

For a Palliative psychiatry: Applying palliative care to Brazilian public psychosocial care (RAPS) users

Por uma Psiquiatria paliativa: Aplicação de cuidados paliativos a usuários da Rede de Atenção Psicossocial (RAPS)

Por una Psiquiatria paliativa: La aplicación de los cuidados paliativos a los usuarios de la red brasileña de atención psicossocial (RAPS)

RESUMO

Objetivo: Esse artigo cuidou da possibilidade de se falar em uma Psiquiatria paliativa na Rede de Atenção Psicossocial (RAPS), ao colocar-se em cuidados paliativos pacientes com agravos de saúde mental momentânea ou permanentemente impossibilitados à reabilitação. Assim, o objetivo geral foi investigar, nas perspectivas médica e bioética, a viabilidade de portadores de sofrimento psíquico, transtornos mentais e abuso ou dependência de substâncias serem submetidos a cuidados paliativos na RAPS, em função desses agravos e não como condição secundária a doenças de base orgânica. Foram objetivos específicos: identificar os fundamentos bioéticos da ideia de cuidado; examinar o papel da clínica ampliada e do Projeto Terapêutico Singular (PTS) no contexto da atenção psicossocial; e vislumbrar o eventual caráter paliativo das intervenções em saúde mental. Tendo natureza exploratória, o estudo propôs uma análise de dados obtidos a partir de levantamento não-sistemático da literatura. Do ponto de vista bioético, medidas paliativas justificam-se na perspectiva integradora de uma ética do cuidado. Verificou-se também que termos como "cura" e "cuidado" comportam uma imprecisão – e, portanto, uma plasticidade conceitual – que possibilita estender a ideia de paliatividade às práticas dentro da RAPS, de maneira alinhada aos princípios do movimento *hospice* e da Reforma Psiquiátrica brasileira. Para tanto, o ponto de partida deve ser a elaboração do PTS, no âmbito da clínica ampliada. Por fim, ao incluir medidas suportivas, isoladamente ou em conjunto com ações terapêuticas, o modelo de intervenção atual parece admitir a possibilidade de inclusão de práticas paliativas. Ressalta-se a necessidade de as equipes multidisciplinares atuantes em saúde mental receberem treinamento quanto a técnicas específicas em cuidados paliativos, com vistas ao aperfeiçoamento da assistência prestada.

DESCRIPTORES: Agravos em saúde mental; Cuidados paliativos; Dependência química; Rede de Atenção Psicossocial (RAPS); Psiquiatria paliativa.

ABSTRACT

Objective: This study sought to understand the existence of a Palliative psychiatry as Brazilian Psychosocial Care Network (RAPS) offers palliative care to patients momentarily or permanently ineligible for rehabilitation. Therefore, its main purpose was to search medical and bioethical bases for palliative practice under the circumstances of non-physical illnesses. The specific goals were to identify the bioethical foundations of the idea of care; to examine the role of individualized care plan (PTS) in the background of the psychiatric reform; and to glimpse palliative strategies in mental care interventions. The author conducted an exploratory study based on bibliographic data. From a bioethical standpoint, the Ethics of care justifies palliative approaches. The investigation also revealed that words such as "cure" and "care" have some sort of conceptual imprecision (and therefore plasticity) that enables the use of palliative measures within the context of RAPS, in light of the hospice movement and the psychiatric reform. It can be accomplished through a non-asylum approach when developing users' PTS. By including supportive measures alone or in association with healing interventions, the current model is likely to encompass palliative practices. Nonetheless, mental care multiprofessional teams require proper training to improve assistance skills.

DESCRIPTORS: Mental health issues; palliative care; chemical dependency; Brazilian Psychosocial Care Network (RAPS); Palliative psychiatry.

RESUMEN

Objetivo: Divulgar la importancia de la lactancia materna en el desarrollo del bebé y en la relación afectiva entre madre e hijo. Método: Se trata de una revisión integradora, realizada a través de búsquedas en Internet utilizando el portal de la Biblioteca Virtual en Salud (BVS) a través de las bases de datos LILACS, BDNF y MEDLINE. Se buscaron artículos registrados utilizando los descriptores de salud "lactancia materna", "mujeres puérperas", "dificultades en la lactancia materna" y "niños primogénitos", y se seleccionaron para la muestra todos los artículos disponibles en su totalidad y publicados en portugués entre 2018 y 2023. Resultados y discusiones: se destacaron las principales dificultades en la lactancia de las mujeres primíparas, tanto físicas como psicológicas y socioculturales. Conclusión: las experiencias, dudas y expectativas presentadas por las mujeres muestran las fallas que comienzan en la atención prenatal y se extienden hasta el período en que la puérpera está en casa con toda la familia.

DESCRIPTORES: Lactancia materna. Cuidados de enfermería. Dificultades de la lactancia materna.

RECEBIDO EM: 30/01/2024 APROVADO EM: 09/02/2024

How cited: König LRC. For a Palliative psychiatry: Applying palliative care to Brazilian public psychosocial care (RAPS) users. *Saúde Coletiva* (Edição Brasileira) [Internet]. 2024 [acesso ano mês dia];14(89):13278-13287. Disponível em: DOI: 10.36489/saudecoletiva.2024v14i89p13278-13287

**Luiz Roberto Curia König**

Médico (PUCPR) especializando em Psiquiatria no Hospital São Lucas (PUCRS). Especialista em Terapia Cognitivo-Comportamental pelo Instituto Paranaense de Terapia Cognitiva (IPTC). Psicólogo clínico (UNIP).
ORCID: 0000-0003-0334-6085

INTRODUCTION

Presenting as its audience people suffering from suffering or mental disorders, including the use of alcohol, crack and other substances, the Psychosocial Care Network (RAPS) has rehabilitation and reintegration as some of its specific scopes. Other actions aimed at service users include promoting care for the most vulnerable, preventing substance use and dependence and reducing harm from their consumption. This study, therefore, was guided by the question of whether or not it is possible to apply the concept, criteria and management techniques of palliative care to RAPS users who are temporarily or permanently beyond the possibility of rehabilitation.

A preliminary bibliographic survey found few studies relating palliative care to disorders directly linked to mental health care. One explanation for the gap would be the difficulty in establishing, in relation to psychiatric illnesses, what it means to be “outside the possibility of cure”, or even the character of “threat to life”, criteria historically associated with the idea of palliative care. The current definition of palliative care extends it to situations other than just threatening or incurable illnesses^[1], leaving the concept of cure in mental health unclear as well as the notion of care flexible^[2-6].

Thus, the general objective of the study was to investigate, from bioethical,

legal and medical perspectives, the viability of people with psychological distress, mental disorders and substance abuse or dependence are subject to palliative care due to these conditions and not organic-based diseases. Specific objectives were: to identify the bioethical foundations of the idea of care; examine the role of the expanded clinic and the Singular Therapeutic Project (STP) in the context of psychosocial care; and envision the palliative nature of mental health interventions.

Thinking about situations not oriented towards rehabilitation and reintegration is necessary so that the multidisciplinary teams involved can review and expand the spectrum of assistance provided. The study of palliative care, which has been establishing itself as an autonomous discipline, would also benefit from the inclusion of a chapter that would make it possible to build specific knowledge about assistance in mental illnesses, in the same way that it already does for other categories, such as elderly populations, oncology patients, pediatrics, among others^[7].

METHOD

This study was based on exploratory research, based on a non-systematic review of the literature that brought together materials on bioethics, palliative care, the administrative structure of the Unified Health System (SUS) and men-

tal health care.

To this end, the VHL and SciELO databases were consulted between December 2023 and January 2024.

In a first search, the descriptors “Sistema Único de Saúde” AND “Mental Health Services” were used, returning 224 articles between both platforms searched, of which 28 were pre-selected for the research that gave rise to the study. In the second search, the terms “Mental Health Services” AND “Palliative care” were applied, returning 418 studies. When searching for the descriptors “Mental Disorders” OR “Mental Illness” OR “Psychiatric Illness” AND “Palliative Care” in the title or summary of publications, 56 foreign articles and 1 national article were found, among which 19 articles were pre-selected. Subsequently, studies that did not address the issue of palliative care due to psychiatric illness, but only aspects of mental care in patients undergoing palliative care due to an organic-based illness, were discarded from the research. As exclusion criteria, publication time of more than 5 years, language other than English and Portuguese, the organic nature of the underlying disease (including neurological diseases), as well as the inadequacy of the material, after qualitative analysis, were also applied.

Finally, the abstract and manuscript were prepared in accordance with SRQR recommendations^[8].

RESULTS

Psychosocial assistance and palliative care as historical processes

One of the difficulties historically faced by mental health in Brazil was the existence of a secular culture, based on a hospital-centric and exclusionary model, which invoked its legitimacy to determine who, how, where and why to treat^[9]. From the last decades of the 20th century, people began to think about a new model of service, arising from the desires and questions of labor representations in the 1970s, which was followed by the successful inclusion of a new perspective on health, with the advent of the Federal Constitution of 1988, culminating in the Psychiatric Reform Law and subsequent regulations^[10].

On the other hand, in the first hospices, equipment that represented the embryo of the process that culminated in the creation of the practice of palliative care, there was an orientation to focus on serving a disadvantaged social class, almost always with no other place to turn to^[9]. This fact places palliative care, since its origins, as a movement identified with an inclusive practice and, in some countries, supported by a public and universal health system.

Thus, the palliative care movement^[9] and the psychosocial assistance model derived from the Brazilian psychiatric reform^[10] both resulted from processes of non-conformity with practices in force at the time^[9,11]. From this perspective, talking about palliative care in psychosocial care suggests the convergence of constructions made over decades and focused on correcting social distortions.

The same can be said in relation to the growing scope of the population of palliative care recipients. Along the same lines as the current definition^[12], which overcomes the old criteria of incurability and life-threatening diseases, new research suggests the extension of its reach to populations with neurological or psychiatric disorders^[13].

In fact, palliative care applies to anyo-

ne with a serious illness, not just those in the terminal process, but with high risk and negative impact on quality of life and daily life functions, symptoms and therapies that are stressful for the patient and their caregiver are included^[14]. The International Association for Hospice and Palliative Care – IAHPC proposes the definition of palliative care focused on intense suffering caused by severe illness, highlighting the terminal stages, but not restricted to these^[1]. Although it is not perfect, it contributes to new practice and advances in health systems, having been produced based on contributions from professionals from all over the world^[11]. This construct, therefore, seems to reinforce the idea of care committed to social vulnerability, by seeking a consensus supported by plural cultural and economic perspectives.

In Primary Health Care (PHC), palliative care can also be part of the planning of the constituent actions of the Singular Therapeutic Project (STP), always taking into account the link for agreement and the so-called social diagnosis of the person and their family members. It is also considered urgent to include palliative care among those provided on an ongoing basis by the SUS, as well as adequate training of care teams, in order to favor universal access, comprehensiveness and equity in network care^[15].

Psychosocial care, expanded clinic and unique therapeutic project: concepts in motion

The model of action that socially includes the subject, instead of excluding him, is that of an expanded clinic, in this sense opposed to what could be called an asylum clinic. It presupposes attention to social reality, family support, work with groups and a transdisciplinary approach^[6].

Such a clinic operationalizes the creation of new possibilities for intervention, in a process of rupture, not confirmation, of pre-existing solutions^[2]. Thus, the “concept of therapeutic project has

been under construction since the beginning of the 1990s, changing along with the history of the SUS, the health movement and psychiatric reform”. It implies saying that the STP is a flexible instrument, molding itself to each identified need and each advance in understanding the subject and the care they require.

Discounting the setbacks observed in its recent past^[10], the history of the SUS testifies to the improvement of the STP as a device for integrating and organizing team work. More than that, it constitutes an instrument of co-management and co-production of the therapeutic process of individuals or groups in a context of vulnerability. The care project is a reflection of the humanization of health and efforts to promote citizenship^[15].

The formulation of a STP would involve four distinct moments: diagnosis and analysis, considering the physical, psychological and social aspects, with a view to establishing a diagnosis taking into account the patient's risks and vulnerability; definition of short, medium and long-term actions and goals to be co-established with the patient and/or their guardians and caregivers and respecting “key moments” such as changes in the life cycle, onset of diseases, etc.; division of responsibilities and tasks between team members and the patient and their caregivers, ensuring continuity of care; reevaluation aiming at continuous discussion of evolution and the need for adjustments to the project^[15]. In this way, the STP is an open instance of identification, reflection, creation of horizons with and for the subject, within their singularity and complexity. In an ideal scenario, it seeks to adapt tools and resources to the individual's universe, and not the other way around.

DISCUSSION

Palliative care and mental health: combining possibilities

One of the reasons that may have kept palliative care outside the scope of psychosocial care is the vague, ambiguous

and imprecise concept of mental health cure^[16-17], from which it can be deduced that, in the pre-reformist model and within the scope of theoretical science and laws, the idea of cure would be linked to the reestablishment of socially accepted conduct and values. Today, terms such as remission of acute episodes, symptom control, stability, recovery and single-episode disorder are prioritized, among others, with references to disorders capable of complete and permanent remission being rare^[3-4, 17-18].

Rehabilitation and recovery constitute not a “cure”, but the perception of an improvement in functioning and quality of life, from the patient’s point of view and not merely from the professional who assists them^[17]. Thus, even what is understood as psychiatric treatment actually encompasses a considerable part of support measures, aiming to alleviate symptoms and prolong the progression of the condition or the onset of secondary illnesses. Thus, even the oldest concept of palliative care, related to the idea of incurability^[7], does not seem to rule out its application to the field of mental health. This occurs because the understanding of a vulnerable person must permeate all the possibilities of the person and the collective, necessarily involving their unique contexts in determining the therapeutic project^[15], without also disregarding the threat that vulnerability and the social injustices that determine it represent to human dignity and the very continuity of life^[2].

The care model based on a care network is “a commitment to organize singular care, articulating the individual and the collective, with health understood in an expanded way, not only referred to the biological body and its illnesses”^[19], demonstrating that there are no obstacles, in theory, for palliative care to be part of the range of care, in relation to this scope of assistance.

There is, however, no closed concept of care^[5-6]. The lack of precision is positive, as it allows for individualized approaches to each situation. The conceptual

plasticity of the term also extends to the concept of health, which is characterized as “a complex object, therefore, multifaceted, plural, capable of generating countless discourses from different points of view; it is plural in looks and meanings”^[2]. Therefore, “cure” and “health” involve a dynamic, moldable, which sees the individual, on the one hand, in their unique needs and potential and, on the other, in their condition as a citizen, part of a social environment and a context of integrality and multidetermination^[5,20].

Care then becomes an ethical principle or reference, with transversality in the involvement of the different knowledge and practices that compose it, and not a set of formulas to be applied. The concept acts as a guide for ethical-political conduct^[2], preventing the denial of vulnerability, the disqualification of comprehensiveness and, as a consequence, the compartmentalization of assistance between distinct and incompatible “curative”, “rehabilitative” and “palliative” modalities^[13].

Indeed, regarding abuse or dependence on alcohol, crack and other drugs, it is reasonable to admit that the idea of control or harm reduction does not differ, in essence, from that of palliative care^[21]. Here, assistance would already be, in some way, guided by a palliative philosophy, seeking the best available result and supporting the subject in carrying out a life project that is as feasible or as least harmful as possible^[22]. In other sociocultural contexts, the condition of severe mental illness, including the most diverse categories and classifications here, encompasses the idea of palliative care, although this nature of care has not yet been properly operationalized, implying the risk that multidisciplinary care is still undersized for this population^[23].

It is worth mentioning that there is already talk of palliative psychiatry, whose contours are still a theoretical-practical entity under construction. It is based on the assumption that, even with adequate treatment, individuals with severe and persistent mental disorders do not reach

an acceptable level of mental health, psychosocial functioning and quality of life, bringing psychiatric interventions closer to the idea of harm reduction and relief of suffering^[13].

In this context, the provision of palliative care to psychiatric patients could be a parallel practice to cure, when possible, as well as rehabilitation, complementing it, merging with curative treatment or even replacing it, in individualizable situations that encompass: intense suffering, as required by the most recent definition of palliative care^[11]; threat to life, according to the previous WHO concept^[12]; or even the impossibility of cure referred to in the original idea of palliative care^[7]. Therefore, palliative practice can coexist with other psychosocial care measures or constitute the only possible intervention modality, in the case of symptom relief and damage control, always safeguarding the person's dignity and the individualization of care and highlighting the necessary training of the multidisciplinary team in the specific techniques of this autonomous area of knowledge^[13].

Não existem, até o momento, instrumentos e modelos de intervenção validados para a abordagem em cuidados paliativos de pacientes com doença mental severa^[23-25]. Nesse viés, muitas intervenções tipicamente utilizadas no tratamento de distúrbios psiquiátricos refratários ao tratamento podem ser consideradas de natureza paliativa^[24].

Therefore, it is believed that palliative care is a feasible stance in the context of comprehensiveness^[21] and STP, which is the result of the humanization of health care and, by definition, open and oriented to the needs of the person being cared for, the uniqueness of their experiences, needs and objectives^[15]. So much so that “each encounter transforms the ways of acting in the health system, their ways of being, working, getting sick and living”^[2].

CONCLUSION

This article has some limitations. As he relied exclusively on bibliographical

sources, it was not possible to empirically confirm the ideas he defends. Furthermore, the lack of other works with the same focus, especially in Portuguese, resulted in the absence of parameters to determine the advances achieved. Therefore, its merit consists solely in representing a provocation to debate.

Despite these reservations, it is confirmed, in conceptual terms, the viability of palliative care in the assistance provided by RAPS, whether in parallel

to rehabilitation or as the only means of supporting the person receiving care. The impossibility of involving certain users in rehabilitation strategies does not imply the suppression of citizenship and rights. On the contrary, it requires ensuring them in different ways: support for dignity based on an ethics of care, supportive or comfort measures, minimization of the effects of their condition and, finally, respect for the potential of the person being ca-

red for, however minimal they may be, such as the ability to receive love when they have nothing else to offer, actions that make up what can be understood as palliative Psychiatry.

It is hoped that, given the scarcity of bibliography, this work can inspire future research that delves deeper into the issue of perception, use and integration of palliative care into mental health care in Brazil.

REFERENCES

1. International Association for Hospice and Palliative Care (IAHPC) [homepage na internet]. Consensus-Based Definition of Palliative Care (2019). Disponível em: Consensus-Based Definition of Palliative Care (2019) - International Association for Hospice & Palliative Care (hospicecare.com). Acesso em: 8 jan 2024.
2. Barros MEB, Gomes RS. Humanização do cuidado em saúde: de tecnicismos a uma ética do cuidado. *Fractal, Rev Psicol* 2011;23(3):641-58. Disponível em: <https://www.scielo.br/pdf/fractal/v23n3/v23n3a13.pdf>. Acesso em: 27 dez 2023.
3. Davidson L, Rowe M, DiLeo P, Bellamy C, Delphin-Rittmon M. Recovery-oriented systems of care: a perspective on the past, present, and future. *Alcohol Res* 2021;41(1):09. doi: 10.35946/arc.v41.1.09.
4. Weaver N. Recovery and care continuity experiences of people in mental health care: A conciliatory approach to the challenge of implementing recovery-based services. *Social Health Illn* 2021;00:1-19. doi: 10.1111/1467-9566.13373.
5. Penha JS, Marques MCP, Sousa SMA, Passos HM, Pinheiro PNC, Ferreira AGN. Integralidade do cuidado em saúde sob a perspectiva filosófica de Emmanuel Lévinas. *Rev Enferm Atual In Derme* 2022;96(38):e-021240. doi: 10.31011/reaid-2022-v.96-n.38-art.1306.
6. Fagundes GS, Campos MR, Fortes SLCL. Matriciamento em saúde mental: análise do cuidado às pessoas em sofrimento psíquico na Atenção Básica. *Cien Saude Colet* 2021;26(6):2311-2322. doi: 10.1590/1413-81232021266.20032019.
7. Castilho RK, Silva VCS, Pinto CS (editores). *Manual de Cuidados Palliativos ANCP*. 3 ed. São Paulo: Atheneu, 2021.
8. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for Reporting Qualitative Research: a synthesis of recommendations. *Acad Med* 2014;89(9):1245-51. doi: 10.1097/ACM.0000000000000388.
9. Knight HP. St. Luke's Hospice: Prioritizing Comfort, Not Cure, in the Hospital Setting. *Bull. Hist. Med* 2020;94:268-288. doi: 10.1353/bhm.2020.0037.
10. Sampaio ML, Bispo Júnior JP. Entre o enclausuramento e a desinstitucionalização: a trajetória da saúde mental no Brasil. *Trab Educ Saude* 2021;19:e00313145. doi: 10.1590/1981-7746-sol00313.
11. Radbruch L, De Lima L, Knaut F, Wenk R, Ali Z, Bhatnagar S, et al. Redefining palliative care: a new consensus-based definition. *J Pain Symptom Manage* 2020. doi: 10.1016/j.jpainsymman.2020.04.027.
12. Organização Mundial de Saúde (OMS) [homepage na internet]. Who definition of palliative care. Disponível em: <https://www.who.int/cancer/palliative/definition/en/>. Acesso em: 27 dez 2023.
13. Westermair AL, Buchman DZ, Levitt S, Perrar KM, Trachsel M. Palliative psychiatry in a narrow and in a broad sense: A concept clarification. *Aust N Z J Psychiatry* 2022;56(12):1535-1541. doi: 10.1177/00048674221114784.
14. Tatum PE, Mills SS. Hospice and palliative care: an overview. *Med Clin North Am* 2020;104:359-73. doi: 10.1016/j.mcna.2020.01.001.
15. Grande MM, Carretta RYD, Kronka AG, Inocenti A, Forster AC. Gestão do trabalho interprofissional no projeto terapêutico singular: proposta de modelo de processo de trabalho. *Medicina (Ribeirão)* 2023;56(2):e-203959. doi: 10.11606/issn.2176-7262.rmp.2023.203959.
16. Nielsen JM, Niels B, Berring LL. Mental Health Recovery in Social Psychiatry Policies: A Reflexive Thematic Analysis. *Int J Environ Res Public Health* 2023;20(12). doi: 10.3390/ijerph20126094.
17. Brasier C, Brophy L, Harvey C. Constructing recovery: A Lived Experience and post-structuralist exploration of how the meaning of personal recovery and rehabilitation has changed over time. *Australas Psychiatry* 2023;31(5):607-609. doi: 10.1177/10398562231194193.
18. Solomon HV, Sinopoli M, DeLisi LE. Ageing with schizophrenia: an update. *Curr Opin Psychiatry* 2021;34(3):266-274. doi: 10.1097/YCO.0000000000000694.
19. Merhy EE, Feuerwerker LCM, Santos MLM, Bertussi DC, Baduy RS. *Saúde Debate* 2019;43(6):70-83. doi: 10.1590/0103-11042019S606.
20. Almeida SA, Merhy EE. Micropolítica do trabalho vivo em saúde mental: Composição por uma ética antimanicomial em ato. *Psicol Polit* 2020;20(47):65-75. Disponível em: <http://pepsic.bvsalud.org/pdf/rpp/v20n47/v20n47a06.pdf>. Acesso em: 19 jan 2024.
- [21]. Magoon C, Shalev D. Toward holistic care: including substance use in mental health-palliative care integration. *Palliat Support Care* 2022;20:453-454. doi: 10.1017/S1478951522000591.
22. Ebenau A, Dijkstra B, Huurne C, Hasselaar J, Vissers K, Groot M. Palliative care for people with substance use disorder and multiple problems: a qualitative study on experiences of patients and proxies. *BMC Palliat Care* 2019;18:56. doi: 10.1186/s12904-019-0443-42018
23. Shalev D, Fields L, Shapiro PA. End-of-Life Care in Individuals With Serious Mental Illness. *Psychosomatics* 2020;61:428-435. doi: 10.1016/j.psych.2020.06.003.
24. Strand M, Sjöstrand M, Lindblad A. A palliative care approach in Psychiatry: clinical implications. *BMC Medical Ethics* 2020;21:29. doi: 10.1186/s12910-020-00472-8.
25. Toor H. Palliative care in patients with severe mental illness. *Can Fam Physician*. 2019;65:799-801. doi: 10.1186/s12910-020-00472-8.