health production process<sup>34</sup>. He began to attend meetings of a local association that discussed citizenship and income generation issues for people in psychological distress. Living networks provided the shared construction of care and new forms of attention and care in mental health<sup>18,34</sup>. Therapeutic resources adopted both relationship and accountability, and the several devices boosted the inclusion in emancipatory community groups.

At the same time, CEREST carried out investigations in the company to avoid the illness of other workers, which comforted the user-guide, as he felt he could contribute with other coworkers. Occupational health surveillance was part of the production of health care<sup>38</sup> and redefined the user's ethical-political distress<sup>39</sup>. In pain from so-

cial injustice and the stigma of his "crazy" condition, he accessed comprehensive health care and expanded his power to act on the world.

CEREST performed matrix support in all CAPS<sup>9</sup> in the city, reporting the case of organic psychosis as a sentinel event and advising on the notification of cases of workers from the same company, characterizing an active search for new users<sup>40</sup>. Work-related mental disorders have been aggravated by compulsory notification since 2004, including organic personality disorders. Notifications are essential tools in the comprehensive care of people as they give visibility to situations, prevent new cases, and promote workers' rights<sup>41</sup>.

The user-guide biography reveals the suffering separated from the concrete life of the working man. The organic aspects that trigger a mental disorder were trivialized or neglected in understanding the distress that originated in his work. The several manifestations of anguish, respiratory problems, and behavioral changes resulting from brain injuries caused the loss of identity, a weak and limited life.

In the wake of much pain, the loss of references and immense fragmentation led the user-guide to keep a diary. The annotations created some linearity and stored information that one's mind could not. The integrated health team worked as an organizer of his being in the world and created conditions to put together a new functioning of his mental apparatus and continue his daily life.

The empathetic, humanized, and committed relationship allowed, from listening to the initial request for "help to get the INSS benefit because I need to support my family", to circulate knowledge and practices and enhance comprehensive care for the user, an expression of radical commitment with the user-citizen of rights.

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The experience on the articulation of care in a network, including CAPS, CEREST, and UBS, was being implemented in the municipal health network in that period,<sup>38,41</sup> per the municipal health plan for workers and other specific areas permanently, however, under construction.

## Final considerations

The connectivity of the Psychosocial and Occupational Health Care networks and the live health care networks emerge from the narrative of the user-guide's life, which enables the multifaceted understanding of being in the users' world. It shows that health teams, mobilized by an ethical commitment, can connect with the user's needs and design special care, operating as a helmsman searching for comprehensiveness.

Attentive and respectful listening creates conditions to understand and integrate the various health determinants beyond the clinical aspect. It produces a situational diagnosis, in which the subject is seen in the established context and the interrelationships. The social production of madness and its connection with the neglect of health protection in work environments, with the disconnection between social security policy and health policy, corroborates the need to engender support for establishing health care networks.

In times of so many attacks on the SUS, we can highlight that this standard of health care, produced in the case of the user-guide, does not have similarities in supplementary health. The

confluence of the multidisciplinary aspect, the integration of different points of care, the intersectorality orchestrated by the emphasis on human dignity, the right to life, care in freedom, and health as a fundamental right, assess the value of this health policy.

Relying on health guidelines that look at the singular and the collective attest to the humanization woven in the daily life of primary care. With their micropolitics and capacity to produce bonds, health territories can give new meaning to the lives of people with complex illnesses.

The user-guide reveals the complexity and daily challenges of doing health care. The system's efficiency and resolvability bring satisfaction to the user and the health teams, who see their expectations fulfilled.

Aligned with current studies in Work-related Mental Health, this paper confirms the need for a clinical context of work<sup>18</sup>. It contributes to the training of health professionals insofar as it dialogues with SUS guidelines and public policies on Mental and Occupational Health, based on the right to life, respect for dignity, and ethical commitment to people's health.

## Collaborations

The authors contributed equally to the production of the manuscript.

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Article submitted 25/05/2020

Approved 26/07/2021

Final version submitted 28/07/2021

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Chief editors: Romeu Gomes, Antônio Augusto Moura da Silva

