Quality of Life of People with Schizophrenia: A Discussion Paper

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Abstract: The Quality of life in people with schizophrenia is a critical yet often overlooked aspect of mental health care. This paper discusses the state-of-the-art quality of life in people with schizophrenia, highlighting the key dimensions beyond clinical aspects, including psychological well-being, social and community relationships, and environmental factors. The existing research and interventions focused on the quality of life of people with schizophrenia are also discussed to identify the progress made in understanding and improving the quality of life for this population and to outline future directions, nursing practice, and strategies needed to support their well-being further. This includes examining the complex factors influencing quality of life, evaluating the effectiveness of current interventions and support systems, and proposing new approaches to enhance the overall quality of life for persons with schizophrenia.

Keywords: Quality of life, Schizophrenia, Severe and chronic mental illness

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Introduction

Schizophrenia has a profound impact on individuals who suffer from it. Those with schizophrenia experience significant disturbances in thinking and feelings, often accompanied by hallucinations. The psychotic symptoms, particularly hallucinations and delusions, reduce their social interactions. The ability to learn and solve problems also declines as the illness progresses. Personality and various bodily functions deteriorate, with a noticeable decline during the first five years of illness, followed by gradual and significant deterioration if the illness persists beyond five years or through multiple exacerbations. In the initial 5-10 years, patients often experience occasional relapses, which further deteriorate their personality and their ability to fulfil social, professional, and self-care roles. Relapse rates have been reported to be 28%, 43%, and 54% in the first, second, and third years, respectively.[1] Prolonged use of psychotic medications and their side effects can cause discomfort, affecting daily routines and preventing individuals from meeting their basic needs, ultimately hindering a good quality of life.

The quality of life (QoL) in people with schizophrenia has garnered significant attention and has been the subject of extensive study for many decades. Owing to the nature of cyclical schizophrenia, after treatment, many patients can reintegrate into the community, living with their families and seeking treatment during periodic relapses. Thus, supporting these individuals involves not only treating their mental illness but also preparing them, as much as possible, to regain their independence. Therefore, the current treatment approach extends beyond emphasizing psychotic symptoms to include rehabilitation efforts aimed at helping individuals secure employment and income,

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enabling them to lead fulfilling lives within their communities.[2]

Research on the QoL of people with schizophrenia has expanded beyond symptom-focused assessment. It has become evident that after controlling symptoms, unmet needs and social support significantly impacted QoL for this group of people.[3] Furthermore, people with schizophrenia report lower satisfaction with education, social life, and current circumstances compared with those with physical disabilities or psoriasis.[4] Murwasuminar et al. highlighted that cultural, economic, and social support factors and mental health service availability influence QoL in people with schizophrenia.[5] Therefore, to study QoL in this group, the tools used to measure the general population may not be appropriate for them. This may require acknowledging the multifaceted nature of QoL in schizophrenia beyond simply symptoms, treatment, and rehabilitation.

This paper, therefore, discusses the progress made in understanding and improving QoL for this population, outlines future directions, nursing practice, and strategies needed to support their well-being further, and proposes new approaches to enhancing the overall QoL for people with schizophrenia.

Current Understanding of QoL in People with Schizophrenia

QoL for people with schizophrenia encompasses multiple dimensions, including social integration and employment.[6] Generally, physical and mental health are crucial and may involve symptom management and illness-related impairments. However, other important factors include family understanding, stigma, finances, social relationships, and independent living.[6] Over more than two decades, Laliberté-Rudman et al.[7] identified themes of managing time, connecting and belonging, and maintaining control as central to the QoL of people with schizophrenia. Furthermore, the key components of QoL for people with schizophrenia in India included work, family understanding, stigma, finances, social life, and mental/physical health.[6] Tungpunkom et al.[8] also found seven components of QoL based on the perspectives of people with schizophrenia and their caregivers in Thailand using a thematic analysis approach, including 1) everyday life, 2) residual symptoms, 3) side effects and attitude to treatment, 4) role and function, 5) family, 6) social and community, and 7) human rights. Mortensen et al.[9], using an anthropological approach exploring via in-depth interviews with participants in France, the UK, and the USA, also found that the most important aspects of QoL for people with schizophrenia were close relationships, a safe home and meaningful daily activities. Normalization and independence were central themes for the participants regarding their QoL and hopes for social integration. However, these components are less likely to be included in measuring the QoL for people with schizophrenia.

The QoL components based on the people with schizophrenia and caregiver perspectives do not exhibit significant discrepancies.[8] However, in the context of assessment, research indicates significant disparities between people with schizophrenia and their caregivers. Caregivers' QoL can indirectly impact patients' QoL through its influence on symptom severity.[10] Factors affecting caregivers' QoL include the degree of kinship, with parents and children experiencing lower QoL than siblings.[11]

Research on QoL assessments in people with schizophrenia reveals significant disparities between patient self-reports and healthcare provider perspectives. This differs from the wider agreement on clinical aspects rather than social and occupational ones.[12] Studies consistently show that patient-rated QoL is higher than provider-rated QoL.[13] Factors influencing these disparities include patient insight, negative symptoms, depression, and attitudes toward treatment.[14] This discrepancy highlights the need for treatment strategies that address a wide range of patient-perceived needs.[12] Notably, psychiatric treatment is rarely associated positively with QoL by patients,[15] emphasizing the importance of considering patients' perspectives in QoL assessments and interventions.

Measurement of QoL for People with Schizophrenia

Generic QoL Measurement

Quality of life (QoL) assessment is crucial for understanding health and social care needs in general populations, including people with schizophrenia. The World Health Organization Quality of Life (WHOQOL) instrument, including its brief version (WHOQOL-BREF), is widely used to measure QoL across different domains, including physical, psychological, social, and environmental domains.[16] Other popular instruments include the Short Form-36 (SF-36) and EQ-5D.[17] These tools assess the physical, psychological, social, and environmental aspects of QoL. Studies have shown that socioeconomic status, age, and residence type significantly influence QoL scores.[18] A meta-analysis to compare the QoL between people with schizophrenia and healthy controls, using the World Health Organization Quality of Life (WHOQOL) or its brief version (WHOQOL-BREF) and the Short Form-36 Health Survey (SF-36) as standardized measures found that people with schizophrenia had QoL lower across four domains, including physical, psychological, social, and environmental compared to healthy controls.[19] However, some instruments may include functional content, which can affect measurements for people with long-standing limitations.[20]

Health-related quality of life (HRQoL) measurement has evolved significantly in recent years, with numerous generic and disease-specific instruments now available.[21] Generic measures like SF-36, SF-12, and EQ-5D are widely used, while disease-specific measures offer greater sensitivity to specific conditions.[17] The PROMIS and Neuro-QOL initiatives represent efforts to develop standardized HRQoL measures across various health conditions.[22] To use HRQoL to measure the QoL for people with schizophrenia, one may need to consider whether the component can apply to the schizophrenia context.

Health-related quality of life (HRQoL) is distinct from overall quality of life (QoL) and health status, though these terms are often used interchangeably.[23] HRQoL focuses on how health affects QoL, while QoL encompasses broader aspects of life beyond health.[24] Generic HRQoL measures allow comparisons across diseases, while disease-specific measures capture condition-specific burdens.[25] Many popular HRQoL scales include functional content, which may not accurately reflect health for individuals with long-standing functional limitations,[26] i.e., people with schizophrenia. HRQoL is influenced by both expectations and experiences, and perceptions can vary between individuals and over time.[27]

Nevertheless, standardized HRQoL instruments have become increasingly important in clinical research and healthcare decision-making.[25] Population norms for various HRQoL instruments have been established, showing similar age-related trends but differing absolute values across indexes.[28] These measures include generic instruments like SF-36, EQ-5D, and condition-specific questionnaires.[29] Interpreting HRQoL data requires a comprehensive strategy that considers statistical significance, clinical relevance, and comparison with population norms.[30] Interestingly, researchers have also found correlations between HRQoL scores and factors, such as gross domestic product (GDP) per capita and healthcare expenditure.[31] This sheds light on the relevance of socioeconomic factors impacting individuals' HRQoL levels.

Specific QoL Measurement

Quality of life (QoL) measurement for people with schizophrenia has gained significant attention in recent years. Several instruments have been developed and validated for this purpose, including the Quality of Life Measure for Persons with Schizophrenia (QOLM-S),[32] the Quality of Life Scale (QLS),[25] and the Schizophrenia Quality of Life Scale (SQLS).[33] These tools assess various dimensions of QoL, including interpersonal relations, functioning, and symptoms. Few scales have tried to capture both objective and subjective quality of life for

people with schizophrenia, for example, the Lehman Quality of Life interview, to capture the outcome from their own perspectives.[34]

Hadzi et al.[35] conducted a systematic review and found that the Personal and Social Performance Scale and the Global Assessment of Functioning are commonly used to measure functional outcomes. The Manchester Short Assessment of Quality of Life, the Heinrich Carpenter Quality of Life Scale, the Schizophrenia Quality of Life Scale, and the EQ-5D are also commonly used to evaluate QoL in people with schizophrenia.

QoL assessment is valid and has been widely used to measure the outcomes in clinical practice, the early QoL improvement in people with schizophrenia, the better long-term symptomatic and functional remission.[36] However, the need for more consensus on QoL scales sheds light on further research to evaluate its predictive validity, necessitating future investigation to standardize QoL measurement in people with schizophrenia.[36]

Factors Influencing QoL in People with Schizophrenia

Various factors beyond symptom severity influence QoL in people with schizophrenia. Even after controlling for symptoms, social support, unmet needs, and employment status significantly impact QoL.[37] Socio-cultural factors, such as social integration and interpersonal relationships, were important in physical and psychological well-being.[38] Age, employment, and lower symptom scores are associated with higher QoL across different mental disorders, including schizophrenia.[39] However, the strength of these associations may vary between diagnostic groups. Clinical variables such as illness duration, recurrent hospitalizations, and knowledge about schizophrenia are significant predictors of QoL.[40]

Additionally, demographic factors like gender, marital status, and education level can influence QoL in people with schizophrenia.[40] General psychopathology has the strongest negative relationship with QoL in schizophrenia. The association between psychiatric symptoms and QoL varies depending on the stage of illness and treatment setting. Longitudinal studies found weaker relationships between psychiatric symptoms and QoL than cross-sectional studies.[41]

Substance use among people with schizophrenia has complex effects on QoL and functioning. While some studies found that substance use was associated with poorer QoL,[42] others reported higher or equivalent overall psychosocial functioning in substance users compared to abstainers.[43] Tobacco use and khat chewing negatively impacted various QoL domains.[44] Multimorbidity, including both psychiatric and substance use comorbidities, was associated with worse QoL compared to schizophrenia alone.[45] Understanding these multifaceted influences on QoL is essential for developing comprehensive treatment approaches and improving outcomes for people with schizophrenia.

Interventions to Enhance QoL in People with Schizophrenia

Research indicates that interventions can improve QoL and physical health in people with schizophrenia. Community-based rehabilitation (CBR) has shown effectiveness in enhancing QoL for people with schizophrenia.[46] Various interventions, including family interventions, psychoeducation, cognitive-behavioral therapy, and social skills training, have been identified as potentially beneficial for improving QoL for people with schizophrenia.[47] A 30-month program combining individual counselling, group sessions, and usual treatment demonstrated improvements in physical health risk factors for long-term patients and QoL for newly diagnosed patients.[48] These findings suggest that multifaceted, targeted interventions can effectively enhance QoL and physical health in people with schizophrenia.

Psychosocial and Pharmacological Interventions

Psychosocial interventions are proven to improve the QoL and well-being of persons with schizophrenia.

Recently, Petkari et al.[49] evaluated psychological interventions aiming to improve the QoL of people with schizophrenia and schizophrenia spectrum disorders; these interventions included 1) psychoeducation, 2) cognitive behavioral therapy (CBT), 3) cognitive interventions, 4) combination of several types of interventions (e.g., psychoeducation and CBT, cognitive and social skills training), and 5) other psychological interventions (e.g., psychodynamic, systemic, mindfulness-based). They found that psychological interventions, especially psychoeducation, were more effective for improving objective QoL compared to subjective QoL in people with schizophrenia-spectrum disorders. Combination interventions that included multiple therapeutic approaches (e.g., psychoeducation, CBT, problem-solving) were most effective for improving subjective QoL, although the effects were small. Group interventions appeared to be more beneficial for enhancing subjective QoL than individual or combined interventions, but this finding should be interpreted cautiously.

A systematic review and meta-analyses evaluated the effectiveness of pharmacological and psychosocial interventions focusing on physical health outcomes among people with schizophrenia spectrum disorders. They demonstrated that receiving individual lifestyle guidance and exercise showed the most effectiveness for weight reduction, followed by psychoeducation combined with aripiprazole, topiramate, d-fenfluramine, and metformin. It was found that aripiprazole and topiramate revealed the most effectiveness on waist circumference reduction, followed by dietary interventions. Only nutritional interventions could improve diastolic blood pressure significantly.[50] Another RCT study in Thailand found that the pharmaceutical care intervention group significantly improved in several aspects of medication-related QoL compared to the control group for people with schizophrenia.[51] When combined with pharmacological interventions, these psychosocial treatments can promote functional recovery by addressing symptom stability, independent living, work functioning, and social functioning.[47] However, more research is needed to establish these interventions' long-term effects and better understand their comparative efficacy.[50, 52]

Community and Support Services

Community-based rehabilitation and psychosocial activities can effectively improve QoL by enhancing social skills and integration.[53] Sociodemographic factors such as employment, marital status, and living conditions also impact QoL.[54,55] Cultural and economic factors, family support, and mental health service availability are crucial in determining QoL across different populations.[56] Comorbid depression and anxiety negatively affect QoL, highlighting the importance of comprehensive treatment approaches.[57,58] Therefore, healthcare providers must consider these factors to tailor community-based interventions to specific groups' needs.

Gaps in Current Knowledge of QoL in People with Schizophrenia

Variability in QoL Assessment

Research on QoL in schizophrenia reveals inconsistent findings. While psychiatric symptoms generally show negative associations with QoL, the strength of these relationships varies.[41] Subjective and objective QoL measures often demonstrate low to moderate correlations, suggesting they may represent distinct constructs.[59] Factors influencing this discrepancy include depression, insight, and negative symptoms.[60] Neurocognition, social cognition, and symptomatology contribute to different aspects of QoL.[61] Social cognition, particularly mental state reasoning, plays a crucial role in subjective well-being.[62] The lack of consensus on QoL measures complicates research and interpretation.[63] While symptoms impact QoL, their relationship remains unclear.[64] Some studies suggest that subjective QoL ratings may be influenced by adaptation and personality factors.[65] Cultural, economic, and social factors also influence QoL in schizophrenia.[66] Despite these challenges, QoL remains a valid and important outcome measure in schizophrenia research and treatment.[63]

Barriers to Care

Research on barriers to care for people with schizophrenia highlights several key challenges. The factors impeding people with schizophrenia from care included poor insight, preferring to use other alternative care, financial difficulty, and severity of illnesss.[67] Being women were more likely to report greater overall treatment barriers and stigma-related barriers compared to male patients. Notably, attitudinal barriers were more dominant than stigma-related barriers in a Nigerian sample, in contrast to a UK sample, where stigma-related barriers were more prominent.[68] The family plays a vital role in escorting patients to follow-up treatment; it was found that inadequate support from family members and the healthcare system, financial difficulties, and social stigmatization and rejection due to limited public knowledge about psychiatric disorders perceived by family caregivers could all serve as barriers to care.[67] Barriers to self-management, including knowledge gaps, financial issues, and uncoordinated mental health services, were also found among caregivers in China.[68] Lastly, QoL measures, though important, are underutilized in clinical practice.[63] Solving these barriers requires a multifaceted approach involving patients, caregivers, healthcare providers, and policymakers to enhance care and QoL for people with schizophrenia.

Future Directions and Recommendations

Research Priorities

Recent research on QoL in schizophrenia has highlighted its importance as an outcome measure in clinical practice.[63] Studies have found that QoL is negatively correlated with factors such as advanced age, male gender, longer illness duration, and typical antipsychotic medication use.[19] Psychiatric symptoms, particularly general psychopathology, have shown consistent negative associations with QoL across various studies.[69] Sociodemographic factors like employment and marital status positively influence QoL.[39,40] Longitudinal studies have demonstrated that early QoL improvement predicts long-term symptomatic and functional remission.[70] However, the lack of consensus on QoL scales highlights further investigation. Future research should focus on standardizing QoL measures and exploring the association between symptoms, functioning, and QoL to develop more effective interventions for people with schizophrenia.[71] Finally, longitudinal studies are recommended to explore the relationships between these factors further and develop effective psychosocial interventions to enhance QoL for people with schizophrenia.[72] Furthermore, future research should focus on developing comprehensive, evidence-based interventions to address the multifaceted nature of QoL in people with schizophrenia.[73]

Policy and Practice Recommendations

Research on QoL in people with schizophrenia has highlighted its importance for patient care and outcomes. However, challenges remain regarding the conceptualization, implementation, and usefulness of QoL assessments.[71] As mentioned earlier, it was empirical that people with schizophrenia generally report lower QoL compared to non-disabled individuals, with factors such as symptoms, medication side effects, and social support influencing QoL. Policy recommendations emphasize providing integrated care addressing mental and physical health needs, supporting community integration, and involving stakeholders in policy development.[74] Despite progress, disparities in healthcare access and implementation challenges persist, necessitating continued efforts to improve care and outcomes for people with schizophrenia.[74] Moreover, we need to ensure the research and interventions are considered context and tailored to the diverse needs of different populations. This will also correspond to the WHO's Comprehensive Mental Health Action Plan 2013-2030, which highlights the actions of all member states to provide standardized, high-quality services for people with mental disorders, including schizophrenia. This action plan emphasized deinstitutionalization, shifting the services to the community to ensure that more people with schizophrenia have access to evidence-based, high quality and affordable care.[75]

Implication for Nursing

Nurses can provide effective interventions that have been proven by prior research studies to enhance the QoL for people with schizophrenia, as aforementioned, for example, psychoeducation, cognitive behavioral therapy (CBT), cognitive intervention, multifaceted interventions that combine required types of interventions, e.g. psychoeducation and CBT, cognitive and social skills training, and other psychological interventions such as psychodynamic, systemic, mindfulness-based intervention.[49] The most important matter is tailoring those interventions to patients' needs and contexts. Furthermore, QoL assessment, by using valid and schizophrenia-specific scales, should be embedded into routine nursing care, especially during the follow-up period once the patients return to stay with their families in the community and evaluate what dimension needs to intervene. Adherence to the antipsychotic drug is one of the predictive factors for QoL.[47] Therefore, adherence intervention should be integrated into psychoeducation groups through an interactive strategy. Telenursing, such as telephone intervention for medication adherence and problem-solving, can enhance adherence and functional ability to improve the QoL when they return home. Finally, functional recovery intervention, such as life skills training, can lead to improved QoL for people with schizophrenia when they return home to live in the community. Nurses need to work collaboratively with community stakeholders to enhance the personal recovery of people with schizophrenia, leading to improving their QoL. This requires the inclusion of immediate caregivers and key persons in the community in the intervention to strengthen their capability to take care of people with schizophrenia at home. Nursing outcomes must be monitored to ensure the quality of nursing care and to update interventions based on the new evidence.

Conclusion

Schizophrenia's impact on QoL has been extensively studied. People with schizophrenia generally have lower QoL than those with other disabilities and with the general population. Cultural, economic, and social factors influence QoL in people with schizophrenia. Social support, unmet needs, employment status, and socio-cultural factors are significant beyond symptoms. Demographic characteristics, including age, gender, marital status, and educational level, could predict QoL. Comorbidity, especially with substance use, also varies the QoL in people with schizophrenia.

Generic measures (WHOQOL, SF-36, EQ-5D) are widely used but may fail to identify schizophrenia-specific aspects. Importantly, these schizophrenia-specific scales (QOLM-S, QLS, SQLS) assess various QoL dimensions, and valid QoL assessment is crucial for predicting outcomes and developing interventions.

Effective interventions include community-based rehabilitation, family interventions, psychoeducation, cognitive-behavioral therapy, social skills training, and pharmacological intervention. Combining psychosocial and pharmacological treatments shows promise in enhancing QoL for this group. Inconsistent QoL assessments highlight the need for standardized measures. Barriers to care include lack of insight, financial constraints, and social stigma. A comprehensive approach involving all stakeholders is needed. Nursing care needs to highlight multifaceted interventions to cover complex factors influencing the QoL of people with schizophrenia and to include all stakeholders in the intervention. Policies should support integrated care, community support, and stakeholder involvement and comprehensive strategies are needed to improve QoL in people with schizophrenia.

CONFLICT OF INTEREST

The author is aware that this study has no conflict of interest.

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Ethical Considerations

All analyses were based on previously published studies and author opinions; no ethical approval or patient consent was required.

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คุณภาพชีวิตของผู้ที่เป็นโรคจิตเภท : บทความเชิงอภิปราย

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บทคัดย่อ: คุณภาพชีวิตของผู้ที่เป็นโรคจิตเภทเป็นปัจจัยที่สำคัญแต่มักถูกมองข้ามในการดูแลทางสุขภาพจิต บทความนี้มีวัตถุประสงค์เพื่ออภิปราย ถึงสถานะองค์ความรู้ในเรื่องคุณภาพชีวิตของผู้ที่เป็นโรคจิตเภท โดยเน้นประเด็นที่นอกเหนือจากอาการทางคลินิก ได้แก่ สุขภาวะด้านจิตใจ สัมพันธภาพกับสังคมและชุมชน และปัจจัยด้านสิ่งแวดล้อม และยังได้อภิปรายถึงงานวิจัยและการช่วยเหลือเพื่อเสริมสร้างคุณภาพชีวิตในผู้ที่เป็นโรคจิตเภท ความก้าวหน้า และแนวทางการทำวิจัยในอนาคตเพื่อแนะนำแนวทาง/วิธีการ การให้การพยาบาลแบบบูรณาการเพื่อเพิ่มคุณภาพชีวิตหรือสุขภาวะของบุคคลกลุ่มนี้ โดยได้วิเคราะห์ปัจจัยที่ซับซ้อนที่มีอิทธิพลต่อคุณภาพชีวิต วิเคราะห์และสรุปผลการวิจัยที่ทำการทดสอบประสิทธิผลของโปรแกรมที่เพิ่มคุณภาพชีวิตของผู้ที่เป็นโรคจิตเภท ตลอดจนระบบสนับสนุน และนำเสนอข้อคิดเห็นเพื่อการพัฒนาคุณภาพชีวิตในภาพรวมสำหรับบุคคลกลุ่มนี้ต่อไป

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คำสำคัญ: คุณภาพชีวิต โรคจิตเภท การเจ็บป่วยทางจิตที่รุนแรงและเรื้อรัง

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