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Challenges of Care in Patients with Severe Mental Disorders: An Integrative Review

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Abstract

Background and Aim: The increasing prevalence of severe mental disorders (SMDs), and the complexity of managing and treating them, have imposed significant psychological, social, and economic burdens on societies. Consequently, caring for these patients presents numerous challenges to health care organizations, so identifying these challenges can help increase the quality of care provided to these patients. This integrative review aims to identify the challenges of care in patients with severe mental disorders.

Materials and methods: This study was conducted as an integrative review during 2000 - 2022. Keywords such as severe mental illness, serious mental disorders, mental disorders, relapse, challenges, barriers, and care as well as their Persian equivalents were used to retrieve relevant articles. Reputable Persian and international databases, including PubMed, Science Direct, Web of Science, Scopus, IranDoc, CINAHL, IranMedex, MagIran, SID, and Google Scholar were used to search for relevant articles. In total, 106 full-text articles in Persian or English, which were aligned with the purposes of this study were retrieved from the aforementioned databases before being analyzed by the Broome method.

Results: The findings revealed, the challenges of care in patients with SMDs, which included "Care Burden", "Stigma and social isolation", "Complexity in diagnosis, treatment, and disease management", "Weakness in the responsiveness of the health care system", and "Limited psychosocial support.

Conclusion: This integrative review highlights the multifaceted challenges of care in patients with SMDs. Addressing these challenges requires a coordinated effort of health care providers, policymakers, and society which ultimately improves care outcomes for individuals with SMDs. Comprehensive strategies that focus on enhancing system responsiveness, reducing stigma, and providing support structures are crucial for mitigating these challenges and ensuring effective management and support for these patients.

Keywords: Care, Mental Disorders, Patient, Review Literature.

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Introduction

Mental disorders are prevalent worldwide, affecting 6.9% to 27.8% of the global population [1,2]. In 2019, one in eight people, including 20% of children and adolescents, were living with mental disorders [3,4]. In the Middle East, these disorders significantly contribute to the burden of disease, with Iran enduring the highest burden compared to other countries in the region [5]. A mental health survey in Iran reported that 23.6% of the population had experienced mental disorders in 2015 [6]. As the demand for mental health services increases, a shortage of mental health professionals is anticipated by 2025 , particularly in the U.S. [7]. Despite the fact common mental disorders like that depression and anxiety cost the global economy one trillion dollars annually, governments allocate less than 2% of health care budgets to mental health [8].

Severe mental disorders (SMDs) refer to mental, behavioral, or emotional conditions significant functional that result in impairments. These include disorders such as schizophrenia, bipolar disorder, and major depressive disorder, which are often chronic and debilitating conditions with frequent relapses that reduce the social and occupational functioning of affected people [9-11]. Relapse, characterized by the recurrence of symptoms after at least 28 Knowledge of Nursing Journal.Autumn 2023,1(3)

days of recovery [12], poses serious risks, including increased hospitalizations, reduced quality of life, and elevated risk of suicide [13,14]. Each relapse contributes to the loss of brain tissue and worsens clinical outcome, highlighting the complexity of care in individuals with SMDs [15,16].

Many studies have examined the barriers of care in patients with SMDs. For instance, Thornicroft et al. (2019) identified stigma, fragmented health care systems, and lack of integrated services as major obstacles [17], while Geller (2020) highlighted poor coordination between psychiatric services and primary care [18]. Maoz et al. (2024) underscored the difficulty of maintaining long-term engagement with patients due to the chronic nature of SMDs [19], and Hastings et al. (2013) pointed to the challenges of accessing care in rural areas [20]. Additionally, Addo et al. (2018) found that the high economic costs of treatment and support services place a substantial burden on families and health care systems [21].

Despite this growing body of research, an integrative review is needed to synthesize these findings and provide a comprehensive understanding of multifaceted challenges associated with the care of patients with SMDs. Most existing studies focus on Saber and Kianian

isolated issues, such as systemic barriers or patient adherence, without considering how these factors affect the care of SMD patients. Furthermore, many studies are geographically or contextually limited, failing to capture the global scale of these challenges or cultural variations in care. By consolidating fragmented knowledge, this integrative review aims to identify the challenges of care in patients with SMDs and provide actionable insights into these issues in order to improve mental health care policies and quality of care, which ultimately enhance the care outcomes for patients and reduce costs for health care systems worldwide.

Methods

This is an integrative review study that was conducted between 2000-2022. To analyze the findings of relevant studies using Broome method. The study was done in stages: searching for relevant three the literature, evaluating retrieved information, and analyzing the data. In the first stage, the retrieved articles were examined in terms of inclusion criteria, compliance with the required terms and conditions, researcher's review. and relevance of the content. Finally, after data reduction. data display, comparisons,

conclusions, and data verification, the necessary analysis was performed [22].

Inclusion criteria for the study were included; SMDs-related articles, studies that examine the challenges of caring for patients with mental disorders, full text articles, and articles written in Persian or English. In this regard, the strategy of searching for Persian and English articles was that all the published articles with the keywords of care, mental disorders, major depressive disorder, schizophrenia, bipolar disorder, patient, relapse, and challenges were searched. Persian search was done in SID, IranMedex, Magiran, and Iran Medical Research Portal and English EMBACE, search was done in SienceDirect, Scopus, MEDLINE, Google Scholar, and CINAHL databases. Google Scholar search engine was also used.

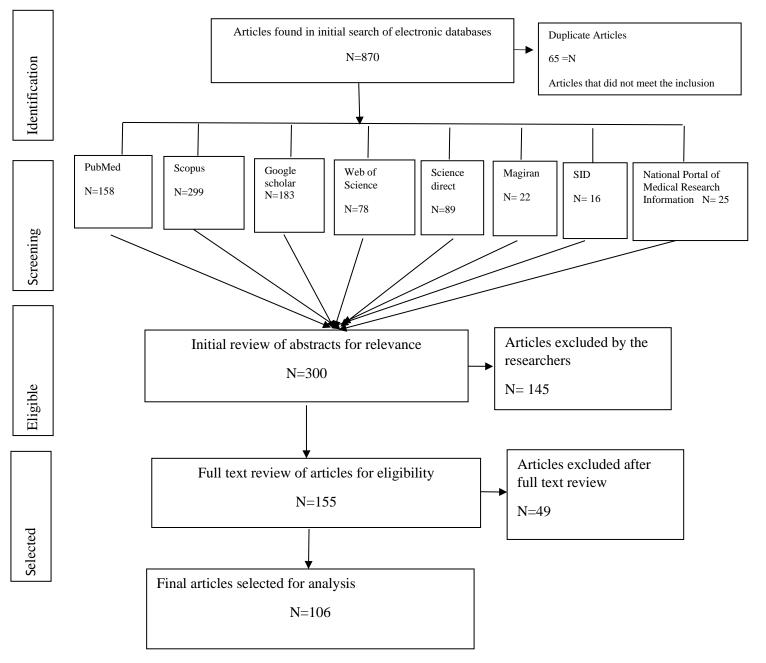
In the first stage, out of 870 articles, 65 were excluded due to duplication and not meeting the language criteria. Also, 505 studies were excluded for not aligning with the study's objectives. In the second stage, 145 articles were excluded after reviewing their abstracts, and in the third stage, 49 articles were eliminated due to irrelevant content after reviewing their full texts. Ultimately, 106 articles that met the inclusion criteria were selected for the analysis (Flowchart 1).

Broome method was used for data analysis, which includes data reduction, display, comparison, conclusion, and validation. Two independent researchers separately reviewed and confirmed the validity of analysis. Their goal was to compare their findings, and in case of any discrepancies, consult with a third party. However, they found no discrepancies.

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Results

review of literature revealed The numerous challenges associated with the care of patients with SMDs. These challenges include: "Care Burden", "Stigma social isolation", and "Complexity in diagnosis, treatment, and disease management", "Weakness in the responsiveness of the health care system", "Limited psychosocial and support". These challenges are presented in detail in Box 1.



Flowchart 1. Searching strategy

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box 1. Chanenges of care in patients with SMDs
Related Evidence
Care Burden [2,13,23-51]
Physical and emotional burdens
Financial strain
Stigma and social isolation [2-54]
Public stigma surrounding mental illness
Self-stigma among patients and caregivers
Complexity in diagnosis, treatment, and disease management [2,13,24-29,31-
33,36,38,41-44,48-51,54-104]
Diverse symptoms and signs
Comorbidity with other mental, physical, and behavioral disorders
Inefficient disease management
Weakness in the responsiveness of the health care system
[2,24,41,42,48,50,60,69,75,80,82,104,105]
Lack of standard treatment and guidelines
Limited access to mental health specialists
Limited psychosocial support [2,13,23,26,29,34,37,44,49,50,56,68,70,75,81,82,87,105-109]
Lack of peer support and counseling services
Insufficient trainings on life skills and social integration
Poor access to vocational and rehabilitation programs

Discussion

Based on the findings, there are five main challenges of care in patients with SMDs. One of the primary challenges is the significant care burden placed on both families and society. Families often endure physical, emotional burden, and financial while society strains. experiences an increased demand for health care systems and reduced economic productivity. The literature review indicated that the physical and emotional toll of these conditions in families and caregivers is a critical factor Knowledge of Nursing Journal.Autum 2023,1(3)

affecting the quality of care. A study by Nenobais et al. (2019) demonstrated that families face considerable physical strain due to the long-term and comprehensive care required by patients with SMDs. These families frequently face challenges such as lack of rest time, reduced social interactions, exhaustion, loss of energy, and Other studies disrupted sleep [46]. addressing the burden of mental disorders have highlighted the emotional toll of these condition in families, which include sense of sadness, shame, and fear related to the patient's behavior, particularly during the disease relapses [2,24,26]. Many families for patients with **SMDs** caring report emotional pain, guilt, and anxiety, worrying that mental illness may lead to permanent can severely impact the disability that patient's quality of life [110]. The Saudi National Mental Health Survey emphasizes on the need for improved mental health policies [111]. A study in South Africa severe caregiver similarly highlight the in burden rural communities, where economic. social. and clinical factors contribute to the widespread distress among caregivers, with most experiencing mild to severe symptoms [112]. Collectively, these emphasize the multifaceted studies on nature of care burden and call for systemic solutions to address these challenges.

Another major factor contributing to the burden of care associated with SMDs is the financial strain that these conditions may impose on both patients and their families. Gauthier et al., in their study to examine the economic impact of major depression. found that the total costs of caring for these patients were more than 50% higher than other [23]. Zarei Shabkhaneh's patients study conducted on schizophrenia high highlighted the costs of cares associated with this disorder, stressing the need for identifying factors that may accelerate the disease relapse [113]. Dalgard (2008) found that families of

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patients with SMDs incur higher direct and indirect costs, such as health care services, education, regular visits to medical centers, transportation, and daily necessities. compared to families of other patients [25]. sometimes Economic pressures can discourage families from pursuing treatment or continuing care, as reported by Saber et al.(2023) thus, they argue that comprehensive providing insurance coverage for these patients would greatly reduce their financial concerns, burden of illness and also help them to prevent disease relapse [114]. SMDs significantly increase the health care needs of patients, not only for psychiatric care but also for other medical needs, and if they are not met, they will lead to higher hospitalization rates, a greater risk of chronic illness, caregiver and treatment stress. costs. Frequent disease relapse and the need for constant care result in the loss of workforce, lower government revenue and reduced productivity, and increase unemployment. and Kassaw Agenagnew (2020) stated that by 2030, the global economic cost of mental health issues could reach to \$16 trillion, making it a priority for global health organizations all over the world [24]. Kadakia et al. (2022) also noted the estimated excess economic that burden of schizophrenia in the US in 2019 was \$343.2 billion, including \$251.9 billion in indirect costs (73.4%), \$62.3 billion in direct health care costs (18.2%), and \$35.0 billion in direct non-health care costs (10.2%) [115]. Therefore, it is essential to design and develop care programs for patients with SMDs through the collaboration of health care teams and government agencies in order to promote effective reintegration of these patients into society. Ensuring the continuous treatment follow-up and programs helps to mitigate the long-term financial and social costs disability, of which could otherwise place an even greater burden on governments.

identified This literature review also stigma and social isolation as significant challenges of care in individuals with SMDs. Stigma affects the process of patient in public care two ways, stigma surrounding mental illness and self-stigma among patients and caregivers. Stigma may be imposed on patients and their families by society or can originate from within patients or families. Studies by Adebiyi et al. (2018) [2] and Agenagnew and Kassaw (2020) [24] indicate that patients with SMDs frequently experience frustration due to the negative social attitudes and criticism of caregivers and family members. This frustration often leads to self-imposed isolation, resistance to seek medical help, and nonadherence to treatment and Knowledge of Nursing Journal.Autum 2023,1(3)

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medication regimens, or continuing care. Sartorius (2023) refers to stigma as a barrier to social inclusion, and states that it affects not only patients but also their families and health care providers [116]. al. (2023)Guan et examined social isolation and loneliness among caregivers of people with SMDs, and showed a considerable knowledge gaps in this area, for further research calling into that interventions target isolation [117]. Agenagnew and Kassaw (2020)emphasized that the recurrence of mental illness can exacerbate stigma, and reduce social functioning for both patients and their families, which negatively affect their health, social standing, and human rights [24]. Adebiyi et al. (2018) reported that social stigma may lead to non-adherence medication regimen, which result in the disease relapse and re-hospitalization [2].

Another challenge of caring for patients with SMDs is complexity in diagnosis, treatment, and disease According literature. management. to diverse symptoms and signs such as altered sleep pattern [28,66,78,79,118], changes of appetite [119-121], loss of sexual desire, and neglect of grooming and personal hygiene [28]. Studies also highlight the feelings of fatigue and reduced energy in with mental illness [29,79,120]. patients Saito et al. (2020) reported that patients

schizophrenia exhibit with cognitive, perceptual, and emotional changes several weeks before a relapse, showing as nonspecific symptoms such as anxiety, malaise, poor concentration, insomnia, and mild psychotic [31]. Gaebel symptoms and Riesbeck (2014)identified several SMDs. predictors of including worry, irritability, low mood, diminished energy, forgetfulness. neglect of hygiene and appearance and lack of interest in usual activities [28]. However, these symptoms may also be indicative of physical illnesses, **SMDs** making timely diagnosis of particularly challenging. Failure to recognize early warning signs can lead to delayed diagnosis and treatment, and increases the burden of care [31].

Additionally, comorbidity with other mental, physical, and behavioral disorders significant risk factor for presents а treatment failure and disease relapse in patients with SMDs. Buckman et al. (2018) found that the presence of multiple conditions, such as depression combined with alcohol addiction or anxiety disorders, significantly increases the risk of relapse [109]. Similarly, Hoertel et al. (2017)referred comorbid conditions to as predictors of relapse in major depression [68]. Fikreyesus et al. (2016) also found that physical illnesses such cancer. as osteoporosis, and rheumatoid arthritis contribute to relapse in individuals with severe mental disorders [26]. Integrated care models which address both psychiatric and non-psychiatric problems and needs, are essential for improving health outcomes in these patients.

Inefficient disease management is another challenge of care in patients with SMDs. Poorly designed treatment plans, incomplete follow-up, non-adherence to medication regimen, and drug side effects are among suboptimal care outcomes [75]. Schizophrenia, in particular, presents diagnostic complexities due to its diverse symptoms, requiring careful coordination between clinical and psychosocial aspects of care [38]. Frequent follow-ups, extended medication periods, and monitoring of treatment efficacy and drug side effects are essential for the relapse prevention, yet drugs side effects can disrupt treatment adherence and increase risk of relapse by up to 35.6 times [75]. Ensuring continuous monitoring of patient's symptoms and behaviors remains crucial, even during the recovery phase when the disease appears to be under control.

Finally, weakness in the responsiveness of the health care system, including lack of standardized treatment and guidelines and limited access to mental health specialists, are critical obstacles to effective care. As emphasized by Chaurotia

et al. (2016) [41] and Zipursky et al. (2014) [82], high treatment costs, particularly for inpatient psychiatric and care. long distances from specialized treatment centers may further reduce the patients' desire to seek continuous care. Non-specialized care often results in poor treatment outcomes and higher relapse rates [94]. Improved access to mental health specialists and clear, evidence-based treatment guidelines are necessary to meet the needs of patients with SMDs [78,82].

This literature review also revealed the limited psychosocial support, particularly peer support, patient empowerment, and reintegration. Social social support of patients by family, friends, and colleagues, such as expression of empathy and respect, plays a critical role in patient recovery [34,103,110]. However, many patients are deprived of such support due to their illness. Social stigma often causes families to hide their mentally ill members or delay treatment [24]. Disease relapse causes distress in patients and their families, puts relationships under stress and negatively affects educational and care prospects [49]. Improving the public awareness of SMDs and enhancing community support systems among essential factors that reduce are stigma and promotes patients' reintegration into society [2]. The role of mass media, virtual platforms, and non-governmental organizations is pivotal in achieving this goal.

Conclusion

Results of this review study highlight several key challenges associated with the of patients with SMDs. These care include challenges heavy physical, emotional. and financial burden on caregivers, systemic weaknesses in health care systems such as lack of guidelines and limited access to specialized care, and the pervasive stigma and social isolation experienced by patients and families. Additionally, complexities of disease diagnosis and treatment, as well as comorbid conditions. make disease management difficult. even more Addressing these challenges and issues requires some efforts. which include improving the response of health care system, providing integrated care models, reducing stigma, and offering robust psychosocial support, with intention of improving patient outcomes and promoting reintegration into society.

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Conflict of interest disclosures

There is no conflict of interest in this study.

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