Service users' negative experiences of community mental health services: A scoping review protocol

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This is an original protocol paper registered in the Open Science Framework.

Abstract

Objective: This scoping review aims to map and describe the existing literature that explores service users' negative psychosocial experiences with community mental health services (MHS).

Introduction: Despite its significant impact on outcomes, research on service users' negative experiences while receiving community MHS is scarce, with limited amounts dispersed across several areas. Summarizing the current evidence is required to identify common negative experiences across services and to provide implications for future research and practice.

Inclusion criteria: Academic articles that focused on individuals with mental health problems and reported negative experiences of service users concerning the psychosocial aspects of community MHS will be included. This review is open to several types of articles, including quantitative and qualitative studies, reviews, and letters.

Methods: MEDLINE, PsycINFO, and CINAHL databases will be searched for relevant studies. The search will be limited to articles published in English. After developing search strategies through discussion with a librarian, title and abstract screening and full-text screening will be conducted by two independent reviewers. After full-text screening, the references of the included articles will be screened for additional studies. The details of each included article will be extracted using a data extraction chart. A basic qualitative content analysis will be performed to describe the negative experiences reported in the articles. A cross-tabulation of the codes/categories of negative experiences and service settings will be presented to demonstrate the distribution of the literature, accompanied by a narrative summary.

Keywords: mental health services; negative events; psychiatric care; psychosocial intervention; service user experience; lived experience

Introduction

It is crucial for service users to avoid negative experiences while receiving mental health services (MHS). This requires as much attention as the negative side effects of pharmacological treatments. This is supported not only by the simple and powerful ethical principle of “do no harm,” but also by the fact that negative experiences could leave lasting adverse effects or cause individuals to drop out of services [1, 2]. Removing all negative experiences is unfeasible and sometimes inefficient; however, monitoring them is essential for patient satisfaction and prevention of symptom deterioration or dropping out of services. Despite the substantial impact of service users’ negative experiences, the research and service provider communities have not succeeded in establishing consistent research findings on service users’ negative experiences or improving relevant practices [3, 4].

Negative experiences refer to events or situations in which service users experience distress, dissatisfaction, or harm during their interactions with service providers, environments, or systems. As negative experiences has no clear definition, we referred to Parry et al.’s suggested definitions for a range of negative effects of psychotherapy [3]. They proposed three definitions: a) adverse events, which are significant episodes during or shortly after treatment (e.g., suicidal events and hospital admissions); b) clinically significant deterioration, which is a worsened mental state after treatment (e.g., increased anxiety and emergence of new symptoms); and c) patient-experienced harm, which refers to negative experiences of treatment outside of the previous two definitions. As this review focuses on service users’ perspectives on their experiences and not on the clinical outcomes or effects of services, we consider the last definition (i.e., patient-experienced harm) as negative experiences.

Although research exists on negative experiences in psychosocial mental health care, the available literature varies depending on the service setting. The experiences of psychiatric admissions and psychotherapies have been relatively well studied and summarized in this field. Several reviews [5-9] including a meta-review [10] vividly describe negative experiences in psychiatric wards, such as poor-quality staff-inpatient relationships, a sense of powerlessness and fear induced by coercive measures, violations of autonomy caused by involuntary admissions, and a rule-dominated environment. Coercive treatment of psychiatric admissions may lead to substantial attention to negative experiences in psychiatric wards. For instance, involuntary admissions, seclusions, and restraints are currently assumed to be indispensable as part of inpatient care; however, they might risk human rights, which frequently induces patients’ negative feelings.

Interest in the adverse effects of psychotherapy has increased over the past few decades. An alarm was heard on the assumption that psychotherapy is harmless [4, 11], while the definition and classification of adverse events in psychotherapy have been suggested [3, 12, 13] and surveys on the prevalence of negative effects have been conducted [2, 14-20]. Three qualitative meta-analyses were published to identify clients’ negative experiences during psychotherapy sessions [21-23]. They explained that the interaction between a therapist and client can be unhelpful owing to multiple factors, such as lack of empathy, over-control, hindered therapeutic relationship, and treatment mismatch.

Despite the accumulation of evidence in inpatient and psychotherapy settings, negative experiences with other community MHS have rarely been studied. The focus of the literature varies and is dispersed among researchers. Some studies explore service users’ experiences by focusing on specific disorders or service settings and partly report negative experiences. For instance, Barr et al. [24] reported that people with personality disorders struggled to identify service providers who understood their disorder correctly. Labourot et al. [25] observed that people who sought help from primary care during mental health-related sick leave faced difficulties related to timely access and appropriate referrals to specialized services. Such studies were conducted and discussed in the context of each population or setting, which hinders the adoption of the findings elsewhere. Additionally, first-person accounts of negative experiences have been published in academic journals [1, 26]. Although these narratives of lived experiences are powerful, they would become more convincing if discussed within the context of existing literature. As described above, the existing literature on negative experiences in community MHS includes several perspectives, research areas, and study methods.

Concerning the scarcity and dispersion of literature on negative experiences in community MHS that are not limited to psychotherapies, it is necessary to summarize the findings of related studies. Considering that the existing literature has been reported from various research perspectives, study designs, and article types, grasping the overall picture of the related literature must be prioritized rather than synthesizing evidence to answer specific questions. Thus, a scoping review is most appropriate for providing an overview of all relevant literature [27]. Conducting a scoping review promotes a more comprehensive understanding of service users' experiences, making it possible to grasp the concepts that are currently emphasized and identify research gaps. In other words, we will be able to recognize the relatively well-studied service settings and types of negative experiences, which, in turn, will allow us to identify unexplored areas that require further study. A preliminary search of MEDLINE and PsycINFO was conducted, and no current or ongoing systematic reviews or scoping reviews on the topic were identified.

Therefore, this scoping review aimed to identify and present the available information from the academic literature exploring service users' negative psychosocial experiences of community MHS in terms of types of negative experiences, service settings, targeted populations, and geographic locations.

This protocol was developed following the guidance of the JBI Scoping Review Methodology Group [28] and registered in the Open Science Framework Registry (osf.io/49s37).

Review questions

This scoping review attempted to answer three research questions as follows:

1. How much academic literature has been published on service users' negative experiences concerning the psychosocial aspects of community MHS?
2. Which types of negative experiences were the most reported while using community MHS and how were they described?
3. What types of services were investigated, what populations were targeted, and in which countries were the studies conducted?

Methods

The proposed scoping review was designed based on the JBI methodology for scoping reviews [29] and will be reported along with the PRISMA ScR [30, 31].

Inclusion criteria

Participants

This review will include adults with mental health problems. Additionally, individuals without formal diagnoses will be included since experiences related to help-seeking are also of interest in this review. Studies or literature that focus exclusively on children and adolescents (aged 19 and under) or older adults (aged 65 and over) will be excluded, as their experiences are presumed to be qualitatively different from those of adults, making it appropriate to conduct a separate review.

Concept

Academic literature reporting the negative experiences of service users concerning the psychosocial aspects of community MHS will be included. For example, studies that investigate service users' experiences or perspectives in certain types of interventions or settings (e.g., outpatient clinics, primary care, and community mental health teams) and report negative events or aspects (e.g., negative patient-provider interactions and undesirable environments) will be included.

Adverse events or clinically significant deterioration will not be considered negative experiences because this review does not focus on clinical outcomes or effects. Articles that did not report any details of negative experiences from the perspective of service users will be excluded (e.g., studies that reported only the prevalence of people who experienced negative events while receiving the service). Patient-reported outcomes related to aspects of services (e.g., patient satisfaction and doctor–patient relationship scores) will not be considered negative experiences. Although these scales may include items that indicate negative experiences (e.g., "Did the doctor have a negative attitude toward you?"), they are usually designed to measure concepts in a positive direction and do not provide sufficient information about the details of negative experiences. Moreover, as studies do not necessarily report the results for each item, it is not feasible for this review to include literature using these scales. However, questionnaires or scales designed and used to understand service users' negative experiences directly related to the service content or environment will be included.

The following types of information will be excluded because they are outside the scope of this review: literature that reports on 1) experiences related to the illness itself or the side effects of pharmacological treatments, 2) experiences of individuals who were not service users (such as caregivers or experts), 3) unmet needs of service users, and 4) experiences during hospital admissions and psychotherapies.

Context

As the focus of this scoping review is on community MHS that are not limited to psychotherapies, research that only reports on experiences during psychiatric admissions or psychotherapies will be excluded. This review will include studies on other contextual settings (i.e., settings of community MHS), geographic locations, social or cultural factors, and racial or gender-based interests. Only English literature will be included for feasibility reasons. Publication dates will not be limited.

Types of sources

This scoping review will consider quantitative studies regardless of whether they are experimental or observational. This review will also consider qualitative studies, regardless of their design and framework, such as interviews, focus groups, thematic analyses, phenomenology, grounded theory, or ethnography. Furthermore, systematic reviews, other types of reviews, first-person accounts/narratives of lived experiences, letters, and opinion papers will be considered for inclusion. Gray literature, which is material produced outside of academic publishing such as reports, theses, conference abstracts, and policy statements, will not be considered because this review aims to assess published academic literature.

Search strategy

A three-step search strategy will be used. First, an initial limited search of PubMed and PsycINFO (via Ovid) was performed to identify relevant articles. The text words contained in the titles and abstracts of relevant articles and the index terms used to describe the articles were used to develop a full search strategy (Appendix 1). The search strategies were reviewed by a librarian and finalized after discussions between the authors and the librarian. Second, database searches will be conducted using MEDLINE, PsycINFO, and CINAHL databases. Third, the references of the articles included after full-text screening will be screened for additional studies. A manual search will also be conducted to complement the search results.

Study/Source of evidence selection

All article records identified in the screening process will be imported into EndNote 20 (Clarivate, 2022), and duplicates will be removed. A pilot test of screening random 50 titles and abstracts will be conducted by all reviewers, which includes a discussion and refinement of the inclusion criteria. Once a 75% agreement is achieved, the remaining titles and abstracts will be screened by two independent reviewers. If at least one of the two reviewers considered an article record potentially relevant, we will obtain the full text of that article. Full-text articles will be assessed based on the inclusion criteria of two independent reviewers. We will report the reasons for the exclusion of full-text articles. Any disagreements between the reviewers at each stage of the selection process will be resolved through discussion, or by an additional reviewer. The results of the search and study inclusion processes will be presented in the final scoping review publication using a PRISMA flow diagram [30, 32].

Data extraction

Data will be extracted from the articles included in the scoping review by one reviewer using a data extraction chart (see Appendix 2) developed by the reviewers. The extracted data will be double-checked by another reviewer, and any disagreements will be resolved through discussion. The data extraction chart includes specific information on the authors, publication year, study designs or article types, focused populations, service settings, and key findings relevant to the review questions. This chart will be modified and revised as necessary during data extraction, and the modifications will be detailed in the scoping review. If appropriate, the authors of the articles will be contacted to request for missing or additional data.

Data analysis and presentation

The frequency counts and percentages of the following fields of data will be presented: countries, study designs/article types, focused populations, and service settings. Basic qualitative content analysis will be used to describe and map existing evidence regarding service users' negative experiences. Basic qualitative content analysis is a recommended approach to address the scoping review questions of experiences and meaningfulness [33], which is based on qualitative content analysis [34] but avoids deeper interpretation of data. This is suited to our review objective of summarizing service users' negative experiences with community MHS. We will analyze the sections of each included paper that provide detailed descriptions of negative experiences. The analysis steps will be as follows: reading and re-reading the literature to gain a deep understanding, open coding, developing a coding framework and modifying it within the team, and reviewing and confirming the coding. All reviewers will agree upon the final coding framework. The coding will be double-checked by the two authors, and any disagreements will be resolved through discussion. MAXQDA will be used for the analysis. After the analysis, the developed codes/categories of negative experiences will be used to create a cross-tabulation and presented with the corresponding service settings. A narrative summary will also be presented to describe each code/category of service users' negative experiences from the perspective of where they occurred.

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Declarations

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Author declarations

MIg and YY have experience as mental health service users.

Author contributions

MIg initially designed the review and drafted the protocol. The other authors contributed to the refinement of the study design and reviewed the manuscript. All the authors agree with the final version of the manuscript.

Conflicts of interest

There is no conflict of interest in this project.

References

1. Aves W. Escaping iatrogenic harm: A journey into mental health service avoidance. J Psychiatr Ment Health Nurs. 2024;31(4):668-73.
2. Crawford MJ, Thana L, Farquharson L, Palmer L, Hancock E, Bassett P, et al. Patient experience of negative effects of psychological treatment: results of a national survey. Br J Psychiatry. 2016;208(3):260-5.
3. Parry GD, Crawford MJ, Duggan C. Iatrogenic harm from psychological therapies – time to move on. Br J Psychiatry. 2016;208(3):210-2.
4. Vaughan B, Goldstein MH, Alikakos M, Cohen LJ, Serby MJ. Frequency of reporting of adverse events in randomized controlled trials of psychotherapy vs. psychopharmacotherapy. Compr Psychiatry. 2014;55(4):849-55.
5. Bartl G, Stuart R, Ahmed N, Saunders K, Loizou S, Brady G, et al. A qualitative meta-synthesis of service users' and carers' experiences of assessment and involuntary hospital admissions under mental health legislations: a five-year update. BMC Psychiatry. 2024;24(1):476.
6. Schmidt M, Uman T. Experiences of acute care by persons with mental health problems: An integrative literature review. J Psychiatr Ment Health Nurs. 2020;27(6):789-806.
7. Katsakou C, Priebe S. Patient's experiences of involuntary hospital admission and treatment: A review of qualitative studies. Epidemiol Psichiatr Soc. 2007;16(2):172-8.
8. Lendemeijer B, Shortridge-Baggett L. The use of seclusion in psychiatry: A literature review. Sch Inq Nurs Pract. 1997;11(4):299-315.
9. van der Merwe M, Muir-Cochrane E, Jones J, Tziggili M, Bowers L. Improving seclusion practice: Implications of a review of staff and patient views. J Psychiatr Ment Health Nurs. 2013;20(3):203-15.
10. Modini M, Burton A, Abbott MJ. Factors influencing inpatients perception of psychiatric hospitals: A meta-review of the literature. J Psychiatr Res. 2021;136:492-500.
11. Barlow DH. Negative effects from psychological treatments: a perspective. Am Psychol. 2010;65(1):13-20.
12. Linden M. How to Define, Find and Classify Side Effects in Psychotherapy: From Unwanted Events to Adverse Treatment Reactions. Clin Psychol Psychother. 2013;20(4):286-96.
13. Klein JP, Rozental A, Sürig S, Moritz S. Adverse Events of Psychological Interventions: Definitions, Assessment, Current State of the Research and Implications for Research and Clinical Practice. Psychother Psychosom. 2024:1-8.
14. McQuaid A, Sanatinia R, Farquharson L, Shah P, Quirk A, Baldwin DS, et al. Patient experience of lasting negative effects of psychological interventions for anxiety and depression in secondary mental health care services: a national cross-sectional study. BMC Psychiatry. 2021;21(1):578.
15. Rozental A, Kottorp A, Boettcher J, Andersson G, Carlbring P. Negative Effects of Psychological Treatments: An Exploratory Factor Analysis of the Negative Effects Questionnaire for Monitoring and Reporting Adverse and Unwanted Events. PLoS One. 2016;11(6):e0157503.
16. Strauss B, Gawlytta R, Schleu A, Frenzl D. Negative effects of psychotherapy: estimating the prevalence in a random national sample. BJPsych Open. 2021;7(6):e186.
17. Moritz S, Fieker M, Hottenrott B, Seeralan T, Cludius B, Kolbeck K, et al. No pain, no gain? Adverse effects of psychotherapy in obsessive–compulsive disorder and its relationship to treatment gains. Journal of Obsessive-Compulsive and Related Disorders. 2015;5:61-6.
18. Hardy GE, Bishop-Edwards L, Chambers E, Connell J, Dent-Brown K, Kothari G, et al. Risk factors for negative experiences during psychotherapy. Psychotherapy Research. 2019;29(3):403-14.

19. Lindgren A, Rozental A. Patients’ experiences of malpractice in psychotherapy and psychological treatments: a qualitative study of filed complaints in Swedish healthcare. Ethics & Behavior. 2022;32(7):563-77.
20. Coutinho J, Ribeiro E, Hill C, Safran J. Therapists' and clients' experiences of alliance ruptures: A qualitative study. Psychotherapy Research. 2011;21(5):525-40.
21. Ladmanová M, Řiháček T, Timulak L. Client-Identified Impacts of Helpful and Hindering Events in Psychotherapy: A Qualitative Meta-analysis. Psychotherapy Research. 2022;32(6):723-35.
22. Vybíral Z, Ogles BM, Řiháček T, Urbancová B, Gocieková V. Negative experiences in psychotherapy from clients’ perspective: A qualitative meta-analysis. Psychotherapy Research. 2024;34(3):279-92.
23. Curran J, Parry GD, Hardy GE, Darling J, Mason A-M, Chambers E. How Does Therapy Harm? A Model of Adverse Process Using Task Analysis in the Meta-Synthesis of Service Users' Experience. Front Psychol. 2019;10.
24. Barr KR, Jewell M, Townsend ML, Grenyer BFS. Living with personality disorder and seeking mental health treatment: patients and family members reflect on their experiences. Borderline Personal Disord Emot Dysregul. 2020;7:21.
25. Labourot J, Pinette É, Giguère N, Menear M, Cameron C, Marois E, et al. Factors affecting patients' journey with primary healthcare services during mental health-related sick leave. Health Expect. 2024;27(2):e14036.
26. Gray B. A voice of experience: Positive and negative experiences of mental health from a service user's/lived experience perspective. J Psychiatr Ment Health Nurs. 2023;30(5):875-9.
27. Munn Z, Peters MDJ, Stern C, Tufanaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. BMC Med Res Methodol. 2018;18(1):143.
28. Peters MDJ, Godfrey C, McInerney P, Khalil H, Larsen P, Marnie C, et al. Best practice guidance and reporting items for the development of scoping review protocols. JBI Evidence Synthesis. 2022;20(4).
29. Peters MDJ GC, McInerney P, Munn Z, Tricco AC, Khalil, H. Scoping Reviews. JBI; 2020 updated 2024. https://synthesismanual.jbi.global/.
30. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med. 2018;169(7):467-73.
31. McGowan J, Straus S, Moher D, Langlois EV, O'Brien KK, Horsley T, et al. Reporting scoping reviews—PRISMA ScR extension. J Clin Epidemiol. 2020;123:177-9.
32. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ. 2021;372:n71.
33. Pollock D, Peters MDJ, Khalil H, McInerney P, Alexander L, Tricco AC, et al. Recommendations for the extraction, analysis, and presentation of results in scoping reviews. JBI Evidence Synthesis. 2023;21(3).
34. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs. 2008;62(1):107-15.

Appendices

Appendix I: Search strategy

Databases: MEDLINE (via EBSCO), PsycINFO (via Ovid), and CINAHL (via EBSCO)

Search terms and limits
(mental[Title] OR psychiatr*[Title] OR "Mental Disorders"[MeSH] OR "Mental Health"[MeSH] OR "Mental Health Services"[MeSH] OR Psychiatry[MeSH]) AND ("service user*" OR patient* OR consumer* OR client*) AND (experienc* OR perspective* OR view* OR perception*) AND (negativ* OR hinder* OR unhelpful OR harm* OR dissatisf* OR unwanted OR unsatisf* OR fear* OR uncomfort* OR bad OR unfavorable OR unethical OR inconvenien* OR undesirable) Limit: language (English)

Appendix II: Data extraction chart

Author (Year)	Country	Purpose	Methods/type of sources	Population and sample size	Key findings/summary of negative experiences
	The country will be determined by the locations of authors' affiliations if sufficient information is not provided within the article.	e.g.) To understand the patients' experience with primary healthcare services while they were on sick leave due to mental disorder.	e.g.) Qualitative study/ Quantitative study/ Systematic review/ Narratives of lived experiences/ etc.	e.g.) 14 participants with common mental disorders.	e.g.) Patients experienced the fragmented interventions provided by family physicians.